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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Paying for Plasma: Commodification, Exploitation, and Canada's Plasma Shortage

Vida Panitch[1], Lendell Chad Horne[2]

Résumé
Une entreprise privée à but lucratif a récemment ouvert deux centres de don de plasma au Canada. Les donneurs peuvent y recevoir jusqu'à 50 $ pour un don de leur plasma. Cela a suscité un débat national sur l'éthique de la compensation des donneurs de plasma. Dans cet article, notre objectif est de réorienter le débat actuel, c'est-à-dire de déterminer qui devrait compenser les donneurs de plasma plutôt que de déterminer s'ils devraient être compensés. Pour examiner les arguments contre la compensation des donneurs de plasma, nous tenons compte des préoccupations liées à l'exploitation, à la marchandisation et à la logique lucrative. Ils nous paraissent tous non concluants d'un point de vue normatif, mais aussi trop généraux compte tenu de la dépendance persistante du Canada à l'égard du plasma provenant de donneurs rémunérés aux États-Unis. Nous croyons qu'il y a de bonnes raisons de s'opposer à ce qu'une entreprise privée tire profit de l'approvisionnement en plasma du Canada, mais ces préoccupations peuvent être dissipées si le paiement est effectué par un organisme public sans but lucratif. Bref, nous rejetons l'idée de tirer profit du don de plasma alors que nous appuyons la compensation d'un don de plasma; nous sommes donc partisans d'un nouveau régime canadien public de collecte de plasma et de sa compensation.

Mots-clés
marchandisation, exploitation, plasma, don de sang, profit

Abstract
A private, for-profit company has recently opened a pair of plasma donation centres in Canada, at which donors can be compensated up to $50 for their plasma. This has sparked a nation-wide debate around the ethics of paying plasma donors. Our aim in this paper is to shift the terms of the current debate away from the question of whether plasma donors should be paid and toward the question of who should be paying them. We consider arguments against paying plasma donors grounded in concerns about exploitation, commodification, and the introduction of a profit motive. We find them all to be normatively inconclusive, but also overbroad in light of Canada's persistent reliance on plasma from paid donors in the United States. While we believe that there are good reasons to oppose allowing a private company to profit from Canada's blood supply, these concerns can be addressed if payment is dispensed instead by a public, not-for-profit agency. In short, we reject profiting from plasma while we endorse paying for plasma; we therefore conclude in favour of a new Canadian regime of public sector plasma collection and compensation.

Keywords
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Introduction

Blood plasma is the straw-coloured fluid in which blood cells and platelets travel. It is a valuable medical resource used to treat a range of immunological, hematological, and respiratory conditions. A direct transfusion of plasma is used to treat certain kinds of bleeding disorders, such as hemophilia, but plasma is also a raw material used in a variety of plasma-derived medicinal products (PDMPs). In Canada, the highest demand among these PMDPs is for immune globulins, which are used to treat immune disorders [1].[1]

Since its founding in 1998, Canadian Blood Services (CBS) has been tasked with managing Canada's blood supply, including its plasma supply, outside of Quebec. CBS was created as a publicly-funded, not-for-profit organization to take over management of Canada's blood system from the Canadian Red Cross, after the Krever commission found the Canadian Red Cross to be negligent for its role in the Canadian blood scandal of the 1980's. CBS, like the Red Cross before it, relies exclusively on unpaid donations [2].

Canada currently suffers a shortage of domestically produced blood plasma. While voluntary, unpaid donations yield enough plasma to meet Canada's needs for direct transfusions, Canada falls far short of self-sufficiency when it comes to the plasma needed to produce PDMPs. Canada currently meets only 17% of its need for immune globulins, the highest-demand PDMP, through domestic donations. The rest of the plasma needed to produce these products is collected in the US from paid donors [1,3].

Recently, the private, for-profit corporation Canadian Plasma Resources (CPR) has entered the picture. CPR gained national notoriety for its controversial practice of offering plasma donors a gift card worth up to $50 in exchange for their donation. (Donors also have the option to gift their payment to a charitable organization.) CPR opened their first clinic in Saskatoon in February of 2016 [4]. They opened a second clinic in Moncton the following year, and they have expressed plans to open as many as 8 more clinics across Canada [5,6]. The opening of these two CPR clinics has sparked a nationwide debate around the ethics of paying for blood plasma. While paying donors is seen as acceptable by groups like the Nuffield Council on Bioethics and could bolster domestic supply, it also raises concerns around safety, commodification, and exploitation [7-9]. Citing precisely these issues, British Columbia recently joined Alberta, Ontario, and Quebec in banning payment for blood and blood plasma [10]. Advocates are pushing for a similar ban in Nova Scotia [11]. At the federal level, Senator Pamela Wallin has introduced a bill that would ban such payments all across Canada [12].

Our view is that the terms of the current debate are unproductive, and our aim in this paper is to shift the debate in a more helpful direction. We worry that too much attention has been devoted to the question of *whether* Canada should pay plasma donors, and too little to the question of *who* should be paying them. As such, our project here is two-fold: first, to show that we

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needn't worry so much, morally speaking, about whether to pay donors and second, that we should worry quite a bit more about who should be paying them. Given the urgency of Canada's need for PDMPs and our persistent reliance on paid plasma donors abroad, it is senseless to hold that Canada should not pay for plasma; we already do, and there has been no suggestion that we should stop. While there are many legitimate ethical concerns around paying plasma donors, we believe these ethical concerns can be adequately addressed if donors are paid by a public, not-for-profit entity like CBS instead of a private, for-profit entity like CPR.

Our argument proceeds in four sections. In Section I, we defend the claim that a secure domestic supply of blood plasma is a morally important goal, and we show that paying patients for plasma can reasonably be expected to promote this goal. In the next three sections, we show that standard arguments against paying plasma donors fail. We begin in Section II with arguments around the exploitation of donors. We show that exploitation is actually worse in a regime where donors are expected to provide a valuable resource for free compared to one where donors are paid. We turn in Section III to various arguments against treating blood and blood products as a commodity. We claim that these arguments are not only normatively inconclusive but also overbroad, given that Canada already relies on plasma protein products manufactured from paid donations from the United States. Finally, in Section IV, we turn to the controversial issue of profit. Although there are good reasons to refuse to allow private corporations to profit from Canada's blood supply, these reasons have nothing to do with the morality of compensating donors. We argue that a system where donors are paid by a public, not-for-profit agency is preferable for many reasons, most notably because it would help bolster Canada's domestic plasma security in ways that for-profit payment would not.

I. Sufficiency, Security, and Safety

The memory of the blood scandal of the 1980's shapes many Canadians attitudes toward their blood system. In the first half of that decade, roughly 1,000 people were infected with HIV and another 30,000 with Hepatitis C due to tainted blood products, making it arguably the largest public health disaster in Canadian history. Significantly, many of those infections occurred after tests for HIV and Hep-C were available, and indeed even after many peer countries had implemented testing regimes to screen blood for these pathogens [13].

In 1997, Justice Horace Krever's Commission tabled the results of its years-long investigation into the blood scandal. They recommended more than 50 changes to Canada's blood system, guided by these five core principles:

1. Blood is a public resource.
2. Donors of blood and plasma should not be paid for their donations, except in rare circumstances.
3. Whole blood, plasma, and platelets must be collected in sufficient quantities in Canada to meet domestic needs for blood components and blood products.
4. Canadians should have free and universal access to blood components and blood products.
5. Safety of the blood supply system is paramount [14, p.1047].

The report's third principle champions self-sufficiency in blood components and blood products. Self-sufficiency is desirable for several reasons. Blood and blood products are important for preserving the health and indeed the lives of thousands of Canadians. At the same time, demand for these products is growing worldwide, both as we discover new treatments and as demand from developing countries for existing treatments grows. The fact that Canada is currently able to import enough plasma to meet its needs is no guarantee that it will be able to do so in the future; sudden outbreaks of disease or shutdowns of particular fractionation facilities have been known to cause supply interruptions in the recent past [3]. This is why, twenty years after the Krever report, Canadian Blood Services continues to emphasize the importance of blood and plasma self-sufficiency [1]. In addition, the Canadian Government's Expert Panel on Immune Globulin Product Supply and Related Impacts in Canada has issued a recent report emphasizing its importance [3].

The goal of plasma self-sufficiency, however, would appear to conflict with the Krever report's second principle, according to which donors should not normally be paid. It is true that Canada has achieved self-sufficiency in whole blood and in plasma for direct transfusions through unpaid donations. But self-sufficiency in the plasma needed to produce PDMPs is another story. Canada relies heavily on paid foreign sources for the plasma needed to produce these products; indeed, unpaid Canadian donors provide only 17% of the plasma necessary to produce such products, with the rest coming from paid donors in the United States [1,3]. The shortfall in domestic supply is so large that CBS does not even pretend to have a plan to meet it; their current goal is to find a way to source just *half* of the plasma needed for PDMPs domestically through significant new outlays in facilities and outreach [15].

Canada is hardly unusual in being unable to source adequate quantities of plasma from voluntary, unpaid donations. A 2013 study estimated that, in a world where access to immune globulins was determined by clinical demand rather than supply restrictions, a country would need to produce approximately 30 liters of plasma per 1,000 population each year to ensure an adequate supply of those products. On that basis, the study observed that *no country in the world* came close to producing enough plasma to achieve self-sufficiency by relying exclusively on voluntary, unpaid donations. The four countries that did cross the 30 liters per 1000 population threshold – the US, Austria, the Czech Republic, and Germany – all relied on a mix of paid and unpaid donations [16].

There is good evidence that introducing payments or other material incentives for donation would significantly increase supply. There is, first, the intuitive support coming from the just-mentioned fact that the countries that allow payment for plasma are exactly the countries with the largest supply [16]. In addition, a variety of observational and experimental studies have found significant benefits from incentives [17,18]. A 2013 review essay in *Science* reported that incentives had been shown to increase whole blood donation rates in specific interventions by as little as 5 or as much as 40 percent, depending largely on the size of the incentive [17].[2] Moreover, offering such incentives appeared to be quite cost-effective. For example, one study in the US case found that a mere $10 USD payment led to an increase of nearly 7 extra units of whole blood per 100 individuals contacted to donate, at a net cost of $34.40 USD per additional unit of blood [19]. On any plausible estimate of the social benefits of an extra unit of whole blood, it is far in excess of $34.40.[3]

Of course, one might worry that a system of paid donation might yield an adequate *quantity* of plasma at the expense of plasma of adequate *quality*, thus undercutting not only Krever's second principle but also his fifth – that the safety of the blood supply is paramount. These kinds of concerns are often grounded in Richard Titmuss's landmark study of paid versus unpaid whole blood donation, which found a tendency for paid donations to be of lower quality and hence to be less safe [20]. It is worth noting that, to some extent, Titmuss's study has been yet another victim of the broader replication crisis in the social sciences; a 2013 meta-analysis found no evidence that paying donors reduces the quality of donations [21].

But concerns about the safety of paid donations are ultimately extraneous to the current debate in Canada, for two reasons. First, Canada's choice is not between relying on paid versus unpaid donations, but between relying on paid *American* donations versus relying on paid *Canadian* donations. The option of relying entirely on unpaid donations is not on the table now nor in the foreseeable future, unless we are prepared to let thousands of Canadians go untreated. And second, because of the extensive processing that PDMPs undergo, the risks to the blood system from plasma *products* – as compared to the risks from whole blood or direct plasma transfusion – is extremely low. The production of PDMPs involves purification techniques that all but eliminate risks to the blood system caused by unsafe donations [1]. Indeed, there has not been a single confirmed case of a disease transmitted through PDMP's in over 20 years [3].[4]

Contemporary arguments against paying for plasma sometimes insinuate that paying Canadians for plasma means ignoring the lessons of the tainted blood scandal [23]. But while the scandal had many causes, paying Canadians for their blood was not one of them; the Canadian Red Cross never paid donors. In fact, the system we currently have, where we rely on blood components purchased from questionable sources abroad, has more in common with the system that produced the tainted blood scandal compared to one that relies on federal oversight of a paid domestic donor system.

The security of the blood supply is an important goal, and the considerations in this section suggest that this goal can perhaps be promoted by paying donors for their plasma. This does not by itself entail that it is incumbent upon us to pay donors; there may be other, countervailing moral reasons that speak against it. We turn to a consideration of some of those reasons in the sections that follow.

II. Exploitation

Advocacy groups like *Blood Watch*, *Canadian Doctors for Medicare*, and *The Registered Nurses Union* have argued against paying plasma donors on the grounds that it not only supposedly threatens public safety, but just as troublingly, that it exploits the poor [24]. Exploitation is a concept with a great deal of rhetorical force. The term is often used as a bludgeon in public debate, to decry any sort of practice its opponents find problematic, without it being given much content or analysis. Nonetheless, the intuition that underlies common appeals to this term is the worry that vulnerable persons are somehow being manipulated or treated unfairly. This intuition captures something about the concept: for a relationship, transaction, or practice to be exploitative, there has to be someone who is taken *wrongful advantage of* by another. Even if both parties walk away better off than they were before, a relationship may still be exploitative if one party coerced, lied to, or deprived the other of what she is truly owed.

In order for a transaction to qualify as exploitative, what therefore has to be shown is that one party acts in contravention to one of two criteria. Either they mislead or coerce the other party, thus undermining the extent to which the other party can meaningfully be said to give consent to the arrangement – call this the *consent* criterion. Or they deny the other party something they are truly owed, a fair share of the benefits of the exchange – call this the *fairness* criterion [25]. For it to be held that a private system of paid donation is exploitative, what therefore has to be shown is that the party who pays donors – CPR in this case – acts in contravention of either (or both) of the consent or the fairness criterion.

Let us take the consent requirement first. Is it true that paid donors in Canada are lied to? CPR informs its donors of the minimal risks of the procedure, its duration, invasiveness, and payment schedule. As such, it cannot be reasonably claimed that donors are exploited because they are misinformed, and in that sense taken wrongful advantage of by CPR. The more

[2] Of the 19 incentive items studied in [17], only one – the offer of a free cholesterol test – was shown to have no effect in increasing the number of donations. To be fair, a more recent review in *Transfusion* found more mixed results, with some incentives delivering significant increases in turnout and retention of donors and others producing a negligible increase or no increase; however, no incentives were shown to have negative effects [18].
[3] We assume here that if payment is effective in promoting whole blood donation, it would also be effective in promoting plasma donation.
[4] When it comes to paying for plasma, there may be legitimate worries about the safety not of *donations* but of *donors*. Little is known about the health impact of regular weekly or even twice-weekly plasma donations, but anecdotal evidence suggests it may be significant. If so, this would be a reason to limit the frequency of donations, but it does not in our view speak to the morality of payment *per se* [22].

interesting question with respect to the consent criterion is whether paid donors are manipulated or coerced by CPR. Of course, the question is not whether CPR literally coerces a person into donation – say, by putting a gun to her head and issuing the ultimatum, "your plasma or your life." The question, rather, is whether the offer of payment is so tempting to those who are truly desperate that it amounts to an offer they cannot refuse – and thus an offer to which they cannot give meaningful consent.

Understood in this way, the question is whether the offer of $25-50 to a needy person acts in much the same way as the gun would, effectively coercing her into selling her plasma. The argument that this is indeed coercive goes like this: "the fewer alternatives a person has to obtain the financial means offered through blood donation, the higher the coercive influence or pressure exerted through the offer of payment...offering someone in extreme material need and without alternative opportunities for income money for blood instead of other, more meaningful options…[is] an unacceptable way of compromising this person's autonomy" [26, p.330].

This type of argument might have some plausibility when applied to the question of organ sales in developing countries, for example, where potential vendors are profoundly desperate, and where the payment offered typically exceeds what that individual might otherwise earn over many years [27]. But the argument is unpersuasive when it comes to plasma donation in Canada. While in some social contexts the offer of $25-50 can be the difference between life and death, and thus constitute an offer someone cannot reasonably refuse, this is unlikely to be so in Canada against the backdrop of a social safety net that provides needed social services and income support. However inadequate we might take these provisions to be, they are certainly robust enough to provide an alternative to selling one's plasma for $25-50.

Of course, a $25-50 payment represents a single donation. With plasma, unlike with whole blood, you can donate once a week (or in the US, twice a week, something that may eventually become the case here as well). This means paid donors can make up to $200 a month. That is a more compelling sum. But it is a sum that may look attractive to a good number of less vulnerable Canadians as well. The more compelling the offer becomes, the less badly-off someone has to be to accept it. And the less it therefore makes sense to say that the party who extends the offer takes unfair advantage of the most vulnerable. But even if it were true that the offer of this much money were coercive of the worst off, this would not necessarily be an argument against payment; it might instead be an argument for a means-tested system in which only those donors determined to have alternative options for earning this much money would be eligible for payment [28].

A further point is worth making about coercion as it pertains to exploitation. There is a moral distinction that needs to be drawn between coercion and incentivization. The gunpoint ultimatum works by removing options until the victim's best course of action is the one the gunman prefers. In other words, the gunman restricts the victim's options until his choice becomes the victim's most attractive option. By contrast, offering an incentive *adds* to a person's range of options, and the incentive succeeds only if it is preferred to any option the person had before. A coercive offer thus restricts a person's options, whereas an incentive adds to them. From this perspective, what CPR offers is clearly incentivizing, not coercive. Preventing CPR from making such an offer does not improve the situation of vulnerable people; it merely takes away from them what they currently regard as their best option, rather like the gunman does [29].

The other criterion that can substantiate an exploitation claim is that, while both parties might benefit from their interaction, one party benefits disproportionately, thus depriving the other of what she is fairly owed. According to the fairness criterion, what we would need to establish is that CPR denies their donors something they are rightfully due qua donors. On the most obvious interpretation of this, we should presumably worry about whether CPR profits by paying their donors too little. In fact, CPR pays its donors the equivalent of about 30% of what their plasma is worth when it is sold [9, sec.7.4]. We need not puzzle over whether this percentage is too large or too small in an era in which wages are steadily falling and profits rising relative to GDP. Instead, all we need to note is that, according to the fairness criterion, removing the payment would actually make the transaction even *more* exploitative. Whether 30% represents a fair share of the benefits of the exchange, it is clearly a lot fairer than 0%.

From that point of view, given that wages are earned and profits are made from plasma, there is good reason to think that it is unpaid donors who are being taken wrongful advantage of. And this advantage-taking is arguably made worse by the anti-commodification rhetoric used to justify non-payment: when donors are told that their plasma is too valuable to have a price – and told this by the very agency that later assigns it a price – the unfairness of nonpayment is compounded by outright deception. It is thus not a paid system but rather our current volunteer regime that flouts both fairness and consent considerations.[5]

III. Commodification

Arguments against paying plasma donors that are grounded in concerns about safety or exploitation have at least this much in common: they claim that paying plasma donors would cause concrete harms or wrongs to identifiable individuals, in the

[5] It might even be said that the current volunteer system is exploitative to the extent that it takes unfair advantage of the beneficent. When it comes to living organ donation, for example, the majority of donors are female, and the recipients primarily male [30]. Given the social expectation of gendered altruism, this is not altogether surprising, and some evidence suggests that this also has an effect on gender demographics in blood donation [31]. Women are far more likely to cite altruism as their reason for giving; women in their 20s give blood at a much higher rate than men in this age group, and while, as they age, women tend to give less, this is often due to higher rates of adverse reactions and associated restrictions placed on the number of donations women are permitted to make in a year as compared to men [32].

form of either greater risks for plasma recipients or exploitation of plasma donors. However, such claims are quite difficult to substantiate, or so we have argued in the first two sections of this paper. Another set of arguments against paying for plasma appeals to more abstract harms against societal norms or moral values, and we turn to these arguments here and in the next section. We begin, here, by considering arguments to the effect that blood or its components should not be treated as a commodity. On this line of thinking, we must avoid paying donors because doing so invites the intrusion of market forces into the blood system, and these market forces tend to corrupt or crowd out important social values. In the next section, we consider arguments to the effect that we must not pay donors because it is wrong to allow individuals or corporations to profit from human blood.

There is a long tradition of anti-commodification arguments purporting to show that certain important goods must be protected from the distorting influence of the market, and which therefore should not be bought or sold. Broadly speaking, we can distinguish two lines of critique. The first focuses on the effects of the market on the good being exchanged, while the second focuses on the effects of the market on the motivations of the parties to the exchange. According to the first line of argument, which we will call the *corruption* argument, assigning a price or a market value to a morally significant good corrupts its true worth, turning it into a mere commodity. According to the second, which we will call the *crowding out* argument, buying and selling morally significant goods introduces self-interest into a domain that should be governed by altruism or public-spiritedness; and self-interest, once unleashed, crowds out these more valuable motivations.

The *corruption* argument suggests that the problem with paying plasma donors is that it involves putting a price on plasma, thereby turning it into a mere commodity or market resource. In that way, we fail to value it properly as the kind of good that it truly is. As Michael Sandel argues, “putting a price on the good things in life can corrupt them…because markets don’t only allocate goods; they also express and promote certain attitudes toward the good being exchanged” [33, p.9]. Elizabeth Anderson shares this worry, noting that assigning something a market price expresses the idea that it can and should be valued solely in terms of the instrumental use to which it may be put [34]. On her account, the body is not the kind of the thing that should be valued in such terms.[6]

We do not question the central insight here, which is that even in a market economy certain goods should remain exempt from market valuation. Nonetheless, there are a number of things wrong with this line of thinking as applied to plasma specifically. First of all, our current ‘unpaid’ plasma regime in Canada already relies heavily on paid donors. The claim that it is wrong to assign price values to blood seems to be mere rhetoric in light of the fact that 80% of our plasma for PDMPs comes from clinics in the US, where donors are paid. How can we claim that blood is too valuable to have a price, unless we are prepared to say that Canadian donors (or their plasma) have greater moral worth than their American counterparts? Second, while we may not pay Canadian donors themselves, this doesn’t mean that their plasma is never assigned a price; it simply acquires its price tag a little further down the supply chain [31]. In the case of PDMPs, Canadians’ raw plasma must be screened and shipped to fractionation facilities in the US for manufacture. It is then sent back to Canadian hospitals for use as treatment. All of this costs money. Moreover, the highly trained professionals who carry out these processes earn wages, as we think they should, despite the fact that this clearly introduces financial incentives into the blood donor system. Once all of these costs are accounted for, CBS bills provincial insurers for the calculated costs of the treatments used by hospitals in their jurisdiction [36].

At a minimum, these considerations suggest that as a case against paying donors, the corruption argument would have to be applied in an arbitrarily narrow way. If assigning a price to blood and blood products corrupts their true worth, this has implications that go far beyond the non-payment of donors. Canada’s blood system already assigns a price to plasma – not only to the raw plasma of American donors, who are paid, but also to PDMPs at all phases of production *except* for the acquisition of plasma from Canadian donors. It is therefore rather arbitrary to insist that this is the *one* element of the blood system that must never be assigned a price.

According to the second version of the anti-commodification argument, the *crowding out* argument, blood and blood plasma are the kinds of resources that should be offered from a motive of altruism or public-spiritedness.[7] The introduction of payment inspires self-interest, and thereby supplants or *crowds out* these nobler motives. According to the Krever Report, blood should be “given altruistically by persons in Canada for the benefit of other persons in this country” [14, p.1047]. In defense of her proposed bill banning payment for plasma donation, Senator Wallin echoes this view, stating that “Canada’s blood collection system must remain one that is driven by the human instinct to help one another, not by personal gain” [12]. These concerns echo Titmuss’s view that introducing payment into the blood system “represses the expression of altruism, and erodes the sense of community” [20, p.314].

We agree that altruism is desirable. Certainly, a community in which acts are performed for altruistic reasons is preferable to one in which they are not. Not all social relations should be mediated by market mechanisms, nor should all human interactions be driven by self-interest rather than regard for the needs of others. But granting the desirability of this goal, it’s not altogether clear that it is best promoted, or even promoted at all, by restricting payment to plasma donors, for several reasons.

[6] Immanuel Kant initially raised such concerns when he avowed that “what has a price can be replaced by something else as its equivalence; what on the other hand is raised above all price and therefore admits of no equivalent has a dignity” [35, 4:434].

[7] Of course, crowding out also is often used to refer to the predicted effect that, when the option of payment is made available, fewer people will be inclined to donate for free. This is simply the practical side of the moral problem we are addressing here: that when pecuniary incentives are introduced, this has an effect on (diminishes the number of actions taken from) altruism. We discuss this briefly below, and in more detail in the following section, where we show that this concern is not supported by the available evidence.

To begin with, the provision of literally any good provides an opportunity for the expression of altruism. Thus, it bears asking why a more altruistic society must be promoted through the donation of plasma specifically, rather than some other good. We could instead promote altruism by encouraging citizens to contribute to food drives or clothing drives rather than blood drives. It seems arbitrary to isolate the donation of plasma (or even bodily goods more generally) as the one area where our efforts to promote altruism should be focused.

Second, even assuming that the promotion of altruism in society should be focused on the provision of plasma, it is not necessary to restrict payment for plasma in order to promote charitable giving. This is a bit like holding that the state should encourage contributions to soup kitchens by closing down grocery stores. Just as food markets can coexist with food drives, a system of paid plasma donation can exist right alongside a parallel system of unpaid donation. The US demonstrates just this, by paying plasma donors while nonetheless maintaining a per capita rate of voluntary, unpaid whole blood donation that is approximately 50% higher than Canada's [9]. Likewise, Germany, Austria, and the Czech Republic, where plasma donors can be paid if they choose, all have higher per capita rates of unpaid whole blood donation than Canada [37].

Third, and relatedly, there is no reason to assume that the introduction of payment necessarily supplants altruistic motivation. People's motivations are complex. Those who are financially compensated can be motivated simultaneously – perhaps even primarily – by altruistic impulses. This is true of many actors in the healthcare system, such as doctors and nurses. Indeed, most of us take pride in the aspects of our work that allow us to help others, while also believing we should earn a fair wage for doing so. Why then should we think that a paid plasma donor must be primarily or exclusively motivated by personal financial gain?

Titmuss held that as soon as money enters the picture, it distorts a person's incentive structure. He based his conclusions partly on the results of surveys conducted among unpaid whole blood donors in the UK and paid whole blood donors in the US. Survey respondents in the UK cited altruistic motives for donating, inspired not infrequently by having lost someone in the Second World War whose life might have been saved by a transfusion. American respondents, by contrast, mostly cited the need for money [20]. But the American donors were not asked *why* they needed the money, leaving open the very real possibility that they were looking to help support their children, partner, or parents. Surely theirs would not have been selfish motives in such cases, despite the fact that money influenced their choice. This suggests that the offer of money does not necessarily supplant but can clearly coexist with – and maybe even enable – altruism.

Finally, it is arguable that maintaining the view that unpaid donors are noble while paid donors are selfish contributes to the unjustified stigmatization of those who are paid, marking them as non-cooperative social actors, despite the fact that they are very much helping to save lives. This kind of social stigma not only prevents agents from acting in accordance with their genuine preferences but can threaten the security of the plasma supply to which paid donation otherwise contributes [38].

IV. Profits and Payments

One of the most commonly expressed and intuitively powerful objections to a system of paid plasma donation invokes the first principle of the Krever Report, according to which blood is a public resource. The opposite of a public resource is of course a private resource, one controlled by individuals or corporations for their own profit. If blood is a public resource, then it should not become part of a profit-making initiative, nor should Canadians become pawns of profit-seeking corporations. In elaborating on his first principle, Krever writes that "profit should not be made from the blood that is donated in Canada. The operator of the blood supply system must act as a trustee of this public resource for the benefit of all persons in Canada" [11, p.1047]. Wallin again echoes Krever in defense of her proposed bill, saying "Canadian donors are not meant to be a revenue stream for private companies looking to make a profit" [12].

The term "profit" is itself ambiguous and deserves some unpacking. Colloquially, it can mean any kind of gain, especially a financial one. However, if those who oppose profiting from Canada's blood supply mean to say that no one should derive any financial gain from the blood system whatsoever, then clearly they ask for something impossible; the only way to satisfy such a demand would be by turning the entire healthcare system into an all-volunteer enterprise. More plausibly, they mean profit in the narrow sense of return to equity: the residual claim held by ownership, typically stockholders, to whatever value is left after all other obligations of the enterprise are settled. In this sense, the difference between a for-profit and not-for-profit enterprise is just that with the latter, any residual is re-invested in the enterprise rather than being returned to ownership.

While it may be philosophically and politically controversial, it is common sense in the business world that managers in for-profit companies work *for* stockholders and are obliged to put their financial interests ahead of the interests of all other stakeholders [39]. Without questioning whether such an attitude is appropriate in business, it is clearly out of place in medicine, where it is understood that physicians' and nurses' first obligation is to their patients rather than to their own or their employers' bottom line. Such an attitude seems no less out of place in the blood supply system. There, the interests of those who depend on blood and blood products (or who may one day so depend, i.e., the public at large), as well as the interests of those who generously supply such products, should come before the interests of those who merely seek a return on their investment.

Understood in this way, concerns about the profit motive are just the demand-side analogue to the concerns we encountered in the previous section regarding the self-interested motives of suppliers. Just as one might worry about the nefarious effects of payment on the motivations and behaviours of those who *donate* blood, one might also worry about the effects of profit on the motivations and behaviours of those who *collect* it. We agree that these worries offer legitimate grounds to resist allowing Canada's blood and plasma supply to be controlled by for-profit corporations, and we will turn to substantiating those grounds momentarily. But we must first point out that concerns about the profit motive are quite separate from the question of whether plasma donors should be paid.

Profit-seeking and paying donors are two distinct issues. Whether an agency is organized as a for-profit venture has nothing to do with whether they pay (or should pay) their suppliers, and vice versa. For instance, Canada's provincial health insurance programs are properly public, not-for-profit agencies; the fact that these programs dispense payments to almost everyone involved in the provision of medical care in Canada has never been thought to threaten these insurers' not-for-profit status. Conversely, a for-profit agency should be inclined toward non-payment wherever they can get away with it, as a way of cutting costs and thus increasing profits.

The question of *payment* therefore has nothing to do with the question of *profit*. To say that private companies should not profit from the blood system may be effective as an argument against allowing a private company like CPR to operate, but it has no bearing on the general question of whether plasma donors should be paid. We point this out, not to discredit anti-profit arguments as such, but only anti-profit arguments against paying for plasma. And to show that there is conceptual space available for a novel position: one that endorses paying *for* plasma while rejecting profiting *from* plasma.

The first three sections of this paper were intended to show that there are strong reasons in support of paying for plasma, and few good reasons against it. In particular, paying for plasma can be expected to lead to a more secure domestic supply without compromising safety or exploiting the vulnerable. But if there are legitimate concerns about the distorting effects of the profit motive – and we believe there are, as we will argue momentarily – it is possible to address those concerns by simply taking the controversial issue of profit off the table. Payment may instead be dispensed by a not-for-profit agency.

In the interests of profit, we should expect a private company like CPR to sell the blood it collects from Canadian donors to the highest bidder, and the highest bidder may not be in Canada. In other words, CPR can be expected to sell Canadian blood abroad if doing so proves more lucrative than selling it domestically. As such, the licensing of for-profit clinics might not, in the end, address the very security of supply worries which (we argued in Section I) speak in favour of a paid system. Since one of the primary reasons (if not *the* primary reason) to support a paid system is to increase Canada's supply and to ensure the ongoing security thereof, then to the extent that the profit motive threatens this goal, this is grounds for serious concern with a for-profit system of plasma acquisition.

As difficult as it may be to imagine a for-profit company like CPR putting Canada's domestic supply needs ahead of its own bottom line, it is equally difficult to imagine a not-for-profit, like CBS say, selling Canadians' plasma abroad on the open market. This is because CBS's mandate is to protect the security of Canada's plasma supply, and also because it is accountable not just to shareholders but to government, advocacy groups, donors, and citizens. This suggests that, in light of the compelling reasons to pay plasma donors, there are considerable reasons to prefer that such payment come from a public, not-for-profit agency like CBS rather than a private, for-profit agency like CPR.

There is a helpful parallel to be drawn here to the ethical analysis of clinical research trials involving human subjects. The benefits of trial participation are not enjoyed by subjects in the form of medical treatment as such, since they may be randomized to a placebo group, and/or because the experimental treatment may prove ineffective. Instead, the benefits of participation are generally twofold: in the short term, there is payment, and in the longer term, there are the benefits of living in a society with safe, new, and effective treatment protocols, which can only be achieved in most cases through research on human subjects. It is broadly regarded as ethical to perform research on human subjects if the latter of these two benefits can be reasonably assured, that is, if the research will very likely have ongoing social value in which the participants will share [40,41].

In the context of plasma donation, we have similar reason to think that donors are owed the opportunity to live in a society with a more secure and plentiful plasma supply in the long term, as well as payment for their contribution to this social good in the short term. As with medical research, the greatest good that comes out of a system of plasma acquisition is increased access to treatment in the future. Thus, it seems reasonable to suppose that donors should be entitled to share in this good. And on our view, this speaks in favour of securing our supply by pursuing a publicly accountable payment scheme. When the private sector gets involved in the acquisition of plasma and sells the plasma they acquire in Canada to the highest bidder abroad, Canadian donors can reasonably worry they might be deprived of access to the social good to which they contribute. This is why, on our view, we need a publicly controlled system of plasma acquisition. But we would emphasize again that, although the opportunity of donors to live in a society with a more secure plasma supply is an important long-term benefit of plasma donation, this long-term benefit is not at all inconsistent with short term financial payment to donors for their time and trouble.

Continuing with the parallels to research ethics, some bioethicists argue that while living in a society with new medical interventions is the primary benefit of clinical research involving human subjects, this cannot always be reasonably guaranteed

to trial participants for any number of reasons.[8] As such, ethical research requires that some more direct form of benefit-sharing is owed to participants [42]. We are making a similar case: the primary benefit of plasma donation should be living in a society with an adequate supply (which we secure through public control), but donors who may never access this supply themselves are owed some more direct benefit (which we assure through payment). In sum, a not-for-profit agency that collects plasma through paid donation would best ensure that the plasma collected in Canada would in fact serve to secure the Canadian plasma supply, which in our view is the principle rationale for payment. Payment would enhance domestic supply, while the public mandate of a not-for-profit would help to ensure that the supply is managed for the benefit of all Canadians rather than for the benefit of the shareholders of a firm. A publicly governed payment scheme would realize the benefits of increasing supply through incentivization, without the risk that Canada's plasma supply would go to whomever was willing to pay the highest price for it.

There are additional reasons to favour payment coming from a not-for-profit rather than a for-profit agency. One common complaint against CPR is that they have chosen particularly disadvantaged parts of Saskatoon and Moncton as sites for their first two clinics. We argued in a previous section that worries around exploiting vulnerable individuals seem somewhat overblown; it is difficult to see the offer of a $25 or $50 payment as one that poor people are incapable of resisting, not least of all because many poor Canadians do indeed refuse it. Nonetheless, we agree there is something troubling about the fact that CPR has opened its clinics in Saskatoon and Moncton in underprivileged parts of town. This does seem to suggest that they know their clients will come mainly from among the worst off. This is a problem of inequality, on our view, not one of exploitation. It looks as though CPR is taking advantage, not of vulnerable individuals, but rather of the fact of income inequality in Canada itself. Were income and wealth more equitably distributed, particular neighbourhoods, and thereby particular segments of the populace, would not become the targets of for-profit agencies. That disadvantaged neighbourhoods exist to become the target of for-profit agencies is a serious problem of social justice, and not simply of plasma acquisition. Nonetheless, our reason for raising this issue is to point out an additional advantage of vesting the responsibility for paid plasma acquisition in the hands of a not-for-profit public agency like CBS. The advantage is that CBS could pay for plasma from their vast network of existing donation sites, and thus would not rely so heavily on any one particular segment of the population. Indeed, CBS could proceed with opening its new proposed donation sites in diverse neighbourhoods across Canada and pay donors from those sites.

Of course, not-for-profit status is not a panacea. Not-for-profits are perfectly capable of short-sighted and self-interested behaviour of their own, as the history of the Canadian blood scandal attests. But to the extent that the profit motive is seen to be particularly distorting of agents' incentives and thus their behaviour, we can expect some improvement by simply taking that motive off the table. This can be expected to have a couple of concrete benefits, as we have already argued. But additionally, because a public agency like CBS is accountable to a broader range of stakeholders for their decisions, if we want the blood system to be managed for the good of all Canadians rather than for the interests of a private company's shareholders, such broader accountability is preferable.

In closing this section, we acknowledge that our proposal raises a number of legitimate practical concerns. If CBS were to begin paying Canadians for their plasma, what would be the impact on Canada's whole blood supply? What would be the budgetary implications for CBS? Would paying donors really increase supply, and security of supply, as much as we suggest? We acknowledge that these are legitimate concerns, and certainly any attempt to implement a proposal like this should investigate them carefully before proceeding. Here we would just emphasize that our aim in this paper is more modest. Our aim is to offer arguments that purport to show that paying plasma donors does not raise serious *moral* concerns, where such payment is dispensed by an accountable public agency. Whether there are practical obstacles to its implementation is an area for further research.

Nonetheless, despite the fact that our intervention in this paper is meant to be moral and conceptual rather than empirical, there are a few practical points it behooves us to make before concluding. First, on the question of CBS's finances, while our proposal may lead to some net increase in costs, we think a more secure domestic supply of plasma is worth paying for. Indeed, CBS itself has recently requested just shy of $100 million over six years in order to build and staff new plasma donation centres, in the hopes of increasing domestic supply to meet about half of Canada's demand for PDMPs. They have also requested $800,000 for a public relations campaign designed to bolster domestic donations [43]. We see no good reason why these funds should not be devoted in part to paying donors, and many good reasons why they should. Second, while some may worry about the impact of paying for plasma on CBS's ongoing efforts to source adequate quantities of whole blood, in general there is no evidence of a "crowding out" effect here. When the Government's Expert Panel on Immune Globulin Product Supply and Related Impacts in Canada examined the literature, they found no evidence that expanding paid plasma collection negatively affected the whole blood supply [3]. And indeed, as we have already said, many countries that allow for paid plasma donation *also* maintain higher rates of uncompensated blood donation than Canada [31].[9]

[8] In the context of medical research, this may be because some participants die before the intervention becomes widely available, or because the cost of some new intervention may make it inaccessible to certain participants, particularly those in poorer regions, or nations with inadequate drug subsidies or healthcare provisions. With respect to plasma in Canada, the first of these is more relevant, as is the likelihood that healthy donors will themselves never require medical interventions involving the use of plasma.

[9] Of course, under our proposal, the very same organization (CBS) could be responsible for collecting both unpaid blood donations and paid plasma donations, and this might give rise to crowding-out problems that do not obtain when different agencies are doing the collecting. Clearly more research is called for here, but such problems could potentially be mitigated by, for example, having blood and plasma collection performed at separate sites or under distinct "brands."

We have argued in this section that while there are legitimate reasons to be worried about the effects of the profit motive on Canada's blood system, these worries have nothing to do with the question of paying donors. Indeed, many of the concerns people have about CPR could be assuaged by allowing CBS or another not-for-profit entity to pay plasma donors.[10] Evidence suggests that a large majority of Canadians support paying for plasma provided that it does in fact increase the Canadian plasma supply [45]. Our proposal shows that it is possible to accommodate the aversion many Canadians have toward profit-oriented initiatives, while still realizing the increased supply that payment makes possible.

Conclusion

We have argued that the current debate around payment for plasma in Canada avoids the central issue, which is not about whether donors should be paid, but about who should be paying them. There are many good reasons to favour paying plasma donors, and few good reasons against. Paying for plasma would increase domestic supply, making Canada's blood system more self-sufficient and secure in an increasingly uncertain world. To object to payment on the grounds that blood should not be commodified belies the fact that Canada already depends on paid donors in the US for plasma. To say that paying Canadian donors would be exploitative ignores the fact that not paying them exploits them more, in virtue of assigning them an even smaller share of the benefits of cooperation.

The introduction of the profit motive is a legitimate cause for concern, and a good reason to worry about licensing private plasma acquisition clinics. But fortunately, it is not a legitimate reason to refuse to pay plasma donors. The question of payment is separate from the question of profit; a not-for-profit can pay donors as easily as can a for-profit. And in fact, if we are going to pay donors, there are good reasons to favour such payment coming from a not-for-profit source. A not-for-profit can be expected to keep domestic plasma donations in Canada for the benefit of Canadians, rather than selling them to the highest bidder abroad. In this way, not-for-profit payment would contribute to the security of the plasma supply in a way that for-profit payment would not. With this in mind, we have advocated for a new Canadian regime of public sector plasma collection and payment.

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

Vulnérabilité des femmes enceintes en éthique de la recherche : un problème sémantique

Sihem Neïla Abtroun[1]

Résumé
Ce commentaire s'intéresse à la notion de vulnérabilité appliquée aux femmes enceintes en recherche clinique. L'utilisation de cette notion, liée à un problème sémantique, soulève un enjeu éthique et participe à l'exclusion quasi systématique de cette frange de la population du processus de recherche.

Mots-clés
éthique de la recherche, femmes enceintes, vulnérabilité, stigmatisation, recherche clinique

Abstract
This commentary explores the notion of vulnerability applied to pregnant women in clinical research. The use of this notion, related to a semantic problem, raises an ethical issue and participates in the quasi-systematic exclusion of this sub-population from the research process.

Keywords
research ethics, pregnant women, vulnerability, stigmatization, clinical research

Introduction

La vulnérabilité des femmes enceintes, dans le domaine de la recherche, est sujette à controverse du fait de la définition même du terme « vulnérabilité » : il s'agit d'un paradigme qui existe entre certains textes de régulations de la recherche qui ont évolué et ne catégorisent pas les femmes enceintes comme vulnérables, et la réalité du milieu de la recherche qui les exclut continuellement du fait de la simple perception de cette frange de la population comme vulnérable [1-4]. À l'instar du conseil des organisations internationales des sciences médicales (CIOMS), l'Énoncé de Politique des Trois Conseils, deuxième édition (EPTC2) – a qui régit la recherche avec des participants humains au Canada – ne catégorise pas les femmes enceintes comme une population vulnérable, mais l'attention particulière qui leur est portée pourrait participer à leur perception comme des personnes vulnérables et porter à confusion [5,6,7]. Bien qu'il n'existe pas de définition uniformisée du concept de vulnérabilité, il en existe diverses compréhensions et appréhensions par les chercheurs en recherche clinique qui l'utilisent abusivement pour exclure les femmes enceintes. Il est aussi important de souligner que dans d'autres textes règlementaires à l'international, comme les textes législatifs régissant la recherche en France [8] ou le Code of Federal Regulations aux États-Unis [9], aussi bien que dans la littérature biomédicale [4], les femmes enceintes sont encore clairement qualifiées de « vulnérables ». On comprend donc que cette notion de vulnérabilité et le problème sémantique qu'elle soulève sont fortement ancrés dans la pratique en recherche et plus particulièrement en recherche clinique. On s'intéressera donc dans ce commentaire à la notion de vulnérabilité des femmes enceintes selon deux conceptions : la première, aisément réfutable, liée à la capacité décisionnelle et la seconde liée au risque de tort potentiel. On conclura par le fait que la compréhension erronée de la notion de vulnérabilité et son application aux femmes enceintes ont participé à leur exclusion systématique de la recherche, d'où la nécessité de se libérer de la vision surprotectrice et contre-productive de la vulnérabilité supposée des femmes enceintes et ainsi promouvoir leur participation à la recherche.

Femmes enceintes : participantes vulnérables

Comme nous l'avons souligné précédemment, il existe plusieurs conceptions de la vulnérabilité. Les plus répandues sont la vision nord-américaine où la vulnérabilité est liée à une altération de la capacité décisionnelle et la vision internationale à prédominance européenne liée au risque de tort couru par le participant. Au Canada, selon l'EPTC2, « la vulnérabilité résulte souvent d'une capacité décisionnelle limitée ou d'un accès limité à des biens sociaux comme des droits, des opportunités de développement et du pouvoir » [7]. Tout en sachant que l'EPTC2 ne qualifie pas les femmes enceintes de vulnérables per se, nous utiliserons sa définition dans un premier temps pour pouvoir analyser cette conception souvent utilisée à tort de la vulnérabilité chez la femme enceinte [5,7]. Cette conception de la vulnérabilité est aisément réfutée, car dans le cas des femmes enceintes, le fait d'avoir été fécondé et donc de porter un être vivant en elle ne modifie pas leur pouvoir décisionnel ni leur statut socioéconomique. Ainsi, si cette définition de la vulnérabilité proposée par l'EPTC2 est appliquée stricto sensu à la femme enceinte, elle renverrait donc à une notion erronée. En ce qui concerne cette sous-population féminine, il n'existe pas de problème de compréhension ni de limitation de ressource ou d'accès ; sachant qu'il existe des situations où les femmes peuvent être désavantagées, du fait d'inégalités de genres et socioculturelles, indépendamment de leur statut de gestation [10]. Cette définition apparait donc comme obsolète et ne saurait être appliquée aux femmes enceintes. Cependant, Basaia décrit la femme enceinte comme vulnérable du point de vue psychologique, à cause des changements liés à la grossesse, mais qui « conserve toutes ses aptitudes qui la maintiennent libre de ses choix » reprenant le concept de « personne vulnérable, mais capable » [8]. Cette description problématique de la femme enceinte « vulnérable, mais capable » pourrait potentiellement contribuer à son exclusion systématique, mais aussi celle de l'ensemble des femmes en s'inscrivant dans une version paternaliste extrême, certes peu probable, où toutes femmes subissant des variations physiologiques seraient exclues.

van der Zande et collègues ont quant à eux analysé « la vulnérabilité des femmes enceintes en recherche clinique ». Ils ont identifié quatre notions de vulnérabilité pour la femme enceinte : 1) la difficulté à obtenir un consentement éclairé, qui ne peut être appliqué dans ce cas ; 2) une susceptibilité accrue à la coercition par le fait d'être induit en erreur en mettant le bien-être

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éventuel du fœtus avant leur propre bien-être ; 3) la vulnérabilité propre du fœtus comme un participant inapte ; et enfin 4) une augmentation du risque lors de la recherche par manque de données scientifiques concernant les femmes durant la grossesse. Les auteurs ont finalement réfuté les trois premières visions et ont conclu que la vulnérabilité de la femme enceinte est due au manque de savoir scientifique concernant cette sous-population qui entraine un risque plus élevé par rapport aux autres participants à la recherche [4].

Si plusieurs visions en recherche clinique contribuent à la catégorisation des femmes enceintes comme vulnérables, la plus répandue actuellement serait peut-être celle liée au fait d'un risque possiblement plus élevé lors de leur participation aux processus de recherche [2,3,11-13]. Cette conception de la vulnérabilité répond à la vision internationale de la vulnérabilité liée aux risques potentiels auxquels s'exposent potentiellement les participants. Ainsi, Hurst définit la vulnérabilité comme « un risque accru de subir un tort et qui peut exister ponctuellement ou durablement, face à toutes sortes de torts, pour différentes raisons » [12, p.1057]. Tout en évoquant la multifactorialité de la vulnérabilité, celle-ci pourrait alors s'appliquer aux femmes enceintes de différentes façons. Tout d'abord, elles font face à des modifications physiques et physiologiques de leurs corps qui s'apprêtent à faire grandir un être en elles ainsi qu'à des modifications psychiques : les émotions par rapport à leurs fœtus existent dès le début de la grossesse. À cela sont associées une responsabilité accrue et une protection instinctive de la future mère envers son enfant à venir. Enfin, le fœtus représente une entité propre exposée à des risques malformatifs et abortifs, et il est aussi appelé à être individu vivant (enfant puis adulte) qui pourrait subir les conséquences de la recherche, avec comme une ombre noire qui plane les réminiscences des dérives de la recherche liées à la thalidomide ou au distilbène.

Dans le milieu de la recherche clinique, la santé physique et psychologique de la femme enceinte est souvent mise au second plan par rapport à la santé du fœtus. Selon la conception traditionnelle de la grossesse, il y aurait une dichotomie entre le fœtus et la femme gestante (la mère) qui peut parfois mener à la priorisation du fœtus au détriment de la mère [2,14]. Toutefois il semble que l'on devrait considérer la femme enceinte et son fœtus comme un couple indissociable et interconnecté ; une modification de l'état de l'un a inévitablement des répercussions sur l'autre, qu'il soit bénéfique ou non [1]. On peut imaginer, par exemple, qu'une participation à une recherche clinique qui améliorerait la santé du fœtus et de l'enfant à venir améliorera par conséquent la santé psychologique et la qualité de vie future de la mère. De la même manière, les risques ainsi que les éventuelles répercussions à court et long terme pour la femme gestante seule, le couple mère-fœtus et l'enfant à venir sont incontestables. Mais si la femme enceinte appartient à une sous-population à risque accru, cela signifie-t-il nécessairement que ce groupe est vulnérable et doit être surprotégé? Sachant que cette catégorisation pourrait conduire à son exclusion en se basant sur une vulnérabilité plus « hypothétique » que réelle [5].

En réponse à van der Zande et collègues [4], Krubiner et Fraden [14] ont relevé le fait que les femmes gestantes représentent une partie importante des soins thérapeutiques administrés dans les différentes sociétés, mais leur exclusion de la recherche biomédicale perpétue « un cercle vicieux » qui induit un manque de connaissance et donc leur exclusion systématique. Le point le plus pertinent étant que les femmes enceintes doivent « être protégées durant la recherche et non pas de la recherche elle-même » [14]. Le statut des femmes enceintes en recherche est qualifié de « vulnérabilité paradoxale » [13] car la majorité des médications prescrites aux femmes durant la grossesse ne sont pas agréées pour être utilisées chez les femmes enceintes [3-4]. Dans certains cas, seul l'état de grossesse induit une iniquité face à la participation potentielle des femmes enceintes à la recherche. Ainsi à travers l'exemple allemand, Wild [2] illustre parfaitement ce concept : bien qu'il n'existe pas de législation précise régulant la recherche sur les femmes enceintes en Allemagne, leur vulnérabilité est largement acceptée. Elle rapporte plusieurs cas où les femmes enceintes sont exclues catégoriquement de la recherche clinique. Un des exemples les plus parlants est celui du ministère de la santé allemand qui, en 2009, a publié que des essais cliniques en vue de l'approbation d'une vaccination contre la souche H5N1 n'ont pas été conduits sur les femmes enceintes pour raisons éthiques. L'auteure note que « les raisons éthiques » ne sont ni spécifiées ni explicitées, mais résultent de stéréotypes [2]. Il est évident que considérer les femmes gestantes comme vulnérables restreint la conduite d'essais cliniques qui permettraient pourtant d'augmenter les données scientifiques probantes les concernant. L'existence de telles données améliorerait leur participation aux processus de recherche [3] alimentant un puits sans fin. Une mesure de protection qui, en finalité, entraine une exclusion. Par conséquent, l'utilisation et la perception mêmes du terme de « vulnérabilité » pour décrire la population des femmes enceintes est inadéquat. Il pose un problème sémantique réel, car il fait référence dans le domaine de la recherche soit à une possible incapacité décisionnelle qui est généralement absente dans ce cas, soit à un risque incommensurable par le seul fait que la femme est gestante. Ainsi, la femme qui était une participante compétente et potentielle perd cette possibilité par le seul fait de porter un fœtus et nécessite donc une protection accrue qui finit par l'exclure quasi systématiquement de la recherche.

Femmes enceintes : participantes particulières

Prenons l'exemple des textes de régulation de la recherche qui ne considère pas les femmes enceintes comme vulnérables per se [5-7,15]. Ainsi, L'EPTC2 ne catégorise pas les femmes enceintes comme vulnérables, mais requiert à travers l'article 4.3 que « les femmes ne doivent pas être indûment exclues de la recherche uniquement en raison de leur capacité de procréer ou parce qu'elles sont enceintes ou qu'elles allaitent. […] À moins qu'il n'y ait une raison valable de le faire, les chercheurs ne devraient pas exclure les femmes de la recherche en raison de leur capacité de reproduction ou parce qu'elles sont enceintes ou parce qu'elles allaitent » [7], et cela tout en tenant compte des risques et des bénéfices de leur participation. Cette conception de participante particulière est confortée par le Conseil des organisations internationales des sciences médicales (CIOMS) qui, en 2016, a affirmé que « les femmes enceintes ne doivent pas être considérées comme des personnes

vulnérables simplement en raison de leur état. Toutefois, des circonstances particulières, telles que les risques pour le fœtus, peuvent justifier la mise en place de mesures de protection spéciales. » [6] Cependant, bien que L'EPTC2 et le CIOMS, dans la ligne directrice 19, encouragent la participation des femmes enceintes à la recherche, ils soulèvent la difficulté de son application concrète dans le milieu de la recherche. Par exemple, le CIOMS met en avant le bénéfice personnel de la femme et de son fœtus : si le bénéfice de la recherche est sociétal et non individuel, les femmes enceintes ne pourront y participer que si le risque est minime, ceci met clairement en évidence le problème de l'évaluation éthique du bénéfice-risque ; bien qu'il tente d'apporter des solutions et préconise d'inclure les femmes gestantes « uniquement après un examen rigoureux des meilleures données pertinentes possibles » [7,15]. Ces données probantes étant le plus souvent insuffisantes, le CIOMS tout comme l'EPTC2 dans l'application de l'article 4.3 (cité ci-dessus), s'en remet aux chercheurs et aux comités d'éthique [6,7], qui ont tendance à être surprotecteurs [1,9]. Mais cette surprotection des femmes et de leur fœtus ne doit pas participer à leur exclusion systématique. Comment alors résoudre ce dilemme? Est-il lié au terme lui-même de vulnérabilité ou à son signifié?

Même si la femme enceinte est potentiellement exposée à plus de risque dans la recherche du fait du manque de connaissances, sa protection doit s'affranchir de cette vision paternaliste historique et par conséquent ne pas considérer l'utilisation du terme de vulnérabilité pour les femmes enceintes. Si les femmes enceintes ne doivent pas être catégorisées comme vulnérables, elles sont des participantes particulières et le risque potentiel encouru nécessite une évaluation éthique plus raisonnable et plus prudente pour leur inclusion dans la recherche, mais ce postulat est valable pour tout participant à la recherche. Afin de promouvoir la participation des femmes enceintes à la recherche, van der Graaf propose de s'appuyer sur un système de santé apprenant ce qui répondrait aux attentes cliniques et de développement de la recherche, ce qui permettrait de dépasser les mécanismes surprotecteurs liés à une surestimation des risques par la communauté de la recherche [15]. Cependant un tel système ne permettrait que d'améliorer des protocoles existants, mais ne permettrait pas nécessairement le développement de nouveau traitement. Par exemple : il est évident que pour une condition comme l'hypertension gravidique et la prééclampsie, l'étude continue des données permettrait d'améliorer la santé de la mère et de l'enfant par une amélioration de la démarche diagnostique et thérapeutique, mais il serait tout de même difficile d'inclure des femmes enceintes pour tester de nouveaux médicaments. Quel que soit le domaine de recherche, il s'agit plus d'une évaluation éthiquement acceptable du risque encouru pour la santé physique et psychologique de la future mère et de la santé du fœtus et/ou de l'enfant à venir, que de vulnérabilité telle que perçue dans ce milieu. En considérant les principes éthiques de base de la recherche, soit la bienfaisance et la non-malfaisance, la considération et l'évaluation du risque – même si celui-ci est plus élevé pour les femmes enceintes – ne doivent pas signifier pour elles systématiquement leur non-inclusion ou leur exclusion des processus de recherche.

Conclusion

Il serait préférable de supprimer le terme « vulnérabilité », utilisé à tort pour les femmes enceintes, et de les considérer certes comme une sous population à part entière en tenant compte de leurs particularités physiques et psychologiques, mais sans surprotection. La femme enceinte est certes une participante particulière, cependant la grossesse n'est pas un état débilitant, mais un cycle immuable de la vie humaine qui permet de perpétuer l'humanité. Ainsi les femmes enceintes doivent être incluses dans la recherche en tenant compte des différents enjeux éthiques sans stigmatiser ou surprotéger cette frange de la population par rapport à une autre. Comme tout participant, elle peut faire face à des situations ou contextes augmentant sa vulnérabilité, mais cela est indépendant de son statut gestationnel. Une vision éthique acceptable serait plutôt de promouvoir leur inclusion et de leur offrir une information plus détaillée : des risques encourus à court et long terme pour elles et leur fœtus et surtout des bénéfices potentiels et attendus de leur participation à la recherche pour la sous-population des femmes enceintes, de la population des femmes et de la société en général. Un défi futur et peut-être utopique en éthique de la recherche serait donc d'abolir définitivement le terme sémantiquement problématique de vulnérabilité pour les femmes enceintes.

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Responsabilités des évaluateurs externes
Les évaluations des examinateurs 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 examinateur n'indique pas nécessairement l'approbation de ce manuscrit. Les éditeurs de *Revue canadienne de bioéthique* assument la responsabilité entière de l'acceptation finale et la publication d'un article.

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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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COMPTE RENDU / REVIEW

Review of: Magnussen H. (2017) The Moral Work of Nursing – Asking and Living with the Questions

Nico Nortjé[1]

Résumé
Une description narrative des défis moraux personnels d'une infirmière au service de diverses communautés.

Abstract
A narrative description of personal moral challenges of a nurse serving diverse communities.

Mots-clés
éthique infirmière, santé communautaire, diversité culturelle, bioéthique mondiale

Keywords
nursing ethics, community health, cultural diversity, global bioethics

The Moral Work of Nursing – Asking and Living with the Questions [1] is both a reflection on Hazel Magnussen's personal journey as a nurse and a report on developments in health care in Canada. Magnussen illustrates how the social, economic and political changes of the past half century have influenced the nursing profession and the health and well-being of nurses. This book successfully illustrates that nursing is not only a physically and mentally demanding vocation, but also one riddled with moral questions and conundrums, and that ethical reflection is essential in the moral work of nursing. Moral work includes advocating for patients and requires facing dilemmas in which there could be a breach of a nurse's duty to another. With its skillful integration of anecdotal reflections and scholarly arguments, this book challenges readers to think critically about their own positions in health care and how they can effect change.

The book describes the many issues that nurses face on a daily basis in community health nursing, primary care settings and professional nursing at large. There are four broad themes: the practical application of and approach to nursing knowledge; the institutional challenges faced by nurses; the political reforms affecting the profession; and the social and technological problems that could create ethical challenges for nurses. Of particular interest is one of three new chapters in this second edition, namely a chapter on how the new Canadian law legalising assisted death influences nurses' practice. Magnussen draws on her own personal journey in this chapter when she reflects on the death of her husband, Lloyd. She illustrates why it is important for society to support and take care of health care providers who are involved in providing end-of-life care. Each chapter offers pearls of wisdom and ends with thought-provoking questions that challenge readers to reflect upon what they have read and how they can apply it in their own settings.

This book makes an important contribution to the field of global bioethics in that the author reflects on her time practicing in Alaska and in remote areas of Canada, such as the Baffin Region in the Northwest Territories, the island hamlet of Igloolik close to the Melville Peninsula, and Frobisher Bay. She convincingly argues that in order to adequately serve culturally diverse populations, nurses need to work to remove the vestiges of colonial approaches to medicine and focus instead on upholding local value systems. Respecting First Nations and their traditions will enable health care professionals to build partnerships among individuals, families and communities that will be beneficial to the successful implementation of health care programs. The Canadian population in general is becoming more diverse, and applying the principles of global bioethics will become crucial for the development of sustainable health care practices that enshrine respect for patients [2,3].

Furthermore, this book contributes to the growing body of knowledge on burnout among nurses [4]. What is particularly useful is the way that the author destigmatises burnout, refuting the notion that only the weak can suffer from burnout. She also describes practical ways that nurses can alleviate pressure by making personal mental health a priority, focusing on the wisdom of the cartoon "Ziggy": if you are going to take care of others, you first need to take care of yourself [5]. As with the first edition, the book's frank discussion about workplace abuse (emotional, physical and sexual) stands out, drawing the attention of the reader to the fact that many nurses are victims and arguing that there needs to be a collective stand against abuse and bullying.

This book reads easily and persuasively, and the focus on lived experiences makes it accessible for the general public as well as clinicians. Magnussen has succeeded in giving us a look into her life, her struggles, her accomplishments, and that which gives her joy. This is truly a book for those interested in thoughtful reflections on the intricacies of life.

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Canadian Journal of Bioethics
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COMPTE RENDU / REVIEW

Review of *Clinical Ethics Consultation - A Practical Guide*

Canadian Bioethics Society / Société canadienne de bioéthique
En collaboration avec / In collaboration with

Julia Gill[1,2]

Résumé
Dans ce guide portant sur la conduite d'une consultation en éthique clinique, Bashir Jiwani note que le succès des interventions en éthique repose souvent sur les compétences personnelles du consultant concerné. Par conséquent, il a écrit ce volume pour articuler les éléments de la consultation en éthique clinique afin d'aider à favoriser l'intégrité chez ceux qui ne possèdent pas ces compétences inhérentes. En mettant l'accent sur la promotion de l'intégrité, ce livre offre une perspective et un processus nouveaux sur la façon d'aborder la consultation en éthique clinique sans nécessairement avoir à se fier à l'enseignement ou aux conseils des autres pour simplement reproduire ce que nous avons vu les mentors faire.

Mots-clés
consultation en éthique clinique, intégrité, soins de santé

Abstract
In this guide to conducting clinical ethics consultation, Bashir Jiwani notes that the success of ethics interventions often relies on the personal skills of the particular consultant involved. Therefore, he wrote this volume to articulate the elements of clinical ethics consultation to help foster integrity in those who may not have these inherent skills. By focusing on fostering integrity, this book provides a fresh perspective and process for how to approach clinical ethics consultation without necessarily having to rely on the teaching of others or the advice to simply do what we have seen mentors do.

Keywords
clinical ethics consultation, integrity, healthcare

In this guide to conducting clinical ethics consultation [1], Bashir Jiwani reflects on his own experience in healthcare institutions in Alberta and British Columbia beginning in the 1990's. He notes that the success of ethics interventions often relies on the personal skills of the particular consultant involved, therefore he embarked on a project to articulate the elements and processes of ethics consultation to help foster integrity in those who may not have exceptional personal qualities or inherent skills. This volume is the culmination of that project. By focusing on fostering integrity, this book provides a fresh perspective on how to approach clinical ethics consultation without necessarily having to rely on the teaching of others or the advice to simply do what we have seen mentors do. The intended audience is ethicists who are looking for a clear and well-developed method for their practice, and perhaps a different perspective on the processes that already exist. It would suit a reader who is trying to develop or refine their unique style of conducting clinical ethics consultation.

The first half of the book begins with a comprehensive overview of the background necessary to successfully navigate the world of ethics consultation. It walks the reader through the goals of ethics consultation and how to live and practice with integrity. It introduces the reader to the different types of consult requests and consult support, as well as the different models of ethics consultation services that are available in Canada. In the second half of his book, the author then introduces his proposed process of ethics consultation, including Stage 1: Pre-Consult; Stage 2: Interviews; Stage 3: Mid-Consult (including initial ethics analysis and planning next steps); Stage 4: The Consult Meeting; and lastly, Stage 5: The Post Consult. The elements of the Post-Consult include documentation, follow-up support plan, evaluating the ethics consult, and identifying systematic issues. Interestingly, the author seeks to describe but not necessarily defend his model.

In the background sections, Dr. Jiwani argues that ethics is not a discrete area of activity, and in fact, all decisions involve ethics. In the words of the author, "Ethics is not an area or compartment of life; it is a way of looking at life – a lens through which to see any and all of our experience." Therefore, we should not just ask whether an issue is ethical, but instead and more importantly, whether the position taken in response to an issue is ethically justified. This is what his book strives to achieve. This work references the companion piece, *The Clinical Ethics Consultation Toolkit* [2], and is designed to be used in tandem with documents contained in this toolkit.

The process the author puts forward is based on the foundational values of trust and respect, with a unique emphasis on living and practicing with integrity. The author emphasises that living with integrity is a lifelong struggle to deepen and refine our understanding of what life is about, and although facing difficult situations is part of the moral life of all individuals, ethicists are often well placed to help people think through these issues. He argues that people with different convictions can all find a place under the umbrella of integrity.

In his thought-provoking discussion, Dr. Jiwani argues that living with integrity requires both understanding our own values and understanding how we see the world. We must be able to understand all the values we are demonstrating to the world and be able to critically examine what should matter in life. He emphasises that integrity, in life and in ethical practice, requires being able to articulate and then challenge our own beliefs. Since our beliefs about reality and our values are intimately connected, we need to be able to talk openly with others about them in order to further the ethical discourse. Such sentiments are the underpinning of the process that follows.

While not significantly divergent in terms of content, this guide to clinical ethics consultation provides a different lens and a distinct process through which to navigate the world of ethical issues. Although the process and consult description sections are useful and practical, the real strength of this book lies in the moral analysis. By advocating to ground clinical ethics consultation in the integrity of the consultant and the consultee, the author has created a work that is holistic and refreshing in its honesty and breadth of discussion. The process described in the second half of the work is the logical extension of the

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deeper analysis that goes before, and is well worth reviewing in order to improve one's own capacity for integrity and proficiency at clinical ethics consultation.

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COMPTE RENDU / REVIEW

Book Review: *What time is the 9:20 bus? A Journey to a Meaningful Life, Disability and All*, by Lucinda Hage (2014)

Aedan Garcia[1]

Résumé
Ce compte rendu examine les défis de l'éducation d'un enfant ayant une déficience intellectuelle telle que vue dans le livre *What time is the 9:20 bus?* de Lucinda Hage. En plus d'être le récit émouvant et convaincant d'une mère qui lutte pour naviguer à travers les systèmes de soutien médical et social du Canada, le livre est aussi une excellente introduction aux domaines de la bioéthique, de l'éthique du handicap et de l'allocation des ressources.

Mots-clés
bioéthique, éthique du handicap, allocation des ressources, soutien communautaire, services résidentiels

Abstract
This book review considers the challenges of raising a child with a developmental disability as seen in the book *What time is the 9:20 bus*? by Lucinda Hage. Beyond being an emotional and compelling narrative of a mother struggling to navigate Canada's medical and social support systems, the book is also an excellent introduction to the fields of bioethics, disability ethics, and resource allocation ethics.

Keywords
bioethics, disability ethics, resource allocation, community support, residential services

What time is the 9:20 bus? [1] is an account of a mother, Lucinda Hage, raising her son, Paul, who has a rare neurological disorder called tuberous sclerosis complex (TSC). Beyond the book being an emotional and compelling narrative of a mother struggling to navigate Canada's medical and social support systems, it is also an excellent introduction to the fields of bioethics, disability ethics, and resource allocation ethics. Overall, the book shows the immense difficulties that children with disabilities face in hospitals, schools, social programs, and in sustaining independent living strategies. The book is also very much about the emotional and social impact of raising a child with a developmental disability.[1]

The book is broken up into four parts. In part I, Lucinda and her husband John make the decision to adopt a baby (Paul). Soon thereafter, it was discovered that Paul had TSC, which brings challenges for Lucinda as she realizes that her son will likely fall behind other children in his neurological development. Due to the stress of raising a child who constantly suffered from seizures, in addition to the collapse of Lucinda's social life and relationships, the common theme of chaos arises. In parts 2 through 4, Paul enters his high school years and the book centres on the theme of recovery. Lucinda remarries a man named Murray (after her initial marriage to John ended). The marriage brings stability and more support for Paul and this affords Lucinda a novelty in her life: free time. The themes of opportunity and community arise as well. At this time, Lucinda begins to consider, what will Paul do after he graduates? In response to this question she forms a support circle consisting of people who wanted to help Paul. When they convene, they discuss strategies to help Paul attain two main goals: 1) find him a fulfilling job and 2) find him housing so he can live independently. For employment, the support circle considers Paul's passions. Since he was young, Paul had a love for vacuums, motors, and lawn mowers. With some help he was provided the opportunity to work as a housekeeper at the Holiday Inn. Following these events, Paul was put into contact with another boy with a developmental disability. A living accord was made between the two and they would split living expenses and rent an apartment. The plan worked and Lucinda let go, not just of Paul but of two decades of hardships and triumphs. From that point onwards, Paul lived alone. Although he encountered some hurdles, Paul managed to adjust to living independently and completed a transformation that defied the odds.

The book brings to attention many realities surrounding family life when a child has a developmental disability. In her book, Lucinda seems to spare no detail, of both successes and setbacks, when speaking about the pressures that families face in these scenarios. In relation to bioethics, disability ethics, and the ethics of resource allocation, *What time is the 9:20 bus?* speaks to the issue of a society-wide focus on solely helping young children with disabilities, and as a result, neglecting them as adults. It is mentioned that there are many resources, institutions, government funds, and charities that help children with disabilities, however, these resources dwindle as children enter the adult world.

In the childhood of Paul, the book shows that children with developmental disabilities are often treated solely through a medical lens that attempts to address their disability with the use of prescription drugs and other treatments, but their social well-being is often missed. In this light, one major theme to be drawn from this work is that we must treat the person, not the disability. At many points, the book mentions the massive amount of prescription drugs that Paul is given, mostly to control his seizures. However, Lucinda notes that Paul made his greatest improvements when he was given the opportunity to make friends and develop social connections beyond his parents (although, medication was necessary to allow him to get to this point). He made further progress as he grew older and was employed by the YMCA Camp Wanakita and eventually the Holiday Inn. In these places, Paul did not just make friends; he learned social etiquette and how to meaningfully contribute to society. It was at these various points that Paul grew more aware of the world around him and was able to find his place. This is one of the major reasons why Paul's story is a success story.

[1] I chose to use the term "developmental disability" when I refer to Paul because it seems to best describe his condition. In the book, the doctor explained that Paul's development will likely be delayed. To give better context, the doctor who diagnosed Paul explained to Lucinda that, "Yes. His development will likely be quite delayed" [p.16]. It might also be important to add that the diagnosis was made in 1986 and there was even less of an understanding of TSC when compared to now.

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It cannot be stressed enough the importance of creating community and pushing institutions toward constructive change. A major theme in this work (which is important for students in the world of disability ethics), is that community needs to be created to help those with developmental disabilities. It can be challenging for many of these individuals to obtain housing and employment opportunities, and parents alone cannot overcome these many obstacles. Because people with developmental disabilities may suffer from limited social contact, support circles can help them overcome many issues. On a larger scale, community is a necessity in treating and understanding developmental disabilities. It is mentioned in the book that in 1996, Lucinda organized the Tuberous Sclerosis Medical Education conference in which "over 200 parents and medical personnel rubbed shoulders" [p.58]. This conference and the ones that followed contributed to a better understanding of strategies to more effectively address Paul's (and other children's') developmental disability. This is especially important because some disabilities are less common than others, and symptoms and challenges can differ greatly. Advocacy within communities can also improve government allocation of funds. In the book, Lucinda mentions that the amount of funding available was usually not an issue, given that the Ontario government contributed 1.7 billion dollars into a developmental and residential services fund in the 2011-2012 fiscal years. However, the book also makes note of the fact that there were still 13,000 people on a waiting list to access these funds [p.169]. This goes to show that one of the biggest challenges is not a lack of funding, but rather the allocation of the funds. An example of addressing this problem is provided in the book.

Despite the praise for this book, there is one major detail that must be noted. It is clear that Paul's success story was dependent on the almost super human ability and stamina of Lucinda, his mother; and this means that Paul's success was circumstantial. Without her, Paul's likelihood of success would likely have be diminished, as not every child with a disability has a mother or father with the will, power, and drive to follow through with ideas, to not be hindered by rejection, and to have the financial stability that allowed Paul's mother to take time off work to help him. This may speak to the broader point of creating a better system to distribute resources to parents in need of such aid. In many cases where a child does not have a parent like Lucinda, or in the situation where both parents are working, how can parents properly help? In other words, it must be noted that not all parents display the same incredible characteristics as Lucinda or have similar financial circumstances. This is a vital point because if Paul's success story is to be seen in other children with developmental disabilities, we must ask, how can we help parents make this happen?

I would recommend this book to anyone new to the field of bioethics, disability ethics, and resource allocation ethics, especially undergraduate students. It highlights some of the main issues that people with developmental disabilities often encounter from childhood to their transition into adulthood, but it does so through the perspective of a mother trying to raise her child. This gives the reader a much more complete picture of the emotional consequences as well as the social implications in raising a child with a developmental disability. As I concluded the book, I pondered on the example of Paul and the long-term investment in services that are needed for children and adults with developmental disabilities; I encourage the reader to do so as well. This book inspires the aforementioned types of constructive dialogues.

Remerciements
M. Christopher Grafos m'a guidé tout au long du processus d'élaboration d'un compte rendu et a joué un rôle déterminant dans la réalisation de ce texte.

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Dr. Christopher Grafos has mentored me through the process of constructing a book review and has been instrumental in bringing this book review to fruition.

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Canadian Journal of Bioethics
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COMPTE RENDU / REVIEW

Review of: Kaposy C. (2018) *Choosing Down Syndrome*

Canadian Bioethics Society / Société canadienne de bioéthique
En collaboration avec / In collaboration with

Meghan Chevalier[1]

Résumé
Avec l'avènement du test prénatal non invasif, Chris Kaposy croit que plus de gens devraient choisir d'élever des enfants atteints du syndrome de Down. Kaposy plaide en faveur du modèle de handicap social et recommande une approche normative pragmatique comme norme. Il utilise des données quantitatives et qualitatives pour étayer sa position.

Mots-clés
trisomie 21, test prénatal, avortement sélectif

Abstract
With the advent of Non-Invasive Prenatal Testing, Chris Kaposy believes that more people should choose to parent children with Down Syndrome. Kaposy advocates for the Social Disability Model and recommends a normative pragmatic approach as standard. He makes use of both quantitative and qualitative evidence to support his position.

Keywords
Down syndrome, prenatal testing, selective termination

Choosing Down Syndrome [1] by Chris Kaposy situates itself within a modern era of prenatal testing. The book is motivated by the advent and proliferation of Non-Invasive Prenatal Testing (NIPT), which seems to be occurring without sufficient reflection. Kaposy questions the potential repercussions of widespread use of NIPT in the larger framework of prenatal testing for Down syndrome and selective termination. *Choosing Down Syndrome* puts forth thorough and convincing arguments for choosing to parent children with Down syndrome, addressing previously published sources on the topic. Kaposy clearly outlines the structure of each chapter in the book's introduction, and what Kaposy intends to argue is clear.

Choosing Down Syndrome begins by establishing itself within a context of ongoing debates regarding the ethics of prenatal genetic testing for Down syndrome. NIPT offers a low-risk, highly accurate screen for Down syndrome. Ultimately, Kaposy suggests that more people should choose to parent a child with Down syndrome following a prenatal diagnosis, rather than terminate their pregnancy. To support this claim, Kaposy begins with an analysis of several autobiographical accounts written by parents of children with Down syndrome. He subsequently presents empirical research about families of children with Down syndrome, while discrediting suggestions that the happiness that these families experience is due to adaptive preferences, i.e., the preferences that people develop based on a limited amount of potentially oppressive and less than ideal options. Kaposy then discusses the morality of bringing into the world a child with a disability, as well as the morality of selective termination. The penultimate chapter considers how the identity of a person with Down syndrome is perceived by society, and Kaposy recommends a normative pragmatic approach as standard. This means that we should employ the Social Disability Model (the perspective that disability results from the failure of society to accommodate individual needs, rather than from the individual themselves) while recognizing their disability as a medical condition when it is in their best interest, such as in therapeutic or educational contexts. The concluding chapter of the book examines the capitalist influence on selective termination. Kaposy argues that biases against people with Down syndrome result from their difficulty in achieving the type of monetary success that is valued in a capitalist society.

The primary strength of Kaposy's arguments comes from his decision to use both qualitative and quantitative supporting evidence. The qualitative analysis of autobiographical accounts written by parents of children with Down syndrome and quantitative empirical findings are mutually supportive. Kaposy includes autobiographical accounts (Chapter 3) before addressing empirical research statistics (Chapter 4), emphasizing the importance of these autobiographical accounts and avoiding this chapter being read through solely a statistical lens. The points raised in Chapter 3 are later supported by statistics, but the order in which they are presented allows the autobiographical accounts to be read independently as legitimate and valuable evidence.

After discussing and evaluating autobiographical accounts and empirical statistics, Kaposy considers questions of morality with respect to continuing pregnancies and selective termination. He clarifies and questions potential motives for selective termination. Kaposy writes with a nuanced understanding of context. For example, while some could view legislation that has been passed to promote accessibility and inclusivity as indicators that society is progressing away from biased attitudes, Kaposy discusses the presence of informal bias. Further, when addressing previously published literature, he examines and critiques their definitions of important concepts, such as disability, well-being and quality of life. Kaposy effectively challenges assumptions about people with disabilities, simplistic arguments, and arguments based on intuition in other works. In a well-rounded approach, *Choosing Down Syndrome* calls into question both individual and structural issues that contribute to the bias toward people with Down syndrome.

Throughout *Choosing Down Syndrome*, Kaposy writes with transparency. He acknowledges a perceived conflict of interest, the fact that he parents a son with Down syndrome, and handles potential criticism well, demonstrating that this perception is a by-product of the bias he is arguing exists. Further, he admits the faults of the Social Disability Model to which he often alludes. From my perspective, these critiques do not weaken Kaposy's arguments, but rather demonstrate that he has thoroughly considered the validity of his arguments and understands the social and academic context in which he is writing.

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While Kaposy acknowledges disabilities other than Down syndrome and explains that they are beyond the scope of this book, a broader context of prenatal testing and disability would lead to a better understanding of populations with disabilities, as well as the Down syndrome advantage, that appears when families of children with Down syndrome function better than families of children with other disabilities. Though passages are occasionally wordy, *Choosing Down Syndrome* is written in accessible language. A shorter, practical and therefore more accessible resource for prospective parents would be a welcome companion to *Choosing Down Syndrome*.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Stigmatisation, Exaggeration, and Contradiction: An Analysis of Scientific and Clinical Content in Canadian Print Media Discourse About Fetal Alcohol Spectrum Disorder

John Aspler[1,2], Natalie Zizzo[1,3], Emily Bell[1,4], Nina Di Pietro[5], Eric Racine[1,6,7]

Résumé

Contexte : L'ensemble des troubles causés par l'alcoolisation fœtale (ETCAF), un diagnostic complexe qui comprend une vaste gamme de troubles neurodéveloppementaux, résulte de l'exposition à l'alcool dans l'utérus. L'ETCAF demeure mal compris par les Canadiens, ce qui pourrait contribuer à la stigmatisation dont souffrent les personnes atteintes d'ETCAF et les femmes qui consomment de l'alcool pendant leur grossesse.

Méthodes : Pour mieux comprendre comment l'information sur l'ETCAF est présentée dans la sphère publique, nous avons analysé le contenu de 286 articles tirés de dix grands journaux canadiens de langue anglaise (2002-2015). Nous avons utilisé le codage inductif pour établir une grille de codage à partir des données, puis nous avons appliqué de façon itérative des codes identifiés sur l'échantillon, en vérifiant la fiabilité intercodeurs.

Résultats : Nous avons identifié six grands thèmes liés au contenu cliniques et scientifiques des médias : 1) prévalence de l'ETCAF et de la consommation d'alcool chez les femmes ; 2) recherche en lien avec l'ETCAF ; 3) diagnostic d'ETCAF ; 4) traitement de l'ETCAF et de l'abus de substances par les mères ; 5) incapacités primaires associés à l'ETCAF ; et 6) effets de l'alcool pendant la grossesse.

Discussion : Dans le cadre de ces six thèmes, nous examinons trois types d'exagération et de fausse représentation qui ont des conséquences sur le plan éthique : 1) l'exagération des taux d'ETCAF dans les communautés autochtones ; 2) la contradiction entre les articles sur les effets de l'exposition prénatale à l'alcool ; et 3) l'information scientifiquement exacte qui néglige le contexte social de la consommation et de l'abus d'alcool par les femmes. Respectivement, ces représentations pourraient mener à des croyances stéréotypées préjudiciables au sujet des peuples autochtones, pourraient créer de la confusion quant aux choix sains pendant la grossesse et risqueraient d'enflammer inutilement les débats sur des questions délicates concernant les choix des femmes.

Mots-clés

ensemble des troubles causés par l'alcoolisation fœtale, ETCAF, stigmatisation, alcool et grossesse, incapacité, communication scientifique, Autochtones, Canada

Abstract

Background: Fetal alcohol spectrum disorder (FASD), a complex diagnosis that includes a wide range of neurodevelopmental disabilities, results from exposure to alcohol in the womb. FASD remains poorly understood by Canadians, which could contribute to reported stigma faced by both people with FASD and women who drink alcohol while pregnant.

Methods: To better understand how information about FASD is presented in the public sphere, we conducted content analysis of 286 articles from ten major English-language Canadian newspapers (2002-2015). We used inductive coding to derive a coding guide from the data, and then iteratively applied identified codes back onto the sample, checking inter-coder reliability.

Results: We identified six major themes related to clinical and scientific media content: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy.

Discussion: Across these six themes, we discuss three instances of ethically consequential exaggeration and misrepresentation: 1) exaggeration about FASD rates in Indigenous communities; 2) contradiction between articles about the effects of prenatal alcohol exposure; and 3) scientifically accurate information that neglects the social context of alcohol use and abuse by women. Respectively, these representations could lead to harmful stereotyped beliefs about Indigenous peoples, might generate confusion about healthy choices during pregnancy, and may unhelpfully inflame debates about sensitive issues surrounding women's choices.

Keywords

fetal alcohol spectrum disorder, FASD, stigma, alcohol and pregnancy, disability, science communication, Indigenous, Canada

Introduction

Fetal alcohol spectrum disorder (FASD), a complex diagnosis that spans a wide range of neurodevelopmental disabilities affecting roughly 1 in 100 Canadians [1], results from alcohol exposure in the womb. A heterogeneous and difficult-to-diagnose disorder, FASD presents in myriad ways, including with characteristic facial features (e.g., thin upper lip, no philtrum), and with disabilities in executive function (e.g., hyperactivity, impulse control), cognition (e.g., low IQ, learning difficulties), and other brain domains (e.g., motor function, language, mood regulation) [2,3]. Previous diagnostic guidelines included diagnoses like fetal alcohol syndrome (FAS), partial FAS, and alcohol-related neurodevelopmental disability [2], but more recent guidelines have simplified the diagnosis into the following categories: 1) FASD with sentinel facial features; 2) FASD without sentinel facial features; and 3) an at-risk category [3].

Although more recent studies indicate that the prevalence of FASD could prove higher than 1 in 100 (i.e., as high as 2-5 in 100 in the US and some European countries) [4], it remains a largely "invisible disability": only about 10% of people diagnosed with FASD present with identifiable physical features [5]. Compounding the issue, survey data indicate that while most Canadians know that FASD exists (86%) and that drinking alcohol when pregnant can harm a fetus (76%), they provide less accurate descriptions of its signs and symptoms [6-8]. This lack of public knowledge could indicate that sources other than exposure or personal experience, such as the news media, could be important for the public's understanding of FASD. They could also be sources of stigmatisation for people with FASD and women who drink while pregnant.

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Stigmatisation, a process of negative stereotyping causing discrimination [9], remains a tremendous social challenge and a barrier to the wellbeing of marginalized groups. Link and Phelan [9] describe this process as one where certain identified differences between groups become fodder for stereotyping, othering, and discrimination – in a context where various forms of power align against the group in question. As an example, some people with FASD report experiencing problems ranging from social exclusion to employment discrimination [10,11]. In addition, since FASD results from alcohol exposure in the womb, some women who drink alcohol during pregnancy can also face stigmatisation [12]. This stigma might be exacerbated by judgmental public discourse and health messaging that emphasize individual blame and responsibility [13], and which stereotype women who drink while pregnant as unfit – or even criminally negligent – mothers [14].[1]

Public discourse could be one potential factor contributing to the stigmatisation of people with FASD and women who drink while pregnant – especially given the media's long history of misrepresenting and stereotyping people with disabilities (e.g., as victims, as villains, as superhuman) [17]. Broadly speaking, since the mass media are thought to both reflect and impact public attitudes and opinions [18], this could include how the public perceives and constructs identities around issues such as health and disability. As we will discuss later in this paper, these perceptions can also include Indigenous identities and stereotypes surrounding alcohol use.

Previous media studies exploring discourse related to FASD in the US, the UK, and Australia indicated a larger media focus on the implications of alcohol use during pregnancy than on stories about the lives of people with FASD [14,19,20]. This was sometimes by design [21]; however, even when FASD itself was the primary focus of a study, pregnant women and issues of alcohol consumption usually came to the fore – including in study discussion sections. Ultimately, these articles identified common narratives framing women who drink while pregnant as dangerous, blameworthy, and irresponsible, as well as discussions about how women should behave when pregnant [14]. In contrast, FASD was framed as a crisis [21], with occasional stories about people with FASD who were "blameless victims" of their mothers' drinking [19,20], or occasionally as themselves victimizing others [14]. To the best of our knowledge, no research has characterized media coverage about FASD in Canada. Accordingly, to gain deeper insight into the kind of information the public receives about FASD, which could inform public attitudes toward individuals with the disorder as well as women who drink while pregnant, we conducted an analysis of the FASD-related content found in Canadian media.

Methods

In this study, we employed a qualitative media content analysis approach [22], similar to several previous media studies [23-25]. We reported these methods in full in an article about the social dimensions of discourse identified during the same content analysis, some of which is reprinted here or else is specific to this manuscript [26].

Sample

Using the Factiva news database, we searched for English and French print news articles published in Canada between January 1st 2002 and October 31st 2015. We searched for the following keywords in headlines and lead paragraphs: "fetal alcohol spectrum disorder" OR "FASD" OR "fetal alcohol syndrome" OR ("alcohol" AND "pregnancy") OR "ensemble des troubles causés par l'alcoolisation foetale" OR "ETCAF" OR "syndrome d'alcoolisation foetale" OR ("grossesse" AND "alcool").

We restricted our search to 10 of the most-distributed Canadian print news sources [27], all of which are available electronically: *The Toronto Star* (n=20), *The Globe and Mail* (n=22), *The Montreal Gazette* (n=11), *The Vancouver Sun* (n=30), *The Vancouver Province* (n=6), *The National Post* (n=11), *The Winnipeg Free Press* (n=100), *The Calgary Herald* (n=32), *The Ottawa Citizen* (n=13), and *The Edmonton Journal* (n=41). Note that more than one third of this sample (100/286 articles) came from *The Winnipeg Free Press*, which won a 2010 Canadian Institutes of Health Research (CIHR) grant to specifically cover FASD and its "causes, social costs, treatments, and prevention" [28].[2] Of the rest of the articles, more than a third came from the other Western provinces (British Columbia and Alberta – no newspaper from Saskatchewan was included). In total, almost three quarters of the sample came from these three Western provinces, with only 27% (77/286 articles) coming from Ontario, English Quebec news, or national papers like *The Globe & Mail*. We had to exclude *Le Journal de Montréal*, *La Presse*, *Le Journal de Québec,* and *The Toronto Sun* because Factiva only began archiving these sources in 2011. See Figure 1 for more information about the distribution of the sample by year and by source.

[1] In some jurisdictions in the US, the use or abuse of certain substances during pregnancy, including alcohol, can be used as evidence of crimes that include child abuse and neglect [15]. These approaches have not yet materialized in the Canadian context [16].
[2] The article cited here was included in the sample. In addition, given these funds, the coverage was typically more nuanced and in depth than other coverage, despite the somewhat sensational series title "Wounded in the Womb".

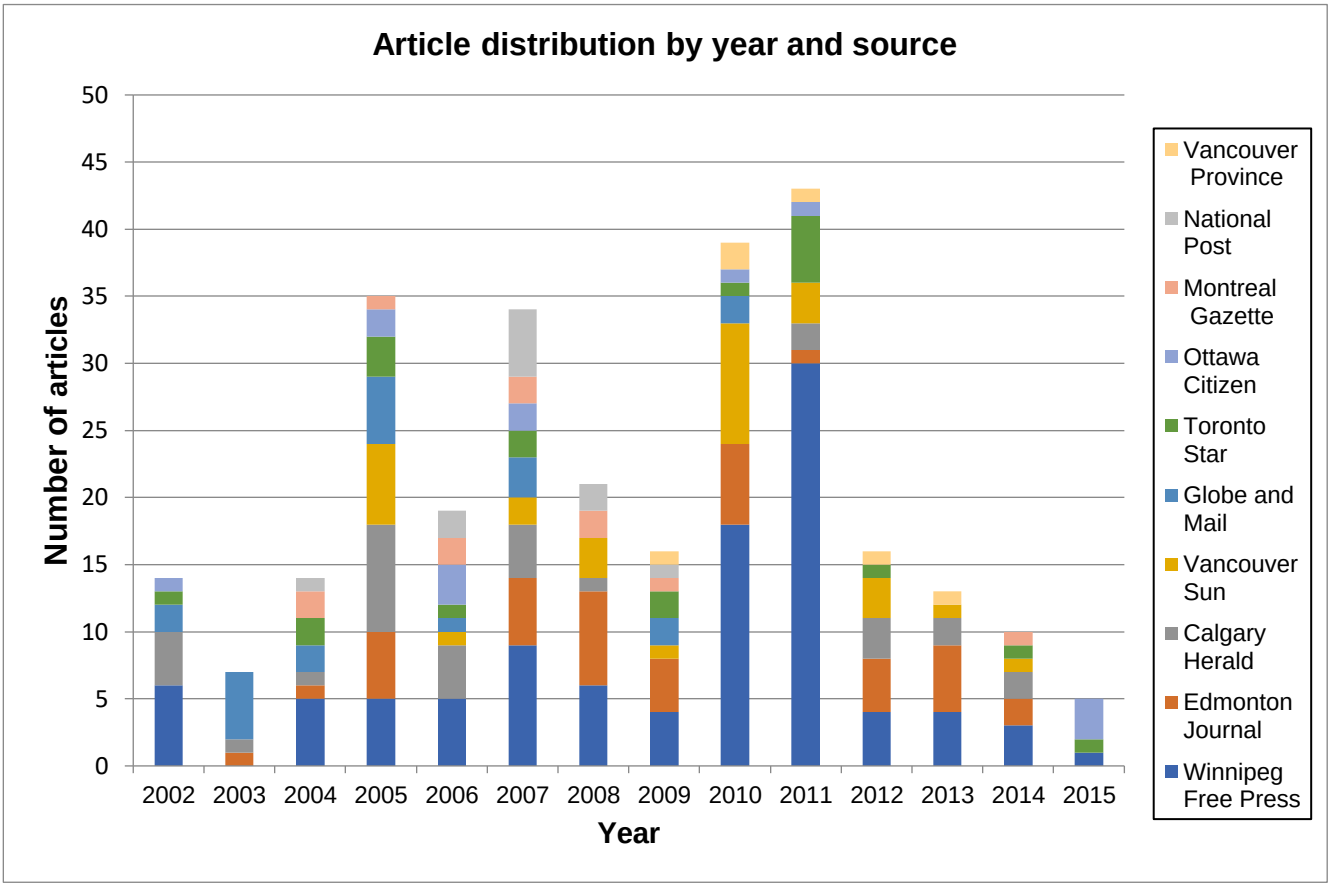

Figure 1: Stacked bar graph indicating the distribution of articles across the sample, sorted by year and by source. The colour legend for sources and the stacked bars themselves are organized in ascending order, from the Winnipeg Free Press at the bottom (n=100) to the Vancouver Province on the top (n=6). Figure reprinted with permission from [26].

Coding Process

Three coders used a random sample of 25 articles to develop a coding guide inductively, capturing key areas of content present in the sample. The coding guide was then systematically applied to the remainder of the sample. This process was repeated through several sample updates and coding guide refinements. We assessed intercoder reliability for each code through each iteration, discarding six codes and five sub-codes with a percent agreement below 0.75.

Coding Guide

We coded 286 articles for coverage of three broad categories: 1) scientific content; 2) clinical content; and 3) social content. This article reports on the six codes (and fifteen sub-codes) in the scientific (See Table 1) and clinical (See Table 2) categories. Scientific content reflects scientific knowledge about FASD as reported by the media (e.g., research related to FASD). Clinical content reflects clinical care for people with FASD (e.g., diagnosis of FASD) and mothers (e.g., treatment of maternal substance abuse), as well as descriptions of what FASD entails symptomatically (i.e., primary disabilities associated with FASD). The 'Effects of alcohol exposure during pregnancy' code, categorized in clinical content, has also been further broken down into four categories beyond the parameters defined in the coding guide to gain deeper insight into this particularly complex area of discourse. Another article reported on the findings of the social content code since there are too much data to report in a single article, and the data in that content category provides opportunities to engage with different literatures [26].

Results

We identified six major themes, or content areas corresponding to our codes, broken down across fifteen sub-themes (sub-codes), with the most frequent being descriptions of the primary disabilities associated with FASD (48%, n=136), and prevalence of FASD and of women's alcohol consumption (46%, n=131). Tables 1 and 2 describe the coding structure in detail, and explain the scope of each code and sub-code (with pertinent examples). After each table, we elaborate on some of the more complex and multidimensional codes, which require more space for elaboration than the table can provide (i.e., a richer unpacking of the content found in the 'diagnostic challenges' sub-code than seen in Table 2), with illustrative in-text examples provided to exemplify important nuances of the content. When providing quotes, both in text and in the tables, we reference each article by newspaper and year, to avoid singling out any given journalist, while maintaining transparency on data sources. We do not include these sources in the References section, as they are data.

Scientific content

Table 1: Scientific Content Results: Coding Structure and Examples

Code	Sub-code	Scope	% of sample & total number of articles	Examples
Prevalence of FASD and of women's alcohol consumption		Article reports on FASD prevalence, or on alcohol consumption rates in different groups of women.	46% (n=131)	
	General population	Article reports on FASD prevalence across all ages around the world, but mainly in Canada's Western provinces.	35% (n=99)	"It's estimated that there are more than 36,000 Albertans with FASD" (Edmonton Journal 2014).
	Uncertainty	Article reports a lack or insufficiency of current FASD prevalence estimates.	14% (n=39)	"There are no clear numbers to determine how many people are living with FASD in Manitoba" (Winnipeg Free Press 2006) and "A relatively new paper… says all the best estimates are lowballed" (Winnipeg Free Press 2011).
	Criminal justice system	Article reports on FASD prevalence in the criminal justice system. Includes proportion of offenders with FASD, and proportion of people with FASD behaving criminally.	11% (n=32)	"A study of 91 inmates… found 10 per cent have some form of fetal alcohol spectrum disorder – 10 times the incidence in the general population" (Calgary Herald 2007).
	Indigenous populations	Articles reports on FASD prevalence in Indigenous populations in Canada.	8% (n=24)	"Among aboriginal people, the prevalence of FAS is much higher than the national average—as high as 10 per cent in some communities where alcohol abuse is widespread" (The Globe and Mail 2005).
	Child welfare system	Articles reports on FASD prevalence in the child welfare system. Includes proportion of kids in the system with FASD, and proportion of kids with FASD in the system.	5% (n=14)	"Another study indicated that 80 per cent of FASD-affected individuals are [raised] by adoptive parents or through foster care" (Ottawa Citizen 2006).
	Women's alcohol consumption	Article reports on the prevalence of pregnant women's alcohol intake. Also includes discussions about drinking in relation to unplanned pregnancies, or rates of women who consume alcohol in general.	5% (n=14)	"In 2003, about 12 per cent of women in Winnipeg admitted to consuming alcohol while expecting. In 2008, that number inched up to 14 per cent" (Winnipeg Free Press 2011).
Research related to FASD		Article reports research into any dimension of FASD. Excludes examples with no research findings.	26% (n=73)	
	Diagnosis & screening	Article reports research on novel diagnostic or screening tool/methods. Includes screens in subgroups (e.g., criminal justice system).	9% (n=26)	"…a simple test that tracks eye movements may offer a new tool to accurately diagnose fetal alcohol syndrome" (Edmonton Journal 2005).
	Treatment & prevention	Article reports research into novel treatments for FASD itself, or novel prevention methods ('treating fetuses').	6% (n=18)	"… aboriginal researchers had to consider a number of questions when designing programs to prevent FASD, including: How would you approach a woman in the community?" (Vancouver Sun 2006)
	Levels of prenatal alcohol exposure	Article reports research findings connecting levels of prenatal alcohol exposure to FASD outcomes (see text).	5% (n=15)	"The University of Pittsburgh recently released findings from a study following 565 mothers and children since 1982, when the women were all four months pregnant. Even children whose mothers drank less than 1.5 drinks a week during pregnancy were a few pounds smaller as adolescents" (The Globe and Mail 2003).
	Primary disabilities	Article reports on research into specific disabilities and symptoms that may appear in cases of – or help identify – FASD.	2% (n=5)	"Writing in the journal Alcoholism: Clinical and Experimental Research, researchers say their findings indicate that deficits in so-called eye-blink conditioning, or EBC, can identify children with probable fetal alcohol syndrome." (Vancouver Sun 2008)

Prevalence of FASD in the general population – Societal burden and public health concerns

Prevalence was sometimes used to frame FASD as a burden on society, e.g., "…it's estimated that at least one child is born with fetal alcohol syndrome each day in Canada, with the lifetime costs of caring for such children estimated at $1.4 million" (Edmonton Journal 2007). In addition, a focus on the need to decrease FASD prevalence was associated with public health concerns, e.g., "Brain damage from alcohol exposure in the womb is the leading preventable cause of mental retardation in the Western world" (Globe and Mail 2010). Notably, FAS prevalence was sometimes conflated with FASD prevalence – e.g., "…[FAS], a developmental disorder that affects about one in every 100 Canadian children" (Vancouver Sun 2005), "about one in 100 people have FASD" (Winnipeg Free Press 2010) – with only a few articles making the distinction, e.g., "Health

Canada estimates nine in every 1000 babies born here have FASD; one to three of those babies will have full [FAS]" (Calgary Herald 2005).

Research related to FASD: Levels of prenatal alcohol exposure – Inconsistent definitions, findings, and variables across the sample

Many articles used the amount of alcohol consumed while pregnant as a stand-in for prenatal alcohol exposure. Definitions of these amounts differed across the sample, as in the case of 'light drinking', e.g., "… light drinkers had a mean consumption of a drink a week" (Winnipeg Free Press 2002), "light drinking during pregnancy says one study… found detectable 'deficits'… at exposure levels of less than one drink a day" (Edmonton Journal 2007); however, a few articles explicitly commented on this confusion, e.g., "…people tend to vary in what is considered light drinking" (Winnipeg Free Press 2010). In addition, the definition of a standard drink differed between reports, e.g., "355 mL of beer or 118 mL of wine" (Calgary Herald 2006), "175 [ml] of wine… or just under a pint of beer" (Vancouver Sun 2009). Articles also presented inconsistent findings across the sample, suggesting that light drinking 1) caused harm, e.g., "[children] whose mothers drank even lightly were shorter, lighter and had smaller head circumferences" (The Globe and Mail 2003); 2) caused no harm, e.g., "light drinking is fine" (Vancouver Province 2013); or 3) was potentially beneficial, e.g., "… [babies of mothers who drank lightly] were markedly less likely to demonstrate behavioural problems" (Winnipeg Free Press 2010). The articles that reported potential benefits of alcohol all pointed to a British study first published online in 2010 [29]. Finally, the variables measured to indicate harm varied between studies, and included anything from physical features – e.g., "detectable 'deficits' in height…" (Edmonton Journal 2007) – to behavioural features, e.g., "3.2 times more likely to have behaviour and aggression problems" (Montreal Gazette 2007).

Clinical content

Table 2 – Clinical Content Results: Coding Structure and Examples

Code	Sub-code	Scope	% of sample & total number of articles	Examples
Diagnosis of FASD		Article reports on FASD diagnosis. Includes examples from Research related to FASD sub-code on diagnosis and screening.	20% (n=58)	
	Diagnostic challenges	Article reports on real-world challenges in diagnosing FASD. Includes discussions about misdiagnosis (see text).	19% (n=55)	"But it's often an invisible brain injury, difficult to diagnose and masked by articulate speech and regular appearance" (Ottawa Citizen 2015).
	Diagnostic process	Article reports on different elements of the FASD diagnostic process. Includes both medical and logistical processes.	8% (n=24)	"Everyone from defence lawyers to judges to probation officers can refer a youth to the program, where a team of co-ordinators does an initial screen… even tracking down biological mothers to ask if they drank…" (Edmonton Journal 2010).
	Diagnostic criteria	Article reports explicit and clear features of FAS (not FASD) that may lead to diagnosis.	2% (n=6)	"Physicians make the diagnosis of FAS in children who exhibit a small head, characteristic features of the face and cognitive and neurological abnormalities" (Winnipeg Free Press 2002).
Treatment of FASD and maternal substance abuse		Article reports on treatments for elements of FASD, or, in a minority of cases, alcohol addiction for pregnant women. The latter case does not necessarily reflect a causal connection between addiction and FASD, but rather, one target for treatment in the context of our sample (which included the term "alcohol and pregnancy", independent of FASD). Includes interventions for features of FASD. Includes examples from Research related to FASD sub-code on treatment and prevention.	28% (n=80)	"The Ministry of Education is trying to change attitudes and help students with FASD succeed in school through the Provincial Outreach Program for FASD…" (Vancouver Sun 2010).

Primary disabilities associated with FASD		Article reports on features, symptoms, or disabilities associated with FASD. Includes examples from Research related to FASD sub-code on primary disabilities. Excludes social concerns sometimes described as secondary disabilities (e.g., homelessness).	48% (n=136)	
	Cognitive and behavioural features of FASD	Article reports examples of primary social, behavioural, cognitive, & emotional features of FASD. Includes broad range of features, categorized differently across articles.	42% (n=121)	"The consequence of these physical changes can be profound… impairment of fine motor skills, hearing loss, ability to coordinate gait and hand-eye functions. From these deficits cascade a host of others… Subsequent learning difficulties involve poor capacity for abstract thought, which limits development of mathematical and language skills, all compounded by problems with memory, attention span and poor judgment" (The Vancouver Sun 2005).
	Physical features of FASD	Article reports examples of primary physical features of FASD. Includes facial features, and growth, organ, and sensorimotor issues.	28% (n=80)	"…a very thin upper lip and no groove between the upper lip and nose" (Calgary Herald 2012), "Other defects include malformation of such organs as the heart, liver, and kidneys. Vision and hearing problems…" (Montreal Gazette 2008)
Effects of alcohol exposure during pregnancy		Article reports on concerns about the impact of different variables related to alcohol consumption on FASD outcomes (see text). Includes examples from Research related to FASD sub-code on levels of prenatal alcohol exposure. Note that in text, four further subdivisions are reported that were not assessed for inter-coder reliability.	19% (n=55)	"'I have patients who think a couple of beers a day is not an issue. And the question is, is it an issue? That's what we're going to look at,'… She said one doctor may tell a pregnant woman, or one trying to get pregnant, 'don't drink at all,' while another may say 'moderate drinking' is OK." (Edmonton Journal 2009).

Diagnosis of FASD: Diagnostic challenges – Medical, healthcare systems, and social barriers

A main challenge identified in the articles was the issue of delaying or missing diagnosis, and its consequences, e.g., "Being misdiagnosed can have serious lifelong effects because children miss out on specialized therapy" (Vancouver Sun 2005). Otherwise, three broad kinds of challenges were reported: 1) medical barriers; 2) healthcare system barriers; and 3) social barriers. *Medical barriers* included issues like difficulty identifying and defining features across a wide spectrum of disabilities, e.g., "Because it's a spectrum disorder, effects can range from very subtle to full-blown and intense. You don't know what you're dealing with" (Calgary Herald 2005), or a lack of appropriate tests. *Healthcare system barriers* included issues like lengthy waitlists, difficulty accessing diagnostic services based on location (e.g., "…and many kids in rural and remote communities never get diagnosed" (Winnipeg Free Press 2010)) or age (e.g., "…only children can get a diagnosis…. Adults are out of luck." (Winnipeg Free Press 2013)), or limited resources (e.g., "If resources were available, justice staff say they could send five times that many kids with suspected FASD to the clinic" (Edmonton Journal 2010)). *Social barriers* included issues like possible racial biases (e.g., "FASD is also seen as an aboriginal disease, so it goes under-reported among non-aboriginals" (Winnipeg Free Press 2011)), or a reluctance to report drinking while pregnant (e.g., "'Researchers say the number is an underestimate because… mothers […] fear the stigma from admitting they drank alcohol while pregnant'" (Ottawa Citizen 2015)).

Treatment of FASD – Early social interventions for people with FASD and at-risk women

For the treatment of people with FASD, an emphasis was placed on early interventions, e.g., "The sooner a baby is properly diagnosed, the faster special social and education services can be provided" (Montreal Gazette 2006). Most discussed interventions had social goals, like stopping criminal behaviour, e.g., "The… FASD program is designed to aid youths with the disorder before their troubles either land them in jail or in harm's way" (Winnipeg Free Press 2006). Very few articles mentioned biomedical treatments. The few options mentioned were speculative or novel, e.g., "…vitamin A could act almost like an antidote to the effects of alcohol on very early embryos…" (Edmonton Journal 2011). While most articles discussing the treatment of at-risk women focused on treating alcoholism, a few editorials suggested extreme measures that included criminalization and forced interventions, e.g., "These doped-up druggies should be sterilized after the second child…" (Calgary Herald 2005).

Effects of alcohol exposure during pregnancy

Alcohol consumption – Abstention advice and uncertainty

Many articles mentioned that a) women should not drink alcohol when pregnant (e.g., "The best advice is to abstain from alcohol while expecting a baby" (Calgary Herald 2006)) or that b) alcohol is never safe for pregnant women (e.g., "But [the doctor] stressed modern evidence shows no amount is safe" (Toronto Star 2015)). Additionally, several articles mentioned uncertainty about the link between alcohol consumption and FASD outcomes, with a few framing uncertainty as the reason for advising abstinence, e.g., "[She] is correct that no one knows what amount of alcohol during pregnancy is safe. That's why [many organizations] recommend that the most prudent choice for women who are pregnant is to abstain from alcohol" (Ottawa Citizen 2002).

Alcohol consumption – Cross-border debates about harmful amounts

Many articles mentioned how much drinking can harm a fetus, e.g., "A number of studies have linked heavy drinking on a regular basis during pregnancy to stunted growth, birth defects and brain development problems" (National Post 2007). These articles described harm as caused by: 1) heavy drinking, 2) single or occasional binges, 3) drinking in moderation or moderate amounts, 4) light drinking, and 5) a single drink. In contrast, several of these articles discussed British research and policy contradicting advice that any amount of alcohol is harmful: "…it's safe to drink a little bit of alcohol during pregnancy… experts have concluded 'no consistent evidence' exists that low-to-moderate alcohol consumption during pregnancy – less than one drink per day – is harmful to the fetus after the first three months of pregnancy, though they can't rule out risk completely" (Vancouver Sun 2007). Suggestions that some alcohol is acceptable were based on: 1) reports of new British guidelines, based on inconsistent evidence; 2) parenting books suggesting inconsistent evidence; 3) research suggesting a lack of evidence connecting light drinking or occasional binge drinking to harm; and 4) a study suggesting that a little alcohol when pregnant may prove beneficial. Various amounts were described as relatively safe, including: 1) low-to-moderate amounts; 2) light amounts; and 3) even occasional binge drinking. Several articles outlined how Canadian experts found the British approach surprising, e.g., "[The doctor]… called the British move 'scary.' 'It's quite shocking for us to see it. It neglects, or just ignores, a huge body of evidence that does show mild drinking does cause issues'" (Edmonton Journal 2007). Of the articles suggesting the possibility of no harm after light or moderate drinking, only a few did not cite these British sources.

Drinking advice about risk factors for FASD development

Drinking advice focused on the safety of 1) different amounts of alcohol; 2) alcohol at different times; or 3) different kinds of alcohol. Fewer articles mentioned other factors besides alcohol involved in assessing risk. A few of these articles specified that not only alcoholics have children with FASD, e.g., "'The first myth is that FASD only occurs in alcohol-dependent women. All women are at risk.'" (Ottawa Citizen 2015).

Concerns about publicly communicating information about alcohol and pregnancy

Several articles outlined concerns about communication and public understanding of the risks of alcohol consumption during pregnancy. These included concerns about mixed messages leading to confusion (e.g., "Even her own doctor advised her to drink one or two gins to settle her stomach as a cure for morning sickness" (Vancouver Sun 2010)), and tension about what or how to tell women (e.g., "[The adoptive mother]… thinks it is 'mind-boggling irresponsible' for anyone to produce pregnancy materials that even hint at the possibility that drinking during pregnancy might be acceptable" (Toronto Star 2011)).

Discussion

Stigma surrounding FASD has been identified as an important issue for both individuals who are affected by FASD as well as women who give birth to children with FASD [12]. The implications of this stigma include negatively-affected life trajectories for individuals with FASD and fear of blame [30] and criminalization for women who drink while pregnant [31,32]. Our analysis of scientific and clinical print media content about FASD provides an overview of key science and health-oriented FASD themes to which the Canadian public could be exposed, and which could, in part, contribute to stereotyped understandings of FASD. We identified six themes related to scientific and clinical content (see Tables 1 and 2 respectively). Across these themes, we now explore three ethical concerns about this discourse that could perpetuate or produce stigma: 1) exaggeration about FASD rates in Indigenous communities, which could lead to harmful stereotyped beliefs about Indigenous peoples; 2) contradiction between articles about the effects of prenatal alcohol exposure, which might cause confusion about healthy choices during pregnancy; and 3) scientifically accurate information that neglects social context, which might unhelpfully inflame debates about sensitive issues (e.g., whether pregnant women should be punished for drinking alcohol). To discuss these issues, we take a two-pronged approach: 1) we compare information reported in the media with scientific literature, and 2) we discuss why we think each problem could perpetuate stigma about FASD.

Exaggeration: A potential source of harmful stereotypes about Indigenous peoples in Canada

Exaggeration beyond a given set of research findings can raise serious ethical concerns. For example, if hyperbolic and misleading claims are granted the veneer of scientific legitimacy by experts, previously untenable positions become more easily (if wrongly) defensible.[3] And while the goal of much research is to create generalizable knowledge, there exists a fine line between appropriately generalized claims and inappropriate exaggeration. When those claims begin to impact the social world, and beliefs about particular groups of people, there exists a danger of endorsing positions that turn generalizations into stereotypes. In this section, we explore current FASD prevalence data in Canada, and then discuss some of the reasons why Indigenous communities might have or be seen as having higher rates of FASD.

[3] We want to emphasize that possible sources of exaggeration in media also include academic institutions and researchers, not only journalists and news editors. For example, a 2014 study by Sumner [33] concluded that "exaggeration in news is strongly associated with exaggeration in [institutional] press releases". Additionally, a 2015 study by Vinkers et al [34] found an increase in the use of superlatives (e.g., novel, innovative), and negative terms to a lesser extent, in scientific abstracts published from 1974-2014, concluding frankly that "scientists may assume that results and their implications have to be exaggerated and overstated in order to get published". Hype and exaggeration should be explored more thoroughly both within academic contexts as well as outside of them.

FASD prevalence in the general population: A case of limited data and extrapolation

Most conservative estimates suggest that FASD affects roughly 9 in 1000 Canadians [35]. However, given a lack of Canadian prevalence studies, this estimate has relied on American and European data from the 1980s and 1990s [1,2]. This means that we do not know what proportion of the Canadian population has FASD [1]. When journalists, the experts interviewed, or editorial writers reported rates of roughly 1 in 100, and then translated that into "330,000 Canadians" or "11,000 Manitobans", they extrapolated based on external estimates combined with Canadian demographic data; these numbers do not necessarily represent diagnosed cases. That was rarely done transparently – although, as reported, a fair number of articles qualified these estimates with uncertainty, indicating a general acknowledgement of the limitations of current knowledge. Ultimately, readers could have assumed that these estimates were based on studies of the general population of Canada, when none exist.

Exaggerated FASD prevalence reported in Indigenous communities

The epidemiological studies that do exist in Canada have been done with subpopulations often deemed vulnerable, such as Indigenous peoples and criminal offenders [36], and sometimes at the intersection of these populations. Most of this work has been conducted in western Canadian provinces (i.e., Saskatchewan, Manitoba, and British Columbia), which aligns with our observation that most Canadian news coverage about FASD has emerged from those provinces. Despite variations in prevalence across studies, most of these subpopulation studies found rates far higher than the expected 1 in 100 (e.g., 1 in 10). In the case of Indigenous populations, these studies were conducted on specific, often remote reserves, with results that likely cannot be generalized to all Indigenous communities or groups; however, several news articles did not specify the region of study, simply reporting higher rates for Indigenous people overall – an exaggeration beyond existing findings. The results of these prior prevalence studies should not be taken as suggesting that all Indigenous groups are at higher risk for FASD, or that all Indigenous communities actually have higher rates.

What factors might contribute to exaggeration of FASD prevalence in Indigenous communities?

Concern about an exaggerated focus on Indigenous peoples reaches beyond the media. A disproportionate focus on FASD research in Indigenous groups in Canada – and a corresponding lack of research in the general population – may also contribute to exaggerated beliefs and assumptions about which groups are most affected by FASD. For example, one recent study noted that 51 of 52 reports on neurodevelopmental disabilities in Indigenous communities in Canada since 1981 focused exclusively on FASD (rather than other neurodevelopmental disabilities, like autism or cerebral palsy) [37]. Such biases in research could be fueled in part by common stereotypes attributed to Indigenous individuals (e.g., irresponsible drinking) [38], which may themselves be perpetuated in the kind of discourse we have analyzed here. This kind of reporting could lead to misconceptions about FASD as an Indigenous-only problem [37], which could lead to over-diagnosis or misdiagnosis of FASD in Indigenous peoples (see work by Tait for a more detailed exploration of this topic [39]). Beyond the FASD context, the needs of Indigenous peoples in Canada do not always match the goals of Canadian health research [40].

Articles addressing prevalence among Indigenous communities sometimes sought to mitigate the harm of problematic racial stereotypes; however, they did not analyze the situation in depth. Only one article in the sample featured an explanation for why some Indigenous people have FASD: "The grandmother is a survivor of the Indian residential school system who had her share of trouble with alcohol, a rough crowd and an abusive relationship as a young mother. 'That's how my children saw me… I passed it on'" (Winnipeg Free Press 2011). It is important to keep in mind that Canada's racist residential school system kidnapped Indigenous children from their families, forcing them to assimilate – stripping them of their languages and cultural practices (sometimes referred to as 'cultural genocide') [41]. Many suffered from abuse, and many other children died. Residential schools are only one recent example of forced assimilation in Canada, the effects of which are still felt today in some Indigenous communities where high suicide rates, increased alcohol consumption, disproportionate prison representation, and poor health outcomes can be prevalent [42].

Only a few articles implied a connection between a history of colonialism, any potential alcoholism, and FASD, presenting the information in a list of facts that allowed readers to draw their own conclusions: "98% of adults are alcoholics. That includes 99% of the community's residential school survivors" (National Post 2007). Readers here are given little context as to why some Indigenous groups might drink more. The public could therefore interpret this in a way that conforms to pernicious, racist stereotypes about Indigenous peoples. This situation stands in stark contrast to the recent Calls to Action of the Truth and Reconciliation Commission of Canada regarding "media and reconciliation", calling for more comprehensive coverage of Indigenous populations with a specific focus on and careful attention to the history and legacy of residential schools in Canada (Call to Action 84, point iii) [41].[4]

Contradictions between articles about the effects of prenatal alcohol exposure: A potential source of confusion

Identifying causal links between different amounts of alcohol, prenatal alcohol exposure, and developmental outcomes remains difficult given a number of confounding variables (e.g., genetics, metabolism, socioeconomic status). This complexity can pose a major challenge to communicating clear public health information. Consequently, many health

[4] We should note that Calls to Action 33 and 34 explicitly address the issue of FASD in Indigenous communities [41]. Action 33 calls for FASD prevention programs developed collaboratively and "delivered in a culturally appropriate manner". Action 34 calls for criminal justice reforms for offenders with FASD. The latter Call to Action reflects concerns seen in our data in discussions about Indigenous communities, FASD, and criminal behaviour. Please see our other manuscript based on this dataset for further discussion of the connection between crime and FASD [26].

organizations, including the Public Health Agency of Canada [43], favour the message that no amount of alcohol is safe to drink at any time during a pregnancy. When this topic was raised in our media sample, the 'no alcohol' message was dominant; however, contradictions between articles appeared as we analyzed the whole sample. For example, as reported, light drinking was presented as harming, not harming, and even helping child development – with different definitions of light drinking presented. These contradictions could lead to public confusion about whether or not drinking small amounts of alcohol is harmful when pregnant, despite attempts at clear public health messaging.

Contradiction about how much alcohol can harm a fetus in the academic literature

High levels of prenatal alcohol exposure, linked to heavy regular drinking or binging, can have a negative impact on neurodevelopment [44]. This amount of alcohol does not have an impact in each and every case, but increased prenatal alcohol exposure is generally associated with increased risk of FASD [45]. In contrast, debate continues over the effects of light – and to a lesser extent moderate – prenatal alcohol exposure [46]. Depending on the outcomes measured (e.g., IQ, head size), the definition of light drinking, the variables controlled for, or the population studied, light drinking has been found to be both harmful [47] and not harmful [48]. The overall evidence seems to be weighted toward 'not harmful', but uncertainties that persist in the academic literature appear to extend into the public sphere, potentially contributing to conflicting medical advice about alcohol use – i.e., some evidence suggests that medical professionals may not broach the topic of alcohol with their pregnant patients beyond routine screening, or else might provide unspecific advice about medical risks, partly to ease patient anxieties [49].

When can clear and certain messaging backfire – and what messages might work better?

Although clear messaging and discourse that fosters negative public attitudes toward drinking while pregnant can be useful from a public health perspective (i.e., discouraging unhealthy behaviour at the population level), it could also unhelpfully stigmatise individual women who do drink [12,50]. The clarity and certainty of abstinence messaging could, in some cases, have an effect opposite to the one intended, rigidifying public opinion against women most in need of support, and driving those women 'underground' [31]. Concerns about drinking have even begun to expand beyond the category of pregnancy, as medical advice shifts toward the implication that fertile women live in a constant state of pre-pregnancy. For example, recent CDC advice to doctors suggested they should "recommend birth control to women who are having sex (if appropriate), not planning to get pregnant, and drinking alcohol" [51]. In this way, responsibility and blame for FASD largely lands on women alone [32,52]. This concern is highlighted by the fact that barely any of the articles in our sample mentioned the contribution of family, partners, or social circles to an alcohol-free pregnancy. If both alcohol use and parenthood were understood in more community-oriented terms, rather than as the individual actions and responsibilities of solitary women, prevention methods and messages could shift toward social support, rather than blame and shame.[5]

However, even with less judgmental and more community-oriented approaches, the problem of uncertainty remains. A clear tension exists between 1) public health and medical guidelines requiring clear and actionable messages; 2) ensuring that marginalized women feel supported throughout their pregnancies; and 3) the importance of communicating the truth about research findings – even if that truth involves complexities. If media were to communicate only the clear but rigid message of abstinence in all cases, then the previously outlined issues of stigmatisation could arise, along with questions about paternalistic approaches to women's healthcare [53]; however, if contradictions are reported without care, some worry that this could provide women with a "license to drink" [50]. In our sample, contradiction more often appeared without comment between, rather than within, articles. To that end, a kind of compromise could be reached, whereby news articles could try to place such claims in the context of the literature – emphasizing both the public health messages and the current state of research together.

Accurate science and health information, without context: A source of stigma?

Even if science and health communication were completely accurate, the social context of the research in question may nevertheless be considerably important. Presenting only the 'facts of the matter' without an understanding of this context could unnecessarily inflame tensions, and further stigmatise affected groups. For example, presenting Indigenous prevalence data without qualification could exacerbate racial tensions in Canada, which, again, goes against the spirit of the Truth and Reconciliation Commission's Calls to Action [41]. In this section, we examine the importance of social context for better understanding different dimensions of FASD.

Social context and women who drink while pregnant

While it is technically true that "FASD… is 100 per cent preventable" (Calgary Herald, 2005) – in the sense that if all pregnant women abstained from alcohol, no child would ever be born with FASD – women typically have reasons for drinking that are not so easily addressed. For example, some struggle with addiction, or use alcohol as a coping mechanism, while others are entirely unaware of their pregnancy [54]. Explaining the social context of alcohol use is therefore both constitutive of a truly scientific understanding of FASD and necessary so as to avoid simplistic public narratives about alcohol and pregnancy. Failing to critically attend to reasons for drinking ultimately feeds into narratives that emphasize maternal blame and shame, which could have the unintended effect of making it more difficult for women to reach out for help [31], or can lead to punitive rather than rehabilitative or supportive interventions. In our sample, although a few articles

[5] For a more detailed discussion of gendered concerns around how and why women can sometimes be framed as the sole actor responsible for the wellbeing of their children – and where blame and shame can become criminalization and forced intervention – see [26].

explored how women might need a non-judgmental environment in which to seek assistance, most described FASD as "the leading cause of" preventable disability, some even going so far as to describe FASD as "easily" or "highly" preventable. Calls for public acknowledgement of more critical and nuanced messaging were few; most media discourse concluded that abstinence-only messaging remains both necessary and appropriate. Concerns about stigmatisation could be a strong reason to re-examine current prevention messaging and awareness campaigns, to better understand unwanted or unintended side-effects of FASD discourse. If FASD is seen as easily preventable, then women who fail in the task of prevention can be more easily marginalized.

Social context and people with FASD

In the case of people with FASD, discourse was often negative, even hopeless – e.g., as reported, people with FASD were sometimes described as a financial burden on society. People with FASD were commonly described as victims (e.g., of 'irresponsible mothers', of crime) [26], and long lists of symptoms categorized, organized, and explained differently in each case served as unqualified examples of their suffering. And while we should never dismiss the self-reported struggles and pain of people with FASD, focusing so strongly on weaknesses and challenges, rather than on any strengths and successes, painted their lives rather bleakly. Ultimately, framing FASD as hopeless and desirably preventable might also stigmatise people currently living with the diagnosis. Hopelessness could contribute to the sense that nothing can be done (leading to limited or poor interventions and support), while prevention framing raises concerns similar to the 'expressivist objection': that "prenatal diagnosis expresses a discriminatory or negative attitude towards people with disability" [55]. Managing the tension between respecting individuals who have already been born with FASD, and the desire to prevent individuals from being born with it in the future, should be carefully considered. Within prevention efforts, how scientists, healthcare professionals, journalists, and members of the public choose to talk about FASD as unwanted could have a major impact on the lives of people with FASD. The framing of health and science information matters; it is important to acknowledge the social context in which research and medicine are embedded.

Limitations

This study has several limitations, which we have reported in full elsewhere, some of which is reprinted here or specific to this text [26]. First, we only searched for keywords in article headlines and lead paragraphs to ensure that they were central to the story being told. Second, our sample focused on stories from the most-distributed newspapers in Canada, which meant only those from Canada's larger cities and provinces. Third, there were several limitations tied to the availability of sources. For example, Factiva only included major French newspapers in Canada as of 2011. While we do not know if these sources discussed FASD before 2011, no articles were found from 2011-2015. This could be due to differences in knowledge across Canada [6-8], differences in attitudes about drinking [56], or our choice of keywords. Three sources also have minor gaps in database coverage (i.e., the *Toronto Star*, the *Edmonton Journal*, and the *Vancouver Province*). In addition, as of 2010, six of ten newspapers were owned by a single corporation (Postmedia), which might have had an influence on the kind of coverage we analyzed. Fourth, most of the discarded codes that failed the reliability test related to key issues in the study of and care for people with FASD – specifically, prevention and FASD's cause. In part, the theme of prevention overlaps with our analysis of the theme of treatment, since care for at-risk or alcoholic mothers often serves as FASD prevention. In the case of FASD's cause, while we lack a detailed analysis, several other codes clarified relevant variables connected to risks for having a child with FASD, so the missing analysis has been partly addressed elsewhere. Finally, we did not undertake separate analyses on the impact of events that could have led to increased or decreased media coverage (e.g., the CIHR award for *Winnipeg Free Press* coverage of FASD).

Conclusion

Our analysis of science and health content in Canadian newspaper articles discussing FASD identified six key themes: 1) prevalence of FASD and of women's alcohol consumption; 2) research related to FASD; 3) diagnosis of FASD; 4) treatment of FASD and maternal substance abuse; 5) primary disabilities associated with FASD; and 6) effects of alcohol exposure during pregnancy. These results were discussed in light of three major concerns: 1) exaggeration about FASD rates in Indigenous communities, which could perpetuate harmful stereotypes and myths about Indigenous peoples (e.g., 'the drunk Indian'); 2) contradiction between articles about the effects of prenatal alcohol exposure, which could create public confusion; and 3) scientifically accurate (but incomplete) information that neglects the social context of alcohol use/abuse by women, which could unnecessarily inflame social tensions and attitudes toward marginalized group (e.g., leading to calls for pregnant women who drink to be 'locked up'). Looking forward, ethical considerations surrounding communication about FASD, alcohol, and pregnancy in the public sphere should be further explored, to better understand, recommend, and test more appropriate messaging, especially in the context of stigmatisation, scientific uncertainty, and stereotyping about Indigenous peoples, women who consume alcohol during pregnancy, and people with disabilities. We hope that such work and coverage would help improve public attitudes, social accommodations, and opportunities or programs for support.

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COMPTE RENDU / REVIEW

Book Review: Thomas Murray on Doping – Are We Doing the Right Thing?

Bertrand Alexandre Stoffel[1]

Résumé
La politique antidopage est une des politiques internationales du sport les plus importantes. Pourtant, sa justification demeure controversée. *Good Sport: Why Our Games Matter – and How Doping Undermines Them*, Oxford University Press 2018, par Thomas Murray (président émérite du Hastings Center) offre une analyse complète et convaincante des questions éthiques soulevées par les améliorations biomédicales dans le sport.

Mots-clés
dopage, sport, amélioration humaine, hyperandrogénisme, consommation de substances

Abstract
Anti-doping policy is one of the most important international sport policies. Yet its justification remains controversial. *Good Sport: Why Our Games Matter – and How Doping Undermines Them*, Oxford University Press 2018, by Thomas Murray (President Emeritus of the Hastings Center) provides a convincing and comprehensive exploration of ethical questions raised by biomedical enhancements in sport.

Keywords
doping, sport, human enhancement, hyperandrogenism, substance use

Anti-doping policy is one of the most important international sport policies, yet its justification remains controversial. Competitive sport demands complete physical dedication from professional athletes, even at the risk of severe injuries, but it takes a zero-tolerance approach when it comes to doping. Within the growing body of literature addressing the rationale for anti-doping, *Good Sport: Why Our Games Matter – and How Doping Undermines Them* [1] by Thomas Murray (President Emeritus of the Hastings Center) provides a convincing and comprehensive exploration of ethical questions raised by biomedical enhancements in sport.

Murray makes no secret that justifying anti-doping is a difficult task. After all, "[s]port accepts many technologies that boost athletes' performances such as fiberglass poles and hinged skates – why ban drugs?" (p.xiii). The key element, to Murray, is that sport consistently refuses technologies that make things easier. To the author, this is a core value that binds together all sports: respect for natural talents, as well as the perseverance and dedication required to perfect those talents. Murray's premise is not new, but it is no less powerful [2]. To him, sport is not just about measuring performance against comparably talented competitors. What makes sport meaningful is measuring performance against adversity. From the outset of the book, Murray argues that what drives an athlete towards doping is relatively straightforward. Athletes dope because they believe that their competition is doing so already (Chapter 1). The more difficult question is why it matters whether doping affects the outcome of the competition. *Good Sport* is an attempt to provide a convincing answer to that question. It is also the result of Murray's extensive experience with the international sport community, including working with the U.S. Olympic Committee and chairing the Ethics Panel of the World Anti-Doping Agency.

Murray adopts a methodological approach informed by what he refers to as John Rawls's reflective equilibrium. The idea is to move back and forth from close observations of what sport appears to care about to more abstract generalizations about justice and injustice (p.149). In Chapter 2 for example, Murray explains that neither natural talent nor performance enhanced by drugs are the result of hard work and dedication. What they have in common is that they are both unearned. In this sense, allowing one but not the other goes against equality on the playing field. However, in Rawlsian fashion, Murray explains that "unequal" is not the same as "unfair", and that justice does not require redress for all inequalities [3]. Murray exemplifies this with the case of a Finnish cross-country skier, Eero Mäntyranta. A genetic modification allowed this skier to produce a number of red blood cells far exceeding the average, providing an undeniable endurance advantage. Yet, Mäntyranta still trained hard, admitted to using the occasional amphetamines and hormones, and did not win every race he entered. Murray continues: "Fairness becomes relevant to doping once we've decided doping should not be permitted. At that point, we have an obligation to provide non-doping athletes the reasonable assurance that doping won't overwhelm the competition" (p.167-8). But fairness does not tell us which performance-enhancing technologies should be allowed. For that, Murray goes on, we must understand what gives sport its values and meaning.

Murray expands on the value and meaning of sport in Chapters 3 and 4. Performance-enhancing technologies in sports can simply overshadow the talent and discipline at the heart of a sport. In golf, balls designed to fly straight are not allowed in tournaments because they make the sport almost too easy. Similarly, swimming federations have banned body-shaping, buoyant, and slippery swimsuits. Murray draws two conclusions from this. First, the rules of a sport are not arbitrary: they tell us what sport values and minimize the influence of factors apart from those that sport believes ought to matter. Second, the difficulty in drawing the line between what is natural and what is unnatural does not render the distinction useless. Valuing performance-enhancing drugs and valuing natural talent are simply two different things, and in the context of sport, they are mutually exclusive. Chapter 5 and 6 delve into inequalities and gender. Support, access to equipment and training, time, money, as well as geographical location, all influence an athlete's chances to succeed. Murray argues that it would be good to reduce the impact of differences in opportunities – and discriminatory ones should be outright eliminated – because they may distort the differences in talent, courage, and dedication that should matter. Yet to the author, the only route acceptable here is to give more people a chance to play, and not to resort to doping as a means of opportunity adjustment. He adopts a similar position with respect to female athletes with hyperandrogenism, arguing that high androgen levels in some female

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athletes pose a problem to fair and meaningful competitions for women, and illustrating his position with Caster Semenya's dominant and predictable results in middle-distance running competitions[1].

Murray dedicates the last three chapters of *Good Sport* to ethical questions for collective action in anti-doping. To Murray, given the growing body of research that demonstrates athletes' general support for anti-doping policy [4,5], the discussion should not be about whether we should eliminate doping in sport, but about how to do it best. Collective action might require investing in education, research, investigation, as well as identifying and punishing "the key actors in the ecosystem promoting doping: coaches, trainers, physicians, scientists, and officials" (p.137). But more than anything else, Murray advances that successful anti-doping policy ought to be based on clear rules about what is permitted and what is prohibited. He insists that athletes ought to be able to understand and learn the rules. Here, Murray's commitment to the rule-of-law ideal that rules ought to be good at guiding action, becomes fully apparent. Coupled with detection-deterrence methods and a fair adjudication system, Murray's claim is that desirable anti-doping policy is possible. This can only be read as an answer to some of the most radical critics of anti-doping policy who advance that, given the continued prevalence of doping in elite sport and alleged inefficiencies in catching dopers, we should either legalise doping or concentrate our efforts on detecting substances that are harmful and test athletes for health [6,7].

Good Sport is a must read for anyone who works in anti-doping, but readers from disciplines such as bioethics and public health ethics may find it equally interesting. Doping is not restricted to sports. The growing demand by the healthy for cognitive and performance enhancement, for example in education and at work, presents similar challenges for society. Some of Murray's ethical considerations and lessons around doping might, in his own words, "help us deal sensibly and wisely with promises of technological enhancement in other realms of human life" (p.145).

Murray's analysis is compelling, yet at the end two questions remain. The first one is obvious: What really is natural talent? Murray's apparent acceptance of a cross-country skier's genetic modification contradicts his willingness to require female athletes to lower their testosterone levels. This leads to the second question, which is how we ought to justify public action in sports, and whether the defense of natural talent is sufficient here. Elite sports today are ripe with dangers and inequities. They involve numerous risks ranging from severe injuries to overtraining and stress. The field is never entirely level. Differences in access to facilities and coaching, as well as financial inequalities are very common. This points to a fundamental tension in what anti-doping policy should be. If its objective is to lay out rules for the game, then collective action might not be warranted. On the other hand, concerns regarding health and pressure to dope might very well justify public involvement. With little known benefit other than the performance-enhancing ones, and many potential side effects, we ought to assess, manage and, if necessary, attempt to reduce the risks of doping for the broader population. There is also a lack of knowledge about the influences on athletes' willingness to dope. Most of our understanding about the upstream causes for doping comes from individuals who have come forward to tell their story [8]. With growing interest in anti-doping research, this has begun to change [9,10]. In this sense, one of *Good Sport*'s main contributions is to shed light on doping as a complex phenomenon, and thus to open the door to further research questions. Doping appears to be an issue of fair play, a problem for public and athletes' health, and the result of a "win at all cost" mentality, all at the same time. And if this is the case, are we doing the right thing to address all of these concerns?

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[1] Attempts to regulate the issue, e.g., by allowing female athletes to compete if they stay below a certain androgen level, have faced legal challenges. For example, the initial regulation on the issue by the International Association of Athletics Federations (IAAF) was suspended by the Court of Arbitration for Sport for lack of sufficient scientific evidence about the relationship between testosterone levels and improved performance, see CAS 2014/A/3759 *Dutee Chand v. Athletics Federation of India (AFI) & The International Association of Athletics Federations (IAAF)*, Interim Arbitral Award, 24 July 2015. The regulation was replaced by a new regulation which only requires lowered levels of testosterone for a narrowed range of events. It was due to come in effect as from 1 November 2018 but was again suspended pending a decision by the Court of Arbitration for Sport, which is expected to be announced by the end of April 2019, see https://www.iaaf.org/about-iaaf/documents/rules-regulations.

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

Overuse of Diagnostic Tests in Canada: A Critical Perspective

Julia Borges[1], Tiffany Lee[1], Abdullah Saif[1], Amit Sundly[1], Fern Brunger[1]

Résumé
Dans ce commentaire, nous décrivons l'interaction entre 1) les conceptions populaires et professionnelles contemporaines du « risque » et de la « normalité » en santé et en soins de santé, et 2) la promotion par l'État et par les forces du marché de l'autorégulation individuelle de la santé. Nous nous appuyons sur les travaux de théoriciens critiques qui ont décrit la relation entre le risque, la peur et la notion de « normalité » dans le discours sur la santé afin de soutenir que ces facteurs agissent principalement par l'entremise des médias populaires, en vue de façonner le discours sur les tests diagnostiques et leur utilisation excessive au Canada.

Mots-clés
normalité, risque, tests diagnostiques, professions de la santé, soins aux patients

Abstract
In this commentary we describe the interplay between 1) contemporary popular and professional understandings of "risk" and "normality" in health and healthcare, and 2) the promotion by state and market forces of individual self-regulation of health. We draw upon the work of critical theorists who have described the relationship between risk, fear, and the notion of "normal" in health discourse to argue that these factors act, primarily via the popular media, to shape the discourse on, and overuse of, diagnostic tests in Canada.

Keywords
normality, risk, diagnostic tests, health professions, patient care

Introduction

The overuse of diagnostic tests has received a great deal of attention in Canada over the last five years, particularly in relation to costs to the healthcare system. It has been estimated that up to 30 percent of the care received by Canadians is unnecessary [1]. *Choosing Wisely Canada*, a campaign established to facilitate conversation between patients and clinicians regarding unnecessary care, has shaped our current understanding of the overuse of diagnostic tests [1]. The culture of overuse[1] has been attributed to clinician factors such as "access to resources, training, and peer influences" and "patient expectations and preferences" [1, p.10]; patients and practitioners alike are encouraged to "choose wisely" [1] in order to reduce unnecessary care in Canada. However, there are several other factors not part of the *Choosing Wisely* discourse that interact to contribute to the trend of unnecessary care.

In this commentary we describe the interplay between 1) contemporary popular and professional understandings of "risk" and "normality" in health and healthcare, and 2) the promotion by state and market forces of individual self-regulation of health. We draw upon the work of critical theorists who have described the relationship between risk, fear, and the notion of "normal" in health discourse to argue that these factors act, primarily via the popular media, to shape the discourse on, and overuse of, diagnostic tests in Canada in ways that are far subtler and more persuasive than the *Choosing Wisely* campaign would have us imagine.

Self-Regulation and Monitoring of Health

The overuse of diagnostic tests in Canada is fundamentally shaped by, and in turn perpetuates, deeply culturally rooted ideas about normality, deviance, and risk. In the last few decades, it has been emphasized that individuals have a duty to take proactive measures to improve and gain more control over their own health [2-5]. This emphasis stems from the idea that self-controlled individuals have fewer health complications, resulting in healthcare cost savings. The recent trend of the overuse of diagnostic tests is an outcome of such self-surveillance. In order to have more control over health through proactive measures, both physicians and patients are relying more on diagnostic tests. As a result, campaigns such as *Choosing Wisely* emerge with an aim to reduce any potential adverse health impacts and unnecessary medical costs.

Further, it is part of the contemporary "habitus" [6] for individuals to compare their health status to what epidemiological data portrays as the *normal* healthy body. Bourdieu's concept of habitus refers to "systems of durable, transposable dispositions" [6, p.72]. Bourdieu describes habitus as a character or persona that informs all of an individual's behaviours, and which results in particular behaviours that in fact reinforce the social conditions producing that character. These internalized dispositions mediate between social structures and practical activity. Habitus is accessed and reproduced not only through words, but also in imitation, repetition, and in day-to-day actions by the repetitious engraving of practices and dispositions into the body. The social conditions that produce the habitus are reproduced by the very behaviours and beliefs that result from the habitus. The habitus of needing and valuing diagnostic tests, then, emerges from, and in turn reinforces, a cluster of interconnected and interdependent assumptions and behaviours. Clinical decisions and communication about the need for and use of diagnostic tests, and patient understandings of the need for and use of diagnostic tests are mutually reinforcing. In turn, the need for and use of diagnostic tests are shaped by, and perpetuate, broader social assumptions about risk, normality, and health.

Our present understanding of normality was adopted in the 1820s; today in medicine, as in lay discourse, the word connotes both "average" and an ultimate perfection toward which we should strive [7]. As social scientists have long argued, the act of transposing the concept of risk from the probabilities of epidemiology into clinical practice means that risk is interpreted as something from which the patient suffers; being at risk in itself comes to mean being diseased [8]. Patients seek advice from

[1] We acknowledge that the characterization of diagnostic tests as "overused" in Canada or elsewhere would itself benefit from a critical inquiry; however, that is not the purpose of this particular commentary.

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medical practitioners, wanting tangible proof of their own normality or deviance in the form of diagnostic test results. Physicians seek to acquire quantifiable data on the body through various diagnostic tests so that they can compare the patient's body with the epidemiological norm. In this way, individuals find motivation for self-regulation and seek diagnostic tests as an instrument for self-monitoring.

This individual motivation also emerges from broader collectivizing interests, where the state continuously invests in regulating the population to self-monitor, as the onus for maintaining "normal" health is seen as the responsibility of the individual [9]. For example, the increasing availability of at-home diagnostic tests, such as pap smears and colorectal screening, demonstrate how individuals have been influenced by the state to self-regulate their health. Patients' expectations about their health care and the resultant pressure they may place on clinicians have been shaped by the public health movement of the twenty-first century, where intense value has been placed on health education and health promotion. A culture of "active citizenship" has been around since at least the 1970s, with individuals being encouraged by health experts and governments to take a more active role in their health and well-being [10]. As a result, patients seek health information – increasingly from online sources – to further their understanding of disease, risk, and potential treatment and prevention options. The Internet also serves to enhance patients' perceived control over disease through the act of gaining new knowledge [11].

Lupton, following Foucault, explains this phenomenon in terms of governmentality, an approach to regulation and control that is "directed at the autonomous, self-regulated individual" [7, p.118]. Health promotion messages are communicated to individuals as advice on how they should live and regulate their bodies. For example, Canada's Food Guide [12] aims to help people follow a healthy diet by providing recommendations as to what and how much people should eat. While the intent may be to empower individuals to take control of their health and lifestyle behaviours, other less-acknowledged consequences can ensue, such as fear and anxiety about one's current and future health. This can result in patients demanding access to diagnostic tests as an attempt to relieve anxieties and concerns.

Corporations, Media and the Construction of Risk

Organizations engaged in manufacturing new technologies also influence medical standards, clinical guidelines, policies and practices, and scientific knowledge production [13-15]. A large body of research suggests that medical associations, government agencies, and public awareness movements are lobbied by pharmaceutical corporations to gain buy-in for new drugs [16]. Public campaigns, such as the "Pink ribbon campaign" or "Shave for the brave," influence the discourse of risk and may propagate fear and anxiety. The individuals experiencing and accessing the discourse of risk through the media then start perceiving themselves as at risk. When promoted by health professionals and pharmaceutical companies, and supported by the mass media, these assumptions are perpetuated, establishing moral imperatives regarding health behavior [5,17].

Market forces have been shaped by, and have capitalized on this popular and professional health consciousness [5,18,19]. Corporations influence the trend of overuse of diagnostic tests through the identification and creation of a need and subsequent marketing of a new drug or technology to meet that need [20-22]. The abundant supply of biomedical technologies to evaluate and manage risk engages individuals with technological choices and options, which are publicized through the media. These technologies are promoted and marketed as part of the package of health behaviours that individuals must undertake in order to take charge of their own health and prevent disease [5]. This influences the culture and discourse of risk in society and contributes to the overuse of diagnostic tests. Overall, corporations are incentivized to identify and create a need in the population, create public awareness about that need, and further fulfill this need with new technologies.

Conclusion

The *Choosing Wisely* campaign is meant to spur conversation about what is appropriate and necessary treatment, in order for clinicians and patients to work together to determine an appropriate treatment plan [1]. This campaign is certainly a positive movement in Canada; however, it is important to recognize that what leads us as a society to the culture of overuse is quite complex and not merely the result of physician and patient decisions. Recommendations for specific tests fail to account for the broader social, political, and economic contexts shaping health beliefs, values and behaviours on the part of both patients and providers. Here we have discussed how the state, health campaigns, media, and corporations, in addition to physicians and patients, all contribute to the discourse of risk that perpetuates self-regulation and monitoring of individual health. This discourse has manifested itself in increasing demand for diagnostic tests, which has contributed to the trend of unnecessary healthcare use in Canada.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Le ton d'évidence en éthique relève-t-il de la violence verbale? Analyse des mémoires envoyés à la Commission parlementaire québécoise sur la question de mourir dans la dignité

Daniel Burnier[1]

Résumé
Cet article interdisciplinaire analyse la manière avec laquelle des citoyens débattent lors d'une consultation publique organisée sur une question éthique profondément conflictuelle : l'euthanasie. Le cas étudié concerne la consultation publique québécoise organisée en 2010-2011 par la *Commission spéciale sur la question de mourir dans la dignité*. Ces voix citoyennes débattant publiquement sur l'euthanasie ont jusqu'ici peu retenu l'attention des chercheurs. Nous avons analysé à l'aide des outils de la rhétorique aristotélicienne les mémoires écrits (n = 149) envoyés par des citoyens à la Commission spéciale. À de très rares exceptions près, toutes les personnes engagées politiquement dans cette consultation publique, aussi différentes soient-elles, affichent une grande certitude dans leurs croyances éthiques. Chacun fait comme si les convictions de l'adversaire étaient inférieures aux siennes, qu'il présente souvent comme universelles. Concernant la formule « mourir dans la dignité », les participants prétendent implicitement à l'objectivité de leur définition. Ils agissent même comme s'il existait une seule définition de la formule « mourir dans la dignité » et une seule vérité éthique. À la suite de ces analyses, nous discutons du concept de « violence verbale » qui pourrait être associé à ces manières de débattre sur un sujet complexe.

Mots-clés
euthanasie, dignité, consultation publique, croyances éthiques, violence verbale

Abstract
This interdisciplinary article analyses how citizens debate in an organized public consultation on a deeply conflictual ethical issue: euthanasia. The case in question concerns the Quebec public consultation organized in 2010-2011 by the *Special Commission on the Question of Dying with Dignity*. The citizen voices debating publicly on euthanasia have so far attracted little attention from researchers. Using Aristotelian rhetorical tools, I analyzed the written submissions (n=149) sent by citizens to the Special Commission. With very few exceptions, all those politically involved in this public consultation, however different they might be, had a high degree of certainty in their ethical beliefs. Everyone acted as if their opponent's convictions were inferior to their own, which they often presented as universal. With regard to the formula "dying with dignity", participants implicitly claimed the objectivity of their definition. They even acted as if there were a single definition of the phrase "dying with dignity" and a single ethical truth. Following these analyses, I discuss the concept of "verbal violence" that could be associated with these ways of debating a complex subject.

Keywords
euthanasia, dignity, public consultation, ethical beliefs, verbal violence

Introduction

En décembre 2009, l'Assemblée nationale du Québec a créé une *Commission spéciale sur la question de mourir dans la dignité* [1]. Celle-ci a été chargée d'organiser une large consultation publique d'experts et de citoyens sur les questions de fin de vie, notamment l'euthanasie qui peut se définir comme « l'acte qui consiste à provoquer intentionnellement la mort d'une personne à sa demande pour mettre fin à ses souffrances » [2, p.17]. De par le nom même de cette Commission multipartite, une « formule », c'est-à-dire une séquence verbale cristallisant des enjeux politiques et sociaux [3-4], s'est retrouvée au centre de ces débats : « Mourir dans la dignité ». Cette formule peut être vue comme un lieu de rencontres et d'affrontement, une « arène en réduction où s'entrecroisent et luttent des accents sociaux à orientation contradictoire » [5, p.67]. Elle porte en elle des enjeux sociopolitiques très concrets, notamment, la légalisation de l'euthanasie, mais également le développement des soins palliatifs, la vision de la « bonne mort », etc. Si les protagonistes divergeaient sur la définition de la formule, luttant pour en imposer le sens, chacun utilisait le langage de la dignité pour défendre ses positions. En évoquant la problématique de la fin de vie, on semblait ne plus pouvoir se passer de ces mots. À la suite de cette consultation, l'« aide médicale à mourir » – une forme d'euthanasie – a été légalisée dans cette province en juin 2014. Le droit ici semble avoir suivi les mœurs, car depuis plusieurs années, l'euthanasie et le suicide assisté étaient devenus acceptables pour une majorité de citoyens canadiens [6]. L'euthanasie, ainsi que l'avortement et la peine capitale, sont des sujets sur lesquels les compromis sont difficiles. Nous sommes ici dans ce que Robert Fogelin [7] appelait des « *deep disagreements* ». Ces désaccords profonds se maintiennent souvent, car la source du désaccord réside dans le fait que certaines prémisses (« le fœtus est une personne »; « la liberté prime sur la vie », « la dignité humaine est intrinsèque », etc.) sont placées par les individus en retrait, à distance de ce sur quoi ils acceptent de débattre. On peut donc supposer que des individus et des mouvements sociaux y seront encore longtemps opposés, car ces croyances éthiques semblent indélogeables « [e]n deçà des convictions que les hommes sont prêts à argumenter », comme l'écrit Marc Angenot [8, p.183].

La plupart des intellectuels intervenants dans le débat sur l'euthanasie – qu'ils soient juristes, philosophes, bioéthiciens, professionnels de la santé – écrivent des articles en affirmant ce qu'il faut faire ou ne pas faire en matière de législation sur la fin de vie [9]. Ces auteurs participent à la discussion en se plaçant dans un camp et en débattant avec l'autre camp. Ils écrivent alors des articles ou des ouvrages de « combat » [10, p.12]. Dans les débats sur l'euthanasie, les principaux arguments *pro* et *contra* sont connus. Nous ne chercherons pas ici à départager les arguments « rationnels » des arguments « fallacieux », et nous ne ferons aucun de prêche en faveur de l'euthanasie ou contre cette pratique. Cet article a plutôt pour but d'analyser la manière avec laquelle les citoyens participant à la consultation publique québécoise débattent sur un sujet polémique [11]. Plus spécifiquement, seront analysés ici les documents écrits envoyés par ces citoyens à la Commission spéciale. Si

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d'excellents travaux existent déjà sur les organisations militantes, les mouvements sociaux en lien avec l'euthanasie [12-13], très peu de choses sont connues sur les manières de dire des citoyens débattant sur une question éthique.

Cadre d'analyse

La polémique n'est pas à comprendre ici dans le sens péjoratif qu'en donnent généralement les dictionnaires, renvoyant à un débat vif ou agressif. Il faut la concevoir ici comme la confrontation d'arguments polarisés ou antagonistes qui rend difficile la possibilité d'un accord. Cet accord n'est d'ailleurs pas forcément souhaité par les protagonistes, ceux-ci voulant plutôt faire valoir leurs opinions et leurs arguments dans la sphère publique, peser sur des décisions politiques, construire une image de soi ou encore former des coalitions [11]. Ces discours éthiques politiques et polémiques (du grec *polemos*, qui renvoie à la guerre, au combat) que nous souhaitons analyser se caractérisent par des représentations d'un discours adverse marquées par des jugements de valeur. Précisons ici que par « éthique », nous entendons des « discours et pratiques rationnels ayant comme objectif une systématisation ou une réflexion formelle sur la conduite morale ou le bien agir des individus » [14, p.31]. Lors d'une polémique, on essaie typiquement de discréditer et de disqualifier l'adversaire, son groupe d'appartenance ou son discours. Souvent, les valeurs défendues par les polémistes constituent une part fondamentale de leur identité. Dès lors, remettre en question ces valeurs, c'est attaquer personnellement l'identité de l'autre. Dans un affrontement de ce type, les présentations de soi et de l'autre jouent un rôle majeur dans l'affirmation des positions de chacun [11].

Environ trois quarts des 273 mémoires écrits envoyés à la Commission spéciale proviennent de citoyens et non d'organismes collectifs telles des associations ou des fondations, des ordres, des assemblées, des fédérations, etc. D'une moyenne d'environ 5 pages, ils peuvent varier énormément : les moins imposants sont écrits sur 1 seule page, mais d'autres sont des textes de 80, voire 250 pages ou plus. Devant la taille et le nombre important de documents, nous avons utilisé la formule « Mourir dans la dignité » comme un point d'accès à ce débat. Nous n'avons pas limité l'analyse des manières de débattre des participants à cette formule, mais nous sommes partis de celle-ci pour comprendre comment ces participants argumentent, avant de regarder ailleurs, dans les autres parties de ces mémoires où la formule n'était pas présente. Ainsi, 35 mémoires n'ont pas été retenus, car ils n'utilisaient simplement pas la formule « Mourir dans la dignité » ou des formules similaires. Parmi les mémoires écrits, une quinzaine environ sont signés par plusieurs personnes (quelques infirmières qui écrivent un mémoire commun, une famille, des citoyens qui se regroupent, etc.). Mis à part les cas où ces personnes formaient un groupe formellement identifiable, avec un nom de collectif par exemple, un porte-parole clair, des réunions de travail, etc., nous avons gardé ces « mémoires individuels » signés par plusieurs personnes. En fin de compte, le nombre de mémoires écrits individuels sur lequel nous avons travaillé est précisément de 149.

Afin de dégager des types moyens de participants, nous avons utilisé les concepts aristotéliciens de l'*ethos*, c'est-à-dire l'image que l'orateur projette de lui-même dans son discours, du *pathos*, l'émotion que l'orateur cherche à susciter chez son auditoire et du *logos*, le raisonnement mis en œuvre pour justifier sa position et persuader [15]. Dans différents travaux récemment publiés dans le champ rhétorique francophone [8,15-17], les preuves aristotéliciennes administrées par le discours sont à analyser dans leur articulation. Suivant cette même position théorique, nous avons par exemple postulé que l'argumentation (*logos*) et les émotions (*pathos*) participent de l'image de soi du locuteur (*ethos*). Afin d'opérationnaliser ces concepts, nous avons commencé par repérer des schèmes argumentatifs (*logos*), par exemple l'argument d'autorité, l'argument par la définition ou les valeurs, l'argument de la pente glissante, etc. Les émotions (*pathos*) peuvent être dites directement par un nom, un verbe, un adjectif ou un adverbe (peur, dégoûter, agaçant, etc.) ou de manière plus indirecte, faisant référence à l'expression de ces émotions (rire, pleurs, larmes, etc.), des états somatiques (fatigué, corps tordu, fort, etc.), des traits comportementaux liés à des émotions (gentillesse, compassion, sincérité) ou encore des états d'esprit (confusion, incertitude, excitation, etc.). Les émotions peuvent être également montrées par une manière d'écrire (phrase exclamative, ordre des mots, figures, etc.) ou à partir du contenu même des énoncés. Quant à l'*ethos*, il se repère à travers ce que la personne dit explicitement d'elle-même (par exemple : « je suis infirmière depuis 40 ans en unité de soins palliatifs »), mais surtout à travers ses manières de dire (l'« *ethos montré* ») qui se voient notamment à travers le choix des mots, le niveau de langue, l'usage des expressions toutes faites, l'humour, etc. Ces manières de dire – objets de cet article – construisent elles aussi une certaine image du locuteur. Si les preuves aristotéliciennes sont à analyser dans leur articulation, cet article, faute de place, ne peut analyser les liens entre l'*ethos,* le *pathos et* le *logos* qui se retrouvent dans les citations de mémoires ci-dessous*.* Notre méthodologie a permis de dégager quatre types moyens de participants décrivant pleinement la réalité de notre matériau, les mémoires écrits individuels envoyés à la Commission spéciale.

Les quatre figures moyennes

Il n'existe, selon nous, aucun moyen de démontrer définitivement que la légalisation de l'euthanasie est un acte éthique ou non. Chez les participants à la consultation publique « Mourir dans la dignité » – des individus convaincus, impliqués politiquement et peu représentatifs de la population québécoise dans son ensemble – le verbe *croire* doit se comprendre au sens fort. Il implique une adhésion rationnelle, émotionnelle et éthique envers l'objet de leur croyance. Selon la position sociale occupée par le participant, l'adhésion à sa croyance éthique – l'euthanasie est éthiquement acceptable ou non – peut s'appuyer sur des connaissances venant de l'expérience ou de l'expertise, mais aussi sur une argumentation bien plus partielle, comme nous allons le voir. Quatre types moyens de présentation de soi se sont dégagés de notre matériau, à savoir l'expert (n=40), le témoin (n=40), l'opinant (n=52) et l'amateur (n=17). Nous les présentons très sommairement ci-dessous, car nous visons dans cet article un propos d'ordre plus général sur les manières de dire, ou plutôt d'écrire, des participants.

Pour convaincre, l'expert fait appel à son expertise. Il dit en somme : « Je suis bien placé pour en parler, car j'ai les compétences requises. » Le témoin se base lui sur son expérience personnelle. Il dit implicitement : « Je suis bien placé pour en parler, je l'ai vécu. » Ce sont là deux formes de connaissance personnelle qui viennent soutenir leurs croyances éthiques. Là où l'expert se présente professionnellement de manière détaillée, là où le témoin développe son récit, l'opinant, lui, dit très peu de choses sur lui-même. Il se distingue des autres figures moyennes par la faible présence – et parfois l'absence – d'informations personnelles ou professionnelles. L'amateur se situe ici souvent entre l'opinant et l'expert : les faits biographiques (personnels ou professionnels) tiennent généralement sur quelques lignes. La présentation de l'amateur, ce « bricoleur », fait souvent dialoguer des éléments de présentation qui appartiennent aux autres figures synthétiques mentionnées. Celui-ci se présente également comme amateur lorsque, ayant la possibilité de s'appuyer sur une expertise ou expérience personnelle, il choisit plutôt de dire, implicitement ou non, ce que ne dit jamais l'expert : « les personnes ordinaires comme moi » ou « je n'ai pas la compétence ».

Quelle que soit leur position dans le débat, les experts, témoins, opinants et amateurs abordent de très nombreux thèmes liés à la formule : les valeurs, les abus, les soins, la souffrance, le rôle de l'état ou de la religion, le rôle des médecins, le débat lui-même, le rôle des groupes de pression, etc. On retrouve ainsi chez l'opinant ou le témoin la même diversité de thèmes liés à la formule que chez l'expert ou l'amateur, mais de manière moins élaborée, moins théorique.

L'évidence ordinaire

Premièrement, de ces mémoires, ressort un ton d'évidence, des « je ne vois pas pourquoi », des « bien entendu » explicitement ou implicitement exprimés. Ces thèses péremptoires ne sont pas réservées aux « grandes ambitions intellectuelles » dont parlait Pierre Bourdieu [18, p.13], mais sont le lot commun des participants à la consultation publique, de l'expert au simple opinant. Le participant moyen n'affiche guère de doutes et ne fait pas preuve de modestie intellectuelle dans son propos. En voici deux exemples[1]:

> Les chartes canadienne et québécoise proclament par ailleurs le respect des droits à la dignité et à l'intégrité de la personne […] qui mieux que moi peut définir le sens que je donne à mon existence en fin de vie? **N'est-il pas raisonnable de réclamer** la liberté de choisir de mourir selon « notre propre échelle de dignité »? (Mémoire de Nicole Gladu, nous soulignons.)

> Cet argument [celui de la pente glissante] **ne tient pas la route.** Il suppose que les milieux de soins de sont pas suffisamment bienveillants, alors qu'il le sont par définition puisque c'est leur raison d'être. (Mémoire de Luc Thériault, nous soulignons.)

Toutes les personnes engagées politiquement dans cette consultation publique, même celles qui livrent une opinion qui ne repose sur aucune expérience ou expertise, affichent « normalement », pourrait-on dire, leurs certitudes. Comme devant l'ordre militaire, il faudrait obéir à l'« évidence » sans poser de questions. N'est-ce pas l'évidence même qui demande ceci ou cela? Pour ces êtres de conviction, l'évidence, dans le cadre public, semble banale. Le doute, règle d'or cartésienne ou montaignienne, ne s'affiche pas ici. Les participants semblent incapables – du moins c'est ainsi qu'ils présentent les chose – d'envisager le point de vue de l'adversaire. Ils semblent ne pas comprendre cet autre, ne pas se mettre à sa place. Dans un conflit de ce type où il n'existe pas de moyen de démontrer définitivement le caractère éthique ou non de l'euthanasie, leurs discours produisent en permanence de l'ordre: ils organisent, hiérarchisent des arguments, distribuent catégoriquement la bonne attitude éthique, affirment avec évidence la solution à suivre.

Un a priori épistémologique et linguistique

Deuxièmement, les participants ne se présentent pas comme s'il était impossible de trancher entre des opinions diverses comme le ferait un sceptique, ni ne disent, dans une posture de complexité, que la vérité est plurielle. Pour ces participants, la vérité est unique et la pratique euthanasique est soit éthiquement un bien, soit un mal. Manichéens – ils opposent de façon binaire les termes – ils rejettent les propos de l'adversaire de façon systématique. Ici, l'argumentation semble suivre une très ancienne métaphore, celle du combat, de la guerre. L'autre bord du débat a toujours tort et les arguments de l'ennemi ne sont jamais recevables. La prétention à la vérité (éthique) unique peut s'observer dans les deux exemples précédemment cités. En voici deux autres :

> **Pourquoi on ne respecte pas la volonté de chacun dans ces cas…?** […] Je ne suis pas contre la recherche, les nouvelles technologies, ni les nouvelles découvertes, au contraire…mais à quoi sert tout cela si ça ne sert pas dans le mieux-vivre de l'être humain […]. (Mémoire de François Gaumont, nous soulignons.)

[1] Précisons ici que nous n'avons pas corrigé l'orthographe ou la grammaire des citations provenant des mémoires écrits. Ces documents étant publics, nous avons également gardé les noms des auteurs de ces mémoires.

> […] peu importe les situations, l'état clinique de la personne ou son opinion ou celle d'autrui, **toute personne possède en elle-même une valeur inaliénable du fait qu'elle est humaine.** L'évidence de ce fondement anthropologique de la dignité impose à chacun un respect pour lui-même et autrui à son égard, et des exigences quant aux décisions en fin de vie. (Mémoire de François Primeau, nous soulignons.)

Les participants à la consultation « Mourir dans la dignité » semblent toujours dire : « Il faut être bien insensé (ou déraisonnable, fou, idiot, etc.) pour ne pas partager mon avis. » Cet a priori fort de la vérité unique qui ressort de ces débats éthiques est en réalité utilisé dans nos perceptions les plus courantes (ceci expliquant sans doute son caractère « intuitif »). Je peux bien percevoir la forme ou la couleur d'une table d'une manière différente selon ma position dans la pièce ou l'heure de la journée, cet objet peut en réalité n'avoir qu'une forme et couleur particulière [19, p.279]. Pourtant, il est des objets – telle la problématique de l'euthanasie – autrement plus complexes qu'une table et cet a priori épistémologique de la vérité unique, soutenu par l'expérience ordinaire et toute une tradition philosophique, paraît en réduire la complexité. Tout se passe comme si les participants ne pouvaient se passer de ce principe d'unicité de la vérité. Ils débattent comme s'ils visaient la détermination de la Vérité, unique et absolue.

On pourrait dire que cet a priori épistémologique est aussi linguistique puisque les participants utilisent, et pour certains d'entre eux définissent, implicitement ou non, la formule « Mourir dans la dignité », comme si celle-ci avait et devait avoir un sens unique, aussi unique qu'un mot désignant un objet spécifique tel qu'un « tapis » ou du « pain », ou bien un individu particulier comme « Justin Trudeau » ou « Napoléon Bonaparte ». Or tous les mots ne désignent évidemment pas des objets ou des êtres uniques; ils n'ont même pas tous de signification claire comme le rappelle Wittgenstein [20]. Non seulement il existe des mots polysémiques qui nomment des réalités complexes (raison, dignité, folie, etc.) – ce sont des « concentrés d'une multitude de significations », comme le dit Koselleck [21, p.109] –, mais il y a aussi des mots qui ne sont pas des noms, qui ne nomment ou qui ne désignent pas des réalités aussi simples que des objets ou des individus particuliers. Or il nous semble que quand les participants visent à définir la formule « Mourir dans la dignité », ils ont d'abord en tête cette vision simpliste du langage que Wittgenstein appelait « augustienne » et dont l'illusion peut se résumer ainsi : « [l]es mots du langage dénomment des objets ». Comme suggéré par Raymond Boudon, c'est peut-être à nouveau la vie ordinaire qui influence ici leur vision : si cet a priori linguistique est répandu, « c'est tout simplement qu'il s'oppose constamment à nous dans la vie courante : il est vrai que dans d'innombrables cas, "les mots nomment les choses" » [19, p.341]. Influencés par l'ordinaire qui habitue à ramener les mots à des noms communs qui désignent des objets simples, les participants font comme si les définitions n'étaient pas polysémiques. Les participants sont peut-être également influencés par le dispositif polémique : ils font alors comme si les définitions et les formules n'étaient pas enjeux de luttes, comme si elles n'étaient pas prises dans des jeux de langage, des conflits sociaux et des idéologies, comme si elles étaient définitives et jamais questionnées par des discours antagonistes. Ci-dessous figurent trois exemples parmi d'autres de cet a priori linguistique implicite concernant la formule « Mourir dans la dignité » ou ses variantes :

> […] je vous présente ma mère, une femme aimante qui a su élever ses six enfants avec courage et amour. Elle a su nous transmettre des valeurs solides. Aujourd'hui, le grand âge fait en sorte que tous ses organes, articulations et systèmes sont usés et fatigués […] Des dires même de cette personne admirable : « J'aime trop ma famille pour m'enlever la vie ». **Dans ce cas, ce ne serait pas de « mourir dans la dignité », mais plutôt de mourir « dans la honte ».** On peut vivre dans la dignité, mais se donner la mort n'est pas digne, c'est plutôt lâche et honteux. (Mémoire de Jean Deslauriers, nous soulignons.)

> Toutefois, il me semble que ces personnes, qui le demandaient avec insistance et à répétition, auraient dû avoir **le droit de mourir un peu plus dignement, entourées de leurs proches, au moment où elles disaient de façon irrévocable : « C'est assez** ». (Mémoire de Jana Havrankova, nous soulignons.)

> **La solution pour assurer le « mourir dans la dignité » demeure dans** l'approche palliative compétente, le respect, l'accompagnement et la tendresse et la vraie compassion. (Mémoire de Linda Couture, nous soulignons.)

L'objectivité et l'universalité

Troisièmement, lorsqu'ils s'expriment sur la formule « Mourir dans la dignité », tous les participants tiennent très régulièrement des propos objectivants. S'ils affirment ce que « Mourir dans la dignité » veut dire, ils l'affirment non pas pour eux, mais « en vérité ». Dans un effet d'objectivité provoquant un effet d'évidence et de validité, chacun semble dire « mourir dans la dignité, c'est ceci ou cela », plutôt que « je crois que mourir dans la dignité signifie ceci ou cela ». Les participants définissent implicitement ou non la formule comme s'il était possible de le faire de manière objective. En voici deux courts exemples représentatifs :

> **Vivre et mourir dans la dignité c'est** d'abord assurer les soins de santé à tous, quelque soit sa situation – rendre les médicaments accessibles, créer un milieu de vie sanitaire, nourrir l'espérance et aimer. (Mémoire de Gilles Marleau, nous soulignons.)

> **« Mourir dans la dignité » n'a rien à voir avec** une dignité d'apparat dans laquelle on se draperait pour la galerie, comme au théâtre. Il s'agit au contraire de pouvoir faire sienne sa mort […]. (Mémoire de Thomas de Koninck, nous soulignons.)

Or il nous semble que dans un conflit d'opinions éthiques (« il est juste de légaliser l'euthanasie ») ou esthétiques (« Picasso est un grand peintre ») – et sans faire l'amalgame entre jugements éthiques et esthétiques – le caractère éthique d'un changement de loi ou l'importance d'un peintre relèvent avant tout du jugement du locuteur plutôt que d'une propriété intrinsèque au principe éthique jugé ou à la valeur de l'artiste. Similairement, le sens à donner à la formule « Mourir dans la dignité » dépend non pas de la nature de la formule, mais de la *«* tournure particulière *»* [22, p.32] de l'esprit qui l'utilise. Face à la difficulté d'atteindre le consensus, les participants donnent *la* (et non pas *leur*) définition de la formule « Mourir dans la dignité ». Ils lancent un propos subjectif en le présentant comme objectif : « Si je dis : "ce que je veux est bon", mon voisin dira : "non, ce que je veux, moi." Pour échapper à ce dialogue, on dit alors "c'est bon" » [23, p.228].

Tous les intervenants construisent un auditoire composite. À des degrés divers, les participants s'adressent explicitement ou implicitement aux adversaires du débat, en argumentant, en répondant à leurs arguments. Ce discours adverse est d'ailleurs systématiquement passé au filtre des opinions et valeurs « personnelles » du locuteur. Les participants s'adressent également directement aux membres de la Commission. De plus, tout en présentant un propos fragile, qui relève de la croyance éthique (concernant l'euthanasie) ou de la subjectivité (pour la définition de la formule « Mourir dans la dignité »), chaque participant s'adresse à un auditoire que Perelman et Olbrechts-Tyteca [24] appelaient « universel ». Face aux incertitudes éthiques, conflit durable entre des valeurs et des points de vue ultimes, l'intervenant dans le débat sur l'euthanasie présente un propos qui transcende les particularités sociales. Ce faisant, il éloigne celui-ci de l'opinion individuelle et du particularisme, pour le tirer du côté de l'être humain universel. De manière paradoxale, cette manière de s'adresser à un auditoire universel idéal, sorte de « construction purement intellectuelle », comme le dit Meyer [25, p.72], peut se faire à plus ou moins grande distance des lecteurs à qui ces mémoires s'adressent plus directement, c'est-à-dire aux membres de la Commission spéciale. Afin de se positionner sur la question de la légalisation et du caractère éthique de l'euthanasie, le témoin (ainsi que l'amateur favorable à l'euthanasie et, dans une moindre mesure, l'opinant) argumente typiquement à faible distance de ceux-ci. C'est une dominante narrative, où l'émotion (*pathos*) est déterminante, qui prévaut chez les témoins participant à la consultation publique :

> Souffrir ressemble beaucoup à grelotter. C'est un recroquevillement, une contraction de tout le corps, de la racine des cheveux jusqu'aux pieds. Ça fait MAL !!! Et ça fait mal longtemps. Ce grelottement prend toutes vos forces, toute votre attention, c'est épuisant. Pensez-y : supporteriez-vous de grelotter dix jours, vingt jours, deux mois…? (Claire Morissette, citée dans le témoignage de Julie Bélanger.)

En racontant son intime récit, le témoin a beaucoup de chances de toucher un grand nombre de personnes. Comme le savent les écrivains, pour atteindre l'universel, il faut parler de soi, de sa réalité singulière. A contrario, face au vécu du corps du témoin s'affiche le masque du locuteur expert, celui qui veut dépassionner les débats et les problèmes, réfléchir à distance du vécu des corps individuels, loin de la charge émotive et critique du témoin. L'expert éthique (et l'amateur opposé à l'euthanasie) vise ainsi plutôt à transcender ses intérêts, ses émotions. Dans l'effacement énonciatif, il parle au nom de l'Histoire, de l'Éthique immémoriale, des Valeurs supérieures, des Règles sacrées dont il rappelle l'importance :

> Peut-on réfléchir à l'euthanasie autrement? Peut-on considérer l'acte d'euthanasie hors de la sphère privée; mais d'un point de vue davantage macroscopique, c'est à dire sociétal? (Mémoire de Danielle Blondeau.)

> Chaque être humain, quel qu'il soit et quelle que soit sa condition, est unique au monde et possède une égale dignité, celle d'une fin en soi, justement. On ne peut dès lors jamais dire ou penser : « lui ne compte pas », ou encore « sa vie à elle ne mérite plus d'être vécue ». Avec la dignité humaine entendue en ce sens rigoureux, qui est à l'opposé de la dignitas romaine de jadis, aucun compromis n'est possible. Tout être humain compte. (Mémoire de Thomas de Koninck.)

Face à la souffrance rejetée par tous, devenue insupportable, presque scandaleuse [26], la compassion, ce vieux principe religieux laïcisé, construit également un auditoire universel. Celle-ci est une émotion sur laquelle l'opinant s'appuie implicitement pour convaincre, davantage que sur un sentiment de justice par exemple. L'universalité et l'origine naturelle de la compassion sont certes des idées contestables et contestées. Une présentation rigoureuse et interdisciplinaire de ce débat déborderait très largement les contours de cet article. Disons simplement ici que la compassion peut être rattachée philosophiquement, biologiquement et même neurologiquement à une nature de l'être vivant doté de sensibilité [27], que celui-ci soit membre de la communauté humaine ou même de certains groupes non humains, comme l'a montré le primatologue Franz de Waal [28]. Ce qui importe d'un point de vue rhétorique, c'est que le locuteur s'adapte à cet auditoire universel qu'il construit et imagine, « à partir de ce qu'il sait de ses semblables, de manière à transcender les quelques oppositions dont il a conscience » [24, p.43]. Voici chez l'opinant deux exemples représentatifs où celui-ci s'adresse à cet universel « être humain compatissant » :

> **Le problème, c'est que certaines personnes sont atteintes de maladies incurables et qu'elles souffrent énormément. Je crois qu'il serait normales** de leurs offrir le repos éternel sans qu'elles aient besoin de passer à travers la souffrance et la douleur. (Mémoire de Kariane Thibault, nous soulignons.)

> Le temps ne serait-il pas venu de dissocier la loi des humains des croyances religieuses? Devant une maladie incurable, accompagnée de souffrance et d'une perte d'autonomie avancée**, la plupart d'entre nous souhaiteraient d'abréger ses souffrances**. (Mémoire de Jocelyne Pichette, nous soulignons.)

Une « violence verbale »?

Résumons-nous: on ne s'insulte pas dans les mémoires que nous avons analysés, mais on réfléchit de manière dichotomique; on présente son point de vue comme évident. On prétend souvent à l'universalité et à l'objectivité de son propos. Les participants agissent même comme s'il existait une seule définition de la formule « Mourir dans la dignité » et une seule vérité éthique (toutes ces manières d'écrire font partie de l'*ethos montré*). Ces manières de débattre relèvent-elles de la « violence verbale »? Peut-on parler de « violence verbale » quand par exemple une personne, se présentant comme un opinant, exprime sur le ton de l'évidence une croyance qui n'existe pas en dehors de sa subjectivité? Le « cela-va-de-soi » peut-il se concevoir comme une agression, une « violence », comme le pensait Barthes [29, p.101]? Le concept même de « violence verbale » est difficile à définir et est contestable. Son sens selon les personnes et l'époque peut être restreint ou s'étendre plus largement. Où commence la violence verbale? Dominique Mainguenau affirme par exemple que la violence verbale est une « notion intuitive qu'il est très difficile de traduire en termes linguistiques » [cité dans 11, p.177]. En élargissant le concept, son sens ne se dérobe-t-il pas? Une partie des débats sur le concept de violence (verbale) – avec des conséquences sociales importantes pour la reconnaissance et la lutte contre la violence – concerne donc l'ampleur à donner à ce concept : faut-il y donner une définition plutôt englobante ou la restreindre à des formes plus facilement observables empiriquement? Ce concept n'est pas seulement contesté sur le plan de sa définition, mais aussi de par sa connotation morale. Il s'agit assurément d'un concept normatif : « […] *it is a word that denotes a wrong; and hence the definition of violence is (implicitly and normally) a matter of judgment and politics.* » [30, p.10] Dire qu'une action, un texte, est « violent », c'est donc à la fois faire un constat analytique et, souvent, dénoncer moralement cette action, ce texte.

Le ressenti, la subjectivité, est au cœur des définitions de certains linguistes spécialistes de la violence verbale. Ici, ce concept est à comprendre comme « l'ensemble des pratiques langagières menaçantes ressenties comme des infractions contre la personne en tant qu'individu et en tant que membre d'une collectivité » [31, p.10]. Pour échapper au problème de définition du concept de violence verbale, Fracchiolla, Moïse, Romain et Auger [32] étudient la violence verbale via le phénomène de sa montée en tension, en décrivant les interactions verbales d'un point de vue linguistique et en tenant compte des représentations sociales liées à la violence et des différents contextes (spatial, temporel, sensoriel) où ces interactions se déroulent. Dans la définition précitée, la violence verbale est à comprendre au-delà des gros mots, de l'insulte, l'injure, le propos ouvertement raciste, haineux, homophobe, misogyne, stéréotypé, menaçant ou encore le propos qui réduit l'autre au silence. Dans le même sens élargi, Ruth Amossy retient les situations suivantes pour définir la violence verbale : 1) la pression ou la coercition est utilisée pour empêcher l'autre d'exprimer son point de vue; 2) la parole adverse est totalement déconsidérée; 3) l'adversaire subit des attaques personnelles (argument *ad hominem*); 4) l'adversaire ou son point de vue sont assimilés au Mal absolu; 5) des sentiments violents sont exprimés; 6) des insultes sont proférées; 7) on incite à la violence [11]. Selon les dires de l'auteure, cette liste n'est pas exhaustive. Ainsi, dans une acceptation élargie du concept de violence verbale, un discours pourrait être jugé violent sans comporter d'insultes. Un discours négationniste sans propos antisémites pourrait par exemple être jugé verbalement violent de par la nature même du propos tenu. Toute contestation ou critique, tout trait d'humour, discours politique ou idéologique, jugement (juridique ou quotidien), ne pourrait-il pas en ce sens élargi, être potentiellement désigné comme « agressif » ou « violent »? La rhétorique elle-même dans sa visée persuasive (convaincre/vaincre) pourrait se percevoir comme une violence. Ainsi, pour Chaïm Perelman, l'action de celui qui cherche à persuader l'autre constitue « […] une agression, car elle tend toujours à changer quelque chose, à transformer l'auditeur. Même lorsqu'elle vise à renforcer l'ordre établi, elle ébranle la quiétude de celui auquel elle s'adresse et dont elle veut soutenir les croyances menacées. » [Perelman, cité dans 33, p.323]

Non sans provocation, il pourrait même être affirmé que la violence est en réalité comprise au sein même de la langue [34] puisque celle-ci classifie, oblige – différemment, selon les langues – à dire les choses d'une certaine manière.

Un concept subjectif

Il y aurait certes quelques raisons de soutenir que le manque d'ouverture à la pensée de l'autre est un fait qui contraste objectivement avec la nature même d'une problématique pour laquelle il existe nécessairement des visions éthiques conflictuelles, des manières plurielles et contradictoires d'agencer des valeurs. Plus généralement, le manque d'ouverture à la pensée de l'autre (et les manières de dire des participants dans leur ensemble) contraste avec l'idéal de la démocratie délibérative qui perçoit l'engagement politique raisonnable comme consistant à « être prêt à écouter même ceux dont nous considérons qu'ils ont tort » [35, p.139]. Or les mémoires écrits analysés ici ne nous semblent pas ressembler à des dialogues où l'autre est véritablement écouté. Nous pourrions dès lors parler comme proposé en son temps par Abraham Kaplan [36] de « duologue », une sorte d'art de la non-écoute ou alors une écoute sélective, centrée sur elle-même, où les interlocuteurs ne sont pas véritablement ouverts les uns aux autres. Pourtant, si l'on voulait soutenir que ces manières communes de débattre des participants au débat sur l'euthanasie relèvent d'une « violence verbale », il faudrait reconnaître que c'est en partie notre ressenti personnel à la lecture des mémoires qui nous amènerait à parler en ces termes. Sans un attachement personnel à une éthique complexe [37], parlerions-nous de violence verbale? Aurions-nous envisagé de parler de violence

verbale si la polémique avait porté non pas sur une question éthique où nous avons une position personnelle, mais sur une question scientifique où, par manque de compétences, nous n'aurions aucun avis? Le coefficient de violence d'un texte est une affaire en partie subjective, contrairement au coefficient de violence d'une action physique par exemple. Dominique Garand [38] soutient par exemple que ce coefficient n'est pas à chercher dans l'acte illocutoire, mais avant tout dans l'effet perlocutoire du texte, c'est-à-dire dans les conséquences, les effets produits par le texte sur les pensées, les sentiments de l'auditoire. L'auteur souligne à quel point les individus et les sociétés ont des seuils de tolérance différents à la violence verbale. Le niveau à partir duquel le propos est jugé violent et inacceptable varie selon les personnes, les cultures, les temps. D'ailleurs, d'un point de vue sociologique, la dénomination de violence, verbale ou non, a tendance à s'étendre selon Laurent Mucchielli [39]. Poursuivant le long processus de pacification des mœurs que décrivait jadis Norbert Elias, nos sensibilités et normes affectives continuent d'évoluer : des pratiques autrefois tolérées sont désormais dénoncées, relevant d'une violence illégitime dénuée de sens. Le contexte d'interaction modifie également la perception. Les mêmes mots peuvent s'interpréter différemment selon les situations de communication. Ce qui sera qualifié de « violence verbale » dans un certain contexte et sera dénoncé, sera accepté ailleurs, perçu comme véhémence, comme force de conviction, conflit, trait d'humour, etc.

Limites de l'étude et positionnement personnel

Une des limites attachées à notre matériau consiste à ne pas connaître les conditions et le processus de production de ces textes « de prise de position ». Certains mémoires que nous avons analysés ont pu être délibérément aseptisés, neutralisés, à des fins stratégiques en vue « d'établir un consensus pratique entre des agents ou des groupes d'agents dotés d'intérêts partiellement ou totalement différents » [40, p.64]. Ce processus de neutralisation n'est ni forcément conscient, ni même stratégique. On peut penser que nombre de ces mémoires n'ont pas cette visée, car nous ne sommes pas ici, de manière générale, en présence de communicateurs professionnels. Cependant, la neutralisation du discours peut également résulter d'une intériorisation des normes dominantes, une anticipation des attentes des membres de la Commission spéciale, etc. La « présentation de soi » des intervenants peut ne pas correspondre à la personne réelle. Le personnage n'est pas l'acteur. Dans le cadre de cette étude, nous n'avons pas analysé, à l'aide d'entretiens par exemple, ce contexte de production.

À plusieurs reprises, notre texte semble exprimer un positionnement relativiste. Nous aimerions préciser que l'acceptation du pluralisme des vues éthiques n'implique pas nécessairement une posture relativiste absolue. Toute opinion éthique n'est pas à placer selon nous au même niveau. De plus, nous avouons ici ne pas savoir si des vérités existent ou non en éthique, c'est-à-dire s'il existe ou non en éthique quelque chose qui, en fin de compte, ne soit pas subjectif. Néanmoins, suivant ici la position prudente de Gabriel Abend [41], nous faisons en pratique, c'est-à-dire dans nos analyses, comme s'il n'en avait pas. Un mot enfin sur notre opinion sur l'euthanasie et les autres pratiques médicales qui lui sont associées. Pour nous, la distinction entre « tuer » (à la demande du patient) et « laisser mourir sans donner la mort » (à la demande du patient) ne nous apparaît pas éthiquement fondamentale, pour autant que les caractéristiques de l'action ou de son auteur soient les mêmes. Lorsque dans une situation donnée, l'action est bienveillante, lorsque par exemple celle-ci vise le respect de l'autonomie du patient, lorsque, à sa demande, c'est la qualité de vie de celui-ci qui est recherchée, peu importe au fond si l'action est une euthanasie, un suicide assisté, un arrêt de traitement ou une sédation palliative; la pratique nous apparaît éthiquement acceptable [42]. Dans des cas opposés où l'action serait entreprise pour des motifs crapuleux, par égoïsme, paresse, etc., toutes ces procédures médicales pourraient selon nous être éthiquement remises en question. Précisions que nous ne voulons pas forcément dire ici que tout agent vertueux ou toute action vertueuse soit éthiquement souhaitable.

Conclusion

La dignité et les droits humains, la sacralité de la vie, l'importance de l'autonomie, la primauté de l'individu ou du collectif, sont autant de croyances éthiques que certains individus tiennent pour vraies et défendent. Contrairement à la loi de la gravitation par exemple, les croyances éthiques sur lesquelles tant d'intervenants au débat sur l'euthanasie s'appuient n'ont pourtant aucune validité objective. Elles ont une histoire, sont nées dans l'esprit de quelques individus et se maintiennent plus ou moins bien, à travers des institutions (par exemple la Déclaration universelle des droits de l'homme, la naissance de la bioéthique aux États-Unis), des discours, des lois, des mythes qui les racontent, etc. Ces idées, « objets de discussion sans fin » [43, p.56], n'existent également que parce que des individus y croient. Certaines d'entre elles apparaissent ainsi plus vraisemblables que d'autres à un moment donné. Il en est par exemple ainsi aujourd'hui de l'idée d'égalité entre les êtres humains, une idée saugrenue pour la plupart des hommes et des femmes de l'Antiquité ou du Moyen-Âge. Il en est de même pour le caractère éthique de l'euthanasie ou du suicide assisté, des pratiques qu'une majorité de personnes vivant dans les pays occidentaux considèrent aujourd'hui comme éthiquement acceptables.

Le débat sur l'euthanasie que nous avons analysé ressemble à une guerre de position figée (ou à la guerre des Dieux dont parlait Weber) où la défense l'emporte sur l'attaque. Le ton d'évidence, la visée d'objectivité et d'universalité, l'unicité de la vérité éthique et des définitions sont des pièces d'artillerie lourde qui figent le rôle de chacun et immobilisent une ligne de front. Ces façons de dire et de débattre sur un sujet polémique construisent des réponses absolues et irréductibles masquant la subjectivité des croyances éthiques. Présentées comme telles, les opinions personnelles ou locales sont des positions facilement attaquables (« ce n'est *que* ton opinion »; « ton avis n'est que valable dans cette situation particulière ou pour tels individus »). Plus protecteurs et excluants sont les propos qui se présentent de manière évidente. Lorsque l'évidence éthique est présentée de manière indiscutable, c'est alors « le fait de la discuter qui paraît discutable », comme dit Bourdieu [cité dans 44, p.121]. Ces manières de débattre construisent donc des frontières éthiques peu poreuses entre les camps qui s'affrontent

sur le caractère éthique ou non de l'euthanasie. Le duologue est une non-rencontre, le rapport entre des lignes parallèles qui ne se croisent jamais [36]. On peut penser que tous les propos sur l'euthanasie échangés dans la consultation publique analysée doivent justement s'énoncer de cette manière puisque, selon nous, aucune preuve définitive ne pourra jamais être amenée pour que l'une des parties en présence remporte le débat sur le caractère éthique ou non de cette pratique. En public, la certitude doit peut-être se faire aveugle pour ne pas voir la « dangereuse » certitude de l'autre, celle qui en réalité se rapproche de la sienne, qui peut peut-être apparaître, par moments, tout aussi raisonnable que la sienne. En prenant position de la sorte, ces discours semblent ainsi ne jamais se rencontrer, comme l'écureuil de William James et son observateur, tournant sans fin autour de l'arbre dans la même direction.

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LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

A Response to Nico Nortjé's Review of *The Moral Work of Nursing*

Hazel Magnussen[1]

Texte discuté/Text discussed: Nortjé N. Review of: Magnussen H. (2017) The Moral Work of Nursing – Asking and Living with the Questions. Can J Bioeth/Rev Can Bioeth. 2019;2(2):15-16

Mots-clés
éthique infirmière, éthique des soins de santé

Keywords
nursing ethics, healthcare ethics

I am writing in response to Nico Nortje's review of my book, *The Moral Work of Nursing: Asking and Living with the Questions* [1], which was published in the March issue of this journal [2]. The reviewer effectively summarizes four themes in the book: "practical application and approach to nursing knowledge; the institutional challenges faced by nurses; the political reforms affecting the profession, and the social and technological problems that could create challenges for nurses." Suggesting that the book makes a contribution to global ethics, he refers to my accounts of northern nursing early in my career and recognition of *vestiges of colonialism* in Canadian healthcare. Reviews of current research regarding the moral nature of nurses' work in the broader context of healthcare, such as public health and home health in chapters 9 and 10, receive little attention.

The review highlights the section on burnout and workplace violence and bullying, which are discussed in chapters 12 and 13 on Nurses' Health and Psychological Health and Safety in the Healthcare Workplace. These are sensitive matters that may be perceived differently by readers, depending on their experience and understanding of the issues. The review states: "the book's frank discussion about workplace abuse (emotional, physical and sexual) stands out, drawing the attention of the reader to the fact that nurses are victims and arguing that there needs to be a collective stand against abuse and bullying." I am uncomfortable with this interpretation. I do not make reference to sexual abuse in the book, nor do I refer to nurses as victims. I note that nurses may be targets of abuse; but I deliberately try to avoid the word "victim" since for many, it implies powerlessness. In fairness, the review does include my call for a collective stand against abuse and bullying.

Perhaps the reviewer is referring to the fact that much of the moral work of nursing is related to the imbalance of power in the system as reviewed in chapter 5 on Power in Physician Nurse Relationship and in chapter 7 on Moral Distress in Nursing. From that power perspective, the moral work of nurses involves advocacy that requires moral courage when exercising moral agency. My goal in writing the book, *The Moral Work of Nursing*, was to validate and encourage nurses in their work; and to raise awareness of other readers of the uniqueness of the nursing experience and responsibilities in promoting safe and ethical healthcare for all.

Conflits d'intérêts
Je suis l'auteure de *The Moral Work of Nursing, Asking and Living with the Questions.*

Conflicts of Interest
I am the author of *The Moral Work of Nursing, Asking and Living with the Questions*.

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

Health Misinformation and the Power of Narrative Messaging in the Public Sphere

Timothy Caulfield[1], Alessandro R. Marcon[2], Blake Murdoch[2], Jasmine M. Brown[3], Sarah Tinker Perrault[4], Jonathan Jarry[5], Jeremy Snyder[6], Samantha J. Anthony[7], Stephanie Brooks[8], Zubin Master[9], Christen Rachul[10], Ubaka Ogbogu[11], Joshua Greenberg[12], Amy Zarzeczny[13], Robyn Hyde-Lay[2]

Résumé
De nombreuses pressions sociales, économiques et académiques peuvent avoir un impact négatif sur les représentations de la recherche biomédicale. Nous passons en revue plusieurs des éléments qui jouent un rôle de plus en plus pernicieux dans l'interprétation, le partage et l'utilisation de l'information sur la santé et les sciences; ce qui nous mène à nous intéresser au rôle du récit. Par conséquent, nous explorons comment les aspects narratifs sont utilisés dans divers contextes sociaux et environnements de communication, puis présentons des réponses novatrices susceptibles de contribuer à contrer les tendances négatives. Comme les méthodes de communication traditionnelles ont échoué à bien des égards auprès du public, des changements d'approche s'imposent, dont l'utilisation novatrice des récits.

Mots-clés
communication en santé, communication scientifique, réseaux sociaux, récit, santé publique

Abstract
Numerous social, economic, and academic pressures can have a negative impact on representations of biomedical research. We review several of the forces playing an increasingly pernicious role in how health and science information is interpreted, shared, and used, drawing discussions towards the role of narrative. In turn, we explore how aspects of narrative are used in different social contexts and communication environments, and present creative responses that may help counter the negative trends. As traditional methods of communication have in many ways failed the public, changes in approach are required, including the creative use of narratives.

Keywords
health communication, science communication, social media, narrative, public health

Introduction

There is growing recognition that numerous social, economic, and academic pressures can have a negative impact on representations of biomedical research. Empirical evidence indicates spin or interpretive bias is injected throughout the knowledge production process, including at the stage of grant writing, in the execution of the research, and in the production of the relevant manuscripts and institutional press releases [1-3]. The popular press, marketing forces, and online media also play significant roles in misrepresenting biomedical research [2,4-6]. Here, the wilful or unintended dissemination of misinformation through increasingly interactive media platforms also stands as a very real and growing concern [7,8] and presents a significant challenge to generating rational, evidence-based conversations about biomedicine generally, and its benefits and risks, in particular.

Exacerbating these forces, numerous trends have emerged which further complicate the science communication landscape, especially in the context of health. In this commentary, we review several of the forces playing an increasingly pernicious role in how information is interpreted, shared, and used. In particular, we focus on the role that narrative plays in communicating science and misinformation to explore how aspects of narrative are used in different social contexts and communication environments. While most people have an inherent understanding of storytelling, narrative has been defined as a type of communication that "describes the cause-and-effect relationships between events that take place over a particular time period that impact particular characters" [9]. Narrative is a powerful tool that can enhance engagement and understanding of both truths and falsehoods [10]. Online, and specifically in the context of misinformation (e.g., conspiracy narratives, pseudoscience), research has shown that the construction and dissemination of narratives requires the efforts of numerous participants with differing levels of engagement [11]. It is dynamic, incorporating numerous discursive elements (multiple sources, hashtags, hyperlinks, memes, etc.) as well as flexible, adopting and discarding both story elements and participants as time passes [11].

This commentary is not meant to be a comprehensive survey of emerging health communication developments or an exhaustive account of the role that narrative plays in that context. While many of the concerns and ideas presented herein are broadly relevant across many jurisdictions with advanced communication infrastructures, our focus is on the United States and Canada. We highlight elements that have increasingly troubled health communication in recent times and present creative responses that may help counter the negative trends. Indeed, as we will see, traditional methods of communication have in many ways failed the public, and changes in approach are required.

Online Communities

Much has been written about the growing influence of social media on public discourse, including in the context of health [12]. While traditional news outlets, such as newspapers, remain the dominant source of science information [13], social media platforms – including Facebook, Twitter, Instagram, YouTube and Reddit – have become important sources of health information and sites for public engagement and community-building [14-18]. Studies show younger generations are increasingly willing to share personal health information online, and people of all generations increasingly go online to seek

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others with similar health concerns or conditions for information and support [19]. All age groups in North America use social media heavily [20,21], so the influence of social networking platforms will continue to be significant.

We know, however, that the health and science information on these platforms is often problematic [22,23]. Research has found, for example, that social media are used to spread harmful health messages, including, to cite just a few examples, antivaccine rhetoric [24,25], misinformation about the Zika virus [26] and Lyme disease [27], as well as Ebola-related prevention and treatment strategies [28]. Studies have also shown that falsehoods can diffuse "farther, faster, deeper and more broadly" than the truth [29], and while notions of the "echo chamber" might be overstated [17,30], online environments do exhibit polarization characteristics where misinformation can spread virally [31].

Social media also clearly affects bioscience communication, and this influences not only the general public's understanding of health and science information but also research funding allocation and policy development [32-34]. Clinicians, scientists and funding institutions can all experience pressure to fund research or change policy in response to social media advocacy. For example, roughly 10 years ago a large online community advocated in Canada for an unproven and scientifically implausible intervention for multiple sclerosis called "liberation therapy", based on anecdotal evidence that it could generate life-altering improvements for people afflicted by the condition [32]. This pressure led the Canadian Institutes of Health Research in 2010 to convene an expert panel on the topic [32,33], and allocate funds to conduct research, the resulting data of which showed the treatment to be ineffective [35].

Social media consists of diverse communication ecosystems, shaped by the algorithmic logistics of each particular platform. A core component shared by these ecosystems is "social homophily": how people more commonly associate and are more influenced by those similar to themselves [14,18,36,37]. The clustering of individuals online into various communities highlights the role that algorithms as well as public intellectuals, celebrities, or influencers can play in knowledge transmission [38-42]. In more contentious social contexts, sharp divisions can emerge between various groups, resulting in the creation of "discourse coalitions" [43,44], where communal terms and arguments are used to promote perspectives [45-48]. Here, heuristics such as confirmation bias [49] and information avoidance [50] work towards enforcing rather than questioning established beliefs. Research has shown there is polarization between antagonistic discourse communities [37,48,51], raising questions about how to transmit accurate information through groups with differing perspectives [37,48,52]. This matter is becoming increasingly complicated with the rise of misinformation, or "fake news" [52,53]. Research has also shown that fake news affects everyone – even those who know the information to be false [54]. Indeed, mere exposure to information can influence belief [55] and repeated exposures can strengthen perceptions of authenticity [56,57]. Online bots (software robots) are also playing a role by taking advantage of platforms' algorithms to promote particular stories, events or narratives, drown out others, and influence online social ecosystems [52,58,59].Continued research of online discourse is required, including on platforms such as Instagram, Reddit, YouTube, and blogs. These popular spaces exhibit novel and powerful uses of narrative and pose numerous methodological challenges, requiring collaborative interdisciplinary approaches.

A growing body of literature suggests that narratives can have tremendous sway. Across disciplines, studies have shown how narratives facilitate recall [9,60] and spur emotional responses [61-65], which in turn can increase empathy [9,60,62] and perceptions of a source's trustworthiness [66,67]. Narratives therefore possess some power of persuasion [66,68,69], whether that be to solidify one's membership in a particular identity group [60,69] or merely to draw one towards a particular perspective [68]. Recent research has shown how misinformation, and even credible information interpreted and then skewed in a particular manner, can serve as a means of substantiating a particular narrative [11]. As a result, a narrative can gain strength from the supportive "evidence" it creates and draws upon [11]. Social media platforms have become powerful tools for sharing narratives about therapies [70], experiences [71] and emerging science. Social media also allows individuals to form parasocial relationships [72], which may heighten the influence of messaging [73] and strengthen social homophily. Indeed, research has noted that "a person like you" is just as credible a source of information as an academic or technical expert [74].

Not all participation in online communities is necessarily negative. Research has shown how interactive online networks can help to connect individuals seeking similar health information or dealing with similar conditions. Benefits from this connectivity include sharing information and receiving support, which in turn can help individuals consider health strategies or treatment options, build social networks, cope with depression, and overcome social stigma [16,19,75,76]. For example, Mumsnet.com, based in the UK, has approximately 5 million monthly visitors, who use the website to discuss a range of motherhood topics including miscarriage and breastfeeding [75]. On the platform patientslikeme®, with over 600,000 members with nearly 3,000 different conditions, 30% of patients with epilepsy did not know someone with epilepsy prior to using the site [75]. Research has also shown that on a general non-health specific platform like Instagram, women congregate around breastfeeding related hashtags and images, creating supportive networks [77]. Questions remain, however, around the accuracy of information, especially when highly-personal narratives are generated and circulated [63]. Specifically in the case of vaccines, it is now well-known that anti-vaccination perspectives exist and are propagated through social media sites like YouTube and Facebook, the latter of which includes organized groups dedicated to this cause [78-81].

Implicit Hype and "Scienceploitation"

The phenomenon of science hype – the exaggeration or excessive promotion of scientific developments and applications – is getting more attention from the scientific community [82,83] and popular media [84].The sources of this hype are complex and

interrelated, and they exist throughout the knowledge production pipeline [2]. Science hype can cause a range of social issues, including, *inter alia*, eroding public trust [83], confusing policy debates [35], and facilitating the premature implementation of technologies and the marketing of unproven therapies [85,86]. While the problems with explicit hype are increasingly recognized, we are now seeing the growth of a more subtle form of hype.

The popular press, for example, sometimes presents emerging therapies in a manner that implies efficacy [87]. This "implicit hype" occurs when unproven or even disproven interventions are presented as routine and/or uncontroversial in media reports. For example, recent research about the media portrayal of platelet rich plasma (PRP), an unproven therapy for various ailments including musculoskeletal injuries, found that it was most commonly covered in sports-related stories, and specifically in relation to elite athletes using the therapy as part of injury recovery or performance preparation [87]. The therapy was portrayed as routine, and its use by elite athletes may imply that it is a cutting edge treatment [87]. But given the actual state of research surrounding PRP [88,89], these representations are implicit hype. These stories may have significant sway with the public as they combine high exposure (a story about a professional athlete in popular media), an interesting narrative (an athlete recovering from injury), and a suggestion that an emerging therapy is efficacious. Since narrative communication is persuasive, this implicit hype may be more resonant with most audiences than typical communications about the unproven nature of a therapy.

Another issue is that of pseudoscience, that is to say theories, assertions or interventions that claim or appear to be scientific but are not. Pseudoscientific phraseology is too often accepted in popular media without any critical reflection. A recent study of Spanish science journalists found that only 44.9% agreed that pseudoscientific information in the media is dangerous, with many respondents dismissing concern or expressing apathy as to the effects of false messaging in the media [90]. Journalistic apathy concerning the distinction between science and pseudoscience can only further hinder public understanding of novel health or biomedical developments, especially in cases where the public only has basic knowledge about the topic at hand.

There are also explicit marketing strategies that leverage hype. Recent research has shown, for example, that some complementary and alternative medicine (CAM) providers combine hype and stem cell language in their marketing for both unproven stem cell therapies and other pseudoscientific products and therapies [91]. For instance, the language of quantum physics [92], genetics [93], and microbiome research [94] have been used to market therapies that have not been scientifically tested. By capturing the interest around the scientific domain of stem cells, marketers can increase the attractiveness of, and exposure to, their products – even if they have no actual relation to stem cells. This phenomenon, which we call "scienceploitation", occurs in many contexts but is understudied [91]. Because this type of misrepresentation uses language that can confer scientific legitimacy, it can be particularly difficult to address, especially if it is accompanied by other tokens of legitimacy (e.g., reference to publications in predatory journals or registered clinical trials) [95] and is part of a broader, memorable narrative.

Patients in the Public Sphere

Patients are also harnessing the power of the narrative to promote public awareness, build community and raise money and a profile for certain therapies. For example, the use of online crowdfunding has recently grown at an explosive rate [96,97]. Health related crowdfunding has proven to be a highly competitive affair, and campaign leaders often attempt to construct "worthy bodies" that justify or morally compel donation [98]. In this way, the creation of powerful and compelling narratives is a key aspect of successful crowdfunding [99-101]. A similar effect can occur with public solicitation for organ donation, where patients can be judged not only on their personal appearance but also the biographical narratives they create to engender sympathy [102,103].

Narratives often include information about the interventions sought and their efficacy, creating problems when these interventions are unproven or pseudoscientific. Indeed, recent research has shown that the narratives of crowdfunding campaigns for unproven stem cell therapies "underemphasize risks", "exaggerate the efficacy" and "convey potentially misleading messages about stem-cell based interventions" [104].

These examples show another way in which persuasive narratives can mislead. Marketing can extend into the personal narratives of individuals seeking aid, as campaigns often propagate the marketing language of the clinics where treatment is sought [104]. This can act as a legitimizing force for unproven interventions, and legitimacy is subsequently reinforced when popular media outlets publish uncritical human-interest stories about such campaigns [105].

Policy Options

As noted, science communication is happening in the context of a research translation process prone to hype [2], a media environment rife with ambiguity and false balance [106-108], and an online environment marred by inaccurate news [52,53]. Meanwhile, the potential sway of the misinformation is often heightened by the use of engaging narratives. These forces add to the complexity of crafting effective, evidence-based policy responses. Complicating things further is the reality that not all audiences are affected by narratives in the same manner or to the same degree. Some research has shown, for example, that audiences engaging a topic peripherally are more likely to find testimonials more convincing and persuasive than those highly motivated to engage the topic and analyze the information [109]. With a wide range of audiences encountering numerous and

diverse topics in popular media at any given time, the role of narrative is likely having some impact on how the public makes sense of biomedical issues – particularly in the contexts of nascent, developing science and health topics about which little is known.

Addressing the spread of misinformation through persuasive narratives seems essential, though it will not be easy. Many of the entities that twist information operate over the Internet. When online sources and communities come under fire, they can quickly and easily spring up in a new form elsewhere. The law can be an unwieldy, slow and overly blunt tool in the face of amorphous messaging and shifting actors. Still, existing legal and regulatory tools can have important roles to play in the right contexts. We must better enforce existing truth in advertising law, which can act to curb misrepresentations in marketing and the proliferation of unproven and disproven treatments [85,91,110]. Given this is a complaint driven regulatory framework, non-profit organizations and individuals can play an important role, as we have seen, for example, with recent claims of false advertising made against Goop by the non-profit group Truth in Advertising [111]. The law of negligent and fraudulent misrepresentation is also useful for all manner of claims that are false and relied upon [112]. And when health care professionals are involved, as is often the case [113], governing regulatory bodies should take steps against members who breach practice norms through the provision of misleading information [114,115].

Despite these useful avenues, law and policy have limits. They can be slow, expensive, and, when government action is needed, constrained by political considerations. As such, more informal policy responses should also be considered. Individual public advocacy, at both the grassroots level and among prominent experts, can have a significant effect [116-118]. For example, David Stephan, whose son died of meningitis in 2016 after his parents treated him solely with “natural remedies”, was removed as a keynote speaker from a wellness exposition in Western Canada after backlash on Twitter caused many corporate event sponsors to threaten to pull out if he was left on the program [119]. One important aspect of this success story was the timeliness of the critical response online. Real time social media interventions that rapidly counter misinformation are needed to ensure that belief systems founded on misinformation do not take hold [25]. Codified standards, norms, and guidelines in the scientific community defining appropriate media engagement – as some scientific societies have begun to develop [120] – are imperative to encourage a sense of responsibility to engage with and correct misinformation in the public sphere. Further, influential and reputable voices from various communities need to persistently encourage responses from powerful social media platforms regarding their influential role in information dissemination [121]. Some positive responses from platforms are already evident [81,122,123], but these need continual monitoring. It also necessary for public health initiatives to move beyond the monitoring of online communities and begin developing ways to engage effectively with them, especially those existing on established and popular platforms outside of traditional public health institutions and practices.

Importantly, it should also be possible to use a narrative communication style to improve public understanding of evidence-based medicine, both through social media and more traditional avenues. To do so effectively will require health and science communicators to recognize the important research around “virality” [124-126] in terms of both information dissemination and interaction with platform algorithms, and to design communication strategies that use these findings to their benefit. Examples of this type of messaging are already evident [127] and can be drawn upon to experiment with new approaches. Further, scientists and science communicators new to social media should learn tactics and strategies from successful colleagues. The power of social media and the impact of narrative are prevalent and strong, so there is an imperative to strategically draw upon their advantages to counter some of their more problematic applications. For example, research has shown that narratives presenting the ramifications of not vaccinating – specifically children’s suffering from preventable illness – can have a real impact on intention to vaccinate [128,129]. Additionally, clear and definitive statements with a narrative component, made by respected and trusted voices will prove highly useful, and also provide dependable resources upon which journalists can rely.

Opinion editorials offer another useful pathway for narrative communication; indeed, recent research has found them to have an influence on public perception [130]. That said, science writing could also benefit from narrative style, if applied in a manner that does not compromise the truthfulness and comprehensiveness of the content [131]. We should not use narratives to fight anecdote with anecdote. Rather, narratives can serve as a vehicle not only to communicate science and relevant science-informed policy in a more engaging and digestible manner but to foster an understanding around “the process and credibility of scientific reasoning” [132]. The spread of misinformation causes real harm. Unfortunately, countering this noise is growing increasingly more complex and challenging. It will require the use of a host of science communication tools and strategies, including the creative use of narratives.

Policy and communication responses

Legal and Policy tools

- Better enforcement of existing truth in advertising law, and/or improvements thereto
- Regulatory policy change and enforcement for health professionals spreading misinformation
- Policy outlining rules for and encouraging expert media engagement and the use of narrative
- Litigation

Social Tools

- Advocacy by non-profit organizations (e.g., litigation against Goop)
- Advocacy by individuals (official complaints, social media activism)
- Expert engagement in the popular press and on social media to counter misinformation
- Encouragement of social media companies to combat misinformation by modifying platforms
- Opinion editorials
- Use of creative communication strategies that utilize narratives, art, video, etc.
- Support and adoption of further research on effective communication strategies

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COMPTE RENDU / REVIEW

Book Review: F. Baylis & A. Ballantyne (2016) *Clinical Research Involving Pregnant Women*

Canadian Bioethics Society / Société canadienne de bioéthique
En collaboration avec / In collaboration with

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Résumé
Les preuves scientifiques à l'appui des soins prénataux sont rares en raison de l'exclusion généralisée des femmes enceintes de la recherche clinique. L'ouvrage de Baylis et Ballantyne, *Clinical Research Involving Pregnant Women*, est un puissant défenseur de la promotion de la recherche clinique avec des femmes enceintes, bien que quelques questions méritent une attention plus soutenue pour faciliter cette recherche.

Mots-clés
recherche clinique, pratique fondée sur des données probantes, fœtus, justice, sélection des patientes, femmes enceintes, soins prénataux

Abstract
There is a paucity of scientific evidence to support prenatal care due to the wide exclusion of pregnant women from clinical research. Baylis and Ballantyne's book, *Clinical Research Involving Pregnant Women,* stands as a powerful advocate for promoting clinical research with pregnant women, although a few issues may deserve further attention to facilitate such research.

Keywords
clinical research, evidence-based practice, fetus, justice, patient selection, pregnant women, prenatal care

Fair participant selection is one of the basic ethical principles for conducting clinical research [1]. Specifically, in terms of women, the Canadian research ethics guideline stipulates that: "Women shall not be inappropriately excluded from research solely on the basis of their reproductive capacity, or because they are pregnant or breastfeeding." [2] Nevertheless, pregnant women have been widely excluded from clinical research across jurisdictions despite their needs for medication and healthcare procedures for both obstetrical and non-obstetrical conditions. Recognizing the underrepresentation of pregnant women in clinical research as a justice issue, in their edited book *Clinical Research Involving Pregnant Women*, Baylis and Ballantyne have compiled the scholarly work of leading authors to argue for a paradigm shift in understanding pregnant women as research participants [3]. Overall, this book stands as a powerful advocate for promoting clinical research with pregnant women, although a few issues may deserve further attention to facilitate such research.

Part I elaborates on clinical problems generated by an almost automatic exclusion of pregnant women from clinical research. The lack of scientific evidence to guide prenatal care seriously compromises both maternal and fetal health. The main argument is clear: Pregnant women should be presumed eligible to participate in clinical research. *Part II* examines reasons behind excluding pregnant women from clinical research, such as fetal safety, liability, and insufficiency of regulatory guidance. An empirical study with pregnant or postpartum women illustrates their attitude of refraining from using medication during pregnancy as well as emotional and physical distress due to the fear of harm when they had to use medication. *Part III* focuses on theoretical issues, specifically, alleged vulnerability of pregnant women and key concepts in study designs. Two chapters concern the inappropriateness of attempting to protect pregnant women by identifying them as a vulnerable population while the other two chapters question critical concepts in study design, namely, the notion of equipoise and randomized controlled trials (RCT). *Part IV* introduces a variety of topics through case studies, starting off with research investigating lifestyle interventions, which is a shift from *Parts I* to *III* where much discussion appears to revolve around medication. Other topics in *Part IV* include cutting edge and/or ethically charged issues, such as maternal gene transfer, research with women seeking abortion, and uterine transplantation.

This book persuasively illustrates current clinical problems and potential paths to enhance clinical research with pregnant women. However, a few critical issues that deserve more discussion include strategies to improve understanding by the general public about clinical research with pregnant women, additional costs for including pregnant women in research, and emerging study designs that could support research with this particular population.

First, a paradigm shift of this contentious issue requires a wide consensus among the general public. In this book, Wild and Biller-Andorno (Chapter 7) have drawn upon their empirical work to illustrate that pregnant women considering participation in research would not accept any fetal risk. In societies where people expect a healthy baby to be born, a persistent desire for fetal safety across cultures is extremely challenging to address. Baylis and MacQuarrie (Chapter 2) rightly emphasize the risk of using drugs off label as part of clinical care – prescribed or over the counter – where monitoring is much less intensive compared with research contexts. Nevertheless, research inherently involves unknowns; and unknown risks in research are worrisome even with a sophisticated monitoring system, given a fetus with a high sensitivity to chemicals or other exposure due to rapid development in-utero. The general public, including pregnant women, may presume that research participation is riskier than receiving clinical care. Ideas are needed to inform the general public about risks, safety, and benefits of clinical research and the importance of research evidence to support maternal and fetal health. Promoting research with pregnant women requires understanding at a societal level to support pregnant women, their partner/family, researchers, and sponsors toward the inclusion of pregnant women in research.

Second, the inclusion of pregnant women in clinical research is costly, even though they constitute a relatively small market. Mandating pregnant animal studies for any product that may be useful for pregnant women, as Ells and Lyster suggest (Chapter 6), may be a way forward. Nonetheless, conducting pregnant animal studies as a prerequisite and a separate analysis for pregnant humans entails additional costs. Will pharmaceutical companies or funding agencies be ready to fund projects for

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including pregnant women? In societies where funding can be a major delimiting factor, researchers have been frustrated with resource constraints. Moreover, sponsors as well as researchers may perceive increasing liability concerns for including pregnant women, which might incur further costs. Securing adequate resources is a huge barrier to be addressed in conducting clinical research with pregnant women.

Third, emerging study designs may be a reasonable topic to discuss when seeking optimal approaches to researching pregnant woman. Building pregnancy registries is recommended in two chapters, one from risk perspectives (Ballantyne and Rogers, Chapter 8), and the other from study design perspectives (Healy and Mangin, Chapter 11). Pregnancy registries are indeed useful as they can help accumulate clinical data that informs clinical practice without exposing anyone to additional risks for the sake of research. Healy and Mangin (Chapter 11) argue that a pregnancy registry from "the greatest possible input from the widest range of sources" will be an ideal resource for clinical decision-making. They also lay out reasons against RCTs and the difficulty of employing their recommended approach involving "challenge-dechallenge-rechallenge" tests in drug studies with pregnant women. Nevertheless, the research community has been making advancements in trial design to complement conventional RCTs, the current gold standard. Novel study designs that are in line with precision medicine aim at more tailored approaches in contrast to one-size-fits-all approaches. Also worth considering are adaptive designs where some features are adapted during the course of research based on the data collected earlier in the study. These study designs are all worthy of consideration in the careful crafting of research designs to include pregnant women.

Clinical Research Involving Pregnant Women may interest a wide readership, such as clinicians across specialties who treat pregnant women in their practice, potential investigators of research with pregnant women, basic scientists in reproductive sciences, policy makers, lawyers, and ethicists. Informing the readers, this book sparks further questions and discussions that may keep the ball rolling toward a fair inclusion of pregnant women in clinical research.

Conflits d'intérêts
Aucun à déclarer

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None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Les grèves de médecins en République Démocratique du Congo : quels repères éthiques généralisables?

Laurent Ravez[1], Stuart Rennie[2], Robert Yemesi[3], Jean-Lambert Chalachala[4], Darius Makindu[3], Frieda Behets[5], Albert Fox[1], Melchior Kashamuka[6], Patrick Kayembé[6]

Résumé

Depuis plusieurs années, la République Démocratique du Congo est le théâtre de grèves menées par les médecins du pays. Les revendications des grévistes en question sont essentiellement financières et statutaires, et visent à faire pression sur le gouvernement. Dans ce pays, comme c'est le cas presque partout dans le monde, les grèves médicales sont autorisées. Tout travailleur a le droit de dénoncer par la grève des conditions de travail jugées inacceptables. Mais les médecins sont-ils des travailleurs comme les autres? N'ont-ils pas des obligations morales particulières liées aux spécificités de leur profession? Pour éclairer ces questions, les auteurs de cet article proposent trois repères moraux essentiels généralisables à des situations de grèves médicales ailleurs dans le monde. Le premier porte sur la reconnaissance du droit de grève pour les médecins, y compris pour des motifs strictement financiers. On ne peut demander à des professionnels de santé d'exercer leur métier dans des conditions de travail inhumaines ou sans un salaire permettant de faire vivre leur famille. Le deuxième repère estime que l'on ne peut pas accepter que ce droit de grève s'exerce en sacrifiant les patients les plus fragiles et en niant ainsi l'essence même de la profession médicale. Un troisième repère vient complexifier la réflexion en rappelant que l'extrême délabrement du système de santé congolais rend impossible l'organisation d'un service minimum de qualité en cas de grève. Pour sortir de ces difficultés, nous proposons une alliance thérapeutique nationale entre les médecins et les citoyens pour replacer les patients au centre des préoccupations du système de santé.

Mots-clés

grève, médecins, éthique, droits humains, République Démocratique du Congo, alliance thérapeutique

Abstract

For several years, the Democratic Republic of Congo has been the scene of strikes by the country's doctors. The strikers' demands are essentially financial and statutory and are intended to put pressure on the government. In this country, as is the case almost everywhere in the world, medical strikes are allowed. Every worker has the right to denounce by strike working conditions that are considered unacceptable. But are doctors just like any other workers? Do they not have particular moral obligations linked to the specificities of their profession? To shed light on these questions, the authors of this article propose three essential moral benchmarks that can be generalized to medical strike situations elsewhere in the world. The first concerns the recognition of the right to strike for doctors, including for strictly financial reasons. Health professionals cannot be asked to work in inhuman working conditions or without a salary to support their families. The second benchmark argues that it is unacceptable for this right to strike to be exercised if it sacrifices the most vulnerable patients and thus denies the very essence of the medical profession. A third benchmark complicates the reflection by reminding us that the extreme dilapidation of the Congolese health system makes it impossible to organise a minimum quality service in the event of a strike. To overcome these difficulties, we propose a national therapeutic alliance between doctors and citizens to put patients back at the centre of the health system's concerns.

Keywords

strike, doctors, ethics, human rights, Democratic Republic of Congo, therapeutic alliance

Introduction

Ces dernières années, la République Démocratique du Congo (RDC) a connu de nombreuses grèves au sein du corps médical. Les revendications de ces médecins sont essentiellement financières. En RDC, beaucoup de médecins sont payés par l'État. Or celui-ci peine à honorer ses engagements à l'égard de ses agents de santé. Beaucoup de médecins se plaignent d'être mal payés et certains ne sont simplement pas payés.

Dans cet article principalement axé sur une réflexion d'ordre éthique, nous aimerions mettre en tension trois repères moraux essentiels appliqués aux récentes grèves médicales en RDC. Le premier est de rappeler que les mouvements de grève de médecins correspondent à un droit fondamental de tout travailleur auquel celui-ci peut recourir face au comportement jugé abusif de son employeur. Si celui-ci n'assume pas ses responsabilités à l'égard de ses agents, il est légitime pour ceux-ci de revendiquer le respect de leurs droits et de faire grève s'ils n'obtiennent pas satisfaction. Le deuxième repère que nous proposons est probablement inséparable du premier : le droit de grève pour les médecins doit être encadré par des repères éthiques liés aux spécificités de la profession. Ainsi, on peut difficilement accepter qu'une grève médicale ne soit pas accompagnée d'un dispositif sanitaire minimum pour assurer les urgences. Mais un troisième repère est nécessaire si l'on veut rendre compte de la complexité des situations : face au délabrement du système de santé congolais, il faut pouvoir comprendre le désarroi des médecins du pays dont on exige ce qu'il leur est parfois impossible d'offrir. Ainsi, on peut comprendre qu'il soit difficile pour les médecins congolais d'assurer un « service minimum » en cas de grève, alors même qu'un tel « service minimum » ne peut parfois pas être offert dans le cadre du fonctionnement habituel des structures de santé, faute de moyens suffisants. Mais de telles difficultés ne peuvent cependant pas justifier l'abandon des patients.

Les réflexions que nous proposons prennent certes appui sur le contexte spécifique de la RDC, mais nous montrons dans nos conclusions qu'elles pourraient inspirer des questionnements plus larges sur la légitimité des grèves menées par les professionnels de la santé.

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Le contexte socio-économique des grèves médicales en RDC

Depuis la fin des années 1980, la RDC est confrontée à d'énormes difficultés qui minent son économie et détricote son tissu politico-administratif, entraînant dans la misère une partie importante de la population. La RDC figure aujourd'hui parmi les pays les moins développés de la planète, ce qui contraste avec l'énorme potentiel et les immenses ressources dont regorgent son sol et son sous-sol. En 2016, le Programme des Nations Unies pour le Développement (PNUD) situait la RDC à la 176ème place sur 188 pays classés pour son indice de développement humain. Ainsi, plus de 63% de la population vit sous le seuil de pauvreté, ce qui est supérieur à la moyenne sous régionale de 44% [1].

Dans ce contexte de pauvreté généralisée, une économie de la débrouille guide la vie de la plupart des citoyens. Peu d'entre eux ont un emploi dans le secteur formel, ce qui ne fait pas de ceux-ci des inactifs, mais les fait néanmoins entrer dans la catégorie des chômeurs dans un sens élargi incluant des personnes qui « face à une absence d'opportunités sur le marché du travail, les gens peuvent en effet choisir de s'engager dans d'autres activités empêchant leur disponibilité immédiate ». Pour ce genre de chômeurs, différents de ceux que l'on rencontre en Occident, le taux de chômage tourne autour d'un tiers de la population selon les statistiques officielles [2]. Dans le secteur formel, l'État, à travers la fonction publique et ses différents services spécialisés, constitue le principal employeur du pays avec plus d'un million de fonctionnaires [3]. Ce nombre augmente d'année en année en raison du manque de débouchés dans le secteur privé et des avantages propres à un emploi dans la fonction publique.

Confronté à d'innombrables défis, l'État congolais peine à maîtriser cette pléthore d'agents et à leur assurer un salaire décent. Dès lors, beaucoup de fonctionnaires ne parviennent pas à faire vivre leur famille avec leurs maigres revenus et d'autres ne sont tout simplement pas payés. Cette situation chaotique est à l'origine d'une grogne sociale quasi permanente débouchant régulièrement sur des grèves de fonctionnaires : les enseignants du primaire et du secondaire, les professeurs d'université, les magistrats et bien entendu les professionnels de la santé. Mis au pied du mur, l'État est alors contraint pour préserver la paix sociale de négocier avec les délégations syndicales et de conclure des accords en promettant d'améliorer la situation. Chaque corps professionnel a bien sûr ses revendications spécifiques en plus de revendications d'ordre général qui tournent le plus souvent autour des salaires. Les gouvernements successifs du pays ont pris l'habitude de négocier au cas par cas et à faire des promesses d'amélioration, parfois irréalistes, juste pour calmer la grogne sociale et remettre les gens au travail. Les promesses du gouvernement congolais débouchant rarement sur des mesures concrètes, un cycle infernal s'installe de manifestations et de grèves plus radicales que les précédentes avec de nouvelles négociations.

Les médecins travaillant comme fonctionnaires au sein des divers services du Ministère de la Santé et au sein des structures publiques de soins s'inscrivent dans cette logique politico-administrative. Portées par de nombreuses grèves, certaines revendications des médecins ont fini par être au moins partiellement satisfaites, ainsi le paiement de certaines primes en plus du salaire, le réajustement du traitement au taux réel du marché et non plus à un taux forfaitaire désavantageux fixé par le gouvernement, l'intégration des médecins nouvellement engagés aux listes de paie ainsi que la montée en grade selon les statuts de fonctionnaires de carrière avec des conséquences non négligeables sur les différentes rémunérations[1]. Mais les puissants syndicats médicaux, le Syndicat National des Médecins du Congo (SYNAMED) et le SYMECO (Syndicat des Médecins du Congo) déplorent le manque de réactivité du gouvernement [5].

L'État congolais prend très au sérieux les revendications des médecins, car il sait combien les grèves médicales sont redoutées par une population dont la grande majorité des citoyens n'a pas les moyens de se tourner vers les structures privées et encore moins d'aller se faire soigner à l'étranger. Au Congo, l'accès aux soins dans les hôpitaux publics n'est ni plus ni moins qu'une question de vie et de mort pour cette population.

Bien conscientes des effets désastreux de leurs grèves sur la population, les organisations syndicales des médecins organisent les mouvements des grèves en veillant à maintenir un service minimum pour les urgences pendant que les discussions ont lieu avec les responsables gouvernementaux, comme ce fut le cas en février 2017. Mais en août de cette même année, face au silence du gouvernement, le mouvement de grève s'est radicalisé et a débouché sur des grèves de plusieurs jours sans service minimum (« grèves sèches »), les médecins ne prenant en charge dans le meilleur des cas que les patients déjà hospitalisés [6-7]. Même si on ne dispose pas de chiffres officiels, la presse congolaise fait état de plusieurs dizaines de décès provoqués par ces grèves [8]. On peut enfin signaler qu'un préavis de grève lancé le 23 avril 2018 a rapidement pris fin le 30 avril avec l'annonce par les syndicats de la satisfaction de leurs revendications [9].

La grève est un droit pour tous les travailleurs moyennant le respect de certaines conditions

Une majorité de pays dans le monde reconnaissent que la grève constitue un droit pour tous les travailleurs. L'Organisation Internationale du Travail (OIT) propose des balises pour l'exercice de ce droit. S'exprimant au travers de deux organes de son système de contrôle, le Comité de la liberté syndicale et la Commission d'experts pour l'application des conventions et recommandations, l'OIT a, dès 1952, clairement défendu l'idée que « le droit de grève était un droit fondamental des

[1] Le salaire d'un médecin travaillant pour l'État est compris, en fonction de son grade, entre 91 182 Francs Congolais (plus une prime de 882 603 FC) et 125 147 (plus une prime de 1 354 672 FC), soit en additionnant salaire et prime, entre 622 USD et 945 USD (cours du 25/07/18) [4].

travailleurs et de leurs organisations » [10], en définissant le champ d'application et ses limites. L'OIT reconnaît cependant la possibilité pour un État d'interdire la grève à certains fonctionnaires exerçant dans des « services essentiels » [10].

Dès 1983, une commission d'experts du Bureau International du Travail (secrétariat permanent de l'OIT) a proposé une définition de ces « services essentiels ». Il s'agit de services « dont l'interruption mettrait en danger, dans l'ensemble ou dans une partie de la population, la vie, la sécurité ou la santé de la personne » [11]. Il est évident que le secteur hospitalier fait partie de ces services essentiels, à l'instar par exemple des services d'électricité, des services d'approvisionnement en eau, des services téléphoniques ou de contrôle du trafic aérien [12]. Cela étant dit, les experts de l'OIT évoquent également les « garanties compensatoires pour les travailleurs privés du droit de grève » : « Lorsque le droit de grève a été restreint ou supprimé dans certaines entreprises ou services considérés comme essentiels, les travailleurs devraient bénéficier d'une protection adéquate de manière à compenser les restrictions qui auraient été imposées à leur liberté d'action » [12].

Un dernier concept mérite d'être précisé : c'est celui de « service minimum ». Les experts de l'OIT l'envisagent comme une solution possible « dans les situations où une limitation importante ou une interdiction totale de la grève n'apparaît pas justifiée et où, sans remettre en cause le droit de grève de la plus grande partie des travailleurs, il pourrait être envisagé d'assurer la satisfaction des besoins de base des usagers ou encore la sécurité ou le fonctionnement continu des installations » [12]. Mais il est clair qu'un tel service minimum ne devrait être imposé que « dans les services dont l'interruption risquerait de mettre en danger la vie, la sécurité ou la santé de la personne dans une partie ou dans l'ensemble de la population (services essentiels au sens strict du terme) » [12].

Le droit de grève est classiquement présenté comme la seule arme efficace dans les négociations collectives contre l'arbitraire patronal qui sans ce droit pourrait imposer n'importe quelles conditions de travail. La législation congolaise s'inscrit parfaitement dans cette logique internationale. Ainsi, le droit de grève est-il reconnu par la Constitution [13] en son article 39[2], ce qui signifie implicitement que l'État congolais est responsable à l'égard des conséquences possibles des grèves. Concernant plus spécifiquement les fonctionnaires, la Loi n°16/013 du 15 juillet 2016 portant statut des agents de carrière des services publics de l'État, Article 93 garantit le droit de grève pour tous les agents des services publics de l'État. L'exercice de ce droit ne peut être limité que dans les conditions fixées par la loi, notamment pour tenir compte du fonctionnement régulier des services publics d'intérêt vital, qui ne peuvent souffrir d'aucune interruption. Le Décret n°06/130 du 11 octobre 2006 portant statut spécifique des médecins des services publics de l'État précise toutefois dans son Article 44 que : « Le médecin s'engage à assurer ses services et à prodiguer les soins avec attention et conscience. Les prestations auront lieu aux jours et heures convenus ».

Le droit de grève ne s'applique que moyennant certaines conditions dont l'une est essentielle à nos yeux en matière de grève des médecins : l'obligation pour certains fonctionnaires, dont les professionnels de santé, d'assurer un service minimum en raison du caractère vital de leur travail pour la population[3]. Les formations sanitaires doivent donc continuer à fonctionner pendant la grève malgré les inévitables perturbations qu'entraîne celle-ci. À cela, on devrait ajouter l'obligation formulée dans le Code pénal pour tout citoyen congolais, a fortiori s'il est professionnel de la santé et singulièrement médecin, de porter assistance à une personne en danger[4].

La réalité du système de santé congolais

Cependant, l'obligation générale d'assurer un service minimum et de porter assistance à autrui se heurte à un problème de taille en RDC : l'état de grande précarité dans lequel se trouve tout le système de santé du pays, tant au niveau de l'offre de soins que de l'accès à ceux-ci. Pour s'en convaincre, il suffit de parcourir un récent rapport issu de la Banque Mondiale, *Améliorer la dépense de santé pour renforcer le capital humain et assurer une croissance inclusive* [15]. Le constat est accablant, d'abord au niveau de l'offre :

[2] La Loi n° 11/002 du 20 janvier 2011 portant révision de certains articles de la Constitution de la République Démocratique du Congo du 18 février 2006. Article 39 : « Le droit de grève est reconnu et garanti. Il s'exerce dans les conditions fixées par la Loi qui peut en interdire ou en limiter l'exercice dans les domaines de la défense nationale et de la sécurité ou pour toute activité ou tout service public d'intérêt vital pour la nation ». La procédure pour l'application de ce droit de grève est organisée par le Code du travail aux articles 303 à 315 ainsi que par les deux arrêtés suivants : l'Arrêté Ministériel n°12/CAB.MIN/TPS/113/2005 du 26 octobre 2005 fixant les droits et obligations des parties pendant la suspension du contrat de travail et l'Arrêté Ministériel n°12/CAB.MIN/ETPS/039/08 du 08 août 2008 portant fixation des droits et obligations des employeurs et des travailleurs, parties à un conflit collectif de travail.

[3] L'Annexe de l'Arrêté ministériel n°12/CAB.MIN/TPS/113/2005 du 26 octobre 2005 fixant les droits et les obligations des parties pendant la suspension du contrat de travail indique clairement que : « En cas de cessation collective du travail ou de fermeture d'établissement, doivent être effectuées toutes les prestations qui consistent à assurer : A. Dans toutes les entreprises : - Les mesures conservatoires pour éviter la dégradation du matériel, des installations ou la perte des produits ou matières ; B. Dans les hôpitaux, dispensaires et autres formations sanitaires publiques et privées : - la dispensation des soins médicaux, chirurgicaux et pharmaceutiques ; - le transport des malades et blessés ; - le fonctionnement des hôpitaux, cliniques, maternités, sanatoriums, établissements pour des malades mentaux, crèches et pouponnières ; - le fonctionnement des services publics et privés veillant à la prophylaxie des maladies contagieuses ». Par ailleurs, une note circulaire émanant du Ministère de l'Emploi, du Travail et de la Prévoyance Sociale datée du 14 août 2009 renvoie à l'arrêté ministériel de 2005 évoqué plus haut et précise : « Pendant toute la durée de la cessation collective du travail ou de la fermeture d'établissement, les parties sont tenues d'assurer le service minimum obligatoire en faveur de la population en tant que prestations d'intérêt public » [14].

[4] Constitution de la République Démocratique du Congo [13], Article 66 ter : Sera puni d'une servitude pénale de trois mois à deux ans et d'une amende de cinq à cinquante zaïres ou de l'une de ces peines seulement, quiconque s'abstient volontairement de porter à une personne en péril l'assistance que, sans risque pour lui ni pour les tiers, il pouvait lui prêter, soit par son action personnelle, soit en provoquant un secours. Article 66 quater : Si les infractions prévues aux articles précédents sont commises par une personne chargée par état ou par profession d'assister les autres en danger, la peine sera la servitude pénale d'un à trois ans et l'amende de cinq à cent zaïres.

> L'offre de soins de santé reste limitée, avec seulement la moitié des structures sanitaires de premier niveau à même de fournir le service minimum. Les structures sanitaires ont généralement une capacité de prise en charge réduite en raison des déficiences persistantes au niveau des infrastructures et des équipements. En effet, seulement 22% des hôpitaux disposent de l'électricité et 29% ont l'eau courante (potable ou non). La majorité des structures hospitalières du pays (59%) datent d'avant l'indépendance et seulement 28% des Hôpitaux Généraux de Référence (HGR) fournissent un Paquet Complémentaire d'Activités complet, tandis que seulement 55% des Centres de Santé sont à même d'offrir un Paquet Minimum […]. Face aux faiblesses du système de santé public, il est estimé qu'environ la moitié de la demande en soins de santé est orientée vers les centres de santé privés, principalement à travers les structures confessionnelles [15, p.33].

Le rapport de la Banque Mondiale évoque également les problèmes de ressources humaines avec notamment une insuffisance du nombre de médecins (0,67 praticien pour 10 000 habitants en 2013), une concentration de ceux-ci en milieu urbain, en particulier dans la capitale (un médecin pour 7 574 habitants à Kinshasa) et des difficultés à gérer le personnel paramédical [15]. À cela, il faut ajouter que « les ressources publiques allouées au secteur de la santé sont en augmentation mais demeurent insuffisantes » [16, p.40]. Cela crée inévitablement de terribles injustices. Selon les chiffres de la Banque Mondiale provenant de l'enquête 1-2-3 menée en RDC en 2013 : « 34% des personnes ayant eu un problème de santé ont déclaré ne pas avoir consulté un service de santé, un guérisseur ou un marabout » et « parmi ceux-ci, 35% mettent le coût élevé de la consultation en tête des raisons de non-consultation » [15, p.49]. Pour ceux qui consultent, une majorité se plaint du coût trop élevé de la prise en charge, mais beaucoup aussi se plaignent de l'inefficacité des traitements proposés et de l'absence de médicaments [15].

Le rapport de la Banque Mondiale est particulièrement pessimiste, non seulement au niveau des constats sur le délabrement actuel du système de santé congolais, mais également sur ce qui risque d'arriver dans un futur proche. Ainsi, il apparaît que la dépense publique en matière de santé (20,6 dollars par an par habitant en 2015) est essentiellement (80%) consacrée à payer les salaires des personnels et que cela n'a pas cessé d'augmenter depuis 2007 [15]. Mais, ce qui inquiète le plus les auteurs du rapport, c'est que le salaire des professionnels de santé repose moins sur la rémunération en tant que telle que sur une « prime de risque » mise en place en 2005/2006 et qui est aujourd'hui bien supérieure au salaire classique[5]. Or pour certains, si cette prime a incontestablement permis d'améliorer la situation des professionnels concernés, sa systématisation risque de ne pas être soutenable financièrement [15]. En effet, si l'on tient compte du fait qu'en 2013, 32% du cadre de professionnels reconnus par le Ministère de la Santé Publique touchaient un salaire, que 81% recevaient une prime et que 13% ne recevaient rien, il faudrait tout simplement doubler la dotation publique octroyée au paiement des salaires des personnels, ce qui mangerait presque l'entièreté du budget de la santé du pays [15].

Il est clair que, dans le contexte actuel de la RDC, parler d'un service minimum à assurer dans les hôpitaux et du devoir des médecins à porter assistance aux patients en danger apparaît presque paradoxal. On peut difficilement demander à des individus, furent-ils médecins, d'assurer individuellement une fonction de salut des patients alors que l'État ne leur offre souvent pas les moyens minimaux pour y parvenir. En outre, on le voit, les revendications salariales des médecins risquent tout simplement de faire exploser tout le système de santé déjà très fragile. Ne pourrait-on pas réclamer une forme de solidarité sociale de la part des médecins, non pas à l'égard de l'État, mais plutôt à l'égard des patients eux-mêmes et plus largement des citoyens? Nous reviendrons sur ce questionnement dans la suite de l'article.

Les médecins auraient-ils des responsabilités morales particulières en matière de grève?

Cela étant dit, cet article ne traite pas du droit de grève en général, mais plus spécifiquement des grèves organisées par des médecins dans le contexte socioéconomiquement précaire de la RDC. Notre effort porte principalement sur la dimension éthique de ces grèves. Nous nous questionnons sur les arguments moraux qui conduisent à justifier ou au contraire à refuser le droit de grève aux médecins congolais? Si le droit de faire grève est bien un droit acquis pour tout travailleur et donc aussi pour les médecins, ceux-ci n'ont-ils pas cependant des responsabilités morales particulières qui limiteraient ou conditionnerait l'exercice de ce droit? Autrement dit, y aurait-il éventuellement quelque chose de spécifique au métier de médecin qui imposerait à celui-ci des responsabilités particulières et l'empêcherait moralement de faire grève?

La relation de confiance particulière entre le médecin et son patient

La relation qui unit les médecins à leurs patients est d'une nature très particulière : les derniers acceptent de confier leur santé et leur vie. Une telle relation suppose évidemment que les patients soient convaincus que les médecins ont pour priorité leur santé. Sans cette confiance dans la bienveillance et le professionnalisme des médecins, la relation évoquée devient caduque. Or, des grèves médicales portant essentiellement sur des revendications d'ordre salarial et statutaire ne risquent-elles pas de semer le doute dans l'esprit des patients qui pourraient être amenés à penser que les médecins seraient davantage motivés par la soif de l'argent que par l'intérêt de leurs malades? [16]

[5] Le salaire d'un médecin fonctionnaire en RDC varie en fonction de son grade. Le salaire mensuel de base tourne autour de 110 000 francs congolais (67 USD) avec une prime de risque variant en fonction du grade du médecin. Tout en bas de l'échelle, cette prime est de 1 150 000 francs congolais (700 USD) [4]. Par comparaison, selon la Banque Mondiale, le revenu mensuel moyen par habitant en RDC était de 36 USD en 2016.

Comme le font remarquer Pellegrino et Thomasma, la confiance est un élément essentiel de la vie sociale quotidienne, mais elle est l'est bien plus encore lorsque nous sommes placés dans une situation de fragilité et de dépendance telle que celles créées par la maladie et le handicap [17]. Mais, au-delà de ce qui pourrait apparaître aux yeux de certains comme une évidence, la grande question morale que posent les grèves médicales porte sur les prérequis d'une telle relation de confiance. Si les médecins doivent en quelque sorte mériter la confiance des patients, il faut également qu'ils aient les moyens de la mettre en place. Or, on pourrait se demander comment les médecins pourraient assumer leurs responsabilités à l'égard de leurs patients lorsque leurs propres besoins personnels essentiels ne sont pas comblés ou lorsque l'environnement de travail est dégradé.

Pour Grosskopf, Buckman et Garty: « […] si un médecin est sous payé et forcé à travailler de façon excessive, la qualité des soins médicaux et sa capacité à agir dans le sens des meilleurs intérêts des patients vont être négativement affectées » [18]. On pourrait donc argumenter que lorsque le texte du contrat social entre les médecins et les patients est brouillé, une grève peut se justifier. Autrement dit, pour pouvoir se montrer à la hauteur des attentes légitimes des patients et de la société tout entière à leur égard, les médecins doivent disposer des moyens nécessaires à l'exercice de leur métier en étant à la hauteur des responsabilités liées à celui-ci.

Les arguments utilitaristes pour défendre le droit de grève en médecine

Ainsi, les arguments de ceux qui défendent le droit de grève pour les médecins s'appuient souvent sur des convictions utilitaristes. Celles-ci sont notamment bien mises en évidence dans l'article de Thompson et Salmon consacré à l'histoire des grèves de médecins aux États-Unis : « Les défenseurs des médecins issus des syndicats ou des mouvements de grève mettent souvent en avant l'argument selon lequel les bénéfices à long terme pour les futurs patients l'emportent sur tous les inconvénients à court terme pour les patients actuels. En d'autres mots, ils voient les perturbations à court terme sur les soins comme un outil nécessaire pour obtenir de plus grands bénéfices pour les patients dans le futur » [19, p.346]. En somme, il faudrait accepter de sacrifier provisoirement le bien de quelques patients qui seront victimes des conséquences de la grève pour permettre une amélioration future de la santé du plus grand nombre. En obtenant de meilleures conditions de travail, les médecins seront plus heureux et serviront mieux les intérêts des patients [20]. Cela reste évidemment à démontrer, car cela reviendrait à défendre l'idée que les médecins les mieux payés et profitant des meilleures conditions de travail sont également les plus motivés à prendre soin de leurs patients.

On pourrait d'ores et déjà se demander dans quelle mesure un tel raisonnement utilitariste serait applicable en RDC, car comme le remarque Tshikandu [21], les revendications des médecins y sont strictement salariales et statutaires, et n'invoquent à aucun moment la qualité des soins ou la sécurité des patients. Au regard des documents que nous avons pu examiner, les grèves médicales en RDC portent exclusivement sur des revendications statutaires et salariales, ce qui pourrait paraître paradoxal au regard de l'image du médecin dévoué et désintéressé que beaucoup de patients ont. Comme on peut le constater en prenant connaissance des revendications du puissant Syndicat National des Médecins de la RDC (Synamed), les médecins grévistes n'évoquent pas, comme c'est le cas ailleurs [22-23], la précarité des structures de soins, l'insécurité, le manque de matériel, la surcharge de travail, l'insalubrité de certains locaux, etc., mais se concentrent sur le paiement de la prime de risque, les salaires non versés, les promotions et les titularisations, ainsi que sur les indemnités de fin de carrière [24]. Nous n'avons pas pu trouver d'arguments laissant entendre que l'argent ne serait au fond qu'une manière pour les médecins d'être plus respectés par la population en accédant à une plus grande reconnaissance.

Il ne s'agit donc pas à travers la grève d'accepter de sacrifier la santé de quelques patients en visant une amélioration globale de la qualité des soins, mais d'instrumentaliser les patients pour atteindre certains objectifs corporatistes. Cela dit, comme nous venons de le voir, certains estiment que la frontière entre les intérêts des professionnels de la santé et ceux de leurs patients est floue et que maltraiter les soignants revient finalement à maltraiter les patients [19]. Mais l'argument est faible, car il est difficile de mettre en balance la satisfaction des revendications des médecins concernant leurs intérêts propres avec les conséquences dramatiques que les grèves peuvent avoir sur la santé voire la vie de milliers de patients [19]. Et quand bien même il ne serait pas question de mettre directement en danger la vie des malades, c'est la confiance même que la population a à l'égard des médecins qui est en péril [25]. On voit donc que les arguments de type utilitariste justifiant les grèves de médecins sont peu convaincants.

Les arguments hippocratiques et déontologiques pour critiquer le droit de grève

De l'autre côté de la barrière, ceux qui critiquent sur le plan moral le droit de grève pour les médecins se réfèrent souvent au Serment d'Hippocrate [19]. On pourrait ainsi suivre Pellegrino pour qui derrière toute prise en charge médicale il y a la promesse de la part du praticien de veiller au bien de son patient. Cela implique non seulement de protéger le patient de ce qui pourrait nuire à sa santé, mais aussi de veiller à agir pour son bien. L'intérêt propre du médecin devrait pouvoir s'effacer devant ceux de son patient [17]. L'essence même de la médecine, sa caractéristique propre par rapport à d'autres professions doit être située à ce niveau. Sans cela, le risque d'abus de pouvoir est important.

Dans cet ordre d'idées, la Déclaration d'Helsinki rappelle clairement que : « Le devoir du médecin est de promouvoir et de sauvegarder la santé, le bien-être et les droits des patients, y compris ceux des personnes impliquées dans la recherche médicale. Le médecin consacre son savoir et sa conscience à l'accomplissement de ce devoir. » [26] À cela, on pourrait ajouter les devoirs du médecin décrit dans le Code International d'Éthique Médicale de l'Association Médicale Mondiale : « Le médecin devra agir uniquement dans l'intérêt de son patient […] » ou encore : « Le Médecin devra toujours avoir à l'esprit le

souci de conserver la vie humaine. […] Le médecin devra considérer les soins d'urgence comme un devoir humanitaire à moins qu'il soit assuré que d'autres désirent apporter ces soins et en sont capables. » [27] Il est intéressant aussi de se souvenir de la Déclaration de Genève que l'on considère souvent comme le Serment d'Hippocrate moderne et dans lequel on peut lire : « Je considérerai la santé de mon patient comme mon premier souci » [28]. Enfin, on doit signaler que le Guide Européen d'Éthique Médicale aborde spécifiquement et de façon très claire la question de la grève médicale dans son article 37 : « Lorsqu'un médecin décide de participer à un refus collectif organisé des soins, il n'est pas dispensé de ses obligations éthiques vis-à-vis des patients à qui il doit garantir les soins urgents et ceux nécessaires aux malades en traitement » [29].

Le code de déontologie médicale congolais lui-même s'inscrit dans la ligne hippocratique et serait de nature à fournir des arguments à ceux qui s'opposent au principe des grèves médicales, en particulier celles sans service minimum. Ainsi, l'article 1 de ce code déontologie indique que : « L'exercice de la médecine est un ministère. Le respect de la vie et de la personne humaine constitue en toute circonstance le devoir primordial du médecin ». Cela a pour conséquence que : « Quelle que soit sa fonction ou sa spécialité, tout médecin doit, hors le seul cas de force majeure, porter secours d'extrême urgence à un malade en danger immédiat si d'autres soins médicaux ne peuvent lui être assurés » (Art. 2). Le code de déontologie précise en outre que : « Le médecin peut se dégager de sa mission à condition : 1° de ne jamais nuire, par ce fait, au malade dont il se sépare ; 2° d'en avertir le malade ou son entourage ; 3° de fournir les renseignements qu'il juge, en conscience, utiles à la continuité des soins, compte tenu des obligations du secret médical » (Art.22) [30].

La déontologie médicale, tant au niveau international qu'au niveau congolais, ne s'oppose donc pas au fait que des médecins puissent faire grève, mais elle rappelle les devoirs propres à la profession et fournit par la même occasion des balises morales pour encadrer le droit de grève. On pourrait formuler ces balises de cette façon : 1) le premier devoir du médecin est, sauf cas de force majeure, de sauvegarder la santé et la vie de ses patients en leur offrant les soins dont ils ont besoin ; 2) laisser la santé d'un patient se détériorer de façon grave, voire le laisser mourir alors qu'il était possible de lui porter secours est en totale opposition avec l'esprit même de la déontologie médicale. La déontologie médicale fournit dès lors des arguments pour accepter que des médecins puissent faire grève à condition que tout soit organisé pour que la santé et la vie des patients ne soient pas menacées par les actions menées.

Une approche utilitariste peu convaincante du droit de grève pour les médecins

A contrario, on pourrait cyniquement argumenter, comme le font Thomson et Salmon [24], que si l'on veut qu'une grève serve à quelque chose, il faut qu'elle cause du tort à l'employeur, ici l'État, par l'intermédiaire des clients affectés, ici les patients. Plus les grévistes causeront du tort à ceux-ci et plus ils auront d'atouts en main pour négocier avec les autorités. On pourrait de cette façon à la fois justifier le recours à une grève sans service minimum et faire peser sur les épaules des décideurs institutionnels et politiques tout le poids de la responsabilité morale à l'égard des patients. Dans cette logique, la fin justifiant les moyens, les grévistes auront tout intérêt à mener des actions les plus dures possible.

L'argument est évidemment utilitariste et souffre des mêmes faiblesses que celles évoquées plus haut. En effet, tout va reposer sur les finalités de la grève. S'agit-il en fin de compte d'améliorer la prise en charge des patients et la qualité des soins qui leur sont offerts? Ou bien les médecins n'ont-ils que des objectifs corporatistes et salariaux? La cause est-elle noble en visant le bien des patients ou bien bassement vénale et tournée vers le seul confort matériel des professionnels de la santé? On voit bien qu'il sera compliqué de convaincre à la fois les patients et les autorités de la légitimité de mouvements de grève basés uniquement sur des revendications corporatistes.

L'approche utilitariste de l'éthique de la grève chez les médecins est bien entendu stimulante, mais elle doit être complétée par une vision plus spécifique de la profession médicale. Dans ce cadre, il peut être intéressant d'aller jeter un œil du côté de l'éthique des vertus, sans nécessairement faire d'une telle approche le modèle idéal pour réfléchir à la moralité des grèves médicales. Ainsi, pour Pellegrino et Thomasma [17], les vertus propres à l'exercice de la médecine sont déterminées par les finalités mêmes de la discipline. Or, ces finalités pourraient être exprimées de cette façon : permettre au patient de recouvrer la santé ou à tout le moins d'améliorer son état, c'est-à-dire guérir la maladie quand c'est possible et à tout le moins soigner, en aidant le patient à vivre avec ses handicaps et ses difficultés. La compétence du médecin est dès lors mise au service de la vulnérabilité du patient par rapport à qui il s'engage. Autrement dit, la responsabilité morale du médecin est d'agir dans le sens du bien du patient qui lui a offert sa confiance en acceptant de faire passer ses propres intérêts après ceux de ses malades. Pellegrino et Thomasma considèrent ainsi que l'effacement de soi est une vertu essentielle pour un médecin [17]. Une telle approche met en évidence une responsabilité morale particulière des médecins en grève à l'égard de leurs patients : en charge d'êtres humains particulièrement vulnérables, il est du devoir des médecins de faire passer les intérêts des patients avant les leurs propres. Cela a notamment pour conséquence, comme l'indiquent Thomson et Salmon, qu'un médecin doit accepter l'idée qu'une grève ne peut être que le recours ultime et qu'elle ne peut mettre en danger la santé de ceux qui leur sont confiés [24].

Des responsabilités morales particulières

À la question de savoir s'il existe des responsabilités morales spécifiques aux médecins en matière de grève, nous répondons donc par l'affirmative. La relation thérapeutique est basée sur la confiance que le patient a dans la bienveillance du médecin à son égard. Les arguments utilitaristes justifiant l'arrêt de travail des médecins au nom du bien commun vont inévitablement éroder cette confiance. Il est difficile de demander aux patients de sacrifier leur santé voire leur vie pour permettre une amélioration des conditions de vie de ceux qui les soignent. Bien loin de cette approche utilitariste, nous rappelons quelques

grands repères éthiques et déontologiques fondamentaux d'inspiration hippocratique qui s'accordent parfaitement avec le Code de déontologie congolais. Ces repères se résument aisément : les médecins peuvent faire grève, mais à la condition expresse que ni la santé ni la vie de leurs patients soient mise en danger. Les médecins sont appelés à mettre leurs compétences au service de la vulnérabilité de leurs patients ; cela crée inévitablement pour eux des responsabilités morales particulières.

Impliquer les patients dans le débat pour construire une alliance thérapeutique nationale

Lorsque l'on réfléchit à la légitimité morale des grèves médicales en RDC, deux repères essentiels émergent rapidement. Le premier est que les médecins congolais, comme tous les autres travailleurs, ont le droit de défendre leurs intérêts propres, y compris financiers. Il n'est pas légitime de les soumettre à des conditions de travail inhumaines ou de les priver d'un salaire juste. On retrouve de telles revendications pour des grèves médicales dans d'autres pays. Ainsi, au Pakistan en 2012-2013, des revendications ont émergé de la part des jeunes médecins en formation, rapidement relayées par leurs aînés, concernant leur sécurité, leurs conditions de travail et des rémunérations trop faibles voire inexistantes [22]. En Inde, en 2006, des grèves médicales ont été menées pour dénoncer les mauvaises conditions de travail, les salaires trop bas, mais aussi les problèmes de sécurité dans les hôpitaux, ainsi que l'inadéquation de ceux-ci aux besoins des patients [21]. Au Malawi, en 2001, une grève générale très dure a frappé le Queen Elizabeth Central Hospital en entraînant la fermeture totale de l'hôpital pendant plusieurs jours. Les motifs de la grève concernaient principalement les salaires et les primes qui étaient jugées indignes par l'ensemble des fonctionnaires de la santé de cet hôpital, y compris les médecins [31].

Mais ce n'est pas tout. Un deuxième repère moral est nécessaire, car si les médecins ont le droit de faire grève, ils ont également des responsabilités légales, déontologiques et morales particulières à l'égard de leurs patients, comme nous l'avons montré plus haut. Ces responsabilités convergent toutes vers la nécessité de maintenir un service minimum adéquat, réduisant l'impact de la grève sur les personnes les plus vulnérables. Les urgences médicales doivent donc continuer à être prises en charge et ceux qui assurent celles-ci ne doivent pas être considérés comme des briseurs de grève.

Notre travail critique pourrait en rester là, mais cela reviendrait malheureusement à se rendre aveugles et sourds à la complexité de la situation congolaise, singulièrement en matière de soins de santé. En effet, en évoquant le contexte socioéconomique des grèves médicales en RDC, nous avons insisté à la fois sur la fragilité financière du pays et également sur l'extrême précarité du système de soins de santé dans le pays. Quand un État ne parvient pas à organiser un système de santé à la hauteur des besoins du pays, peut-il exiger des professionnels de santé, en particulier des médecins, le respect d'un service minimum en cas de grève, alors même que ce « service minimum » peine à être assuré habituellement?

Dans le contexte de la RDC, il faudrait ainsi accepter une situation apparemment paradoxale. D'un côté, une évaluation à la fois juridique, déontologique et éthique permet d'identifier des responsabilités spécifiques à la profession médicale en cas de grève. Et de l'autre côté, il faut reconnaître qu'assumer concrètement ces responsabilités spécifiques – par exemple, en assurant la prise en charge des urgences, quelle que soit la situation – est particulièrement difficile dans la plupart des structures de santé en RDC. Il pourrait donc sembler paradoxal de demander à des médecins de cesser une grève ou de mettre en place un service minimum afin de sauvegarder la santé des patients les plus fragiles, alors que ces mêmes médecins n'auraient souvent pas les moyens ni humains ni matériels de prendre soin des patients en général en dehors de tout contexte de grève.

Nous proposons de sortir de ce paradoxe en ouvrant le débat aux patients et plus largement à la société congolaise tout entière. Les patients sont en effet les grands absents de ce bras de fer tragique entre les médecins et l'État congolais, alors même qu'ils sont les plus impactés par la grève, particulièrement les plus pauvres, car ceux-ci n'ont pas les moyens financiers de s'adresser aux structures privées qui ne sont pas concernées par les grèves. C'est donc un large débat citoyen que nous appelons de nos vœux. Il est de la responsabilité des syndicats médicaux concernés de chercher une alliance thérapeutique nationale avec les patients de façon à ce que l'État ne puisse pas reprocher aux médecins de créer le chaos alors qu'ils en sont les victimes, à l'instar des patients eux-mêmes. N'y a-t-il pas là une base pour l'ouverture d'un dialogue national visant une plus grande justice sociale en matière de santé? Les modalités de cette alliance thérapeutique nationale devront bien entendu être explorées, mais nous suggérons de les structurer autour d'un engagement solennel des médecins congolais à mettre tout en œuvre, malgré la précarisation du système de santé congolais, pour assurer une continuité des soins aux plus fragiles. Il faut que l'alliance en question soit le signe de la reconnaissance par les médecins qu'une grève médicale n'est pas une grève comme les autres, en ce sens que les premiers impactés seront les patients alors que la cible est en réalité l'employeur. Seul un appel à la solidarité à travers une alliance des causes s'avèrera efficace : professionnels de la santé et patients unis dans la revendication de soins de qualité offrant un salaire juste aux soignants à un coût raisonnable pour les malades.

Conclusions

Plusieurs grèves de médecins ont frappé la RDC ces dernières années, particulièrement en 2017 et 2018. Toutes étaient destinées à faire pression sur l'État congolais pour améliorer les conditions salariales des médecins que ceux-ci jugent inacceptables. Parallèlement à ces mouvements de grève « classiques » et devant l'immobilisme du gouvernement face à

leurs revendications, les médecins congolais ont été amenés, à plusieurs reprises, et dans différentes régions, à durcir leur position en arrêtant totalement de prendre en charge les patients, même en cas d'urgence. Ces mouvements de grève ont évidemment eu des conséquences dramatiques.

Dans cet article, tout en reconnaissant le droit de tout travailleur à faire grève, y compris en RDC, nous nous interrogeons sur la légitimité des grèves sans service minimum, en particulier dans un secteur aussi vital que celui des soins de santé. Nous estimons que les professionnels de la santé ont ainsi des responsabilités morales particulières lorsqu'ils font grève, différentes de celles d'autres travailleurs. Les bénéficiaires des soins offerts par le personnel médical et paramédical sont par définition des personnes fragilisées par la maladie ou le handicap et qui accordent leur confiance aux professionnels. Ceux-ci se doivent d'être à la hauteur des besoins et des attentes de leurs patients. L'utilisation des patients comme moyen de chantage pour faire pression sur le gouvernement congolais nous apparaît difficilement justifiable d'un point de vue éthique, d'une part parce que les revendications des grévistes sont strictement financières et corporatistes, et, d'autre part, parce que les sacrifices demandés aux citoyens sont disproportionnés par rapport aux hypothétiques bénéfices attendus. Selon nous, une telle attitude entre en contradiction profonde avec ce qui est attendu sur le plan moral d'un professionnel de la santé : viser le bien du patient en faisant passer ses intérêts propres après ceux des malades.

Cette position de principe doit cependant être mise en balance avec des éléments de contexte qu'il est impossible d'ignorer. La situation financière de la RDC est extrêmement fragile, ce qui impacte évidemment le système des soins de santé. Les professionnels de la santé doivent faire face à des conditions de travail insupportables qui ne leur permettent pas toujours d'être à la hauteur des exigences morales que l'on doit avoir à l'égard des soignants en général. Il n'est pas juste de demander à des professionnels d'offrir des soins de qualité, alors que l'État ne leur offre pas les moyens minimaux pour y parvenir. Un paradoxe semble ainsi peser sur les médecins congolais : accepter des responsabilités spécifiques en cas de grève tout en étant parfois dans l'incapacité matérielle de les assumer par manque de moyens. Cela n'enlève rien à l'exigence morale particulière qui s'applique aux médecins grévistes par rapport à d'autres catégories de travailleurs mécontents, mais cela montre néanmoins l'extrême complexité de la situation. Autrement dit, les médecins, quelle que soit leur situation, ont le devoir moral de tout mettre en œuvre pour que leurs patients ne se trouvent pas privés de soins du fait de la grève, même s'il faut reconnaître que les défaillances de l'État compliquent terriblement l'accomplissement de ce devoir.

Nous proposons de tenter de sortir du paradoxe auquel les médecins congolais semblent confrontés en ouvrant la discussion autour des grèves médicales aux grands oubliés du débat national congolais : les patients et plus largement les citoyens, surtout les plus précaires. Ce n'est qu'en créant une alliance thérapeutique nationale avec les malades et les citoyens en général autour d'intérêts communs que les professionnels de la santé pourront espérer faire entendre leurs revendications. Des recherches seront nécessaires pour déterminer les moyens pratiques à mettre en œuvre pour parvenir à atteindre un tel objectif.

La situation de la RDC est évidemment particulière, mais nous pensons que notre réflexion pourrait aisément s'appliquer à d'autres contextes. Voici quelques éléments de généralisation possibles. Tout travailleur a le droit de se mettre en grève, à moins de le considérer comme un esclave, ce qui revient à nier sa dignité d'être humain et qui est inacceptable d'un point de vue éthique [32]. Mais la situation du professionnel de la santé est particulière en raison de l'impact que la grève aura sur les patients alors même que les revendications s'adressent à l'employeur. Cela risque évidemment d'entrer directement en conflit avec l'objectif professionnel du soignant : prendre soin de la santé du malade et veiller à préserver sa vie. On ne peut sortir de ce paradoxe qu'en cherchant à construire une alliance entre les professionnels grévistes et les patients. Une telle alliance, dont il faudrait étudier les modalités, passera, d'une part, par l'affirmation par les premiers de leur engagement inconditionnel pour préserver la santé de ceux qui leur sont confiés et, d'autre part, par la reconnaissance par les seconds qu'une offre de soins de qualité ne peut pas faire l'économie de conditions de travail dignes pour les soignants. C'est là un chantier urgent sur lequel nous attirons l'attention des syndicats médicaux ainsi que des décideurs politiques.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Refusing Care as a Legal Pathway to Medical Assistance in Dying

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Résumé
Une personne compétente peut-elle refuser des soins afin de rendre son décès naturel raisonnablement prévisible pour être admissible à l'aide médicale à mourir (AMM)? Prenons l'exemple d'un patient compétent atteint d'une paralysie du côté gauche à la suite d'un accident vasculaire cérébral droit qui ne devrait pas mourir avant de nombreuses années ; normalement, la cause de son décès ne serait pas prévisible. Cependant, il refuse de se retourner régulièrement, de sorte que son médecin peut prédire que des plaies de pression se développeront, entraînant une infection pour laquelle il refusera le traitement et mourra par conséquent. Est-il maintenant admissible à l'AMM? Prenons l'exemple d'un patient compétent atteint d'une sténose spinale (affection non mortelle) qui refuse de manger (mais pas de boire pour ne pas perdre sa capacité à cause de la déshydratation). Par conséquent, son médecin peut prédire la mort par famine. Est-elle maintenant admissible à l'AMM? Pour répondre à ces questions, nous devons répondre à trois sous-questions : 1) les patients compétents ont-ils le droit de refuser des soins ; 2) les prestataires de soins de santé ont-ils l'obligation de respecter ces refus ; et 3) les décès résultant de refus de soins sont-ils naturels aux fins de déterminer si un patient est admissible à l'AMM? Si un patient compétent a le droit de refuser certains soins particuliers et que les prestataires de soins de santé ont l'obligation de respecter ce refus, et si le décès qui résulterait du refus de ces soins est naturel, alors ce refus de soins est une voie légale vers le AMM. Toutefois, si le patient compétent n'a pas le droit de refuser certains soins particuliers, ou si les prestataires de soins de santé n'ont pas l'obligation de respecter ce refus, ou si le décès qui résulterait du refus de ces soins n'est pas naturel, alors ce refus de soins ne constitue pas une voie légale vers le AMM. Dans cet article, nous explorons ce terrain juridique complexe avec les implications éthiques les plus profondes : l'accès à l'AMM.

Mots-clés
assistance à mourir, aide médicale à mourir, AMM, arrêt volontaire de manger et de boire, AVMB, raisonnablement prévisible, mort naturelle

Abstract
Can a competent individual refuse care in order to make their natural death reasonably foreseeable in order to qualify for medical assistance in dying (MAiD)? Consider a competent patient with left-side paralysis following a right brain stroke who is not expected to die for many years; normally his cause of death would not be predictable. However, he refuses regular turning, so his physician can predict that pressure ulcers will develop, leading to infection for which he will refuse treatment and consequently die. Is he now eligible for MAiD? Consider a competent patient with spinal stenosis (a non-fatal condition) who refuses food (but not liquids in order not to lose capacity from dehydration). Consequently, her physician can predict death from starvation. Is she now eligible for MAiD? Answering these questions requires that we answer three sub-questions: 1) do competent patients have the right to refuse care?; 2) do healthcare providers have a duty to respect such refusals?; and 3) are deaths resulting from refusals of care natural for the purposes of determining whether a patient is eligible for MAiD? If a competent patient has the right to refuse some particular care, and healthcare providers have a duty to respect that refusal, and if the death that would result from the refusal of that care is natural, then that refusal of care is a legal pathway to MAiD. However, if the competent patient does not have the right to refuse some particular care, or if healthcare providers do not have a duty to respect that refusal, or if the death that would result from the refusal of that care is not natural, then that refusal of care is not a legal pathway to MAiD. In this paper, we explore this complex legal terrain with the most profound of ethical implications – access to MAiD.

Keywords
assisted dying, medical aid in dying, MAiD, voluntary stopping eating and drinking, VSED, reasonably foreseeable, natural death

Mr. Smith is a 55-year-old man with quadriplegia as a result of a stroke five years ago. He experiences extreme neuropathic pain that cannot be controlled without profound sedation. He recently asked his physician about medical assistance in dying (MAiD). He was assessed and told that he does not meet the eligibility criteria for medical assistance in dying. Mr. Smith experiences enduring and intolerable suffering that cannot be alleviated by any means acceptable to him and he is in an advanced state of decline in physical capability. He has been told that he has an incurable condition but that, as he could live on for decades, his natural death has not yet become reasonably foreseeable. Desperate, he refuses consent to being turned, knowing that this will result in pressure sores that will get infected, and he refuses consent to antibiotics for any resulting infection, knowing that this will lead to his death. He then claims that, as a result of these refusals, his natural death has become reasonably foreseeable and so he is eligible for MAiD. (fictional case)

Introduction

One of the most talked-about criteria for eligibility for medical assistance in dying (MAiD) in Canada is s.241.2(2)(d) of the *Criminal Code of Canada* [1]:

> (2) A person has a grievous and irremediable medical condition only if they meet all of the following criteria:
> …
> (d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.

The phrase "reasonably foreseeable" has received most of the attention directed at this subsection of the federal legislation,[1] largely because it has been taken to exclude a number of individuals who would have qualified for MAiD under the Supreme Court of Canada (SCC) decision in *Carter v. Canada* [8]. In that decision, the SCC declared the prohibition on MAiD to be unconstitutional insofar as it prohibits access to MAiD for "a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes

[1] Indeed, this was at the centre of the firestorm during the process of Bill C-14's passage through Parliament in the Spring of 2016. See, for example [2-5]. It is also the subject of two Charter challenges currently before the courts [6-7].

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enduring suffering that is intolerable to the individual in the circumstances of his or her condition." [8, para 127]. Bill C-14 (which brought in the MAiD provisions of the *Criminal Code*) narrowed access by adding, among other things, the requirement that the person's "natural death has become reasonably foreseeable." [9] As a result, individuals experiencing enduring and intolerable suffering are being denied access on the grounds that their natural death has not become reasonably foreseeable. In response, they are exploring three pathways to access MAiD: first, arguing in court that the provision breaches their *Charter* rights [7]; second, advocating for interpretations of "reasonably foreseeable" that are broader than those being used in their denials;[2] and third, taking steps to make their deaths "reasonably foreseeable" even on a narrow interpretation of the phrase.[3]

In this paper, we explore this third potential pathway to access MAiD, i.e., competent patients refusing care so that their death will become reasonably foreseeable on any of the leading interpretations of that phrase (if the patient is likely to remain steadfast in their refusal), as it will be predictable **that**, **when**, and **how** the person will die [10,12]. In these cases, the word "natural" requires attention. Does the very thing that makes their death "reasonably foreseeable" (refusal of care) also render their death not "natural" (but rather "accident," "suicide," or "homicide)? Section 241.2(2)(d) of the *Criminal Code* contains two conditions, both necessary for eligibility; as one eligibility door opens, does the other one shut?

Consider the following set of illustrative fictional examples of the conundrum of "natural death" in the context of MAiD. In each, as a result of steps taken by a competent patient, death has become reasonably foreseeable — but would the manner of death be "natural"?

1. A competent patient with Huntington's disease (a neurodegenerative condition not expected to result in the patient's death for many years) develops pneumonia that is treatable but, without treatment, will likely result in her death. The patient refuses treatment, so her physician can say that her death is likely to be as a result of pneumonia.
2. A competent patient was rendered ventilator-dependent three years ago by an unusually severe case of Guillain-Barré syndrome. Facing the prospect of permanent ventilator dependence and an anticipated survival of more than ten years, she requests the ventilatory support be discontinued. Her physician can predict death as a result of the support being discontinued.
3. A competent patient was in a car accident and, as a result, in the hospital attached to a ventilator for a year. Facing the prospect of permanent ventilator dependence, the patient requests the ventilatory support be discontinued. His physician can predict death as a result of the support being discontinued.
4. A competent patient with multiple sclerosis who is dependent on a percutaneous endoscopic gastrostomy (feeding tube) tube for nutrition asks that artificial nutrition be stopped (but doesn't stop liquids in order not to lose capacity from dehydration). Consequently, her physician can predict death from starvation.
5. A competent patient with left-side paralysis following a right brain stroke is not expected to die for many years; normally his cause of death would not be predictable. However, he refuses regular turning, so his physician can predict that pressure ulcers will develop, leading to infection for which he will refuse treatment and consequently die.
6. A competent patient with quadriplegia following a diving accident three years ago is not expected to die for many years; normally his cause of death would not be predictable. However, he refuses regular turning, so his physician can predict that pressure ulcers will develop, leading to infection for which he will refuse treatment and consequently die.
7. A competent patient with spinal stenosis (a non-fatal condition) refuses food (but not liquids in order not to lose capacity from dehydration). Consequently, her physician can predict death from starvation.

These examples display the key variables to watch for throughout the following analysis: the origin of the underlying condition (i.e., disease or disability, accident, intentional injury by self or other); the nature of the underlying condition (i.e., fatal vs. chronic condition); the type of care (e.g., ventilator, antibiotics, turning, artificial or oral hydration or nutrition); and the goal of the care (e.g., preventative, curative, palliative).[4]

There will be patients among those in the examples provided above who will not be eligible for MAiD without refusing care and for whom palliative care will be either unavailable, ineffective, or undesired or by whom MAiD will be preferred. It is therefore important to ask: can competent individuals refuse care to make their natural death reasonably foreseeable in order to qualify for MAiD? Answering this question requires that we answer three sub-questions: 1) do competent patients have the right to refuse care?; 2) do healthcare providers have a duty to respect such refusals?; and 3) are deaths resulting from refusals of care not natural for the purposes of determining whether a patient is eligible for MAiD? If a competent patient has the right to refuse some particular care, and healthcare providers have a duty to respect that refusal, and the death that would result from the refusal of that care is natural, then that refusal of care is a legal pathway to MAiD. However, if the competent patient does not have the right to refuse some particular care, or healthcare providers do not have a duty to respect that refusal, or the death that would result from the refusal of that care is not natural, then that refusal of care is not a legal pathway to MAiD.

[2] For example, arguing that "reasonably foreseeable" does not mean "death expected within 12 months" or denying that there is a temporal proximity condition [10].
[3] Individuals might also request deep and continuous sedation and refuse artificial hydration and nutrition as a path to death when found to be ineligible for MAiD or if they object to MAiD but wish a hastened death. This path to death is analyzed in full in [11].
[4] We are assuming here that the withholding or withdrawal of treatment would not cause death in less time than it would take for a patient to avail themselves of MAiD.

Do competent patients have the right to refuse care?[5]

It is very clear that competent adult[6] patients have a common law right to refuse any or all medical treatment (including artificial nutrition and hydration) even where the consequence of the refusal is death. As Justice Smith noted in *Carter*: "[...] the law in Canada is that: (a) Patients are not required to submit to medical interventions (including artificial provision of nutrition and hydration), even where their refusal of or withdrawal from treatment will hasten their deaths, and physicians must respect their patients' wishes about refusal of or withdrawal from treatment." [15] It is also clear that competent adult patients have a common law right to refuse oral hydration and nutrition. In *Carter v. Canada (Attorney General)*, Justice Smith noted that "[h]e [Mr. Copley for British Columbia] submits that 'the able bodied and the disabled can equally commit suicide by refusing to eat or drink or by refusing provision of artificial nutrition or hydration'." [15, para 1067] Justice Smith did not take issue with this characterization of refusing oral or artificial hydration or nutrition as suicide (and the SCC in the *Carter* appeal did not take issue with her acceptance of the characterization). Similarly, in *Bentley v. Maplewood Seniors Care Society*, Justice Greyell noted that "adults have a common law right to consent or refuse consent to personal care services [including oral hydration and nutrition]." [16, para 84]

It is also clear that the right to refuse extends to individuals beyond those with a fatal condition to those with chronic conditions to those who are healthy (whether able-bodied or with a disability) [15]. While there is no case law directly on point, it can be argued that the right to refuse extends to preventive care if it involves touching the patient. The SCC has clearly grounded its decisions regarding treatment in the individual's constitutional right to bodily integrity. The right to bodily integrity would equally ground the position that patients have a right to refuse preventive care. This was recognized recently by Justice Greyell in *Bentley* when he stated:

> I am not aware of any statute in British Columbia that sets out a legislated standard for informed consent for personal care or basic care. However, there is common law authority for the proposition that it is necessary to obtain consent before providing personal care or basic care. Indeed, intentional non-consensual touching can amount to the tort of battery (Malette at 327; Norberg v. Wynrib, 1992 CanLII 65 (SCC), [1992] 2 S.C.R. 226 at 246). Although most cases relating to consent rights have been decided in the context of a right to consent or refuse consent for health care treatment, the principles on which that right is based is the general right to personal autonomy and bodily integrity.
>
> For instance, in Ciarlariello v. Schacter, 1993 CanLII 138 (SCC), [1993] 2 S.C.R. 119 at 135 Cory J. said for the Court: "Everyone has the right to decide what is to be done to one's own body." Similarly, in Fleming at 312 Robins J.A. observed that "[t]he common law right to bodily integrity and personal autonomy is so entrenched in the traditions of our law as to be ranked as fundamental and deserving of the highest order of protection." These statements recognizing the common law right to be free from non-consensual touching or care of one's body must encompass the right to consent or refuse consent to personal care or basic care. [16, para 46]

Thus it can be concluded that competent adults have a common law right to refuse care no matter the origin of the underlying condition (disease or disability, accident, intention or self-induced injury), the nature of the underlying condition (fatal or chronic), the type of care (e.g., ventilator, antibiotics, turning, artificial or oral hydration and nutrition), the goal of the intervention (preventative, curative, or palliative) and whether the person is able-bodied or has a disability but is otherwise healthy.

Do healthcare providers have a duty to respect refusals of care?

Criminal and civil law

Healthcare providers have a legal duty to respect competent adult patients' refusals of care. They are required by both criminal and civil law to respect such refusals. To touch a person in the course of delivering care against the patient's wishes would constitute battery[7] or assault [1, s.265]. Healthcare providers risk criminal and civil liability if they provide treatment or preventive medical care (including artificial hydration and nutrition) or force oral hydration or nutrition against a competent adult's wishes, regardless of whether the person has a fatal or chronic conditions or is healthy (whether able-bodied or with a disability).

It should be noted here that it has been suggested that healthcare providers have a duty to provide care because of the *Criminal Code* duty to provide the necessaries of life.[8] However, patients in the circumstances under discussion are capable of removing themselves from the care of the physician, so this provision of the *Criminal Code* would arguably not be triggered.

[5] Parts of the next two sections are drawn from [13].
[6] This is not to say that mature minors do not have this right. Rather, this paper is focused on MAiD and under Canadian legislation only adults are eligible. We therefore limit our analysis to adults to avoid the unnecessary complications of the uncertainty surrounding the mature minor rule in Canadian common law. For an explanation of mature minors and end-of-life decision-making, see [14].
[7] The SCC has clearly endorsed the view that the common law concept of bodily integrity requires that healthcare providers not touch patients without their consent. Starting or continuing treatment is touching and, if done against a patient's wishes, is considered tortious battery [17].
[8] "(1) Everyone is under a legal duty (a) as a parent, foster parent, guardian or head of a family, to provide necessaries of life for a child under the age of sixteen years; (b) to provide necessaries of life to their spouse or common-law partner; and (c) to provide necessaries of life to a person under his charge if that person (i) is unable, by reason of detention, age, illness, mental disorder or other cause, to withdraw himself from that charge, and (ii) is unable to provide himself with necessaries of life" [1, s.215].

Furthermore, failure to provide the necessaries of life is only an offence under the *Criminal Code* if there is no lawful excuse,[9] and one could argue that the patient's refusal of the care is a lawful excuse and therefore there would be no offence.

Provincial/territorial consent legislation

Some provincial/territorial consent legislation includes elements relevant to the analysis: the requirement of consent to treatment and personal care or personal assistance services (which could include assistance with eating and drinking) and the definitions of these terms.[10] However, the statutes either codify the common law or are silent and therefore leave the common law position undisturbed. Thus, healthcare providers have a duty to respect competent adult patients' refusals of care no matter the origin of the underlying condition (disease or disability, accident, intention or self-induced injury), the nature of the underlying condition (fatal or chronic), the type of care (e.g., ventilator, antibiotics, turning, artificial or oral hydration and nutrition), the goal of the intervention (preventative, curative, or palliative), and whether the person is able-bodied or has a disability but is otherwise healthy.[11] Hence, inasmuch as there is provincial/territorial legislation on point, healthcare providers have a statutory obligation to respect all competent adult patients' refusals of care (including preventive care and oral and artificial hydration and nutrition).[12]

Are deaths resulting from refusals of care "natural deaths" for the purpose of determining whether an individual is eligible for MAiD?

The final question that must be addressed is whether a death following a refusal of care is "natural" (as opposed to the other possible classifications: "accident," "suicide," "homicide," "undetermined," or "other"). There are a variety of potential sources for guidance regarding the meaning of "natural death" in the Canadian MAiD legislation: 1) the MAiD provisions of the *Criminal Code*; 2) the *Criminal Code* beyond the MAiD provisions; 3) case law interpreting relevant part(s) of the *Criminal Code*; 4) College of Physicians and Surgeons' decisions interpreting relevant part(s) of the *Criminal Code*; and 5) legislation, guidelines, and established practices in relation to the completion of medical certificates of death. We consider each in turn.

The MAiD provisions within the *Criminal Code*

The MAiD provisions within the *Criminal Code* use the phrase "natural death" but do not include a definition of the phrase.

The *Criminal Code* beyond the MAiD provisions

The phrase "natural death" only appears once in the *Criminal Code* – in the provisions with respect to MAiD. No definition for the phrase is provided anywhere in the *Criminal Code*.

Case law

There has been only one case in which the meaning of "natural death" has been mentioned in the context of the federal MAiD legislation. In *A.B. v Canada (Attorney General)*, Justice Perell wrote:

> In referring to a "natural death" the language denotes that the death is one arising from causes associated with natural causes; i.e., the language reveals that the foreseeability of the death must be connected to natural causes, which is to say about causes associated with the functioning or malfunctioning of the human body. These are matters at the core if not the whole corpus of medical knowledge and better known to doctors than to judges. The language reveals that the natural death need not be connected to a particular terminal disease or condition and rather is connected to all of a particular person's medical circumstances [20, para 81].[13]

There is nothing in the decision to tell us what "associated with" means and it is not clear when, if ever, natural causes brought on as a result of a person's choices (e.g., refusal of care) would constitute "causes associated with natural causes." In addition, the case did not involve a refusal of care and so these comments could be considered *obiter dicta*. Finally, deference is shown here to the views of physicians on the issue (and such views will be discussed in detail later in this paper).

[9] "(2) Every one commits an offence who, being under a legal duty within the meaning of subsection (1), fails without lawful excuse, the proof of which lies on him, to perform that duty, if (a) with respect to a duty imposed by paragraph (1)(a) or (b), (i) the person to whom the duty is owed is in destitute or necessitous circumstances, or (ii) the failure to perform the duty endangers the life of the person to whom the duty is owed, or causes or is likely to cause the health of that person to be endangered permanently; or (b) with respect to a duty imposed by paragraph (1)(c), the failure to perform the duty endangers the life of the person to whom the duty is owed or causes or is likely to cause the health of that person to be injured permanently" [1, s.215].

[10] Newfoundland and Labrador, New Brunswick, Manitoba, Saskatchewan, Alberta, Northwest Territories, and Nunavut do not have relevant legislation and so are governed by the common law as explained above. For a full review of the provincial/territorial law regarding refusals of treatment, see [18].

[11] Nova Scotia, Prince Edward Island, Quebec, Ontario, British Columbia, and Yukon have relevant legislation but none of the statutes displace the common law right to refuse care. Rather, they reinforce the duty to respect refusals of care [18].

[12] It must be noted that, in some provinces (e.g., British Columbia), patients who are involuntary confined under mental health legislation but who have decision-making capacity can nonetheless be treated for their mental disorder against their will. However, "[t]reatment for purposes unrelated to the person's mental disorder is subject to the generally applicable laws regarding consent to treatment." [19]

[13] Therefore, this exception to the general rule does not displace the conclusions drawn in this section.

There have been a few cases in which "natural death" has been discussed (outside of the context of the federal MAiD legislation). In *Nancy B.,* Justice Dufour reflected on whether withholding or withdrawing potentially life-sustaining treatment results in a "natural death" rather than "suicide."

> Sections 222 to 241 of the Criminal Code deal with different forms of homicide. What I have just reviewed is sufficient to conclude that the person who will have to stop Nancy B.'s respiratory support treatment in order to allow nature to take its course, will not in any manner commit the crimes prohibited by these sections. The same goes for s. 241, aiding suicide.
>
> I would however add that homicide and suicide are not natural deaths, whereas in the present case, if the plaintiff's death takes place after the respiratory support treatment is stopped at her request, it would be the result of nature taking its course [21, para 61].

While Justice Dufour did not explicitly consider whether the refusal of artificial nutrition and hydration would constitute suicide, he did state, albeit in the context of considering a different point under the *Civil Code of Québec*, that placing someone on a respirator was "a technique of the same nature as that of feeding a patient. One cannot therefore make distinctions between artificial feeding and other essential life-sustaining techniques." [21] The logic of this passage suggests that if he had turned his mind to it, he would have concluded that the refusal of artificial nutrition and hydration also does not constitute suicide.

It is important to note, however, that the conclusion may be narrower than the entire range of cases captured by the right to refuse care described above and the examples set out at the beginning of this paper. That is, it may only apply in circumstances in which the death can be characterized as "letting nature take its course." This case arguably stands for the proposition that death following a refusal of life-sustaining treatment (including artificial nutrition and hydration) is "natural" if the resulting death can be characterized as "letting nature take its course" (whatever that may mean). While this is, of course, only the decision of a single judge in the Quebec Superior Court, it has been widely and approvingly cited (including, e.g., in *Carter*) without any exception being taken to these conclusions.

Turning to the issue of refusing oral hydration and nutrition, there is some evidence that this might be considered suicide: in *British Columbia (Attorney General) v. Astaforoff,* Justice Bouck held that dying via a self-imposed hunger strike was equivalent to suicide [22]. It must be noted, however, that this case took place many years ago and in the context of a prison rather than a hospital. It is also a case of someone who could but chose not to eat as opposed to someone who relied on being fed by another person and refused that assistance – which is perhaps a closer analogy to *Nancy B.*

Further complicating matters, there is also some evidence that refusing either oral or artificial hydration and nutrition might be considered suicide: in *Carter*, Justice Smith noted that "[h]e [Mr. Copley for the Attorney General of British Columbia] submits that 'the able bodied and the disabled can equally commit **suicide** by refusing to eat or drink or by refusing provision of artificial nutrition or hydration'." [22, para 1067] Justice Smith did not take issue with this characterization of refusing oral or artificial hydration or nutrition as **suicide** (and the SCC in the *Carter* appeal did not take issue with her acceptance of the characterization). However, the Attorney General of BC and Justice Smith may well not have contemplated the implications of their statements for end of life care outside the context of the issue of whether to strike down the *Criminal Code* prohibitions on MAiD. Calling the refusal of oral and artificial hydration and nutrition "suicide" (rather than simply saying that they are legal) [8,15] suggests that wherever a patient dies as a consequence of the withholding or withdrawal of oral or artificial hydration and nutrition, their death should be treated as "suicide." Which, of course, in practice, it is not.

Ultimately, a review of the cases discussing manner of death – directly or indirectly and with or without attention or awareness of the broader implications of the statements being made – does not provide sufficient clarity to conclusively evaluate the legality of this paper's set of possible pathways to MAiD. It seems like refusals of life-sustaining treatment are not suicide, regardless of the cause of the underlying condition precipitating the request for MAiD (i.e., scenarios 1,2,3,5, and 6). However, competing conclusions have been drawn about whether refusals of artificial nutrition and hydration are suicide ("no" where it is "nature taking its course" in *Nancy B*, but "yes" in *Carter*). Finally, at first glance, it seems like refusals of oral nutrition and hydration are suicide (in *Astaforoff* and *Carter*). However, *Astaforoff* was a case in the prison context and *Carter* was a case about the legality of a prohibition on assisted dying (which does not include the withholding and withdrawal of nutrition and hydration). It is simply not clear from a review of the case law what a court would conclude about artificial and especially oral hydration and nutrition (i.e., scenarios 4 and 7).

It therefore seems wise – and consistent with the only case to consider the meaning of "natural death" in the context of the federal MAID legislation – to turn to medical sources and authorities that address the determination of the manner of death directly.

Colleges of Physicians and Surgeons

No College of Physicians and Surgeons has provided guidance on this issue to their members through MAiD Standards or Guidelines. However, there has been one complaint made to a College and the College's response is directly on point [23]. In June 2016 and again in December 2016, Dr. Ellen Wiebe assessed a patient with advanced multiple sclerosis who was requesting MAiD. Dr. Wiebe found that her natural death was not yet reasonably foreseeable. At the end of February 2017, the patient stopped eating and drinking and fourteen days later, Dr. Wiebe concluded that her natural death was now

reasonably foreseeable and provided her with MAiD. The chief medical officer and coroner for British Columbia wrote to the BC College of Physicians and Surgeons to raise questions about whether this instance of MAiD was legal – was the patient's natural death reasonably foreseeable given that "her decision to decline treatment arguably contributed to the serious nature of her disease and her act of voluntarily stopping eating and drinking precipitated her advanced state of decline." [24] An Inquiry Committee for the BC College found that the patient met the criteria for MAiD "despite the fact that her refusal of medical treatment, food, and water undoubtedly hastened her death and contributed to its 'reasonable foreseeability.'" [24] Based on this, it is reasonable to conclude that at least one College of Physicians and Surgeons is of the view that deaths that would result from a refusal of care (including treatment, food, and water) are "natural" for the purposes of determining eligibility for MAiD (for scenarios 1-7).

Medical certificates of death

Federal guidelines regarding medical certificates of death

In April 2017, the federal government published "Federal guidelines: reporting of deaths in cases of medical assistance in dying (April 2017)." [25] The purpose was to "address the completion of the Medical Certificate of Death where a patient has received medical assistance in dying, to facilitate the identification of cases of medically assisted deaths and to encourage consistency in approaches across provinces and territories." [25] However, the government also recognized that "death reporting and investigation is the responsibility of individual provinces and territories. Also, some provinces and territories have already adopted their own approaches to death certification for medically assisted deaths. That is why the federal guidelines are non-binding and respect provincial and territorial oversight for reporting deaths."

The federal guidelines indicate that "[m]anner of death [for MAiD] should be certified as natural if such an option exists." Unfortunately, this does not explicitly help resolve the questions raised by this paper, as the guidelines address only how to certify the manner of death for deaths after MAiD has occurred, but not how to certify the manner of death in the absence of MAiD. It is this second fact that is relevant to whether someone qualifies for MAiD in the first place. However, it could be argued that an implication can be drawn from the guidelines. That is, it could be argued that a refusal of care is as natural a manner of death as the lethal injection or ingestion associated with MAiD. If MAiD is to be classified as "natural," regardless of any of the variables outlined at the start of this paper, then arguably so too should be refusals of care. On this argument, all of the scenarios outlined at the beginning of this paper should be classified as "natural."[14]

Counter to this, it might be argued that "natural death" is defined with different goals in the context of medical certificates of death than eligibility for MAiD. For medical certificates of death, MAiD is defined as "natural" so as not to skew the national mortality data and lead to mistakes being made about, for example, public health initiatives. For example, if it were recorded as suicide, we would see a significant increase in suicide deaths and so might redirect public funding to suicide prevention where that would be an inappropriate response to the phenomenon. Eligibility for MAiD has no such mortality data and public health spending implications. On this argument, the federal guidelines give us no direction regarding the scenarios.

Statistics Canada – Canadian Coroner and Medical Examiner Database: Annual Report

The Canadian Coroner and Medical Examiner Database Annual Report, 2006 to 2008 [26] defines natural death as "[a]ll deaths where a disease initiates the chain of events ending in death" and suicide as "[a]ll deaths where a self-inflicted injury initiates the chain of events ending in death where the decedent intends to cause their own death." Accident is defined as "[a]ll deaths where an injury initiates the chain of events ending in death and there is no element of intent in the circumstances leading to the injury. Undetermined deaths are defined as "[a]ll deaths where investigation is unable to attribute one of the previous manners are characterized as undetermined. Note that in such circumstances, the cause of death may be known."

If one were to apply these definitions to the scenarios outlined at the beginning of this paper and to our central question, the following conclusions might be drawn:

- Where a patient has pneumonia not precipitated by an accident or self-inflicted injury, refuses antibiotics and is going to die of pneumonia, then the death should be classified as natural. However, if the pneumonia was precipitated by an accident or self-inflicted injury, then the death should be classified as an accident or suicide respectively.
- Where a patient requiring turning in order to avoid pressure ulcers (the requirement for turning precipitated by a disease), refuses turning and as a result gets pressure ulcers, which then get infected and the patient then refuses antibiotics and is going to die from the infection, then the death should be classified as natural. However, if the requirement for turning was precipitated by an accident or self-inflicted injury, then the death should be classified as an accident or suicide respectively.
- Where, a patient requires artificial hydration or nutrition (the requirement for artificial nutrition and hydration precipitated by a disease), refuses that artificial hydration or nutrition, and is going to die of starvation or dehydration, then the death should be classified as natural. However, if the requirement for artificial hydration or nutrition was precipitated by an accident or self-inflicted injury, then the death should be classified as an accident or suicide respectively.
- Where a patient refuses oral hydration or nutrition and is therefore going to die of starvation or dehydration, then the death should be classified as suicide or "undetermined" (depending on whether starvation or dehydration is considered a "self-inflicted injury").

[14] It should be noted here that, as will become clear later in the paper, these guidelines dissociate the classification of death from the disease or injury that set in motion a chain of pathophysiologic derangements that end in death (the traditional approach taken by coroners and medical examiners to classification of death).

Instructions regarding completion of medical certificate of death forms

Some provincial/territorial governments provide instructions for completing medical certificates of death, not specific to MAiD. Ontario's instructions state: "Is the death due to non-natural causes (such as accident, homicide, or suicide)? For example, an injury (e.g., hip fracture) that precedes a terminal medical event (e.g., pneumonia) is considered to be non-natural, and therefore a coroner must be notified to determine if the death may be attributable to the initial injury." [27][15] British Columbia's instructions lead to the same conclusion [28]. This suggests that if a death follows a refusal of care (whether preventative, curative, or palliative and whether artificial or oral hydration or nutrition) responding to a medical condition attributable to an initial injury caused by an accident, then the death should be determined to be accidental rather than natural. However, if a death follows a refusal of care (whether preventative, curative, or palliative, whether artificial or oral hydration or nutrition) responding to a medical condition attributable to a disease or naturally occurring disability, then the death should be determined to be natural. This seems consistent with the definition of "natural" found in the Canadian Coroner and Medical Examiner Database Annual Report discussed above.

Interestingly, in Alberta, a death resulting from MAiD is to be classified as "'unclassified' which is neither 'natural' nor 'suicide' but indicates a drug poisoning." [29] In Yukon, MAiD is dealt with by inserting "MAID" rather than ticking any of the boxes for manner of death (accident, suicide, homicide, undetermined): "[m]edical assistance in dying (or MAID) must be reported (hand written) on the form in Section 29 as the manner of death." [30] In Manitoba [31] and British Columbia [28], the cause of death is the underlying disease and the manner of death is to be natural.

Unfortunately, the available provincial/territorial instructions do not explicitly help resolve the questions raised by this paper. First, they reveal a lack of one consistent approach across the country. Second, they address only how to certify the manner of death for deaths after MAiD has occurred, but not whether someone qualifies for MAiD in the first place. That said, a very important lesson can be drawn from them, i.e., in the context of MAiD and for the specific purposes of MAiD, provincial/territorial authorities can issue instructions and make it clear what they believe constitutes "natural death".

The traditional approach to classification of death by coroners or medical examiners

The individuals with the greatest experience with, and understanding of, the classification of death are coroners and medical examiners. How then do they classify death? And is there any consensus among these groups as to how the manner of deaths should be classified that could provide insight into the questions posed in this paper? In effect, what can we draw from "first principles"?

The meaning of the word "natural" varies with context but, in the community of coroners and medical examiners, the word has a specific technical meaning. Amongst coroners and medical examiners, the cause of death is the disease or injury that sets into motion a chain of pathophysiologic derangements that end in death. The manner of death for any death where the chain of derangements was set into motion by a disease is natural. Deaths where the chain was set into motion by an injury are classified according to the circumstances of that injury, e.g., the manner is accidental where the injury was unintentional or suicide where the injury was inflicted in a deliberate attempt at self-harm. The chain of pathophysiologic derangements itself is called the mechanism of death.

When the death is in close temporal proximity to the onset of disease or the time of the injury, the analysis is usually straightforward. The problematic cases (from the point of view of classification) are those where the onset is distant in time, and this is usually a consequence of the large number of physiologic derangements that may dominate the person's terminal course, and thus their treatment decisions. Consider the person who suffers a spinal cord injury from a gunshot wound: such a person may be expected to live a long time, and may well suffer repeated bouts of urinary tract infection, sepsis from pressure sores, and bronchopneumonia. Although this person's death from sepsis years after the injury may not prompt a treating physician to think of trauma as the proximate cause (and therefore the manner as natural), in the minds of coroners and medical examiners, it is logical to construct that person's death as a late complication of a gunshot wound (hence manner as non-natural), since but for the gunshot wound, that person would not have been paraplegic, and would not have suffered from sepsis from a urinary tract infection. Physicians and others may refer to sepsis and pressure sores as "natural" consequences of paraplegia, meaning that these are logical or expected consequences of the underlying pathology. This may be so, but it does not make these deaths "natural" from the point of view of coroners and medical examiners.

Let us now apply these standard practices of coroners and medical examiners to the novel question of whether a death following a refusal of care should be considered a "natural" death. On the logic of the specific technical meaning of "natural death" in the community of coroners and medical examiners, if the patient refuses care that is necessary due to an accident (scenarios 3 and 6), then the manner of death is not natural – even if the mechanism is, for example, an infection. If the patient refuses care that is necessary due to a disease, then the manner of death is natural (scenarios 1, 2, 4, and 5).

What about a death following refusal of oral nutrition and hydration? The need for oral nutrition and hydration does not flow from a disease, disability, injury, accident, or violence. This need is a simple consequence of normal human physiology. There is no causal chain of pathophysiologic derangements resulting in a dependence on oral nutrition and hydration that one can then refuse. However, perhaps one could rely upon the long-established tradition that deaths due to complications of therapy

[15] Note: according to these instructions, "natural causes" is manner of death and not a cause of death.

for a disease or injury ought to be classified as due to the disease or injury that caused the patient to seek the therapy. Death due to refusal of oral nutrition and hydration might be classified as due to the disease or injury that caused the patient to refuse the oral nutrition and hydration. If so, the manner of death following a refusal of oral nutrition and hydration in response to a disease would be "natural" (scenario 7). Similarly, the manner of death following a refusal of oral nutrition and hydration in response to an injury caused by an accident would be "accident."

Conclusion

It has been observed that there are no national standards for the classification of death [32]. This situation, a consequence of the division of powers, has introduced great variability in the practice of death classification generally, not just in the context of MAID. It is thus unsurprising that a search of the medical literature reveals numerous examples of studies demonstrating significant variability in the classification of the manner of death by various professionals (e.g., attending physicians, coroners and medical examiners) in response to scenarios [33].

The need for clear guidance

Because Canadian MAiD legislation requires that the reasonably foreseeable death must be a "natural death," the law must be clear about whether the deaths that would follow respect for refusals of care constitute "natural death." Specifically, whether the following reasonably foreseeable deaths are "natural" (vs. "accident" or "suicide"):

- a patient with a treatable pneumonia refuses antibiotics
- a paralyzed patient refuses life-sustaining ventilator support
- a patient refuses turning, which leads to pressure ulcers, which leads to treatable infection, for which the patient refuses antibiotics
- a patient refuses artificial nutrition, which leads to starvation
- a patient refuses oral nutrition, which leads to starvation

If the reasonably foreseeable death would be a "natural death," then the individual meets the eligibility criterion of s.241.2(2)(d) of the *Criminal Code* once it is reasonable to conclude that they will not change their mind about the refusal of care. In addition, healthcare providers do not risk liability for aiding or abetting suicide by disclosing or facilitating the exercise of that refusal pathway to MAiD [13,34].

Taking into account all the sources of authority examined in this paper, we can conclude that, in some cases, the law is clear. A reasonably foreseeable death is natural if:

- it flows from the refusal of medical interventions such as ventilators or antibiotics (but not including artificial hydration and nutrition);
- the reasonably foreseeable death would be "nature taking its course;" **and**
- disease (rather than accident or injury whether inflicted by self or other) precipitated the need for the care that is being refused.

It is critically important that this clarity be acknowledged and disseminated so that individuals who could legally refuse care as a path to MAiD are not denied access due to a misguided fear of criminal liability on the part of health care providers or institutions.

Unfortunately, in some cases the law is not as clear. It is not as clear whether the following reasonably foreseeable deaths would be natural:

- deaths that would flow from the refusal of artificial or oral hydration and nutrition;
- deaths that would flow from the refusal of preventive care;
- deaths that would not be the result of "nature taking its course;" and
- deaths that would flow from the refusal of care where accident or injury (whether inflicted by self or other) precipitated the need for the care being refused.

It is critically important that the law regarding these cases be clarified so that individuals who could legally refuse care as a path to MAiD are not denied access due to a reasonable fear of criminal liability on the part of health care providers or institutions and that individuals who could not legally refuse care as a path to MAiD are not given access to MAiD due to a misunderstanding of the law on the part of MAiD assessors and providers.

Proposed clarification

In order to harmonize the various aspects of the case law, provincial/territorial consent legislation, and the *Criminal Code*, the definition of "suicide' for the purposes of s.241(1) of the *Criminal Code* should be clarified. In order for patients and providers to know for certain which, if any, of the examples outlined at the beginning of this paper constitute "natural death" and so can function as a path to MAiD, a clear definition of "natural death" for the purposes of s.241.2(2)(d) should be established. Such clarification can come from Parliament (through an amendment to s.241.2 of the *Criminal Code*) or from the courts (through a case turning on the definition).

Given that individuals have a right to refuse treatment, preventive care, and artificial and oral hydration and given that physicians have a duty to respect refusals (and may be liable for assault or battery if they touch patients without their consent), the *Criminal Code* should be amended/interpreted to make it clear that, in the context of s.241.2(2)(3), a reasonably

foreseeable death from a refusal of treatment or preventive care or artificial and oral nutrition or hydration would be "natural" if an underlying medical condition (regardless of whether caused by disease or naturally-occurring disability, accident, or intentional injury by self or other) precipitated the refusal.

In the meantime, the federal government should revise the "Federal guidelines: reporting of deaths in cases of medical assistance in dying (April 2017)" [25] to make it clear when refusing care renders a patient's death not "natural." Provinces and territories should, in turn, harmonize their vital statistics instructions regarding medical certification of death with these federal guidelines. Where they have a mandate to do so, chief coroners/medical examiners should issue instructions for the completion of medical certificates of death by coroners/medical examiners/physicians/nurse practitioners to harmonize their approach to medical certification of death with the federal guidelines. Colleges of Physicians and Surgeons as well as Colleges of Nurses should direct physicians/nurse practitioners to follow the instructions provided by the authorities in their province/territory and, if none, the federal guidelines. These instructions should be included in their professional standards regarding medically assisted dying, as they are in Nova Scotia.

Any of these entities, as well as the Canadian Association of MAiD Assessors and Providers, need not wait for the federal government to act. They could reasonably offer guidance immediately to those they regulate or serve.

Clarifying documents could state either of the following:

1. *Template text consistent with the traditional approach to the classification of death and Statistics Canada database*

   If a person refused care – including preventive, curative, and palliative heath care (including artificial and oral nutrition and hydration and nutrition) – and died as a result of the withholding or withdrawal of that care, we would consider their death to be natural if the care was necessary due to a disease or naturally-occurring disability. We would not consider it to be natural if the patient refused care that was necessary due to an accident or intentional injury by self or other, even if the mechanism of death would be, for example, an infection.

OR

2. *Template text consistent with inference from the federal guidelines regarding medical certificates of death in cases of MAiD*

   If a person refused any type of care – including preventive, curative, and palliative heath care (including artificial and oral nutrition and hydration and nutrition) – and died as a result of the withholding/withdrawal of that care, we would consider their death to be natural if an underlying medical condition (regardless of whether cause by disease or naturally-occurring disability, accident, or intentional injury by self or other) precipitated the refusal.

   A person's natural death has become reasonably foreseeable when they have refused care without which they will die and it is reasonable to conclude that they will not deviate from that refusal.

The latter of these two options is preferable for at least two reasons. First, because it is grounded in guidelines drafted after the passage of the federal MAiD legislation and specifically for the purpose of providing guidance in the context of MAiD. Second, because it avoids the indefensible position that a person's access to MAiD would depend on the ethically irrelevant and arbitrary fact of whether the cause of their underlying medical condition causing enduring, intolerable, and irremediable suffering was an accident or a naturally occurring disease, disability, or disorder (e.g., a person who is quadriplegic due to a stroke would have different rights than a person who is quadriplegic due to a motorcycle accident).

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

In Our Own Words: A Qualitative Exploration of Complex Patient-Provider Interactions in an LGBTQ Population

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Résumé
Bien que les minorités sexuelles et de genre courent un risque accru de problèmes de santé, on dispose de peu de données sur les interactions patient-prestataire de soins. Dans cette étude, nous avons exploré les perspectives des patients LGBTQ et leurs rencontres avec les médecins afin d'améliorer notre compréhension des expériences patient-médecin. À l'aide d'une sélection ciblée de patients LGBTQ auto-identifiés, nous avons réalisé quatorze entrevues semi-structurées en profondeur sur des sujets comme l'orientation sexuelle et l'identité de genre, ainsi que leur rôle perçu dans la relation patient-fournisseur. Un codage utilisant une approche modifiée de la théorie ancrée a été effectuée pour générer des thèmes. Nous avons identifié trois grands thèmes qui démontrent la complexité des expériences vécues par les patients LGBTQ. La première, *le manque de confiance*, identifie la méfiance et la perte de la relation médecin-patient résultant d'une mauvaise communication des médecins ou d'un jugement porté sur eux, ou du fait que les médecins font des suppositions sur le genre, utilisent des pronoms incorrects et ne reconnaissent pas l'hétérogénéité dans la communauté transgenre. Un deuxième thème, *être vulnérable*, décrit les défis et les craintes liés au réconfort des patients face à la divulgation de leur orientation sexuelle ou de leur identité de genre. Un dernier thème, *la discrimination sélective*, met en relief la discrimination raciale ou ethnique qui crée un fardeau supplémentaire en plus de la maladie et de l'identité stigmatisée. Nos résultats révèlent les besoins complexes des personnes aux multiples identités stigmatisées lorsqu'il s'agit d'établir des relations avec les prestataires. En utilisant une perspective intersectionnelle qui tient compte de la pluralité des identités des patients, les prestataires peuvent aider à améliorer leurs relations avec les patients LGBTQ. L'intégration d'une formation intersectionnelle pour les étudiants en médecine et les résidents pourrait grandement profiter aux patients LGBTQ et à leurs médecins.

Mots-clés
LGBTQ, santé, relation patient-médecin, intersectionnelle, inégalités de santé

Abstract
While sexual and gender minorities are at increased risk for poor health outcomes, there is limited data regarding patient-provider interactions. In this study, we explored the perspectives of LGBTQ patients and their encounters with physicians in order to improve our understanding of patient-physician experiences. Using purposive selection of self-identified LGBTQ patients, we performed fourteen in-depth semi-structured interviews on topics of sexual orientation and gender identity, as well as their perceived role in the patient-provider relationship. Coding using a modified grounded theory approach was performed to generate themes. We identified three major themes that demonstrate the complexity of LGBTQ patient experiences. The first, *Lacking trust*, identifies mistrust and loss of the physician-patient relationship resulting from physicians' poor or judgmental communication, or from physicians making assumptions about gender, using incorrect pronouns, and not recognizing heterogeneity within the transgender community. A second theme, *Being vulnerable*, describes the challenges and fears related to comfort of patients with disclosing their sexual orientation and/or gender identity. A final theme, *Navigating discrimination*, outlines racial or ethnic discrimination which creates an additional burden on top of illness and stigmatized identity. Our results reveal the complex needs of individuals with multiple stigmatized identities when developing relationships with providers. By using an intersectional perspective that appreciates the plurality of patients' identities, providers can help to improve their relationships with LGBTQ patients. Incorporating intersectional training for medical students and residents could greatly benefit both LGBTQ patients and their physicians.

Keywords
LGBTQ, health, patient-physician relationship, intersectionality, health disparities

Introduction

Understanding the issues related to LGBTQ health is an important and growing area of research and scholarship within bioethics [1-3]. Sexual and gender minorities are at increased risk for various adverse health outcomes [4-11]. Sexual minorities face social stigma and discrimination over their lifetimes, frequently causing significant stress, increased chronic health problems, and maladaptive coping behaviours [4-8]. Research on sexual and gender minorities and health has gained traction over the past few decades, yet limited data exists with regards to patients and their interactions with health care providers.

Lesbian, gay bisexual, transgender and queer (LGBTQ) self-identified patients may experience health disparities or discrimination from health providers that can harm the patient-provider relationship and affect negatively the health outcomes of patients. Questions surrounding how LGBTQ patients select physicians and maintain relationships with health providers remain largely unexplored. For example, what qualities in a physician are considered when choosing a provider, and how is trust in a patient-physician relationship maintained or lost? Several studies have shown that sexual and gender minorities are at increased risk of a variety of adverse health outcomes [4-11]. Sexual and gender minorities are at higher risk for violent hate crimes, sexually transmitted infections (STIs) including HIV/AIDS, mental health conditions, substance abuse, and other adverse health outcomes [4-5]. Social stigma, prejudice, and discrimination towards sexual minorities over the life course can cause significant stress and result in chronic health problems or can perpetuate the use of maladaptive coping behaviours [4-7].

It is clear from the current literature that there have been few, yet promising, efforts to use narrative methodology to determine quality of patient-physician relationships or comfort of sexual and gender minorities in a healthcare setting [12-17]. Investigating the quality of patient-physician relationships is crucial to improving the health of this population. For example, sexual orientation of the patient, if openly self-identified, can become a hindrance to patient-physician communication especially if the patient senses hesitancy on the part of the physician after disclosure [18]. This can get in the way of trust and respect between the

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two parties which is incredibly important for fostering an effective medical relationship in order to address specific health needs. LGBTQ patients' trust in the medical establishment may have already been compromised due to a history of medical legitimization of invasive procedures in homosexual males and refusal of treatment for transgender individuals [19]. Issues of trust are often exasperated by intersections of minority status, such as is the case for ethnic and racial minority LGBTQ individuals [10]. Research has shown that improving patient-physician relationships allows for increased shared decision making, improved patient satisfaction, and better patient health outcomes [5,20-23]. Approaching patients with an understanding of intersectionality and inquiring about that individual's priorities may improve the development of these relationships.

Intersectionality is a theoretical concept described as the interlacing of multiple identities such as gender, sexual orientation, race and ethnicity, socioeconomic status, education level, among others, and how each component of a person's identity is inseparable from the other [24]. Each aspect of identity is interdependent on the others in formulating an overall experience. This allows a more complicated understanding of how forces of discrimination and oppression (racial, gender, sexuality), which should be understood as a complex set of forces, rather than the simple addition of these forces. Such intersecting forces can both overlap yet still negatively affect people in different ways. Intersectionality has been used across multiple disciplines to describe the intersection of multiple identities with social issues and structural barriers, including those that contribute to health disparities [25-26]. This framework is often used as a lens through which to view individual experiences in relation to social issues, power dynamics, and health disparities as well as the unique needs of minority populations. Intersectionality requires physicians to take a comprehensive look at all spheres of influence on an individual's health and quality of life. Its importance has been highlighted by the American Association of Medical Colleges (AAMC) as its application in medicine can provide guidance, help remediate structural barriers for underserved populations and so reduce the reliance on simplistic interpretations of identity and culture [27]. While the concept of intersectionality and its application in physician practice is evolving, we believe such an approach can and will improve patient care.

The purpose of this study was to explore LGBTQ patients' experiences and relationships with their providers in order to gain a better understanding of existing disparities in care and identify areas where improvements can be made to patient-physician relationships for this population. We report on three major themes: *lacking trust*, *being vulnerable*, and *navigating discrimination*. Our results illustrate the complex needs of individuals with multiple stigmatized identities when developing relationships with providers. By understanding multi-faceted and complex identities through an intersectional perspective, providers can improve their relationships with their LGBTQ patients. Incorporating intersectional training for medical students and residents could greatly benefit LGBTQ patients and their physicians.

Methods

Terminology

Like other specific public groups, the LGBTQ community is not homogenous. "Trans" will refer to individuals whose assigned gender at birth differs from the gender with which they identify. For example, a male to female transgender individual is a trans-woman, whereas a female to male is a trans-man. The transgender community may also include individuals who are gender-fluid or gender non-conforming and who do not identify with the traditional male/female binary. For individuals whose assigned gender at birth is consistent with the gender with which they identify, the term we will use is "cisgender" or "cis". Other terms used in this paper refer to variances in sexual orientation and include Lesbian, Gay, Bisexual, Queer (a more broad and reclaimed term for some individuals identifying as other than heterosexual that can sometimes include individuals who identify as pan-sexual, asexual, and/or polyamorous, among others) [28], as well as individuals who prefer "no label" to identify their sexual orientation. All interviewee descriptors and labels are self-reported by the participant on how they chose to describe themselves.

Recruitment and Participant Demographics

In order to explore the depth of LGBTQ patient perceptions, we adopted a qualitative approach using individual interviews. A convenience sample of LGBTQ participants living in New York state was recruited from two LGBTQ centres after obtaining permission from both organizations. Centre 1 is a community organization providing resources for HIV positive individuals and Centre 2 is a regional community centre serving the needs of the LGBTQ community. We have omitted further recruitment information in order to protect participant privacy. Prior to conducting interviews, participants were given an information sheet about study procedures and written informed consent was obtained. Participants were given a $20 grocery store or Walmart gift card for participation. Ethics review was conducted and approved by Albany Medical Center Committee on Research Involving Human Subjects Institutional Review Board prior to participant recruitment.

Fourteen individual interviews were conducted over a two-month period at the Centre 1 (10 participants) and Centre 2 (4 participants). Participants (by chance fell within the age range of 28-57) consisted of 3 cisgender women, 8 cisgender men, and 3 transgender women. In terms of sexual orientation, 6 identified as gay, 4 as bisexual, 2 as heterosexual, 1 as queer, and 1 preferred no label. Participants were from a diversity of racial/ethnic backgrounds including 6 who identified as Caucasian, 5 as African-American, 2 as Hispanic, and 1 as both African-American and Peruvian.

Interviews and Qualitative Analysis

Semi-structured interviews consisted of a series of questions around self-rated health, access to the health care system, sexual orientation/gender self-identification, demographics, and the patient-provider relationship from patients' perspectives. Interview questions were developed based on existing literature [29-34] and pre-tested with three experts who study ethical issues surrounding sexual and gender minorities to ensure question clarity and appropriateness. The interview guide was modified accordingly (see Supplemental Materials: Interview Guide). Individual interviews (30-60 minutes) were conducted in English. Interviews were recorded using a digital voice recorder, transcribed by a third-party provider, and transcripts were validated against audio recordings and de-identified of any personal information. Participants were recruited and interviewed until data saturation, specifically until similar themes arose from the interviews conducted.

Analysis of interview transcripts was performed by the primary coder (SM) using an abridged grounded theory approach [35] with constant comparison analysis [36] with a codebook that was inductively developed. The primary coder first performed a descriptive analysis of all of the transcripts followed by a second round of coding to develop overarching themes. Qualitative coding was performed using QSR International NVivo version 10 to develop themes.

Results

The analysis of the interviews resulted in three major themes that demonstrate the complexity of experiences among this specific group of sexual and gender minority individuals.

Lacking Trust: Communication, Mis-gendering, and Respect

One theme that emerged centred on the importance of trust in the patient-provider relationship and how it can be damaged through poor communication, mis-gendering, and disrespect. Clinicians' use of medical jargon and explanatory tone significantly affects whether patients will continue to see the provider [37]. Poor communication by physicians can lead to mistrust and ultimately the loss of the physician-patient relationship [37]. For LGBTQ patients, and patients in general, poor communication often hinders establishing a mutually respectful relationship. Some interviewees expressed a need for providers to communicate respectfully and intelligibly, as one participant explained:

> I have [gone] to doctors who've talked down to me using just only doctor language and I have to say what is that, what is that? There's an incident where a doctor would tell me what I have or what they found but didn't explain to me what that was, so I walked. (Participant 13, heterosexual transwoman)

Another participant reported a negative experience due to a provider's condescending tone:

> I hate when people depreciate me. I'm no longer in [kindergarten]…My parents taught me [you have] got to give respect to get respect. You know, so if you're not going to respect me or…just want to shovel me in and shovel me out, it doesn't work like that. (Participant 7, gay cisman)

Many providers are unfamiliar with the needs of transgender patients [38]. Yet, participants wanted physicians' acceptance:

> There are not many people that treat transgender patients. One of the biggest [problems] that a lot of people in the transgender community [have] is finding a care provider that will be open [and] accepting instead of judging. Even for endocrinologists there are not many out there that do that. (Participant 12, bisexual transwoman)

For participants, trusting providers requires open and nonjudgmental communication and mutual respect.

Many transgender participants cited *mis-gendering* – making assumptions about gender without clarifying patients' identity or verifying a patient's previous documentation – as disrespectful. Not all transgender patients equally prioritized its importance, given personal preferences or transition status. Most transgender patients, however, appreciated being asked preferences and only began to feel disrespected when repeated, willful mistakes failed to reflect patients' wishes.

> Walking into the doctor's office, it would always be, 'miss, miss, miss...' and they would ask me, 'Are you pregnant? Did you do a Pap smear?' And I'm like, 'did you look at my own records.' (Participant 13, heterosexual transwoman)

The participant then goes on to describe a more respectful and appropriate approach to transgender or gender-variant patients:

> 'What's your pronoun? How would you like to be addressed?' Or if you're looking at someone's file and you see it says 'Ted' but then you look up and Ted looks like Tammy. You might want to just say, 'How do you identify?' And I find that if a physician uses words like 'What is your pronoun?' 'How do you identify?', [it] gives us [a] sense of comfort. Wow! They're at least on the same page. (Participant 13, heterosexual transwoman)

For many transgender or gender-variant individuals, much of the physician-patient relationship hinges on a mutual respect that often is expressed in the physician's understanding of gender identity and the patient's preferred pronouns; yet basic knowledge about pronouns may not be enough. As this interviewee discusses, providers need to recognize that there is heterogeneity among sexual and gender minorities:

> Being transgender doesn't mean one thing and that's the thing that shocked [me] the most is I thought everybody was like me. …Well, I'm currently [a] girl, but there's some transgender [people who] are boys, [or] are more butch, some are right in the middle, some like guys, some like girls, some like both. So then you get into the middle… where you have gender neutral or it doesn't matter. (Participant 14, heterosexual transwoman)

For transgender and gender variant individuals, it is especially important that their providers recognize how they identify and individualize their care appropriately.

Being Vulnerable: Disclosing Sexual Orientation or Gender Identity

Another theme addressed the vulnerability of disclosing personal information. Many interviewees described concerns they had about disclosing their sexual orientation and/or gender identity to their health care professional. These concerns contributed to their comfort with discussing personal issues with their providers. The following participant described how a provider might approach the topic:

> Not just assuming one thing or anything, just asking very open, honest questions…So like instead of saying 'do you sleep with men and do you sleep with women', 'are you sexually active [and] with whom?' (Participant 11, queer ciswoman)

The importance of disclosure to their providers was stressed by many interviewees:

> Of course if you don't tell them, they won't know [anything] about you. (Participant 8, bisexual cisman)

> I feel that [anyone] that's taking care of me physically…they should know [if] you're homosexual, bisexual, straight. (Participant 7, gay cisman)

Yet, interviewees were often hesitant to disclose their sexual orientation because they were concerned about the provider's response. Interviewees were sensitive to providers' change in demeanor after disclosure, as it suggested a discomfort with the patient.

> When I did disclose it, I felt as if something changed in him. (Participant 4, gay cisman)

> But some people like Dr. [de-identified], I think once I told him I was gay that kind of turned him more, you know, he was kind of standoffish with me. (Participant 7, gay cisman)

Such reactions may cause the patient to stop disclosing personal information and hinder the patient-provider relationship [18]. At least one participant claimed that disclosing gender identity was more challenging than disclosing sexual orientation.

> At least gay, lesbian, [and] bisexual people are well-known and more accepted than transgender people…The difficult part [is] explaining to a doctor that, 'Hey I am also transgender'…to this day there [are] still people that don't understand transgender people. (Participant 12, bisexual transwoman)

Most interviewees described some challenges related to disclosing their sexual orientation and/or gender identity. This burden of disclosure may often be in the setting of multiple minority stressors, such as racial/ethnic structural discrimination, economic disadvantages, or other stigmatized identities. However, most participants still felt it was important for providers to know their orientation and/or gender identity and for providers to improve their approach to asking about it. For many individuals, disclosing something as personal as orientation or gender identity required being vulnerable to the reaction of the other person, in this case the provider.

Navigating Discrimination: Burden of HIV and Racial/Ethnic Discrimination

A third theme focused on discrimination that participants faced not related to sexual orientation or gender identity. Since participants were recruited from a community organization focused on providing care for HIV positive individuals, many interviews revolved around HIV stigma and management. One individual described the process of discovering his HIV status and how the provider responded inappropriately to his vulnerability:

> I think it was the very first time I had to really face the fact that I was HIV positive and what it meant and all the things that could happen to me. So I was in a very bad space emotionally and so I kind of broke down. And his response was kind of like 'man up'. Like you know, get a hold of yourself. And it just – it totally was

> the most [disturbing] thing that a doctor could have done to me. And it turned me off… for a little while I didn't trust doctors… of course that was the last time I saw him but I internalized what he said and I took it around with me for a little while. (Participant 4, gay cisman)

Another individual described an experience of feeling stigmatized by his own physician because the physician seemed afraid to touch him:

> They are scared to get close to you. I said, well how did you get [to] the position of being [an] HIV doctor when you're scared to touch the patient. All you want to do is give us this medication…and then call the next morning and let you know how it worked. No, it doesn't work like that with me. (Participant 8, bisexual cisman)

The physician's reluctance to touch the patient revealed an overall reluctance to care for the patient – a message that was clearly felt by the patient.

For at least one participant, the stigma of HIV was much greater than the stigma of their sexual orientation:

> People like me who are older, we can say without any hesitation who we are and what we want because we started identifying ourselves as HIV positive long before we started identifying ourselves or maybe at the same time, our gayness and our HIV-ness. Having HIV was like having the scourge of the earth, you know what I mean. So much worse than being gay and if I can identify myself [as] having AIDS, then my god, being gay is nothing compared to having HIV. (Participant 5, bisexual ciswoman)

Additionally, many patients experienced stigmatization regarding their HIV status, thereby compounding the burden of stigmatized gender/sexuality minority identities. It may thus be necessary to broaden the original definition of intersectionality to include HIV status and other clinically relevant stigmatized identities. Participants thought providers should respond appropriately to patient vulnerability and emotions.

Racial/ethnic identities also influenced patient experiences. For example, one African American participant described how her treatment by physicians had been influenced by both assumptions regarding her race as well as her chronic illness. She referenced stereotypes about drug-seeking behaviour in racial/ethnic minorities in the context of her inadequate pain management:

> The things that they say about you being a drug addict, you just want pain medicine, you just want whatever, oh just pull yourself [up] by [your] bootstraps. [They are] perpetuating today's negative stereotypes. (Participant 11, queer ciswoman)

This participant went on to describe other racialized assumptions:

> First of all they see you, they see I'm a brown women and they're like, "Oh, another one. Well what's your education?" I'm like, "You don't know, I could be a doctor too." And then if I seem like I'm invested in my health, they pick it up as black woman power (like trying to be dominant) [but] if it was a white woman doing the same thing…they would say, "oh she's being in charge." (Participant 11, queer ciswoman)

For some participants, racial/ethnic background was a source of discrimination and stereotypes, an additional stressor on top of illness and stigmatized identity.

Discussion

Our results show that many within the LGBTQ community worry about disclosing their sexual orientation and/or gender identity to their provider despite feeling that it was important for their provider to know. We argue that this dilemma is shaped by patients' rational responses to systems of oppression in medicine (both real and perceived), rather than a moral failure of patients. Many fear that disclosure would lead to discomfort or judgment on behalf of the provider [3,19,39-40]. Yet, failure to disclose can have adverse health outcomes, such as delaying medical diagnoses and hindering shared decision-making and patient autonomy [39-40]. Furthermore, non-disclosure of orientation or gender identity due to fear of judgment may result in fewer opportunities for preventive care [39]. In contrast, one study found that higher levels of sexual orientation disclosure are associated with greater health service use among sexual minority cis-gendered men [39]. Another study looking at cancer patients also found a positive association between sexual orientation disclosure to care providers and self-rated health [40].

The fear surrounding disclosure is closely related to the theme of respect and communication. Many participants in our study were concerned due to previous negative experiences, especially regarding poor communication and judgmental attitudes, making them reluctant to disclose potentially stigmatizing information. Some of these negative experiences can be considered micro-aggressions; common examples experienced by the LGBTQ community include assumptions of heteronormativity, the lack of inclusive intake forms that offer options for same-sex relationships or options to identify as trans or non-binary, in addition to encounters that invalidate the role of the patient's life partner in decision-making or ignoring the life partner

altogether [3]. Patients sensing hesitancy from their providers after disclosure ultimately can limit patient-physician communication [40].

The narratives also reflect the broader literature that there are differences in health needs and concerns among different segments of the LGBTQ population and that this is not a homogenous patient population [18]. Many of the issues that participants expressed having with providers were less around sexual orientation for cisgender individuals and more around issues of provider practices in terms of trust, empathy, comfort, and discrimination related to race, HIV status, or other chronic health conditions. Gender identity was more of a central issue among the transgender patients in terms of developing trusting relationships with providers.

Many patients experience challenges based on multiple aspects of their identity, suggesting that an *intersectional* approach to physician education and training may improve patient-physician relationships among diverse populations. Intersectionality recognizes the importance of understanding patients' overall experiences via the interlacing of their multiple identities (e.g., gender, sexual orientation, race, socioeconomic status) [24-26]. Intersectionality prioritizes individual experiences in relation to social issues, power dynamics, and health disparities as well as the unique needs of minority populations. Intersectionality requires a comprehensive view of all spheres of influence on an individual's health and quality of life.

Participants in our study identified serostatus as a meaningful axis in need of intersectional attention. For many, their HIV status added additional identity meanings and raised further discriminatory fears or burdens, including discriminatory assumptions made about the patient's activities that caused their infections. More attention should be given and research done on serostatus as an axis of intersectional health analysis.

For marginalized and minority populations, patients' multiple burdens may cause overwhelming long-term stress, negatively affecting their well-being and quality of life. Facing discrimination or microaggressions from health providers, LGBTQ patients may be less likely to trust medical professionals, weakening the physician-patient relationship. One participant who identified as Hispanic, gay, and HIV+, stated that "physicians should have… an idea [of] all of the facets [of] the person…people are so multidimensional" (Participant 4, gay cisman). Physician-patient relationships based on mutual respect and an understanding of patients' complex identities and needs are more likely to result in shared decision making and patient adherence. An intersectional and individualized approach to patient care would enable physicians to positively influence historically marginalized and disadvantaged communities [41].

Intersectional approaches to patient care might also improve a physician's ability to develop relationships with LGBTQ patients by addressing the impact of systems of discrimination and oppression on patients' lives. Providers can improve their relationships with patients by becoming aware of how the power gap between patients and providers is influenced by existing power dynamics and bias [26]. As Baker and Beagan described in *Making Assumptions, Making Space: An Anthropological Critique of Cultural Competency and its Relevance to Queer Patients*, "cultural competency" training has historically valued physician neutrality in order to avoid being insensitive or uncertain, but this instead reinforces a heteronormative and cis-normative narrative when interacting with a largely invisible LGBTQ population [18]. Neutrality discourages providers from asking their patients questions about their identities and cultures for fear of making assumptions. Yet, these questions and conversations are necessary for disclosure for many patients and serve as a foundation for "safe spaces," or places to be vulnerable without judgment; these conversations can serve as an acknowledgment of an individual's complex lived experience [18]. If a patient knows that a provider or clinic is a safe space, they are more likely to be vulnerable and disclose personal aspects of their identity.

In addition, an intersectional analysis allows patients to have richer ways to understand themselves and their own identities. This can improve self-analysis, but also doctor-patient interactions. First, an intersectional analysis provides a theoretical framework for patients to better identify the source of personal values that are shaping their healthcare decisions. In addition, as we have argued, it allows for an understanding that when values conflict, this is a product of an intersectional analysis, rather than an irrational or unthoughtful patient. Second, it allows patients a means by which they can understand personal complexities as real and as a resource, rather than a political statement that should be overcome or ignored when engaging physicians.

Similarly, with regards to medical education, medical students trained in overly simplistic approaches to diversity may devalue a patient's multiple identities and miss opportunities to improve rapport with their patients [27]. Although cultural competency is encouraged and medical student training is improving, cultural sensitivity is still lacking with regards to LGBTQ patients which may require additional training, such as differences between behaviour and identity, among other aspects of LGBTQ care [42-43]. For example, one study found that LGBTQ health is briefly taught in medical schools (median of 5 hours) and with no standardization in content covered [42]. Another review of LGBTQ healthcare training in U.S. Medical Schools found significant variability in training methods, on many occasions limited to a single lecture [43]. Similar issues of inadequate medical education on LGBTQ health has been echoed in Canada [44]. In clinical practice, physicians taking a "neutral" approach tend to reinforce heteronormative and gender-normative assumptions [18]. For instance, the gender of a patient's sexual partners is often overlooked (i.e., not asked) in electronic health records, and require physicians to make additional efforts to note important information about a patient's sexual practices and partners [45].

It may be useful for future research to explore more standardized methods of LGBTQ training as well as intersectional approaches in training medical students and physicians – e.g., incentivizing physicians with continuing medical education credits. Training focused on understanding intersectionality may improve the health care provider's ability to build trusting relationships with marginalized individuals. Yet, with diversity training alone, providers and trainees who consider themselves competent and sensitive without explicit bias may not recognize areas for improvement and miss areas to enhance patient care. It is also possible that training could lead providers to become overly sensitive and avoid terminology or detailed discussions with patients. This avoidance could be perceived by patients as provider discomfort or disengagement. Brief training alone is also unlikely to alter years of unconsciously biased thoughts and beliefs [46-49]. It may be useful to have visual signs of acceptance and openness in clinic spaces or on name badges, guidelines and staff training on how to approach sexual and gender minority patients and which topics to address sensitively, as well as having a tangible list of community resources. Other suggestions include encouraging providers and trainees to watch movies, read literature, or engage in LGBTQ community events [48-49]. Ultimately, training on an individual level is only a first step; institutional, structural, and governmental policies must also evolve to guide and create a culture that combats discrimination and microaggressions.

As with all research, our study has limitations. In keeping with qualitative research methodologies, our results are not generalizable to a given population of LGBTQ patients because the experiences in this study are highly individual and only represent the views of the participants. Since several interviewees were recruited from a centre specializing in HIV services, their experiences may not reflect the experiences of other sexual and gender minorities since HIV status is often central to health care navigation among HIV positive individuals. We did not interview any transgender individuals who were HIV positive, which may have revealed a different perspective on multiple stigmatized identities.

Conclusions

The three themes that emerged from our research – *lacking trust*, *being vulnerable*, and *navigating discrimination* – underscore the need for healthcare providers to take an intersectional approach when caring for LGBTQ patients. Indeed, by recognizing and understanding the multifaceted and often stigmatized identities of LGBTQ patients, health care providers will be better positioned to care for individuals in this community. We believe that incorporating intersectional training into medical student and resident curricula would greatly benefit not only LGBTQ patients and their providers, but perhaps other patients, especially those with multiple stigmatized identities. This is an important first step in improving provider empathy, understanding, and connection with LGBTQ patients. These conclusions are in line with much of the research done over the last few decades [12-17].

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Supplemental Materials: Interview Guide

Demographics

1. How old are you?

2. What is your race and/or ethnicity?

3. Do you currently have health insurance?

General Health

4. Would you say that your health is excellent, very good, good, fair, or poor?

PROBE: What do you think prevents you from being in good health?
What factors do you think contributes to your health?
Tell me about how _____ has helped you

5. Do you have a primary care physician? Do you see specialists? If so, what specialty?

6. Which physician would you consider your primary provider or who is primarily responsible for your care?

7. How often do you see this physician? (e.g., annual visits; sick visits, etc…)

8. How did you choose this physician? (primary physician)

PROBE: Did you ask friends or family for recommendations?
Did you look online?
Did you meet with the physician once before making a decision?

9. Do you trust this physician? Why or why not?

10. How did you feel/know you could trust them?

11. Can you describe a time when you saw a physician whom you did not trust?

12. Why did you not trust them?

PROBE: Was it a specific interaction? If yes, can you tell me about an example?
If you can, think about how you might have wanted the interaction or encounter to go/ be handled by the physician? Can you describe that for me?

13. Can you describe a time when you saw a physician with whom you had a good relationship?

14. What qualities do you look for when choosing a physician?

Sexuality/Identity

Now I want to ask you some personal questions about your sexuality and sexual orientation.

15. What is your sexual orientation?
For the purposes of this study I am using the definition of Sexual orientation as by which gender(s) a person is physically attracted- gay, lesbian, bisexual, queer, pansexual, other

16. How would you describe your gender identity?
For the purposes of this study I am defining Gender identity as personal identification with a particular gender- male, female, genderfluid, or other- that may or may not correspond to the person's assigned sex at birth

17. (for transgender/gender variant respondents) What sex were you assigned to at birth on your original birth certificate?

18. Do you think it is important for your primary physician to know about your sexual orientation (and/or gender identity)? Why or why not?

PROBE: Can you give me an example when a physician might need to have this information and/or when they might not?

19. Is your physician aware of your sexual orientation (and/or gender identity)?

If yes, can you describe having a conversation about your sexual orientation (or gender identity) with your physician? When did this conversation take place?

How do you decide to tell a provider about your orientation?

If no, why have you not shared this information with this physician? Have you shared this information with any provider?

20. Do you feel comfortable discussing your sexuality (and/or gender identity) with your physician?
Why or why not?

21. Is there anything else about sexuality and physician care that you would like me to know?

Do you have any questions for me?

Do you know of others who might be willing to meet with me to share their experiences with me for this study?

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

Is Genetic Discrimination Back on the Radar? A Commentary on the Recent Court of Appeal Reference Decision on the Genetic Non-Discrimination Act (GNDA)

Yann Joly[1], Gratien Dalpé[1], Miriam Pinkesz[1]

Résumé
Dans ce commentaire, nous examinons de façon critique la décision de renvoi de la Cour d'appel du Québec à l'effet que la Loi sur la non-discrimination génétique (LNDA) est inconstitutionnelle. En résumé, la Cour a conclu que le gouvernement fédéral a outrepassé ses pouvoirs en matière de droit pénal par l'entremise de la LNDA, car celle-ci n'avait pas d'objet valide en droit pénal. Cette décision a fait l'objet d'une opposition car les groupes de défense des intérêts des Canadiens souffrant de maladies génétiques ou de prédispositions génétiques considéraient la LNDA comme un pas dans la bonne direction et espéraient qu'elle offrirait une protection contre la discrimination génétique. En terminant, nous soutenons que les conséquences de l'avis de la Cour d'appel seront moins graves que ne le prévoient certains groupes de défense. En fait, nous suggérons que cette décision offre une occasion unique de progrès, où les intervenants peuvent faire participer le public et les décideurs à un débat tourné vers l'avenir sur l'utilisation de l'information génétique.

Mots-clés
discrimination génétique, vie privée, soins de santé, engagement des parties prenantes, ELSI

Abstract
In this commentary, we critically review the Quebec Court of Appeal's reference decision to the effect that the *Genetic Non-Discrimination Act* (GNDA) is unconstitutional. In sum, the court held that the federal government exceeded its criminal law power through the GNDA, as the Act did not have a valid criminal law purpose. The decision was met with opposition, as advocacy groups for Canadians suffering from genetic diseases or genetic predispositions viewed the GNDA as a step in the right direction and were hopeful that it would offer protection from genetic discrimination. In closing, we argue that the consequences of the Court of Appeal's opinion will be less dire than anticipated by some advocacy groups. In fact, we suggest that this decision brings about a unique opportunity for progress, where stakeholders can engage the public and policymakers in a forward-looking debate on the use of genetic information.

Keywords
genetic discrimination, privacy, health care, stakeholder engagement, ELSI

On December 21, 2018, the Quebec Court of Appeal rendered an important advisory opinion on the constitutional validity of the *Genetic Non-Discrimination Act* (GNDA) [1]. The GNDA, initially sponsored by Senator Jim Cowan, aims at preventing genetic discrimination by instituting a criminal prohibition against imposing genetic testing or, obtaining the access to or being forced to disclose information obtained through genetic testing with regards to the provision of goods and services. Contravening this prohibition, without the written consent of the individual concerned, constitutes a criminal offense.

Although the GNDA touches upon insurance and employment contracts, the overarching scheme with which Parliament justified the Act, is criminal law, a designated federal power [2, art. 91(27)]. The constitutional division of powers designates certain prerogatives, such as banking, criminal law, and naturalization to the federal government [2, s 91], whereas others, among them, property and civil rights in the province, which include employment and insurance, are delegated provincial powers [2, s 92]. Because the GNDA affects matters under provincial jurisdiction, namely, employment and insurance (through regulating contracts), it must have a subject matter that is under a federal head of power, and only encroaches employment and insurance incidentally [3, paras 36 and 38]. As such, in the case of criminalizing genetic discrimination in insurance and employment, genetic discrimination must constitute an "evil" as per the meaning of criminal law (i.e., found to pose a threat to public peace, order, security, or health in Canada) [4, para 24]. However, the Quebec Court of Appeal concluded that the GNDA does not have a criminal law purpose, and therefore infringes upon provincial jurisdiction.

Preventing genetic discrimination using criminal law?

The above discussion on the GNDA and its potential overstepping of the constitutional division of powers did not go unnoticed by important stakeholders. Notably, the Attorney General of Canada, who would normally represent the federal Parliament in such constitutional cases, shared Quebec's view that the GNDA unjustifiably encroached upon provincial powers. Therefore, he could not represent the Parliament. Under such circumstances, the court may designate an *amicus curiae* (i.e., "friend of the court"), a nonpartisan with an interest in the outcome of the case, that contributes relevant nonpartisan facts or relevant legal arguments, which may otherwise escape considerations by the court [5]. Therefore, when the Quebec government referred to the Court of Appeal the question of the constitutionality of sections 1-7 of the GNDA, the central component of the Act, the appointed *amicus curiae* argued in the place of the federal Attorney General.

The provisions in question specifically criminalize genetic discrimination in insurance and employment by prohibiting any person to require an individual to undergo a genetic test as a condition of providing goods or services to that individual, or of entering into or continuing a contract of agreement, or of offering or continuing specific terms or conditions in a contract or agreement with that individual [6, s 3(1)]. Furthermore, the Act also prohibits any persons to refuse to engage in these activities on the grounds that the individual refused to undergo a genetic test [6, s 3(2)] or refused to disclose the results of a genetic test [6, s 4]. Due to the criminal aspect of infringing the GNDA, violating these stipulations can result in important fines (up to a million dollars) and/or imprisonment of up to 12 months [6, s 7]. Importantly, however, the GNDA includes exceptions to this prohibition for health care practitioners and researchers in the conduct of their activities [6, s 6]. The Act also permits that persons engaged in the prohibited activities can use or disclose the genetic test results of an individual where written consent is provided [6, s 5]. Additionally, the GNDA only applies to genetic tests (as opposed to other types of genetic information),

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which are defined as the analysis of DNA, RNA, and chromosomes for the purpose of predicting diseases, the vertical transmission of risks, diagnosis or prognosis [6, s 2].[1]

In a unanimous decision, the court determined that the purpose of sections 1-7 is to encourage the use of genetic tests to improve Canadians' health, by "suppressing the fear of some that this information could eventually serve discriminatory purposes" [4, para 11]. According to this interpretation, by reassuring people about their apprehensions concerning genetic testing and potential discrimination, the Act promotes access to personalized medicine. The court therefore concluded that the objective of the GNDA ("to prevent that Canadians refrain from undergoing genetic tests for medical purposes for fear that the results be used without their consent in the context of a contract or of a service") [4, para 9] does not constitute a criminal law object and therefore, the Act is unconstitutional. From a legal standpoint, the opinion of the court on this matter is significant, as it sheds light on the boundaries of the federal government's competence to criminalize the use of genetic information in a field typically considered a provincial head of power, namely, contracts and services.

The Court of Appeal's opinion has the value of a judgement and can be appealed to the Supreme Court of Canada [7, art. 5.1]. As such, sections 1-7 of the GNDA remain in effect, although this may soon change. Disappointed by the decision of the Court of Appeal [7], the Canadian Coalition for Genetic Fairness has since appealed the judgement to the Supreme Court of Canada [8]. Should the Supreme Court render a similar decision to that of the Quebec Court of Appeal, the GNDA would be, for all practical purpose, invalidated. Nevertheless, in the meantime, the Canadian Life and Health Insurance Association Inc. (CLHIA) stated that its members would continue to comply with the GNDA [9].

Would the end of the GNDA open the door to genetic discrimination in Canada?

The answer to this question is more complex than it first appears. In the short term, the invalidation or abrogation of the GNDA would likely raise concerns among patients and carriers of genetic mutations for known monogenic hereditary diseases (diseases associated with a mutation in a single gene), such as Huntington's disease, inherited breast cancers associated with BRCA 1 & 2, and several other rare monogenic disorders.

However, the long-term effects of invalidating the GNDA will likely not amount to the much-dreaded drastic outcome. The Act has important loopholes and raises equity concerns that significantly weaken its capacity to prevent genetic discrimination in most cases. For example, while insurers are not able to impose or request information regarding genetic tests under the GNDA, they could still require information about applicants' family history of disease, an alternative source of genetic information that can impact insurance risk, as they can do for other predictive conditions not associated with known genes, such as cholesterol levels or history of mental illness. The decision to provide protection for some predictive genetic conditions in the GNDA as opposed to others is controversial. Therefore, in the long run, invalidating the GNDA will likely not lead to a "floodgates" situation as it concerns genetic discrimination, because the Act does not provide extensive protection to begin with. Although not directly relevant to the reference decision, this very issue was raised by the Court of Appeal during the hearing, as an attempt to understand the choice of the legislator to include certain (genetic) information as opposed to others. Moreover, the definition of genetic tests used in the Act and its scope of applications (contracts or agreements about the provision of goods and services) further limit the scope of the Act, which the court duly noted [10]. The protection provided by the GNDA is likely not sweeping enough to trigger long-term negative effects in the case it is invalidated.

Importantly, the Quebec Court of Appeal's opinion offers an opportunity to advance on the issue of genetic discrimination and the role of the law and policy-making on this issue.

So, what should we do now?

The current publicity surrounding genetic discrimination and the GNDA sets the stage for stakeholders to engage the public, along with provincial and federal policymakers, in an inclusive and forward-looking debate on the use of genetic information. We propose that, as part of this debate, a successful strategy to address genetic discrimination involves the adoption of a complementary framework of federal and provincial policies in which scientific content (i.e., scope, definitions, sectoral application, responsible authorities, and applicable sanctions) could be determined and updated via easily accessible administrative regulations. These regulations (e.g., administrative decrees, guidelines) would be adopted annually by ministries or agencies having legislative competence in the various areas (employment, insurance, immigration, criminal law) affected by genetic discrimination. Such a mechanism, unlike laws, could resist the test of time, as it is easily modifiable and is thus able to respond quickly to scientific advancements in the field of genetics and emerging social consensus regarding genetic discrimination. It is particularly important to ensure that this framework remains adaptive and flexible, as genetic discrimination is an evolving phenomenon.

Furthermore, this framework should benefit from dynamic and nuanced information campaigns on genetic discrimination and the ideal methods to prevent it, as well as the importance of social solidarity on this matter. An example of such an approach is the Genetic Discrimination Observatory, a communication platform developed to enable collective prevention of genetic discrimination. The platform developed features and activities such as an online forum on genetic discrimination in 2018 and

[1] The Act also modifies the *Canadian Labour Code* in order to prohibit an employer from taking any form of disciplinary action against an employee who refused to take a genetic test or communicate the results of already existing genetic tests [6, s 8]. The Act also modifies the *Canadian Human Rights Act* by adding "genetic characteristics" to the list of prohibited grounds of discrimination [6, s 9]. We note that these provisions were not included in the GNDA reference. However, the application of these protections is limited to the scope of the application of laws in which they are embedded, namely in federal laws.

a report-a-case system where victims of genetic discrimination can securely and confidentially document the circumstances of their case. This information can be used anonymously for statistical and research purposes.

A complementary component to our proposal is to update Canada's obsolete information privacy laws to specifically address and regulate the use of genetic data, especially given the current context of the collection, processing, and transfer of personal data through AI (artificial intelligence), social media, and the Internet. Importantly, in these contexts, individuals' control over personal data is progressively being eroded, and therefore, specially adapted privacy laws may provide much-needed protection. For instance, the growing popularity of social media and genealogy websites or participation in genomic research studies may permit the re-identification of an individual by third-parties [11]. Finally, the growth in government and private DNA databases further supports the development of more stringent privacy oversight and accountability frameworks that promise ample protection against possible misuses of genetic information.

Importantly, however, the governance framework we propose will not be easy to develop, as it requires concerted actions from multiple provincial and federal stakeholders. Nevertheless, it may, in fact, represent the best approach in light of the complex challenges stemming from recent advancements in genetics, in this era of fast-paced science.

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

Contracting Compliance: A Discussion of the Ethical Implications of Behavioural Contracts in the Rehabilitation Setting

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Résumé
L'utilisation généralisée de contrats dans les soins de santé est une source de malaise pour de nombreux éthiciens de la santé et associations de patients. Ce commentaire examine l'utilisation de tels contrats avec des personnes en milieu de réadaptation ayant des problèmes médicaux et comportementaux complexes. Les objectifs de ce commentaire sont d'examiner les nombreux facteurs qui peuvent conduire à l'utilisation de contrats, de discuter de certaines implications juridiques et éthiques de l'utilisation de contrats et d'évaluer leur utilisation à la lumière des préoccupations relatives à l'équité en matière de santé. Le commentaire conclut par quelques alternatives pratiques à l'utilisation de tels contrats et se réfère spécifiquement aux outils pouvant être empruntés au domaine de la thérapie comportementale.

Mots-clés
contrats, contrats de patients, comportements, réadaptation, éthique

Abstract
The pervasive use of contracts in healthcare is a source of unease for many healthcare ethicists and patient advocates. This commentary examines the use of such contracts with individuals in rehabilitation settings who have complex medical and behavioural issues. The goals of this paper are to examine the many factors that can lead to contract use, to discuss some legal and ethical implications of contract use, and to assess contract use in light of concerns about health equity. The paper concludes with some practical alternatives to the use of such contracts, and refers specifically to tools that might be borrowed from the field of behavioural therapy.

Keywords
contracts, patient contracts, behaviours, rehabilitation, ethics

Introduction

The term "patient contract," for the purposes of this paper, refers to a written document developed by clinical teams and/or healthcare administrators, with the goal of encouraging patients to modify behaviours. A patient contract generally contains a list of expectations that the patient must adhere to in order to retain access to services, while some may be employed to encourage patients to adopt a healthier lifestyle [1]. Although their legal standing is disputed (even though they are often signed by patients and providers), patient contracts are familiar to healthcare audiences in many contexts since they are employed for a myriad of purposes including suicide prevention, medication management, and behaviour modification [1].

Diversity with respect to their intended functions and content has led to varied assessments of their efficacy, and the literature is replete with articles that endorse and condemn their use. The authors' clinical experiences have led them to suspect that there has been an increase in the implementation of patient contracts in Canada and other western countries, and health care literature is beginning to note that development [2].

While advocates of contracts champion them as a means to foster transparency and reduce the potential for harm, contracts have received scrutiny from some clinicians and members of the bioethics community. Those opposed to contracts typically cite the power imbalances that make contracts seem coercive and speak to their potential to undermine trust and stigmatize vulnerable populations. Importantly, the erosion of trust has been shown to lead to treatment non-adherence [1]. We believe that gaining greater clarity about exactly what is at stake is important as contracts continue to be used in a range of settings despite inadequate evidence about their effectiveness [3]. Given increased interest in enhancing patient-centred and equitable care (as evidenced by the rise in patient councils and advisory committees), this is a particularly auspicious moment for reconsidering the ethical standing and clinical efficacy of contracts. Although our goal is to provide guidance to clinicians working in rehabilitation settings, we anticipate that our suggestions will be transferable to other contexts.

Use and Advocacy

Arguably, the most uncontroversial defense of a contract is its purported ability to promote the good of patients. Patient contracts are advocated as a means to increase adherence to treatment regimens, and there has been a strong desire across healthcare professions for tools that can further this goal. It has been said that "increasing the effectiveness of adherence interventions may have a far greater impact on the health of the population than any improvement in specific medical treatments" [4], whereas poor adherence is known to reduce treatment effectiveness and undermine health outcomes [3]. Clinicians can be attracted to contracts simply because they are a vehicle to get patients to pledge their commitment to treatment plans.

Another factor that seems to drive contract use is the desire to eliminate the effects of unwanted patient behaviours. Challenging behaviours associated with withdrawal or continued substance use can surface in rehabilitation facilities because these patients have survived their acute episode and have recovered greater function and independence. Particularly in the context of the opioid crisis, clinicians may be searching for strategies that can offer safeguards against dependency in the case of prescribing opioid therapy to manage chronic pain. Behavioural contracts have been employed as one of these (somewhat controversial) strategies, where the patient is notified that their doctor may discontinue prescription if certain terms of use are not followed [2,5,6]. Additionally, and not necessarily related to substance use disorders, worries about violence

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against healthcare providers, other patients and visitors can motivate the imposition of behavioural contracts [7]. Contracts may also be employed in an attempt to mitigate physician risk and safeguard against medical malpractice litigation (e.g., the risk of being sued for an unsafe discharge) [5].

In addition to the belief that contracts promote positive outcomes, they may also be appealing from an administrative perspective. Contracts are easily reproduced and there is a misperception that they require little training to implement; templates are available online and adaptable to various situations; clinicians can simply modify them to suit their needs [5,7]. Because of this, some contract advocates have suggested that they constitute a fiscally responsible way to standardize departmental practices [3]. For instance, contracts may be employed to educate patients or to clarify hospital policies, and signing these contracts may be a way to reinforce important information and verify comprehension [1]. We have worries, however, about a one size fits all approach since contracts used in this way require little critical engagement, and stress the importance of tailoring information to meet the specific needs of individual patients.

Ethical and Legal Considerations

The physician-patient relationship is typically characterized as a fiduciary relationship both from an ethical standpoint and as a matter of common law [7]. This understanding ought to prompt reflection on the nature and extent of healthcare providers' duties to act in the best interests of their patients. In addition to these obligations, healthcare providers are expected to possess professional virtues (expressed through the guidelines of their respective regulatory colleges), such as trustworthiness, compassion, and integrity [8], which are oriented toward good health outcomes. Patients rely on clinicians to receive care and, because of their dependence on clinicians, the relationship is marked by a power imbalance. It is important to note, moreover, that some patients are more vulnerably situated than others owing to their socioeconomic status, limited understanding of medical terminology, and/or histories of trauma or abuse [1,9]. With some patients, particularly those who are more vulnerably situated, an attitude of trust can be difficult to establish and maintain. Even when contracts are presented with the best of intentions, these patients may feel pressured to sign them and fear that if they do not their health may be compromised or access to care terminated. As patients' needs are significant and pressing, and access to treatment is often limited by geographical inequities or available expertise, patients may face what is essentially a Hobson's choice; that is, they may accept services on their providers' terms or find themselves with no offer of services at all. We believe that patient worries regarding abandonment are not unwarranted, as some guides to behavioural contracts specify that contracts are useful tools to "support terminating provider-patient relationships" [10].

Under common law, if contracts are to be legally binding, they must include: 1) an agreement between the parties and 2) consideration (i.e., the exchange of something of value). Patient contracts often fail to meet these conditions. First, owing to the power imbalance that exists between patients and clinicians, many patients do not enter freely into contracts, and some patients may lack the capacity to consent. As ethicists often note, for consent to be valid, a patient must be able to "understand the information that is relevant to making a decision and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision" [11]. In a recent study of 162 opioid contracts, researchers found that the contracts were written, on average, at a Grade 14 reading level despite recommendations that such documents be composed at the Grade 6-7 level [5]. Many patients in the rehabilitation setting (e.g., those with progressive neurological disorders) may be incapable of giving valid consent or may have capacities that are unclear or fluctuating. Second, the consideration criterion requires that each of the parties agree to exchange something of value. In our experience, most patient contracts simply include a list of rules that the patient must accept. Without reciprocal promises from clinicians, there is no consideration exchanged, unless the consideration could be described as the continued provision of health care – care to which patients have a pre-existing right [1]. When a duty of care is legally required, however, the language of contracts can be redundant or even conflict with the fiduciary relationship that binds providers and patients.

In addition to the fact that many contracts may not be legally valid, there are other issues to consider. In instances where there is no legal basis for imposing contracted consequences against the patient, a case recently has been made for the documents to be re-named 'agreements' in order to avoid the legal connotations associated with the term 'contract' [13]. However, while this may seem more palatable, the term 'agreement' may also mislead. While it suggests a departure from the power imbalances inherent in many examples of contracts, with the term 'agreement' connoting an arrangement that is equally and freely agreed upon between parties, this is often *not* the case for the reasons we have already offered. Moreover, even if the name 'contract' is replaced with 'agreement,' so long as such documents are presented in a manner that resembles a contract, patients may believe that they have no option but to sign. Additionally, if consequences are articulated in the contractual document but not enforced (which may be the case if they are not legally-binding), then this may exacerbate mistrust and erode the credibility of healthcare providers.

Known impact of contract use on patient outcomes

Good ethics requires good facts. Efforts to assess the ethical standing of patient contracts must address the question of their efficacy. Despite significant interest in the topic, studies have repeatedly failed to show conclusive evidence of the benefits of contract use. A 2009 review conducted by The Cochrane Collaboration and a 2010 review by Starrels and colleagues evaluated available data related to contract efficacy and the results were not reassuring [3,14]. The Cochrane review evaluated thirty-one published trials on patient contracts and assessed contract success by measuring various outcomes such as reduced

harm, improved health status and decreased costs. The review concluded that, despite some limited benefit, there was not enough reliable evidence to recommend the use of contracts in healthcare [3]. Similarly, the review by Starrels and colleagues, which looked at the effectiveness of opioid treatment agreements, showed weak evidence supporting a modest reduction in "opioid misuse" when contracts were used. The lack of high-quality evidence has implications for the ethical defensibility of patient contracts. A common argument in favour of contracts is their purported ability to increase treatment adherence [3], but without robust evidence to support this claim, the use of contracts appears to increase patient burden without providing concomitant benefits.

Health Equity and Contracts

Health equity, which "involves the fair distribution of resources needed for health, fair access to the opportunities available, and fairness in the support offered to people when ill" [15], is an underappreciated consideration in efforts to assess the merits of patient contracts. Patient contracts can undermine efforts to promote health equity, since the factors that lead to a contract may include implicit biases that result in disproportionate burdens for marginalized patients. Multiple studies have identified the presence of implicit and explicit biases among healthcare professionals against vulnerable and historically underserved groups [16,17]. Because these groups are sometimes seen as less trustworthy by healthcare providers, it is reasonable to be concerned that this could translate into the overuse of contracts [18]. While discriminatory behaviours may exist toward marginalized populations even without a contract, the implementation of a contract may more explicitly reinforce existing patterns of discrimination. As patient-clinician trust is a "key component of the therapeutic relationship" and "may impact important health-related behaviours, relationships, and outcomes" [18], all practices that have the potential to exacerbate negative stereotypes warrant substantial ethical attention.

Equity-based considerations are especially salient in a rehabilitation setting, where there are often shortages of available beds and pressure to provide care only to those who are most likely to benefit. Whereas access to acute care is generally seen as a right (especially in urgent circumstances), the authors have seen that it can be easier to conceive of access to rehabilitation as a privilege. Such beliefs may persist despite the fact that timely access to rehabilitation often offers the best hope for patients to recover function or to live with greater independence [19]. The result of this framing can be a temptation to accept termination of care as the inevitable consequence for contract breaches. However, a patient's substance use disorder, psychiatric illness, or complex psycho-social dynamics do not obviate the patient's need for, and ability to benefit from, rehabilitation. In fact, screening out patients with these needs is contrary to principles of health equity. The authors have found that in many cases, offers of support and the introduction of harm reduction strategies have been more effective and ethically defensible than the imposition of inflexible rules. Many patients can benefit from participation in rehabilitation programs, but certain behaviours or histories can present barriers to access these services (e.g., behaviours such as alcohol misuse that can co-present with symptoms of a major health event [20]).

None of our observations are intended to challenge the reality that rehabilitation clinicians are stewards of limited resources. However, we offer a reminder that, as in the case in acute care facilities, some rehabilitation patients require additional resources or more creative solutions to achieve desired health outcomes. Patients' challenging psychosocial circumstances ought not to count as grounds for denying them opportunities to achieve worthwhile rehabilitation goals. Indeed, the most complex patients might be better understood as those with the greatest need owing to their multiple vulnerabilities. On many occasions, even when their preferences and values are seen as problematic from a clinical perspective, a patient's aims may be achievable and consistent with the broader commitments of their rehabilitation providers. A patient who works hard to return a state of relative independence – even when that independence includes practices or an environment that outsiders find distressing – is someone who may well be rehabilitation-ready.

Solutions and Next Steps

We recognize that where patient contracts are likely to be ineffective, or ethically and legally problematic, other tools and techniques are needed. A promising and often underused source of guidance can be found in the discipline of behavioural therapy. Behavioural therapy tools are designed to benefit patients by identifying and capitalizing on their existing strengths rather than by emphasizing their vulnerabilities. They provide alternatives that do not entail a reduction in the quality or availability of care provided to patients with serious psychological and physical illnesses. Below, we provide a brief glimpse of tools and strategies that we have found helpful in our rehabilitation setting. They doubtless are transferable to other contexts as well.

Behavioural tools come in many forms, and their implementation may begin even prior to a patient's formal admission. For instance, we have found social scripts [22], which are similar to movie scripts in their attention to detail and ability to clarify roles, have been invaluable in preparing patients for a rehabilitation stay. They can be used to set facility expectations and goals, and to help patients and clinicians mitigate foreseeable concerns. Once patients have arrived at a facility, collaborative goal setting can be used to increase patients' investments in their own care, investments that are positively correlated with better patient outcomes [23]. As one might expect, success in achieving such goals is more likely when care plans are rooted in patient values, as opposed to those of staff [24].

Additional behavioural tools are well-suited to patients who exhibit challenging behaviours. These tools include those outlined by William R. Dubin, whose core clinical strategy for psychiatric patients consists of using verbal intervention techniques, as well as active clinician responses, such as direct eye contact and body language. Dubin emphasizes prevention in his non-pharmacological strategies, which include risk assessments and psychotherapeutic interventions when caring for patients who exhibit behavioural challenges or show warning signs of aggression. His observation that "implementing strategies that minimize humiliation and helplessness will almost always lead to a safer and more successful outcome" [25], is important because it shifts some of the onus for patient behaviours away from the patient and toward the professional(s). Another promising technique is motivational interviewing, which originated in efforts to address alcohol-dependence disorders [1]. At its core, this technique aims to return a sense of power and responsibility to the patient by inviting clinicians to focus on three skills (listening, asking, and informing) and four principles (resist the righting reflex, understand the patient's motivation, listen to the patient, and empower the patient) [25]. This is a particularly appropriate approach in a rehabilitation context due to its compatibility with goal setting and a rehabilitation philosophy that aims to empower patients and foster independence. Finally, clinicians might employ "token economies" [27] to motivate patients to complete tasks and engage in their care. Successful implementation of this strategy requires a careful assessment of the rewards that are likely to motivate a specific patient. Patient rewards should be designed to enrich the care experience and are not meant to serve as compensation for deprived environments. Although these methods differ from one another, and require different levels of expertise, the purpose is the same: to effectively and equitably mitigate the impact of variables that negatively influence a patient's clinical care and subsequent health outcomes.

Conclusions

In conclusion, we suggest that the widespread use of patient contracts ought to be re-evaluated on practical and ethical grounds. Although contracts may have limited value in select circumstances, the evidence for their effectiveness is weak and their potential to undermine trust and exacerbate existing disparities makes them problematic. It is our view that rehabilitation (and other) professionals would benefit from access to a more comprehensive "toolkit" designed to help address challenges that arise in the care of patients who present with so-called "behavioural difficulties". Behavioural therapists, and the strategies that are well-developed in their practices, have the potential to offer significant benefits to their colleagues in rehabilitation medicine and beyond. Equitable, accessible, and patient-centred care are goals that we believe all healthcare providers can embrace. In that case, it is worth further examining the ethical standing of contracts and exploring alternatives to "contracting compliance."

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Some of the authors (Heesters, Bianchi, Rodrigues, and Brown) work as salaried employees for a publicly funded hospital network that includes rehabilitation facilities. Our opinions are not necessarily those of our employer.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Deficit-Based Indigenous Health Research and the Stereotyping of Indigenous Peoples

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Résumé
La recherche en santé a tendance à être basée sur les déficits ; en tant que chercheurs, généralement nous quantifions ou qualifions l'absence de marqueurs de santé ou la présence d'une maladie. Cela peut créer un récit ayant des effets d'une grande portée pour les communautés déjà victimes de stigmatisation. Dans le contexte de la recherche en santé autochtone, un discours basé sur les déficits peut contribuer aux stéréotypes et à la marginalisation des peuples autochtones dans une société élargie. C'est particulièrement vrai lorsque les chercheurs ne parviennent pas à explorer les racines des déficits de santé, à savoir la colonisation, l'occidentalisation et les traumatismes intergénérationnels, au risque de confondre des problèmes de santé complexes avec des caractéristiques autochtones inhérentes. Dans cet article, nous explorons l'incompatibilité de la recherche basée sur les déficits avec les principes de plusieurs cadres éthiques, y compris le chapitre 9 de l'Énoncé de politique des trois Conseils (EPTC2), les principes PCAP® (propriété, contrôle, accès, possession), la Stratégie nationale sur la recherche inuite Inuit Tapiriit Kanatami et les principes de la Coalition canadienne pour la recherche en santé mondiale (CCRSM). En outre, nous nous appuyons sur des cas de recherche basée sur les déficits et le stéréotypage dans le domaine des soins de santé, dans le but d'identifier leur lien avec l'injustice épistémique et d'explorer des approches alternatives.

Mots-clés
recherche autochtone, peuples autochtones, recherche axée sur les déficits, recherche axée sur les forces, recherche en santé, stigmatisation, éthique

Abstract
Health research tends to be deficit-based by nature; as researchers we typically quantify or qualify absence of health markers or presence of illness. This can create a narrative with far reaching effects for communities already subject to stigmatization. In the context of Indigenous health research, a deficit-based discourse has the potential to contribute to stereotyping and marginalization of Indigenous Peoples in wider society. This is especially true when researchers fail to explore the roots of health deficits, namely colonization, Westernization, and intergenerational trauma, risking conflation of complex health challenges with inherent Indigenous characteristics. In this paper we explore the incompatibility of deficit-based research with principles from several ethical frameworks including the Tri-Council Policy Statement (TCPS2) Chapter 9, OCAP® (ownership, control, access, possession), Inuit Tapiriit Kanatami National Inuit Strategy on Research, and Canadian Coalition for Global Health Research (CCGHR) Principles for Global Health Research. Additionally we draw upon cases of deficit-based research and stereotyping in healthcare, in order to identify how this relates to epistemic injustice and explore alternative approaches.

Keywords
Indigenous research**,** Indigenous Peoples, deficit-based research, strength-based research, health research, stigmatization, ethics

Introduction

Research is responsible for many of the improvements in human health. Where disparities in health outcomes exist for certain groups of people, research can help to identify where systems are failing to serve these groups. However, historically Indigenous Peoples have been research subjects rather than participants; they have been subjected to unethical experiments, misrepresented in academic literature, and have had their knowledge exploited [1-3]. As Indigenous Peoples increasingly assert self-determination and control in research with their communities, Indigenous-led, collaborative research has the potential to enhance transformative changes in the health status of Indigenous Peoples [4]. To date, some communities have organized their own research and ethics processes – the Manitoulin Anishinaabek Research Review Committee (MARRC), and the Six Nations Research Ethics Committee, for example [5-7]. These community-based policies and processes can help ensure researcher priorities align with community goals, concerns and cultural norms, particularly given the diversity of Indigenous communities in Canada [7], which university and hospital research ethics boards are not necessarily positioned to understand. Furthermore, Indigenous scholars are conducting research using their own methods and methodologies [8-10], which present an avenue to the production of knowledge that is meaningful in Indigenous contexts, created by and for Indigenous Peoples.

Presently, ethical policy in Canada outlines the importance of free, prior, and informed consent for both Indigenous and non-Indigenous research participants [11]. Indigenous Peoples in Canada have some additional protections through the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) that provides guidance on Research Involving the First Nations, Inuit and Métis People of Canada [3]. The TCPS2 chapter on Indigenous research was established as national policy in 2010 and was largely based on the prior 2007 guidelines, developed with wide Indigenous community consultation and published by the Canadian Institutes of Health Research (CIHR) [3,12]. However, the previous CIHR guidelines were specific to health research with Indigenous Peoples, as opposed to Indigenous research in general. Having these separate guidelines specific to Indigenous health research strengthened the ethics process in many ways [13]. All institutions that are eligible to administer and receive funding from the three federal funding research agencies in Canada must adhere to the TCPS2 guidelines [11]. Some researchers additionally align themselves with other frameworks such as *OCAP*® (ownership, control, access and possession) principles, the *Royal Commission on Aboriginal Peoples statement on research ethics*, *Assembly of First Nations: First Nations Ethics Guide on Research and Aboriginal Traditional Knowledge*, *First Nations Regional Longitudinal Health Survey: Code of Research Ethics*, *CIHR Guidelines for Health Research Involving Aboriginal People*, and *Inuit Tapiriit Kanatami: National Inuit Strategy on Research* among others [12,14-19]. Different frameworks may be appropriate for different projects, and in some instances, are more comprehensive than the TCPS2 guidelines [14].

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In addition, the Canadian Coalition for Global Health Research (CCGHR) *Principles for Global Health Research* (Figure 1) [20], hold relevancy for Indigenous health research. CCGHR principles are based on a number of works including the aforementioned CIHR guidelines [12,20].

Figure 1: Canadian Coalition for Global Health Research - Principles for Global Health Research

While ethical guidelines can assist with the conduct of research, even well-intentioned health research can sometimes have unintended consequences. Deficit-based research, which by its nature highlights poorer health outcomes in one group as compared to another, can perpetuate deficit-based narratives that contribute to stigmatization and stereotyping [21]. Taken alone, these findings can assist in identifying issues that require system-based responses. However, they can also contribute to stereotyping of Indigenous Peoples as having, for example, poor health lifestyles (e.g., in the case of diabetes) or negligent mothers (e.g., in the case of FASD). Harm may be especially likely when research is repetitive and re-quantifies well-established issues. In his 2015 article in *The Guardian*, Scott Gorringe explored deficit discourses regarding Indigenous Peoples [22]. He described a deficit discourse as “a mode of thinking that frames and represents Aboriginal identity in a narrative of negativity, deficiency and disempowerment” [22]. As healthcare providers digest and apply academic literature to practice, health research can have a negative impact on healthcare. If health research supports stereotypes about Indigenous Peoples, and over-emphasizes stigmatized health challenges, this may affect the cultural safety of Indigenous people seeking care. By contrast, reframing research around strengths can focus on enabling individuals and communities through familiar cultural and traditional approaches to health and healthcare. As an alternative, strength-based health research is research that focuses on positive aspects of health, or positive approaches or solutions to negative health issues, i.e., ways of knowing, knowledge and skills that can lead to health transformations or health gains.

Objectives

The purpose of this paper is to delineate the potential consequences of deficit-based Indigenous health research, how to avoid these harms, and how to consider strength-based research as an alternative. Relevant ethical guidelines – as they relate to the concept of deficit-based research – are reviewed. Aspects of deficit-based research that do not align with these ethical guidelines are identified and discussed, and we then explore measures to avoid harm that are drawn from ethical principles, literature, and research examples. We draw upon ethical guidelines and principles to examine how, despite the notion that health research is often deficit-based, this approach is not typically useful on an Indigenous community level. Additionally, we discuss how alternative strength-based approaches and/or reframing of health inequities are/is needed to avoid the continued marginalization of Indigenous Peoples.

Definitions

In this paper, *Indigenous* in the context of Canada will refer to the First Nations, Métis and Inuit peoples; Indigenous may also refer to peoples globally who occupy their traditional and historic territory. Indigenous *community* will not necessarily refer to a geographically defined community, but instead any group of people that defines themselves as an Indigenous community.

Stereotyping refers to an over-generalized belief about a given group of people. Stereotypes involve the assumption that a general characteristic applies to every person in this category of people. *Stigmatization* refers to explicit or implicit labeling of something as disgraceful. A stigmatized topic is associated with general public disapproval.

Avoidance of Stigmatization and Stereotyping

Deficit-based research can contribute to stigmatization when problematic health issues are repeatedly characterized in the context of a specific population. Additionally, when any given health deficit is repetitively associated with Indigenous Peoples through research, there is risk of stereotyping. Unfortunately, due to a lack of critical exposure in education and media, deficit-based research given without proper framing can perpetuate negative characterizations of Indigenous Peoples [23]. If Indigenous health issues are presented in academic literature with little historical and social contextual information, an "epidemiological paradox" arises. Although it is in society's interest to bring attention to health risks, this same attention can repeatedly portray Indigenous Peoples negatively and lead to a presumed "population level pathology" that is "an insidious, pervasive and subtle form of structural racism and discrimination" [24]. OCAP principles point out that some information resulting from research can "lead to discrimination and stigmatization" of communities [14]. Nevertheless, deficit-based research can be beneficial in identifying and offering treatment for health problems. To avoid transferring the stigma of a stigmatized health issue to entire communities or peoples, researchers can engage in a discussion of the influence of colonization and Westernization, thereby reframing the issue and reassigning the shame to such influences rather than to Indigenous Peoples.

One example of a health challenge with associated stigma is type 2 diabetes. Research into high levels of type 2 diabetes in Indigenous communities has included substantial investigation of potential genetic explanations, sometimes referred to as the "Thrifty Gene Hypothesis" [25]. This hypothesis postulates that some Indigenous Peoples are genetically predisposed to diabetes. However, both early and more contemporary researchers investigating this topic ultimately conceded that genetics does not capture the complexity of factors resulting in high levels of type 2 diabetes in some Indigenous populations, and argued for the greater attention to the effects of various colonial policies. But this extensive body of work on the genetic causes of type 2 diabetes continues to be cited today [25]. Hence, there is potential for deficit-based narratives regarding stigmatized health issues to become deeply rooted stereotypes if precaution is not exercised.

To avoid stigmatization in deficit-based research, health issues must be contextualized. Such an example is demonstrated in a 2016 study evaluating a harvest sharing program in Northern Ontario [26]. The authors highlighted a number of potentially stigmatizing deficits including reduction in dietary quality, physical activity and an increase in obesity in First Nations communities [26]. However, the authors explained that the reasons for these challenges were complex and include the transition to Western lifestyles that First Nations experience, which at least in part contributes to their health challenges [26]. In this way, the authors were laudably careful to contextualize their findings and to inform readers of some of the root causes of the examined deficits, thus mitigating risk of stigma.

Importantly, avoidance of harm does not equate to total avoidance of research concerning stigmatized topics. For example, if a community would like to explore local prevalence of type 2 diabetes, such as in a 2009 study by Wahi and colleagues, the research can confer benefit in that they provide a community with desired information [27].

When Stereotypes Interfere with Care

A major problem with the stereotypes supported by deficit-based research is that they pose a risk to Indigenous people when seeking care, especially if stereotypes are related to stigmatized health topics such as addiction. In their 2015 report, Allan and Smylie discussed barriers to care that Indigenous Peoples face, including racism [23,28-30]. Stereotypes such as the 'drunken Indian' affect how health providers interact with Indigenous patients. The deaths of Brian Sinclair in a Winnipeg emergency room and Hugh Papik in his elder's home are stark examples of this. Both Indigenous men were presumed to be drunk although they were not, and died of a bladder infection and a stroke, respectively, while trying to access care [23,31,32].

Researchers should consider the extent to which their research may reinforce stereotypes about Indigenous Peoples. If a given health issue has been extensively characterized, it may be worthwhile reframing the approach or researching topics identified as being of interest to communities, rather than potentially contributing to further stereotype reinforcement.

Responsiveness to Community Needs

A significant issue that can arise in deficit-based research is a lack of responsiveness. Responsiveness is a principle that refers to the obligation of global health researchers to use research to respond to inequities affecting the participants in their research, rather than exploit inequities for research or conduct research irrelevant to the communities involved [20]. This concept of responsiveness is outlined in the CCGHR Principles, and aligns with the Inuit Tapiriit Kanatami's assertion that research must be a tool for creating social equity [19]. Deficit-based research may be particularly prone to identifying inequities without explaining how such an identification acts to mitigate inequities or confer benefit. It is important to note that Indigenous Peoples may be polarized on certain topics, including whether or not exploration of a particular health deficit confers sufficient

benefit or produces significant harm. In these scenarios, researchers are encouraged to engage all stakeholders to the extent possible, but to also consider the risk of increasing polarization, which may “actually impede the advancement of social justice” [3]. The CIHR guidelines recommend collaborating with community members in cases of polarization to assess conflicts of interest, and to look to existing community structures and systems for resolving disputes [12].

Historically, lack of responsiveness has been an issue in Indigenous health research, and is exemplified by the nutritional experiments carried out on children who were forced into the residential school system. These experiments were carried out despite the government and researchers already recognizing malnutrition as a systemic issue in residential schools [2]. Rather than trying to intervene to improve the nutritional status of these children, the researchers exploited the malnourished children to test various hypotheses [2]. The research characterized by Mosby demonstrates that researchers working in the residential school system were not responsive in this sense but instead exploited and perpetuated an existing inequity (starvation and malnutrition) with no benefit to those being studied.

Problems relating to responsiveness are also a contemporary issue. For example, a 2011 study of the prevalence of tobacco, alcohol and drug use by Indigenous youth in Canada was characterized using existing data [33]. This information may have been useful in attracting resources or informing policy. However, such benefits were not discussed, contextualization for the issue was not provided, and no disclosure of Indigenous collaboration was present. Overall, it is impossible for a reader to discern if such research was desired by or responsive to the interests of Indigenous Peoples. Deficit-based research is particularly prone to lacking responsiveness because identifying a problem, even when researchers are well-intentioned, does not intrinsically result in transformative health interventions or improved social equity. Importantly, responsiveness can be a component of any research methodology. For example, responsiveness does not exclude randomized controlled trials where benefit cannot be known in advance, if the involved communities agree that the trial has the potential to result in benefit.

Authentic Partnering and Indigenous Voice to Combat Deficit Narratives

Deficit-based research may be particularly prone to harming Indigenous communities if researchers do not engage Indigenous stakeholders. An important point to consider with regard to Indigenous health research, and especially for deficit narratives, is the difficulty for non-Indigenous researchers to provide the full context regarding any particular deficit. A non-Indigenous researcher can never be an expert on the lived experience of health challenges facing Indigenous Peoples [34]. Additionally, potential benefit of characterizing a health deficit cannot be presumed without Indigenous engagement.

Not recognizing Indigenous voices creates epistemic injustice by excluding members of Indigenous populations from formulating their own research and asserting their self-determined knowledge. In their discussion of epistemic injustice in healthcare, Carel and Kidd assert that healthcare providers are epistemically privileged because they “occupy an authoritative procedural role in epistemic exchanges, for instance by acting as gatekeepers controlling which persons and groups are included, and what degree of credibility and authority they are assigned” [35]. The same epistemic privilege applies to Western researchers. The frameworks already referenced support Indigenous engagement in all aspects of research: The First Nations Principles of OCAP®, the CCGHR principle of shared benefits and inclusion which draws upon OCAP®, the Inuit Tapiriit Kanatami’s National Inuit Strategy on Research, and community-specific policies [5,6,14,19,20]. The substantial resources required for meaningful engagement may have historically discouraged some researchers, as funding systems have tended to be inadequate for such approaches. Recently, the Network Environments for Indigenous Health Research (NEIHR) Program has been established by CIHR [36]. This initiative is important and timely and speaks to the fundamental idea that Indigenous peoples and communities are taking control of their own research and community needs [36].

Another example of deficit-based research that does not disclose any sort of Indigenous participation is a 2011 study relating to effects on Inuit children of maternal ‘binge drinking’ during pregnancy [37]. With a lack of discussion around the factors related to consumption of alcohol by pregnant Inuit women, the article left readers to draw their own conclusions, potentially based on stereotypes and bias. Inuit participation could have resulted in helpful contextualization. By contrast, an example of research that effectively demonstrated authentic partnering and privileging of Indigenous voice is a 2014 study relating to enacted Stigma and HIV Risk behaviours among sexual minority Indigenous youth in Canada, New Zealand, and the United States [38]. This paper included multiple Indigenous authors, Indigenous and sexual minority research team members, Indigenous advisory groups, and community consultations [38]. Before the study, the research team additionally consulted with other Indigenous Peoples in Canada, New Zealand, and Native American researchers about the “purpose, design, sampling, and measurement issues” [38]. A Māori advisory group was consulted continuously about interpretation and dissemination, and additional advisory engagement with other Indigenous entities was sought [38]. This work clearly prioritizes Indigenous voice and took a number of steps to engage guidance from Indigenous stakeholders.

When weighing the benefits and harms of research, one must consider restoring control to Indigenous Peoples as a benefit. Additionally, perpetuation of a deficit-discourse should be considered a valid harm. An important way to restore control is to privilege Indigenous voices in Indigenous health narratives, which will in turn reduce risk of harm from deficit-based research due to Indigenous input on framing and dissemination. There may, nonetheless, be situations where disagreement about interpretation arise between researchers and the community [3]. At minimum, if these cannot be resolved, the TCPS2 states that researchers should either provide opportunity for the community to communicate its views, or accurately and fairly report the disagreement in any dissemination activities [3]. However, researchers must be cautious to consider what harms may be

associated with disseminating information that a community believes to be inaccurate, especially in relation to deficit-based topics. Some ethical principles, such as the OCAP principle of control, suggest that Indigenous communities should always direct how knowledge is shared [15].

Methodological Choices

While implementing Indigenous voice in deficit-based discourse requires a conscious effort, some methodologies and approaches are helpful in naturally including Indigenous voice. Community-Based Participatory Research (CBPR) is an approach to research that inherently facilitates inclusion of Indigenous voices. The intention of CBPR is to increase community ownership of research [39]. CBPR strives for relevancy to local community, enhances local capacity, builds trust, imparts knowledge of community contexts, and creates results directly used for sustainable change [39]. Community members become researchers and come to understand their own circumstances on their terms [39]. CBPR thus satisfies the requirements of numerous ethical guidelines, including TCPS2's requirement of community engagement, the OCAP principle of control, Inuit Tapiriit Kanatami's National Inuit Strategy on Research's goal of self-determination, and the CCGHR principle of authentic partnering [3,15,20,21].

An example of CBPR is demonstrated in a 2015 study examining children's experiences of food insecurity in Alexander First Nation [40]. In this project, high school co-researchers conducted photovoice interviews, were included in data analysis and in the development and dissemination of a photobook [40]. The project had a community research committee, which included community members, and the community is listed as an author on the resulting publication [40]; the committee approved the research protocol and the published manuscript. The photobook resulting from the project served as a community knowledge dissemination tool for community members; and the incorporation of co-researcher perspectives provided important information for the research committee, who were in a position to elicit change within their community [40]. This research engaged the community in various ways and facilitated local leadership in the research. When researching a sensitive and potentially stigmatized topic such as food insecurity, CBPR may be a particularly helpful approach to avoid harm and confer benefit.

Acknowledgement of Community Strengths

Questioning and deconstructing deficit-based approaches to research does not mean denying the existence of health inequities faced by Indigenous communities. However, in 2019, it is also fair to say the majority of health deficits in Indigenous communities in Canada have been extensively quantified. Many health researchers have been advocating a switch from deficit-based narratives to a strength-based narrative. As described above, strength-based research can amplify existing capacities in Indigenous communities to address health issues, rather than focusing on community 'shortcomings' or 'deficits' [41-43]. This can provide a good model through which to identify health challenges, but also to address and present them in a positive and solution-oriented way. Indigenous communities have strengths that contribute to their well-being, for example "norms of sharing and reciprocity and traditional perspectives, respect for the wisdom of elders, balance, and interconnectedness with nature" [44].

One example of strength-based research is Gabel and colleagues' 2016 project "Using Photovoice to Understand intergenerational Influences on Health and Well-Being in a Southern Labrador Inuit Community" [45]. This project explored intergenerational relationships using a CBPR approach and the arts-based method of photovoice [45]. The authors concluded that within the community there were strong relationships between old and young generations, and that this contributed significantly to the health and wellbeing of the community [45]. They point to these relationships as a significant strength and asset in promoting health and well-being in Indigenous communities [45]. Photovoice is a powerful participatory technique that enables participants to 1) assess community strengths and concerns, 2) communicate community ideas to researchers and policymakers, 3) put the power of photography into the hands of community members, 4) promote critical dialogue and knowledge about issues through group discussion of photos, 5) facilitate power-sharing by having the participant rather than the researcher determine the subject and meaning of the photo, 6) facilitate a richer understanding of the issues being studied, and 7) help participants reflect on and recognize their own perspectives on issues facing their communities [45-50]. It is an ideal approach for research with Indigenous communities because it "fosters trust, gives community members ownership over research data, and shifts the balance of power to community members"; and it is consistent with a CBPR paradigm [49,51-53].

This research described a substantial community strength that already exists. They point to intergenerational relationships as a way to support cultural continuity and to promote overall wellbeing of community members [45]. In their paper, the authors also highlighted how cultural continuity was disrupted by colonization, and that communities with continuity were overall healthier [45]. This is an excellent example of research that frames Indigenous issues in the context of colonization, works closely with the community participating in the research, and points out features that will be useful to promoting community well-being and perhaps is also useful to promoting well-being in other Indigenous communities. Rather than presenting information that can lead to shame and stereotyping, their research can be empowering for Indigenous communities. One can see then how this research may be: 1) more useful to Indigenous communities than the deficit-based research described earlier and 2) does not stigmatize or shame the community or Indigenous Peoples as a group.

Conclusions

Deficit-based research risks contributing to the stereotyping and stigmatization of Indigenous Peoples. Strength-based and solution-oriented research provides a promising alternative to this normative approach. Ensuring that Indigenous Peoples have authority over how they are researched and how they are portrayed as a result of that research is critical to producing effective and beneficial research [15]. Understanding the problematic history of Indigenous health research in Canada demands significant accountability on the part of researchers to communities. Considering how deficit-based research may stigmatize communities is a harm that must be addressed in any project. Likewise, researchers should consider how their work is contributing to a more equitable future for participants, and how the work itself is responsive to existing inequities. Framing Indigenous health disparities in an Indigenous context must expressly encompass colonization and Westernization, so that research can contribute to how non-Indigenous Peoples view Indigenous Peoples. Finally, strength-based and/or solution-oriented research provides ways for researchers to enact the significant elements in existing ethics and good practices guidance. A simple and important measure to produce good Indigenous health research is to privilege Indigenous voice, as Indigenous Peoples are primary stakeholders in the research with their communities. Indigenous health research is inextricably connected to how the wider society perceives Indigenous Peoples, and how Indigenous Peoples are perceived inherently affects their overall health and well-being – and this must guide the approach of ethicists and health researchers to this field of work.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Objection de conscience et aide médicale à mourir : une étude qualitative auprès de médecins québécois

Isabelle Dumont[1], Jocelyn Maclure[2]

Résumé
Les patients québécois peuvent légalement obtenir une aide médicale à mourir s'ils sont aptes à donner un consentement éclairé, atteints d'une maladie grave et incurable, en fin de vie et ont des souffrances qu'ils jugent intolérables. Depuis l'arrêt Carter (2015) de la Cour Suprême du Canada, l'accès, sous certaines conditions, à l'AMM est même devenu un droit constitutionnel. Les médecins québécois sont ainsi maintenant susceptibles de recevoir des demandes d'AMM de leurs patients. Les lois québécoise et canadienne reconnaissent aux médecins un droit à l'objection de conscience, mais le droit est contesté tant dans les écrits en éthique médicale que dans le débat public. L'article présente les résultats d'une étude qualitative menée auprès de vingt médecins québécois qui n'ont pas intégré l'AMM à leur pratique médicale en raison de leur opposition ou ambivalence à l'égard de l'AMM. Les entrevues visaient à explorer les raisons – religieuses et séculières – expliquant l'opposition ou l'ambivalence par rapport à l'AMM. Les raisons séculières exprimées par les participants ont ensuite été regroupées en quatre catégories et analysées. Les quatre catégories sont : 1) Finalités de la médecine et identité professionnelle, 2) Philosophie de la médecine palliative et allocation des ressources en soins palliatifs, 3) Paternalisme bienveillant, « bonne mort » et intérêts du soi futur, 4) Risque de la pente glissante et protection des personnes vulnérables.

Mots-clés
aide médicale à mourir, euthanasie, objection de conscience, éthique médicale, identité professionnelle, croyances religieuses et séculières

Abstract
Patients in Quebec can legally obtain medical assistance in dying (MAID) if they are able to give informed consent, have a serious and incurable illness, are at the end of their lives and are in a situation of unbearable suffering. Since the Supreme Court of Canada's 2015 Carter decision, access to MAID, under certain conditions, has become a constitutional right. Quebec physicians are now likely to receive requests for MAID from their patients. The Quebec and Canadian laws recognize a physician's right to conscientious objection, but this right is contested both in the medical ethics literature and in the public sphere. This paper presents the results of a qualitative study conducted with twenty Quebec physicians who did not integrate MAID into their medical practice, either because they were opposed to or deeply ambivalent about MAID. The interviews aimed to explore the reasons – religious and secular – for opposition to or ambivalence towards MAID. The secular reasons given by participants were grouped into four main categories: 1) the ends of medicine and professional identity, 2) the philosophy of palliative medicine and resource allocation in palliative care, 3) benevolent paternalism, the "good death", and the interests of future selves, 4) the risk of a slippery slope and the protection of vulnerable people.

Keywords
medical assistance in dying, euthanasia, conscientious objection, medical ethics, professional identity, religious and secular beliefs

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

Introduction

Le Québec a légalisé l'« aide médicale à mourir » (AMM) avec l'adoption de la *Loi concernant les soins en fin de vie* en 2014 [1]. Ne pouvant modifier le Code criminel, qui est de compétence fédérale, le Québec a choisi d'inclure l'AMM dans le continuum de soins offerts aux personnes en fin de vie. Pour être admissibles à l'AMM, les personnes doivent être 1) assurées au sens de la Loi sur l'assurance maladie ; 2) majeures et aptes à consentir aux soins ; 3) en fin de vie ; 4) atteintes d'une maladie grave et incurable ; 5) dans une situation médicale qui se caractérise par un déclin avancé et irréversible de leurs capacités et 6) dans un état de souffrance physique et ne pas pouvoir être apaisées dans des conditions qu'elles jugent tolérables.

Suite à l'arrêt Carter de la Cour suprême du Canada en 2015, l'accès à l'AMM est devenu un droit constitutionnel partout au Canada. Renversant l'arrêt Rodriguez de 1993, la Cour suprême a jugé que les patients atteints de « problèmes de santé graves et irrémédiables » leur causant des souffrances persistantes et intolérables devaient maintenant pouvoir obtenir une aide, administrée ou supervisée par des professionnels de la santé, pour mettre fin à leurs jours [2]. Ce droit à l'autonomie concernant les choix en fin de vie découle, selon le plus haut tribunal du pays, du droit à la vie, à la liberté et à la sécurité de la personne garanti par l'article 7 de la Charte canadienne des droits et libertés [3,4]. Selon la Cour, l'interdiction de l'AMM force certaines personnes à se suicider pendant qu'elles en sont encore capables, donc à s'enlever la vie plus tôt que souhaité, et restreint abusivement leur autonomie quant aux décisions relatives à leur intégrité physique et à leur fin de vie. Comme cela a été affirmé par nombre de philosophes ainsi que par les penseurs des soins palliatifs, le processus du mourir fait partie de la vie [5]. Pour la plupart d'entre nous, une réflexion personnelle sur ce qu'est une vie bonne, emplie de sens, comprend une réflexion sur la fin de vie que l'on se souhaite. Ce qui caractérise les sociétés pluralistes est précisément que les conceptions de la « vie bonne », et par extension de la « bonne mort », varient [6].

Le gouvernement du Canada a ainsi adopté la *Loi modifiant le Code criminel et apportant des modifications connexes à d'autres lois (aide médicale à mourir)* [7] en 2016 afin de se conformer au jugement de la Cour suprême. La loi crée une exemption dans le Code criminel afin d'exclure l'aide médicale à mourir de la catégorie des « infractions d'homicide coupable ». La différence principale entre les lois québécoise et canadienne sur le plan de l'admissibilité à l'AMM concerne le stade de la maladie grave et incurable dont une personne est atteinte. La loi fédérale énonce que la « mort naturelle » de la personne doit être « devenue raisonnablement prévisible compte tenu de l'ensemble de sa situation médicale, sans pour autant qu'un pronostic ait été établi quant à son espérance de vie [7].»

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Les médecins qui pratiquent auprès de personnes en fin de vie ou souffrant de maladies dégénératives incurables doivent maintenant répondre à des patients qui souhaitent se prévaloir de ce nouveau droit ou obtenir des informations à son sujet. Comme la mort est un enjeu qui soulève des questions à la fois métaphysiques et éthiques relatives au caractère et à la valeur de la vie humaine – des questions auxquelles plusieurs réponses raisonnables sont possibles –, il est normal que plusieurs personnes, y compris des professionnels de la santé, continuent de penser qu'aucune intervention humaine provoquant intentionnellement la mort ne soit moralement justifiable.

Le cadre législatif actuel prévoit explicitement le droit à l'objection de conscience des professionnels de la santé. Aucun médecin ne doit être contraint d'administrer une injection létale ou d'évaluer l'admissibilité d'un patient si cela contrevient à ce que lui prescrit sa conscience. Alors que l'on trouve un engagement à « respecter les convictions personnelles des fournisseurs de soins de santé » dans le préambule de la loi fédérale, la loi québécoise énonce qu'« un médecin peut refuser d'administrer l'aide médicale à mourir en raison de ses convictions personnelles et [qu'] un professionnel de la santé peut refuser de participer à son administration pour le même motif [1]. »

Ce droit est toutefois contesté. Tant dans les écrits en éthique médicale que dans les débats de société, certains remettent en question la légitimité de l'accommodement prévu par la loi [8-11]. D'autres soutiennent que le droit à l'objection de conscience est présentement instrumentalisé afin de justifier la décision de médecins qui ne souhaitent pas participer au processus entourant l'AMM pour des raisons qui ne sont pas philosophiques, morales ou religieuses [12].

L'étude que nous avons réalisée offre un point de vue différent. Elle ne permet d'aucune façon de réfuter la thèse voulant que certains médecins fassent un usage abusif et injustifié du droit à l'objection de conscience, mais elle suggère que le refus de plusieurs médecins de participer au processus de l'AMM découle d'une délibération morale authentique au sujet du rapport entre leurs valeurs (professionnelles et personnelles) et l'acte consistant à provoquer intentionnellement la mort d'un patient. La légalisation de l'AMM a forcé plusieurs médecins à réfléchir au sens de la médecine et de leur pratique, aux rapports entre leurs croyances personnelles et leur éthique professionnelle, ainsi qu'aux conséquences éthiques et sociales de la création d'un droit à l'AMM.

Après avoir présenté l'étude, nous ferons état du rôle des raisons religieuses et séculières exposées par les participants et analyserons ensuite plus en profondeur les raisons séculières justifiant l'opposition ou l'ambivalence eu égard à l'AMM. Les réponses des participants ont été regroupées en quatre ensembles de raisons séculières. Dans la dernière partie du texte, nous réfléchirons au sens et aux implications de certaines des préoccupations exprimées par les participants, ainsi qu'à la contribution de cette étude à la poursuite du débat public sur l'AMM.

Objectifs de l'étude et présentation du volet qualitatif

L'objectif général de cette étude est de faire progresser la réflexion éthique sur les demandes d'exemption revendiquées par des médecins relativement à l'aide médicale à mourir (AMM). Pour ce faire, les objectifs spécifiques sont : 1) de clarifier les enjeux éthiques inhérents aux demandes d'exemption des médecins et 2) d'assembler des éléments en vue de l'élaboration d'une position claire et rigoureuse au sujet du conflit entre les droits des patients et ceux des médecins. L'étude comporte deux volets : un volet qualitatif et un volet normatif. Le volet qualitatif et descriptif vise un troisième objectif spécifique : 3) mieux comprendre et décrire, à partir du discours de médecins, les raisons (religieuses et séculières) justifiant l'opposition ou les réserves de ces derniers eu égard à l'AMM. L'argumentation normative concernant les droits et les devoirs des médecins et l'harmonisation des droits des médecins et des patients sera présentée dans un article subséquent.

Méthodologie

Échantillon et recrutement

Le volet qualitatif de cette étude s'est intéressé aux médecins qui, dans leur pratique, reçoivent des demandes d'aide médicale à mourir et qui s'opposent ou ont des réserves sérieuses à l'égard de l'AMM. Vingt médecins ont été recrutés de novembre 2017 à mai 2018. En se basant sur d'autres études comparables [12,13], il est possible de conclure que ce nombre a permis d'atteindre un degré de saturation des données menant à une analyse considérée comme fiable. Étant donné le caractère exploratoire et non confirmatoire de cette recherche qualitative et descriptive, celle-ci ne prétend pas à la représentativité statistique. L'intérêt de cette démarche réside principalement dans la richesse des points de vue obtenus. Une méthode d'échantillonnage par réseau (boule de neige) a été privilégiée. Pour cela, les informations sur cette étude ont d'abord été envoyées à quelques médecins correspondant au profil recherché qui ont, à leur tour, transmis ces mêmes informations à d'autres médecins au profil similaire.

Les critères de sélection des participants sont les suivants :

- être membre du Collège des médecins du Québec ;
- être appelé, dans sa pratique, à recevoir des demandes d'AMM ;
- s'être prévalu ou prévoir se prévaloir du droit à l'objection de conscience

Cette étude a été approuvée par les comités d'éthique de l'UQÀM (1520_e_2017) et de l'Université Laval (116964). Le consentement écrit des participants a été obtenu et l'étude a été menée conformément aux principes énoncés dans l'Énoncé de politique des trois Conseils du Canada : Éthique de la recherche avec des êtres humains [14].

Mode de collecte des données et analyses

Le mode de collecte des données qui a été retenu est celui de la passation d'entretiens individuels semi-structurés. Ces entretiens étaient d'une durée approximative d'une heure et ont entièrement été réalisés par l'un des deux chercheurs responsables de cette étude. Le guide d'entrevue comprenait une question ouverte suivie de questions de relance en lien avec les objectifs de la recherche. Le guide original a d'abord été élaboré en étroite articulation avec le cadre théorique de cette recherche portant sur le sens et l'extension de la liberté de conscience [15]. Il a ensuite laissé place à l'émergence de nouveaux thèmes tout au long de la réalisation des entretiens.

Le traitement des données a été accompli à partir de la retranscription intégrale du matériel recueilli auprès des médecins selon les procédures décrites dans l'analyse thématique en continu de Paillé et Mucchielli [16]. Cette analyse mixte (à partir du cadre conceptuel de référence, mais ouverte à l'inclusion de codes qui tiennent aussi compte d'informations imprévues, nouvelles) a été réalisée par les deux chercheurs ayant mené l'étude. Ce type d'analyse a permis d'identifier les principaux thèmes associés aux raisons et aux motivations justifiant l'opposition ou les réserves des médecins eu égard à l'aide médicale à mourir. La lecture des retranscriptions a d'abord mené à l'identification des attitudes et croyances des participants qui ressortaient le plus fréquemment et avec le plus de force. Les données ont été ensuite regroupées en quatre thèmes principaux : 1) finalités de la médecine et identité professionnelle, 2) philosophie et pratique de la médecine palliative et allocation des ressources en soins palliatifs, 3) paternalisme bienveillant, « bonne mort » et meilleur intérêt du soi futur, 4) risque de la pente glissante et protection des personnes vulnérables. L'identification et la description de ces thèmes ont permis de poser les bases, en complémentarité avec le volet normatif, d'une position plus claire et rigoureuse au sujet de l'interrogation normative qui est au cœur de cette étude.

Résultats

Description des caractéristiques des participants

L'âge des participants au moment de l'entrevue variait entre 25 et 75 ans. L'échantillon était composé de 20 médecins. La majorité d'entre eux avaient une expertise en soins palliatifs ou étaient médecins de famille. Les autres participants pratiquaient dans des domaines de spécialisation variés : médecine interne, chirurgie thoracique, santé publique et communautaire, anesthésiologie et soins intensifs, endocrinologie et gériatrie. Un peu plus de la moitié de l'échantillon avait entre 21 et 40 ans de pratique et provenait de Montréal et des environs. Quelques médecins de Québec, Lévis et d'autres régions ont aussi pris part à l'étude. Ces caractéristiques sont regroupées dans le Tableau 1.

Tableau 1: Caractéristiques des participants

Caractéristiques		**N=20**	**%**
Sexe	Féminin	12	60
	Masculin	8	40
Âge (ans)	Moyenne (étendue)	50 (25-74)	
Spécialité	Soins palliatifs	5	25
	Médecine de famille	8	40
	Autres	7	35
Années d'expérience	1-10	4	20
	11-20	5	25
	21-30	3	15
	31-40	8	40
Provenance	Montréal et les environs*	15	75
	Québec et Lévis	3	15
	Autres	2	10

** Environs de Montréal : Longueuil et Laval. Autres : Gatineau et Shawinigan*

Attitudes et croyances des participants

L'opposition au concept d'«aide médicale à mourir »

L'ensemble des participants déplore l'utilisation de la notion d'« aide médicale à mourir » pour décrire l'acte médical qui consiste à administrer une injection létale à un patient dans le but de lui donner la mort. La presque totalité des participants

(19/20) considère que l'AMM est dans les faits une forme d'euthanasie[1] et qu'il serait plus honnête de l'admettre : « c'est de l'euthanasie, ça serait moins hypocrite de le dire » (Pierre). Sur ce point, il nous apparaît clair que l'AMM est, au Canada, une forme d'« euthanasie volontaire ». L'euthanasie est « volontaire » lorsqu'une personne compétente d'un point de vue cognitif demande qu'un geste qui entrainera sa mort soit posé, généralement par un professionnel de la santé. S'il est conceptuellement possible de faire l'argument que la notion d' « aide médicale à mourir » décrit adéquatement l'acte médical dont il est question et qu'elle est cohérente avec l'approche législative québécoise qui intègre l'AMM à un continuum de soins de santé en fin de vie, cela n'en fait pas pour autant un acte distinct de l'euthanasie volontaire [17,18]. Il est vraisemblable, comme l'ont affirmé certains des participants, que la multiplication des concepts contribue à augmenter la confusion ambiante au sujet des soins de fin de vie (soins palliatifs, sédation palliative continue, aide médicale à mourir, euthanasie, suicide assisté, etc.).

Selon un participant:

> Je pense que c'est un terme qui semble meilleur que ce qu'il est en réalité. Hmm... J'aimerais qu'on l'appelle différemment…mais ça sonne bien pour le public... Je ne pense pas que le terme soit exact. Des fois, j'ai l'impression que c'est presque comme si nous l'avions inventé pour justifier ce que nous faisons en tant que société. Je n'aime pas le terme… (Timothy)[2]

D'autres ont mentionné que :

> L'appellation, je crois que c'est un euphémisme, personnellement. En fait, partout dans le monde, où il y a de l'euthanasie, c'est nommé. On innove ici. Je ne sais pas si c'est une innovation ou s'il y a un but derrière ça. Moi je pense qu'il y a un but derrière ça. C'est pour alléger. Pour rendre ça moins grave. (Debbie)
>
> …la plupart des gens s'imaginent que l'aide médicale à mourir c'est de donner des soins palliatifs de qualité. Puis là quand je leur explique un petit peu ce que c'est, ils disent «Ah oui! Ah bien vu de même… (Maria)
>
> Puis, ça me choque qu'on appelle ça un soin [l'AMM]. Tu sais, ça se peut que je devienne émotive. Pour moi, ce n'est pas un soin. En tout cas, pas un comme les autres là. (Suzanne)

Les sources de l'opposition ou de l'ambivalence par rapport à l'AMM

Cinq participants ont dit que leur identité religieuse était une partie intégrante de leur identité personnelle et que leurs convictions religieuses expliquent en partie leur opposition à l'AMM. Il faut toutefois noter que chez *tous* les participants qui ont déclaré avoir des croyances religieuses, l'opposition à l'AMM était *aussi* justifiée sur la base de raisons séculières ou publiques. Comme un participant l'a affirmé : « C'est intéressant, parce que tout bon argument seculier que je pourrais donner vient de mes croyances religieuses. » (Timothy)

Ces participants semblent spontanément accepter le critère de légitimité politique [19] selon lequel les normes publiques communes doivent être fondées, dans les sociétés marquées par le pluralisme raisonnable des conceptions de la vie bonne, sur des raisons que tous peuvent en principe accepter. En d'autres termes, les normes publiques communes ne doivent être justifiées uniquement par des raisons dérivées d'une conception englobante de ce qu'est une vie qui a un sens. Pour John Rawls (2016), les « raisons publiques » sont issues d'une « conception politique de la justice ». Une conception de la justice est « politique », chez Rawls, lorsque ceux qui adhèrent à une conception raisonnable de la vie bonne peuvent potentiellement l'accepter [19][3].

Ces participants voyaient leur identité comme unifiée ou intégrée plutôt que segmentée. Les valeurs et croyances religieuses et séculières sont pensées et vécues comme cohérentes les unes par rapport aux autres plutôt qu'en tension : « et ça, je ne peux pas accepter ça... comme médecin. Comme citoyen avant tout, comme médecin ensuite, comme Catholique en fin de compte » (Justin). Une autre participante a dit : « je suis croyante. Je suis Catholique. Sûrement que ça fait partie. Je ne pourrais pas vous dire à quel pourcentage. Je suis une personne… c'est un des facteurs qui m'influencent. » (Line)

Cinq autres participants ont déclaré que leur foi ou leur éducation religieuse teinte, dans certains cas « peut-être inconsciemment », leur jugement sur l'AMM et leur refus de l'intégrer à leur pratique. Cela étant dit, les raisons séculières sont très largement prédominantes chez ces participants. Une participante a par exemple déclaré qu'elle demeure probablement croyante, qu'elle pratique peu sa religion, mais qu'il était possible que sa trajectoire spirituelle l'influence plus ou moins consciemment. Toutefois, les raisons qui étaient déterminantes chez elle étaient toutes séculières. Une autre a dit : « Oui, la dimension religieuse est présente chez moi, mais disons que ce serait la dernière invoquée. » (Pascale)

[1] Certains participants ont plutôt rapproché l'AMM du « suicide assisté ».
[2] Les prénoms des participants ont été remplacés par des pseudonymes afin d'assurer l'anonymat. Toutes les autres informations nominatives qui auraient pu permettre de les identifier ont également été omises.
[3] Les conceptions « déraisonnables » de la vie bonne sont celles qui soutiennent que les normes et institutions publiques devraient favoriser les citoyens adhérant à une conception particulière de vie bonne et, par extension, défavoriser les citoyens qui adhèrent à d'autres conceptions. En d'autres termes, la raisonnabilité s'incarne dans l'acceptation de critères de réciprocité et d'équité dans la distribution des avantages et des charges de la coopération sociale [19].

Un peu plus d'un tiers des participants (7/20) ont affirmé qu'ils sont athées ou que la religion n'influe pas sur leur positionnement eu égard à l'AMM, et trois autres n'ont pas répondu explicitement aux questions portant sur leur rapport à la religion. Les raisons mentionnées par ces dix participants étaient exclusivement séculières. Dans les termes de nos participants :

> J'suis pas religieux. J'suis né Catholique, mais ça fait 50 ans ou plus que je ne suis pas allée dans une église, c'est pas une question. (Pierre)

> Je connais des gens qui sont objecteurs de conscience qui sont très catholiques, puis j'en connais qui sont des objecteurs de conscience athées. Moi je suis dans la catégorie athée. Je suis… très très athée (rires). (Julie)

Notre étude permet ainsi d'émettre des doutes quant à la perception voulant que la majorité des objections de conscience soient motivées, au Québec, par des croyances religieuses, essentiellement catholiques, fortes. Déplorant la représentation sociale des médecins objecteurs de conscience, l'une de nos participantes a dit :

> J'ai un ami qui est très adversaire de cela [AMM]. Mais lui, il est spécialiste en soins palliatifs. C'est un être de lumière, mais il s'est fait traiter de tous les noms : 'toi tu es une espèce de catho', mais il n'est pas catholique du tout, il est athée, autant que moi. C'est pour cela que moi ça me faisait du bien quelque part de venir vous voir… Il se fait rentrer dedans, lui, cela n'a pas de bon sens. (Julie)

De l'objection à l'ambivalence

Les attitudes et croyances des participants par rapport à l'AMM se situent sur un continuum allant de l'opposition principielle et catégorique à l'ambivalence profonde et déchirante. Trois attitudes générales relatives à l'AMM sont discernables dans les réponses des participants : 1) une opposition principielle et catégorique; 2) une opposition plus contextuelle, contingente et une pensée personnelle en évolution; 3) une volonté de ne pas participer au processus tout en acceptant la légitimité du choix collectif permettant l'AMM. Les positions (2) et (3) témoignent d'une ambivalence morale plus ou moins grande selon les cas par rapport à l'AMM.

Les premiers pensent que tout acte causant intentionnellement la mort est moralement répréhensible. Près de la moitié des participants (9/20) peuvent être rangés dans cette catégorie. Pour certains, « l'euthanasie est un meurtre ». Un autre nous a dit « je suis contre dans toutes les situations. » (Line)

Les seconds – 6 de nos participants – admettent spontanément qu'il s'agit pour eux d'une question éthique difficile et que, s'ils étaient d'abord plutôt opposés à la légalisation de l'AMM et qu'ils ne souhaitent pas pour l'instant l'intégrer à leur pratique, leur pensée est en mouvement. Leurs discussions avec des patients et des collègues influencent leurs réflexions. Il n'est pas impossible que certains d'entre eux acceptent un jour d'évaluer des patients ou d'administrer l'AMM à un patient qu'ils suivent depuis longtemps. Comme l'a dit une participante : « mon point de vue a changé depuis que la loi a été adoptée et que des collègues ont fait des aides médicales à mourir. C'est possible que j'accepterais un jour de le faire si un patient que je suis depuis longtemps me le demande. » (Lucie)

Enfin, les derniers ne sont pas opposés moralement à l'AMM, mais ils ne se sentent pas capables de l'administrer eux-mêmes et, comme les seconds, ils considèrent qu'il aurait été préférable d'attendre que l'accès à des soins de fin de vie de qualité soit meilleur avant de permettre l'AMM. Cinq de nos participants font partie de cet ensemble. Dans leurs propres termes :

> Moi, je…finalement, je pense que je prêche plutôt pour que les patients, ils aient droit, accès aux soins palliatifs et à l'aide médicale à mourir… Je ne veux pas faire d'aide médicale à mourir. Je suis *grateful*. J'ai de la gratitude pour les médecins qui veulent bien le faire parce que moi je ne suis pas prête à le faire. Puis ces patients-là, ils ont le droit à l'euthanasie. Donc, il faut qu'il y en ait des médecins pour le faire. (Talia)

L'opposition ou l'ambivalence par rapport à l'AMM : quatre catégories de raisons

Les croyances et valeurs séculières sont ainsi ressorties de façon nettement prédominante dans notre étude. Comme précisé plus haut, puisqu'il s'agit du type de raisons qui doivent fonder les lois et les politiques publiques dans les sociétés pluralistes où prévaut la laïcité de l'État [15], nous avons choisi d'en faire l'objet central de notre analyse. Nous les avons regroupées en quatre grandes classes : 1) Finalités de la médecine et identité professionnelle, 2) Philosophie de la médecine palliative et allocation des ressources en soins palliatifs, 3) Paternalisme bienveillant, « bonne mort » et intérêts du soi futur, 4) Risque de la pente glissante et protection des personnes vulnérables. Les considérations et arguments classés dans l'une ou l'autre de ces catégories peuvent évidemment se recouper et se renforcer mutuellement.

1) Finalité de la médecine et identité professionnelle

La plupart des participants voient une incompatibilité ou une tension forte entre l'acte de provoquer intentionnellement la mort et les principes et finalités guidant la pratique de la médecine. La médecine est vue, dans un premier temps, comme une lutte contre la maladie et la mort. Ensuite, lorsque confrontés aux limites de la médecine curative, les participants pensent que leur rôle est d'accompagner le patient jusqu'à la fin en leur offrant des soins permettant la meilleure qualité de vie possible. Comme

l'a dit l'une des participantes : « Au début, je voulais sauver mes patients. Maintenant, je suis plus sage, je sais que mon rôle est surtout de les accompagner. » (Kim) S'ils sont de grands promoteurs de la médecine palliative, des critiques de l'acharnement thérapeutique et des défenseurs du droit des patients à refuser des traitements, ils considèrent que la médecine doit en quelque sorte être un espace entièrement consacré à la protection de la vie, de sa qualité et à la diminution de la souffrance. La mort est vue comme faisant partie du cours normal de la vie, mais le médecin a l'obligation déontologique de ne pas la provoquer ou la précipiter délibérément. Ils voient donc une différence éthiquement significative entre donner la mort et laisser mourir. Leur conception des normes éthiques inhérentes à la pratique de la médecine (*role morality*) ne laisse aucune place à un geste causant délibérément la mort : « que l'on provoque la mort, ça dépasse mon entendement comme médecin. » (Pierre) Pour une participante, cesser les traitements et contrôler la douleur signifie que l'on cesse de « retarder la maladie », ce qui est différent de « provoquer la mort » (Debbie). Ces participants ont intériorisé la prescription contenue dans le Serment d'Hippocrate en vertu de laquelle : « je ferai tout pour soulager les souffrances. Je ne prolongerai pas abusivement les agonies. Je ne provoquerai jamais la mort délibérément. » [20]

Comme l'exprime clairement un participant :

> Moi, je croyais à ce qui nous était enseigné à ce moment-là, la première affaire c'est 'premièrement, ne pas nuire', puis en suite de cela on aide et on accompagne… Je n'ai jamais fait un cours de médecine pour tuer du monde. Je ne pense pas qu'il y a besoin d'être médecin pour tuer du monde… J'ai été membre pendant des années d'Amnistie Internationale, j'étais complètement opposée à ce qu'il y ait des médecins dans les salles de torture, qu'il y ait des médecins qui appliquent la peine de mort. Un médecin c'est là pour aider les gens, leur donner de l'espoir et travailler jusqu'à la fin de leur vie pour que la vie soit la meilleure possible. C'est ma conception de la médecine. (Julie)

Pour d'autres:

> La pratique de la médecine scientifique ça consiste à administrer, poser un geste dont le bénéfice est plus grand que le risque. Toute la médecine repose là-dessus, a toujours reposé là-dessus. Même avant qu'elle soit scientifique, les médecins essayaient de pas, de pas aggraver le mal… ça toujours été le *primum non nocere*. D'abord ne pas nuire. (Pascale)
>
> De poser le geste là. De mettre fin à la vie de quelqu'un. Honnêtement… (Lola)
>
> C'est comme si je devenais le tueur à gages de personnes, c'est comme ça que je le vis. (Éloise)

De façon imagée, un participant exprime ainsi l'incompatibilité entre les finalités de la médecine et l'AMM :

> Tu sais, au football, tu as les deux, vous avez chacun une extrémité du terrain, mais si moi je m'en vais vers une ligne, moi ma profession c'est aller vers ça. Puis là si l'euthanasie est légale, ça veut dire que je fais un 180 degrés puis je vais l'autre ligne. Moi je le vois comme ça. (Timothy)

De façon générale, les équipes médicales ont la prérogative d'établir quels sont les « soins appropriés » pour les patients. L'intégration de l'AMM dans la gamme de services offerts aux patients en fin de vie impose une redéfinition partielle de l'identité professionnelle des médecins et de leurs prérogatives et responsabilités. Depuis l'adoption de la *Loi modifiant le Code criminel et apportant des modifications connexes à d'autres lois (aide médicale à mourir)* [7], un patient qui satisfait les critères des lois sur les soins de fin de vie a un droit constitutionnel à l'obtention de l'AMM, ce qui limite nécessairement l'autonomie professionnelle des médecins. Comme l'ont dit des participants :

> Et puis, en quelque part, on m'enlève mon jugement, parce que ce n'est pas moi qui juge. C'est la loi qui met ses critères… Donc ce n'est pas vraiment, par définition, un geste médical. Moi comme médecin, je dois faire ce qui est médicalement requis. (Kim)
>
> C'est la collusion avec le Collège des médecins, mais dans le fond c'était imposé par le gouvernement du Québec. C'est pas de la médecine. Ce ne sont pas à eux de définir c'est quoi la médecine. C'est pas à la Cour suprême du Canada de définir c'est quoi la médecine. (Line)

2) Philosophie et pratique de la médecine palliative et allocation des ressources en soins palliatifs

Considérant qu'un quart des participants pratique la médecine palliative et que tous les autres en ont fait dans le passé ou sont des promoteurs de cette approche, la question du rapport entre l'AMM et les soins palliatifs s'est avérée l'un des thèmes ressortant avec le plus de force des entretiens. Pour certains, la philosophie même de la médecine palliative est incompatible avec l'AMM. Les soins palliatifs doivent, selon ce point de vue, être entièrement consacrés à la gestion des symptômes physiques provoquant la douleur et à l'accompagnement psychosocial et, lorsque souhaité, spirituel des patients. Si la médecine palliative est fortement opposée à l'acharnement thérapeutique [21], sa réhabilitation du processus du mourir comme partie intégrante de la vie la mettrait en tension avec l'AMM.

De plus, d'un point de vue clinique, des participants considèrent que la médecine palliative a des moyens assez efficaces pour offrir une qualité de vie acceptable aux patients aux prises avec une maladie incurable. Le savoir clinique et l'accroissement des connaissances sur les effets des analgésiques opioïdes ou non opioïdes permettraient dans presque tous les cas aux palliativistes de contrôler les douleurs des patients [5]. Dans le cas des douleurs réfractaires en fin de vie, la sédation palliative (continue ou non) permettrait de soulager le patient, si elle est pratiquée dans les règles de l'art, sans provoquer ou précipiter la mort [22].

Selon les données recueillies :

> Des souffrances intenses, unbearable suffering, je ne suis pas sûr que ce soit vraiment courant ça. S'il y a beaucoup qui en ont vraiment une souffrance qui n'est pas traitable, je pense que ça doit être extrêmement rare et trop rare pour créer le besoin de l'euthanasie. (Timothy)

> Je pense que si, comme médecin en soins palliatifs, j'accueille quelqu'un, et bien moi mes outils ils sont assez puissants. (Kim)

Un médecin ayant quarante ans de pratique a déclaré : « Je n'ai jamais été confronté à une souffrance insoutenable que je ne pouvais pas contrôler. » (Justin)

Et si les souffrances ressenties par un patient sont réfractaires et insupportables, le recours à la sédation palliative s'impose : « Donc, si on a des douleurs réfractaires d'une façon incroyable, je pense que ce sont des cas de sédation palliative continue. »[4] (Debbie)

Une participante dit aussi que :

> L'avantage de la sédation palliative, c'est que ce n'est pas le médecin qui décide quand le patient va mourir. Il meurt quand il meurt. On le veille, on reste à côté, on lui tient la main, puis à un moment donné il s'en va. Et moi j'aime bien que ce ne soit pas le médecin qui décide. (Julie)

À ce sujet, certains participants ont tenu à préciser qu'il n'y a pas d'équivalence entre sédation palliative continue et AMM :

> La sédation ne cause pas la mort si on la fait comme il faut. Si on a tout essayé pour soulager le patient. On donne une sédation pour qu'il ne soit pas conscient, pour que ce soit temporaire, que ce soit jusqu'à la fin. C'est sûr que si on parle d'un patient qui n'est pas à la veille de mourir, on lui donne une sédation à long terme et on ne lui donne pas à manger ni à boire, ça, c'est tuer le patient. S'il est en fin de vie, que de toute façon on ne pourra pas lui donner à manger ou à boire, on lui donne une sédation pour soulager les derniers jours, c'est une chose.[5] (Line)

Pour la grande majorité des participants, la légalisation de l'AMM, et en particulier son intégration, au Québec, dans un « continuum de soins en fin de vie », ne peut qu'accroître la méconnaissance qui sévit à propos des soins palliatifs. Des personnes craignent déjà les soins palliatifs, car elles croient que les patients sont euthanasiés sans leur consentement ou que l'administration de doses importantes et répétées de morphine précipite la mort. Ces mythes seront renforcés, selon des participants, si l'AMM est pratiquée dans des maisons ou unités de soins palliatifs. Une participante souligne que les craintes par rapport à la médecine palliative, en particulier eu égard à l'utilisation de la morphine, demeurent répandues :

> Donc quand je dis à cette personne-là : « Écoutez, la morphine que je vous donne je la calcule d'une façon qui n'est pas dangereuse pour vous. Je ne vous tuerai pas. Et je fais attention. Je fais très attention. » Et donc, ça c'est quelque chose qui est important pour moi. Que le patient que je soigne se sente en sécurité, fasse confiance. Puis, il y a une peur présentement de la morphine. (Kim)

Des participants craignent ainsi que l'intégration de l'AMM se fasse au détriment des soins palliatifs, dont le statut était déjà précaire au Québec et ailleurs au Canada [23,24]. Cette participante résume clairement les préoccupations exprimées par plusieurs autres :

> L'autre raison, puis c'est probablement la principale, c'est que, moi je crois qu'on peut faire des choses extraordinaires en soins palliatifs. Je pense que c'est une discipline qui est très complexe, qui évolue, qu'il faut encourager. Il y a beaucoup de science qui se fait là-dedans... Je pense que cela va se présenter en dichotomie : l'aide médicale à mourir et les soins palliatifs, et j'ai peur qu'il y ait des patients à qui on n'a pas offert la panoplie de service de soins palliatifs, je vois qu'on a encore beaucoup de progrès à faire comme

[4] Comme nous l'a suggéré une évaluatrice, il importe de rappeler que des patients aptes à consentir à leurs soins refusent parfois les soins palliatifs, ou la sédation palliative en particulier, et que plusieurs personnes qui ont reçu l'AMM ont aussi bénéficié de soins palliatifs avant de demander l'AMM. De façon générale, nous croyons que le législateur a eu raison de ne pas établir une hiérarchie entre les différents soins de fin de vie et de ne pas permettre l'AMM uniquement après l'administration de soins palliatifs.

[5] Preuve que le flou persiste au sujet de la sédation palliative, un de nos participants, qui ne pratique pas la médecine palliative, a affirmé que la sédation palliative peut être acceptable « même s'il entraine la mort la plupart du temps ». (Pascale)

> société par rapport à la connaissance de la mort… Ce qui fait que les gens sont pas au courant des soins palliatifs, ce qu'ils pensent encore que les soins palliatifs c'est vraiment juste dans le champ de la mort, juste à la dernière minute, ne savent pas que ça peut s'étendre sur des longues périodes, qu'on peut augmenter la qualité de vie beaucoup, que les gens on peut les soulager. Et puis moi j'ai peur que ça [l'AMM] devienne la porte facile… (Julie)

De plus, puisque les soins palliatifs épousent une conception holistique du bien-être des patients – une conception selon laquelle les dimensions physique, psychosociale et spirituelle du bien-être doivent être pensées ensemble [25] – les participants soulignent que l'environnement offert par les maisons ou unités de soins palliatifs peut favoriser une fin de vie sereine et satisfaisante. Lorsque les ressources sont suffisantes, les soins palliatifs offrent un environnement physique apaisant, ainsi qu'un accompagnement médical, psychosocial et spirituel permettant aux patients d'être entourés de leurs proches et d'aborder les enjeux qui les préoccupent ou dont ils ont envie de discuter avec des professionnels et des bénévoles.

Soulignant que la souffrance des patients est souvent de nature « existentielle » et regrettant le manque de ressources pour embaucher des travailleurs sociaux et des psychologues, une participante a dit : « Est-ce que c'est acceptable de dire : On va mettre fin à votre vie parce que je n'ai pas les ressources nécessaires pour vous aider? Je trouve ça inacceptable. Je trouve ça horrible. » (Talia)

Les participants affirment que ce qu'ils perçoivent comme le sous-financement des soins palliatifs rend moralement inacceptable, du moins dans le contexte actuel, la légalisation de l'AMM. Comme cela a été précisé plus haut, l'AMM s'insère au Québec dans une politique plus large de soins de fin de vie. Une des conditions d'acceptabilité de l'AMM énoncée par la Commission spéciale sur la question de mourir dans la dignité était que les patients québécois en fin de vie devaient avoir accès à des soins palliatifs de qualité et que, conséquemment, la légalisation de l'AMM devait impérativement être accompagnée de l'octroi de ressources supplémentaires en soins palliatifs [26]. Or, la Loi concernant les soins de fin de vie [1] ayant été adoptée au même moment que les mesures de rigueur budgétaire mises de l'avant par le gouvernement du Québec, les participants pensent de façon quasi-unanime que la condition d'acceptabilité n'est pour l'instant pas satisfaite :

> Si ça [l'AMM] répond à une lacune de ressources, eh bien moi je me dis que c'est éthiquement complètement inacceptable. C'est pour ça que je me dis tant que j'aurai ce sentiment -là, je ne pense pas pouvoir m'impliquer dans les processus comme ça. (Debbie)

> Donc, un moment donné, quand on parle de dignité, il faudrait comme questionner : est-ce que c'est vraiment la maladie qui rend indigne ou le système de santé dans lequel on est? (Debbie)

> l y a une clinique de la douleur. Ils sont fantastiques, mais ça prend deux ans pour les voir. Ça n'a pas de bon sens. Alors on dit bon: « on peut vous tuer la semaine prochaine ou on peut régler votre douleur dans deux ans ». (Line)

> Parce qu'on n'est pas organisé dans notre secteur [milieu urbain] pour avoir des bénévoles pour passer la nuit avec les patients […] et dire : « J'ai fait ça parce que je n'avais pas accès aux ressources », je serais bien fâchée. (Hélène)

3) Paternalisme bienveillant, « bonne mort » et intérêts du soi futur

Il nous est apparu que l'une des catégories de motifs expliquant le positionnement de nos participants eu égard à l'AMM relève d'une forme de « paternalisme bienveillant ». En théorie éthique, le paternalisme réfère aux positions selon lesquelles il est parfois légitime d'ignorer la volonté d'une personne sur la base qu'elle n'est pas toujours la mieux placée pour déterminer la nature de son propre bien ou de ses intérêts [27]. Nous proposons de voir le paternalisme comme « bienveillant » lorsqu'il s'ancre dans un authentique souci pour le bien-être des personnes visées. Le paternalisme prend une forme « politique » lorsque l'on considère que l'État peut légitimement utiliser son pouvoir pour prescrire ou proscrire des comportements au nom des intérêts bien compris des citoyens [27]. Les politiques mises de l'avant au nom de la santé publique, comme l'obligation de porter une ceinture de sécurité lors des déplacements en voiture, se rangent généralement dans la catégorie du paternalisme politique bienveillant.

Les écrits en éthique médicale sur l'acceptabilité du paternalisme par les professionnels de la santé sont abondants [28]. Dans le contexte de notre étude, les positions que nous qualifions de paternalistes sont celles avançant que les personnes ne sont pas bien outillées pour comprendre comment elles vivront la progression de la maladie ou que des appréhensions comme la peur de souffrir, d'être un fardeau pour les proches ou de vivre dans des conditions de vie indignes ont un poids démesuré dans leur évaluation de la valeur de leur vie avec une maladie avancée. Une idée sous-jacente exprimée à répétition est qu'il est très difficile pour ce que nous appelons le « soi présent » d'anticiper quelle sera la réalité du « soi futur » et la nature de ses intérêts une fois rendue à l'étape de la fin de vie. Des médecins expérimentés ont dit avoir suivi des patients qui, après des moments de découragement où ils voulaient en finir, ont retrouvé une certaine qualité de vie et vécu des expériences chargées de sens.

La possibilité que le patient « s'adapte » à sa maladie et change d'idée sur la valeur de la vie qui reste à vivre, en particulier s'il a accès à des soins de qualité, est l'une des considérations les plus déterminantes dans le positionnement de plusieurs des participants.

Pour les participants :

> Les gens, ils changent d'idée. Tout d'un coup, un jour, ils se réveillent déprimés. Puis le lendemain, il y a quelque chose qui a changé dans leur vie puis qui lui redonne un sens. Qu'est-ce qui me dit que dans une semaine ce patient-là il n'aurait pas envie de vivre? Et moi, j'aurai enlevé cette vie. Je ne trouve pas ça acceptable. Parce qu'il y a ce risque que j'enlève une vie qui aurait pu être encore d'une certaine qualité. Ce n'est peut-être pas quelqu'un qui est capable de courir un marathon-là, mais quelqu'un qui va vivre ses jours paisiblement, confortablement, et qui va retrouver un sens à sa vie. L'arrière-petite-fille est enceinte. Tout d'un coup, il y a un désir, une envie de vivre un jour de plus, une semaine de plus, un mois de plus. Donc il y a ça. Il y a cette incertitude. (Talia)

> Avoir écouté les patients, avoir vu des changements entre un patient qui était mort de peur quand il apprend sa maladie puis qui te dit : « Moi j'aime autant mourir tout de suite. » Et puis quelques mois plus tard, il s'attache, peut-être il y a un espoir, un nouveau protocole… Il y a le moment où tu reçois une tonne de brique sur la tête, tu sais, et c'est trop lourd pour toi, et puis c'est là qu'il faut vraiment accompagner tranquillement, et dire bon on traversera le pont quand on sera rendu à la rivière, et puis là on va regarder comment on peut améliorer, qu'est-ce qu'on peut faire pour tout de suite… Puis là j'ai vu des patients évoluer par rapport à leur maladie. (Julie)

> J'ai l'impression souvent que certaines personnes sont probablement plus en déni ou inacceptation de leur condition quand ils décident de se prévaloir de l'aide médicale à mourir. Puis, j'ai l'impression qu'avec le temps qui passerait, probablement qu'ils accepteraient plus la situation. Puis, ça leur permettrait probablement de vivre certains moments encore bénéfiques pour eux. (Jérôme)

Sans surprise, plusieurs participants ont exprimé une forte opposition à l'idée que le dispositif des « directives médicales anticipées » puisse être utilisé pour permettre aux personnes de faire une demande de l'AMM par anticipation dans l'éventualité où ils seraient atteints d'une maladie neurodégénérative comme l'Alzheimer. Aux Pays-Bas, les personnes ayant reçu le diagnostic d'une maladie grave et irrémédiable qui les rendra éventuellement inaptes au consentement libre et éclairé peuvent exprimer leur souhait d'être euthanasié à un certain moment dans l'évolution de la maladie dans une déclaration médicale anticipée [29-31]. Pour une participante, les demandes anticipées d'AMM sont « une aberration totale ». (Kim)

Certains font remarquer que l'application des demandes anticipées d'AMM poserait des difficultés majeures :

> Est-ce qu'ils ont considéré que, même si on l'écrit dans nos directives médicales anticipées, quand est-ce qu'on va décider que c'est trop pour le patient? Parce que là, tant qu'il te reconnait, c'est correct? Un moment donné, c'est quand il est incontinent que ce n'est plus correct? Est-ce que c'est quand il arrête de manger? Est-ce que c'est quand il devient agité? Moi, je me dis : c'est qui qui va se mettre dans un panel pour aller décider ça? Je ne comprends même pas comment ils vont finir par décider à quel stade… la personne démente, elle ne le saura pas. Elle ne comprendra pas. Je me dis : est-ce que vous avez réalisé qu'il va falloir probablement les attacher? Parce que ce n'est pas comme si on va dire : « Bon, bougez pas. Regardez l'oiseau là-bas. » Puis là, on va…, ça n'a aucun sens-là. (Debbie)

En lien avec la difficulté pour le patient de se projeter correctement dans l'avenir, des participants justifient leur refus de participer au processus de l'AMM en s'appuyant sur une conception implicite ou explicite de la « bonne mort ». Qu'il s'agisse de ce que nous découvrons à propos de nous-mêmes dans la maladie ou du rapprochement avec des membres de notre famille et des amis, se donner la chance de vivre pleinement la fin de vie offre la possibilité de croître et de bien conclure le dernier chapitre de notre vie. Le paternalisme devient ici une forme de perfectionnisme[6]. Bon nombre de participants ont ajouté que la « souffrance fait partie de la vie » et, dans quelques cas, qu'il faut l'accepter et y faire face « avec courage » : « une vie sans souffrance n'existe pas. Il faut que tu affrontes la souffrance avec courage » (Justin), a dit l'un des participants.

Ces extraits montrent bien qu'une part de paternalisme (bienveillant) et de perfectionnisme subsiste dans l'opposition ou l'ambivalence de plusieurs participants par rapport à l'AMM :

> La mort fait partie de la vie…c'est inclus. On ne peut pas avoir le contrôle sur tout. Moi j'pense que l'évolution narcissique des Occidentaux, de penser strictement à eux puis à chaque individu, ce qui a amené des choses positives, mais là je pense que c'est un chemin qui montre les côtés négatifs là de l'individualité. (Pierre)

[6] Le perfectionnisme moral réfère aux positions éthiques selon lesquels il demeure possible, malgré le pluralisme des valeurs, d'identifier un idéal de « perfection morale » ou, de façon plus prosaïque, de soutenir que certaines conceptions de la vie bonne sont supérieures aux autres possibles. La théorie morale et politique libérale soutient généralement que l'État doit éviter le perfectionnisme et aspirer à la neutralité eu égard aux conceptions « raisonnables » de la vie bonne [32].

> Il y a tellement de gens aussi qui m'ont dit : « les derniers mois de ma vie ça été les plus beaux. » Et bon. On peut dire qu'ils rationalisent, je ne suis pas sûre de cela, je pense qu'ils n'étaient plus à se raconter des histoires au moment où ils m'ont dit cela. Je pense qu'ils parlaient vrai, ils n'avaient plus rien à perdre de rien, ils n'avaient pas d'image à préserver. Je me dis, bon…, il faut peut-être écouter cela aussi de ces patients-là qui ont apprivoisé la mort puis qui ont décidé de vivre. Moi j'ai accompagné un de mes amis sidéens il y a très longtemps, il y a 20 ans, et on avait une espèce d'éthique de l'instant présent, d'essayer que chaque instant soit le plus parfait possible. J'ai appris cela avec lui. (Julie)

> Mais, mettons que le patient [en soins palliatifs] est confortable. Chaque journée, c'est un cadeau de la vie. Parce que les gens vont se mettre à dire les vraies affaires. Un vrai legs. Beaucoup de choses se passent. Des deuils sont complètement différents. Puis, ça nous permet d'apprivoiser notre propre mort dépendant de ce qu'on voit. Présentement, si l'aide médicale à mourir augmente, ça va être ça qu'on va voir de la mort. Elle a mis sa belle robe comme elle voulait. C'est ça qu'on veut représenter comme fin de vie. Bon, c'est un choix de société, mais… (Debbie)

> Je vais le dire au patient: « moi, vous voyez, je suis un médecin de soins palliatifs. Je vous explique mes affaires. Je ne suis aucunement contre l'aide médicale à mourir. Je vous le dis d'emblée. » Là, j'explique mes affaires. Puis, je dis : « j'ai une fermeture complète de votre part. Même avec une agressivité, une colère que je sens. Parce que j'essaie de vous faire réfléchir sur d'autres choses. » (Debbie)

L'interruption par l'AMM du processus du mourir prive non seulement la personne mourante d'une expérience significative, mais aussi les proches qui l'accompagnent. Une participante a dit que cela ne peut pas justifier une objection conscience, mais que cela fait néanmoins partie du coût éthique inhérent à l'AMM :

> Puis, je pense aussi aux conséquences sur les proches disons de quelqu'un qui mourrait par l'aide médicale à mourir. Pour moi, accompagner un mourant, on apprend à vivre, on apprend des choses précieuses. En quelque sorte ce que la personne nous dit. Et puis, je pense que la personne minimise sa valeur à ce moment-là. La valeur et le rôle social qu'elle joue. Je profite d'une conversation pour parler du rôle qu'ils ont à jouer auprès de leurs proches qui viennent les visiter. Que non ce n'est pas un fardeau et puis qu'il y a du bon qui ressort de ça. Puis les personnes qui viennent visiter un mourant, ils font un geste de solidarité, ils font un geste de générosité. Mais ce n'est pas à moi de juger si la personne pense que ça a de la valeur ou non. Je ne dois pas faire objection pour ça, mais ça fait partie de ma réflexion. (Kim)

4) Risque de la pente glissante et protection des personnes vulnérables

L'argument de la pente glissante est celui en vertu duquel une action ou une décision particulière n'est pas souhaitable parce qu'elle mènerait inévitablement ensuite à d'autres décisions qui seront éthiquement inacceptables. Au Canada, seules les personnes majeures aptes au consentement éclairé, vivant avec une maladie grave et irrémédiable, dont la mort est raisonnablement prévisible et aux prises avec des souffrances qu'elles jugent intolérables, sont admissibles à l'AMM. Si le gouvernement du Québec soutient qu'il a procédé avec prudence en légalisant l'euthanasie volontaire pour des adultes en fin de vie, les participants à l'étude voient comme plus ou moins inévitable l'élargissement des critères d'admissibilité à l'AMM, au gré des revendications des citoyens [31,33][7]. Au moment des entrevues, la plupart savaient que le Ministère de la Santé du Québec avait mis sur pied un groupe d'experts travaillant sur la question de l'inaptitude au consentement éclairé causée par les maladies neurodégénératives. Ils savaient aussi que le gouvernement fédéral, de son côté, avait mandaté le Conseil des académies canadiennes de créer des comités de travail sur les « mineurs matures », la santé mentale et les demandes anticipées [31-33]. Par rapport à l'adulte en fin de vie et apte au consentement, les catégories de personnes qui pourraient éventuellement avoir accès à l'AMM sont vues comme plus « vulnérables ».

Une participante a rappelé qu'en plus de l'autonomie, le principe de bienfaisance fait partie des principes cardinaux de la bioéthique [34]: « Quand l'autonomie a été énoncée comme principe bioéthique avec les trois autres. Même ces gens-là, ne disaient pas que c'est suprême. La bienfaisance par exemple. Il y a beaucoup de domaines dans la vie dans lesquelles notre autonomie est limitée. » (Line)

Le danger de la pente glissante est explicitement évoqué par l'un des participants :

> Lorsque nous ouvrons la porte à une chose qui, dans notre société, n'est peut-être pas la meilleure, nous ouvrons la porte à de plus en plus de choses. Vous avez parlé de droits il y a quelques minutes, je veux dire, c'est drôle que leur droit de mourir, ça vient d'ouvrir la porte. Je m'attends à ce qu'à mesure que les années passeront, à cause des arguments des droits des gens, il sera dépensé de plus en plus et cela me fait encore plus peur. Je pense qu'en tant que société, voulez-vous commencer à dire que la vie n'a plus de valeur? Tu sais que c'est une pente très glissante. (Timothy)

[7] Pour une interprétation du processus ayant mené à l'adoption de la Loi concernant les soins de fin de vie et de la loi elle-même, voir la référence [31].

Selon d'autres:

> …puis en plus maintenant ce n'est plus seulement les personnes âgées…Une loi, c'est tout le temps ça, ça élargit… c'est qu'on est rendu dans l'eugénisme, là. Tous ceux qui ne seront pas comme on le souhaite, ils vont être flushés. (Maria)

> Je pense que ça pourrait aller à la dérive. Ça je pense que c'est l'ultime danger. Comme société, on veut pas se débarrasser des gens qu'on juge inutiles là, bien que certains pensent qu'ils entrainent des couts. (Patrick)

Certains craignent les répercussions de l'élargissement de l'accès de l'AMM sur d'autres groupes de la société, comme des personnes vivant avec des handicaps ou avec des pensées suicidaires :

> Il y a un gars qui travaille avec nous qui est en chaise roulante, un gars dans la quarantaine. Lui était contre l'euthanasie parce qu'il se sentait visé par rapport à ça. Il dit : « il y a des gens dans la rue que je ne connais pas qui me disent j'aimerais mieux être mort que d'être comme toi. » Alors, il y a tout un groupe de personnes handicapées qui ont très peur de cette loi parce qu'ils se sentent visés. On dit si vous ne pouvez plus aller à la toilette tout seul. Il dit : « moi toute ma vie je ne pouvais pas aller à la toilette tout seul. Je pense que ma vie a autant de valeur que le voisin. » (Sacha)

> C'est un peu la même raison pour laquelle je suis, je suis contre la peine de mort. C'est qu'il y a toujours des erreurs. La peine de mort, on condamne à mort des innocents. Et bien dans l'euthanasie, on va euthanasier des gens dans des conditions qui ne sont pas tout à fait claires, ou on ne leur a pas vraiment demandé leur avis, ou on leur a fait pression. (Gérard)

> C'est parce que l'aide médicale à mourir est une loi, qu'il faut laisser mourir les gens qui se suicident. Et plusieurs cas de gens qui ont fait des tentatives de suicide, qui ont été amenés à l'hôpital, qu'on a dit 'bah ils veulent mourir, laissez-les mourir'. c'est la première bavure, si je peux dire de cette loi. (Pascale)

La rareté des ressources dans le système de santé a aussi été identifiée comme l'une des sources de dérives potentielles :

> Les dérives pour moi sont tellement probables … c'est peut-être moi qui suis borné, mais, un hôpital de 800 lits, tu as besoin de deux lits, t'en tues deux le matin, deux l'après-midi, du lundi au vendredi, t'as même pas d'infirmière les fins de semaine. T'as personne là les fins de semaine, tu règles 10 situations. Tu as une unité de soins palliatifs, 10 lits, tu as des soins toute la journée, de l'ergothérapie, de la physiothérapie, de l'inhalothérapie, toutes sortes de services, ça coûte cher. Donc placer un administrateur qui regarde deux lits, qui règle 10 situations par semaine, qui coûte 10 fois moins que les 10 autres lits… c'est comptable là. Et de dire 'ah, on va encourager quand même les soins palliatifs' quand tu as cette option là, ça n'arrivera pas, selon moi. (Pierre)

La pression qui pourrait être mise sur les patients par des membres de leur entourage a aussi été évoquée :

> Toutes de conflits de famille. Moi une chose que je fais, c'est d'évaluer l'aptitude des personnes âgées avec des troubles cognitifs. Et des fois je suis appelée à témoigner dans les tribunaux pour des familles qui sont en chicane. « Est-ce qu'il est apte est-ce qu'il est inapte? » Et souvent ce sont des questions de sous. Celui qui veut que le parent soit inapte c'est celui qui est en train de vider le compte de banque. Des fois, c'est juste des sous, des fois ce sont des émotions et ils n'arrivent pas à se mettre d'accord. Le patient dit oui à celui-là un jour. Il dit oui à l'autre, l'autre jour parce qu'il ne veut pas faire de peine à personne. C'est très très complexe. (Line)

Les arguments fondés sur la crainte de la pente glissante sont rarement jugés convaincants en éthique [33,35]. Toute liberté ou possibilité offerte aux personnes peut mener à des excès ou à des applications moralement troublantes. La réponse à la crainte de la pente glissante est de réfléchir aux limites souhaitables du droit garanti aux citoyens et de se donner les moyens institutionnels de faire respecter les règles établies. Par exemple, s'il est vrai que le droit à la liberté d'expression peut permettre la profération de propos haineux ou diffamatoires, la solution à ce problème réel est d'interdire les discours haineux et diffamatoires, et non de supprimer la liberté d'expression. Cela étant dit, les revendications sociales concernant l'élargissement de l'accessibilité à l'AMM se multipliant, les craintes des participants quant au sort de personnes présentant d'indéniables vulnérabilités sont sérieuses et méritent d'être entendues.

Discussion et conclusion

La reconnaissance du droit à l'objection de conscience des médecins soulève logiquement la question des obligations résiduelles de l'objecteur de conscience, dont la difficile question de la référence. Quelles devraient être les responsabilités d'un médecin qui ne souhaite pas pratiquer l'AMM à l'égard du patient qui lui soumet une demande? Peut-il s'en tenir à dire

au patient qu'il se prévaut de son droit à l'exemption? Doit-il le confier à un autre médecin ou à un administrateur? Les positions divergent sur cette question. La *Loi concernant les soins en fin de vie* [1] prévoit que l'objecteur de conscience doit s'assurer de la « continuité des soins offerts à la personne » et aviser la direction de son établissement de sa position [art. 31].

Dans un article précédent, nous avons fait valoir que la « doctrine du double effet » peut être mobilisée pour soutenir que l'obligation de référer ne constitue pas une restriction répréhensible de la liberté de conscience des médecins [36]. Nous ne nous répéterons pas cet argument ici. Nous nous contenterons de faire ressortir que 14 de nos participants ont dit que l'enjeu de la référence ne suscitait pas chez eux un inconfort moral particulier. Ces derniers réfèrent leurs patients, le plus souvent, à leur Direction des services professionnels (DSP) ou au Groupe interdisciplinaire de soutien à l'AMM (GIS) auquel ils ont accès. Il faut toutefois noter que 4 participants – parmi les plus fortement opposés à l'AMM – ne veulent pas référer. Deux d'entre eux n'interprètent pas la direction des patients vers une instance administrative ou une autre unité de soins comme une véritable référence médicale. Pour une de ces participantes, « c'est être complice que de référer [un patient] à quelqu'un d'autre. »[8] (Julie) Notre étude semble indiquer que la référence à une instance organisationnelle impersonnelle plutôt qu'à un collègue réduit le coût moral inhérent à l'obligation de référer pour les médecins qui sont opposés ou ambivalents par rapport à l'AMM, tout en s'avérant possiblement plus efficace pour les patients puisque la responsabilité de veiller au respect de leur droit est transférée à une structure organisationnelle imputable plutôt que portée par une personne.

Sur le plan des limites de l'étude, la nature exploratoire et qualitative de cette recherche ne nous permet pas de déterminer dans quelle mesure les médecins qui y ont participé sont représentatifs de l'ensemble des médecins québécois ne souhaitant pas pratiquer l'aide médicale à mourir sur la base de raisons proprement morales. Il est aussi vraisemblable que le type d'échantillonnage choisi (boule de neige) ait engendré une certaine homogénéité chez nos participants. Les participants nous ont parfois référés à des collègues de leur milieu de pratique ou avec lesquels ils ont l'habitude de discuter des enjeux relatifs à l'AMM. Enfin, il serait pertinent, pour en arriver à un portrait plus général des attitudes des médecins québécois eu égard au rapport entre l'aide médicale à mourir et leur conception des finalités de la médecine et des valeurs inhérentes à leur rôle professionnel, de mener une étude comparable avec des médecins qui ont accepté d'intégrer l'AMM à leur pratique. Leur discours permettrait de mieux comprendre la diversité des points de vue sur les fondements et finalités de la médecine au sein même de la communauté médicale.

En conclusion, les résultats de cette étude montrent que des raisons séculières sérieuses et profondes, figurant dans l'orbite de la liberté de conscience, motivent la décision d'un sous-ensemble des médecins québécois qui ne souhaitent pas intégrer l'AMM à leur pratique médicale. Les cinq médecins qui ont admis avoir des convictions religieuses difficilement conciliables avec l'AMM appuient également leur décision sur des raisons séculières semblables à celles mobilisées par les participants ayant déclaré ne pas être influencés par la foi religieuse. Que l'on soit d'accord ou non avec leurs positions, l'opposition et l'ambivalence à l'égard de l'AMM découlent d'une authentique délibération morale. En plus de donner des arguments à ceux qui soutiennent que la décision des législateurs québécois et canadiens de prévoir un droit à l'objection de conscience dans les lois sur les soins de fin de vie était avisée, cette étude révèle que la prise de parole des médecins qui s'opposent à l'AMM ou qui ont des réserves à son égard est l'une des conditions à un débat démocratique incluant des points de vue variés et minoritaires sur le droit à l'AMM et à ses limites. En effet, même ceux qui soutiennent que la légalisation de l'AMM est justifiée et fondée sur des principes éthiques comme la dignité humaine, l'autonomie morale et le respect de l'intégrité physique doivent admettre que la réflexion sur les effets de l'AMM et sur les limites au droit à l'AMM est délicate et nécessaire. Sur ces enjeux, le point de vue de nos participants doit selon nous être entendu. Dans un texte subséquent, nous nous appuierons sur les résultats de cette étude qualitative afin de défendre une position normative sur les droits et devoirs des médecins et sur la conciliation des droits des médecins et des patients en contexte d'AMM.

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[8] Une participante a dit référer malgré le fait qu'elle ne sent pas complètement à l'aise de le faire, alors qu'un autre n'a pas répondu clairement à la question.

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Conscientious Objection To Medical Assistance in Dying: A Qualitative Study with Quebec Physicians

Introduction

Quebec legalized “medical assistance in dying” (MAID) with the adoption in 2014 of the *Act Respecting End-of-Life Care* [1]. Unable to amend the Criminal Code, which is a federal jurisdiction, Quebec has chosen to include MAID in the continuum of care provided to people at the end of their lives. To be eligible for MAID, persons must be 1) insured within the meaning of the *Health Insurance Act*; 2) the age of majority and able to consent to care; 3) at the end of their lives; 4) suffering from a serious and incurable illness; 5) in a medical situation characterized by an advanced and irreversible decline in their abilities; and 6) in a state of physical suffering that cannot be alleviated under conditions they consider tolerable.

Following the Supreme Court of Canada’s *Carter* decision in 2015, access to MAID became a constitutional right across Canada. Reversing the 1993 *Rodriguez* decision, the Supreme Court ruled that patients with “serious and irreparable health problems” causing them persistent and intolerable suffering must now be able to obtain assistance to end their lives, administered or supervised by health professionals [2]. This right to autonomy regarding end-of-life choices derives, according to the highest court in the country, from the right to life, liberty and security of the person guaranteed by section 7 of the Canadian Charter of Rights and Freedoms [3,4]. According to the Court, the prohibition of MAID forces some people to commit suicide while they are still able to do so, thus taking their lives earlier than desired and unduly restricting their autonomy with regard to decisions relating to their physical integrity and end of life. As has been affirmed by many philosophers and palliative care scholars, the process of dying is part of life [5]. For most of us, a personal reflection on what constitutes a good life, one that is meaningful, includes a reflection on the end of life we wish for ourselves. What characterizes pluralistic societies is the fact that conceptions of the “good life”, and by extension of “good death”, vary [6].

The Government of Canada passed the *Act to Amend the Criminal Code and Make Related Amendments to Other Acts (Medical Assistance in Dying)* [7] in 2016 to comply with the Supreme Court’s decision. The law creates an exemption in the Criminal Code to exclude medical assistance in dying from the category of “culpable homicide offences”. The main difference between the Quebec and Canadian laws in terms of eligibility for MAID concerns the stage of a serious and incurable illness of which a person is suffering. The federal law states that the person’s “natural death” must have “become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining” [7].

Physicians caring for people at the end of their lives or who are suffering from incurable degenerative diseases must now respond to patients who wish to avail themselves of this new right or obtain information about it. Since death is an issue that raises both metaphysical and ethical questions about the character and value of human life – questions to which several reasonable answers are possible – it is normal that many people, including health professionals, continue to believe that no human intervention intentionally causing death is ever morally justifiable.

The current legislative framework explicitly provides for the right of conscientious objection of health professionals. No physician should be required to administer a lethal injection or assess a patient’s eligibility if this contravenes his or her conscience. While there is a commitment to “respect the personal beliefs of health care providers” in the preamble to the federal law, the Quebec law states that “a physician may refuse to administer medical assistance in dying because of personal beliefs and [that] a health professional may refuse to participate in its administration for the same reason.” [1]

However, this right is contested. In both the medical ethics literature and in societal debates, some question the legitimacy of statutory accommodation [8-11]. Others argue that the right to conscientious objection is currently being used to justify the decisions of physicians who do not wish to participate in the MAID process for reasons that are not philosophical, moral or religious [12].

The study we conducted offers a different perspective. It does not in any way refute the thesis that some physicians abuse or instrumentalize the right to conscientious objection, but it does suggest that the refusal of many physicians to participate in the MAID process stems from an authentic moral deliberation about the relationship between their values (professional and personal) and the act of intentionally causing a patient’s death. The legalization of MAID has forced many physicians to reflect on the meaning of medicine and their practice, the relationship between their personal beliefs and professional ethics, and the ethical and social consequences of creating a right to MAID.

After presenting the study, we will discuss the role of religious and secular reasons presented by participants and then analyze the secular reasons for opposition or ambivalence with regard to MAID. The participants’ responses were grouped into four sets of secular reasons. In the last part of the text, we reflect on the meaning and implications of some of the concerns expressed by participants, as well as on the contribution of this study to the continuation of the public debate on MAID.

Objectives of the study and presentation of the qualitative component

The overall objective of this study is to advance ethical reflection on physician requests for exemption from medical assistance in dying (MAID). To this end, the specific objectives are to: 1) clarify the ethical issues inherent in physicians' requests for exemption and 2) present elements for a clear and rigorous position on the conflict between patients' and physicians' rights. The study has two components: a qualitative and a normative component. The qualitative and descriptive component has a third specific objective: 3) to better understand and describe, on the basis of physicians' discourse, the reasons (religious and secular) justifying the opposition or reservations of the latter with regard to MAID. A normative argument concerning the rights and duties of physicians and the harmonization of the rights of physicians and patients will be presented in a subsequent article.

Methodology

Sampling and recruitment

The qualitative component of this study focused on physicians who, in their practice, receive requests for medical assistance in dying and who oppose or have serious reservations about MAID. Twenty physicians were recruited from November 2017 to May 2018. Based on other comparable studies [12,13], it can be concluded that this number permitted a reasonable level of data saturation and an analysis that would be considered reliable. Given the exploratory and non-confirmatory nature of this qualitative and descriptive research, it does not claim to be statistically representative. The interest of this approach lies mainly in the richness of the points of view obtained. A network sampling method (snowball) was preferred. To do this, the information about this study was first sent to a few physicians corresponding to the desired profile who, in turn, forwarded the same information to other physicians with a similar profile.

The criteria for selecting participants were as follows:

- be a member of the Quebec Collège des Médecins;
- be called upon, in their practice, to receive MAID requests;
- have exercised or plan to exercise the right to conscientious objection

This study was approved by the research ethics boards of UQÀM (1520_e_2017) and Université Laval (116964). Participants' written consent was obtained and the study was conducted in accordance with the principles set out in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* [14].

Data collection method and analysis

The data collection method used was semi-structured individual interviews. These interviews were approximately one hour long and were conducted entirely by one of the two researchers in charge of this study. The interview guide included an open-ended question and follow-up questions related to the research objectives. The original guide was first developed in congruence with the theoretical framework of this research, which focused on the meaning and extension of freedom of conscience [15]. This then enabled the emergence of new themes throughout the interview process.

Data analysis was carried out based on the complete transcription of the material collected from physicians according to the procedures associated with continuous thematic analysis as described by Paillé and Mucchielli [16]. This mixed analysis (based on the conceptual framework but open to the inclusion of codes that also take into account unexpected or new information) was carried out by the two researchers who conducted the study. This type of analysis made it possible to identify the main themes associated with the reasons and motivations for physicians' opposition to or reservations regarding medical assistance in dying. Reading the transcripts first led to the identification of the attitudes and beliefs of the participants that emerged most frequently and forcefully. The data were then grouped into four main themes: 1) the ends of medicine and professional identity, 2) the philosophy and practice of palliative medicine and resources allocation in palliative care, 3) benevolent paternalism, "good death" and interests of future selves, 4) the risk of a slippery slope and the protection of vulnerable people. The identification and description of these themes made it possible to lay the foundations, in complementarity with the normative aspect, for a clearer and more rigorous position on the normative question at the heart of this study.

Results

Description of the participants' characteristics

The age of participants at the time of the interview ranged from 25 to 75 years of age. The sample consisted of 20 physicians. The majority had expertise in palliative care or were family physicians. The other participants practiced in a variety of specialty areas: internal medicine, thoracic surgery, public and community health, anesthesiology and critical care, endocrinology and geriatrics. Just over half of the sample had between 21 and 40 years of practice and came from Montreal and surrounding areas. A few physicians from Quebec City, Lévis and other regions also participated in the study. These characteristics are summarized in Table 1.

Table 1: Participants' characteristics

Characteristics		N=20	%
Sex	Female	12	60
	Male	8	40
Age (years)	Average (Extended)	50 (25-74)	
Speciality	Palliative care	5	25
	Family Medicine	8	40
	Other	7	35
Years of experience	1-10	4	20
	11-20	5	25
	21-30	3	15
	31-40	8	40
Provenance	Montreal and surrounding areas*	15	75
	Québec and Lévis	3	15
	Other	2	10

** Near Montréal: Longueuil and Laval. Others: Gatineau and Shawinigan*

Participants' attitudes and beliefs

Opposition to the concept of "medical assistance in dying"

All participants deplored the use of the notion of "medical assistance in dying" to describe the medical act of administering a lethal injection to a patient in order to cause his or her death. Almost all participants (19/20) considered that MAID was in fact a form of euthanasia[9] and that it would be more honest to admit it: "it is euthanasia, it would be less hypocritical to say so" (Pierre). On this point, it seems clear to us that MAID is, in Canada, a form of "voluntary euthanasia". Euthanasia is "voluntary" when a cognitively competent person requests that an action that will result in his or her death be taken, usually by a health professional. While it is conceptually possible to argue that the notion of "medical assistance in dying" adequately describes the medical procedure in question and is consistent with the Quebec legislative approach that integrates MAID into a continuum of end-of-life care, this does not make it a separate act from voluntary euthanasia [17,18]. It is likely, as some of the participants stated, that the proliferation of concepts contributes to increased confusion about end-of-life care (palliative care, continuous palliative sedation, medical assistance in dying, euthanasia, assisted suicide, etc.)

According to one participant:

> I think it's a term that looks better than what it actually is. Hum... I wish we call it differently because it sounds nice to the public... I don't think the term is accurate. Someday I feel it's almost like we invented it to justify what we do as a society. I don't like the term... (Timothy)[10]

Others mentioned that:

> The term, I think it's a euphemism, personally. In fact, everywhere in the world, where there is euthanasia, it is called that. We are innovating here. I don't know if it's an innovation or if there's a purpose behind it. I think there's a purpose behind it. It's to soften it. To make it less serious. (Debbie)

> ...most people believe that medical assistance in dying is about providing quality palliative care. Then when I explain a little bit to them what it is, they say, "Oh yes! Oh, well noted..." (Maria)

> It shocks me that we call it a treatment [MAID]. You know, I might get emotional. For me, it's not a treatment. At least not one like the others. (Suzanne)

Sources of opposition or ambivalence to the MAID

Five participants said that their religious identity was an integral part of their personal identity and that their religious beliefs partly explained their opposition to MAID. It should be noted, however, that among all participants who reported having religious beliefs, opposition to MAID was *also* justified on secular or public grounds. As one participant stated: "It's interesting, because any good secular argument that I may give I would say comes from my religious beliefs." (Timothy)

These participants seem to spontaneously accept the criterion of political legitimacy [19] according to which public norms must be based, in societies marked by reasonable pluralism of conceptions of good life, on reasons that all can in principle accept. In other words, common public norms must not be justified solely by reasons derived from a comprehensive conception of

[9] Some participants instead likened MAID to "assisted suicide".
[10] The first names of the participants have been replaced by pseudonyms to ensure their anonymity. All other nominative information that could have made it possible to identify them has also been omitted.

what constitutes a good and meaningful life. For John Rawls (2016), “public reasons” are derived from a “political conception of justice”. A conception of justice is “political” for Rawls when those who adhere to a reasonable conception of the good life can potentially accept it [19][11].

These participants saw their identity as unified or integrated rather than segmented. Religious and secular values and beliefs are conceived of and lived as consistent with each other rather than being in tension: “and that, I cannot accept that...as a doctor. As a citizen first of all, as a doctor second, and finally as a Catholic” (Justin). Another participant said, “I am a believer. I am a Catholic. It must be part of it. I couldn’t tell you what percentage. I am a person... that’s one of the factors that influences me.” (Line)

Five other participants stated that their faith or religious education shaped, in some cases “perhaps unconsciously”, their judgment on MAID and their refusal to integrate it into their practice. That being said, secular reasons were very much predominant among these participants. For example, one participant stated that she remains somewhat a believer, that she practices little her religion, but that it is possible that her spiritual trajectory may influence her more or less consciously. However, the reasons that were decisive for her were all secular. Another said, “Yes, the religious dimension is present in me, but let’s say it would be the last one invoked.” (Pascale)

Just over a third of participants (7/20) stated that they were atheists or that religion did not influence their positioning with regard to MAID, and three others did not explicitly answer questions about their relationship to religion. The reasons mentioned by these ten participants were exclusively secular. In the words of our participants:

> I’m not religious. I was born a Catholic, but it’s been 50 years or more since I went to church, it’s not an issue. (Pierre)

> I know people who are conscientious objectors who are very Catholic, and then I know people who are atheist conscientious objectors. I’m in the atheist category. I am... very very very atheist (laughs). (Julie)

Our study thus raises doubts about the perception that the majority of conscientious objections in Quebec are motivated by strong religious beliefs, essentially Catholic. Deploring the social representation of conscientious objectors, one of our participants said:

> I have a friend who is very opposed to this [MAID]. But he is a palliative care specialist. He is a “being of light” but he has been called all the names: “You, catho”, but he is not Catholic at all, he is an atheist, as much as I am. That’s why it felt somehow good to come to see you... He’s getting attacked, it doesn’t make sense. (Julie)

From objection to ambivalence

Participants’ attitudes and beliefs towards MAID lie on a continuum that ranges from principal and categorical opposition to deep and agonizing ambivalence. Three general attitudes about MAID can be discerned in participants’ responses: 1) a principled and categorical opposition; 2) a more contextual, contingent opposition and an evolving personal view; and 3) a willingness not to participate in the process while accepting the legitimacy of the collective choice allowing MAID. Positions (2) and (3) reflect, to different degrees, moral ambivalence with respect to MAID.

Those within the first group believe that any act intentionally causing death is morally reprehensible. Almost half of the participants (9/20) can be classified in this category. For some, “euthanasia is murder”. Another told us, “I am against it in all situations.” (Line)

The second group – 6 of our participants – spontaneously admitted that this was a difficult ethical issue for them and that, while they were initially rather opposed to the legalization of MAID and did not wish to integrate it into their practice at this time, their views were in motion. Their discussions with patients and colleagues influenced their thinking. It is not impossible that some of them may one day agree to evaluate patients or administer MAID to a patient they have been following for a long time. As one participant put it: “My perspective has changed since the law was passed and colleagues have conducted medical assistance in dying. It is possible that I would one day agree to do so if a patient I have been with for a long time asks me to do so.” (Lucie)

Finally, the last group are not morally opposed to MAID, but they do not feel able to administer it themselves and, like the second group, they consider that it would have been preferable to wait until there was better access to quality end-of-life care before allowing MAID. Five of our participants were part of this group. In their own words:

> I...finally, I think I’m preaching more that patients have a right to access both palliative care and medical assistance in dying... I don’t want to do medical assistance in dying. I am grateful. I am grateful for the

[11] “Unreasonable” conceptions are those that argue that public norms and institutions should favour citizens who adhere to a particular conception of the good life and, by extension, disadvantage citizens who adhere to other conceptions. In other words, reasonableness is embodied in the acceptance of criteria of reciprocity and equity in the distribution of the benefits and burdens of social cooperation [19].

> doctors who are willing to do it because I am not ready to do it. But these patients, they have the right to euthanasia. So there must be doctors to do it. (Talia)

Opposition or ambivalence to MAID: four categories of reasons

Secular beliefs and values thus emerged as clearly predominant in our study. As mentioned above, since these are the kinds of reasons that should underpin laws and public policies in pluralistic societies where secularism of the state prevails [15], we have chosen to make them the central focus of our analysis. We have grouped them into four main classes: 1) the ends of medicine and professional identity, 2) the philosophy of palliative medicine and resource allocation in palliative care, 3) benevolent paternalism, the "good death" and the interests of future selves, 4) the slippery slope argument and the protection of vulnerable people. The considerations and arguments classified in one or other of these categories can obviously overlap and reinforce each one another.

1) The ends of medicine and professional identity

Most participants saw a strong incompatibility or tension between the act of intentionally causing death and the principles and purposes guiding the practice of medicine. Medicine is primarily seen as a struggle against illness and death. Then, when confronted with the limits of curative medicine, participants believed that their role was to accompany the patient to the end by offering them care that allows the best possible quality of life. As one of the participants said: "At first, I wanted to save my patients. Now I am wiser, I know that my role is above all to accompany them." (Kim) If they are great promoters of palliative medicine, critics of aggressive therapy and defenders of patients' right to refuse treatment, they consider that medicine must in some way be a space entirely devoted to the protection of life, its quality and the reduction of suffering. Death is seen as part of the normal course of life, but the physician has an ethical obligation not to provoke or deliberately precipitate death. They therefore see an ethically significant difference between killing and letting die. Their conception of the ethical norms inherent in the practice of medicine (role morality) leaves no room for an act deliberately causing death: "that one can cause death, that is beyond my understanding as a doctor." (Pierre) For a participant, stopping treatment and controlling pain means stopping "delaying the disease", which is different from "causing death" (Debbie). These participants internalized the requirement contained in the Hippocratic Oath that: "I will do everything to relieve suffering. I will not unduly prolong the agonies. I will never deliberately cause death." [20]

As one participant made clear:

> I believed in what was taught to us at that time, the first thing is "first, do no harm", then we help and support... I did not study medicine to kill people. I don't think you need to be a doctor to kill people... I was a member for years of Amnesty International, I was completely opposed to having doctors in torture chambers, to having doctors who apply the death penalty. A doctor is there to help people, give them hope and work until the end of their lives to make life the best it can be. That's my conception of medicine. (Julie)

For others:

> The practice of scientific medicine consists in administering, performing an act whose benefit is greater than the risk. All medicine is based on this, has always been based on this. Even before it was scientific, doctors tried not to aggravate the disease... it was always *primum non nocere*. First, do no harm. (Pascale)

> To make that gesture... To end someone's life. Honestly... (Lola)

> It's as if I'm becoming a hired killer, that's how I see it. (Eloise)

One participant expressed in a vivid way the incompatibility between the aims of medicine and MAID:

> You know, in football, you have both, you have got each one end of the field, but if I go to a line, my profession is to go to that. Then if euthanasia is legal, it means I do a 180 degree and then I go to the other line. That's how I see it. (Timothy)

In general, medical teams have the prerogative to determine what is "appropriate care" for patients. The integration of MAID into the range of services offered to patients at the end of life requires a partial redefinition of the professional identity of physicians and their prerogatives and responsibilities. Since the adoption of the *Act to Amend the Criminal Code and Make Related Amendments to Other Acts (Medical Assistance in Dying)* [7], a patient who meets the criteria established in the legislation has a constitutional right to obtain MAID, which necessarily limits the professional autonomy of physicians. As participants noted:

> And then, in some ways, my judgment is taken away from me, because I am not the one who judges. It's the law that sets the criteria... So it's not really, by definition, a medical act. As a doctor, I have to do what is medically required. (Kim)

> It's collusion with the College of Physicians, but basically it was imposed by the Government of Quebec. It's not medicine. It is not up to them to define what medicine is. It's not for the Supreme Court of Canada to define what medicine is. (Line)

2) The philosophy and practice of palliative medicine and resource allocation in palliative care

Considering that a quarter of the participants practice palliative medicine and that all the others have done so in the past or are advocates of this approach, the question of the relationship between MAID and palliative care was one of the themes that emerged most strongly from the interviews. For some, the very philosophy of palliative medicine is incompatible with MAID. According to this view, palliative care must be entirely devoted to the management of the physical symptoms causing pain and to the psychosocial and, when desired, spiritual care of patients. If palliative medicine is strongly opposed to aggressive medical treatments [21], its rehabilitation of the dying process as an integral part of life would put it in tension with MAID.

In addition, from a clinical perspective, some participants felt that palliative medicine has fairly effective means of providing an acceptable quality of life for patients with incurable diseases. Clinical knowhow and increased scientific knowledge on the effects of opioid and non-opioid analgesics would in almost all cases allow palliative care specialists to control patients' pain [5]. In the case of refractory pain at the end of life, palliative sedation (continuous or not) can provide relief to the patient, if practiced properly, without causing or precipitating death [22].

According to two participants:

> Unbearable suffering, I'm not sure that's really common. Are there many who really have suffering that is not treatable? I think it must be extremely rare and too rare to create the need for euthanasia. (Timothy)

> I think that when, as a palliative care physician, I follow someone, well, my tools are powerful enough. (Kim)

A doctor with forty years of practice said, "I have never faced unbearable suffering that I could not control." (Justin)

And if the suffering felt by a patient is refractory and unbearable, palliative sedation is then necessary: "So, if we have refractory pain in an incredible way, I think continuous palliative sedation is called for."[12] (Debbie)

One participant also said that:

> The advantage of palliative sedation is that it is not the doctor who decides when the patient will die. He dies when he dies. We watch him, we stay by him, we hold his hand, then at some point he leaves. And I like that it's not the doctor who decides." (Julie)

In this regard, some participants pointed out that there was no equivalence between continuous palliative sedation and MAID:

> Sedation doesn't cause death if you do it right. If we've tried everything to relieve the patient. We give him a sedation so that he is not conscious, so that it is temporary, so that it is until the end. Of course, if you're talking about a patient who is not on the verge of death, you give him long-term sedation and you don't give him food or water, that's killing the patient. If he is at the end of his life, when we cannot anyhow give him food or drink, we give him a sedation to relieve him in the last days, that's another thing.[13] (Line)

For the vast majority of participants, the legalization of the MAID, and in particular its integration into a "continuum of end-of-life care" in Quebec, can only increase the current lack of knowledge and understanding about palliative care. Some people already fear palliative care because they believe that patients are euthanized without their consent or that the administration of large and repeated doses of morphine precipitates death. These myths will be reinforced, according to participants, if MAID is practiced in palliative care units or hospices. One participant noted that fears about palliative medicine, particularly with respect to morphine, remain widespread:

> So when I say to that person, "Listen, the morphine I give you, I calculate it in a way that is not dangerous for you. I will not kill you. And I'm careful. I am very careful." And so, that's something that's important to me. That the patient I'm treating feels safe, that there is trust. But there is a fear of morphine right now. (Kim)

Some participants feared that the integration of the MAID would be to the detriment of palliative care, whose status was already precarious in Quebec and elsewhere in Canada [23,24]. This participant clearly summarized the concerns expressed by several others:

[12] As one reviewer suggested, it is important to remember that patients able to consent to their care sometimes refuse palliative care, or palliative sedation in particular, and that many people who have received MAID have also received palliative care before requesting MAID. In general, we believe that the legislator was right not to establish a hierarchy between the various end-of-life care options and not to allow MAID only after palliative care had been provided.

[13] As evidence that there is still confusion about palliative sedation, one of our participants, who does not practice palliative medicine, stated that palliative sedation may be acceptable "even if it brings about death most of the time". (Pascale)

> The other reason, and it's probably the main reason, is that I think we can do extraordinary things in palliative care. I think it is a very complex and evolving discipline that must be encouraged. There is a lot of science being done in there.... I think it's going to be a dichotomy: medical assistance in dying and palliative care, and I'm afraid there are patients who have not been offered the palliative care interventions package, I see that we still have a lot of progress to make as a society in terms of understanding of death.... So people are not aware of palliative care, they still think palliative care is really just in the field of death, just at the last minute, they don't know that it can extend over long periods of time, that we can increase the quality of life a lot, that people can be relieved. And then I'm afraid it [MAID] will become the easy option... (Julie)

In addition, since palliative care embraces a holistic view of patient wellness – a view according to which the physical, psychosocial and spiritual dimensions of wellness must be considered together [25] – participants emphasized that the environment provided by palliative care hospices or units can foster a serene and satisfying end of life. When resources are sufficient, palliative care provides a soothing physical environment, as well as medical, psychosocial and spiritual support that allows patients to be surrounded by their loved ones and to address issues that concern them or that they wish to discuss with professionals and volunteers.

Noting that patients' suffering is often of an "existential" nature and regretting the lack of resources to hire social workers and psychologists, one participant said, "Is it acceptable to say: We will end your life because I don't have the necessary resources to help you? I find that unacceptable. I think it's horrible." (Talia)

Participants stated that what they perceive as the underfunding of palliative care makes it morally unacceptable, at least in the current context, to legalize MAID. As mentioned above, MAID is part of a broader end-of-life care strategy in Quebec. One of the conditions of acceptability of MAID set out by the Select Committee on Dying with Dignity was that Quebec patients at the end of their lives must have access to quality palliative care and that, consequently, the legalization of MAID must be accompanied by the allocation of additional resources for palliative care [26]. However, since the *Act Respecting End-of-Life Care* [1] was adopted at the same time as the budgetary restraint measures put forward by the Government of Quebec, participants were almost unanimous in their opinion that the acceptability condition had not yet been met:

> If this [MAID] responds to a resource gap, well, I say to myself that it is completely ethically unacceptable. That's why I think as long as I have that feeling, I don't think I can get involved in processes like that. (Debbie)

> So, at some point, when we talk about dignity, we should ask ourselves: is it really the disease that makes us undignified or the health system in which we are in? (Debbie)

> There is a pain clinic. They're fantastic, but it takes two years to see them. It doesn't make sense. So we say: "ok, we can kill you next week or we can fix your pain in two years". (Line)

> Because we are not organized in our area [urban area] to have volunteers to spend the night with patients...and say: "I did this because I didn't have access to resources", I would be very angry. (Helen)

3) Benevolent paternalism, the "good death" and the interests of future selves

It appeared to us that one of the categories of reasons explaining the positioning of our participants with regard to MAID is a form of "benevolent paternalism". In ethical theory, paternalism refers to the position that it is sometimes legitimate to ignore a person's will on the basis that he or she is not always in the best position to determine the nature of his or her own good or interests [27]. We propose viewing paternalism as "benevolent" when it is anchored in an authentic concern for the well-being of the people concerned. Paternalism takes a "political" form when it is considered that the state can legitimately use its power to prescribe or prohibit behaviour in the name of the rightly understood self-interests of citizens [27]. Policies put forward in the name of public health, such as the requirement to wear seat belts when travelling by car, generally fall into the category of benevolent political paternalism.

There is a wealth of literature in medical ethics on medical paternalism [28]. In the context of our study, the positions we call paternalistic are those that argue that people are not well equipped to understand how they will experience the progression of the disease or that emotions such as the fear of suffering, being a burden to loved ones or living in undignified living conditions are disproportionately important in assessing the value of their lives with advanced disease. An underlying idea expressed repeatedly is that it is very difficult for the "present self" to anticipate what the reality of the "future self" will be and the nature of its interests once it reaches the end of life stage. Experienced doctors have reported following patients who, after moments of discouragement when they wanted to end it, have regained a certain quality of life and had meaningful experiences.

The possibility that the patient will "adapt" to their illness and change their mind about the value of the life that remains to be lived, especially if they have access to quality care, is one of the most important considerations in many of the participants' deliberations.

For participants:

> People, they change their minds. Suddenly, one day, they wake up depressed. Then the next day, there is something that has changed in their lives and gives it back meaning. How do I know that in a week's time this patient wouldn't want to live? And I would have taken that life. I don't find that acceptable. Because there is this risk that I will take away a life that could still have been of a certain quality. Maybe it is not someone who is able to run a marathon, but someone who will live his days peacefully, comfortably and who will find meaning in his life. The great-granddaughter is pregnant. All of a sudden, there is a desire, a desire to live one more day, one more week, one more month. So there's that. There is this uncertainty. (Talia)

> Listening to patients, seeing changes in a patient who was scared to death when he learned of his illness and telling you, "I might as well die right now." And then a few months later, he gets attached, maybe there's a hope, a new protocol... There's the moment when you get a ton of bricks on your head, you know, and it's too heavy for you, and then that's when you really have to go quietly, and say good we'll cross the bridge when we get to the river, and then we'll look at how we can improve, what can we do right now,... Then I saw patients' view of their disease evolves. (Julie)

> I often have the impression that some people are probably more in denial of their condition when they decide to seek medical assistance in dying. Then I have the impression that with the passage of time, they would probably accept the situation more. Then, it would probably allow them to experience some moments that are still beneficial for them. (Jérôme)

Not surprisingly, several participants expressed strong opposition to the possibility that "advanced medical directive" tools could be used to allow people to apply for MAID in advance in the event that they have a neurodegenerative disease such as Alzheimer's. In the Netherlands, persons diagnosed with a serious and irreversible disease that will eventually render them incapable of free and informed consent may express their wish to be euthanized at some point in the course of the disease in an advanced medical directive [29-31]. For one participant, advanced MAID requests are "a total aberration". (Kim)

Some pointed out that the application of advanced MAID requests would pose major difficulties:

> Did they consider that, even if we write it in our advanced medical directives, when will we decide that it is too much for the patient? Because right now, as long as he recognizes you, is that okay? At some point, it's when he's incontinent that it's no longer correct? Is that when he stops eating? Is it when he gets agitated? I say to myself: who's going to put themselves on a panel to decide that? I don't even understand how they're going to decide at what stage... the demented person, they won't know. She won't understand. I say to myself, "Did you realize that they're probably going to have to be tied up?" Because it's not like we're going to say, "Okay, don't move. Look at the bird over there." Then we go ahead..., that doesn't make any sense. (Debbie)

In connection with the difficulty for the patient to project herself accurately into the future, some participants justify their refusal to participate in the MAID process on the basis of an implicit or explicit conception of the "good death". Whether it is what we discover about ourselves in illness or reconnecting with family and friends, giving ourselves the chance to live the end of life to the fullest offers the opportunity to grow and close the last chapter of our lives. Paternalism becomes a form of perfectionism here. Many participants added that "suffering is part of life" and, in some cases, that it must be accepted and faced "with courage": "a life without suffering does not exist. You have to face suffering with courage" (Justin), said one of the participants.

These excerpts clearly show that a certain amount of (benevolent) paternalism and perfectionism remains in the opposition or ambivalence of several participants with regard to MAID:

> Death is part of life... it's included. We can't have control over everything. I think that the narcissistic evolution of Westerners, to think strictly of themselves and then of each individual, which has brought positive things, but here I think it is a path that shows the negative sides of individualism. (Pierre)

> So many people also told me: "The last months of my life were the most beautiful months of my life". We can say that they are rationalizing, I'm not sure about that, I think they were no longer telling themselves stories when they told me that. I think they spoke the truth, they had nothing more to lose, they had no image to preserve. I say to myself, well..., maybe we should also listen to this from those patients who have learned about death and then decided to live. I accompanied one of my friends with AIDS a very long time ago, 20 years ago, and we had a kind of ethics of the present moment, to try to make every moment as perfect as possible. I learned that from him. (Julie)

> But, let's say the patient [in palliative care] is comfortable. Every day is a gift of life. Because people are going to start saying the real stuff. A real legacy. A lot of things are happening. Grief is completely different. Then, this allows us to gain some control over our own death depending on what we see. Right now, if the number of medical assistance in dying increases, that's how we're going to see death. She put on her

> beautiful dress the way she wanted. That's how we want to represent the end of life. Well, it's a societal choice, but... (Debbie)

> I'm going to tell the patient: "I, you see, I'm a palliative care doctor. I'll explain my business to you. I am in no way against medical assistance in dying. I'll tell you right away." Then I explain my business. Then I say, "I have a complete closure from you. Even with an aggressiveness, an anger that I feel. Because I'm trying to make you think about other things." (Debbie)

MAID's interruption of the dying process deprives not only the dying person of a significant experience, but also the relatives who accompany the person. One participant said that this cannot justify conscientious objection, but that it is nevertheless part of the ethical cost inherent in MAID:

> Then I also think of the consequences for the relatives, say, of someone who would die by medical assistance in dying. For me, accompanying a dying person means learning to live, learning precious things. In some way, what the person is telling us. And then I think the person minimizes his or her value at that time. Their value and the social role they play. I take the opportunity of a conversation to talk about the role they have to play with their loved ones who come to visit them. That no, it's not a burden and then there's some good that comes out of it. Then the people who come to visit a dying person, they make a gesture of solidarity, they make a gesture of generosity. But it's not for me to judge whether the person thinks it's valuable or not. I don't have to object on the basis of that, but it's part of my thinking. (Kim)

4) The risk of a slippery slope and protection of vulnerable persons

The slippery slope argument affirms that a particular action or decision is not desirable because it would inevitably lead to other decisions that are ethically unacceptable. In Canada, only adult persons capable of giving informed consent, living with a serious and irreversible disease, whose death is reasonably foreseeable and whose suffering they deem unbearable, are eligible for the MAID. While the Government of Quebec maintains that it has proceeded cautiously by legalizing voluntary euthanasia for adults at the end of their lives, the study participants saw it as more or less inevitable that the eligibility criteria for MAID would be broadened, in line with citizens' claims [31,33][14]. At the time of the interviews, most were aware that the Quebec Ministry of Health had set up a group of experts working on the issue of incapacity to provide informed consent in the case of neurodegenerative diseases. They were also aware that the federal government had mandated the Council of Canadian Academies to create working committees on "mature minors", mental health and advanced requests [31-33]. Compared to adults at the end of their lives and who are capable of consent, the categories of people who could potentially have access to MAID are seen as more "vulnerable".

One participant recalled that, in addition to autonomy, the principle of beneficence is one of the cardinal principles of bioethics [34]: "When autonomy has been stated as a bioethical principle with the other three. Even these people didn't say it's supreme. Beneficence, for example. There are many areas in life in which our autonomy is limited." (Line)

The danger of the slippery slope was explicitly mentioned by one of the participants:

> When we open a door to one thing that in our society is maybe not the best, we open the door to more and more and more. You talked about rights a few minutes ago, I mean, it's funny their right to die, this just opened the door. I expect that as years go on because of the arguments of rights of people, that it will be expended more and more and more and that is even more scary to me. I just think as a society, do you want to start saying that life is no longer valuable? You know it's a very slippery slope. (Timothy)

According to others:

> ...and now it's not just the elderly anymore... A law, it's always like that, it broadens... it's now eugenics. Anyone who doesn't look the way we want, they'll be flushed. (Maria)

> I think it could drift. That I think is the ultimate danger. As a society, we don't want to get rid of people we think are useless, even though some people think they are burdensome. (Patrick)

Some fear the impact of expanding MAID to other groups in society, such as people living with disabilities or suicidal thoughts:

> There's a guy who works with us who's in a wheelchair, a guy in his forties. He was against euthanasia because he felt targeted by it. He says: "There are people on the street I don't know who tell me I'd rather be dead than like you". So there is a whole group of people with disabilities who are very afraid of this law because they feel targeted. They say [life is not worth living] if you can't go to the bathroom alone anymore. He said, "I couldn't go to the bathroom alone all my life. I think my life is as valuable as the neighbour's." (Sacha)

[14] For an interpretation of the process that led to the adoption of the *Act Respecting End-of-Life Care* and the Act itself, see the reference [31].

> It's kind of the same reason I'm here, I'm against the death penalty. It's that there are always mistakes. The death penalty is sometimes a death sentence for innocent people. Well, in euthanasia, we are going to euthanize people in conditions that are not quite clear, or we have not really asked them for their opinion, or we have put pressure on them. (Gérard)

> It is because medical assistance in dying is a law, that we must let people who commit suicide die. And several cases of people who have attempted suicide, who have been brought to the hospital, who have been told "well they want to die, let them die". This is the first blunder, if I can say so about this law. (Pascale)

The scarcity of resources in the health system has also been identified as one of the sources of potential abuses:

> The excesses for me are so likely... maybe I'm the one who's narrow-minded, but, an 800-bed hospital, you need two beds, you kill two in the morning, two in the afternoon, from Monday to Friday, you don't even have a nurse on weekends. You don't have anyone there on weekends, you settle 10 situations. You have a palliative care unit, 10 beds, you have care all day long, occupational therapy, physiotherapy, inhalation therapy, all kinds of services, it is expensive. So placing an administrator who looks at two beds, who deals with 10 situations per week, which costs 10 times less than the other 10 beds... that's accounting there. And to say "ah, we're still going to encourage palliative care" when you have that option, that won't happen, in my opinion. (Pierre)

The pressure that could be put on patients by members of their entourage was also mentioned:

> All of these are family conflicts. One thing I do is assess the cognitive competence of older people with cognitive disabilities. And sometimes I am called to testify in court for families who are in conflict. "Is he fit, is he unfit?" And often it's about money. The one who wants the parent to be unfit is the one who is emptying the bank account. Sometimes it's just money, sometimes it's emotions and they can't agree. The patient says yes to this one day. He says yes to the other one the other day because he doesn't want to hurt anyone. It's very, very complex. (Line)

Slippery slope arguments are rarely considered convincing in ethics [33,35]. Any freedom or opportunity offered to people can lead to excesses or morally disturbing applications. The answer to the fear of a slippery slope is to reflect on the desirable limits of the right guaranteed to citizens and to build institutional capacity to enforce established rules. For example, while it is true that freedom of expression may allow hate or defamatory speech, the answer to this real problem is to prohibit hate and defamatory speech, not to suppress freedom of expression. That being said, as social demands for greater accessibility to MAID increase, participants' fears about the fate of people living with vulnerabilities are serious and deserve to be heard.

Discussion and Conclusion

The recognition of physicians' right to conscientious objection logically raises the question of the residual obligations of the conscientious objector, including the difficult question of referral. What should be the responsibilities of a physician who does not wish to practice MAID to the patient who submits such a request? Can they simply tell their patient that they are exercising their right to be exempted? Should they refer their patient to another physician or administrator? There are divergent positions on this issue. The *Act Respecting End-of-Life Care* [1] provides that the conscientious objector must ensure the "continuity of care provided to the person" and notify the relevant administrative authority [s. 31].

In a previous article, we argued that the "double effect" doctrine can be invoked to argue that the obligation to refer does not constitute an excessive restriction of physicians' freedom of conscience [36]. We will not repeat this argument here. We will simply point out that 14 of our participants said that the issue of referral did not cause them any particular moral discomfort. These participants usually refer their patients to their Professional Services Directorate (PSA) or to the Interdisciplinary Support Group for MAID (ISU) to which they have access. It should be noted, however, that 4 of the participants who were most strongly opposed to MAID did not want to refer. Two of them do not interpret the referral of patients to an administrative authority or other care unit as a true medical referral. For one of these participants, "it is complicity to refer [a patient] to someone else."[15] (Julie) Our study suggests that referring to an impersonal organizational body rather than a colleague reduces the moral cost inherent in the obligation to refer, while possibly proving more effective for patients since the responsibility for ensuring that their rights are respected is transferred to an accountable organizational structure rather than carried by a busy physician.

In terms of the study's limitations, the exploratory and qualitative nature of this research does not allow us to determine to what extent the physicians who participated are representative of all Quebec physicians who do not wish to practice medical assistance in dying on the basis of moral considerations. It is also likely that the type of sampling chosen (snowball) resulted in a certain homogeneity among our participants. Participants sometimes referred us to colleagues in their practice environment or with whom they are used to discussing MAID issues. Finally, in order to obtain a more general picture of the attitudes of Quebec physicians regarding the relationship between medical assistance in dying and their conception of the ends of medicine and the values inherent in their professional role, conducting a comparable study with physicians who have

[15] One participant said she referred despite the fact that she did not feel completely comfortable doing so, while another did not clearly answer the question.

agreed to integrate MAID into their practice would be desirable. Their discourse would help to better understand the diversity of views on the values and ends of medicine within the medical community.

In conclusion, the results of this study show that serious and profound secular reasons, situated in the ambit of freedom of conscience, motivate the decision of a subset of Quebec physicians who do not wish to integrate MAID into their medical practice. The five physicians who declared having religious beliefs that were difficult to reconcile with MAID also based their decisions on secular reasons similar to those mobilized by participants who reported that they were not influenced by religious faith. Whether or not one agrees with their positions, the opposition to or ambivalence towards MAID derives from authentic moral deliberations. In addition to providing arguments to those who argue that the decision of Quebec and Canadian legislators to provide for a right of conscientious objection in end-of-life care legislation was wise, this study reveals that the voice of physicians who oppose or have reservations about MAID is one of the conditions for a robust democratic debate including varied and minority views on the right to MAID and its limits. Indeed, even those who argue that the legalization of MAID is justified and based on sound ethical principles such as human dignity, moral autonomy and respect for physical integrity must recognize that reflection on the effects of MAID is complex and valuable. On these issues, we believe that the views of our participants must be heard. In a subsequent text, we will use the results of this qualitative study to defend specific normative positions on the rights and duties of physicians and on the conciliation of the rights of physicians and patients in the context of MAID.

References

(See Références)

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Favoriser l'autonomie du patient face aux données additionnelles en médecine génomique

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Résumé
Depuis ces dernières années, nous assistons à une révolution technologique en génétique moléculaire avec l'avènement du séquençage de nouvelle génération (NGS). Lors des consultations médicales de génétique à l'hôpital, le patient est confronté à la question difficile de la recherche et de la divulgation des données dites additionnelles, qui ne sont pas en lien avec sa pathologie, la donnée primaire. Il peut s'agir de données incidentes (la découverte est fortuite) ou de données secondaires, c'est-à-dire des données recherchées activement dans une liste de gènes définie. Comment s'assurer de l'autonomie suffisante des patients face à cette question? Quel est le rôle de l'équipe soignante? Peut-on harmoniser les pratiques relativement à ces données? Nous proposons une *stratégie de l'échelle variable* appliquée à la génétique qui consiste à adapter le degré d'autonomie exigé en fonction de l'impact médical et du niveau de fiabilité des données génétiques transmises au patient. Nous apportons également des éléments pour favoriser l'autonomie du patient. Il nous paraît nécessaire de dissocier distinctement la donnée primaire des données additionnelles, de développer les moyens visant à délivrer une information adéquate au patient et enfin d'accompagner le patient dans sa démarche par un soutien psychologique et de respecter un délai de réflexion. De manière ultime, il appartient à l'équipe médicale d'évaluer au cas par cas du bienfondé de la recherche de ces données et de leur révélation au patient.

Mots-clés
autonomie, génétique, données additionnelles, éthique, séquençage de nouvelle génération

Abstract
In recent years, we have witnessed a technological revolution in molecular genetics with the advent of next-generation sequencing (NGS). During medical genetics consultations in hospitals, patients are confronted with the difficult question of research and disclosure of so-called additional data, which are not related to their pathology, the primary data. This may be incidental data (the discovery is incidental) or secondary data, i.e., data actively searched for in a defined list of genes. How can we ensure that patients are sufficiently autonomous in dealing with this issue? What is the role of the healthcare team? Can we harmonize practices with respect to these data? We propose a *variable scale strategy* applied to genetics that consists in adapting the degree of autonomy required according to the medical impact and the level of reliability of the genetic data transmitted to the patient. We also provide elements to promote patient autonomy. We believe it is necessary to separate primary from additional data, to develop the means to provide adequate information to patients, and finally to support patients in their process with psychological support and to respecting a certain period of reflection. Ultimately, it is the responsibility of the medical team to assess, on a case-by-case basis, the appropriateness of seeking this data and disclosing it to the patient.

Keywords
autonomy, genetics, additional data, ethics, new generation sequencing

Introduction

Depuis ces dernières années, nous assistons à une révolution technologique en génétique moléculaire avec l'avènement du séquençage haut débit ou séquençage de nouvelle génération (NGS : Next Generation Sequencing) qui permet de séquencer simultanément l'ensemble des régions codantes de nos 21 000 gènes (exome ; 1,5% de notre ADN) voire la totalité de notre ADN (génome). La chute vertigineuse du coût de ces techniques – le coût du génome est passé d'environ 50 millions de dollars en 2003 à 1 300 USD$ en 2019 [1] – a permis leur accessibilité croissante en recherche et actuellement en diagnostic. L'apport de ces techniques pour l'identification de la cause génétique de nombreuses pathologies est essentiel, en particulier dans le domaine des maladies rares [2]. De nombreux patients sont déjà concernés et le seront d'autant plus en France dans les prochaines années par le déploiement du Plan France Médecine Génomique 2025 [3]. Ce plan est mis en place à la demande du gouvernement français dans le but d'examiner l'accès au diagnostic génétique actuellement et de l'améliorer sous 10 ans. Or ce séquençage massif soulève de nombreuses questions éthiques : sous prétexte d'avoir l'accessibilité au séquençage de l'exome ou du génome, doit-on rechercher d'autres informations que celles souhaitées initialement par le patient? Quelle est la fiabilité de l'interprétation des variants identifiés en population générale? Quels seraient les bénéfices et les risques pour le patient dans ce contexte? Comment pouvons-nous harmoniser nos pratiques sur le territoire français et face à la mondialisation? Dans cet article, nous nous intéressons aux problèmes liés à ses applications dans les consultations médicales de génétique à l'hôpital et en particulier à la question de la recherche ou non des données dites additionnelles comprenant les données incidentes et secondaires.

Prenons l'exemple d'une femme de 30 ans, Madame B, souffrant d'un diabète atypique d'étiologie inconnue et à qui une étude de génome est proposée pour rechercher la cause de sa pathologie (donnée primaire). Ayant accès à l'ensemble de la séquence de son génome, il est possible d'identifier une anomalie génétique sans rapport avec la donnée primaire, soit de manière fortuite (donnée incidente), soit en recherchant activement si Mme B est porteuse de variations ailleurs dans son génome (données secondaires). Mme B ne présente pas de signes en rapport avec cette découverte de données additionnelles : elle est dite « asymptomatique » pour cette indication. L'*American College of Medical Genetics* (ACMG) a défini une liste de 59 gènes (ACMG SF v2.0) dits médicalement « actionnables » et correspondant à 27 pathologies [4] pour lesquelles des mesures de prévention ou de soins pourraient être proposées au patient. Il s'agit principalement de prédispositions aux cancers, à des maladies cardiovasculaires avec risque de mort subite (dissections artérielles, troubles du rythme ou de la conduction cardiaque) et certaines maladies métaboliques. L'ACMG recommande ainsi la recherche systématique de telles données additionnelles depuis 2013, quel que soit l'âge du patient. Il serait techniquement possible d'aller plus loin et d'étendre les pathologies recherchées : maladies récessives avec risque pour la descendance (ex. :

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mucoviscidose, amyotrophie spinale infantile), maladies neuro-dégénératives d'apparition tardive (ex. : sclérose latérale amyotrophique, maladie d'Alzheimer précoce), etc. Contrairement à l'ACMG, l'*European Society of Human Genetics* (ESHG) recommande une approche ciblée afin d'éviter la découverte de données additionnelles [5,6]. Dans le même sens, le *Canadian College of Medical Geneticists* (CCMG) se positionne en 2015 contre la recherche de données secondaires, même dans le cas de gènes actionnables [7]. Devant cette divergence des points de vue, il nous semble important de nous questionner sur ce sujet en prenant en compte l'autonomie du patient face aux données additionnelles. À l'heure de la mondialisation, la société évolue vers plus de libertés individuelles ; comme nous l'avons vu, les techniques de génétique moléculaire sont de plus en plus performantes et accessibles, mais faut-il pour autant donner l'accès au patient à des données additionnelles sans se préoccuper de son degré d'autonomie et de sa préparation à recevoir ces informations?

Jusqu'en 2019, la loi française ne semblait pas à première vue favorable à la transmission de données additionnelles au patient. L'arrêté du 27 mai 2013 commence par disposer que « le droit en vigueur (…), pour protéger le patient d'informations inutiles, angoissantes ou dont la révélation n'est pas désirée, n'est pas en faveur de la transmission d'informations autres que celle initialement recherchée et pour laquelle le patient a consenti à la réalisation de l'examen. » [8]. Or, lors d'une consultation de génétique, le consentement à la divulgation d'informations fortuites est une condition disposée par le même arrêté : le patient doit être informé du « risque éventuel d'identification de caractéristiques génétiques sans relation directe avec la prescription » et de son droit de refuser ces résultats. Finalement, concernant les données additionnelles « dont les conséquences sont susceptibles de mesures de prévention, y compris de conseil génétique, ou de soins », l'appréciation de la situation (divulguer, rechercher des informations) est laissée au médecin – sur la base du consentement exprès[1] du patient et donc de son autonomie. Le projet de révision de la loi de bioéthique en 2019 semble aller dans ce sens et prévoit, sous condition du consentement de l'intéressé, « d'informer la personne de découvertes génétiques incidentes, au cours d'un examen réalisé à d'autres fins, dès lors que ces informations présentent une utilité au plan médical pour elle-même ou pour les membres de sa famille » [9]. Cet article vise à étudier les conditions du recueil d'un consentement libre et éclairé [10] du patient relativement aux données additionnelles. À quelles conditions un patient peut-il prendre une décision autonome relative à ces données? Quel doit être le rôle de l'équipe soignante? Peut-on harmoniser les pratiques relativement aux données additionnelles?

Les conditions de l'autonomie du patient

À l'origine politique, le grec « autonomia » signifie l'indépendance ou l'autodétermination d'un État. C'est ce sens qu'on trouve chez les historiens grecs comme Thucydide ou Xénophon. Aristote, les stoïciens, mais plus encore les philosophes modernes Rousseau et en particulier Kant intériorisent et individualisent la notion. Conformément à l'étymologie (du grec auto, soi-même, et nomos, la loi), est autonome le sujet *législateur* de son action, c'est-à-dire l'individu qui établit lui-même les lois de son agir. Selon ce modèle kantien de l'auto-législation, la volonté est autonome lorsqu'elle n'est pas déterminée par les sentiments ou par les désirs, mais par la seule loi morale, c'est-à-dire la loi qu'elle trouve en elle-même, dans la raison : « L'autonomie de la volonté est cette propriété qu'a la volonté d'être à elle-même sa loi (indépendamment de toute propriété des objets du vouloir) » [11]. Elle est au contraire hétéronome lorsqu'elle est déterminée, de manière « pathologique » par la sensibilité, c'est-à-dire par le sentiment de plaisir ou de peine que lui procure tel ou tel objet. Être autonome, c'est agir conformément aux lois universelles – aux « impératifs catégoriques » [11] – que la raison nous prescrit. Au XXe siècle, la bioéthique, l'éthique médicale et clinique – en particulier anglo-américaines – réhabilitent la sensibilité et le particulier pour penser l'autonomie selon une acception plus large que celle de la seule tradition kantienne. Selon ce second modèle de l'indépendance ou de l'autodétermination [12] – dans la continuité des écrits des philosophes libéraux tels que J. Locke et J. S. Mill – l'autonomie signifie la capacité ultime qu'aurait l'individu de penser et d'agir, en connaissance de cause, selon ses opinions, ses croyances, ses valeurs et ses désirs. Dans la lignée des travaux de T. Beauchamp et J. Childress, une décision est dite autonome, si celle-ci satisfait au moins deux conditions [13] : la liberté, soit l'absence d'influence contraignante sur la volonté ; l'intelligibilité, c'est-à-dire la compréhension de la situation et de ses conséquences. La décision du patient qui se rend en consultation génétique et à qui on pose la question de la révélation de données incidentes et de la recherche des données secondaires remplit-elle ces deux conditions?

Lorsqu'un patient délibère et prend une décision, il est influencé par des facteurs externes (médecin, proches, culture, etc.) et aussi internes (désirs, croyances, etc.). Par exemple, la confiance qu'un patient a envers son médecin peut le conduire à accepter aveuglément ce que celui-ci lui propose : il est rare qu'un patient refuse les examens médicaux qui lui sont proposés [14]. Le désir de savoir est aussi nourri par le passif d'errance médicale de beaucoup de patients consultant en génétique et qui peuvent alors confondre dans leur précipitation donnée primaire et données additionnelles [15]. Est-ce le désir de savoir, un désir ici irréfléchi et incontrôlé, qui détermine la décision du patient? Or une influence n'est pas nécessairement une contrainte : une influence *incline*[2] à adopter un choix, sans nécessité, alors qu'une contrainte force la volonté. Un patient peut demeurer libre d'exercer son autonomie, malgré différents types d'influences, plus ou moins coercitives, si le soignant l'aide à mettre en place un recul critique à l'égard de ces influences et qu'il lui garantit des conditions favorables à l'exercice libre de sa volonté (durée et lieu de la consultation, délai de réflexion, accompagnement psychologique, etc.). Plutôt qu'une propriété catégorielle, l'autonomie est pour l'éthique biomédicale une propriété graduelle et variable ; elle admet donc des degrés [17]. Selon cette conception scalaire, l'autonomie du patient, en génétique comme dans toute consultation médicale, est *l'horizon*

[1] L'arrêté du 27 mai 2013 portant sur les bonnes pratiques exige en effet le recueil du consentement exprès du patient avant la divulgation de résultats ayant une conséquence clinique connue sans rapport avec la prescription.
[2] Une inclination n'est pas une nécessité ; voir Leibniz [16, §46].

de la relation de soin et non un simple *déjà-là* devant lequel le soignant devrait s'incliner. On peut encore soutenir que l'autonomie psychique est relationnelle, au sens où elle est l'horizon de la relation médecin-patient et qu'elle est favorisée par celle-ci : ni simplement paternaliste, ni simplement informative (où le médecin serait simple prestataire de service et informerait le patient qui déciderait seul de la voie à suivre, selon ses propres valeurs), cette relation est à la fois « délibérative » et « interprétative » selon la formule d'Ezekiel Emanuel [18]. Il s'agit d'aider le patient à choisir, par le dialogue, la meilleure voie d'un point de vue médical et aussi de l'aider à prendre une décision qui réalise au mieux ses valeurs. Le médecin participe ainsi à l'autonomisation du patient et rend parfois plus cohérent son système de valeurs.

Dans cette logique, selon l'arrêté du 27 mai 2013, avant la prescription d'une étude génétique, le médecin doit informer dûment le patient sur le cadre de l'examen, ses limites, ses conséquences individuelles et familiales, mais également sur « le risque éventuel d'identification de caractéristiques génétiques sans relation directe avec la prescription » [8]. Mais est-il encore possible, dans cette durée limitée et déjà chargée de la consultation, de recueillir un consentement (ou un refus) véritablement libre et éclairé quant à la recherche des données additionnelles? Et comment préserver le droit de ne pas savoir? [19] Ce sont en particulier la complexité et les incertitudes relatives à ces données qui compliquent la compréhension possible du patient.

En effet, la liste des gènes actionnables de l'ACMG (ACMG SF v2.0) est souvent prise en référence pour la recherche de données secondaires et correspond essentiellement à des prédispositions génétiques qui pouvaient être recherchées jusque-là uniquement en cas d'antécédents familiaux. Une personne ayant suivi une démarche de diagnostic présymptomatique et porteuse de l'anomalie familiale a donc un risque supérieur au reste de la population générale, mais elle ne développera pas nécessairement la maladie. La médecine n'est ici que partiellement *prédictive*, c'est-à-dire probabiliste et en l'absence d'antécédents familiaux, il n'existe pour l'instant pas de données fiables permettant d'estimer précisément le potentiel sur-risque conféré par un variant dans ces gènes pour un individu donné comme le montre les résultats de la cohorte de personnes âgées en bonne santé, Wellderly, dans laquelle la fréquence des variants de la liste des gènes de l'ACMG n'est pas différente d'une cohorte de personnes jeunes [20]. Il peut exister chez le même individu des facteurs protecteurs génétiques et/ou environnementaux qui vont à l'inverse faire diminuer le risque de survenue de la pathologie. Ensuite, le séquençage de génome met en évidence de nombreux variants chez une personne (environ 100 000) [2]. La plupart de ces variants sont bénins, mais certains sont des variants de signification inconnue (VSI), dont on ne sait déterminer leur caractère bénin ou pathogène dans l'état des connaissances actuelles. L'interprétation de ces variants reste très complexe et il est donc difficile pour le patient – comme pour le médecin – d'avoir une perception fiable et précise des risques qu'il a de développer la maladie [7]. Or, lorsque le niveau de risque ne peut être déterminé de façon fiable, se pose la question de la prise en charge médicale, c'est-à-dire du degré d' « actionnabilité » du variant identifié, qui sera proposée au patient et qui pourrait ne pas être adaptée au risque réel [19].

Dans le sens de cette incertitude, l'ACMG a recommandé en avril 2019 d'utiliser la liste ACMG SF v2.0 uniquement pour la recherche de données additionnelles chez des patients et non en population générale du fait de la pénétrance incomplète de variants dans certains gènes et au nom du principe de non-malfaisance [21]. Comme d'autres auteurs, cette position nous interroge puisqu'une donnée additionnelle chez un patient n'ayant pas d'antécédents familiaux particuliers et asymptomatiques pour la pathologie en question est aussi incertaine qu'une donnée additionnelle identifiée chez une personne de la population générale ; l'ACMG le souligne elle-même : « We also recognize the danger in moving forward with population-based screening in the absence of robust evidence » [22,23]. Au lieu de réduire les incertitudes, le rendu des données additionnelles risque donc d'en ajouter, accompagnées de nouvelles angoisses, en plus de celles liées à la donnée primaire [24].

Or l'angoisse générée chez le patient par une information médicale est le fait de la plupart des annonces de maladies. Si elle peut être traumatisante pour le patient, elle peut également le conduire à adapter ses habitudes de vie à ses risques génétiques, à se préparer psychologiquement à l'arrivée de la maladie et à prendre des dispositions pratiques (la rédaction de directives anticipées par exemple). C'est le phénomène d'anticipation décrit par J. Sutter [25]. De plus, l'accompagnement par l'équipe médicale, la compréhension et l'adhésion du patient sont donc primordiales pour qu'il puisse apprécier les bienfaits de l'angoisse sans être débordé par sa dimension traumatisante. Il convient donc d'évaluer avec prudence les capacités du patient à décider en connaissance de cause s'il souhaite faire face à de telles informations, mais aussi et surtout de l'accompagner vers une décision la plus autonome possible. Quels sont donc les outils qui nous permettent de favoriser et d'évaluer l'autonomie du patient?

Favoriser l'autonomie du patient face aux données additionnelles

Un consentement éclairé quant aux données génétiques n'exige pas une compréhension *complète* de la situation, qui est sans doute en elle-même impossible à atteindre, mais une compréhension *adéquate* des enjeux et de ses conséquences [17]. Un travail doit être initié par les généticiens pour déterminer de quelles informations les patients ont besoin pour une compréhension des enjeux suffisante. Il s'agit aussi d'éviter la *surcharge* d'informations qui entrave l'exercice du jugement et paralyse la volonté [26]. Remarquons qu'en France, la loi impose le recueil d'un consentement explicite (opt-in) du patient pour toute analyse génétique. Une autre approche possible du problème serait celle du consentement présumé (opt-out), comme c'est le cas en France pour le don d'organe post mortem (loi n°2016-41 du 26 janvier 2016) : si le patient n'est pas opposé de son vivant explicitement au don de ses organes, il est considéré comme consentant. Outre la question de savoir si un consentement présumé est un véritable consentement (*qui ne dit mot consent?* [27]), une telle approche est-elle concevable en médecine génomique et à la question des données additionnelles? Si l'on peut concevoir que la population française est

aujourd'hui mieux informée qu'hier quant au don d'organe, une telle information serait-elle envisageable et souhaitable concernant l'analyse génétique et en particulier les données additionnelles? Un rapport du Comité Consultatif National d'Ethique sur les États Généraux de 2018 a mis en lumière le manque de connaissance de la population générale sur la génétique et les tests [28]. Présumer un consentement du patient en la matière nous paraît donc à ce jour non pertinent. Surtout, déclarer au patient lors de la consultation en génétique que la loi le considère *a priori* comme consentant à la recherche et à la divulgation de données additionnelles, risquerait d'être interprétée par les patients comme une recommandation à réaliser l'analyse : son accord correspondrait au choix standard, par défaut. Cela constituerait une influence supplémentaire s'ajoutant à toutes celles qui s'exercent déjà sur les patients. Le recueil d'un consentement explicite à une analyse génétique, et plus particulièrement aux données additionnelles, nous semble donc préférable afin de préserver et de favoriser l'autonomie de la décision des patients.

Dans le cas où le patient souhaite être informé des données additionnelles issues du séquençage d'exome ou du génome, nous proposons de distinguer avec lui différents degrés de complexité en fonction de la fiabilité des données médicales et du type de pathologies recherchées. Il convient d'accompagner le patient « asymptomatique » pour la(les) pathologie(s) recherchée(s) vers un degré d'autonomie adapté à sa demande. Telle est la *stratégie de l'échelle variable* qui consiste à adapter le degré d'autonomie recherché à la complexité de la décision à prendre: principalement, le degré d'incertitude du diagnostic et/ou du pronostic, le nombre d'options thérapeutiques envisagées, la complexité de la situation médicale en tant que telle, mais aussi l'importance des répercussions de la décision dans l'existence. Dans la lignée des travaux du philosophe américain J. F. Drane [29], nous distinguons trois catégories de données génétiques additionnelles (des plus simples aux plus complexes). Ces différentes catégories sont déclinées dans le tableau 1 et nous proposons pour chaque situation un niveau d'autonomie à atteindre associé à un accompagnement médical et psychologique adapté. Il s'agit ici d'un guide pour le médecin qui reste libre d'adapter sa prise en charge en fonction de la situation particulière rencontrée.

Tableau 1: Niveau d'autonomie requis pour un patient asymptomatique selon le type de données additionnelles

Catégorie	Type de données additionnelles	Données génétiques(1)	Compétences requises	Exemples de personnes « incompétentes » A	Exemples de personnes « compétentes » B	Consultation médicale	Entretien psychologique
1	Risque pour la descendance (Pathologies accessibles au DPN ou DPI)	Fiables	• Conscience • Capacité à consentir	• DI sévère ou profonde • Troubles psychiatriques sévères • Personnes inconscientes ou totalement désorientées • Personnes sous tutelle ou mineurs	• DI modérée ou légère • Troubles psychiatriques modérés • Conditions listées en 2-B et 3-B	Demander au patient d'indiquer sa préférence	À la demande du patient
	Pathologies « actionnables »: prévention possible et/ou traitement curable disponible						Très recommandé en amont et en aval des résultats avec délai de réflexion
2	Pathologies « actionnables »: prévention possible et/ou traitement curable disponible	Incertaines	• Compréhension de la situation médicale et du traitement • Choix éclairé (sur la base des connaissances théoriques) • Possibilité d'apprécier la part d'incertitude des résultats	• DI modérée • Troubles sévères de la personnalité • Conditions listées en 1-A	• DI légère • Personnes borderline • Conditions listées en 3-B	Interroger le patient sur la situation médicale, la prise en charge et les raisons objectives de son choix	À proposer en aval des résultats
							Très recommandé en amont et en aval des résultats avec délai de réflexion
3	Pathologies incurables à révélation tardive avec possibilité de DPN/DPI	Fiables ou incertaines	• Appréciation de la situation et de ses conséquences • Décision rationnelle: prise en compte des risques et des avantages sur le plan médical, mais aussi personnel (valeurs, croyances, etc.)	• DI légère • Personnes borderline • Personnes indécises ou ambivalentes • Conditions listées en 1-A et 2-A	Personne majeure, esprit critique et réfléchi	Interroger le patient sur la situation médicale et les raisons de son choix, y compris ses raisons personnelles	Indispensable en amont et en aval des résultats avec long délai de réflexion

DI: déficience intellectuelle; DPN: diagnostic prénatal; DPI: diagnostic préimplantatoire.
(1) prenant en compte la pénétrance du variant, l'estimation du risque de pathologie et la conduite à tenir pour le patient et sa famille.

La première catégorie (C1) concerne des données génétiques fiables qui sont soit actionnables avec des mesures de prévention ou de soin directes pour la personne, soit qui comportent un risque de transmission de pathologie d'une particulière gravité pour la descendance. Dans ce dernier cas, il sera possible de recourir à un diagnostic prénatal ou préimplantatoire afin d'éviter la transmission à sa progéniture. Nous entendons par données « fiables » l'identification de variants pathogènes ou probablement pathogènes, respectivement de classe 5 ou 4 selon la classification de l'ACMG [30] dans des gènes bien connus en pathologie, pour lesquels une corrélation génotype-phénotype est clairement établie avec un haut degré d'actionnabilité pour le patient et sa famille.

La seconde catégorie (C2) concerne des données génétiques ou des prédispositions avec un certain degré d'incertitude, mais là encore qui sont actionnables ou qui comportent un risque de transmission de pathologie d'une particulière gravité pour la descendance. Dans ce cas, il existe des incertitudes pouvant être de différentes natures. Il peut s'agir, d'une part, d'un variant déjà décrit en pathologie, mais pour lequel il est difficile de savoir s'il confère un véritable sur-risque de la pathologie pour la personne donnée en cas de pénétrance incomplète (expression inconstante de la pathologie) ou en l'absence d'antécédents familiaux par exemple. D'autre part, il peut également s'agir d'un variant pour lequel la corrélation génotype-phénotype n'est pas clairement établie ou très variable et pour lequel le pronostic est imprécis.

La troisième catégorie (C3) concerne des données génétiques fiables ou incertaines (pénétrance incomplète, faible degré d'actionnabilité) pouvant être à l'origine de pathologies incurables à révélation tardive (sclérose latérale amyotrophique, maladie d'Alzheimer précoce, etc.) pour lesquelles un diagnostic prénatal ou préimplantatoire peut être proposé. L'accès d'un patient à de telles données additionnelles peut alors suivre l'arbre décisionnel suivant :

Pour C1

- Connaître de telles données est justifié d'un point de vue médical puisqu'une prise en charge spécifique peut être proposée au patient. Le degré de capacité exigé est ici simplement la conscience et la capacité à consentir de manière explicite. Dans ces situations, le patient évalué en définitive par le médecin comme incompétent est le plus souvent une personne reconnue comme légalement incompétente : un patient dans le coma, une personne atteinte de déficience intellectuelle profonde ou souffrant de troubles psychiatriques sévères, etc.
- Revenons au cas de Mme B, atteinte d'un diabète atypique : la recherche de données additionnelles met en évidence un statut d'hétérozygote pour le gène *DMD* impliqué dans la dystrophie musculaire de Duchenne (DMD). La DMD est une pathologie récessive liée au chromosome X. Mme B est donc à risque de 50% de transmettre une atteinte musculaire sévère à un enfant de sexe masculin. Il s'agit d'un variant pathogène non-sens, déjà rapporté dans les bases de données de patients DMD ayant une pénétrance complète chez le garçon et une bonne corrélation génotype-phénotype. Nous le classons dans la catégorie C1. Des mesures de prévention pour elle (suivi cardiologique) et de conseil génétique (diagnostic prénatal ou préimplantatoire) pourront lui être proposées en cas de projet parental.
- Dans le cas particulier du mineur ou du majeur sous tutelle, l'étude pourra être envisagée comme le prévoit la loi concernant le diagnostic présymptomatique si « celui-ci ou sa famille peuvent personnellement bénéficier de mesures préventives ou curatives immédiates » [31]. La restriction légale de prescription dans ces cas particuliers permet de respecter l'autonomie future du mineur, mais également le respect du secret médical envers celui-ci et l'impact psychologique de ce résultat sur le mineur et le majeur sous tutelle.

Pour C2

- Le soignant doit rechercher et favoriser des capacités de compréhension et de raisonnement : la compréhension de la situation médicale et de la prise en charge proposée, l'appréciation de la part d'incertitude, la capacité de comparer les alternatives proposées et de prendre une décision basée sur cette compréhension. Bien accompagnées, certaines personnes atteintes de déficience intellectuelle légère ou de troubles mentaux (narcissiques, obsessionnels, borderline) se montreront capables de prendre une décision.
- Les individus qui pourraient être jugés comme insuffisamment compétents sont, en plus des types cités dans la première catégorie, les personnes souffrant de troubles sévères de la personnalité, phobiques, ou encore ayant des troubles de la mémoire à court terme qui entraverait leur compréhension et leur raisonnement.
- Par exemple, l'identification d'une mutation pathogène dans le gène *BRCA1* chez Mme B suggère une prédisposition aux cancers du sein et de l'ovaire. Or, en l'absence d'antécédents familiaux de cancers, il est difficile d'estimer son risque réel de développer un cancer du sein ou de l'ovaire. Ira-t-on jusqu'à lui conseiller une mastectomie bilatérale et une annexectomie (ablation des ovaires et des trompes de Fallope) prophylactiques? La part d'incertitude doit pouvoir être suffisamment appréhendée par la patiente.

Pour C3

- Décider de connaître de telles données exige que la personne apprécie la situation et qu'elle justifie sa décision, de manière cohérente, en s'appuyant sur ses opinions et ses valeurs. L'appréciation de la situation est ici le degré le plus haut de compétence selon Drane : une « compréhension qui est à la fois technique et personnelle, intellectuelle et sensible » [29]. Le sujet incompétent, en plus des types précédents, est un patient « ambivalent », hystérique ou encore dépressif. De manière générale, mais chaque situation doit être considérée comme singulière, le patient autonome est majeur, légalement compétent, réfléchi et autocritique.
- Par exemple, si Mme B souhaite savoir si elle est porteuse d'une prédisposition génétique à la sclérose latérale amyotrophique ou à une démence précoce de type Alzheimer alors que la pénétrance peut être incomplète et que nous n'avons pas à disposition des mesures préventives ou curatives à lui apporter dans l'immédiat, il est important qu'elle puisse apprécier justement quels seraient, pour elle et pour sa famille, les bénéfices et les risques de connaître son statut génétique. Nous prévoyons ainsi une prise en charge avec des consultations spécialisées, un délai long de réflexion et un suivi psychologique.

Afin d'accompagner au mieux les différents patients vers ces différents degrés d'autonomie, nous proposons de dissocier clairement la recherche de la donnée primaire (i) de celle des données additionnelles (ii) et de recueillir ainsi deux consentements à des moments bien distincts. Dans notre expérience et comme rapporté dans la littérature, les patients

souhaitent majoritairement connaître leurs données incidentes lorsqu'ils signent le consentement initial. Ceci permettrait au patient de ne pas faire d'amalgame entre la donnée primaire et les données additionnelles et de ne pas être influencé par la volonté de connaître la donnée primaire qui retentit sur le choix de connaître également les données additionnelles [15]. Les patients sont également influencés par la confiance qu'ils ont dans leur médecin qui leur fait signer le consentement et par le manque de recul sur les conséquences que peuvent avoir de telles connaissances sur eux. Distinguer deux consentements leur permettrait de bénéficier d'un délai de réflexion ainsi que d'une information plus complète nécessaire à la prise de décision comme cela est actuellement recommandé dans le diagnostic présymptomatique [24,32]. Nous nous inquiétons du retentissement personnel et familial, potentiellement délétère, pour les individus d'avoir connaissance de données additionnelles sans y avoir été bien préparés. D'ailleurs, les personnes ayant une meilleure connaissance des tests génétiques et de leurs conséquences sont généralement les plus réticentes à connaître leurs données additionnelles [33,34]. En pratique, pour le laboratoire, cela signifierait, à partir de la même étude d'exome ou de génome, un rendu des résultats en deux temps; d'abord la donnée primaire et, ensuite, seulement si le patient le souhaite, les données additionnelles :

1. Le premier consentement porterait uniquement sur la donnée primaire et serait recueilli à l'issue de la première consultation – pour une personne reconnue comme suffisamment autonome au regard de sa situation et dans le respect légal des règles de bonnes pratiques [31].
2. Après le rendu des résultats pour la donnée primaire, les patients seraient informés de la possibilité de connaître des données additionnelles. Une consultation dédiée serait alors proposée avec recueil d'un deuxième consentement spécifique pour les données additionnelles en proposant le choix pour le rendu des données de catégorie C1, C2 et/ou C3. Il faudra enrichir les différents supports existants d'aide à l'information et à la décision du patient dédié à la consultation de génétique: des films pédagogiques de la filière AnDDI-Rares sur le séquençage à haut débit et les données secondaires [35], mais aussi différents modèles d'aide à la décision [36]. Dans certains cas, en particulier face à des données de type C3, un long délai de réflexion et un accompagnement psychologique pourraient être exigés avant toute divulgation, dont le but serait de permettre au patient de gagner en autonomie. L'enjeu est d'éclairer et d'émanciper au maximum les individus des différentes formes d'influences qui peuvent entraver leur jugement et leur volonté. Là encore, selon les types de données et de degrés d'autonomie, il appartiendrait à l'équipe médicale d'évaluer les capacités du patient à décider de rechercher et de recevoir finalement les données (tableau 1), mais aussi de l'autonomiser dans cette prise de décision.

Conclusion

À ce jour, le rendu des données additionnelles chez le patient nous paraît délicat dans l'état des connaissances actuelles du fait d'incertitudes importantes concernant l'interprétation de nombreux variants, l'estimation du risque et la conduite à tenir pour les patients et leur famille. À l'avenir, une meilleure connaissance de l'impact des variants en dehors d'un contexte pathologique permettra de mieux estimer le risque et d'adapter la conduite à tenir pour un patient donné dans le cadre d'une médecine de précision. Il sera alors envisageable de proposer aux patients de rechercher ces données additionnelles en prenant en compte leur niveau d'autonomie et en les aidant à augmenter leur degré d'autonomie en fonction de leur demande. La prescription pour la recherche de la donnée primaire doit être bien dissociée de celle pour les données additionnelles. De manière ultime, il appartiendra à l'équipe médicale d'évaluer au cas par cas du bienfondé de la recherche de ces données et de leur révélation au patient pour que la balance bénéfice-risque pour un patient donné penche en sa faveur.

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ÉTUDE DE CAS / CASE STUDY

Respecting Cultural Differences in Goals of Care Conversations

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Résumé
Les conversations sur les objectifs des soins sont souvent difficiles lorsque les patients font face à un mauvais pronostic, mais lorsque les patients proviennent d'une autre culture, cela peut être encore plus difficile. Cependant, le fait de considérer les valeurs culturelles comme complémentaires plutôt qu'opposées pourrait être bénéfique pour les soins du patient.

Mots-clés
objectifs des soins, conversations, patients, culture, valeurs

Abstract
Goals of care conversations are often tough when patients face a poor prognosis, yet when patients are from a different culture it may be even more difficult. However, seeing cultural values as complementing rather than opposing could be beneficial to the care of the patient.

Keywords
goals of care, conversations, patients, culture, values

Case Study

Mr X. was a sixty-something year old male with high-risk myelodysplastic syndrome (MDS) and a history of colon cancer and diabetes mellitus. The patient and his family were from the Middle East, where he was initially diagnosed, but came to the USA for further and more aggressive treatment.

MDS constitutes a group of bone marrow failure syndrome associated with leukemia [1]. In patients with MDS, cause of death is often bone marrow failure, although MDS can also be a precursor to acute myeloid leukemia (AML) [2]. The treatment course for MDS depends on the health status of the patient and their goals of care. One option which is often presented is stem cell transplant, which can lead to long-term disease-free survival, but it can also result in life-threatening complications [3]. In this situation, Mr. X and his family decided to pursue intensive treatment, and he received an allogeneic stem cell transplant 301 days prior. The transplant was successful and put Mr. X in remission, but he developed significant complications, including steroid-resistant Graft-versus-Host-Disease (which is common following non-autologous stem cell transplants), disseminated viral infections (adenovirus and cytomegalovirus), renal failure, and persistent gastrointestinal (GI) bleeding. Furthermore, Mr. X was intubated for airway protection.

Goals of Care Conversation

As the days turned into weeks, the medical team wanted to speak with him regarding his goals of care, given that he developed new lung infiltrates, progressive pneumonia, pneumothorax and anasarca with renal failure that would require the patient to be on dialysis. These goals of care included palliative treatment, code status changes, and even transitioning Mr. X back to the United Arab Emirates, as he was developing other issues and his GI bleed was a major concern and not responding to any treatments. But when attempting to have a conversation with the patient, his family constantly blocked any attempt. Their reasoning was that they felt it would be unfair to tell the patient about his dire medical situation. The family repeatedly insisted that no "negative news" or questions regarding choices should be given to the patient.

The patient was deconditioned, on total parenteral nutrition (TPN), anemic and thrombocytopenic, but was alert and oriented with appropriate mood and affect. He was able to communicate via a white board on which he could write in Arabic. Essentially, the patient had decision-making capacity, and considering his critical, terminal condition, the team felt he should be involved in a conversation about his goals of care and code status.

Cultural Values

The primary ethical issue of this case was a disagreement between the medical team and the family regarding what should be disclosed to the patient regarding his medical condition. This disagreement is likely the result of cultural differences. In the USA, it is standard practice to inform the patient of his or her medical condition, and to be honest about prognosis, whereas in many other cultural contexts it is common to withhold information from a patient and let the family make medical decisions on the patient's behalf [4]. It is also common within the Islamic tradition for families to continue care to the greatest possible extent because of their belief that the patient's life is in God's hands [5]. The central ethical issue involves a conflict between upholding the values of patient autonomy and nonmaleficence and respecting the cultural views that inform the wishes of the family. Because the family was preventing the medical team from speaking with the patient directly, his preferences and goals of care could not be known. Since in this case there were no further treatment options to consider, the contentious aspect of the situation is the question of what should be disclosed to Mr. X regarding his medical condition. Open and honest communication with the patient is especially important because of the lack of knowledge about the patient's preferences and goals of care.

To navigate this stressful situation, a family meeting without the patient was held with the assistance of an interpreter. The medical team explained to the family why they believed it was important for the patient to be informed about his condition, and that since the patient was alert and aware, he retained decision-making capacity and had a right to exercise his autonomy,

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within the US context. With the help of the ethicist a dialogue was had with the family to understand their reasoning behind not wanting the patient to know the truth about his situation. After a long, but respectful conversation, it was agreed that the team would engage with the patient about his goals of care.

The medical team entered the room with the patient's family present and in a culturally sensitive manner, respecting their values, first asked the patient what he knew about his present situation and how much information he wanted. It turned out that Mr. X was well informed and wanted to know his full clinical prognosis. The team updated him in an honest, yet respectful manner by not mentioning the word "death" or any other negative aspects of his situation, as requested by the family. Mr. X understood that his condition was dire and his wish was to transition back to his home country. Furthermore, he also changed his code status to do not resuscitate (DNR), indicating that if Allah was ready to take him he would not stand in the way. The case management team worked with the medical team and organized Mr. X's transition back to the Middle East.

The take-away from this case study is that cultural values may come into conflict with the value systems of healthcare systems. Navigating this conflict in a culturally sensitive manner, i.e., by creating a platform for the family to explain why they have specific opinions/ways of doing things, can be hugely beneficial to the care of the patient and also to the respect afforded to the family. In the case of Mr. X, it was important to the family not to crush the spirit of Mr. X by being negative, although as it turned out he already knew his medical situation. Cultural values should not necessarily stand in opposition to other value systems. In entering into a non-threatening dialogue, it is possible to respect patient autonomy as well as other value systems.

Questions to Consider

1. What resources exist at your institution to conduct a family and goals of care conversation with patients who do not necessarily speak English?
2. What is the role of the ethicist to assist in facilitating goals of care conversations with patients from different cultural backgrounds?

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