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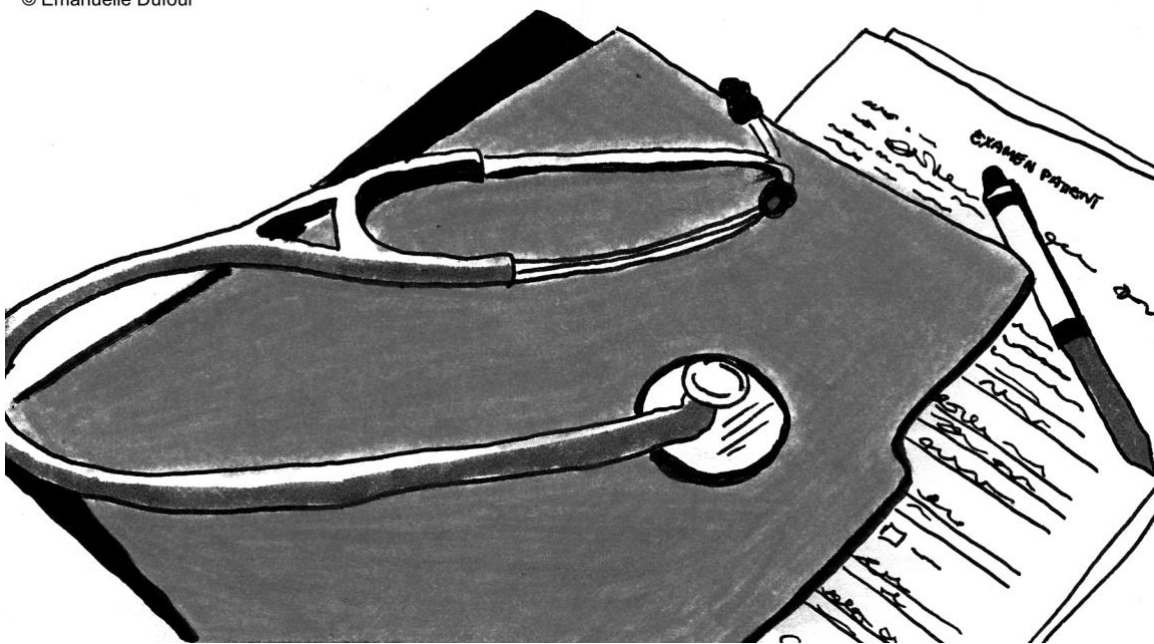


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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Memory, Neuroscience and Memory Enhancement

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Résumé

Le présent texte avance une compréhension nouvelle et actualisée de la mémoire qui devrait également modifier les coordonnées du débat sur l'amélioration de la mémoire. Au lieu de considérer la mémoire comme un entrepôt, nous devrions penser la mémoire d'un point de vue narratif. Ce point de vue permet de mieux comprendre le processus par lequel nous construisons réellement nos souvenirs, c'est-à-dire en élaborant des résumés significatifs, plutôt que d'ajouter des éléments distincts. Je soutiens que cette nouvelle façon de penser la mémoire rend la plupart des technologies d'amélioration de la mémoire, que nous avons ou que nous aurons dans un proche avenir, beaucoup moins problématique sur le plan éthique. L'idée principale est que la mémoire (biologique) interagit avec l'amélioration de la mémoire de manière créative et réélaborative comme elle le fait habituellement. Pour conclure, j'évoquerai quelques cas pour illustrer les points précédents.

Mots-clés

mémoire, amélioration de la mémoire, identité narrative, neurosciences, neuroéthique

Abstract

This paper advances a new and updated understanding of memory that should also change the coordinates of the memory enhancement debate. Instead of thinking of memory as a storehouse, we should think of memory from a narrative perspective. This view allows for a better understanding of the process in which we actually construct our memories by elaborating meaningful summaries, rather than adding discrete elements. I argue that this new way of thinking about memory makes most of the memory enhancement technologies we have or will have in the near future much less ethically problematic. The main idea is that (biological) memory interacts with memory enhancement in the creative and re-elaborative way it ordinarily does. To conclude, I discuss some cases to illustrate the previous points.

Keywords

memory, memory enhancement, narrative identity, neuroscience, neuroethics

Introduction

Neuroscience is still in its infancy, but its investigations are showing to be highly influential in many fields. Some of its topics, however, have been discussed for centuries. Memory is one of them, having been studied in philosophy, psychology and biology. Biology in particular only started to focus on memory “as technological advances made it feasible to move beyond description to explorations of mechanism” (1). This has also happened with neuroscience, a discipline only possible due to the recent technological developments that allowed a more precise knowledge of our brains. Among the different themes studied by neuroscience, memory is arguably one of the main topics since the creation of this field (2). However, it is only in the last few years that we have started to discuss seriously the possibility of memory enhancement. The problem with this discussion is that it has been carried out with old conceptions of memory that confuse the matter. Even though the past decades have seen an “increased interdisciplinarity among philosophers working on memory” (2), the truth is that many philosophical debates – particularly ethical debates regarding identity – are still carried out with old concepts and categories.

I will begin by showing why this old understanding of memory is flawed. Specifically, current neuroscientific research shows that memory does not work the way most philosophers have argued it does. It is thus necessary to try new explanations and elaborate new metaphors regarding memory that better match the scientific data. This new comprehension of memory is key to tackling issues with memory enhancement, as I will show. After this discussion on memory, I will then turn to some cases that demonstrate how the proposed new comprehension of memory should affect the memory enhancement discussion.

Reconsidering memory in the light of neuroscience

Before getting to memory enhancement and the announced case discussion, it is paramount to first understand memory. The predominant and intuitive view of memory is to think of it as a storage system, an idea that “has always been at the center of the Western understanding of memory” (3, p.1). As Schechtman explains, this view of memory is based upon “the ‘storehouse’ concept, arguably held by Plato, Augustine, Hobbes, Hume, and Locke himself, to name just a few. On this view, memory is seen as a sort of warehouse in which our ideas and experiences are laid away for later retrieval in their original form” (4, p.6). The basic idea is that our *conscious experiences* are somehow kept somewhere in our brain, ready to be retrieved when needed. The question “do you remember X?” is usually understood as a petition to search for specific information that you store and can share voluntarily. This widespread conception of memory is what most philosophers, until the last century, have conceptualized, validating this interpretation. For over a century now, psychology has fought this understanding of memory (5,6). In recent decades, neuroscience has been deconstructing this notion with more precise data about the brain and its inner workings. These investigations show that the common, stereotypical view of memory does not hold, for two main reasons: strictly speaking, human biological memory does not store anything, and what we recall is never the same thing that we first saw or experienced.

Humans, as any other biological organism, are concerned with survival (7), and our memory is focused on that: on being functional, not on being truthful or extensive¹. In fact, both of these characteristics (truthfulness and comprehensiveness) can be detrimental in many contexts, as cases that of Solomon Shereshevsky show (8). Our memory is concerned with meaning, not data, and this implies an emphasis on creation, rather than storage. As Quian Quiroga explains, memory is “based on the construction of meaning, an interpretation of the outside world that relies on selecting a minimum of information and making abstractions – while discarding a multitude of detail” (9, p.48)².

Even if a full, technical description of how memory works would take us too far, it is necessary to at least explain the basics of its functioning. Philosophical theories should be sound and try to not directly contradict these scientific findings. The philosophical account on memory I will put forward should also respect this principle. In order to give a brief contextualization, it is useful to attend to the classic taxonomy of memory that divides it into declarative and nondeclarative memory. The declarative memory is divided into semantic memory (dedicated to facts) and episodic memory (dedicated to events). Nondeclarative memory is related to skills, dispositions and other practical related aspects of memory (2). This classification, while widely accepted and relatively useful, is insufficiently nuanced for the understanding of memory we are trying to reach.

Neuroscience, on a more concrete level, explains that memory is related to the strength of neuronal synapses (10, p.98). This current understanding is based on the work of E. Kandel, who discovered a particular kind of neuron, modulatory neurons, which can strengthen the synapses between sensory and motor neurons (10, p.95). Modulatory neurons carry out a chemical process that adds a phosphate molecule (3, p.95-96); this phosphorylation delays the connection between sensory and motor neurons from disappearing, strengthening their connection and making their future connections easier. When phosphorylation is temporary, it produces short-term memory; when it is stable (because gene induced), it produces long-term memory. This depends primarily on the number of times the modulatory neurons repeat the process, which in turn depends on the number of times the action triggering the modulatory neuron is repeated (10, p.96-97).

Squire, in his comprehensive review of the last decades of neuroscientific studies on memory (1), seems to embrace this interpretation were he explains that one of the latest and most promising schema on memory is that “retrieval of a memory provides an opportunity for updating or modulating what was originally learned” (1, p.12712). This process, in which a memory becomes long-term, is referred to as reconsolidation. The bottom-line reflection, again, is that forming memories is not about storing, but rather going through a previously walked path, reinforcing that act and making it easier to repeat in the future. The main conclusion we should take from this is that the storehouse metaphor regarding memory is flawed. As Liao and Sandberg put it, “While it is common to speak of memory’s being ‘stored’, memories are not spatially localized. They are spread across different structures, likely as distributed networks of potentiated synapses” (11, p.87). And even though it could be said that memories are “stored” in distributed connectionist networks, this way of thinking the storage process is completely different to what philosophers have for the most part thought and explained. One of the first philosophers to identify this problem was Marya Schechtman (4). This author carries out a very insightful critique of this “storehouse” model of memory that serves as a basis for psychological views on identity. She argues that while some memories could be considered simple reproductions of the past, much of what we call memories are far less concrete ideas or beliefs that cannot be located and precisely described (4, p.7). As she explains,

Memory, on this view, is not always or only a reproduction of past experiences or a simple connection between two discrete moments of consciousness. It is also a way of weaving the facts about ourselves and our histories into a coherent and intelligible story, expressive of the overall contours of our characters and our lives; our autobiographical memory is, that is, more like a biography than a photo album (4, pp.12-13).

Schechtman, who has developed a very interesting philosophical inquiry on personal identity, was able to clarify the shortcomings of the “storehouse” model of memory. However, her conclusion is that there still is something true and compelling with these theories, and that what is indicated “is not a rejection of memory-based accounts of identity, but an attempt to give such an account with a structure which can accommodate memory in all of its complexity” (4, pp.13-14). I do not fully agree with this conclusion, and think rather that these misleading ideas should be dismissed. As we have seen, nothing in the way our brain works resembles this “storehouse” conception, and even if we are used to thinking in those terms, we must abandon them and search for better interpretations of memory³. As we will see in the case discussion section, abandoning the storehouse model of memory has decisive consequences for the memory enhancement discussion. Mainly, it means that enhancing memory can no longer be understood as improving any sort of storage capacity. It also means that, in a way, human memory, due to its creative nature, has always been enhanced. Human memory and enhanced memory turn out to be, under this comprehension, synonyms. I will further explain these ideas in the last section of the article.

¹ This reference to survival or the biological goals of memory is simply to point out its evolutionary origin. Memory, as with many human attributes and capacities, is used for many non-survival related purposes. But the point, in this part of the discussion, is to understand its evolutionary origin and why it functions the way it does.

² Konrad et al. go into more detail, explaining that “Organic memory has four different strategic biases. First, people tend to remember more positive than negative events (38). Second, negative details of individual events are forgotten more than positive details (39). Third, there is an emotional asymmetry in the time course of past events with negative affect fading more rapidly than positive affect (40). Finally, the ways that people view past events become less self-focused over time, indicating adaptive distancing from negative experiences (41).” (36, p.2).

³ Even if not the topic of this paper, this objection to the storehouse model goes beyond its neuroscientific inaccuracy. As Brockmeier notes, “memories are transindividual or collective phenomena” (3, p.2). Further, memory could also be argued to be an extended or distributed reality that reaches objects and technologies to which we are intertwined (20).

Overall, however, we must be realistic about the possibilities of overturning the accepted view of memory. Brockmeier is right when he states that this new way of understanding memory will not, at least in the short term, replace the established conception of memory, and the reason for it is that “the archival model is deeply moored in Western cultural traditions. Sedimented in science, philosophy, literature, and language there are numerous metaphors and models of memory that for a long time have given shape to our ideas of remembering and forgetting” (3, pp.22-23). This is very true, but it is also true that we cannot refrain from putting these changes into motion, even if this kind of shift, like the one we I propose regarding memory, takes a lot of time and effort. Next, I will analyse memory enhancement more concretely and in the last section I will delve into some case discussions to show how many of the criticisms directed at memory enhancement are based on the old, flawed comprehension of memory that I have argued is unsustainable.

Memory enhancement and its ethical implications

If giving a definition of memory is difficult, giving a definition of memory enhancement is even more complicated. The classic understanding of memory as a container makes this task easy: if normal memory allows us to store 100 memories, memory enhancement would allow us to store 1000 memories. However, as has been argued, this way of thinking about memory is wrong, and so too is an understanding of memory enhancement based on this conception. From my proposal, memory enhancement could be one of two things. A first way could be to see it as an enhancement of the neural workings of our brain, so that it is easier to reactivate a certain neural path when needed. A second possible understanding of memory enhancement could be to consider it as an improvement of the functionality of memory; not so much enhancing memory but manipulating it in different ways so that it serves better its objectives. I will draw on both of these comprehensions, although the second one will be the less problematic and the one to which I will mostly refer.

One point should also be addressed regarding these definitional issues. Memory is a polysemic and problematic word, as we already know; but the same is true for enhancement. Distinguishing between therapy and enhancement usually proves to be more difficult than expected; but even at a conceptual level it is hard to establish clearly why something can be called enhancement, to what standard level of performance we are referring, and if it truly enhances some capacity or simply changes it altogether. This complicated point has been tackled by Erler, who distinguishes memory editing from memory enhancement, saying that “By memory editing, I shall understand all methods of modifying memory in a desirable way that do not involve enhancing it – at least not directly” (12, p.240). Although he states clearly this distinction, he also points out that some forms of memory modification can end up being memory enhancement.

Although the motivations and usefulness of this classification are clear, ultimately, I cannot follow this distinction between memory editing and memory enhancement, especially after the previous discussion on the neuroscience of memory. Memory editing, in my framework, would be a redundancy, as our memory is always and continuously being edited, even without any technology involved. Giving a clear-cut definition of memory enhancement is, nonetheless, extremely difficult; and part of this difficulty is that, as I shall argue, the enhancement of human memory has been a constant through millennia. This familiarity with enhancement makes it very difficult to draw a line between non-enhanced and enhanced memory. Are the narratives about the origins of a tribe, repeated over and over again through generations, non-enhanced or enhanced memory? Is labelling different herbs and spice bottles a form of non-enhanced or enhanced memory? Memory enhancement is so natural and old to humankind that it is intrinsically difficult to distinguish it from a supposedly pure, non-enhanced, human memory. In this paper I focus on the new technologies that enhance memory; but bearing in mind that memory has been enhanced in humans since their origin as a species, with old technological realities such as language, writing or music as notable examples.

Modern bio-medical memory enhancement has been a major scientific goal in the last decades, in great part because of dementia related diseases, but also as a way to enhance ourselves cognitively. Techniques to treat post-traumatic stress disorder (PTSD) by erasing or weakening specific memories have also been quite important (13, p.70). It would be simply impossible to give a comprehensive account of all the different types of memory enhancers (for one such comprehensive account see (14)). These new enhancements can be technological (15), genetic (16) or pharmacological (17,18). I cannot delve into each of these technologies, but there are a couple of important points that should be raised. The first is that in many cases, the external difference between these technologies is not very relevant, as the effects produced are essentially the same⁴. But it is true that pharmacological, and even more so genetic enhancement, could imply physiological changes that would radically alter the way memory functions. It is difficult to elaborate further on this possibility as we really do not know that much of the genetic underpinnings of memory. We know more about the effects of some drugs, but this knowledge is mostly casuistic and not a comprehensive understanding of the relationship between drugs and memory.

We can hypothesize, for example, that some form of biological intervention could turn temporary phosphorylation into stable phosphorylation, giving us the power to create long-term memories out of short-term memories at will. This kind of intervention may change the way we experience the act of remembering. An even more drastic intervention could be one in which Shereshevsky's condition (1) is emulated by discovering the genetic configuration that propitiated it, making our memory more similar to what the storage house conception of memory proposes. These kinds of enhancement are, at the moment, out of the realm of possibility, so they will not be addressed. In any case, the only thing that can be said for sure at the moment is

⁴ Technological memory enhancements can be more problematic, because “some components of our autotopography are mere triggers to biorecognition, whereas other components are constitutive parts of one's autobiographical memory systems” (42, p.1840). Distinguishing these two types of enhancers is impossible without a case by case consideration; but it is still important to be aware of this double aspect.

that memory enhancement by techno-bio-medical means is already feasible and, even though these procedures are still quite “crude and weak” (13, p.70), it is foreseeable that they will be perfected and expanded in the near future.

If we focus on the ethical implications of memory enhancement, the first thing to realise is that these ethical concerns are usually thought of in connection with personal identity issues. Here, I will very briefly present a defence of narrative identity, the approach I consider to be the most solid and comprehensive theory on identity. Explaining and justifying these points adequately would take us too far; however, it is crucial to at least delineate this position in order to properly address the cases discussed in the next section.

From what I have argued previously, it should be clear that we cannot advocate for any of the psychological views regarding identity. Psychological theories are heavily based on what I consider the mistaken storage house conception of memory. The psychological view, enunciated by John Locke in the 17th century and recuperated in the last decades by authors like Derek Parfit, understands personal identity as consisting in the continuity of mental states connected by memory. The basic idea is that our identity consists of the unity of many distinct memories that we can retrieve at any moment, forming a virtual chain that would amount to our identity. This theory has innumerable problems (4, p.7-8), something that, however, does not prevent it from being the theory most people hold intuitively. The point, as we will see, is that it correctly points to a life-continuity which is very near and dear for all of us. But the way it is described is mistaken and based on 17th century scientific knowledge (19). Much more accurate and richer is the narrative view of identity, which also points to the aforementioned continuity as the core of our identity but does so in a more complex and nuanced way. What proponents of narrative identity theories defend is that our identity, *who* we are, is the result of the story we (and our context) tell of ourselves. We could say, following this metaphor, that we are the main character of this story. Memory is, of course, central for this vision of identity. But the idea of memory it is based upon is not the storage memory displayed in the psychological theories, but an autobiographical memory comprised of much more general ideas, emotions and summaries (4, p.7).

However, even though this paper aligns itself clearly with narrative theories, I believe that these kinds of theories must be very firmly rooted in our biological, social and technological nature. We must understand how exactly our biology produces and demands narratives; how our social context also demands, reinforces and creates individual and collective narratives; and how our technological environment (20, p.3140) also contributes crucially to the creation of our narrative identity by reinforcing, solidifying and evoking certain ideas, emotions and moods that form human narrative memory. The point is that, even though I believe that the best framework to comprehend memory is the one provided by the narrative model, we should not fall into a subjectivist understanding of this model. Such subjectivist understandings, which might imply a certain degree of arbitrariness, should be discarded in favour of an understanding that emphasizes the importance of our biology, our social constitution and our technological condition, all factors that greatly limit the creative freedom of our memory.

Returning to the point about the ethical implications of memory enhancement, I agree with DeGrazia that memory enhancement critiques are usually directed at how it would affect our identity, and more precisely our narrative. DeGrazia distinguishes identity – which he defends as basically our body – from our narrative (21, p.232). From my perspective this distinction is somewhat unwarranted: our identity and our narrative are completely intertwined. However, I would agree with DeGrazia in that no change to our narrative can directly and only by itself imply a change in our identity. I can change my narrative, deciding I no longer want to be a philosopher, but instead desire to be a journalist. Whatever my decision is, I would still be *me*, who was a philosopher and is now a journalist. Even when we see people who undergo deeper changes, like a killer who becomes an NGO leader, we still think this is the same human being who was a murderer and is now a good person. DeGrazia believes this is the case because no change in our narrative can lead to a sufficiently drastic bodily change. For my position, this is also true, but not completely.

The key point for us is that narratives are very flexible, and it is very difficult, almost impossible, to imagine an event that we could not incorporate into our autobiographical narration and that would imply the start of a new identity. Because when this happens, we do not talk of a new identity or an identity change, we consider it a disruption of our identity that should be addressed by psychiatry. If I suddenly started to say that I am Julius Caesar – even if I acted, spoke and thought in a way that showed full conviction about it – nobody would say that I had become a different person (a different *I*); they would simply say that I went crazy. If I changed from being a charitable, goodhearted and nice person to a selfish, evil and despicable person, they would assume that the same person (that is, *me*), probably had undergone some horrible event or situation that created these changes in me, looking for a narrative reason that would explain the transformation.

These reflections on personal identity, which as I noted and we will see are crucial to addressing the possible ethical problems of memory enhancement, can and should receive some illumination from the initial neuroscientific discussion. As I have defended, the narrative model of memory matches much better the latest neuroscientific findings on memory, and this also applies to narrative identity theories. If this were to be true, it would further support my thesis that new biomedical memory enhancement does not bring something essentially new to the table. One of the main points is that, even if we are not used to seeing it this way, as a matter of fact, all narrative modifications influence our brain and cause physical (synaptical) changes. This, however, does not mean that our identity changes: the margin of variability in which these changes take place is perfectly within the explanatory range of a sufficiently subtle biological definition of human identity (19). Synaptical changes do not turn us into another person. The important point here regarding memory enhancement is that our brain is very accustomed to functioning in direct relationship with all sorts of memory enhancers. If the new enhancers do not directly interfere with or radically change this neuro-synaptical infrastructure, then we could argue that their moral treatment should be the same as old

enhancers with similar effects⁵. For instance, if we find acceptable/unacceptable to use psychotherapy to blunt the vividness of a victim of child abuse, we should also accept/reject modern memory enhancers that involve technology or pharmacology (12).

Case discussion

To conclude, I will go through some examples that will hopefully clarify the position I have defended, i.e., that memory is a creative and reconstructive endeavour that is not fundamentally affected by memory enhancement technologies. What this means is that we do not face new ethical implications for memory enhancement. The new conception of memory I have presented, a conception that neuroscience seems to confirm, makes it so that memory enhancement brings no substantial or radically new ethical implications. I will further explain this thesis with some cases and examples. The kind of thought-experiments I discuss here are, however, substantially different from science-fictional thought experiments in that the conditions are part of our current realm of possibility, or very close to it. Most of these cases, it should be noted, have to do with the discussion surrounding memory erasure or memory blunting in PTSD patients, for which among other means, the beta-blocker Propranolol has already proven successful (22). The examples and cases that could be examined are many, but I will leave aside the easiest ones in favour of those that are the most problematic.

First, let's tackle the case of Martin Luther King (23), which goes as follows: "If Martin Luther King had blunted or forgotten his memories, he would not have become the civil rights champion he got to be". An analogous case would be the "mourning husband" case, in which a husband decides to erase the memories of his dead wife to overcome the pain of losing her. In both cases I would argue that there is a false assumption that these memories are pernicious. In a sense, it is clear that Martin Luther King and the husband are not "happy" to retain their memories: it is painful to remember a wife's loss or to feel again the racism suffered as a child. But they can arguably still value those memories as a key part of their narratives, as a key part of their self-projects⁶. This is very different, however, to the cases of memories that hold no value. In these cases, people may not want their life to be defined by those valueless memories, as could be the case of children abused during their infancy. In this kind of case, I do not see the problem with blunting or erasing those memories. Our brains naturally erase or at least bury undesirable memories. As was shown above, remembering is a creative action in which information is continuously re-elaborated. Also, at a more conscious level, we sometimes simply elect to not make those memories a central part of our narrative. The point is not that memories and narrative are not essential to identity, but that no specific memory or narrative is essential, at least in principle, for anyone. Only retrospectively can we have the illusion that an event of our life was necessary, or that the narrative we effectively constructed is the only one we could have crafted. But the truth is that there is no necessity in any of these: there are always many ways in which events could have unfolded and there are many different narratives that can be elaborated⁷. Technology does not change this fundamentally, and that is why it does not raise radically new problems.

Another typically discussed case is the possibility of erasing a murderer's memories⁸. In Erler's opinion, "There is something seriously disturbing about a murderer who lives his life believing that he has never done much harm to anyone. Also, it is plausible to think that Carl owes it to his victim to remember that he has shot him dead" (12, p.244). We may intuitively agree with this, but if we think about it, we have to ask ourselves what we really pursue with incarceration, punishment and the penitentiary system. Because, if we go beyond our emotions and intuitions, we might find that there really is nothing wrong with erasing a murderer's memory. We have to ask ourselves if there is any good reason to maintain a murderer's memory other than the impression that doing so would be disrespectful or dishonourable to the relatives (or the society as a whole). "Keeping the memory" of our victims is probably very important, but this does not necessarily collide with erasing a criminal's memories. We could, as a society, remember the crime, even build memorials, but nonetheless erase the murderer's memory and send him to another city, state or country so that he can start a new life (similar to what happens in witness protection cases). But even if we end up determining that there are good reasons to maintain a murderer's memory, we would have to balance those reasons with the arguably enormous social benefit of removing a dangerous criminal from society (arguably with much less adverse side-effects than currently used methods) and the also formidable gain of re-orienting a person away from a criminal life into a life of goodness. All this presumes that memory erasure of this kind becomes feasible and that their effects would be the ones described here, conditions that, of course, may never become reality.

This proposal, however, could be socially and ethically problematic if we take into consideration the deterrent power of punishment. From this perspective, a potential criminal would be encouraged to commit a crime if he understands that possible punishment is soft or inexistent. This is a fair concern, but it can be disputed. One point is that losing your memories arguably implies losing a key part of your identity, which is not negligible. For many potential criminals, however, this could be a more than acceptable trade-off. This line of reasoning, though, also carries important problems. Understanding deterrence as the main goal of criminal legislation could force us to endorse a hardening of punishment that seems contrary to the tendency that

⁵ This argument, even though not entirely equal, is similar to Levy's ethical parity principle (43), which argues that internal and external enhancers should be treated equally.

⁶ The point here is to understand that no concrete memory is valuable in itself, but always depends on the general narrative in which an actual person is immersed. Martin Luther King's memories of racism had value for him, as the champion of human rights he wanted to become and became. For a quiet housewife that has no political preoccupations and only wants to have a peaceful life, the memories of a particular incident in which she received some racist insults could hold much less value or not be valuable at all.

⁷ The only problem with these kinds of procedures, as we will see with another of the examples, is that the social and objectual component of memory would still be there, in most cases, which would result in an unsustainable situation if that component is not also taken into account for the procedure.

⁸ We should be careful and say, more accurately, that those memories would not be erased. It would be more precise to talk about a prevention of the recreation of certain memories. But, for the sake of simplicity, I will simply acknowledge that "erasing a memory" is a metaphor just as when we talk about "the rising sun".

legislation has exhibited over the last centuries. If our goal is to create a better society and strive for criminals' reintegration, it is quite possible that erasing murderers' memories is the best way to achieve such goals, as it would presumably prevent them from reverting to their murderous narrative. This might be thought of as a "hard bullet to bite", but the underlying reasoning does not seem completely implausible. Greene and Cohen (24), among others, have defended such a consequentialist justification, criticizing the retributivist, common-sense view.

In any case, if we accept the creative nature of memory I have been defending throughout the paper, it could even be argued that this memory erasure procedure should not necessarily imply a reduction of the criminal's sentence. Under a retributivist paradigm, there could be reasons to still make the murderer undergo the suffering of being incarcerated as a reparation for the rest of the community. Erasing the criminal's memories would not be, in this regard, so much an alternative form of punishment but a way of creating the conditions for the criminal's true reinsertion in society. Incarceration, on the other hand, would be maintained as the criminal's punishment and as a way of repaying society. Furthermore, it could be right to erase memories even without consent. This could raise problems of bodily integrity – "a right to be free from physical interference" (25, p.241) – and cognitive liberty – "the right to mental self-determination, defined as the right to change his or her own mind and choose the means by which this change occurs" (26, p.295). These are legitimate concerns that should be addressed, but we already have examples of both that could serve as precedents. Bodily integrity is not respected in penalties of chemical castration for sexual criminals. Cognitive liberty, aside from being a very a problematic concept, is arguably not respected with many of the obligatory reinsertion courses (psychological, psychiatric, motivational, etc.) that are designed to completely change the way the criminal thinks and feels. And, in general, it could be argued that mere incarceration involves the disposal of the body and mind of the convict. This reflection is another example of how the proposed new understanding of memory could help us see these memory interventions in a different light, maybe even concluding that we are not in completely new territory.

These cases and the associated discussions, inadvertently raise one important problem with these types of memory erasure procedures: that, for the new narrative to successfully settled, no one of the subject's personal environment should know or remember him as a murderer (or racism victim, or widower), which could prove to be quite difficult. Narratives are external in many ways. Liao and Sandberg have noticed this problem, explaining that "If everyone else around you remembers what in fact has happened, you may be constantly told of this even if you removed certain memories. The social nature of remembering can put a limit to how inconsistent or false memories can be" (11, p.91). However, social environments also (slowly) evolve; and it wouldn't be out of the question to think that society could grow to understand and tolerate these cases of memory erasure and blunting, trying not to contribute to recreating those harmful memories, or even undergoing the same memory erasure procedure.

Memory, however, is not only external in a social, collective way. Memory is also external in an objectual, technological way. Heersmink has developed an interesting framework in which extended or distributed mind accounts merge with narrative identity theories showing how artefacts are a constitutive part of our mind, narratives and identities (20). As this author claims, personal identity can neither be reduced to psychological structures instantiated by the brain nor to biological structures instantiated by the organism, but should be seen as an environmentally-distributed and relational construct. In other words, the complex web of cognitive relations we develop and maintain with other people and technological artifacts partly determines our sense of self (20, p.3135).

The relative solidity of this artefactual component of memory is, in some respect, more problematic than the social component of memory previously discussed. People can change their minds, or simply forget collectively about certain things. But the objects that surround us and that are an integral part of our memory seem less malleable. However, the same argument as before is applicable. If we want to display an effective memory enhancement, we should take into account the objectual component of memory and make sure that it will not contradict our enhancing purpose.

These previous cases also raise one typical issue brought up by memory enhancement critics, which is that these memory erasing procedures "might cause a loss of empathy if we would habitually erase our negative experiences, and because it would violate the human duty to remember and oppose crimes and atrocities" (27, p.287). I would say that this argument is flawed, as I tried to show with the examples above. Such an appeal to our emotions is quite dangerous and misleading. The justice system does not work thanks to emotion; on the contrary, justice was born when instead of following our instincts and falling into vengeance's wheel, we approached crimes and faults rationally, creating the institutions and laws that we thought would promote what we considered a fairer and better society. The argument above seems to imply that by blunting or erasing memories, our rational capacities would be disrupted, and we would start thinking that murder, racism or child abuse are fine – something that is highly unlikely. While it is true that we are not pure rational beings, and that our rationality is profoundly mixed with irrational and emotional elements, we should address these kinds of problems via laws and institutions, which should be as rational as possible.

For the sake of discussion, I would like to explore two other examples. The first one is about Sara, a hard-core fan of *Casablanca* who is offered a memory erasing procedure to make her forget about the film, so that she can experience the pleasure of watching it again for the first time. The second example involves Phil, a lonely office worker who is having some

⁹ Greene and Cohen similarly argue and recommend "a shift away from punishment aimed at retribution in favour of a more progressive, consequentialist approach to the criminal law". (24, p.1775)

serious confidence problems and has become too insecure to approach any women. He is offered a memory implantation procedure by which his narrative would be rewritten to remember many past romantic successes, which would plausibly reinforce his confidence. As with the cases of Martin Luther King and the mourning husband, the important point here is the value each individual assigns to any specific memories, and how those memories relate to their self-project. The corollary is that our assessment of memory enhancement inevitably must be case dependant. We cannot, on principle, determine whether a memory enhancement intervention is positive or negative. It will always depend on the intentions and consequences of the acts involved; a conclusion that reinforces our thesis that memory enhancement does not constitute a novelty for our understanding of memory, identity and ethics.

Erasing a good memory, as in the case of the hardcore fan of *Casablanca*, could be a loss, in some way; but if the expected benefit derived from being able to watch it again for the first time is greater than the loss, I do not see any reason why it would be ethically problematic. The lonely office worker case could become problematic in the same sense as we discussed before: the social environment could render the memory implantation ineffective. However, this is not a given, and if implemented wisely and proportionately, memory implantations of this kind could be highly beneficial.

I have argued throughout the paper that memory enhancement does not bring a radical novelty to memory, because human memory is and has always been an enhanced reality. However, new technologies such as computers and smart phones do seem to drastically improve our memory in ways no other previous technology has ever done. Do these technologies entail new and important ethical problems? A recent experiment can answer this question. The theoretical problem this experiment addresses is the following: “Some may believe that enhancing memory or cognition means that the memory trace will be irrevocably etched in our brain and/or everything we hear, smell, see, etc. will be equally encoded and stored, making our brain a wasteland of non-interpretible junk memory traces, as Rose implies” (28, p.188). This is the scenario of the chapter “The story of my life” from the TV Show *Black Mirror*, a chapter where little bean-sized implants let us record every experience we go through. In any case, the severe downside of not being able to forget (discussed long ago by Nietzsche in the second treatise of his *On the Genealogy of Morality*), is not even a hypothesis, as the case of Solomon Shereshevsky shows how impairing is this condition (1).

Since the 2000s, some authors have explored this preoccupation about the possibility of total recall (29-31). The issue could consist of a real – not only conceptual – confusion or, better put, appropriation of biological memory by computer-like memory. Furthermore, this scenario is far from science-fictional, because, as Clowes explains, “Whereas drugs that may produce cognitive enhancements or more direct brain-machine interfaces garner great academic and popular attention, it almost seems as though Cloud-Tech is already becoming so widespread and everyday that we scarcely bother to examine it deeply.” (32, p.264). The compulsory question, therefore, is: “What are the cognitive implications of relying heavily on these particular technologies [Google, Wikipedia and the ever growing panoply of smart phones, personal gadgets, devices and software technologies] which fulfil tasks and functions that we once would have performed either with our brains alone, or with radically different set of cognitive artefacts?” (32, p.264).

Clowes shows that there is already an important literature on the topic (33-35), but all these theoretical approaches can benefit now from a recent and very illuminating experiment carried out by A. Konrad and his colleagues. In their article “Technology-Mediated Memory: Is Technology Altering Our Memories and Interfering With Well-Being?” (36), they ask themselves a concrete question: “Do we benefit from revisiting rich digital records of our past, or are some details best forgotten?” (36, p.2). The question is phrased this way because “psychological theories show that everyday organic memory presents a non-veridical view of our past that benefits our well-being” (36, p.2). The experiment involved the creation of an application, “Echo”, which allowed participants to record in great detail their daily lives and their retrospections about it (36, p.8-13). The results showed that the application improved well-being (36, p.13), and crucially, that this external memory enhancer “can also manifest exactly the same adaptive memory biases as organic memory, including overall positivity as evidenced in emotion ratings, content words, and ratio of positive to negative posts. Furthermore, the content of posts became more positive over time, suggesting rosy retrospection” (36, p.22). Even though there are other studies with divergent conclusions (37), this particular experiment clearly shows that (biological) memory interacts with memory enhancement in the creative re-elaborative way I have presented, and that memory enhancers can in fact promote well-being by helping to build up our narrative in a better way. This conclusion, even if not definitive, constitutes a clear support of the main thesis of this paper: that memory enhancement does not substantially change the way our memory works, and that, therefore, its ethical implications are not significantly different. Arguing that devices and applications such as “Echo” distort our memory is ignoring the creative way in which human memory has always worked. Concluding that such technologies will necessarily diminish our well-being is unwarranted, as the above experiment shows. This, again, does not mean that technological interventions on memory are free of ethical issues. It just means that its ethical implications – that is, authenticity concerns, responsibility issues – are basically the same as the ones related to “non-enhanced” memory.

Conclusion

To conclude, I would like to say that, if there is one thing that should always be remembered about human enhancement, and even more so regarding memory enhancement, is that we must be cautious in our assessments. I have defended the position that memory enhancement does not introduce radical novelty in the way memory affects human identity – at least with the current state of memory enhancement techniques. Memory enhancers do not change the way our biological memory works,

because it is mainly creatively. Neuroscience has shown beyond a doubt that memory is not a storehouse but instead a restless factory that never ceases to construct and reconstruct memories. Also, memory is and has always been external (socially and objectively), so enhancement devices also are not a substantial innovation. In the memory enhancement cases presented here, I could not find strong enough arguments to reject a responsible and autonomous use of memory enhancement. This means that memory enhancement does not raise special ethical implications. But none of these conclusions are set in stone: new scientific investigations might change our understanding of human identity and memory; new technological creations might transform our way of being in the world. In any case, philosophy shall keep thinking from and through these scientific investigations and technological creations, making sure our ethical understanding keeps pace with techno-scientific development.

Conflits d'intérêts

Aucun à déclarer

Conflicts of Interest

None to declare

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References

1. Squire LR. [Memory and brain systems: 1969–2009](#). The Journal of Neuroscience. 2009; 29(41):12711–12716.
2. Kourken M, Sutton J. [Memory](#). The Stanford Encyclopedia of Philosophy. Edward N. Zalta (ed.), 2017.
3. Brockmeier J. Beyond the archive: memory, narrative, and the autobiographical process. Oxford Scholarship Online. 2015. DOI: 10.1093/acprof:oso/9780199861569.001.0001
4. Schechtman M. [The truth about memory](#). Philosophical Psychology. 1994;7(1):3-18. DOI: 10.1080/09515089408573107
5. Miller MD. [What college teachers should know about memory: a perspective from cognitive psychology](#). College Teaching. 2011;59(3):117-122, DOI: 10.1080/87567555.2011.580636
6. Baddeley AD. Human memory: Theory and Practice. Boston: Allyn & Bacon; 1998.
7. Blatti S. [Animalism](#). The Stanford Encyclopedia of Philosophy, Edward N. Zalta (ed.); 2019.
8. Luria AR. The mind of a mnemonist: A little book about a vast memory. Harvard: University Press; 1987.
9. Quian Quiroga R. The forgetting machine: memory, perception, and the “Jennifer Aniston neuron”. Dallas: BenBella Books; 2017.
10. O'Shea M. The Brain. A very short introduction. Oxford: Oxford University Press; 2005.
11. Liao SM, Sandberg A. [The normativity of memory modification](#). Neuroethics. 2008;1:85–99.
12. Erler A. [Does memory modification threaten our authenticity?](#) Neuroethics. 2010;4:235–249.
13. Levy N. [Neuroethics: ethics and the sciences of the mind](#). Philosophy Compass. 2009;4(1):69–81.
14. Bostrom N, Sandberg A. [Cognitive enhancement: Methods, ethics, regulatory challenges](#). Science and Engineering Ethics. 2009;15:311–341.
15. Spiers HJ, Bendor D. [Enhance, delete, incept: Manipulating hippocampus-dependent memories](#). Brain Research Bulletin. 2014;105:2–7.
16. Jacobs S, Tsien JZ. [Genetic overexpression of NR2B subunit enhances social recognition memory for different strains and species](#). Plos one. 2012;7(4):1-11.
17. Glannon W. [Psychopharmacological enhancement](#). Neuroethics. 2008;1:45–54.
18. Maslen H, Faulmüller N, Savulescu J. [Pharmacological cognitive enhancement - how neuroscientific research could advance ethical debate](#). Frontiers in Systems Neuroscience. 2014;8:Article 107.

19. Boniolo G. [The Ontogenesis of human identity](#). Royal Institute of Philosophy Supplement. 2005;80(56):5.
20. Heersmink R. [Distributed selves: personal identity and extended memory systems](#). Synthese. 2017;194:3135–3151. DOI 10.1007/s11229-016-1102-4
21. DeGrazia D. Human Identity and Bioethics. New York: Cambridge University Press; 2005.
22. Pitman RK, Delahanty DL. Conceptually driven pharmacologic approaches to acute trauma. CNS Spectrum. 2005;10:99–106.
23. Vaiva G, et al. [Immediate treatment with propranolol decreases posttraumatic stress disorder two months after trauma](#). Biol Psychiatry. 2003;54:947–9.
24. Greene J, Cohen J. [For the law, neuroscience changes nothing and everything](#). Philosophical Transactions of the Royal Society. B. 2004;359:1775–1785. doi:10.1098/rstb.2004.1546
25. Feldman D. Civil Liberties and Human Rights in England and Wales, Oxford University Press; 2002.
26. Weissenbacher A. [Defending Cognitive liberty in an age of moral engineering](#). Theology and Science. 2018;16(3):288-299. DOI: 10.1080/14746700.2018.1488476.
27. Bolt LLE. [True to oneself? broad and narrow ideas on authenticity in the enhancement debate](#). Theoretical Medicine and Bioethics. 2007;28:285–300.
28. Gerlai R. [Memory enhancement: the progress and our fears](#). Genes, Brain and Behavior. 2003;2:187–190.
29. Bell C, Gemmell J. Total recall: how the E-memory revolution will change everything. Dutton; 2009.
30. Sellen AJ, Whittaker S. [Beyond total capture: A constructive critique of lifelogging](#). Communications of the ACM. 2010;53(5):70–77.
31. Mayer-Schönberger V. Delete: the virtue of forgetting in the digital age. Princeton University Press; 2011.
32. Clowes R. [Thinking in the cloud: the cognitive incorporation of cloud-based technology](#). Philos. Technol. 2015;28:261–296.
33. Carr N. The shallows: how the Internet is changing the way we think, read and remember. London: Atlantic; 2010.
34. Greenfield, S. ID: the quest for identity in the 21st Century. London: Sceptre; 2008.
35. Turkle S. Alone together: why we expect more from technology and less from each other. New York: Basic; 2011.
36. Konrad A, Isaacs E, Whittaker S. [Technology-mediated memory: is technology altering our memories and interfering with well-being?](#) ACM Transactions on Computer-Human Interaction. 2016;23(4):Article 23.
37. Sas C, Whittaker S. [Design for forgetting: disposing of digital possessions after a breakup](#). Proceedings of the SIGCHI Conference on Human Factors in Computing Systems, Paris, France. ACM. 2013.1823–1832.
38. Walker WR, Skowronski JJ, Thompson CP. [Life is pleasant—and memory helps to keep it that way!](#) Rev. Gen. Psychol. 2003;7:203–210.
39. Mitchell TR, Thompson L, Peterson E, Cronk R. [Temporal adjustments in the evaluation of events: The “rosy view”](#). J. Exp. Soc. Psychol. 1997;33:421–448.
40. Walker WR, Skowronski JJ. [The fading affect bias: But what the hell is it for?](#) Appl. Cogn. Psychol. 2009;23:1122–1136.
41. Campbell RS, Pennebaker JW. [The secret life of pronouns: Flexibility in writing style and physical health](#). Psychol. Sci. 2003;14:60–65.
42. Heersmink R. [The narrative self, distributed memory, and evocative objects](#). Philos Stud. 2018;175:1829–1849.
43. Levy N. Neuroethics: Challenges for the 21st Century. Cambridge: Cambridge University Press; 2007.

COMPTE RENDU / REVIEW

1^{er} Café de bioéthique « Le citoyen et ses objets connectés : qu'advient-il de ses données? »

Antoine Boudreau LeBlanc¹, Marie-Alexia Masella¹

Résumé

Ce compte-rendu résume les échanges tenus lors du 1^{er} Café de bioéthique de 2019, qui a porté sur le thème : « Le citoyen et ses objets connectés : qu'advient-il de ses données? » Trois experts panélistes et un public de 70 personnes ont participé à cette rencontre. La discussion a notamment précisé les avantages que peuvent avoir les objets connectés, tels qu'une autonomisation et une responsabilisation des individus, mais a aussi mis en lumière certains risques comme une hypernormativité ou encore la question d'obtention d'un consentement valide. Des pistes de solution et de réglementation ont été proposées par le public et les experts. Cette rencontre s'inscrit dans une série de trois Cafés de bioéthique tenue à Montréal et à Québec sur le sujet de l'éthique, de la santé et des données.

Mots-clés

éthique des données, mégadonnées, intelligence artificielle, objets connectés, GAFA, transfert de connaissance, événement public, bioéthique globale

Abstract

This review summarises the discussion during the 1st Bioethics Café of 2019, which focused on the theme: "Citizens and their connected objects: what happens to their data?" Three expert panelists and an audience of 70 people participated in this event. The discussion clarified the benefits that connected objects can have, such as empowerment and individual responsibility, but also highlighted some risks such as hyper normativity or the issue of obtaining valid consent. Potential solutions and regulations were proposed by the public and experts. This event was part of a series of three Bioethics Cafés held in Montreal and Quebec City on the subject of ethics, health and data.

Keywords

data ethics, Big Data, artificial intelligence, internet of things, GAFA, knowledge transfer, public event, global bioethics

The English version of this text appears below / La version anglaise de ce texte figure ci-dessous.

Introduction

Le mercredi 3 avril 2019 s'est tenu à Montréal le 1^{er} de trois [Cafés de bioéthique](#) portant sur l'éthique, les données et la santé, intitulé « Le citoyen et ses objets connectés : qu'advient-il de ses données? » Cette rencontre a été diffusée en direct et enregistrée sur [YouTube](#). L'événement a été organisé par des étudiants des Programmes de bioéthique de l'École de santé publique de l'Université de Montréal (ÉSPUM) et animé par le directeur des Programmes de bioéthique, M. Bryn Williams-Jones. Trois experts ont participé comme panélistes : Mme Catherine Régis, professeure agrégée de la Faculté de droit de l'Université de Montréal et titulaire de la Chaire de recherche du Canada sur la culture collaborative en droit et politiques de la santé ; M. Guy Paré, professeur titulaire au Département de technologies de l'information à HEC Montréal et titulaire de la Chaire de recherche en santé connectée ; et M. Ma'n H. Zawati, directeur exécutif du Centre de génomique et de politiques du Département de génétique humaine de l'Université McGill et membre associé de l'Unité d'éthique biomédicale. Ce Café visait à réunir des experts provenant de divers champs académiques intéressés par les grands défis et enjeux éthiques actuels qui entourent la santé et l'effervescence associée aux mégadonnées en recherche et en société.

Cette réunion a ainsi offert une plateforme idéale pour favoriser une rencontre et un échange interactif et dynamique entre des experts d'horizons différents et le public, sur un sujet d'actualité qui nous concerne tous. L'objectif de ce compte-rendu est de présenter les idées centrales qui ont émergé de cet événement dans un format synthétique. Les arguments soulevés s'inscrivent dans le large débat entourant les mégadonnées, l'intelligence artificielle et leurs nombreuses déclinaisons en objets et applications intelligentes. Nous allons présenter, selon un plan thématique, les différents questionnements et arguments des échanges entre les experts et le public. Dans un premier temps, nous exposerons les principaux concepts qui ont servi de fil conducteur à cette activité puis nous aborderons les espoirs et les promesses que suscitent les objets connectés. Par la suite, nous verrons quels sont les risques associés à l'utilisation et à la circulation de ces applications. Enfin, nous nous attarderons sur un enjeu souvent évoqué, tant par le public que par les experts : la responsabilité liée au fonctionnement et à l'utilisation de ces technologies. *Qui est responsable de la technologie? Qui est responsable d'assumer le fardeau des risques? Qui est responsable et comment doit-on rendre des comptes?*

Les principaux concepts

Mégadonnées, intelligence artificielle et objets connectés

Les mégadonnées (MD), l'intelligence artificielle (IA) et les objets connectés (OC) sont des concepts distincts, mais de plus en plus utilisés par les experts et le citoyen pour désigner un phénomène sociotechnologique qui nous dépasse : celui de la production massive de données (MD) traitables par des techniques sophistiquées (IA et statistique) et pouvant produire des technologies précises et personnalisées (OC) qui modifient la relation entre l'humain et la technologie. Cependant, en lien avec tous ces concepts et leur omniprésence grandissante dans nos sociétés, de nombreux enjeux éthiques apparaissent, imbriqués dans de multiples dilemmes légaux, sociaux, économiques et techniques (1,2).

Objets connectés

M. Paré a souligné que l'une des dernières grandes innovations technologiques de l'ère contemporaine est représentée par l'apparition des objets connectés qui permettent, à travers leurs utilisations diverses, de relier la vie réelle à la vie numérique. Le rapport émis par le *Centre facilitant la recherche et l'innovation dans les organisations* (CEFRIO) en 2017 donne la définition suivante : « Un objet connecté peut être simplement défini comme étant un objet du monde réel ayant une capacité de communication » (3, p.5). Élément de mode ou bénéfice réel pour le citoyen, nous retrouvons néanmoins 15 milliards de ces objets dans le monde en 2015, et ce marché continue de se développer, précise M. Paré (3). Ces objets sont reliés à un nombre important d'applications, sans cesse en augmentation, dont la plupart ont la capacité d'échanger automatiquement de l'information via internet (d'où l'appellation connectée) (4). En outre, 70% de ces applications toucheraient au domaine de la santé et du bien-être (4).

La quantification de soi

Les panélistes ont tous confirmé le lien étroit qui existe entre ces objets connectés et les principes d'autonomisation et de responsabilisation des citoyens. Les individus peuvent réaliser ce que les experts appellent une quantification de soi : « il s'agit de collecter, mesurer, comparer différentes variables biologiques, physiques, comportementales et environnementales, dans un objectif de mieux-être, de maintien ou d'amélioration de l'état de santé » (4, p.5).

Personne ou citoyen

Par le choix du thème – « Le citoyen et ses objets connectés » –, les organisateurs voulaient souligner les enjeux politiques et légaux liés à la production et l'utilisation des objets connectés. Le terme citoyen se rapporte aux droits et devoirs que possède une personne dans l'État dans lequel elle vit. Il apparaissait donc important pour l'événement d'aborder également les enjeux éthiques touchant aux droits de la personne et à la protection des renseignements personnels, mais aussi à la globalisation et à la commercialisation des données de santé, ainsi qu'à la question de responsabilité, qui touche à la fois l'individu, le citoyen et les instances publiques et privées dans lesquels le citoyen évolue.

Espoirs et promesses

Les espoirs et les promesses que peuvent apporter ces nouvelles technologies concernent la société (dimension macro), s'enrichissant de nouveaux services fluides et sophistiqués, mais aussi l'individu utilisant ces objets connectés (dimension micro).

La société

Amélioration du système de santé et limite de l'accessibilité à des données de qualité

Les trois experts ont relevé l'avantage envisagé de ces objets connectés et de leurs données compilées dans l'amélioration du système de santé, en évoquant de nombreuses utilisations avérées qui accroissent l'efficacité du système et la pertinence de soins. Selon Mme Régis, ces « données plus fines et plus précises » vont permettre « de documenter davantage ce qui est fait, ce qui fonctionne et ce qui ne fonctionne pas dans le système de santé ». Comme elle le souligne, le Commissaire à la santé et au bien-être du Québec a comme mandat d'évaluer le système de santé pour enrichir le débat public et la prise de décision gouvernementale, mais « que l'un des défis primaires qui est posé à son activité au Québec est l'accessibilité à des données de qualités pour évaluer et améliorer ce que l'on fait ». Cette amélioration repose donc sur l'acquisition de données numériques de qualité via le réseau de la santé, mais aussi, de plus en plus, par des objets connectés offrant des données personnalisées sur le patient.

Accessibilité équitable aux objets connectés entre les citoyens et les sociétés

Un questionnement revenait de la part du public : *Comment garantir une accessibilité équitable et juste dans le monde et au Québec ?* À l'international, comme le précise Mme Régis, « c'est aussi une aubaine », car ces avancées accroissent l'accès aux nouvelles technologies permettent d'apporter et de rendre plus accessibles certaines ressources jusqu'alors inaccessibles pour des régions du monde. Elle propose comme exemple le téléphone qui, « de façon globale, permet de joindre des personnes dans plusieurs pays qui n'auraient pas accès à des soins [...] ; cela leur permet d'avoir accès à une base d'information pour leur santé, pour se diagnostiquer ou comprendre ce qu'il se passe ou quoi faire, c'est quand même utile ». M. Zawati transpose cette promesse au cas québécois en indiquant que la couverture internet est de plus en plus homogène et complète, « il y a plus de connexions que d'habitants en Amérique du Nord ». D'après lui, cette accessibilité est présente et va continuer de se développer et de se démocratiser. Cette évolution nécessite cependant du temps, et confirme ainsi les défis reliés à l'analphabétisme numérique et aux disparités des ressources et services entre les métropoles et les régions (5).

Autonomisation, responsabilisation et démocratisation

Dans une optique où l'accessibilité continue à progresser, l'autonomisation qu'elle engendre permet de proposer les ressources nécessaires aux personnes pour qu'elles puissent s'occuper d'elles-mêmes. M. Paré évoque notamment le cas actuel des sociétés vieillissantes dont les besoins en soins à domicile sont en hausse. D'après lui, que ce soit par des bracelets, des capteurs ou des traqueurs, une personne âgée pourrait, selon ces promesses, rester plus longtemps à domicile de manière sécuritaire et en recevant presque tous les soins nécessaires. Il existe déjà plusieurs innovations sur le marché qui

alimente ces espoirs. M. Paré souligne que « l'industrie des technologies de l'information tente de faire et de soutenir la promesse de vivre et se développer en santé longtemps et si possible chez soi ».

Ainsi, d'un point de vue sociétal, ces objets connectés et les données qu'ils génèrent permettent non seulement de favoriser le maintien à domicile des personnes âgées, mais peuvent également aider à améliorer le système de santé ici, au Québec, et contribuer à une dissémination des connaissances scientifiques à travers le monde.

L'individu

Connaissance de soi, autonomisation et responsabilisation

Ces nouvelles technologies (montres, bracelets, téléphones et autres objets intelligents) permettent aux citoyens de mieux se connaître physiologiquement, mais aussi psychologiquement. Comme l'indiquait Mme Régis, l'individu peut se passer de l'aide d'un professionnel dont les services sont souvent onéreux et désadaptés pour plusieurs populations. Pour un parent ou un travailleur ayant un emploi du temps bien rempli, il est souvent difficile de dégager le temps requis pour consulter. Ainsi, ces appareils peuvent venir en aide en fournissant un soutien plus personnalisé que les services sociaux et de santé conventionnels. Cela entraîne un réel avantage au niveau de « la personnalisation des soins, mais aussi de la démocratisation ou de l'autonomisation des soins », nous a-t-elle indiqué. Les données compilées pourront épauler une gamme de soins et de services sociaux plus individualisé et qui respecte le fait que chacun est un être unique et a des besoins qui lui sont propres. Parallèlement à cette personnalisation et à cette autonomisation, un accès en temps réel à nos données de santé et à nos données comportementales, en considérant par ailleurs l'intégration des informations trouvées sur le web, pourrait devenir un « accélérateur de la révolution de la démocratisation de l'information » alimentant également un phénomène d'*empowerment*, expliqué par M. Zawati comme à la jonction entre la responsabilisation et l'autonomisation.

Responsabilisation

Plusieurs exemples ont été présentés au sujet de technologies offrant au patient une meilleure compréhension de sa condition et des soins. Comme l'indique Mme Régis, une meilleure compréhension peut amener l'individu à se responsabiliser et, donc, à jouer un rôle actif dans sa prise en charge (ou autonomie) et dans son bien-être. Dès lors apparaît une décentralisation de l'expertise, selon M. Zawati : le soignant n'est plus le seul à posséder l'expertise de la santé. Le patient, particulièrement dans les cas de maladies chroniques ou rares, possède aujourd'hui plus de connaissances et fait preuve d'une expérience particulière : vivre avec sa maladie et sa santé. Cette vision va d'ailleurs de pair avec les récentes initiatives de patient-partenaire. Non seulement le patient peut instruire les soignants par la connaissance intime de sa maladie, mais il peut également bénéficier d'une personnalisation des ressources et de l'offre de soins mis à sa disposition pour effectuer son suivi médical et son traitement. Selon les panélistes, la frontière qui séparait autrefois le patient du soignant et qui était déterminée par le savoir pourrait doucement disparaître pour favoriser un partenariat équitable et unique dans l'histoire médicale.

Libérer du temps et efficacité des soignants

Sans naïveté, Mme Régis ajoute que ces technologies permettent également de libérer du temps aux professionnels de santé. L'intelligence artificielle (IA), notamment, offre de plus en plus d'applications basées sur des algorithmes sophistiqués qui permettent de poser des diagnostics ou d'établir des plans traitements personnalisés, laissant ainsi plus de temps au soignant pour interagir avec son patient. Elle précise cependant que, malgré ses espoirs de machines remplaçant certains actes humains, il nous faut réfléchir à l'effritement des relations humaines – soignants-patient : une conséquence possible de l'omniprésence des machines dans cette relation. Mme Régis soulève une question pertinente à poser dans diverses situations cliniques lié au rôle des machines dans l'offre de soins et de services : « Qu'est ce qui est vraiment important pour nous et que nous ne voudrions pas déléguer à une machine? » Le positif derrière de simples relations humaines entre patient et soignants permet de remettre l'humain au centre de la discussion et rappelle les énoncés de la [Déclaration de Montréal sur le développement responsable de l'IA](#) (6). D'ailleurs, aucune technologie n'est bienveillante d'elle-même, nous ont rappelé les panélistes à bons nombres de reprises : la technologie est un outil dont les bienfaits ou méfaits dépendent de l'utilisateur (voire du concepteur) (7).

Craines et risques

Les experts et le public ont aussi soulevé des risques inhérents à ces technologies et à leur utilisation.

Hypernormativité

Mme Régis évoque un risque d'hypernormativité : « la technologie est très normative et elle inscrit rapidement un sentiment de normalité » au sein de la société. Elle illustre cet argument en faisant référence à une époque, pas si lointaine, où l'on aurait considéré anormal de réaliser une conférence en direct, alors que pourtant ceci est conventionnel de nos jours pour faire rayonner un événement comme le présent Café de bioéthique. Lorsqu'inférée à d'autres sujets comme le partage de renseignements personnels, elle souligne que « ce sentiment de normalisation d'une surveillance constante nous fait perdre un peu conscience de l'importance de la vie privée ou de ce qui nous amène à désirer protéger cette valeur ».

Consentement

Consentement relationnel

Malgré un formulaire de consentement et des politiques de confidentialité, plusieurs corporations nient encore aujourd'hui l'interconnectivité entre le citoyen, sa famille et son voisinage, négligeant ainsi de prendre en compte la possibilité d'obtenir des renseignements sur une personne à partir d'une seconde, ex. : les renseignements génétiques. En effet, M. Zawati suggère que, « lorsque ces données vont devenir plus précises, on va parler de plus en plus de certaines données qui sont sensibles, des données qui ont à trait à vous en tant qu'individu, mais peut-être à d'autres personnes dans votre famille ». Sans politique plus adéquate, ces données sensibles continuent d'être utilisées par les exploitants de différents logiciels et ceci, sans avoir recours à un consentement libre, éclairé et continu, et sans considération supplémentaire pour ces risques dits relationnels liés aux familles et au voisinage.

Prévenir par l'éducation

Les formulaires de consentements proposés par la grande majorité des corporations actuelles ne contiennent pas toutes les informations nécessaires à l'utilisateur pour prendre une décision éclairée, et sont même parfois imposés au consommateur, ce qui va définitivement à l'encontre de tout cadre éthique concernant le consentement libre, éclairé et continu (8). D'après M. Paré, le premier facteur menant à un mauvais consentement – c.-à-d. un consentement ni libre, ni éclairé, ni continu – est lié au fait que peu de gens ont conscience des enjeux éthiques de confidentialité et de sécurité de l'information recueillie. Cette promotion des risques et le besoin d'éducation qui en découle deviennent évidemment une responsabilité partagée entre le citoyen, l'État et la corporation; la responsabilisation de cette dernière s'avère souvent lacunaire comme l'indique M. Paré. Mme Régis rappelle d'ailleurs la notion d'autodéfense intellectuelle introduite par M. Normand Baillargeon (9) qui peut aider les citoyens à être plus critiques et elle souligne les rôles qu'ont à jouer l'éducation publique et la santé publique dans cette éducation.

Complexité et subtilité des conséquences

Selon M. Paré, la nature des données peut être en cause, en raison de leur nombre, de leur complexité et de la subtilité des effets néfastes potentiels qui leur sont rattachés, rendant ainsi difficile pour le citoyen, mais aussi pour l'expert, d'y voir clair. Cette complexité et subtilité propre aux mégadonnées et à ces enjeux peut en effet rendre les citoyens moins suspicieux devant les diverses applications et être ainsi plus ouverts à consentir aveuglement au partage de leurs données. Par ailleurs, M. Paré précise qu'il y a également une culture sociale du laisser-aller à propos de certains types d'informations. Ainsi, il précise qu'il devient moins gênant d'accepter de communiquer librement des informations reliées à notre bien-être en général (comportements, habitudes de vies, émotions, etc.) que des données précises sur notre santé physique.

Inintelligibilité des formulaires, non-transparence et renforcement par récompense

En dépit de sa longueur, le formulaire de consentement renferme souvent des informations insuffisantes ou incomplètes ce qui laisse croire à un grave manque de transparence. Mme Régis indique que les individus acceptent plus facilement de fournir des informations au secteur privé qui leur offre une récompense immédiate. Elle ajoute que ces entreprises se nourrissent grandement des données obtenues à l'aide de modalités de consentement qu'elle qualifie d'inappropriées. Si ceci semble contre-intuitif au sens de maximiser l'intérêt individuel, Mme Régis nous montre cependant tout le sens commercial et publicitaire derrière cette mesure, rendant ainsi ce phénomène compréhensif en considérant le point de vue des stratégies d'entreprises, puis du consommateur. D'ailleurs, M. Paré indique qu'il existe, au Québec, une inégalité d'accès aux données entre le secteur privé et le secteur public, les chercheurs ne pouvant parfois pas réaliser leur recherche à cause de données inaccessibles ou insuffisantes, ce qui n'est pas le cas des entreprises privées. Ce phénomène expliquerait donc une certaine monopolisation de l'expertise par les grandes corporations (Google, Amazon, Facebook, Apple, Microsoft; GAFAM) par rapport aux gouvernements, pourtant des organismes publics.

Consentement par choix binaire

En référence aux formulaires de consentement à remplir, le public a aussi soulevé des craintes au sujet du choix binaire soit « accepter » ou « refuser » concernant les conditions d'utilisation à valider avant de pouvoir utiliser une application, un site ou tout autre support technologique. M. Paré suggère ainsi une option alternative soit « accepter, mais ». M. Zawati renchérit sur cette remarque en indiquant que plusieurs applications mobiles à l'international et au Canada présentent uniquement ce choix binaire auquel les utilisateurs doivent se conformer sans pouvoir faire de nuances, sans quoi ils n'ont pas accès au contenu. Ce dernier a souligné notamment des exemples de cas en santé dont l'intervention dépendant désormais de certaines de ces technologies et a également indiqué plus largement l'utilisation de plus en plus nécessaire de certaines applications intégrées directement à nos vies (ex. : Google Map).

Double usage et utilisation secondaire des données

L'utilisation de ces données provenant d'appareils connectés peut être risquée pour l'individu, notamment, en lien avec les possibilités de commercialisation secondaire de celles-ci (ou double usage), imposant de sérieux questionnements à propos de la propriété et de la profitabilité de celles-ci (*Qui profite ? À quelles fins ? Quelqu'un est-il exploité ?*). Pour illustrer ces risques, les experts et le public ont soulevé l'utilisation par les assurances de certaines données, ce qui peut entraîner une stigmatisation et une discrimination des individus, voire de groupes sociaux entiers, en raison des risques relationnels liés à l'interconnexion entre les données compilées. Face à ces risques, les trois experts s'accordent pour dire qu'il faut éduquer les citoyens et leur faire prendre conscience de ces situations. Mme Régis évoque à ce propos qu'il est important de demeurer

un citoyen avec des capacités de réflexion critique afin que le citoyen puisse se questionner par rapport à ces technologies et aux circonstances dans lesquelles celles-ci peuvent devenir problématiques, mesurer les liens entre ces technologies, ne pas croire tout ce que l'on dit et finalement, développer des outils d'autodéfense intellectuels (9).

Responsabilité partagée

À l'intersection entre ces risques et ces espoirs annoncés vient se positionner une vraie préoccupation qu'à la fois les experts et l'auditoire soulèvent : *la responsabilité*.

Responsabilité de la machine et de son utilisateur

Mme Régis aborde ce sujet en parlant de l'aide que peut apporter l'intelligence artificielle au médecin via le développement d'algorithmes plus performants que la capacité diagnostique du médecin. Elle soulève le « poids normatif que [ces algorithmes] auront », pour décider de la vie ou de la mort de patients. Il est vrai, comme elle le mentionne, que plusieurs questions se posent : *Quelle sera la réaction des professionnels soignants face à cela ? Existera-t-il une liberté de s'en écarter ? Quelle sera la réaction des tribunaux dans le cas où un médecin n'aurait pas utilisé ces outils à sa disposition ?* En tant que juriste, elle propose que les lois à venir précisent le rôle de l'algorithme : la machine est un outil pour l'humain qui, a contrario, ne doit jamais devenir au service de la machine, comme l'a soulevé d'ailleurs la [Déclaration de Montréal sur le développement responsable de l'IA](#) (6).

Responsabilité interdisciplinaire et transsectorielle

M. Zawati exprime un point de vue différent, notamment, en rappelant la nécessaire collaboration et intégration d'une diversité de parties prenantes autour des enjeux sociotechniques. Il aborde la question de la responsabilité pénale quant aux applications mobiles qui « font des associations entre un symptôme et une condition médicale ». Il y a là une vraie préoccupation quant à savoir qui propose cette information ainsi que la véracité et la clarté de celle-ci. Il ajoute également le fait que ce n'est pas de la responsabilité d'une seule personne, mais qu'il est important d'aborder cette responsabilité en concevant la cascade d'acteurs, du concepteur à l'utilisateur. D'après lui, il y a bien sûr l'individu qui a une « responsabilité de s'informer », mais le « Collège des médecins » a aussi une responsabilité : il devrait énoncer des principes et des lignes directrices sans équivoque en matière de mégadonnées, d'intelligence artificielle et de l'usage des objets connectés. Il pousse également la réflexion au long terme, en proposant l'émergence d'une nouvelle discipline comme le « medical computing » qui serait enseigné dans les facultés de médecine pour former les futurs soignants à l'utilisation de ces technologies.

Responsabilisation des médecins

M. Paré aborde aussi ce point de collaboration à l'interface entre les citoyens, le légal et les autres secteurs de la société, en insistant particulièrement sur la formation des médecins. Ceux-ci ne sont actuellement pas préparés au « tsunami » que sont les mégadonnées, l'intelligence artificielle et leurs applications dérivées, et ce fait a d'ailleurs été souligné par le public. Selon lui, plusieurs acteurs ont un rôle dans la mise en place de collaborations et d'échanges bien articulés – « une interopérabilité », soulève-t-il – permettant de développer un réseau solide à l'intérieur duquel les responsabilités seraient partagées : les facultés, les ordres, les professionnels, le citoyen, le ministère, etc. Il mentionne également le flux incessant et gigantesque de nouvelles applications mises sur le marché : « combien y a-t-il d'applications mobiles en santé sur Apple store ? 500 000. Et il en sort 500 par mois. [...] Qui est responsable de ça ? »

Dépenser le droit

À propos de cette responsabilité partagée, Mme Régis indique qu'il est parfois difficile de compter sur le droit pour tout réglementer, car selon elle, « le temps du droit n'est pas le même que celui de l'innovation », d'où d'ailleurs la figure forte et décevante du droit à la remorque du progrès scientifique, technique et social. Face à cette différence de vitesse, les décideurs, qu'ils soient parlementaires, de l'Institut National d'Excellence en santé et services sociaux (INESSS), ou de toute autre grande institution, ont un rôle à jouer que ce soit pour orienter ou faire des recommandations ajoute-t-elle.

Conclusions

Ce premier Café de bioéthique fait ressortir de nombreux enjeux. Certains mettent en contraste les espoirs et les craintes, d'autres, les risques et les promesses, mais de part et d'autre des questionnements apparaissent au sujet du partage des responsabilités. Ces objets connectés peuvent favoriser un *empowerment* des individus, mais des questions d'équité d'accès sont aussi présentes. M. Paré indique qu'il est donc important d'avoir une réflexion « sur ce qui peut contribuer à diminuer les inégalités et aussi contribuer à augmenter l'accessibilité », mais également d'améliorer la formation des soignants afin de les habiliter à l'utilisation de ces nouvelles technologies et de les sensibiliser aux risques qu'elles comportent. Cependant, un grand défi demeure quant au maintien d'un équilibre sain entre éthique (consentement, protection de la vie privée, double usage, etc.) et usage (accès, qualité, applications, etc.) des données.

Les réflexions éthiques entourant ce vaste phénomène sociotechnique sont fondamentales car le citoyen est rarement conscient de ce « qui advient de ses données » comme le laisse transparaître le dialogue entre experts et citoyens qu'a permis

ce 1^{er} Café de bioéthique. La question d'un consentement libre, éclairé et continu se pose donc comme un formidable défi, car le participant est maintenant sorti du cadre clinique et du laboratoire. Ainsi, il faut permettre à différents domaines d'évoluer tout en respectant la vie privée des consommateurs. Or, si la responsabilité qui est liée à l'utilisation de ces objets connectés et de leurs données est une question qui préoccupe activement le corps législatif et juridique, ces progrès demandent nécessairement un dialogue constant entre le social, l'éthique et le juridique.

Pour conclure ce compte-rendu du 1^{er} Café de bioéthique réalisé autour du thème « le citoyen et ses objets connectés », nous aimerions présenter les messages de clôture qu'ont voulu transmettre les trois experts :

- Mme Régis insiste sur le fait qu'il faut rester optimiste, malgré les risques et les défis : « Nous avons du pouvoir collectivement ; ensemble, chacun a un rôle à jouer ».
- M. Paré, de son côté, conclut avec le concept de responsabilité : « la responsabilité nous appartient, c'est notre santé personnelle ; que l'on utilise ou non des objets connectés ou des applications mobiles, on doit être responsable de sa santé ».
- M. Zawati, quant à lui, souligne « l'importance de travailler avec les différentes parties prenantes : premièrement, les identifier et, deuxièmement, ouvrir des avenues, des moyens de communication et de dialogue pour pouvoir mieux comprendre ». Il insiste sur l'importance du dialogue et de sa mise en application, car « à plusieurs, on est plus fort ».

Références

1. Future of Life Institute. [Asilomar AI Principles](#). Future of Life Institute. 2017; 1-42.
2. UNESCO. [Déclaration universelle sur la bioéthique et les droits de l'homme](#). 2005 oct 19.
3. Paré G, Bourget C. [Diffusion de la santé connectée au Canada](#). Montréal, Québec: CEFRIO; 2017 sept.
4. Cambon L. [Objets connectés, mobiles, communicants en prévention : dépasser l'outil, penser l'intervention...](#). Sante Publique. 2016;28(1):5-6.
5. Zawati MH. [There will be sharing : population biobanks, the duty to inform and the limitations of the individualistic conception of autonomy](#). Health Law Review. 2014;21:97-140.
6. Gibert M, Mondin C, Chicoisne G. [Portrait 2018 des recommandations internationales en éthique de l'IA](#). Dans : Déclaration de Montréal pour un développement responsable de l'intelligence artificielle. 2018;82-103.
7. Myers-West S, Whittaker M, Crawford K. [Discriminating systems: gender, race, and power in AI](#). AI Now Institut; 2019.
8. Conseil de recherches en sciences humaines, Conseil de recherches en sciences naturelles et en génie du Canada, Instituts de recherche en santé du Canada. [Énoncé politique des trois conseils : Éthique de la recherche avec des êtres humains](#) (EPTC2). 2018 déc.
9. Baillargeon N. Petit cours d'autodéfense intellectuelle. Montréal: Lux; 2016.

1st Bioethics Café “Citizens and their Connected Objects: What Happens to their Data?”

Introduction

On Wednesday, April 3, 2019, the first of three [Bioethics Cafés](#) on ethics, data and health was held in Montreal entitled “Le citoyen et ses objets connectés: qu’il y a pas de ses données?” This event was broadcast live and recorded on [YouTube](#). The event was organized by students from the Bioethics Program of the School of Public Health at the Université de Montréal (ÉSPUM) and hosted by the Director of Bioethics Program, Bryn Williams-Jones. Three experts participated as panelists: Catherine Régis, Associate Professor, Faculty of Law, Université de Montréal and Canada Research Chair in Collaborative Culture in Health Law and Policy; Guy Paré, Professor, Department of Information Technology, HEC Montréal and Chair in Connected Health Research; and Ma'n H. Zawati, Executive Director, Centre for Genomics and Policy, Department of Human Genetics, McGill University and Associate Member of the Biomedical Ethics Unit. This Café aimed to bring together experts from various academic fields interested in the major current ethical challenges and issues surrounding health and the excitement associated with the use of big data in research and in society.

This meeting thus provided an ideal platform for an interactive and dynamic meeting and exchange between experts from different backgrounds and the public on a topical subject that concerns us all. The purpose of this review is to present the central ideas that emerged from the event, in a synthetic format. The arguments raised are part of the broad debate surrounding big data, artificial intelligence and their many articulation in intelligent applications and objects. Using a thematic approach, we will present the different questions and arguments that arose during the exchanges between the experts and the public. First, we present the main concepts that served as the guiding principle for this activity and then discuss the hopes and promises that connected objects generate. Then, we will explore the risks that are associated with the use and circulation of these applications. Finally, we focus on an issue often raised by both the public and experts: responsibilities related to the operation and use of these technologies. *Who is responsible for the technology? Who is responsible for bearing the burden of risk? Who is ultimately responsible and how should they be held accountable?*

The main concepts

Big data, artificial intelligence and connected objects

Big data (BD), artificial intelligence (AI) and connected objects (CO) are distinct concepts, but are increasingly used by experts and citizens to designate a socio-technological phenomenon that is overwhelming: the massive production of data (BD) that can be processed by sophisticated techniques (AI and statistics) and can produce precise and personalized technologies (CO) that modify the relationship between humans and technology. However, in connection with all these concepts and their growing omnipresence in our societies, many ethical issues appear, intertwined in multiple legal, social, economic and technical dilemmas (1,2).

Connected objects

Mr. Paré pointed out that one of the latest major technological innovations of the contemporary era is the emergence of connected objects (or “internet of things”) that make it possible, through their various uses, to connect real life to digital life. The report issued by the Centre for Research and Innovation in Organizations (CEFRIO) in 2017 defines CO as follows: “A connected object can simply be defined as a real-world object with a communication capacity” (3, p. 5). A fashion object of something with real benefit for citizens, there were 15 billion of such objects in the world in 2015, and this market continues to grow, notes Mr. Paré (3). These objects are linked to a large and ever-increasing number of applications, most of which have the ability to automatically exchange information via the Internet (hence the connected name) (4). In addition, 70% of these applications are in the field of health and well-being (4).

The quantification of self

The panelists all confirmed the close link between these connected objects and the principles of citizen empowerment and responsibility. Individuals can achieve what experts call self-quantification: “it is about collecting, measuring, comparing different biological, physical, behavioural and environmental variables, with the aim of improving well-being, maintaining or improving health status” (4, p.5).

Person or citizen

By choosing the theme – “Citizens and their connected objects” – the organizers wanted to highlight the political and legal issues related to the production and use of connected objects. The term citizen refers to the rights and duties that a person has in the State in which they live. It therefore seemed important for the event to also address ethical issues related to human rights and the protection of personal information, but also linked to the globalization and commercialization of health data, as well as the issue of responsibility, which affects the individual, the citizen, and the public and private authorities with whom the citizen interacts.

Hopes and promises

The hopes and promises that these new technologies necessarily involve society (macro dimension), which is enriched by new dynamic and sophisticated services, but also the individual using these connected objects (micro dimension).

Society

Improving the health system and limiting access to quality data

The three experts noted the potential benefits of these connected objects and their compiled data for improving the health system, citing many proven uses that increase the efficiency of the system and the relevance of care. According to Mme Régis, these “finer and more precise data” will make it possible to “better document what is being done, what works and what does not work in the health system”. As she points out, the Quebec Commissioner for Health and Welfare has a mandate to evaluate the health system to enrich public debate and government decision-making, but “one of the primary challenges facing this activity in Quebec is the availability of quality data to assess and improve what is being done”. This improvement is therefore based on the acquisition of quality digital data via the health network, but also, increasingly, by connected objects offering personalized patient data.

Fair access to objects connected between citizens and societies

A question raised by the public was: *How can we guarantee fair and equitable access in the world and in Quebec?* Internationally, as Mme Régis points out, “it is also a godsend”, because these advances, which increase access to new technologies, make it possible to bring and make more accessible certain resources that were previously inaccessible to regions of the world. As an example, she proposed the telephone which, “in a global way, makes it possible to reach people in several countries who would not have access to care [...]; it allows them to have access to an information base for their health, to diagnose themselves or understand what is happening or what to do, it is still useful”. Mr. Zawati transposes this promise to the Quebec case by indicating that Internet coverage is increasingly homogeneous and complete, “there are more connections than inhabitants in North America”. According to him, this accessibility is established and will continue to develop and become more democratic. However, this evolution requires time, and thus confirms the challenges related to digital illiteracy and the disparities in resources and services between metropolitan and rural areas (5).

Empowerment, accountability and democratization

In a perspective where accessibility continues to progress, the empowerment it generates makes it possible to provide the necessary resources for people to take care of themselves. Mr. Paré referred in particular to the current case of aging societies whose home care needs are increasing. According to him, whether through bracelets, sensors or trackers, an elderly person could, based on these promises, stay at home longer in a safe manner and receive almost all the necessary care. There are already several innovations on the market that are fuelling these hopes. Mr. Paré pointed out that “the information technology industry is trying to make and support the promise of long and, if possible, healthy lives and development at home”.

Thus, from a societal perspective, these connected objects and the data they generate can not only help to maintain seniors in their homes, but can also help to improve the health system here in Quebec and contribute to the dissemination of scientific knowledge around the world.

The individual

Self-knowledge, empowerment and responsibility

These new technologies (watches, bracelets, telephones and other intelligent objects) allow citizens to get to know themselves better physiologically, but also psychologically. As Mme Régis pointed out, individuals can do without the help of a professional whose services are often expensive and unsuitable for many populations. For a parent or worker with a busy schedule, it is often difficult to find the time required to consult. Thus, these devices can help by providing more personalized support than conventional health and social services. This has, she noted, a real advantage in terms of “personalization of care, but also democratization or empowerment of care.” The data compiled will support a more individualized range of care and social services that respects the fact that everyone is unique and has unique needs. In parallel with this personalization and empowerment, real-time access to our health and behavioural data, as well as the integration of information found on the web, could become an “accelerator of the revolution in information democratization” that also fuels an empowerment phenomenon that, Mr. Zawati explained, is at the interface between accountability and empowerment.

Accountability

Several examples were presented of technologies that provide patients with a better understanding of their condition and care. As Mme Régis noted, a better understanding can lead the individual to take responsibility and, therefore, to play an active role in their care (or autonomy) and well-being. This has led to a decentralization of expertise, according to Mr. Zawati: the caregiver is no longer the only one with health expertise. The patient, especially in the case of chronic or rare diseases, now has more knowledge and a particular experience: living with their disease and health. This vision is consistent with recent patient-partner initiatives. Not only can the patient educate caregivers through intimate knowledge of their illness, but they can also benefit from a personalization of the resources and care available to them for medical follow-up and treatment. According to the

panellists, the former knowledge-based boundary between patient and caregiver could slowly disappear to foster a more fair partnership that is unique in medical history.

Free up caregivers' time and efficiency

It would be naive, Mme Régis noted, to not recognize that these technologies also free up time for health professionals. Artificial intelligence (AI), in particular, offers more and more applications based on sophisticated algorithms that make it possible to make diagnoses or establish personalized treatment plans, thus allowing caregivers more time to interact with their patients. However, she pointed out that, despite her hopes for machines to replace certain human acts, we must also reflect on the erosion of human-caregiver-patient relationships: a possible consequence of the omnipresence of machines in this relationship. Mme Régis raised a relevant question to ask in various clinical situations related to the role of machines in the provision of care and services: "What is really important to us and what we would not want to delegate to a machine?" The positive aspect behind simple human relationships between patients and caregivers puts the human being back at the centre of the discussion and recalls the statements of the [Montreal Declaration for Responsible AI Development](#) (6). Moreover, no technology is benevolent in itself, the panelists reminded us many times: technology is a tool whose benefits or harms depend on the user (or even the designer) (7).

Fears and risks

The experts and the public also raised the risks inherent in these technologies and their use.

Hypernormativity

Mme Régis pointed to a risk of hypernormativity: "Technology is very prescriptive and quickly entrenches a sense of normalcy" in society. She illustrated this argument by referring to a time, not so long ago, when it would have been considered abnormal to live-stream a conference online, whereas this is now normal practice in order to promote an event such as the present Bioethics Café. Drawing on other topics such as the sharing of personal information, she noted that "this sense of normalization of constant monitoring makes us lose some awareness of the importance of privacy or what makes us want to protect it."

Consent

Relational consent

Despite a consent form and privacy policies, many corporations still ignore the interconnectivity between citizens, their families and their neighbourhoods, thus neglecting to take into account the possibility for obtaining information about one person from another, e.g., genetic information. Indeed, Mr. Zawati suggested that "when this data becomes more accurate, we will talk more and more about certain data that is sensitive, data that relates to you as an individual, but perhaps to other people in your family". Without more appropriate policies, this sensitive data will continue to be used by operators of different software products without the need for free, informed and continuous consent, and without additional consideration for these so-called relational risks involving families and neighbours.

Prevention through education

The consent forms proposed by the vast majority of current corporations do not contain all the information necessary for the user to make an informed decision, and are sometimes even imposed on the consumer, which definitely goes against any ethical framework concerned with protecting free, informed and continuous consent (8). According to Mr. Paré, the first factor leading to poor consent – i.e., consent that is neither free, informed nor continuous – is related to the fact that few people are aware of the ethical issues of confidentiality and security of the information collected. This promotion of risks and the resulting need for education obviously becomes a shared responsibility between the citizen, the State and the corporation; the latter's accountability is often lacking, as Mr. Paré noted. Mme Régis also recalled the notion of intellectual self-defence introduced by Mr. Normand Baillargeon (9) which can help citizens to be more critical, and she underlined the roles that public education and public health have to play in this education.

Complexity and subtlety of the consequences

According to Mr. Paré, the nature of the data may be at issue, because of their number, complexity and the subtlety of the potential harmful effects associated with them, making it difficult for the citizen, but also for the expert, to see clearly. The complexity and subtlety of big data and these issues can make citizens less suspicious of various applications and more open to blindly consenting to the sharing of their data. In addition, Mr. Paré pointed out that there is also a social culture of *laissez-faire* about certain types of information. Thus, he noted that it has become less embarrassing to accept to freely communicate information related to our general well-being (behaviours, lifestyle habits, emotions, etc.) than specific data on our physical health.

Inadequate understanding of forms, lack of transparency and reinforcement by reward

Despite its length, the consent form often contains insufficient or incomplete information, suggesting a serious lack of transparency. Mme Régis noted that individuals are more willing to provide information to the private sector, which offers them an immediate reward. She added that these companies rely heavily on data obtained through consent procedures that she described as inappropriate. While this may seem counter-intuitive in the sense of maximizing individual interest, Mme Régis nevertheless showed all the commercial and advertising sense behind this measure, making this phenomenon understandable

by considering the point of view of business strategies and then the consumer. In fact, Mr. Paré pointed out that in Quebec, there is unequal access to data between the private and public sectors, as researchers are sometimes unable to conduct their research because of inaccessible or insufficient data, which is not the case for private companies. This phenomenon would therefore explain a certain monopolization of expertise by large corporations (Google, Amazon, Facebook, Appel, Microsoft; GAFAM) compared to governments, even though they are public bodies.

Consent by binary choice

With reference to the consent forms to be completed, the public also raised concerns about the binary choice of either “accept” or “refuse” regarding the conditions of use to be validated before using an application, site or other technological medium. Mr. Paré thus suggested an alternative option of “accept, but”. Mr. Zawati added that several international and Canadian mobile applications only present this binary choice that users must comply with without being able to make nuances, otherwise they do not have access to the content. He highlighted examples of health cases where intervention now depends on some of these technologies and also pointed more broadly to the increasing need to use some applications that are integrated directly into our lives (e.g., Google Maps).

Dual use and secondary use of data

The use of this data from connected devices can be risky for the individual, particularly in relation to the secondary marketing possibilities of these devices (or dual use), raising serious questions about their ownership and profitability (Who benefits? For what purposes? Is someone being exploited?). To illustrate these risks, the experts and the public raised the issue of use by insurers of certain data, which can lead to stigmatization and discrimination of individuals, or even entire social groups, due to the relational risks associated with the interconnection between the compiled data. Faced with these risks, the three experts agree that it is necessary to educate citizens and to make them aware of these situations. Mme Régis mentioned in this regard that it is important to remain a citizen with critical thinking skills, so that citizens can question themselves about these technologies and the circumstances in which they can become problematic, measure the links between these technologies, not believe everything we say and finally, develop intellectual self-defence tools (9).

Shared responsibility

At the intersection of these risks and hopes is a real concern that both experts and audience raised: responsibility.

Responsibility of the machine and its user

Mme Régis approached this subject by talking about the help that artificial intelligence can bring to the physician through the development of algorithms that are more efficient than the physician’s diagnostic capacity. She highlighted the “normative weight that (these algorithms) will have” in deciding the life or death of patients. As she noted, several questions arise: *What will be the reaction of health professionals to this? Will there be any freedom to deviate from it? What will the courts do if a doctor has not used these tools?* As a lawyer, she proposes that future laws specify the role of the algorithm: the machine is a tool for the human being which, on the contrary, must never be at the service of the machine, as is articulated in the [Montreal Declaration on the Responsible AI Development](#) (6).

Interdisciplinary and cross-sectoral responsibility

Mr. Zawati expressed a different point of view, recalling the need for collaboration and integration of a diversity of stakeholders around socio-technical issues. He addressed the issue of criminal liability for mobile applications that “make associations between a symptom and a medical condition”. There is a real concern here about who is providing this information and the veracity and clarity of it. He also added that it is not the responsibility of a single person, but that it is important to address this responsibility by thinking about the cascade of actors, from the designer to the user. According to Mr. Zawati, there is of course the individual who has a “responsibility to be informed”, but the “College of Physicians” also has a responsibility: it should set out clear principles and guidelines for big data, artificial intelligence and the use of connected objects. He also pushed for long-term thinking, by proposing the emergence of a new discipline such as “medical computing” that would be taught in medical schools to train future caregivers in the use of these technologies.

Physician accountability

Mr. Paré also addressed this point of collaboration at the interface between citizens, the law and other sectors of society, with a particular emphasis on physician training. Physicians are not currently prepared for the “tsunami” of big data, artificial intelligence and their derived applications, and this fact has been highlighted by the public. According to Mr. Paré, several actors have a role in the establishment of well-articulated collaborations and exchanges – “interoperability” in particular – to develop a solid network within which responsibilities would be shared: faculties, orders, professionals, citizens, the ministry, etc. He also mentioned the relentless and gigantic flow of new applications coming to market: “How many mobile health applications are there on the Apple store? 500,000. And 500 are released every month. Who is responsible for this? »

Moving beyond the law

With regard to this shared responsibility, Mme Régis noted that it is sometimes difficult to rely on the law to regulate everything, because, in her opinion, “the time of the law is not the same as that of innovation”, hence the strong and disappointing figure of the law being behind scientific, technological and social progress. Faced with this difference in speed, she added, decision-makers – whether they are parliamentarians, the National Institute of Excellence in Health and Social Services (INESSS), or any other major institution – have a role to play whether in guiding or making recommendations.

Conclusions

This first Bioethics Café highlighted many issues. Some put into contrast hopes and fears, while others raised risks and promises, but on both sides there were questions about the sharing of responsibilities. Connected objects can empower individuals, but issues of equity of access are also present. Mr. Paré indicated that it is therefore important to reflect “on what can contribute to reducing inequalities and also contribute to increasing accessibility”, but also to improve the training of carers in order to enable them to use these new technologies and to raise their awareness of the risks they entail. However, a major challenge remains in maintaining a healthy balance between ethics (consent, privacy, dual use, etc.) and use (access, quality, applications, etc.) of data.

The ethical reflections surrounding this vast socio-technical phenomenon are fundamental because citizens are rarely aware of what is happening to their data, as shown by the dialogue between experts and citizens that this first Bioethics Café enabled. The issue of free, informed and ongoing consent is a formidable challenge, as the participant has now moved beyond the clinical and laboratory setting. Thus, different areas must be allowed to evolve while respecting the privacy of consumers. However, if the responsibility for the use of these connected objects and their data is an issue that actively concerns the legislative and legal bodies, these advances also require a constant dialogue between the social, ethical and legal spheres.

To conclude this review of the 1st Bioethics Café on the theme “Citizens and their connected objects”, we would like to present the closing messages that the three experts sought to transmit:

- Mme Régis insisted that we must remain optimistic, despite the risks and challenges: “We have power collectively; together, everyone has a role to play.”
- Mr. Paré, for his part, concluded with the concept of responsibility: “responsibility belongs to us, it is our personal health; whether or not we use connected objects or mobile applications, we must be responsible for our health.”
- Mr. Zawati, for his part, stressed “the importance of working with the various stakeholders: first, to identify them and, second, to open avenues, means of communication and dialogue to better understand them.” He stressed the importance of dialogue and its implementation, because “together we are stronger.”

References

(See Références)

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M. Boudreau Leblanc est éditeur de la *Revue Canadienne de bioéthique* et fait partie du comité organisateur des Cafés de bioéthique.

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Conflicts of Interest

Mr. Boudreau Leblanc is editor at the *Canadian Journal of Bioethics* and is a member of the organizing committee of the Bioethics Cafés.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Les enjeux éthiques de l'enseignement en ergothérapie : des injustices au sein des départements universitaires

Marie-Josée Drolet¹, Karoline Girard², Rébecca Gaudet³

Résumé

Si les enjeux éthiques de l'enseignement sont bien documentés dans les écrits, tel n'est pas le cas des enjeux éthiques que pose l'enseignement en ergothérapie. Aucune étude n'a été menée sur le sujet au Québec. Pour pallier cette lacune, une recherche a été réalisée. Cet article en présente les résultats. Puisque l'état des connaissances sur le sujet est limité, un devis qualitatif a été utilisé. Onze ergothérapeutes-enseignantes ont participé à un entretien individuel semi-dirigé pour discuter des enjeux éthiques que soulèvent leurs enseignements. Six unités de sens émergent des données : 1) l'équité entre les étudiants : un défi ; 2) la santé et le bien-être des étudiants et des enseignantes : un portrait troublant ; 3) des injustices au sein du corps enseignant : l'éléphant dans la pièce ; 4) l'identité professionnelle tiraillée par des conflits de rôles ; 5) la présence de conflits d'intérêts préoccupants et 6) l'équilibre occupationnel : un mythe plus qu'une réalité. Les résultats rejoignent en général ceux documentés dans les écrits. Cela dit, un élément peu documenté dans les écrits émerge, soit la présence d'une culture académique hiérarchisée où l'autorité épistémique est détenue par les professeurs-chercheurs au détriment des autres types d'enseignants et des milieux cliniques. Ainsi, bien que la profession ergothérapeutique valorise la justice occupationnelle, les départements universitaires sont dominés par une injustice épistémique qui, par ricochet, engendre une injustice occupationnelle, ce qui d'un point de vue ergothérapeutique est préoccupant. Aussi, le contexte universitaire est lié à une surcharge de travail peu propice à l'agir éthique et à la pratique réflexive.

Mots-clés

éthique, enjeux éthiques, enseignement, ergothérapie, injustice épistémique, injustice occupationnelle

Abstract

While the ethical issues of education are well documented in the literature, the ethical issues of occupational therapy education are not. No studies have been conducted on the subject in Quebec. To fill this gap, we conducted a study and this article presents the results. Since the state of knowledge on the subject is limited, a qualitative approach was used. Eleven occupational therapist-teachers participated in semi-directed individual interviews to discuss the ethical issues raised by their teachings. Six units of meaning emerge from the data: 1) equity among students: a challenge; 2) student and teacher health and well-being: a disturbing picture; 3) injustices within the teaching staff: the elephant in the room; 4) professional identity torn by role conflicts; 5) the presence of worrisome conflicts of interest; and 6) occupational balance: a myth more than a reality. The results are generally consistent with those documented in the literature. That said, one element that is poorly documented in the literature emerges, namely the presence of a hierarchical academic culture in which epistemic authority is held by professor-researchers to the detriment of other types of teachers and clinical settings. Thus, although the occupational therapy profession values occupational justice, university departments are dominated by an epistemic injustice which, in turn, creates occupational injustice, which from an occupational therapy perspective is a concern. Also, the university context is linked to a work overload that is not conducive to ethical action and reflective practice.

Keywords

ethics, ethical issues, teaching, occupational therapy, epistemic injustice, occupational injustice

Introduction

Pour les futurs ergothérapeutes qui étudient et désirent pratiquer au Québec, l'accès à la profession requiert depuis 2009 un diplôme de maîtrise professionnelle en ergothérapie (1). Ainsi, tout étudiant québécois en ergothérapie acquiert sa formation via un enseignement universitaire au baccalauréat puis à la maîtrise, totalisant ainsi environ quatre années et demie d'études. Un grand nombre des enseignants impliqués auprès de ces étudiants universitaires portent à la fois le titre d'ergothérapeute et de professeur ou chargé de cours, et poursuivent des tâches de recherche (pour les premiers) ou une carrière en clinique (pour les seconds). La conciliation de ces rôles professionnels peut potentiellement soulever des conflits de valeurs ou même des conflits de loyautés multiples (2). Mais qu'en est-il exactement lorsqu'un ergothérapeute doit concilier à la fois le rôle d'enseignant et celui de chercheur ou de clinicien? Les enjeux éthiques vécus par les enseignants ergothérapeutes sont-ils semblables à ceux vécus par tout autre enseignant en milieu universitaire?

Dans cet article, un enjeu éthique correspond à toute situation susceptible de compromettre, en tout ou en partie, le respect d'au moins une valeur (3), laquelle est considérée comme un concept abstrait de nature évaluative, voire une conception du souhaitable (4). Ainsi, parler des enjeux éthiques implique de repérer les valeurs bafouées dans le quotidien de la pratique enseignante.

Enjeux éthiques de l'enseignement en général

Les enjeux éthiques que pose l'enseignement, dont l'enseignement en milieu universitaire, sont bien documentés dans les écrits et ceux-ci sont de diverses natures. Par exemple, des écrits discutent des enjeux éthiques reliés au traitement équitable ou juste des étudiants, notamment lors des évaluations de leurs travaux (5,6). D'autres enjeux abordent les pratiques jugées non éthiques pouvant être observées chez des enseignants, telles que le manque de professionnalisme ou le bris de confidentialité (7,8), le non-respect des règles institutionnelles (6,8) ou le favoritisme (5,8). L'abus de pouvoir, l'intimidation et l'atteinte au consentement libre et éclairé des étudiants sont également discutés dans les écrits, notamment dans le contexte de relations intimes qui surviennent parfois entre un enseignant et un étudiant (9) ou lors de l'embauche d'étudiants comme assistants de recherche ou d'enseignement (8). Stein (10) note aussi le fait que des enseignants universitaires peuvent se

retrouver en situation de conflit d'intérêts, en outre lors de la signature de contrats d'enseignement exclusifs ou lorsqu'un professeur recommande à ses étudiants l'achat d'un livre dont il tire des profits puisqu'il en est l'auteur.

D'autres enjeux éthiques sont rapportés dans les écrits. Par exemple, Vehviläinen et ses collaborateurs (11) témoignent de la détresse vécue par des enseignants universitaires lorsqu'ils sont confrontés à des situations de plagiat chez des étudiants. Ces enseignants se sentent alors dans l'obligation de réagir à de tels actes et se considèrent responsables de faire respecter les droits d'auteurs et d'appliquer les règlements. Sachant qu'ils devront traverser le lourd processus disciplinaire et que le lien développé avec l'étudiant fautif sera brisé, les enseignants vivent parfois de la détresse éthique dans ces situations (11). De plus, des enseignants vivent de l'impuissance et de la frustration lorsque l'institution ne donne pas de suites aux mesures disciplinaires qu'ils ont enclenchées pour régler ces situations (8). Dans un autre ordre d'idées, Scager et ses collaborateurs (12) discutent du fait de mettre au défi les étudiants (*to challenge the students*), ce qui place les enseignants universitaires en situation de dilemme. Les enseignants sont partagés entre, d'une part, *challenge* les étudiants et, d'autre part, augmenter leur anxiété, brimer leur envie de répondre aux questions, briser le lien établi avec eux, miner leur enthousiasme et avoir à accomplir plus de travail. En bref, le fait de mettre au défi les étudiants vient avec plusieurs risques ou défis, selon ces auteurs.

Somme toute, de nombreux enjeux éthiques sont inhérents à la pratique de l'enseignement (5-12). Pour ne nommer que quelques exemples distincts de ceux rapportés plus haut, Colnerud (6) mentionne que l'enseignant doit quotidiennement faire des choix éthiques, en considérant le fait de « prendre soin » des étudiants et d'être juste à leur égard. Plus précisément, l'enseignant doit distribuer de façon juste le « prendre soin », ce qui ne va pas toujours de soi. Par ailleurs, l'enseignant est constamment coincé entre une éthique des règles ou des principes (comme l'éthique déontologique ou le conséquentialisme) et une éthique des vertus (comme l'éthique du *care*) puisqu'il doit respecter et faire respecter les règles, en assurant la qualité et le bénéfice de ses actions au plus grand nombre, et ce, dans sa façon d'être et dans ses enseignements pour des étudiants qui sont dans une situation de relative vulnérabilité. Les résultats d'une étude, quoique menée auprès d'enseignants du secondaire, vont dans le même sens; les dilemmes éthiques ressortis sont les suivants : 1) climat du prendre soin versus climat formel ; 2) standards scolaires versus justice distributive ; 3) règles scolaires versus confidentialité ; 4) normes scolaires versus loyauté envers les collègues ; et 5) standards éducatifs versus croyances et pratiques éducatives de la famille de l'étudiant (13). Quoi qu'il en soit, la difficulté pour l'enseignant d'être à la fois une bonne personne et un bon enseignant étant donné la position d'autorité qu'il occupe ainsi que la responsabilité éthique du contenu enseigné sont deux enjeux qui méritent une attention particulière (6).

Enfin, Berg et Seeber (14) montrent dans leur ouvrage *The Slow Professor: Challenging the Culture of Speed in the Academy*, que la culture de la performance et la grande valorisation de la recherche au détriment de l'enseignement apportent leur lot d'enjeux éthiques affectant négativement la qualité de l'enseignement ainsi que la santé et le bien-être au travail des enseignants universitaires. En bref, les enjeux éthiques de l'enseignement sont bien documentés dans les écrits, mais qu'en est-il des enjeux éthiques vécus par les enseignants qui sont aussi des professionnels de la santé membres d'un ordre professionnel et qui sont, ce faisant confrontés à des conflits de rôles et possiblement à des conflits de loyautés multiples (2)?

Enjeux éthiques de l'enseignement dans les disciplines de la santé

Des études concernant les enjeux éthiques vécus par les enseignants des diverses disciplines de la santé, notamment en sciences infirmières, en psychologie et en médecine, ont également été recensées. En sciences infirmières, Ganske (15) établit un rapprochement entre la détresse éthique vécue dans le milieu académique et celle vécue par les infirmières œuvrant en clinique. D'une part, l'auteure met en lumière des études suggérant qu'un climat éthique en milieu hospitalier est inversement proportionnel à la présence de détresse éthique chez le personnel. D'autre part, elle indique que la détresse éthique vécue dans le milieu universitaire, qui peut être liée aux comportements d'étudiantes (incivilité, plagiat, tricherie), à de l'intimidation ou des incivilités de la part de collègues, aux standards de la profession ou d'admission ou encore aux différences culturelles, est un phénomène bien documenté. D'ailleurs, Diener et ses collaborateurs (16) attestent que les enseignantes-infirmières ayant participé à leur étude vivent de la détresse éthique et mentionnent que le manque de soutien entourant l'enseignement, le manque de respect de l'éthique et des valeurs infirmières, de même que la discrimination perpétrée par l'administration y contribuent. De plus, les participantes jugent que l'intégrité académique devrait être renforcée face aux comportements non éthiques des étudiantes puisque cela pourrait mener à des soins inadéquats aux patients¹. Aussi, selon Yoes (17), les enseignantes en sciences infirmières peuvent vivre une détresse liée à la perception qu'elles ont de n'avoir qu'une influence limitée sur les soins prodigués aux patients. De plus, les résultats de Waite (18) confirment que les sources de la détresse éthique des infirmières qui enseignent incluent les étudiantes, les collègues et l'administration. Des enjeux, tels que le fardeau d'être une gardienne de la profession, le souci du bien-être des étudiantes, le manque de pouvoir et le manque de soutien ainsi que les symptômes physiques ou psychologiques ressentis sont des facteurs contribuant à la détresse éthique vécue par les infirmières-enseignantes (18).

D'autres enjeux éthiques vécus par des infirmières-enseignantes sont discutés dans les écrits. Bien qu'ils ne soient pas nommés comme tels, ils peuvent donner lieu à des conflits de valeurs. C'est le cas de l'étude de Gerrish, Ashworth et McManus (19) où six grands dilemmes sont identifiés par les participantes interrogées, soit : 1) élargir les connaissances de base versus approfondir les connaissances acquises dans la conceptualisation du niveau maîtrise en sciences infirmières ; 2) la pertinence de la pratique ou de l'application des connaissances versus le détachement académique ; 3) faciliter la pensée créative versus

¹ Dans cet article, les mots patients, clients, usagers et bénéficiaires sont utilisés comme des synonymes et de manière interchangeable pour désigner la personne qui reçoit des soins de santé ou de services sociaux.

renforcer la rigueur ; 4) encourager ou supprimer différents modes de pensée critique ; 5) les infirmières post-graduées en tant qu'agents loyaux de changement versus le problème des étudiantes qualifiées non conformistes ; et 6) l'expérience professionnelle comme facilitateur ou obstacle au rendement au niveau maîtrise.

Quant aux défis liés aux différences culturelles dans différentes disciplines de la santé (dont l'ergothérapie, la médecine, la physiothérapie et les sciences infirmières), Kai, Spencer et Woodward (20) indiquent que la plupart des enseignants n'ont reçu qu'une formation de base ou encore aucune formation visant à enseigner et à mieux intervenir auprès de personnes issues de minorités ethnoculturelles. Par conséquent, ceux-ci sont inquiets quant à leur aptitude à enseigner des sujets touchant le racisme, la discrimination ou les stéréotypes (20).

Dans un autre ordre d'idées, une étude concernant la confidentialité dans le domaine de la psychologie souligne le manque de clarté des politiques des institutions d'enseignement postsecondaire canadiennes en regard de la confidentialité, notamment entourant la définition de ce qu'est une conversation privée entre étudiants et enseignants (21). La perception et les attentes des étudiants en termes de confidentialité dans la relation qu'ils entretiennent avec leurs enseignants sont également des aspects pouvant influencer les enjeux éthiques vécus par les enseignants en psychologie (21). Par ailleurs, une étude conduite par Andresen, Olson et Krasowski (22) suggère que les centres d'enseignement de la médecine gagneraient à adopter des politiques plus rigoureuses entourant les conflits d'intérêts. Ainsi, leurs résultats soulèvent la présence de conflits d'intérêts préoccupants et omniprésents dans le quotidien des enseignants en médecine. Mais qu'en est-il plus spécifiquement des enjeux éthiques de l'enseignement en ergothérapie?

Enjeux éthiques de l'enseignement en ergothérapie

En ce qui a trait aux enjeux éthiques de l'enseignement en ergothérapie, quatorze publications ont été recensées par notre équipe. Parmi ces écrits, deux appartiennent à la littérature grise et douze rapportent des résultats d'études, dont huit ont été menées aux États-Unis, deux au Royaume-Uni, une en Australie et une en Afrique du Sud. Que disent ces études? Kanny et Kyler (23) discutent de deux grandes catégories d'enjeux éthiques auxquels sont confrontés les enseignants universitaires en ergothérapie, soit 1) les enjeux éthiques reliés à l'environnement éducatif et 2) les responsabilités éthiques des enseignants. Selon ces auteures, l'environnement éducatif est, entre autres choses, lié à des enjeux éthiques relatifs à la protection du public et à la promotion de la profession (ex. : sévir face à des comportements inadéquats de la part des étudiants), aux demandes d'étudiants (ex. : admettre un étudiant au programme, faire des accommodements suivant des besoins spéciaux et modifier la note d'un étudiant) ainsi qu'à la confidentialité qui devrait être respectée de la même façon dans la relation avec les étudiants qu'en clinique avec les clients. Les responsabilités éthiques des enseignants en ergothérapie se rapportent à l'obligation : 1) de rassembler et d'interpréter l'information afin de préparer les étudiants à travailler avec le public, 2) de renouveler ses connaissances et de les incorporer à ses enseignements, 3) de promouvoir un environnement scolaire qui puisse soutenir l'étudiant dans le développement de ses aptitudes éthiques et sociales (23). De plus, puisque tout ergothérapeute se doit d'être compétent, celui qui débute comme enseignant devrait se faire aider par un mentor (23).

Ensuite, mener à bien une carrière académique comporte des défis d'ordre institutionnel qui peuvent être traités sous un angle éthique. À ce sujet, Masagatani et Grant (24) soulignent les difficultés de la conciliation des rôles de chercheur et d'enseignant, tout en conservant un sain équilibre entre sa carrière ainsi que sa vie personnelle et familiale. On trouve aussi des écrits concernant le double mandat de la productivité à la fois sur le plan de la recherche et relativement à l'excellence en enseignement (25), et ce, dans un contexte où la compétition pour obtenir un poste de professeur ou une promotion est très grande (24-26).

Par ailleurs, le fait de faire échouer ou non un étudiant est vécu comme un dilemme éthique qui amène de l'anxiété et de la détresse chez le personnel enseignant en ergothérapie (27) comme c'est aussi le cas chez le formateur clinique, c'est-à-dire l'ergothérapeute clinicien qui accueille et forme des stagiaires (28). Une telle décision, prise dans l'objectif de protéger le public et la profession, peut mettre fin à la carrière de l'étudiant. Elle a donc des conséquences importantes sur l'étudiant, mais également sur sa cohorte, sa famille et l'enseignant (27).

Plus encore, à propos de la responsabilité relative à la compétence et au contenu enseigné, Fleming-Castaldy et Gillen (29) affirment que, au même titre que l'ergothérapeute clinicien doit maintenir ses compétences professionnelles et pratiquer des interventions basées sur la science, l'enseignant en ergothérapie doit demeurer réceptif aux changements et questionner régulièrement les notions qu'il enseigne. Faillir à cette responsabilité peut entraîner une diminution de la qualité des soins prodigués aux clients qui seront desservis par les ergothérapeutes de demain (29). Dans le même ordre d'idées, il est de la responsabilité éthique des ergothérapeutes-enseignants de s'assurer que le cursus universitaire soutienne véritablement le développement de la pratique centrée sur le client (30). Selon cette auteure, lorsqu'ils ne vont pas au-delà de la zone de confort théorique pour inclure des activités visant à reconnaître, critiquer et modifier les pratiques et les politiques inéquitables, les enseignants en ergothérapie nuisent à la formation des étudiants et, par le fait même, aux futurs clients de ces derniers.

Aussi, une étude menée par Murray et ses collaboratrices (31) suggère que la transition de la clinique vers l'enseignement universitaire est difficile pour les ergothérapeutes, étant donné la charge de travail plus importante dans le monde académique et la nature du travail qui y est passablement différente. Les exigences élevées en termes d'énergie mentale dans le but de se centrer sur les étudiants ainsi qu'apprendre à jongler avec les protocoles et les procédures académiques sont des exemples de défis que les enseignants rencontrent (31).

Copolillo, Peterson et Helfrich (32) ainsi que Fisher et ses collaborateurs (33) ont aussi mis en lumière d'autres enjeux vécus par des membres de facultés d'enseignement en ergothérapie. L'absence de sécurité d'emploi, le manque de soutien de la part des départements, l'importance de la charge de travail durant la première année, le manque de rétroaction sur l'enseignement, le contact limité avec les pairs, le choc culturel dû au passage de la clinique vers l'académique, les responsabilités variées et la diversité des styles d'apprentissage des étudiants font partie des défis exprimés par les participants. Le manque d'enseignants qualifiés disponibles et les difficultés sur le plan du recrutement sont également des défis vécus par des facultés (33). En somme, il semble que la conciliation entre le rôle d'ergothérapeute et d'enseignant en ergothérapie (notamment lors de la transition de la clinique vers l'enseignement) implique pour les ergothérapeutes de s'adapter et de relever de nombreux nouveaux défis parfois difficiles à gérer. Les conflits de valeurs ou de rôles qui en émergent peuvent certainement se traduire en enjeux éthiques de diverses natures qu'il convient d'examiner.

Questions et objectif de la recherche

Aucune étude n'a jusqu'à maintenant documenté les enjeux éthiques de l'enseignement en ergothérapie au Canada, voire au Québec. Compte tenu de la spécificité de la formation universitaire en ergothérapie dans cette province canadienne (un baccalauréat et une maîtrise sont requis pour porter le titre d'ergothérapeute au Québec comparativement à une maîtrise dans les autres provinces du pays), il convient d'examiner la pratique enseignante au Québec. Les questions à l'origine de la recherche étaient les suivantes : *Quels sont les enjeux éthiques vécus par les enseignants universitaires en ergothérapie du Québec? Quels moyens sont utilisés ou envisagés par les ergothérapeutes qui font de l'enseignement universitaire pour résoudre ces enjeux?* L'étude avait donc pour objectif de documenter les enjeux éthiques que vivent les ergothérapeutes qui prodiguent des enseignements au sein d'un programme ou d'un département universitaire en ergothérapie ou en réadaptation ainsi que leurs solutions. Cet article présente les résultats relatifs aux enjeux éthiques de l'enseignement. Les moyens qu'utilisent les enseignants en ergothérapie pour résoudre ces enjeux feront l'objet d'une publication subséquente. La section suivante décrit les méthodes de recherche qui ont été utilisées pour atteindre cet objectif.

Méthodes de recherche

Cette section précise le devis de la recherche, les participants recherchés, les modalités de recrutement des participants, les méthodes de collecte et d'analyse des données ainsi que les considérations éthiques.

Devis de la recherche

Puisque les connaissances sur le sujet sont limitées, un devis de recherche inductif de nature qualitative a été choisi (34,35). Plus précisément, l'équipe a opté pour un devis d'inspiration phénoménologique étant donné que ce type de devis est recommandé pour documenter des phénomènes de nature éthique (35), et ce, comme tel fut le cas dans des études similaires que notre équipe a menées (28,37-41). Le devis phénoménologique descriptif et transcendantal s'inspirant de la philosophie de Husserl (42,43) a été sélectionné, car celui-ci permet d'accéder à l'essence de phénomènes par l'entremise d'entrevues qualitatives réalisées avec des personnes ayant une expérience intime du phénomène investigué (44).

Participants recherchés

Des ergothérapeutes prodiguant des enseignements à des étudiants en ergothérapie au sein des programmes ou des départements d'ergothérapie des différentes universités du Québec-Canada étaient recherchés. Le statut de ces enseignants nous importait peu. Ainsi, qu'ils soient professeurs, chargés de cours ou tuteurs, nous étions à la recherche d'ergothérapeutes contribuant à la formation de la relève par leurs enseignements universitaires. Bien que les superviseurs de stagiaires contribuent de manière significative à la formation clinique des étudiants en ergothérapie, ils n'étaient pas visés dans cette étude, étant donné que ces ergothérapeutes sont des cliniciens sans être formellement des enseignants universitaires². Pour assurer la saturation des données, un nombre de six à douze participants était souhaité comme le recommandent Thomas et Pollio (45) pour ce type de devis.

Recrutement des participants

L'Ordre des ergothérapeutes du Québec (OEQ) a transmis par courriel l'invitation à participer à la recherche aux ergothérapeutes ayant préalablement accepté d'être sollicités pour prendre part à des études. Les ergothérapeutes intéressés à participer à la recherche ou à obtenir plus d'informations étaient invités à écrire à une assistante de recherche. Les documents de la recherche (lettre d'information, formulaire de consentement, schéma de l'entretien et questionnaire sociodémographique) ont été envoyés par courriel aux participants ayant témoigné un intérêt pour l'étude pour que ceux-ci puissent prendre une décision éclairée quant à leur possible participation à la recherche. Pour compléter l'échantillon, des ergothérapeutes-enseignants connus de la chercheuse principale ont aussi été contactés par courriel par une assistante de recherche.

² Pour connaître les enjeux éthiques que soulève le fait de superviser des stagiaires en ergothérapie, voir (28). Pour en savoir plus sur les moyens de solutionner ces enjeux, voir (36).

Collecte des données

Une entrevue individuelle qualitative téléphonique a été réalisée avec chacun des ergothérapeutes désireux de participer à la recherche par des assistantes de recherche. La durée de l'entrevue variait entre 45 et 120 minutes, selon les participants. Les entretiens ont été enregistrés sur une bande audionumérique et intégralement transcrits aux fins de l'analyse. Un questionnaire sociodémographique a permis de recueillir des informations sur les participants. Le schéma de l'entretien comportait deux sections : une sur les enjeux éthiques de l'enseignement et une autre sur les moyens utilisés ou envisagés pour gérer ces situations problématiques sur le plan de l'éthique.

Analyse des données

Les données collectées ont été analysées suivant les cinq étapes proposées par Giorgi (46) pour effectuer la réduction phénoménologique husserlienne (42,43). Ainsi, premièrement, les témoignages des ergothérapeutes-enseignants ont été collectés et enregistrés. Deuxièmement, les deux analystes, à savoir les deux premières auteures de l'article, ont lu attentivement, chacune de leur côté, les verbatim des trames narratives collectées. Troisièmement, elles ont été divisées en unités de sens et compilées dans des tableaux d'extraction les données analysées de manière concertée. Quatrièmement, les données ont été organisées et énoncées dans le langage disciplinaire. Cinquièmement, les unités de sens ont été examinées de nouveau afin de ne retenir que celles rendant pleinement justice aux attributs essentiels du phénomène investigué. Par ailleurs, tout le long de la réduction phénoménologique, les analystes ont confronté leurs interprétations en vue de demeurer fidèles aux perceptions des ergothérapeutes. Pour ce qui a trait aux données recueillies via les questionnaires sociodémographiques, celles-ci ont été compilées dans un fichier Excel et, lorsqu'applicable, des statistiques simples et descriptives ont été calculées par la troisième auteure de l'article.

Considérations éthiques

Après avoir obtenu une certification éthique du Comité d'éthique de la recherche avec des êtres humains de l'Université du Québec à Trois-Rivières, chaque participant a consenti à participer à l'étude et a signé un formulaire de consentement. Aussi, les données ont été traitées dans le respect de la plus stricte confidentialité.

Résultats de la recherche

Cette section présente les résultats de la recherche. D'abord, les participants sont brièvement décrits. Ensuite, les enjeux éthiques de l'enseignement en ergothérapie sont discutés. Des extraits des verbatim des entretiens réalisés avec les participants illustrent ces enjeux.

Participants à l'étude

Onze ergothérapeutes du Québec-Canada ont participé à la recherche. Toutes étaient des femmes. Au moment de la collecte des données, les participantes avaient en moyenne 43 ans d'âge : la plus jeune avait 25 ans, tandis que l'aînée avait 62 ans. Relativement à leur expérience comme ergothérapeute, elles avaient en moyenne 18,5 années de pratique : la novice avait une année et demie d'expérience, alors que la plus expérimentée détenait 38 années de pratique de la profession. En ce qui a trait à leur expérience en enseignement, les participantes avaient en moyenne huit années d'expérience comme enseignante : la moins expérimentée avait une année et demie d'expérience, alors que la plus expérimentée avait 22 ans d'expérience en enseignement. Trois participantes étaient chargées de cours et huit étaient professeures. Parmi les professeures, certaines occupaient ou avaient occupé des fonctions administratives au sein d'une université. Aussi, leur temps dédié à la recherche variait, mais toutes enseignaient ou avaient enseigné.

Eu égard à leur plus haut degré de scolarité, deux participantes étaient détentrices d'un baccalauréat³, une avait une maîtrise, cinq détenaient un doctorat et trois avaient un postdoctorat. Relativement à leur formation en pédagogie, deux participantes n'avaient aucune formation en pédagogie, six avaient eu quelques heures ou journées de formation traitant de pédagogie et trois avaient suivi au moins un cours universitaire sur le sujet. Quant à leur formation en éthique, une participante n'avait aucune formation en éthique, trois avaient eu quelques heures ou jours de formation en éthique et sept avaient suivi au moins un cours universitaire en éthique. Enfin, les ergothérapeutes enseignaient soit à l'Université Laval, à l'Université de Montréal, à l'Université de Sherbrooke ou à l'Université du Québec à Trois-Rivières.

Enjeux éthiques de l'enseignement en ergothérapie

Comme l'illustre la Figure 1, six unités de sens émergent des discours des participantes, soit : 1) l'équité entre les étudiants : un défi ; 2) la santé et le bien-être des étudiants et des enseignantes : un portrait troublant ; 3) des injustices au sein du corps enseignant : l'éléphant dans la pièce ; 4) l'identité professionnelle tiraillée par des conflits de rôles ; 5) la présence de conflits d'intérêts préoccupants ; et 6) l'équilibre occupationnel : un mythe plus qu'une réalité. Les paragraphes suivants expliquent chacun de ces enjeux éthiques et les illustrent par des extraits des verbatim des entretiens.

³ Avant 2009, le baccalauréat était requis pour exercer la profession.

Figure 1 : Les enjeux éthiques de l'enseignement en ergothérapie



1) L'équité envers les étudiants : un défi

L'ensemble des participantes mentionne vivre des enjeux éthiques liés à l'équité envers les étudiants, notamment dans le contexte de l'évaluation des travaux. Que ce soit lorsque des étudiants demandent une révision de notes, un délai pour remettre un travail, une rétroaction sur un travail avant la date de remise ou des informations complémentaires à l'enseignante, lorsqu'ils font des travaux d'équipe où l'iniquité des efforts entre étudiants est présente, lorsqu'ils vivent des périodes difficiles dans leur vie personnelle ou encore lorsque des étudiants sont en situation d'échec, nombreuses sont les situations où l'équité envers les étudiants peut être compromise.

Certaines participantes expliquent avoir de la difficulté à ne pas acquiescer à une demande d'un étudiant qui vit des difficultés personnelles, tandis que d'autres appliquent de manière égalitaire les règles comme l'illustrent ces extraits. Dans les cas où « un étudiant a beaucoup de détresse dans sa famille par exemple, a beaucoup de difficultés à cause de toutes sortes de facteurs : [c'est embêtant], mais je me dois d'être équitable et ne pas lui donner une note qu'il ne mérite pas » (participante 2).

J'essaie quand même d'être très équitable, mais c'est sûr qu'il y a des situations personnelles qui vont me toucher davantage pour lesquelles je commence à sortir de l'empathie, puis à être plus sympathique, puis où j'aurais tout à fait le goût de dire : « oui, oui, pour toi, c'est correct, viens me porter ton travail demain, puis tu ne seras pas pénalisée » (participante 6).

Plusieurs étudiants demandent des révisions de notes souhaitant ainsi obtenir un résultat plus élevé que celui octroyé. Les enseignantes sont alors déchirées entre l'équité envers l'ensemble des étudiants et récompenser le mérite et les efforts d'un étudiant qui démontre du sérieux et de l'engagement dans ses études.

Quand la personne vient me voir, puis je sais que c'est une bonne étudiante qui est assidue, je peux me laisser charmer par la démarche ; ou, au contraire, je pourrais aussi, si c'est un étudiant qui m'a dérangé toute l'année, ne même pas regarder la demande, puis passer outre. (participante 1)

Dans le fond, je vois la partie d'efforts de ceux qui viennent me voir directement et le temps qu'ils prennent avec moi. Le reste des efforts et il y en a plein d'autres types d'efforts, je ne les vois pas. Je ne peux pas vouloir valoriser ça, ce serait très injuste. Donc, c'est vraiment un des éléments vraiment importants pour moi. (participante 8)

Lorsqu'un étudiant demande de l'information supplémentaire sur un sujet spécifique abordé en classe. Les renseignements supplémentaires ne sont alors qu'offerts et accessibles qu'à cet étudiant. Les enseignantes sentent alors un conflit de valeurs entre l'équité envers tous les étudiants qui ont droit aux mêmes explications et le soutien offert à un étudiant qui semble avoir davantage de difficultés. La participante 9 mentionne ceci sur ce sujet :

Les étudiants, des fois, qui sont plus demandant, on ne veut pas non plus les avantager en donnant plus d'informations qu'aux autres, puis souvent on nous le rappelle de toute façon. Maintenant, je ne communique que par des forums. Je me suis trop fait prendre à dire de l'information verbalement puis que ça m'est revenu dessus après. Je dirais qu'en termes d'équité [je préfère donner les mêmes informations à tout le monde dans le forum].

La participante 8 discute aussi du fait que bien que les travaux d'équipe sauvent du temps de correction aux enseignantes, ils sont potentiellement inéquitables.

J'ai des fois ce dilemme-là, en lien avec la gestion du temps. Moi, les travaux d'équipe, je n'aime pas ça. Je déteste faire faire des travaux d'équipe parce que je sais très bien que dans des travaux d'équipe, la

personne qui travaille le mieux (...) n'acceptera pas d'avoir un travail de moindre qualité. Elle va pédaler et travailler pour ramener la qualité, le niveau du travail à son niveau à elle. C'est elle qui va avoir travaillé plus que les autres. Et les autres vont bénéficier de cette note : la note qui est le fruit de son travail à elle. Ça, je trouve que c'est injuste. Ça me dérange énormément.

Par ailleurs, les situations d'échec sont grandement préoccupantes pour les enseignantes :

Qu'est-ce qu'on fait avec les cas limites? Est-ce qu'on est un peu indulgente, puis on les fait passer, ou est-ce qu'on les coule? C'est très difficile. Dieu merci, je n'ai pas eu souvent à transiger avec ce genre de situations là, mais il y a une responsabilité professionnelle [en jeu ici]. On ne donne pas seulement un diplôme, on donne un droit de pratique. (participante 3)

Certaines participantes sont préoccupées par leur propre iniquité dans l'évaluation des étudiants qu'elles apprécient ou connaissent davantage. Sur ce sujet, des enseignantes affirment être parfois tentées d'évaluer plus favorablement les travaux des étudiants qu'elles apprécient davantage et pour lesquels une sympathie s'est développée au fil du temps, avoir un préjugé favorable pour les étudiants qu'elles connaissent personnellement ou encore être tentée d'embaucher comme assistante d'enseignement ou de recherche une étudiante plus faible académiquement qu'une autre candidate, mais plus sympathique.

J'ai un biais : cet étudiant-là, c'est sûr que c'est ma soupape. Dans un cours, si j'ai une question qui n'est pas répondue, il va me répondre. C'est ma soupape, ma béquille. Fait que je ne suis pas objective, là. C'est certain que je vais avoir tendance à [être complaisante avec lui lors de l'évaluation des travaux, mais] par souci d'équité, [j'essaie d'être vigilante]. (participante 9)

C'est déjà arrivé que j'hésite bien gros entre deux étudiantes d'été à prendre en ergo. Il y en a vraiment une qui était meilleure académiquement et tout ça, mais j'hésitais. (...) Sa face ne me revenait pas, vraiment pas. Mais tout me disait que je devais la prendre. Selon mes critères d'entrevue, je devais la prendre. Elle avait bien répondu, tout ça. L'autre était à peu près pareille, mais je la trouvais plus sympathique. (participante 7)

C'est tentant des fois (...), par exemple, les gens qui participent en classe puis que tu sens qu'ils s'impliquent, c'est tentant de regarder leur nom sur [l'examen] quand tu corriges un travail puis (...) de dire : « (...) est-ce que la personne mérite ça? » Moi, j'évite de regarder les noms pour corriger, mais c'est tentant. Tu regardes la note, puis tu te dis : « la note est basse, mais est-ce que ça fit avec la personne? » Ça ne devrait pas être ça, c'est son travail que tu évalues, ce n'est pas l'individu. Mais, ça, c'est extrêmement tentant. (participante 7)

Enfin, d'autres participantes vivent des malaises éthiques en lien avec des enjeux liés à la qualité inégale de la direction des travaux de recherche des étudiants des cycles supérieurs. Par exemple, certains directeurs d'étudiants sont perçus comme trop sévères, alors que d'autres, trop laxistes. Des participantes perçoivent un manque d'équité relativement à l'obtention du diplôme, en ceci que certains étudiants auront dû travailler beaucoup plus fort que d'autres, voire au-delà de ce que le niveau de diplôme exige.

Somme toute, la valeur qu'est l'équité peut être mise en péril dans différentes situations d'enseignement, soit : lors de l'évaluation des travaux des étudiants, lors de la planification des travaux d'un cours, dans la gestion quotidienne d'un cours et lors de la direction du travail des assistants ou des étudiants de cycles supérieurs. Une autre catégorie d'enjeux éthiques est liée à la santé et au bien-être des enseignantes et des étudiants.

2) La santé et le bien-être des enseignantes et des étudiants : un portrait troublant

La majorité des participantes rapporte que la vie universitaire n'est pas propice à la santé ni au bien-être des enseignantes et des étudiants, voire à l'agir éthique en général, notamment parce que celle-ci est liée à la surcharge.

Je pense que c'est juste la charge de travail qu'on nous demande qui est assez importante. (...) Ça, c'est un phénomène : dans quelle mesure la surcharge te fait avoir des comportements des fois plus ou moins éthiques? Je pense que ça, ça pourrait être une des conclusions du projet de recherche. (...) Un moment donné, t'as juste pu le temps puis l'énergie de t'arrêter pour bien réfléchir ou bien te remettre en question. (...) Ce n'était pas délibérément de la négligence [en faisant référence aux comportements d'une collègue], mais carrément d'être pris dans une machine. Puis, un moment donné, tu as tellement de retard que tu es tout le temps en train d'éponger ton retard, mais dans le fond tu ne réussis jamais à reprendre le dessus. (...) On vit tous des enjeux éthiques qui se ressemblent (...). Les gens sont bien intentionnés, mais un moment donné (...) tu te fais avaler par la surcharge. (participante 9)

On est à l'université, on devrait avoir le temps de penser! Mais souvent, on l'a pas vraiment le temps de penser : c'est qu'il faut produire. Bien, quand tu produis, tu ne penses pas nécessairement en même temps (...). Je veux dire, ce n'est pas de même que tu as des nouvelles idées ou des idées plus pertinentes. Des

fois, il faudrait que tu sois peut-être plus en contact avec les gens en clinique (...). Je suis comme écoeurée de la détresse éthique. C'est quelque chose que je n'aime pas et qui me frustre. (participante 4)

Un moment donné, on a tellement de choses à faire, on est tellement éparpillé que, là, ça nous amène à réfléchir et à nous dire : « Est-ce qu'en bout de ligne, à faire tout ça en même temps, est-ce que je fais quelque chose de qualité? » (...) Un moment donné tu te dis : « Ma tête est-elle capable de faire tout ça en même temps? » (...) Est-ce vraiment une bonne façon de travailler? (...) Est-ce qu'on est obligé de faire tout ça? (...) C'est l'espèce de multi-tasking qui n'est pas tout le temps évident à gérer. (participante 10)

La participante 5 observe que ce contexte de travail malsain affecte non seulement la santé et le bien-être au travail des enseignantes, mais également leurs relations interpersonnelles. Elle constate une culture très individualiste, voire égocentrique qu'elle condamne et trouve très difficile à contrer.

Un autre dilemme éthique que je vis dans le cadre de mon travail, c'est l'impact justement aussi de la charge de travail sur les relations. (...) On est en train de prendre des façons de travailler qui sont de plus en plus individualisées. Pour pouvoir pallier puis répondre aux besoins de manque de temps quand cet élément-là est amené au groupe, mettons que je l'amène au groupe, bien la réponse du groupe, c'est : « oui, oui, oui, c'est bien vrai ». Tout le monde s'entend qu'il y aurait ce désir-là de plus de collaboration, d'entraide, et tout ça, mais concrètement, ce n'est pas ce qui se fait. Les actions ne vont pas dans ce sens-là. Je pense qu'individuellement les gens portent la valeur en soi, mais ne trouvent pas la façon de l'actualiser. C'est comme si le mode survie prend le dessus, le soi pour soi avant la communauté. (...) On est de plus en plus individuels dans notre travail, puis moi ça me heurte dans mes valeurs collectives.

Des participantes affirment qu'un climat toxique règne au sein de leur département comme en atteste cet extrait :

Il y a des situations où ça arrive d'être témoin de différentes choses : de gestes d'agression par exemple de la part de l'employeur ou de gestes d'agression de la part d'autres collègues, d'être témoin de différents gestes, finalement, qui sont malsains. (...) L'historique fait en sorte que des fois, je n'ose pas dire ou nommer [le problème] parce que par le passé il y a eu des gens qui ont dit ou qui ont nommé [les choses], puis ces gens-là se sont fait taper sur les doigts ou mis de côté. Il y a une crainte chez plusieurs membres de l'équipe qui s'est installée, puis les gens n'osent pas parler. (participante 5)

La surcharge de travail élevée dans un contexte de bureaucratisation où les processus de reddition de compte sont souvent longs et compliqués est propice aux enjeux éthiques, voire aux manquements éthiques. Les enseignantes souhaitent offrir un enseignement de qualité aux étudiants, mais la pression liée à la performance dans un système de gestion néolibérale amène plusieurs défis, dont la perte de sens due à la logique marchande qui met de l'avant des valeurs économiques et individualistes, plutôt qu'humanistes et collectivistes. La valeur qu'est la signification occupationnelle entre alors en conflit avec la gestion managériale contemporaine :

Quand tu es dans un système qui est orienté vers du profit, la rationalisation [vers] des modèles qui sont basés sur la compartimentation du travail, bien y a une perte de sens, là. Y a une perte de sens, parce qu'à côté t'as des valeurs, peut-être humanistes (ou bien de rendre service, ou bien de produire une recherche qui va être utile pour aider les gens à s'en tirer mieux, à être plus en santé), puis à côté de ça, t'as une logique économique de rationalisation. (participante 1)

Par ailleurs, alors que la surcharge de travail ainsi que la culture d'excellence et de performance liée à la vie universitaire affectent la santé et le bien-être des enseignantes, il en est de même pour les étudiants. Plusieurs participantes constatent que les étudiants font montre de problème de santé mentale et que les exigences que les départements ont à leur égard sont élevées.

L'autre chose aussi qui m'interpelle comme enseignante, c'est d'être mis en contact d'année en année avec une population étudiante qui m'apparaît elle-même avoir de plus en plus de difficulté à gérer sa propre anxiété, ses propres émotions. J'ai l'impression d'être de plus en plus en contact avec des gens qui ont divers symptômes liés aux troubles de l'humeur ou aux troubles anxieux. (...) Il y a une fragilité actuellement chez notre population étudiante. (participante 5)

Dans le cadre du cours d'advocacy que j'ai donné, c'est un cours qui valorise beaucoup le fait (...) d'être un agent de changement. Je suis tout à fait d'accord avec cette valeur-là, c'est pertinent. En tant que département, ils veulent créer des ergothérapeutes idéaux, en quelque part, donc qui vont être des agents de changement. (...) Mais, en même temps, en voyant beaucoup de détresse chez mes amis nouvellement ergothérapeutes que je côtoie qui ont fini récemment, des fois je me dis qu'il faut faire attention à ce qu'on transmet comme message pour les protéger, eux aussi. (...) Comment présenter une pratique idéale, tout en étant réaliste, puis en les préparant à la réalité, que ce soit les coupures budgétaires ou le manque d'autonomie professionnelle? (participante 11)

En résumé, le contexte universitaire affecte la santé et le bien-être des enseignantes et des étudiants, ce qui préoccupe plusieurs participantes. Un autre enjeu préoccupant émerge des données qui met en péril l'égalité entre les personnes, voire la justice au sein du corps enseignant.

3) Des injustices au sein du corps enseignant : l'éléphant dans la pièce

Si la vie académique rime avec surcharge de travail dans le contexte d'une culture de l'excellence et de la performance, elle rime aussi avec hiérarchie académique où le professeur-chercheur occupe le sommet de cette structure sociale inégalitaire. Plusieurs participantes ont discuté et condamné cette organisation sociale qui favorise l'enseignant-chercheur au détriment des autres types d'enseignants (chargés de cours, professeurs-enseignants, superviseurs de stagiaires, cliniciens, etc.). Les extraits suivants illustrent cette injustice académique qui, paradoxalement, peut affecter négativement l'enseignement aux étudiants et le transfert des connaissances aux cliniciennes :

C'est un milieu qui est très, très hiérarchisé. (...) Il y a quand même une grande différence entre le professeur et le chargé de cours. C'est un non-dit. (...) En réunion, si c'est un professeur qui le dit versus un chargé de cours, ça n'a pas la même portée. Aussi, les chargés de cours, on n'est pas invités aux assemblées de département : on n'est pas au courant de ce qui se passe. Ce qu'on apprend sur les développements, c'est s'il y a quelqu'un, un professeur, qui daigne bien nous en parler. (...) Ce sont des collègues de travail : on travaille ensemble. L'objectif est le même au niveau de la formation des étudiants, au niveau de la recherche, au niveau de faire progresser la profession, mais il y a comme un clivage quand même entre les deux titres qui fait que je ne sais pas, la notoriété [n'est pas la même]. (participante 6)

Puis, au-delà de ça, ce que j'ai trouvé difficile de voir, c'est à quel point les charges de cours pour les professeurs en recherche, ce n'était pas prioritaire, tandis qu'on est quand même dans une formation clinique. (...) En étant plus dans le milieu, je réalise que [l'enseignement], c'est une tâche nécessaire pour plusieurs. Il y en a qui sont motivés et qui veulent défendre les étudiants, il ne faut pas généraliser, mais dans plusieurs cas, j'ai vu à quel point ça avait l'air de plus les déranger qu'autre chose cette tâche-là. Puis ça, ça me dérange beaucoup, parce que moi, au départ, pour moi la recherche, c'est une façon de créer des cliniciens aussi. (...) Il faut collaborer avec les étudiants ou avec des cliniciens, donc il ne faut pas être méprisant de cette partie-là, c'est du transfert de connaissances, puis c'est important. (participante 11)

La hiérarchie académique fait en sorte que la parole de la chargée de cours et des cliniciens en général est dévaluée par rapport à celle du professeur, notamment du professeur-chercheur.

Pour donner un exemple concret, si mettons le contenu de certains cours est discuté : moi qui est encore dans le milieu clinique, dans la pratique, je vais dire : « ben écoutez, le type de situation qu'on rencontre régulièrement, ce serait important que ce soit vu et enseigné. » Si ça ne correspond pas nécessairement au champ de recherche du professeur, un sujet qu'il maîtrise moins, bien lui va vendre le point par rapport à lui et ses sujets qu'il maîtrise davantage, et c'est souvent ces points-là qui vont être retenus versus les éléments que j'apporte. (...) Je trouve ça frustrant que mon opinion ne soit pas davantage prise en compte. Fait que dans le fond, on sort de la réunion, puis entre nous on ventile. (participante 6)

Ainsi, les chargées de cours vivent des « conflits de valeurs » (participante 5) lorsqu'on leur impose des contenus de cours qu'ils considèrent moins pertinents ou que leur demande d'enlever des éléments des cours qu'elles donnent qu'elles estiment essentiels à la formation. Comme le résume la participante 5, « avec les années, il y a de plus en plus de situations où je vis de l'insatisfaction par rapport à l'espace que j'aie pour pouvoir donner mes enseignements », c'est-à-dire ceux qu'elle considère signifiants et importants pour former de la meilleure façon la relève. Enfin, comme l'illustre l'extrait suivant, la mode actuelle de la pratique probante (*evidence-based practice*) dévalue les pratiques mises de l'avant par plusieurs cliniciens, en plus de contribuer à la déprofessionnalisation de la profession.

Puis ça [la hiérarchie entre les mondes académiques et cliniques], je trouve ça un peu tendancieux parce que moi j'ai tendance à plutôt penser que les cliniciens ils peuvent nous en apprendre, parce qu'ils ont un type de connaissance qui n'est pas la connaissance scientifique, mais qui est une connaissance intime de la pratique clinique, puis du client. Je pense que leurs connaissances sont supérieures aux nôtres parfois. Notre rôle de chercheur devrait plutôt d'être capables d'extraire cette connaissance-là, puis de la formaliser. Souvent le chercheur, je trouve que beaucoup de chercheurs font le contraire. C'est qu'ils pensent qu'eux possèdent la science puis qu'ils doivent transmettre la bonne nouvelle aux cliniciens en leur disant : « là, vous avez pu à penser, vous avez maintenant une façon de faire. » Je trouve que ça déprofessionnalise beaucoup la profession parce que c'est de dire : « maintenant, ne pensez plus, faites juste appliquer des guidelines. » Donc, en même temps, on leur dit (maintenant l'ergothérapie, c'est une maîtrise) : « mais oh! Attention! Ne pensez plus par vous autres, n'ayez plus de jugement clinique parce qu'il y a des données probantes qui peuvent vous éclairer dans vos décisions. » C'est comme de leur dire : « vous avez maintenant une maîtrise, mais la nature de votre travail, c'est un travail de technicien qui consiste à appliquer des procédures. » Ça, ça m'agace vraiment beaucoup. (participante 1)

4) *L'identité professionnelle tirillée par des conflits de rôles*

Qu'elles soient professeures ou chargées de cours, les ergothérapeutes-enseignantes sont confrontées à des conflits de rôles dans le cadre de leurs enseignements. Leur identité professionnelle est alors partagée entre les différents chapeaux inhérents à l'enseignement universitaire. Selon les situations vécues dans leur quotidien de professeure-chercheuse ou de chargée de cours-clinicienne, les participantes vivent des enjeux éthiques quant aux rôles à jouer compte tenu de leurs responsabilités multiples. Par exemple, des conflits se présentent entre l'enseignante, d'une part, et la chercheuse ou la thérapeute, d'autre part, comme en attestent ces participantes.

J'essaie de concilier puis jongler avec les différents rôles (...). Parce que le temps, c'est limité : on n'en a pas à l'infini. Je trouve que la question de la gestion du temps, je dirais que c'est le plus gros enjeu parce qu'il y a une partie du temps qu'on veut mettre sur la recherche, mais moi, personnellement, ce n'est jamais sur l'enseignement que je veux couper. (...) Je considère que mes étudiants méritent que je leur donne un cours qui soit le plus complet, le plus précis possible, et moi, j'ai toujours en tête que je veux les outiller pour être des bons ergothérapeutes (...). Donc, mon principal défi, c'est de trouver comment arriver à ça, sans y mettre tout mon temps. (...) Enseigner, pour moi, c'est un service direct et ça mérite beaucoup de mon temps. (...) Je sais très bien qu'à travers la recherche, il y a des retombées aussi, mais elles sont moins directes. (...). Ma porte est pratiquement toujours ouverte [aux étudiants]. Ils ont mon numéro de téléphone. Je veux être disponible pour les aider. Mais, en fait, c'est parce que ça prend du temps et ce temps-là, je ne l'ai pas pour les autres tâches que j'ai à faire. (participante 8)

Le grand dilemme, c'est si j'ai des deadlines en même temps que mes étudiants ont des deadlines, ce qui arrive souvent pendant la saison des demandes de fonds. Qui vais-je prioriser? Si j'ai 2 heures de sommeil à amputer, sur le projet de qui je vais les mettre? Le mien ou le leur? (...) La compétition est forte. Des fois, le stress monte. Des fois, on coupe un peu : on coupe le sommeil, mais ça ne dure jamais. Je ne peux pas dire que j'ai été en souffrance, mais il y a des petits bouts où le passage était un peu plus étroit. (participante 3)

Ainsi, concilier les responsabilités reliées à l'enseignement et celles liées à la recherche n'est pas évident, notamment parce que le temps manque dans le contexte de surcharge de travail qui est lié à la vie académique. Quelquefois le rôle de thérapeute peut prendre le dessus sur celui d'enseignante. Il y a des situations où l'enseignante souhaiterait pouvoir décider pour l'étudiant qui, selon elle, se place dans une situation difficile ou prend des mauvaises décisions. Par exemple, lorsqu'une étudiante enceinte s'inscrit à trop de cours durant la session, alors que son accouchement est prévu avant la fin de session, l'enseignante ressent une grande sollicitude pour l'étudiante et estime que celle-ci « met en jeu son intégrité physique et psychologique, en en prenant trop en même temps » (participante 7). Il serait tentant de lui recommander d'agir autrement, mais l'enseignante hésite, car elle n'est pas sa thérapeute, ni son amie, ni sa mère. Dans le même ordre d'idées, la participante 6 mentionne ceci :

C'est sûr que je suis quand même très sensible à la situation personnelle des étudiants. De prime abord, je suis quand même ergothérapeute. Donc, j'ai toujours été dans la relation d'aide et c'est une portion importante dans mon travail. (...) J'essaie de maintenir ce niveau-là de relation d'aide, mais aussi, mon rôle n'est pas d'être là pour les supporter et leur donner des stratégies face à leurs difficultés. Il faut que je garde mon rôle de chargée de cours, d'enseignante. (participante 6)

En plus des conflits de rôles, des participantes notent que l'enseignement universitaire est lié à des conflits d'intérêts parfois préoccupants.

5) *La présence de conflits d'intérêts préoccupants*

Deux types de conflits d'intérêts sont rapportés par des participantes, soit le fait de donner de bonnes notes aux étudiants afin d'obtenir en retour des bonnes évaluations de ses enseignements ou le fait d'insister fortement des étudiants à faire un doctorat sous sa direction afin de bonifier son *curriculum vitae* (CV). Ces participantes estiment que ces situations sont préoccupantes parce qu'elles questionnent l'intégrité des enseignants. La participante 11 indique ceci sur ce sujet : « C'est aussi tentant de donner des bonnes notes parce que les élèves aiment mieux les profs qui donnent des bonnes notes! (...) Si tu donnes des moins bonnes notes, ils vont sûrement moins bien te coter. (...) Ce n'est pas le seul critère, mais ça joue ».

Un autre enjeu éthique qu'on n'a pas nommé : former des étudiants pour former des étudiants, c'est-à-dire est-ce qu'on leur fait faire un doctorat? Dans quel but? Parce que ça rapporte à l'université? Est-ce que c'est parce que ça rapporte à notre dossier [notre CV] ou parce qu'on pense que ça va aider la personne dans son cheminement ou parce qu'elle le veut, on va l'accompagner? (participante 11)

Ces extraits montrent que l'enseignement universitaire est lié à des intérêts qui sont parfois en tension, soit les intérêts des étudiants, ceux des enseignantes, ceux des chercheurs et ceux des universités. Il se présente des situations où il peut être tentant pour certaines enseignantes de faire passer leurs intérêts personnels devant ceux des étudiants. La prochaine section traite des enjeux éthiques mettant en péril l'équilibre occupationnel valorisé en ergothérapie.

6) L'équilibre occupationnel : un mythe plus qu'une réalité

Enfin, deux participantes mentionnent que la conciliation travail-famille est très difficile, que la gestion de temps entre la vie personnelle et la vie professionnelle est un défi important. L'équilibre occupationnel pour ces enseignantes est un enjeu important. Sur ce sujet, la participante 9 mentionne ceci : « si je n'avais pas de famille, ce serait moins compliqué (...) si j'investis dans ce projet-là, c'est moins de temps avec mes enfants ou c'est la culpabilité aussi de ne pas être présente pour eux ». La participante 8 mentionne ceci sur ce sujet :

J'ai tendance à banaliser les besoins qui me sont propres et j'inclus dans ça les besoins de ma famille. C'est comme ma vie, ça m'appartient, c'est à moi versus tout ce qui retombe sur d'autres personnes. Des considérations ou des contraintes familiales, si ça empêche la réalisation de trucs qui ont des implications sur plusieurs autres personnes, on dirait que je me sens mal. Ce sont des situations qui vont probablement encore continuer à me faire vivre de la détresse éthique. (...) C'est clair qu'il faut que j'arrive à concilier ça, mais ce n'est pas encore clair pour moi comment je vais arriver à faire ça.

Tels sont les enjeux éthiques de l'enseignement en ergothérapie selon les participantes. La section suivante formule des pistes de réflexion sur ces résultats.

Discussion des résultats

Cette étude, qui avait pour objectif de documenter les enjeux éthiques de l'enseignement en ergothérapie, a donné la parole à onze ergothérapeutes chargées de cours ou chercheuses qui enseignent au Québec, en vue de former la relève professionnelle. Cette section articule une réflexion critique sur les résultats présentés à la section précédente, tout en établissant des liens avec les résultats d'autres études.

Comparaison des résultats avec ceux d'autres écrits

Mis à part les injustices vécues au sein des départements ou des programmes universitaires en ergothérapie sur lesquelles nous reviendrons au point suivant, tous les enjeux éthiques qui émergent de la présente étude sont discutés dans les écrits traitant des enjeux éthiques de l'enseignement. De fait, tout enseignant est confronté tôt ou tard à des enjeux éthiques reliés à l'équité dans le cadre de ses enseignements, notamment lors de l'évaluation des travaux des étudiants (5,6,8), lors des situations d'échec (27,28) ou lors de demandes étudiantes (23). Bien que les enseignantes tentent d'être objectives et impartiales, l'équité envers les étudiants demeure pour plusieurs un idéal vers lequel tendre (28). Aussi, plusieurs auteurs, tout comme les participantes à l'étude, observent que la vie académique est liée à une charge de travail importante (14,31,32) qui met en péril l'équilibre occupationnel (24) et qui affecte la santé et le bien-être des enseignantes (16-18) et des étudiants (23), et ce, dans un contexte qui valorise l'excellence, la productivité et la performance (14,25). Paradoxalement, ce contexte se révèle peu favorable à l'agir éthique (14), comme le notent aussi certaines participantes. De fait, des comportements non éthiques sont documentés dans les écrits, que ceux-ci aient pour cibles des étudiants ou des collègues (7-9). Bien que certains des comportements discutés dans les écrits n'aient pas été rapportés par les participantes à l'étude, comme le fait d'avoir des relations intimes avec des étudiants, des relations conflictuelles entre collègues ont été observées par certaines participantes. Ces situations conflictuelles semblent moins fréquentes que dans certains départements de sciences infirmières où l'intimidation entre collègues mène parfois à de la détresse éthique (15). Des participantes mentionnent toutefois avoir observé des relations agressives entre des collègues qui affectent le climat départemental jusqu'à le rendre toxique. Par ailleurs, plusieurs écrits discutent des conflits de rôles vécus par les enseignants (6,33). Ainsi, à l'instar de maintes participantes, ces auteurs notent que l'enseignement est lié à des conflits de rôles engendrant parfois des conflits de valeurs, voire du mal-être au travail (2). Enfin, des auteurs discutent aussi des conflits d'intérêts pouvant être rencontrés dans l'enseignement (10,22), tel que rapporté par des participantes.

Cela dit, certains enjeux éthiques discutés dans les écrits n'ont pas été abordés par les participantes à l'étude. Par exemple, les enjeux éthiques ayant trait au bris de la confidentialité d'informations relatives aux étudiants (21,23), aux cas de plagiat chez les étudiants (8,11) et au fait de mettre au défi les étudiants dans ses enseignements (12) n'ont pas été rapportés par les participantes. Aussi, des auteurs discutent du fait que le développement de certaines compétences professionnelles suscite des enjeux éthiques, notamment parce que ces compétences considérées essentielles sont parfois négligées ou requièrent une certaine expertise pour être enseignées (28). Sur ce sujet, Kai, Spencer et Woodward (20) discutent des compétences culturelles, tandis que Kanny et Kyler (23) mentionnent les compétences éthiques et sociales. Pour leur part, les participantes n'ont pas discuté de ces compétences en particulier. Enfin, plusieurs auteurs discutent du fait que l'enseignant a une responsabilité éthique quant au contenu des cours qu'ils donnent (6), en outre la protection du public et la promotion de la profession (23) et de l'approche centrée sur le client (30) devraient être des principes phares des enseignements en ergothérapie. Les participantes à l'étude ont peu abordé cette question, à l'exception d'une participante qui a discuté du fait qu'il peut y avoir des conséquences négatives chez les étudiants à les inciter à être des agents de changement, surtout dans le contexte actuel où les milieux de pratique sont liés à des contraintes importantes, voire à de la détresse éthique (40,47-49).

Injustices épistémique et occupationnelle au sein des départements d'ergothérapie

Tandis que des résultats documentés dans les écrits n'ont pas été nommés par les participantes, un enjeu éthique assurément préoccupant émerge du discours des participantes. Il s'agit d'un élément peu documenté dans les écrits, mais qui correspond

à une réalité pourtant omniprésente dans le monde académique. Comme nous le disions plutôt, c'est l'éléphant dans la pièce que personne n'ose nommer, alors qu'il est radicalement injuste et condamnable d'un point de vue éthique. Rappelons que pour qu'il y ait une relation éthique entre des personnes, la symétrie et la réversibilité sont requises. Or, la culture universitaire est fondamentalement inégalitaire et hiérarchique. Aussi, au sein de cette culture, l'autorité épistémique, c'est-à-dire l'autorité prodiguée à une personne en raison de ses connaissances, est détenue par le professeur-chercheur au détriment de tous les autres types d'enseignants, voire des milieux cliniques et des cliniciens. Cette organisation sociale révèle une injustice épistémique (50), suivant laquelle le chargé de cours et le professeur-enseignant (celui qui fait peu ou moins de recherche que le professeur-chercheur) se voient dévalués dans leur parole (injustice testimoniale) et dans leur capacité à interpréter les savoirs et de rendre compte de leur vécu expérientiel (injustice herméneutique). Pour sa part, le professeur-chercheur, en particulier celui qui est considéré prolifique en recherche, impose de manière quasi naturelle sa vision des choses à ses pairs et a tendance à dévaluer les autres types de savoirs, dont fait partie le savoir expérientiel. Alors que le professeur-chercheur brille par sa notoriété et par son expertise considérée comme probante, il marginalise dans l'ombre et le silence ses collègues enseignantes. Sans que cette injustice épistémique et l'injustice occupationnelle qui y est associée ne soient intentionnelles, la culture de l'excellence des milieux académiques crée un contexte propice à leur occurrence. Ainsi, bien que la profession ergothérapique valorise la justice occupationnelle, les départements universitaires sont dominés par une injustice épistémique qui par ricochet engendre une injustice occupationnelle, soit une forme de marginalisation occupationnelle (51-55), ce qui d'un point de vue ergothérapique est plutôt préoccupant. Ce résultat, à notre connaissance, est inédit.

Forces et limites de l'étude

Cette étude comporte des forces et des limites. Eu égard aux forces, elle a donné la parole à des enseignantes en ergothérapie qui occupent différents rôles au sein de départements ou de programmes ergothérapiques ou de réadaptation d'universités québécoises. Ce faisant, elle a pu mettre au jour des injustices préoccupantes en leur sein. Aussi, elle a examiné un rôle peu étudié en ergothérapie, soit l'enseignement, et ce, via une lunette éthique. Ainsi, elle contribue au développement des connaissances dans les domaines de l'enseignement et de l'éthique appliquée en ergothérapie. Relativement aux limites, il aurait été intéressant que des hommes participent à l'étude afin de déterminer dans quelle mesure les enjeux éthiques documentés ici sont ou non liés aux genres, voire aux injustices de genre. Enfin, bien que la saturation des données ait été obtenue, l'échantillon demeure petit, ce qui explique peut-être en partie le fait que des enjeux éthiques documentés dans les écrits n'aient pas été rapportés par les participantes à l'étude.

Conclusion

Cette étude a documenté pour une toute première fois les enjeux éthiques de l'enseignement en ergothérapie au Québec. Ces enjeux éthiques mettent en péril différentes valeurs, notamment l'équité, la santé, le bien-être, la justice épistémique, la justice occupationnelle, le professionnalisme, l'intégrité et l'équilibre occupationnel. Bien que les résultats de l'étude rejoignent en général ceux documentés dans les écrits en enseignement, en santé ou en ergothérapie, ils révèlent que des injustices sont présentes au sein des départements ou des programmes universitaires d'ergothérapie ou de réadaptation, soit des injustices épistémiques et occupationnelles, lesquelles n'avaient pas à notre connaissance été documentées à ce jour. Ce résultat est préoccupant non seulement d'un point de vue éthique, mais également d'un point de vue ergothérapique, car la profession valorise la justice, notamment la justice occupationnelle (49-53).

Cette étude est susceptible d'avoir des retombées sur la pratique. Sur le plan de l'enseignement, il est souhaité que les résultats de cette étude puissent participer à renverser les injustices vécues au sein des départements ou programmes universitaires afin que la parole des uns comme des autres soit égale et que tout enseignant en ergothérapie puisse avoir accès aux mêmes informations. Sur le plan de la recherche, il est souhaité que l'écart entre les mondes académiques et cliniques se réduise, voire disparaisse, de façon à valoriser le savoir expérientiel des cliniciens et à établir un dialogue fécond entre les chercheurs et les cliniciens. Sur le plan de la clinique, il est souhaité que les préoccupations et les réalités des cliniciens puissent être mieux comprises et étudiées par les chercheurs, de façon à que ces derniers puissent coconstruire ou codévelopper en collaboration avec les cliniciens des outils et des ressources répondant aux besoins des cliniciens et à ceux des clients. Sur le plan de la gouvernance, il est souhaité que les directions des universités puissent mettre en place des environnements de travail contribuant à la santé et au bien-être des enseignants et des étudiants, ce qui nécessitera une sorte de révolution dans le monde académique. Plus spécifiquement, il est souhaité qu'une culture éthique soit mise en place minimisant ainsi les impacts négatifs de la culture académique qui rime avec excellence, productivité et performance, sans toutefois que cette culture ne soit réduite à une approche déontologique et légale de contrôle et de reddition de compte. D'autres valeurs plus humaines auraient avantage à être tout autant valorisées pour que la science rime aussi avec conscience, car « science sans conscience n'est que ruine de l'âme » comme l'affirmait Rabelais dans le *Pantagruel* (56).

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Conflits d'intérêts

Marie-Josée Drolet dirige un projet de recherche sur lequel Bryn Williams-Jones, éditeur en chef de la revue, est co-chercheur. Williams-Jones n'a pas été impliqué dans l'évaluation ou l'approbation du manuscrit.

Responsabilités des évaluateurs externes

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateurs n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la [Revue canadienne de bioéthique](#) assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

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Conflicts of Interest

Marie-Josée Drolet directs a research project on which Bryn Williams-Jones, Editor-in-chief of the journal, is a co-investigator. Williams-Jones was not involved with the evaluation or approval of the manuscript.

Peer-reviewer responsibilities

Reviewer evaluations are given serious consideration by the editors and authors in the preparation of manuscripts for publication. Nonetheless, being named as a reviewer does not necessarily denote approval of a manuscript; the editors of [Canadian Journal of Bioethics](#) take full responsibility for final acceptance and publication of an article.

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References

1. Ordre des ergothérapeutes du Québec (OEQ). [Lois et règlements](#); 2019.
2. Centeno J, Bégin L. Les loyautés multiples: Mal-être au travail et enjeux éthiques. Montréal, Éditions Nota Bene; 2015.
3. Swisher LLD, Arslanian LE, Davis CM. [The Realm-Individual Process-Situation \(RIPS\) model of ethical decision-making](#). HPA Resource. Official Publication of the Section on Health Policy & Administration. 2005;5(3):3-8.
4. Drolet MJ. De l'éthique à l'ergothérapie. La philosophie au service de la pratique ergothérapeutique. Québec, Presses de l'Université du Québec; 2014.
5. Dukewich KR, Wood, S. ["Can i have a grade bump?" the contextual variables and ethical ideologies that inform everyday dilemmas in teaching](#). Collected Essays on Learning and Teaching. 2016;9:97-110.
6. Colnerud G. [Teacher ethics as a research problem: syntheses achieved and new issues](#). Teachers and Teaching. 2006;12(3):365-385. doi: 10.1080/13450600500467704
7. Bruhn JG, Zajac G, Al-Kazemi AA, Prescott Jr LD. [Moral positions and academic conduct: Parameters of tolerance for ethics failure](#). The Journal of Higher Education. 2002;73(4):461-493.
8. Ehrich LC, Cranston N, Kimber M, Starr K. [\(Un\) ethical practices and ethical dilemmas in universities: academic leaders' perceptions](#). International Studies in Educational Administration (Commonwealth Council for Educational Administration & Management (CCEAM)). 2012;40(2):99-114.
9. Dixon N. [The morality of intimate faculty-student relationships](#). The Monist. 1996;79(4):519-535.
10. Stein PC. [Conflict of interest and conflict of commitment: ethical questions and dilemmas for faculty members](#); 1992.

11. Vehviläinen S, Löfström E, Nevgi A. [Dealing with plagiarism in the academic community: emotional engagement and moral distress](#). Higher Education. 2018;75(1):1-18. doi:10.1007/s10734-017-0112-6
12. Scager K, Akkerman SF, Pilot A, Wubbels T. [Teacher dilemmas in challenging students in higher education](#). Teaching in Higher Education. 2017;22(3):318-335. doi:10.1080/13562517.2016.1248392
13. Shapira-Lishchinsky O. [Teachers' critical incidents: Ethical dilemmas in teaching practice](#). Teaching and Teacher Education. 2011;27(3):648-656.
14. Berg M, Seeber B. Slow professor: Challenging the culture of speed in the academy. Toronto, University of Toronto Press; 2016.
15. Ganske KM. [Moral distress in academia](#). Online Journal of Issues in Nursing. 2010;15(3):6.
16. Diener EJ, Stratton E, Abdul-Raheem J, Al-Rjoub S, Kelley J, Mack R. [Moral distress in Nursing Academia](#). Affiche présentée au 43e Biennial Convention, Las Vegas, États-Unis; 2015, November.
17. Yoes T. [Addressing Moral Distress: Challenge and Strategies for Nursing Faculty](#). Oklahoma Nurse. 2012;57(2):14.
18. Waite SA. Exploring the experience of moral distress in nursing faculty. Disponible à ProQuest Dissertations & Theses Global; 2018.
19. Gerrish K, Ashworth PD, McManus M. [Some dilemmas of master's level nurse education](#). Journal of Advanced Nursing. 2000;32(4):834-841.
20. Kai J, Spencer J, Woodward N. [Wrestling with ethnic diversity: toward empowering health educators](#). Medical Education. 2001;35(3):262-271.
21. Dalton S, Harris GE. [Examining student-professor confidentiality: What are the expectations for psychology professors](#). Morning Watch; 2010:37.
22. Andresen NS, Olson TS, Krasowski MD. [Medical student and medical school teaching faculty perceptions of conflict of interest](#). BMC Research. 2017; Notes 10:1-6. doi:10.1186/s13104-017-2596-7
23. Kanny EM, Kyler PL. [Are faculty prepared to address ethical issues in education?](#) American Journal of Occupational Therapy. 1999;53(1):72-74.
24. Masagatani GN, Grant HK. [Managing an academic career](#). American Journal of Occupational Therapy. 1986;40(2):83-88.
25. Scott PJ, Justiss MJ, Schmid AA, Fisher TF. [A framework for promoting scholarship productivity in occupational therapy curricula](#). Occupational Therapy in Health Care. 2013;27(1):35-45. doi:10.3109/07380577.2012.757409
26. Cusick A, Froude E, Bye R, Zakrzewski L. [Building a strong academic workforce: challenges for the profession](#). Australian Occupational Therapy Journal. 204;61(3):131-131. doi:10.1111/1440-1630.12135
27. Ilott I, Murphy R. [Feelings and failing in professional training: the assessor's dilemma](#). Assessment & Evaluation in Higher Education. 1997;22(3):307-316.
28. Drolet MJ, Sauvageau A, Baril N, Gaudet R. [Les enjeux éthiques de la formation clinique en ergothérapie](#). Revue Approches inductives. 2019;6(1):148-179.
29. Fleming-Castaldy RP, Gillen G. [Ensuring that education, certification, and practice are evidence based](#). American Journal of Occupational Therapy. 2013;67(3):364-369. doi:10.5014/ajot.2013.006973
30. Fleming-Castaldy RP. [A macro perspective for client-centred practice in curricula: Critique and teaching methods](#). Scandinavian Journal of Occupational Therapy. 2015;22(4):267-276. doi:10.3109/11038128.2015.1013984
31. Copolillo AE, Peterson EW, Helfrich CA. [Combining roles as an academic instructor and a clinical practitioner in occupational therapy: benefits, challenges, and strategies for success](#). Occupational Therapy in Health Care. 2002;15(1/2):127-143.
32. Fisher G, Dones W, Petit-Frere N, Dillow K, Behler T. Contemporary issues and trends facing occupational therapy faculty. (Poster Session). American Journal of Occupational Therapy. 2017; July:71, 7111510190p1. doi:10.5014/ajot.2017.71S1-PO3155
33. DePoy E, Gitlin LN. Introduction to Research. St. Louis, Elsevier Mosby; 2010.
34. Hammell KW, Carpenter C, Dyck I. Using qualitative research: A practical introduction for occupational and physical therapists. Edinburgh: Churchill Livingstone; 2000.
35. Hunt MR, Carnevale FA. [Moral experience: a framework for bioethics research](#). Journal of Medical Ethics. 2011;37(11):658-662.
36. Drolet MJ, Baril N, Sauvageau A, Renaud S. (sous presse). Solving the ethical issues of clinical training in occupational therapy: Results of an empirical study conducted in Quebec-Canada. Canadian Journal of Bioethics/Revue Canadienne de Bioéthique.
37. Drolet MJ, Viscogliosi C. (sous presse). Ébauche d'une éthique interculturelle de la pratique de l'ergothérapie en contexte autochtone : sur la base de résultats de recherche et d'une recension des écrits. Ethica – Revue interdisciplinaire de recherche en éthique.
38. Drolet MJ, Gaudet R, Pinard C. [Résoudre les enjeux éthiques de la pratique privée : des ergothérapeutes prennent la parole et usent de créativité](#). Ethica – Revue interdisciplinaire de recherche en éthique. 2018;22(1):109-141.
39. Drolet MJ, Goulet M. [Les barrières et facilitateurs à l'actualisation des valeurs professionnelles : perceptions d'ergothérapeutes du Québec](#). Revue ergOTHérapie. La revue française de l'ergothérapie. 2018;71:31-50.
40. Drolet MJ, Pinard C, Gaudet R. [Les enjeux éthiques de la pratique privée : des ergothérapeutes du Québec lancent un cri d'alarme](#). Ethica – Revue interdisciplinaire de recherche en éthique. 2017;21(2):173-209.
41. Drolet MJ, Maclure J. [Les enjeux éthiques de la pratique de l'ergothérapie : perceptions d'ergothérapeutes](#). Revue Approches inductives. 2016;3(2):166-196.
42. Husserl E. The crisis of European sciences and transcendental phenomenology. Evanston, IL: Northwestern University Press; 1970.

43. Husserl E. The train of thoughts in the lectures. Dans EC Polifroni, M Welch (Éds), *Perspectives on philosophy of science in nursing*. Philadelphia, PA: Lippincott; 1999.
44. Corbière M, Larivière N. Méthodes qualitatives, quantitatives et mixtes dans la recherche en sciences humaines, sociales et de la santé. Québec: Presses de l'Université du Québec; 2014.
45. Thomas SP, Pollio HR. *Listening to Patients: A Phenomenological Approach to Nursing Research and Practice*. New York: Springer Publishing Company; 2002.
46. Giorgi A. De la méthode phénoménologique utilisée comme mode de recherche qualitative en sciences humaines : théories, pratique et évaluation. Dans J Poupart, LH Groulx, JP Deslauriers, A Laperrière, R Mayer, AP Pires (Éds), *La recherche qualitative: enjeux épistémologiques et méthodologiques*. Boucherville: Gaëtan Morin; 1997. pp. 341-364.
47. Durocher E, Kinsella EA, McCorquodale L, Phelan S. [Ethical tensions related to systemic constraints: occupational alienation in occupational therapy practice](#). *Occupation, Participation and Health*. 2016;36(4):216-226.
48. Penny NH, Ewing TL, Hamid RC, Shutt KA, Walter AS. [An investigation of moral distress experienced by occupational therapists](#). *Occupational therapy in health care*. 2014;28(4):382-393.
49. Rivard AM, Brown CA. [Moral distress and resilience in the occupational therapy workplace](#). *Safety*. 2019;5(1):10. doi:10.3390/safety5010010
50. Fricker M. *Epistemic injustice: Power and the ethics of knowing*. Oxford: Oxford University Press; 2007.
51. Larivière N, Drolet MJ, Jasmin E. La justice sociale et occupationnelle. Dans E Jasmin (dir). *Des sciences sociales à l'ergothérapie. Mieux comprendre la société et la culture pour mieux agir comme spécialiste en habilitation à l'occupation*. Québec, Les Presses de l'Université du Québec, 2019;129-153.
52. Durocher E. Occupational justice: A fine balance for occupational therapists. Dans D Sakellariou, N Pollard (eds.) *Occupational therapies without borders. Integrating justice with practice, second edition*. Toronto: Elsevier; 2017. pp. 8-18.
53. Townsend E, Polatajko HJ. *Habiliter à l'occupation : Faire avancer la perspective ergothérapique de la santé, du bien-être et de la justice par l'occupation (2e éd.)*. Ottawa: CAOT Publications ACE; 2013.
54. Wilcock AA. *An occupational perspective of health*. Thorofare, Slack Incorporated; 2006.
55. Whiteford G, Townsend E, Bryanton O, Wicks A, Pereira R. The participatory occupational justice framework: salience across contexts. Dans D Sakellariou et N Pollard (eds.) *Occupational therapies without borders. Integrating justice with practice, second edition*. Toronto: Elsevier; 2017. pp. 163-183.
56. Rabelais F. *Pantagruel*. Paris, Sociétés les Belles Lettres; 1959.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The Complicated but Plain Relationship of Intellectual Disability and Well-being

James Gould¹

Résumé

La croyance commune est que le handicap est mauvais pour la personne handicapée, qu'il a un effet négatif sur le bien-être. Certains philosophes et militants des droits des personnes handicapées, cependant, affirment que le handicap a peu ou pas d'impact sur la qualité de vie d'une personne, qu'il est neutre quant à son épanouissement. Dans des articles récents, Stephen Campbell et Joseph Stramondo, tout en rejetant les deux points de vue, affirment que nous ne pouvons pas faire de larges généralités concernant le handicap sur le bien-être. Qu'ils aient raison sur les handicaps physiques et sensoriels, je ne sais pas, mais je soutiens qu'ils ont tort sur les handicaps intellectuels. Une large généralisation des déficiences intellectuelles (DI) est justifiée: elle a toujours un impact négatif sur la qualité de vie, même s'il n'y a pas d'impact négatif unique. Les inconvénients de la DI sont clairs (toute DI est mauvaise), mais compliqués (sa gravité dépend des influences multidimensionnelles, y compris la condition biologique, l'environnement social et le tempérament personnel).

Mots-clés

déficience intellectuelle, satisfaction de vivre, simple différence, qualité de vie, bien-être

Abstract

The common belief is that disability is bad for the person who is disabled, that it has a negative effect on well-being. Some disability rights activists and philosophers, however, assert that disability has little or no impact on how well a person's life goes, that it is neutral with respect to flourishing. In recent articles Stephen Campbell and Joseph Stramondo, while rejecting both views, claim that we cannot make any broad generalizations about the effect of disability on well-being. Whether they are right about physical and sensory disabilities, I do not know, but I argue that they are wrong about intellectual disabilities (ID). A broad generalization about intellectual disabilities *is* justified: it always has a negative impact on quality of life, even though there is no single negative impact. The disadvantages of ID are *plain* (all ID is bad) but *complicated* (its badness depends on multidimensional influences including biological condition, social environment and personal temperament).

Keywords

intellectual disability, life satisfaction, mere difference, quality of life, well-being

Consider Three Individuals

Vicky is an adult woman with profound cognitive disabilities. She has a mental age of 5 months, is doubly incontinent and bottle-fed. *Vicky* spends each day in a wheelchair, incapable of all but minimal responses to her caregivers. She will never have a sense of past and future or of herself as a person. *Vicky* has no language, inner life or purposive agency; she cannot engage in any important elements that characterize human lives – meaningful communication, significant relationships and productive activity (1).

My adult son *David* is intellectually disabled from a prenatal brain injury causing periventricular leukomalacia (PVL). PVL involves the destruction of small areas of brain tissue around fluid-filled areas called ventricles – the damage creates holes in the brain's white matter. His evaluative scores fall within the moderate range of mental impairment: he does not read or write, is nonverbal and has significant deficits in adaptive living skills. He will need residential arrangements, employment assistance and other disability services his entire life. *David* is, however, more than PVL. He has numerous virtues (cheerfulness, humor and empathy), talents (he rides his recumbent tricycle hundreds of miles each summer, stocks shelves at a food pantry and plays Special Olympics sports) and relationships (with family and friends).

My daughter *Sarah* is an intellectually typical adult. She completed graduate school in Europe and lives in England, where she is program manager at a disability agency. She and her husband travel extensively, brew beer, ride motorcycles, run marathons, attend concerts and entertain a wide circle of friends.

The common belief is that disability is bad for and harmful to the person who is disabled, that it has a negative effect on well-being. Some disability rights activists and philosophers, however, assert that disability has little or no impact on how well a person's life goes, that it is neutral with respect to flourishing. In recent articles Stephen Campbell and Joseph Stramondo (2,3), while rejecting both views, claim that we cannot make any broad generalizations about the effect of disability on well-being. Whether they are right about physical and sensory disabilities, I do not know; but I shall argue that they are wrong about intellectual disabilities (ID). A broad generalization about ID is justified: it always has a negative impact on quality of life, even though there is no single negative impact.

What Campbell and Stramondo Think

Campbell and Stramondo group all disabilities together – physical, sensory and intellectual – and since their analysis covers disabilities in general, I interpret their claims as applying to ID in particular. They reject the *Standard View* that ID has a negative impact on well-being in the vast majority of cases. They also reject the *Neutral View* that in most cases ID has no impact on

well-being. They affirm, instead, the *Complicated View* that ID has an individualized impact on well-being which makes it difficult to generalize about whether it is bad or not. This is true on both subjective and objective accounts of well-being (3).

Why the Standard View is False

There are four ways in which ID might be bad for a person, and the Standard View is false on all interpretations.

1. ID is not *intrinsically bad*. By itself, apart from its consequences, ID does not make a person worse off. While being pain-free is a basic element of well-being, possessing typical intellectual abilities is not. In isolation from its effects, ID on its own is neither good nor bad, but neutral (3, pp. 156–157).
2. ID is seldom *instrumentally bad*. It is true that ID can prevent a person from obtaining particular goods of life, experiencing certain things and performing specific tasks. But the fact that ID is instrumentally bad in some ways does not mean it is instrumentally bad in all ways. This is because particular goods like social relationships can be achieved in multiple ways; while ID cuts off some avenues for realizing human goods, it does not destroy all avenues to them. Even if ID does block specific goods entirely, the person still enjoys enough functionings to have a good life overall. Social arrangements and individual characteristics (what a person is like and how they respond to their condition) can also prevent the achievement of important goods and negatively impact well-being. Circumstantial variations in life lead to diverse variations in well-being and so it is impossible to make any simple generalizations about the disadvantages of ID itself (3, pp. 157–160).
3. ID is not *comparatively bad*. It does not make a person's life worse than it would have been without ID. A judgment of relative badness requires a comparison between someone's actual well-being with ID and their supposed well-being without ID. This comparison, however, cannot be drawn: "counterfactual opacity" makes it impossible to know that a person would have had a better life without ID than they have with it – any such judgment reflects "ableist fantasy." In addition, ID is identity-constitutive – it is central to who the individual is and shapes their identity in substantive rather than incidental ways. Being unavoidable, its removal would obliterate the person (3, pp. 160–161).
4. ID is seldom *overridingly bad*. Few conditions are so "very, very...bad" – so awful – that life with them is guaranteed to be bad all things considered and on the whole. Most IDs are compatible with important goods of life such as knowledge, achievement, happiness and relationships. ID may be a local bad that reduces well-being in some aspects of life, but to label it as a global bad that makes life go worse in all dimensions is reductive synecdoche – a general, negative assumption about a whole human person on the basis of one characteristic (3, pp. 161–162).

These considerations lay to rest the Standard View, the generalization that ID tends to be bad for a person most of the time.

Why the Neutral View is False

That the Standard View is false does not mean the Neutral View is true, that ID is neither good nor bad for a person. Campbell and Stramondo affirm that ID is *intrinsically* neutral and deny that it is *overridingly* neutral. But it is misleading to think that ID has no *instrumental* or *comparative* impacts on well-being; in combination with a person's internal dispositions and external environments, ID tends to have momentous consequences for their lives. Sometimes this influence is for the worse: ID can lead to bad things and prevent good things, but with varying disadvantages due to contingent factors (3).

Why the Complicated View is True

Campbell and Stramondo reason that, since the Standard and Neutral Views are false, the Complicated View must be true. We cannot generalize about the impact of ID on well-being because of three facts.

1. There are variations *between* types of ID. Inter-disability variation occurs because ID comes in different types, e.g., Fragile X, Down syndrome, PVL, autism and other diagnoses. Each condition has varying impacts on intellectual functioning.
2. There are variations *within* types of ID. Intra-disability variation occurs because ID comes in different degrees, i.e., mild, moderate, severe and profound. Each level has varying effects on mental abilities. Down syndrome, for example, is not expressed to the same extent and in the same way in each case; it has considerable variation and while most people have mild or moderate symptoms, some are severe.

The fact of significant variation between different IDs and within the same ID means that we cannot generalize about the impact of ID on well-being (3, pp. 165–166).

3. IDs are high-impact traits. *Low-impact traits* (such as being left-handed) are causally inert; they are mere differences that have little or no effect on quality of life. But *high-impact traits* (such as ethnicity and sex) have significant causal effects on how someone's life goes. ID substantially shapes personal well-being; it has varying impact both in combination with social arrangements and individual dispositions as well as apart from these factors (3, pp. 166–168).

Why ID is Probably Comparatively Bad

Campbell and Stramondo concede that it is *probable* that ID is *comparatively* bad: if we consider averages rather than the vast majority of cases, then ID is likely to make a person worse off. Two types of ID, in particular, reduce average well-being: severe congenital disabilities like Tay Sachs Disease are comparatively bad because they significantly undermine capacities necessary for flourishing; acquired disabilities like Traumatic Brain Injury are comparatively bad because they involve transition

costs. In addition, unfriendly social environments can create lower quality of life. These factors explain why the average person with ID has a worse life than the average person without ID (3, pp. 168–169).¹

Summarizing the Complicated View

Campbell and Stramondo do not understand human flourishing in terms of species essentialism – a common, core nature by which all persons are measured. Instead, whether a particular individual flourishes is contingent; it depends on the specific circumstances of their life (4). They conclude that:

1. “the Standard View is false... [It] is simply untrue that, as a general rule, IDs are bad for those who have them.”
2. “[While] most IDs are intrinsically neutral, we cannot generalize about whether IDs in general are good, bad or neutral for people.”
3. “It may be possible to generalize about ID’s likelihood of rendering a person worse off to some extent” (3, p. 176).

The countless variations in IDs and life circumstances create very different patterns of well-being and thus no simple generalizations can be made concerning the impact of ID on quality of life. Instead, “the relationship between ID and well-being is a complicated one” (3, p. 176).

What I Think

I *agree* with Campbell and Stramondo on several things. We should avoid the simplistic assumption that ID leads to poor quality lives. The relationship of ID and well-being is complicated; both internal functions and external circumstances vary, and so assessing the precise effect of ID on quality of life is difficult. In evaluating the impact of ID on well-being we should not ignore the positive testimony of people with ID concerning their quality of life. Intersectionality also matters: people with ID from rich families or who have many loved ones may experience less overall disadvantage than people without ID from poor families or who are lonely (5, p. 30 and 62). There is no single dimension of well-being and disadvantage; a person with ID may flounder with respect to meaningful activity but flourish in their personal relationships. As David Wasserman and colleagues (6, p. 20) note, we should not accept “unjustified or overbroad generalizations about the impact of impairments on well-being, ignoring the highly variable effects of different impairments in different settings.” Vicky’s profound ID has a significantly different effect on flourishing than David’s moderate ID does; social environment and individual temperament also affect quality of life in multiple ways.

But I *disagree* with Campbell and Stramondo on other things. They come close to the Neutral View that there is nothing essentially worse about having ID than lacking it. Campbell and Stramondo acknowledge that their “response to the Standard View, while not as simple as the...‘neutral trait’ response, yields many of the same [conclusions]” (3, p. 152). The plain fact is, I argue, that ID is harmful to well-being in the vast majority of cases. Its impact is always (or almost always) bad, even though that badness varies due to biological impairment, individual temperament and social setting. Campbell and Stramondo show that *the negative impact of ID is complicated* but they do not show that ID typically has *no negative impact at all*. We can, then, generalize about ID: in all (or almost all) cases it results in disadvantages which lower quality of life even though we may be unable at times to say how much and in what specific ways.

In what follows I argue that as a general rule ID is bad for people who have it; in the vast majority of cases they are harmed, but to varying degrees. ID is:

1. *objectively bad* – it brings real disadvantages and reduces quality of life;
2. *instrumentally bad* – it causes intrinsic bads and prevents intrinsic goods of life;
3. *globally bad* – it lowers a person’s well-being overall, not just in some domains but across a wide range of circumstances;
4. *comparatively bad* – it makes a person’s life worse than it would have been without ID.

ID, however, is not

5. *overridingly bad* – most ID is compatible with many goods of life and does not ruin life on the whole.

Most ID, to use Tom Shakespeare’s (7, p. 224) words, is neither irrelevant nor tragic. My view should not be misunderstood. First, the fact that ID is *bad* does not mean it is *tragic*. I do not wish to perpetuate widely held but simplistic assumptions about the kind of life a person with ID experiences. I do not want to add to unexamined social stereotypes of ID by painting it as poor quality of life – as a tragedy – when it is not.² But nor do I wish to pretend that ID is irrelevant – like being left-handed – when it is not. Second, the fact that *ID* is bad (because it makes a person unable to do typical things and thus hinders flourishing) does not mean that *people with ID* are morally inferior or less worthy of respect. There is an important difference between devaluing a trait (a man’s cruelty) and devaluing a person (the man himself); and there is an important difference between devaluing David’s PVL and devaluing David.

¹ Campbell and Stramondo deny that ‘as a general rule’ ID is bad for someone, but grant that ‘on average’ it makes a person worse off. I am not sure that the conceptual distinction between ‘as a general rule’ (the majority of people with ID are worse off) and ‘on average’ (more than half of them are worse off) makes a difference.

² I am skeptical of using general claims about lower or bad quality of life for people with ID, for example, to justify prenatal testing and selective abortion (8).

In sum, I affirm what Campbell and Stramondo deny, i.e., that “it is generally true that life without ID involves higher well-being than life with ID” (3, p. 161). I defend what they claim to have refuted, i.e., that “having ID tends to be bad for a person” in the vast majority of cases (3, p. 162). Where they assume that the Standard and Complicated Views cannot both be true, I see no logical conflict between them. The impact of ID on well-being is both definite (its effect is always negative and so the Standard View is true) and complicated (its negative effect varies and so the Complicated View is true). Individuation does not rule out generalization.

The Nature of Well-being

My argument assumes a particular view of well-being. I adopt an essentialist species conception in which human flourishing consists of a bundle of basic goods such as personal relationships and meaningful activity which are given in human nature. Particular natural functionings, such as mental abilities, make these goals possible.

Dan Brock (9, p. 70) defines well-being (or quality of life) as “an overall assessment of how good a person’s life is, one that includes the person’s own subjective assessment of or happiness with his [or her] life as well as objective components such as accomplishments, personal relations and self-determination, including having the reasonable array of opportunities that self-determination requires.” Subjective well-being is based on a person’s mental states: hedonist theories define well-being as the presence of positive experiences and desire-fulfillment theories define it as the satisfaction of properly formed preferences. Objective well-being is based on a person’s life situation: substantive list theories define well-being as achievement of important elements that constitute a good life.

Like many philosophers, I reject subjective accounts – well-being is not a purely psychological phenomenon. It requires, in addition, the fulfillment of human needs and the exercise of human capacities – the achievement of valuable activities and states of being, not just pleasant mental experiences. Human flourishing consists in a set of goods such as knowledge, accomplishment and relationships. These are constitutive components of a good life, and a person’s life goes better objectively if it includes more of them and worse if it has fewer.³ If life can be good, then it can also be bad when key dimensions are missing. We are social beings, so social isolation is bad; we are creative beings, so routine mindless work is bad; we are physical beings, so pain is bad (10,11). This does not mean that all natural functionings are necessary to have a decent life. It is good to have partners and children, but people with autism, for example, can live well without romantic relationships. While there is no single recipe for well-being, there are common elements of a good life. “Different people flourish differently,” Jonathan Glover (12, pp. 95–96) states. “A plausible account of flourishing is unlikely to have one blueprint. Instead, there will be different ingredients variously combined.” Yet “underneath all this variety there is also some degree of deeper unity.” Since human beings all belong to the same species, well-being is basically similar for everyone. To repeat: while not all functionings are necessary for a good life (e.g., being able to manage money independently may not be), the more basic abilities that are compromised, the more well-being is decreased.

Life satisfaction is necessary for well-being since we cannot flourish without being happy. But pleasant mental experience is not sufficient for well-being – non-mental conditions of life are also necessary. As Glover (12, p. 95) says, there are two strands to a good life: *happiness* (a subjectively contented life) and *flourishing* (an objectively rich-in-human-goods life).

Two Arguments for Why ID is Generally Bad

Before addressing Campbell and Stramondo directly, let me explain why all ID has a negative impact on well-being.

The ID Harm Chain Argument

Consider this chain argument that moves from profound ID to mild ID and concludes that all ID is disadvantageous.

1. Profound ID is bad. Vicky’s ID disrupts basic elements of her well-being.
2. If profound ID is bad then moderate ID is bad. David’s ID is bad for the same reason as Vicky’s – it disrupts his well-being, but to a lesser degree.
3. Therefore, moderate ID is bad.

Now consider Tim, David’s friend with mild ID. Tim can be independent for several hours at a time, rides the bus alone and works a janitorial job with minimal supervision. But he requires oversight with many aspects of life: medication, money, literacy.

4. If moderate ID is bad then mild ID is bad. Tim’s mild ID is bad for the same reason as David’s – it disrupts his well-being, but to an even smaller degree.
5. Therefore, mild ID is bad.

Now notice:

6. If profound, moderate and mild ID are bad then all ID is bad.
7. Therefore, all ID is bad.

³ This does not imply a maximalist view that parents should bear and rear children who possess the greatest capacities.

Because the argument reiterates, we can draw a broad, general conclusion about the negative impact of ID – variable as it may be – on quality of life.

Campbell and Stramondo grant that a child with Tay Sachs Disease may be better not being born at all (3, p. 165 and 168). And so they should allow that profound ID disadvantages Vicky by interfering with life activities that are central to flourishing. But then it follows, by extension, that David's, and even Tim's, ID negatively impact well-being. The reasons for thinking that profound ID is bad generalize to all ID: it impedes achievement of important goods, to varying degrees, but always negatively. This contradicts Campbell and Stramondo's view that we cannot generalize about the badness of ID.

It might be objected that the argument, by repeating again and again, slides down a slippery slope. After all, if mild ID is bad then low normal intelligence is bad. Ron Amundson (13, pp. 106–107) points out that because intellectual abilities are scalar properties, not binary ones, there is no sharp distinction between typical and atypical function. "There is a great range of functional variation among humans... The variation is so great, and so multidimensional, that the belief in an objective dividing line between normal and abnormal" is untenable. The boundaries are indistinct, fuzzy and hard to judge.⁴

True: cognitive abilities come in a wide range and there are vagueness worries concerning categories of intellectual function. But this does not mean that there is no reality to the ability/disability distinction, only that it is a standard sorites paradox. While many concepts are vague and distinctions between categories difficult to make, we can and do draw definite lines between things on a continuum. There *is* a difference between a large heap and a small pile of sand, even though no tiny change is sufficient to make the difference. As Tony Hope (15, p. 73) says, "the precise drawing of the line is arbitrary, but it is not arbitrary that a line is drawn." While there are no precise cut-off points that define the threshold of typical intellectual functioning, and while we may have trouble classifying borderline cases, there are clear differences between the abilities of Sarah, David and Vicky. Buchanan and colleagues (14, p. 122) point out that the line between typical and atypical intellectual abilities is, for the general run of cases, uncontroversial and ascertainable. Vagueness and indeterminacy do not threaten the distinction between intellectual ability (within a normal range) and disability. While the decision to draw the line of normality at some precise point is arbitrary, the distinction between average intellectual abilities and severe ID is not arbitrary.

It might also be objected that the conditionals stated in the chain argument are false. If we can draw a clear line between Vicky's profound ID and David's moderate ID, then premise 2 is inaccurate; and if there is a definite distinction between David's moderate ID and Tim's mild ID, then premise 4 is incorrect as well.

True: there are qualitative differences between profound, moderate and mild ID. Dan Wikler (16, pp. 187–190 and 195) suggests two conceptions of ID: on neither theory are the conditionals faulty. On the one hand, we might think of mental abilities as *scalar properties* (relative, more-or-less attributes). Intellectual capacities occur on a hierarchy or sliding scale; there is a wide array of competencies, and a person has intellectual abilities in degrees that can be compared to others. David has less capacity than Sarah but more capacity than Vicky. Tim's mild ID has a smaller disadvantage and Vicky's profound ID a greater disadvantage than David's moderate ID. But all are disadvantaged compared to Sarah. On the other hand, we can think of mental abilities as *binary properties* (non-relative, absolute attributes) that one either possesses or lacks. There are only two categories: however vague and uncertain the boundary, some people have impaired mental abilities and others have unimpaired mental abilities. Intellectual abilities are a 'range property' which is possessed equally by everyone who has or lacks them. All persons above the threshold equally possess typical mental abilities (all are haves, even if some have more and others less) and all below equally lack typical mental abilities (all are have-nots, even if some lack more and others less) – an IQ of 70 is often taken as the cut-off. I assume that there is a threshold below which it is very problematic to have limited cognitive capacities. This does not mean, however, that above the baseline ID has no negative effects. All passing students in a class are above a grade of F, but there is a significant difference between the bare knowledge of a D student and the excellent understanding of an A student. In the same way, a certain range of cognitive capacity is compatible with a meaningful life, while below that a person lacks what is necessary for one. People with mild and moderate ID fall with the livable range; people with profound ID may not. While both Sarah and David have the mental abilities necessary for well-being, their functioning differs significantly (just like students earning As and Ds both pass, but their knowledge and skills differ greatly). These considerations support the conditionals in premises 2 and 4.

The chain argument suggests that Campbell and Stramondo are mistaken, that we can make generalized judgments about ID and its effects on well-being.

The Troubling Implications Argument

Peter Singer (17, p. 165) says that the idea that disability is bad "is the only way to make sense of actions that we all take for granted", like the banning of drugs that cause impaired births. "If we really believed that there is no reason to think the life of a disabled person is likely to be any worse than that of a normal person, we would not have regarded the use of thalidomide by pregnant women as a tragedy... The children would merely have been 'different'... If this sounds grotesque, that is only because we are all in no doubt at all that it is better to be born with limbs than without them." The same goes for ID – it is better to be born with typical intellectual function than without it.

⁴ Alan Buchanan and colleagues (14, chapter 4) discuss 'low normal' cases, i.e., individuals who fall at the low end of the normal distribution of human abilities.

No true theory can entail things that make no sense, so *reductio* arguments raise real problems.

1. If ID is not a harm that makes a person worse off, then it is permissible to *cause* it. Nothing bad happens when a pregnant woman cognitively disables her healthy fetus with fetal alcohol syndrome by drinking.
2. If ID is not a harm that makes a person worse off, then it is unnecessary to *prevent* it. Suppose David's PVL was caused by changes of blood flow to his developing brain somewhere in the third trimester of gestation due to uterine infection, vaginal bleeding or inflammation of the umbilical cord. If we could treat these conditions and prevent his PVL we need not do so, just as we do not try to stop the birth of left-handed babies.
3. If ID is not a harm that makes a person worse off, then it is not important to *remove* it. If David's PVL is not bad, then I have acted in an unjustified way and wasted scarce resources in mitigating its effects through speech, physical and occupational therapies.

Since we have reason to think that causing any ID is bad and that curing any ID is good, we have reason to think that ID is a real loss that reduces overall well-being in the vast majority of cases. This undermines Campbell and Stramondo's claim that no true generalizations about the negativity of ID can be made.⁵

Why ID is Essentially Bad

The Americans with Disabilities Act defines disability as a physical or mental impairment that *substantially limits* at least one *major life activity* (23, p. 72). ID restricts, in a non-trivial way, a person's ability to perform general life tasks because the mind is unable to do things typical of human beings. The World Health Organization says that 'disability' is "an umbrella term, covering impairments, activity limitations and participation restrictions. An *impairment* is a problem in body function or structure; an *activity limitation* is a difficulty encountered by an individual in executing a task or action; while a *participation restriction* is a problem experienced by an individual in involvement in life situations" (23, p. 60). These definitions imply (but do not entail) that by limiting opportunities, ID lowers quality of life and causes significant and lasting disadvantage.

Brock (9, p. 108) states that "serious disabilities...by definition, typically reduce a person's quality of life." Someone with ID is always worse off than a similar unimpaired person. Barnes (5, p. 11) objects that this begs the question: "it should not be built into the very definition of disability that disability is something that's bad or suboptimal." Harm *is*, however, essential to the concept of ID: ID and some degree of disadvantage always go together. As Stephen Wilkinson (24, p. 63) says, "there is an *a priori* connection between disability and welfare... Characteristics only get to count as disabilities, as opposed to mere differences, if they impair the capacity to flourish." Two conditions are individually necessary and jointly sufficient for a cognitive trait to constitute an ID (25,26). It must be

1. a deviation from typical intellectual functioning.
2. that reduces well-being.

The factual element is an empirical judgment about mental malfunction (it is an inability to perform activities in the normal range for human beings) and the value element is a normative judgment that the malfunction is bad (it causes difficulties in living and thereby worsens a person's life). The factual condition is not sufficient for a trait to be a disability. Some deviations from typical functioning (like being left-handed) are not disadvantageous, and if there are no disadvantages to a trait then it is mere difference, not disability. Nor is the value condition sufficient for a trait to be a disability. External conditions that reduce well-being (like racism or sexism) are not disabilities; if there are only social disadvantages to a trait, then it is injustice, not disability.

It might be objected that this definition slips from description to evaluation. True: it does, but does so legitimately. ID reduces functioning – that is what a disability is. Because ID reduces functioning, it would be better, all things being equal, not to have it. And it would be better not to have it because ID reduces well-being. There is, then, a necessary conceptual connection between description and evaluation; both factual and value conditions are essential for disability.

The *conceptual argument* indicates that ID is by definition bad:

1. If a trait is a disability, then by definition it deviates from typical human intellectual functioning *and* reduces well-being.
2. ID is a disability.
3. Therefore, ID deviates from typical human intellectual functioning.
4. Therefore, ID reduces well-being.

The *factual condition* relies on the notion of typical function. Intellectual abilities are biologically determined. Human beings are members of a species – a natural kind – that has evolved with brain structures and mental process that have particular functions which are necessary for the survival and flourishing of the individual. For the mind to function properly is for it to carry out the jobs – thinking and choosing – that it is meant to perform. ID is not simply an invented category: it is a state of reality involving real deficiencies in human powers, when structures and processes do not work as they should. As Hans Reinders

⁵ Similar *reductio* arguments are made in (18–21). Both Elizabeth Barnes (5, chapter 5) and Chris Kaposy (22, p. 179) address these objections, unsuccessfully, I think.

(27, p. 56) puts it: “since there is a ‘normal’ functioning for human minds...it follows that, when your...mind...[is] functioning ‘abnormally,’ then you are disabled.”⁶

The *value condition* asserts that in order to constitute disability, atypical functioning must make a person worse off. Flourishing varies by biological species: what it means to live well is determined by the kinds of beings we are. The constituents of human well-being fulfill important aspects of human nature. “Among the things needed for a good human life,” Glover (12, p. 11) says, “are [various] mental capacities.” Cognitive function enables the personal relationships and productive activities which are central elements of a flourishing life.

ID is a malfunction that prevents the achievement of vital goals which are either components of or prerequisites for a good life (30, p. 52). Given his cognitive limitations, David cannot engage in many activities necessary to live well. Vicky is so disabled as to lack the minimal capacities for a meaningful life: self-consciousness, reasoning, self-motivated activity and language. Intellectual abilities make flourishing possible; because it impedes or prevents human goods, ID is bad. [I acknowledge my limited experience with profound ID and recognize that it is difficult to determine the dividing line between livable and non-livable conditions. Eva Feder Kittay (31, p. 403) claims that “most severely retarded people...can be and are involved in activities and relationships.” Her daughter Sesha with profound ID has a definite personality – she responds to her environment, has relationships and enjoys classical music.]

People with ID should not, of course, be defined solely by their deficits. Despite his impairments, David has significant abilities and enjoys many goods of life. But I reject the suggestion that David’s PVL is not plainly bad. The fact that he has strengths and talents does not mean that he does not have significant challenges and difficulties as well. Nor does it mean that his abilities offset his disabilities for a net neutral effect on his well-being. David is not *differently* abled. This euphemism is dishonest: he is *disabled*. By being nonverbal, a dog is differently abled than Sarah, but by being nonverbal, David is disabled compared to her. His species nature is damaged, the dog’s is not; while the dog can do what dogs typically do, David cannot do many things humans typically do, and these impairments negatively impact his well-being. This is even more true of Vicky, and is also true to a lesser degree of Tim.

Disability is, by definition, an *adverse* departure from typical functioning. Atypical conditions are either beneficial, neutral or harmful.

1. If an atypical cognitive condition is *beneficial* then it is not a disability. Physicist Stephen Hawking, whose exceptional brain had unusually large bundles of nerve fibers connecting its lobes, was not intellectually disabled because his abilities depart from typical functioning in ways that are helpful (32).
2. If an atypical cognitive condition is *neutral* then it is not a disability. Being musically intelligent rather than kinesthetically intelligent is a mere difference; my friend Ted who plays numerous instruments but is not athletic is not disabled (33).
3. If an atypical cognitive condition is *harmful* then it *is* a disability. David’s PVL affects him negatively by interfering with opportunities and preventing him from achieving important human goods, and so he is disabled.

ID is a *mal* function that is harmful; it always has a value connotation as something undesirable. If David’s PVL caused no decrease in quality of life, then it would not be a disability at all. But because it is disadvantageous, it *is* a disability. So is all ID.

Human flourishing consists in a cluster of goods given in human nature. Mental abilities make these goals possible. As Serene Khader (34, p. 49) says, a person’s life is going well if they are “exercising certain valuable capacities that it is in the nature of human beings to exercise.” Because basic intellectual function is necessary for achieving the human good, cognitive limitations negatively impact quality of life. Campbell and Stramondo’s view that no generalizations about the badness of ID can be made is not plausible.

Why ID is Objectively Bad

Campbell and Stramondo claim that it is false *on any account* of well-being that ID has a negative impact in the vast majority of cases (3, pp. 152–153). They may be right on subjective conceptions of well-being but are wrong on objective theories.

The Nature of Well-being Restated

As noted earlier, there are two ways to describe quality of life: by subjective enjoyment and by objective achievement. Hedonic happiness is a matter of internal experience (a person’s satisfaction with their life), while eudaimonic happiness involves external standards for a good life (how someone’s life is actually going). Subjective theories of well-being emphasize pleasing sensations and desire fulfillment. Objective theories require participation in substantive goods like worthwhile activities and meaningful relationships. Quality of life has both subjective and objective dimensions, and life satisfaction is not equivalent to flourishing. Well-being – having a life full of varied human goods – requires more than feeling happy.

⁶ Typical human functioning combines both a statistical aspect (how most people function) and a biological aspect (a benchmark of proper function). The notion of normal function is defended by Boorse (23) and Vehmas and Pekka (28) and disputed by Amundson (29) and Barnes (5, chapter 1).

The Nature of Harm

Personal harm affects a particular individual negatively. *Subjective harm* is feeling worse or badly off, i.e., experiencing lower life satisfaction. *Objective harm* is being worse or badly off, i.e., having valuable elements of well-being damaged. *Comparative harm* makes a person worse off than they would have been under other circumstances. *Non-comparative harm* makes a person experience or places them in a bad state, a disadvantaged condition involving loss of things that make life good.

To be harmed, Joel Feinberg (35, chapter 1) says, is to have our interests set back. To have an interest is to have a stake in something and to gain or lose depending on the condition of that thing. Any entity with interests has a well-being that can be harmed or benefited. In our network of interests some are more important than others. Ultimate interests are things like writing a novel or traveling the world. Welfare interests – both *external welfare interests* like financial resources and *internal welfare interests* like mental abilities – are the necessary means to ultimate goals, the basis of a good quality life. When they are damaged a person is very seriously harmed because their entire set of interests is diminished, if not defeated. John Rawls (36, p. 93) states that *primary social goods* (liberties, opportunities and wealth) are resources that all people need: “whatever one’s system of ends, primary goods are necessary means” to their realization. In the same way, *primary intellectual goods* are also universally necessary for flourishing – basic human functions and capacities are valid for all persons.

The Deprivation Argument for ID Harm

The argument for the objective badness of ID is simple and intuitive. Suppose, Thomas Nagel (37, p. 181) says, “an intelligent person receives a brain injury that reduces him to the mental condition of a contented infant, and that such desires as remain in him can be satisfied by a custodian, so that he is free from care. Such a development would be widely regarded as a severe misfortune...for the person himself.” Even though he experiences no transition costs and is subjectively content with a full stomach and a dry diaper, the deprivation in what he can do makes it objectively bad. Because “disability substantially limits a major life activity,” Brock (9, p. 75) says, it “closes off an important area of functioning, and the activities that such functioning makes possible, even if the person may not ‘miss’ them.”

ID affects essential psychological capacities necessary for living well. The burden of ID – the harms and disadvantages it involves – depends on its severity. Professional organizations identify four categories of ID – mild, moderate, severe and profound – using severity codes based on functional limitations and intensity of needed supports.⁷ Because ID traits come in degrees, so do the resulting harms, as measured by the amount of objective well-being lost: mild conditions are mildly bad while profound conditions are profoundly bad. But all are bad, just not equally bad. This undermines Campbell and Stramondo’s claim that we cannot generalize about the negative impacts of ID.

It might be objected that well-being is entirely subjective and that since people with ID report good quality of life, ID is not harmful. An established body of evidence finds that people with disabilities are about as happy, on average, as people who do not have disabilities (40). Brian Skotko’s (41) research team, for example, found that 99 percent of people with Down syndrome are happy with their lives. So is David: the fact that he cannot care for himself, make life choices or function independently does not mean that he is unhappy.

True: people with ID usually experience satisfying lives. But this does not mean that ID is not bad. Subjective life satisfaction is only one aspect of overall well-being, and so the fact that people with ID report being happy does not mean that ID is not disadvantageous. Because subjective well-being and objective well-being differ, evidence for one is not evidence for the other: as in Nagel’s scenario, a person’s quality of life can be subjectively good and at the same time objectively diminished. We cannot infer that ID is not bad from the fact that people with ID have meaningful lives.⁸

While ID may not lower subjective quality of life, it almost always reduces objective quality of life. Intellectual abilities are not an irrelevant trait like being left-handed – because they are indispensable for achieving valuable human goods, ID is an objective disadvantage in the vast majority of cases even if it does not create subjective distress.

Why ID is Instrumentally Bad

By understanding why intellectual abilities are instrumentally good, we can see why ID is instrumentally bad. Intellectual abilities are personal assets that facilitate well-being. Just as people need external resources (like income and wealth) in order

⁷ Diagnostic criteria for ID include medical diagnosis (conditions such as Down syndrome), psychological testing (having an IQ of 70 or less) and adaptive functioning (difficulty in everyday activities without significant support). People with mild ID are mostly self-sufficient and can live independently with intermittent support. People with moderate ID can perform most self-care activities but may require assistance; many live in group homes with limited supervision. People with severe ID have very basic communication skills and require help with self-care activities; many live in housing with extensive support. People with profound ID possess very limited communication skills, depend on caregivers for all aspects of daily life and require pervasive assistance. These four categories form a continuum. Categorization of severity is complicated – people with ID show considerable variability in performance of abilities because skills are often uneven (individuals have selective, not global, incompetence) and because neuroplasticity means that the brain continues to develop in cognitive function, particularly in stimulating environments (38,39).

⁸ The mistreated slave and abused woman may report being happy, but their lives would be better if they were not mistreated. As Amundson (13 p. 111) says, “slavery and oppression reduce the quality of life even for those of the oppressed who do not subjectively recognize the fact.” Daniel Haybron (42) agrees: “a happy person might be leading an impoverished or stunted life... Related worries involve people with diminished capacities (blindness, Down syndrome)” whose lives might be “narrow and cramped or simpleminded... Worries about impoverished lives are a prime motivator of Aristotelian theories of well-being, which emphasize the full and proper exercise of our human capacities.”

to flourish, so we need internal resources (like cognitive functions) to flourish. Intellectual abilities produce quality of life by supporting a normal opportunity range and wide array of life choices.

ID is instrumentally bad because it causes intrinsic bads and prevents intrinsic goods. People with profound ID like Vicky are incapable of controlled movement, thought, speech and self-awareness; some never walk, talk, think, eat, see or hear. Very low functioning makes her permanently infantile and undermines her flourishing. People with moderate ID like David are also prevented from obtaining important goods of life. Being non-verbal, David has difficulty labeling feelings and expressing thoughts, which he finds frustrating. He does some signing and vocalizing, and he uses a tablet with a chat app for voice talk. These tools give David some ability to communicate but there are many times when he remains trapped in his own mind, unable to get his message across.

Campbell and Stramondo claim that ID only cuts off *some* avenues for achieving human goods – it does not cut off *all* avenues to their realization (3, pp. 157–158). While goods like communication can be achieved in multiple ways, however, the ways that David has to communicate are not as good as the ways he lacks. His communication is often barely adequate: even basic messages are limited, and he has no ability whatsoever to express complex or abstract ideas. So, while David's PVL does not entirely cut him off from the good of interpersonal communication, it does significantly limit it; and since communication enriches life in numerous ways, being non-verbal disadvantages him. His life is worse because he cannot form thoughts properly and communicate them effectively. This is true not just of David but of many people with ID.

Campbell and Stramondo deny that intellectual abilities are a basic component of well-being (3, p. 156). It is true that mental capacities are not direct *elements* of well-being like activities and relationships are. But they are direct *prerequisites* – possessing and using them is indispensable if a person is to live well. There is a close connection between intellectual functioning and human flourishing. Vicky's profound ID is bad because it ruins the mental faculties necessary for pursuing human goods, which are simply not (or barely) available to her. The same reasons that make Vicky's ID instrumentally bad for her also make David's ID instrumentally bad for him. This goes for all ID. We can, *contra* Campbell and Stramondo, generalize about the negative impact of ID on instrumental well-being.

Why ID is Globally Bad

Intellectual abilities are instrumentally valuable for all human beings, not just for particular individuals; they are useful for all plans of life, not only for particular aims. An ID like David's does not just limit one specific function but disrupts many basic functions. Consider the difference between a *general-purpose* workshop tool like a flat-head screwdriver that can be used to perform many tasks (tightening and loosening screws, acting as a lever, a crowbar, a punch, a chisel) and a *single-purpose* tool like a basin wrench used for only one task (removing and installing the nuts that hold a faucet onto a sink). Intellectual abilities to think, plan, choose and communicate are – like the primary good of financial resources – general-purpose capacities necessary to pursue major life activities. ID limits these capacities and lowers *overall* well-being, not just *one domain* of well-being.⁹

Intellectual abilities differ from specific abilities (like musical intelligence) whose value depends on particular plans of life which only some individuals desire. ID is not a relative harm like being tone deaf, which might disadvantage a musician but not an athlete. Instead, the loss of intellectual abilities is bad in all lives and for all persons. Intellectual abilities are necessary conditions for living any good human life and for any of the diverse plans of life people might pursue. They apply to every person and are – as Martha Nussbaum (43, p. 252 and 266) puts it – a “human constant” which play an “architectonic role” in life by supporting and suffusing all other functions. David's PVL prevents the realization of many basic goods as well as higher order goods that are typical of mature adults.

It may be objected that we cannot infer a general conclusion about a person's well-being from deficits in *specific abilities* (31, p. 301). David cannot do particular things like drive a car because he has ID. This inability is, at most, a local bad. I cannot pilot an airplane, yet the fact that I lack this specific talent does not reduce my well-being.

True: but we can infer a general conclusion about well-being from deficits in *primary functions*. David lacks general-purpose abilities like reading and speaking. He has difficulty thinking, planning, choosing and communicating, and these limitations undermine his ability to achieve an entire range of life goals. David's lack of basic intellectual abilities is globally bad because it negatively impacts a whole set of interests that constitute flourishing (just like abject poverty is globally bad for a person).

People with ID often cannot meet their own basic needs, perform in important domains of life or maintain deep relationships. This is because ID interferes with two sets of general-purpose abilities. According to the American Psychiatric Association (44), ID is defined by deficits in intellectual functioning (reasoning, problem-solving, planning, judgment, abstract thinking and academic learning) and adaptive functioning (activities of daily life such as communication, social participation and independent living).

⁹ Buchanan and colleagues (14, p. 167) put it well: intellectual abilities “may be thought of as a general-purpose means – useful and valuable in carrying out nearly any plan of life or set of aims that humans typically have. [They are] a ‘good’ not only from a distinct perspective or plan of life that some may adopt but many others may reject... [They] can be thought of as a ‘natural primary good’ analogous to...‘social primary goods’ – in each case ‘general-purpose means useful or valuable in carrying out nearly any plan of life... [The] loss of a general-purpose capacity...significantly diminishes the range, and makes more difficult the pursuit, of life plans that humans value.”

Executive functions are mental skills that enable individuals to control thoughts, emotions and actions – to pay attention, organize, plan and self-monitor – and thus to manage life tasks of all types (45). These skills include working memory (being able to keep information in mind and use it in some way), cognitive flexibility (being able to think about something in more than one way) and inhibitory control (being able to ignore distractions, regulate emotions and keep from acting impulsively). *Adaptive behaviors* are skills necessary to meet the demands of everyday living (46–48). A person with deficits in these conceptual, practical and social skills needs significant support and assistance to succeed. Key areas are self-care (dressing, grooming and feeding oneself), communication (understanding and using language), self-direction (problem-solving, initiating and planning activities), social (making friends, maintaining relationships, understanding emotions, social cues and basic moral values), leisure (participating in personal and community activities), home living (housekeeping, cooking, doing laundry), functional academics (reading, writing, math), community use (shopping, using public transportation and services), work (maintaining employment, responding to supervision, cooperating with coworkers, being reliable and meeting work standards) and health and safety (being able to protect oneself and respond to health problems). Limited executive function and adaptive behavior are defining features of ID – and the disadvantages they cause are global, not local. They affect the totality of a person’s life.

It might be objected that David need not meet *sophisticated goals* like college, career and marriage in order to flourish. True: but his inability to meet his own *elementary needs* compromises his well-being. Because of deficits in skills of daily living and self-management, he requires direct supervision, regular prompts and simplified routines. David has poor task completion and problems following all but easy instructions; he has trouble with organization and planning, with solving problems and good judgment, with setting goals and completing tasks. The absence of these general-purpose skills has negative consequences on his well-being, and not just on one aspect of his life but across multiple environments and all spheres of activity.

Campbell and Stramondo acknowledge that ID may be a local bad which reduces well-being in some aspects of life. But to label it as a global bad that makes life go worse in all dimensions is reductive synecdoche – a general, negative assumption about a whole human person on the basis of one characteristic (3, p. 162). They are wrong about this. ID causes what Christopher Riddle (49, pp. 81–85) calls “corrosive disadvantage”, i.e., disadvantage that negatively impacts not just one valuable function, but the securing of many valuable activities and states of being. Because intellectual abilities are basic prerequisites for other capabilities, ID affects every aspect of a person’s life and creates, Christopher Boorse (23, p. 56) says, “whole-person impairment.”

It might also be objected that the argument proves too much since many people in the average intellectual range are deficient in general purpose skills like planning and task completion. True: there are many such individuals. But while they may have a good quality life, their lives may be worse because of these deficits, especially if they run into repeated problems with work and relationships. Rather than capturing too much, the argument suggests that correcting stupidity, where possible, is always desirable.

Cognitive resources have a place in every life and play a crucial role in the pursuit of any life plan and so ID has a negative impact not just on a narrow set of life plans but on all life plans. It affects a person in the broadest of ways, not just in some particular aspects. ID is more than the local bad Campbell and Stramondo allow – it is a global bad that reduces well-being overall and on the whole, across a broad range of domains.

Why ID is Comparatively Bad

ID is bad because it sets back interests and compromises welfare. The concept of harm as reduced well-being is counterfactual: a person is harmed in a given situation if there exists some alternative situation where they have more well-being. If ID not been present, then the person’s quality of life would be higher and so ID makes them less well off than they would be without it.

Campbell and Stramondo deny that people with ID are comparatively worse off in the vast majority of cases (3, p. 161). They do, however, identify three factors which explain why the average person with ID has a lower level of well-being than the average person without ID: “very harmful disabilities (those causing severe chronic pain and/or an early death) and transition costs that often accompany the acquisition of disabilities” – as well as “disability-unfriendly social environments” (3, pp. 170–171). If the presence of these conditions and settings make ID comparatively bad then, by implication, in their absence it is not bad. Since David’s ID is neither severe nor acquired—and if he lived in a social utopia – he would not be worse off with than without PVL. I agree that David’s well-being would be worse if his ID was severe or acquired and is worse than it need be because of inadequate social services. But I deny that in the absence of these factors he is no worse off than Sarah.

To argue that ID is comparatively bad requires comparing a person’s actual and counterfactual well-being. The deprivation argument shows that life without ID is preferable to one with ID.

1. A fully functional adult – Sarah – becomes disabled in an accident that reduces her mental abilities to the level of a 4-year old. She does not know it. She is perfectly happy all day long playing ‘Go Fish’ even though she is unable to exercise human talents and pursue meaningful activities. Did something bad happen to her? The answer is yes; she is deprived of the experiences, projects and activities she could do if not ID. We compare the real Sarah against an

imaginary Sarah* who was not hurt in the accident, and the gap between them constitutes the deprivation of objective well-being she suffers. Sarah misses out on the life she would have had had she not been disabled, and something bad happens to her even though she does not experience it as bad. While she is equally happy subjectively, her quality of life is worse objectively.

Now take a parallel story.

2. A person – David – is born with ID and never functions, even when full grown, beyond the level of a 4-year old. He cannot read, write, count or think, but is not aware of the disadvantages. While unable to pursue significant activities, he is completely content. Did something bad happen to him? The answer once again is yes; he is deprived of the things he could do if not ID. As with Sarah, we compare the real David against a hypothetical David* who was born without ID and the gap between them constitutes the loss of objective well-being. The objective quality of his life could be better even if his subjective satisfaction remained the same.

If ID is neutral and not detrimental to flourishing, then nothing bad happens to Sarah (who should be indifferent between remaining as she is now and becoming ID) or David (who should toss a coin if the Disability Fairy gives him, before birth, the choice of life with or without PVL [5, pp. 67–68]). But these implications are absurd.

It may again be objected that empirical evidence demonstrates that people with ID do not suffer poor quality lives but enjoy good quality lives. It is easy to catastrophize ID as bad quality of life. But the assumption that people with ID cannot flourish because they do not function typically is based on incomplete information, unfair stereotypes and negative attitudes. Most people with ID have fulfilling lives. Kaposy (22, p. 178) notes that “when researchers ask [them] what makes their lives go well, then tend to discuss the sorts of things in objective list theories, such as friendships, family life, enjoyable and rewarding activities.”

True: people with ID generally have good lives both subjectively and objectively. But the issue in comparative well-being is not whether David has a *subjectively good* life or even an *objectively good* life, it is whether he could have had an *objectively better* life. In all likelihood, he could have. The fact that David has a satisfactory quality of life with ID does not mean that his life would not be better if he functioned typically. It is better to be able to use our minds to read and write and count, to know how to tie shoes and fasten buttons, to verbally express thoughts and emotions, than to be like David with none of these abilities. ID disadvantages him objectively by restricting basic life opportunities, primary components of a good life that most people enjoy. This is why his life would be better without PVL. It is also false that people with ID would be as well off as people without ID in a society that accommodates and does not discriminate. David will never do certain things regardless of social adjustments, even if he can do other things with adequate support. Because the disadvantages of ID are partly due to biological impairments, a society free of injustice will not eliminate the badness of ID.

Campbell and Stramondo resist this argument because of “counterfactual opacity.” Epistemic limitations make it hard to determine the truth of counterfactual claims and so we cannot know that ID is comparatively bad. Since we cannot compare possible alternatives to what has actually happened, we cannot know that life without ID is better than life with ID (3, p. 161). There is no hypothetical David* against whom to compare David.

True: such comparisons are shrouded in mystery. I cannot know that had I been an airline pilot I would have had a better life than I have had as a college professor. And we cannot know that life without ID is better than life with ID if we focus on subjective well-being – Sarah’s experiential quality of life may be no more satisfying than David’s. But I deny counterfactual opacity with respect to objective well-being. Consider *reductio* arguments again. If I cannot know that life without ID is better than life with ID, then why do I grieve at seeing my friend’s 4 year-old daughter doing things that 26 year-old David will never do: talking coherently, counting to 100, learning to read. Is my sadness based, as Campbell and Stramondo suggest, on “ableist fantasy” (3, p. 161)? Should Vicky’s family not regret her deficits and difficulties? Should I be indifferent to whether Sarah remains fully-abled or suffers a brain injury that, without transition costs, reduces her to David’s level of functioning? And if we cannot know that life with ID is comparatively worse than life without ID, then why is it wrong to disable another person? Suppose Vicky is impaired because, while born cognitively typical, her parents beat her viciously. If nothing bad happened to her, why punish them for a victimless crime that harmed no one? These implications call into question the view that there is nothing comparatively bad about ID in almost all situations. Campbell and Stramondo are right that epistemic humility is warranted, since it is difficult to evaluate counterfactuals. But they are wrong to conclude that no generalizations can be made about the comparative badness of ID. While David has sufficient intellectual capacity to enjoy a good life, he is worse off than Sarah – his life would likely go better objectively with fuller mental abilities.

Campbell and Stramondo also argue that ID is identity-constitutive – it shapes individual identities in substantive ways (3, p. 161). Its removal would involve the destruction of the person: David without PVL is simply not David. Given the non-identity problem, his ID is unavoidable; the only choices for him are life with PVL or no life at all. This analysis is not quite right. Because David’s ID was caused by a contingent prenatal injury he could, in fact, have been born without PVL. This is different from ID due to a chromosomal condition like Down syndrome, where disability truly is unavoidable for the particular person that has it.

True: there is no scenario in which he, the same person, can have a life without ID. There is no phantom non-disabled David* compared to whom David is worse off. But the fact that ID is identity-affecting is irrelevant to whether it is a harm. That David

had no other way of getting born does not mean that his PVL is not bad, that it does not diminish his quality of life. That he or Vicky are not harmed relative to any life they actually could have had does not mean they are not harmed *simpliciter*.

ID is *comparatively bad* (it makes people worse off) even if not *overridingly bad* (it does not make them badly off). Life with ID can lack important features without falling below zero on an objective line of welfare. As Anita Silvers (50, p. 54) states, burdensome *limitations* do not necessarily mean burdensome *lives* – ID is bad even though *life with ID* is often good. But, to repeat, this is not the question: the real issue is that people with ID could have objectively better lives without ID. This is why ID is almost always comparatively bad, despite what Campbell and Stramondo say.

Concluding Remarks

Many scholars agree with Campbell and Stramondo's position. Robert Wachbroit (51, p. 30 and 33) argues that "we cannot state what impact a particular health condition has on well-being. We cannot, for example, determine the effect that diabetes has on well-being, because the impact that [it] has on well-being will vary with the environment. We should therefore be skeptical of . . . quality of life assessments of different health conditions." The same can be said of Down syndrome or PVL. Shakespeare (7, p. 217 and 224) concurs: "every life is different, so it is dangerous to generalize about the experience of impairment." He continues: "the creation of a disabled 'ideal type' – either as a neutral or benign experience, or as a negative and tragic experience – does not do justice to the complexity and variability of the experience of disability." Because challenges and disadvantages are individualized, we cannot generalize about the impact of ID on well-being. Garret Merriam (4), too, asserts that the differences in individual and social circumstances make abstract assessment of ID and quality of life difficult. Rather than taking species typical functioning as the standard of flourishing, we should look at whether a person is living well in the particular concrete circumstances of their life. There is no absolute hard and fast relationship between ID and flourishing – we can only consider specific individuals on a case by case basis. Since we cannot generalize about the well-being of a whole class of people with ID, we must reject the blanket assumption that ID is bad. "Are we worse off?" disability rights activist Harriet McBryde Johnson (5, p. 54) asks. "I don't think so. Not in any meaningful sense. There are too many variables."

I agree that the relationship between ID and well-being is complicated by multidimensional influences including biological condition, social environment and personal temperament. I agree that we should not exaggerate the disadvantages of ID or simply assume that life with ID is an unremitting tragedy. The fact that something is individualized, however, does not mean that it cannot be generalized. Campbell and Stramondo reason, in effect, as follows:

1. The disadvantages of ID are individualized.
2. Therefore, the disadvantages of ID are not generalized.

Their argument, however, assumes the following:

3. If the disadvantages of ID are individualized then they are not generalized.

This conditional is equivalent to a disjunction:

4. The disadvantages of ID are either individualized or generalized.

But this is a false dilemma: one possibility does not exclude the other since

5. the disadvantages of ID are both individualized and generalized.

Aristotle (52, p. 38) posits that wicked "men are...bad in many [ways]" and Leo Tolstoy (53, p. 3) observes that "every unhappy family is unhappy in its own way." These statements entail two truths: the first is *general* (immoral people are all immoral and unhappy families are all unhappy), the second is *individual* (immoral people and unhappy families vary a great deal; each immoral person is immoral in their own way and each unhappy family is unhappy in its own way). The general fact and the individual fact are compatible.

The same is true of ID: every person with ID is disadvantaged but each is disadvantaged in his or her own way. The general fact that all are harmed – *there is always a negative score to ID* – is not contradicted by the individual fact that the harms vary – *there is no single negative score*. The disadvantages of ID are *definite* (all ID is bad) but *complicated* (its badness depends on multiple factors). It is wrong to think that flourishing is assessed either by universal species essentialism or by particular individual circumstances. Evaluation of ID and well-being involves both: ID is always bad since the functions indispensable for flourishing are given in human nature. But this badness varies with specific life situations that aggravate or mitigate the disadvantages of sub-typical mental functioning. To affirm the latter is not to deny the former.

According to Campbell and Stramondo, there is *no ID in general*. There is David's ID and that of his friends Minnie and Adam, Claudia and Steve, Lisa and Ernie; and there are their very different life situations: some work competitive jobs while others attend day training workshops; some live independently while others live with parents or in group homes. Determining how bad ID is and how its disadvantages are influenced by internal and external factors is complicated and so *the disadvantages of ID come in varying degrees*. But since intellectual abilities are general-purpose means to human flourishing, this broad generalization is also true: *ID is disadvantageous – all people with ID are harmed*. Because they have difficulty performing key life tasks, ID prevents David, his friends and everyone with ID from enjoying some, often many, important goods of life and so they do not flourish as fully as people without ID.

David's PVL harms him, limits his attainment of important goods, negatively affects his whole life and makes it worse than if he was cognitively typical. It might be objected that since his ID is objectively, instrumentally, globally and comparatively bad, it must also be overwhelmingly bad. Not true: ID can bring significant disadvantages without destroying welfare – it can reduce quality of life without ruining it. That ID lowers well-being, and may do so pronouncedly, does not mean that it makes life with ID not worth living. A family may be unhappy in important ways without being so dysfunctional that divorce is preferable. As I have stressed, ID can be bad without being tragic.

Finally, it might be objected that my entire position reinforces intelligism, the view that intellectually typical people are morally more valuable, and thus more entitled to life, than people with ID. Simo Vehmas (54, p. 40) claims that such a view is discriminatory in the same way as racism and sexism. The intelligist argument is as follows: "since the life of a normal human being is more full, it is also more valuable than the life of a person with ID." Put formally:

1. An intellectually typical life is *more full*.
2. Therefore, an intellectually typical life is *more valuable*.

Vehmas refutes the argument by denying the truth of the premise. It is false that intelligence is a precondition of a happy and fulfilling life and that people with ID have little prospect of a satisfactory or full life. Evidence indicates otherwise. In addition, there is no such thing as a perfect or ideal life. All lives have restricted possibilities, and so people with ID have the same chance of achieving a good life as intellectually typical people do (54, p. 44).

True: there is no such thing as a perfect life. But while my lack of particular musical talents does not affect my well-being, David's lack of general-purpose abilities does lower his quality of life. Abilities are not all equal – some are more important to flourishing than others. Intelligence, while not the only factor relevant to well-being, is a crucial factor. The things Vehmas (54, p. 45) identifies as elements of a meaningful life – work, hobbies, relationships – do depend on some sort of intellectual competence. While intellectual capacity and well-being do not fall on a straightforward continuum (where more ability means more flourishing), quality of life is in part a function of mental abilities.

I affirm the basic truth of the premise found in the intelligist argument, and have argued, in Vehmas' (54, p. 47) words, that intelligence can be valued in a way that is not connected with intelligist intuition and does not lead to discrimination against individuals with ID. But I deny the argument's validity, that the conclusion follows from the premise. As noted earlier, quality of life and moral status are two different things, and lower well-being does not imply inferior human value. Mental properties are irrelevant to moral status: Sarah does not have a stronger right to life than David or Vicky. But intellectual abilities are relevant to quality of life: Sarah does enjoy more objective well-being than David or Vicky. That all three have equal moral status does not mean that they have equal quality of life, nor does the fact that Sarah's life is more full mean that it is more valuable.

In the vast majority of cases people with typical intellectual function have access to more valuable activities and relationships. ID limits the level of basic activities and roles that an individual can perform and achieve, and so it lowers well-being most of the time. While ID is not usually a tragedy, it is not irrelevant either – it is disadvantageous even if not destructive. While people with ID enjoy subjectively good quality lives, they could have objectively better quality lives if they did not have ID. Campbell and Stramondo are wrong to think that we cannot make a broad generalization about the relationship of ID and well-being. We can generalize (ID is always bad) without overgeneralizing (it is uniformly or terribly bad). As a general rule ID is bad for people who have it. ID always has a negative impact on quality of life even though that negative impact is complicated and varied.

Conflicts d'intérêts

Aucun à déclarer

Conflicts of Interest

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References

1. Byrne P. *Philosophical and Ethical Problems in Mental Handicap*. New York: St. Martin's; 2000.
2. Campbell S, Stramondo J. [Disability and well-being: Appreciating the complications](#). *APA Newsletter: Philosophy and Medicine*. 2016; 16:35–37.
3. Campbell S, Stramondo J. [The complicated relationship of disability and well-being](#). *Kennedy Institute of Ethics Journal*. 2017; 27:151–184.
4. Merriam G. [Rehabilitating Aristotle: A virtue ethics approach to disability and human flourishing](#). In DC Ralston & J Ho (eds.), *Philosophical Reflections on Disability*. Dordrecht: Springer; 2010.
5. Barnes E. *The Minority Body*. Oxford: Oxford University Press; 2016.
6. Wasserman D, Bickenbach J, Wachbroit R. Introduction. In D Wasserman, J Bickenbach, R Wachbroit (eds.), *Quality of Life and Human Difference*. Cambridge: Cambridge University Press; 2005.
7. Shakespeare T. The social context of individual choice. In D Wasserman, J Bickenbach & R Wachbroit (eds.), *Quality of Life and Human Difference*. Cambridge: Cambridge University Press; 2005.
8. Gould J. [Epistemic virtue, prospective parents and disability abortion](#). *Journal of Bioethical Inquiry*. 2019;16:389–404.
9. Brock D. Preventing genetically transmitted disabilities. In D Wasserman, J Bickenbach & R Wachbroit (eds.), *Quality of Life and Human Difference*. Cambridge: Cambridge University Press; 2005.
10. Nussbaum M. *Frontiers of Justice*. Cambridge: Belknap Press; 2006.
11. Sen A. Capability and well-being. In M Nussbaum, A Sen (eds.), *The Quality of Life*. Oxford: Clarendon Press; 1993.
12. Glover J. *Choosing Children: Genes, Disability and Design*. Oxford: Oxford University Press; 2006.
13. Amundson R. Disability, ideology and quality of life. In D Wasserman, J Bickenbach & R Wachbroit (eds.), *Quality of Life and Human Difference*. Cambridge: Cambridge University Press; 2005.
14. Buchanan A, Brock D, Norman D & Wikler D. *From Chance to Choice*. Cambridge: Cambridge University Press; 2000.
15. Hope T. *Medical Ethics: A Very Short Introduction*. Oxford: Oxford University Press; 2004.
16. Wikler D. Cognitive disability, paternalism and the global burden of disease. In EF Kittay & L Carlson (eds.), *Cognitive Disability and Its Challenge to Moral Philosophy*. Malden: Wiley-Blackwell; 2010.
17. Singer P. *Practical Ethics*. 3d ed. Cambridge: Cambridge University Press; 2011.
18. Andric V, Wundisch J. [Is it bad to be disabled?](#) *Journal of Ethics and Social Philosophy*. 2015;9:1–16.
19. Bognar G. [Is disability mere difference?](#) *Journal of Medical Ethics*. 2016;42:46–49.
20. Kahane G & Savulescu J. [Disability and mere difference](#). *Ethics*. 2016;126:774–788.
21. Mosquera J. Why inflicting disability is wrong: A reply to Barnes. Paper presented at Philosophy of Disability Conference, Knoxville; 2017.
22. Kaposy C. *Choosing Down Syndrome*. Cambridge: MIT Press; 2018.
23. Boorse C. Disability and medical theory. In DC Ralston, J Ho (eds.), *Philosophical Reflections on Disability*. Dordrecht: Springer; 2010.
24. Wilkinson S. *Choosing Tomorrow's Children*. Oxford: Oxford University Press; 2010.
25. Murphy D. [Concepts of disease and health](#). *Stanford Encyclopedia of Philosophy*. 2015.
26. Wasserman D, Asch A, Blustein J, Putnam D. Disability: Definitions, models, experience. *Stanford Encyclopedia of Philosophy*. 2011. Online at <https://plato.stanford.edu/entries/disability/>
27. Reinders H. *Receiving the Gift of Friendship*. Grand Rapids: Eerdmans; 2008.
28. Vehmas S & Makela P. [A realist account of the ontology of impairment](#). *Journal of Medical Ethics*. 2008;34:93–95.
29. Amundson R. [Against normal function](#). *Studies in History and Philosophy of Biological and Biomedical Sciences*. 2000;31C:33–53.
30. Nordenfelt L. Ability, competence and qualification: Fundamental concepts in the philosophy of disability. In DC Ralston, J Ho (eds.), *Philosophical Reflections on Disability*. Dordrecht: Springer; 2010.
31. Kittay EF. The personal is philosophical is political. In EF Kittay, L Carlson (eds.), *Cognitive Disability and Its Challenge to Moral Philosophy*. Malden: Wiley-Blackwell; 2010.
32. Kalb C. [What makes a genius?](#) *National Geographic*. 2017.
33. Gardner H. *Frames of Mind*. New York: Basic; 1983.
34. Khader S. *Adaptive Preferences and Women's Empowerment*. New York: Oxford University Press; 2011.
35. Feinberg J. *Harm to Others*. New York: Oxford University Press; 1984.
36. Rawls J. *A Theory of Justice*. Cambridge: Harvard University Press; 1971.
37. Nagel T. Death. In S Brennan, R Stainton (eds.), *Philosophy and Death: Introductory Readings*. Peterborough: Broadview Press; 2010.
38. Reynolds T, Zupanick CE, Dombeck M. [Diagnostic criteria for intellectual disabilities](#). *Mentalhelp.net*.

39. Reynolds T, Zupanick CE, Dombeck M. [Intellectual disability and severity codes](#). Mentalhelp.net.
40. Wasserman D, Asch A, Blustein J, Putnam D. [Disability: Health, well-being and personal relationships](#). Stanford Encyclopedia of Philosophy. 2016.
41. Skotko B, Levine S, Goldstein R. [Self-perceptions from people with Down syndrome](#). American Journal of Medical Genetics 2011;Part A. 155:2360–2369.
42. Haybron D. [Happiness](#). Stanford Encyclopedia of Philosophy. 2011.
43. Nussbaum M. Non-relative virtues: An Aristotelian approach. In M Nussbaum, A Sen (eds.), The Quality of Life. Oxford: Clarendon Press; 1993.
44. American Psychiatric Association. [Diagnostic and Statistical Manual of Mental Disorders](#): 5th Edition. 2013.
45. Cooper-Kahn J, Dietzel L. [What is executive functioning?](#) LDOnline
46. Reynolds T, Zupanick CE, Dombeck M. Adaptive behavior. Mentalhelp.net.
47. Reynolds T, Zupanick CE, Dombeck M. [Behavioral and psychological features of intellectual disabilities](#). Mentalhelp.net.
48. Reynolds T, Zupanick CE, Dombeck M. [Intellectual functioning](#). Mentalhelp.net.
49. Riddle C. Disability and Justice. Lanham: Lexington; 2014.
50. Silvers A. Predicting genetic disability while commodifying health. In D Wasserman, J Bickenbach, R Wachbroit (eds.), Quality of Life and Human Difference. Cambridge: Cambridge University Press; 2005.
51. Wachbroit R. Assessing quality of life. In D Wasserman, J Bickenbach & R Wachbroit (eds.), Quality of Life and Human Difference. Cambridge: Cambridge University Press; 2005.
52. Aristotle. The Nicomachean Ethics. D Ross, ed. Oxford: Oxford University Press; 1980.
53. Tolstoy L. Anna Karenina. New York: Modern Library; 1993.
54. Vehmas S. [Discriminative assumptions of utilitarian bioethics regarding individuals with intellectual disabilities](#). Disability and Society. 1999;14:37–52.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The Ethics of Screening and Treating Persons with Hepatitis C: A Canadian Perspective

Ramseyer Apau Bediako¹

Résumé

Dans cet article, je soutiens que la position du gouvernement du Canada contre le dépistage du virus de l'hépatite C (VHC) et le financement public de son traitement est éthiquement injustifiable. Le coût des médicaments et la probabilité d'aggraver les inégalités de santé existantes sont l'argument du gouvernement pour ne pas financer le traitement du VHC et pour l'absence de programme de dépistage. Je m'oppose à cette position et plaide en faveur d'un programme de dépistage et d'un financement public du traitement du VHC. Je soutiens que ces barrières sont éthiquement injustes. En conclusion, se voir refuser le dépistage et un traitement précoce revient à se voir refuser le meilleur pronostic possible.

Mots-clés

financement public, hépatite C, programme de dépistage, populations vulnérables, allocation de ressources, éradication

Abstract

In this article, I argue that the Canadian government's position against screening for hepatitis C virus (HCV) and publicly funding HCV treatment is ethically unjustifiable. Cost of medication and likelihood of widening existing health inequality are the government's argument for not funding HCV treatment and for also not having a screening program. I object to this position and argue in favour of a screening program and public funding of HCV treatment. I argue that these barriers are ethically unjust. Conclusively, being denied screening and early treatment is to be denied the best possible outcome.

Keywords

public funding, hepatitis C, screening program, vulnerable populations, resource allocation, eradication

Introduction

The World Health Organisation (WHO) estimates that about 130 to 150 million people are chronically infected with hepatitis C virus (HCV), with 1.75 million people being newly infected every year, and a whopping 350,000 die each year of hepatitis C related liver disease (1,2). Aside from increased risk of developing chronic liver disease, cirrhosis, and hepatocellular carcinoma (HCC), HCV-infected persons also serve as a reservoir for transmission to others (3). In Canada, it is estimated that about 251,000 persons in Canada have hepatitis C (4), but close to 44% of that population is unaware of their hepatitis C infection (5,6). Hepatitis C first gained public health attention in the 1980s when it was discovered that blood transfusions were a common source of infection or transmission (7). Even though the incidence rate of HCV in Canada has decreased in recent times, its prevalence has been relatively high (4).

Several studies and reports have shown that persons who inject drugs (66%), inmates in federal or provincial prisons (23.3-24%), people living in nursing and long-term care homes (3%), men who have sex with men (5%), and immigrants (1.19%) are at an increased risk of HCV (1,5). A similar report by the Public Health Agency of Canada (PHAC) in 2011 suggested that using needles and other equipment by an infected person constitute an increased risk of HCV. The most common ways that people become infected were through receiving blood transfusions in Canada before 1992 and before blood was effectively screened for hepatitis C, or receiving a blood transfusion in a country where procedures for screening blood are insufficient. In addition, sharing or borrowing personal items (such as razors, toothbrushes or nail clippers that contain traces of blood from a previous user), unsafe medical practices that involve reusing medical equipment that has not been properly sterilized, using tattoo or body-piercing or acupuncture equipment that has been reused without being properly sterilized, having unprotected sex, mother-infant transmission during pregnancy and delivery are also means of infection (7,8). The majority of all HCV cases are among Canadians who are 30 years or older and the highest reported rates are in the Yukon, Saskatchewan and British Columbia (7). The risk of reinfection is relatively low for the general population (1.1%), except for persons with HIV coinfection which increases the risk to about 21.7% (9).

Undoubtedly, HCV infection poses serious challenges to Canada's public health and remains a global health issue. Subsequently, in 2016, the WHO adopted its first strategy to fight hepatitis "Global Health Strategy on Viral Hepatitis, 2016-2021". This strategy seeks to eliminate viral hepatitis as a public health problem, and it is captured in the global target of reducing new viral hepatitis infections by 90% and reducing its associated deaths by 65% by 2030 (2). The Federal Government of Canada signed onto this strategy, but several expert commentaries (including those from hepatologists) suggest Canada is not on track to possibly meet those targets (10). Worst yet, there are no clear indications that either the federal or provincial governments are committed to or are on track towards eliminating viral hepatitis.

Interestingly, several studies have shown sustained virologic response-SVR (treatment success rates) to be between 90-100% after 4 to 12 weeks treatment (11,12,13). The improved SVR cuts across all populations (14). Notwithstanding the advances in treatment and improved SVR, HCV remains a significant medical and economic burden in Canada (4) because it requires an expensive and resource-intensive course of treatment. I argue that the Canadian (federal and provincial) government's position against screening for hepatitis C virus (HCV) and publicly funding HCV treatment is ethically unjustifiable. The argument that the high cost of medication and the likelihood of widening existing health inequalities justify not funding HCV

treatment or screening programs is ethically untenable. To be denied screening and early treatment is to be denied the opportunity for the best possible outcome.

Arguments against treatment and screening

In recent years, the pace of HCV drug development has increased dramatically (15). Despite these advances, multiple barriers stand in the way of HCV eradication, chief among these being the cost of medication/treatment. For instance, the Canada Taskforce on Preventive Health Care (16) reported that the high cost of medication discourages provincial governments from conducting widespread hepatitis C risk-based screenings. Thus, the cost of medication hinders population wide and even risk-based screening. Provincial governments have argued that they cannot publicly fund treatment for the many people that are likely to be identified as true positives (people who are accurately identified as having HCV) through screening because of the cost of treatment. For instance, between 2015 and 2016, Ontario spent \$290 million on a new discounted hepatitis medication for 3,700 patients for a 12-week treatment course (17). However, there are doubts as to whether other provincial governments could even do the same. How could Ontario and the other provinces provide population-wide screening and fund treatment for all persons with HCV? The argument is that public funding of HCV treatment will unnecessarily drain the government's finances or the public purse. Note, however, that other equally expensive treatments for HIV, tuberculosis, and cancer are being publicly funded.

This argument against screening follows directly from the cost-related argument, i.e., that screening has the potential to increase or widen existing health inequality since the government has no intention to publicly fund HCV treatment. Currently, it is estimated that 44% of HCV-infected persons are not aware of their HCV-positive status [6], and in the event of public access to screening, this percentage would decrease while the percentage of people who know about their HCV status would increase substantially. Further, individuals at increased risk of HCV are mostly people with lower socioeconomic status (3), will most likely be without any comprehensive private insurance plans and may also not be able to pay out of pocket. The assumption is that, given their social class (or socio-economic status), those at higher risk of HCV may not be able to afford HCV treatment. Most screen-detected HCV patients would thus not benefit, except for those very few who may have comprehensive drug insurance plans or can pay out of pocket. Further, identified but untreated HCV-infected people would suffer an obvious harm (psychological and emotional) from having a known diagnosis (i.e., information) but no access to treatment (i.e., ineligibility to act on the information).

So, the argument goes that publicly funding screening, while affordable, will increase the number of persons with known HCV but they will, for the most part, be unable to access publicly funded treatment. Thus, it is argued, screening would do more harm than good.

Arguments in favour of funding treatment and screening

Benefits of funding HCV treatment

Despite the advances in therapeutic options and understanding of current trends in treatment in recent years (15), several barriers stand in the way of HCV eradication. As I have already argued, the high cost of HCV treatment is one of several barriers (18). Nonetheless, I object to this 'cost-related argument' and instead argue that HCV patients have a justified claim to publicly funded full course treatment, just like persons with HIV/AIDS, cancer and tuberculosis.

Given the importance of pharmaceutical drugs in modern healthcare delivery, it is puzzling that largely universal health service coverage in a nation like Canada ends when a patient is handed a prescription. In fact, Canada is one of the very few developed nations with a universal public health insurance system that does not include universal coverage of prescription drugs outside the hospital setting (19). Sadly, 1 in 10 Canadians cannot afford to take their medicines as prescribed and several studies within and outside the Canadian context show that such barriers worsen health outcomes, including premature deaths and severe disabilities (19,20). And this outcome can be even worse for those who are already "worse off", i.e., HCV patients.

The various governments positions on access to hepatitis C medication is simply a case of injustice in the allocation of health care resources. I do not in any way suggest that governments have infinite resources to fund all healthcare services, but rather that these HCV positive individuals do have claims to equal access to essential healthcare services. Therefore, the government's position also raises concerns about moral entitlement and equity in health, especially when other out-of-hospital drugs and treatments are being publicly funded. This underscores an arbitrary system.

As already mentioned, there is evidence to suggest that "less well-off citizens" generally suffer a greater number of health-related problems throughout their lives. For instance, lower socio-economic status is associated with an increased risk of HCV infection and patients with low SES also have higher mortality (3) and disability rates. For example, Shah et al.'s study in Ontario showed that HCV causes more lost years of life and illness than any other infectious disease (21). Against this backdrop, a Rawlsian egalitarian will argue that a society like Canada has an obligation to correct already existing inequalities in resource distribution (22). As Coughlin et al. argue, this theory favours the unequal but equitable distribution of resources to favour the worst off (i.e., persons with HCV). Persons who inject drugs, prisoners, street youth and others who also have

HCV do have greater health needs. Therefore, any system that does less for these HCV patients, who are already worse off, is unjust.

The egalitarian argument is that all individuals in our society deserve equal concern and respect with regard to access to needed health care services and that the basis for determining how health care ought to be distributed justly is need, but should not be based on social worth or ability to pay (23). The egalitarian's goal is to reduce disparities in health status among different groups in societies: including the poor, people living in rural areas, ethnic or racial minorities and others (24). Therefore, the egalitarian's concept of justice as being fair implies the right to free and universally accessible healthcare for every citizen, including access to medication for HCV patients. Thus, the availability of free health care remains central to the egalitarian's concept of a fair society.

Also, a common assertion central to the theory of justice is that "equals must be treated equally, and unequals must be treated unequally." This suggests that when all circumstances for all persons are equal, everyone should be treated equally (25). Unfortunately, all persons cannot be equal. Therefore, the principle of justice requires not only fair distribution of resources but also doing more for an already vulnerable population with compounding HCV. In fact, fair distribution of healthcare resources should favour persons with HCV. Similarly, applying the rule of fair opportunity would require that disadvantaged individuals receive healthcare benefits that improve the unfortunate effects of life's lottery. So, as these individuals cannot be held responsible for their HCV infection, the rule of fair opportunity demands they receive publicly funded treatment to help reduce the unfortunate consequences of life's lottery (25).

There are opposing arguments suggesting that HCV patients do not have a just claim to social resources needed to restore their health because of the strong social disapproval attached to behaviours that result in HCV infection, which suggest individuals are responsible for their health status (26). There are also arguments that it is unfair to individuals who have been responsible, to be paying for the excessive health needs of those who have been irresponsible with their health (26). These victim-blaming arguments are seriously flawed. As Holland (27) argues, to focus on a person's behaviour is to shift focus from the underlying determinants of health that are usually a multitude of environmental factors rather than personal responsibility. Providing access to healthcare to these vulnerable persons is a moral responsibility. HCV infection is curable, and early detection and intervention lead to improved overall health outcomes (21). Treatment aims to eradicate HCV viral load thereby increasing the quality of life and reducing the risk of cirrhosis and hepatocellular carcinoma (28). Victim-blaming and ignoring the medical needs of these individuals compounds existing inequality. It is also worth noting that inequalities beget inequalities, and existing inequalities compound, sustain and reproduce a multitude of deprivations, and the cycle continues (29).

Benefits of public screening

Hepatitis C is often touted as a silent killer because it can be asymptomatic for decades (6) until an infected person develops serious liver disease (30). Therefore, the first step toward improving health outcomes and preventing transmission is the identification of those with active HCV infection (31). Screening will reduce the harms associated with Hepatitis C by "providing presumptive identification of an unrecognized disease or defect through the application of tests, examinations or procedures which can be applied rapidly to sort out persons who probably have the disease from those who probably do not" (32). Even though the Public Health Agency of Canada (PHAC) and the College of Family Physicians recommend testing of individuals at increased risk for HCV, there are currently no screening programs across Canada (21). The lack of screening programs in Canada ought to be treated as a major public health concern, given that almost half of persons with HCV are not aware of their HCV status, and could be unknowingly exposing others to HCV or putting a whole population at risk. In fact, a population wide screening is recommended.

Social utility benefit

The utilitarian argument in favour of screening is that it is essential for early detection, and when the infection is treated, is linked to improved health outcomes. Essentially, screening and early treatment of HCV provide both public health and personal benefits by interrupting viral transmission or onward transmission, and by reducing associated mortality and morbidity (6,33).

There are several benefits of screening without treatment. Just knowing about one's HCV status without treatment has a social-utility benefit, that is, it could cut down on viral transmission or onward transmission (34). For instance, Trepka et al. (34) reported that all interviewed patients in their study reported one or more positive behaviours to prevent HCV transmission to others or to protect their liver. For instance, 93.2% of persons that screened HCV-positive reported being careful not to share personal care items such as razors that could expose others to the infection, and 70.5% reported they had not donated blood, tissue, or semen since they were screened positive. Trepka et al. (34) also reported that 83.7% to 88% of HCV patients admitted cutting down alcohol use, stopping intravenous drug use (IDU), or had completed the hepatitis A or B vaccination series. The goal of vaccination against hepatitis A and B is to prevent liver failure occurring in individuals with liver affliction. Vaccination against hepatitis B also prevents potentially more severe liver damage associated with hepatitis B coinfection. These positive behaviours were adopted when people were screened and they became aware of their HCV positive status. A screening program with or without treatment stands to benefit a good number of persons who would otherwise be undiagnosed or unaware of their HCV status, and thus also the general public who are being exposed to or being placed at risk of HCV infection. Therefore, the government argument against screening, i.e., that it will increase existing health inequality and provide no clear benefit to those that will be identified as true positives, is weak and even unfounded. If anything, the government is doing more harm and placing the society at risk by not funding public screening.

Cost-effectiveness

HCV is very often asymptomatic until an infected person gets to the advanced stage. However, HCV infection is curable, and early detection and intervention lead to improved overall health outcomes (21). Thus, screening would lead to early diagnosis, which when linked to care could reduce HCV-related morbidity, mortality, and transmission (35).

Patients whose infection has been eradicated before cirrhosis develops have a life expectancy similar to that of uninfected people (36). However, in the absence of treatment, advanced stages of liver disease may present complications that may need inpatient hospital care, including liver transplantation (37), which can be very expensive. For instance, a study in the United States showed that Hepatitis C antiviral treatment averaged \$10,000 to \$30,000 per year, while liver transplant costs were at \$203,434 for the transplantation and first year of postoperative care (38). Ultimately, if the government were to provide screening, detect persons with HCV and treat, it will be more cost-effective than waiting for an HCV patient to develop a liver complication that will require hospital in-patient treatment, which will be much more expensive. Further, the average incremental cost-effectiveness ratios for all HCV patients was US \$55,400 per QALY (39). Baggaley et al.'s study (40) found that incremental cost-effectiveness ratios for screening for HIV in primary care were £22,201 per QALY gained, £372,207 per death averted, and £628,874 per HIV transmission averted. More important, the overall budget needed for HCV treatment is reasonable when compared to the treatment of other diseases like HIV (39,40). HCV is curable between 4-12 weeks, and therefore, spending on HCV would sharply decrease with time when compared to HIV treatment, which is a lifetime treatment. This direct and comparative evidence suggests that screening and early treatment of HCV would cost-effective.

The right to know or not to know

Text for this sub-section. Ensuring that HCV positive people have access to screening is a means of supporting “the right to know about a diagnosis”, a core means of respecting patient autonomy, as well as being consistent with the principles of non-maleficence and beneficence. Despite the obvious harms associated with not knowing about a diagnosis (34), not knowing can sometimes be beneficial, especially in cases where there are no treatments. For instance, knowing about a diagnosis and not having treatment can lead to serious psychological consequences (i.e., the veil of ignorance has been unveiled without treatment) (41), and so can be less harmful to the individual. This has been governments' position against screening and treating persons with HCV. However, in the case of HCV, there are effective treatments with SVR of more than 90% (11—13). Also, as already discussed, most people with known HCV tend to take on healthier lifestyles in order to reduce risk to self and others (34).

Conclusion

The overarching goal of a publicly funded screening and treatment program for HCV is to decrease hepatitis-related morbidity, mortality, and transmission. To eradicate HCV, the government ought to have a population screening program, and publicly fund HCV treatment in order to increase treatment success rates and decrease treatment duration. Indeed, the elimination of HCV seems very possible if appropriate and timely steps are taken (40). The value of screening has been demonstrated and should be implemented and expanded beyond targeting at-risk populations. Not only is it just to screen and publicly fund treatment, but it is also cost-effective. Costs and other budgetary constraints impose difficult choices that influence the services that are provided, the patients whose drugs will be funded and the circumstances of general healthcare in Canada. However, the threat of arbitrary decision-making looms. How government decides which healthcare service to fund (which is based on medical necessity) is often described as arbitrary, which is in sharp contrast with accountability for reasonableness. Arbitrariness creates an unfair system which consequently leads to injustice in resource allocation. Going forward, these problems are likely to threaten the trust of Canadian citizens (patients) have in their healthcare system.

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Conflits d'intérêts

Aucun à déclarer

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Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateurs n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la [Revue canadienne de bioéthique](#) assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

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Conflicts of Interest

None to declare

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References

1. World Health Organization. [Global health sector strategy on viral hepatitis 2016-2021. Towards ending viral hepatitis](#); 2016.
2. World Health Organization. [Global hepatitis report 2017](#). World Health Organization; 2017.
3. Omland LH, Osler M, Jepsen P, Krarup H, Weis N, Christensen PB, Roed C, Sørensen HT, Obel N. [Socioeconomic status in HCV infected patients—risk and prognosis](#). *Clinical epidemiology*. 2013;5:163.
4. Myers RP, Krajden M, Bilodeau M, Kaita K, Marotta P, Peltekian K, Ramji A, Estes C, Razavi H, Sherman M. [Burden of disease and cost of chronic hepatitis C virus infection in Canada](#). *Canadian Journal of Gastroenterology and Hepatology*. 2014;28(5):243-50.
5. Trubnikov M, Yan P, Archibald C. [Hepatitis C: Estimated prevalence of Hepatitis C Virus infection in Canada, 2011](#). *Canada Communicable Disease Report*. 2014;40(19):429.
6. Ha S, Totten S, Pogany L, Wu J, Gale-Rowe M. [Infectious disease as chronic disease: Hepatitis C in Canada and the importance of risk-based screening](#). *Canada Communicable Disease Report*. 2016;42(3):57.
7. Public Health Agency of Canada. [Hepatitis C in Canada: 2005–2010 Surveillance Report](#).
8. Bevilacqua E, Fabris A, Floreano P, Pembrey L, Newell ML, Tovo PA, et al. [Genetic factors in mother-to-child transmission of HCV infection](#). *Virology*. 2009;390(1):64-70.
9. Hill A, Simmons B, Saleem J, Cooke G. Risk of late relapse or re-infection with hepatitis C after sustained virological response: meta-analysis of 66 studies in 11,071 patients. In: Conference on Retroviruses and Opportunistic Infections, Seattle, WA, 23–26 February 2015.
10. Ireland, N. [Hepatitis C could be eliminated in Canada, but drug prices, screening barriers stand in the way](#). CBC News. 3 November 2017.
11. Kowdley KV, Gordon SC, Reddy KR, Rossaro L, Bernstein D, An D, Svarovskaia E, Hyland RH, Pang P, Symonds WT, McHutchison JG. [764 Sofosbuvir/Ledipasvir with and without Ribavirin for 8 weeks compared to Sofosbuvir/Ledipasvir for 12 weeks in treatment-naïve non-cirrhotic genotype-1 HCV-infected patients: the phase 3 ion-3 study](#). *Gastroenterology*. 2014;146(5):S-926.
12. Detering K, Spinner CD, Schott E, Welzel TM, Gerken G, Klinker H, Spengler U, Wiegand J, zur Wiesch JS, Pathil A, Cornberg M. [Ledipasvir plus sofosbuvir fixed-dose combination for 6 weeks in patients with acute hepatitis C virus genotype 1 mono-infection \(HepNet Acute HCV IV\): an open-label, single-arm, phase 2 study](#). *The Lancet Infectious Diseases*. 2017;17(2):215-22.
13. Basu P, Shah NJ, John N, Aloysius M, Brown R. [Sofosbuvir and ledipasvir versus sofosbuvir and simeprevir combination therapy in the management of acute hepatitis C: a randomized open label prospective clinical pilot study](#). SLAM C study. *Journal of Hepatology*. 2016;64(2):S806.
14. Naggie S, Cooper C, Saag M, Workowski K, Ruane P, Towner WJ, Marks K, Luetkemeyer A, Baden RP, Sax PE, Gane E. [Ledipasvir and sofosbuvir for HCV in patients coinfecting with HIV-1](#). *New England Journal of Medicine*. 2015;373(8):705-13.
15. Lam JT, Yamaki J, Kayali Z. [Advances in Hepatitis C treatment: at the crossroads](#). *The Journal for Nurse Practitioners*. 2015;11(7):669-79.
16. Canadian Task Force on Preventive Health Care. [Recommendations on hepatitis C screening for adults](#). *Canadian Medical Association Journal*. 2017;189(16):E594-604.
17. Grant K. [Deal reduces price of life-saving hepatitis C drugs for Canadians](#). *The Globe and Mail*. February 21 2017.
18. Konerman MA, Lok AS. [Hepatitis C treatment and barriers to eradication](#). *Clinical and translational gastroenterology*. 2016;7(9):e193.
19. Morgan SG, Boothe K. [Universal prescription drug coverage in Canada: Long-promised yet undelivered](#). *Healthcare Management Forum*. 2016;29(6):247-254.
20. Morgan S, Daw J, Law MR. [Rethinking pharmacare in Canada](#). *C.D. Howe Institute Commentary* 384; 2013
21. Shah HA, Heathcote J, Feld JJ. [A Canadian screening program for hepatitis C: Is now the time?](#) *Canadian Medical Association Journal*. 2013;185(15):1325-8.
22. Coughlin SS, Soskolne CL, & Goodman KW. *Studies of vulnerable populations*. Case Studies in Public Health Ethics. Washington, DC: American Public Health Association. 1997; pp. 101-103.
23. Fleck L. [The ethical challenges raised by hepatitis C drugs](#). Center for Ethics and Humanities in the Life Sciences at Michigan State University. MSU Bioethics. 2014 Oct 23.

24. Macklin R, Cowan E. [Given financial constraints, it would be unethical to divert antiretroviral drugs from treatment to prevention](#). Health Affairs. 2012;31(7):1537-44.
25. Beauchamp TL, Childress JF. Principles of Biomedical Ethics. 7th ed. New York, NY: Oxford University Press; 2013.
26. Fleck LM. [Just caring: do the indolent, the inebriated and the irresponsible deserve equal access to needed health care](#). Ind. Health L. Rev. 2014;11:553.
27. Holland, S. Health promotion as behavior modification. Public Health Ethics. Malden, MA: Polity Press; 2007. pp. 111-134.
28. Jafferbhoy H, Gashau W, Dillon JF. [Cost effectiveness and quality of life considerations in the treatment of hepatitis C infection](#). ClinicoEconomics and Outcomes Research. 2010;2:87.
29. Gostin LO, Powers M. [What does social justice require for the public's health? public health ethics and policy imperatives](#). Health Affairs. 2006;25(4):1053-60.
30. Dore GJ, Ward J, Thursz M. [Hepatitis C disease burden and strategies to manage the burden](#). Journal of Viral Hepatitis. 2014;21:1-4.
31. Smith BD, Morgan RL, Beckett GA, Falck-Ytter Y, Holtzman D, Teo CG, Jewett A, Baack B, Rein DB, Patel N, Alter M. [Recommendations for the identification of chronic hepatitis C virus infection among persons born during 1945–1965](#). Morbidity and Mortality Weekly Report: Recommendations and Reports. 2012;61(4):1-32.
32. Deber RB, Mah CL, editors. Case studies in Canadian health policy and management. University of Toronto Press; 2014 Apr 30.
33. Wilson JM, Jungner G, World Health Organization. Principles and practice of screening for disease. 1968.
34. Trepka MJ, Zhang G, Leguen F, Obiaja K, Malow RM, De La Rosa M. [Benefits and adverse effects of hepatitis C screening: early results of a screening program](#). Journal of Public Health Management and Practice. 2007;13(3):263-9.
35. Suthar AB, Harries AD. [A public health approach to hepatitis C control in low-and middle-income countries](#). PLoS medicine. 2015;12(3):e1001795.
36. Veldt BJ, Heathcote EJ, Wedemeyer H, Reichen J, Hofmann WP, Zeuzem S, Manns MP, Hansen BE, Schalm SW, Janssen HL. [Sustained virologic response and clinical outcomes in patients with chronic hepatitis C and advanced fibrosis](#). Annals of Internal Medicine. 2007;147(10):677-84.
37. Kim W. [Motion—the available treatments for Hepatitis C are cost effective: arguments against the motion](#). Canadian Journal of Gastroenterology and Hepatology. 2002;16(10):710-5.
38. Hill L, Henry B, Schweikert S, Bretsch JK. [Screening for chronic Hepatitis C: American College of Preventive Medicine practice policy statement](#). American Journal of Preventive Medicine. 2005;28(3):327-30.
39. Chhatwal J, Chen Q, Kanwal, F. [Why we should be willing to pay for Hepatitis C treatment](#). Clinical Gastroenterology and Hepatology. 2015;13(10), 1711–1713. doi:10.1016/j.cgh.2015.06.00
40. Baggaley RF, Irvine MA, Leber W, Cambiano V, Figueroa J, McMullen H, Anderson J, Santos AC, Terris-Prestholt F, Miners A, Hollingsworth TD. [Cost-effectiveness of screening for HIV in primary care: a health economics modelling analysis](#). The Lancet HIV. 2017;4(10):e465-74.
41. Andorno R. [The right not to know: an autonomy based approach](#). Journal of Medical Ethics. 2004;30(5):435-439.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

La stérilisation volontaire chez les femmes sans enfant de moins 30 ans : dilemme éthique et déontologique

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Résumé

Avec les modifications sociales des dernières décennies, particulièrement avec l'avènement de l'avortement, de la contraception et de la libéralisation du marché du travail, les femmes ont pu trouver leur place hors de leur rôle de mère et se construire en tant qu'individu propre, non résumé à un rôle reproductif. Ainsi, pour bien des raisons que nous allons présenter, certaines femmes désirent et font le choix de rester sans enfant, elles sont, dans ce cas, appelées *childfree* (c'est-à-dire, sans enfant par choix). C'est notamment le cas de jeunes femmes de moins 30 ans qui, par peur notamment d'une grossesse non désirée, vont s'orienter vers la ligature tubaire plutôt que vers des méthodes dites non définitives. Cependant, nos sociétés occidentales sont encore assez pronatalistes, et cette décision de mettre un terme à leur capacité reproductive choque et interpelle. Le personnel soignant, et plus précisément les médecins, confronté à ces demandes de stérilisations les rejette souvent lorsqu'elles sont faites par des femmes sans enfants de moins 30 ans, en s'appuyant sur plusieurs justifications que nous allons expliciter, dont la peur d'apparition de regrets chez celle-ci. Il ressort de cette situation une confrontation entre le principe d'autonomie de la personne qui s'exprime par le respect de sa décision d'agent autonome d'une part et, d'autre part, la déontologie du médecin, encore parfois teintée d'un certain paternalisme. Nous allons donc analyser ce dilemme éthique et tenter d'apporter quelques pistes de recommandations pour une prise en charge plus adaptée de ces situations, grâce notamment à l'approche de l'éthique narrative et du partenariat relationnel, aussi appelé le *Montreal Model*.

Mots-clés

stérilisation, jeunes femmes, aptitude, autonomie, *childfree*, éthique narrative, déontologie

Abstract

With the social changes of recent decades, particularly with the advent of abortion, contraception and work market liberalization, women have been able to create spaces for themselves outside their role as mothers and so build individual identities, not just as reproductive individuals. For many different reasons, which we will present here, some women decide to remain childless. This is for instance the case for young women under 30 years of age, who out of fear of an unwanted pregnancy turn to tubal ligation rather than to non-definitive methods such as oral contraception. But Western societies are still quite pronatalist and so decisions by young women to permanently end their reproductive capacity are shocking and challenging for many. Caregivers, and more precisely doctors confronted with these requests for sterilization, often reject them when they are made by women without children under 30 years of age, based on several justifications, including the fear that these women will later regret their decision. This situation leads to a confrontation between the principle of women's autonomy, which is expressed through respect for their decision as autonomous agents, and the deontology of the practitioner, sometimes still tinged with a certain medical paternalism. We will thus analyze this ethical dilemma and try to provide some recommendations for a more appropriate response to these situations, mobilizing in particular a narrative ethics and relational partnership approach, also known as the *Montreal Model*.

Keywords

sterilization, young women, competency, autonomy, *childfree*, narrative ethics, deontology

Nous sommes bien conscientes que les professions décrites dans l'article sont constituées en grande partie de femmes, et nous ne voulons pas éclipser ce fait. Toutefois, pour alléger le texte et favoriser une meilleure clarté et lisibilité, la forme masculine est utilisée.

Introduction

Depuis quelques années, de nombreux témoignages de jeunes femmes de moins de 30 ans qui ne souhaitent pas avoir d'enfant et veulent recourir à une stérilisation par ligature tubaire apparaissent (1). De nombreux médias relaient ces narrations et il est possible de les retrouver notamment sur Internet, dans des blogues, des forums ou encore des sites d'actualités féminines (1). Ainsi, la ligature tubaire consiste à « bloquer les trompes de Fallope afin d'empêcher l'ovule de se rendre à l'utérus » (2). Plusieurs méthodes sont possibles : la première, efficace immédiatement, repose sur la réalisation d'une laparoscopie sous anesthésie générale pour lier ou cautériser les trompes et ainsi les rendre imperméables (2). La seconde consiste à mettre en place un dispositif dont l'objectif est d'entraîner une fibrose qui obstruera les trompes. On peut alternativement installer des clips qui vont écraser les trompes via un passage transcervical. La fibrose ou l'écrasement des trompes, pour être efficaces, nécessitent un délai de trois mois (2). Les risques associés pour les femmes sont rares et sont généralement liés à l'intervention en elle-même, c'est-à-dire en lien avec l'anesthésie générale ou en lien avec un risque infectieux (2). Cependant, des effets indésirables peuvent être relevés ultérieurement par les femmes ayant subi cette intervention, tels des saignements, nausées, étourdissements ou encore douleurs abdominales (2). Quelle que soit l'approche, l'efficacité de cette stérilisation est de 99,5% (2). La ligature tubaire est, par définition, une intervention peu voire non réversible (3). Toutefois, la technique des clips offre le taux de succès le plus élevé lorsqu'il s'agit de rendre perméables à nouveau les trompes (3,4). En effet, la reperméabilisation tubaire, qui vise à rétablir la continuité des trompes pour leur rendre leur fonctionnalité, est très approximative et son succès variable (5). Dans ce cas, la ligature tubaire ne devrait pas être présentée comme réversible, c'est une méthode de contraception dite définitive (2). C'est dans ce contexte d'irréversibilité que le désir de stérilisation des femmes se heurte au refus quasi catégorique des professionnels soignants, dont la responsabilité est de renseigner, aider, réaliser ou encore orienter vers ceux aptes à la réaliser comme l'illustre les nombreux témoignages de femmes dans cette situation (6,7).

Le discours que l'on retrouve bien souvent est assez semblable d'une femme à l'autre : une jeune femme, dans la vingtaine, ne souhaitant pas avoir d'enfant demande une ligature tubaire pour ne plus avoir à se soucier d'une possible grossesse non désirée (8). Généralement, face à cette demande, elle reçoit un « jugement moral » ou une réaction qui rejette toute intervention de ce type sur une femme aussi jeune et qui pourrait par la suite regretter ce geste quasi-définitif (9). Si cette stérilisation soulève autant d'enjeux, c'est bien à cause de son caractère irréversible et du désir de certaines femmes de ne pas avoir d'enfant, décision qui choque encore la société et le monde médical (1). En effet, bien que la stérilisation soit la quatrième méthode contraceptive la plus utilisée au Canada, sa réalisation chez des femmes de moins de 30 ans est encore rare (10).

Nous allons d'abord explorer le contexte et les raisons qui mènent certaines femmes à ne pas désirer d'enfant. Puis, nous présenterons les justifications qu'elles soulèvent pour avoir recours à la stérilisation ainsi que les arguments présentés par les soignants pour réaliser ou non l'intervention chez cette population de femmes. Par la suite, nous porterons notre attention sur le principe d'autonomie des femmes qui serait en faveur du respect de leur choix de se faire ligaturer. De là, nous expliciterons l'importance du rôle joué par la déontologie professionnelle et expliquerons les possibles dérives vers un paternalisme médical. En terminant, nous essayerons d'apporter quelques pistes de réflexion et recommandations pour mieux guider les pratiques entourant la stérilisation féminine volontaire chez des femmes de moins de 30 ans sans enfant, en nous appuyant notamment sur le modèle de partenariat relationnel et d'éthique narrative, aussi appelé le *Montreal Model*, développé par la Faculté de Médecine de l'Université de Montréal en 2014.

Le désir de ne pas avoir d'enfant : un choix personnel encore tabou

Plusieurs modifications sociales au cours des dernières décennies ont mené à une augmentation des demandes de stérilisation. Nous pouvons citer notamment l'émergence et l'accès libre à la contraception et à l'avortement, ainsi que l'apparition d'une vision plus positive de la société vis-à-vis de la limitation du nombre des naissances (1,11,12). Qui plus est, la prise de distance avec la religion qu'a connue le Québec dans les années 1960 a entraîné une chute importante de fécondité (12) et n'a fait qu'entériner la tendance à la baisse de la fécondité. En effet, l'indice synthétique de fécondité (soit le nombre d'enfants qu'aurait une femme au cours de sa période reproductive si elle suivait la tendance de fécondité par âge observé au cours d'une année donnée) est nettement plus important avant 1960, où une femme avait en moyenne quatre enfants, contre deux dans les années 1970 et 1,5 en 2018 (13). Parallèlement à cette tendance, la décriminalisation de la contraception le 1^{er} juillet 1969 au Canada par le Parlement (2) a permis une libéralisation des pratiques entourant la contraception et plus particulièrement la stérilisation (12). Toutes ces évolutions mènent au constat suivant : il y a de plus en plus de couples sans enfant au Canada et notamment au Québec ; c'était le cas en 1986 avec 30,7% des couples contre 43% en 2016 (14). Dans la même veine, il faut également noter que 33,3% des ménages au Québec sont constitués de personnes seules, ce qui en fait la province avec le plus haut taux au Canada (14).

Ces chiffres mettent en lumière les changements sociaux qui s'opèrent, tels que l'émergence de mouvements féministes, et qui bien que divers et multiples, sont un « ensemble de mouvements et d'idées politiques, philosophiques et sociales qui partagent un but commun : promouvoir et atteindre l'égalité politique, économique, culturelle, personnelle, sociale et juridique entre femmes et hommes » (15, p.44). Ces mouvements ont donné de plus grandes opportunités d'accès à l'éducation et à des carrières aux femmes et ont ainsi favorisé un contexte où la ligature tubaire devient une intervention possible et voulue par certaines femmes sans enfant (1,3,5). Si nous nous attardons sur les chiffres mettant en lumière ces tendances, nous pouvons observer qu'à travers les dernières décennies les taux de stérilisation, notamment chez les jeunes femmes, ont connu diverses variations. En effet, il est possible d'observer une explosion des demandes de ligature tubaire dans les années 1970-80, suivi d'une baisse, elle aussi importante : le taux de femmes de 20-30 ans ligaturées passe de 26,7 pour 1000 en 1978 à 1,5 pour 1000 en 2011 (14). Même si, de nos jours, comme l'illustrent les chiffres précédents, peu de jeunes femmes ont recours à la ligature comme technique de contraception définitive, il n'en reste pas moins que certaines la souhaitent. Il est donc important de prendre ce désir en considération et de porter une réflexion sur le contexte de refus auquel se heurtent parfois ces femmes dans leur parcours de stérilisation.

De plus, il peut être interpellant de constater que les taux de vasectomie, soit de stérilisation masculine, pour les mêmes tranches d'âge soient plus importants (2,9 hommes sur 1000, entre 25 et 29 ans, en 2010 au Québec, ont subi une vasectomie) (17). Les témoignages de femmes souhaitant avoir recours à une ligature tubaire évoquent les recommandations des médecins de plutôt proposer une vasectomie à leur conjoint que de réaliser cette ligature (6). Il est vrai que la vasectomie est une intervention moins invasive (18), mais l'on peut toutefois se questionner sur l'impact du genre dans la décision de mettre fin à la fertilité d'une personne (19).

Part de là de ces premiers constats, force est de constater que de plus en plus de femmes souhaitent rester et restent sans enfant dans les sociétés occidentales. Dans la littérature, elles portent plusieurs noms : *childfree*, *childless* ou encore *nonmother* (1, p.123). *Childless* (c'est-à-dire, sans enfant par contrainte) renvoie au fait qu'une personne ou un couple n'a pas d'enfant, bien qu'ils soient en âge de procréer, que ce soit une décision personnelle (aussi nommé *voluntary childless*) ou pour raison médicale comme une infertilité (appelée ici *involuntary childless*) (1,16). *Childfree* se rapporte plus au fait de ne pas avoir d'enfant par choix. Ces termes peuvent être vus de manière négative, dans le sens où le fait de ne pas vouloir d'enfant

est vu comme une « déviance de la norme » (1, p.159). Mais, chez certaines associations et personnes concernées, ce dernier terme ne comporte pas de sens péjoratif. Ainsi, être *childfree*, est formulé positivement : c'est désirer ne pas avoir d'enfant¹.

Les motivations d'être *childfree*

À travers cette même littérature, nous retrouvons différents motifs formulés par les femmes dans leurs décisions de ne pas avoir d'enfant. Ce désir d'être *childfree* peut naître chez une femme dès son adolescence (1) et perdurer. Beaucoup énoncent le désir de mettre un terme à leur possible maternité, de passer à autre chose et de se concentrer sur d'autres aspects de la vie (8, p.109) tels que leurs carrières (1,8,20) ou leurs loisirs (1,20) comme des voyages. Elles cherchent à garder ici une plus grande liberté (20,21). Les femmes *childfree* soulèvent également des raisons médicales, afin de justifier le choix de ne pas avoir d'enfant. Par exemple, c'est dans le but d'éviter de transmettre une pathologie génétique à l'enfant (8,22) ou pour sauvegarder leur propre santé qu'une grossesse pourrait menacer (22), certaines vont décider de mettre fin à leur capacité reproductive.

Sur un plan psychosocial, d'autres motivations peuvent émerger. Nous pouvons retrouver un refus en réaction à la perception de la vie de leur mère, qui a pu être difficile. C'est notamment le cas des femmes dont la mère a eu beaucoup d'enfants ou qui a dû abandonner une carrière dans laquelle elle s'épanouissait pour élever ses enfants (12). Dans une autre perspective, certaines femmes vont justifier leur choix par un désir de se (ré)approprier leur corps et leur sexualité (12). Ce dernier motif rejoint les justifications s'appuyant sur le mouvement du féminisme radical (1), qui est un courant féministe naît dans les années 1960 et qui perdure toujours aujourd'hui. C'est un courant du féminisme où les femmes dénoncent les dictats du patriarcat sur leur vie privée et militent pour une reconnaissance de la culture féminine à travers une révolution sexuelle qui s'accompagne bien souvent d'une émancipation sexuelle (15). Cette renonciation à la maternité peut donc se justifier par le désir de s'opposer à la société, à ses attentes et à ses politiques (23). Dans ce mouvement féministe, on observe également un intérêt grandissant pour la protection de la planète via une réduction de la surpopulation, qui sont aussi deux justifications données par les femmes *childfree* (1,16,22).

Enfin, d'autres causes s'expliquent par un mécanisme de défense psychologique mis en place par ces femmes en réaction à un vécu difficile (23), à un traumatisme dans l'enfance (16,23), à l'association de la maternité à de trop grandes responsabilités impossibles à assumer (23), ou encore au fait qu'elles aient été confrontées à d'autres histoires vécues par leur entourage (1,16). Certaines motivent leurs choix en parlant de conformisme vis-à-vis des attentes parentales, quand leurs parents prônaient le *childfree*, mais aussi vis-à-vis des attentes sociétales dans le cas des grossesses adolescentes (23). De manière plus générale, beaucoup se disent heureuses d'être en couple, d'avoir un bon salaire et que cette absence d'enfant leur permet de bien se concentrer sur leur relation et sur leur partenaire (1,11,16). Cette relation privilégiée qu'elles entretiennent avec leur partenaire est également une réelle motivation à rester sans enfant selon elles (1,16,21).

En conclusion, d'après ces femmes, nombreux sont les avantages de ne pas avoir d'enfant. Elles disposent de plus d'opportunités (16), et de meilleures situations financières, car élever un enfant peut coûter cher (22). Elles relèvent également les inconvénients de la maternité tels que le fait que les enfants sont peu intéressants et représentent un poids (1,16), que l'éducation et la gestion du quotidien sont difficiles (1,16), que cela a peu d'intérêt (24), et que les responsabilités engendrées sont trop lourdes à assumer (1). Ainsi, l'absence de maternité est un choix important pour ces femmes, et dans l'optique de sauvegarder leurs désirs et choix de vie, elles vont faire appel à la stérilisation.

Le choix de la stérilisation en réponse à la peur d'une grossesse non désirée

Pour ces femmes, la principale peur liée à ce non-désir d'enfant est d'être confrontée à une grossesse non désirée qui pourrait potentiellement se solder par un avortement (22). En prévision de cette situation redoutée, les *childfree* vont se protéger en misant sur le rôle de la contraception : empêcher une grossesse non voulue. Elles ont une attente bien particulière vis-à-vis de la méthode qu'elles vont choisir : que celle-ci soit quasi infaillible (25). Cette peur de l'inefficacité des méthodes de contraception sur le marché, surtout lorsque ces méthodes sont dites non définitives, est une des raisons principales pour laquelle ces femmes se tournent vers la ligature tubaire (25). Nous pouvons retrouver dans la littérature également d'autres justifications expliquant que les femmes *childfree* vont s'orienter vers une ligature tubaire plutôt que vers des méthodes de contraception plus conventionnelles.

Tout d'abord, d'après les femmes *childfree*, des raisons médicales peuvent motiver ce recours à la stérilisation, comme dans le cas d'une intolérance aux hormones ou dans le cas de pathologies qui contre-indiquent la prise d'hormones (26). D'autres justifications qu'elles présentent portent sur des notions en lien avec le bien-être et la qualité de vie. Prenons l'exemple du préservatif, qui peut être, dans les relations au long terme, coûteux, engendrer une perte de spontanéité ou encore être contraignant (8). Il existe également une autre méthode de contraception : les dispositifs intra-utérin, qui peuvent être faits de cuivre ou imprégnés d'hormones (26). Ils peuvent être refusés par les femmes pour des effets indésirables en lien avec les hormones, pour des gênes entraînées par le cuivre qui peut induire des règles très abondantes notamment, ou encore à cause du risque de perforation de l'utérus que ces dispositifs peuvent entraîner (26).

¹ Nous utiliserons le terme *childfree* dans notre article pour nommer les femmes ne souhaitant pas d'enfant, car nous souhaitons un terme qui reflète une réalité positive et sans jugement, et ce terme est défendu et reconnu par les associations et les écrits sur le sujet.

De même, elles indiquent que les méthodes hormonales peuvent causer de nombreux effets secondaires plus ou moins lourds comme une absence de libido, une sécheresse vaginale, une prise de poids, un état dépressif, des douleurs mammaires, des vomissements ou encore des saignements (8), ce qui entraîne un impact négatif sur leur qualité de vie et réduit significativement leur bien-être. De plus, avec la pilule, une dernière justification apparaît, soit celle du risque d'oubli et du danger de sa réalisation, qui mènerait à une possible grossesse non désirée (26). Cette inquiétude est omniprésente et, bien que des méthodes d'urgence existent, celles-ci ne peuvent être prises de manière régulière, ce qui demande donc à la femme d'être très attentive et vigilante dans sa prise (26). Cependant, même si la prise est parfaite, le taux d'efficacité n'est pas total (26) et elle comporte des effets secondaires qui réduisent la qualité de vie de certaines femmes.

Ainsi, pour toutes ces raisons, les femmes *childfree* s'orientent vers la stérilisation. Mais cette décision de renoncer à leur capacité reproductive se heurte au refus de certains médecins de pratiquer l'intervention. C'est ce sur quoi nous nous penchons dans la prochaine partie.

La déontologie professionnelle du soignant

Les critères utilisés par le médecin pour réaliser ou non la ligature

La partie précédente examinait les raisons invoquées par les femmes qui demandent l'obtention de la stérilisation. En nous appuyant sur la littérature, nous allons maintenant présenter les justifications données par les médecins pour soutenir leur décision de réaliser ou non une stérilisation chez une femme, mais aussi sur la pertinence de ces justifications.

Les médecins semblent se référer à certains critères à la lumière desquels ils justifient leur décision. Ces critères ne sont pas formels et clairement inscrits dans un code de pratique. Toutefois, ils sont largement répandus dans la communauté médicale, et, d'après la littérature sur le sujet, ils sont récurrents dans la justification de réaliser l'intervention ou non. Parmi ces critères, il y a bien entendu des critères de nature physique et biologique (3,23), comme pour toute intervention médicale : il faut être en bonne santé et être apte à subir une anesthésie générale, le cas échéant. Mais des auteurs présentent également d'autres critères qui vont être utilisés par les médecins pour évaluer la demande faite par la femme et, notamment, les critères de l'âge de la personne qui formule la demande (3,23,27), de sa situation conjugale et familiale (3,23) ou encore de sa santé mentale.

Les études menées auprès des médecins ont permis de classer ces critères d'accès par leur force d'impact sur le choix d'accéder ou non à une requête de stérilisation (28)². Le premier, le plus important, est l'âge ; plus la femme est jeune, moins le médecin sera enclin à pratiquer la ligature. En seconde position, nous pouvons noter la parité ; les femmes nullipares se verront plus souvent refuser une stérilisation que les femmes multipares. Finalement, la demande de ligature sera donc plus souvent refusée si la raison de la stérilisation n'est pas médicale, relève de l'exercice du libre choix d'une personne apte et majeure et correspond à un choix de vie personnel de la femme.

Les critères présentés précédemment et soulevés par différentes études et personnels soignants (3,23,27,28) ne semblent pas infondés, dans la mesure où les femmes qui regrettent leur choix répondent souvent à ces critères. En effet, les regrets, d'un point de vue psychologique et émotionnel, sont le principal risque de la stérilisation (10,29). Lorsqu'un médecin se retrouve confronté à ces particularités chez une femme, il peut craindre pour celle-ci l'apparition de regrets, et cela peut le freiner à réaliser des stérilisations chez de jeunes femmes sans enfants (30). À travers leur revue systématique des écrits, Curtis *et al.* (31) ont montré que le risque de regret existait. Toutefois ils précisent que malgré le risque existant, rares sont les femmes qui manifestent des regrets suite à cette procédure.

Il est possible d'établir une corrélation entre les critères présentés par les médecins pour juger d'une admissibilité au processus de stérilisation que nous avons énoncés précédemment et l'apparition de regrets chez la femme qui aurait subi la ligature. Tout d'abord, le regret est plus présent chez les femmes qui ont été stérilisées avant 30 ans, notamment car la période de fertilité possible a été plus longue et qu'elles sont aussi sujettes à plus de changements socio-économiques et conjugaux (23,28,31,32). De plus, l'état de la relation conjugale de la femme au moment de la demande de stérilisation peut également influencer l'apparition de regrets ; si elle a connu des difficultés conjugales ou émotionnelles avant et au moment de la ligature, il y a un risque plus élevé qu'elle regrette sa décision par la suite (33). Mais il faut noter que ce risque de regret n'est pas très bien défini ni explicite. En effet, son délai d'apparition est plus long chez les femmes jeunes, environ 8 ans, que chez des femmes plus âgées où c'est en moyenne 3,7 ans (25). En outre, ces femmes ne définissent pas le regret comme un sentiment profond et insupportable à vivre. Elles apparentent plus le regret à des sentiments qui surviennent dans des « occasions spécifiques lorsqu'elles éprouvaient des sentiments « nostalgiques », ou des « grondements » troublants, ou des « pincements » de doute, ou des « pensées incontrôlables » sur une voie qu'elles n'ont pas suivie » (1, p.167 ; cite Morell, 1994, traduction libre).

En somme, la littérature rend bien compte de la tension qui existe entre la décision prise par une femme la concernant, décision qui relève de son autonomie, et le désir du médecin de faire ce qu'il pense être le mieux pour elle, qui peut s'apparenter à un certain paternalisme.

² Les auteurs indiquent également que le médecin acceptera plus facilement de procéder à la chirurgie si la femme présente des raisons médicales (p.568-569), comme des pathologies endocriniennes ou génétiques, car cette intervention s'inscrit dans l'administration de soins nécessaires au vu de l'état de santé général de la patiente. Cette justification ne s'inscrit toutefois pas dans le sujet du présent article qui porte sur la stérilisation volontaire.

Bien que ces regrets ne soient pas tous profonds et insurmontables, certains médecins demeurent plus hésitants à répondre aux demandes de stérilisation faites par des femmes de moins de 30 ans sans enfant (ou refusent catégoriquement). Cela est d'autant plus vrai lorsqu'ils auront été confrontés, dans leur propre pratique professionnelle, à ces situations de regret de la part de leurs patientes. Au Québec, par exemple, il est inscrit au Code de déontologie des médecins, code qui dicte les devoirs s'appliquant à ces professionnels (34), qu'un soin ne doit être réalisé que s'il est nécessaire pour la santé du patient, mais aussi que le médecin se doit de promouvoir la santé et le bien-être des personnes dont il s'occupe (35, art. 3 et 50). Ainsi, en altérant les capacités reproductives des femmes dont il s'occupe, le médecin peut avoir le sentiment, en se référant à ces articles, d'aller à l'encontre de ses devoirs. Et, bien que ce code ait été remanié au cours des siècles, il reste encore fidèle à son premier texte fondateur, le Serment d'Hippocrate. Ce serment, apparu au IV^e siècle avant J.-C. et attribué à Hippocrate, médecin et philosophe grec, était prêté par les médecins en Occident avant de débiter leur exercice de la médecine. Il est souvent perçu comme le premier code de déontologie des médecins.

L'impact de la déontologie et du Serment d'Hippocrate sur la vision des médecins

En effet, les premiers devoirs des médecins ont été pour la première fois inscrits de manière normative dans le Serment d'Hippocrate (36) qui est encore aujourd'hui à la base du Serment prêté par de nombreux médecins lors de l'obtention de leur diplôme dans le monde. Mais le Serment d'Hippocrate se rapporte à un code de bonne conduite, qui énonce les devoirs du médecin, ainsi que les sanctions qui se rapportent à son non-respect (37). Lorsque nous parlons de déontologie, nous faisons référence aux devoirs, exigences et normes notés dans un « code de déontologie » reconnu par une autorité (38,39). Par-delà le Serment d'Hippocrate, c'est notamment le cas du Code de déontologie des médecins du Québec (35), ainsi que celui de l'Association médicale du Canada qui s'appliquent au Québec. Les médecins doivent respecter ces deux derniers codes qui précisent leurs devoirs et responsabilités envers les patients. Le but de ces codes est d'assurer la sécurité, l'accessibilité et la qualité des services prodigués. Ils reflètent les devoirs, obligations et prescriptions qui s'appliquent aux médecins membres de l'ordre et font opposition à l'analyse, l'échange et la réflexion sujette à l'éthique réflexive (39).

Malgré son ancienneté, le Serment d'Hippocrate présente des principes comme le *Primum non nocere*, « premièrement ne pas nuire », qui restent toujours d'actualité et centraux dans l'exercice moderne de la médecine (37). Le *Primum non nocere* se rapporte au principe que nous appelons aujourd'hui en bioéthique le principe de non-malfaisance : ne pas faire de mal ou nuire au patient (37). Le médecin est là pour faire le bien, agir dans l'intérêt du patient et ne pas causer de tort à ceux dont il s'occupe (37). De plus, on retrouve dans le Serment l'énoncé suivant : « je ne remettrai à aucune femme de peussaire abortif ». Ceci illustre une posture ancienne du médecin face à la natalité et la fécondité (36). À l'époque de la Grèce Antique, l'avortement ou le fait de mettre un terme à la fertilité d'une femme s'apparentait à un acte de malfaisance de la part du médecin ; celui-ci n'agissait pas dans l'intérêt de la patiente et allait donc à l'encontre du Serment. Par conséquent, il pouvait dans ce sens subir des sanctions. Peut-être que cette association entre le principe de ne pas nuire et celui de la préservation de la fertilité/natalité trouve encore écho aujourd'hui? Comme l'indique Gillespie, « les médecins ont exercé une influence puissante et légitimant la manière dont la maternité a été définie comme le rôle naturel, primaire et souvent unique de la femme en bonne santé » (30, p.142, traduction libre). Et même si les pensées se libéralisent de nos jours, il peut être encore difficile pour eux de se défaire d'une approche pro-nataliste et hétéronormative, notamment en mettant un terme à la fertilité d'une jeune femme sans enfant (30). Le refus de certains médecins de donner suite à une demande de stérilisation d'une jeune femme peut s'apparenter, pour les femmes *childfree*, à un certain paternalisme et à un processus d'infantilisation (1) qui vient se heurter à leur principe d'autonomie.

Le respect du principe d'autonomie des femmes *childfree*

Aujourd'hui, malgré l'évolution du statut des femmes dans la société, et notamment relativement au droit de disposer de leur corps, le choix d'être *childfree* et d'avoir recours à la stérilisation, surtout pour les femmes de moins de 30 ans, est une décision qui peut encore déranger les mentalités. Effectivement, le choix de ne pas enfanter et la privation de l'expérience de la maternité chez la femme peuvent être vus comme une déviance, une anormalité, une opportunité manquée (16). Bydlowski exprime très bien cette attente sociale et familiale vis-à-vis du rôle de la femme et de son devoir de maternité :

[...] la pression sociale et familiale attend [sic] naturellement d'une jeune femme, un jour ou l'autre, la naissance d'un enfant, et cette pression ne s'est pas affaiblie malgré les nombreuses nouveautés dans ce domaine ni malgré le nouveau statut social accordé aux femmes. Le devoir de filiation reste impérieux, même s'il s'accommode éventuellement d'un enfant unique (23, p.28)

En effet, pour plusieurs, la construction de l'identité féminine passe par la maternité et le maternage (16,30). Et par conséquent, une absence de maternité peut sous-entendre que la femme est malheureuse. Pourtant, des études ont montré que les femmes *childfree* peuvent être aussi, voire, plus heureuses et épanouies que des parents (40). Il faut toutefois nuancer ce dernier argument ; il existe peu de littérature permettant de juger de l'épanouissement apporté par le rôle de parent vis-à-vis de femmes qui seraient *childfree*, du fait du possible jugement sociétal qui s'abattraient sur une femme expliquant qu'elle aurait préféré ne pas avoir d'enfant (40).

Bien que ce choix de stérilisation puisse encore se confronter aux normes sociétales et interpeller, la demande faite par une femme d'être ligaturée touche à son corps et est motivée par des raisons qui sont les siennes. Elle se rapporte à son principe

d'autonomie. L'autonomie est un principe majeur en éthique. Il se définit comme le fait que chaque personne puisse décider pour elle-même de ce qu'elle souhaite. Il suppose donc, en santé, que « chaque être humain a le droit et la capacité de prendre ses propres décisions concernant les procédures médicales, le traitement » (41, p.218). Ce principe est omniprésent dans le milieu médical. Comme l'explique le Collège des médecins du Québec (CMQ) :

La société québécoise reconnaît le principe éthique de l'autonomie de la personne comme base de la relation entre les individus. Le terme « autonomie » s'entend ici au sens « d'autodétermination de l'individu », c'est-à-dire de sa capacité à décider et à agir de son propre chef. Ce principe sous-entend le respect de la personne et la reconnaissance de son pouvoir décisionnel et, conséquemment, en médecine particulièrement, il impose la règle du consentement aux soins ainsi que le droit à l'information et le droit à la vérité (34, p.13).

Dans ce contexte, un consentement libre et éclairé est demandé pour que la personne puisse prendre les décisions qui lui conviennent en étant pleinement informée. Ce consentement permet de respecter l'autonomie de la personne en ne la soumettant pas aux faits et gestes d'une autre personne sans son plein accord. D'après le *Code civil du Québec* (art. 10 et 11) et le *Code de déontologie des médecins* (art. 28 et 29), le consentement doit être libre et éclairé. Le CMQ indique que pour obtenir un consentement le « plus libre possible, il doit être obtenu sans pression, menace, contrainte ou promesse de la part du médecin, de la famille ou de l'entourage du patient, voire des instances administratives et des impératifs budgétaires » (34, p.23). Il ajoute également que, pour respecter le volet éclairé du consentement, « le patient apte, ou bien celui qui prendra la décision à sa place s'il est inapte, doit être bien informé des tenants et aboutissants des différentes options qui lui sont proposées par le médecin » (34, p.23). D'après le Consensus canadien de la contraception et l'article de Ehman et Costescu, cela signifie que le médecin doit donner toutes les informations concernant le déroulement de l'intervention, ici la ligature tubaire, ainsi que ses risques (dont le risque de regrets) et ses bénéfices, mais aussi, informer la demanderesse des méthodes contraceptives alternatives réversibles existantes (10,29). Il doit également s'assurer que la patiente les a bien compris (34).

Ce consentement peut être donné par tout majeur apte, soit les personnes de 18 ans et plus (42, art. 10 et 11). La définition québécoise de l'aptitude à consentir a été inspirée de critères émis par la législation de la Nouvelle-Écosse, qui sont les suivants : « la personne comprend la nature de sa maladie », « la personne comprend la nature et le but du traitement », « la personne comprend les risques associés à ce traitement », « la personne comprend les risques encourus si elle ne subit pas le traitement », et enfin, « la capacité à consentir de la personne est compromise par la maladie » (43)³. De même, bien que le consentement aux soins au Québec puisse être donné par les adolescents de 14 ans et plus, ils ne peuvent pas toujours consentir seuls à ce type d'intervention qui est dite non requise par l'état de santé (42, art. 17). En effet, il existe deux types de soins, ceux requis par l'état de santé de la personne et ceux non requis. Dans le cadre de la première catégorie, l'adolescente de 14 ans et plus peut consentir seule à ses soins, comme cela est le cas par exemple pour la réalisation d'une stérilisation qui lui sauverait la vie (42, art. 14 al. 2). En revanche, dans le cadre de soins non requis par l'état de santé, l'adolescente ne pourra consentir seule si l'intervention présente des risques sérieux pour sa santé qui peuvent lui causer des effets graves et permanents, ce qui est le cas de la ligature tubaire réalisée par choix (42, art. 17)⁴. Ainsi, pour certaines interventions comme l'avortement, qui n'est pas un choix médical, mais un choix de vie, les adolescentes de plus de 14 ans peuvent déjà exercer leur consentement et celui-ci sera respecté. Pourtant ce même consentement n'est pas respecté dans le cas de femmes majeures qui souhaitent une stérilisation, qui s'inscrit également dans un choix de vie.

Suite à la présentation de ces concepts, il peut sembler interpellant qu'une femme dans la vingtaine soit parfois dite trop jeune pour être jugée apte à consentir pour une ligature, en invoquant le fait qu'elle ne sait pas encore ce qu'elle veut pour elle-même (19). De manière analogue, tel que le soulève McQueen, il existe également un paradoxe entre le fait de remettre en question, voire de refuser, une demande de stérilisation d'une femme dite trop jeune et le fait de ne pas émettre de réserves sur une femme qui souhaiterait avoir un enfant jeune, voire très jeune (19). Dans les deux cas de figure, les conséquences sont majeures et quasi-irréversibles. De manière générale, il est moins courant d'interroger un désir d'enfant, même s'il est formulé par une femme très jeune, que d'émettre un jugement sur le désir d'une femme de rester sans enfant (1). Ces interrogations et ces remises en question régulières poussent les femmes *childfree* à exprimer une certaine frustration quant au fait que les médecins et la société ne croient pas à leur choix, disqualifient leur jugement, discréditent leur choix et n'accordent pas de valeurs à leur témoignage (1,16,44), ce qui mène à une injustice épistémique pour les femmes. C'est ici une injustice épistémique, car le cadre de vie que ces femmes souhaitent est altéré et modifié de manière forcée par un autre groupe de personnes (société et professionnels de santé) (45). Il y a donc une vraie réflexion éthique à réaliser sur cette confrontation entre l'autonomie des femmes et les motivations de refus des soignants. Les réserves présentées par certains médecins dans la décision de ne pas réaliser une ligature peuvent être multiples et tenir de la justification médicale à la justification de la peur d'apparition de regrets.

³ Nous nous concentrons uniquement sur la population apte ici, car la relation entre les femmes inaptes et la stérilisation demandent d'autres prérequis et soulèvent d'autres enjeux qui nécessiteraient à eux seuls un autre travail tant la question est vaste.

⁴ La stérilisation pour motif non médical n'est pas considérée comme un soin à part entière selon le CMQ, car elle n'a pas de visée thérapeutique (34). Toutefois, il n'en reste pas moins que c'est un acte médical qui a un intérêt important et particulier pour la femme (34). Nous trouvons que cette classification est un peu réductrice, car bien que la ligature tubaire ne soit pas réalisée dans un but thérapeutique, elle répond tout de même à la définition du terme *care* donné par le dictionnaire de Cambridge : « the processus of protecting something or someone and providing what that person or things needs » (<https://dictionary.cambridge.org/fr/dictionnaire/anglais/care>). La dimension de soin est plus globale et ne prend pas en compte uniquement la thérapeutique, mais aussi les besoins et désirs du patient, ce qui est le cas de la stérilisation.

Le refus de ligature : tension entre paternalisme et autonomie

En effet, il existe dans la demande de stérilisation faite par une jeune femme de moins de 30 ans sans enfant, un réel conflit entre le respect de son autonomie, via l'acceptation de sa demande, et la non-malfaisance souhaitée par le personnel soignant, c'est-à-dire ne pas nuire à la femme en étant à l'origine de regrets ou en portant atteinte à sa capacité reproductive. Les soignants s'appuient donc sur la volonté d'agir dans le meilleur intérêt de leur patiente. Or, comme le présente Ronald Dworkin, l'appréciation du meilleur intérêt du patient peut être subjective (46). Le médecin peut transposer ses propres valeurs et principes sur la décision autonome de son patient (46), qui est dans notre situation est une femme majeure et apte qui souhaite être stérilisée. Si l'on suit l'argumentaire de Dworkin et qu'on l'applique à notre cas, le médecin peut penser que la femme fait une erreur en décidant de subir une ligature, et qu'il sait mieux qu'elle ce qui est dans son meilleur intérêt (46). Mais cet argument est rarement vrai (46). Pour le bien-être de la femme, il est préférable de respecter sa décision, qui s'inscrit dans les choix de vie qu'elle fait pour elle-même, selon ses propres valeurs et principes. Ce refus d'opérer peut, pour la femme, s'apparenter à un certain paternalisme de la part du médecin, qui va contre son autonomie. Si nous nous basons sur la définition du paternalisme proposée par Dworkin comme étant « l'interférence d'un État ou d'un individu avec une autre personne [sic], contre sa volonté, et justifiée et motivée par la croyance qu'elle s'en portera mieux ou qu'elle sera protégée d'un mal » (47), nous pouvons voir qu'elle s'applique bien à notre situation.

Dans la littérature, nous pouvons retrouver différents types de paternalisme, définis selon plusieurs caractéristiques. Nous allons en présenter quelques-unes particulièrement intéressantes pour notre analyse.

Tout d'abord, le paternalisme peut être qualifié de doux, c'est-à-dire qu'il va avoir un impact sur la volonté d'un enfant, d'un adulte inapte ou alors qu'il touche à des actes involontaires (47). Comme exemple nous pouvons citer l'interdiction de consommer de l'alcool pour les mineurs de moins de 18 ans. Cette interdiction touche les enfants et consiste à les protéger de choix qui peuvent être involontaires et dangereux pour eux. A contrario, le paternalisme peut être qualifié de dur et il va donc toucher aux actes volontaires et pleinement réfléchis de personnes autonomes, aptes, rationnelles et informées (47). Prenons comme exemple l'obligation pour les adultes du port du casque à vélo. C'est une décision imposée à des adultes pleinement aptes et autonomes, mais qui se fait parfois contre leur volonté. Toutefois, ils doivent la respecter.

Il peut aussi avoir comme caractéristiques d'être coercitif ou non (47). Lorsque l'interférence d'autrui se fait sur la décision de la personne via un moyen très contraignant comme l'élimination ou la restriction d'une option à laquelle elle avait accès, nous parlerons d'un paternalisme coercitif (47). Cela est par exemple le cas d'une interdiction de vente de cigarettes : il y a suppression d'une option à laquelle la personne avait accès. Dans le cas contraire, si l'action entreprise ne fait qu'informer ou rendre une autre option disponible, le paternalisme sera non coercitif, c'est-à-dire que la personne se verra orientée vers d'autres choix sans toutefois y être contrainte (47). Comme cela est le cas pour les informations nutritionnelles indiquées sur les aliments : le consommateur a accès à des informations pouvant modifier ses choix, mais il n'y sera pas contraint. De plus, si la contrainte interfère avec une liberté fondamentale, comme la liberté de procréer ou non, elle sera éthiquement moins acceptable que si elle touche à une liberté triviale (47).

Le refus de réaliser une ligature tubaire, qui est demandée par une femme majeure, apte, qui a réfléchi à la situation et qui utilise son autodétermination, est considéré comme une atteinte à une liberté fondamentale. Ainsi, le paternalisme reprend les caractéristiques les plus contraignantes et restrictives dont il peut faire preuve, soit : dur, coercitif et touchant une liberté fondamentale. Selon les auteurs, ce type de paternalisme demeure assez problématique (47). Cette forme de paternalisme entraîne des risques importants, mais différents pour les femmes et pour le médecin. En effet, ce type de paternalisme peut porter atteinte à l'autonomie des femmes, et donc à leur capacité d'autodétermination. Il impacte également le médecin, qui peut se retrouver confronté à des demandes qui le dérangent et auxquelles il peut donc risquer de ne pas répondre adéquatement. Compte tenu des conséquences majeures pour les femmes, au lieu de restreindre ou de supprimer l'option d'une ligature, nous soutenons que le médecin devrait, par exemple, informer la femme des autres méthodes de contraception non définitives disponibles et ainsi engager un échange plutôt que de décider seul de ne pas réaliser l'opération. Après discussion, le consentement de la femme pour une mesure ou une autre devrait être respectée. Cette avenue permettrait une plus grande autodétermination et autonomisation des femmes. De même, dans le cas où le médecin ne souhaiterait pas réaliser l'intervention en faisant valoir son objection de conscience, il serait optimal qu'il réfère la patiente à un de ses collègues qui pourrait être plus à même de prendre en charge sa demande. Ainsi, le médecin qui serait mal à l'aise face à la demande n'irait pas contre ses principes, mais la femme aurait toujours l'opportunité de voir sa demande considérée par le corps médical.

D'autre part, la question du genre ne devrait pas interférer dans cette prise de décision. Comme le soulève McQueen, le fait de refuser une ligature tubaire à une femme par peur des regrets qu'elle pourrait ressentir suggérerait « une différence de genre inquiétante, qui pourrait refléter un discours problématique qui définit que toutes les femmes voudraient élever des enfants » (19, traduction libre, p.312). Il ajoute que cette différence de traitement selon le genre du demandeur de la stérilisation indiquerait « que les hommes sont considérés plus autonomes que les femmes et donc plus en mesure de prendre des décisions sur leur vie » (19, traduction libre, p.312). Il conclut qu'aucune justification n'est acceptable pour prendre en charge différemment une demande de stérilisation venant d'une femme ou d'un homme (19).

Ainsi, suite à ces constatations qui peuvent être dites problématiques, nous soutenons qu'une approche fondée sur l'échange, la discussion et la réflexion est préférable lors de demandes de stérilisation tubaire, notamment chez les femmes de moins de

30 ans sans enfant, car elle respecte plus l'autonomie de la femme et cherche à mettre les motivations de celle-ci au premier plan plutôt que de juger ce choix de vie. À ce titre, l'apport d'un échange et d'une discussion, ainsi qu'une connaissance de l'histoire plus personnelle de la femme seraient bénéfiques pour orienter la prise de décision. Cette décision se prendrait donc en collaboration, d'où l'intérêt d'utiliser une approche basée sur l'éthique narrative.

Apport de l'éthique narrative dans la décision

Hubert Doucet avance qu'une éthique narrative est « centrée sur les récits des divers acteurs d'une situation médicale », ce à quoi Michelle Pimont ajoute « à l'information scientifique, il convient d'intégrer et de considérer l'histoire des personnes » (38, p.11). Cette approche, centrée sur les discours de vie des personnes ou sur leurs émotions et sentiments, est de plus en plus appliquée en clinique, comme l'illustre le document de référence sur le sujet édité par le Collège des Médecins du Québec (34). La discussion entre le médecin et la femme permet un échange d'informations à double sens dans la relation de soins : de la femme vers le médecin et du médecin vers la femme. Dans ce cadre, le recours à l'éthique narrative est bénéfique. Celle-ci a été définie, traitée et débattue par de nombreux auteurs. Au Québec particulièrement, Doucet a beaucoup travaillé sur cette éthique pendant une grande partie de sa carrière. Son approche et sa vision se prêtent particulièrement à notre analyse de cette situation. Voyons donc plus précisément comment cette éthique narrative peut s'installer dans la relation de soins.

Dans l'optique d'une meilleure communication entre le médecin et la femme, Doucet propose quatre étapes primordiales pour avoir une « médecine plus humaine » (48). Tout d'abord, il s'agit de mettre en place une « alliance thérapeutique », c'est-à-dire pouvoir instaurer une relation de confiance entre les deux interlocuteurs qui ont chacun leurs valeurs, leurs passés, leurs environnements, leurs attentes, mais où chacun écoute et échange dans le respect avec l'autre. Le Collège des Médecins du Québec (34) encourage d'ailleurs également la mise en place de cette « alliance thérapeutique », qui représente la meilleure prise en charge possible du patient via son implication active dans les soins. Toutefois, il est important de noter que bien qu'encouragée, cette alliance peut être difficile à mettre en place notamment à cause des contraintes de temps imparties aux consultations médicales. Le fait de s'écouter, de se découvrir et de se comprendre demande de l'investissement de la part des deux parties et du temps, ce qui peut manquer dans nos systèmes de soins actuels (49).

L'étape suivante demande de mettre en place une « écoute empathique » qui requiert une bienveillance envers l'autre, tout en conservant une certaine distance pour éviter une « contamination » émotionnelle. La femme, dans sa demande de stérilisation, fait appel au médecin pour ses qualités dans le domaine recherché. Elle demande de l'aide et elle peut donc se retrouver en position de vulnérabilité face au médecin (34). Il est important ici que celui-ci en ait conscience, qu'il favorise autant que possible l'autonomie de sa patiente, tout en gardant une « distance émotionnelle » avec celle-ci (48). En effet, une écoute teintée de compréhension, d'ouverture et de respect est à privilégier par le médecin, mais en parallèle à cette approche, il serait préférable qu'il se protège d'un trop grand investissement émotif qui pourrait altérer son jugement et biaiser la relation professionnelle d'un médecin avec sa patiente (48). Ainsi, grâce à la recherche du récit de vie, des motivations, ou encore des attentes des femmes, le soignant pourra mieux comprendre les raisons pour lesquelles la personne demande la stérilisation, discuter avec celle-ci de manière optimale en se concentrant sur son histoire et non sur des généralités, et ainsi voir que la décision prise par la femme est murement réfléchie et souhaitée, mais aussi déceler de possibles facteurs qui pourraient engendrer un regret par la suite et l'en informer. Aussi faut-il souligner qu'une discussion ne cherchant finalement qu'à faire voir à la patiente qu'elle risque de regretter son choix et, ultimement, à la faire changer d'idée ne pourrait être retenue, car elle ne respecterait pas l'ouverture et le respect de la part du médecin.

C'est dans cette optique qu'intervient la troisième étape, soit le « discernement ». Doucet explique que, dans cette phase, « l'expérience du médecin lui apprend à discerner les forces et les faiblesses du récit du patient » et que cela permet pour la femme de « favoriser une prise de décision qui cherchera à respecter son unité » (48, p.69). Cela sous-entend que le médecin, à travers sa pratique et son expérience, pourra reconnaître des détails ou des indicateurs dans le discours de la patiente qui peuvent indiquer que la femme pourrait douter de sa décision, via une certaine ambivalence dans ces propos, mais aussi entendre et comprendre ses motivations. Ces détails ou ces indicateurs peuvent se rapporter aux critères que nous avons mis en relief précédemment, comme l'âge ou le climat de mésentente conjugal (25). Ces indicateurs, qu'il serait important que le médecin relève dans le discours de sa patiente, devraient pouvoir l'aider à mieux accompagner la femme, à la faire réfléchir sur les motivations profondes de son choix et à lui expliquer qu'il existe un risque de regret, notamment si un changement de partenaire survient par la suite (23,25) ; ce qui est d'autant plus vrai si la femme est jeune. Toutefois, le médecin devrait également bien avoir conscience que ces indicateurs ne sont pas prédictifs. Ils peuvent soulever une probabilité de regrets, mais cela ne reste qu'une probabilité et pas un état de fait. Une discussion permettrait ainsi de favoriser un consentement libre et éclairé, dans le cas où la femme serait informée des possibles risques existants (dont les risques de regrets). Ainsi, la seule véritable raison qui pourrait motiver un refus de la part du médecin, sauf les contre-indications médicales, serait l'ambivalence dont fait preuve la femme quant à sa décision (10). Le cas échéant, un laps de temps devra lui être accordé afin de mûrir ses choix. Le fait de discuter avec elle permettrait de bien mettre en évidence l'existence ou non de cette ambivalence, sur laquelle repose la décision d'intervention.

Après cette phase d'analyse du discours de la femme, de ses motivations et du discernement réalisé par le médecin vient finalement le temps de la « décision ». Cette phase au cours de laquelle le choix de pratiquer ou non la ligature tubaire « devient ainsi une démarche de solidarité, un travail de collaboration, de décision partagée » (48, p.70). C'est à travers

l'obtention d'un juste équilibre entre le récit de vie de la femme, les données probantes et l'expérience clinique du médecin qu'une décision juste et valide est prise. Chaque composante de cet équilibre est importante et prévaut autant que les autres. Un déséquilibre mènerait à des décisions non éthiques et briserait la relation entre la patiente et le soignant. La décision doit se baser sur des évidences scientifiques et non pas sur un jugement personnel du médecin ou sur une peur d'apparition de regrets ultérieurs (10,29).

Nos recommandations faites sur la prise en charge de ces demandes de stérilisation par des femmes de moins de 30 ans sans enfant s'appuient sur ce cadre d'échange, de respect et d'attention qui est la base de l'éthique narrative (34). Cette éthique narrative, où le patient est un acteur central dans sa prise en charge, est une approche de plus en plus utilisée et bénéfique en clinique. Ainsi, des modèles de soins se basant sur cette approche apparaissent et se développent. Nous allons en utiliser un particulier, mis au point au Québec, qui s'applique particulièrement bien à notre cas de stérilisation. Il s'agit du *Montreal Model* (50). Après une brève description de celui-ci, nous fournirons quelques suggestions pour mettre en œuvre ce modèle dans une relation de soins.

Quelques recommandations

Le « Montreal Model »

Développé en 2010 à la Faculté de Médecine de Montréal, le *Montreal Model* se base sur un partenariat relationnel entre le patient et les professionnels soignants. Il met l'accent sur le rôle actif, central et participatif qu'est censé jouer le patient dans sa prise en charge médicale ; il devient un intervenant de l'équipe de soins (50). Ce partenariat relationnel « s'appuie sur la reconnaissance des savoirs expérientiels du patient, issus de la vie avec la maladie, et complémentaire des savoirs scientifiques des professionnels de la santé » (50, p.41). Cette prise en charge particulière du patient prônée par le *Montreal Model* est également privilégiée par l'approche narrative de Doucet (50). Ainsi, comme nous l'avons vu précédemment, Doucet met l'accent sur l'importance de prendre en compte l'expérience professionnelle du médecin et d'établir un partenariat, ce qui permet à la patiente et au médecin de co-construire une décision sur des soins. Selon ce modèle, la patiente partage son expérience, son histoire de vie, ses motivations tout en permettant aux soignants d'apporter leur expérience clinique (50). Pour favoriser la participation, la réflexion et l'implication de la patiente, il est préférable que la prise en charge repose sur l'échange, mais aussi sur l'utilisation de documents explicatifs, de délais de réflexion, le recours à d'autres professionnels ou encore au soutien de pairs-aidants ou d'associations concernées par la situation qui apporteront soutien et conseils à la femme (50). Si nous appliquons ces grandes lignes directrices aux femmes de moins de 30 ans sans enfant souhaitant une stérilisation, la prise en charge devrait comporter plusieurs éléments. Voyons, pour terminer, plus précisément comment opérationnaliser le *Montreal Model*.

Opérationnalisation du partenariat relationnel dans le cas de la stérilisation tubaire

Afin de mettre en œuvre une relation de soins selon le *Montreal Model*, tout d'abord, plusieurs rencontres avec le médecin sont nécessaires. Elles le sont à la fois pour discuter des autres méthodes alternatives à la stérilisation définitive qui peuvent convenir à certaines femmes, qui ne les connaissaient pas, mais aussi pour sonder les motivations et les raisons pour lesquelles elles la demandent. Cette analyse bienveillante devrait s'accompagner aussi d'une anamnèse médicale, c'est-à-dire un questionnaire dans lequel le médecin recueille les antécédents médicaux de la patiente pour vérifier qu'aucune contre-indication médicale n'est présente. De plus, il sera nécessaire d'évaluer l'état psychologique actuel de la femme et de sa situation conjugale. Cela peut s'effectuer directement par le médecin. Mais, afin d'éviter un possible manque d'objectivité de la part d'un médecin qui ne souhaiterait pas réaliser la ligature, cette évaluation pourrait également être réalisée par un psychologue ou un psychiatre, à la demande de la femme ou du médecin. Il est vrai que cette évaluation représente une étape de plus dans le processus de stérilisation pour les femmes ayant pris leur décision depuis longtemps. Mais cette étape leur permettrait d'aborder avec le milieu médical, qui peut être hostile à leur décision, le cheminement qu'elles ont effectué pour en arriver à cette volonté de stérilisation. Les femmes expliciteront, via la narration, les valeurs, principes et intérêts qui les ont menés à cette décision, et elles permettront donc d'être perçues comme des individus à part entière avec leur propre identité et leurs propres motivations. Ces informations obtenues pourraient amener plus de médecins à accepter leur demande et leur éviter de consulter plusieurs praticiens durant plusieurs années. Ainsi, bien qu'une étape ait été rajoutée, le temps entre la demande et l'intervention s'en trouverait réduit.

L'éthique narrative permet à la personne de prendre contact avec ses intérêts, valeurs, et principes de vie qui guident la trame narrative de son existence. Par conséquent, elle est en mesure de prendre des décisions qui sont fidèles à qui elle est profondément, à ce qui fait du sens pour elle, en fonction de son identité propre. Cette évaluation permettrait également de déceler des facteurs d'ambivalence ou de risque de regrets, tels qu'évoqués précédemment. Une femme en cours de séparation ou qui semble en détresse psychique se verra de préférence orientée vers un psychologue ou un psychiatre qui pourra adéquatement la prendre en charge et analyser sa motivation à se faire ligaturer. Ainsi, des situations qui pourraient mener au regret de l'acte seront plus aisément détectées et évitées. Un autre avantage de multiplier les rencontres, que ce soit avec le médecin ou le psychologue, est le délai de réflexion qui s'offre à la femme, qui sera de préférence de quelques mois. Ce délai est très important, car il lui permet de réfléchir à la fois à ses motivations, mais aussi aux arguments exposés par le médecin, basés sur des faits empiriques et sur son expérience professionnelle, que celle-ci ne connaissait peut-être pas avant de le rencontrer. Durant ces rencontres, le professionnel soignant devra expliquer les risques et bénéfices inhérents à la stérilisation par ligature tubaire dans le but d'obtenir le consentement libre et éclairé de la femme. L'information devra

avoir été clairement donnée et la femme devra attester l'avoir reçue et comprise. Puisqu'elle vise une meilleure connaissance de soi, cette approche des consultations permet une décision éthique, fondée sur des valeurs et principes, dans le respect de l'autonomie de la femme. Elle assure aux femmes le droit de décider pour elles-mêmes de leur vie procréative, en fonction de leurs aspirations profondes, droit retrouvé et défendu dans plusieurs lignes de conduite professionnelles (10), tout en bénéficiant d'informations et de conseils donnés par le médecin qui favorise un consentement éclairé. En effet, en plus de donner son consentement, elle permet à la patiente « de prendre sa propre décision ou de participer au processus de décision » (41, p.218), comme l'évoque également Doucets (48), dans l'éthique de la narration ou encore, le Collège des Médecins du Québec (34).

Conclusion

Pour conclure, nous avons pu voir pour bien des raisons, qu'elles soient comportementales, psychologiques, sociétales, environnementales ou encore médicales, certaines femmes ne souhaitent pas avoir d'enfant. Elles désirent recourir à la ligature tubaire pour diverses raisons. Le but principal est d'éviter une grossesse non désirée qui pourrait se solder par une interruption de grossesse. Cela étant dit, la demande de stérilisation faite par de jeunes femmes de moins de 30 ans, majeures et aptes (d'autres enjeux et approches sont à entrevoir pour les femmes inaptes, sous tutelle ou curatelle), heurte les pratiques médicales et sociétales actuelles, notamment sur le « supposé » rôle de la femme de devenir mère et sur le caractère définitif et peu réversible de l'acte chirurgical. À l'autonomie de la femme vient se confronter la déontologie et le principe de non-malfaisance du médecin, pour qui le jeune âge de celle-ci et l'absence d'enfant peuvent être perçus comme des facteurs inquiétants. La peur d'un possible regret exposé par la femme après l'intervention due à un changement de situation conjugale, ou d'état d'esprit, ou encore l'apparition d'un désir d'enfant tardif font que bien des médecins leur refusent l'opération.

Mais le caractère fort et coercitif du paternalisme n'est pas souhaitable. Dans le but d'alléger cette emprise et de libéraliser les pratiques, la mise en place d'une approche basée sur l'éthique narrative serait bénéfique. Ainsi, le médecin pourrait arriver à une décision plus adaptée en ayant recours à une alliance thérapeutique, à la prise en compte de l'histoire et du cheminement de la femme, ainsi qu'en identifiant la présence de possibles facteurs de risque de regrets chez celle-ci. Cette décision serait également plus respectueuse de l'autodétermination de la femme, car elle se ferait en collaboration avec celle-ci sans pour autant que le médecin délaisse les données probantes et son expérience clinique. Le *Montreal Model* met en avant un partenariat relationnel entre la patiente et les soignants qui reprend cette approche éthique et l'opérationnalise sur le terrain. Ainsi, en appliquant ce modèle et en s'inspirant de l'approche de l'éthique narrative sur la question, il est possible de proposer des recommandations de prise en charge. Celles-ci consisteraient en des échanges, des rencontres, à la mise en place d'un délai de réflexion, à la collaboration et à l'intervention de professionnels extérieurs, notamment d'un psychologue, mais aussi à la rencontre avec des pairs-aidant ou des associations. La construction de la décision devra donc se faire dans un climat de partenariat.

Il est toutefois important de noter qu'il existe plusieurs freins à la mise en place de ce partenariat. Tout d'abord, le temps imparti ainsi que l'incapacité de certains médecins de créer ou de s'investir dans la relation avec la patiente, d'écouter, et de l'accompagner dans la prise de décision ne permettent pas toujours actuellement de favoriser un contexte et un climat dans lequel l'éthique narrative se développe et perdure. Comme le mentionne Dion-Labrie et Doucet :

Si l'histoire du patient et de ses interactions avec divers professionnels de la santé représente un élément central à la fois de la pratique médicale et de la résolution de problèmes éthiques, elle s'inscrit cependant dans un contexte plus large : celui de la pratique de la médecine contemporaine qui possède ses propres règles et qui s'inscrit dans un cadre institutionnel, voire sociétal (51, p.67).

Une réflexion serait donc à mener sur une réorganisation du système de la santé ainsi qu'à une éducation différente des personnels soignants quant à la relation de soin pour concilier au mieux ces différents paramètres. D'autre part, ce partenariat peut aussi sembler aller à l'encontre même du principe d'autonomie des femmes : si on suit ce principe, la femme seule décide. Pourtant, dans la réalité clinique, elle a besoin d'un praticien pour réaliser l'intervention et n'a pas toujours toute la connaissance sur celle-ci. Il peut bien sûr avoir des dérives de la part de soignants qui parfois refusent l'intervention dès qu'une femme pose la question, sans chercher à comprendre ses motivations, car c'est un choix auquel ils n'adhèrent pas et qu'ils n'auraient pas souhaité pour eux (10). Cependant, le risque de regrets ou les biais personnels des médecins ne sont pas des motifs valables pour refuser une stérilisation chez une femme de moins de 30 ans sans enfant, car la décision finale doit être basée sur des faits et non sur un jugement personnel (10). Il est important de noter que cet argument est recommandé par des rapports comme le Consensus canadien sur la contraception (29). Pour que son autonomie soit respectée, la femme doit pouvoir donner un consentement libre et éclairé. Et pour cela elle a besoin de l'aide d'un professionnel, qui connaît cette intervention ainsi que ses bénéfices et surtout ses risques. Ainsi, il faut travailler à réduire ces freins et favoriser une mise en applicabilité la plus éthique et juste possible d'un partenariat relationnel adapté aux demandes de stérilisation faites par des femmes de moins de 30 ans sans enfants, qui respecterait au maximum le principe d'autodétermination de celles-ci.

⁵ Mentionnons que nous nous sommes essentiellement fondées sur les écrits de Doucet, compte tenu de son rôle prédominant en tant que bioéthicien au Québec, mais d'autres auteurs, comme Paul Ricœur pour en nommer qu'un, ont également largement contribué à l'essor de l'éthique narrative (51).

Conflits d'intérêts

Aucun à déclarer

Conflicts of Interest

None to declare

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Références

- Kelly M. [Women's voluntary childlessness: a radical rejection of motherhood?](#) *WSQ Womens Stud Q* 2009;37:157–72.
- Fédération du Québec pour le planning des naissances (FQPN). [Ligature des trompes](#). 2016. (accessed April 20, 2019).
- Organization WH. *La Stérilisation féminine : guide du prestataire de services*. Genève : Organisation mondiale de la Santé; 1994.
- Marret H. [Y a-t-il un âge limite à la stérilisation volontaire féminine ?](#) *Gynécologie Obstétrique Fertil* 2013;41:1–3.
- Hoffmann P, Racinet C, Bringer S, Desmons F, Ayoubi J-M. [Déstérilisation tubaire microchirurgicale : une option efficace. Évaluation d'une série de 42 cas selon le modèle biparamétrique de Guzick](#). *Gynécologie Obstétrique Fertil* 2010;38:6–12.
- Whitwell C. [Stérilisation au féminin: le grand tabou](#). *Elle Qué* 2017. (accessed April 20, 2019).
- Mattoni A. [De la difficulté de se faire stériliser](#). *Vice.com* 2017. (accessed April 20, 2019).
- Charton L. *Le recours à la stérilisation contraceptive. Quelques considérations éthiques*. *Éthique Santé*, Strasbourg: Université Marc Bloch; 2008, p. 106–13.
- Noël R. [Ligature des trompes : Mon corps, mon choix, même si je suis jeune](#). *Ton Petit Look* n.d. (accessed April 20, 2019).
- Ehman D, Costescu D. [Tubal sterilization in women under 30: case series and ethical implications](#). *J Obstet Gynaecol Can* 2018;40:36–40.
- Gillespie R. [Childfree and feminine: understanding the gender identity of voluntarily childless women](#). *Gend Soc* 2003;17:122–36.
- Charton L, Lapierre-Adamcyk E. [Systèmes de valeurs et méthodes contraceptives : mise en perspective à partir du recours à la stérilisation contraceptive en France et au Québec](#). Communication présentée au Colloque National de l'Aidef, Québec, 25-29 août 2008.
- Institut de la Statistique du Québec. [Taux de fécondité selon le groupe d'âge de la mère, indice synthétique de fécondité et âge moyen à la maternité, Québec, 1951-2018](#) n.d. (accessed August 28, 2019).
- Institut de la Statistique du Québec. [Familles selon la structure, la présence d'enfants et l'âge des enfants, Québec, 1986-2016](#). 2018. (accessed April 20, 2019).
- Regroupement des groupes de femmes de la région de la Capitale-Nationale. [Les courants du féminisme](#) n.d. (accessed April 20, 2019).
- Gillespie R. *Voluntary childlessness in the United Kingdom*. *Reprod Health Matters* 1999;7:43–53.
- Ministère de la santé et des services sociaux. [Taux de vasectomie - Statistiques de santé et de bien être selon le sexe - Tout le Québec - Professionnels de la santé - MSSS](#) n.d. (accessed September 16, 2019).
- Fédération du Québec pour le planning des naissances. [Vasectomie](#) n.d. (accessed September 16, 2019).
- McQueen P. [Autonomy, age and sterilisation requests](#). *J Med Ethics* 2017;43:310–3.
- Agrillo C, Nelini C. [Childfree by choice: a review](#). *J Cult Geogr* 2008;25:347–63.
- Gotman A. [Le choix de ne pas avoir d'enfant, ultime libération ?](#) *Trav Genre Sociétés* 2017;37:37.

22. Richie C. [Voluntary sterilization for childfree women: understanding patient profiles, evaluating accessibility, examining legislation](#). Hasting Center Report 2013;43:36–44.
23. Detchart C. “Mes enfants, je vous aime, donc je ne vous ai pas” Les personnes sans enfant par choix à l’épreuve de la norme procréative dans le parcours vers la contraception définitive. Université Toulouse Jean Jaurès, 2017.
24. DeVellis BM, Wallston BS, Acker D. [Childfree by choice: Attitudes and adjustment of sterilized women](#). Popul Environ 1984;7:152–62.
25. Nervo P, Bawin L. [Regrets après stérilisation tubaire](#). J Gynecol Obstet Biol Reprod 2000;29:485–91.
26. Coutellier M, Lajoie D, Centre intégré de santé et de services sociaux de Chaudière-Appalaches (Québec), Direction de santé publique. Guide sur la contraception hormonale et le stérilet: guide destiné aux infirmières. Sainte-Marie: Centre intégré de santé et de services sociaux de Chaudière-Appalaches; 2015.
27. Panel P, This P. [Stérilisation tubaire : ce qui a changé](#) – Tubal sterilization: what has changed. Lett Gynécologue 2008;328–329:15–6.
28. Harrison DD, Cooke CW. [An elucidation of factors influencing physicians' willingness to perform elective female sterilization](#). Obstet Gynecol 10/88;72:565–70.
29. Black A, Guilbert E, Costescu D, Dunn S, Fisher W, Kives S, et al. [Consensus canadien sur la contraception](#) (2 e partie de 4). J Obstet Gynaecol Can 2015;37:1036–9.
30. Gillespie R. [Contextualizing voluntary childlessness within a postmodern model of reproduction: implications for health and social needs](#). Crit Soc Policy 2001;21:139–59.
31. Curtis KM, Mohlajee AP, Peterson HB. [Regret following female sterilization at a young age: a systematic review](#). Contraception 2006;73:205–10.
32. Hardy E. [Risk factors for tubal sterilization regret, detectable before surgery](#). Contraception. 1996; 54(3):159-62.
33. Leader A. Reversal of sterilization. Adv Contracept. 1989;5:213–6.
34. Collège des médecins du Québec. Le médecin et le consentement aux soins. 2018.
35. [Code de déontologie des médecins du Québec](#). 2002. Comprend la Loi médicale (L.R.Q, c. M-9, a. 3) et le Code des professions (L.R.Q, c. C-26, a 87).
36. Hippocrate. [Serment d'Hippocrate](#). 4e siècle av. J.-C.
37. Saint-Arnaud J. Repères éthiques pour les professions de la santé. Liber. 2019.
38. Pimont M. L'éthique : Fondements, Approches et Applications en santé et services sociaux. Équilibre. 2016;11:4–15.
39. Marceau E. [Les défis de l'éthicisation du droit : validité conceptuelle des lois éthiques en contexte québécois](#). Thèse de PhD, Université de Sherbrooke, 2015.
40. Mertes H. [The role of anticipated decision regret and the patient's best interest in sterilisation and medically assisted reproduction](#). J Med Ethics. 2017;43:314–8.
41. ten Have H, editor. [Encyclopedia of Global Bioethics](#). Cham: Springer International Publishing; 2016.
42. Code civil du Québec 1991. (accessed April 20, 2019).
43. Curateur Public du Québec. [Aptitude et consentement aux soins](#). n.d. (accessed August 28, 2019).
44. Gillespie R. [When no means no: disbelief, disregard and deviance as discourses of voluntary childlessness](#). Women's Studies International Forum. 2000;23:223–34.
45. Bhargava R. [Pour en finir avec l'injustice épistémique du colonialisme](#). Socio Nouv Rev Sci Soc 2013:41–75.
46. Dworkin R. Autonomy and the demented self. Milbank Q 1986;64:4.
47. Bellefleur O. [Paternalisme\(s\), biais cognitifs et politiques publiques favorables à la santé 2015 dans le cadre des Journées annuelles de santé publique-Faut-il protéger les gens contre eux-mêmes ?](#) CCNPPS, Quebec.
48. Doucet H. L'éthique clinique: pour une approche relationnelle dans les soins. Montréal: Les Presses de l'Université de Montréal; 2014.
49. Phaneuf M. [L'alliance thérapeutique comme instrument de soins](#). Prendresoin.org; 2016.
50. Pomey M-P, Flora L, Karazivan P, Dumez V, Lebel P, Vanier M-C, et al. [Le « Montreal model » : enjeux du partenariat relationnel entre patients et professionnels de la santé](#). Santé Publique. 2015;S1:41–50.
51. Dion-Labrie M, Doucet H. [Médecine narrative et éthique narrative en Amérique du Nord : perspective historique et critique](#). À la recherche d'une médecine humaniste. Éthique Santé. 2011;8:63–8.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Troutville: Where People Discuss Fairness Issues

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Résumé

Contexte. Les efforts d'engagement du public en politique de santé ont posé de nombreuses questions chargées de valeur, mais celles qui tiennent compte de la complexité et de la diversité du concept d'équité en matière de santé sont rares. Nous présentons les *Fairness Dialogues*, une nouvelle méthode pour débattre de l'équité en matière de santé auprès du grand public. Nous en fournissons les fondements théoriques et en présentons l'illustration empirique et l'évaluation qualitative. **Méthodes.** Principalement inspirés par l'érudition de la délibération, nous avons conçu les *Fairness Dialogues*, caractérisés par une délibération de groupe objective et inclusive utilisant un scénario hypothétique (la ville de Troutville) qui présente des cas soigneusement conçus, simples, ouverts et axés sur une question d'équité et de justice. Pour évaluer si les *Fairness Dialogues* encouragent la réflexion, nous avons mené une enquête qualitative en nous concentrant sur l'équité et l'iniquité des inégalités en matière d'espérance de vie. **Résultats.** Nos résultats ont révélé les intuitions complexes des gens et leur curiosité, leur patience et leur volonté de les examiner en profondeur dans le cadre d'un dialogue en petit groupe. Les intuitions partagées par les participants à notre étude sont similaires à celles présentées dans la littérature philosophique académique. **Conclusions.** Les *Fairness Dialogues* sont une méthode prometteuse pour intégrer les points de vue du public dans l'élaboration de politiques impliquant un jugement de valeur et pour développer la capacité du public à discuter de questions chargées de valeurs de manière réfléchie et inclusive.

Mots-clés

inégalité de santé, équité en santé, délibération, engagement public, valeurs

Abstract

Context. Public engagement efforts in health policy have posed many value-laden questions, yet those that appreciate the complexity and diversity of the concept of health equity are rare. We introduce the *Fairness Dialogues*, a new method for deliberating health equity among the general public. We provide its theoretical underpinning and present its empirical illustration and qualitative assessment. **Methods.** Primarily informed by the scholarship of deliberation, we designed the *Fairness Dialogues*, featured by reason-giving and inclusive group deliberation using a hypothetical scenario (the town of Troutville) that presents carefully designed, simple, open-ended cases focusing on a chosen equity and fairness issue. To assess whether the *Fairness Dialogues* encourages reflective views, we conducted a qualitative investigation by focusing on fairness and unfairness of inequalities in life expectancy. **Findings.** Our results revealed the complex intuitions that people have and their curiosity, patience, and willingness to scrutinize them in-depth through a small group dialogue. Intuitions shared by our study participants are similar to those presented in the scholarly philosophical literature. **Conclusions.** The *Fairness Dialogues* is a promising method to incorporate the public's views into policy-making involving value judgment and to develop the capacity of the public to discuss value-laden questions in a reflective and inclusive manner.

Keywords

health inequality, health equity, deliberation, public engagement, values

Introduction

The public increasingly plays an important role in health policy (1). The simple question “What do people think?” drives many public engagement efforts. Posing this question is particularly meaningful when issues relate to values, such as equity or fairness, where the “right” answers cannot be found easily or at all. Public value elicitation is important because a well-functioning health system is not only effective and efficient but is also an embodiment of social values. While public engagement efforts have posed many value-laden questions in the past, those that appreciate the complexity and diversity of the concept of health equity are rare. The consideration of equity is prominent when making policy decisions regarding priority setting, which often engages various stakeholders including the public (2). However, in priority setting discussions, equity is often a “black box” and elaboration on what equity means in a given context is relatively new (3).

A related but distinctly separate line of work explores distributional principles that people employ in allocating limited health care resources (4,5). As a classic example, in a series of questionnaires using stylized, hypothetical resource allocation scenarios, Nord (1999) uncovered the importance of concerns for severity of disease – little discussed in the scholarly literature – when the public makes resource allocation decisions (6). Largely situated within the discipline of economics, this subfield of value elicitation regarding resource allocation employs careful empirical examination of values underlying distributional principles through ongoing methodological development as to how best to elicit such values (7–10). Equity concerns in health policy go beyond the context of resource allocation, and these concerns await a similar, rich exploration. For example, what are society's responsibilities for, and its limits to, promoting healthy behaviours? How should we operationalize a well-accepted equity principle, such as “equal access for equal need” (11), across a large and diverse geographic area? For these types of equity questions, the focus has often been on people's experiences (e.g., accessing care) and not their judgment (e.g., what constitutes equitable access) (12,13).

Equity is a complex concept, which is evident from the fact that even experts working in the field have been unable to reach a single, agreed-upon definition of health inequity (14–17). Arguably, the most widely cited definition is by Whitehead, for whom health inequities are “differences in health which are not only unnecessary and avoidable but, in addition, are considered unfair and unjust” (18). This all-encompassing definition, however, is circular as it does not clarify what unfair and unjust mean (19). Despite the absence of a single, agreed-upon definition, equity is a key health policy goal endorsed by many jurisdictions (20).

Ongoing debate as to what constitutes equity or fairness might indeed be what we would expect for a complex concept upon which many health system decisions pivot. Public engagement squarely focusing on equity can add a new dimension to health policy by enriching our understanding of equity and fairness, working towards health systems that are informed by societal values, and developing capacity among the public to engage in value-related questions.

Myriad methods are available for public value elicitation on a range of topics and are applicable to the topic of equity. Primarily informed by the scholarship of deliberation (21,22), we designed the Fairness Dialogues, a method that encourages collective, thoughtful reflection about health equity among the general public. In this paper, we first situate our conceptualization of the Fairness Dialogues within the rich literature on public value elicitation on health and health care issues in order to present its theoretical underpinning. We then provide an empirical illustration of the Fairness Dialogues and its qualitative assessment.

Theoretical underpinning of the Fairness Dialogues

Why ask people?

Value-related questions are difficult, and those in the context of health and health care, such as equity or fairness, are no exception. Addressing them seriously requires going beyond gut feelings and intuitions; it demands a reflective thought process. Careful examinations do not often spontaneously take place, and even when they happen, they rarely point to the “right” answer. Answers are most often multiple, not because there is no right or wrong answer but because there are likely many right or partially right answers. Balancing these right answers is often challenging but is necessary to make policy decisions on health and health care. There are many professionals who are trained to examine these value-related issues, such as academics and policy makers. It is thus important to articulate why we should ask the public to engage in such a taxing process. The literature suggests four purposes: foundational, instrumental, process-oriented, and educational (10,23,24).

Foundational purposes. Public engagement can serve a foundational purpose, that is, enhancing our understanding of value-related issues. Precisely because value-related issues are complicated, by asking the public we might arrive at a more nuanced, layered understanding of the issues. Trained professionals who study and work in related fields often have shared assumptions and approaches, and the public’s views can provide a counterforce to offset these positions, or even highlight overlooked viewpoints in the professional discourse (10). For example, in asking people about distributional principles, Hurley and colleagues discovered a view that “everybody must get something, nobody should get nothing,” a concept not well discussed in the academic literature (4,25).

Instrumental purposes. Purposes of public engagement can be instrumental, that is, acting upon the values revealed through public engagement. When assessing many plausible values in the context of health and health care, it is not clear nor consistent whose values should take priority. The values of trained professionals are presumably well informed and cohesive, but that does not make their values more correct than those from others. Value-laden questions in health and health care can affect people profoundly through personal experiences situated within social policies and norms. It is thus important to take public values seriously and act upon them (23).

Depending on the way that one decides to act upon the public’s values, the instrumental purposes can be either direct or indirect. With *direct* instrumental purposes, public engagement can be designed to inform specific policy decisions, such as decisions related to planning, priority setting, and coverage of health services and health technologies (26–28). With *indirect* instrumental purposes, public engagement can be designed to develop a set of guiding principles related to social values to inform multiple policy decisions, such as the public dialogue sessions organized to explore a shared health care contract to inform health reform and the Citizens’ Reference Panel on Health Technologies to derive core values for health technology assessments (29,30). Arguably, the most notable example of public engagement for the indirect instrumental purpose is the Citizens’ Council in the National Institute for Health and Clinical Excellence (NICE) in the United Kingdom (31). With the premise that advice on best care must be based both on scientific and social value judgments, the NICE formed the Citizens’ Council in 2002 to inform social value judgments, i.e., “what is good for society” (32). About 30 people, largely representative of the populations of England and Wales, met to discuss a selected question for two days once a year. The questions selected were deliberately broad as the Citizens’ Council was not designed to inform individual policy decisions. Rather, public values revealed in the Citizens’ Council discussion have been incorporated in social value judgement principles that guide the NICE’s specific recommendations as well as the process and methodologies through which the NICE makes these recommendations (33,34).

Process-oriented and educational purposes. Interests in public engagement can be focused on process rather than outcomes. Daniels and Sabin argue, for example, that reasonable people can disagree about value-related questions, and, rather than trying to identify the right answer, society might make greater progress by focusing on the process through which these value-related questions are examined (24). In addition, public engagement can be considered as a means of showing respect to the public, and in so doing, can improve the legitimacy of decision-making (23,24). Thus the third purpose of public engagement is process-oriented. In a similar manner, the process of public engagement can be considered as an educational opportunity. The fourth purpose of public engagement is then educational, increasing the knowledge and capacity of the public involved in the engagement (23,24).

Public engagement on value-related questions can be designed with one or any combination of these four reasons in mind. Whatever the purpose may be, an important commonality among public value elicitation efforts is the pursuit of reflective values derived from a careful thought process.

How to ask?

The relevant literature offers a variety of methods for public engagement that aim to obtain reflective values through a careful thought process. This literature is multidisciplinary, ranging from health sciences (e.g., public health and health services research) to social sciences (e.g., sociology, political science, and economics). The methods proposed include, but are not limited to, surveys (35,36), experiments (4,37–40), focus groups (41–43), and deliberation (30,31,44,45), each of which comes with a wide range of variation (e.g., Citizens' jury, Citizens' panel/council, Deliberative Poll, and Town halls) (22,27,46). The choice of the method is often driven by the disciplinary orientation of the investigators. For example, the use of questionnaire-based experiments, focus groups, and some form of deliberation are well-accepted traditions among health economists, health researchers, and political scientists, respectively. This multidisciplinary literature with distinct disciplinary orientations hinders comparison of methods across disciplines. Yet, only through such comparison can we distinguish the available methods and identify advantages and disadvantages of using one method over another to obtain reflective values from people through a careful thought process.

Schneiderhan and Khan offer a useful framework to assist in the comparison of diverse value elicitation methods (47). These authors are interested in deliberation, more specifically, what features distinguish deliberation from other similar methods to obtain people's views. Central features of deliberation are much debated (48), yet they build on the premise of *reasons* and *inclusion* as central features. By reasons, deliberative dialogues ask participants not just to talk and offer opinions, but to provide reasons for their views. By inclusion, deliberative dialogues ask participants to listen to each other and remain open to new proposals.

To operationalize these two features in an empirically observable manner, the Schneiderhan-Khan framework considers rules of communication ("unspecified" or "reason-giving and inclusive ethic") and interactive context of communication ("communication with oneself" or "with others") (47). These considerations create four modes of public value elicitation as shown in Table 1. Schneiderhan and Khan consider Mode 4 to be a deliberation, where a person communicates with others in a group and is encouraged to provide reasons, as opposed to only opinions, in an inclusive manner. In contrast to deliberation is a discussion or "just talk" (Mode 2), where a person still communicates with others in a group, but the rules of communication are unspecified (47). When the rules of communication are unspecified and a person communicates with oneself, Schneiderhan and Khan call it a spontaneous essay (Mode 1) (47). They are ambivalent about Mode 3, as inclusive communication arguably cannot occur when a person communicates with oneself. Emphasizing the reason-giving, however, they consider Mode 3 as legitimate, an internal reflective mode.

Table 1. Modes of public value elicitation

		Interactive context of communication	
		Communicate with oneself	Communicate with others
Rules of communication	Unspecified	1	2
	Reason-giving, inclusive ethic	3	4

Source: Schneiderhan & Khan (47)

This classification can map onto some existing public value elicitation efforts in health and health care. Opinion surveys, such as one conducted by Rigby et al. (35), which asked about public support for government interventions to address income-, education- and race-related health inequalities, would be an example of the spontaneous essay (Mode 1). The aforementioned, common method among health economists to obtain people's values regarding resource allocation using questionnaire-based experiments can be considered as an internal reflective mode (Mode 3). Focus groups, common in the health sciences literature at large, are primarily structured around people's experiences and are an example of the discussion (Mode 2). Some group dialogues that emphasized reason-giving and inclusive ethic are examples of deliberation (Mode 4) (see (30,31,43)). Mapping out the diverse methods available in the literature in this way, we can begin to discuss which methods may be more suited for the purpose of eliciting values related to health and health care from the public. Because public engagement in this context seeks reflective values derived from a careful thought process, the reason-giving and inclusive ethic rules of communication are critical features. This points to the methods of either the internal reflective mode (Mode 1) or deliberation (Mode 4) rather than spontaneous essay (Mode 1) and discussion (Mode 2).

Reason-giving and inclusive dialogue (in a group or alone) rarely occurs naturally, and existing public engagement efforts employ a variety of strategies for that to take place. These strategies attempt to address potential factors that prevent reason-giving and inclusive dialogue from happening. For example, people may have a hard time thinking beyond personal experiences and circumstance. Personal anecdotes can help assist reflective thoughts, but too many anecdotes can be distracting. People may also be uninformed about the topic or informed in a particular manner without the appreciation for other perspectives. To understand the strategies to encourage reason-giving and inclusive dialogue used in the literature, it is helpful to ask: 1) Who are the participants — oneself or not oneself?; and 2) Within which context are the questions posed — hypothetical or real world? Answers to these questions classify four strategies as shown in Table 2.

Table 2. Strategies to encourage reason-giving, inclusive dialogue

		Context within which questions are posed	
		Stylized / hypothetical	Real world
Who the participants are asked to be	Oneself	1	2
	Non-self	3	4

Strategy 3 in Table 2 is rooted in the work of philosopher John Rawls (1971) and has served as a foundation for the scholarship of deliberation (47,49,50). To derive fundamental principles of justice for institutional arrangements, Rawls’s thought experiment, “the veil of ignorance” asks us to imagine being deprived of personal characteristics and social and historical contexts but having a knowledge of basic facts and functions of the society (50). Strategy 4 is a social scientist’s empirical operationalization of Rawls’s philosophical thought experiment. Some social scientists have operationalized the idea of the veil of ignorance with the “bracketing” of personal identities. Participants of the group dialogues are prompted to put aside their identities (such as race/ethnicity) in order to discuss real-world issues in group dialogues (51).

Strategy 1 is used by health economists when they elicit values from the public on resource allocation (4,7). Contrary to Strategies 3 and 4, participants are not asked to be someone else or bracket their identities, but they are asked to answer questions in highly stylized, hypothetical scenarios. The use of these scenarios can be considered as an attempt to reduce the “noise” brought by the participants that could hamper reason-giving and inclusive dialogue (with oneself, in this case). Strategy 2 is the most unrestricted among the four strategies as it instructs the participants to be themselves and discuss real-world issues. The strategy to encourage reason-giving and inclusive dialogue here is to prepare participants with sufficient, well-rounded information for the topic to be discussed. The spirit is, as often discussed in the deliberation literature, to imagine how a dialogue of *ideal* citizens would look. This strategy is used extensively in deliberations on value-related questions in health and health care, so much so that the provision of sufficient, well-rounded information is sometimes considered as a defining characteristic of deliberation (48).

The Fairness Dialogues, a deliberative group dialogue using the Troutville scenario

Informed by the literature discussed in the previous section, we designed a public value elicitation method, the Fairness Dialogues, to obtain the public’s values on equity and fairness issues in health and health care. The primary purposes of the Fairness Dialogues are foundational and educational, that is, to enhance our understanding of equity and fairness issues and to increase the capacity of the public to engage in collective, thoughtful reflection about these issues. The Fairness Dialogues has the following three features:

- The mode of public value elicitation is deliberation, where a person communicates with others in a group, and is encouraged to provide reasons in an inclusive manner (Mode 4 in Table 1).
- The strategy to encourage reason-giving, i.e., inclusive dialogue, is the use of a hypothetical scenario (Strategy 1 in Table 2), specifically, a fictional town of Troutville, a typical mid-sized town in the region where the group dialogue takes place.
- The Troutville scenario presents carefully designed, simple, open-ended cases focusing on a chosen equity and fairness issue.

The particular equity issue we chose for the first Fairness Dialogues sessions, reported in this paper, is fairness and unfairness of inequalities in life expectancy. The Troutville scenario presents inequalities in life expectancy between men and women, between poor and rich people, and between extreme sport lovers and non-extreme sport lovers (Table 3 and Appendix 1). Regardless of the comparison, life expectancy is 70 years for the unhealthy group and 80 years for the healthy group. The data are hypothetical but designed to be close to what the participants might observe in their real lives. The dialogue opened with the following question: “Is this difference or inequality in health between [the group with lower life expectancy] and [the group with higher life expectancy] unfair? Why and why not?” After the discussion on fairness judgments about these health inequalities, the question of whether Troutville should address these health inequalities follows (Table 3). The Troutville scenario further includes questions regarding health inequalities over generations, with a specific aim to obtain insights about the measurement of health inequalities (Appendix 1).

Table 3. Questions in the Troutville scenario on fairness and unfairness of health inequalities

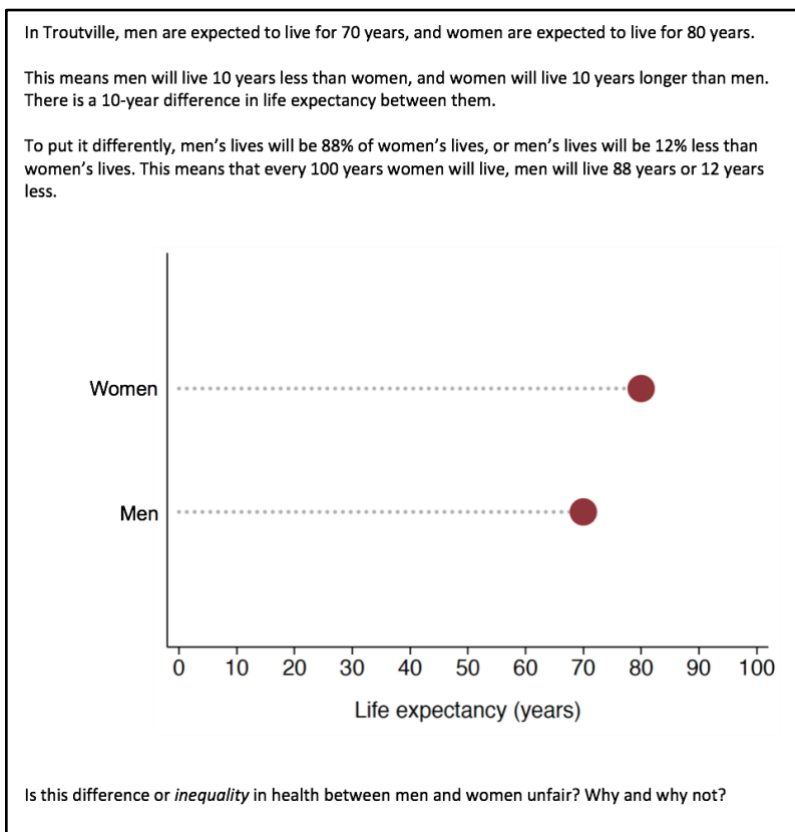
Fairness judgments
In Troutville, [the unhealthy group] are expected to live for 70 years, and [the healthy group] are expected to live for 80 years.*
<ul style="list-style-type: none"> • Is this difference or <i>inequality</i> in health between men and women unfair? Why and why not? • Is this difference or <i>inequality</i> in health between poor people and rich people unfair? Why and why not? • Is this difference or <i>inequality</i> in health between extreme sport lovers and non-extreme sport lovers unfair? Why and why not?
Roles and responsibility
<ul style="list-style-type: none"> • Should your town, Troutville, address these inequalities? Why? If so, which ones, Why? • Which inequality should Troutville address first, second, and last? Why? • Whose responsibility is it to address these inequalities? Why?

* For each inequality, the participants also received verbal and graphic explanations of the inequality (see Appendix 1 and Figure 1 for the exact explanation of the inequality).

The Troutville scenario presents the inequalities verbally, including numeric expressions, and graphically as the literature shows that different presentation modes may influence participants' thought processes and answers (Figure 1 and Appendix 1) (52). The verbal expression is informed by the risk communication literature (53,54). Verbal explanation of an inequality is particularly difficult as the same difference can be expressed absolutely (e.g., 10-year difference) and relatively (e.g., 12% less), and there are multiple ways to express relative terms (52). Our choice of words balances the cognitive burden and the importance of explicitly communicating different ways to express inequality. The use of dot charts, a particular type of graph, is informed by the literature on graph perception (55,56). Dot charts are easier to understand and more accurate than bar charts, a more common type of graph used to communicate health inequality (52).

We pilot tested the Fairness Dialogues as described here — i.e., a group dialogue using the Troutville scenario on fairness and unfairness of inequalities in life expectancy — with students at Dalhousie University, in the province of Nova Scotia (Canada). We subsequently conducted a qualitative investigation to ascertain whether the Fairness Dialogues is engaging for participants and encourages reflective views. Two specific questions were asked in the qualitative investigation: How does a small sample of Nova Scotians who participated in the group dialogues consider the fairness and unfairness of health inequalities presented in the Troutville scenario? And what do the participants think of the Fairness Dialogues as a method to engage and incite reflective views?

Figure 1. Troutville scenario – inequality in life expectancy between men and women



Empirical illustration: Qualitative investigation of the Fairness Dialogues

Methods

The empirical illustration and qualitative investigation consisted of group dialogues and telephone interviews. Specifically, we conducted two 1.5 to 2-hour group dialogues in community facilities in the fall of 2016, one in an urban setting (n = 8) and another in a rural setting (n = 6) in Nova Scotia, Canada. About one week after each group dialogue, we conducted half hour individual telephone interviews with the participants (n = 12). The group dialogues were the empirical illustration of the Fairness Dialogues, and the telephone interviews were primarily to aid the assessment of the Fairness Dialogues from participants' perspectives.

We recruited the general public in the study areas using purposeful and snowball sampling recruitment strategies. For this study, we defined the general public as persons without training and/or expertise in health and excluded persons who were currently or formerly health care professionals; academics and/or government employees whose primary focus area is/was health; or students whose primary focus area is/was health. For logistic reasons, we also excluded persons who were not residents of Nova Scotia; were younger than 19 years old; or could not read and converse effectively in English. To select

participants with as diverse personal attributes as possible for a rich group dialogue, during the screening process a research assistant asked the interested potential participants three brief questions regarding their education, home ownership, and recreational activities. This study was approved by the Dalhousie Research Ethics Board. Each participant gave written informed consent, including permission for audio-recording and anonymized quotes, and received a modest stipend for participating.

Before the start of the group dialogue, participants answered a brief sociodemographic survey. The participants were generally healthy and socio-demographically diverse (Table 4). While they mostly identified as female ($n = 11$) and never smoked ($n = 10$), on other aspects they came from diverse sociodemographic backgrounds. Most participants were either in their 20s or 30s ($n = 7$) or 60s or 70s ($n = 6$). About half had some post-secondary education or less, and another half had above that level. Household income varied greatly, spanning household income of less than \$20,000 for a family of 3 persons to that of over \$100,000 for a family of two persons. One participant rated their physical and mental health as fair, and all others rated as good, very good, or excellent.

Table 4. Participant characteristics

	Range	Most frequent category (n)
Sex	Male – female	Female (11)
Age	20s – 70s	20s (5)
Marital status	Single, married or common-law, divorces, widowed	Single (8)
Self-reported physical health	Fair – excellent	Very good (8.5*)
Self-reported mental health	Fair – excellent	Very good (5.3*)
Smoking	No – yes, currently	No (10)
Education	Less than high school – university graduate	University graduate (6)
Household income	< \$20,000 for family of 3 to \$100,000+ for family of 2	< \$20,000 for family of 1 (7)
Employment	Not employed – full time	Full time (4) / retired (4)

Full sample ($n = 14$)

*When a participant responded to two of the five response categories, 0.5 was given to each of the two categories. Similarly, when a participant responded to three of the five response categories, 0.3 was given to each of the three categories.

A research team member facilitated each group dialogue (MB or RU). The facilitator's role included an implicit emphasis on inclusivity, by paying attention to the speaking time used by individuals, and on reason-giving dialogue, through using language that encouraged dialogue and probed for meaning. The group dialogues followed the Troutville scenario as described in the previous section. This scenario was provided to each participant in the form of a booklet (Appendix 1) and projected on a screen. Both group dialogues lasted for approximately 100 minutes. In addition to the facilitator, 3-4 research team members were present at the group dialogues, including 1-2 note taker(s) (MB, EM, or RU), one content expert (YA), and one logistic support assistant (the research assistant). All but one participant from each group dialogue took part in follow-up individual telephone interviews about one week after the group dialogue the participant attended. The interviewer was a member of the research team who was not the facilitator of the group dialogue the participant attended (MB or RU). The interviewer followed an interview guide, consisting of questions regarding the participant's reflections on the content and process of the group dialogue (Table 5). Each interview lasted for about 20-30 minutes. The group dialogues and interviews were audio recorded and later transcribed. The transcripts were not returned to the participants for comments or correction.

Table 5. Interview questions

Understanding of the scenario	
(1)	Tell me if you found the scenario easy to understand. <ul style="list-style-type: none"> • [If yes] tell me how you understood it. [If no] tell me what you found difficult. • Tell me about any ideas you have to make the scenario easier to understand.
(2)	We explained life expectancies in different ways. For example, between men and women, we said [read out the script for the inequality between men and women]. <ul style="list-style-type: none"> • Did you find different explanations helpful? Which one was most helpful for you? Why? • Tell me about any ideas for explaining the scenario that may have helped you to better understand.
(3)	We showed you several graphs. Were graphs helpful for you to understand the scenario? <ul style="list-style-type: none"> • [If yes] tell me how you understood it. [If no] tell me what you found difficult.
(4)	When we presented inequalities in life expectancy between the poor and the rich at different times – we talked about now, your grandparents' time, and a long time ago – we presented two different graphs. <ul style="list-style-type: none"> • Did you find them helpful? • Tell me which one was most helpful.
The degree of engagement of the scenario	
(5)	Did you find the scenario interesting? <ul style="list-style-type: none"> • [Either yes or no] in what way? • What ideas do you have to make it more interesting to people?
(6)	Tell me how you found the focus group discussion. <ul style="list-style-type: none"> • Was it helpful? [If yes] in what way? [If no] why? • Did the focus group discussion change your view? [If yes] in what way? [If no] why? • Tell me if there was anything you wish you had discussed in the focus group discussion but did not. • Tell me if there was anything that you found difficult during the discussion. [If yes] what was it?

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- Tell me if there was anything I could have done better during the discussion as the facilitator.
- Reflective thoughts on fairness
- (7) When we were talking about the Troutville scenario during the focus group, did you think of your own experiences or real-world issues?
 - [Either yes or no] can you tell me what you were thinking about?
 - How did your thoughts impact what you said during the focus group?
 - (8) Tell me what you thought about the Troutville scenario after you left the focus group.
 - Can you give me an example of when you thought about the focus group and what you thought about?
- Format of the session
- (9) If we were to do this kind of project again and wanted to learn about people's views on health inequalities, what would be your preferred way of doing it?
 - Would you be willing to attend a focus group?
 - What are your thoughts on using surveys (online or paper-based) to do this kind of project?
- Do you have anything else you would like to talk about?
- Do you have any final questions for me before we hang up?
-

We analyzed data from the group dialogues and interviews using thematic analysis. One research team member (YA) initially coded the transcripts. The development of these codes was primarily inductive, but also informed by the literature on concepts on health inequalities and inequities and social determinants of health. In an iterative process through discussion, team members (YA, RU, and MB) revised the codes and reached consensus on coding decisions. In a similar iterative manner, the research team collectively identified the most prominent themes relating both to the content (i.e., how the study participants considered fairness and unfairness of health inequalities) and the methods (i.e., whether the Fairness Dialogues was engaging and inviting reflective views). Whenever possible, we relied on field notes and our own reflections. We managed data and coding with word-processing software and NVivo (57).

Results

We describe the findings in accordance with the two specific questions we posed for the qualitative investigation. First, we report how the study participants considered fairness and unfairness of health inequalities presented in the Troutville scenario. Specifically, we explain: 1) whether, and if so, in what way, participants considered unfair inequalities between men and women, between poor and rich people, and between extreme sport lovers and non-extreme sport lovers; 2) who participants felt was responsible for addressing these inequalities; and 3) what strategies participants used to contemplate the questions related to fairness. Second, we describe findings pertaining to the Fairness Dialogues — a deliberative group dialogue using the Troutville scenario — as a method to engage and invite reflective views.

Considerations for fairness and unfairness of health inequalities presented in the Troutville scenario

Fairness judgments regarding health inequalities

For each of the three inequalities (i.e., men vs. women, poor vs. rich people, and extreme sport lovers vs. non-extreme sport lovers) participants presented and examined arguments considering them as unfair or fair. Below we describe key arguments discussed in the group dialogues.

Inequality between men and women: Some participants considered it fair because they saw inevitability — *“It’s always been like that”* (Participant R5) — or they thought men’s shorter life expectancy was due to choices men made. Other participants considered the primary reason for men’s shorter life expectancy to be fundamentally social in nature: that is, it is not the result of men’s choosing but rather of social expectations for men to be breadwinners, take risks, and not seek help, hence, the inequality is unfair. Yet, other participants thought men’s shorter life expectancy is unfair simply because men do not live as long as women do and it is unfair for women to be left behind because *“you’ve got 10 years that you’ve got to do everything that used to be done by two people”* (Participant R2).

Inequality between poor and rich people: The primary view of most participants was that it is unfair because the inequality is socially constructed through differences in finances, resources, and connections that have compounding effects. They noted that poor people are often provided less opportunity than rich people, often from an early onset. They considered this inequality as addressable, as one participant stated, *“I think it’s a little bit more unfair than the...male and female thing because other people can help you...out if you’re poor. Like they can help change that outcome”* (Participant U8). Still, some participants contemplated opposing views. One participant argued that being rich is not the fault of rich people, who have worked hard to be rich; therefore, the inequality for rich people is deserving. Highlighting health damaging behaviour among poor people that may have contributed to their shorter life expectancy, another participant argued that engaging in such behaviour is human nature and everybody, no matter socioeconomic circumstances, should accept the resulting shorter life expectancy.

Inequality in life expectancy between extreme sport lovers and non-extreme sport lovers: The prevailing view was that it is fair because extreme sport lovers made a choice to engage in risky sports: *“Because it’s up to them if they want to take these sports”* (Participant U7). This argument served as an anchor with which the discussion started and to which it repeatedly went back. Some participants presented counterarguments that questioned the definitive judgment. One participant stated, *“Well, presumably someone engaging in extreme sports is engaging in sports and conditioning themselves to operate better”*

physically. And is punished for it (Participant U2). Participants also acknowledged that extreme sport lovers can inspire people while *“non-extreme sports lovers sit on a couch and watch TV and drink pop and eat chips”* (Participant U6).

Amenability: Even when the participants were mostly content with particular views presented, as a group they attempted to articulate those views further and examine them by testing with potential analogies and overlooked assumptions. For example, when discussing inequality in life expectancy between men and women, amenability emerged as a key concept to distinguish fairness and unfairness. To examine what may be and may not be amenable, the participants contrasted “natural” factors such as biology or genetics from social factors. In both group dialogues, there was a strong consensus to consider inequality in life expectancy caused by natural factors as not amenable, and thus, fair. Reflecting on changing gender roles in society over time, they further wondered about the amenability of social norms. For example, one participant argued that even social norms are amenable, stating: *“We talk about sociological factors like it’s a machine that’s operating the way machines are supposed to operate. But we choose our culture collectively and imperfectly”* (Participant U2).

Assumptions: Participants frequently assessed overlooked assumptions when discussing inequalities in life expectancy between poor and rich people and between extreme sport lovers and non-extreme sport lovers, cases for which they had, at least initially, easier fairness judgments than for the sex case. For example, while agreeing that inequality by income is unfair, one participant pondered whether inequality is inherently objectionable, using humour and an image: *“Now, maybe all the trout in Troutville are the same. For all I know, maybe all the people in Troutville look like trouts and are all the same”* (Participant U2). Some participants wondered what they were assuming when they were thinking about extreme sport lovers. By comparing to potentially analogous cases, such as smoking, illicit drug use, and obesity, some participants thought extreme sport lovers may have *“addiction to risk”* in much the same way as some people have *“addiction to food”* (Participant U1), and they were then hesitant to label addiction to risk as choice. Another participant thought that risk-taking of extreme sport lovers may be contributing to their mental health and wondered if the group made too quick a judgment to consider the shorter life expectancy of extreme sport lovers as their choice, and thus, fair.

Good health: Throughout the discussion regarding fairness and unfairness of the three types of health inequalities, participants repeatedly examined what good health actually is. They agreed that health is more than life years, as the scenario presented, and that quality of life is equally important. For example, while discussing inequality in life expectancy between men and women, one participant asked, *“But also fairness, I would look at it in terms of quality. What if a man lives 70 years but has a much better life than a woman?”* (Participant U6). They also underscored the importance of diversity among people and their circumstances, even when they share a common characteristic such as being male, poor or engaging in extreme sports. As one participant vividly expressed, *“You see so many different shades of differences”* (Participant R2). Participants also distinguished what is expected and what has actually happened (i.e., not everyone will live as long as the life expectancies presented in the scenario).

Roles and responsibilities to address health inequalities

On the question of who should be responsible for addressing the three types of health inequalities presented, the simple answer from the participants is *“everyone”* (Participant R1). They pointed to the responsibility of government, but at the same time, they thought everybody should be responsible because *“we are the government”* (Participant R2). In addition, participants wanted men, poor people, and extreme sport lovers to be responsible as well, not to blame them for what they did or did not do, but to respect their agency. One participant stated, for example, *“We’re all old enough that we make our own choice”* (Participant U7). Income-related health inequality was overwhelmingly supported as the priority among the three types of inequalities presented. Participants referred to it as *“the base”* (Participant U1) and considered it as *“more direct”* and its effect likely *“very immediate”* (Participant R3) than the other two. One group discussed as promising strategies identifying an underlying principle for all three types of inequalities that may be addressed all at once; for example, the access to certain forms of opportunity or identifying an optimal group to address all inequalities such as children.

Strategies to contemplate questions related to fairness

Participants, individually and collectively, employed various strategies to answer the questions in the scenario. Many of them often relied upon something tangible to them, for example, experiences of their own or their family and close friends or stories they have heard or read. Some used elaborate imagination to personalize the presented cases or attempt to immerse themselves in the shoes of affected people in the scenario (e.g., poor people) and think through how they would feel in Troutville. The use of real-world anecdotes and imagination went back and forth fluidly within individuals and as a group. In fact, in both groups, when real-world anecdotes predominated, there was always someone who initiated a balancing act by saying, *“in Troutville...”* In addition, participants often used their understanding of multiple determinants of health to contextualize the questions asked. They thought about the questions in the context of psychosocial determinants of health, for example, discussing complex relationships between income, occupation, geography, food security, gender, stress, and coping mechanisms and their effects on physical and mental health.

Another strategy that participants often used was to contrast with health care, i.e., they frequently compared the cases presented on inequalities in life expectancy to inequalities in access to or use of health care. For example, participants had the following exchange:

And are you saying then that the Troutville community hospital should deny treatment to the people who are smoking? (Participant U2)

No. No, it's unfair. It's unfair if they do that. Like it's not...it's dehumanizing. You know what I mean? It's not right of Troutville to do that because they smoked or they did drugs, or they did this, or they're rich or they're poor, or they did rock climbing. They should treat all people alike. (Participant U7)

Furthermore, both groups implicitly identified what we might call base assessments of fairness where a clear judgment could be made, such as considerations for children and the principle of “*all people should be treated with respect*” (Participant U6). When discussion became difficult, the groups resorted to these base assessments to clarify their core arguments.

Fairness Dialogues as a method to engage and invite reflective views

The discussion that took place, as described in the previous section, demonstrated that the Fairness Dialogues — a deliberative dialogue among several people with diverse backgrounds using a hypothetical scenario — used a method wherein participants explored in-depth the idea of fairness pertaining to health. Views expressed during the follow-up individual telephone interviews corroborated the high level of engagement we observed during the group dialogues. A general consensus among participants was that the scenario was easy to understand and verbal, numerical, and graphic expressions of inequalities were helpful to assist their understanding. For the most part, participants appreciated both absolute and relative numerical expressions of health inequality and used both to form their views. They understood the absolute expression (i.e., in life years) more clearly than the relative expression (i.e., in percentile), and while most saw the point of presenting both, a minority thought the relative expression redundant or unnecessary.

While it was common for participants to want further information about the hypothetical town of Troutville, such as its geographic location and sociodemographic composition, most found the use of a hypothetical town interesting. Some participants endorsed it wholeheartedly, for example, stating, “*...it really resonated with me...it was easy to kind of try to slip into that mindset*” (Interviewee R3). One participant thought the use of a hypothetical town limited the role of personal stories, and in turn, helped the discussion stay focused: “*And I thought that that made the focus group much more interesting, much more thought provoking and much more really asking...trying to answer the questions that you were asking*” (Interviewee U6). Many participants reported they had used personal experiences and real-world events as anchors from which to imagine Troutville.

Participants often said that they liked learning about different viewpoints and attributed that to group dialogue among a small number of people with different backgrounds — “*...it was an unusual mixture. I mean I think it was a good mixture*” (Interviewee R2). They thought good facilitation was also critical for the quality of discussion, corroborating our observation of the important active listener role that the facilitators played by implicitly emphasizing inclusivity and reason-giving dialogues, through reassurance, encouragement, and probes (e.g., “*Why do you say so?*”), yet never bringing new viewpoints not discussed by participants. While most participants thought the group dialogue was inclusive, some encouraged further consideration for allocation of speaking time. The discussion resonated with many participants, evident from some of them recalling details of the discussion and adding further thoughts during the interviews and/or reporting that they had talked to their family, friends, and co-workers about the scenario after participating in the group dialogue. Although a minority, a few reported the participation in the group dialogue changed their views. For example,

I guess it's just like I said, even though...I've always been interested in social justice and fairness, I never really sat down and thought, like, what exactly is fair. You know, like how can we define it? Why do I think this is unfair and why do I think this fair? And I just kind of really had to think afterwards about that. Like I'll be honest, I still don't even really have it settled. I'm still kind of going back and forth (Interviewee R3).

Most participants found participation in the Fairness Dialogues worthwhile. One participant stated, for example, “*Well, I wanted to keep the discussion going, and I tried to talk about it with a lot of people*” (Interviewee U5).

Discussion

In this paper, we introduced the Fairness Dialogues, a method to elicit the public's views on equity and fairness issues in health and health care, featured by reason-giving and inclusive group deliberation using a hypothetical scenario (Troutville) that presents carefully designed, simple, open-ended cases. Our qualitative investigation using questions of fairness and unfairness of health inequalities revealed complex intuitions that people have and their curiosity, patience, and willingness to scrutinize them in-depth through a small group dialogue. The simplicity of the Troutville scenario should not be confused with superficial discussion. The richness of the discussions and the high level of engagement we observed during the group dialogues are corroborated by the participants' own reflections on the process. Taken together, this demonstrates the merits of the Fairness Dialogues as a theoretically grounded empirical method.

The intuitions that our study participants shared are similar to those presented in the scholarly philosophical literature. For example, in both group dialogues, responsibility, choice, and amenability are key concepts that emerged while examining inequalities in life expectancy between men and women, between poor and rich people, and between extreme sport lovers

and non-extreme sport lovers. Responsibility is a key concept with which participants assessed whether the inequality in question was fair (because someone was responsible for it) or unfair (because someone was not responsible for it). The concept of responsibility was, in their minds, tightly connected to the concept of personal choice. At the same time, they were keenly aware that personal choices only apply to matters amenable to the choices, for example, if life expectancy is entirely determined biologically and genetically, then, there is nothing to make choices for men to extend life expectancy. In addition, they fully acknowledged that personal choices are conditional upon available opportunities. This line of reasoning mirrors closely the equity perspective often referred to as equal opportunity for health or luck egalitarianism (14). The struggle of our participants to articulate what is amenable (e.g., “nature” vs. social factors) and what is personal choice is in fact the core of the extensive discussion in the view of equal opportunity for health, that is, drawing the line between “legitimate” and “illegitimate” factors that distinguish responsibility (58). Furthermore, participants’ views on treating people equally in health care regardless of the choices they made have been discussed extensively in the scholarly literature as a harsh implication of the view of equal opportunity for health if applied literally to health care (14,59). Moreover, the consideration for available opportunities within which choices were made resonates strongly with feminist ethics (60).

Participants did not develop a theory from their intuitions, and the Fairness Dialogues was not designed to encourage collective identification of a coherent view at the end of the group dialogue. What our analysis tells us is that the views expressed in this study are reflective values that came from the participants’ own exploration with minimal scholarly guidance; values explored and discussed were what the participants have sought by themselves rather than being given to them. A ground-up approach to discuss value-laden questions such as those related to fairness is of paramount importance in two ways. First, the values obtained can help us understand what the public think (10). Second, this process is in itself beneficial as a means for education and capacity development. Post-dialogue interviews of some participants indicated that the group dialogue was the beginning of a new or reinforced thought process for them, hinting that the Fairness Dialogues might not only capture “values out there” but might also contribute to participants discovering and forming values. These two aspects correspond to two of the four purposes of public engagement discussed earlier: foundational and educational. As the public is increasingly called upon for many aspects of health and health care – such as delivery, financing, organization, research, and policy – it is critical to assist them to enable the best possible participation.

The use of the Fairness Dialogues for the instrumental purpose merits further exploration. As discussed earlier, public engagement can be designed to inform either specific policy decisions (direct) or the identification of core values or principles that can inform multiple policy decisions (indirect). Given the use of a hypothetical scenario, the Fairness Dialogues is logically better suited to *indirect* instrumental purposes. As the first empirical application of the Fairness Dialogues idea, our focus was on whether this method of engagement can encourage reason-giving and inclusive dialogues, rather than to determine what policy context the values revealed in the group dialogues might apply. Hence, at this stage, it is unclear whether, and if so, in what way, the Fairness Dialogues can serve indirect instrumental purposes. It would be useful to determine what gains the Fairness Dialogues brings compared to existing public engagement methods. NICE Citizens’ Council, for example, asked broad questions for indirect instrumental purposes, such as: *What are the societal values that need to be considered when making decisions about trade-offs between equity and efficiency?* (report 17, 2014); *Should NICE and its advisory bodies take into account the severity of a disease when making decisions?* (report 10, 2008); and *Is there a preference to save the life of people in imminent danger of dying?* (report 6, 2006) (www.nice.org.uk/get-involved/citizens-council). It would be informative to examine whether the answers would be different, and if so, in what way, if the same questions were set in a hypothetical town, like Troutville. One of the critiques to the NICE Citizens’ Council was that people’s real views can only be revealed in a specific, concrete context and, by asking broad questions, the Citizens’ Council was likely unable to reveal the public’s views (61). Future work needs to examine if a similar critique applies to the use of the Troutville scenario.

With the promising results from the empirical illustration and its qualitative assessment, there is still much more work to be done to further develop the Fairness Dialogues. Specifically, in need of rigorous examination are the aspects of the Fairness Dialogues that may have contributed to value elicitation. For example, both the participants themselves and the research team took note of the potential contribution that diverse backgrounds among participants may have played to the quality of the discussion. We did not analyze participants’ views in relation to their characteristics, but in their study exploring lay persons’ values on health inequalities in the United States, Blacksher and colleagues found socioeconomic clustering of participants’ preferences regarding how to address health inequalities (62). It will be important to examine if this applies to the Fairness Dialogues and to understand in what ways diversity might contribute to the dynamics of the discussion and the exploration of new perspectives and values. In addition, both the participants and the research team identified inclusivity as an important factor for the quality of discussion. Inclusivity was an implicit emphasis in this study, for example, through the attentive facilitators and considerations for others among the participants. Furthermore, the emphasis on reason-giving dialogue relied primarily on the setup of the Troutville scenario supported by the facilitator’s implicit role. These aspects of inclusivity and reason-giving dialogue could be developed as an explicit ground rule, as some have tried (47). In sum, what is needed is the articulation of essential features of the Fairness Dialogues. To do so, further contextualization and comparison of the Fairness Dialogues to existing comparable work would be beneficial. For example, this could take the form of a randomized trial of public deliberation methods to determine whether, in fact, longer deliberative processes are more likely to result in greater knowledge acquisition and changes in perspectives among participants (45). The Fairness Dialogues uses a short deliberative process, and it would also be important to examine if a longer process would enhance the quality of the discussion we observed. With cautious optimism, the results from our qualitative investigation indicate the promise of the Fairness Dialogues as a method to incorporate the public’s views into policymaking involving value judgment.

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None to declare

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References

1. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. [Patient and family engagement: A framework for understanding the elements and developing interventions and policies](#). Health Aff. 2013;32(2):223–31.
2. Mitton C, Smith N, Peacock S, Evoy B, Abelson J. [Public participation in health care priority setting: A scoping review](#). Health Policy. 2009;91:219–28.
3. Norheim OF, Baltussen R, Johri M, Chisholm D, Nord E, Brock DW, et al. [Guidance on priority setting in health care \(GPS-Health\): The inclusion of equity criteria not captured by cost-effectiveness analysis](#). Cost Eff Resour Alloc. 2014;12(18). doi: 10.1186/1478-7547-12-18
4. Hurley J, Buckley NJ, Cuff K, Giacomini M, Cameron D. [Judgments regarding the fair division of goods: The impact of verbal versus quantitative descriptions of alternative divisions](#). Soc Choice Welfare. 2011;37(2):341–72.
5. Rowen D, Brazier J, Mukuria C, Keetharuth A, Hole AR, Tsuchiya A, et al. [Eliciting societal preferences for weighting QALYs for burden of illness and end of life](#). Med Decis Mak. 2016;36(2):210–22.
6. Nord E. Cost-value analysis in health care: Making sense of QALYs. Cambridge: Cambridge University Press; 1999. 157 p.
7. Cookson R, Ali S, Tsuchiya A, Asaria M. [E-learning and health inequality aversion: A questionnaire experiment](#). Health Econ. 2018;27(11):1754–71.

8. Ali S, Tsuchiya A, Asaria M, Cookson R. [How robust are value judgements of health inequality aversion? Testing for framing and cognitive effects](#). *Med Decis Mak.* 2017;37(6):635–46.
9. Clark MD, Determann D, Petrou S, Moro D, de Bekker-Grob EW. [Discrete choice experiments in health economics: A review of the literature](#). *Pharmacoeconomics.* 2014;32(9):883–902.
10. Gaertner W, Schokkaert E. *Emperical social choice: Questionnaire-experimental studies on distributive justice*. 1st ed. New York: Cambridge University Press; 2012. 215 p.
11. Oliver A, Mossialos E. [Equity of access to health care: Outlining the foundations for action](#). *J Epidemiol Community Health.* 2004;58(8):655–8.
12. Osborn R, Squires D, Doty MM, Sarnak DO, Schneider EC. [In new study of eleven countries, US adults still struggle with access to and affordability of health care](#). *Health Aff.* 2016;35(12):2327–36.
13. Waibel S, Henao D, Aller M-B, Vargas I, Vazquez M-L. [What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies](#). *Int J Qual Heal Care.* 2011;24(1):39–48.
14. Segall S. *Health, luck and justice*. 1st ed. Princeton: Princeton University Press; 2010. 239 p.
15. Ruger JP. *Health and social justice*. 1st ed. Oxford: Oxford University Press; 2010. 276 p.
16. Braveman P. [Health disparities and health equity: Concepts and measurement](#). *Annu Rev Public Health.* 2006;27(1):167–94.
17. Norheim OF, Asada Y. [The ideal of equal health revisited: Definitions and measures of inequity in health should be better integrated with theories of distributive justice](#). *Int J Equity Health.* 2009;8(40).
18. Whitehead M. [The concepts and principles of equity and health: A fair chance for all](#). *Health Promot Int.* 1991;6(3):217–28.
19. Daniels N. *Just health: Metting health needs fairly*. New York: Cambridge University Press; 2008. 408 p.
20. World Health Organization. *Rio Political Declaration on Social Determinants of Health*. Rio de Janeiro; 2011.
21. Abelson J, Forest P, Eyles J, Smith P, Martin E, Gauvin F. [Deliberations about deliberative methods: issues in the design and evaluation of public participation processes](#). *Soc Sci Med.* 2003;57:239–51.
22. Carman K, Herringa J, Heil S, Garfinkel S, Windham A, Gilmore D, et al. *The use of public deliberation in eliciting public input: Findings from a literature review*. Rockville: Agency for Healthcare Research and Quality; 2013.
23. Abelson J, Giacomini M, Lehoux P, Gauvin FP. [Bringing “the public” into health technology assessment and coverage policy decisions: From principles to practice](#). *Health Policy.* 2007;82(1):37–50.
24. Daniels N, Sabin JE. *Setting limits fairly: Can we learn to share medical resources?* 1st ed. Oxford: Oxford University Press; 2002. 191p.
25. Giacomini M, Hurley J, Dejean D. [Fair reckoning: A qualitative investigation of responses to an economic health resource allocation survey](#). *Heal Expect.* 2012;17(2):174–85.
26. Abelson J, Blacksher EA, Li KK, Boesveld SE, Goold SD. [Public deliberation in health policy and bioethics: Mapping an emerging, interdisciplinary field](#). *J Public Delib.* 2013;9(1):1–35.
27. Street J, Duszynski K, Krawczyk S, Braunack-Mayer A. [The use of citizens' juries in health policy decision-making: A systematic review](#). *Soc Sci Med.* 2014;109:1–9.
28. Degeling C, Carter SM, Rychetnik L. [Which public and why deliberate? - A scoping review of public deliberation in public health and health policy research](#). *Soc Sci Med.* 2015;131:114–21.
29. Maxwell J, Rosell S, Forest P. [Giving citizens a voice in healthcare policy in Canada](#). *BMJ.* 2003;1031–3.
30. Bombard Y, Abelson J, Simeonov D, Gauvin FP. [Eliciting ethical and social values in health technology assessment: A participatory approach](#). *Soc Sci Med.* 2011;73(1):135–44.
31. Littlejohns P, Rawlins MD. *Patients, the public and priorities in healthcare*. Oxford: Radcliffe Publishing; 2009.
32. Rawlins MD, Culyer AJ. [National Institute for Clinical Excellence and its value judgments](#). *BMJ.* 2004;329(7459):224–7.
33. National Institute for Health and Clinical Excellence. *Social value judgements - Principles for the development of NICE guidelines*. 2nd ed. 2006. 36 p.
34. Shah KK, Cookson R, Culyer AJ, Littlejohns P. [NICE's social value judgements about equity in health and health care](#). *Heal Econ Policy Law.* 2013;8(2):145–65.
35. Rigby E, Soss J, Booske BC, Rohan AMK, Robert SA. [Public responses to health disparities: How group cues influence support for government intervention](#). *Soc Sci Q.* 2009;90(5):1321–40.
36. Booske BC, Robert SA, Rohan AM. [Awareness of racial and socioeconomic health disparities in the United States: The National Opinion Survey on Health and Health Disparities, 2008-2009](#). *Prev Chronic Dis.* 2011;8(4):1–9.
37. Amiel Y, Cowell FA. *Thinking about inequality: Personal judgment and income distributions*. 1st ed. Cambridge: Cambridge University Press; 1999. 181 p.
38. Devooght K. [Measuring inequality by counting “complaints”: Theory and empirics](#). *Econ Philos.* 2003;19(2):241–63.
39. Leibler JH, Zwack LM, Levy JI. [Agreement with inequality axioms and perceptions of inequality among environmental justice and risk assessment professionals](#). *Heal Risk Soc.* 2009;11(1):55–69.
40. Rigby E, Lynch J. *Who Cares if the Bucket Leaks ? Efficiency Concerns and Support for Redistributive Policy among the American Public*. 2013;
41. Blacksher E, Rigby E, Espey C. [Public values, health inequality, and alternative notions of a “fair” response](#). *J Health Polit Policy Law.* 2010;35(6):889–920.
42. Cookson R, Dolan P. [Public views on health care rationing: a group discussion study](#). *Health Policy.* 1999;49:63–74.
43. Lundell H, Niederdeppe J, Clarke C. *Public views about health causation, attributions of responsibility, and inequality*. *J Health Commun.* 2013;18(9):1116–30.

44. Goold SD, Biddle AK, Hall CN, Danis M. [Choosing healthplans all together: A deliberative exercise for allocating limited health care resources](#). *J Health Polit Policy Law*. 2005;30(4):653-601.
45. Carman KL, Mallery C, Maurer M, Wang G, Garfinkel S, Yang M, et al. [Effectiveness of public deliberation methods for gathering input on issues in healthcare: Results from a randomized trial](#). *Soc Sci Med*. 2015;133:11–20.
46. Degeling C, Carter SM, Rychetnik L. [Which public and why deliberate? - A scoping review of public deliberation in public health and health policy research](#). *Soc Sci Med*. 2015;131:114–21.
47. Schneiderhan E, Khan S. [Reasons and inclusion: The foundation of deliberation](#). *Sociol Theory*. 2008;26(1):1–24.
48. Blacksher EA, Diebel A, Forest PG, Goold SD, Abelson J. [What is public deliberation?](#) *Hastings Cent Rep*. 2012;42(2):14–6.
49. Fishkin JS. *When the people speak: Deliberative democracy and public consultation*. 1st ed. New York: Oxford University Press; 2009. 256 p.
50. Rawls J. *A theory of justice*. 1st ed. Cambridge: Harvard University Press; 1971. 607 p.
51. Schneiderhan E, Khan S, Elrick J. [Deliberation and ethnicity](#). *Sociol Forum*. 2014;29(4):791–807.
52. Asada Y, Abel H, Skedgel C, Warner G. [On effective graphic communication of health inequality: Considerations for health policy researchers](#). *Milbank Q*. 2017;95(4):801–35.
53. Zipkin DA, Umscheid CA, Keating NL, Allen E, Aung K, Beyth R, et al. [Evidence-based risk communication: A systematic review](#). *Ann Intern Med*. 2014;161(4):270–80.
54. Lipkus IM, Peters E. [Understanding the role of numeracy in health: proposed theoretical framework and practical insights](#). 2009;36:1065–81.
55. Kosslyn SM. *Graph design for the eye and mind*. 1st ed. New York: Oxford University Press; 2006. 290 p.
56. Cleveland WS. *The elements of graphing data*. 1st ed. Monterey: Wadsworth Advanced Books and Software; 1985. 323 p.
57. QSR International Pty Ltd. NVivo (Mac) qualitative data analysis software. 2015.
58. Fleurbaey M, Schokkaert E. [Unfair inequalities in health and health care](#). *J Health Econ*. 2009;28:73–90.
59. Cappelen AW, Norheim OF. [Responsibility in health care: A liberal egalitarian approach](#). *J Med Ethics*. 2005;31(8):476–80.
60. Sherwin S. *The politics of women's health: Exploring agency and autonomy*. 1st ed. Philadelphia: Temple University Press; 1998. 321 p.
61. Daniels N. *Accountability for reasonableness and the citizens council*. In: Littlejohns P, Rawlins MD, editors. *Patients, the public, and priorities in healthcare*. 1st ed. Oxford: Radcliffe Publishing; 2009. p. 139–47.
62. Blacksher E, Rigby E, Espey C. [Public Values, Health Inequality, and Alternative Notions of a "Fair" Response](#). *J Health Polit Policy Law*. 2010;35(6):889-920

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Legal Governance in HTA: Environment, Health and Safety Issues / Ethical, Legal and Social Issues (EHSI/ELSI), the Ongoing Debate

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Résumé

Nous voulons mieux comprendre les lois circonscrivant le rôle social de l'Évaluation des technologies en santé (ETS) et les raisons empêchant l'inclusion de l'éthique en ETS. Nous avons ciblé un débat qui est au cœur du rôle perçu du droit réglementaire dans le développement de technologies en santé: l'opposition entre les enjeux environnementaux, sécuritaires et sanitaires (EHSI) et les enjeux éthiques, légaux et sociaux (ELSI), issus de la gouvernance technologique. La collecte de données est basée sur une revue de la littérature issue de travaux antérieurs, et sur une analyse de cas où trois agences d'ETS ont été sélectionnées en utilisant différentes catégories d'obligation légale selon leur degré de force contraignante. La revue de littérature a révélé cinq thèmes relatifs au rôle social de l'ETS et une distinction entre le rôle/utilisation du droit dur et du droit souple dans le droit réglementaire, permettant ainsi de comprendre comment les agences ont utilisé le droit pour intégrer (ou non) l'éthique en ETS. Les deux approches ont démontré que le débat, EHSI/ELSI observé initialement dans la gouvernance et l'évaluation de technologies est reproduit en ETS. La principale tendance confirmée par ces analyses est la présence d'un pacte entre la science et le droit réglementaire. La demande sociale d'intégrer les ELSI, particulièrement l'évaluation éthique en ETS, n'est pas prise en compte par le droit réglementaire traditionnel régissant l'ETS et doit plutôt être considérée par le droit souple. Les difficultés d'intégration de l'éthique en ETS démontrent la nécessité de repenser la gouvernance juridique de l'ETS.

Mots-clés

gouvernance, rôle social, évaluation des technologies en santé, éthique

Abstract

This paper aims to provide a better understanding of the law circumscribing the social role of Health Technology Assessment (HTA) and gain insight into the reasons challenging the inclusion of ethics into HTA. We focused on a debate at the core of the perceived role of regulatory law in health technology development, namely: Environment, Health and Safety Issues (EHSI) vs Ethical, Legal and Social Issues (ELSI) that arose in technology governance. Data collection was based on a literature review and a case study analysis. The former was founded on previous work. Three HTA agencies were selected for the latter using categories ranging from a greater to a lesser level of legal obligatory intensity. Our literature review revealed five different themes relating to the social role of HTA and a distinction between the role/use of "hard law" and "soft law" in regulatory law, thus providing an understanding of how agencies used law for handling ethics in HTA. Both approaches revealed that the debate, first observed in the EHSI/ELSI technology-governance and assessment, is reproduced in HTA. The main trend revealed by the literature review and the case study, is the presence of a pact between science and regulatory law. The social demand for integrating ELSI, and more precisely, ethical evaluation into HTA, is not the main preoccupation of the traditional legal frameworks governing HTA and remains to be considered primarily by alternative, soft law initiatives. The reported difficulties in integrating ethics into HTA demonstrate the need for rethinking legal governance in HTA.

Keywords

gouvernance, social role, health technology assessment, ethics

Introduction

Traditionally, the regulatory system of law has been exclusively concerned with health and safety issues in technological assessment but, over time, environmental issues came to be included in any conventional technology evaluation in what is now referred to as Environmental, Health and Safety Issues (EHSI). With genetic research's impact on modified organisms and gene therapy, the integration of Ethical, Legal and Social Issues (ELSI) have also come to the forefront of the technological assessment field, involving a complex exercise operationalized either by reference to an integrated framework (1) or to a responsible innovation procedure (2). Over the last decade, the EHSI/ELSI debate prevailing in technological assessment has migrated into the Health Technology Assessment (HTA) field. According to the World Health Organisation, "Health technology assessment (HTA) refers to the systematic evaluation of properties, effects, and/or impacts of health technology. It is a multidisciplinary process that summarises information about the medical, social, economic and ethical issues related to the use of a health technology in a systematic, transparent, unbiased, robust manner. The main purpose of conducting an assessment is to inform a policy decision making" (3). Based on this definition, we can conclude that both EHSI and ELSI analysis are required in HTA and are necessary in order to best inform decision makers. However, in HTA agencies' everyday practice, such dual analysis is not easily achieved, since this directly effects their social role.

In 2003, INHATA published the results of a survey conducted amongst its members, providing them with data on how ethics is being integrated into HTA (4). This initiated a report and recommendations from INAHTA's Working Group in Ethics on how best to handle ethical issues in HTA. Since the publication of this report in 2005, the pros and cons of integrating ethics into HTA have been at the centre of many initiatives and debates in the literature. For instance, EUnetHTA sought to develop its HTA Core model (5), integrating chapters (domains) on Ethical, Legal and Social Issues (ELSI) in order to address this topic. Recent studies, under the leadership of Assasi, have also charted what they term barriers and facilitators for the integration of ethics into HTA (6,7). As shown in Table 3B of Assasi et al's 2015 study (7), 38.5% of respondents insisted on the enhancement of existing guidelines and frameworks to promote more ethics in HTA while 57.7% mentioned that a clear demand from policy makers would be a way to facilitate the integration of ethics into HTA. As noted by some authors (8–10), the different ways in which HTA agencies interpret and fulfill their mandates contributes to limit and restrain a coherent

integration of ethics into HTA. More precisely, demands for scientific assessments by decision makers seem often to preclude a more extensive and complete technology appraisal within the process. What has been referred to as Parliamentary Technology Assessment (PTA), whereby ethical inquiry is left to political forces and enshrined in regulatory or political priorities, is a way to frame what should be the scope and focus of HTA. In this context, the question raised is: should ethical analysis be limited to PTA and thus excluded from agency's concrete HTA or should it also be the task of HTA professionals? (11,12)

This paper aims to clarify how the EHSI/ELSI distinction in regulatory law has migrated into HTA and structures the debate on the integration of ethics in HTA. Since this distinction rests on the scope of the legal constitutive statutes of HTA agencies and their official mandates, analysis of these constitutive laws should show how well ELS issues are considered. However, even if ELS issues are not clearly mentioned in the official mandates of agencies, the integration of ethical considerations in HTA practices have emerged in the field but have not been subjected to clear analysis to this date. A prerequisite step for setting the debate in regulatory law is required to fully understand the migration of the EHSI/ELSI debate in HTA (part 1). An analysis of the HTA literature can then identify what specific issues in the general debate on legal governance are raised (part 2). Finally, a case study of three HTA agencies' constitutive laws (hard law) and practices (soft law) highlights different ways in which HTA agencies integrate ethics (part 3).

EHSI/ELSI debate in legal governance (regulatory law)

Many countries have created agencies to protect their citizens from harm coming from different foods, drugs and dangerous products, as well as protecting the environment from damaging pollutants and biohazards. These agencies have the power to regulate the production and distribution of substances in different ways. Their decisions are supported by laws and regulations and they can impose sanctions upon noncompliant individuals or companies. Regulatory law's concerns are limited to the impacts of these products and processes on EHSI and the agencies' decisions must be legitimized at two levels: the degree of harm that can justify public constraints and the degree of proof that warrants the decision. This is where the hard sciences play a major role in the legitimization of the agencies' decision. How can science accomplish this role if not through its access to truth, thus providing truth to power? (13) The so called "objectivity of science" based on its access to the laws of nature (14) can justify the agencies' focus. If we adopt this view, risk assessment is exclusively science-based (14) and completely independent of risk management. Risk management is another process that takes risk assessment into account and introduces economists' cost-benefit analyses in final decisions with respect to risk hazards.

Many social factors can explain why this conception of regulatory science has been criticized. In our view (1), the governance crisis relating to genetically modified organisms (GMO) that has risen within the European Community, in some nations of the Americas (the United States, Canada, Mexico, Brazil and Argentina) as well as in other countries such as Australia, India and New Zealand, clearly shows the limitation encountered by scientific investigation when it comes to risk management. The difference in perspectives lies in the answer given to two basic questions emerging from the regulatory agencies: the degree of harm that can justify public constraints and the degree of proof that warrants a decision. Risk analysis rests essentially on the framing of what is considered as health, safety or environmental risks. To identify such EHS risks, some concepts and objects such as "fine particulate matter", "maximum tolerated doses" (13) and in particular with GMOs, "substantial equivalence", must be defined. But they cannot be defined by science alone because risk perception rests on other key contextual, psycho-social and cultural dimensions. Furthermore, one may wonder, should only short-term risk or both short-term and long-term risk be considered? Does one examine the toxicity of the agent by itself or should other synergetic aspects also be taken into consideration? Moreover, the debate over the level of evidence needed to warrant a decision depends on: i) how many risk factors an agency is willing to expose its population to, ii) how much scientific evidence is needed for decision-making, and iii) how scientific evidence can draw the line between *ignorance* (not knowing what will occur), *uncertainty* (knowing what will occur without knowledge of the probabilities) and *some degree of certainty* (knowing what will occur and the probability of its occurrence) (15).

Debates in the fields of biotechnology and nanotechnology have highlighted other limitations of the regulatory process, namely that there exist other effects of these technologies which are not accounted for in regulatory law. These include those that affect the way persons live individually and collectively, and more precisely: their quality of life, their privacy, their rights and freedoms, their jobs, and their "living togetherness". These effects are all gathered under the heading of ELSI. In regulatory law, they are not considered as a basis for constraints but are relevant to the social dynamics between producers and consumers. Therefore, these effects should be taken into consideration by technology producers in order to guarantee trust and acceptance of novel technological developments. ELSI are thus left in the hands of stakeholders. Here, different Social Sciences and Humanities studies are mobilized to understand risk perception, risk communication, social engagement practises, etc., in order to help technology developers to respond to the possible barriers of technologies' social acceptance. In other words, regulatory law is concerned exclusively with environmental, health and safety risks, while stakeholders remain responsible for the other ELSI impacts of technological developments. Therefore, when stakeholders define their corporate responsibility in relation to their products and processes and when they publicize written pledges relating to corporate social responsibility in order to reassure citizens, their social engagement is viewed as a form of law referred to as "soft law". According to Trubek, Cottrell and Nance, "soft law is a very general term, and has been used to refer to a variety of processes. The only common feature between these processes is that while all have normative content they are not formally binding" (16). As Snyder puts it, soft law can be defined as "rules of conduct which in principle have no legally binding force but which nevertheless may have practical effects" (17), such as financial, administrative or social consequences. In this context, what

this expression denotes contrasts sharply with “hard law”, which refers to traditional statutory laws and regulations that entail a legal binding force. Hard law “can be characterized as command and control, court based dispute resolution, uniform rules, punitive sanctions, and court challenges for noncompliance” (18).

The EHSI/ELSI debate lies primarily on the scope of legal governance, but it also relies on the power of science to deliver truth to a given authority in order to legitimize its decisions. This debate has highlighted several limitations with respect to truth delivery by science. Its first limitation relates to the means for obtaining truths: epistemology. It gives rise to the following questions: Can science really capture truths in the laws of nature? Are empirical sciences only based on quantifiable data? Can qualitative research also provide valid information for decision-making? The second limitation relates to the fact that the scientific methodologies applied in risk analysis are value-laden. The choice of outcome measures and comparators such as in the concept of “substantial equivalence”, for example, are grounded in values (19). The third limitation refers to the intrinsic validity of scientific research and the way scientific proof, in itself, is enough to legitimize agencies’ decisions, despite what is ignored and what is uncertain (20).

At the governance level, the exclusion of ELSI in regulatory law can be criticized on two grounds. The first is the lack of justification for limiting scientific inquiry to only EHSI, even when it clearly encompasses broader effects on people’s lives and more globally, on society itself. This is why an approach integrating all impacts of scientific innovations (whether positive or negative) on Environmental, Ethical, Economical, Legal and Social issues (E₃LS) was introduced in the contexts of genomic research funding (21), governance in nanotechnologies (22) and regulation of nanomedicine (23) in Canada. The second ground for critique is the democratic deficit resulting from a “post-war social contract” (10) between science and regulatory law, where risk acceptability is wrongfully considered as a scientific fact and not as a value-laden process. Yet, pressure to include citizens’ point of view has made its way through different initiatives (e.g., citizen conferences and public debates), each time, trying, albeit with difficulty, to include ELSI in regulatory law (24).

The EHSI/ELSI debate in legal governance raises different issues. Those supporting this distinction claim that: i) the scope of regulatory law is to protect against important harms; ii) the role of scientific proofs is the fundamental guide to regulatory decisions; and iii) appraisal of scientific proofs and other outcomes should rest in political decision making. In contrast, opponents to this distinction claim that: i) the scope of regulatory law should not only focus on limiting harm; ii) relying on scientific proofs alone is not enough given scientific uncertainty on numerous issues; iii) scientific methods used in decision making processes remain value-laden; and iv) priority given to the scientific community in regulation impairs democracy.

Methodology

Data collection was based on two methodological approaches: a literature review and a case study analysis. The literature review was based on results of our systematic review on the integration of ethics into HTA (25). In this systematic review, an analytical qualitative approach known as the general inductive method (26) was used to select relevant quotes from eligible articles. A subset of quotes referring to the integration of ethics into HTA was then extracted in order to identify similarities between the obstacles inherent to ethical integration into HTA and the EHSI/ELSI dichotomy. Keywords relating to “ethics in” and “ethics of” (HTA) were defined and used in the process.

Since the strategies and procedures of HTA agencies can vary because of their national settings and, more precisely, the legal conventions defining their mandates, we decided to undertake a case study originally focussing on four different HTA agencies in order to help highlight different approaches of the integration of ELSI into HTA. To this end, a conducive selection of agencies based on our geographical and cultural specificities was performed. Since our research project is based on the particular context prevailing in the Province of Québec, Canada, the first agencies chosen were the Institut national d’excellence en santé et services sociaux (INESSS) and the Canadian Agency for Drugs and Technology in Health (CADTH). Moreover, in order to adequately capture the duality of cultures (French and English) on which the Province of Québec takes roots, the French Haute Autorité de Santé (HAS) and the United Kingdom National Institute for Health and Care Excellence (NICE) were also selected for this study.

In order to categorize the normative documents emerging from these agencies, we built upon the 2013 annual study of the French ‘Conseil d’État’ (27). Legal governance was then divided into three categories, each of them ranging from a greater to a lesser level of legal obligatory intensity:

1. Traditional *hard law*: fully obligatory and constraining (i.e., the HTA agencies’ constitutive statutory laws)
2. *Soft law integrated in hard law*: included normative instruments that can either be employed as auxiliary means to complement regulations (used by legislators) or be used to interpret hard law normative documents (used by judges) (e.g., legal recognition of ethical codes)
3. *Soft law*: without being explicitly recognized by traditional hard law, *soft law* includes non-obligatory and non-constraining normative instruments aiming to orient the human conduct and behaviours (e.g., ethical charters, codes of conduct, etc.)

This categorization allowed us to review, in different contexts, whether traditional *hard law* or *soft law integrated in hard law* defines the HTA agencies' mandate and also, whether these agencies based their decisions solely on EHS issues (EHSI) leaving it to *soft law* to address ELS issues (ELSI).

Results

Literature review

Table 1 shows that the EHSI/ELSI distinction (theme a) is a specific indication of the challenge of integrating ELSI in HTA. ELSI is generally an add-on to the HTA process (viewed as a separate chapter of the HTA report or a separate part or process of HTA). Since a typical HTA assessment is evidence-based, findings on clinical effectiveness, health and safety for patients, and cost analysis are central and there is little doubt that the EHSI/ELSI debate is reproduced in the HTA context.

Table 1. The EHSI/ELSI distinction debate in HTA literature converges on five different themes

Distinction	Comment	References
Theme a) <i>EHSI/ELSI</i>	Integrating ELSI in HTA: as an add-on to the real thing.	Ali-Khan et al., 2015 (28); Potter et al., 2008 (29); Potter et al., 2009 (30); Hofmann et al., 2014 (12).
Theme b) <i>Assessment/Appraisal</i>	The aim of HTA variables: assessment / appraisal; synthesize knowledge / make recommendations	Ten Have, 2004 (31); Refolo et al., 2016 (10); Hanvoravongchai, 2008, (32); Lysdahl et al., 2016 (33); Martin et al., 2011 (34); Sandmann et Heintz, 2014 (35); Burls et al., 2011 (36); Hofmann, 2008, (37).
Theme c) <i>Fact/Value dichotomy</i>	Epistemological reasons explaining the resistance of integrating non testable data into HTA.	Refolo et al., 2016 (10); Hofmann al., 2014 (12); Hofmann, 2005 (38); Rawlins, 2014 (39); Assasi et al., 2015 (7); Reuzel et al., 1999, (40).
Theme d) <i>Neutral/Value-laden</i>	The HTA process is neutral as a scientific unbiased process / Value judgments are part of the assessment process.	Grunwald, 2004 (41); Sacchini et al., 2010, (42); Hofmann al., 2014 (12); (Ten Have, 2004 (43); Ashcroft, 1999 (44); Hofmann, 2005 (38); Saarni et al., 2008 (45); Saarni et al., 2011 (46); Duthie & Bond, 2011 (47); Reuzel et al., 2004 (48); Burls et al., 2011 (36); Hofmann et al., 2015 (49); Hofmann, 2008 (37); Oortwijn et al. 2004 (11); Abelson et al., 2007 (50); Autti-Rämö & Mäkelä, 2007 (51).
Theme e) <i>Patient/citizen's involvement</i>	Participation of patients / citizens in acceptability discussions of a technology.	Culyer, 2016 (52); Daniels & Van Der Wilt, 2016 (53); Gagnon et al., 2012 (54); Kleme et al., 2014 (55); Grunwald, 2004 (41); McMillan et al., 2006 (56); Martin et al., 2011 (34); Rawlins, 2014 (39); Abelson et al., 2013 (50); Bombard et al., 2011 (8); Arellano et al., 2011 (57); Assasi et al., 2014 (6); Facey et al., 2017 (58).

The EHSI/ELSI debate on the social role of HTA is reflected in the dichotomy between assessment and appraisal (Table 1, theme b). Even if the difference of national settings is recognized as a cultural factor defining the mandate of HTA agencies, the debate is focussed on the nature of HTA reports. For some agencies, the reports should only be centred on knowledge synthesis, stating that the evidence be based on its findings (31). Other agencies (34) suggest a two phase report: the first being an assessment followed by another consisting in an appraisal. In HTA reports, the assessment basically covers clinical effectiveness and safety. This clinical review of scientific literature on the health technology or intervention assesses the scientific proof related to the clinical effects on health and security. The economic evaluation of the technology, which is also based on a quantitative scientific approach, establishes its cost/effectiveness. Implementing a health technology or intervention has other impacts on the hospital organisation or healthcare services for the population, on the quality of life of patients, and also triggers ethical and legal issues. Analysis of these is conducted in the appraisal phase, where contextual studies are undertaken and explicit recommendations are made in the reports. In other words, assessment covers EHS issues while appraisal covers ELS issues.

The EHSI/ELSI debate takes a notable turn in HTA when the barriers concerning the integration of ethics in this process are considered as a fundamental epistemological distinction between facts and values (Table 1, theme c) (7). Since traditional HTA has been linked to the capability of science to demonstrate according to levels of evidence, ethical considerations could only be integrated in its reports if the results produced were testable or verifiable (10). Emerging from discussions on patients' involvement, the integration of the findings that were not evidence-based also align with the role allocated to qualitative studies included in HTA (58).

The value-ladenness of HTA (Table 1, theme d) raises questions about the role of science in regulatory law, especially the link between risk assessment and risk management. The main question being: is risk assessment value free? When risk assessment is not considered related to the decision-making process, it seems value free. But since the aim of HTA is to guide and ground governmental decisions, there is an essential link between risk assessment and risk management, because risk assessment is part of the decision-making process. The HTA process is therefore considered value laden because it aims to guide the choice of the best alternative which in turn implies a value judgment as to which alternative is best. The value-ladenness of the decision process in HTA, from the initial scoping phase to the final report, has been explicitly addressed (22-24). Furthermore, methodological decisions in effectiveness, safety and cost analysis have also been found to be value-laden (25-26).

The democratic deficit recognized in the EHSI/ELSI debate is imbedded in the value-ladenness of assessments (Table 1, themes d and e). Can the scientific values entrenched in assessments justify the acceptability of risks and benefits for patients and citizens? Citizen's forums, public participation, and national debates have been proposed to cope with such democratic deficit. In HTA, this concern has been addressed through particular involvement of patients and citizens in the HTA processes referred to, in this field, as participatory approaches (58).

Case study

As previously stated, four HTA agencies were originally selected for our case study: Haute Autorité de Santé/HAS (France), National Institute for Health and Care Excellence/NICE (United Kingdom), Canadian Agency for Drugs and Technologies in Health/CADTH (Canada) and Institut national d'excellence en santé et services sociaux/INESSS (Québec, Canada). Since CADTH does not have a constitutive statutory law, it was ultimately excluded from the case study; so only three agencies were compared. In our investigation to identify how ethics is being mobilized in different HTA contexts, we performed an analysis of the legal, administrative and procedural documents relating to the existence and assessment processes of these three agencies. This analysis was conducted by taking into consideration: i) the normative strength of the documents associated with the categories of *hard law* or *soft law*, ii) the definition of the agencies' social role expressed in legal constitutive documents, and iii) the integration of ethics in the agencies' mandates and actions. We also made the distinction between "ethics of" and "ethics in" HTA in our case study analysis. The examination of these formulations brought additional light to how those two expressions are used in the literature (5,38,44,59). Indeed, we found that, throughout our case study, the expression "ethics of" HTA referred to how ethics is being mobilised to govern the process or the agencies' functioning *per se* (e.g., management of conflicts of interests, objectivity standards, transparency, equity requirements, etc.). As for the expression "ethics in" HTA, it refers specifically to the ethical dimension needed for assessment and appraisal activities.

INESSS

The Québec *Institut national d'excellence en santé et services sociaux* (INESSS) was created in 2011 through a binding constitutive law: the *Act respecting the Institut national d'excellence en santé et en services sociaux* (60). Such an act represents traditional hard law and defines the agency's mandate in its Sections 4 and 5. Ethics were first mobilised through hard law in reference to the agencies' values and the unfolding of its mission. Referring to excellence, independence, openness, scientific rigor, transparency, integrity and equity, Section 4 of the INESSS act defines the conduct that should be expected of stakeholders involved in HTA activities. Sections 5 and 10 of the INESSS act (7) refer to the requirement for public involvement in the agency's consultations and scientific activities. Such use of ethics in framing the agencies' practices, deontology and stakeholder conduct is best described as the "ethics of" HTA. It differs from "ethics in" HTA which refers to the social role of HTA and how ELSI have made their way into the actual appraisal of health technologies.

In relation to "ethics in" HTA, the INESSS act not only focusses on the assessment of the health technologies' impact on EHSI but it also explicitly integrates ELSI in its overall mission, through singular and unique effort, using hard law, in order to ensure a definite role for ethics in assessment activities (Section 6, *in fine*, INESSS act). Thus, in addition to the traditional concerns on EHSI, the core regulatory mandate of the Québec agency in charge of HTA has included the integration of ELSI in its assessment activities. To this end, the act explicitly refers to an ethical framework that has to be drafted and published and lay out principles guiding the assessment and appraisal of scientific evaluations, and for stakeholders to explain the reasons behind their recommendations and practice guides. In this sense, for INESSS, hard law seems to play an important role in the integration of ELSI into HTA.

As we look closer, we realise that despite clear constraining obligations emerging from regulatory law, INESSS and its stakeholders have, so far, fallen short on delivering and putting into place the prescribed ethical framework. Indeed, despite Section 6 of the INESSS constitutive act, it appears that no ethical framework has been adopted or published to this date. However, recent work on an ethical framework based on Accountability for Reasonableness (A4R), presented at the HTAi annual meeting in 2018, proposes a multicriteria analysis including ethics and patient involvement. In the soft law initiatives produced by INESSS, we found some reference to ethics but no ethical framework *per se*. In fact, INESSS published two codes of ethics (one for the agencies' leaders and one for external experts) and some rules governing its scientific committee actions on drug evaluation (61-63). In those soft law documents, INESSS refers to values that should be at the heart of the agency's and committees' mission ("ethics of" HTA). It also refers directly to the need for its scientific committee to respect the ethical framework prescribed by hard law (Sections 4 and 7, INESSS act). Moreover, in some of its best-practice documents regarding the consultation of stakeholders and on practice guidelines, the agency recognises, albeit in very general terms, the importance

of the inclusion of ELSI for fulfilling its mandate. For example, referring to ethical issues emerging from HTA practices (64) or by including ethical issues in the scientific and contextual data collected for an HTA (65).

Even if hard law seems to play a central role in the integration of ethics in the general mandate of INESSS, it has not yet been translated in a defined and concrete role for ELSI in HTA. EHSI thus remains the main focus of HTA despite some clear legal intentions to the contrary.

HAS

The French *Haute Autorité de Santé* (HAS) is an independent public scientific authority, created through the French Social Security Code (66), and has two distinct missions: 1) assessment and recommendation, 2) accreditation and certification (articles L161-37- L161-40 & R161-71 to R161-78-18). The constitutive act of HAS, referred herein as its Code (*hard law*), requires that when establishing and publicising recommendations and medico-economic positions on efficient prevention, care or prescription strategies, HAS should take into consideration the respect of ethical principles. The Code, however, places the focus of HTA activities on EHSI, privileging mainly clinical, economic and scientific data for fulfilling the agency's missions. In this sense, *hard law* defines the HAS mandate as based solely on EHSI.

Looking outside the realm of *hard law* into the agency's documents and procedures, an ethics Charter establishes ethical obligations for stakeholders involved in HAS' mission (67). Again, this refers to "ethics of" HTA and does not shed light on the role of "ethics in" HTA. Another HAS document, a methodological guide for the assessment of ethical aspects (68), gives an interesting take on the inclusion of ELSI into HTA through *soft law*. This guide is not prescribed by *hard law* but is offered as a *soft law* initiative coming from HAS itself in order to help public decision-making through better information on ethical issues arising from health interventions targeted towards decision-makers and stakeholders (p. 5 of this guide). This guide uses descriptive ethics and principlism in a very specific way and is intended for specific situations where controversial aspects of the technologies are addressed and where value conflicts are anticipated. It proposes an ethical analysis by which the ethical debate in society is compared to an ethical evaluation that would imply using value judgments in its appraisal. The proposed standardised approach in reference to ethics includes many interesting elements on the social role and mission of HAS aimed at public decision-making. However, in order to help solve value conflicts and facilitate complex decisions, it remains limited to issues that are deemed important with regards to challengeable elements of some given medical technologies. It does not propose a method that would allow highlighting of every ethical issue that could arise from any given health technology in defined health care settings (p. 12 of this guide). One example of this restrictive use of ethics is that some methodological approaches involved in medical, economic and public health choices are not being subjected to any ethical assessment because they are deemed scientifically sound and efficient (p. 9 of this guide).

Thus, this guide proposes a descriptive ethics approach, but it does not provide a thorough inclusion of ELSI into HTA. Ethics is mobilised separately, on the fringe of an assessment process that remains independent. It is not questioned by ethical analysis.

NICE

In 2012, the UK Health and Social Care (HSC) act legally recognised the National Institute for Health and Care Excellence (NICE) but left the details of the agency's mission and functioning to be included in a Charter framed and governed by regulations (s. 232 & 242, HSC act). In 2013, these NICE regulations were adopted and prescribed the publication of a NICE Charter in order to provide guidance on procedures and consultations in carrying out NICE's mission. NICE regulations s. 3 (*hard law*) and NICE Charter s. 19 & principles on social value judgement section 3.2 (*soft law*) also prescribe the inclusion of some form of "ethics of" HTA by requesting that the agency publish some procedures for dealing with its members' conflicts of interest and refers to mandatory independence and transparency of stakeholders as well as procedural principles to follow.

Moreover, the Charter further adopted by NICE (69) represents *soft law integrated in hard law*. With regards to "ethics in" HTA, the Charter indicates that NICE should ensure that value judgments made in relation to recommendations and decisions do in fact reflect the values of the UK society. It establishes a Citizens Council to inform the agency of the public's point of view (Section 21). The aim of this 30 member Council is therefore to provide a broad public perspective on overarching moral and ethical issues that should be taken into consideration in the agency's decisions and recommendations. In addition, a Guide was produced to address the social value judgments that should be made in the process of developing NICE recommendations in the context of HTA, especially when NICE has to make choices on effectiveness and cost-effectiveness (61). This Guide builds on reports and recommendations from a Citizens Council and also refers to, among other things, the four principles of bioethics, different theories of justice and fundamental rights/values (e.g., non-discrimination and equality), that are all relevant to healthcare decision-making. This *soft law* initiative outlines the need to include ELSI in NICE's HTA methodology without targeting it to specific appraisals. In a way, it represents some sort of inclusion of ELSI in the field of HTA without applying it systematically throughout the HTA process.

Discussion

The case study clearly demonstrates that the social role of HTA varies according to the legal agencies' mandates involved and thus confirms that within two of the three agencies studied, the ultimate goal defined by law is scientific assessment. It is only in the legal mandate of INESSS that there is a requirement for making an ethical evaluation in the actual HTA process. This

prerequisite is clearly linked to the requirements of appraisals and recommendations, and for the need to give reasons to support final decisions. In contrast, the legal mandates of HAS and NICE clearly confirm the post-war social contract between science and governance in regulatory law whereby science, by its assessments, speaks the truth to decision-makers.

The need for taking ELSI into account in regulatory law is fulfilled differently by the different agencies analysed. In fact, the “ethics of” HTA matters for the three agencies studied and each has voiced the importance of excellence, independence, openness, scientific rigor and transparency. This contrasts with the “ethics in” HTA statements, which are handled quite differently. In one agency (NICE), ELSI are addressed by a general discussion between citizens. Although this solves the democratic deficit problem, such an approach does not have a direct impact on the actual assessment part of HTA. HAS proposes a different approach supported with an optional ethical evaluation guide that focusses on the diversity of ethical arguments applicable to the technology being assessed. Such evaluation remains an add-on to the assessment. INESSS’ statutory law requires the integration of an ethical evaluation in the HTA process, but this requirement has not yet been fulfilled and is an indication of the difficulty of integrating ethical evaluation in the usual HTA process.

The approach of these agencies towards the fact/value dichotomy and the value-ladenness of the HTA process stems from their stand on assessment and appraisal. The NICE approach takes the social values that are expressed by the Citizens Council into account and considers that the scientific assessment of HTA should thus integrate the social values identified in its final goal. Since HAS has proposed a guide for ethical evaluation of HTA, it has also specified that the value-ladenness found in assessments should not be the object of the ethical evaluation. Therefore, the approach of science speaking the truth to power is not open to debate. What distinguishes the INESSS approach is that it is clearly oriented towards being discursive, aiming to justify the best decisions in a given context. The value-ladenness of all decisions made in the HTA process should therefore be clearly spelled out.

The democratic deficit identified in the criticism of the pact between science and regulatory law is addressed directly by the Citizens Council of NICE, and also, to a different extent, through the general public’s involvement in INESSS’ consultations and scientific activities, while HAS does not have such requirements. Nevertheless, there is much discussion in the literature on the necessity of patient involvement in the HTA process and on the different local initiatives that have been put into place to fulfill this need. However, a tension remains between taking patients’ perspectives as data for assessment or as resources to be considered for ethical evaluation and appraisal.

Conclusion

Our review of literature and our case study clearly show that the debate between EHSI/ELSI observed in technological assessment is essentially reproduced in HTA. In the literature studied, the five main themes of this debate are replicated: EHSI/ELSI distinction, assessment/appraisal, fact/value dichotomy, neutrality/value-ladenness and democratic deficit. The case study indicates that the main trend still remains the pact between science and regulatory law. Our results demonstrate that, through their existing practices, these three agencies seem to circumscribe their social role further than their constitutive laws. They also show that the social demand for integrating ELSI, and more precisely that of ethical evaluation into HTA, are accounted for primarily through soft law. In one instance, hard law redefines the social role of HTA by integrating EHSI/ELSI in the requirement for appraisal and in the reasons for grounding recommendations. This highlights the importance of the role of social actors in the context of regulatory law, and in defining, structuring and operationalizing the integration of ELSI into HTA. Nevertheless, without a clear political re-examination of the HTA agencies’ statutes that proposes the integration of both ELSI and EHSI into HTA, ethical evaluation will remain essentially an add-on to the evaluative process.

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Conflicts of Interest

One of the peer-reviewers, Isabelle Ganache, is Director of the Methodologies and Ethics Office at the National Institute of Excellence in Health and Social Services (INESSS), and she assists HTA colleagues with integrating ethics into their evaluations.

Responsabilités des évaluateurs externes

Les recommandations des évaluateurs externes sont prises en considération de façon sérieuse par les éditeurs et les auteurs dans la préparation des manuscrits pour publication. Toutefois, être nommé comme évaluateur n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de la [Revue canadienne de bioéthique](#) assument la responsabilité entière de l'acceptation finale et de la publication d'un article.

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References

1. Patenaude J, Legault G-A, Bernier L, Beauvais J, Béland J-P, Boissy P, et al. [Framework for the analysis of nanotechnologies' impacts and ethical acceptability: basis of an interdisciplinary approach to assessing novel technologies](#). *Sci Eng Ethics*. 2015;21(2):293–315.
2. Legault GA, Verchères C, Patenaude J. [Support for the development of technological innovations: promoting responsible social uses](#). *Sci Eng Ethics*. 2018;24:529–49.
3. WHO. Health Technology Assessment. 2019.
4. International Network of Agencies for Health Technology Assessment. [Results of the survey on Ethical Issues among INAHTA organizations](#). 2003.
5. European Network for Health Technology Assessment (EUnetHTA). [Joint Action 2, Work Package 8: HTA Core Model](#), v.3. 2016.
6. Assasi N, Schwartz L, Tarride JE, Campbell K, Goeree R. [Methodological guidance documents for evaluation of ethical considerations in health technology assessment: a systematic review](#). *Expert Rev Pharmacoecon Outcomes Res*. 2014;14(2):203–20.
7. Assasi N, Schwartz L, Tarride JE, O'Reilly D, Goeree R. [Barriers and facilitators influencing ethical evaluation in health technology assessment](#). *Int J Technol Assess Health Care*. 2015;31(3):113–23.
8. Bombard Y, Abelson J, Simeonov D, Gauvin F-P. [Eliciting ethical and social values in health technology assessment: A participatory approach](#). *Soc Sci Med*. 2011;73:135–44.
9. Daniels N, Porteny T, Urrutia J. [Expanded HTA: enhancing fairness and legitimacy](#). *Int J Heal Policy Manag*. 2016;5(1):1–3.
10. Refolo P, Sacchini D, Brereton L, Gerhardus A, Hofmann B, Lysdahl KB, et al. [Why is it so difficult to integrate ethics in health technology assessment \(HTA\)? The epistemological viewpoint](#). *Eur Rev Med Pharmacol Sci*. 2016;20(20):4202–8.
11. Oortwijn W, Reuzel R, Decker M. Introduction. *Poiesis Prax*. 2004;2(s 2-3):97–101.
12. Hofmann B, Cleemput I, Bond K, Kronen T, Droste S, Sacchini D, et al. [Revealing and acknowledging value judgments in health technology assessment](#). *Int J Technol Assess Health Care*. 2014;30(6):579–86.

13. Jasanoff S. [Technologies of humility: citizen participation in governing science](#). *Minerva*. 2003;41(3):223–44.
14. Jasanoff S. *Designs on Nature: Science and Democracy in Europe and the United States*. Mercer County, New Jersey: Princeton University Press; 2005.
15. Scott D. [Framing and responding to scientific uncertainties: biofuels and synthetic biology at the convention on biological diversity](#). *Jurimetrics J*. 2016;56:245–60.
16. Trubek DM, Cottrel MP, Nance M. [“Soft law,” “hard law,” and European integration: toward a theory of hybridity](#). *Univ Wisconsin Leg Stud Res Pap*. 2005;1002:43 p.
17. Snyder F. *Soft law and institutional practice in the European Community*. In: Martin S, editor. *The Construction of Europe*. Dordrecht: Springer; 1994.
18. Trubek LG. [New governance and soft law in health care reform](#). *Indiana Health Law Rev*. 2006;3(1):137.
19. Legault G-A, K-Bédard S, Béland J-P, Bellemare CA, Bernier L, Dagenais P, et al. *Eliciting value-judgments in health technology assessment*. *Int J Technol Assess Health Care*. 2019; Submitted.
20. Knudsen GR. [Where's the beef? how science informs GMO regulation and litigation](#). *Ida Law Rev*. 2012;48:225–50.
21. Genome Canada. [Introducing Canada's GE3LS projects](#).... GE3LS. 2002.
22. Patenaude J, Legault GA, Tapin D. *Nano engineering: ethical issues and social governance*. In: Dolez P, editor. *Nano Engineering: Global Approaches to Health and Safety Issues*. Amsterdam: Elsevier; 2014. p. 305–37.
23. Patenaude J, Legault GA. *A Proposal for an E3LS (ethical, environmental, economic, legal and social) approach to the regulation of nanomedicine*. *Bioética saude, Pesqui Educ Brazilia, Cons Fed Med Soc Bras Bioética*. 2014;2(77):100.
24. Daniel CÉ, Legault GA, Bernier L. [La régulation des nanotechnologies, le débat national français et le dialogue social : nanomonde, grandes attentes normatives?](#) *Lex Electron*. 2015;20(1):93–123.
25. Bellemare CA, Dagenais P, Bédard SK, Béland JP, Bernier L, Daniel CÉ, et al. [Ethics in health technology assessment: a systematic review](#). *Int J Technol Assess Health Care* [Internet]. 2018;34(5):447–57.
26. Thomas DR. [A General Inductive Approach for Analyzing Qualitative Evaluation Data](#). *Am J Eval*. 2006;27(2):237–46.
27. France. *Conseil d'Etat. Etude annuelle 2013 du Conseil d'Etat - Le droit souple*. Paris, France; 2013.
28. Ali-Khan SE, Black L, Palmour N, Hallett MT, Avard D. [A systematic review of english language health technology assessments of gene expression profiling tests for breast cancer prognosis](#). *Int J Technol Assess Health Care*. 2015;31(1–2):1–15.
29. Potter BK, Avard D, Graham ID, Entwistle VA, Caulfield TA, Chakraborty P, et al. [Guidance for considering ethical, legal, and social issues in health technology assessment: Application to genetic screening](#). *Int J Technol Assess Health Care*. 2008 Oct 1 [cited 2017 Jul 4];24(04):412–22.
30. Potter BK, Avard D, Entwistle V, Kennedy C, Chakraborty P, McGuire M, et al. [Ethical, legal, and social issues in health technology assessment for prenatal/preconceptional and newborn screening: a workshop report](#). *Public Health Genomics*. 2009;12(1):4–10.
31. ten Have H. [Ethical perspectives on health technology assessment](#). *Int J Technol Assess Health Care*. 2004;20(1):71–6.
32. Hanvoravongchai P. [Health system and equity perspectives in health technology assessment](#). *J Med Assoc Thai*. 2008;91 Suppl 2.
33. Lysdahl KB, Oortwijn W, van der Wilt GJ, Refolo P, Sacchini D, Mozygamba K, et al. [Ethical analysis in HTA of complex health interventions](#). *BMC Med Ethics*. 2016;17(1):16.
34. Martin C, Williams-Jones B, de Ortúzar MG. [Ethical Health Technology Assessment in Latin America: Lessons from Canada and Argentina](#). *Acta Bioeth*. 2011;17(2):225–36.
35. Sandman L, Heintz E. [Assessment vs. appraisal of ethical aspects of health technology assessment: can the distinction be upheld?](#) *GMS Health Technol Assess*. 2014;10:Doc05.
36. Burls A, Caron L, Cleret de Langavant G, Dondorp W, Harstall C, Pathak-Sen E, et al. [Tackling ethical issues in health technology assessment: a proposed framework](#). *Int J Technol Assess Health Care*. 2011;27(3):230–7.
37. Hofmann BM. [Why ethics should be part of health technology assessment](#). *Int J Technol Assess Health Care*. 2008;24(4):423–9.
38. Hofmann B. [On value-judgements and ethics in health technology assessment](#). *Poiesis und Prax*. 2005;3(4):277–95.
39. Rawlins MD. [Evidence, values, and decision making](#). *Int J Technol Assess Health Care*. 2014;30(2):233–8.
40. Reuzel RP, van der Wilt GJ, ten Have HA, de Vries Robbe PF. [Reducing normative bias in health technology assessment: interactive evaluation and casuistry](#). *Med Heal Care Philos*. 1999;2(3):255–63.
41. Grunwald A. [The normative basis of \(health\) technology assessment and the role of ethical expertise](#). *Poiesis Prax*. 2004;2(2–3):175–93.
42. Sacchini D, Refolo P, Virdis A, Casini M, Traisci E, Dalouis V, et al. *Electronic Medical Diary (EMD): Ethical analysis in a HTA process*. In: 5th Conference of the Italian Chapter of the Association for Information Systems, ItAIS 2008. Paris: Physica-Verlag; 2010. p. 313–20.
43. ten Have H. [Ethical perspectives on health technology assessment](#). *Int J Technol Assess Health Care*. 2004;20(1):71–6.
44. Ashcroft R. [Ethics and health technology assessment](#). *Monash Bioeth Rev*. 1999;18(2):15–24.
45. Saarni SI, Hofmann B, Lampe K, Luhmann D, Makela M, Velasco-Garrido M, et al. [Ethical analysis to improve decision-making on health technologies](#). *Bull World Health Organ*. 2008;86(8):617–23.

46. Saarni SI, Braunack-Mayer A, Hofmann B, van der Wilt GJ. [Different methods for ethical analysis in health technology assessment: an empirical study](#). *Int J Technol Assess Health Care*. 2011;27(4):305–12.
47. Duthie K, Bond K. [Improving ethics analysis in health technology assessment](#). *Int J Technol Assess Health Care*. 2011;27(1):64–70.
48. Reuzel R, Oortwijn W, Decker M, Clausen C, Gallo P, Grin J, et al. [Ethics and HTA: some lessons and challenges for the future](#). *Poiesis Prax*. 2004;2(2–3):247–56.
49. Hofmann B, Oortwijn W, Bakke Lysdahl K, Refolo P, Sacchini D, van der Wilt GJ, et al. [Integrating ethics in health technology assessment: many ways to Rome](#). *Int J Technol Assess Health Care*. 2015;31(3):131–7.
50. Abelson, J, Giacomini, M, Lehoux, P, Gauvin F. [Bringing “the public” into health technology assessment and coverage policy decisions: from principles to practice](#). *Health Policy*. 2007;81(1):37–50.
51. Autti-Ramo I, Makela M. [Ethical evaluation in health technology assessment reports: an eclectic approach](#). *Int J Technol Assess Health Care*. 2007;23(1):1–8.
52. Culyer A. [HTA - algorithm or process? comment on “expanded HTA: enhancing fairness and legitimacy”](#). *Int J Health Policy Manag*. 2016;5(8):501–5.
53. Daniels N, van der Wilt GJ. [Health technology assessment, deliberative process, and ethically contested issues](#). *Int J Technol Assess Health Care*. 2016;32(1–2):10–5.
54. Gagnon MP, Gagnon J, St-Pierre M, Gauvin FP, Piron F, Rhainds M, et al. [Involving patients in HTA activities at local level: a study protocol based on the collaboration between researchers and knowledge users](#). *BMC Health Serv Res*. 2012;12(14):7pp.
55. Kleme J, Pohjanoksa-Mantyla M, Airaksinen M, Enlund H, Kastarinen H, Peura P, et al. [Patient perspective in health technology assessment of pharmaceuticals in Finland](#). *Int J Technol Assess Health Care*. 2014;30(3):306–11.
56. McMillan J, Sheehan M, Austin D, Howell J. [Ethics and opportunity costs: Have NICE grasped the ethics of priority setting?](#) *J Med Ethics*. 2006;32(3):127–8.
57. Arellano LE, Willett JM, Borry P. [International survey on attitudes toward ethics in health technology assessment: An exploratory study](#). *Int J Technol Assess Health Care*. 2011;27(01):50–4.
58. Facey KM. Health technology assessment. In: Facey K, Ploug Hansen H, Single A, editors. *Patient Involvement in Health Technology Assessment*. Singapore: Springer Nature Publishing; 2017. p. 3–16.
59. Braunack-Mayer AJ. [Ethics and health technology assessment: handmaiden and/or critic?](#) *Int J Technol Assess Health Care*. 2006;22(3):307–12.
60. Publications Québec. [Act respecting the Institut national d'excellence en santé et en services sociaux](#). 2018 p. I-13.03.
61. INESSS. [Code d'éthique des experts externes et cadre d'application aux partenaires](#). 2012. p. 11
62. INESSS. [Code d'éthique et de déontologie applicable aux dirigeants nommés par l'Institut et aux employés](#). 2015 [cited 2018 Jul 17]. p. 6
63. INESSS. [Code d'éthique applicable aux collaborateurs externes de l'INESSS](#). 2016 [cited 2018 Jul 17]. p. 9
64. INESSS. [Consultation des parties prenantes](#). 2014 [cited 2018 Jul 17]. p. 32
65. INESSS. [Élaboration et adaptation des guides de pratiques](#) [Internet]. 2017 [cited 2018 Jul 17]. p. 112
66. France. [Légifrance: Code de la sécurité sociale](#). 2018 [cited 2018 Jul 18].
67. Haute Autorité de Santé (HAS). [Charte de déontologie](#). 2008 [cited 2018 Jul 18]. p. 19
68. Haute Autorité de Santé HAS. [Assessment of ethical aspects](#). 2013 [cited 2018 Jul 18].
69. National Institute for Health and Care Excellence (NICE). [NICE Charter 2017](#). 2017 [cited 2018 Jul 18].

LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

COVID-19 : quelle bioéthique pour après?

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Mots-clés

bioéthique, science, complexité, interdisciplinarité, transdisciplinarité

Keywords

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La bioéthique peut nous aider à préparer l'après-crise causée par la pandémie du COVID-19. Toutefois, il serait efficace de revenir à sa vraie nature.

Rappelons-le, car cela semble aujourd'hui trop souvent oublier (1): l'inventeur du néologisme « bioéthique », l'oncologue américain Van Rensselaer Potter, définit la bioéthique comme une « science de la survie » ; une science où les sciences, en particulier les sciences de la vie, s'entremêleraient avec l'éthique, dans l'étude des progrès scientifiques et médicaux afin d'en dégager le meilleur pour nos sociétés et leurs individus. La bioéthique s'intéresserait surtout à la survie réelle de l'espèce humaine, celle de tous les Hommes.

Cette véritable crise de la modernité, dans la manière de l'étudier, de la résoudre, pour laquelle se focalise finalement Potter à travers son travail sur la bioéthique, a été également largement abordée par le philosophe français Paul Ricœur ; crise de la modernité analysée à partir des progrès scientifiques acquis en bien plus d'un demi-siècle (2). En effet, Ricœur parle de la nécessité d'une approche « médicale » dans l'analyse même des sociétés touchées par cette crise ; c'est-à-dire de les soigner. Un autre philosophe français, mais aussi sociologue, Edgar Morin (3), insiste-lui sur la nécessité de pratiquer l'« interdisciplinarité », cette nouvelle façon de faire la science. Il souligne l'intérêt d'une science collective et raisonnée, transdisciplinaire, sondant l'être humain et son environnement. Ces différentes références, dans leurs singularités, font largement échos à celle de Potter.

Nous assistons aujourd'hui par cette crise causée par la pandémie du COVID-19 à la nécessité d'un renouveau de la bioéthique. Dans une période comme la nôtre, la référence à l'assise scientifique – il suffit en effet de se référer au récent avis N°106 du Comité Consultatif National d'Éthique (CCNE) en France, à propos d'une possible pandémie grippale (4) –, la bioéthique se proclame, comme nature, être le régulateur de la science, celle à l'origine du progrès.

La bioéthique ainsi renouvelée par cette crise demande l'intervention de toutes les sciences en son centre réalisant une multiplicité d'approches pour une unique visée : l'Homme. Chacune est interpellée par la crise et toutes doivent fournir une réponse cohérente au monde, tenant compte de sa diversité. La bioéthique doit être pratiquée et enseignée comme cette science, nouvelle, à l'interface de toutes – qui n'ignore évidemment pas la philosophie et le droit – qui est capable par une interdisciplinarité, voire une transdisciplinarité, réelle et bien pensée, d'étudier et de résoudre au mieux la complexité des crises que l'humanité traverse, et continuera à traverser, le tout dans la recherche de l'intérêt de tous et de chacun ; vers une humanité de la connaissance (3).

Seule – après l'analyse de l'excessive importance de l'économie sur la pensée humaine – cette bioéthique s'affermira avec un travail d'évaluation des événements survenus à l'aune des valeurs humaines qu'il s'agit de refonder dans ce nouveau monde, véritable « phronesis » aristotélicienne pour laisser éclore la visée éthique privilégiant alors « la vie bonne avec les autres dans des institutions justes », comme l'appelait de ses vœux Ricœur (5).

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Références

1. Stoeklé HC, Hervé C, Vogt G. [La bioéthique en tant que science : réflexion épistémologique et méthodologique](#). Ethics, Medicine and Public Health. 2020;13.
2. Hervé C. [La crise comme devenir de l'homme](#). Revue d'éthique et de théologie morale. 2013;276:11-26.
3. Morin E. La Méthode : la connaissance de la connaissance. Paris : Le Seuil; 1986.
4. [Questions éthiques soulevées par une possible pandémie grippale](#), Avis n°106 du Comité Consultatif National d'Éthique français. 2009.
5. Ricœur P. Soi-même comme un autre. Paris : Le Seuil; 1990.

ÉTUDE DE CAS / CASE STUDY

Questioning the Ethics of Promoting Weight Loss in Clinical Practice

Andria Bianchi¹, Maria Ricupero²

Résumé

Cette étude de cas examine la défendabilité éthique de recommander la perte de poids comme traitement pour les patients ayant un indice de masse corporelle plus élevé. La recommandation d'une perte de poids peut être motivée par les préjugés des cliniciens à l'égard des personnes vivant dans des corps plus volumineux, par des perceptions erronées du poids et de sa pertinence pour la santé globale ainsi que par l'absence de prise en compte d'autres facteurs éthiques, tels que ceux liés à l'équité et aux déterminants sociaux de la santé.

Mots-clés

biais de poids, stigmatisation du poids, poids inclusif, déterminants sociaux, cycle du poids

Abstract

This case study considers the ethical defensibility of recommending weight loss as a treatment for patients with higher body mass indexes. Recommending weight loss may be motivated by clinicians' biases toward people living in larger bodies, misperceptions about weight and its relevancy to overall health, and a failure to consider other ethical factors such as those related to equity and the social determinants of health.

Keywords

weight bias, weight stigma, weight inclusive, social determinants, weight cycling

Introduction

Healthcare practitioners may, at times, find themselves recommending weight loss for patients of a higher weight. This action may be motivated by clinicians' biases toward people living in larger bodies, misperceptions about weight and its relevancy to overall health, and a failure to consider other ethical factors such as those related to equity and the social determinants of health. The goal of this case study is primarily to encourage clinicians to reconsider recommending weight loss to their patients. We ultimately argue that a weight-inclusive approach is preferable.

Case Study

Jamie lives with psychosis and is on a mental health leave from work. Working with his psychiatrist, Jamie found a medication to manage his symptoms that resulted in 40lbs of weight gain; Jamie is now fat.

Upon visiting his family physician for an annual check-up, Jamie was given a prescription for semaglutide. Semaglutide is an injectable medication for type 2 diabetes. A one-year trial showed that semaglutide lowered A1c (i.e., a test used to diagnose and monitor diabetes) and resulted in a maximum 12lb reduction in weight (1). The company's website states that semaglutide "is not a weight loss drug... [b]ody weight reduction was a secondary endpoint in clinical trials (2)."

Jamie's A1c is 4.8%, which is normal. The doctor's rationale for prescribing off-label use of semaglutide was: "It's just a matter of time before he develops diabetes because of his weight." Recall that the purpose of Jamie's visit was for a checkup, not weight loss. This scenario is an example of a weight-related microaggression¹ (3).

Maintaining weight loss: practical considerations

A weight reduction of 5% to 10% of body weight for people with a higher body mass index (BMI) is often associated with improved health outcomes (4). Increasingly, and based on the authors' experiences, some patients report receiving advice from physicians to lose weight by eliminating carbohydrates, joining Weight Watchers, etc. These diets do not promote healthy eating as per Canada's Food Guide and/or do encourage calorie restriction that is not sustainable in the long term (5). Moreover, restricting energy intake with or without increasing energy expenditure does not result in long-term sustained weight loss for most people. A meta-analysis of 29 weight loss studies found that more than 50% of lost weight was regained within 2 years, and more than 80% by year 5 (6).

Maintaining lost weight is difficult due to hormonal adaptations that resist weight loss² (7). When weight regain occurs, individuals will often re-attempt losing weight, which promotes weight cycling ("yo-yo dieting") (4). Weight cycling has physical and emotional health consequences (e.g., insulin resistance predisposing people to type 2 diabetes, low self-esteem, poor body image) (8). Furthermore, while a higher BMI is typically associated with greater risk of developing chronic diseases, losing weight does not necessarily result in prolonged life.³ (9).

¹ According to Tylka et al., "microaggressions are the intentional or unintentional verbal, behavioral, or environmental indignities that communicate hostility or negativity toward people who hold less power in society" (3).

² More specifically, body weight is regulated via hormones that increase appetite and decrease satiety in response to weight loss.

³ The Look AHEAD trial (a large multicenter randomized control study with a follow up period of 9.6 years) found that participants living with diabetes who maintained a 7% weight loss failed to reduce cardiovascular mortality in 5145 overweight individuals (9).

Recognizing the consequences of *focusing* on weight loss for people like Jamie leads the authors to question the ethical defensibility of weight loss as a primary clinical recommendation.

Health gains in the absence of weight loss

Systematic reviews and meta-analyses show how health benefits via lifestyle changes can prevent and treat diabetes and heart disease *irrespective of weight loss* (10-13). According to Blair, physical inactivity and low cardiorespiratory fitness may be the most important public health risk factors and not *obesity* itself (14). Thus, we advocate for a weight inclusive approach that accepts size diversity and promotes health and well-being for all by addressing the social determinants of health (15,16). The social determinants that contribute to a person's lifestyle (and to the prevention and treatment of chronic illness such as, diabetes and heart disease) include income, employment, living arrangements, physical environments, education, social status, and support networks (15). Rather than make weight loss the default recommendation when it comes to patients in larger bodies, clinicians can better assist all their patients by familiarizing themselves with how the social determinants influence one's health and wellbeing. Clinicians can then make recommendations that accord with their patients' lifestyles, and advocate for social change.

Addressing criticisms of weight inclusivity: some ethical considerations

In response to the idea that weight loss is problematic for people like Jamie, some practitioners may say: 1) It is irresponsible to *not* encourage people to lose weight given the *obesity epidemic* and/or 2) It is important to help patients lose weight, especially if they make an autonomous request for weight loss.

We have already shown that the first argument is moot because of the impracticability of sustaining weight loss and the harms associated with weight cycling. While encouraging weight loss could be considered compatible with respecting autonomy, we argue that telling patients what they want to hear and recommending a treatment that has a high failure rate is not in line with patient-centred care. Additionally, and according to a 2016 study, the stressors associated with weight stigma and trying to lose weight may be more harmful than the weight itself, leading to maladaptive eating behaviours and increased weight gain (17).

A recommendation of weight loss is likely motivated by sincere intentions; however, biases regarding body image and people in higher weight bodies are prevalent, and these biases may influence a provider's perspective on whether a patient should lose weight. In their discussion of weight stigma, Phelen et al. state that physicians may wrongly and/or unnecessarily attribute symptoms or problems to *obesity* for people who are classified as obese. Additionally, they may fail to refer the patient for testing and/or to propose alternative treatment options beyond simply advising the patient lose weight (18). Conversely, those who are of *'normal'* weight may be overlooked. Another article also notes that "[a] cluster of studies have reported that physicians view obese patients as less self-disciplined, less compliant and more annoying than nonobese ones and that, as patients' BMI increases, physicians are likely to have less patience and desire to help them (Hebl and Xu, 2001; Huizinga et al, 2009)" (19). One of these studies analyzed physicians' perceptions of patient sizes. The study found that physicians treat patients differently based on their size, from which overweight and obese patients receive a lower quality of care (20).

The biases held toward patients of a higher weight may influence physicians to recommend weight loss without considering: 1) the social determinants of health, 2) that weight loss is unsustainable for most, and 3) that positive health outcomes can be achieved without losing weight. All of these factors must be taken into account when considering the ethics of a recommendation. Additionally, communicating accurate and transparent information to patients about weight loss is an important part of providing patient-centred and ethical care, and enabling patients to make informed decisions about their overall health. In order to ensure that an ethical recommendation(s) is made to patients of higher weight (and since patients typically trust their healthcare team's recommendations), we suggest that clinicians ought to reflect deeply upon why they may decide to recommend and/or celebrate weight loss in certain contexts.

Clinical Implications

In order for patients like Jamie to make sustainable improvements to their health, we encourage practitioners to consider the following before recommending weight loss:

- 1) How do I feel about people of higher weight? Do I have potential biases that may be influencing my recommendation(s)?
- 2) Is the patient requesting weight loss? If so, why? Note: If they are requesting weight loss for health outcomes, it may be worth flagging that health improvements can often be achieved with lifestyle changes irrespective of losing weight.
- 3) Is the patient informed about the likelihood of weight regain? Am I being transparent?
- 4) Are lifestyle changes possible given the patient's social circumstances?
- 5) Would a referral to a dietitian help the patient make lifestyle changes?

Contemplating these questions may enable clinicians to more effectively contribute to the overall health of people like Jamie and provide patient-centred care.

Conclusion

Clinicians must reflect on why they may recommend weight loss for some patients since studies have shown that practitioners may treat patients differently based on biases related to their size. As a result of these biases, clinicians may not communicate accurate or transparent information about possible consequences associated with attempting to achieve and sustain weight loss. Instead of weight loss, it may often be more helpful to focus on a person's lifestyle and the social determinants of health. The ethical defensibility of proposing weight loss as a recommendation to achieve certain health outcomes may be lacking in certain cases.

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References

1. Ozempic semaglutide injection. Novo Nordisk. [While Ozempic® Is Not for Weight Loss, You May Also Lose Some Weight](#); c2019 [cited 2019 July 22]
2. Ozempic semaglutide injection. Novo Nordisk. [Superior weight reduction vs Trulicity® and Bydureon®](#); c2019 [cited 2019 August 21]
3. Tylka, TL, Annunziato, R, Burgard, D, Danielsdottir, S, Shuman, E, Davis, C, et al. [The weight inclusive versus weight-normative approach to health: evaluating the evidence for prioritizing well-being over weight loss](#). *Journal of Obesity*. 2014;1-18.
4. Tuomilehto J, Lindström, J, Eriksson, JG, Valle TT, Hämäläinen H, Ilanne-Pirakka P, et al. [Prevention of type 2 diabetes mellitus by changes in lifestyle among subjects with impaired glucose tolerance](#). *New England Journal of Medicine*. 2001;344(18):1343-50.
5. Dansinger, M, Gleason, J.A, Griffith, J.L. Selker, H.P., Schaefer, E.J. [Comparison of the Atkins, Ornish, Weight Watchers, and Zone Diets for weight loss and heart disease risk reduction a randomized trial](#). *JAMA*. 2005;293(1):43-53.
6. Hall KH, Kahan S. [Maintenance of lost weight and long-term management of obesity](#). *The Medical Clinics of North America*. 2018;102:183-197.
7. Sumithran P, Prendergast LA, Delbridge E, Purcell K, Shulkes A, Kriketos A, et al. [Long-term persistence of hormonal adaptations to weight loss](#). *New England Journal of Medicine*. 2011;365(17):1597-1604.
8. Aphramor, L, Bacon L. [Weight science: evaluating the evidence for a paradigm shift](#). *Nutrition Journal*. 2011;10(9):1-13.
9. Look AHEAD Research Group. [Cardiovascular effects of intensive lifestyle intervention in type 2 diabetes](#). *New England Journal of Medicine*. 2013;369(2):145–154.
10. Estruch R, Ros E, Salas-Salvador J, Covas M, Corella D, Arós F, et al. [Primary prevention of cardiovascular disease with a Mediterranean diet](#). *New England Journal of Medicine*. 2013;368(14):1279-1290.
11. Boule NG, Haddad E, Kenny GP, Wells GA, Sigal RJ. [Effects of exercise on glycemic control and body mass in type 2 diabetes mellitus: a meta-analysis of controlled clinical trials](#). *JAMA*. 2001;286(10):1218-1227.
12. Barry VW, Varuth M, Beets MW, Durstine JL, Lieu J, Blair SN. [Fitness vs. fatness on all-cause mortality: a meta-analysis, progress in cardiovascular diseases](#). 2014;56(4):382-90.
13. Church TS, LaMonte MJ, Barlow CE, Blair SN. [Cardiorespiratory fitness and body mass index as predictors of cardiovascular disease mortality among men with diabetes](#). *Archives of Internal Medicine*. 2005;165:2114–20.
14. Blair SN. [Physical inactivity: the biggest public health problem of the 21st century](#). *British Journal of Sports Medicine*. 2009;43(1):1-3.

15. Medvedyuk S, Ahmednur A, Raphael D. [Ideology, obesity and the social determinants of health: a critical analysis of the obesity and health relationship](#). *Critical Public Health*. 2018;28(5):573-585.
16. Public Health Agency of Canada. [Social Determinants of Health](#). Canadian Best Practices Portal. Government of Canada; c2016 [cited 2019 August 21].
17. Puhl RM, Phelan SM, Nadglowski J, Kyle TK. [Overcoming weight bias in the management of patients with diabetes and obesity](#). *Clinical Diabetes*. 2016;34(1):44-50.
18. Phelan SM, Burgess DJ, Yeazel MW, Hellerstedt WL, Griffin JM, van Ryn M. [Impact of weight bias and stigma on quality of care and outcomes for patients with obesity](#). *International Association for the Study of Obesity*. 2015;16:319-326.
19. Flint SW. [Obesity stigma: Prevalence and impact in healthcare](#). *British Journal of Obesity*. 2015;1:14–18.
20. Hebl MR, Xu J. [Weighing the care: physicians' reactions to the size of a patient](#). *International Journal of Obesity and Related Metabolic Disorders*. 2001;25(8):1246-52.

ART, CULTURE ET OEUVRE DE CRÉATION / ART, CULTURE & CREATIVE WORKS

Dialogue entre un infectiologue et un biochimiste

Jacques Quintin¹

Résumé

Les événements entourant la pandémie du Covid-19 suscitent beaucoup de questions éthiques qui touchent aussi bien la médecine que la santé publique, l'économie, la vulnérabilité des personnes ainsi que toutes les sphères de la vie comme la mort et les questions entourant le sens de l'existence. La motivation chez les chercheurs est grande de fabriquer un vaccin qui permettrait de protéger la population contre une telle catastrophe. Mais il arrive que l'objet du désir soit si envahissant qu'il obnubile la conscience morale. Le dialogue suivant propose une illustration de ce qui peut se passer dans l'esprit de deux chercheurs confrontés à l'idée de faire du bien de manière absolue.

Mots-clés

éthique, recherche scientifique, conscience, devoir, intégrité, Covid-19, pandémie

Abstract

The events surrounding the Covid-19 pandemic raise many ethical questions that affect medicine as well as public health, the economy, the vulnerability of individuals, and all spheres of life such as death and questions about the meaning of existence. There is a strong motivation among researchers to make a vaccine that would protect people from such a disaster. But sometimes the object of desire is so pervasive that it overwhelms moral consciousness. The following dialogue offers an illustration of what can happen in the mind of two researchers confronted with the idea of doing good in an absolute way.

Keywords

ethics, scientific research, conscience, duty, integrity, Covid-19, pandemic

– L'infectiologue : Il fait beau aujourd'hui. N'est-ce pas ?

– Le biochimiste : Oui, effectivement. Mais depuis quand observes-tu une chose pareille ? D'habitude, tu ne vois rien de ce qui se passe autour de toi, sinon des microbes, des bactéries et des virus.

– I : Bah, la vie change. On voit des choses qu'on ne voyait pas avant. Pourtant, elles étaient là.

– B : J'entends un gars qui est sur le bord de la retraite. Tu n'as quand même pas envie de prendre ta retraite ?

– I : Pourquoi pas. En tant qu'infectiologue, j'ai fait tout ce que j'avais à faire. J'ai eu une carrière de chercheur enviable, mais sans éclat. À part quelques collègues, personne ne me connaît.

– B : Justement, pourquoi tu ne tentes pas de produire un vaccin contre le Covid-19 ? Tu pourrais devenir célèbre.

– I : C'est quoi d'être célèbre pour un scientifique ? Tu es célèbre seulement si tu apparais dans les médias fréquemment. Et tu apparais dans les médias seulement si ta gueule est sympathique.

– B : Tu es vraiment pessimiste. Fais-moi confiance, si tu développes un vaccin qui réussirait à éradiquer une pandémie, c'est clair que tu seras perçu comme un héros. C'est la planète entière qui saura que tu es un grand infectiologue.

– I : Peut-être. Mais il y a déjà une pléthore de chercheurs qui se penchent sur ce défi. On ne sera pas les seuls si notre équipe s'y mettait.

– B : Ce n'est pas compliqué. C'est une occasion en or. Profitons-en. Nous pourrions faire rapidement des tests. Nous pourrions même les faire sur nous-mêmes pour ne pas perdre trop de temps. Je connais même des gens autour de moi qui seraient prêts à se porter volontaires comme cobaye. Une fois qu'on aura trouvé une piste intéressante, on pourra suivre les protocoles.

– I : Le risque est grand de créer du tort à des personnes vulnérables.

– B : Bah, peut-être. Il faut souvent sacrifier quelques personnes pour en faire bénéficier plusieurs.

– I : Mais c'est quand même de la tricherie.

– B : Ben voyons donc. Qui ne triche pas ? Tu le sais mieux que quiconque.

– I : Même si plusieurs contournent les règles, ce n'est pas une raison pour tricher.

– B : Penses-y deux fois. C'est la gloire qui t'attend. Elle est là au bout de ton nez.

– I : Écoute-moi bien. Toi, tu es jeune, tu as tout à gagner, tandis que moi j'ai tout à perdre.

– B : C'est plutôt le contraire. Moi, en tant que biochimiste, j'ai tout à perdre et toi tout à gagner. Vois-tu, si je perds, c'est ma carrière qui est foutue. Toi, si tu perds, ce n'est pas grave, car tu es en fin de carrière. C'est toi-même qui viens de le dire. Tu veux prendre ta retraite.

– I : Pas tout à fait. Car si je perds, c'est toutes mes recherches précédentes qui seront à risque d'être discréditées. De toute façon, je ne me sentirais pas confortable dans ma conscience. Je préfère être méconnu et me sentir intègre que célèbre et pervers. De toute façon tout se sait en ce monde. Ce n'est qu'une question de temps. Et plus tu joues gros, plus tu risques de tomber de haut.

– B : Tu parles comme un infectiologue qui sait de quoi il parle.

– I : Ce n'est pas sorcier, il y a plein d'exemples de chercheurs qui ont perdu la face.
– B : Mais tu oublies tous les autres qui s'en sortent plutôt bien.

– I : J'ai l'impression d'entendre le diable qui laisse miroiter le miracle. C'est sûr que la tentation est toujours là, mais je ne peux pas. Ce n'est pas honnête.
– B : Je ne te demande pas de faire un vol de banque, de cacher tes avoirs dans des abris fiscaux, ni de produire un vaccin inefficace. Mais seulement d'aller plus vite.

– I : Tu vois, pour moi, inefficace, ce n'est pas seulement un vaccin de piètre qualité. Ce sont des gens qui décèdent en pensant qu'ils étaient immunisés. La recherche scientifique c'est plus que ce qui se passe dans une éprouvette. Il y a des vies humaines.
– B : Bah, des vies humaines. De toute façon, les gens qui vont mourir, ce sont des gens déjà en fin de vie qui décéderont dans l'année qui suit. C'est quand même drôle. Les gens sont prêts à se prémunir de l'aide médicale à mourir, mais ne prendraient pas le risque d'un vaccin qui, dans le meilleur des mondes, les protégerait, tandis que nous sommes déjà dans le pire scénario.

– I : Ce n'est pas possible. C'est vendre mon âme. Je suis certain que j'en ferais une dépression.
– B : Ben voyons donc. Il n'y a rien là. Tu parles comme si la vie avait une valeur. Ce n'est pas compliqué. On naît, on mange, on baisse et on meurt. C'est tout. Nous n'avons pas à nous questionner sur des enjeux existentiels. Ni à écouter notre conscience. De toute façon, c'est quoi ça la conscience? N'est-elle pas uniquement un outil à notre disposition pour s'adapter au monde et survivre du mieux que l'on peut?

– I : Je ne sais pas. J'ai des doutes.
– B : C'est justement cela le problème, tu penses trop. Ton devoir moral c'est de tout faire pour trouver une solution à un problème technique. C'est le sens de l'éthique de la recherche scientifique. Alors, la fin justifie les moyens. De toute façon, on est tous des Prométhée qui volent le feu.

– I : Justement, ils sont là mes doutes. Tu oublies que Prométhée a été puni pour son geste.
– B : Peut-être, mais c'est toute l'humanité qui en profite encore aujourd'hui. Il me semble que cela en valait la peine.

– I : C'est une manière de voir les choses. Et si on se disait que, depuis ce vol, les hommes ne se posaient plus les bonnes questions. Ils se sentent immortels. Alors, à quoi bon se questionner sur le sens de l'existence.
– B : Sauf, que pour nous, il ne s'agit pas seulement de se sentir immortels, mais de le devenir. Imagine-toi un vaccin qui assurerait l'immortalité, ou disons, pour être plus modeste, un vaccin qui nous donnerait cinquante ans de plus à vivre.

– I : Je veux bien, mais dans quelle condition? Cinquante ans de plus sans qualité de vie, ça ne vaut pas le coût. Je ne prendrais pas le risque. Tu oublies que c'est grâce à l'idée bien présente dans notre esprit, celle qu'un jour on va mourir, que les choses s'éclairent un peu mieux pour nous. Tu es peut-être trop jeune pour le sentir. Pour toi, c'est sûrement une question un peu abstraite. Tu vois, pour moi, c'est une question que je ressens dans mes tripes. Statistiquement, il me reste à peine quinze ans à vivre. Cette idée me jette par terre.
– B : Ben voyons donc, tu es en pleine forme. Encore hier, dimanche, tu t'es flanqué cent cinquante kilomètres de vélo. Pas si mal pour un gars de soixante-dix ans.

– I : Tu devrais savoir que cela ne donne aucune garantie pour la suite.
– B : C'est vrai, mais tu ne pars pas avec deux prises contre toi comme une personne qui se retrouve avec de multiples comorbidités.

– I : De toute façon, ce que tu me suggères, c'est l'appât du gain.
– B : Ce n'est quand même pas la pomme d'Adam.

– I : Au contraire, c'est justement cela que tu me proposes : une nouvelle chute de l'humanité.
– B : Ouah, tu vois grand. Je ne me projette pas jusque-là.

– I : Penser, c'est voir les choses à la hauteur de l'universel.
– B : Alors, je ne dois pas penser beaucoup.

– I : C'est ce que je pense.
– B : C'est drôlement prétentieux de ta part. Monsieur l'infectiologue pense. Lui, il pense, tandis que les autres, la masse, ne sont que des Eichmann. Dis-toi bien qu'effectivement la masse des gens n'a pas le loisir ou le luxe de penser. Ils sont en mode de survie.

– I : Je ne te parle pas d'une activité intellectuelle. Je parle de ce qu'est une vie humaine.
– B : Et c'est quoi?

– I : C'est en grande partie un dialogue avec notre propre conscience. C'est comme si je lui posais des questions et que celle-ci me répondait. Peu importe ce que je fais, mon métier, ma profession, mes intérêts dans la vie, il y a toujours quelque chose à l'intérieur de nous qui nous parle.

– B : Oh là là, monsieur est devenu philosophe!

– I : Et pourquoi pas? Ce sont des questions philosophiques qui n'appartiennent pas qu'aux philosophes. Ces questions habitent toutes les consciences humaines.

– B : Dans ce cas, moi le biochimiste, je pense autant que toi. Alors, ne dis pas que je ne pense pas.

– I : Disons que tes questions et les réponses que tu te donnes se limitent plutôt à ce que tes sens te fournissent.

– B : On croirait entendre Platon!

– I : Ce n'est pas lui qui parle en moi. En fait, ce qui me fait penser, ce sont ces événements comme la pandémie. Ces événements produisent une brèche dans ma conscience.

– B : Comme moi, le biochimiste, qui te parle de faire avancer la recherche à tout prix.

– I : Oui, mais ta proposition ne me fait pas autant réfléchir comme cette pandémie de la Covid-19.

– B : Alors, tu es d'accord avec ma proposition.

– I : Je n'ai jamais dit cela. Je dis seulement que les événements comme la pandémie nous amènent un éclairage nouveau sur l'humain, si on se laisse interroger, évidemment.

– B : Eh bien, pour moi, ce n'est qu'un problème qui trouvera son issu dans des solutions techniques.

– I : Tu crois que nous ne devrions pas y penser plus qu'il ne faut. Que nous pourrions un jour, pas très éloigné, reprendre notre vie comme si rien ne s'était passé.

– B : C'est à peu près cela. De toute façon, tu as probablement raison, moi les soubresauts existentiels, ce n'est pas mon fort.

– I : En autant que tu reçoives ta paie comme à l'habitude.

– B : C'est à peu près cela.

– I : Les autres comptent peu.

– B : Oui, mais il ne faut pas en faire un plat. C'est déjà assez difficile comme cela pour nous les biochimistes.

– I : Finalement, c'est pour cela que tu es prêt à tout pour arriver à tes fins.

– B : Si tu veux.

– I : À l'évidence, nous ne vivons pas sur la même planète.

– B : Pourtant, nous travaillons ensemble depuis une quinzaine d'années.

– I : Il fallait seulement une situation à la limite de notre imagination pour qu'on se rende compte que nous ne pensons pas pareil, que nous n'avons pas les mêmes valeurs.

– B : Mais cela ne signifie pas que tu as raison. Je ne connais rien à la philosophie, mais l'un de mes copains est justement philosophe ou disons qu'il enseigne la philosophie. Un jour, il m'a dit que pour Hegel, la raison avance dans l'histoire en se servant des passions humaines.

– I : Et alors!

– B : Si nous acceptons cette prémisse, qu'est-ce qui laisse croire que mes plans ne seront pas au service de la raison ou de l'humanité, même si je suis un pervers comme tu le dis si bien.

– I : Ne le prends pas si mal. Je voulais seulement dire que ton plan était un peu tordu. Mêmediabolique. Effectivement, je te le concède. Comment savoir? De toute façon, on ne s'en sortira pas. Dans ce cas, je préfère le pari de Pascal.

– B : Ne viens pas mêler Dieu avec tout cela.

– I : Je réfère à Pascal par analogie. Je préfère me mettre au service de ma conscience même si celle-ci me trompe. Au moins, je n'aurai pas l'impression d'avoir vendu mon âme.

– B : Pour moi, il n'y a pas d'âme, de Dieu, de conscience. Il n'y a que des désirs, des intérêts personnels à défendre. Un point c'est tout.

– I : C'est une façon de voir.

– B : Il n'y a rien de scientifique dans tout ce que tu dis. C'est étonnant de la part d'un infectiologue de ton envergure.

– I : Là n'est pas la question.

– B : C'est quoi alors la question?

– I : C'est une question éthique. Il ne faut pas tout mêler.

– B : Bon, en plus d'être un pervers, le Diable en personne, quelqu'un qui ne pense pas, je mêle tout maintenant.

– I : Je veux seulement dire la chose suivante. Ce n'est pas parce que nous pouvons trouver une solution technique à un problème que nous devons nécessairement le faire. Pour moi, ce n'est pas une justification.
– B : Ça prendrait quoi pour te faire entendre raison?

– I : Je suis d'accord que sauver des vies est une chose importante pour tout être humain. Mais je crois aussi que la mort fait partie de la vie et qu'elle mérite qu'on y réfléchisse un peu plus. Je crois qu'une réflexion sur la mort peut nous éclairer sur le sens de notre vie.

– B : Pourrions-nous alors faire une pierre-deux-coups?

– I : Qu'est-ce que tu veux dire?

– B : Faire tout notre possible pour créer un vaccin tout en maintenant vivant la question éthique du sens de la vie et de la mort.

– I : Bien sûr. Mais je ne crois pas que cela soit possible.

– B : Pourquoi?

– I : Lorsque nous sommes en santé, nous oublions facilement certaines choses importantes de la vie. Nous tenons tout pour acquis, ce qui nous rend souvent téméraires.

– B : Alors, elle est où la solution?

– I : Je ne sais pas. Peut-être que les questions de sens sont réservées seulement à un certain groupe de gens.

– B : Un groupe d'élite?

– I : Non, seulement un groupe de gens marginaux. Et même là, je ne suis pas certain.

– B : Monsieur l'infectiologue doute encore!

– I : Oui, toujours. Il serait peut-être plus juste de dire que tous les êtres humains se posent ces questions, mais à des niveaux différents.

– B : Alors, ce ne serait pas une question de nature, mais de degré.

– I : C'est à peu près cela.

– B : Finalement, il y a de la place pour tout le monde. Et c'est cela qui compte.

– I : Oui, en autant qu'il puisse y avoir des lieux de réflexion. Et cela c'est moins certain dans une société de consommation comme la nôtre qui vante les mérites de la suractivité et de la performance.

– B : C'est drôle, je ne me sens pas bien tout d'un coup. J'ai mal partout dans mon corps.

– I : Merde. Tu dois te faire tester dès maintenant.

– B : On se calme. Ce n'est pas une mort annoncée. De toute façon, il n'y a pas de remède.

– I : Je me sens impuissant.

– B : Peut-être pas!

Conflicts of Interest

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COMMENTAIRE CRITIQUE / CRITICAL COMMENTARY (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

« Brisées par leur travail! OU Au bout du rouleau » : Réflexion critique sur les modes managériaux en santé

Marie-Josée Drolet^a, Mireille Lalancette^b, Marie-Ève Caty^c

Résumé

Après avoir introduit et décrit les modes managériaux en santé, les auteurs articulent une réflexion critique sur quatre enjeux éthiques qui découlent de ces modes.

Mots-clés

système de santé, management, enjeu éthique

Abstract

After introducing and describing managerial health practices, the authors critically reflect on four ethical issues that arise from these practices.

Keywords

health system, management, ethical issue

Introduction

En 2018, le cri du cœur lancé dans les médias sociaux de l'infirmière Émilie Ricard est devenu viral. Partagée plus de 35 000 fois en seulement 24 heures après sa publication via Facebook, la vidéo la présente en larmes à la suite d'un quart de travail de nuit où elle a dû couvrir plus de 70 patients avec une infirmière auxiliaire et deux préposés aux bénéficiaires. Elle y raconte comment elle a été brisée par son métier et comment elle a honte des soins prodigués aux patients. À la suite de cette diffusion, l'Ordre des infirmières et des infirmiers du Québec a fait un bilan et a estimé que l'épuisement professionnel était alors à son plus haut. La crise actuelle avait été présentée comme « du jamais vu ». Un an après la diffusion de cette vidéo virale, on pouvait lire dans un quotidien que : « Les infirmières sont toujours au bout du rouleau » (1). Dans le même esprit, un article relatait que le manque de ressources professionnelles et le surcroît de travail amènent les sages-femmes à l'épuisement (2). Dans une optique apparentée, l'association du personnel professionnel et technique de la santé et des services sociaux se mobilisait pour améliorer les conditions de travail de ses membres, en lançant une campagne intitulée « Allo, y'a quelqu'un ? » (3).

La dernière réforme de la santé inquiète et semble avoir des effets directs sur les professionnelles¹ de la santé. Le président de l'Ordre des ergothérapeutes du Québec (OEQ), Alain Bibeau, soulignait justement, dans un bulletin de l'OEQ, ses préoccupations en lien avec la dernière réforme et mentionnait que les modifications à « l'organisation du travail ne doivent pas placer les ergothérapeutes dans des situations de faute professionnelle ou de manquement déontologique » (4). Il révélait aussi que l'OEQ était « interpellé de plus en plus fréquemment par des ergothérapeutes s'alarmant de ce contexte où l'organisation et les conditions de travail nuisent à l'accès et la qualité de services. Les notions d'indépendance et d'autonomie professionnelles elles-mêmes seraient de plus en plus affectées » (4, p.2). Dans la même lignée que les infirmières, certains ergothérapeutes sont prêts à se dénoncer à leur ordre professionnel parce qu'elles estiment qu'elles ne peuvent plus réellement accompagner les patientes², tel que demandé par leur ordre. « De l'avis de l'OEQ, il est grand temps que le gouvernement porte un regard critique sur la situation actuelle et qu'il reconnaisse l'urgence d'agir » (4, p.2). C'est cet appel qui nous a poussés à mieux comprendre les modes managériaux qui président en santé et à porter un regard critique sur ceux-ci. Quatre enjeux éthiques, c'est-à-dire des situations compromettant le respect, en tout ou en partie, d'au moins une valeur éthique (5) sont discutés dans ce texte.

Modes managériaux en santé vus par les chercheurs

Depuis une trentaine d'années, à des fins de rationalisation, les organisations publiques de santé se transforment et adoptent de nouveaux modes managériaux (6). Plusieurs pays occidentaux, dont le Canada, ont en effet procédé à des réformes de leur système de santé. Ces réformes sont justifiées par les demandes des patientes, l'évolution des technologies et le vieillissement des populations (6,7). Elles ont amené les décideurs à effectuer des transformations des organisations de santé, en adoptant les valeurs et principes de la nouvelle gestion publique (NGP). Selon Jetté et Goyette (7), la NGP est « une école de pensée en administration publique qui fait la promotion de pratiques managériales provenant du secteur marchand et qui met l'accent sur l'atteinte de résultats misant sur l'imputabilité de services et la mise en place d'incitatifs à la performance » (p.25). La logique marchande, voire bureaucratique liée à la NGP se heurte à d'autres logiques, notamment à la logique professionnelle, qui dominait les rapports sociaux avant l'introduction de la logique bureaucratique (6,8). Tandis que la logique professionnelle s'appuie sur les savoirs scientifiques, techniques et expérimentaux des professionnelles pour solutionner les problèmes au quotidien, la logique bureaucratique par contraste opte plutôt pour le suivi de protocoles stricts émanant des gestionnaires, lesquels sont souvent déconnectés des particularités des contextes et de la spécificité des patientes (6-9). En bref, alors que la logique professionnelle limite le travail prescrit et repose sur le jugement clinique des professionnelles, la logique bureaucratique transforme pour sa part les relations de travail, en donnant préséance aux gestionnaires qui désormais imposent un travail prescrit au nom de l'uniformisation des pratiques (6-9). La logique bureaucratique de la NGP en vient à

¹ Nous utilisons volontairement le féminin dans ce commentaire, car les travailleurs de la santé sont en majorité des femmes.

² Nous féminisons aussi le mot patient, car la majorité d'entre eux sont aussi des femmes.

³ Dans cet article, c'est la situation canadienne qui nous intéresse, bien que cette réflexion puisse aussi s'étendre à d'autres pays occidentaux.

uniformiser les pratiques, faisant en sorte que les professionnelles deviennent interchangeable et subissent de fortes pressions pour donner toujours plus de soins et de services au plus grand nombre de patientes.

Plusieurs chercheurs s'entendent pour dire que les problèmes en santé proviennent notamment de l'implantation de la NGP au système de santé. Cette approche qui transpose les valeurs et les principes néolibéraux de gestion du secteur privé au secteur de la santé afin d'accroître, argue-t-on, l'efficacité des pratiques se heurte aux valeurs humanistes qui ont longtemps présidées au sein des organisations de santé (10). Concrètement, la NGP se caractérise par l'adoption d'une gestion par résultats, la recherche de la qualité, la reddition de comptes, l'approche client, l'évaluation des programmes, l'imputabilité des fonctionnaires, la privatisation, la mise en concurrence des établissements et, enfin, la décentralisation et le délestage des pouvoirs à de nouvelles instances (10,12). Ses promesses reposent sur une soi-disant meilleure qualité des soins et sur leur efficacité. Dans la lignée de l'approche Lean, elle ambitionne une meilleure efficacité. Des études montrent notamment qu'elle permet, du point de vue de la gestion, une meilleure performance (13). Force est de constater cependant que son adoption ne se fait pas sans heurts du point de vue des professionnelles de la santé et des patientes. Selon Bourque « l'application [de la NGP] transforme les fondements des systèmes de santé » (10, p.1). Son adoption remet en question l'*ethos* public des gouvernements, dont le nôtre qui était auparavant centré sur « une éthique du bien commun, l'universalité de l'accès aux services de qualité et une philosophie de redistribution des richesses » (14). Le rôle de l'État est revu et calqué sur celui de l'entreprise privée qui gère des objets, des marchandises, plutôt que des êtres humains, voire des communautés souvent en situation de vulnérabilité. L'État devient davantage préoccupé par des considérations budgétaires et économiques que sanitaires et démocratiques. C'est comme si l'équilibre budgétaire et la croissance économique étaient plus importants que la santé, la qualité de vie et la vie des personnes et des communautés qui habitent le territoire sous sa gouvernance. Ainsi, les récents changements qu'a connus le système de santé québécois ne sont ni cosmétiques ni anodins : ils modifient les racines sociales démocrates du système de santé, lesquelles étaient associées à des valeurs telles que l'accessibilité universelle, l'équité, l'intégrité, l'impartialité et la solidarité. On assiste de nos jours à un paradigme de gouvernance dicté par les lois du marché où tout ce qui compte au final est « la norme quantitative du value-for-money et la conscience des coûts du service public dérive vers une vision essentiellement économique du rôle de l'État. On oublie par ailleurs de considérer dans la balance des coûts de ces restructurations elles-mêmes, non seulement en termes monétaires et de temps, mais aussi en coût humain » (14, p.817-8).

Réflexion critique

Perte d'autonomie professionnelle

Grenier et Bourque (11) soulignent que l'introduction de la NGP dans le secteur public a occasionné des conséquences structurelles, organisationnelles, mais aussi des conséquences axiologiques, notamment une modification graduelle de l'*ethos* des professionnelles qui y évoluent. L'*ethos* d'une profession est lié aux valeurs des professionnelles et à leur vision éthique de leur engagement envers la population qu'ils desservent. Avec la NGP, la logique bureaucratique en vient à remplacer la logique professionnelle. Graduellement, les professionnelles en viennent à se soumettre aux normes prescrites qu'on leur impose, même si elles considèrent que celles-ci ne sont pas celles qui devraient présider dans certains contextes (ex. avec cette patiente, il faudrait plus de traitements, il faudrait intervenir à domicile). Car, à défaut de s'y soumettre, elles en subiront des conséquences négatives (ex. dossier disciplinaire). Plus encore, les contraintes systémiques exercées sur les professionnelles qu'engendrent ces nouvelles pratiques de gestion en viennent petit à petit à moduler leurs valeurs, notamment en portant atteinte à leur autonomie professionnelle. Or, l'autonomie professionnelle est non seulement une valeur qui est chère aux professionnelles, mais elle est aussi et surtout « un prérequis pour offrir des soins et des services de qualité » (15, p.127). La NGP amène à penser le travail prescrit en termes individuels, où la performance des individus est privilégiée au détriment de la réponse adéquate aux besoins de la collectivité, affectant ainsi négativement la qualité et la sécurité des soins (11,15). En outre, la NGP évacue la dimension humaine de la relation patiente-professionnelle et expose continuellement les professionnelles de la santé à un dilemme majeur : se conformer aux exigences de la NGP ou suivre leur jugement professionnel et les meilleurs standards de pratiques cliniques (16). En ce sens, la logique de la NGP peut être vécue comme une déprofessionnalisation par les professionnelles qui peuvent ressentir une remise en cause de l'essence axiologique de leur profession et une perte de sens à leur travail (17).

Système inique et médecins-centrés

La NGP modifie les relations de travail et les rapports de force entre les acteurs sociaux. La logique professionnelle octroyait beaucoup de pouvoir aux professionnelles, car leur jugement professionnel était valorisé : il était à la base des décisions de santé. Avec la logique bureaucratique de la NGP, ce sont les gestionnaires qui décident et qui établissent avec les médecins des protocoles et des normes auxquelles les professionnelles devront se soumettre. Ces normes s'inscrivent en effet dans une logique médicale où les approches biopsychosociales de la santé ainsi que les voix citoyennes sont dévaluées (8,10). Ainsi, les récentes réformes ont retiré du pouvoir aux professionnelles et aux patientes, allant jusqu'à éliminer « la voix citoyenne dans les conseils d'administration » (18, p.78). D'office, l'organisation actuelle du système de santé avantage certains acteurs au détriment d'autres acteurs sociaux généralement plus vulnérables que les premiers. De fait, les acteurs qui sont avantagés (en l'occurrence les médecins et les compagnies pharmaceutiques) ne sont pas a priori vulnérables, bien au contraire, ce qui crée des écarts encore plus importants entre les privilégiés et les désavantagés. Sur ce sujet, comme le révèlent les nombreuses études épidémiologiques sur les déterminants sociaux de la santé, nous savons que plus une société est égalitaire, plus sa population est en santé et heureuse, et ce, de manière statistiquement significative et probante (19). Or,

les inégalités sociales sont en croissance au pays comme au Québec, notamment parce que les budgets alloués au filet social, aux services publics ne cessent de diminuer (16). Plus encore, le fait de centrer le système de santé sur le traitement médical et pharmacologique des patientes fait en sorte que la mise en place d'environnements urbains, ruraux, organisationnels et sociaux contribuant quotidiennement à la santé et à la qualité de vie des personnes et des communautés est pour une large part délaissée. Nous savons par exemple que les transports actifs contribuent à la santé, mais nos modes de vie et nos aménagements urbains et ruraux sont, pour une large part, centrés sur la voiture. Nous savons aussi que la motivation et la performance au travail se nourrissent de trois besoins psychologiques fondamentaux, soit l'autonomie professionnelle, le sentiment de compétence perçu et le fait d'entretenir des relations saines et satisfaisantes avec ses collègues, et ce, dans un contexte où il est possible de travailler en cohérence avec ses valeurs éthiques (20). Or, comme vu précédemment, en tant qu'héritière du néo-libéralisme, la NGP conçoit le système public de santé comme une entreprise privée, ce qui impacte négativement non seulement les soins et les services prodigués aux patientes – notamment à celles qui sont jugées les plus vulnérables qui se retrouvent davantage marginalisées (21) –, mais également la santé physique et mentale des professionnelles de la santé elles-mêmes (22), ce qui par extension contribue à la baisse de la qualité et de la quantité des soins et des services prodigués aux populations. Autrement dit, l'injustice systémique liée aux fondements mêmes du système de santé qui attribuent de grands pouvoirs aux acteurs sociaux médicaux et pharmacologiques, lesquels ont pour la plupart une vision individualiste de la santé centrée sur la maladie ou l'accident, empêche de donner plus de places à des visions alternatives et sociales de la santé centrée sur les environnements, les populations, les personnes, la prévention des maladies et des accidents ainsi que la promotion de la santé et du bien-être. Ainsi, bien qu'un nombre croissant d'acteurs clame l'insuffisance du paradigme médical, celui-ci demeure présent, voire dominant, dont la mise en place des groupes de médecine familiale en est une illustration parmi d'autres (23).

Injustice de genre

L'austérité en santé en général et la NGP en particulier affectent en très grande proportion des femmes. Comment cela est-il possible? Rappelons que 82% du personnel en santé est des femmes et que la majorité des patients est aussi des femmes (16). De fait, le secteur de la santé est dominé par des professionnelles; et les femmes, pour diverses raisons (agressions sexuelles, avortement, contraception, famille mono-parentale, grossesse, pauvreté, proches aidantes, violence conjugale, etc.), consultent davantage les professionnelles de la santé pour elles, leur(s) enfant(s) et leur(s) proche(s) (16). Ainsi, comme l'observent l'ONU-Femmes (24) et le Réseau québécois d'action pour la santé des femmes (25), les mesures d'austérité et les pratiques managériales liées à ces mesures affectent négativement et en premier lieu les femmes. « Elles augmentent les inégalités sociales et nuisent à l'égalité entre les femmes et les hommes » (16, p.64), car les services publics, notamment ceux en santé, favorisent l'égalité entre les genres. Privatiser le système de santé, c'est priver des femmes d'emplois syndiqués, c'est appauvrir des femmes en leur retirant « des gains obtenus par le mouvement féministe qui se sont traduits dans des lois ou des politiques gouvernementales extrêmement importantes pour les femmes : l'équité salariale, l'assurance parentale, le retrait préventif, un régime de retraite qui assure des prestations décentes, etc. » (16, p.65). C'est aussi retirer des soins et des services nécessaires à l'égalité entre les genres (26). Comme l'affirme le Réseau québécois d'action pour la santé des femmes : « Pas d'égalité sans santé » (25, p.1).

Injustice épistémique

Les injustices soulevées précédemment sont liées à une autre injustice, soit une injustice épistémique. La notion d'injustice épistémique a été introduite par la philosophe Fricker (27,28). Cette notion connaît à l'heure actuelle un engouement dans les théories féministes, mais aussi dans le monde de la santé (29). Il faut dire que celle-ci est pertinente et rend compte d'injustices de la vie quotidienne insidieuses, mais bel et bien réelles. L'injustice épistémique est liée à la connaissance, au savoir (*épitémè*) et se manifeste de deux manières, soit la capacité attribuée à une personne (généralement un groupe de personnes ayant des caractéristiques communes) de : a) produire des discours crédibles et b) comprendre des phénomènes complexes. Il s'ensuit que Fricker (27,28) distingue deux formes d'injustice épistémique, soit : a) l'injustice testimoniale et b) l'injustice herméneutique. La première, l'injustice testimoniale, se présente lorsqu'un interlocuteur est dévalué dans sa capacité à transmettre des connaissances avérées et donc à produire des discours considérés crédibles, pertinents et donc convaincants. Dans le présent contexte, suivant ce type d'injustice, il est possible d'affirmer que les discours de certaines professionnelles de la santé (infirmières, sages-femmes, ergothérapeutes, orthophonistes, etc.) ne parviennent pas à convaincre le gouvernement que ses pratiques managériales nuisent à la qualité des soins de santé et des services sociaux, et ce, en dépit des nombreuses évidences scientifiques qui vont en ce sens. Suivant l'effet de halo – qui est un biais cognitif suivant lequel un auditoire est plus facilement convaincu par un interlocuteur ayant les mêmes caractéristiques que lui qu'un interlocuteur ayant des caractéristiques différentes (30) –, le gouvernement constitué en majorité d'hommes de pouvoir se laisse convaincre par d'autres hommes de pouvoir. En ce sens, il s'agit d'une injustice épistémique de type testimoniale vécue par les professionnelles. Leur parole est dès lors perçue comme peu crédible ou moins crédible que celles d'autres interlocuteurs davantage valorisés socialement et d'ores et déjà en position de pouvoir. La seconde injustice épistémique est l'injustice herméneutique (27,28). Celle-ci se présente lorsque des personnes ne parviennent à exprimer leur vision des choses dans les paradigmes actuellement dominants. Cette injustice est vécue par les professionnelles qui ont de la difficulté à revendiquer leur autonomie professionnelle et promouvoir la qualité des soins, dans le contexte actuel où la NGP semble être la norme socialement désirable. Cette injustice est aussi vécue par certaines patientes, notamment celles qui présentent des problèmes de santé mentale ou qui sont très jeunes ou âgées. On présume alors souvent à tort que celles-ci n'ont pas les capacités de comprendre et qu'il vaut mieux, pour leur bien, prendre pour elles les décisions qui les concernent. De la même manière, les décisions qui sont prises de manière autoritaire et sont imposées aux professionnelles correspondent aussi à une injustice

épistémique de nature herméneutique. C'est pourquoi Medina (31) affirme que les injustices épistémiques (testimonial et herméneutique) sont intimement liées aux injustices sociales.

Conclusion

En conclusion, nous estimons que les modes managériaux actuels sont préoccupants, notamment parce qu'ils sont liés à des enjeux éthiques qui bafoient des valeurs sociales importantes, soit l'autonomie professionnelle, la qualité des soins, l'égalité interprofessionnelle, l'égalité de genre et la justice épistémique. Nous considérons que plus d'attention devrait être portée à ces enjeux éthiques, voire ces injustices sociales qui sont liés à une transformation radicale et néolibérale des fondations mêmes de notre système de santé. À l'instar de chercheuses qui adoptent parfois la posture de la « *slow professor* » (32) pour résister à la culture de la vitesse et de la performance dans le monde académique, les professionnelles de la santé peuvent adopter la posture de la « *slow therapist* » pour contester ces modes managériaux et ainsi prendre soin d'elles et protéger les valeurs qui leur sont chères. Néanmoins, cette solution ne saurait régler le problème à sa source. Une révolution managériale serait-elle dès lors de mise pour remettre au cœur de nos organisations de santé des valeurs humanistes plutôt qu'économistes afin que celles-ci soient véritablement au service de la santé, du bien-être, de la qualité de vie, de l'autonomie, de l'égalité et de la justice?

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Références

1. Bouchard MC. [Les infirmières sont toujours au bout du rouleau](#). La Tribune. 2019;31 janvier.
2. Trahan B. [L'épuisement gagne aussi les sages-femmes](#). Le Nouvelliste. 2019;31 janvier.
3. Bélizile F. [Autre cri du cœur dans le réseau de la santé](#). 96,5 CKMN.FM. 2018;28 février.
4. Bibeau A. [Une réforme qui continue d'inquiéter... Mot du président-directeur général](#). *Ergothérapie Express*. Le bulletin de l'Ordre des ergothérapeutes du Québec. 2018;29(1):1-2.
5. Swisher LL, Arsalin IE, Davis CM. [The Realm-Individual-Process-Situation \(RIPS\) model of ethical decision making](#). HPA Ressource. 2005;53(1):3-8.
6. Banoun A, Rochette C. [Le gestionnaire public au cœur de logiques contradictoires : Le cas des centres de services partagés](#). *Revue Française de Gestion*. 2017;3(266):11-30.
7. Jetté C, Goyette M. [Pratiques sociales et pratiques managériales. Des convergences possibles?](#) *Nouvelles pratiques sociales*. 2010;22(2): 25-34.
8. Chénard J, Grnier J. [Concilier des logiques pour une pratique de sens : exigence de solidarité](#). *Intervention, la revue de l'Ordre des travailleurs sociaux et des thérapeutes conjugaux et familiaux du Québec*. 2012;1:18-29.
9. Sereno MN. [Logique bureaucratique et logique professionnelle](#). *Direction*. 2001;87:38-39.
10. Bourque M. [Le nouveau management public comme prémisses aux transformations des systèmes de santé nationalisés : les cas du Québec et du Royaume-Uni](#). *Revue Gouvernance*. 2007;4(1):1-13.
11. Grenier J, Bourque M. *Les services sociaux à l'ère managériale*. Québec : PUL; 2018.

12. Dubois C-A. [Renouveau managérial dans le contexte des réformes des services de santé : mirage ou réalité?](#) Sciences sociales et santé. 2003;21(4):41-71.
13. Landry S, Beaulieu M. Lean, kata et système de gestion au quotidien. Réflexions, observations et récits d'organisations. Montréal : JFD; 2016.
14. Fortier I. [La « réingénierie de l'État », réforme québécoise inspirée du managérialisme](#). Revue française d'administration publique. 2010;136:803-820.
15. Dubé C. Vers des solutions : l'APTS propose. Dans N Baillargeon (dir.). La santé malade de l'austérité : Sauver le système public... et des vies! Saint-Joseph-du-Lac: M. Éditeur; 2017.
16. Larocque L. Notre système de santé : historique, diagnostic, remèdes. Dans N Baillargeon (dir.), La santé malade de l'austérité : Sauver le système public... et des vies! Saint-Joseph-du-Lac: M. Éditeur; 2017:55-67.
17. Wittorski R, Roquet, P. [Professionnalisation et déprofessionnalisation: des liens consubstantiels](#). Recherche et formation. 2013;72:71-88.
18. Leblanc I. Pour un régime public. Dans N Baillargeon (dir.), La santé malade de l'austérité : Sauver le système public... et des vies! Saint-Joseph-du-Lac: M. Éditeur; 2017:69-85.
19. Wilkinson R, Pickett K. L'égalité, c'est mieux. Pourquoi les écarts de richesses ruinent nos sociétés. Montréal: Les éditions écosociété; 2013.
20. Forest J, Dagenais-Desmarais V, Crevier-Braud L, Bergeron É, Girouard S. [Le lien entre la santé mentale et la satisfaction des besoins d'autonomie, de compétence et d'affiliation sociale](#). Gestion. 2010;35(3):20-26.
21. Smith HC. Austerity and the rise of hostility towards marginalized groups. Dans D Sakellariou et N. Pollard (dirs.), Occupational Therapies Without Borders. Integrating Justice with practice, Toronto, Elsevier, 2017;49-61.
22. Baillargeon N. La santé malade de l'austérité : Sauver le système public... et des vies! Saint-Joseph-du-Lac : M. Éditeur; 2017.
23. Benoit J. Banque mondiale, austérité et marchandisation du système public de santé et des services sociaux. Dans N Baillargeon (dir), La santé malade de l'austérité : Sauver le système public... et des vies! Saint-Joseph-du-Lac : M. Éditeur; 2017:31-54.
24. ONU-Femmes. [Le progrès des femmes dans le monde 2015-2016](#). Transformer les économies, réaliser les droits; 2015.
25. Réseau québécois d'action pour la santé des femmes (RQASF). [Pas d'égalité sans santé. Mémoire déposé à la ministre responsable de la condition féminine dans le cadre des consultations en vue du futur Plan gouvernemental en matière d'égalité entre les femmes et les hommes](#); 2016.
26. Nussbaum MC. Femmes et développement humain: l'approche des capacités. Paris : Des femmes – Antoinette Fouque; 2008.
27. Fricker M. Epistemic injustice: Power and the ethics of knowing. Oxford: Oxford University Press; 2007.
28. Fricker M. [Replies to Alcoff, Golberg, and Hookway on epistemic injustice](#). Episteme. 2020;7:164-178.
29. Leblanc S, Kinsella EA. [Toward epistemic justice: A critically reflexive examination of 'sanism' and implications for knowledge generation](#). Studies in Social Justice. 2016;10(1):59-78.
30. Kahneman D. Système 1 / Système 2 : Les deux vitesses de la pensée. Paris: Flammarion; 2012.
31. Medina J. The epistemology of resistance: Gender and racial oppression, epistemic injustice, and the social imagination. Oxford: Oxford University Press; 2012.
32. Berg M, seeber BK. The Slow Professor. Challenging the culture of speed in the academy. Toronto: University of Toronto Press; 2017.

LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

COVID-19 : comment résoudre la crise?

Henri-Corto Stoeklé^a, Christian Hervé^b

Mots-clés

COVID-19, bioéthique, crise, utopie, approche systémique, pensée complexe

Keywords

COVID-19, bioethics, crisis, utopia, systemic approach, complex thinking

Cela fait désormais plusieurs mois que de nombreux pays sont durement touchés par la pandémie du COVID-19. En l'espace de quelques semaines, nous avons pu observer l'engorgement des hôpitaux, en particulier des services de réanimation, dans les régions du globe les plus touchées par la pandémie, notamment en Europe occidentale, en Extrême-Orient et en Amérique du Nord. La crise que nous traversons est véritablement mondiale, allant d'est en ouest, et bientôt du nord au sud.

Mais cette crise est bien plus qu'une simple crise sanitaire. Elle est avant tout une crise éthique, civilisationnelle, systémique, qui interroge les aspects tant : philosophiques (rapports entre l'économie et la santé) ; épistémologiques (rapports entre le soin et la recherche) ; politiques (rapports entre l'élite et le peuple) ; sociaux (rapports entre l'individu et le collectif) ; ou moraux (rapports entre les valeurs et les normes). À notre sens, cette liste, loin d'être exhaustive, révèle toute la complexité de la crise, et son importance à être comprise en toute transdisciplinarité.

D'un point de vue étymologique, le mot « crise¹ » vient du grec *krisis* qui signifie « décider ». Ainsi, une crise peut être définie comme un instant critique, accompagné d'une nécessité de décisions, probablement difficiles. Nous voyons que cette définition est parfaitement applicable à notre cas, celui de la pandémie du COVID-19. Pourtant, le philosophe français Paul Ricoeur, dans un article publié en 1988 dans la *Revue de Théologie et de Philosophie*, en proposa une autre que l'on peut qualifier de « transhistorique² », qui nous semble, peut-être, plus appropriée à la situation.

En effet, Ricoeur écrit : « Lorsque l'espace d'expérience se rétrécit par un déni général de toute tradition, de tout héritage, et que l'horizon d'attente tend à reculer dans un avenir toujours plus vague et plus indistinct, seulement peuplé d'utopies ou plutôt d'« uchronies³ » sans prise sur le cours effectif de l'histoire, alors la tension entre horizon d'attente et espace d'expérience devient rupture, schisme » (1). En d'autres termes, Ricoeur définit une crise comme l'instant où le décalage entre l'idée et le réel devient trop important et fait que les espérances possibles, celle d'une diminution de leur écart, s'effondrent.

Le COVID-19 est donc une crise, au sens où elle a révélé l'existence d'utopies : l'utopie d'une philosophie où l'économie primerait sur la santé ; l'utopie d'une épistémologie où la clinique serait déconnectée de la science ; l'utopie d'une politique où l'élite dominerait le peuple ; l'utopie d'une société où l'individu précéderait le collectif ; l'utopie où les normes seraient déconnectées des valeurs.

En ce sens, voilà pourquoi la bioéthique, transdisciplinaire et se prêtant à l'approche systémique (2) ainsi qu'à la pensée complexe (3), comme présentée dans une précédente lettre (4), est désignée comme l'un des meilleurs moyens à notre disposition pour tenter d'avoir un constat éthique sur leurs possibles survivances ou leurs corrections nécessaires pour rendre le monde d'après vivable et résoudre les effets de cette crise.

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¹ <https://www.larousse.fr/dictionnaires/francais/crise/20526>

² <https://www.universalis.fr/dictionnaire/transhistorique/>

³ <https://www.larousse.fr/dictionnaires/francais/uchronie/10910032>

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Références

1. Ricoeur P. [La crise : un phénomène spécifiquement moderne?](#) Revue de Théologie et de Philosophie. 1988;120:1-19.
2. Stoeklé HC. Médecine personnalisée et bioéthique : enjeux éthiques dans l'échange et le partage des données génétiques. L'Harmattan; 2017.
3. Morin E. Introduction à la pensée complexe. Editions du Seuil; 1990.
4. Stoeklé HC, Hervé C. [COVID-19 : quelle bioéthique après?](#) Canadian Journal of Bioethics Revue/Canadienne de Bioéthique. 2020;3(1):93-94.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Deploying the Precautionary Principle to Protect Vulnerable Populations in Canadian Post-Market Drug Surveillance

Maxwell J. Smith^a, Ana Komparic^b, Alison Thompson^b

Résumé

Les organismes de réglementation des médicaments visent à garantir que les patients aient accès à des médicaments sûrs et efficaces. Toutefois, quelle que soit la qualité des études préalables à l'autorisation de mise sur le marché, l'incertitude subsistera quant à la sécurité et à l'efficacité des médicaments nouvellement approuvés tant qu'une population nombreuse et diversifiée n'utilisera pas ces médicaments. Des analyses récentes du système canadien de surveillance des médicaments après leur mise sur le marché (PMDS) ont révélé que le PMDS du Canada doit être renforcé et que les efforts doivent être améliorés pour surveiller et traiter la sécurité et l'efficacité des médicaments approuvés parmi les populations vulnérables. Étant donné l'incertitude qui règne lorsque les médicaments entrent sur le marché, certains ont suggéré que le principe de précaution est pertinent pour guider la prise de décision dans ce contexte. Ce document répond aux recommandations selon lesquelles le système canadien de surveillance des médicaments après leur mise sur le marché devrait répondre aux besoins de santé des populations vulnérables en évaluant l'utilité de déployer le principe de précaution pour guider une stratégie post-commercialisation pour les populations vulnérables.

Mots-clés

principe de précaution, incertitude, populations vulnérables, surveillance des médicaments après leur mise sur le marché, réglementation pharmaceutique

Abstract

Drug regulatory bodies aim to ensure that patients have access to safe and effective drugs; however, no matter the quality of pre-licensure studies, uncertainty will remain regarding the safety and effectiveness of newly approved drugs until a large and diverse population uses those drugs. Recent analyses of Canada's post-market drug surveillance (PMDS) system have found that Canada's PMDS system requires strengthening and that efforts must be improved to monitor and address the safety and effectiveness of approved drugs among vulnerable populations. Given the uncertainty that exists when drugs enter the market, some have suggested that the precautionary principle is relevant to guiding decision-making in this context. This paper responds to recommendations that the Canadian PMDS system should be responsive to the health needs of vulnerable populations by assessing the utility of deploying the precautionary principle to guide a post-market strategy for vulnerable populations.

Keywords

precautionary principle, uncertainty, vulnerable populations, postmarket drug surveillance, pharmaceutical regulation

Introduction

An expansive literature exists that concerns itself with the principles and values that ought to govern the research, development, and oversight of pre-licensure pharmaceuticals, particularly with respect to how human participants and vulnerable populations ought to be treated (1-4). Reflecting movements to adopt a life-cycle approach to drug regulation (5), interest is now increasingly turning toward assessing the appropriate mechanisms that ought to guide the surveillance, evaluation, and regulatory management of pharmaceuticals once they have been approved and licensed for public consumption (hereafter understood as 'post-market surveillance').

Yet, the attention paid thus far to the welfare of vulnerable populations in Canadian post-market surveillance has been surprisingly asymmetrical relative to pre-licensure drug research. This is problematic because certain vulnerable populations may be at increased risk of suffering adverse reactions from newly approved drugs or may require special consideration for increased protection due to systematic disadvantage. This paper therefore seeks to analyze how the interests and welfare of vulnerable populations might be better incorporated into Canadian post-market drug surveillance.¹ In particular, given the uncertainty that exists when drugs enter the market, this paper examines the prospect of adopting the precautionary principle as a guide to decision-making to achieve this aim – a principle that is increasingly cited in drug safety (6-8) and which emphasizes that precautionary measures should be taken when an activity raises threats of harm, even when cause and effect relationships between that activity and harm are not fully established. We proceed by providing a brief description of Canada's post-market surveillance system, discuss what we mean by 'vulnerable populations' and the 'precautionary principle', and then examine whether and how the precautionary principle might be deployed to protect vulnerable populations from harm in this context.

Post-Market Surveillance of Drugs in Canada

Historically, a significant number of drugs have been found to have serious health concerns only *following* approval for public use. For instance, 23.7% of drugs examined between 1995 and 2010 demonstrated a serious safety issue post-approval in Canada (9). Post-market surveillance is a systematic mechanism to monitor, assess, manage, and report on these issues.

¹ This paper is concerned chiefly with post-market surveillance as it applies to drugs, and not necessarily to biologics or vaccines. This is not to say, however, that the analysis cannot be similarly considered in light of health products other than drugs.

Once drugs receive market approval from Health Canada, the Marketed Health Products Directorate (MHPD) within Health Canada's Health Products and Food Branch (HPFB) conducts monitoring. Operated by the Canada Vigilance Program, reports of suspected adverse drug reactions submitted by health professionals, drug manufacturers, and consumers both domestically and internationally are collected and subsequently analyzed for risk signals and safety trends. Signal detection involves a "preliminary indication of a product-related safety issue," where "assessment consists of the scientific/medical review of multiple data sources to analyse risks and benefits, while determining the likelihood of the association between the reaction and the health product" (10). Once risks are identified, Health Canada may then choose to initiate a risk management approach, which may include the communication of risk to health professionals and the public, labelling changes including black box warnings, and recommending the removal of a product from the market. In order to determine which action to take in the presence of a risk signal, Health Canada applies a risk-based approach that prioritizes safety issues and conducts an analysis to determine whether any further action is required.

In a move to increase capacity for active surveillance of post-approval drugs, the Drug Safety and Effectiveness Network (DSEN) was created in 2009 within the Canadian Institutes of Health Research (CIHR), which is at arm's length from Health Canada. DSEN is tasked with carrying out post-approval studies in response to potential safety signals of authorized pharmaceuticals identified by Health Canada, with the objective of generating evidence to support policy decisions at the federal and provincial/territorial levels. DSEN responds to requests for more information from regulators, health technology assessors, drug plan managers, and policymakers. Some of the research DSEN has funded, for instance, has found high-potency statin drugs causing acute kidney injury, but the Network's overall effectiveness has been questioned, largely due to insufficient funding (11). CIHR's Strategy for Patient-oriented Research (SPOR) also contributes to post-market surveillance in Canada through funding investigator-initiated research (12).

Despite these initiatives, analyses of Canadian post-market surveillance activities published within the past decade have argued that Canada's post-market surveillance system requires strengthening, and in particular, have noted that efforts must be improved to monitor and address the safety and effectiveness of approved drugs among population subgroups, such as children, pregnant women, the elderly, and First Nations, Métis, and Inuit populations. For instance, a 2011 Report by the Auditor General of Canada on the regulation of pharmaceutical drugs noted that Health Canada had not implemented a strategy for monitoring adverse drug reaction reports from vulnerable populations (13) – something that was also labelled an 'issue of concern' in a 2013 Report on post-market drug safety and effectiveness surveillance by the Canadian Standing Senate Committee on Social Affairs, Science and Technology (12, p.7). Overall, it has been noted that the adverse drug reaction reports submitted to Health Canada represent less than 10% of the actual total, with others noting that this number may more likely be less than 5% (12-13). In the absence of significant system overhaul and improvement in reporting rates, a different approach for risk-benefit analysis and risk communication about potentially harmful drugs may be warranted.

While the need to strengthen post-market surveillance for vulnerable populations has been recognized in Canada, there has been limited discussion of what it requires in practice, and in particular, when and on what grounds different approaches to post-market surveillance may be justified. For example, the Senate Report offered 19 recommendations to strengthen post-market pharmaceutical safety and effectiveness surveillance in Canada, including calling for greater investment into post-market surveillance and granting Health Canada greater regulatory authority for requesting post-market surveillance studies and making labelling changes for marketed drugs (12). Furthermore, in recognition of the need to collect post-market data from population subgroups, recommendation 12 called for "the implementation of a post-approval strategy for drug manufacturers and/or the Drug Safety and Effectiveness Network to conduct studies of new drugs in relevant sub-groups of the population." (12, p.23) The Report also specifically recommended that a modernized drug regulatory framework include "systematic safety reviews of drugs used in the paediatric population." (12, p.24) Nonetheless, the Report provided little guidance with respect to criteria for determining an appropriate or ethically justifiable post-market surveillance strategy for vulnerable populations. Our analysis of the precautionary principle and its component features and implications highlights normative considerations relevant to the development of strategies aimed at improving the safety and effectiveness of drugs used by members of vulnerable populations.

On 'Vulnerable Populations'

A prerequisite for developing a specific post-approval strategy for 'vulnerable populations' or 'relevant population subgroups' is the ability to identify and characterize such groups. Other than identifying categorical examples of groups traditionally considered to be vulnerable by virtue of their routine exclusion from clinical trials (e.g., 'children,' 'the elderly'), the aforementioned reports do little to characterize which other population subgroups may be relevant, or specify the criteria through which such subgroups ought to be identified. A post-approval surveillance strategy for vulnerable populations will require some specificity if it is to meaningfully and consistently identify those groups for whom it is supposed to be concerned.

A significant literature has devoted itself to the analysis of what constitutes 'vulnerability' and 'vulnerable populations.' It is beyond the scope of this paper to reflect on what this could, or ought to, mean in any robust manner. However, it is worth noting that some population subgroups could be considered vulnerable *a priori* by virtue of their exclusion from pre-licensure clinical trials. As such, special attention – whatever that means at this point – in surveillance and risk management activities could be paid to those groups who have been excluded from the pre-licensure studies. Even if included in clinical trials, though,

some population subgroups may prove vulnerable for other reasons, due to genetic, biological, behavioural, or social factors, and may therefore be worthy of special attention in post-market surveillance activities. Those populations who are at higher risk of morbidity and mortality due to age, genetic mutations, or physiological factors, for instance, may be one basis for special consideration. Focus exclusively on these biological considerations, though, may mean that vulnerabilities arising from systematic social, economic, and political marginalization and disadvantage will be altogether missed. For instance, how certain populations are socially and economically situated may affect their capability to access drugs or comply with drug regimens, thus exposing them to risks related to lessened effectiveness or even safety risks (14-15). The exclusion of social vulnerability in the assessment of effectiveness and safety among population subgroups in post-market surveillance in favour of the (sole) consideration of biological vulnerability could therefore lead to the omission of vulnerabilities that result from relevant social determinants of health and thereby fail to protect some vulnerable groups who might require enhanced surveillance and preventative health interventions.

Unfortunately, there is no way of knowing with complete certainty which groups will be most vulnerable to adverse drug reactions or harm resulting from diminished drug effectiveness. The use of population categories traditionally considered to be at risk (which justify their exclusion from pre-market clinical trials) – such as pregnant women, nursing women, children, and the elderly – is one approach. However, using such an approach for the real-world context may tend to include individuals or populations typically considered at risk, when in reality they are not at risk, and exclude those that actually are at risk (and, again, neglect those who may be socially vulnerable for other reasons) (16). Relying on fixed, predetermined categories of (predominantly biological) vulnerability may neglect contextual factors that will be necessary to remediate if population subgroups are to be adequately protected from harm. Engaging with communities that are expected to use particular drugs may be one strategy to reveal important information about how surveillance and risk management interventions ought to be conducted, as communities may be aware of their unique (biological and social) vulnerabilities (17). As will become apparent in the following section, this strategy would be aligned with the Government of Canada's *Framework for the Application of Precaution in Science-Based Decision-Making about Risk*, which asserts that decisions guided by the public's chosen level of protection against risk ought to be considered legitimate (18). Ultimately, a community's chosen level of protection against risk will be intimately linked with that community's understanding and awareness of their own vulnerabilities.

Precautionary Principle

The precautionary principle is derived from environmental risk management policy and has more recently been applied to public health decision-making (19-21). There is no consensus definition or interpretation – legal or otherwise – of the precautionary principle in either environmental or public health policy. Two oft-cited definitions are provided here in order to develop an understanding of the core elements of the principle.

Rio Declaration on Environment and Development

Where there are threats of serious or irreversible damage, lack of full scientific certainty shall not be used as a reason for postponing cost-effective measures to prevent environmental degradation (United Nations, 1992) (22).

The Wingspread Consensus Statement on the Precautionary Principle

When an activity raises threats of harm to the environment or human health, precautionary measures should be taken even if some cause and effect relationships are not fully established scientifically. In this context the proponent of an activity, rather than the public, bears the burden of proof (Wingspread Conference Participants, 1998) (23).

Key elements present in both formulations of the precautionary principle, and most others, include the potential for an irreversible or serious harm to health, the need to make a decision or take preventive and/or anticipatory action, and a lack of scientific certainty. Formulations like the Wingspread Statement also include exploring a wide range of alternatives to the potentially harmful actions, increasing participation from the public in decision-making, and shifting the burden of proof of a cause and effect relationship from the public (e.g., a decision-maker) to the proponent of the activity or product. In short, the precautionary principle advances that, in situations where risk of serious or irreversible harm exists, a greater level of uncertainty shall not be a reason for policymakers not to take action to protect against that risk. Precautionary reasoning may be viewed as a recognition that acting under conditions of scientific uncertainty relies on the distinctly political process of determining an 'acceptable' level of risk (24).

Stephen John distinguishes between two common motivations behind the precautionary principle (25). On the one hand, the precautionary principle may be interpreted as suggesting a lowering of the epistemic standards used to appraise evidence in a certain class of outcomes that are, or ought to be, viewed as special (e.g., on account of their severity or irreversible nature or due to the fact that they occur among particular population groups), and accordingly cannot be assessed solely through standard means of appraisal, such as traditional risk-benefit analysis. Conversely, the precautionary principle may be interpreted as suggesting a duty-based recognition of the wrongness of different types of risks (e.g., risks to the health of vulnerable populations).

The precautionary principle can be formulated in its strong or weak form. The strong form, which is reflected in the Wingspread Statement, claims that regulation is required *whenever* a risk of harm to health exists *even if* evidence supporting the existence of such a risk is speculative. The strong formulation usually does not consider the costs associated with applying the principle. The weak form, on the other hand, merely proposes that precautionary action not be precluded simply due to a lack of evidence, particularly if the consequences of not taking action would be serious and irreversible. Here, benefits of precautionary action may be weighed against its associated costs (26).

The precautionary principle has been adopted in numerous international treaties, legislations, and policies. Debate about the relevance of the precautionary principle to post-market surveillance and pharmaceutical risk management in particular is still in its early stages; that is to say, the principle has been identified as having some relevance in this context but it is not yet clear whether, how, and when it ought to be used in decision-making within an improved post-market surveillance regulatory system (6-8,27-30). In Canada, there has been a long history of applying precaution in federal regulatory decision-making about risk (18). Advocating for an approach aligned with the precautionary principle is not a novel idea in public health, either. Indeed, two Canadian judicial inquiries, the Krever Commission of Inquiry on the Blood System in Canada and the Campbell Commission following the outbreak of Severe Acute Respiratory Syndrome (SARS), recommend the use of the precautionary principle to guide Canada's response to public health threats (31-32). Additionally, Health Canada identifies using a precautionary approach as one of its three guiding principles in the Health Canada *Decision-Making Framework for Identifying, Assessing, and Managing Health Risks*, and released a framework in 2003 to guide the application of precaution in science-based decision making about risk in areas of federal regulatory activity for the protection of health and safety (33). The latter framework, hereafter referred to as the 'Canadian Framework,' describes 10 guiding principles that are meant to achieve the "coherent and cohesive application of precaution" in federal decision-making in contexts of uncertainty, which are outlined in Table A.

Table A: Government of Canada (2003) principles for the application of precaution in science-based decision making about risk

<ol style="list-style-type: none"> 1. The application of precaution is a legitimate and distinctive decision-making approach within risk management. 2. It is legitimate that decisions be guided by society's chosen level of protection against risk. 3. Sound scientific information and its evaluation must be the basis for applying precaution; the scientific information base and responsibility for producing it may shift as knowledge evolves. 4. Mechanisms should exist for re-evaluating the basis for decisions and for providing a transparent process for further consideration. 5. A high degree of transparency, clear accountability and meaningful public involvement are appropriate. 6. Precautionary measures should be subject to reconsideration, on the basis of the evolution of science, technology and society's chosen level of protection. 7. Precautionary measures should be proportional to the potential severity of the risk being addressed and to society's chosen level of protection. 8. Precautionary measures should be non-discriminatory and consistent with measures taken in similar circumstances. 9. Precautionary measures should be cost-effective, with the goal of generating (i) an overall net benefit for society at least cost, and (ii) efficiency in the choice of measures. 10. Where more than one option reasonably meets the above characteristics, then the least trade-restrictive measure should be applied (p. 6-13).

Source (36, p.13)

A significant literature now exists that seeks to clarify or modify the directives of the precautionary principle, and an equally significant literature exists seeking to critique the principle on several grounds.² While certainly relevant to the broader discussion, it is beyond the scope of this paper to incorporate either a defence of the principle or advocate for a particular interpretation of the principle that ought to be employed. Rather, the purpose of this paper is perhaps more practical: to apply a common interpretation of the precautionary principle to the context of post-market surveillance in Canada with special attention given to the guidance provided by the Government of Canada Framework in its assessment of the precautionary principle as a guide for a post-market strategy for vulnerable populations. While the analysis that follows could no doubt be challenged according to several criticisms of the precautionary principle itself (and these are welcomed, as this can only help advance the discussion), it warrants consideration in this context if not only because the precautionary principle will inevitably be considered relevant by policy-makers and decision-makers in this context because (a) the Government of Canada acknowledges the importance of the precautionary principle in federal decision-making about risk, and (b) the precautionary principle appears to be of *prima facie* relevance in post-market surveillance due to the inherent context of uncertainty and the heightened uncertainty surrounding post-market drug safety and effectiveness among vulnerable populations.

² For example, the precautionary principle has been criticized as being internally inconsistent, vague, an obstacle to innovation, and conducive to paralyzing decision-making. Debate also exists as to whether the precautionary principle ought to be considered a principle at all. Many criticisms are outlined in (18).

Precautionary Principle, Post-Market Surveillance, and Vulnerable Populations

Protecting Vulnerable Populations from Harm

A core presumption of the precautionary principle is the importance of protecting the public good, or in this context, the public's health (28). This requires drug regulators to favour those measures that protect public health, even if evidence of a threat to the public's health has not been fully established. This contrasts with scenarios where activities or products are assumed to be safe until demonstrated otherwise. When a presumption exists that an approved drug is safe until concerns of safety emerge, patients, especially those for whom no previous safety information exists, are put at increased risk. Accordingly, if they are to protect the public from harm, drug regulators guided by the precautionary principle should not assume, based on pre-licensure clinical trial information and even market approval, that drugs are safe until proven to be dangerous (6). A post-market surveillance strategy guided by the precautionary principle would therefore aim to *avoid* potential harms before a more complete picture about the existence of those harms emerges.

One of the primary features of public health and, indeed, the precautionary principle, is taking preventive and/or anticipatory action to mitigate a serious or irreversible harm to the population's health. Of course, in order to be able to take such anticipatory action, information will be required about whether risk of harm exists, might exist, or might soon exist. This information, if not available from pre-licensure studies, is generated from surveillance activities, including post-market research. Thus, surveillance activities capable of informing decision-makers such that they are able to *anticipate* and *prevent* serious or irreversible harm to the population's health, and not simply react to such harms once they emerge, should be considered a requirement of a precautionary approach to post-market surveillance.³ This has significant implications for a post-market surveillance strategy for vulnerable populations. Because even less information about drug safety and effectiveness tends to be available for vulnerable populations following market approval, targeted, active surveillance may be necessary to generate the safety and effectiveness data required to trigger swift risk management interventions if diminished effectiveness or safety concerns obtain in those populations.⁴ By contrast, a traditional risk assessment paradigm may not warrant the proactive implementation of special measures to capture safety and effectiveness information for vulnerable populations, but rather await the emergence of safety signals within such populations through universal, passive surveillance before more targeted surveillance, post-market studies, or risk management measures are initiated.

Once signals of a drug's diminished effectiveness or safety emerge, the precautionary principle might also be instructive for the initiation of risk management measures. The determination of whether, and how, to intervene following a safety signal in post-market surveillance, if based on an examination of known causal relationships between a drug and a safety concern, may result in the affected population sustaining harm while enough data is collected to be able to infer a causal relationship, which would constitute a failure of the drug regulator to mitigate substantial harm to the public's health. By contrast, the precautionary principle permits the introduction of risk management measures to prevent harm to the public's health even in the absence of scientific certainty of a threat. For example, in the past Health Canada has issued warnings or other public advisories about potential safety concerns before a safety assessment was completed – an activity that seems aligned with this precautionary approach (12). This contrasts with a *reactive* approach that is more commonly taken by regulators through the use of passive adverse drug reaction reporting and the subsequent initiation of post-market studies.

In accordance with the presumption in favour of protecting the public's health, the precautionary principle may also militate against competing interests borne out of profit or other ends that may be of interest to the pharmaceutical industry, or in other words, "the putative ability of commercial producers to manipulate regulatory policies and decisions to their self-interested ends; either directly by exerting pressure on agency decision makers or indirectly through elected officials" (7, p.339). The worry is that drug regulatory policies and decisions may, at times, serve the interests of drug manufacturers rather than the public good due to industry influence on data collection and reporting (35). If these worries do indeed reflect reality, this ought to be troubling because the vast majority of safety and efficacy data resulting from pre-approval studies is generated from industry, and because industry may ultimately end up playing a greater role in post-market studies (35-36). There is all the more reason, then, to adopt a regulatory approach that is guided by a principle that has at its core a presumption in favour of protecting the public's health rather than acting in accordance with the presumption that a drug is safe until proven otherwise.

However, different degrees of protection may be required by the precautionary principle depending on whether it is understood in its weak or strong form. A weak formulation of the precautionary principle in this context would authorize, but not require, regulators to place constraints on the use of a drug that poses a threat to human health and allow regulators to balance risks and benefits when making that decision. Judgments could be made resulting in the acceptance of a given risk to health in virtue of a benefit or because it would be too costly to avoid. For instance, if safety signals emerge for a newly approved drug that addresses a serious, life-threatening, or severely debilitating disease or condition for which no alternative therapy exists, a weak precautionary approach may tolerate those risks in virtue of the benefits that may accrue from the drug and/or the harms that may be reasonably expected to result from initiating a risk management strategy (e.g., removing the drug from the market). On the other hand, if the comparative effectiveness of a newly approved drug is called into question as a result of

³ Furthermore, a precautionary approach may necessitate the inclusion of vulnerable populations in pre-licensure studies in order to generate pertinent information to protect vulnerable populations post-licensure.

⁴ Enhanced surveillance activities such as this have, for instance, been implemented within Canadian hospitals to actively monitor adverse events following immunization in paediatric populations (34). Similar surveillance activities do not exist, however, for other vulnerable populations or for other pharmaceutical products, like drugs.

post-market surveillance data, a weak precautionary approach may tolerate less exposure to risk, as a comparable therapy exists.

Alternatively, a strong formulation of the precautionary principle would require regulators to place constraints on a drug when a risk to human health is present regardless of potential benefits or costs of avoiding risk (7). A drug, therefore, may need to be removed from the market until it was demonstrated that it no longer posed the risk to health that caused it to be removed in the first place. An application of the precautionary principle in its strong form therefore raises important questions in this context about its unwillingness to permit the weighting of the relative benefits and harms that may accord to different populations. Two scenarios may emerge if strong precautionary action is taken: either safety signals will emerge from within vulnerable populations, resulting in the drug being removed from the market for further study (even if other ‘non-vulnerable’ populations may still benefit from the drug), or safety signals will emerge from within the general population, resulting in the drug being removed from the market for further study (even if vulnerable subpopulations may still benefit from the drug).⁵ Resolving what ought to be done in either case, it seems, would typically require some assessment of risks and benefits – something that is not countenanced by a strong formulation of the precautionary principle. This, it seems, could pose a problem for vulnerable populations. To avoid such aggressive actions but maintain special concern for vulnerable populations, other precautionary measures, like boxed warnings,⁶ could be utilized for those populations. As the Canadian Framework reminds us, a re-evaluation of decisions to take precautionary action may be triggered by the emergence of new information, such as evidence of harms that result from withdrawing a drug from the market, or from a change in society’s risk tolerance [18]. Ultimately, the weighing of risks and benefits tolerated by such measures will be based on values and priorities, which requires input from those affected by such decisions in addition to the broader public.

Proportionality

Some claim that the principle of proportionality is intrinsic to the precautionary principle (8,37). This means that precautionary safety measures ought to be proportionate to the level and severity of risk to human health, or the public’s chosen level of protection – something that may be achieved via broad and inclusive stakeholder engagement (18). Proportionate action required to protect the health of vulnerable populations in post-market surveillance may, *pro tanto*, require increased anticipatory safety measures (e.g., active surveillance) and more aggressive risk management for populations routinely excluded from pre-licensure clinical trials.

The implications of this are, for instance, that queries received by DSEN involving vulnerable populations ought to be prioritized for study, or that safety concerns ranked by Health Canada for review ought to be prioritized if they occur among populations considered to be vulnerable. Currently, both DSEN’s prioritization of queries to study and Health Canada’s ranking of safety concerns to review do not appear to take into account the population subgroups within which those safety concerns or queries originate (12). Another implication might be that more aggressive interventions, such as recommending removal of a drug from the market, would be more justifiable when safety signals are identified among vulnerable populations than when identified among other populations. At the moment, it may be difficult to justify the removal of a drug from the market if regulators require substantial evidence that a drug is the cause of a safety concern. Indeed, some have expressed concern about Health Canada’s lack of authority to enforce the withdrawal of a drug after the emergence of safety concerns (38). The precautionary principle could be used to justify the issuance of authority to Health Canada to enforce the withdrawal of a drug from the market (or to issue a boxed warning) even when a causal relationship between the drug and a safety concern has not been fully scientifically established.

Lowering the Evidentiary Threshold

The precautionary principle involves the lowering of the epistemic standards necessary to justify the implementation of measures to protect the population from harm. If the evidentiary standard required to initiate a risk management intervention of any kind (e.g., further study of a drug, removal of a drug from the market) is too high, then the public’s health may be threatened while waiting for that standard to be met. If the evidentiary standard required to initiate an intervention of any kind is too low, then the public may suffer unnecessary anxiety or fear, and drugs important for the health of the public may be under-accessed or not accessed at all. Thus, it is critically important to strike the right balance to determine what evidentiary standard ought to be required to initiate different regulatory interventions.

In its 2013 Report on post-market surveillance, the Canadian Standing Senate Committee on Social Affairs, Science and Technology emphasized that “there should not be a lower threshold of drug safety and effectiveness” for specific subgroups of the population, such as children, pregnant and nursing women, and the elderly (15, p.7). The Committee also asserted that “post-approval monitoring of prescription drugs must be strengthened in order to protect these subgroups” (p. viii), and suggested that this could be accomplished by including subgroups in pre-licensure clinical trials and by conducting post-approval studies and systematic safety reviews in relevant population subgroups. Finally, the Committee recommended that issues discovered by DSEN be considered for follow up studies.

⁵ The latter case, it seems, presents another sense in which such groups may be considered vulnerable.

⁶ A boxed warning is a warning included on a drug’s box or package insert indicating that the drug may carry significant risk of serious or life-threatening adverse reactions.

The key difference between traditional risk-benefit assessments and risk management decisions under the rubric of the precautionary principle is that a lower evidentiary threshold exists to take precautionary measures in decision-making under the rubric of the precautionary principle. Thus, perhaps in strengthening post-market surveillance to protect vulnerable populations, there should be an *increased* threshold of drug safety and effectiveness. This means that drugs must be demonstrably *more* safe and effective if they are to be used among vulnerable populations. This would, perhaps, require a lowering not of drug safety and effectiveness, but rather a lowering of drug safety and effectiveness evidentiary thresholds required to initiate a risk management intervention. Furthermore, as previously mentioned, a precautionary approach may require enhanced surveillance as a mechanism of precaution in the first place – a mechanism that seeks to rectify evidentiary deficits about drug safety and effectiveness among vulnerable populations. This may be particularly relevant for drugs that receive approval through Health Canada’s priority review system, where a shorter and arguably less stringent review process occurs for drugs that purport to address serious, life-threatening, or severely debilitating diseases or conditions.

Shifting the Burden of Proof

Perhaps the most significant insight that can be gleaned from the consideration of the precautionary principle in this context has to do with who bears the burden of proof to demonstrate drug safety and effectiveness in post-market surveillance. This burden of proof lies with the manufacturer when applying for regulatory approval. Once a drug is approved, however, this burden largely shifts from the manufacturer of the drug to the drug regulator. With that said, some proposals for post-market surveillance regulation consider giving drug regulators the authority to compel pharmaceutical manufacturers to undertake further post-market studies on safety and effectiveness (36).

Recall that the Wingspread Statement asserts that the “proponent of an activity, rather than the public, bears the burden of proof.” In the context of a threat to population health, the ‘activity’ at hand can be considered a drug, or the licensure and distribution of a drug. And, it seems intuitive that, because the drug manufacturer has been responsible for the development and marketing of the drug, that they more justifiably ought to be considered the proponent of the activity.

As such, a reading of the Wingspread Statement’s formulation of the precautionary principle suggests that, in the context of a threat to population health, the drug manufacturer rather than the drug regulator may bear the burden of proof for demonstrating safety and effectiveness when an activity raises threats of harm to human health. In the current regulatory environment this is not the case, as industry-sponsored phase IV trials are not required by Health Canada and queries stemming from safety signals or about diminished effectiveness require a response from Health Canada and DSEN, not the drug manufacturer.

However, there are reasons, namely concerns of credibility stemming from potential conflicts of interest, that could caution against drug manufacturers bearing the sole burden in demonstrating a drug’s post-approval safety and effectiveness (39). This creates a potential challenge, as drug manufacturers and the pharmaceutical industry more generally may be in the best position to generate scientific data in a timely manner. Thus, innovative strategies involving collaborative arrangements among regulators, arms-length research and surveillance bodies, and drug manufacturers may be necessary in order to ensure the generation of scientific data is feasible, timely, and credible (18). As one option, to mitigate the spectre of conflicts of interest regulators could conduct (or fund) studies by third parties, or otherwise partner with third parties, to examine the safety of the drug.

Conclusion

Recent analyses of the Canadian post-market surveillance system have noted that efforts must be improved to monitor and address the safety and effectiveness of approved drugs among vulnerable populations. Consideration of how to identify and address the risks among vulnerable population within Canada’s post-market surveillance system, and whether to adopt a precautionary approach in this setting, is critical given Canada’s recent announcement that they are working to optimize the use of real-world evidence for drug regulatory decisions (40). While drug regulators involved in post-market surveillance must routinely operate in the context of uncertainty, heightened uncertainty about drug safety and effectiveness and, indeed, heightened risk exists for vulnerable populations. Given this heightened uncertainty and risk, the precautionary principle should be considered relevant to guiding decision-making in this context. Historically, the precautionary principle has arguably amplified the duties and powers of governments with respect to the protection of the environment (8). As such, it is similarly expected that, if applied in a post-market strategy for vulnerable populations, the precautionary principle may have the effect of amplifying duties and powers of drug regulators with respect to the protection of the health of society’s most vulnerable populations.

Pre-licensure drug studies produce at least some evidence about safety and effectiveness that could inform many post-market surveillance and risk management activities for the general population. As such, a traditional risk-benefit approach may benefit a post-market surveillance strategy. The question, then, may not be whether and how the precautionary principle ought to figure in Canada’s post-market surveillance system generally, but rather how it might be deployed in a post-market strategy to protect the health of vulnerable populations – populations for whom less evidence of safety and effectiveness tends to be available. Due to the increased uncertainty of risk and the enhanced potential for harm for vulnerable populations, a post-market strategy for vulnerable populations guided by the precautionary principle may be most appropriate to protect the health of those already disadvantaged. Without some consideration of the precautionary principle in this context, the post-market drug regulatory system in Canada could be considered unethical as it would place vulnerable Canadians at an unreasonably

heightened risk of exposure to drugs that may cause serious, though previously undetected, side-effects. Moreover, it would indicate a failure on the part of Health Canada to fulfil its mandate with respect to patient safety. The outstanding challenge in a precautionary approach, though, is to prevent the creation and/or exacerbation of vulnerability as a result of precautionary measures (e.g., from withdrawing a drug from the market). To better protect the health of vulnerable populations, the application of precaution with a post-market strategy ought to be guided by the unique health needs and awareness of community vulnerability that may exist among relevant population subgroups.

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None to declare

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References

1. Fisher CB. [A relational perspective on ethics-in-science decisionmaking for research with vulnerable populations](#). IRB Ethics Hum Res. 1997;19(5):1–4.
2. Emanuel EJ, Wendler D, Killen J, Grady C. [What makes clinical research in developing countries ethical? The benchmarks of ethical research](#). J Infect Dis. 2004;189(5):930–7.
3. Flaskerud JH, Winslow BJ. [Conceptualizing vulnerable populations health-related research](#). Nurs Res. 1998;47(2):69-78.
4. Zion D, Gilliam L, Loff B. [The declaration of Helsinki, CIOMS and the ethics of research on vulnerable populations](#). Nat Med. 2000; 6(6):615-7.
5. Health Canada. Forward Regulatory Plan 2019-2021: [Regulations amending the Food and Drug Regulations, Part C, and the Medical Devices Regulations \(Flexible Lifecycle-Based Licensing for Drugs and Medical Devices\)](#). Canada.ca. Ottawa (ON): Government of Canada; 2019.
6. Callreus T. [The precautionary principle and pharmaceutical risk management](#). Drug Saf. 2005;28(6):465-71.
7. Soule E. [The precautionary principle and the regulation of US food and drug safety](#). J Med Philos. 2004;29(3):333-50.
8. Osimani B. [The precautionary principle in the pharmaceutical domain: a philosophical enquiry into probabilistic reasoning and risk aversion](#). Health Risk Soc. 2013;15(2):123-43.
9. Lexchin J. [New drugs and safety: what happened to new active substances approved in Canada between 1995 and 2010?](#) Arch Intern Med. 2012;172(21):1680-1.
10. Health Canada. [Risk Classification of Good Pharmacovigilance Practices \(GVP\) Observations](#). Health Products and Food Branch Inspectorate.
11. Canadian Medical Association Journal Editorial. [Is Canada's drug safety network effective?](#) CMAJ, May 19, 2015, 187(8).

12. Ogilvie KK, Eggleton A, Cordy J, Dyck LE, Eaton N, Enverga T, et. al. [Prescription pharmaceuticals in Canada: post-approval monitoring of safety and effectiveness](#). Ottawa (ON): Standing Committee on Social Affairs, Science and Technology, Senate, Parliament, Canada; 2013 Mar [cited 2019 Jan 26]. 42 p. Catalogue No.: YC17-0/411-20E-PDF.
13. Maxwell N, Dube L, Carroll M, Andayo I, Lamontagne D, Ysselstein M. [2011 Fall report of the Auditor General of Canada](#) [Internet]. Ottawa (ON): Office of the Auditor General of Canada; 2011. Chapter 3, Regulating Pharmaceutical Drugs—Health Canada; [cited 2019 Jan 26]; [about 33 screens].
14. Gordillo V, del Amo J, Soriano V, Gonzalez-Lahoz J. [Sociodemographic and psychological variables influencing adherence to antiretroviral therapy](#). AIDS. 1999;13(13):1763-9.
15. Kaplan RC, Bhalodkar NC, Brown EJ Jr, White J, Brown DL. [Race, ethnicity, and sociocultural characteristics predict noncompliance with lipid-lowering medications](#). Prev Med. 2004;39(6):1249-55.
16. Mastroianni AC. [Slipping through the net: social vulnerability in pandemic planning](#). Hastings Cent Rep. 2009; 39(5):11-2.
17. Smith MJ, Bernard C, Rossiter K, Sahni S, Silva D. [Vulnerability: a contentious and fluid term](#). Hastings Cent Rep. 2010;40(1):5-6.
18. [A framework for the application of precaution in science-based decision making about risk](#). Ottawa (ON): Privy Council Office; 2003 [cited 2017 Jan 30]. 13 p. Catalogue No.: CP22-70/2003E-IN.
19. Kriebel D, Tickner J. [Reenergizing public health through precaution](#). Am J Public Health. 2001;91(9):1351-5.
20. [The treaty of Amsterdam amending the treaty on European Union, the treaties establishing the European communities and certain related acts](#). Luxembourg: Office for Official Publications of the European Communities; 1997 [cited 2017 Jan 28]. 144 p. ISBN: 92-828-1652-4.
21. Goldstein BD. [The precautionary principle also applies to public health actions](#). Am J Public Health. 2001;91(9):1358-61.
22. [Report of the United Nations conference on environment and development](#). New York: Department of Economic and Social Affairs, United Nations; 1992 Aug [cited 2017 Jan 30]. Report No.: A/CONF.151/26 (Vol. I)
23. Ashford N, Barrett K, Bernstein A, et. al. [Wingspread statement on the precautionary principle](#). Eugene (OR): Science & Environmental Health Network; 1998 [cited 2017 Jan 30]. 2 p.
24. Jensen KK. [The moral foundation of the precautionary principle](#). J Agric Environ Ethics. 2002;15(1):39-55.
25. John S. Risk and Precaution. In: Dawson A, editor. Public health ethics: key concepts and issues in policy and practice. New York: Cambridge University Press; 2011. p. 67-84
26. Sachs NM. [Rescuing the strong precautionary principle from its critics](#). Univ Ill Law Rev. 2011;1285.
27. Waller PC, Evans SJ. [A model for the future conduct of pharmacovigilance](#). Pharmacoepidemiol Drug Saf. 2003;12(1):17-29.
28. Gordon C. [International pharmaceutical social risk regulation: an ethical perspective](#). Acta Pharm. 2011;61(1):15-23.
29. Callreus T. [Pharmacovigilance and public health ethics](#). Pharmaceut Med. 2013;27(3):157-64.
30. Callreus T, Schneider CK. [The emergence of regulatory science in pharmaceutical medicine](#). Pharmaceut Med. 2013;27(6):345-51.
31. Campbell A. [The SARS commission interim report: SARS and public health in Ontario](#). Biosecur Bioterror. 2004;2(2):118-26.
32. Krever H. [Final report: commission of inquiry on the blood system in Canada](#). Ottawa (ON): Commission of Inquiry on the Blood System in Canada; 1997 [cited 2019 Jan 26]. 375 p. Catalogue No.: CP32-62/3-1997E-PDF.
33. Ross W, Birkwood P, Henter T, Krewsiki D, Muise AM, Nahas A. [Health Canada decision-making framework for identifying, assessing and managing health risks](#). Ottawa (ON): Health Canada; 2000 Aug 1 [cited 2017 Jan 30]. 80 p.
34. Scheifele D. [IMPACT after 17 years: Lessons learned about successful networking](#). Can J Infect Dis Med Microbiol. 2009;20(1):12-14.
35. Lexchin J. [Those who have the gold make the evidence: how the pharmaceutical industry biases the outcomes of clinical trials of medications](#). Sci Eng Ethics. 2012;18(2):247-61.
36. Bill C-17, Protecting Canadians from Unsafe Drugs Act (Vanessa's Law), 2nd Sess, 41st Parl, 2014
37. [Communication from the commission on the precautionary principle](#). Brussels: European Commission; 2002 Feb 2 [cited 2017 Jan 26].
38. [Bill C-17 An Act to amend the Food and Drugs Act - Protecting Canadians from Unsafe Drugs](#). Ottawa(ON): Canadian Medical Association; 2014 [cited 2017 Jan 26].
39. Lemmens T, Bouchard RA. Regulation of pharmaceuticals in Canada. In: Downie J, Caulfield T, Flood C, editors. Canadian Health Law and Policy. 3rd ed. Toronto: Butterworths; 2007. p. 318-87
40. Health Canada. [Optimizing the Use of Real World Evidence to Inform Regulatory Decision-Making](#). Health Products and Food Branch Notice.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Addressing the Ethical Issues Associated with Fieldwork Education in Occupational Therapy: Results of an Empirical Study Conducted in Quebec

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Résumé

Les ergothérapeutes qui contribuent à la formation clinique sont appelés à vivre des enjeux éthiques lorsqu'ils supervisent des stagiaires. Ces enjeux éthiques sont peu documentés dans les écrits et il en est de même des moyens mis de l'avant par les superviseurs pour les solutionner. Une recherche qualitative a été menée pour documenter ces enjeux et leurs solutions auprès d'ergothérapeutes du Québec-Canada. Vingt-trois ergothérapeutes ayant de l'expérience comme superviseurs ont participé à la recherche. Tous vivent des enjeux éthiques lorsqu'ils supervisent des stagiaires. Cet article présente les résultats relatifs aux moyens qu'ils utilisent ou envisagent pour résoudre les enjeux éthiques de la formation clinique. Ces solutions sont de nature intrinsèque ou extrinsèque. Les solutions intrinsèques sont liées aux compétences des superviseurs aux plans éthique, pédagogique ou ergothérapique. Les solutions extrinsèques sont liées aux mesures de soutien pouvant et devant être mises en place pour mieux soutenir les superviseurs et mieux reconnaître l'importante contribution des ergothérapeutes qui forment la relève ergothérapique dans les milieux cliniques. Cette recherche est susceptible d'avoir des retombées pour la clinique, l'enseignement, la recherche et la gouvernance.

Mots-clés

formation clinique, supervision, solution, enjeu éthique, ergothérapie

Abstract

Occupational therapists who contribute to fieldwork education are exposed to ethical issues when supervising trainees. Both the ethical issues and the solutions to address these ethical issues are undocumented in the literature. A qualitative study was conducted to document these issues and their solutions. Twenty-three occupational therapists with supervising experience participated in this study. All the participants reported experiencing ethical issues while supervising trainees. This article aims to present the solutions proposed by the participants in order to address the ethical issues of fieldwork education. Intrinsic solutions are linked to supervisors' ethical, pedagogical or occupational therapy competences. The extrinsic solutions deal with the appropriate measures which can and should be implemented so as to better support the supervisors' work and better recognize the important contribution of occupational therapists who train the next generation of occupational therapists in clinical settings. This study is likely to have implications on clinical practice, teaching, research and governance.

Keywords

fieldwork education, supervision, solution, ethical issue, occupational therapy

Introduction

Traineeships are an integral part of an occupational therapy student's education. Regardless of their country of origin, occupational therapy students must complete and pass a minimum of 1,000 hours of field training in order to obtain the diploma leading to the practice of the profession (1). Although fieldwork education is a prerequisite for occupational therapy, not all occupational therapists contribute to the preparation of future occupational therapists for a variety of reasons (2). On this subject, a plethora of writings has been published about insufficient fieldwork placements in the profession (3-11). However, although there is a great deal of literature about **fieldwork education** (12), little attention has been paid to the ethical issues associated with supervising trainees and, subsequently, the means of addressing these issues in practice. It should be noted that in this article we take an ethical issue to comprise any situation that jeopardizes conformity with at least one value (13). In this sense, a value refers to an ethical ideal that is distinct from a rule (which is imposed and sometimes related to sanctions) or from a principle (which is a statement that allows a value to be applied) (14). This article specifically discusses ways to address the ethical issues raised by fieldwork education in occupational therapy. However, before engaging with the solutions proposed to address these ethical issues, it is important to first address the ethical issues faced by occupational therapists who supervise trainees in clinical settings.

Our team conducted an empirical study to document the **ethical issues** associated with fieldwork education¹ through qualitative interviews with occupational therapy supervisors in Quebec (15). Similar to Barton and colleagues (3) and De Witt (15), we found that occupational therapists who contribute to the fieldwork education of the next generation of occupational therapists experience loyalty conflicts. These conflicts are ethical issues because they put professional roles under tension that are ultimately based on different ethical values and that are difficult to reconcile (16). Specifically, many feel divided between their roles as clinicians (loyalty to clients), supervisors (loyalty to trainees), employees (loyalty to their employers) (15), and guardians of the profession (loyalty to the profession). As with Drake and Irurita (17), Ilott (18), James and Musselman (19) and Le Maistre *et al.* (20), we also noticed that supervisors, when having to deal with trainees experiencing difficulties or failing, may themselves experience stress, perhaps even distress. As guardians of the profession, many supervisors do not feel comfortable with failing a student (13). We have also noted, as did Lemay (21), that the role of trainees' supervisor may be paradoxical. On the one hand, the supervisor must support the trainee's learning process (thus developing a pedagogical posture based on trust and proximity), while, on the other hand, the supervisor must evaluate the achievement of the objectives

¹ The article on the ethical issues in clinical training documented by our team is published elsewhere (13).

of traineeship (thus developing a normative posture based in neutrality and distance from the trainee). This may in turn result in a lack of neutrality or in biases on the part of the supervisor evaluating the trainee's learning process and competences. We also uncovered other ethical issues such as the difficulty some supervisors may encounter when teaching to their trainees in a work environment dominated by management practices that are oriented toward efficiency and productivity (22), thus leaving out important professional values like the quality of care, the client's dignity or professional autonomy (13). Another ethical issue has to do with the difficulty for many supervisors to support the development of their trainees' ethical and cultural competencies due to a lack of knowledge on these topics (13). Traineeship supervisors also noted various injustices in clinical settings. For instance, the support offered to supervisors may vary from one clinical context to another. Equally important is the fact that the responsibility for the fieldwork education is unfairly distributed amongst supervisors; i.e., it is frequently the same occupational therapists who are responsible for training the next generation of occupational therapists (13).

While it is relevant to shed light on these ethical issues, it is also important to document **ways to address them**, notably because these issues are likely to have negative repercussions for many individuals (e.g., clients, trainees, supervisors, colleagues, care partners) and organizations (e.g., trainee settings, universities, professional orders), if they are poorly resolved or ignored. For example, disregarding these issues may compromise the quality of trainee supervision and consequently the quality of occupational therapy services provided by trainees to clients. It can also cause distress to supervisors whose desire to contribute to fieldwork education may thus decrease, which may then limit the number of traineeship positions available to students. We therefore base our argument on the reasonable assumption that the greater the ability and commitment of the actors and organizations involved in fieldwork education to resolve these ethical issues, the more barriers to traineeships will be removed, the better will be the training provided to occupational therapy students, and the more comfortable, supported and recognized occupational therapists will feel in this essential role in the training of tomorrow's occupational therapists. This is why our team considers that the ethical issues of fieldwork education must be better known, as well as the means to address them.

Literature review regarding solutions

Our literature review in four databases (Academic Search Complete, CINAHL, PsycINFO and Medline) helped us identify 48 texts dealing with different issues related to fieldwork education in different health disciplines. Reading these texts allowed us to identify various ways to address the ethical issues of fieldwork education. The following provides a summary of these solutions.

To support the **development of supervisory competencies** required to provide quality fieldwork education for occupational therapists, some authors recommend that supervisors be better trained in pedagogy and teaching supervision, which may be accomplished through continuing education (3,7-10,23-26). According to Richard (27), this education should be mandatory to supervise a trainee. In addition, supervisors should be allowed to gain feedback on their supervision skills (8,28). Some authors also suggest that students be introduced to their supervisor's role at the beginning of their occupational therapy degree (3,26). Others suggest the pairing up of experienced and novice supervisors, that groups of supervisors be created or that communities of practice dedicated to supervision be established in the workplace (24,26).

Regarding the **failures** that may sometimes occur at the end of traineeships, some authors believe that universities should better prepare students for their traineeships (9,19,25,28,29). In addition, expectations for trainees must be made clear (30) and they must receive regular feedback from their supervisor on their achievement of the traineeship's objectives (17). Communication between traineeship settings and universities must be regular and accurate (7,19,28), and traineeship failures must be resolved in collaboration with the fieldwork coordinator at the student's home university (25). In addition, explicit policies and procedures must be established to manage these cases (31). Moreover, occupational therapists who agree to host students must be trained in pedagogy to ensure quality of their fieldwork education and they must be supported by universities when experiencing difficult situations with trainees (18,19,28,31) because these can be quite demanding (13).

To reduce the **paradox of fieldwork education**, Le Maistre, Boudreau and Paré (20) recommend that supervisors gradually move from a pedagogical posture based on trust and proximity to a normative posture based on neutrality and distance. These authors also suggest that formative assessments and self-evaluations made by the trainee should be integrated throughout the traineeship. They also believe communication between supervisor and trainee to be fundamental, perhaps even a key feature to the successful conduct of the traineeship. Communication must be continuous, clear and honest.

With respect to issues related to **work overload** and **performance pressure** experienced by supervisors, some authors believe that the clinical environment must better acknowledge and support the supervisor's work, particularly by reducing their workload (24,26,28). In addition, more resources must be allocated to the supervisors (time, training, online forums, etc.) (9). A third party should be responsible for the logistical aspects of hosting trainees (provide an identity card, an office, a key, a telephone, a computer access, etc.) (7,26).

As for the **fieldwork placements issue**, because not all occupational therapists contribute to this professional duty, several authors believe that the role of traineeship supervisor should be recognized even more, both financially and formally (3,5,7,8,10,11,26,32). One way to formally recognize this role would be to provide continuing education workshops for supervisors or to grant them an official title in addition to their professional one (7,26,32). Some authors also consider that the

traditional one-on-one supervision model is not ideal (4,7,8,10,11). These authors believe that other models of supervision should be explored and tested, such as having a supervisor oversee the traineeship of up to two or three trainees at a time, or perhaps to co-supervise.

Finally, to support **fairness** and **impartiality** in the evaluation of trainees, supervisors should have access to accurate and clear university documentation in order to facilitate a just assessment of their trainees' competencies (15,23,32).

These points sum up the solutions discussed in the literature to address the ethical issue of fieldwork education in occupational therapy. **Two main findings** emerged from our literature review. First, an analysis of these texts (n=48) reveals that only one study was conducted in Quebec, and it dealt with various health professionals outside the field of occupational therapy (26). Second, two types of solutions are documented in the literature: *intrinsic* solutions, i.e., solutions for which supervisors are responsible, and *extrinsic* solutions, i.e., solutions that pertain to the environments (micro, meso and macro) in which the supervisors work. Further, similar to Glaser (33), our team noted that micro-environmental solutions (solutions identified by individuals other than supervisors), meso-environmental solutions (solutions emerging from clinical settings) and macro-environmental solutions (solutions provided by universities or other social organizations) are documented in the literature.

The **research question** guiding our investigation was the following: What are the ethical issues associated with fieldwork education in occupational therapy experienced by Quebec occupational therapist supervisors and how do they propose to solve the ethical issues they encounter? This article presents the results of this study.

Research methods

Study design

An inductive research design was used due to the lack of knowledge currently available on the subject in Quebec (34). To better understand the phenomenon under investigation, a descriptive qualitative inductive research design was chosen (35). More precisely, this research is inspired by Husserl's (36,37) descriptive and transcendental phenomenology. That said, the purpose of the study here was not to describe the objects of consciousness, but to access the essence of the phenomenon being studied through interviews with the people who were best able to share their perceptions and experiences of the phenomenon (37). Our team has used this research design successfully in other studies aimed at documenting and assessing the ethical issues arising in the context of occupational therapy (39-41). This design is also widely used in the field of rehabilitation (34,35,38,42).

Participants

In order to gain the fullest possible insights, we sought out people already familiar and experienced with the topic of our research (34). We thus chose occupational therapists who had supervised at least one trainee. No exclusion criteria were used. We hoped to obtain a large and diverse pool of participants, in terms of gender, professional experience, pedagogy and ethics training, clinical setting, areas of practice (physical, mental, cognitive, social, public health), clientele (child, adolescent, adult or senior) and roles (clinician, fieldwork coordinator, lecturer, teacher, etc.). We also wanted to gain insights from occupational therapists working all over the province.

Recruitment

The *Ordre des ergothérapeutes du Québec* (professional regulatory college for occupational therapists in Quebec) sent an email invitation to occupational therapists who had given their permission to be solicited to take part in various studies. Potential participants were invited to contact the research assistant responsible for data collection. To ensure data saturation, four additional occupational therapists known to the team were approached by a research assistant to participate in the study. Because the data collection tools were written in French, we sought only French-speaking and French-reading occupational therapists.

Data collection

Once they had signed the consent form, participants were invited to fill out a socio-demographic questionnaire and to participate in a 45 to 90 minute telephone interview with a research assistant. Telephone interviews were favoured over Skype or other communication applications to reduce the bias of social desirability. Moreover, to avoid group contamination, individual interviews were favoured over focused groups. The interview schedule was based on the four types of ethical issues proposed by Swisher and colleagues (13). Having conducted several studies on the ethical issues in occupational therapy, the use of this typology has been found to allow occupational therapists to deepen their reflections and perceptions of the ethical issues raised by their practice without compromising the inductive nature of the research (43-49). Thus, after discussing the ethical dilemmas, temptations, silences and distresses of supervising trainees, participants were asked to discuss the means they use or could use to address these issues. The interview guide was sent to prospective participants by email. We believed that since it may sometimes be difficult to discuss ethics, giving participants the chance to read the interview guide before the actual interview could enable richer, more focused and clearer responses. The majority of participants had in fact taken the time to reflect on the ethical issues associated with fieldwork education and the means they employ to solve them. The interviews were digitally recorded in order to facilitate their complete transcription.

Data analysis

As suggested by Giorgi (39), who proposed five steps for applying the fundamental principles of Husserlian phenomenological reduction (36,37) in qualitative research, the following steps were carried out: 1) complete transcription of the collected narrative; 2) repeated reading of these narratives by each of the analysts; 3) progressive creation of themes via data extraction tables during workshops with all analysts; 4) formulation and organization of themes in the discipline's language; 5) synthesis of the results. This method of analyzing narratives has shown how occupational therapists attribute meaning to the means they use to solve the ethical issues of fieldwork education (40). No data analysis software was used; the analysts manually coded the data. Throughout their analyses and discussions, the analysts (i.e., the first three authors of the article) were committed to presenting the richness of the narratives collected. Several participants had the opportunity to provide feedback on the interpretation of the data following the presentation of the results at a workshop and during a scientific symposium. In all cases, this feedback validated the analysts' interpretations.

Ethical considerations

An ethics certificate from the Human Research Ethics Committee of the Université du Québec à Trois-Rivières (UQTR) was obtained to conduct this study. As noted earlier, all participants signed an informed consent form in order to participate. By way of appreciation, each participant was given a \$25 gift. Some participants refused compensation on the grounds that research funds are difficult to obtain, so these funds should support students and not them. Throughout the study, several considerations were at the heart of the team's research, including respect and fidelity to participants' comments, confidentiality, and recognition of their participation to name but a few examples.

Results

Participants in the study

As indicated in Table 1, twenty-three (n=23) occupational therapists in Quebec participated in the study. Among these, twenty (n=20) were women and three (n=3) were men. Participants ranged in age from 25 to 56, with an average age of 37. Concerning their experience, on average the participants had been occupational therapists for fourteen (14) years, with the least experienced participant having been an occupational therapist for three (3) years while the most experienced participant had thirty-five (35) years of experience. All participants had experience in supervising trainees. The participants shared an average of 8 years of experience in fieldwork education. The least experienced supervisor cumulated two (2) years of supervising experience while the most experienced had 23 years of experience in supervision.

Table 1: Description of participants

Participant	Age	Experience in occupational therapy (years)	Supervisory experience (years)
1	34	11	3
2	27	4	3
3	52	30	23
4	31	11	7
5	31	5	4
6	37	13	6
7	40	18	7
8	29	7	4
9	31	9	3
10	25	3	2
11	27	4	2
12	49	26	2
13	28	4	3
14	28	5	4
15	30	7	6
16	48	9	7
17	30	7	4
18	29	7	6
19	46	24	20
20	56	35	20
21	51	29	20
22	52	30	15
23	45	22	5

Nine participants had supervised between 1 and 5 trainees, eight participants had supervised between 6 and 10 trainees and six participants had supervised 20 or more trainees. The majority (n=15) had higher education degrees (professional or research master's degree, graduate certificate, etc.) while the minority (n=8) had a bachelor's degree in occupational therapy (university undergraduate degree). Most (n=20) had limited training in pedagogy (a few hours or days of training). Three

participants had taken university courses in pedagogy. The majority (n=13) had little training in ethics (no training or some training ranging from a few hours to days). Nine participants had completed at least one university course in ethics.

Most participants were clinicians (n=17) while three were fieldwork coordinators, and two were professors. Eight worked with adults, five with seniors, five with children and four with both adults and seniors. The majority (n=13) worked in physical health, three in mental health, three in cognitive health, three in various clientele groups and one in public health. Participants practiced the profession in eight of Quebec's seventeen administrative regions, including Montréal, Mauricie, Laurentides, Lanaudière, Estrie, Centre-du-Québec, Saguenay and Montérégie.

Addressing the ethical issues of fieldwork education

Two types of solutions were discussed by participants, namely: 1) *intrinsic* solutions, i.e., those for which supervisors are responsible, and 2) *extrinsic* solutions, i.e., those that relate to the environments in which supervisors work, namely other people (colleagues, trainees interns or superiors), clinical settings and organizations outside clinical settings (universities, the health system and professional associations or colleges). When discussing intrinsic solutions, participants referred to supervisors' professional competencies. When discussing extrinsic solutions, participants discussed the measures that have been or will be put in place to help supervisors. It should be noted that participants did not explicitly use these categories (intrinsic and extrinsic), which are derived from our own analyses.

Intrinsic solutions or three professional competencies

Figure 1 illustrates the intrinsic solutions, divided into three competencies, which occupational therapists accomplish. These competencies can help clinical supervisors to address the ethical issues of fieldwork education: ethical, pedagogical and occupational therapy-specific competencies. The following paragraphs explain and illustrate these competencies with excerpts from the interview transcripts.

Figure 1: Three competencies supporting the resolution of ethical issues in supervision



Ethical competences

Most participants discussed the actions they carried out to resolve the ethical issues of traineeship supervision, which are linked to ethical competencies. Although not all participants used ethical vocabulary to name these competencies, the actions they reported revealed their ethical competencies. For instance, regarding the shortage of clinical placements, one participant demonstrated **ethical motivation**. He believed that it was his duty to contribute to the education of the next generation of occupational therapists. He expressed himself as follows: "I consider that I have a clinical mission, an academic mission and a research mission" (participant 14). Invested with his university's mission, he was committed to doing his part in welcoming trainees. For him, this was an ethical responsibility and part of his professional duty.

When confronted with trainees in a situation of failure, some participants stated that **ethical courage** must be shown, i.e., one should not run away from the fact that failing a student does not deserve to pass his or her traineeship. Although this decision is very difficult, it takes courage not allow incompetent students to gain access to the profession. "Situations of failure are often where ethical situations can emerge.... Do we want this student to practice in a couple of months, if we give the student a passing grade, when we have serious doubts as to his/her competences?" (participant 14). In these situations, supervisors mention the importance of collecting and documenting the facts detailing their decisions. To facilitate the decision-making process, one participant explained using the following thought process: "Would I want this trainee to treat one of my relatives? ... If the student performed an intervention on one of my relatives, how would I feel? This helps me make a decision" (participant 19).

To identify the ethical issues related to fieldwork education, supervisors considered it important to recognize the emotions they experienced, to distinguish the values involved, and to take the time to assess verbally what they experienced with their trainees. These supervisors showed **ethical perception**, that is, they could identify the issue. Identifying and self-actualising with regard to their own values permitted them to express the ethical issues they experienced.

I feel it is important to understand yourself and to know what your values are. When we are at ease or when we feel there is an ethical conflict, I ask myself: "What value is being violated right now? Mine, or theirs?... What is happening?"... [I] take a moment to stop, then I discuss this with the student: "There, this happened. I feel uncomfortable or sad or I feel that the patient has not been respected. Not enough thought has been given to the professional autonomy of this or that other person" (participant 18).

To ensure impartiality and fairness in the evaluation of trainees, participants considered it important to manage their axiological or cognitive biases, which are based on information provided to them by various people regarding their trainees. In becoming aware of their biases (which can be either positive or negative) participants demonstrated ethical perception towards their trainees and in managing their biases.

Supervisors demonstrated their **ethical sensibility** viz. their ability to intuitively feel the presence of an ethical issue. For example, supervisors felt uncomfortable when circumstances were such that trainees were imposed on the clientele or made it seem that they gave their consent to be seen by trainees from the outset. For these supervisors, the free and informed consent of the clientele accompanied by trainees is primordial. Other supervisors paid particular attention to trainee confidentiality. For them, the importance of respecting confidentiality is relevant for both trainees and the clientele. With regard to neoliberal management methods, one participant considered that an ethical lens was essential to make administrators and managers aware of the values that should govern care and services for clients.

What could be helpful is if managers had appropriate training or sensitivity to this. Often, in terms of cuts, mergers, service restructuring, and, if in the process of adapting to change, there was this notion, the ethical aspect, if only to name the issue, to allow people to verbalize and all that, I think it would make it a lot less dramatic. I believe that, in this whole process of change, there would really be an advantage in identifying all situations with an ethical eye (participant 14).

Several supervisors considered that **ethical reflection** was important and useful in dealing with ethical issues pertaining to internship supervision. This was the ethical competence most discussed by participants: half referred specifically to this competence, while about one quarter of participants addressed another one (motivation, courage, sensitivity, ethical perception or judgment). To better reflect on the values involved in the ethical issues they uncover, some participants used reflective tools which allow them to further their analyses. "I need to take the time to think about it... I made a kind of conceptual map for myself to try to understand what was going on in the situation. I also referred to 'tools'" (participant 10). By questioning managerial methods, a participant added the following: "If all [managers and workers] had even basic training in reflective thinking to be able...to analyze the situation [through an ethical eye] and then realize: "Ok, I live in such discomfort, I live such an emotion with relation to such a situation: What action could I perform? What action could I not do again?"... By applying the principles of reflective thinking, I think it would be very useful in practice" (participant 4). Some participants used a decision-making scale to support their decisions, which involved considering different scenarios and identifying the consequences of the options available to them. Others used models to support ethical deliberation, such as the ten steps of ethical reflection developed by Drolet (42,51) or the "I-you-he/she" model used by Sylvie Boulianne (52), a physician who provides training to supervisors. "(The I-you-he/she) addresses clinical supervision in three steps to determine whether the problem stems from the patient or from the organization. This way of approaching ethics with the student is very imaginative, very concrete. I use this model with students when there is an ethical situation" (participant 14). Other participants prioritized the values at stake in the situation. "Do I prioritize the safety of clients or students,...the [trainee's] need to develop in the action or the clientele's need?...The most important thing is the vulnerable client. The student is in training, I will get back to her later if she feels hurt.... The clientele is vulnerable, it is necessary to protect them" (participant 19).

When participants think from an ethical perspective, they show **ethical judgment**. In other words, when supervisors take a moment to examine and develop their ethical decisions through an "ethical eye", they exercise their ethical judgment.

Pedagogical competencies

In addition to ethical competencies, clinical supervisors discussed the pedagogical competencies they use daily to solve the ethical issues of fieldwork education. More specifically, the majority of participants (n=15) discussed the importance for supervisors to develop their pedagogical competencies. Not only can these competencies enable the provision of quality fieldwork education to trainees, it can also facilitate the resolution of ethical issues that supervisors may encounter. When discussing the pedagogical competencies that supervisors should develop, participants raised the four following themes: 1) building a positive pedagogical relationship, 2) increasing learning, 3) providing constructive feedback, and 4) avoiding doing the tasks for the trainee.

For many supervisors, a **positive pedagogical relationship** between the supervisor and the trainee facilitates effective learning and helps the trainee to develop relevant competencies. These supervisors believed that it is important to take the time to get to know the trainee and to establish a relationship based on trust with him/her, which makes room for compassion and humanity. "Very often, the first day, the trainee arrives, and he/she has clients. [I take the time] to spend an hour, an hour and a half [with him/her] before beginning with the clients. [I want] just to get to know them...to understand their personality" (participant 16). The supervisor "needs to create a partnership in order to eventually confront trainees facing challenges so as to help him/her progress as a future occupational therapist" (participant 19). Without this alliance, learning is impossible. Most

supervisors emphasized the importance of having clear and frequent discussions with their trainees, which may involve scheduling periodic meeting times and frequent feedback concerning their progress in the traineeship.

Once trust has been established between supervisor and trainee, and both of them agree on the “traineeship contract” (participant 7), supervisors explained that it was necessary to **advance the learning** and **offer constructive feedback** to the trainee, all in order to support the development of their competences. As one participant summarized, it always comes down to “gradually raising expectations [and] bringing out one’s strengths” (participant 13). It is important to “bring out the positive”. These supervisors believed that it is important to confront their trainees with “just right challenge” type of situation so as to focus on their strengths while keeping in mind that the point of the traineeship is for the trainee to learn.

When I have a student in difficulty, it is more about sitting down with him/her in order to properly identify the aspects that are problematic, the skills I want him/her to work on, and then to develop an action plan with objectives upon which to work. In doing so, it is a question of increasing the difficulty of the task and finding the best methods of supervision to support it, to accompany it.... [It is relevant] to also return to the evaluation criteria for evaluating the traineeship, and then sometimes to discuss with the fieldwork coordinator [to check] whether there are other elements to consider (participant 7).

Moreover, supervisors insisted on allowing trainees to experiment and to test their knowledge, even if this might lead to mistakes. To put it differently, participants articulated the need to **avoid doing it for the trainee**. In a traineeship, the point is to offer trainees learning opportunities, which implies letting them experience various interventions for themselves. As one participant noted, although it is sometimes tempting to do things for trainees, “I let them experiment, do [things] their way” (participant 18). Supervisors insisted that trainees had a “right to make mistakes” (participant 23) because they are learning. It is through their experimentation that they can learn, train and grow as occupational therapists. Of course, that does not mean letting anything go. “A mistake for me is okay. We are here to [support their] learning....I will make corrections.... [On the other hand], if the error continues and continues,...it will be reflected in my comments or my rating when I do the assessment” (participant 6). In sum, although it may sometimes be tempting to perform some interventions for trainees, supervisors believed that it was more pedagogically beneficial for the trainees to let them do things in their own way, even if it is not perfect, as long as no professional misconduct is involved.

Occupational therapy-specific competencies

In addition to ethical and pedagogical competencies, some participants (n=6) discussed competencies related to roles in occupational therapy that can help to solve the ethical issues associated with fieldwork education. When they discussed such roles, supervisors proposed four related competencies, namely: a) the roles of the agent of change, b) the practice manager, c) the scholar-practitioner, and d) the professional. “We need to get the systems moving” (participant 22). To do this, supervisors must be **an agent of change**, which implies, “conveying messages to [decision makers] and using your influences....You must denounce and be in solution mode. Then, the solution, often, is found in several ways....Take everyone’s perspective and then find win-win solutions. To be the engine that connects the people you need to find the solution, that’s often what you need, and then to be visionary....You must have a vision, it helps us. You have a dream before [and you follow it]” (participant 22).

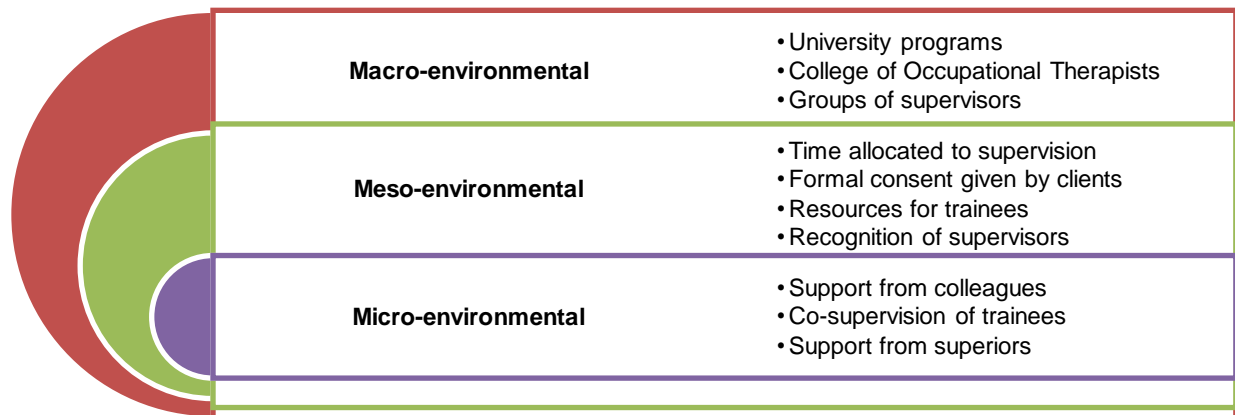
Several supervisors mentioned that supervision was time-consuming in their already busy schedules. Participants noted that they had implemented time management strategies which allowed them to free up their schedule to accommodate trainees. In this sense, they appeared to possess qualities related to the role of **practice manager**. Other supervisors updated their competencies pertaining to their role as a **scholar-practitioner** when training trainees. “I will read articles related to traineeship in order to develop my supervisory skills” (participant 7). Concerning an ethical issue that she had experienced with a trainee, one participant stated that she “looked for articles, documents that could help me to support myself, to make a more objective decision, in a situation where I was uncomfortable” (participant 10). As another participant summarized, “supervisors must equip themselves to deal with ethics” (participant 14). With respect to training he had received, one participant stated that “if I had not had this training, I would feel very helpless to discuss this subject [ethics] with the trainees” (participant 14). Finally, since ethics is a competency that falls within the role of a **professional**, several supervisors noted that accepting trainees requires a supervisor to have already developed their own professionalism.

The ethical, pedagogical and occupational therapy competencies that we have outlined so far can help supervisors to address the ethical issues associated with fieldwork education. Although these competencies are useful and necessary, they are often insufficient. Since the ethical issues that supervisors face have systemic dimensions, additional external resources are often required to address these issues. Building on the intrinsic solutions that presented above, we now turn to extrinsic solutions, viz. solutions that pertain to the work environments in which supervisors operate.

Extrinsic solutions or three levels of supporting measures

Almost all participants (n=22) considered that diverse **supporting measures** facilitated the resolution of ethical issues emerging in supervising trainees or should be available to help supervisors to address these issues in a beneficial way. At the same time, these measures reduce the barriers to supervising trainees and the distress sometimes experienced by some supervisors. As Figure 3 illustrates, the extrinsic solutions discussed by the participants are macro-environmental, meso-environmental and micro-environmental in nature. Again, these categories were not specifically mentioned by participants, but they emerged from our analyses of the data.

Figure 2: Environmental supporting measures for clinical traineeship supervision in occupational therapy



Macro-environmental support measures

Most participants (n=20) considered that the **universities** from which the trainees come should play a crucial role in the resolution of ethical issues emerging in the supervision of trainees. Specifically, in acting as a go-to-person, the fieldwork coordinator is essential in helping supervisors feel more confident when facing certain issues. “The first thing I do when I have a big issue..., I will call the fieldwork coordinator at the university in question and talk to him/her about it. Then often, when I did it, he/she would give me good advice on things to do.” One participant mentioned that “Whether it is the woman at the university or our immediate superior who directs us, who says: ‘this is a good way to do things’, it also helps.... We have very good support from the University” (participant 3).

It is not often that **university programs** will be involved in evaluating trainees who are in difficulty. Supervisors considered that **sharing this responsibility** with universities would be an interesting way both to ensure a fair evaluation of the trainee and to avoid supervisors having to decide on their own whether to fail a student. “I would be of the opinion that the university should be able to participate in the clinical assessment. It’s done in other professions. I think it would triangulate the information a little bit: we would have [the perceptions] of the student, the university and the supervisor, who each have their own vision of evaluation. I think it could eliminate student and supervisor biases, and then objectify the assessment of student learning” (participant 18). Regarding a very acute failing situation, one participant shared the following reflection:

Was it really up to me to judge her future? Because everything has been a little bit on my back.... She flunked her traineeship and they [the university] immediately terminated her curriculum. After that, I got calls from this student for various reasons. She wanted me to take her back, to show me that she was capable. I find that as a clinician, having all that pressure on your shoulders: deciding a student’s future, I think it’s a lot.... I would have thought that the university should have taken a role in this and should have taken on that role, that of the decision.... I referred to them, they helped me to make my judgment, but after that, I would have thought they would have taken over, but they didn’t.... In terms of informing the student, I would have thought that it would have been more their responsibility, but it was the opposite (participant 5).

The **training** offered to supervisors by some **university programs** (in-class or online) was appreciated, since it helped them develop their supervising competences. “The [university’s] training program gives us some ideas [to solve supervision issues]” (participant 1). “Training in relation to traineeships (supervising several students at once, communication [with the trainee]), it helps to guide us.... So later on, we don’t need to call them to ask questions. It eliminates the problems at the root, after all” (participant 3). Another participant added the following: “There are online training courses that exist with different modules..., but it would be fun to have more.... I would like to have small video clips with role-playing games on different themes, if only one on the evaluation, the announcement of a failure, etc.” (participant 21).

Some participants mentioned that **ethical training** specifically applied to supervision would be pertinent. “We still have a good follow-up from the university that gives us training, but the ethical side as such was not a subject that was really addressed. I wanted to be a little better equipped in these things. As part of my continuing education, I decided to go and do a microprogram in which there was an ethics course. It guided me a little” (participant 16). “Having a problem-solving method when you felt you were facing an ethical problem, but the lack of a formal time to establish yourself in an approach like this prevents me from updating it” (participant 18). To address the lack of ethics training, some participants suggested that the results of this study be used to train supervisors. “Having a training after the research could be interesting” (participant 7). This could “help [the supervisors] recognize (ethical issues) and know how to think about them” (participant 19). Another participant felt that Quebec’s College of Occupational Therapists could provide this type of training. “This may be lacking: training in ethical deliberation. I don’t see that in the courses offered by the College, but it could be very interesting to offer training in ethical deliberation and to gather several common dilemmas, challenges, and then just experiment with occupational therapists. Do

a continuous training where everyone discusses their situations and learns to deliberate. That way, they could teach it to students. That would be very interesting!" (participant 20).

Still in connection with Quebec's College of Occupational Therapists, one participant mentioned that it would be useful to have a section in the **OT Express**, the **College's journal**, addressing the ethical issues associated with fieldwork education and solutions to address them.

We could have a section in the OT Express (Ergothérapie Express) so that people [can see that these issues are experienced by others and thus] remove the fear [of supervising trainees]. "Ah, I've been through this too.... I'm not alone in my corner that has experienced this." So, a kind of chronicle on the ethical experiences encountered on a daily basis by occupational therapists with a commentary from an expert on options, how it could be managed. It could also give strength to the profession because I think it's really something that when you discuss it together, you see the light (participant 20).

Participants also noted that constituting a **group of supervisors** between different clinical settings (in person or online), that is, a forum between supervisors all over the province, would be an efficient way of sharing experiences. It could also be relevant to solving ethical issues associated with fieldwork education. "A kind of group, a community of practice for internship supervisors, with a training component regarding specific issues..., to support the development of their skills. How can I give feedback to a trainee facing difficulties or to one who lacks self-criticism?...How to announce or avoid a failed internship?" (participant 22).

Meso-environmental support measures

Most participants (n=19) also wanted more support from their practice settings when they supervised trainees. Occupational therapists believed that **time should be made available** for clinical traineeship supervision, including meetings between supervisors at the mid-point of the internship. "If we had more time to sit down with students in difficulty, it would be better" (participant 5). "We have internship supervisor meetings at the mid-point of the internship.... It is something that helps me, that helps us to solve ethical issues.... If we have any questions, we can ask them.... When there are more senior occupational therapists, they certainly help us" (participant 2).

Participants also felt that clear policies and procedures should be implemented in order to ensure the **free, informed and ongoing consent of clients** to be cared for by trainees. "Having certain policies or procedures, certain guidelines on the work we do, it helps us to think when there is an ethical issue at stake.... Consent by clients to be seen by a trainee [must be formalized because]...it may be that the trainee makes mistakes or that it takes more time, even if I am there to provide supervision; so that still partly responds to one of my dilemmas between [supporting] learning and [providing] quality services" (participant 7).

Material resources (locations, furniture, computers, passwords, etc.) must be dedicated to welcoming trainees in clinical settings. Too often, supervisors noted that trainees did not have access to an office with a computer and faced problems obtaining the credentials required to operate efficiently during their traineeship. "I wish I could accommodate more trainees, but I feel that the receptivity of the community is not necessarily there.... Just getting them a desk, it's complicated. I made the request so that my trainee could access the computer, and then we never received her password" (participant 1).

To be recognized, that is, to be appreciated, was essential for many supervisors. "In any case, I would work on that, recognition. ... There is a way to do this internally within an institution: recognition.... Because monetary recognition, I'm not saying it's not important, but if...your manager...doesn't value it already, it starts off on the wrong foot.... A recognition program for internship supervisors, I find it super what they do here at the university" (participant 22).

Micro-environmental support measures

Many supervisors (n=18) sought and obtained support **from colleagues** to address the ethical issues they faced. In doing so, they had the opportunity to assess their perceptions, analyses and reflections, and to feel supported. "The primary resource is my colleague at work" (participant 12). "I needed support in this situation. I have spoken to my colleagues, not to all my colleagues..., but to my closest ones. I wanted them to support me in this" (participant 2). "Share with colleagues, ask them...if they have experienced similar situations and what they have put in place. You don't always have to reinvent the wheel.... I think you have to open up to people you trust, then hear yourself think, explain, then hear them.... You can't be alone with that. That's when you get bitter" (participant 22).

Some participants **co-supervised** trainees. They felt more comfortable assessing competencies this way and found the responsibility for fieldwork education less burdensome. Novice supervisors appreciated being paired with more experienced supervisors. "It was during my first year, I co-supervised with a more experienced colleague.... Then, in the second year of practice, I had trainees" (participant 14). Another participant noted: "The first student I had, I co-supervised with a colleague.... It was a very nice experience" (participant 16). "I liked it when I co-supervised, because it gave us less time constraints.... It was facilitating. I often do co-supervision with another therapist, so when we have questions, we can validate them" (participant 4). Participants also mentioned that seeking and obtaining **support from their superiors** when experiencing ethical issues with trainees was always appreciated.

Discussion

The purpose of this study was to document the means used or considered by Quebec occupational therapy supervisors in order to solve the ethical issues of fieldwork education. In the following section, we compare the results of the study with those documented in the literature. We then specify the strengths and limitations of the research and explain its potential impacts.

Comparison of results with those documented in the literature

In general, the results of the study are consistent with those previously gathered from the literature. In particular, the **recognition** of the supervisor's role has been shown to be an important aspect in supporting occupational therapists. Although some elements proposed in the literature were not specifically mentioned by participants in our study – such as offering continuing education units to supervisors, giving them an official title or recognizing this role in their tasks, or even in their statistics (7,26,32) – participants felt that this responsibility was inherent in the practice of the profession and should be better recognized. Clinical settings should draw on the recognition workshops organized by some universities to not only formally recognize the role of supervisor, but also to value those who contribute to fieldwork education. Another way to recognize and value clinical supervision is to free up supervisors who engage in this role, thus educating the next generation of professionals from which clinical settings will benefit in the future. While some participants suggested that this role should be recognized as time-consuming, the literature is more explicit on this subject: it is strongly recommended that the supervisors' workload be reduced (24,26,28), and that more human resources be allocated to supervisors. This would include having someone responsible for establishing the logistics of welcoming trainees (7,26).

In general, the results of this study are consistent with the literature (9,18,19,24,26,28,31) in suggesting that **workplaces must do more** to recognize, support and equip supervisors. This role should not be taken for granted. Environmental conditions must be created in clinical settings to enable occupational therapists to contribute to the clinical training of tomorrow's occupational therapists, without neglecting the quality of the professional services provided to clients. While some participants in our study noted that their clinical settings were favourable environments for supervision, this is not the case for the majority of participants. Occupational therapists who value fieldwork education do so out of conviction, duty or interest (there are several positive benefits to supervising trainees (2)), often in a context of overload and performance pressure. Since supervision is an occupation and, as with any occupation, a person carries it out in an environment that is more or less constraining, more or less enabling, it is important that constraints to supervision (2) be reduced. This would allow for a greater number of occupational therapists to contribute to the fieldwork, while at the same time maintaining their mental health and providing quality occupational therapy services. To this end, study participants reported that they appreciated various supervision models (including co-supervision) discussed in the literature (4,7,8,10,11). They also believed that formal policies and procedures should be implemented in contexts where this is not the case to ensure the free, informed and continuous consent of clients to be seen by trainees. This would avoid relying on assumed clientele consent.

The study participants' perceptions are also consistent with the literature when they emphasize the importance of supervisors being better **trained**, particularly in **pedagogy**, and so able to support the trainee's learning and development of competencies (3,7-10,19,23-27). Since the role of a supervisor is essentially pedagogical, supervisor training is required to develop knowledge and pedagogical competencies. To some extent, these are different from the occupational therapist's usual professional competencies. With respect to competencies useful in addressing the ethical issues applied to supervising trainees, study participants brought up two types that have not previously been discussed in the literature. These include ethical competencies and competencies related to the roles of occupational therapists, as defined in the **Profile of practice of occupational therapists in Canada** (41). Given the very nature of the issues addressed in the literature, namely ethical issues, this absence is surprising, to say the least. However, this dearth may be due to the fact that ethical competencies, in particular the ethical competencies discussed by Swisher and collaborators (13) (i.e., ethical motivation, courage, perception, sensitivity, reflection and judgment), are still not widely known within the profession. In Canada, ethics education in occupational therapy programs and in continuing education is still in its early stages (50), which likely in part explains these results. Ethics being a philosophical discipline that is sometimes difficult to grasp (14,42,51), specific training on the ethical dimensions of clinical supervision would certainly be relevant and useful. The results of our study therefore suggest that it is important for occupational therapists who contribute to fieldwork education to continue the development of three main competencies: ethical, pedagogical and occupational therapy roles.

Another relevant element identified by participants, but which remains absent in the literature, concerns the role that their **professional regulatory college** could play in addressing these issues. Practical suggestions were made by some participants, including offering training (face-to-face or online) on the subject, addressing these issues and their solutions in the College's journal and setting up a pan-Quebec web forum for supervisors. The Quebec chapter of the Canadian Association of Occupational Therapists (CAOT) could provide similar support measures, as could other professional associations or colleges of occupational therapists around the world. It is up to each of the clinical settings and each association or college to assess the extent to which the participants' suggestions are relevant.

Strengths and weaknesses of the study

A strength of this study is that it provided supervisors in occupational therapy an opportunity to discuss the solutions that they use to address and solve the ethical issues of supervision. The research was carried out by a team with extensive experience in clinical supervision and expertise in applied ethics. With regard to limits, to prevent an occupational therapy student from

questioning a former supervisor or a supervisor from being reluctant to confide in a former trainee, some of the interviews were conducted by an interviewer who did not have knowledge of occupational therapy; this may have limited the interviewer's ability to discuss with participants the specificities of the occupational therapy practice in the context of traineeship. Additionally, given the fact that occupational therapy programs may differ greatly around the world, and the fact that this was a qualitative study with a small number of participants, the results may not be fully transferable to other contexts.

Potential impacts on practice

This study has the potential to benefit clinical practice, teaching, research and governance. With respect to **clinical practice**, if supervisors are better prepared, occupational therapists may feel more inclined to take on trainees and be in a better position to balance the requirements of supervision with those of clinical practice. As for **teaching**, the results of this study can be used to develop professional continuing education for supervisors, as was proposed by participants. Concerning further **research**, it would be useful for professional development courses dealing with ethical issues in supervising trainees to be evaluated to maximize their benefits. As for **governance**, we invite clinical settings, universities, professional associations and professional regulatory colleges to consider the suggestions made by the occupational therapists who participated in this study.

Conclusion

Although the literature on clinical occupational therapy education is extensive, few studies have documented the ethical issues associated with supervising trainees and how to solve these issues. This article discusses the ethical issues associated with the role of the occupational therapy supervisor and presents the results of a study that documented the means used or considered by occupational therapy supervisors to address these ethical issues. These solutions are intrinsic and extrinsic in nature. The results suggest that occupational therapists who perform their professional duties in training future occupational therapists through fieldwork education must be better recognized. These gaps appear to partly explain the difficulties experienced by university programs in finding sufficient traineeship placements for occupational therapy students. Finally, documenting how students in occupational therapy perceive and address the ethical issues they face during their internships would be essential to further enhance our understanding of the ethical situations and their solutions.

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None to declare Marie-Josée Drolet directs a research project on which Bryn Williams-Jones, Editor-in-chief of the journal, is a co-investigator. Williams-Jones was not involved with the evaluation or approval of the manuscript.

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References

1. World Federation of Occupational Therapy (WFOT). [Minimum Standards for the Education of Occupational Therapists](#). 2016.
2. Drolet MJ, Tremblay L. [Les barrières et les facilitateurs à la supervision de stagiaires en ergothérapie](#). Recueil annuel belge francophone d'ergothérapie. 2019;11:31-57.
3. Barton R, Corban A, Herrli-Warner L, McClain E, Riehle D, Tinner E. [Role strain in occupational therapy fieldwork educators](#). *Work*. 2013;44(3):317-28.
4. Clampin A. [Not the right time to take a student? Think again](#). *British Journal of Occupational Therapy*. 2012;75(10):441.
5. Fisher A, Savin-Baden M. [Modernizing fieldwork, part I](#). *British Journal of Occupational Therapy*. 2002;65(5):229-36.
6. Jung B, Sainsbury S, Grum RM, Wilkins S, Tryssenaar J. [Collaborative fieldwork education with student occupational therapists and student occupational therapist assistants](#). *Canadian Journal of Occupational Therapy*. 2002 April:95-103.
7. Kirke P, Layton N, Sim J. [Informing fieldwork design: Key elements to quality in fieldwork education for undergraduate occupational therapy students](#). *Australian Occupational Therapy Journal*. 2007;54:S13-S22.
8. Rodger S, Webb G, Devitt L, Gilbert J, Wrightson P, McMeeken J. [A clinical education and practice placements in the allied health professions](#). *Journal of Allied Health*. 2008;37(1):53-62.
9. Ryan K, Beck M, Ungaretta L, Rooney M, Dalomba E, Kahanov L. [Pennsylvania occupational therapy fieldwork educator practices and preferences in clinical education](#). *The Open Journal of Occupational Therapy*. 2018; 6(1):1-15.
10. Sloggett K, Kim N, Cameron D. [Private practice: Benefits, barriers and strategies of providing fieldwork placements](#). *Canadian Journal of Occupational Therapy*. 2003;70(1):42-50.
11. Thomas Y, Dickson D, Broadbridge J, Hopper L, Hawkins R, Edwards A, McBryde C. [Benefits and challenges of supervising occupational therapy fieldwork students](#). *Australian Occupational Therapy Journal*. 2007;54:S2-S12.
12. Roberts ME, Hooper BR, Wood WH, King RM. [An international systematic mapping review of fieldwork education in occupational therapy](#). *Canadian Journal of Occupational Therapy*. 2015;82(2):106-18.
13. Drolet MJ, Sauvageau A, Baril N, Gaudet R. [Les enjeux éthiques de la formation clinique en ergothérapie](#). *Revue Approches Inductives*. 2019;6(1):148-79.
14. Drolet MJ. [The axiological ontology of occupational therapy: A philosophical analysis](#). *Scandinavian Journal of Occupational Therapy*. 2014;21(1):2-10.
15. De Witt PA. [Ethics and clinical education](#). *South African Journal of Occupational Therapy*. 2016;46(3):4-9.
16. Centeno J, Begin L. Les loyautés multiples. Mal-être au travail et enjeux éthiques. Montréal, QC : Nota Bene; 2015.
17. Drake V, Irurita V. [Clarifying ambiguity in problem fieldwork placements](#). *Australian Occupational Therapy Journal*. 1997;44(2):62-70.
18. Ilott I. [Ranking the problems of fieldwork supervision reveals a new problem: Failing students](#). *British Journal of Occupational Therapy*. 1996;59(11):525-8.
19. James KL, Musselman L. [Commonalities in level II fieldwork failure](#). *Occupational Therapy in Health Care*. 2005;19(4):67-81.
20. Le Maistre C, Boudreau S, Paré A. [Mentor or evaluator?](#) *Journal of Workplace Learning*. 2006;18(6):344-54.
21. Lemay V. La supervision et la théorie des sphères de la justice. L'équité coincée entre l'arbre et l'écorce. In: Boutet M, Rousseau N, editors. *Les enjeux de la supervision pédagogique des stages*. Québec, QC: Presses de l'Université du Québec; 2002:217-31.
22. Baillargeon N. *La santé malade de l'austérité*. Pointe-Calumet, Quebec, Canada : M Éditeur; 2017.
23. Estes J. Promoting ethically sound practices in occupational therapy fieldwork education. The American Occupational Therapy Association (AOTA). Advisory Opinion for the Ethics Commission. AOTA Official Documents and websites; 2016.
24. Hunt K, Kennedy-Jones M. [Novice occupational therapist's perceptions of readiness to undertake fieldwork supervision](#). *Australian Occupational Therapy Journal*. 2010;57:394-400.
25. Jensen LR, Daniel C. [A descriptive study on level II fieldwork supervision in hospital settings](#). *Occupational Therapy in Health Care*. 2010;24(4):335-47.
26. Leclerc BS, Jacob J, Paquette J. *Incidatifs et obstacles à la supervision de stages dans les établissements de santé et de services sociaux de la région de Montréal : une responsabilité partagée*. Montréal : Centre de recherche et de partage des savoirs InterActions, CSSS de Bordeaux-Cartierville-Saint-Laurent-CAU; 2014.
27. Richard LF. [Exploring connections between theory and practice: Stories from fieldwork supervisors](#). *Occupational Therapy in Mental Health*. 2008;24(2):154-75.

28. Hanson DJ. [The perspectives of fieldwork educators regarding level II fieldwork students](#). Occupational Therapy in Health Care. 2011;25(2-3):164-77.
29. Short N, Sample S, Murphy M, Austin B, Glass J. [Barriers and solutions to fieldwork education in hand therapy](#). Journal of Hand Therapy. 2018;31(3):308-14.
30. Evenson ME, Roberts M, Kaldenberg J, Barnes MA, Ozalie R. [National survey of fieldwork educators: Implications for occupational therapy education](#). American Journal of Occupational Therapy. 2015;69:1-5.
31. Yepes-Rios M, Dudek N, Duboyce R, Curtis J, Allard RJ, Varpio L. [The failure to fail underperforming trainees in health professions education](#). Medical Teacher. 2016;38(11):1092-9.
32. Maloney P, Stagnitti K, Schoo A. [Barriers and enablers to clinical fieldwork education in rural public private allied health practice](#). Higher Education Research and Development. 2013;32(3):420-35.
33. Glaser JW. Three realms of ethics: Individual institutional societal: Theoretical model and case studies. Lanham: Rowman and Littlefield; 1994.
34. DePoy E, Gitlin LN. Introduction to research: Understanding and applying multiple strategies. St. Louis: Elsevier Mosby; 2010.
35. Corbière M, Larivière N. Méthodes qualitatives, quantitatives et mixtes dans la recherche en sciences humaines, sociales et de la santé. Québec (QC): Presses de l'Université du Québec; 2014.
36. Husserl E. The crisis of European sciences and transcendental phenomenology. Evanston: Northwestern University Press; 1970.
37. Husserl E. The train of thoughts in the lectures. In: Polifroni EC, Welch M, editors. Perspectives on philosophy of science in nursing. Philadelphia: Lippincott; 1999:247-62.
38. Hunt MR, Carnevale FA. [Moral experience: A framework for bioethics research](#). Journal of Medical Ethics. 2011;37(11):658-62.
39. Giorgi A. De la méthode phénoménologique utilisée comme mode de recherche qualitative en sciences humaines: théories, pratique et évaluation. In: Poupart J, Groulx LH, Deslauriers JP, Lapierre A, Mayer R, Pires AP, editors. La recherche qualitative: enjeux épistémologiques et méthodologiques. Boucherville: Gaëtan Morin; 1997:341-64.
40. Kinsella EA. [Hermeneutics and critical hermeneutics](#). Forum in Qualitative Social Research. 2006;7(3):19.
41. Canadian Association of Occupational Therapy (CAOT). Profile of practice of occupational therapists in Canada. Ottawa, ON: CAOT Publications ACE; 2012.
42. Drolet MJ. Acting ethically? A theoretical framework and method designed to overcome ethical tensions in occupational therapy practice. Ottawa: CAOT Publications ACE; 2018.
43. Drolet MJ, Goulet M. [Les barrières et facilitateurs à l'actualisation des valeurs professionnelles : perceptions d'ergothérapeutes du Québec](#). Revue ergoThérapie. La revue française de l'ergothérapie. 2018;71:31-50.
44. Drolet MJ, Gaudet R, Pinard C. [Résoudre les enjeux éthiques de la pratique privée : des ergothérapeutes prennent la parole et usent de créativité](#). Ethica – Revue interdisciplinaire de recherche en éthique. 2018;22(1):109-41.
45. Drolet M-J, Goulet M. [Travailler avec des patients autochtones du Canada? Perceptions d'ergothérapeutes du Québec des enjeux éthiques de cette pratique](#). Recueil annuel belge francophone d'ergothérapie. 2018;10:25-56.
46. Drolet M-J, Pinard C, Gaudet R. [Les enjeux éthiques de la pratique privée : des ergothérapeutes du Québec lancent un cri d'alarme](#). Ethica – Revue interdisciplinaire de recherche en éthique. 2017;21(2):173-209.
47. Goulet M, Drolet M-J. [Les enjeux éthiques de la pratique privée de l'ergothérapie : perceptions d'ergothérapeutes](#). BioéthiqueOnline. 2017;6(6):1-14.
48. Brûlé A-M, Drolet M-J. [Exploration des dilemmes éthiques entourant le traitement de la dysphagie à l'enfance et leurs solutions : perception d'intervenants](#). BioéthiqueOnline. 2017;6(10):1-16.
49. Drolet MJ, Maclure J. [Les enjeux éthiques de la pratique de l'ergothérapie : perceptions d'ergothérapeutes](#). Revue Approches inductives. 2016;3(2):166-96.
50. Hudon A, Laliberté M, Hunt M, Sonier V, Williams-Jones B, Mazer B, Badro V, Feldman DE. [What place for ethics? An overview of ethics teaching in occupational therapy and physiotherapy programs in Canada](#). Disability and Rehabilitation. 2014;36(9):775-780.
51. Drolet MJ. De l'éthique à l'ergothérapie. La philosophie au service de la pratique ergothérapique. Québec (QC): Presses de l'Université du Québec; 2014.
52. Boulianne S, Laurin S., Firket P. [Aborder l'éthique en supervision clinique : une approche en trois temps](#), Le Médecin de Famille Canadien-Canadian Family Physician. 2013;59:795-797.

ART, CULTURE ET OEUVRE DE CRÉATION / ART, CULTURE & CREATIVE WORKS

The Golden Curse

Sebastian Straube¹

Résumé

Il s'agit d'un conte de fées aux conséquences imprévues, une nouvelle histoire de Midas, avec des leçons pour répondre à une urgence de santé publique.

Mots-clés

conte de fées, urgence de santé publique, épidémie, conséquences involontaires, effets économiques

Abstract

This is a fairy tale about unintended consequences, a re-telling of the story of Midas, with lessons for responding to a Public Health emergency.

Keywords

fairy tale, public health emergency, epidemic, unintended consequences, economic effects

Legend has it that in a world much like ours there once lived a king whose kingdom was prosperous beyond comparison, because the king possessed a divine gift. The things the king touched turned to gold. You may think that you know the story, but there is a twist. The gift became a curse. One day, the king's touch started to turn people to gold, not things. That sudden change was unexpected and no explanation was found. Not everyone turned to gold, mind you, and there was hope that this curse would stop as suddenly as it had come. But the curse did not stop. One in every hundred people the king touched turned to gold. The other ninety-nine acquired the king's curse: They turned one in every hundred people whom they touched to gold, and passed on the curse to the ninety-nine others, and so forth.

As being of solid gold is not compatible with life, the golden people died upon the touch. Who would die and who would live when touched was not foreseeable with certainty, but there seemed to be patterns: The older subjects of the king were more likely to turn to gold than the younger ones and subjects who were ill were also more likely to turn to gold. However, what would happen in any individual case was not clear until it did happen. What did become apparent was that those who were touched once and survived would also survive any subsequent touch.

Once the king's curse became known, fear spread through the land. The king's astrologers, who had theorized about such a gift turned curse for some time, but who had not been of much prominence in the kingdom nor been involved in government, now wrote horoscopes about who would die and who would live. They genuinely meant well and they became much revered for their skill, even though they were not always right. Some subjects revered the astrologers more than they revered the king himself, so that the king became afraid to contradict his astrologers. What the astrologers advised was done and soon the astrologers essentially governed the kingdom.

In their wisdom, the astrologers advised the king of a temporary cure for the spread of the curse: To stop all the crafts and all the trades in the land except for what they deemed essential for living, so that the chances of people mingling and accidentally touching one another were minimized. They also advised people to not touch one another at home. These measures would last until a definitive cure for the golden curse was found. The king acted on their advice, as had become the norm. The state enforced the astrologers' recommendations and all but the most essential activity ceased. Subjects who disobeyed were punished.

The people were fed and the law was enforced, and it was thought that the definitive cure for the golden curse would be discovered within a year. What would be so hard about doing nothing for a year if there was food and shelter, the astrologers asked? Their advice was logical and the people agreed. Beyond a certain point the golden curse would have been unstoppable if it was not so contained, the astrologers said, and one in every hundred of the king's subjects would die. Such a toll was unacceptable for a kingdom so prosperous, the astrologers reasoned, and again the people of the land agreed. Fear of the golden curse now ruled their hearts, and they distrusted one another, but it seemed that there was no alternative to the drastic measures taken.

There is another twist to the story, a turn the astrologers did not predict. They spent their time studying the intricacies of the golden curse and potential cures, and paid less attention to the mundane crafts and trades, which had ceased. Nor did they think much about the people who had stopped touching one another. Much like the spread of the golden curse would have been unstoppable beyond a certain point, so, it turned out, were the effects of ceasing the crafts and trades. The once prosperous kingdom fell into a recession. The recession became a depression and all the subjects, even the nobles, became poor. Their money was not worth much anymore. What use is money in a kingdom full of gold?

The people did not take well to doing nothing either. Some became so sad that they preferred death by their own hand to life without touch. Children missed the touch of their parents and became strangers to them. Others grew restless and rioting erupted.

When the king finally realized what was happening to his kingdom, he ordered the measures to be reversed and the crafts and trades to start again immediately, as the death of one in a hundred was now felt to be a better lot than poverty and lawlessness

affecting all. But it was too late. The despair and anarchy could no longer be contained and many more died that would have died from the curse. The king and the social order were overthrown and the once mighty kingdom fell without ever being attacked by a foe.

There is an alternative ending to the story, in which the king saw early on what was happening to his people and determined that life could not continue like this. He had a hard conversation with his astrologers. The crafts and trades were allowed to resume after a brief interruption, even though some people still turned to gold. The king took smart measures to protect the people most likely to turn to gold, based on the astrologers' horoscopes. This affected the kingdom less than feared, as few of those most at risk of turning to gold had been engaged in crafts and trades. Eventually, life mostly returned to what it was before the curse, although touching was still avoided where possible. Because steps had been taken to protect the people most likely to turn to gold, far fewer than one in a hundred were affected. One day, a young astrologer discovered the definitive cure and there was much joy throughout the land. The kingdom was now prosperous again and mighty like never before.

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None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Appliquer un procédé argumentaire pour revendiquer une attribution des services en ergothérapie basée sur l'habilitation aux occupations

Kim Jean-Gagnon¹, Martine Brousseau¹

Résumé

Problématique : L'attribution actuelle des services en ergothérapie en CLSC permet difficilement aux ergothérapeutes d'intervenir selon leur expertise première d'habilitation aux occupations. Pour revendiquer cette situation, les professionnels sont appelés à agir comme agent de changement et idéalement avoir recours à un procédé argumentaire. **Objectif** : Appliquer un procédé argumentaire à une situation professionnelle problématique en ergothérapie, soit revendiquer une attribution des services en ergothérapie en CLSC basée sur l'habilitation aux occupations. **Méthode** : Le procédé argumentaire est basé sur le cadre argumentaire Convictions-Réel-Actions-Fondements (CRAF) nécessitant une recherche d'arguments provenant d'une recension critique des écrits. **Résultats** : Les études recensées font valoir des arguments basés sur les valeurs et les fondements théoriques de la profession. Les arguments issus des résultats probants proviennent d'études dont le niveau d'évidence scientifique est élevé. Ils montrent que des interventions basées sur l'habilitation aux occupations ont des retombées sur la participation et le fonctionnement dans les occupations, le bien-être et la santé physique et mentale, la perception d'efficacité personnelle, la satisfaction de vie, les interactions sociales, l'apprentissage de connaissances et l'espérance de vie. **Discussion** : L'habilitation aux occupations dans une approche de prévention et de promotion de la santé est efficace et rentable, et ce, pour une clientèle plus vaste que celle actuellement desservie. Les ergothérapeutes, désireux d'être agent de changement dans leur milieu, pourraient reproduire le procédé argumentaire pour l'appliquer à une situation clinique problématique.

Mots-clés

ergothérapie, habilitation aux occupations, agent de changement, argumentaire, priorisation des services

Abstract

Problem: The current allocation of occupational therapy services in CLSCs makes it difficult for occupational therapists to intervene according to their primary expertise in occupational empowerment. To claim this situation, professionals are called upon to act as agents of change and ideally resort to an argumentative process. **Objective**: To apply an argumentative process to a problematic occupational situation in occupational therapy, that is to claim an allocation of occupational therapy services in CLSCs based on occupation qualification. **Method**: The argument process is based on the "Convictions-Réel-Actions-Fondements (CRAF)" argument framework requiring a search for arguments from a critical review of the literature. **Results**: The studies reviewed put forward arguments based on the values and theoretical foundations of the profession. The arguments based on convincing results come from studies with a high level of scientific evidence. They show that interventions based on occupation empowerment have repercussions on participation and functioning in occupations, physical and mental well-being and health, the perception of personal efficiency, life satisfaction, social interactions, learning knowledge and life expectancy. **Discussion**: Empowering occupations in a prevention and health promotion approach is effective and cost-effective for a broader clientele than that currently served. Occupational therapists, eager to be agents of change in their environment, could replicate the argumentation process to apply it to a problematic clinical situation.

Keywords

occupational therapy, enabling occupation, agent of change, argumentation, prioritization of services

Introduction et recension des écrits

Certaines limites et certains enjeux ressortent des systèmes de priorisation quant à l'attribution des services en ergothérapie dans les CLSC (Centre local de services communautaires) du Québec. Actuellement, la recension des écrits met en évidence deux méthodes de gestion des listes d'attente (1). La première méthode repose sur une approche coutumière ou évolutive, c'est-à-dire que la priorisation se base sur la discrétion du décideur où les décisions sont révisées au cas par cas, rendant difficile l'uniformisation du processus décisionnel (1). La seconde méthode de gestion se base plutôt sur les priorités politiques, comprenant une vision plus systémique visant à optimiser la pratique des professionnels et standardiser le système de priorisation. Or, chacune de ces méthodes comporte ses différents enjeux.

La non-uniformisation de la méthode selon une approche coutumière provient, d'une part, de la variabilité des critères de priorisation (1-3), variant d'un CLSC à un autre, et d'autre part, de la composante subjective lors des prises de décisions (3,4). Le sentiment d'urgence et l'interprétation de la situation peuvent varier d'un professionnel à un autre, pouvant ainsi influencer la prise de décision dans l'attribution des services (1). Cette variabilité est à prendre en considération, d'autant plus que, selon l'étude de Raymond et collaborateurs (3), moins de 20% des personnes qui dirigent vers les services ne sont pas des ergothérapeutes, que 42% sont des coordonnateurs cliniques (toute profession confondue) et qu'ainsi, seuls 38% sont des ergothérapeutes cliniciens (3,5). Une étude récente (6) a montré que le traitement des références en ergothérapie en Nouvelle-Zélande s'adressant à des personnes âgées par un ergothérapeute a permis de diminuer le temps d'attente avant la prise en charge.

Par ailleurs, alors que le temps d'attente médian pour recevoir des services en CLSC est de 18 mois, 16% des CLSC n'ont pas de stratégies pour assurer le service aux personnes classées comme non prioritaires (5). Ces personnes seront donc seulement prises en charge lorsqu'aucune autre demande plus prioritaire ne les devancera, ce qui est peu probable. Elles devront donc attendre que leur condition se dégrade suffisamment pour se voir recevoir des services.

Dans un but de pallier ces disparités et de réduire l'écart entre l'offre et la demande des services, les instances gouvernementales ont instauré de nouvelles politiques visant l'optimisation des services offerts et la standardisation du système de références et de priorisation des services. Les conséquences et les enjeux liés à ce type de priorisation sont toutefois considérables.

L'un des enjeux de ce type de priorisation est la restriction du mandat de l'ergothérapeute, le limitant ainsi à intervenir principalement dans l'autonomie et la sécurité des clients (7,8) pour les occupations spécifiques comme la mobilité et les soins personnels (7,8). Cette méconnaissance du rôle de l'ergothérapeute ou de son champ d'expertise par les décideurs est certes influencée par des vestiges historiques de la conception de l'ergothérapeute comme un spécialiste de l'autonomie. En effet, dans le contexte des réformes du système de l'Éducation et de la Santé, plusieurs « évaluations des activités de la vie quotidiennes » ont été développées en ergothérapie (9). Ceci a eu comme conséquence que les ergothérapeutes se sont définies comme des spécialistes de l'autonomie et ont été perçus de la sorte par les autres professionnels. Cette représentation de l'ergothérapie est d'ailleurs toujours d'actualité (10) et influence toujours les décideurs, comme en fait foi l'utilisation de l'outil Multi-Clientèle (maintenant Outil de Cheminement Clinique Informatisé [OCCI]).

Pourtant, les neuvièmes lignes directrices de la pratique de l'ergothérapie au Canada transcendent les concepts d'autonomie et de sécurité en définissant l'ergothérapeute comme l'expert de l'habilitation aux occupations. L'habilitation aux occupations est d'outiller et accompagner les clients afin qu'ils puissent réaliser et participer aux occupations qu'ils identifient comme étant significatives (11,12). La notion d'engagement y est d'ailleurs sous-jacente, indiquant qu'il faut aller au-delà de l'utilisation des traitements auprès des personnes qui demeurent passives (11). L'habilitation aux occupations favorise la santé, le mieux-être et l'intégration et prévoit un espace pour entendre les opinions des personnes concernées. Les stratégies d'habilitation renvoient aux actions d'adapter, revendiquer, coacher, collaborer, consulter, coordonner, concevoir et réaliser, éduquer, engager, mettre à profit son expertise (11).

Pourtant, le système actuel de priorisation des services en ergothérapie ne permet aux ergothérapeutes que de déployer une parcelle de leur expertise. La question qui se pose alors est de savoir comment en tant qu'ergothérapeute, est-il possible de revendiquer autre chose qui reflète davantage le cœur du métier. Ce devoir de faire valoir la reconnaissance de l'expertise fait partie des compétences liées à l'exercice de la profession d'ergothérapeute au Québec qui suggère de participer à la mise en œuvre des mesures visant à améliorer la qualité des services offerts en ergothérapie (13). Le profil de la pratique de l'ergothérapeute au Canada (13) aborde également cette compétence sous l'angle d'agent de changement et mentionne entre autres que les compétences à cet égard sont celles de promouvoir les possibilités occupationnelles, le rendement occupationnel et la participation occupationnelle des clients et de promouvoir les besoins occupationnels associés aux déterminants de la santé, au bien-être et à l'équité pour les clients recevant des services.

Les ergothérapeutes comme agent de changement

Bien que l'ensemble des ergothérapeutes reconnaisse l'importance de revendiquer une offre de services différente de celle perçue actuellement et de porter ce rôle d'agent de changement, il demeure que la majorité est réticente à adopter ce rôle (14,15). En effet, les termes d'agent de changement et de revendicateur ont encore mauvaise presse (16), pouvant rendre inconfortables les ergothérapeutes à endosser ce rôle (15,16), particulièrement s'ils ne se sentent pas posséder les connaissances et les habiletés (15). À ces défis s'ajoute une difficulté supplémentaire puisque les enjeux décrits nécessitent non seulement de déployer le rôle d'agent de changement, mais de le faire dans une perspective systémique plutôt qu'individuelle, ce à quoi les ergothérapeutes sont souvent moins à l'aise (15,17,18). La perspective systémique est de s'attaquer à des réformes institutionnelles ou politiques et donc de revendiquer pour un ensemble de personnes au lieu d'une seule personne.

Afin de soutenir les ergothérapeutes dans leur rôle d'agent de changement, le modèle « *Advocacy World* » a été conceptualisé visant à mettre en évidence les stratégies et les étapes relatives à l'argumentaire, sans toutefois faire état de la complexité de la démarche (18). Aussi, la démarche proposée par Drolet, Lalancette et Caty (19) suggère d'exercer le rôle politique inhérent à sa pratique professionnelle en ayant recours aux arguments de la méthode *I-DÉ-A-L-E*. Cette méthode renvoie à « I » pour *Induction*, « DÉ » pour *Déduction*, « A » pour *Autorité*, « L » pour *Logique* et « E » pour *Ethique*. Cependant, les cadres proposés ne guident pas assez concrètement les ergothérapeutes pour revendiquer (17), spécifiquement dans un contexte systémique plutôt qu'individuel.

Toutefois, Angenot (20) offre la possibilité de construire un discours argumentatif, et ce, de façon plus concrète et plus simple en proposant le cadre *Convictions-Réel-Actions-Fondements (CRAF)*. Le cadre *CRAF* est composé de quatre pôles énonciatifs pour formuler des arguments, soit les *Convictions et les valeurs à promouvoir (C)*, les *Fondements théoriques du discours (F)*, *l'élaboration et la saisie du Réel (R)*, c'est-à-dire les données de la réalité qu'il est important de prendre en compte (R) et qui portent les *Actions à entreprendre (A)* (21).

La revendication est conçue comme un ensemble de propos réfléchis, exposés avec compétence pour susciter l'intérêt de partenaires, de collaborateurs ou d'interlocuteurs ciblés. Le procédé argumentaire implique aussi d'avoir un accord préalable partagé. Tous (décideurs, coordonnateurs des listes d'attentes, ergothérapeutes) désirent que l'ensemble des personnes âgées aient accès à des services de qualité. Il suffit que les ergothérapeutes trouvent des arguments pour revendiquer une attribution différente des services. Il y a lieu de croire qu'il serait envisageable d'appliquer ce procédé argumentaire selon le

cadre CRAF à une situation professionnelle précise en ergothérapie, soit revendiquer une attribution des services ergothérapeutiques en CLSC basée sur l'habilitation aux occupations. À notre connaissance, l'application d'un tel procédé n'a pas encore été faite.

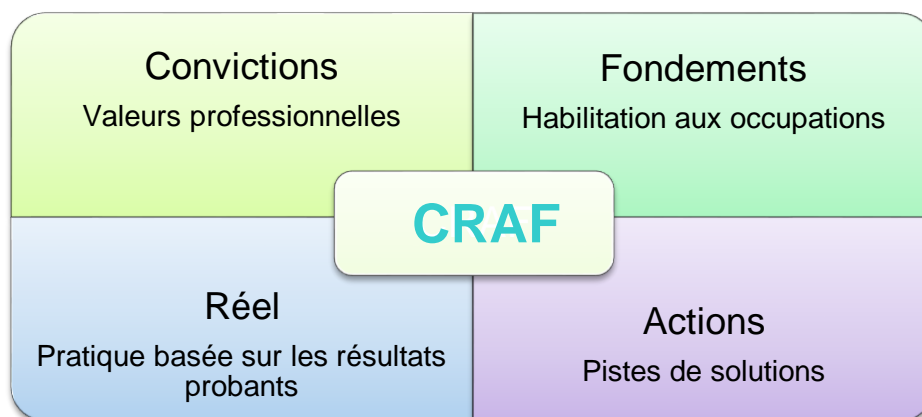
Objectif

L'objectif principal de l'étude est d'appliquer un procédé argumentaire à une situation professionnelle problématique en ergothérapie. Le sous-objectif est d'identifier des arguments pour revendiquer une attribution des services ergothérapeutiques en CLSC, s'adressant aux personnes âgées, basée sur l'habilitation aux occupations.

Méthodologie

Le procédé argumentaire est basé sur le cadre CRAF (*Convictions-Réel-Actions-Fondements*) élaboré par Angenot (20) et Gohier (21) (voir Figure 1). Ce cadre permet d'organiser le discours et le rendre cohérent en l'appuyant par des arguments crédibles. Il a été choisi puisqu'il est constitué de seulement quatre pôles (C-R-A-F), ce qui facilite son utilisation. Par ailleurs, son acronyme facilite la mémorisation des éléments à intégrer. Ces caractéristiques apparaissent importantes puisqu'il est souhaité que les ergothérapeutes s'approprient la démarche pour appliquer un procédé argumentaire et revendiquer à leur tour dans leur propre milieu selon une problématique pertinente dans leur contexte.

Figure 1 : Représentation du modèle CRAF inspiré d'Angenot (20) et Gohier (21)



Notre démarche (méthodologie) part des actions à entreprendre, qui se rattachent aux initiatives et aux manières d'attribuer des services en ergothérapie basés sur l'habilitation aux occupations et ce, dans une approche de prévention et de promotion de la santé (A). Pour justifier et guider cette action, il importe de développer des arguments cohérents avec les convictions et les valeurs (C) propres à l'ergothérapie, les fondements théoriques de l'habilitation aux occupations (F) et les résultats probants (R). Les valeurs et les fondements ont été recensés à partir de la littérature professionnelle.

Quant aux résultats probants, ils correspondent aux évidences scientifiques démontrant les retombées des interventions en ergothérapie basées sur l'habilitation aux occupations. La recherche de résultats probants (R) a consisté à faire une recherche sur les bases de données CINALH (Cumulative Index to Nursing and Allied Health Literature) [une base de données bibliographiques en sciences biomédicales], MEDLINE (en particulier PubMed qui est la version gratuite de MEDLINE) et PSYCHINFO. La recherche incluait les articles parus du 1^{er} janvier 1997 au 1^{er} août 2017. Une mise à jour de la recherche a été réalisée jusqu'en octobre 2019 à l'aide d'alerte prévenant lors d'une nouvelle parution en lien avec le sujet d'intérêt. Les mots-clés utilisés pour générer la recherche étaient les suivants :

- (elder OR old* OR aged OR geriatric) AND occupation* therap* AND (effect OR efficacy OR impact OR outcome OR benef* OR consequence OR influence OR cost OR "cost-effectiveness") AND (communit* OR community-dwelling OR home OR "independent living" OR "aging in place") AND (health* OR "without condition" OR "without diagnos" OR "health promot*" OR promot*).
- Le terme « prevent » a été retiré puisqu'il générerait des études incluant des participants présentant des conditions/diagnostics spécifiques. Le terme de « promotion » a été choisi afin de vérifier l'efficacité de l'ergothérapie auprès d'une clientèle actuellement considérée comme non prioritaire ou non vue en ergothérapie dans les CLSC.

Pour cette section, les critères de sélection des études devaient : 1) être rédigées en français ou en anglais, 2) porter sur l'efficacité ou la rentabilité des services ergothérapeutiques, 3) inclure une clientèle âgée de plus de 60 ans vivant de façon autonome en communauté, 4) proposer des interventions dans une approche de réadaptation dans un contexte de prévention

et de promotion de la santé, 5) proposer des interventions où l'ergothérapeute a une place prédominante (50% et plus) si le programme est multi ou interdisciplinaire et 6) proposer des interventions et mesurer les impacts sur une variété d'occupations.

À l'inverse, les études étaient exclues lorsqu'elles : 1) orientaient leurs interventions ou mesuraient les impacts seulement sur les activités de la vie quotidienne (AVQ), 2) exigeaient comme critère d'inclusion que les participants présentent une condition ou un diagnostic spécifiques (troubles neurologiques, cognitifs, psychologiques ou physiques).

Les données probantes issues de ces études proviennent d'une analyse de contenu effectuée pour catégoriser les retombées des interventions en ergothérapie. Une seconde analyse de contenu a été réalisée afin de comparer les interventions utilisées dans les études aux dix stratégies d'habilitation aux occupations (adapter, revendiquer, coacher, collaborer, consulter, coordonner, concevoir et réaliser, éduquer, engager, mettre à profit son expertise) (11).

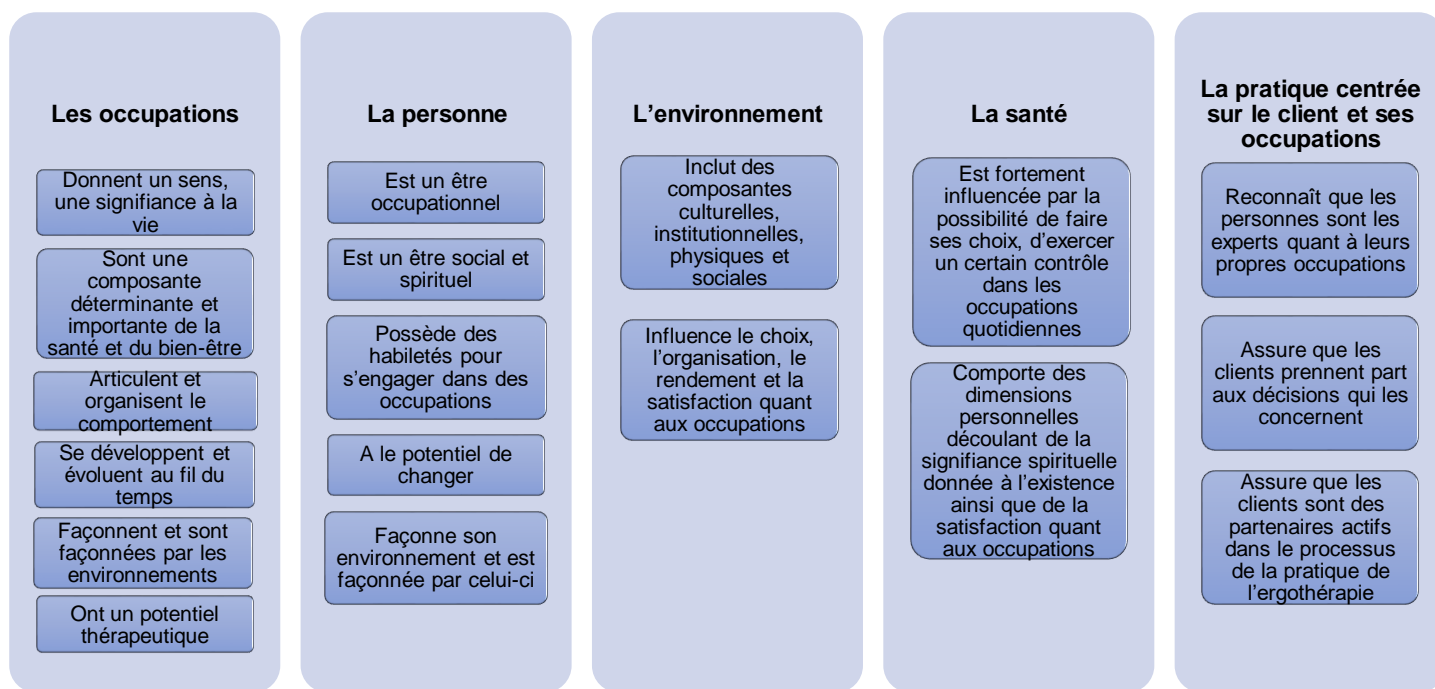
Résultats

Cette section présente les convictions et valeurs de la profession (C), les fondements (F) et les résultats probants (R) qui serviront de base à l'application de l'argumentaire.

Les convictions et valeurs en ergothérapie (C)

Les valeurs et convictions à promouvoir proviennent des neuvièmes lignes directrices de la pratique de l'ergothérapie au Canada (22). Ces lignes directrices sont les plus récentes et servent de documents d'orientation ou de directives pour rehausser la qualité de la pratique des ergothérapeutes. Les ergothérapeutes ont des valeurs et convictions reliées aux occupations, à la personne, à l'environnement, à la santé et à la pratique de l'ergothérapie centrée sur la personne et ses occupations. Elles sont listées en détail dans la figure 2.

Figure 2. Les valeurs professionnelles de l'ergothérapie (23,24)



Les fondements théoriques de la profession en ergothérapie (F)

Telle que présentée dans les neuvièmes lignes directrices canadiennes en ergothérapie et le profil de compétences, l'habilitation aux occupations est au cœur même de la profession puisqu'elle constitue la compétence clé de l'ergothérapie. L'habilitation aux occupations est définie comme une approche visant à rendre apte les personnes de mettre en place des moyens afin qu'elles puissent choisir, organiser et réaliser des occupations qu'elles considèrent comme utiles et signifiantes (11,12). Quant aux occupations, elles sont définies comme ce à quoi une personne consacre son temps et son énergie. Bien qu'elles comprennent tout ce qu'une personne fait pour prendre soin d'elle (soins personnels), se divertir (loisirs) et contribuer à l'édifice social et économique de la communauté (productivité), elles peuvent aussi être considérées comme propres à chacun, comme variées, pouvant s'organiser dans le temps pour chacun de façon bien personnelle et pouvant s'éloigner des

normes établies. En ce sens, les occupations contribuent à la santé et au mieux-être des individus, car le fait de s'engager dans des activités variées et signifiantes répond à des besoins tout au long de la vie (22). Par des activités et occupations, la personne s'exprime, se sent utile, se révèle au monde et à elle-même (25). L'ergothérapeute est à la recherche d'occupations pour et avec son client ou un groupe de clients afin de trouver le « *just right challenge* » et ce, en amenant la personne à vivre des expériences optimales et satisfaisantes qui contribuent à sa santé (26).

Les stratégies inhérentes au déploiement de cette compétence clé qu'est l'habilitation aux occupations sont définies dans le tableau 1. Elle se déploie par les stratégies d'habilitation. Ces méthodes ou stratégies d'habilitation renvoient aux actions d'adapter, revendiquer, coacher, collaborer, consulter, coordonner, concevoir et réaliser, éduquer, engager, mettre à profit son expertise (11).

Tableau 1: Les stratégies d'habilitation aux occupations proposées par Townsend et collaborateurs (11,24)

Stratégies clés d'habilitation aux occupations	Définition selon les auteures	Exemples dans le contexte des soins à domicile pour les personnes âgées
Adapter	Modifier l'occupation ou l'environnement afin d'ajuster le niveau de défi en fonction des capacités du client.	Modifier l'horaire occupationnel du client pour que l'hygiène et sa sortie au parc soient dispersées dans la journée afin de conserver l'énergie d'une personne âgée avec une plus grande fatigabilité.
Revendiquer	Plaidoyer de sorte à fournir des arguments qui soutiennent un changement, des modifications qui sont bénéfiques à la participation du client dans ses occupations.	Revendiquer un tarif réduit des transports en commun pour les personnes âgées pour qu'un plus grand nombre puisse l'utiliser.
Coacher	Établir un partenariat avec les clients visant à les accompagner et les soutenir dans l'atteinte de leurs objectifs et d'en améliorer leur rendement.	Guider une personne âgée dans ses recherches sur l'ordinateur afin de trouver et comprendre les itinéraires des autobus du centre-ville.
Collaborer	Partager le pouvoir d'autorité avec les clients afin de les mobiliser dans les prises de décision et les engager dans leurs occupations. Ce partenariat sollicite un travail de collaboration où l'ergothérapeute réalise les choses avec les clients, plutôt que pour eux ou à leur place.	Mobiliser le client à trouver des stratégies et des façons d'aménager son environnement pour le rendre sécuritaire plutôt que de l'adapter à sa place.
Consulter	Concerter les clients en favorisant le libre-échange et en instaurant le respect des différences afin d'intégrer les perspectives de chacun, synthétiser et reformuler les propos au besoin, puis présenter les options possibles et les choix alternatifs.	Concerter un groupe de personnes âgées afin de connaître leurs besoins quant aux transports en commun. En fonction de leur discussion, formuler les besoins communs et présenter les solutions possibles pour répondre à ces besoins.
Coordonner	Mettre en lien les clients avec les ressources humaines, matérielles ou organisationnelles afin de répondre aux besoins des clients quant à leurs occupations ou à la réalisation de celles-ci.	Mettre en lien les personnes âgées désirant jouer à la pétanque avec le coordonnateur des loisirs de la ville afin qu'ils puissent faire part de leur intérêt pour cette activité et qu'ils discutent des possibilités des lieux, des plages horaires et du matériel disponible.
Concevoir et réaliser	Élaborer un plan et le mettre en œuvre en identifiant les stratégies appropriées.	Élaborer un plan de sortie avec un client pour qu'il puisse faire ses achats au centre commercial en identifiant les stratégies appropriées, par exemple être accompagné de son fils, utiliser le transport en commun, valider son budget.
Éduquer	Favoriser les apprentissages en utilisant les techniques appropriées pour les clients et en insistant sur la mise en action du client par la formation expérientielle (savoir-faire).	Enseigner l'utilisation des aides techniques à la cuisine en les faisant essayer au client plutôt que de seulement lui présenter.
Engager	Inciter les clients à se mobiliser, à prendre part à l'action afin de contrer le désintérêt, la non-implication et l'indifférence du client et ainsi solliciter sa pleine participation dans ses occupations.	Inciter le client à participer à la préparation de repas, ou du moins les portions de l'occupation qu'il est en mesure de réaliser plutôt que de compenser entièrement l'occupation.
Exercer son expertise, mettre à profit son expertise	Utiliser ses connaissances et ses savoirs comme ergothérapeute pour aider les clients selon leurs situations particulières ou encore les inciter à s'aider eux-mêmes. L'expertise de l'ergothérapeute peut se transmettre via des modèles spécialisés ou des approches particulières.	Recommander des équipements et des stratégies de jardinage pour une personne âgée présentant de l'arthrite et qui désire continuer de réaliser cette occupation sans ressentir trop de douleur ou de fatigue.

Les résultats probants (R)

Dix études ont été retenues. Le niveau d'évidence des études retenues a été classé selon les recommandations de la Haute Autorité de Santé (27). Afin d'alléger le texte, le niveau d'évidence de même que les principaux résultats des études sont rapportés dans le tableau 2.

L'efficacité et les retombées des interventions en ergothérapie

L'analyse de contenu a permis de catégoriser sous quels aspects les interventions en ergothérapie sont efficaces (24). Les résultats statistiquement significatifs apparaissent au tableau 2.

Tableau 2: Les résultats probants soutenant des interventions auprès de personnes âgées basées sur l'habilitation aux occupations

Articles et niveau d'évidence	Participants	Méthodologie abrégée	Principaux résultats	Messages clés
Clark et coll. (1997) I (Étude randomisée contrôlée)	361 participants, dont 306 ont complété l'étude. 3 Groupes : GE (n=102) GC (n=204) : 1. Activités sociales générales (n=100) 2. Sans traitement (n=104) Caractéristiques : Personnes âgées de 60 ans et plus, vivant en communauté de façon indépendante.	Programme : 9 mois GE : • Séances de groupe : 2h par semaine; • Séances individuelles : 9h au total. GC (groupe social) : séances de 2,25h/semaine (pour combler le 9h individuel dans le G) Stratégies d'habilitation : Éduquer : « Présentation didactique » Engager : « Expérience directe par la participation à des activités » Indicateurs : Pré et post traitement (0 et 9 mois) • Incapacités potentielles ou interruptions dans les activités quotidiennes liées aux domaines physique et social. (<i>Functional Status Questionnaire</i> , <i>FSQ</i> -activités basiques de la vie quotidienne, activités instrumentales, activités sociales et qualité des interactions); • Satisfaction dans la vie (<i>Life Satisfaction Index-Z</i> , <i>LSI-Z</i>); • Symptômes dépressifs (<i>The Center for Epidemiologic Studies Depression</i> , <i>CES-D</i>); • Perception de la santé générale (<i>Medical Outcomes Study- short form</i> , <i>MOS</i>); • Dimensions de la santé physique et mentale (<i>RAND 36-item Short Form Survey</i> , <i>RAND SF-36</i>).	Bénéfices significatifs pour le GE comparativement aux GC. • Meilleure qualité des interactions (p<0.03); • Meilleure satisfaction de vie (p<0.03); • Meilleure perception de la santé générale MOS (p<0.05); SF-36 : • Moins de douleurs physiques (p<0.03); • Meilleur fonctionnement physique (p<0.008); • Moins de limitations dues à l'état physique (p<0.02); • Plus de vitalité (p<0.04); • Meilleur fonctionnement social (p<0.05); • Moins de limitations dues à l'état mental (p<0.05); • Meilleure santé mentale générale (p<0.02).	1. Un programme préventif en ergothérapie a des effets sur différentes composantes de la santé, du fonctionnement et de qualité de vie; 2. Les effets comparables entre les deux GC affaiblissent l'adage qui dit «qu'il suffit de se tenir occupé pour se tenir en santé»; 3. Le fait de s'engager régulièrement dans des activités sociales ne contribue pas à l'efficacité dans une perspective de promotion de la santé ni le fait de ne recevoir aucun traitement.
Clark et coll. (2001) I (Étude randomisée contrôlée)	361 participants, dont 285 (79%) sur lesquels toutes les mesures ont été prises. Caractéristiques : Personnes âgées de 60 ans et plus, vivant en communauté de façon indépendante.	Programme : *Suite de l'étude Clark et coll. (1997). Suivi de six mois sans interventions supplémentaires à celles reçues pendant 9 mois (Clark et coll., 1997). Stratégies d'habilitation : Idem que Clark et coll. (1997) Indicateurs : Pré et post suivi (6 mois) • <i>RAND 36-item Short Form Survey (RAND SF-36)</i> ; • <i>Functional Status Questionnaire (FSQ)</i> ; • <i>Life Satisfaction Index-Z (LSI-Z)</i> ; • <i>The Center for Epidemiologic Studies Depression (CES-D)</i> ; • <i>Health Perception Scale</i> .	Comparativement aux GC, les bénéfices pour le GE perdurent sur une période de 6 mois. • Qualité des interactions (p=0.05); SF-36 : • Fonctionnement physique (p<0.03); • Limitations dues à l'état physique (p<0.02); • Vitalité (p<0.001); • Fonctionnement social (p<0.01); • Limitations dues à l'état mental (<0.05); • Santé mentale générale (p<0.02).	1. Certains des bénéfices associés au traitement ergothérapeutique perdurent sur une période de 6 mois suivant la fin des interventions; 2. Les effets psychosociaux sont plus importants que ceux physiques.
Clark et coll. (2012)	460 participants, dont 360 ont complété l'étude.	Programme : 6 mois • Séances de groupe : 2h par semaine;	Bénéfices significatifs pour le GE comparativement au GC.	1. Un programme de seulement 6 mois

<p>I (Étude randomisée contrôlée)</p>	<p>2 groupes : - GE (n=187); - GC (n=173) (sans traitement).</p> <p><u>Caractéristiques :</u> Personnes âgées entre 60 et 95 ans vivant en communauté et ne présentant pas de signe de démence ou de psychose.</p>	<ul style="list-style-type: none"> • Séances individuelles : 10 sessions d'une heure chaque. <p>Stratégies d'habilitation: <u>Eduquer :</u> « Présentation didactique »</p> <p><u>Engager :</u> « Expérience directe par la participation active à des activités »</p> <p>Indicateurs : Pré et post interventions (6 mois)</p> <ul style="list-style-type: none"> • Perception du bien-être mental et de la santé physique (version 2 du <i>36-Item Short-Form Health Survey, SF-36v2</i>); • Symptômes dépressifs (<i>The Center for Epidemiologic Studies Depression, CES-D</i>); • Satisfaction de vie (<i>Life Satisfaction Index-Z, LSI-Z</i>); • Tests cognitifs : <ul style="list-style-type: none"> ○ Mémoire immédiate, mémoire à long terme et reconnaissance (Tâche de la liste de mot du <i>Consortium to Establish a Registry of Alzheimer's Disease, CERAD-memory</i>); ○ Recherche visuelle- temps médian de réaction (tâche de repérage visuelle à l'ordinateur); ○ Vitesse psychomotrice (<i>Digit Symbol Substitution Task du Wechsler Adult Intelligence Scale-Revised</i>). 	<ul style="list-style-type: none"> • Satisfaction de vie (p<0,03); • Symptômes dépressifs (p<0,03); <p>SF-36</p> <ul style="list-style-type: none"> • Douleurs physiques (p<0,02); • Vitalité (p<0,03); • Fonctionnement social (p<0,04); • Santé mentale (p<0,03); • Composantes mentales (p<0,03); <p><u>Composantes cognitives :</u> Aucun effet direct provenant des interventions.</p> <p>Analyses secondaires : Changement pré-post sur le groupe contrôle : Amélioration significative de</p> <ul style="list-style-type: none"> • Satisfaction de vie (p<0,02); • Symptômes dépressifs (p<0,01) <p>SF-36</p> <ul style="list-style-type: none"> • Limitations dues à l'état physique (<0,03); • Douleurs corporelles (p<0,05); • Vitalité (p<0,03); • Santé mentale (p<0,01); • Composantes mentales (p<0,04). <p><u>Composantes cognitives :</u></p> <ul style="list-style-type: none"> • Mémoire à long terme (p<0,0001); • Reconnaissance (p<0,01); • Vitesse psychomotrice (p<0,01). <p>Rentabilité :</p> <ul style="list-style-type: none"> • Coût moyen par participants au GE : 783\$; • Coût par QALY= 41 218\$ • Amélioration du QALY de 0,038 (p<0,02) pour le GE comparé au GC. • Rapport coût efficacité acceptable selon l'échelle de prix fournie par le <i>UK National Institute Health and Clinical Excellence</i> 	<p>demeure efficace et rentable;</p> <ol style="list-style-type: none"> 2. Le programme a des impacts plus importants sur la santé et le bien-être mental que physique; 3. Les effets obtenus pour les deux groupes expérimentaux sont comparables, et ce même s'il s'agit de 2 groupes distincts et que les interventions sont effectuées à des moments différents.
<p>Gitlin et coll. (2006)</p> <p>I (Étude randomisée contrôlée)</p>	<p>319 participants, dont 300 (94%) après 6 mois et 285 (89%) après 12 mois.</p> <p>2 groupes (début, après 6 mois, après 12 mois) GE (n=160, 154, 149) GC (n=159, 146, 136)</p>	<p>Programme : 6 mois</p> <ul style="list-style-type: none"> • Entrevues initiale (identifier et prioriser les problématiques) • 5 contacts ergothérapeutiques (visites de 90 minutes et un contact téléphonique de 20 minutes) • 1 contact en physiothérapie (90 minutes); • Suivi de 6 mois (phase de maintenance) : 3 contacts téléphoniques et une visite finale à domicile. 	<p>Les effets bénéfiques du GE comparativement au GC :</p> <p>À 6 mois :</p> <ul style="list-style-type: none"> • AVQ (p<0.03); • AVD (p<0.04); • Environnement (présence de dangers potentiels) (p<0.05); • Utilisation de stratégies adaptatives (p<0.009); <p><u>Perception d'efficacité personnelle :</u></p>	<ol style="list-style-type: none"> 1. Les stratégies adaptatives développées demeurent significatives, et ce jusqu'à 6 mois suivant la fin des interventions.

	<p>Caractéristiques : Personnes âgées de 70 ans et plus, vivant en communauté, ne recevant pas de soins à domicile, mais rapportant des difficultés dans les AVQ'S et les activités instrumentales.</p>	<p>Stratégies d'habilitation: Éduquer : « Enseignement »</p> <p>Engager : « Résolution de problèmes-barrières environnementales et comportementales »</p> <p>Exercer son expertise : « Modifications de l'environnement »</p> <p>Indicateurs : Pré-intervention, post-intervention (6 mois) et post suivi (12 mois)</p> <ul style="list-style-type: none"> • Fonctionnement physique dans les AVQ (s'habiller en haut et en dessous de la taille, les soins de beauté, l'hygiène au bain/douche, toilette, s'alimenter), les AVD (travaux ménagers légers, magasinage, préparer les repas, gestion financière, utilisation du téléphone, prendre sa médication) et la mobilité et les transferts; • Peur de tomber (<i>Falls Efficacy Scale de Tinetti et Balance Confidence Scale</i>); • Perception d'efficacité quant aux habiletés à performer dans une activité (échelle de Likert); • Présence de dangers potentiels pouvant causer une chute (<i>Home hazard index</i>); • Stratégies adaptatives (échelle de Likert pour 8 items). 	<ul style="list-style-type: none"> • Peur de tomber ($p<0.001$), • Efficacité du fonctionnement général ($p<0.02$). <p>À 12 mois :</p> <ul style="list-style-type: none"> • Stratégies adaptatives ($p<0.01$) <p>Perception d'efficacité personnelle :</p> <ul style="list-style-type: none"> • Peur de tomber ($p<0.008$) <p>Coûts : Suite au programme de 6 mois :</p> <ul style="list-style-type: none"> • Matériel : 439\$; • Services à domicile : 783\$; • Total : 1222\$ par participant. 	
<p>Gitlin et coll. (2009)</p> <p>I (Étude randomisée contrôlée)</p>	<p>319 participants</p> <p>2 groupes : GE (n=160); GC (n=159).</p> <p>Caractéristiques : Personnes âgées de 70 ans et plus, vivant en communauté, ne recevant pas de soins à domicile, mais rapportant des difficultés dans les AVQ'S et les activités instrumentales.</p>	<p>*Suite de Gitlin et coll. (2006)</p> <p>Stratégies d'habilitation : Idem que Gitlin et coll. (2006)</p> <p>Indicateurs : 2, 3 et 4 ans suivant l'intervention</p> <ul style="list-style-type: none"> • Niveau de risque- âge, genre, comorbidités et comportements relatifs à la santé, difficultés fonctionnelles (11 des 12 items des indicateurs pronostics par Lee et coll.); • Scores indiquant une santé à faible risque (1-5), à risque modéré (6-9) puis à risque sévère (10-15). 	<p>Effets à long terme sur la mortalité : Effet des interventions sur le GE jusqu'à 3.5 ans en comparaison avec le GC.</p> <p>2 ans</p> <ul style="list-style-type: none"> • Effet significatif ($p<0.016$) • Taux de mortalité : GE : 5,6%; GC :13,2% <p>3 ans</p> <ul style="list-style-type: none"> • Effet non significatif ($p<0.248$) • Taux de mortalité : GE : 16,6%; GC :20,3% <p>4 ans</p> <ul style="list-style-type: none"> • Effet non significatif ($p<0.244$) • Taux de mortalité : GE :24,0%; GC :28,7% <p>Effets des interventions selon le niveau de risque associé :</p> <p>2 ans (significatif)</p> <ul style="list-style-type: none"> • Faibles risques : • Taux de mortalité (GE :0%; GC : 11%) • Risques modérés : (GE : 3%; GC :14%)* ($p<0.021$) • Risques sévères : (GE : 15%; GC : 13%) 	<p>1. Un programme visant les personnes vivant de façon indépendante permet d'avoir un impact positif significatif sur le taux de mortalité, et ce, jusqu'à 2 ans suivant la fin des interventions;</p> <p>2. En regard du niveau de risque, il apparaît que les effets du programme sur le taux de mortalité sont plus importants pour les groupes à faible risque et à risque modéré que celui à risque élevé.</p>
<p>Johansson & Bjorklund (2016)</p>	<p>40 participants</p> <p>2 groupes</p>	<p>Programme : 4 mois GE</p>	<p>Quantitatifs Amélioration significative pour le GE :</p>	<p>1. Un programme de 4 mois permet l'amélioration de</p>

<p>II Mixte : -Quasi expérimental pré-post avec GC -Entrevue semi- structurée</p>	<p>(2010, 2011, 2012) GE : n=22 (9, 7, 6) GC : n=18 (5, 11, 2)</p> <p><u>Caractéristiques :</u> Personnes âgées de 65 ans et plus, vivant en communauté et ne recevant pas de soins à domicile.</p>	<ul style="list-style-type: none"> • Séances de groupe : 2h par semaine; • Séances individuelles : maximum de 4h. <p><u>GC :</u> Visites occasionnelles de l'ergothérapeute, mais aucune intervention de groupe.</p> <p>Stratégies d'habilitation: <u>Adapter :</u> « Adaptations occupationnelles »</p> <p><u>Collaborer :</u> « Échange d'expériences », « Groupe de discussion »</p> <p><u>Éduquer :</u> « Lecture et information sur les thèmes », « Activité liée au thème »</p> <p>Indicateurs : <u>Quantitatifs</u> (pré et post-interventions : 0 et 4 mois) :</p> <ul style="list-style-type: none"> • Perception du bien-être mental et de la santé physique (<i>Short Form 36, SF-36</i>); • Symptômes dépressifs (<i>The Center for Epidemiologic Studies Depression, CES-D</i>); • Satisfaction de vie, perception du bien-être psychologique (<i>Life Satisfaction Index-Z, LSI-Z</i>); • Participation dans des activités significatives (<i>Meaningful Activity Participation Assessment, MAPA</i>). <p><u>Qualitatifs</u> (post-interventions, 4 mois) :</p> <ul style="list-style-type: none"> • Expérience vécue lors du programme et l'application et l'utilisation des connaissances et des stratégies apprises (entrevue de 6 groupes avec 2 à 4 participants); • Thèmes ressortis : désir de maîtriser ses activités, demandes de l'environnement et réponses adaptatives. 	<p>SF-36</p> <ul style="list-style-type: none"> • Vitalité ($p<0.01$); • Santé mentale ($p<0.03$). <p>Qualitatifs Adaptation occupationnelle : <u>Indépendance :</u> Les participants soulignent l'importance d'être indépendant et d'être en mesure de trouver des moyens pour accomplir ce qu'ils veulent et ce qu'ils ont besoin de faire.</p> <p><u>Appartenance à un groupe</u> Les participants insistent sur le fait que les rencontres de groupe étaient importantes et significatives au plan social et structuraient leur routine hebdomadaire. Le groupe est comparé à la construction d'une communauté.</p> <p><u>Estime de soi :</u> Les participants mentionnent l'amélioration de leur estime de soi à travers les rencontres de groupe.</p> <p><u>Changement dans les comportements occupationnels :</u> Les participants énumèrent des stratégies adaptatives concrètes pour leur vie quotidienne.</p> <p>Changement dans l'approche occupationnelle : Les participants rapportent qu'ils se perçoivent eux-mêmes comme des personnes actives et donnent des exemples de comment ils ont adapté leur approche.</p>	<p>certaines composantes liées à la santé et au bien-être (vitalité, santé mentale);</p> <ol style="list-style-type: none"> 2. Les effets sur le bien-être sont plus importants que les effets physiques; 3. Les participants ont fait des changements dans leurs occupations et connaissent des stratégies pour s'adapter; 4. La structure du programme sous forme de groupe entraîne des effets positifs sur les participants (estime de soi, appartenance à un groupe); 5. Un prolongement du programme permettrait d'obtenir des effets plus importants.
<p>Matuska et coll. (2003)</p> <p>II Pré-post avec groupe unique</p>	<p>65 participants, dont 39 ont complété le programme et dont 31 ont répondu au questionnaire de satisfaction du programme.</p> <p><u>Caractéristiques :</u> Personnes âgées de 65 ans et plus, vivant de façon indépendante.</p>	<p>Programme: 6 mois Séances de groupe: 1,5h par semaine.</p> <p>Stratégies d'habilitation: <u>Collaborer :</u> « Discussion » <u>Concevoir et réaliser :</u> « Stratégies »; <u>Éduquer :</u> « Enseignement »; <u>Engager :</u> « Activités et opportunités »</p> <p>Indicateurs : <u>Pré et post-interventions</u> (0 et 6 mois) :</p> <ul style="list-style-type: none"> • Qualité de vie (<i>SF-36 Health Survey</i>); • Participation dans des activités sociales (famille, amis, personnes de support) et des activités communautaires (activités religieuses, activités extérieures, événements, magasinage, ressources) (Fréquence-Échelle de Likert). 	<p><u>Qualité de vie</u> (SF-36) : Amélioration significative :</p> <ul style="list-style-type: none"> • Vitalité ($p<0.05$); • Fonctionnement social ($p<0.01$); • Score global de santé mentale ($p<0.05$). <p><u>Participation dans les activités communautaires</u></p> <ul style="list-style-type: none"> • Augmentation de la fréquence de 56 à 66%; • Augmentation plus marquée pour les activités extérieures, sociales et communautaires. <p><u>Interactions sociales :</u> (au moins 3 fois par semaine)</p> <ul style="list-style-type: none"> • Augmentation, passant de 47 à 56%. <p><u>Caractéristiques des participants :</u></p>	<ol style="list-style-type: none"> 1. Les effets sont plus bénéfiques pour les composantes du bien-être mental que les physiques; 2. La fréquence de participation et d'interactions sociales est augmentée à la suite du programme, particulièrement pour les activités extérieures, sociales et communautaires; 3. Les discussions de groupe et la socialisation sont des aspects qui font en sorte que les participants

		<p>Post-intervention (6 mois) :</p> <ul style="list-style-type: none"> • Satisfaction des participants par rapport au programme (questionnaire avec échelle de Likert- pauvre, acceptable, excellent). 	<p>Les plus assidus au programme, les plus âgés et ceux qui ne conduisent pas.</p> <p>Satisfaction des participants par rapport au programme :</p> <ul style="list-style-type: none"> • 87% le notent de bon à excellent; • Les éléments les mieux notés sont les instructeurs, la présence d'étudiants, la durée des sessions, le groupe de discussion et la socialisation. 	<p>sont satisfaits du programme.</p>
<p>Mulry & Piersol (2014)</p> <p>II Pré-post avec groupe unique.</p>	<p>7 participants.</p> <p>Caractéristiques : Personnes âgées de 60 ans et plus habitant un milieu de vie indépendant, avec une mobilité fonctionnelle (avec ou sans aide technique), qui ne présentent pas de trouble cognitif ou de trouble aphasique.</p>	<p>Programme :</p> <ul style="list-style-type: none"> • 4 sessions étalées sur 4 semaines; • 45 minutes de groupe suivi d'une période individuelle <p>Stratégies d'habilitation: Coacher : « Discussion guidée »; Collaborer : « Échange avec les pairs » Concevoir et réaliser : « Stratégies centrées sur le client »; Eduquer : « Enseignement »; Engager : « Résolution de problèmes »;</p> <p>Indicateurs : Pré et post-intervention (0 et 4^e semaine), suivi de 4 semaines (8^e semaine) :</p> <ul style="list-style-type: none"> • Autonomie extérieure et participation sociale (<i>The Impact on Autonomy and Participation Questionnaire, IPAQ</i>); • Confiance d'éviter les chutes pendant les activités (<i>The Modified Falls Efficacy Scale, MFES</i>); • Connaissances des participants (données démographiques, identification des risques de santé associés à une diminution de la mobilité en communauté, les options alternatives de transport, la fréquence de participation des participants dans des activités communautaires qu'elles valorisent) (échelle de Likert à 5 points); • Perspective des participants (deux entrevues semi-structurées, en pré et post-interventions). 	<p>Les résultats seront présentés comme suit : (résultats obtenus immédiatement après les interventions) (résultats obtenus à la suite du suivi de 4 semaines).</p> <p>Autonomie à l'extérieur : Maintien ou amélioration (100%, n=7) (85,71%, n=6);</p> <p>Participation sociale : Maintien ou amélioration (85,71%, n=6) (100%, n=7);</p> <p>Mobilité en communauté (confiance) : Maintien ou amélioration (71%, n=5) (71%, n=5);</p> <p>État des connaissances :</p> <ul style="list-style-type: none"> • Identification de 2 risques : (42,86%, n=3) (42,86%, n=3); • Identification de 3 moyens de transport alternatifs : (100%, n=7) (100%, n=7); <p>Participation dans des activités communautaires valorisées : (85,71%, n=6, dont une augmentation significative pour 5) (100%, n=7);</p> <p>Perspective des participants : Pré-intervention : Tous les participants ont identifié que :</p> <ul style="list-style-type: none"> • La mobilité en communauté était un défi; • La réalisation des activités à l'extérieur du domicile était difficile. <p>Post-intervention : Tous les participants mentionnent se sentir plus confiants pendant les échanges avec les pairs concernant les sorties et leur planification.</p>	<ol style="list-style-type: none"> 1. Les interventions répondent au type d'apprentissage des personnes âgées, soit d'apprendre des notions, de les appliquer à leur vie personnelle, puis de vivre des expériences réelles; 2. L'effet de groupe (cohésion et support informel) a contribué aux résultats en améliorant le sentiment d'auto-efficacité et en encourageant les changements de comportements; 3. À la suite du programme, les participants et les intervenants ont émis certaines recommandations : <ul style="list-style-type: none"> • Éliminer les interventions individuelles, allonger les sessions de groupes; • Ajouter des leçons à faire à la maison.
<p>Yamada et coll. (2010)</p> <p>I</p>	<p>87 participants, dont 63 qui ont complété le programme.</p> <p>2 groupes : GE (n=30)</p>	<p>Programme : 8 mois Séances de groupes : 2h bimensuel, pour un total de 15 séances.</p> <p>Stratégies d'habilitation:</p>	<p>Satisfaction de vie : Amélioration moyenne significative pour le GE comparativement au GC :</p> <ul style="list-style-type: none"> • Effet modéré 	<ol style="list-style-type: none"> 1. Des interventions en ergothérapie de moindre intensité dans un temps limité permettent

(Étude randomisée contrôlée)	GC (n=33) <u>Caractéristiques :</u> Personnes âgées de 65 ans et plus vivant en communauté et ne bénéficiant pas de réadaptation médicale au moment de l'étude.	<u>Collaborer :</u> « Groupe de discussion » <u>Éduquer :</u> « Lecture », « Devoirs » <u>Engager :</u> « Activités de groupe » <u>Indicateurs :</u> Pré et post-intervention • Satisfaction de vie (<i>Life satisfaction Index-Z, LSI-Z</i>) • Qualité de vie/ bien-être psychologique (<i>WHO Quality of Life-26, QOL-26</i>)	<u>Bien-être psychologique :</u> Amélioration moyenne significative pour le GE comparativement au GC : • Effet modéré à effet élevé.	d'obtenir des impacts positifs; 2. Les lectures, les séminaires, les discussions et la mise en actions répondent au besoin d'apprentissage des personnes âgées, ce qui peut avoir un impact sur leur engagement dans leurs occupations; 3. La motivation, les habitudes et la performance des individus se construisent à travers les interactions découlant du contexte social (dynamique de groupe).
Zinmark et coll. (2016) I (Étude randomisée contrôlée)	177 participants, dont 165 ont complété l'étude jusqu'au 3 ^e mois, puis 157 jusqu'au 12 ^e mois. <u>4 groupes</u> (1 GC et 3 GE) (départ, 3 ^e et 12 ^e mois) <u>GE :</u> GI (41, 40, 38) GA (49, 48, 46) GD (41,35,34) GC (46, 42, 39) <u>Caractéristiques :</u> Personnes âgées de 72 à 82 ans, vivant seules dans une résidence ordinaire, ne bénéficiant pas de soins à domicile et ne présentant pas de problèmes cognitifs ou de communication apparents	<u>Interventions :</u> <u>GI :</u> Interventions orientées vers le répertoire d'activités de la personne et du contexte dans lequel elle les réalise. La personne priorise une ou plusieurs occupations. <u>GA :</u> (5 à 8 participants) Séances de groupe de 1h30 par semaine pendant 8 semaines : <u>GD :</u> (7 à 9 participants) Séance de 2h <u>GC :</u> Aucun traitement. <u>Stratégies d'habilitation:</u> <u>Coach :</u> « Discussion orientée sur les occupations »; <u>Collaborer :</u> « Groupe de discussion », « Partage des expériences et soutien entre les participants du soutien entre eux »; <u>Éduquer :</u> « Lectures à propos des activités sociales », « Devoirs et outils éducatifs »; <u>Engager :</u> « Engagement dans des occupations »; « Réflexion sur comment composer avec les problèmes relatifs à l'engagement occupationnel », « Résolution de problèmes » <u>Indicateurs :</u> (0, 3 ^e mois et 12 ^e mois) • Santé générale (<i>Short Form Health Survey, SF-12</i>); • Coûts liés aux interventions, coûts municipaux et coûts relatifs à la santé; • Rentabilité (à partir du coût et du <i>Quality-adjusted life year, QALY</i>).	<u>Santé générale.</u> Comparativement au GC, les effets sont significatifs pour la santé générale des participants du GA et du GD au 3 ^e mois et demeurent significatifs au 12 ^e mois pour le GD seulement. <u>Coûts</u> <u>Interventions</u> • GI : 6787 €; • GA : 7744 €; • GD : 1242 €. <u>Relatifs à la santé</u> Significativement moindres pour le GD au 3 ^e (p<0.02) et au 12 ^e mois (p<0.04). <u>Coûts totaux</u> Significativement moindre pour le GD au 3 ^e mois (p<0.02) et au 12 ^e mois (p<0.03). <u>QALY</u> Augmentation significative pour le 3 ^e mois pour le : • GA (p<0.04); • GD (p<0.03). <u>Rentabilité</u> • GC et GI : non rentables; • GA : rentable à 3 mois; • GD : rentable à 3 et 12 mois.	1. Le GD et le GA permettent d'obtenir des gains de santé générale et des gains quant au QALY; 2. Le GD s'avère être l'intervention la plus rentable.

Légende : GC : Groupe contrôle ; GE : Groupe expérimental ; GI : Groupe de suivi individuel ; GA : Groupe d'activités ; GD : Groupe de discussion

Participation aux occupations

Deux études (28,29) montrent qu'à la suite d'interventions en ergothérapie, les personnes âgées du programme, participaient plus fréquemment à des activités communautaires, sociales (28), extérieures (28,29) et signifiantes (29). La durée des interventions variait entre 4 semaines (29) et six mois (28).

Fonctionnement dans les occupations

Le fonctionnement dans les occupations a été abordé dans deux études (29,30). Le fonctionnement renvoie à la performance ou la capacité fonctionnelle d'une personne dans ses activités de base et se rattache au fait de faire soi-même ces activités (se laver, de déplacer, s'habiller, etc.). Une des études a montré le ralentissement et la diminution significative des limitations dans les activités de la vie quotidienne (AVQ) et les activités de la vie domestique (AVD) suite à un programme de six mois (30). La diminution des limitations plutôt que l'amélioration même du fonctionnement peut être expliquée par le choix des participants. Ceux-ci présentaient en effet déjà des limitations dès le départ de l'étude et étaient plus avancés en âge (70 ans et plus). Une amélioration ou le maintien de l'autonomie à l'extérieur du domicile a été observé de même que la confiance des participants à se mobiliser en communauté (29).

Santé et bien-être physique

La santé et le bien-être physique sont d'autres retombées des interventions en ergothérapie. Il a été observé (31-33) une diminution ou, du moins, un ralentissement significatif de l'évolution des douleurs physiques de même que des limitations associées à l'état physique chez les personnes âgées ayant participé à un programme offrant des services en ergothérapie sur une période variant de six (33) à neuf mois (31). Le programme d'une plus longue durée permettait quant à lui d'ajouter des bénéfices significatifs en prévenant le déclin du fonctionnement physique (activités physiques) (31). La pérennité des effets observés sur les limitations associées à l'état physique et le fonctionnement physique était significative jusqu'à six mois suivant la fin du programme de neuf mois (32).

Santé et bien-être psychologique

La santé et le bien-être psychologiques sont d'autres retombées importantes obtenues dans six études (28,31-35). Les résultats soulignent que la participation à un programme offrant des services en ergothérapie entraîne des effets significatifs, tels que l'amélioration significative de la santé mentale (28,31,33-35) et de la vitalité (étant l'énergie dont une personne dispose pour vaquer à ses occupations) (28,31,33-34), une diminution des symptômes dépressifs (33) ainsi qu'un ralentissement de l'évolution des limitations dues à l'état mental (33). Plusieurs effets sont partagés entre différentes études alors que la durée des programmes variait entre quatre (34), six (28,33), huit (35) et neuf mois (33). Les effets liés à la santé mentale, aux limitations dues à l'état mental ainsi qu'à la vitalité étaient d'ailleurs significatifs six mois suivant la fin des interventions en ce qui a trait au programme d'une durée de neuf mois (32). Finalement, les personnes âgées mentionnaient dans l'une des études que la modalité de groupe contribuait à l'amélioration de leur estime personnelle (34).

Perception d'efficacité personnelle

La perception d'efficacité personnelle est une autre retombée dont font valoir trois des études sélectionnées (29,30,34). Les résultats révèlent que les personnes âgées ayant participé à un programme de six mois se perçoivent plus efficaces quant à leur fonctionnement général et expriment moins de peur quant au fait de chuter (30). Cette distinction entre les deux groupes (avec et sans intervention en ergothérapie) quant à la crainte de tomber demeure d'ailleurs significative jusqu'à six mois suivant la fin du programme (30). D'autres effets bénéfiques étaient mentionnés subjectivement par les participants, et ce pour des programmes de plus courte durée. Les personnes âgées statuaient sur leur niveau d'activité et se considéraient alors comme des personnes actives en réponse à un programme de quatre mois (34) tandis que le programme de quatre semaines permettait aux personnes de se sentir plus confiantes quant aux échanges avec les pairs portant sur les sorties et leur planification (29).

Satisfaction de vie

Trois autres études mettent en évidence une amélioration significative de la satisfaction de vie chez les personnes âgées ayant participé à un programme d'interventions en ergothérapie d'une durée de six (33), huit (35) et neuf mois (31).

Interactions sociales

Six études rapportent des effets bénéfiques liés au plan du fonctionnement social (28,29,31-34) des personnes âgées ayant reçu des interventions en ergothérapie sur une période de six et neuf mois. Le programme de neuf mois a permis de surcroît une amélioration de la qualité des interactions chez les participants (31). Par ailleurs, les effets attribués au programme de neuf mois perduraient jusqu'à six mois suivant la fin des traitements (32). Un programme plus court de six mois assurait quant à lui l'augmentation de la fréquence moyenne des interactions sociales chez les personnes âgées (28). L'amélioration ou le maintien de la participation sociale des aînés était également observé après le programme de quatre semaines, dont les effets étaient encore présents quatre semaines suivant la fin du programme (29). Finalement, les participants se positionnaient en faveur de la modalité de groupe, laquelle contribuait à forger leur sentiment d'appartenance au sein d'un groupe (34), mais également comme un facteur de leur appréciation quant au programme reçu (28).

Apprentissage de connaissances et de stratégies

L'apprentissage de connaissances et de stratégies constitue une autre retombée mise en valeur par trois études offrant des interventions d'une durée variée de quatre semaines (29), quatre (34) et six mois (30). Les études rapportent que les personnes

âgées, à la suite des interventions reçues, sont en mesure d'identifier les stratégies adaptatives qu'elles utilisent (34), et les appliquent davantage que les personnes n'ayant reçu aucune intervention (30). Cette distinction dans l'utilisation des stratégies adaptatives est significative jusqu'à six mois suivant la fin du programme de six mois (30). Ce même programme assurait que les personnes âgées présentaient moins de dangers potentiels à domicile (30) tandis qu'un programme de quatre semaines suffisait à ce que les personnes âgées identifient trois moyens de transports alternatifs (29).

Espérance de vie

L'espérance de vie est abordée dans l'étude de Gitlin et collaborateurs (36), laquelle mentionne que le taux de mortalité des personnes âgées ayant reçu des interventions en ergothérapie pendant six mois (30) est significativement moindre que celui des personnes n'ayant reçu aucune intervention. Cette distinction est d'ailleurs significative pendant les deux années suivant la fin des interventions. Bien qu'elle ne soit pas significative pour l'année suivante, cette distinction est présente jusqu'à 3,5 années suivant la fin des interventions. Les résultats démontrent également que les effets sur le taux de mortalité sont plus importants chez les personnes présentant un risque de santé faible et modéré comparativement aux personnes présentant des risques de santé sévères.

La rentabilité des interventions ergothérapeutiques dans une perspective d'habilitation aux occupations

L'étude de Zingmark et collaborateurs (37) mentionne que les interventions de groupe sont rentables tandis que les interventions individuelles ne le sont pas. La rentabilité était calculée en fonction des coûts liés aux interventions et aux soins de santé des individus en rapport avec le QALY (année de vie ajustée en fonction de sa qualité). Il existait une amélioration significative du QALY pour les personnes âgées ayant participé à des groupes d'activités et des groupes de discussion, sur une période respective de 3 et 12 mois, tandis que les coûts totaux étaient également significativement moins élevés pour ceux ayant participé au groupe de discussion. Ainsi, les interventions de groupe étaient considérées comme rentables sur une période de trois (groupe d'activité) à 12 mois (groupe de discussion).

L'habilitation aux occupations au cœur des interventions

L'analyse de contenu a montré que les interventions utilisées dans les études correspondaient aux stratégies d'habilitation aux occupations suivantes (adapter, coacher, collaborer, concevoir et réaliser, éduquer, engager, mettre à profit son expertise) (11). L'absence de correspondance avec les stratégies de « revendiquer » et de « coordonner » peut s'expliquer par le contexte de recherche, dans lequel les ressources sont coordonnées dès le départ et les services sont offerts sans restriction. Ainsi, les professionnels agissant dans un cadre de recherche ne sont pas nécessairement à faire face aux enjeux liés aux contraintes institutionnelles et organisationnelles et n'ont donc pas à déployer ces stratégies comme moyens d'interventions. Les stratégies déployées dans chacune des études sont également documentées dans le tableau en annexe.

Discussion

Cette section permettra donc d'étayer les arguments basés sur les convictions (C), les fondements (F) et les résultats probants (R) qui militent en faveur des actions (A) souhaitées.

L'habilitation aux occupations dans une perspective de prévention et promotion de la santé : des services en ergothérapie efficaces

Comme les résultats des études sélectionnées le démontrent, les interventions ergothérapeutiques proposées avaient des effets bénéfiques sous différents aspects, soient la participation et le fonctionnement dans les occupations, la santé et le bien-être tant physique que psychologique, le sentiment d'auto-efficacité, la satisfaction de vie, les interactions sociales, l'apprentissage de connaissances et stratégies ainsi que sur l'espérance de vie.

En plus que les études soulignaient l'implication directe des ergothérapeutes dans les interventions, l'analyse de contenu a renchéri en précisant que les interventions utilisées étaient des stratégies d'habilitation aux occupations, correspondant à l'expertise même de la profession, démontrant ainsi que les services ergothérapeutiques dans une approche d'habilitation aux occupations permettent l'efficacité et la rentabilité des services.

Quant à la portion de l'argumentaire qui revendique d'élargir les services en ergothérapie à une clientèle plus vaste en privilégiant une approche de prévention et promotion de la santé, les participants des études sélectionnées étaient des aînés à risque d'incapacité ou présentant des incapacités légères. Ainsi, l'habilitation aux occupations dans une approche de prévention et promotion de la santé est efficace et rentable.

Certains pourraient vouloir contrecarrer cet argument en prétendant que ce ne sont pas réellement les services ergothérapeutiques qui ont permis d'obtenir les effets bénéfiques répertoriés, mais plutôt l'occasion pour les personnes âgées de participer à différentes occupations. Les études randomisées de Clark et collaborateurs (31-33) réduisent cependant ce contre-argument lorsqu'ils comparent le groupe des interventions en ergothérapie avec deux groupes contrôles, l'un ne recevant aucune intervention, et l'autre participant à des activités sociales. Il en ressort qu'il n'existe pas de différence significative entre les deux groupes contrôles, confirmant ainsi qu'il ne suffit pas de se tenir occuper pour demeurer en santé. En ce sens, l'ergothérapeute accompagne les personnes en les outillant pour qu'elles explicitent le lien entre leurs occupations, la santé et le bien-être afin qu'elles priorisent le choix de participer à des occupations qui contribuent justement à leur santé et leur

bien-être. Par ailleurs, l'ergothérapeute peut soutenir les clients à réduire les occupations néfastes en les outillant, par exemple, à transposer le sens qu'ils accordent à cette occupation vers une occupation plus saine. Par exemple, une personne âgée investie dans une occupation de jeux dans un casino et que les jeux empêchent de s'adonner aux occupations d'auto-soins (se rendre aux rendez-vous médicaux, etc). Le travail de l'ergothérapeute consisterait à accompagner la personne dans la prise de conscience de l'apport de ses occupations à sa santé et à expliciter le sens qui y est accordé. Si le sens est celui de répondre à des besoins d'interaction sociale, il y aura lieu d'identifier en partenariat avec la personne des occupations pouvant répondre à ce besoin.

L'habilitation aux occupations : une réponse aux enjeux actuels

L'habilitation aux occupations telle que proposée permettrait de réduire les enjeux soulevés dans la problématique. Premièrement, le mandat restreint actuel de l'ergothérapeute serait élargi, passant de l'autonomie et la sécurité aux soins personnels et à la mobilité vers l'habilitation aux occupations, l'expertise même de l'ergothérapeute et le fondement de la profession. Dans le même ordre d'idées, le fait d'habiliter aux occupations permet de prendre en considération l'ensemble des occupations, privilégiant celles qui sont significatives pour les clients, favorisant ainsi l'approche centrée sur les clients plutôt que de répondre aux besoins institutionnels (7). Cet élargissement du spectre occupationnel rappelait d'ailleurs l'effet domino de l'ergothérapie, souligné par Stav et collaborateurs (38). Cette étude révélait que lorsque les personnes âgées s'engageaient et participaient à des occupations variées (activités sociales, physiques, religieuses, instrumentales, de loisirs, de travail et le sommeil), elles bénéficiaient d'une protection dans les limitations fonctionnelles, amélioraient leur performance dans les AVQ et les AVD et ressentaient une amélioration sur le plan de leur santé mentale, physique et en lien avec leur satisfaction de vie. L'étude suggérait donc d'impliquer davantage les ergothérapeutes dans une perspective de prévention et promotion de la santé. Tout comme cette étude, les interventions proposées n'étaient pas restreintes aux AVQ, tel qu'il est pourtant recommandé de le faire dans le système actuel. L'étendue des bénéfices observée souligne également la perspective biopsychosociale privilégiée au détriment de l'approche biomédicale actuelle (8), assurant des bénéfices à différents plans, tant physique, psychologique, social, cognitif et affectif. Cette approche prévient ainsi le morcellement des besoins actuellement observés dans les soins (8). Pour ainsi dire, l'habilitation aux occupations dans une approche de réadaptation dans un contexte de prévention et promotion de la santé permet à l'ergothérapeute d'exploiter pleinement son expertise.

L'habilitation aux occupations : l'importance de l'accessibilité

Bien que l'habilitation aux occupations dans une approche de promotion et prévention permette de réduire des enjeux considérables dans le système de priorisation actuel, il demeure d'abord essentiel que l'enjeu relatif à l'accessibilité de ces services soit résolu. Les services ergothérapeutiques sont en effet actuellement surtout offerts aux personnes présentant des incapacités importantes. Pourtant, l'étude de Gitlin et collaborateurs (36) mentionne que les interventions ergothérapeutiques ont un effet plus important sur le taux de mortalité pour les personnes présentant des risques de santé de faibles à modérés comparativement à ceux présentant des risques graves de santé. Ces résultats mettent en lumière l'importance d'agir en amont afin d'offrir des services en temps opportun, et donc de rendre les services ergothérapeutiques accessibles à une clientèle plus vaste que celle présentant des incapacités importantes, tel qu'il est fait actuellement.

Pourtant, actuellement, le temps d'attente des personnes classées comme peu prioritaires permet que très rarement qu'elles puissent recevoir les services en temps opportun (5). Le message parallèle à cette réalité est donc qu'il faut que les personnes âgées soient suffisamment mal en point pour espérer recevoir des services ergothérapeutiques afin d'ensuite pouvoir aller mieux. Cette conception du système de santé n'est-elle pas contradictoire aux valeurs mêmes de l'ergothérapie relatives à la santé et au bien-être des individus?

L'habilitation aux occupations dans une approche de promotion et prévention : une perspective rentable

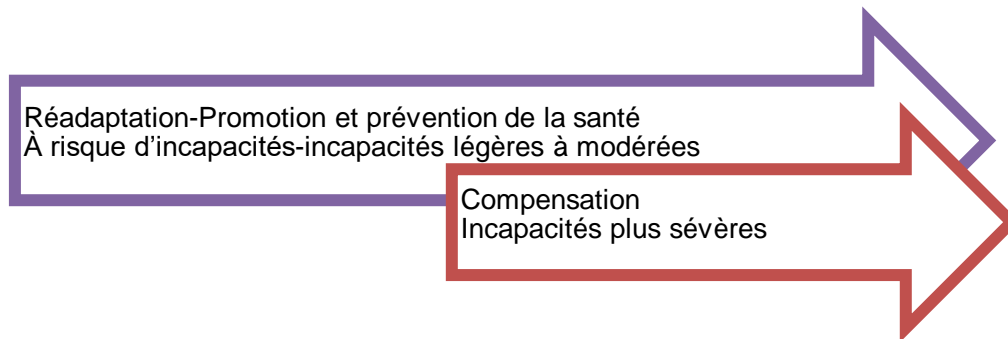
Cette même conception de la santé, par son approche principalement compensatoire et restrictive, permet de seulement mettre un pansement temporaire sur les besoins des clients. À l'inverse, l'habilitation aux occupations permet à l'ergothérapeute d'outiller le client à reconnaître ses problèmes occupationnels, à les analyser puis à trouver des stratégies visant à favoriser sa participation dans les occupations qui lui tiennent à cœur. Ainsi, le client pourra alors transférer cette analyse et l'application de stratégies à de nouveaux problèmes plutôt que de reconsulter à chaque fois puisque ses besoins n'auront été que partiellement comblés. La réponse en amont aux besoins permettra également de décharger à long terme la liste des besoins considérés comme urgents puisque le maintien des capacités et la prévention des pertes auront été privilégiés. Cette reconceptualisation du système d'attribution des services contribuera ainsi à la rentabilité des services. La rentabilité des services ergothérapeutiques dans cette nouvelle perspective proposée est d'ailleurs soutenue dans les études sélectionnées.

Les actions

Bien entendu, il demeure important que les personnes avec des incapacités importantes continuent de recevoir des services ergothérapeutiques puisqu'ils ont des besoins criants. Cependant, ces services ne devraient pas être offerts au détriment du reste de la clientèle qui pourrait également bénéficier des services ergothérapeutiques, comme l'a démontré cette étude. Pour parvenir à un équilibre acceptable, il est proposé de gérer la liste d'attente en offrant parallèlement des services compensatoires aux personnes présentant des incapacités plus importantes et également des services dans une approche

de promotion et prévention pour les clientèles à risque de développer des incapacités ou présentant des incapacités légères à modérées (Figure 3). En ce sens, les ergothérapeutes pourraient ainsi intégrer à leur charge de travail un nombre de clients classés actuellement comme priorité moins élevée à un nombre de clients considérés comme priorités élevées.

Figure 3: Le modèle recommandé d'attribution des services en ergothérapie



Une autre des stratégies qui pourraient être efficaces est de prioriser les interventions de groupes en comparaison des interventions individuelles, puisque ce type d'intervention s'est non seulement avéré rentable, mais apprécié par les participants des études étant donné que l'approche en groupe comportait des bénéfices quant à l'amélioration de l'estime de soi (34), le sentiment d'appartenance à un groupe et le soutien entre participants (29,35). Il importe de conserver certaines périodes individuelles afin de s'assurer que les services répondent aux besoins individuels et à la situation particulière de chaque client, mais ces périodes pourraient être réduites en privilégiant l'approche de groupe.

Une dernière proposition serait que les décisions relatives à l'attribution des services impliquent davantage les ergothérapeutes. Il est ainsi espéré que les services soient attribués en regard à ce que la profession a réellement à offrir. D'ailleurs, l'étude de Bishop et Brott (6) abordant le temps d'attente pour recevoir des services en ergothérapie rapporte que la centralisation des références en ergothérapie et le traitement des références par une ergothérapeute permettaient la réduction du volume de demandes, la diminution du temps d'attente avant la prise en charge et une meilleure équité dans l'attribution des services au sein des différents territoires de la région. Cela peut s'expliquer par le fait que l'ergothérapeute responsable de l'attribution des services peut remettre en question les références reçues et ainsi mieux cibler et prioriser les besoins, facilitant possiblement une attribution des services plus efficace.

L'application du modèle CRAF pour soutenir le rôle d'agent de changement chez les ergothérapeutes

Il est souhaité que cette étude puisse faciliter la démarche du procédé argumentaire chez les ergothérapeutes désirant agir comme agent de changement. En effet, le cadre conceptuel annoncé déjà les convictions et les fondements de la profession. Ceux-ci peuvent donc être directement appliqués à une situation problématique autre. Il reste donc à l'ergothérapeute à chercher les résultats probants (R) pour soutenir de façon crédible ses arguments et le guider vers les actions à entreprendre.

La recherche des résultats probants et leur analyse, bien qu'elle puisse être ardue, demeurent à la portée des ergothérapeutes. En fait, l'application des résultats probants à la pratique constitue les bonnes pratiques en ergothérapie selon l'Association canadienne des ergothérapeutes.

Une seconde étude pourrait être réalisée afin de déterminer si cette application concrète d'un procédé argumentaire basée sur le cadre CRAF facilite la reproductibilité dans une situation problématique autre et si cela contribue à améliorer le sentiment de compétence des ergothérapeutes dans leur rôle d'agent de changement.

Forces et limites de l'étude

Il s'agit d'une des premières études à expliciter un procédé argumentaire défendant une attribution des services en ergothérapie basée sur les fondements et les valeurs mêmes de la profession.

La principale limite reste dans le fait que la revue systématique a été faite par seulement deux personnes. D'autre part, considérant qu'il s'agissait d'une des premières études qui appliquait le cadre argumentaire CRAF comme cadre conceptuel dans un contexte spécifique à l'ergothérapie, son intégration n'a pu être validée et sa reproductibilité est donc à intégrer avec attention.

Toutefois, la crédibilité et le niveau de scientificité des arguments demeurent acceptables considérant que les arguments sont basés sur des études de haut niveau d'évidence et sur des concepts fondamentaux de la profession qui sont largement documentés dans la littérature professionnelle.

Conclusion

L'attribution des services en ergothérapie dans les CLSC du Québec basée sur l'habilitation aux occupations repose sur des arguments issus des valeurs, des fondements théoriques et des résultats probants. Le fait que les personnes âgées puissent s'engager dans des occupations significatives capable de contribuer à sa propre santé a un effet de maintenir leur santé et leur vitalité. Le fait de s'engager régulièrement dans des activités sociales ne contribue pas à l'efficacité dans une perspective de promotion de la santé ni le fait de ne recevoir aucun traitement. Cela affaiblit l'adage qui dit « qu'il suffit de se tenir occupé pour se tenir en santé » (31); certains des bénéfices associés au traitement en ergothérapie basée sur l'habilitation dans une approche de prévention et de promotion de la santé en ergothérapie perdurent sur une période de 6 mois suivant la fin des interventions. Les interventions en ergothérapie basées sur les stratégies d'habilitation aux occupations ont des retombées sur la participation et le fonctionnement dans les occupations, le bien-être et la santé physique et mentale, la perception d'efficacité personnelle, la satisfaction de vie, les interactions sociales, l'apprentissage de connaissances et l'espérance de vie.

Par ailleurs, il est espéré que le modèle CRAF puisse servir d'outil pour les ergothérapeutes cliniciens afin qu'elles puissent agir comme agent de changement en posant des actions basées sur les valeurs et les fondements de la profession de même que sur les données probantes.

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Références

1. Carrier A, Levasseur M, Mullins G. [Accessibility of occupational therapy community services: a legal, ethical, and clinical analysis](#). Occupational Therapy in Health Care. 2010;24(4):360-376.
2. Harries P, Gilhooly K. [Identifying occupational therapists' referral priorities in community health](#). Occupational Therapy International. 2003;10(2):150-164.
3. Raymond MH, Feldman D, Prud'homme MP, Demers L. Who's next? Referral prioritisation criteria for home care occupational therapy...including commentary by Hunt LA, Bissett M and Slater CE. International Journal of Therapy & Rehabilitation. 2013;20(12):580-589.

4. Harding, KE, Taylor, NF, Leggat, SG, Stafford, M. [Effect of triage on waiting time for community rehabilitation: a prospective cohort study](#). Archives of Physical Medicine & Rehabilitation. 2012;93(3):441-445. doi:10.1016/j.apmr.2011.09.021
5. Raymond, MH, Demers, L, Feldman, DE. [Waiting list management practices for home-care occupational therapy in the province of Quebec, Canada](#). Health & Social Care in the Community. 2016;24(2):154-164. doi:10.1111/hsc.12195
6. Bishop A, Brott, T. [Why the wait? a new approach to community occupational therapy waiting list management](#). New Zealand Journal of Occupational Therapy. 2019;66(1):19-23.
7. Carrier A, Freeman A, Levasseur M, Desrosiers J. [Standardized referral form: Restricting client-centered practice?](#) Scandinavian Journal of Occupational Therapy. 2015;22(4):283-292.
8. Carrier A, Levasseur M, Freeman A, Desrosiers J. [Reddition de compte et optimisation de la performance: impacts sur le choix des interventions ergothérapeutiques](#). Santé Publique. 2016;28(6):769-780.
9. Prud'homme J. Professions à part entière. Histoire des ergothérapeutes, orthophonistes, physiothérapeutes, psychologues et travailleuses sociales au Québec. Montréal : Presses de l'Université de Montréal; 2011.
10. Raja M, Laver K. [What does the Australian public know about occupational therapy for older people? A population survey](#). Australian Journal of Occupational Therapy, 2019;66(4):511-518.
11. Townsend EA, Beagan B, Kumas-Tan Z, Versnel J et al. Habilitier : la compétence primordiale en ergothérapie. Dans Townsend EA & Polatajko HJ, rédacteurs. Habilitier à l'occupation : Faire avancer la perspective ergothérapeutique de la santé, du bien-être et de la justice par l'occupation. 2^e éd. (version française N. Cantin). Ottawa, Ont : CAOT Publications ACE; 2013. p.103-158.
12. Townsend EA, Polatajko HJ. Glossaire. Dans Townsend EA, Polatajko HJ, rédacteurs. Habilitier à l'occupation : Faire avancer la perspective ergothérapeutique de la santé, du bien-être et de la justice par l'occupation. 2^e éd. (version française N. Cantin). Ottawa, Ont : CAOT Publications ACE; 2013. p. 434-448.
13. Association canadienne des ergothérapeutes. Profil de la pratique des ergothérapeutes au Canada [En ligne]. Ottawa (ON) : CAOT Publications ACE, 2012. Profil de la pratique des ergothérapeutes au Canada. Disponible à : <https://www.caot.ca/pdfs/2012profil.pdf>
14. Freeman A, Anand H, Boniface G, Carrier A, Larivière N. Promouvoir les services d'ergothérapie de qualité : Trucs du métier. Réflexions découlant du forum de 2016 de Occupational Therapy Canada. Actualités ergothérapeutiques. 2017;19(1):23-25.
15. Restall G, Ripat J. [Applicability and clinical utility of the Client-Centred Strategies Framework](#). Canadian Journal of Occupational Therapy. Revue Canadienne d'Ergotherapie. 2008;75(5):288-300.
16. Dhillon SK, Wilkins S, Law MC, Stewart DA, Tremblay M. [Advocacy in occupational therapy: exploring clinicians' reasons and experiences of advocacy](#). Canadian Journal of Occupational Therapy. 2010;77(4):241-248. doi:10.2182/cjot.2010.77.4.6
17. Dhillon S, Wilkins S, Stewart D, Law M. [Understanding advocacy in action: A qualitative study](#). British Journal of Occupational Therapy. 2016;79(6):345-352. doi:10.1177/0308022615583305
18. Kirsh BH. [Transforming values into action: Advocacy as a professional imperative](#). Canadian Journal of Occupational Therapy. Revue Canadienne D'ergotherapie. 2015;82(4):212-223.
19. Drolet MJ, Lalancette M, Caty ME. ABC de l'argumentation. Pour les professionnels de la santé et toute autre personne qui souhaite convaincre. 2^e éd. Québec: PUQ; 2019.
20. Angenot P. Apprendre à argumenter : l'acquisition de stratégies. Revue de l'Association pour la recherche qualitative. 1994;10:54-68.
21. Gohier C. Le cadre théorique. Dans Karsenti T, Savoie-Zajc L, rédacteurs. Introduction à la recherche en éducation. Montréal : Édition du CRP; 2000. p. 99-125
22. Townsend EA, Polatajko HJ. Habilitier à l'occupation: Faire avancer la perspective ergothérapeutique de la santé, du bien-être et de la justice par l'occupation. 2^e éd. (version française N. Cantin). Ottawa, Ont : CAOT Publications ACE; 2013.
23. Townsend EA, Polatajko HJ, rédacteurs. Introduction. Habilitier à l'occupation: Faire avancer la perspective ergothérapeutique de la santé, du bien-être et de la justice par l'occupation 2^eéd. (version française N. Cantin). Ottawa, Ont : CAOT Publications ACE; 2013. p. 1-10.
24. Jean-Gagnon K. [Procédé argumentaire : Revendiquer une attribution des services ergothérapeutiques en CLSC basée sur l'habilitation aux occupations](#) [Essai]. Trois-Rivières (Qc) : Université du Québec à Trois-Rivière; 2017.
25. Étienne A. [L'activité en Amérique du nord: Évolution vers une science de l'occupation](#). Journal d'Ergothérapie. 1990;12(2):48-53.
26. Rebeiro KL, Polgar JM. [Enabling occupational performance: optimal experiences in therapy](#). Canadian Journal of Occupational Therapy. 1999;66(1):14-22.
27. Haute Autorité de Santé (HAS). [Niveau de preuve et gradation des recommandations de bonne pratique](#). Saint-Denis (FR). France : Collège de la Haute Autorité de Santé; 2013.
28. Matuska K, Giles-Heinz A, Flinn N, Neighbor M, Bass-Haugen J. [Outcomes of a pilot occupational therapy wellness program for older adults](#). American Journal of Occupational Therapy. 2003;57(2):220-224.
29. *Mulry CM, Piersol CV. [The Let's Go program for community participation: a feasibility study](#). Physical & Occupational Therapy in Geriatrics. 2014;32(3):241-254.
30. *Gitlin LN, Winter L, Dennis MP, Corcoran M, Schinfeld S, Hauck WW. [A randomized trial of a multicomponent home intervention to reduce functional difficulties in older adults](#). Journal of the American Geriatrics Society. 2006;54(5):809-816.

31. Clark F, Azen SP, Zemke R, Jackson J, Carlson et al. [Occupational therapy for independent-living older adults](#). A randomized controlled trial. JAMA. 1997;278(16):1321-1326.
32. *Clark F, Azen SP, Carlson M, Mandel D, et al. [Embedding health-promoting changes into the daily lives of independent-living older adults: long-term follow-up of occupational therapy intervention](#). Journals of Gerontology Series B: Psychological Sciences & Social Sciences. 2001;56(1):60-63.
33. *Clark F, Jackson J, Carlson M, Chou C, et al. [Effectiveness of a lifestyle intervention in promoting the well-being of independently living older people: results of the Well Elderly 2 Randomised Controlled Trial](#). Journal of Epidemiology & Community Health. 2012;66(9):782-790. Erratum in: J Epidemiol Community Health. 2012;66:1079-1082.
34. *Johansson A, Björklund A. [The impact of occupational therapy and lifestyle interventions on older persons' health, well-being, and occupational adaptation](#). Scandinavian Journal of Occupational Therapy. 2016;23(3):207-219.
35. *Yamada T, Kawamata H, Kobayashi N, Kielhofner G, Taylor R. [A randomised clinical trial of a wellness programme for healthy older people](#). British Journal of Occupational Therapy. 2010;73(11):540-548.
36. *Gitlin LN, Hauck WW, Dennis MP, Winter L, Hodgson N, Schinfeld S. [Long-term effect on mortality of a home intervention that reduces functional difficulties in older adults: results from a randomized trial](#). Journal of the American Geriatrics Society. 2009;57(3):476-481.
37. *Zingmark M, Nilsson I, Fisher AG, Lindholm L. [Occupation-focused health promotion for well older people: A cost-effectiveness analysis](#). British Journal of Occupational Therapy. 2016;79(3):153-162.
38. Stav WB, Hallenen T, Lane J, Arbesman M. [Systematic review of occupational engagement and health outcomes among community-dwelling older adults](#). American Journal of Occupational Therapy. 2012;66(3):301-310.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Survey of Mental Health Care Providers' Perspectives on the Everyday Ethics of Medical-Aid-in-Dying for People with a Mental Illness

Marjorie Montreuil^{1,2,4}, Monique Séguin^{2,3}, Catherine P. Gros^{1,2,5}, Eric Racine^{4,6,7}

Résumé

Contexte: Dans la plupart des juridictions où l'aide médicale à mourir (AMM) est disponible, cette option est réservée aux personnes souffrant d'affections physiques incurables. À l'heure actuelle, au Canada, les personnes atteintes d'une maladie mentale sont légalement exclues de l'AMM. **Méthodes:** Nous avons développé un questionnaire à l'intention des soignants en santé mentale afin de mieux comprendre leurs points de vue sur les questions éthiques liées à l'AMM dans le contexte de souffrances graves et persistantes causées par une maladie mentale. Nous avons employé une méthode mixte, utilisant un modèle intégré avec des questions fermées et ouvertes. **Résultats:** 477 soignants de la province du Québec (Canada) ont rempli le questionnaire. Un tiers de l'échantillon (34,4%) étaient des infirmières, un quart des psychologues (24,3%) et un quart des psychoéducateurs (24%). Près de la moitié des personnes interrogées (48,4%) ont estimé que les personnes atteintes d'une maladie mentale grave devraient avoir le droit d'opter pour l'AMM afin de mettre fin à leurs souffrances. Les répondants étaient plus susceptibles de se sentir à l'aise d'écouter la personne et de prendre part aux discussions sur l'AMM pour une maladie mentale que d'offrir des soins ou les moyens à la personne d'accéder à l'AMM. La plupart (86,2%) ont déclaré ne pas avoir reçu de formation, d'éducation ou de préparation adéquate/suffisante pour traiter les questions éthiques liées à l'AMM. **Conclusions:** Les résultats soulignent comment l'extension de l'AMM aux personnes atteintes de maladie mentale affecterait les pratiques quotidiennes des soignants en santé mentale travaillant directement avec des personnes susceptibles de demander l'AMM. Les résultats soulignent également les besoins de formation et d'éducation professionnelle adéquates dans ce domaine complexe de soins.

Mots-clés

suicide assisté, aide médicale à mourir, enquêtes et questionnaire, santé mentale, prestataires de soins de santé, éthique

Abstract

Context: In most jurisdictions where medical-aid-in-dying (MAiD) is available, this option is reserved for individuals suffering from incurable physical conditions. Currently, in Canada, people who have a mental illness are legally excluded from accessing MAiD. **Methods:** We developed a questionnaire for mental health care providers to better understand their perspectives related to ethical issues in relation to MAiD in the context of severe and persistent suffering caused by mental illness. We used a mixed-methods survey approach, using a concurrent embedded model with both closed and open-ended questions. **Findings:** 477 healthcare providers from the province of Québec (Canada) completed the questionnaire. One third of the sample (34.4%) were nurses, one quarter psychologists (24.3%) and one quarter psycho-educators (24%). Nearly half of the respondents (48.4%) considered that people with a severe mental illness should be granted the right to opt for MAiD as a way to end their suffering. Respondents were more likely to feel comfortable listening to the person and participating in discussions related to MAiD for a mental illness than offering care or the means for the person to access MAiD. Most (86.2%) reported that they had not received adequate/sufficient training, education or preparation in order to address ethical questions surrounding MAiD. **Conclusions:** The findings highlight how extending MAiD to people with a mental illness would affect daily practices for mental healthcare providers who work directly with people who may request MAiD. The survey results also reinforce the need for adequate training and professional education in this complex area of care.

Keywords

assisted suicide, medical-aid-in-dying, surveys and questionnaire, mental health, healthcare providers, ethics

Introduction

Whether individuals suffering from an incurable illness should have the legal right to access medical-aid-in-dying (MAiD) remains a subject of ongoing debate worldwide. Even more controversial is the question of whether MAiD should also be available as a means for people to end suffering caused by severe mental illness. While a number of countries have passed legislation authorizing MAiD for people with life-limiting physical conditions, Belgium, Luxembourg and the Netherlands are currently the only countries in which MAiD is also allowed for a mental illness. This practice is tolerated, but not officially adopted, in Switzerland (1).

Since 2016, eligible Canadian citizens have the right to request and receive MAiD. Canadian federal legislation stipulates that MAiD is reserved for people with a "grievous and irremediable" illness whose death is "reasonably foreseeable" (2); a recently introduced bill (February 24, 2020), however, proposes changes to Canada's *Criminal code* provision on MAiD that would, whilst assuring procedural safeguards, remove the 'reasonably foreseeable death' criteria (3). The law governing MAiD in the province of Quebec was somewhat narrower since individuals requesting MAiD had to have the additional criteria of being at the end of life (4,5), although these two criteria were invalidated by the Superior Court of Quebec on September 11, 2019 (6). Across all Canadian provinces and Territories, including Quebec, access to MAiD is denied for people whose suffering is related to psychiatric illness alone – a situation which has sparked significant public debate (7,8). In 2016, the federal government asked for an expert report on requests for MAiD for patients for whom mental illness is the only medical condition (9). Released in 2018, this report highlighted the multiplicity of perspectives on MAiD for a severe mental illness (10).

In light of the above, we conducted a survey in order to explore the perspectives of health care providers (HCPs) working in mental health regarding the ethical issues they encounter in their practice (or would encounter if the law were extended to people with a mental illness) with patients who experience intense mental suffering and who might choose to die as a result.

There has been much debate within the academic literature regarding the permissibility of access to MAiD on the grounds of mental illness alone, and associated ethical, legal, and practical challenges (9,11-13). Concerns include issues of capacity and capacity assessment, as well as the conflict between MAiD and the impetus in mental health care to prevent suicide. Little research has examined HCPs' perspectives on ethical aspects of MAiD for mental illness alone, especially among HCPs who specialize in this area. Karesa and McBride (14) surveyed Canadian psychologists' knowledge and perceptions of MAiD from both personal and professional perspectives. They found that respondents supported MAiD for terminal, but not mental, illness. Further, respondents had limited confidence in their ability to assess the competence of terminally ill patients to consent and felt they lacked the training to do so (14). A survey of 528 psychiatrists in Canada on their attitudes toward MAiD for mental illness found that most psychiatrists (70.6%) did not support this practice (15). Surveys have also been conducted with physicians and psychiatrists in the United States and the Netherlands on their attitudes and willingness to provide MAiD in the context of mental illness, and highlighted HCPs' low levels of confidence in their ability to assess the appropriateness of MAiD in the case of a mental illness diagnosis (16,17). Sheehan et al. (13), in a review of cases of requests for MAiD for a mental illness, similarly emphasized a need for educational resources to train current and future mental health providers about MAiD.

The Everyday Ethics of Medical Aid in Dying

The field of bioethics has traditionally focused on “dramatic” ethical issues, associated with, for example, uncommon high-technology and life-threatening interventions (18). We here address MAiD from both this traditional perspective and an everyday ethics perspective. Indeed, focusing exclusively on high stakes situations may lead to oversights regarding ethically charged situations that arise in the day-to-day work of HCPs (19). Recognizing and unpacking these issues is important, both to facilitate their appropriate management in the clinic, but also to ensure that ethics education and resources for HCPs provide the tools to effectively address these issues (19,20).

There is limited literature on the issues of everyday ethics related to MAiD in the context of mental illness alone. Within the literature related to MAiD in general, different ethical concerns for HCPs have been identified through surveys and qualitative studies. These concerns include: assessment of the decision-making capacity of the person who requests MAiD (21), the importance of respecting the person's wishes while preventing potential abuse of decision-making power (22), the pressure HCPs can receive from patients and/or family members to provide MAiD (23,24), and difficulty in navigating discussions with caregivers, especially in cases in which the person is non-verbal (25,26). The emotional impact of MAiD on HCPs has also been emphasized, highlighting the intensity of this practice, as well as the potential negative emotions that compete with the HCPs' will to respect the person's wishes, provide relief and offer a “good death” (27,28). Personal religious beliefs can also influence professionals' views and attitudes toward MAiD, affecting their daily experiences in relation to these practices (16,17). MAiD has also been described as contrary to HCPs' mandate to heal, which could lead to death being perceived as a routine part of everyday practice and thus trivialized (29).

Suicide and Medical Aid in Dying

The distinction between suicide and MAiD is not entirely clear. MAiD is sometimes described as the “thoughtful desire to see your death hastened to end suffering caused by a life-threatening illness” (30, p.15, free translation), whereas suicide involves the desire to end one's life due to suffering from a difficult situation that is not, in itself, considered to be life-limiting. Similarly, the not-for-profit organization Dying With Dignity Canada emphasizes that suicide, or the desire to end one's life, may be a symptom of a mental illness, such as schizophrenia or severe depression, guided by “feelings of hopelessness” whereas MAiD is characterized by wanting “the comfort of knowing that, if worse comes to worst, [patients] faced with a terminal illness will be afforded the choice of a gentle death” (31).

In countries where MAiD for mental illness is legally permitted (i.e., Belgium, Luxembourg, the Netherlands), proponents argue that the suffering due to a mental illness is comparable to the suffering from other medical conditions (32,33). This view changes the focus of psychiatric practice from suicide prevention in all instances, to a recognition that ending one's life could be acceptable if there is “unbearable or untreatable suffering” caused by a mental illness. On the other hand, some argue that in consideration of the vulnerable status of people with a mental illness, allowing MAiD for mental illness alone would be against the recovery model largely prevalent in mental health care (34), and a failure to help people who might feel hopeless, isolated and devalued in our society (35).

It remains unclear whether the general issues identified in the literature on MAiD (in cases of physical/terminal illness and on suicide) represent the ethical challenges HCPs perceive in relation to MAiD in the context of mental suffering alone, in the event it were legally permitted (18). Producing a more robust understanding of the potential everyday ethical challenges of MAiD for mental illness would offer insight into the implications for mental health providers of adopting these practices. We surveyed mental HCPs in order to understand the perceived ethical issues they encounter when caring for patients who wish to die based on severe and persistent mental illness. Our specific study question was: What are the perspectives of mental HCPs in Quebec (Canada) on the ethics of MAiD in the context of severe and persistent suffering caused by mental illness alone? We also explored mental HCPs' perceived training needs in relation to ethical issues related to MAiD.

Methods

Sub-heading We used a mixed-methods survey approach, using a concurrent embedded model in which a questionnaire was developed that included both closed and open-ended questions (36). The questionnaire had four main sections: 1) demographic information; 2) practices related to MAiD; 3) everyday ethics; and 4) training needs. In each section, close-ended questions asked participants how frequently they experience ethical challenges associated with the topic under study. Ethical challenges were identified in a literature review and in consultation with an (interdisciplinary) interprofessional working group composed of four HCPs (i.e., two nurses, one psychologist and one social worker, as well as an ethicist). Open-ended questions asked participants to elaborate on their replies to the close-ended questions (i.e., rationale for their choice, explanation, example from their practice) and included specific questions such as “What other ethical challenges have you encountered in your own practice with patients who express a desire to die?” Questions from existing questionnaires on MAiD and everyday ethics for HCPs were adapted to our specific study questions (14,20,37). The questionnaire also collected demographic information about respondents’ profession or job title, work environment, age, years of practice, previous formal ethics training or education, and religious/spiritual beliefs. The study received approval from the Research Ethics Board of the *Institut de recherches cliniques de Montréal* and was conducted in accordance with the Canadian Tri-Council Policy Statement principles. Informed consent was obtained from each participant before participating to the study.

Pilot-Testing

Before the survey was launched, it was pilot-tested via a pre-test (38) and examination of the best means to collect the data. Six mental health experts with different professional/work titles were recruited to offer feedback on the questionnaire. For example, questions were asked regarding clarity of the questions, how they were understood, and people’s willingness to answer the questions. A pilot-test was also performed with one mental health team in the form of two workshops lasting 75 minutes each, in which members of the team reviewed the questionnaire. Feedback from the experts and the cognitive pre-test were used to revise the questionnaire. The survey was made available in French and English.

Data Collection Procedures

To facilitate recruitment for the survey, seven professional or clinical associations/colleges within Québec were contacted. The questionnaire was available both online (through the SurveyMonkey platform) and in paper form to accommodate people’s preferences. Envelopes with pre-paid postage were given to participants to mail the completed paper questionnaires back to the research team. Data from paper forms were subsequently entered in the online survey software by a member of the research team to facilitate analysis. Each participant who had completed the survey was eligible to enter a raffle to win a prize comprised of two sets of books on the topic of ethics for HCPs (39).

Data Analysis

All quantitative analyses were conducted with SPSS for Windows version 20 (IBM 2011). Frequencies were computed for categorical questions, and descriptive statistics (mean and standard deviations) were computed for continuous questions. Differences between groups based on profession, age and level of professional experience were assessed with chi-square statistics (categorical questions) and univariate analysis of variance (continuous questions). Odds ratio (OR) and their 95% confidence intervals (CI) were calculated when significant chi-square statistics were detected. Qualitative analyses were conducted through a coding process (40). A matrix was created in Excel that included all the codes identified. We then compared and contrasted the codes to create themes. In the presentation of the results, we combined the quantitative and qualitative data as relevant, following a concurrent mixed-methods framework (41).

Results

The present sample was composed of 477 HCPs from the province of Québec, Canada. Approximately one third of the sample were nurses, one fourth were psychologists, and one fourth were psycho-educators. While our initial survey intended to reach a wide range of health and social professionals, very few outside of the categories of nurses, psychologists or psycho-educators responded (their numbers are presented in Table 1), and these other professionals were excluded from further statistical analysis based on statistical relevance. Table 1 presents the socio-demographic and professional profiles of the respondents, and the setting where the professionals work is further categorized according to profession in Table 2. It is noteworthy that most participants had prior training in ethics, with only 10.5% reporting no prior training. While only 9.9% of respondents reported being religious and practicing and 25.8% reported being religious but not practicing, more than a quarter (26%) reported that their religious beliefs and affiliations have an influence on their work.

Table 1. Respondents' socio-demographic and professional profiles

		Frequencies	
		Percentages, %	(n)
Profession	Nurses	34.4	(159)
	Psychologists ^a	24.3	(116)
	Psycho-educators	24.0	(111)
	Social workers	6.71	(32)
	Social interveners	2.8	(13)
	Specialized educators	1.1	(5)
	Occupational therapists	1.3	(6)
	Physicians	0.6	(3)
	Nursing assistants	0.2	(1)
	Patient care attendants	0.2	(1)
	Other	3.2	(15)
	Workplace	Public services in the community	23.9
Private practice		19.1	(91)
External clinic		17.2	(82)
General psychiatric unit		14.7	(70)
Specialized psychiatric unit		13.2	(63)
Community organization		8.80	(42)
Other		19.5	(93)
Age (in years)	18-24	3.70	(17)
	25-34	22.1	(102)
	35-49	42.6	(197)
	50-64	26.6	(123)
	65+	5.00	(23)
Years of professional experience	0-5	19.0	(88)
	6-10	18.4	(85)
	11-15	19.0	(88)
	16-20	12.3	(57)
	20+	31.2	(144)
Previous training in ethics	University course	59.7	(285)
	Discussion groups	26.0	(124)
	Workshops	23.5	(112)
	Written information	19.7	(94)
	Peer support	17.8	(85)
	Presentation from an expert	16.6	(79)
	Mentoring	11.1	(53)
	Online training	10.9	(52)
	Specific training	9.60	(46)
	None	10.5	(50)
Other	4.6	(22)	

^a The category "psychologists" also includes sexologists who participated to the survey.

Table 2. Workplace of the respondents by profession

Workplace ^a	Nurses (n = 159)		Psycho-educators (n = 111)		Psychologists (n = 116)	
	Percentages, %	(n)	Percentages, %	(n)	Percentages, %	(n)
Specialized psychiatric unit	29.6	(47)	3.6	(4)	3.6	(4)
General psychiatric unit	35.8	(57)	0.9	(1)	0.9	(8)
External clinic	25.2	(40)	9.0	(10)	9.0	(18)
Private practice	3.1	(5)	11.7	(13)	11.7	(64)
Public service in the community	17.0	(27)	48.6	(54)	48.6	(18)
Community organization	1.3	(2)	8.1	(9)	8.1	(5)
Other	19.5	(31)	25.2	(28)	25.2	(19)

^a Respondents could choose multiple workplaces therefore the total of each sample size column does not equate to the total number of respondents per profession (number of respondents per profession was used to calculate percentages)

Experience and attitude regarding MAiD for a terminal physical illness

Table 3 presents the quantitative results and statistical analyses of data pertaining to the experiences and attitudes of respondents from the top three professions in the sample, regarding MAiD for individuals with a terminal physical illness. Half of the respondents reported having provided care to people with a terminal illness (49.6%) and a quarter (26.3%) reported

having provided care to people who indicated the desire to receive MAiD. Nurses were more likely than psycho-educators (OR = 6.41, 95% CI: 3.62-11.33) and psychologists (OR = 3.98, 95% CI: 2.32-6.82) to have provided care to people with a terminal illness ($\chi^2(2) = 47.36$, $p < .001$). Similarly, nurses were more likely than psycho-educators (OR = 3.23, 95% CI: 1.67-6.28) and psychologists (OR = 2.21, 95% CI: 1.21-4.02) to have provided care to people who indicated wanting to receive MAiD ($\chi^2(2) = 14.17$, $p < .001$).

Table 3. Experience and attitude regarding MAiD for individuals with a terminal physical illness, all respondents and by profession

	All respondents (n=407)		Nurses (n=141)		Psycho-educators (n=99)		Psychologists (n=103)	
	Percentages, % (n)		Percentages, % (n)		Percentages, % (n)		Percentages, % (n)	
Within your work, have you provided care to people with a terminal illness? ^a								
Yes	49.6	(202)	71.6	(101)	28.3	(28)	38.8	(40)
No	46.7	(190)	27.0	(38)	67.7	(67)	56.3	(58)
Uncertain	3.7	(15)	1.4	(2)	4.0	(4)	4.9	(5)
Have you provided care to people who indicated they would like to receive MAiD? ^a								
Yes	26.3	(107)	34.8	(49)	14.1	(14)	19.4	(20)
No	71	(289)	63.8	(90)	83.8	(83)	74.8	(77)
Uncertain	2.7	(11)	1.40	(2)	2.0	(2)	5.8	(6)
In your opinion, should people with a terminal physical illness and who have the capacity to consent to care have the right to opt for MAiD?								
Yes	78.6	(320)	82.3	(116)	87.9	(87)	69.9	(72)
Yes, but only under certain conditions	14.0	(57)	12.8	(18)	9.1	(9)	16.5	(17)
No	1.0	(4)	2.1	(3)	0	(0)	0	(0)
Uncertain	5.7	(23)	1.4	(2)	3.0	(3)	12.6	(13)
Prefer not to answer	0.7	(3)	1.4	(2)	0	(0)	1.0	(1)
In general, do you believe you have received adequate training, education, or some other sufficient preparation to address ethical questions surrounding MAiD for those with a terminal physical illness? ^a								
Yes	16.5	(67)	24.8	(35)	5.10	(5)	17.5	(18)
No	78.9	(321)	69.5	(98)	92.9	(92)	76.7	(79)
Uncertain	4.7	(19)	5.7	(8)	2.0	(2)	5.8	(6)

^a There is a statistically significant association between profession and the answer to this question ($p < .001$; ***); *uncertain* and *prefer not to answer* responses were not included for the statistical analyses

The idea that people with a terminal physical illness have the right to receive MAiD is largely accepted, with 78.6% of the respondents agreeing with this notion and an additional 14% agreeing provided that specific conditions are met. No significant differences were detected based on respondents' profession, age or professional experience. However, the vast majority of respondents (78.9%) believed they had not received the training, education or other preparation required to adequately address the ethical questions surrounding MAiD for this population ($\chi^2(2) = 17.28$, $p < .001$). Psycho-educators were more likely than nurses (OR = 5.77, 95% CI: 2.47-13.46) and psychologists (OR = 3.99, 95% CI: 1.63-9.76) to report not having received enough training to respond to the ethical questions about MAiD for people with a terminal physical illness. No significant differences were detected on this question based on respondents' age and levels of professional experience.

Experience and attitude regarding MAiD for a severe and persistent mental illness

Three quarters (75.9%) of respondents reported having provided care to people who said they wanted to die because of severe and persistent mental or psychological suffering, as shown in Table 4. Similarly, over two thirds (69%) of respondents believe that their work and profession would be involved with practices pertaining to MAiD for individuals who suffer solely from a severe and persistent psychiatric/mental illness, in the event that the law is extended to this population. Acceptance for this eventual practice was shared by almost half of the participants (48.4%), who agreed that people with only a severe mental illness may have the right to opt for MAiD (agree = 21.9%; agree only in specific conditions 26.5%). Respondents' age and years of professional experience were not found to be significantly related to acceptance level, but respondents' profession was ($\chi^2(2) = 6.54$, $p < .05$). Specifically, nurses (OR = 0.42, 95% CI: 0.25-0.71) and psycho-educators (OR = 0.48, 95% CI: 0.28-0.86) were more likely than psychologists to agree that people with only a severe mental illness should have the right to opt for MAiD, at least under certain conditions. More psychologists were uncertain about their position compared to the other professions.

Table 4. Experience and attitude regarding MAiD for individuals with a severe psychiatric/mental illness, all respondents and by profession

	All respondents (n=407) ^a		Nurses (n=141) ^a		Psycho-educators (n=99)		Psychologists (n=103) ^a	
	Percentages, % (n)		Percentages, % (n)		Percentages, % (n)		Percentages, % (n)	
Have you provided care to people who said they want to die in relation to mental/psychological suffering?								
Yes	75.9	(309)	74.5	(105)	70.7	(70)	78.6	(81)
No	22.4	(91)	24.1	(34)	27.3	(27)	19.4	(20)
Uncertain	1.7	(7)	1.4	(2)	2.0	(2)	1.9	(2)
In your opinion, should people with only a severe psychiatric/mental illness (i.e., people who do NOT have a terminal physical illness) and who have the capacity to consent to care have the right to opt for MAiD?								
Yes	21.9	(89)	24.8	(35)	29.3	(29)	12.6	(13)
Yes, but only under certain conditions	26.5	(108)	33.3	(47)	25.3	(25)	24.3	(25)
No	24.6	(100)	23.4	(33)	20.2	(20)	27.2	(28)
Uncertain	26.5	(108)	17.7	(25)	25.3	(25)	35.0	(36)
Prefer not to answer	0.5	(2)	0.70	(1)	0.0	(0)	1.0	(1)
In the event that the law on MAiD extends to individuals who suffer solely from a severe and persistent psychiatric/mental illness, do you anticipate that your work/profession will be involved in these practices? ^b								
Yes	69.0	(281)	73.8	(104)	63.6	(63)	63.1	(65)
No	10.8	(44)	7.1	(10)	15.2	(15)	15.5	(16)
Uncertain	19.9	(81)	19.1	(27)	21.2	(21)	20.4	(21)
In general, do you believe you have received adequate training, education, or some other sufficient preparation to address ethical questions surrounding MAiD for people with a severe psychiatric/mental illness? ^b								
Yes	7.1	(31)	7.1	(10)	5.1	(5)	10.7	(11)
No	86.2	(351)	85.8	(121)	87.9	(87)	84.5	(87)
Uncertain	5.9	(24)	6.4	(9)	7.1	(7)	4.9	(5)

^a The n for the last two questions equals 406, as one respondent from the nurses and one from the psychologists chose the *does not apply* answer;

^b There is a statistically significant association between profession and the answer to this question ($p < .05$; *, and $p < .001$; ***, respectively); *uncertain* and *prefer not to answer* responses were not included for the statistical analyses. An overwhelmingly high percentage of respondents (86.2%) reported the belief that they had not received adequate or sufficient training, education or other preparation in order to address the ethical questions surrounding MAiD for people with a severe psychiatric/mental illness (Table 4). This data is slightly higher but similar to insufficient training to address the ethical questions surrounding MAiD for a physical illness (78.9%). No significant differences were detected based on respondents' professions, age, and years of professional experience.

For the open-ended question asking about the difference between MAiD and suicide, the main difference stated by 151 respondents pertained to a temporary state for suicide versus a permanent wish to die for MAiD. Many respondents (103) also mentioned that suicide was an impulsive decision (e.g., as part of a crisis situation) in contrast to MAiD, which respondents viewed as a thoughtful process involving the capacity to make informed decisions. Still in relation to the difference between MAiD and suicide, 47 respondents associated MAiD with people who experience suffering due to a chronic illness that also affects the person's quality of life. In contrast, suicide was viewed as a response to intense mental suffering that is contextual and situation-specific in nature. Thirty-nine respondents perceived that people who request MAiD have a "real desire to die", while suicidal people seek "relief" or escape from temporary suffering. Other respondents reported that they saw no difference between the two terms, while a few highlighted that the practice of MAiD was guided by a law, while suicide was not. Some respondents shared their concern that distinguishing between MAiD and suicide in a mental health context is problematic and worrisome.

Levels of comfort with MAiD for people with severe mental illness

Respondents were asked to evaluate their level of comfort (on a scale of 0 corresponding to "not at all" to 9 "absolutely") in relation to five dimensions pertaining to MAiD for people with severe psychiatric/mental illness, should the law be extended to this population (Table 5). On average, respondents reported a fairly high level of comfort related to the dimension of *communicating*, such as listening and discussing the topic of MAiD with a person who has a psychiatric/mental illness (mean = 7.46, SD = 2.02) and *participating in a discussion* associated with MAiD with a person who suffers from a psychiatric/mental illness (mean = 6.80, SD = 2.55).

Table 5. Levels of comfort with five dimensions of MAiD for people with severe psychiatric/mental illness, all respondents

	All respondents
	Mean (SD)
Communicating (i.e., listening and discussing) with a person who has a psychiatric/mental illness about MAiD	7.46 (2.02)
Accompanying/providing care to an individual who suffers from a psychiatric/mental illness and who said he would like to receive MAiD	5.95 (2.96)
Participating in a discussion associated with MAiD with a person who suffers from a psychiatric/mental illness	6.80 (2.55)
Assessing the abilities of a person who suffers from a psychiatric/mental illness to make a decision about MAiD	3.65 (3.11)
Providing the necessary means to an individual so that he/she can access MAiD	3.52 (3.34)

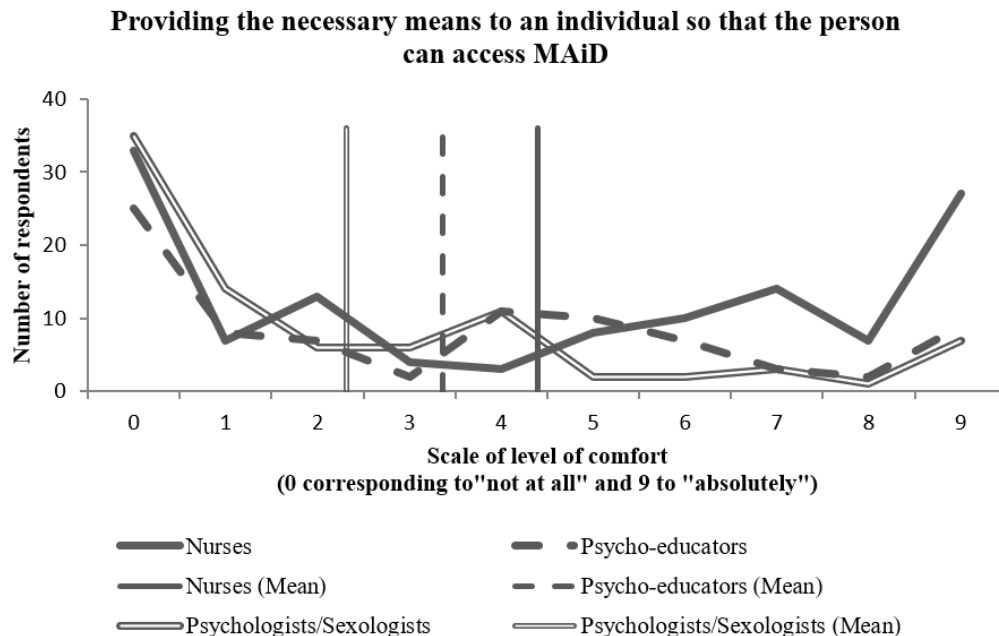
The scale used was from 0 corresponding to "not at all" to 9 "absolutely"

Per respondents' age. Significant differences were found on the dimension related to *assessing the abilities* of a person who suffers from a psychiatric/mental illness to make a decision about MAiD based on participants' age ($F(4, 350) = 3.372, p < .01$). The 65+ age group (mean = 5.59, SD = 3.54) reported significantly higher levels of comfort than the 25-34 years old group (mean = 2.88, SD = 3.19) and the 35-49 years old group (mean = 3.58, SD = 3.29). Similarly, the 50-64 years old group (mean = 4.12, SD = 3.31) reported levels of comfort with this dimension significantly higher than the 25-34 years old group (mean = 2.88, SD = 3.19).

Per respondents' level of professional experience. Significant differences were also detected on three dimensions (*accompanying/providing care*, *participating in a discussion*, and *assessing the abilities*) based on respondents' levels of professional experience with more experience being associated with higher levels of comfort. Respondents who had 20 years of professional experience or more reported significantly higher levels of comfort in the three above-mentioned dimensions ($F(4,363) = 3.59, p < .01$; $F(4,380) = 3.79, p < .01$; $F(4,350) = 3.63, p < .01$) than the other groups.

Per respondent's profession. Significant differences, based on respondents' profession, were found for all but one dimension (*communicating* with a person who has a psychiatric/mental illness about MAiD). Overall, nurses reported statistically higher levels of comfort than psycho-educators and/or psychologists within the four other dimensions pertaining to MAiD for people with severe psychiatric/mental illnesses. Specifically, nurses reported significantly higher levels of comfort ($F(2,306) = 3.04, p < 0.5, *$) than psycho-educators in the dimension of *accompanying/providing care* and significantly higher levels of comfort ($F(2,318) = 3.97, p < .05$) than psychologists in the dimension *participating in a discussion*. Nurses reported significantly higher level of comfort ($F(2,291) = 4.42, p < .01$; $F(2,295) = 10.48, p < .001$) than psycho-educators and psychologists in the dimensions of *assessing the abilities* and *providing the necessary means*, respectively. The distribution of responses for the levels of comfort with *providing the necessary means* so a person can access MAiD is noteworthy: contrary to psychologists and psycho-educators, the nurses' responses show high peaks at both ends of the scale (Figure 1). While the mean is lower than neutral, indicating lower levels of comfort, the standard deviation is quite large and highlights that many nurses were quite comfortable in providing the necessary means to an individual to access MAiD for a psychiatric/mental illness alone.

Figure 1. Distribution of responses (including means), by profession, for the dimension pertaining to the levels of comfort with *providing the necessary means* to an individual to access MAiD



Per respondents' previous education through specific training type. Regarding previous education, a small proportion of respondents (9.6%) who reported receiving specific training in ethics and who felt adequately prepared to address questions related to MAiD for people with physical illness, also had statistically significant higher mean scores in their reported level of comfort along all five dimensions ($F(1,395) = 5.178, p < .05$; $F(1,366) = 21.068, p < .001$; $F(1,383) = 6.540, p < .05$; $F(1,353) = 5.018, p < .05$; $F(1,358) = 22.834, p < .001$).

We also examined whether being in agreement with MAiD had an impact on the participants' level of comfort with the various procedures related to MAiD. We analyzed the differences in the levels of comfort within the five dimensions of MAiD for people with severe psychiatric/mental illness between the respondents' answer to the question "In your opinion, should people with only a severe psychiatric/mental illness (i.e., people who do NOT have a terminal physical illness) and who have the capacity to consent to care have the right to opt for MAiD?". We found that there was a statistically significant difference in the levels of comfort pertaining to the different dimensions of MAiD based on the respondents' answer to the question above ($F(15,751.27) = 5., p < 0.0005$, Wilk's $\lambda = 0.761$, partial $\eta^2 = .087$). The answers to whether or not people with only a severe psychiatric/mental illness should have the right to opt for MAiD have a statistically significant effect on the levels of comfort for all five dimensions of MAiD ($F(3,276) = 12.72, p < 0.0005$; $F(3,276) = 17.09, p < 0.0005$; $F(3,276) = 16.69, p < 0.0005$; $F(3,276) = 11.80, p < 0.0005$; $F(3,276) = 18.85, p < 0.0005$). Mean scores in the reported levels of comfort along all five dimensions were statistically significantly different between those who answered 'Yes' and 'Yes, but only under certain conditions' with those who answered 'No' and 'Unsure', but not between those who answered 'Yes' and 'Yes, but only under certain conditions' and those who answered 'No' and 'Unsure'.

Discussion

In this study, we surveyed HCPs' about their perspectives on the ethics of MAiD in the context of severe and persistent suffering caused by mental illness, as well as on their training needs in terms of ethical issues related to MAiD.

MAiD and Suicide

When addressing MAiD in the context of a mental illness, general, everyday issues related to suicide are at the forefront. The survey results highlight that HCPs tend to see suicide as a more impulsive and temporary state, which contrasts with MAiD as a more reflective process that is sustained over time. This view aligns with the report from the Council of Canadian Academies on MAiD for a mental disorder as the only medical condition in a person who wishes to die (9). In this report, which presents the state of knowledge on this topic, two perspectives are presented on suicide and MAiD, which both differentiate them: 1) the perspective that suicide is against the value of life (both in secular and religious terms) and that a person who is suicidal does not have sound decision-making capacity due to symptoms of a mental health disorder; and 2) the perspective that people who are suicidal have the potential to live a fulfilling life if appropriate means are put in place to support them (without reference to religious beliefs). The ideas of impulsivity and ambivalence are presented in the report for both perspectives as important characteristics of suicide and this is in alignment with the survey results. These characteristics were presented as

specific to suicide, as MAiD cannot be accessed impulsively and has to be a decision that is sustained over time. The view that MAiD and suicide are different is also shared by both proponents and opponents of MAiD for a mental illness (42,43).

In contrast, certain suicide prevention associations and authors do not differentiate between MAiD and suicide, since both MAiD and suicide represent self-directed death (44-46). This view is exemplified in certain countries where MAiD is labelled as “assisted-suicide” (i.e., in Luxembourg, Netherlands and Switzerland). In Canada, where our survey was conducted, the use of the term “suicide” is not part of the main discourse on MAiD. Opening up the discussion to MAiD in the context of a mental illness raises this issue directly and this would have a tangible effect on HCPs working with people considered to be suicidal in a mental health context. For example, currently in Canada, people who are suicidal are largely perceived as not having the capacity to make an informed decision in relation to their well-being. This view also tends to be present in the context of a serious and persistent mental illness (42,43). Extending MAiD to people with a mental illness would challenge these views, the stigma attached to mental illness, and how HCPs care for people with a mental illness who wish to die based on mental suffering. Many survey respondents highlighted the capacity to make an informed decision as a difference between suicide and MAiD. This ethical issue related to capacity would require further attention to better understand how it would affect clinical practice in mental health and suicide prevention.

Everyday Ethics in Mental Health Care Related to MAiD

In a mental health context, allowing MAiD for a mental illness only would likely change HCPs everyday practices. A salient example would be the therapeutic relationship and care. By changing the focus of mental health care from suicide prevention to discussion of potentially accessing MAiD, there would be a form of acceptance of a person ending their life. For instance, in Belgium, it has been reported that for certain people who are suicidal, knowing they could have access to MAiD (referred to as euthanasia in Belgium) and being able to discuss this option led them to choose to continue living, “because simply having this option gave them enough peace of mind to continue living” (32). There would thus be a shift in HCPs daily interactions with people who might wish to die based on mental suffering.

Certain authors argue that extending MAiD to mental suffering alone could lead to a decrease in the will to develop a therapeutic relationship with people who are suicidal and lead to a feeling of hopelessness for the HCP (47). Since HCPs often work in emotionally charged environments, this may contribute to compassion fatigue and a decreased involvement with people who are suicidal and seek MAiD. This argument has been critiqued as being too narrow and not recognizing that the feeling of hopelessness could be felt with or without the availability of MAiD in this context (43). These divergent perspectives reflect the division within the survey results, with about half of respondents supporting and half not supporting extending MAiD to people with a mental illness.

Most HCPs in the survey considered they would be somewhat comfortable discussing MAiD with a person who has a mental illness. However, this comfort decreased in relation to assessing, accompanying or providing care to a person who would want to receive MAiD for a mental illness and dropped significantly in relation to providing the means. Nurses were notably more comfortable than other HCPs with these aspects of care. Nurses are directly affected by the legalization of MAiD (48) and extending it to mental illness would also directly affect their practice, as reported in this survey. These changes to health care practices – in the current Canadian context of MAiD not being available in the case of a mental illness – already warrant specific training to address the emerging needs for all HCPs (48).

Mental HCPs’ Training Needs in Relation to MAiD

The perceived need for training on MAiD in a mental health context was clear from the survey results. Most HCPs who responded to the survey reported they had not received adequate training and support to address ethical issues related to MAiD. Participants who disagreed on – or were unsure about – access to MAiD in a mental health context had statistically significant lower levels of comfort than their counterparts who considered that access to MAiD should be allowed – or allowed under certain conditions – in a mental health context. These results align with other studies conducted on MAiD in different countries where MAiD is permissible (49-54). It is noteworthy that education and specific training in ethics does positively impact the reported levels of comfort along all five dimensions for MAiD. In terms of support to address ethical issues related to MAiD in a mental health context (without MAiD being permissible for people with a mental illness), training could be offered on how to accompany a person who wants to access MAiD, provide care, as well as participate in a discussion with the person and family. Issues around suicide and MAiD would be of primary relevance. They could, for example, be addressed following a more reflective approach in which HCPs are invited to share their own experiences to foster engagement in discussing this sensitive topic (55,56). This approach is also encouraged in training related to suicide prevention given the numerous ethical issues at play (18,57), which would also be of value for MAiD. This training could be a companion to further efforts to raise greater awareness about general health care ethics. Given the extensive nature of public debates about MAiD in Quebec and in Canada over the last years, this topic has become iconic of certain issues related to palliative care, end-of-life, therapeutic communication, and informed decision-making. It could thus be an opportunity to increase health care ethics training and to tackle common issues related to moral awareness in the workplace.

Limitations

This study was conducted with HCPs who self-declared as working in mental health contexts, and for statistical analyses, we only included data from groups in which there were sufficient numbers of respondents for comparative analyses. Physicians, who are the ones performing the evaluation for a person to access MAiD in Canada, were noticeably almost absent (only 3 respondents). A study of their perspectives on the everyday ethics of MAiD would also be of great interest. Moreover, this study was conducted solely in the province of Quebec. Given the cultural differences between Quebec and the rest of Canada, the results may not be representative of the views of Canadian HCPs nationally.

Within the questionnaire used for this survey, we chose to study MAiD in the context of severe and persistent mental illness, which could have affected the results. This decision was made in alignment with current practices related to MAiD for a mental illness in other countries. We also asked questions related to HCPs' training needs in relation to MAiD and suicide with the current Canadian legislation (which excludes people with a mental illness from accessing MAiD), while asking questions related to how extending MAiD to people with a mental illness will influence practice. This distinction was clearly mentioned in the questionnaire but might have affected the training needs identified.

Future Directions

This survey presents the perspectives of 477 HCPs from the province of Québec, Canada, on the everyday ethics of MAiD for people suffering with mental illness. Extending the survey to other Canadian provinces, as well as to countries considering MAiD for a mental illness would be warranted. Understanding the everyday ethics of MAiD contributes to enhancing an understanding of how it may affect daily practices for HCPs who work directly with people who may request MAiD. While offering an important view, this survey does not necessarily present the perspectives of people who have a mental illness or who are suicidal (or have been), nor the perspectives of their relatives. Future work on additional perspectives would bring many additional voices to this conversation that are currently missing in the discussions on MAiD for a mental illness. We anticipate various issues related to research ethics would be raised in order to ethically discuss this sensitive topic, but with adequate safeguards it would greatly contribute to a more thorough understanding of this important issue.

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References

1. Jones RM, Simpson AIF. Medical assistance in dying: challenges for psychiatry. *Front Psychiatry*. 2018;9:678.
2. Chapter 3 : An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying), Bill C-14, House of Commons, First Session, Forty-second Parliament, 64-65 Elizabeth II Sess. (2016).
3. Department of Justice. [Proposed changes to Canada's medical assistance in dying legislation](#). Government of Canada; 2020.
4. Government of Canada. [Medical assistance in dying](#). Government of Canada; 2019 [updated 24.04.2019].
5. Gouvernement du Québec. [Medical aid in dying](#). Government of Quebec; 2019.
6. Truchon v. Attorney General of Canada, 500-17-099119-177 (2019).
7. Chiose S. [Adam Maier-Clayton's death renews debate on assisted-dying access for those with mental illness](#). The Globe and Mail. 2017 Apr 16.
8. Glauser W, Nolan M, Petch J. [Should people with mental health disorders have access to physician-assisted death?](#) *Healthy Debate*. 2016 Jan 21.
9. Council of Canadian Academies. [The state of knowledge on medical assistance in dying where a mental disorder is the sole underlying medical condition](#). Ottawa (ON): The Expert Panel Working Group on MAID Where a Mental Disorder Is the Sole Underlying Medical Condition. 2018.
10. Council of Canadian Academies. [The state of knowledge on advance requests for medical assistance in dying](#). 2018.
11. Appelbaum PS. [Should mental disorders be a basis for physician-assisted death?](#) *Psychiatric Services*. 2017;68(4):315-7.
12. Schuklenk U, van de Vathorst S. [Treatment-resistant major depressive disorder and assisted dying](#). *Journal of Medical Ethics*. 2015;41(8):577.
13. Sheehan K, Gaiind KS, Downar J. [Medical assistance in dying: special issues for patients with mental illness](#). *Curr Opin Psychiatry*. 2017;30(1):26-30.
14. Karesa S, McBride D. [A sign of the changing times? Perceptions of Canadian psychologists on assisted death](#). *Canadian Psychology/Psychologie canadienne*. 2016;57(3):188-92.
15. Rousseau S, Turner S, Chochinov HM, Enns MW, Sareen J. [A national survey of Canadian psychiatrists' attitudes toward medical assistance in death](#). *Canadian journal of psychiatry / Revue canadienne de psychiatrie*. 2017;62(11):787-94.
16. Bolt EE, Snijedewind MC, Willems DL, van der Heide A, Onwuteaka-Philipsen BD. [Can physicians conceive of performing euthanasia in case of psychiatric disease, dementia or being tired of living?](#) *Journal of Medical Ethics*. 2015;41(8):592.
17. Ganzini L, Fenn DS, Lee MA, Heintz RT, Bloom JD. [Attitudes of Oregon psychiatrists toward physician-assisted suicide](#). *American Journal of Psychiatry*. 1996;153(11):1469-75.
18. Zizzo N, E Bell, Racine E. [What is everyday ethics? a review and a proposal for an integrative concept](#). *Journal of Clinical Ethics*. 2016;27(2):117-28.
19. Zizzo F. [The integration of mental health into primary care: international perspectives](#). 2015. In: *The World Book of Family Medicine - European Edition*. Istanbul, Turkey: WONCA Europe [88-90].
20. Moon M, Taylor HA, McDonald EL, Hughes MT, Carrese JA. [Everyday ethics issues in the outpatient clinical practice of pediatric residents](#). *Archives of pediatrics & adolescent medicine*. 2009;163(9):838-43.
21. Kissane DW, Kelly BJ. [Demoralisation, depression and desire for death: problems with the Dutch guidelines for euthanasia of the mentally ill](#). *Australian and New Zealand Journal of Psychiatry*. 2000;34(2):325-33.
22. Lavoie M, Godin G, Vezina-Im LA, Blondeau D, Martineau I, Roy L. [Psychosocial determinants of physicians' intention to practice euthanasia in palliative care](#). *BMC Medical Ethics*. 2015;16:6.
23. Blanker MH, Koerhuis-Roessink M, Swart SJ, Zuurmond WWA, van der Heide A, Perez RSGM, et al. [Pressure during decision making of continuous sedation in end-of-life situations in Dutch general practice](#). *BMC Family Practice*. 2012;13(1):68.
24. Swart SJ, Brinkkemper T, Rietjens JA, Blanker MH, van Zuylen L, Ribbe M, et al. [Physicians' and nurses' experiences with continuous palliative sedation in the Netherlands](#). *Arch Intern Med*. 2010;170(14):1271-4.
25. Draper BM. [Suicidal behavior and assisted suicide in dementia](#). *Int Psychogeriatr*. 2015;27(10):1601-11.
26. Tomlinson E, Spector A, Nurock S, Stott J. [Euthanasia and physician-assisted suicide in dementia: A qualitative study of the views of former dementia carers](#). *Palliat Med*. 2015;29(8):720-6.
27. Denier Y, Dierckx de Casterle B, De Bal N, Gastmans C. ["It's intense, you know." Nurses' experiences in caring for patients requesting euthanasia](#). *Medicine Health Care and Philosophy*. 2010;13(1):41-8.
28. van Marwijk H, Haverkate I, van Royen P, The AM. [Impact of euthanasia on primary care physicians in the Netherlands](#). *Palliat Med*. 2007;21(7):609-14.

29. Boudreau JD, Somerville M. Euthanasia and assisted suicide: a physician's and ethicist's perspectives. *Medicolegal and Bioethics*. 2014.
30. Gupta M, Rivest J, Leclair S, Blouin S, Chammas M. [Exploration de la souffrance psychique dans le cadre d'une demande d'aide médicale à mourir](#). Groupe de recherche sur la souffrance psychique et l'AMM, Département de psychiatrie, CHUM et CRCHUM; 2017.
31. Dying With Dignity Canada. [Why medically assisted dying is not suicide](#). 2016 Sept 23.
32. Melville NA. [Assisted suicide for mental illness gaining ground](#). Medscape. 2015 Jul 31.
33. Thienpont L, Verhofstadt M, Van Loon T, Distelmans W, Audenaert K, De Deyn PP. [Euthanasia requests, procedures and outcomes for 100 Belgian patients suffering from psychiatric disorders: a retrospective, descriptive study](#). *BMJ Open*. 2015;5(7):e007454.
34. Mental Health Commission of Canada. [Recovery Guidelines](#). Ottawa, ON: Mental Health Commission of Canada; 2015.
35. Chochinov HM. [The risky concept of mental illness assisted suicide](#). The Huffington Post. 2016 Mar 28 (Updated 2017 Mar 29).
36. Creswell JW. *Research design: Qualitative, quantitative, and mixed methods approaches*, 3rd ed. Thousand Oaks, CA, US: Sage Publications, Inc; 2009. 260 p.
37. Bator EX, Philpott B, Costa AP. [This moral coil: a cross-sectional survey of Canadian medical student attitudes toward medical assistance in dying](#). *BMC Med Ethics*. 2017;18(1):58.
38. Collins D. [Pretesting survey instruments: An overview of cognitive methods](#). *Quality of Life Research*. 2003;12(3):229-38.
39. Bowling MJ, Rimer BK, Lyons EJ, Golin CE, Frydman G, Ribisl KM. [Methodologic challenges of e-health research](#). *Evaluation and Program Planning*. 2006;29(4):390-6.
40. Maxwell JA. *Qualitative research design: an interactive approach: An Interactive Approach*: SAGE Publications; 2013.
41. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research*. Los Angeles, CA: SAGE Publications; 2011.
42. Dembo J, Schuklenk U, Reggler J. ["For their own good": a response to popular arguments against permitting medical assistance in dying \(MAID\) where mental illness is the sole underlying condition](#). *Canadian Journal of Psychiatry / Revue canadienne de psychiatrie*. 2018;63(7):451-6.
43. Rooney W, Schuklenk U, van de Vathorst S. [Are concerns about irremediableness, vulnerability, or competence sufficient to justify excluding all psychiatric patients from medical aid in dying?](#) *Health Care Anal*. 2018;26(4):326-43.
44. Centre for Suicide Prevention. [Physician-Assisted Death/MAID and Suicide](#). 2018.
45. Kim SYH, Conwell Y, Caine ED. [Suicide and physician-assisted death for persons with psychiatric disorders: how much overlap?](#) *JAMA Psychiatry*. 2018;75(11):1099-100.
46. Vandenberghe J. [Physician-assisted suicide and psychiatric illness](#). *N Engl J Med*. 2018;378(10):885-7.
47. Blikshavn T, Husum TL, Magelssen M. [Four reasons why assisted dying should not be offered for depression](#). *J Bioeth Inq*. 2017;14(1):151-7.
48. Suva G, Penney T, McPherson CJ. [Medical assistance in dying: a scoping review to inform nurses' practice](#). *J Hosp Palliat Nurs*. 2019;21(1):46-53.
49. Castelli Dransart DA, Scozzari E, Voélin S. [Stances on assisted suicide by health and social care professionals working with older persons in Switzerland](#). *Ethics & Behavior*. 2017;27(7):599-614.
50. Downar J, Green S, Radhakrishnan A, Wales J, Kim G, Seccareccia D, et al. [An entrustable professional activity descriptor for medical aid in dying: a mixed-methods study](#). *CMAJ Open*. 2018;6(4):E657-E63.
51. Feldt KS, Bond GE, Jacobson D, Clymin J. [Washington State Death with Dignity Act: implications for long-term care](#). *Journal of Gerontological Nursing*. 2011;37(10):32-40.
52. Liz Cunha de Oliveira M, de Oliveira Cavalcanti E, Alves V, Costa da Silva A. [Euthanasia from the perspective of nursing undergraduate students: concepts and challenges](#). *Reme: Revista Mineira de Enfermagem*. 2014;18(1):134-14.
53. Marcoux I, Boivin A, Arsenault C, Toupin M, Youssef J. [Health care professionals' comprehension of the legal status of end-of-life practices in Quebec: study of clinical scenarios](#). *Can Fam Physician*. 2015;61(4):e196-e203.
54. Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, Bilsen J, Deliëns L. [Establishing specialized health services for professional consultation in euthanasia: experiences in the Netherlands and Belgium](#). *BMC Health Services Research*. 2009;9(1):220.
55. Johns C. *Becoming a reflective practitioner*: John Wiley & Sons; 2009.
56. Schön DA. *The reflective practitioner: how professionals think in action*. London: Routledge; 1992. 384 p.
57. Fiske H. *Hope in Action: Solution-focused conversations about suicide*. Taylor & Francis; 2012.

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Research, Digital Health Information and Promises of Privacy: Revisiting the Issue of Consent

Timothy Caulfield¹, Blake Murdoch¹, Ubaka Ogbogu¹

Résumé

L'obligation de préserver la vie privée des patients et des participants à la recherche est fondamentale en recherche biomédicale. Toutefois, les défis à relever pour maintenir la confidentialité des informations sur les participants suscitent une inquiétude croissante. Un certain nombre d'études récentes a mis en évidence les manières d'utiliser les nouvelles stratégies informatiques pour identifier ou réidentifier les personnes dans les banques de données de santé gérées par des institutions publiques ou privées. Certains commentateurs ont laissé entendre que les concepts de vie privée et d'anonymat sont "morts" dans leur ensemble, ce qui soulève des questions juridiques et éthiques sur le processus de consentement et sur les garanties relatives à la protection de la vie privée en matière de santé. Les membres du public et les participants à la recherche accordent une grande importance à la protection de la vie privée, et l'incapacité à garantir celle-ci pourrait avoir une incidence sur la participation. La common law et la législation canadienne exigent une divulgation complète et exhaustive des risques lors du consentement éclairé, y compris tout ce qu'une personne raisonnable dans la position du participant ou du patient voudrait savoir. Les politiques en matière d'éthique de la recherche exigent des divulgations similaires, ainsi que des descriptions complètes des risques liés à la vie privée et des stratégies d'atténuation lors du consentement. En outre, le droit de se retirer de la recherche entraîne la nécessité d'un consentement continu, et toute information sur l'évolution du risque pour la vie privée doit être divulguée. Étant donné que le concept de "non-identifiabilité" en matière d'éthique de la recherche est de plus en plus discutable, les politiques qui s'y rattachent pourraient devenir intenables. En effet, l'incapacité potentielle à garantir l'anonymat pourrait avoir des conséquences importantes sur l'activité de recherche.

Mots-clés

vie privée, confidentialité, consentement éclairé, informations sur la santé, biobanques, identifiabilité, éthique de la recherche, droit de la santé

Abstract

The obligation to maintain the privacy of patients and research participants is foundational to biomedical research. But there is growing concern about the challenges of keeping participant information private and confidential. A number of recent studies have highlighted how emerging computational strategies can be used to identify or reidentify individuals in health data repositories managed by public or private institutions. Some commentators have suggested the entire concept of privacy and anonymity is "dead", and this raises legal and ethical questions about the consent process and safeguards relating to health privacy. Members of the public and research participants value privacy highly, and inability to ensure it could affect participation. Canadian common law and legislation require a full and comprehensive disclosure of risks during informed consent, including anything a reasonable person in the participant or patient's position would want to know. Research ethics policies require similar disclosures, as well as full descriptions of privacy related risks and mitigation strategies at the time of consent. In addition, the right to withdraw from research gives rise to a need for ongoing consent, and material information about changes in privacy risk must be disclosed. Given the research ethics concept of "non-identifiability" is increasingly questionable, policies based around it may be rendered untenable. Indeed, the potential inability to ensure anonymity could have significant ramifications for the research enterprise.

Keywords

privacy, confidentiality, informed consent, health information, biobanking, identifiability, research ethics, health law

Introduction

More and more people have biological samples and health information stored with a range of public and private entities, including direct-to-consumer health and ancestry genetic testing companies, clinical laboratories, cohort initiatives and large-scale biobanks. Personal health information includes many types of information, ranging from qualitative or demographic information to genomic data and even biobanked tissue itself (1). And with the rise of Big Data research initiatives, personal information from a range of sources is being compiled, shared and analyzed in ever more complex ways (2). Often, individuals are asked to provide consent for the storage and use of their information for research and other permitted purposes. In other circumstances, policies allow research to be conducted without consent.

The obligation to maintain the privacy of the research participant is foundational to biomedical research. It is mentioned in virtually every research ethics guideline, including well-established international statements (3,4), national policies (5,6), and professional ethics codes (7,8). Privacy is expected by the general public and research participants, and it is a key component of public trust in the research enterprise (9). But there is growing concern about the challenges of keeping participant information private and confidential (10,11). Growth in sophisticated information technologies that can facilitate data breaches along with increasing collection and sharing of digitized health information may make it more difficult for researchers, public research institutions and private companies to maintain this obligation (12).

When consent is required for research involving health information and biological samples, the relevant consent process often includes information about data protection, the entities and individuals that will have access, and why confidentiality cannot always be guaranteed. But given the shifting information technology landscape, to what degree does the consent process need to evolve, if at all, to reflect emerging privacy and data protection concerns? Have privacy risks – and the public concerns

and perceptions about those risks – changed enough to warrant re-consenting for samples that were collected with data protection guarantees that are no longer realistic? What privacy risks ought to be disclosed to participants and when? And are the promises of anonymity that are so often made to research participants and research ethics boards still tenable?

In this article we explore these questions through the lens of Canadian health law and research ethics policies. The goal is to map the nature of the emerging consent challenges. As research involving health information and biological samples becomes increasingly common, essential and complex, the issues associated with privacy will intensify. Here, we seek to highlight several areas that warrant immediate attention.

The Emerging Privacy Challenge

A number of recent studies have highlighted how emerging computational strategies can be used to identify individuals in health data repositories managed by public or private institutions (13). And this is true even if the information has been anonymized and scrubbed of all identifiers (14). A study by Na et al., for example, found that an algorithm could be used to re-identify 85.6% of adults and 69.8% of children in a physical activity cohort study, “despite data aggregation and removal of protected health information” (15). A 2018 study concluded that data collected by ancestry companies could be used to identify approximately 60% of Americans of European ancestry and that, in the near future, the percentage is likely to increase substantially (16). Such concerns have led at least one company to offer “anonymous” genome sequencing (17). Furthermore, a 2019 study successfully used a “linkage attack framework” – that is, an algorithm aimed at re-identifying anonymous health information – that can link online health data to real world people and thus, as suggested by the authors, clearly demonstrates “the vulnerability of existing online health data”(18). And these are just a few examples of the developing approaches that have raised questions about the security of health information framed as being confidential. Indeed, it has been suggested that today’s “techniques of re-identification effectively nullify scrubbing and compromise privacy” (19).

In addition, data breaches involving health information are on the rise. A study from the US found that the rate of data breaches increased by 70% between 2010 and 2017 (20,21). Sensitive demographic and financial information is commonly compromised (22). In Canada, there have been a number of high profile breaches involving publicly held health information (23,24). In British Columbia, for example, a 2016 incident led to a province-wide freeze of biomedical research involving health information (25). Data breaches in the private sector are also increasing, with most being caused by malicious or criminal attacks (26,27). In addition, there are examples of inappropriate sharing of data for research purposes, as exemplified by the potential class action lawsuit in the United States that accuses the University of Chicago of sharing identifiable patient data with Google (28).

There have also been highly publicized instances of genetic repositories being used by law enforcement agencies for the purpose of criminal investigations. Probably the most famous was when genetic information from a direct-to-consumer genealogy company was used to uncover the identity of and apprehend the Golden State murderer (29,30). Since then, there have been numerous other examples of repositories of genetic samples being used in similar situations (31). While the use of genetic databases in this context does not necessarily implicate health research biobanks and cohort studies, it once again emphasizes how information that was collected under a presumption of confidentiality may be used in controversial and unexpected ways. These cases have also made the privacy issues very public – as highlighted by this New York Times headline: “Sooner or Later Your Cousin’s DNA Is Going to Solve a Murder ... The price may be everyone’s genetic privacy” (32). This coverage may impact public perceptions and concerns about privacy issues and, perhaps, expectations regarding what is disclosed during the consent process.

The emergence of powerful technologies and re-identification strategies coupled with a rising number of privacy controversies has prompted some commentators to go so far as to suggest that the entire concept of privacy and anonymity is dead (27,33,34). Indeed, it has been suggested that we now live in the era of privacy nihilism – a time when it is becoming near impossible to maintain privacy and to control what others can learn about you (35). Of course, not all data repositories are the same and the risk of a data breach likely differs significantly depending on many factors. Still, these privacy controversies and technology trends highlight that we may need to reconceptualise how we think about and frame privacy for the purposes of consent. This seems particularly so given that much of consent law is based on what a research participant may want to know about risks and not necessarily merely those that are most significant.

Privacy and Public Perceptions

The public, and patients in particular, are mostly supportive of the idea of sharing their health information and biological material for research purposes (36,37). However, that support is often contingent on the promise of privacy and the de-identification of information (38), a strategy that, as noted, may not be effective at protecting privacy. Despite the technological reality that it has become near impossible to guarantee its existence, people still care about privacy, particularly in the context of biological samples (39) and health information (37). A 2017 study from the US found that “[n]inety percent of participants agreed health information privacy was important to them; 64% agreed that they worried about the privacy of their health information” (37). A 2019 study from Canada found that while most people support the contribution of personal data for research purposes, “respondents placed high importance on deidentification of data” and only “58% were confident about the privacy and security procedures in place” (40).

This work highlights the degree to which support for research is linked to assurances of privacy (38). These concerns may be heightened in the context of genetic information. While the way in which individuals think about privacy in the context of health information can vary considerably (41), genetic information is generally viewed, rightly or not (42), as being especially sensitive. Studies have consistently found that, if asked, people will say they are concerned about both genetic privacy (43,44) and data breaches in relation to online data (45).

We need to take care not to oversimplify privacy concerns. Individual circumstances will, for example, change how people rate privacy as a concern in the context of research. A patient or an individual with a sick family member may view the privacy concerns of health information differently than a person who is not directly or indirectly involved in a research initiative (46), and there is also variation within these groups (47). Likewise, whether a research participant is paid or unpaid for their involvement may also change the calculus (44). People balance risks differently for many reasons. Still, the body of available research suggests people are concerned about privacy and the potential for data breaches (38).

Studies have also found that the public is concerned about data custodians sharing personal information without consent. A 2018 survey, for example, found that 85% of Americans are concerned that DTC genetic testing companies will share genetic data without permission and 71% are worried medical researchers will do the same (48). This concern about privacy can impact willingness to use online services (49) and to participate in research that involves the collection of health information and genetic material, such as biobanking (50). Such data again demonstrates public attention to privacy in this context and the need to be sensitive to these issues during the consent process.

Privacy issues are also getting more and more media coverage (32,51,52), which may then increase concern for privacy by making people more aware of the relevant issues. Research has shown that media coverage of a risk can make that risk seem more likely. This is due to the “availability bias”, a well-known cognitive bias that affects our perceptions (53). And there are indications that an increasing percentage of the public wish to retain significant control over their health information. Indeed, we have seen the rise of the concept of “biorights” (54) – that is, the desire for research participants to control and profit from biological material donated for research purposes. This movement has been stirred, at least in part, by both the perception that biological samples are worth a significant amount of money and controversies associated with the mishandling of biological samples (55), such as the much publicized case of Henrietta Lacks (39).

These kinds of developments may heighten the public’s interest in and concern about privacy issues, which may, in turn, trigger interest in heightened disclosure in the context of consent. Indeed, a 2018 survey from the US found that “data privacy” was ranked as the single biggest concern in relation to the private sector, above job creation, access to healthcare and education (56). A 2016 study by the Office of the Privacy Commissioner of Canada found that the public is becoming increasingly concerned about protection of personal privacy, with 92% saying they are at least somewhat concerned (57). Thirty-seven percent say they are extremely concerned, which is up from 25% in 2012 (57).

Consent, Re-consent and Reporting

The collection and use of biological samples and digitized health information for research purposes has long generated legal and research ethics issues (55,58). It seems likely that the privacy issues outlined above may further complicate these challenges. Here we focus more narrowly on two specific and practical questions: what privacy risks need to be disclosed and when recontact and re-consent is required. Again, our aim is to map these challenges to inform future conceptual and empirical work.

Required Disclosure

In the clinical setting, all material information must be disclosed as part of the consent process. The courts have generally treated disclosure expansively to include anything that a reasonable person in the patient’s position would want to know (59). And this obligation is even more onerous in the context of medical research (60,61). Generally, informed consent for medical research requires “full and frank disclosure” of all relevant facts, probabilities and opinions a reasonable person might be expected to consider before giving consent, even if minor disclosures might cause unnecessary worry (60). Canadian consent statutes similarly specify categories that suggest a full and comprehensive disclosure of risks (62).

While the technical risk of a harmful data breach may remain low, the risk is real and, given what we know about how people view privacy concerns in this context, information about this risk may be material. Indeed, what is deemed to be material information about risk in the eyes of the law does not necessarily have to correspond to a scientifically or statistically substantial risk (63). Rather, the question is more whether a reasonable person, who would likely be aware of dominant social and media discourses about health information privacy concerns, would want related information about privacy risks disclosed. Professional guidelines support the idea that even information about “statistically remote” risks must be disclosed if they are “of a serious nature” (64). As such, the changing nature of the privacy threats seems likely to warrant a more robust delineation of privacy risk during informed consent.

The *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* [TCPS2] remains the most important research ethics policy in Canada, as all federally funded research must adhere to it via research ethics board (REB) oversight

(5). For informed consent, the TCPS2 requires patients be provided with “a plain language description of all reasonably foreseeable risks and potential benefits” (5), as well as:

an indication of what information will be collected about participants and for what purposes; an indication of who will have access to information collected about the identity of participants; a description of how confidentiality will be protected; a description of the anticipated uses of data; and information indicating who may have a duty to disclose information collected, and to whom such disclosures could be made (5).

Other sections of the TCPS2 expand on disclosure requirements related to privacy and confidentiality. Notably, researchers must “describe measures for meeting confidentiality obligations and explain any reasonably foreseeable disclosure requirements” both in application materials submitted to research ethics boards and “during the consent process with prospective participants” (4). REBs, in assessing proposed measures to achieve data security, must consider risks to participants “should the security of the data be breached, including risks of re-identification of individuals” (5). These provisions, taken together, suggest a requirement to disclose known and *potential* privacy risks, including risks to data security. Disclosure of potential risks, in our view, should encompass what we presently know about how participant data can be compromised, such as studies that show that re-identification of anonymized data is possible (14,15,18,19).

One issue arising from these standards is that a more robust disclosure of privacy risks may cause individuals to be less likely to agree to participate in biobank and cohort studies. Research has found that people generally rate specific privacy concerns as seeming more severe than abstract concerns (65). In other words, the more detailed the disclosure, the more potential participants view participation as problematic. Researchers may thus be concerned about scaring patients away from participation (66). Yet, from a legal perspective, this concern is not a valid justification for nondisclosure. Indeed, if the disclosure of a risk impacts willingness to participate, it is exactly the kind of information that must generally be disclosed. In addition, international research ethics norms stress that the rights of the research participants are paramount. As stated in the Declaration of Helsinki: “While the primary purpose of medical research is to generate new knowledge, this goal can never take precedence over the rights and interests of individual research subjects.” (67) Besides, negative reactions to full disclosure may have more to do with a lack of understanding of the technicalities surrounding data security than with the need to be fully informed and, as such, may be countered or addressed by a robust disclosure process that educates participants about data security.

Ongoing Consent and Reconsent

Research consent in Canada and internationally often involves the participant agreeing to secondary use of de-identified information and/or biological materials for future research that is undetermined at the time of consent (5,68,69). In a system using this type of research consent, when is recontact and reconsent required?

The TCPS2 requires that privacy measures be maintained for the entire life cycle of health information, including “collection, use, dissemination, retention and/or disposal.” (5) In general, any change or development to relevant risks that is material to the participant’s decision to participate or continue to have his/her information stored will trigger a legal obligation to recontact (59). This is in keeping with the previously noted law concerning disclosure for informed consent (59,60,61). The risk need not be material in an evidentiary sense, but merely in a subjective sense, in that the participant would find it relevant to ongoing participation (63,70). Given evidence that participants care about privacy (46,49), any material change in privacy and confidentiality risk would likely warrant recontact. This raises the issue of whether and when technological developments in re-identification strategies that reduce the effectiveness of existing privacy safeguards could trigger a need for recontact and reconsent. Again, given existing law and public perception data, a compelling argument could be made that they would if they put the relevant database at an increased risk of a breach.

In the context of research ethics, a longstanding principle of international and Canadian policies is the right to withdraw from participation in research at any time (3,4,5). While there are a few exceptions to this right – such as quarantining in the context of some infectious disease research (71) – this is a near universally accepted research ethics norm that aligns with the conceptualization of informed consent as an ongoing process (5). In order for ongoing consent to continue to be informed, the TCPS2 requires participants be “given, in a timely manner throughout the course of the research project, information that is relevant to their decision to continue or withdraw from participation” (5). As noted, it is possible under the TCPS2 to provide a broad consent for future secondary use of identifiable information (5). But this does not vitiate the right to withdraw at any time or the requirement to provide information that may be material to a decision to continue participation.

Given that non-identifiability may no longer be a reality for tissues and some types of information, perhaps the biggest challenge lies with the concept of “non-identifiable” information and its application in the TCPS2. Article 5.5B states that researchers are not required to seek participant consent for research that “relies exclusively on the secondary use of non-identifiable information” (5). Moreover, Article 2.4 of the TCPS currently allows for secondary research use of “anonymous” information or biological materials without REB review, as long as “the process of data linkage or recording or dissemination of results does not generate identifiable information” (5). This policy may be increasingly controversial as re-identification techniques improve and spread (14,15). Indeed, the evolution of re-identification technologies and strategies, while still far from representing a broadly applicable threat, may compel a reconsideration of these kind of exceptions to consent and ethics review.

People care deeply about privacy, including not only actual participants but also and especially the parents of minor participants (48,50). It seems likely that re-consenting could lead to withdrawals and that may make research difficult and affect the integrity of data (72). However, research ethics policies are designed to protect participants. More importantly, the law of disclosure does not change in the face of competing researchers' interests (3,4,5). Privacy-related information may cause some participants to withdraw from research. But, rightly or not, there are no legal and ethical norms that would suggest disclosure practices can be modified for the purpose of avoiding withdrawals or refusals to consent.

Finally, there seems little doubt that data breaches and any unauthorized access to or disclosure of identifiable or re-identifiable participant information must be disclosed. Questions remain as to how we can define the moving target of "re-identifiability" and its relationship to risk of participant harm, but erring on the side of always notifying participants of a breach would be prudent. There is a clear duty pursuant to legislation in most Canadian jurisdictions to inform participants affected by privacy breaches (73). This duty requires, on the one hand, a strengthening of existing research ethics policies, such as by clearly emphasizing participants' rights to be re-contacted and re-consented where a material threat to data privacy emerges, and, on the other hand, a reconsideration of ethical requirements, such as less emphasis on data anonymization and de-identification as mitigation for data security risks.

Conclusion

In this age of Big Data research, it seems likely that there will be an increasing need to collect biological samples and digital health information. At the same time, as computational and information technologies progress, the risks to privacy will expand. The same technologies that are making health information more clinically and scientifically valuable – such as inexpensive sequencing, online databases and AI – are the tools that can also be leveraged to compromise privacy.

The promise of anonymity is becoming ever more tenuous. Yet, it remains a foundational component of the research ethics policies that underlay and enable health research. The potential inability to ensure anonymity could have significant ramifications. The public values privacy and, as a result, the inability to ensure it could re-frame the consent process and how participants think about participation in research initiatives. It would be valuable to generate more data on the public's and research participants' tolerance for the risk of privacy breaches and to engage in research to help determine how best to communicate those risks in a balanced manner.

The fact that privacy is highly valued affirms and even heightens the legal obligation to disclose privacy related risks. Material information about risks, including risks associated with privacy, must be disclosed. If there is a material change in risk, this information needs to be disclosed and may trigger an obligation to re-consent. Given the rapid rate of development in AI and other domains relevant to data protection, important questions arise as to what kind of advances in reidentification technologies could constitute a material change in risk. Such considerations will require ongoing monitoring by the research ethics community and seem likely, at the very least, to complicate the way we think about the protection of privacy.

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Aucun à déclarer

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References

- Ogbogu U, Burningham S, Caulfield T. [The right to control and access genetic research information: does McInerney offer a way out of the consent/withdrawal conundrum](#). *UBCL Rev.* 2014;47:275.
- Powles J, Hodson H. [Google DeepMind and healthcare in an age of algorithms](#). *Health and technology.* 2017;7(4):351-67.
- Council for International Organizations of Medical Sciences, World Health Organization. [International Ethical Guidelines for Health-related Research Involving Humans](#). 2016. [Accessed 2019 Sep 5].
- World Medical Association. [WMA Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects](#). 2018 Jul 9. [Accessed 2019 Sep 5].
- CIHR, NSERC, SSHRC. [Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS2](#) (2018). 2017 Oct 12. [Accessed 2019 Sep 4].
- United States Government. [Electronic Code of Federal Regulations: 690.111 Criteria for IRB approval of research](#). [Accessed 2019 Sep 5].
- Canadian Medical Association. [CMA Code of Ethics and Professionalism](#). 2018 Dec. [Accessed 2019 Sep 5].
- American Medical Association. [Code of Medical Ethics: Privacy, confidentiality & medical records](#). [Accessed 2019 Sep 5].
- Serenko N, Fan L. [Patients' perceptions of privacy and their outcomes in healthcare](#). *International Journal of Behavioural and Healthcare Research.* 2013;4(2):101-22.
- Kolata G. [Your data were 'anonymized'? these scientists can still identify you](#). *New York Times.* 2019 Jul 23. [Accessed 2019 Aug 30].
- McCoy TH, Hughes MC. [Preserving patient confidentiality as data grow: implications of the ability to reidentify physical activity data](#). *JAMA network open.* 2018;1(8):e186029-.
- Dankar FK, Ptitsyn A, Dankar SK. [The development of large-scale de-identified biomedical databases in the age of genomics-principles and challenges](#). *Hum Genomics.* 2018;12(1):19.
- Hayden EC. [Privacy loophole found in genetic databases](#). *Nature News.* 2013 Jan 17. [Accessed 2019 Oct 4].
- Gymrek M, McGuire AL, Golan D, Halperin E, Erlich Y. [Identifying personal genomes by surname inference](#). *Science.* 2013;339(6117):321-4.
- Na L, Yang C, Lo CC, Zhao F, Fukuoka Y, Aswani A. [Feasibility of reidentifying individuals in large national physical activity data sets from which protected health information has been removed with use of machine learning](#). *JAMA network open.* 2018;1(8):e186040-.
- Erlich Y, Shor T, Pe'er I, Carmi S. [Identity inference of genomic data using long-range familial searches](#). *Science.* 2018;362(6415):690-4.
- Begley S. [Amid privacy concerns, startup becomes first consumer DNA company to offer anonymous sequencing](#). *STAT.* 2019 Sep 19. [Accessed 2019 Oct 2].
- Ji S, Gu Q, Weng H, Liu Q, Zhou P, He Q, Beyah R, Wang T. [De-Health: all your online health information are belong to us](#). *arXiv preprint:1902.00717.* 2019 Feb 2.
- Lubarsky B. [Re-identification of "anonymized data"](#). *UCLA L. REV.* 1701;1754(2010).
- McCoy TH Jr, Perlis RH. [Temporal trends and characteristics of reportable health data breaches, 2010-2017](#). *JAMA.* 2018;320(12):1282-1284.
- HIPAA. [Study reveals 70% increase in healthcare data breaches between 2010 and 2017](#). *HIPAA Journal.* 2018 Sep 28. [Accessed 2019 Aug 30].
- Jiang JX, Bai G. [Types of information compromised in breaches of protected health information](#). *Annals of Internal Medicine.* 2019 Sep 24.
- Gerein K. [Former AHS worker inappropriately accessed 1,300 health records, viewed thousands more](#). *Edmonton Journal.* 2016 Sep 26. [Accessed 2019 Aug 30].
- CBC News. [AHS warns 7,000 patients their personal health information compromised in email hack](#). 2019 Aug 22. [Accessed 2019 Aug 30].
- Hunter J. [Privacy breach in B.C. health ministry led to freeze on medical research data](#). *The Globe and Mail.* 2016 Apr 26. [Accessed 2019 Aug 30].
- Solomon H. [Cost of Canadian data breaches continues to rise, says study](#). *IT World Canada.* 2018 Jul 11. [Accessed 2019 Aug 30].
- Burt A, Geer D. [The end of privacy](#). *New York Times.* 2017 Oct 5. [Accessed 2019 Aug 30].

28. Robbins R. [Potential class action lawsuit accuses the University of Chicago of sharing identifiable patient data with Google](#). Stat News. 2019 Jun 26. [Accessed 2019 Aug 30].
29. The Associated Press. [DNA from genealogy site used to catch suspected Golden State Killer](#). CBC News. 2018 Apr 26. [Accessed 2019 Aug 30].
30. Kaiser J. [We will find you: DNA search used to nab Golden State Killer can home in on about 60% of white Americans](#). Science. 2018 Oct 11. [Accessed 2019 Sep 4].
31. Marcus AD. [Customers handed over their DNA, the company let the FBI take a look](#). The Wall Street Journal. 2019 Aug 22. [Accessed 2019 Aug 30].
32. Murphy H. [Sooner or later your cousin's DNA is going to solve a murder](#). New York Times. 2019 Apr 25. [Accessed 2019 Aug 30].
33. Lufkin B. [The reason you can't be anonymous](#). BBC. 2017 May 29. [Accessed 2019 Aug 30].
34. Keshavan M. [There's no such thing as anonymity: With consumer DNA tests, sperm banks reconsider long-held promises to donors](#). STAT. 2019 Sep 11. [Accessed 2019 Sep 11].
35. Bogost I. [Welcome to the age of privacy nihilism](#). The Atlantic. 2018 Aug 23. [Accessed 2019 Aug 30].
36. Kim J, Kim H, Bell E, Bath T, Paul P, Pham A, Jiang X, Zheng K, Ohno-Machado L. [Patient perspectives about decisions to share medical data and biospecimens for research](#). JAMA network open. 2019;2(8):e199550-..
37. Sanderson SC, Brothers KB, Mercaldo ND, Clayton EW, Antommara AH, Aufox SA, Brilliant MH, Campos D, Carrell DS, Connolly J, Conway P. [Public attitudes toward consent and data sharing in biobank research: a large multi-site experimental survey in the US](#). American Journal of Human Genetics. 2017;100(3):414-27.
38. Jones KH, Daniels H, Squires E, Ford DV. [Public views on models for accessing genomic and health data for research: mixed methods study](#). Journal of Medical Internet Research. 2019;21(8):e14384.
39. Dasgupta I, Bollinger J, Mathews DJ, Neumann NM, Rattani A, Sugarman J. [Patients' attitudes toward the donation of biological materials for the derivation of induced pluripotent stem cells](#). Cell Stem Cell. 2014;14(1):9-12.
40. McCormick N, Hamilton CB, Koehn CL, English K, Stordy A, Li LC. [Canadians' views on the use of routinely collected data in health research: a patient-oriented cross-sectional survey](#). CMAJ open. 2019;7(2):E203.
41. Haeusermann T, Fadda M, Blasimme A, Tzovaras BG, Vayena E. [Genes wide open: Data sharing and the social gradient of genomic privacy](#). AJOB Empirical Bioethics. 2018;9(4):207-21.
42. Evans JP, Burke W. [Genetic exceptionalism. Too much of a good thing?](#) Genetics in Medicine. 2008;10(7):500.
43. Clayton EW, Halverson CM, Sathe NA, Malin BA (2018) [A systematic literature review of individuals' perspectives on privacy and genetic information in the United States](#). PLoS ONE 13(10):e0204417.
44. Kaufman DJ, Murphy-Bollinger J, Scott J, Hudson KL. [Public opinion about the importance of privacy in biobank research](#). American Journal of Human Genetics. 2009;85(5):643-54.
45. Canadian Marketing Association. [Data privacy study: what the canadian consumer really thinks](#). 2018 May 24. [Accessed 2019 Aug 30].
46. Chen A. [Treating 'genetic privacy' like it's just one thing keeps us from understanding people's concerns](#). The Verge. 2018 Oct 31. [Accessed 2019 Aug 30].
47. Siminoff LA, Wilson-Genderson M, Mosavel M, Barker L, Trgina J, Traino HM. [Confidentiality in biobanking research: A comparison of donor and nondonor families' understanding of risks](#). Genetic Testing and Molecular Biomarkers. 2017;21(3):171-7.
48. NORC. [Genetic testing: ancestry interest, but privacy concerns](#). NORC Center for Public Affairs Research. 2018 Jul. [Accessed 2019 Aug 30].
49. Baruh L, Secinti E, Cemalcilar Z. [Online privacy concerns and privacy management: A meta-analytical review](#). Journal of Communication. 2017;67(1):26-53.
50. Antommara AH, Brothers KB, Myers JA, Feygin YB, Aufox SA, Brilliant MH, Conway P, Fullerton SM, Garrison NA, Horowitz CR, Jarvik GP. [Parents' attitudes toward consent and data sharing in biobanks: A multisite experimental survey](#). AJOB Empirical Bioethics. 2018;9(3):128-42.
51. Mervosh S. [Jerry Westrom threw away a napkin last month, it was used to charge him in a 1993 murder](#). New York Times. 2019 Feb 17. [Accessed 2019 Aug 30].
52. Mroz J. [A mother learns the identity of her child's grandmother, a sperm bank threatens to sue](#). New York Times. 2019 Feb 16. [Accessed 2019 Aug 30].
53. Tversky A, Kahneman D. [Judgment under uncertainty: Heuristics and biases](#). Science. 1974;185(4157):1124-31..
54. Hayden MA. [The burgeoning biorights movement: its legal basis, what's at stake, and how to respond](#). BCL Rev.. 2018;59:1775.
55. Caulfield T, Murdoch B. [Genes, cells, and biobanks: Yes, there's still a consent problem](#). PLoS Biology. 2017;15(7):e2002654.
56. Brown D. [Americans are more concerned with data privacy than job creation, study shows](#). USA Today. 2018 Nov 9. [Accessed 2019 Aug 30].
57. Office of the Privacy Commissioner of Canada. [2016 Survey of Canadians on Privacy](#). 2016 Dec. [Accessed 2019 Aug 30].
58. Vayena E, Blasimme A. [Health research with big data: Time for systemic oversight](#). Journal of Law, Medicine & Ethics. 2018;46(1):119-29.
59. [Reibl v. Hughes](#), [1980] 2 SCR 880, 1980 CanLII 23 (SCC).
60. [Halushka v. University of Saskatchewan](#) (1965) 53 DLR (2D) 436.
61. Robertson G, Picard E. Legal Liability of Doctors and Hospitals in Canada, 5th Edition. Toronto, Canada: Carswell/Thomson Reuters, 2017.

62. Nelson E, Ogbogu U. Law for Healthcare Providers. Toronto: LexisNexis, 2018;88-89.
63. Nelson E. Informed consent: reasonableness, risk, and disclosure. In: Downie J, Gibson E. (eds.) Health Law at the Supreme Court of Canada. Toronto, Canada: Irwin Law Inc: 2007. p.145-168.
64. Evans KG. [Consent: A guide for Canadian physicians](#). CMPA. Updated 2016 Jun. [Accessed 2019 Aug 30].
65. Gerber N, Reinheimer B, Volkamer M. [Investigating people's privacy risk perception](#). Proceedings on Privacy Enhancing Technologies. 2019;2019(3):267-88.
66. Couper MP, Singer E, Conrad FG, Groves RM. [Risk of disclosure, perceptions of risk, and concerns about privacy and confidentiality as factors in survey participation](#). Journal of Official Statistics. 2008;24(2):255.
67. World Medical Association. [Declaration of Helsinki: Ethical Principals for Medical Research Involving Human Subjects](#). 2013.
68. Master Z, Nelson E, Murdoch B, Caulfield T. [Biobanks, consent and claims of consensus](#). Nature Methods. 2012;9(9):885.
69. Allen C, Joly Y, Moreno PG. [Data sharing, biobanks and informed consent: a research paradox](#). McGill JL & Health. 2013;7:85.
70. [Arndt v. Smith](#), [1997] 2 SCR 539, 1997 CanLII 360 (SCC).
71. Murdoch B, Caulfield T. [The challenge of human challenge research models: A Canadian perspective](#). Medical Law International. 2017;17(4):273-84.
72. Junghans C, Jones M. [Consent bias in research: how to avoid it](#). Heart. 2007;93(9):1024.
73. CMPA. [The new reality of reporting a privacy breach](#). 2018 Nov. [Accessed 2019 Sep 4].

ÉTUDE DE CAS / CASE STUDY

Responding to Hospital Staff's Paranormal Experiences Related to a Medical Assistance in Dying Room

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Résumé

Le personnel a rendu compte d'expériences paranormales dans le cadre de l'aide médicale à mourir (AMM) à l'hôpital. Cette étude de cas rend compte de l'expérience du personnel et illustre comment le rôle de l'équipe d'Éthique s'est élargi pour faire face à cette nouvelle situation en facilitant une réponse interdisciplinaire.

Mots-clés

aide médicale à mourir (AMM), éthique, détresse, interdisciplinaire, paranormal, surnaturel, diversité, professionnels de santé

Abstract

Staff reported paranormal experiences in connection with the outpatient Medical Assistance in Dying (MAiD) room at the hospital. This case study reports on staff experiences and illustrates how the Ethics team's role expanded to deal with this novel situation by facilitating an interdisciplinary response.

Keywords

Medical Assistance in Dying (MAiD), ethics, distress, interdisciplinary, paranormal, supernatural, diversity, healthcare providers

The Medical Assistance in Dying Room

A community hospital system located in Ontario within one of Canada's most culturally-diverse regions opened a Medical Assistance in Dying (MAiD) room for outpatients in 2017. Shortly after opening the MAiD room, nursing and allied health staff on an adjacent unit reported 'paranormal' experiences. Their experiences included unexplained sounds, temperature and lighting changes, feeling a breeze, and feeling a sense of unease and dread when near the MAiD room.

Reports of paranormal experiences related to the MAiD room were brought to Ethics by the unit manager, likely because Ethics has been involved with the development and planning of MAiD services at the hospital. The unit manager was concerned that these experiences were affecting workflow, job satisfaction, and staff well-being. Some staff refused to enter the room, while others avoided walking near it or the nearby storage and meeting rooms, especially when alone or at night. Many staff requested that the room be moved. In addition, the Ethics team recognized that continued reports of paranormal activity could lead to difficulties maintaining the room as a space for outpatient MAiD assessments and procedures. Such difficulties could reduce outpatient access to MAiD.

Given that some of these issues raised by staff extend beyond the domain of Ethics, the departments of Spiritual Health Therapy, and Health Equity & Inclusion were invited to collaborate on this case. The three departments jointly created an Interdepartmental Team headed by Ethics.

The Interdepartmental Team was faced with the following questions: respect for diverse cultural and spiritual beliefs of patients is a core commitment of healthcare (1) – but should this commitment extend to beliefs held by staff? And if it ought to extend, how can an organization respond to experiences staff are having in a way that demonstrates such respect?

In order to demonstrate respect for staff's beliefs and experiences while *also* knowing that it would be difficult or impossible to find other space, we were committed to engaging directly with staff and being transparent about our decision-making process. As we explain in this case study, our aim was not to discern the truth of staff reports, but to understand the problem and reduce staff discomfort by co-creating solutions with them. This approach was guided by health care Quality Improvement principles, which emphasize prevention and improvement strategies through consistent data collection (2). Achieving these aims required the interdisciplinary response of the Interdepartmental Team to address different aspects of the problem.

An Interdisciplinary Approach

After discussions with the unit manager, the Interdepartmental Team (Ethics, Spiritual Health Therapy, and Health Equity & Inclusion) initiated and facilitated a series of weekly 10-30 minutes 'huddles' for a month with nursing and allied health staff on the unit adjacent to the MAiD room. The Interdepartmental Team started the huddles by explaining that their purpose was to provide a safe and respectful environment for staff to share their experiences, if they chose to do so. The aim was to learn about the nursing and allied health staff's experiences, and to co-create solutions with them.

Spiritual Health Therapy offered spiritual support for staff's experience of the paranormal and confirmed that similar experiences are reported in the literature (3-6). Health Equity & Inclusion reaffirmed the hospital's commitment to the diverse religious and cultural belief systems that exist amongst staff. Ethics addressed staff questions related to the eligibility criteria, processes, and current context for MAiD in Canada.

The huddles provided opportunities to listen to staff, learn about their experiences, and understand how these affected their well-being and job satisfaction. Staff were also invited to recommend solutions that would address their concerns. In total, about 35 staff members, excluding the Interdepartmental Team, participated in the various huddles.

Staff Experiences

During the huddles, staff openly shared their experiences. Some staff reported auditory and sensory experiences inside or near the MAiD room, including feeling a breeze, hearing loud noises (including knocks and thuds that sounded like an individual falling out of their bed), hearing whispering, and feeling someone touch their arm. Others felt an unexplained “heavy energy.” One staff member expressed that although she did not believe in the paranormal, her arm had been moved involuntarily when she was in the room, while another reported that mechanical equipment started working on its own. Some staff were apprehensive or fearful to come near the room during night shifts.

Staff Thoughts about MAiD

Although the staff who participated in the huddles were not directly involved with the assessments or procedures in the out-patient MAiD room, some expressed strong feelings and values surrounding MAiD itself. Some said that they were “there to save lives” and “it does not seem natural to let people die.” Others described MAiD as inherently different from other kinds of deaths that happen all the time in the hospital, because such a death is intentional. Others shared that it was unnerving to see people walking and talking, going into the MAiD room, and then later coming out dead. This did not seem to meet their version of ‘normal’ because “God had not been calling them [MAiD patients] and they themselves chose to die.” Others expressed that although MAiD was not against their personal beliefs, it elicited a spiritual response such as saying a blessing or prayer for those who had elected to receive MAiD.

When asked for recommendations, staff requested that they be alerted whenever the room was to be used for an assessment or procedure, and that Spiritual Health Therapy regularly visit the unit. Many also asked that the room be moved away from the unit to another location in the hospital.

Response

Co-designed interventions included Spiritual Health Therapy providing daily room blessings, reading scripture aloud in the room, performing blessings for staff members, and providing a night light for continuous lighting. Smudging and meditation were also provided. Spiritual Health Therapists supported staff by frequently visiting the unit and engaging in one-on-one conversations.

The unit staff will also receive pre-briefs and de-briefs from Ethics whenever the MAiD room is booked for a procedure, in order to review the legal and ethical aspects of MAiD, as well as to enable staff to discuss their feelings. Spiritual Health Therapists are present after MAiD procedures to support individual staff members as needed.

Ethics also affirmed for staff that the hospital is committed to facilitating the provision of MAiD for eligible patients, and is also committed to providing a safe workplace for staff.

The room was not moved as a different space was not available and the issues were likely to persist in a different location.

Outcomes

In this case, the collaborative interdisciplinary approach has encouraged staff engagement and resulted in positive feedback from staff. There have been several MAiD procedures in the room since the interdisciplinary response. Staff have reported feeling more at ease and less distressed and no new paranormal experiences have been reported. We found transparency, engagement, and interdisciplinary collaboration valuable in addressing staff concerns of paranormal experiences related to the MAiD room. The case study raises further questions to consider: Death occurs regularly in the hospital – was MAiD a catalyst for these experiences? Are there strategies, such as increased education or awareness that could prevent similar staff discomfort when MAiD provision occurs?

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Aucun à déclarer

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References

1. Hajibabae F, Joolae S, Charaghi MA, Salari P, Rodney P. [Hospital/clinical ethics committees' notion: an overview](#). Journal of Medical Ethics and History of Medicine. 2016;9(17).
2. Health Quality Ontario. [Quality Improvement Guide](#). Queens Printer for Ontario, 2012.
3. Parra A, Gimenez Amarilla P. [Anomalous/paranormal experiences reported by nurses in relation to their patients in hospitals](#). Journal of Scientific Exploration. 2017;31(1):11-28.
4. Dos Santos CS, Sakamoto Ribeiro Paiva B, Lamas Granero Luchetti A, Eduardo Paiva C, Lucchetti G. [End-of-life experiences and deathbed phenomena as reported by Brazilian healthcare professionals in different healthcare settings](#). Palliative and Supportive Care. 2017;15:425-433.
5. Fenwick P, Lovelace H, Brayne S. [Comfort for the dying: five year retrospective and one year prospective studies of end of life experiences](#). Archives of Gerontology and Geriatrics. 2010;51:173-179.
6. Barbato M, Blunden C, Reid K, Irwin H, Rodriguez P. [Parapsychological phenomena near the time of death](#). Journal for Palliative Care. 1999;15(2):30-37.

ÉTUDE DE CAS / CASE STUDY

Facilitated Conversation: A Useful Tool in an Ethicist's Toolbox

Natalie Hardy¹, Nico Nortje²

Résumé

Le syndrome de Soto est une forme rare de maladie génétique, qui ne met souvent pas la vie du patient en danger. Cependant, cette étude de cas examinera le cas d'une jeune femme atteinte du syndrome de Soto qui a développé un cancer pédiatrique. L'équipe et la famille avaient des objectifs de soins opposés. Les dilemmes éthiques liés à la prise de décisions de substitution pour les personnes atteintes de troubles mentaux peuvent souvent être résolus grâce à une conversation facilitée entre la famille du patient et l'équipe de soins.

Mots-clés

Syndrome de Sotos, cancer, leucémie, capacité, conversation facilitée

Abstract

Soto's syndrome is a rare form of genetic disorder, which is often non-life threatening. However, this case study will examine the case of a young lady with Soto's syndrome who developed a pediatric cancer. The team and family had opposing goals of care. Ethical dilemmas in surrogate decision-making for mentally challenged individuals can often be resolved through facilitated conversation between the patient's family and healthcare team.

Keywords

Sotos syndrome, cancer, leukemia, capacity, facilitated conversation

Introduction

Ethics consults are usually requested when there is a clash on goals of care. Often times the ethicist is faced with conflict between the medical teams and patients/families as to whether or not to pursue treatment. The challenge intensifies when the patient is an adult with limited mental abilities.

Case Study

A.B. is a young, non-verbal woman in her late thirties with a known history of Sotos syndrome and the equivalent mental ability of a 3-year-old. The patient has been taken care of by her family, and her mother was her primary caregiver. The patient was brought to an oncology hospital after an initial incorrect diagnosis of otitis externa. At the oncology hospital, she was diagnosed with acute lymphocytic leukemia (ALL), a fast-growing cancer of the lymphoblastic cells usually occurring only in paediatric patients. According to Brown and Shah (1), ALL is one of the most common cancers predominantly diagnosed during childhood and can be treated with intensive chemotherapy, stem cell transplant, CAR T-Cell therapy, and radiation therapy. Most treatments are successful: 98% of cases go into clinical remission (2). In itself, the patient's cancer diagnosis did not present much challenge, however, her accompanied syndrome presented a much greater issue.

Sotos syndrome, also known as cerebral gigantism, is a rare genetic disorder caused by mutations in the NSD1 gene (3). Affected individuals experience excessive growth, intellectual disabilities, and communication limitations which inhibit social development (4). Whereas the average child would learn, develop, and communicate normally, individuals with Sotos have difficulty forming relationships with others and experience delays in walking, speaking, and coordination that carry into adulthood. Given the fact that those with Sotos often cannot fulfill normative societal roles, form meaningful connections, or engage proactively, they experience more anxiety than others. Depending on the severity of their intellectual disability, patients can have difficulty understanding treatment options and voicing their opinion. Treatment for Sotos syndrome is symptomatic, as there is no cure. However, the condition is not life-threatening, and affected individuals often have normal life expectancies (4).

A multi-disciplinary approach is best for individuals with Sotos syndrome (4). Speech, behavioral, physical, psychological, and occupational therapy are often implemented in addition to prescription medications. In everyday life, it is important to communicate in simple terms and present information concretely, as patients can have difficulty understanding abstract concepts. Being mindful of intellectual abilities is crucial to avoiding anxiety, as an individual with Sotos can appear older and more cognitively able than they truly are. Moreover, consistency is wisely implemented; when placed in stressful, unfamiliar situations, anxiety and behavioral difficulties (like tantrums and compulsive behaviour) arise. Although individuals with Sotos syndrome have an increased likelihood of developing cancer, there are currently no protocols on how to approach patients in the oncology setting.

A.B. was seen by the adult leukemia team upon admission. During her initial work-up, A.B. became very anxious and repeatedly voiced to her mother that she wanted to go to her house (about 3 hours away) and play her video games. Nothing gave her more pleasure than being at home and playing video games.

During admission, A.B. developed respiratory distress and was transitioned to the intensive care unit (ICU). While in the ICU, the patient became agitated, "in an uncontrolled way," per the mother. She added, "I have never seen her like this before."

A.B. exhibited further unfamiliar behaviour when she bit her mother's hand. Psychiatry was consulted, and a mood stabilizer was recommended. Five days later, A.B.'s respiratory distress cleared, and she was transitioned to the leukemia floor.

Facilitated Conversation & Ethics

The leukemia team recommended treating A.B.'s cancer through chemotherapy, however her mother voiced that she did not want to inflict more suffering on her daughter. A.B. was clearly distressed and A.B.'s mother was uncertain whether the treatment would improve her daughter's quality of life. The leukemia team requested an ethics consult, and a family goals of care conference was called.

The ethicist applied the process of facilitated conversation to address the issue at hand. According to Bowling Green State University's Office of Equity and Inclusion (5), a facilitated conversation is one that strives to find a resolution between two parties of differing beliefs – in this case, differing beliefs between the patient's mother and the oncology specialists. By creating a respectful, safe, and trusting environment, the ethicist can identify relevant issues and stimulate dialogue between the two parties. Members of each party are expected to actively listen during the discussion. It is the job of the ethicist to establish guidelines and allow all individuals to relay their concerns in a respectful manner; doing so creates a safe space for effective dialogue and problem-solving. Issues are examined holistically with the intent of reaching an agreement at the end of the discussion. Most times, a resolution can be agreed upon (6).

In the case of A.B., the leukemia team was positive that she could get effective chemotherapy. However, the patient ran a high risk of infection and tumor lysis syndrome. The team was also not convinced that A.B.'s cancer had not metastasized to the brain. For there to be a clear understanding of potential metastases, several brain scans would have to be done, which would cause A.B. considerable discomfort and distress.

A.B.'s parents were in a conundrum, most notably her mother, who was also the medical power of attorney and decision maker. They did not want A.B. to suffer but also did not want to lose their daughter. They inquired about the success rate of chemotherapy, should it be given and brain metastasis be found. The parents were informed that the success rate would have been near 50%, however A.B. would need to stay at the oncology hospital for an extended period of time, which posed additional psychosocial challenges.

The ethical issue in the case of A.B. lies in surrogate decision making for adult mentally challenged patients because of the patient's inability to fully understand the consequences of choices. According to the AMA's Code of Ethics (7), if a patient has a mental illness or disability (such as Sotos) that can impede her ability to make appropriate decisions, then the physician must evaluate her capacity. If the physician concludes that the patient does not have appropriate capacity, then the surrogate decision maker must make decisions according to the substituted judgement standard – that is, she should take into account the patient's preferences and values. If the patient's values are unknown, then the surrogate decision maker should act in accordance with the best interest principle and do what is in the best interest of the patient.

Since A.B. did not have decision-making capacity, her mother was her medical power of attorney and decision maker. To facilitate a conversation and identify risks and benefits, A.B.'s family gathered at a meeting (including her mother, father, and siblings). The meeting was intended to empower the family, provide an opportunity for questions to be answered, and facilitate a discussion of what is in the best interest of the patient. After considerable questioning of the medical team, the family was uncomfortable putting A.B. through additional treatment. Hence, the recommendation was made to consider palliative care. The family accepted the recommendation and transitioned A.B. from the leukemia floor to the palliative care floor. The patient's symptoms were managed, and she was eventually made more comfortable. The family was allowed to be in the room at all times, and A.B. happily passed away two days later.

Conclusion

The benefit of facilitated conversation lies in the fact that any power inequality between the parties present can be managed and that the best outcome for all those around the table can be reached. The process allows for the different role players to tell their narrated stories to the other party. This was evident in the case of A.B. Although the team was suggesting more treatment, they got to hear the story of A.B. and her family and came to realise that the family was indeed acting in her best interest.

Questions

1. What other ethical "tools" might work well in conjunction with facilitated conversation in this case and why?
2. Had the mother been adamant on aggressive treatment for A.B., ethically speaking, should the ethicist have done something differently?

Conflicts d'intérêts

Nico Nortje est éditeur de la Revue canadienne de bioéthique.

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References

1. Brown PA, Shah B. [Emerging treatment options for acute lymphoblastic leukemia: focus on CAR T-Cell therapy](#). Journal of the National Comprehensive Cancer Network. 2019;16(5S):651-5.
2. St. Jude Children's Research Hospital. [Acute lymphoblastic leukemia](#). 2019 [cited 2019 August 6].
3. Türkmen S, Gillessen-Kaesbach G, Meinecke P, et al. [Mutations in NSD1 are responsible for Sotos syndrome, but are not a frequent finding in other overgrowth phenotypes](#). European Journal of Human Genetics. 2003;11(11):858-65.
4. Lane C, Milne E, Freeth M. [Cognition and behaviour in Sotos syndrome: a systematic review](#). PloS One. 2016;11(2):e0149189. doi:10.1371/journal.pone.0149189
5. Bowling Green State University Office of Equity and Diversity. [Facilitated conversation](#). n.d. [cited 2019 August 6].
6. Milz D. [The hidden benefits of facilitated dialogue](#). Journal of Planning Education and Research. 2018; 1-17.
7. Chaet DH. [AMA Code of medical ethics' opinions on patient decision-making capacity and competence and surrogate decision making](#). AMA Journal of Ethics. 2017;19(7):675-7.