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Tables des matieres / Table of Contents

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Mitochondrial/Nuclear Transfer: A Literature Review of the Ethical, Legal and Social Issues

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Résumé

Le transfert mitochondrial / nucléaire (M/NT) visant à éviter la transmission de maladies mitochondriales graves soulève des enjeux éthiques, juridiques et sociaux (ELS) complexes. En février 2015, le Royaume-Uni est devenu le premier pays au monde à légaliser le M/NT, rendant le débat houleux sur cette technologie encore plus pertinent. Cette revue d'interprétation critique identifie 95 articles pertinents sur les enjeux ELS du M/NT, y compris des articles de recherche originaux, des rapports gouvernementaux ou commandés par le gouvernement, des éditoriaux, des lettres aux éditeurs et des nouvelles de recherche. La revue présente et synthétise les arguments présents dans la littérature quant aux thèmes les plus fréquemment soulevés: terminologie; identité, relations et parentalité; dommage potentiel; autonomie reproductive; alternatives disponibles; consentement; impact sur des groupes d'intérêt spécifiques; ressources; « pente glissante »; création, utilisation et destruction des embryons humains; et bienfaisance. La revue conclut en identifiant les enjeux ELS spécifiques au M/NT et en appelant à une recherche de suivi longitudinale clinique et psychosociale afin d'alimenter le futur débat sur les enjeux ELS de preuves empiriques.

Mots clés

transfert mitochondrial / nucléaire, FIV, ELS, Royaume-Uni, revue d'interprétation critique

Abstract

Mitochondrial/nuclear transfer (M/NT) to avoid the transmission of serious mitochondrial disease raises complex and challenging ethical, legal and social issues (ELSI). In February 2015, the United Kingdom became the first country in the world to legalize M/NT, making the heated debate surrounding this technology even more relevant. This critical interpretive review identified 95 relevant papers discussing the ELSI of M/NT, including original research articles, government-commissioned reports, editorials, letters to editors and research news. The review presents and synthesizes the arguments present in the literature in relation to the most commonly raised themes: terminology; identity, relationships and parenthood; potential harm; reproductive autonomy; available alternatives; consent; impact on specific interest groups; resources; "slippery slope"; creation, use and destruction of human embryos; and beneficence. The review concludes by identifying those ELSI that are specific to M/NT and by calling for follow-up longitudinal clinical and psychosocial research in order to equip future ELSI debate with empirical evidence.

Keywords

mitochondrial/nuclear transfer, IVF, ELSI, United Kingdom, critical interpretive review

Introduction

In February 2015, the United Kingdom became the first country in the world to legalize a new *in vitro* fertilization (IVF) technology called **mitochondrial/nuclear transfer** (M/NT) [1-4]. M/NT aims to avoid the transmission of serious mitochondrial diseases from an affected mother to her progeny by using one of two techniques: maternal spindle transfer (MST) and pronuclear transfer (PNT). Both techniques result in offspring with genetic material from three different persons: the nuclear DNA (nDNA) of the two prospective parents and the mitochondrial DNA (mtDNA) of the egg donor [5-9]. These modifications of the germ-line are inheritable and, therefore, transmitted to the offspring's progeny [5,8,10,11]. When mtDNA carries mutations, it can result in serious, potentially fatal, and currently untreatable diseases such as Leigh's syndrome, affecting mostly the organs whose operation requires the most energy: the central nervous system, heart, liver, kidneys, etc. [12].

The UK's decision to legalize M/NT has provoked a heated debate regarding the ethical, legal and social issues (ELSI) related to the technique. UK regulations came into force on October 29, 2015 [1]. However, the first live birth of a boy following M/NT (MST) occurred in Mexico in 2016 [89-92][1]. At the time of our review in 2015, no review of the literature concerning the ELSI of M/NT had been published. The current review addresses this need by identifying the ELSI associated with M/NT that have been put forward in the literature as of July 2015.

Methodology

Critical interpretive review

The ELSI debate on M/NT is taking place in research articles, commentaries, editorials, government-commissioned reports, letters to editors, and research news. We therefore chose to perform a critical interpretive review of all these relevant sources [18]. While considerable discussion also occurs in blog posts, we did not include them in the review due to great variability in their quality. Each step described below was performed independently by two researchers (RDL and SB).

[1] 2017 Update

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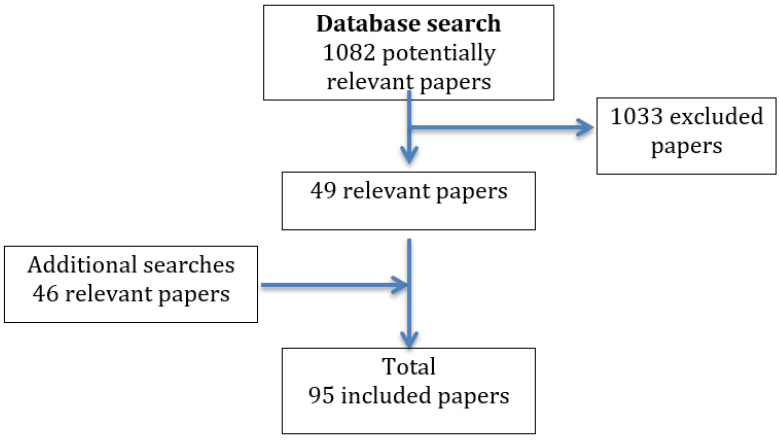
Search

The first step – performed in July 2015 – consisted of a systematic search, with the key words and phrases listed in Table 1, of the following databases which were considered by the authors to be the most relevant for this review: PubMed, CINAHL (EBSCOHost), Science Direct, Embase and PsycInfo. A total of 1 082 potentially relevant titles were found. From these, 1 033 papers were excluded as they did not meet either of the inclusion criteria, which were: a focus on M/NT, discussion of ELSI (i.e., not having exclusively scientific content), availability in French or English, availability online, not being duplicate titles or conference abstracts. The database search thus generated 49 papers that were selected for the review. Key websites (Google Scholar and the Georgetown Library) and journals (Nature, Science, BMJ, Fertility and Sterility, Human Reproduction, Reproductive Biomedicine Online and The Lancet) likely to offer essential papers were also searched. Researchers in the field were consulted to help identify additional papers. Finally, relevant references from bibliographies of included papers were also included (using the same inclusion criteria as above). This generated 46 additional papers, for a total of 95 (see Appendix A).

Table 1: Key words and phrases

Maternal spindle transfer
Mitochondrial donation
Mitochondrial DNA replacement
Mitochondrial DNA transfer
Mitochondrial gene transfer
Mitochondrial gene replacement
Mitochondrial replacement
Mitochondrial transfer
mtDNA replacement
mtDNA transfer
Nuclear genome transfer
Polar body genome transfer
Pronuclear transfer
Three parent baby*
Three parent embryo*
Three parent in vitro fertilization (or IVF)
Three person baby*
Three person embryo*
Three person in vitro fertilization (or IVF)

Figure 1. Paper Selection Process



Analysis

The analysis was performed by two independent researchers using NVivo10 [19] and adapting Burnard's [20] stage-by-stage process of content analysis. The coding of all papers was performed both inductively and deductively, separately by RDL and SB. The results were then compared one by one and discussed by RDL and SB. When necessary, the results were discussed by all three authors until consensus was achieved. The themes were generated by the researchers' codes and subsequently classified into the following categories: terminology; identity, relationships and parenthood; potential harm; reproductive autonomy; available alternatives; consent; impact on specific interest groups; resources; "slippery slope"; creation, use and destruction of human embryos; and beneficence.

Table 2. Ethical, Legal, Social Implications of M/NT addressed in the literature, by theme and type of article

ELSI theme	% of papers	% of scientific articles & reports [rank among themes]	% of editorials & news items [rank among themes]
Harm to future child	86	83 [1]	88 [1]
Beneficence	60	69 [2]	55 [2]
Slippery slope	55	60 [4]	52 [3]
Identity of Child	54	66 [3]	47 [4]
Available alternatives	45	60 [4]	37 [5]
Relationships formed as a result of M/NT, donor status, legal parenthood	42	60 [4]	32 [6]
Harm to future generations	36	49 [7]	28 [7]
Harm to egg donors	32	43 [8]	25 [9]
Resources	27	26 [14]	28 [7]
Long-term follow-up	24	34 [9]	18 [10]
Consent of prospective parents	21	34 [9]	13 [15]
Reproductive autonomy	21	31 [11]	15 [13]
Creation, use and destruction of human embryos	20	29 [13]	15 [13]
Impact of M/NT on scientists and researchers	20	26 [14]	17 [11]
Impact of M/NT on persons suffering from mtDNA diseases	17	31 [11]	8 [16]
Consent of the future child	14	26 [14]	7 [18]
Terminology	14	9 [18]	17 [11]
Harm to prospective parents	9	11 [17]	8 [16]

Supplementary file – Themes (See Annex 1)

Results

Terminology

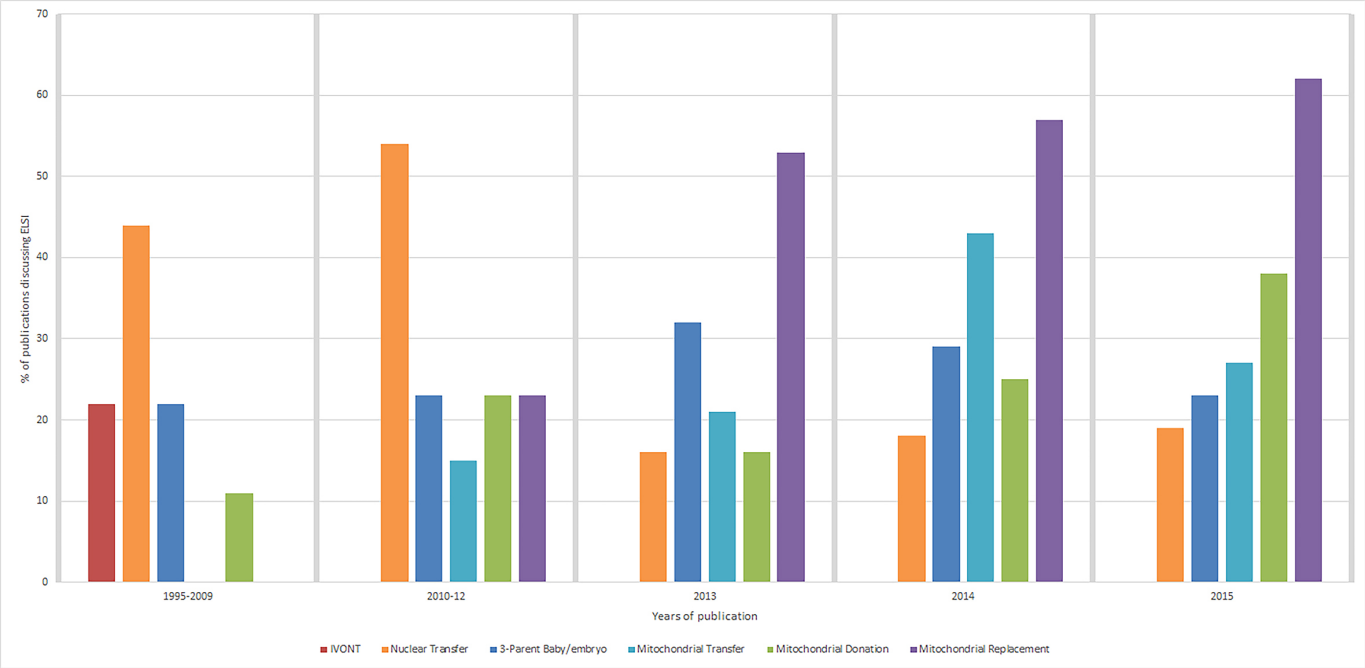
The technology – as well as resulting offspring – is referred to using numerous terms (Table 5). The expression "mitochondrial transfer" does not actually reflect what M/NT involves (i.e., the transfer of the spindle or the *pronuclei* – not of mitochondria – from the prospective mother's egg to the donor's) [7]. Bredenoord et al. use the term "mtDNA modification" citing important previous use in the literature, while stating that "mtDNA replacement" is a more accurate expression [13].

Table 3. Use of Terminology in the Scientific Literature When Referring to the Technology

Term used	% of papers (n=95)	% of scientific articles & reports (n=35) [rank among all terms used]	% of editorials & news items (n=60) [rank among all terms used]
"mitochondria(l) replacement / MRT"	47	37 [2]	53 [1]
"mitochondria(l) (DNA) transfer"	26	29 [4]	25 [3]
"3 / three(-)parent baby(ies) / embryo(s)"	26	17 [6]	32 [2]
"nuclear (genome) transfer / NT"	25	43 [1]	15 [5]
"mitochondria(l) donation"	25	34 [3]	20 [4]
"3 / three(-)parent in vitro fertilization / IVF"	12	20 [5]	7 [8]
"mtDNA replacement"	9	11 [7]	8 [7]
"mitochondria(l) manipulation"	6	9 [8]	5 [9]
"3/three(-)person in vitro fertilization / IVF"	5	6 [9]	5 [9]
"genetically modified baby(ies) / embryo(s) / child(ren)"	5	6 [9]	5 [9]
"oocyte modification"	3	6 [9]	2 [15]
"IVONT / In Vitro Ovum Nuclear Transplantation"	2	3 [12]	2 [15]
"mitochondria(l) (gene) therapy"	2	0	3 [12]
"DNA/genome transplant"	2	0	3 [12]
"3 / three(-)person embryo(s) / baby(ies)"	1	0	2 [14]
"DNA swap"	1	0	2 [15]
No term selected (technique is described but no term used)	6	0	10 [6]

Some terms arguably convey relative neutrality, such as "mitochondrial/nuclear *transfer*", while others are more value-laden, such as "mitochondrial *therapy*" [21]. In the present review, the phrase mitochondrial/nuclear transfer (M/NT) is used to designate both MST and PNT.

Figure 2. Evolution of Terminology Use in the Scientific Literature



Identity, relationships and parenthood

i) Identity of the child

51 papers address the issue of whether M/NT affects the identity of offspring.

> [A] general assumption is that mtDNA does not really constitute our genetic make-up; it does not influence our phenotype, as it only governs cellular energy production. Modification of essential or defining characteristics is considered to be ethically more problematic, because it determines one's identity or personality. Modifying the nuclear DNA is therefore often regarded [as] more problematic than modifying the mtDNA [22, p.674].

A response to the above argument is that one's identity is about more than physical appearance and character traits. Most nuclear genes do not contribute to the physical appearance and character traits of a person, but rather are involved in fundamental processes, just like mitochondrial genes [23]. Hence, it is argued that the reasons for considering energy production to be an "unimportant physical function" are not clear [24, p.6] and that such premises could lead to the conclusion that it is acceptable to "tinker" with most genes [23]. mtDNA's role may be considerably underestimated and it may, in fact, have an impact on traits such as athleticism, fertility, ageing and intelligence, behaviour and health, variables that play a role in defining one's identity [9,22,25,26].

The qualities of DNA may thus be more relevant to the debate than its quantity [27]. Genes carried by mtDNA can have a pervasive effect on metabolism and physical development [28], potentially causing debilitating illness [Murdoch, in 29]. A person born free of mtDNA disease can thus have a very different life story, experience and even personality, because medical conditions can have a determining impact on one's self-perception and identity. If successful, M/NT can thus have a considerable influence on the resulting child's identity [6,13,14,30,31-33]. While mtDNA may not directly impact character or physical traits, it may still be similar in some ways to nDNA modification, which is often perceived as more problematic than M/NT [22]. Study participants believed that because both mtDNA and nDNA can lead to serious disabilities, both kinds of DNA are identity-defining [16]. Like M/NT, "many other medical interventions, whether they involve genetic materials or not, are 'identity-altering' according to a variety of notions of identity" [31, p.55].

Some argue that M/NT is compatible with the child's "right to have one's future options kept open" [11, p.203] [see also 13,16,29], since it would eradicate the disease and therefore arguably broaden one's future options [11,13,16,29]. Others argue that M/NT would to a certain extent impede the child from making her/his own future choices [29].

The child's identity may be subject to confusion or ambiguity as s/he may be considered to have three genetic parents, leading to unknown social consequences [14,22,29,31,35-41]. Some argue that having three genetic parents is not a major ethical

concern [41], but others fear social stigmatization that may influence the child's conception of self [40]. Some suggest that the child should be informed, as in the case of other reproductive technologies involving a third-party contribution [37].

Ancestry tracing using mtDNA can provide genealogical information, which for some "suggests that the maternal input on the part of the donor is far from negligible" [42, p.19]. M/NT could make it impossible for the child to trace maternal genetic lineage [6], causing concerns regarding potential "ancestry confusion" [6,24,27,31,40,43]. However, it is argued that this confusion already exists due to egg, sperm and embryo donation [27].

ii) Relationships formed as a result of M/NT, donor's status and legal parenthood

M/NT may be considered controversial because, like other assisted reproductive technologies, it increases the number of parents a child may possibly have [44].

The third party genetic contribution may threaten some cultures' traditional concepts of family and parenthood [14,22,45]. However, three- (and more) parent families already exist: lesbian couples with a sperm donor, gay couples with a surrogate mother, reconstituted families, etc. [14,45]. M/NT is arguably closer to the "traditional nuclear family" than egg donation, since the prospective mother contributes her nDNA, carries, gives birth to and raises the child [30, p.14]. Nevertheless, M/NT challenges the definition of biological parenthood thus raising ethical and conceptual issues [13,46].

The availability of M/NT can be seen as a "double-edge sword" [47, p.3], making prospective parents responsible whether they choose to use or reject it. This may open the door to blame and possibly affect the parent-child relationship. Counselling of prospective families on how to manage the "three-parent family" may be needed, before and after conception, and at least until puberty – when children start asking questions about their origins [16]. Furthermore, the fact that the child was created to satisfy the parents' need of a genetically linked progeny may affect the relationship between the child and its parents by "commodifying" the child [24,30,42,48].

Some are concerned that the mtDNA donor may develop strong maternal feelings and may want to develop a relationship with the child. The prospective (nuclear) mother may feel that because of the donor's contribution, the offspring is not "fully hers" and confusion may result [49, p.1268]. However, current lack of data makes it challenging to anticipate the effect of M/NT on children's relationships with their parents and the donor, which will probably vary from one family to another, as it does in the case of reproductive egg donation [31].

When considering the third party's genetic contribution, questions about the privileges, rights, obligations and responsibilities of the donor are raised [16,40,43,49,50]. Some doubt whether children born following M/NT should know the donor's identity [16,43,51]. Paller-Rzepka presents some of the arguments put forward against the donor's recognition as a legal parent, highlighting the negative consequences of co-parentage on the child, as well as legislators' potential refusal to change existing legislation accordingly [50].

In the UK, when a child conceived with gamete donation after 2005 reaches adulthood, s/he can access the gamete donor's identity [52]. Moreover, the donor in these cases is not legally related to the resulting child and cannot obtain a parental order [29]. UK law allows the legal recognition of only one "mother" – the woman who carries and gives birth to the child [3,31]. Some argue that the same limitations should apply to M/NT [22,30,31]. According to the UK's M/NT regulations, mtDNA donors will be treated as tissue donors rather than as egg donors, with both children and the donor given access solely to limited non-identifying information about each other [4,29,30]. It is unclear how mtDNA donors would be viewed in other jurisdictions [53].

Currently, there is a dearth of data regarding how mtDNA donors view the social significance of their donation [31]. Nevertheless, a voluntary system of contact or information exchange between the donor and the resulting child, arranged with mutual consent, is suggested [27,31,54,55].

Potential harm

i) Harm to the future child

Issues regarding the limited available information about the safety and efficacy of M/NT as well as the potential physical or psychological harms to the resulting child, include: "mitochondrial disease, as a result of carryover of abnormal mitochondria and heteroplasmy"; "disorders due to nuclear-mitochondrial incompatibility"; "disorders related to aberrant epigenetic modifications"; "birth defects and other disorders associated with the specific mitochondrial manipulation technology procedure"; and "toxicities of reagents used in mitochondrial manipulation technologies" [56, p.20].

Because the goal of M/NT is a viable pregnancy, it "cannot be gradually phased into use" [31, p.65]. Furthermore, the germ-line effects of M/NT on the offspring will be irreversible [10,14,22,31,54]. The possible future discontinuation of M/NT as a treatment due to negative effects outweighing the benefits will be of little consolation to those children who are already negatively affected [31]. However, the risk of not offering M/NT to women who carry mutant mtDNA is that children may be born with diseases caused by mtDNA mutations [29,31].

The potential risks of M/NT raise the question of when it would be appropriate to offer it for the first time [10,16]. Introducing its use in humans through clinical trials is seen as essential, even if the design of such trials must accept some risks [5,6,16,39,55,58,59]. Many currently accepted reproductive technologies would not have been implemented without accepting some risk: e.g., IVF, prenatal genetic diagnosis (PGD) [5,22,14,27]. While the precautionary principle is suggested by some [10,22,29,50], others argue that prioritising precautions "stifles discovery or paralyzes scientific and technical progress…. To govern the introduction of new reproductive technology one could also adhere to a 'proof first' approach, placing the burdens on the regulator to demonstrate a high risk of serious harm" [22, p.673].

Finally, some raise concerns regarding the consequences that the prospective mother's health may have on the wellbeing of the child [31]. If the mother is affected by a serious mitochondrial disorder and consequently has a reduced life expectancy, she might have a limited ability to take care of her child.

ii) Harm to future generations

M/NT involves germ-line modifications that will be transmitted down the generations, thus complicating the risk/benefit analysis [61]. As with other reproductive technologies, the real impact of M/NT will not be known until numerous generations are born [31]. Thus, Baylis mentions the "right of subsequent generations to inherit an un-manipulated genome" [6, p.533-534].

As mitochondria are inherited maternally, male offspring do not transmit their potentially mutant mtDNA to progeny, which leads to a discussion of the ethical acceptability of selecting only male embryos for M/NT in order to avoid the transmission of health risks to subsequent generations [8,13,16,31,36,39,56,62-64]. The UK Human Fertilisation and Embryology Authority (HFEA) ultimately rejected this idea, but recommends that any female born following M/NT be informed of the potential risks of transmitting mtDNA disease to her own children [8].

iii) Long-term follow-up

Because M/NT's effects may not manifest for many years, long-term and even intergenerational follow-up on the safety and efficacy of the technique is suggested, including "social research into how children born from mitochondria replacement feel about their origins" [39, p.5]. Some suggest making parental consent to long-term follow-up of resulting children a condition for participation in trials [16,31,54], but the HFEA recommends that permission to follow-up be obtained from the resulting children when they come of age [8]. Appleby argues that the procedure should only be offered to parents who plan on telling their child that s/he was born following the M/NT, since it would allow her/him to knowingly seek appropriate health care [36].

For some, long-term follow-up raises concerns regarding the burden put on children since "[b]eing made the enforced subjects of research over an indefinite period could be detrimental to their mental and emotional health" [30, p.7-8], while others believe that it would not be ethically problematic [16].

It is anticipated that it will be difficult to ensure long-term follow-up, since this has been a problem in the past for other assisted reproductive technologies [31]. A central register facilitating long-term follow-up that would be accessible to researchers is recommended [31,54], requiring government commitment to its maintenance [31,32,54].

iv) Harm to egg donors

Aside from ELSI related to regular egg donation, M/NT research requires an increase in availability of donated eggs, even as current shortage of donated eggs is acknowledged [22,30,31,32,59,65,66]. Moreover, eggs used for M/NT should be fresh – as opposed to cryopreserved – placing "time pressures on mitochondrial donors in terms of aligning their donation with someone's convenience other than their own" [30, p.11].

v) Harm to prospective parents

Risks of harm to prospective parents include failure to become pregnant [58,60], failure to give birth to a child [56], and health risks during childbirth due to the mitochondrial disorder affecting the mother-to-be [7]. Additionally, risks arising from hormonal stimulation and egg retrieval associated with IVF must be taken into account [6].

Reproductive autonomy

Reproductive autonomy is defined as "a principle concerning the non-interference in reproductive decision making" [31, p.70]. M/NT arguably widens the reproductive options available to women at risk of transmitting serious mtDNA diseases [16,29,31,37,67-71]. However, "[b]ecause an experimental procedure is available, does that mean that every patient who wants the experimental procedure has a right to that procedure" [44, p.188] [see also: 48]? And "is the desire for a genetically related child a positive right and is there a corresponding social obligation to support its realization" [57]? Could M/NT "create needs people never knew they had" [Bonnicksen, in 57, p.19]? Conversely, potential pressure on women to undergo M/NT if it becomes available may result in diminished reproductive autonomy [30,39,56] and in the emergence of a parental duty to prevent the transmission of mtDNA diseases [30].

Available alternatives

Alternatives to M/NT include adoption, IVF with egg donation, pre-implantation genetic diagnosis (PGD) and pre-natal genetic diagnosis (PND). Given available alternatives for preventing the birth of an affected child and for parenting a healthy child, the question of the reasonableness of using the M/NT arises [31]. However, these alternatives are not without limitations. Adoption and IVF with egg donation do not address the parents' desire to have a genetically related child [8,14-16,22,29,32,37,59]. Finding an egg donor can be challenging, especially when considering that the prospective mother's relatives may also be carriers [22]. PGD and PND are not a suitable technique for women with homoplasmy or a very high level of heteroplasmy [8,66,72]. On the other hand, PND can detect mutation in the fetus [22], but this is not necessarily decisive [10].

The drawbacks of these alternatives may be outweighed by being considered less ethically challenging than M/NT [10,28,73]. However, "PGD and other forms of reproductive technology are more prone to promote some kind of eugenics (by their active selection) than M/NT. […] [PGD] involves embryos that have already been created, rather than dealing with the potential of embryos" [14, p.4].

Consent

i) Consent of the future child

The most commonly raised concern related to consent of the prospective child is similarly pertinent to already accepted reproductive technologies: while the prospective mother is the one undergoing the intervention, the one who bears most of the potential risks is the offspring, and who obviously could not consent at the time of the decision [5,9-11,22,31,39,60,74-76].

ii) Consent of prospective parents

While everyone can agree that participants in M/NT trials must be fully informed of the potential risks and benefits of M/NT, "[g]iven the uncertainty – particularly in the early days of human trials – as to the safety and/or efficacy of the new techniques, is it possible that a true, informed consent could actually be given" [29, p.84]? Indeed, while "new genetic technology widens reproductive options for couples, it makes them dependent on experts to make an informed decision, and concepts in mitochondrial inheritance are particularly difficult" [10, p.5].

Possible pressure to undergo M/NT can jeopardize free and informed consent [30]. Couples "may forgo rational considerations of risks, benefits, and long-term consequences" and "are likely to fall victim of the therapeutic misconception in which they 'deny the possibility that there may be major disadvantages to participating in clinical research that stem from the nature of the research process itself'" [Appelbaum et al., in 43, p.188]. The fact that researchers and clinicians will be working very closely might further obfuscate the frontiers between research and clinical practice [61]. There is a lot to learn about the way mitochondrial disease is "experienced, measured and communicated", including "how [the] mutation ratio combines with experience to provide estimations of risk and projections of the future, how normative decisions are made about acceptable levels of mitochondrial mutation and how the boundaries between normal and pathological are negotiated by both patients, families and health professionals" [47, p.9].

Informed consent will vary from one family to another and the acceptable level of risk will remain a personal matter [31]. The "difference across patients in the severity of expected offspring symptoms in the event that [M/NT] is not taken will shape the decision of choosing the treatment versus waiting for the outcomes of further research" [64, p.1346].

Impact on specific interest groups

i) Persons suffering from diseases caused by mtDNA mutations

Some raise concerns regarding stigmatization of persons currently afflicted by mitochondrial disease [29,30,31,37], including a possible "knock-off effect on attitudes towards disabled people more generally" [39, p.18]. However, these arguments apply equally to currently socially accepted reproductive technologies aiming to avoid the transmission of genetic diseases [37,39]. Additionally, there is concern about the stigmatization of children born following M/NT as well as of parents who choose not to undergo the procedure [39].

ii) Scientists and researchers

The implementation of M/NT, or lack thereof, affects the relationship science has with society [10,22]. A specific area of research affected by M/NT is "[h]istorical and anthropological research on human population migration patterns and demographic history us[ing] mtDNA analysis and provid[ing] useful evidence of the geographical origins of humans, likely population sizes, and migration patterns" [6, p.533]. However, this issue was already addressed when egg and embryo donation were debated [27,30].

Resources

An important debate is centred on whether the costs associated with developing and introducing M/NT technology are justified by their supposed benefits [6,31]. Some argue costs are not justified because potential beneficiaries are "a very small minority

for whom there are other reproductive options" [6, p.534]. However, others say that categorizing potential beneficiaries as a "very small minority" tends to diminish their pain [27]. The annual number of women who can benefit from M/NT in the UK had been estimated between 10 [37,74,77] and approximately 150 [69,71].

An argument for the costs of the technology not being justified is that it does nothing for those already affected by the targeted diseases, and that the money invested in M/NT research might be better spent on looking for treatment options [16,22,28]. However, "families may use their own resources to pursue M/NT…minimizing public expenditure while increasing scientific knowledge and experience" [37, p.345]. While it is true that the targeted conditions affect a relatively small portion of the population, the financial cost of mtDNA diseases on children and their families is significant [27,37]. The usual cost-benefit analysis calculations may not be directly applicable to the case of M/NT, since it prevents disease "at the very beginning of life", whereas many therapies used as examples in the debate take place "at the end of life", thus making the net gain of M/NT "considerable" [22, p.676], especially if everyone can access it regardless of their financial situation [16,23,31].

An aspect of the uncertainty involved in implementing a new technology is the way in which it can be applied for other purposes. Scientists expect unexpected "spin-off" applications of M/NT to be significant [10,16,22,77]. Some, such as age-related infertility [16,78], "ageing and cancer" [40, p.10] are already being discussed.

Slippery slope

A slippery slope is defined as "[i]ntroducing or accepting a technology or application A that in itself is not morally problematic, would be problematic if doing so makes it impossible to avoid the subsequent introduction or acceptance of another technology or application B that is morally unacceptable" [22, p.675].

Four different kinds of slippery slopes have been raised in the literature. First, a slippery slope towards eugenics, whereby "once germ-line modification is accepted for therapeutic uses, it will lead to the application for non-medical uses, i.e., enhancement" [22, p.675] [see also: 9,11,14,15,17,24,27,28,29,37,41-45,48,50,51,58,60,61,73,74,79-82]. While M/NT may be eugenic in its "aims", it does not follow that it is "any *more* eugenics than existing methods of selective reproduction (abstinence, adoption, egg donation, etc.)" [34, p.638].

Second, the slope towards reproductive cloning involves the argument that although neither MST nor PNT are equivalent to reproductive cloning [8,11,44], "once they are accepted, they may well lead to [blastomere transfer], which clearly is a type of reproductive embryo cloning" [22, p.675] [see also: 8,11,31,44,58,61,83].

The third slippery slope argument is as follows: "If PNT or MST were approved for treatment in a jurisdiction, and the techniques became accessible and acceptable to prospective parents, clinicians or patients might then ask to use the techniques for purposes other than the avoidance of the transmission of serious disease, or which have no therapeutic intention" [31, p.81]. Three examples of such "misuse" are given:

a) using M/NT as an assisted reproductive technique for older, perimenopausal women seeking to have children [17,22,31,66,70];
b) using M/NT to establish a genetic link between the prospective child and more than two prospective parents when the prospective mother does not carry mtDNA mutations [6,27,30,31,44,73,82]; and
c) using M/NT "to allow a woman with a major genetic problem in her nuclear genes to create a genetic link with her child through the use of her mitochondria, without passing on nuclear DNA" [31, p.82].

Fourth, there may be a legal slippery slope whereby "the lifting of the UK ban may facilitate lifting of the ban and initiation of mitochondrial replacement in other countries" [74, p.154]. This argument may be refuted by the ultimate independence of different jurisdictions' legal systems [81,84].

Some claim that the slippery slope effect is an important enough ethical concern to impede the adoption of M/NT: "once one kind of germ-line therapy is accepted, other kinds will almost certainly follow" [42, p.20] [see also: 72]. However, the slipperiness of the slopes may be doubted. A "clear legal distinction between modification to the different genomes [exists], thereby forming a practical barrier to the threat of 'slippery slope' arguments" [31, p.65] [see also: 27,37,39]. Moreover, "this slippery slope is purely philosophical – not methodological, and it is certainly one that is easy to prevent by regulations" [27, p.518]. While technological innovations often carry the potential of abuse with them, this does not necessarily mean that they should not be implemented when the use does not constitute abuse [27,51].

Some question the wrongness of all those things at the bottom of the slopes: eugenics, reproductive cloning, etc. [22,39]. They argue that these "horrors worthy of a dystopian fiction novel" [61, p.3] are perceived as such because of an argument of last resort, often used to vilify possible applications of genetics in assisted reproduction: "unnaturalness" [55, p.1965]. Moreover, it is pointed out that this kind of debate is not new and that similar fears arise when other new technologies first become available [31,51,55].

Creation, use and destruction of human embryos

The "development of [M/NT] may necessitate the creation of embryos especially for research" [22, p.672] [see also: 10]. While research on human embryos is unacceptable to some [22], others argue that it is ethically acceptable when it aims to alleviate human suffering, and more specifically, that of children at risk of inheriting mitochondrial diseases [37,82]. Adopting a similar perspective and starting from the premise that few alternatives are available to affected families, the Nuffield Council on Bioethics (NCB) Working Group "agreed that, with the appropriate oversight, research that may destroy or alter eggs or embryos (and which may develop treatments which require the same), is justifiable in seeking to prevent serious genetic illnesses being transmitted" [31, p.85].

Beneficence

Physicians have a "duty to act to benefit their patients – both prospective parents and children," and parents have a duty to ensure the children they bring into this world do not suffer needlessly [37, p.345]. Authors point out that M/NT "falls within the good medical practice of preventing serious illness" [29, p.88] and "could offer significant health and social benefits to individuals and families, who could potentially live their lives free from what can be very severe and debilitating disorders" [9, p.74].

While no one debates the validity of the beneficence argument, the question remains "whether the benefit of averting severe disease overrides societal objections to changing the human germ line" [70, p.827]. The lack of debate regarding what constitutes an "acceptable risk-benefit balance" is lamented. "[W]e may be facing a whole new set of ethical questions related to intergenerational risk/benefit analysis" [61, p.4], that may require novel approaches. Braude suggests that prospective parents are "best placed to balance the risks" and benefits of the technology [83, p.1].

How much weight do the benefits carry? Some authors argue that we are nothing less than morally obliged to reduce suffering in future people at risk of disease [30,82]. Others bring to our ethical attention "the potential to remove an entire class of adverse and truly devastating genetic mutations from affected families and possibly from the human population as a whole" [27, p.518] [see also: 26,37,63]. It may be our duty as parents and society to prevent future children from inheriting genetic disorders [30,60]. Yet, given the recognition that it is possible to prevent future suffering without recourse to M/NT, the risk/benefit question becomes: "Does fulfilling some prospective parents' desire to be genetically related to their child override societal objections to changing the human germ line?" [6,9,11,14,31,37,57,83] Indeed, the NCB's Working Group argues that "[i]n light of the health and social benefits to individuals and families living free from mitochondrial disorders, and where potential parents express a preference to have genetically-related children…if the PNT and MST techniques are proven to be acceptably safe and effective, on balance it would be ethical for families wishing to use them to do so" [31, p.88].

This view is based on the often-implicit recognition of prospective parents' desire to be genetically related to their child as "being natural or even instinctive, whilst also being influenced by contemporary cultural and social norms" [31, p.68]. Others, while acknowledging the importance of such a desire, question whether it constitutes a right [16,24,48], especially when juxtaposed with ethical concerns. Then again, such questioning puts in doubt the acceptability of other socially sanctioned reproductive technologies whose main benefit is ensuring genetic relatedness between parents and children [14,53].

While it may seem that the scientific and bioethics communities are largely undecided on the matter, the literature suggests that there is, in fact, almost a consensus, with 15 articles [26,29,31,34,37,39,41,51,53,61,63,83,85-87] explicitly stating that "ethical concerns are outweighed by the arguments in favour of permitting mitochondria replacement" [39, p.4], and only 1 explicitly stating the opposite [24]. The remaining reviewed articles do not make explicit their position on where the ethical balance lies.

Limitations

A potential limitation of the present review is that a significant portion of the debate took place in the blogosphere as well as other types of popular media. While some blogs have a higher degree of credibility than others, it was decided that such texts should be excluded from a review of the scientific literature on the topic of M/NT. Nonetheless, the large number of commentaries, editorials, and letters to the editor that were included in the present review compensates for the omission of blogs and popular media. Moreover, aside from the usual caveats of qualitative analysis – albeit mitigated by the fact that two researchers coded the sources independently – several of the identified ELSI overlapped with one another (for example, the issue of financial "resources" invested in research on N/MT is often discussed in connection with the impact of M/NT on "*persons suffering from diseases caused by mtDNA mutations*", since the resources invested in N/MT are not intended to cure these people).

Discussion

The present critical interpretive review of the ELSI of M/NT highlights the issues most prevalent in the literature. Most of them – namely, identity of the child, relationship with the donor, parenthood, unknown risks to the offspring, risks to egg donors, the existence of available alternatives, consent of the yet unborn child, the impact of the technology on persons suffering of the same disability, the slippery slope argument, and the use of human embryos – have already been raised in relation to other assisted reproduction technologies that have since been accepted by society, such as IVF, PGD and intracytoplasmic sperm injection (ICSI).

The ELSI particular to M/NT are those stemming from the fact that M/NT involves germ-line modification, especially potential harms to future generations. Additionally, M/NT crossing the line into germ-line modification shapes the issues of intergenerational follow-up and the slippery slopes to nuclear DNA modification and misuse of the technique. These novel issues specific to M/NT call for a new framework for risk-benefit analysis, new research ethics guidelines, a register for long-term follow-up, a new system of contact or information exchange between the child and the donor, and an assessment of how M/NT will affect egg donors.

Arguments in the debate on the identity of the child go beyond those in the context of gamete donation, since they address the child's genetic link to three persons. Some of the arguments both for and against the implementation of M/NT are based on how the child's identity is affected by M/NT, and this is influenced by views on the nature of the genetic contribution of mtDNA [16]. These views in turn affect both the terminology chosen to refer to M/NT (e.g. "three-parent babies") and views on the relationship between the donor and child [39].

Given the diversity of potential ethical arguments against implementing M/NT in humans, it is possible to lose sight of the ethical argument in favour: beneficence. Some of the articles reviewed ignore this argument, possibly because the duty to benefit seems so obvious that it goes without saying and does not require discussion.

As M/NT was applied clinically to humans for the first time in 2015, its risks have yet to be studied. This contributes to much of the debate taking place in the media rather than in scientific articles. Commentaries, editorials, letters to the editor, and research news items made up the majority of the papers included in this review, which may lead to an overrepresentation of certain issues. Furthermore, of the 30 research articles reviewed, only two were based on empirical qualitative studies [16,47], neither of which analyzes specifically the views of M/NT's potential users (although Dimond has interviewed people suffering of mitochondrial diseases, they were not necessarily potential M/NT users). Even in the HFEA's public consultation, the focus group meeting included only 7 patients – some patients did, however, attend the "Open consultation meetings" that took place in two different cities [39]. Potential users are the target audience of M/NT and arguably the main stakeholder; they must therefore take significant part in the debate.

It is important to heed the calls of researchers, especially for follow-up research [5,10,24,54]. This should include longitudinal clinical research on all parties involved, as well as psychosocial longitudinal research to equip the ELSI debate with reliable evidence regarding questions such as: are there psychosocial harms and identity issues for the child and for the future generations, and if so, what are they? And what is the impact on egg donors, persons currently suffering of mtDNA diseases, and scientists?

Finally, when the stakes are this high, it is crucial to learn from past mistakes, such as the absence of registries in the context of gamete donation [88]. Registries to record the identities of donors, parents and children conceived through M/NT should be mandatory. The unpredictability of the risks to future generations largely justifies this approach.

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Appendix A. List of Articles and Reports Selected for the Review

Author	Year*	Title	Journal
Natural Science Original Research Articles (n=8)			
Amato, P. et al.	2014	Three-parent in vitro fertilization: gene replacement for the prevention of inherited mitochondrial diseases	Fertility and Sterility
Bongaerts, G.P.A.	2006	How to prevent 'half-bastard' progeny? or An alternative for three-parent babies: Two-parent babies through transplantation of sperm mitochondria	Medical Hypothesis
Mitalipov, S. & Wolf, D.P.	2014	Clinical and Ethical Implications of Mitochondrial Gene Transfer	Trends in Endocrinology & Metabolism
Richardson, J. et al.	2014	Concise Reviews: Assisted Reproductive Technologies to Prevent Transmission of Mitochondrial DNA Disease	Stem Cells
Rubenstein, D.S. et al.	1995	Germ-line therapy to cure mitochondrial disease: protocol and ethics of in vitro ovum nuclear transplantation	Cambridge Quarterly Healthcare Ethics
Smeets, J.M.H.	2013	Preventing the transmission of mitochondrial DNA disorders: Selecting the good guys or kicking out the bad guys	Reproductive Biomedicine Online
Spikings E.C. et al.	2006	Transmission of mitochondrial DNA following assisted reproduction and nuclear transfer	Human Reproduction Update
Wolf, D.P. et al.	2015	Mitochondrial replacement therapy in reproductive medicine	Trends in Molecular Medicine
Social Science Original Research Articles (n=21)			
Appleby, J.B.	2015	The ethical challenges of the clinical introduction of mitochondrial replacement techniques	Med Health Care and Philos
Bredenoord, A. & Braude, P.	2010	Ethics of mitochondrial gene replacement: from bench to bedside	BMJ
Bredenoord, A. et al.	2011[a]	Ethics of modifying the mitochondrial genome	Journal of medical ethics
Bredenoord, A. et al.	2011[b]	Nuclear transfer to prevent mitochondrialDNA disorders: revisiting the debate on reproductive cloning	Reproductive Biomedicine Online
Bredenoord, A. et al.	2010	Avoiding transgenerational risks of mitochondrial DNA disorders: a morally acceptable reason for sex selection?	Human Reproduction
Bredenoord, A. et al.	2008	Ooplasmic and nuclear transfer to prevent mitochondrial DNA disorders: conceptual and normative issues	Human Reproduction Update
Briscoe, R.	2013	Ethical Considerations, Safety Precautions and Parenthood in Legalising Mitochondrial Donation	The New Bioethics
Cheruvu, P.	2014	Three-Parent IVF and its Effects on Parental Rights	Hastings Science and Technology Law Journal
Dickenson, D.	2013	The Commercialization of Human Eggs in Mitochondrial Replacement Research	The New Bioethics
Dimond, R.	2013	Patient and family trajectories of mitochondrial disease: diversity, uncertainty and genetic risk	Life Sciences, Society and Policy
Fischbach, R.L. et al.	2014	Creating a Three-Parent Child: An Educational Paradigm for the Responsible Conduct of Research	Journal of Microbiology & Biology Education
Garasic, M.D. & Sperling, D.	2015	Mitochondrial replacement therapy and parenthood	Global Bioethics
Grossman, S.	2015	Mitochondrial Replacement Therapy and Jewish Law	Derech Hateva
Hens, K. et al.	2015	A leap of faith? An interview study with professionals on the use of mitochondrial replacement to avoid transfer of mitochondrial diseases	Human Reproduction

Jones, C. & Holme, I.	2013	Relatively (im) material: mtDNA and genetic relatedness in law and policy	Life Sciences, Society and Policy
McLean, S.A.	2015	Mitochondrial DNA transfer: some reflections for the United-Kingdom	BioLaw Journal
Moraes, C.T. et al.	2014	Manipulating mitochondrial genomes in the clinic: playing by different rules	Trends in Cell Biology
Paller-Rzepka, A.J.	2014	Are you my mother? Why mitochondrial DNA transfers require states to rework traditional, two-person legal parentage framework	Biotechnology Law Report
Ravindra Fernando, J.	2015	Three's company: A constitutionnal analysis of prohibiting acces to three parent in vitro fertilization	Notre-Dame Journal of Law, Ethics and Public Policy
Tendler, M.D. & Loike J.D.	2015	Mitochondrial Replacement Therapy: Halachic Considerations for Enrolling in an Experimental Clinical Trial	Rambam Maimonides Med J
Wrigley, A. et al.	In Press	Mitochondrial Replacement: Ethics and Identity	Bioethics

Reports & documents (n=6)

Department of Health	2014	Mitochondrial Donation: A Consultation on draft regulations to permit the use of new treatment techniques to prevent the transmission of a serious mitochondrial disease from mother to child	
FDA Cellular, Tissue, and Gene Therapies Advisory Committee	2014	Briefing Document. 2014. Oocyte modification in assisted reproduction for the prevention of transmission of mitochondrial disease or treatment of infertility	
HFEA	2015	Regulating Mitochondrial Donation: Seeking Expert Views	
HFEA	2014	Third scientific review of the safety and efficacy of methods to avoid mitochondrial disease through assisted conception: 2014 update	
HFEA	2012	Mitochondria replacement consultation: Advice to Government	
Nuffield Council on Bioethics	2012	Novel techniques for the prevention of mitochondrial DNA disorders: an ethical review	

Editorials, Commentaries, Letters to the Editor (n=37)

Allahbadia, G.N.	2015	Is the World of ART Ready for a Ménage à Trois?	Official Journal of the Federation of Obstetrics and Gynaecological Societies of India
Anonymous	2014	Three-parent babies: It's more messy than we thought	New Scientist
Anonymous	2014	Mitochondrial manipulations	Nature Medicine
Anonymous	2013	Don't fear babies made with genes from three parents	New Scientist
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Callaway, E.	2014	Reproductive Medicine: The Power of Three	Nature News
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Cyranoski, D.	2009	DNA swap could avoid inherited diseases	Nature
Dyer, C.	2015	UK is set to allow mitochondrial donation after MPs vote in favour	BMJ
Hamzelou, J.	2011	Three-parent babies on their way	New Scientist
Hawkes, N.	2012	Intervention to prevent transmission of mitochondrial disorders should be allowed, subject to safeguards, report says	BMJ
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List, M.	2014	Mighty mitochondria: a tiny organelle that can, and should, save lives	MSU Bioethics
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Passi, G.R.	2015	The Three Parent Embryo	India Pediatrics
Pitts-Tucker, T.	2012	UK fertilisation authority launches consultation on mitochondrial replacement techniques	BMJ
Randerson, J.	2004	Scientists seek to create 'three-parent babies'	New Scientist
Torjesen, I.	2014	Government gives the go ahead for mitochondrial donation during IVF	BMJ
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Vogel, G.	2014	FDA Considers Trials of 'Three-Parent Embryos'	Science
Vogel, G. & Stokstad, E.	2015	UK parliament approves controversial three parent mitochondrial gene therapy	Science
Wise, J.	2015	Mitochondrial donation could benefit 150 UK women a year, study says	BMJ
Wise, J.	2014[a]	Mitochondrial donation is "not unsafe," review confirms	BMJ
Wise, J.	2014	Draft UK regulations for mitochondrial donation are published	BMJ

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Beyond Empathy: Teaching Alterity

Paul Burcher[1,2]

Résumé
L'empathie clinique est de plus en plus reconnue comme un élément important du professionnalisme et des soins adéquats aux patients. Il est généralement compris comme identifiant les points communs entre le patient et l'intervenant, et répondant à cette expérience partagée, accompagnée de soins et d'attentions appropriés. Cependant, de nombreuses rencontres cliniques ont lieu entre des étrangers ayant peu d'expérience partagée, ce qui semble constituer un défi à la fois pour l'empathie et le sentiment de responsabilité envers le patient. Les médecins peuvent également développer un profond sens du caring et de la responsabilité en apprenant à apprécier l'altérité, l'extranéité du patient, et cette compétence comme l'empathie clinique peut être adaptée et enseignée. Le philosophe Emmanuel Levinas a décrit le respect de l'altérité comme fondamental dans les relations humaines. Autrement dit, ma première expérience de rencontre avec d'autres personnes en est une de différence, et non un sentiment immédiat de similarité. Ce sens de la différence est à la fois superficiel et profond, bien que le plus souvent nous ne reconnaissions que le superficiel. Reconnaître la profondeur de la différence ouvre à un sentiment radical d'altérité qui est la source de l'éthique, notamment notre responsabilité envers l'autre. En explorant les descriptions de la responsabilité humaine de Levinas, les humains comme infinis et uniques, et les conséquences de cette philosophie pour la rencontre clinique, il est évident que le respect de l'altérité représente une source sous-estimée de caring humain, accessible dans les relations cliniques, même entre un patient et un médecin avec des expériences de vie radicalement différentes. Les implications de ceci pour la formation médicale sont que nous devons aider les étudiants à apprécier et à respecter les points communs que nous partageons avec nos patients, et les différences qui les rendent spéciaux et dignes de nos soins et de notre attention.

Mots clés
alterité, empathie, Emmanuel Levinas, relations cliniques, éducation médicale

Abstract
Clinical empathy has been increasingly recognized as an important component of both professionalism and good patient care. It is generally understood as identifying commonality between patient and provider and responding to this shared experience with appropriate care and concern. However, many clinical encounters are between strangers with little shared experience, which seems to present a challenge for both empathy and a sense of responsibility toward the patient. Physicians can also develop a deep sense of caring and responsibility by learning to appreciate the alterity, the otherness, of the patient, and this skill, like clinical empathy can be modeled and taught. Philosopher Emmanuel Levinas described respect for alterity as foundational to human relationships. That is, my primary experience in meeting other people is one of difference, not an immediate sense of similarity. This sense of difference is both superficial and profound, although in most cases we will recognize only the superficial. Recognizing the profundity of difference opens one up to a radical sense of alterity that is the source of ethics, including our responsibility to the other. By exploring Levinas' descriptions of human responsibility, humans as infinite and unique, and the consequences of this philosophy for the clinical encounter, it is evident that respect for alterity represents an underappreciated source of human caring, accessible in clinical relationships, even between a patient and physician with radically different life experiences. The implications of this for medical education are that we must help students appreciate and respect both the commonality we share with our patients, and the differences that makes them special and worthy of our care and attention.

Keywords
alterity, empathy, Emmanuel Levinas, clinical relationships, medical education

"One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient."
Francis Peabody MD, 1927

Introduction

While I recognize that empathy as resonance with shared emotion, shared experience, and mirror neurons is all the rage, there is a problem for the clinical encounter if we identify this pathway as the sole or even primary source of clinical caring. Literature on clinical empathy emphasizes the ability to see from another person's perspective, to sense, and even "resonate" with their emotions [1-3]. The problematic implication is that clinicians can care best, or perhaps only really care at all, when patient and physician share enough commonality to form a therapeutic bond grounded in seeing the other as we see ourselves.

I acknowledge that commonality is an easy pathway to empathy and shared investment in a clinical relationship, and I support medical schools seeking to diversify their classes so that patients can seek out doctors who share their life worlds, look like them, and understand their language and idiom. But as a clinician-educator with more than 20 years of experience working with largely underserved populations, I believe there is another inherent pathway to care that is not grounded in recognition of sameness or even similarity, but rather appreciation, even awe, at the incommensurability of the life of a patient with my own. Listening to a patient and finding her story absolutely inconceivable within my experience, I may find that this profound sense of difference, even alterity, is a powerful source of human caring. This respect, even reverence for alterity may come more naturally to some than to others, but it can certainly be cultivated, and educators of medical students would do well to remember and teach both sources of human and clinical caring. Recognizing and respecting alterity is as important to human relationships as empathy, but unlike empathy, medical schools have not yet developed strategies for cultivating or re-awakening this fundamental human ability.

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The twentieth century philosopher, Emmanuel Levinas, spent his career elucidating a concept of care grounded in the recognition of alterity. Although the radical difference, or alterity, that Levinas is describing is present in every encounter, Levinas's writing often seems to suggest that we see this difference best when confronted with an other who strikes us as different in the more mundane sense of the word, particularly when we identify a need in the other (a common occurrence in the clinical encounter): "The Other is what I myself am not. The Other is, for example, the weak, the poor, 'the widow and the orphan.'" [4] The relative difference I may encounter with a patient from a different class, or race, or gender, which may be an impediment to empathy, might actually be an opening onto this sense of alterity.

My intention is not to replace empathy with a Levinasian sense of alterity and care, but rather to place the two beside each other as equally valuable tools in a clinical encounter, and therefore as concepts that both merit attention in medical education. The philosophy of Levinas does not preclude clinical empathy, a resonance grounded in a sense of likeness that allows clinicians to bond with patients and exhibit profound caring. However, this need not be the only avenue available to us as clinicians for caring deeply or feeling responsible for others. My claim is that physicians, and by extension medical training, must recognize both pathways, and their differences, to truly live up to the ideal set by Dr. Francis Peabody – caring for all of humanity.[1]

I will begin by briefly explaining the philosophy of alterity presented by Levinas, and then discuss its implications for the clinical encounter and medical education. His thought runs counter, or at least presents an alternative viewpoint, to the prevalent ideology of empathy taught today, that care for the other arises in recognition of patterns of sameness. Again, without denying the truth of this, our first reaction to meeting other people is not always a sense of similarity, but often of difference, and we do not always see this as a negative. Perhaps we are no longer small tribal cultures precisely because we have an innate capacity to respect, even embrace, difference.[2] This capacity may have increased over historical time from an acceptance of difference to actively enjoying seeing how different cultures, and different people, live in our shared world. Certainly, the great religions of the world have been teaching for more than two millennia that strangers are to be treated well, even honored in their foreignness. Levinas argues that recognition of difference in other people opens me to a world infinitely larger than my own selfish needs, and that this is the ground of my sense of responsibility.

Responsibility for the Other

My thinking on this subject was recently rekindled by a patient encounter I had while working in our prenatal clinic. I saw a young couple, refugees from Nepal, for a follow-up visit in the third trimester for her pregnancy. I noted that she had been diagnosed with latent syphilis at her first prenatal visit and had received the standard three-weekly doses of antibiotics to treat it. The treatments had ended one month prior to this visit, so I asked the husband whether he had yet received testing and treatment. His English was better than his wife's, but it soon became evident that he did not know that the disease was something he likely shared, and that he also needed to be treated. Furthermore, since he had not been treated, and did not understand that this was a communicable sexually transmitted infection, he had had unprotected intercourse with his wife since her treatment had ended, potentially re-infecting her and the fetus. This all unfolded in a slow, difficult conversation with them. A treatment plan took additional time and involved calls to the health department and additional nursing support. By the time the visit was done my clinic was running behind, but I made sure that their next visit was also with me so that I could ensure that the plan had been fully executed.

One could explain my response to this couple as a mere instance of a physician fulfilling his duty to beneficence. However, this characterization does not adequately capture my experience responding to the needs of this couple. Certainly, the feeling that we had failed them in earlier visits increased my sense of the need to make things right, but even greater was the palpable sentiment that these were strangers who needed help, and that to fail them again was to fail in a more ancient duty of hospitality. As I continued to reflect on this couple, the sense of responsibility I felt to them loomed large as the reason I did more than simply arrange partner treatment and move on. I felt responsible beyond simply my role a physician: I felt responsible to them as one person to another in the very primal way one responds to a child crying or a hungry stranger begging for food. This responsibility to the stranger is a central focus of the ethics of Levinas. The claim here is that rather than a duty to beneficence grounded in my role as a physician, I have a deeper duty founded in my humanity that gives rise to a desire to care for others when I sense their need, even though I sense this need as grounded in *difference* rather than something shared. This is responsibility with an emotive component, motivated by a deep sense of care rather than a detached obligation engendered by the physician role. If we accept that there is a second pathway to human caring that is triggered differently than the familiar pathway of empathy, we should acknowledge that, like empathy, it is valuable to teach and preserve this sense of respect for alterity in medical education.

[1] Although I am obviously deeply indebted to the work of Emmanuel Levinas in his elucidation of alterity, I do not strictly follow his language or thought in this essay. For example, while he would reject any attempt to speak about a shared human experience, I do not go this far in my own thinking, and thus am comfortable referring to it in various ways throughout this work.

[2] Many of us in United States are concerned about a descent back into tribalism, nonetheless the capacity to rise above this seems to be present.

In seeing the other as different from myself, I must acknowledge someone I may not fully understand, and in fact, who may have needs and a worldview I do not share. Levinas writes that the encounter with another person produces an imperative from the start – I see her need, and I feel responsible [4].

It is not Levinas's claim that I see or feel this responsibility to an other in each encounter, but rather that it is there, and it is the ground or the condition for my relationship with others [4]. But perhaps the clinical encounter, where physician responsibility is encoded in the nature and goals of the encounter, opens us to seeing this fundamental responsibility to the other. This is then a "teachable" moment, where the physician has perhaps greater awareness of the ground for the more specific clinical ethics of beneficence and nonmaleficence. That is, we may be uniquely open to feeling the responsibility that Levinas believes grounds all authentic human relationships because the role of physician has this duty explicitly enumerated. Or, beginning from the other side, this basic human response may be the source of the duty to the patient that physicians have accepted since the time of Hippocrates. Modeling this openness and responsibility is something clinical educators need to demonstrate and encourage. This must include showing interest and respect for the lives of our marginalized patients, not just tolerance or a neutral "non-judgmental" stance.

But is it fair to ask whether this responsibility to the other necessarily implies alterity? Perhaps responsibility is engendered by a feeling of commonality when we can see the other as a being who, like us, is imperfect and has needs. What is it about seeing a starving child from the developing world that pulls at us – the similarity we feel or the fact that we are not hungry, and we cannot help but care for someone who lacks what we do not? But this still a repetition of the question regarding whether the care is arising from a sense of shared-ness rather than an encounter with someone who shatters the comfortable world that appears to serve only us. To fully grasp Levinas's perspective it is important to examine why he claims that encountering the other is an encounter with infinity, because the alterity of other people is not just the kind of difference between blue and red. It is a difference of kinds.

The Other as Infinite

Levinas's argument for the infinite nature of the other is both phenomenological and a critique of Western philosophy. The history of philosophy, he writes, is the project of reducing the other to the same [5]. To become an object of knowledge, or the aim of one's consciousness, is to be reduced to an object of intentionality, and thus to be placed into a relation with the self where the self has now fully claimed the other as its own, that is, fully knowable. Levinas describes knowing as a grasping and "assimilation." [6] But intentionality, a phenomenological term for the way in which consciousness is directed at something, the object of consciousness, breaks down when consciousness is directed at another person. The other cannot be "encompassed" by thought, cannot become a mere idea or object for us: "A face is pure experience, conceptless experience. The conception according to which the data of our senses are put together in the ego ends, before the other, with de-ception, the dispossession which characterizes all our attempts to encompass this real." [6]

The "conception" ends because we cannot simply make others into things in our world; we are "dispossess(ed)" in that the world belongs to us, but other people do not. We cannot even fully perceive them in the same sense as the rest of the world which lies bare to our perception, and thus they are a "de-ception" an absence, a hole, in our perceiving consciousness. While Levinas's language here is poetic, and also somewhat theological, his point is clear: if I am open to it, the other person confronts me and challenges me in a way wholly different than the rest of the familiar world.

The object of consciousness that cannot be satisfactorily assimilated by consciousness is the Cartesian definition of the infinite, and so Levinas concludes that I experience the infinite, or experience the unexperienceable, when I meet an other, and truly see the other as other. If the other person is my entry point to the infinite, a break from the sameness of the world, it is not surprising that Levinas writes that I experience "height" when I am in relation to another [5]. By "height" he is gesturing both toward the sense of something greater than myself, and also to an asymmetry that I will soon describe. Only in the presence, or as Levinas describes, in "proximity" to another do I have access to someone who shows me the limits of my own world and has the power to truly surprise me.

This notion of "height" has, I believe, implications for the clinical encounter if the physician appreciates it. Paul Ricoeur, a colleague and interlocutor of Levinas, recognized that the patient-physician relationship begins in an asymmetrical power relation with the physician firmly in control [7]. But, he argued, as a patient tells her story, the physician can become drawn into the other, and find herself seeking to serve the person now seen through their story. While Levinas was much less sanguine about our ability to truly or fully "see" another even in dialogue or narrative, he would concur that appreciating the radical exposure to someone truly different from ourselves can neutralize the asymmetry of the clinical encounter. Even in their need, the patient presents a striking opening into a someone who is not us, is not for us, and who is ultimately beyond our control in a way non-human things are not. Levinas's point here has important implications for how we, as clinicians, should understand the "noncompliant patient," which is a theme I have developed previously [8]. Teaching students that we can guide and make recommendations, but to accept that we cannot, and should not, seek to control our patients, is a lesson made easier when we have taught them to respect, not fear, the otherness of our patients.

A New Source of Care

Levinas's philosophy may offer a challenge to commonplace thinking regarding clinical empathy. The too familiar other, the other who we see as a reiteration of ourselves, will not necessarily allow a sense of awe that the true stranger may engender. My suggestion is not that the teaching of empathy as finding resonance with another is wrong, but rather that it is incomplete. We need not despair that physicians must fall back on a specific sense of beneficence when treating patients who are "foreign" to them. As David Hume taught, ethics without emotional engagement lacks motivation [9]. Levinas answers this problem by showing us a pre-socialized sociality that relies on respect and response to alterity, rather than an appreciation of likeness. If this claim is correct, then medical students can be shown that the kind of emotional caring for the other that we have to date ascribed only to empathy, may arise either from seeing the other as similar to ourselves, or by seeing the other as truly and remarkably other in a way that makes our world larger and shows us a new and different way of living. Teaching this begins in seeing it.

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ÉTUDE DE CAS / CASE STUDY

L'utilisation de données de recherche sans votre accord lors d'un partenariat de santé mondiale

Valéry Ridde[1,2]

Résumé
La recherche en santé mondiale est la majeure partie du temps réalisée dans un contexte de collaboration internationale, notamment Nord/Sud. Le contexte particulier de ce type partenariat (pouvoir, argent, distance, normes, formation, etc.) peut notamment entrainer des enjeux importants dans l'utilisation des données collectées. Cette étude de cas permet au lecteur de s'interroger sur cet enjeu et sur les actions qu'il pourrait réaliser pour y faire face.

Mots clés
partenariat, santé mondiale, données, éthique, confiance

Abstract
Global health research is most often spent in a context of international collaboration, particularly North-South. The particular context of this type of partnership (power, money, distance, norms, training, etc.) can lead to important issues in the use of the data collected. This case study enables the reader to reflect on this particular issue and the actions that could be taken to deal with it.

Keywords
partnership, global health, data, ethics, trust

Introduction

Dans le contexte de la recherche en santé mondiale, la majorité des travaux sont effectués en partenariat entre des équipes du Nord et du Sud, et de plus en plus Sud-Sud [1,2]. Ce type de fonctionnement, notamment lorsqu'il s'agit de réaliser des enquêtes de grande ampleur et la production de multiples données, engendre des défis particuliers sur leur utilisation [1,3]. On n'abordera pas ici les défis concernant l'implication des personnes (i.e., consentement éclairé, etc.) mais ceux de la collaboration entre équipes de recherche. La plupart du temps, au risque de caricaturer, les partenaires du Sud collectent les données et ceux du Nord sont chargés de trouver le financement puis coordonnent (voire réalisent) le processus d'analyse, avec ou sans la collaboration des collègues du Sud [4]. Rares sont les équipes qui se dotent de politiques d'accès et d'utilisation de ces données [5]. Ainsi, en leur absence, la gestion des problèmes qui peuvent apparaître à l'égard de l'utilisation de ces données peut poser des défis importants au partenariat. On peut, par exemple, penser à la question de la signature scientifique, à l'utilisation des données secondaires, à la qualité de la collecte des données, à la diffusion des données sans l'autorisation des partenaires, etc. Évidemment, ces problèmes ne sont pas propres à un pays ou un contexte particulier, ils peuvent être provoqués par des chercheurs du Nord comme du Sud et porter préjudice à ceux du Sud comme du Nord [4]. La conduite responsable de la recherche dans ce type de partenariat [6] n'est jamais facile car elle se déroule dans un contexte de relations de pouvoirs, de collaboration à distance, de différences culturelles ou normatives, de formation des étudiants et des chercheurs [2,7], etc. Cette étude de cas, rédigée à partir de situations réelles mais produite pour garantir l'anonymat des contextes, vise à permettre au lecteur de s'interroger, et réfléchir aux actions qu'il aurait réalisées, lors d'une situation problématique de l'utilisation de données sans accord préalable du partenaire.

Cas fictif inspiré de plusieurs histoires réelles

Vous avez une idée de recherche très innovante, qui est ancrée en vous depuis 20 ans mais que vous avez encore du mal à financer. Vous croyiez en effet essentiel, comme la littérature scientifique l'affirme depuis longtemps, de suivre la vie d'un groupe de filles dans une province de l'Inde afin de comprendre leur situation de santé à l'adolescence. En effet, organiser une telle cohorte des mêmes personnes permet de mettre au jour leur parcours de vie, depuis la naissance, et d'étudier le rôle des déterminants sociaux de leur santé sexuelle et reproductive lorsqu'elles arrivent à l'âge de la reproduction. Cela pourrait être même une opportunité pour les suivre très longtemps, y compris dans leur vie de femme et de mère plus tard. Il se trouve justement que la coopération américaine (USAID) a lancé un appel pour financer des études de cohortes en Inde sur ce sujet et pour un minimum de 10 années, renouvelable une fois. C'est une occasion inespérée pour vous, chercheur dans une université de Floride et disposant depuis longtemps de collaborations en Inde. Vous contactez vos collègues en Inde[1], montez une équipe, rédigez la proposition et vous gagnez le concours. Un financement de 6 millions de dollars pour 10 ans vous a été octroyé. Ainsi, vous démarrez enfin votre rêve de chercheur. Vous lancez votre première cohorte de 1500 jeunes filles vivant dans une dizaine de villages de l'un des États les plus pauvres de l'Inde. Elles vont devoir répondre à un questionnaire une fois tous les six mois pendant 10 ans et ainsi vous permettre de suivre l'évolution de leur état de santé, notamment.

[1] Le nom des pays a été choisi au hasard mais est réel afin de rendre le cas plus vivant. Mais il ne présage en rien de l'existence, ou non, de politiques ou de pratiques d'une conduite responsable de la recherche.

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Votre collaboration avec vos collègues est ancienne et vous avez toute confiance depuis longtemps. Ainsi, vous ne vous rendez sur place qu'une fois par année, durant 10 jours, votre coordinateur de recherche s'y rend lui plus souvent, trois fois par année.

Cependant, après trois ans de recherche, vous apprenez par hasard la soutenance d'une thèse de médecine dans cet État de l'Inde dont le sujet est très proche du votre. Vous êtes étonné car vous n'avez encore rien publié sur ce sujet avec les données de la cohorte car vous pensez mieux d'attendre d'avoir des informations sur cinq années pour renforcer la robustesse de vos analyses. Vous pourriez publier plus vite mais vous êtes connu pour procrastiner et il est en effet possible que des données de plusieurs années permettent plus facilement de répondre à vos hypothèses de recherche. Vous arrivez à récupérer le document de la thèse qui a été soutenue publiquement avec mention devant un jury de professeurs du pays. Aucun de ces professeurs ne s'est demandé comment un étudiant de médecine pouvait financer une telle collecte de données et analyser autant d'informations. Mais à juste titre, car vous découvrez que la directrice de cette thèse n'est autre que votre collègue avec qui vous dirigez cette cohorte depuis plusieurs années. À aucun moment, elle ne vous a informé de cette utilisation des données pour cette thèse. De plus, en regardant le nom de cet étudiant vous constatez qu'il était l'un des superviseurs des enquêteurs qui passe tous les six mois dans les villages pour administrer le questionnaire. Il avait donc facilement accès aux données, en effet. Pour votre université de Floride, ce comportement est un manquement flagrant au code d'éthique et des bonnes pratiques de recherche. Vous êtes embêté car votre recherche doit nécessairement se poursuivre car la cohorte doit absolument continuer puisque sans ces données sur 10 ans, vous serez incapable de répondre à vos questions de recherche, vous ne saurez quoi dire à l'USAID et surtout, vous devez renoncer à l'idée qui vous guide depuis toujours!

Questions

1. Quels sont les différents enjeux éthiques mis au jour par ce cas?
2. Quelles options s'offrent à ce chercheur pour agir?
3. Qu'auriez-vous fait à sa place?

Conflit d'intérêts
Aucun déclaré

Conflicts of Interest
None to declare

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ÉTUDE DE CAS / CASE STUDY

Publication et collaboration avec le financeur d'un contrat de recherche

Valéry Ridde[1,2]

Résumé
Cette étude de cas en santé mondiale met au jour les enjeux éthiques associés à la signature scientifique dans le contexte d'un contrat de recherche octroyé par une organisation internationale.

Mots clés
santé mondiale, contrat de recherche, publication, signature scientifique

Abstract
This global health case study uncovers the ethical issues associated with scientific signature in the context of a research contract awarded by an international organization.

Keywords
global health, research contract, publication, scientific authorship

Introduction

En santé mondiale, il arrive parfois que les chercheurs réalisent des études financées par un contrat octroyé par une organisation non gouvernementale ou une organisation internationale. Ce type de financement (parfois compétitif) et cette relation avec un « client » impliquent des formes de collaborations particulières [1]. Elles peuvent avoir des incidences éthiques, notamment en ce qui concerne la signature scientifique [2-4], même si cette question est parfois enchâssée dans le contrat de financement définissant la propriété intellectuelle des travaux. L'objectif de cette étude de cas est de présenter une telle situation afin de permettre aux lecteurs de comprendre les enjeux éthiques que ce contexte de collaboration avec le financeur d'un contrat de recherche met au jour.

Cas fictif inspiré de plusieurs histoires réelles

Une organisation internationale dans le domaine de la santé des personnes âgées lance un appel d'offres international pour recruter une équipe de chercheurs afin de réaliser une revue systématique de type *Realist* des écrits scientifiques. L'objectif est de mieux comprendre l'efficacité, la mise en œuvre et le rôle des contextes locaux des interventions en Afrique pour améliorer la qualité de vie des personnes âgées. L'appel est lancé début janvier 2015 et ils attendent les propositions pour le 13 février 2015. L'appel explicite clairement les « termes de références » et fournit les noms des personnes responsables au sein de l'organisation internationale. Il s'agit de deux de ses fonctionnaires, l'une d'Afrique de l'Est avec un doctorat en anthropologie et l'autre est canadienne avec une maitrise de gérontologie et sociologie.

Vous êtes un-e chercheur-e reconnu-e du domaine au Canada, car vous êtes une des rares personnes à travailler sur le sujet des personnes âgées en Afrique. Intéressée par ce contrat de recherche, vous montez rapidement une équipe d'experts internationaux, deux chercheures en gérontologie de Belgique et du Mali et un spécialiste des revues de type *Realist*. Vous écrivez la réponse à l'appel d'offres et votre proposition finale est retenue. Un budget de 50 000$ vous est octroyé et vous avez 18 mois pour réaliser la recherche et fournir le rapport final. La signature du contrat est un peu longue pour des raisons administratives, comme cela est souvent le cas entre une organisation internationale et une université, mais finalement cela est réalisé. La fonctionnaire canadienne de l'organisation vous répond : « *C'est un plaisir pour moi de savoir que tout est en ordre, merci pour l'appui et aussitôt fini produisons un papier avec* ». Alors qu'elle est le financeur de l'étude dont la sélection a été compétitive et vous êtes les chercheurs, elle semble donc d'emblée se positionner comme voulant publier avec vous par la suite. En effet, dans une conversation téléphonique de suivi du projet, elle vous rappelle le fameux dicton « *publish or perish* » et combien elle, maintenant devenue fonctionnaire et n'œuvrant plus dans le monde universitaire, souhaite continuer à publier.

Comme souvent dans ce domaine, vous décidez de publier le protocole de recherche dans une revue avant de vous lancer dans les analyses. La publication du protocole vous permet d'informer la communauté internationale de la réalisation de la synthèse des écrits et ainsi de vous positionner, mais aussi d'éviter une possible duplication. L'article du protocole est une reprise renforcée et améliorée de votre réponse à l'appel d'offres de cette organisation.

Par la suite, vous avez recruté un assistant de recherche et le projet avance bien. Vous avez quelques réunions avec vos collègues universitaires et l'application des critères stricts de sélection fait en sorte que vous avez retenu plusieurs articles pour votre analyse. Alors que vous étiez encore dans la procédure d'extraction des données, la fonctionnaire vous écrit : « *J'aimerais soumettre un résumé de ce travail en même temps que plusieurs autres provenant de notre organisation pour une conférence internationale qui se tiendra en Russie sur la santé des personnes âgées. Pourriez-vous vérifier le brouillon du résumé que j'ai rédigé ?* » Surpris par le message courriel, vous ouvrez le fichier Word, découvrez le résumé de l'étude que vous aviez soumis, votre nom et celui de vos cochercheurs, celui de la fonctionnaire à la dernière place de la liste des auteurs, mais aussi deux de ses collègues du siège de son organisation dont vous n'aviez encore jamais entendu parlé.

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Questions

1. Quels sont les enjeux déontologiques et éthiques abordés dans cette étude de cas?
2. Proposeriez-vous à cette fonctionnaire de signer l'article de publication du protocole?
3. Comment réagiriez-vous à sa demande de soumission d'un résumé pour une conférence?
4. Penseriez-vous fondé de l'impliquer dans l'écriture et la signature de l'article qui présente les résultats finaux de la revue *Realist*?

Conflit d'intérêts
Aucun déclaré

Conflicts of Interest
None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

From the Middle Ages to the 21st Century. Abortion, Assisted Reproduction Technologies and LGBT Rights in Argentina

Florencia Luna[1,2]

Résumé
Malgré des changements législatifs “progressifs” concernant le collectif de lesbiennes, gays, bisexuels et transgenres et les technologies de reproduction assistée en Argentine, les femmes et leurs droits sexuels et reproductifs ont été négligés. Cet article présente une perspective critique de certaines de ces modifications législatives dans le pays. Il explique pourquoi certains législateurs et membres de la société sont prêts à défier une approche conservatrice, voire traditionnelle, pour certains groupes tout en ignorant les autres. Plusieurs facteurs sont en jeu. Il n’y a pas une seule explication. Je souligne qu’un double standard frappant prévaut en Argentine en ce qui concerne les femmes et leurs droits sexuels et reproductifs. Je soutiens également qu’il existe une discrimination puissante, en particulier contre les femmes pauvres, qui continuent de souffrir et d'être “punies” à travers la criminalisation de l’avortement.

Mots clés
avortement, technologies de reproduction assistée, LGBT, genre, pauvreté, discrimination

Abstract
Despite “progressive” legislative changes concerning the lesbian, gay, bisexual, and transgender collective and assisted reproductive technologies in Argentina, women and their sexual and reproductive rights have been overlooked. This article presents a critical perspective of some of these legislative modifications in the country. It addresses why some legislators and members of the society are prepared to challenge a conservative or traditional approach for certain groups while ignoring others. Several factors are at play. There is no all-inclusive explanation. I stress that a striking double standard prevails in Argentina with respect to women and their sexual and reproductive rights. I also contend that powerful discrimination exists, in particular against poor women, who continue to suffer and are “punished” by the criminalization of abortion.

Keywords
abortion, assisted reproduction technologies, LGBT, gender, poverty, discrimination

Introduction

Latin America (hereafter LA), a region with great potential and abundant resources, still falls behind in matters of justice and gender sensitivity. Health is deemed a social good and a degree of idealism prevails. However, a dark side coexists with these benefits and ideals: deep-rooted problems, widespread corruption, authoritarianism, discrimination and strong inequalities. One issue that is often overlooked or downplayed are women’s conditions and the deficient respect for their sexual and reproductive rights. Even though LA shares a strong cultural and religious heritage, differences between countries exist. To avoid generalizing or trivializing my proposal, I will focus on the Argentine case.

In what follows, I will examine the direction that laws on the Lesbian, Gay, Bisexual and Transgender (hereafter LGBT) collective and assisted reproduction technologies have taken. These laws have a “progressive” position and go beyond the “status quo”. However, even if changes are taking place, they are not consistent. For example, the abortion situation has not varied and it is still strongly criminalized. Thus, some groups’ rights have been protected while others are left aside. Among other possible explanations, I argue that a striking double standard prevails in Argentina with respect to women and their sexual and reproductive rights. I also claim that a powerful discrimination exists that targets poor women in particular: they are ignored, silenced and forgotten.

The article begins with some clarifications. I first explain the links in these three supposedly unrelated areas and explain why I am examining the legal path. I then consider the legal situation of abortion, as well as its impact on women’s health and their lives. Second, I present the legislative changes addressing some marginalized populations, such as the LGBT collective. I then analyze the new Argentine law concerning assisted reproductive technologies (ARTs). Finally, I provide some possible explanations for the dissimilar legal situation present in the aforementioned areas.

Some clarifications

At first glance, the topics in this article may appear to be unrelated. However, they have a relevant common thread: persons who have had an abortion, belong to the LGBT community, or opt for the use of assisted reproductive technologies live their sexuality or reproductive choices in a way that Argentina’s status quo questions. They defy the traditional or conservative morality. Their actions assume a degree of tolerance and respect from others, but such respect is not easily found in the more conservative or traditional sectors of society that tend to interfere or implement restrictions.

In what sense do these persons and their actions defy traditional morality? Abortion is a controversial topic, not just because of the moral status of the embryo but most importantly because it implies that women can choose how many children they want and when to have them. Abortion offers women the opportunity to end undesired pregnancies. Pregnancy ceases to be

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a fate and becomes a decision, a choice. For patriarchal societies where maternity is “essential” this position is highly subversive. The LGBT collective has always been spurned and persecuted. As in many societies, this group has been strongly stigmatized in Argentina. It is very difficult for a traditional society to accept a sexual identity that does not conform to the external perception people have of sexuality. In this regard, LGBT people have been the subject of discrimination, with different legal rulings against them. The third set of practices concerns ARTs. They involve a non-natural way of reproducing and several features have been criticized. Children can be genetically related to their parents or not: they can be conceived with sperm, ova or embryos from another person. In many cases the social, biological and genetic “mother” may be a different person. Other criticisms point to the possibility of the manipulation and destruction of embryos, or surrogacy practices. Although ARTs are offered in private clinics and many women undergo these treatments, for decades they have been performed without the approval of the Catholic Church, without any regulation, and with a problematic judicial ruling.

The practices we are going to examine also involve laws, judicial sentences or rulings that banned their performance or that threatened these groups. For example, since 1921 the Argentine Penal Code (Article 86) has forbidden abortions, with three exceptions: when the woman’s life is endangered, when her health is at risk and when the woman is the victim of sexual violence. But these three exceptions are not necessarily observed. Manifold obstacles exist – from a distorted interpretation of the law to the reluctance of physicians and gynecological services in public hospitals to carry them out owing to conscientious objections. Paola Bergallo interprets such actions as part of an informal rule establishing a de facto prohibition of abortion services [1]. As Bergallo points out, informal rules can operate in the so-called “brown areas” of the State. They can reinforce, subvert or even overturn formal rules, procedures and organizations that try to guarantee that exceptions be respected [2]. The situation regarding the provision of abortion is so deficient that the enforcement of the three exceptions allowed by the Penal Code since 1921 has been and is still a struggle of the women’s movement and feminists in the country. For example, Bergallo [1] shows how conservative actors deployed an array of legal arguments and strategies that inhibited the provision of legal abortion authorized by Article 86. And this is so even if progressive actors developed new strategies to enforce the duty to provide legal abortions.

These struggles began with a first stage characterized by the adoption of simple procedural rules followed by minor implementation policies. This battle transitioned to a second phase when the guidelines became justified in terms of rights and were accompanied by an increasing degree of compliance. A third stage of this process finally occurred when the Supreme Court ruled on F.A.L (a pivotal case of abortion that was taken up to the Supreme Court) in early 2012. But as Bergallo acknowledges, all these changes coexisted within extensive areas of the country that were still subject to the informal rule [1 p.151]. In 2012 the Supreme Court ruling [3] reaffirmed that the exceptions to the Penal Code were constitutional and conventional, thereby establishing that they should be guaranteed. It also produced standards for their implementation. However, the executive and legislative branches of the State have done nothing to foster legal and safe abortion practices. Bergallo points out, “Moreover, President Fernández de Kirchner remained silent about the Supreme Court’s decision. Had the president mandated compliance with the Supreme Court’s order, all the government officials would have followed her order.” And she adds, “Similarly, the National Ministry of Health for Argentina has not advanced any significant initiative to promote the implementation of the Court orders in F.A.L […]”. Today, non-punishable abortion cases are not respected consistently in the country (many provinces ignore them). A survey [4] reported that only five provinces had guidelines that satisfied the standards delineated by the Court in F.A.L, the remaining ten provinces that have procedural requirements are more demanding than those that the Court defined, and the rest of the jurisdictions (9) do not have any rulings. Thus, despite all the efforts depicted by Bergallo, she acknowledges that “by the end of 2012 the actual provision of Article 86 abortion services is far from a reality across the country” [1]. And this has not changed! A formal and informal penalization of abortion and the implementation of exceptions make it difficult to apply. To solve this and end the problem of access to safe abortion, Bergallo argues that legislation introducing an early stage decriminalization model is preferable to exceptions or permissions [5]. However, progressive legislative positions are absent, and the possibility of changing the law regarding abortion remains unthinkable in Argentina.

As was mentioned, Argentina’s LGBT community was discriminated against and marginalized. Not only were their rights not respected, but members of this community were criminalized and persecuted. Even after the last dictatorship (1983), during democratic periods, *Edictos Policiales* (police rulings) criminalized offences and infractions related to homosexuality and transvestite practices. These rulings justified, among other attitudes, violence towards them and, in practice, denied LGBT persons basic public services. For example, sick transgender persons have poor access to health services. As Socias et al. [6] explain, “Transgender women […] often experience multiple forms of oppression for transgressing gender norms, such as stigma, discrimination, isolation and economic hardship”. In 2011 the prevalence of HIV infection reached 34% in these minority groups compared to 0.4% in the general population [7]. Moreover, in Argentina transgender women have a life expectancy of approximately 35 years compared to 79 years in other women [6,8]. Their access to education and formal work has also been quite difficult and most end up as sex workers.

Finally, the third set of practices I examine also shares similar problems. ARTs have long been available in Argentina but they were unregulated. For decades, several bills were proposed but not passed. This difficulty was mainly related to the moral status of embryos. Conservatives and Roman Catholics deemed the entire artificial process unacceptable and they found the possibility of cryopreserving and discarding embryos most questionable. According to their position – quite prevalent in Argentina and the region – embryos are persons (sometimes holding more rights than women). Laws regulating these practices were not sanctioned, but in 2005 a particular judicial figure was created thanks to a ruling of the City of Buenos Aires: the special guardian of embryos. This figure could register and protect embryos, much like the legal guardian of minors [9]. The

latter legal figure is used in the case of orphans but, in this case, the guardian of embryos oversees ex-uterus embryos. At the time, centres or clinics carrying out ARTs opposed this judicial ruling and the new legal figure. They argued that it contravened the privacy and confidentiality of their clients, but they could not modify the ruling.

This legal hurdle jeopardized the practice of ARTs, which were only performed in private clinics. In addition to this challenging ruling, there was also the perception that a new court ruling or law could ban the entire practice of ARTs at any moment in order to protect "innocent embryos" (the emotionally charged terminology used by conservative groups and members of the Catholic Church) [9]. This understanding was by no means an overreaction as something similar had happened in Costa Rica. In 2000, a Supreme Court ruling banned nearly all ARTs in Costa Rica; only homologous insemination for married couples was accepted [10]. The decision was aimed at protecting embryos and preventing their destruction [11]. The case eventually ended in 2012 (note that it took more than a decade to resolve) with the Inter-American Court of Human Rights' sanction of Costa Rica. One of the judgments of this court in the Costa Rica decision was that the protection of life from conception is not applicable between fertilization and embryonic implantation in utero; that is, un-implanted embryos resulting from IVF do not possess a right to life [12,13]. But until this ruling, the possibility of banning all or some of these procedures prevailed in the region. In Argentina, as ARTs were not explicitly forbidden, these techniques could be provided. However, the situation was certainly unsettling.

So, these three groups of practices and the persons involved are all rejected by the status quo, lacked regulation and protection, and face direct prohibition. In this article I will consider legislations that have been enacted in recent years concerning the two latter groups (LGBT collective and ART users). I believe that some laws can have an impact on society. They can be a first step towards accepting different practices and demonstrate an interest in solving specific problems, as well as ignore others. This does not mean that all the changes that a society incorporates must be enacted through laws. However, when persons are stigmatized or when practices are forbidden and/or condemned, there is a need to change the law. For example, in order to gain access to a safe abortion in a public hospital, the Penal Code's current prohibition must be amended. Another case focuses on the transgender population: a study conducted just one year after the enactment of the laws – to be considered later in this article – shows the impact they had enabling this group to access health care [14]. Obviously, this impact not only had to do with the law but also with the work of non-governmental organizations (NGOs) informing transgender people of their rights. But these laws served as a first step towards change in society.

Criminalization and stigmatization are closely related [15]. In this sense, some laws de-criminalizing or accepting certain practices can function as generators of change. However, they may not suffice. In other words, laws may not reverse entrenched prejudices and practices embedded in society. I am fully aware that it takes more than rulings to transform social structures, especially when we are speaking of deeply rooted discrimination. Nevertheless, a law protecting persons, behaviours or actions provides the legal groundwork to require or demand respect for such law. It allows those concerned, lawyers, and NGOs to be able to advocate and demand the fulfillment of that right, as well as restrain those that disrespect them. In this sense, it is quite relevant to analyze what the trend is and whose rights are involved. For this reason, I examine how some laws have developed and which groups they are effectively protecting. I then present some recent laws from 2010 onwards, a period in Argentina where human rights were specifically part of the political discourse and political changes.

The impact of abortion legislation

In global terms, according to the World Health Organization (WHO),

> unsafe abortion accounts for 13% of maternal deaths, and 20% of the total mortality and disability burden due to pregnancy and childbirth. *Almost all deaths and morbidity from unsafe abortion occur in countries where abortion is severely restricted in law and in practice*. Every year, about 47,000 women die from complications of unsafe abortion, an estimated 5 million women suffer temporary or permanent disability, including infertility. Where there are few restrictions on access to safe abortion, deaths and illness are dramatically reduced [16, my emphasis].

Along similar lines, the WHO [16] also explains that 99% of maternal mortality occurs in developing countries. This implies the death of otherwise healthy young women and constitutes an inequality index. For example, compared to 11 maternal deaths per 100,000 born live in Canada, LA registers 72 per 100,000 live births. As Rebecca Cook points out, people have to move beyond quantitative data and show the stigmatizing harms that aborting women suffer. So we should also acknowledge the weight that criminal law instills in society and how women are constructed and stigmatized by criminal law [15].

When the rights of women to make autonomous decisions regarding abortion are restricted, a wide range of human rights are threatened. The right to life is threatened, not only from the risk of undergoing unsafe abortions, but because, for example, the continuation of unwanted pregnancies increases the likelihood of postpartum depression. Evidence shows [17,18] that this is one of the most common causes of postpartum suicide. Restrictive abortion laws affect the right to health, not only because they prevent access to safe abortion practices, but also because women face delays in obtaining health care following complications due to abortions performed outside the health system. Women fear being penalized and thus arrive for care when it is too late, increasing abortion-related morbidity rates. Similarly, the rights to freedom, to privacy, to information

(especially on reproductive matters), to non-discrimination, and not to be subjected to torture or to cruel, inhumane or degrading treatment or punishment, etc. are violated [19,20].

"Almost every one of these deaths and disabilities could have been prevented through sexuality education, family planning, and the provision of safe, legal induced abortion and care for complications of abortion" [16]. Death because of risky or unsafe abortions is absolutely preventable. The WHO maintains that "the risk associated with childbirth cannot be totally eliminated; only deaths due to unsafe abortion are entirely preventable" [21]. "In nearly all developed countries, safe abortions are legally available upon request or under broad social and economic grounds, and services are generally easily accessible and available. In countries *where induced abortion is legally highly restricted* and/or unavailable, *safe abortion has frequently become the privilege of the rich*, while poor women have little choice but to resort to unsafe providers, causing deaths and morbidities […]" [15, my emphasis].

Finally, another relevant issue is that the prohibition of abortion or its criminalization does not necessarily prevent women from undergoing abortions. Indeed, restrictive laws are not effective as they do not achieve the supposed goal of actually preventing abortions. As the WHO and other studies [22] clearly point out, countries without restrictive laws have lower abortion rates than those with more restrictive laws. Abortions are performed anyway but are mostly carried out in unsafe conditions for women with scarce resources (middle- or upper-income groups can cover the cost of safe abortions). Therefore, considering this lack of efficiency, it follows that upholding the prohibition does not prevent abortions; it merely targets poor women and arguably punishes them.

Abortion in Argentina

Argentina replicates these developing-world problems. Argentina is a large country with wealthy provinces and cities (such as the city and province of Buenos Aires), and other quite poor ones (Chaco, Formosa, Jujuy, or La Rioja, among others) with a federal system that extends autonomy to provinces.

The penalization of abortion is a problem for all Argentine women. Not only does it violate women's sexual and reproductive rights, but it also denies them their autonomy and self-determination. They are assigned a lower status. That is, it considers them disabled individuals that are incapable of deciding about their own lives and well-being. In addition, society seems to have idealized maternity, combining motherhood with the view that it is a fate women cannot avoid. Such an image endorses the perpetuation of compulsory pregnancy. Yet, even if we recognize that penalizing abortion affects all women, poor women are worse off. Middle- and upper-income women have the economic and socio-cultural resources to obtain a safe abortion, consequently limiting or decreasing their risks. By contrast, poor women's sexual and reproductive rights are disregarded, deepening strong inequalities and punishing them with death or disabilities. Some empirical data clearly illustrate this situation.

Argentina's maternal mortality rate has reached a plateau, showing little variation over the last 20 years. This in itself is a source of concern. Note that this country enjoys a public and universal healthcare system where over 99% of childbirths occur in institutional contexts. Disquieting and significant are the existing internal differences: in 2012, the City of Buenos Aires recorded a maternal mortality rate of 13/100,000, while the province of Formosa registered extremely high maternal mortality rates – 123/100,000 and Jujuy 115/100,000. Consider that in these provinces, complications derived from unsafe abortions are the leading direct cause of maternal mortality and that abortion is the leading individual cause of death in 17 of the 24 jurisdictions in Argentina. To this situation we can add that this pending debt falls well short of both local and international standards. It is related to the fifth millennium development goal on maternal mortality rates, a goal that Argentina could not achieve. In contrast, neighboring Uruguay obtained quite good indicators with the legalization of abortion and suitable sexual and reproductive rights policies.

Other troubling data are related to adolescent pregnancy rates. According to the 2013 World Population Study of the United Nations, 15% of all childbirths in Argentina occurred among girls between the ages of 10 and 18, frequently from the poorest sectors. Once again, the same inequalities are evident: the City of Buenos Aires registered 7%, while for Formosa it was 24.6% and for Chaco 25%. Of these girls and adolescents, only 14.8% graduated from secondary school (43% did not complete primary school and 39.4% did not complete secondary school). These figures reinforce the inequality parameters and reveal that at least 82.4% of these pregnant teenagers do not receive a basic education.

So, this is Argentina's strong inequality panorama where issues for women are distinctly visible, above all, for those from the poorest sectors. Of course, the causes of these data are varied and it is unquestionable that for this situation to arise there are obstacles of all kinds (social, structural, economic, legal, and so on). Obviously, we should distinguish different levels – empirical and normative. One could argue that it is most difficult to modify these deep socioeconomic structures and that laws may not suffice. Yet, as was mentioned, legislation constitutes a first step that should be followed by a chain of other changes. Once a law has been enacted, people can fight for its effective enforcement. Legislation shows a certain tendency and political will to initiate these changes. But as we will see, no intention exists to authorize abortion. Moreover, the new Civil Code blocks this possibility and endorses the logic of punishing and penalizing abortions. In the following sections, I analyze whether this is the case because society as a whole is very homogenous and conservative, and this is part of a bigger picture, or whether there is an intentional disrespect for resource-less women that could even be deemed discriminatory. Before examining this, let us see what happened with the LGBT collective's rights and ART legislation.

New laws: LGBT rights

To end a trend of discrimination and violence against the LGBT collective, in 2010 Law 26.618 [23] was enacted legalizing matrimonial equality, that is, same-sex marriage. Argentina was the first country in the region to pass such legislation and the tenth in the world. This made a substantial modification in the social structure by enabling persons of the same sex not only to build a family but to adopt children. This law is clear evidence of a willingness to fight against the discrimination of homosexual persons. In addition to sanctioning this law, in May 2012 Law 26.743 [24] was enacted targeting gender identity. The gender identity law orders medical treatments to adapt to the gender expression a person seeks and to include them in the Mandatory Medical Plan (for example, surgery and integral hormone treatments). That is to say, these services must be provided for free by the public health system and included in the private system.

Law 26.743 also allows trans persons (transvestites, transsexuals, transgender) to register for ID documents according to their self-perceived identity. Thus, they can change their first names to adapt them to their new sexual identity. This law may serve babies born with sexual ambiguity: it allows families and the babies themselves to wait until later in life to choose their sexual identity, instead of forcing an early selection or surgery, with the harm this could imply when adapting children to sexual identities that they may later feel do not represent them.

Law 26.743 precludes judges', experts' or physicians' authority to choose a person's gender identity. At the time, this was one of the most progressive laws in the world. It did not treat gender identity or the trans condition as a pathology. It was the first law in the world to embrace a position with the greatest empathy and respect. As Diana Maffia [25] explains, this law is not merely a technical issue; it has to do with power, ethics and philosophy. It involves admitting that sexual identity is an important aspect of one's personal identity and that the right to an identity is a basic right. It also means recognizing each person's epistemic authority over their own body, sexuality and gender. At the same time, it means acknowledging the person as an agent, as a moral being [25]. Remember that for several decades homosexuality was treated as a pathological, mental illness. From 1954 to 1986 the Diagnostic and Statistical Manual of Mental Disorders (DSM) elaborated by the American Psychiatric Association, which rules the world's practice of psychiatry, established that homosexuality was a mental disorder and was included among sexual deviations. Only very recently has homosexuality has begun to be considered a normal variant of human sexuality; it was in 2013 that the DSM-5 modified "disorder of gender identity" and pathological transsexuality to become a "gender dysphoria", referring to the anguish a person could feel when belonging to a different sex to that socially or medically assigned to that person. This classification is still criticized by some authors as being unnecessary and discriminatory [25]. Nevertheless, the law we are analyzing does not rely on the pathological aspect but on the individual's self-perceived assertion.

Ariza and Saldivia also explain how radical this law is: "[…] the recognition of gender identity – perceived by many people as 'simply' the right to change a name and sex on the identity documents – has indeed implied the destabilization of social and legal arrangements, it challenges the binary construction of sexuality and requires rethinking questions such as: what is a woman/man?" [26]. These laws do not reflect a conservative society. On the contrary, it shows a "progressive" and respectful view of a long-overlooked minority.

Note the existing gap between the situation of poor women in Argentina and these laws: the LGBT collective's sexual rights and autonomy are respected. Also note that to be able to sanction these kinds of laws, we are not confronting a consistently conservative society. It implies recognizing the rights and protection of some minorities, usually ignored and discriminated against in conservative societies in addition to modifying a certain status quo. Thus, at first glance we could say that Argentine society is not homogeneous, that is, that traditional values do not prevail and changes are acceptable.

New laws for some women

In the light of these legislative responses, what is happening to Argentine women? In 2013 national Law 26.862 [27] was enacted regulating Assisted Reproductive Technology (ART). It would seem that women had not been forgotten. Law 26.862 put an end to the lack of regulation of ARTs. It established the coverage of ART for all persons (without setting an age or other limits like gender, marital status, sexual orientation, etc., Article 7). Its regulation also established that the public health care system had to provide four low-complexity treatments and three high-complexity treatments annually (Regulatory decree, Article 8). The listing of treatments included cryopreservation for embryos (Regulatory decree, Article 2). However, interestingly, the law did not contemplate the status of embryos and their possible disposal or use.

I will not judge the aptness of the number of treatments or whether it is up to the State to provide them (this is the subject of another article regarding the just allocation of resources in middle-income countries where basic attention and health care provision is not accessible to all). Instead, I will stress three issues. First, by not setting an age limit and embracing all persons, new non-traditional families once again can take shape (say, single women or homosexual partners). This implies open, non-discriminatory policies and it follows previous laws for the LGBT collective. Second, it regulates the provision of these treatments but mentions nothing of the status of the embryos or their possible uses in the implementation of some techniques (that is, whether they can be discarded, used in research, and so on). So, in the light of such progressiveness, the absence of a clear position is striking. And third, those who will benefit from this law are, basically, middle-income women and couples. It does not deal with, for example, the prevention of secondary infertility due to infections from sexually transmitted diseases

(STDs) or due to unsafe, illegal abortions affecting poor women. That is, it does not consider women without access to treatments because of their sexual and reproductive health. If the law were to consider such women and their infertility problems, it would necessitate, at the very least, carrying out serious preventive measures (treating STDs or preventing unsafe abortions). Instead, this law mainly targets middle- and upper-income women who want to become mothers. The law only contemplates information campaigns to promote fertility care, but it does not attack the root of the infertility problem in low resource settings.

Of even more concern was the draft bill of the Civil Code [28] (one of the fundamental legal instruments of Argentine law) proposed in 2012. Authors of this new code expressed particular concern to update the Argentine law and legislate the affiliation of children born via assisted reproduction. In it, when the legal status of the embryos had to be made explicit – Article 19 of the draft bill – it introduced the distinction between *ex utero* and *in utero* embryos. It stated: "The existence of the human person begins with conception in the woman or with the implantation of the embryo in her in cases of human assisted reproduction technologies" [28 (my translation)]. Only *in utero* embryos were considered human persons. This meant that the proposed Civil Code draft intended to accept ARTs and stem cell research, but it continued to penalize abortions as these involve the destruction of *in utero* embryos. More troubling still was the emphasis of this supposed progressive culture to rigorously promote reproduction by differentiating between *in utero* and *ex utero* embryos.

To include and maintain the traditional view that the *in utero* embryo is a person does not allow for a logical regulation of ARTs. ARTs include not only the manipulation of the embryos – which this bill would have allowed – but also the possibility of conducting selective abortions (for example, when a woman becomes pregnant from multiple embryos). This is a possibility given the absence of policies regulating the transfer of only one or two embryos, or for a cycle of artificial insemination, in which the woman is stimulated with hormones and, on generating several ovules, becomes pregnant with multiple embryos at the same time. In such cases, a procedure aborts some of these implanted embryos in gestation so that only one or two embryos remain, making it possible for the pregnancy to safely reach the end of its term. Specialists call this "embryonic or fetal reduction". Despite its creative terminology, in practice, it is an abortion that is carried out for therapeutic reasons (even though it was the therapy itself that caused these high-risk, multiple pregnancies).

Embryonic or fetal reduction deals with implanted embryos and not with *ex utero* embryos. Hence, if the goal had been to allow all of these practices, which, in fact, occurs in Argentina and throughout Latin America, the solution would not have been to dichotomize the notion of an embryo but to coherently define it in order to respond to the implementation of these techniques and what these techniques involve. If we follow the proposed Civil Code draft, selective abortions and, therefore, the practices that generate them (multiple embryo transfer or artificial insemination with hormone stimulation) would be unacceptable. In this regard, it not only poses inconsistencies, but also means that the content of Article 19 would not allow ARTs to be effective and safe (the expressed goal of the authors of the Project).

As it was drafted, Article 19 of the Civil Code bill was problematic. Yet, much more disturbing was the Upper House's rejection of the distinction between embryos in November 2013, upholding the formulation of the 1871 Civil Code. It was the resurgence of "embryolatry" by bluntly deleting the second part of Article 19 of the draft bill. Bowing to political pressure, this questionable article ultimately proved to be far more conservative and regressive. Thus, the recently sanctioned Civil Code states that: "The existence of the human person begins with conception" [29]. And though one could argue that this article can be interpreted more broadly by following the ruling of the Costa Rica case by the Inter-American Court of Human Rights, the wording aims to maintain the traditional formula of the Catholic Church. Even if it can be interpreted to allow the manipulation and destruction of *ex utero* embryos, the new Article 19 ignores the serious public health problems that the country faces owing to illegal abortion. But most disturbing was the fact that all these legal hurdles and last minute changes in Article 19 were deliberately intended to keep abortion illegal.

Possible reasons

How can we make any sense of these laws? How is it possible that some laws can take an innovative and ground-breaking position in the region, while others ignore the most vulnerable and destitute? It seems that totally progressive laws coexist with others that only appear to bear women in mind when it comes to promoting their reproductive role despite the consequences.

Before presenting specific strategic reasons that may clarify the previous questions, let me outline some of the underlying ethical issues. Autonomy is one of the central values in bioethics. As Erin Nelson points out, even if the concept of autonomy is far from established, it is clear that one must have the capacity, together with some accompanying social condition, to be the author of one's own life story [30]. As the reader realizes, the laws we are examining and the lack of others concern our sexual and reproductive autonomy. While sexual autonomy is very important because it relates to our desires, our self-esteem and our perception of ourselves, it does not have the impact that reproductive autonomy has on individuals. As Nelson argues, reproductive autonomy is fundamental in regulating reproduction. Reproductive decisions have a critical impact on one's life, including the ability to live autonomously [30]. And I would add, they also impact the long-term responsibilities and obligations they may create for others.

Nelson argues: "When law and policy fail to respect reproductive autonomy, although it is problematic for women and men alike, it is particularly troubling for women. Reproduction can have dramatically different effects on the lives of men and women.

Reproduction takes places in a context within which women's bodies, needs and interests have a central role. Reproductive activity is literally located within women's bodies" [30, p.56]. Thus, Nelson grounds reproductive autonomy on bodily integrity but she also grounds it on equality. She considers not only the impact reproduction has on the woman's body but also on her economy (she offers evidence of the impact that motherhood and "motherwork" can have on women's career prospects). Statistics illustrate this in graphic terms: "It has been estimated that a woman with children in Britain loses as much as 57% of lifetime earnings after 25% of her childless counterpart." [31] And Nelson adds: across sectors, women lose a staggering 37% of their earning power when they spend three or more years out of the workforce [32]. She argues that "a fragmentary and unreflective approach to reproductive regulation has uneven effects on women and men. Women's capacity for reproductive autonomy is also tied much more intimately to reproductive health than is the case for men" [30, p.56]. Hence, both autonomy and equality are at stake when reproductive autonomy is not respected. In addition, the lack of justice towards women is reinforced when we add the staggering effect abortion has on poor women (which is not the case for wealthier women that can access safe abortions, avoiding morbidity and mortality). So, justice and equality are values and principles that are seriously at risk. This is the ethical background we should consider when examining other reasons involved in the dissimilar approaches to legislation.

The first specific reason for Argentina's contextual situation can be explained by the prevailing political power of the Catholic Church to block any kind of change that would liberalize abortion. Traditional Catholicism does not accept abortion. And, even if the discourse of the Church preaches the defence of the poorest in the world, when it comes to abortion, the situation of the poorest women does not seem to matter. It is clear that the prohibition of abortion affects these women and this is evident from the above maternal mortality and morbidity rates in Argentina's poorest regions.

In addition, political representatives do not want to lose the Church's support. Historically, President Perón defied the Church, and this anti-Church stance was perceived to be a major political mistake. Since then, politicians have been highly reluctant to challenge Argentina's Catholic Church. Although the Church may criticize governments at times, politicians do not want to upset the religious status quo. Nonetheless, politicians did sanction the ART law and same sex marriage. The Church opposes ARTs because they are not natural. That is, they are not the product of "normal" sexual intercourse. Not even artificial insemination is acceptable, not to mention more sophisticated techniques that involve manipulating embryos (which the Church considers innocent persons). The same rejection can be said of homosexuality and gay marriage. At the time of the debate, Bishop Bergoglio – now Pope Francis – criticized it as the "devil's law" and published a letter against the law. Despite this opposition, the law was enacted. This was not the case for laws regarding abortion or changes to the Civil Code. Even though legislators accepted ARTs and wanted to regulate them appropriately, at the last minute (literally) the symbolic and controversial Article 19 which would have permitted new legislation on abortion – if re-written – was changed to satisfy conservative and religious politicians.

Another of the multiple reasons may be the lobbying force of some groups. The LGBT collective has achieved some vindication after years of struggle. Likewise, assisted reproduction physicians and clinics have long lobbied for access to and the regulation of ARTs. And, in the case of ARTs, it is not so much the case of women fighting for their rights and needs, but of families and couples wanting to have babies. These techniques were sometimes promoted using photos of "Gerber babies", healthy, beautiful babies and "nice doctors" bringing desired babies into world, unlike the selfish desire of a woman who is trying to "eliminate an innocent person". In this sense, note that of the six parties running in the 2015 presidential election, only the smallest, most radical leftist party (Frente de Izquierda y de los Trabajadores, FIT) with no representation in the Legislature openly defended abortion rights in its platform. The more important parties strategically skirted the issue. Not one voice defended and lobbied for these women. Of course, active feminists have been campaigning for abortion rights since the 1960s. As Bergallo points out [1] and as was sketched in the previous sections, several battles have been fought against conservative, informal rules. However, differences have arisen between some feminist groups [33]: whether it is preferable to take a stronger, more inflexible position and fight for the legalization of abortion or whether it would be better to compromise and demand the provision of non-punishable abortions (advancing step by step). The lack of clear and precise agreement may have undermined the feminist struggle as no unified agenda has been developed to date [34].

Another reason may be "pink washing", that is, the strategy of granting rights in exchange for political benefits. Ariza and Saldivia [26] raise this possibility and question to what point recognizing the rights of the LGBT collective but not recognizing abortion has to do with the inclusion of sexual minorities or, instead, with calculating electoral costs. Even though the authors explain that the country has implemented policies guaranteeing human rights in the wake of Argentina's last dictatorship, they find striking the contrast between the swift recognition of LGBT rights (and I add the rights of persons to use ARTs), while sexual and reproductive rights are still pending. In reference to ARTs and the pink washing strategy, the two main candidates in the 2015 elections publicly debated and praised the law regulating ARTs, which had been passed by one candidate in his province. He explicitly referred to the 900 babies born thanks to his law [35].

Another way to explain these inconsistencies is through the double moral standard. In an article published in 2010, Arleen Salles and I [9] analyzed the legal silence regarding stem cell research activities in Argentina. This research was practiced and promoted but was not regulated by any law. In that article, we challenged Shawn Harmon's [36] interpretation of legislative silence as a morally incoherent position. Instead, we offered a generous interpretation and argued it was a "survival strategy". Facing the possibility of prohibition, legislative silence was a source of "resistance": buying time to achieve a wider national and international debate and acceptance. We argued that there was a hidden battle with conservative Catholic views. However, marked changes have occurred since 2010. Progressive laws have been enacted without consideration for conservative

positions. Can we state today that not passing a law regulating abortion is another form of resistance? Clearly no. As was mentioned above, we are now witness to different lobbies and interests at play while the rights of poor women are ignored. In that article, Salles and I [9] dismissed what we called “native cunning” (*viveza criolla*), that is, taking advantage of a confusing situation without confronting or solving ethical issues. This position implies the promotion of self-interest – an easy way out where everybody pretends that nothing is really happening when, in fact, something is. The status quo is seemingly unaltered and the powerful lobbies of society go undisturbed. This kind of strategy is usually defended by interested parties on the grounds that the objective is ultimately met (the activity in question is still carried out). If we reconsider the acceptance of ARTs without acknowledging abortion practices or the current practice of genetic screening and testing without the possibility of abortion, the silence and secret around abortion practices appear to be clearly intentional. In light of these situations, no one says anything (neither ART physicians performing selective abortions nor geneticists referring to abortions) and they continue to perform or refer to hidden practices quietly and secretly as if these did not exist. Now that several laws have challenged the status quo, it does not only seem morally incoherent – as Harmon correctly pointed out – but it also promotes cynicism and hypocrisy.

Something similar occurs with LGBT rights. The rights of a vulnerable minority are finally respected. Undeniably, this is a very important fact. We appear to be a society that respects human rights; LGBT persons have recovered ownership of their minds and bodies while this epistemic capacity is denied to women. Sexual autonomy is finally recognized for the LGBT collective through Laws 26.618 and 26.743 as well as reproductive autonomy through Law 26.862. However, in the case of abortion, poor women’s sexual autonomy is restricted and they are denied their reproductive autonomy, together with the ethical costs this bears on their autonomy and equality, as was previously mentioned. So, while the rights of one group are respected, the rights of a silenced majority are still violated. Maternal mortality is ignored and the problem does not seem to exist. Once again, we face a double standard.

Another explanation might also complement this argument. The way “status quo” is understood may be more complex than how we actually consider it. A first approach explains that the status quo frequently prolongs inherited authoritarian patterns and the “traditional values” that oppress certain members of society [37]. However, a deeper analysis seems to show that what we call status quo could have strong hetero-patriarchal structures. The hetero nucleus only acknowledges heterosexual relations. And, the patriarchal side raises men to the top of a hierarchy where women are subordinate to them. This perpetuates traditional family values and roles. Within this traditional pattern there is also a tendency to “normalize” people. That is, people should fit into accepted categories or institutions. In this sense, marriage, building a family and reproduction are the main milestones for traditional thinking. Thus, another way of interpreting the legal difference in the above situations is to interpret these laws as a way of normalizing. For example, by accepting gender identity and allowing LGBT to align with their perceived gender (medically and socially), transgender persons can harmonize with themselves and better fit into some structures; they can work, produce, lead a “normal” life. We might even hold that the marriage institution is still playing a very relevant role: LGBT persons can marry, build a family and assimilate with the “hetero” rules. Family values are still precious things that should be upheld no matter how or by whom. Motherhood “must” apply to laws regulating ARTs. Thus, everything will be provided to have a baby, no matter how many cycles of ARTs are needed and no matter how old the mother may be. Anybody that desires a child should be able to access these techniques. Building a family seems to be the ideal! By contrast, a woman’s choice to end a pregnancy and not to have a baby may be inordinately disruptive and unacceptable. Thus, there is no possibility to escape from pregnancies, no way out. Compulsory pregnancies are the norm. So let us ask: are these women’s reproductive decisions respected as much as those who want to have a baby through ART? Do women have the same degree of autonomy as men or transgender persons? The answer is no. Only the autonomy and rights of some persons are respected. It seems that the progressive thinking in Argentina has a clear limit and it is bound by patriarchy. Thus, the above progressive laws only seem to modify the hetero structure “normalizing” the LGBT collective and leaving the patriarchal nucleus untouched.

Likewise, abortion is still a taboo issue. No group wants to be associated with abortion. Like a leprosy patient in the Middle Ages, abortion renders anything related to it “impure”. It taints whoever suggests that an abortion must be performed. The taboo argument can be complemented with the stigma that abortion produces. As Cook argues, the law affects the operation of stigma in society [15, p.349]. Abortion laws are used to create stigma. “In criminally prohibiting abortion, societies create a category called ‘abortion’ distinct from other medical services in categorically different ways. In exceptionalizing abortion, criminal law perpetuates stigma, and stigma has a social meaning.” [15 p. 352]. As depicted by Cook, “[Stigmatized individuals] may become social pariahs or outcasts. Stigmatized individuals are valued less than individuals without spoiled social identities, that is, so-called ‘normal’ persons” [15 p.353]. And what is also interesting is that the abortion stigma is applied to both: those who seek and those who supply abortions. Indeed, this explains why ART physicians do not concede that they may have to perform abortions on certain occasions. It also explains why geneticists do not acknowledge that they refer to abortions when due to genetic tests patients choose to end a pregnancy. Abortion practices are precluded and denied; they do not exist! Once again, here we see another kind of double standard.

Ariza and Saldivia [26] also signal racism and classism. Even if we leave aside “racism” as an inapplicable category today, their reasoning is valid as an argument that points to classism. It reinforces the double-standard argument with a discrimination angle. Ariza and Saldivia [26] argue that popular consciousness regards the woman that turns to the State to obtain an abortion as a *negrita* (a low-class woman of colour). As was mentioned before, middle- or upper-income women have no need for the State’s help; they can pay for safe abortions. So, even if all women are treated with disrespect and their sexual and reproductive rights are violated, they are not harmed to the same degree as are poor women. Middle-income women can “defend” themselves because they have the economic and socio-cultural means. Poor women do not; they are defenseless and suffer

endless layers of vulnerability [38]. Going back to Nelson's analysis of reproductive autonomy [34], note that she argues that reproductive autonomy should be understood in a deeply contextualized way and that it should be based on equality "given the clear and dramatic impact of reproduction on women's life" [34]. Justice issues are clearly involved. And this class argument reveals the lack of justice these poor women experience in another way. It clearly reinforces the discrimination hypothesis. These women are not worthy; they have no voice or do not deserve the help of the State. Moreover, they should be punished. These prohibition laws are too inefficient to prevent abortions – if the goal were to actually prevent abortions, other kinds of policies would have to be in place. The penalization of abortion not only stigmatizes women, but it also threatens and cripples them. Thus, rather than upholding the idea of preventing abortions, it punishes women.

Surprisingly, all the progressive attitudes towards minorities end when it comes to the situation of poor women and abortion. In this sense, respect for human rights has a categorical limit. We can formulate multiple hypotheses to explain legal differences; but no matter what the reasons are, it is clear that there is a double standard with a strong discriminatory side. Poor women are deliberately being ignored, abandoned and punished.

Final words

This article presents a critical perspective of some of the more recent legislative modifications in Argentina. It provides a strategic argument to defend women with few resources and their reproductive decisions by examining the striking difference between LGBT and ART laws that contrasts sharply to the penalization of abortion. This article shows how legislators and society are prepared to challenge a conservative or traditional approach for certain groups while ignoring others. On the one hand, it describes the willingness to accept gay marriage and changes in sexual identity. This leads to the protection and respect of a minority that has traditionally been ignored, rejected and punished. This is welcome and can be viewed as strongly aligned with human rights. It also implies the acceptance of new family structures through the combination of LGBT laws and ARTs; new families and babies born via ARTs are also considered and protected. But, on the other hand, all these "progressive views" towards these collectives co-exist with an authoritarian mindset whereby women should reproduce no matter what their desires and needs may be. And while the hetero nucleus of the status quo no longer governs, a patriarchal one still does. Reproductive autonomy for poor women is not respected and there is no justice for them; there is no protection and respect for the sexual and reproductive rights of poor women and their situation continues to be disregarded. Why is it that Argentine legislators, the government and society as a whole continue to ignore these realities and the deep inequalities they foster? No one clear explanation exists and, as was pointed out in the previous section, different reasons may coexist. However, among them, what stands out is the double standard and discrimination towards the most vulnerable members of society with no voice or lobbying power.

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ÉTUDE DE CAS / CASE STUDY

La gestion des conflits d'intérêt dans un jury de thèse de doctorat

Valéry Ridde[1,2]

Résumé
Un chercheur ou un enseignant universitaire est souvent amené à être membre d'un jury de thèse. Cela fait partie de ses activités scientifiques. Cependant, dans un monde académique de plus en plus spécialisé, il est parfois difficile de créer un jury de thèse sans être confronté à des conflits d'intérêts entre les membres et l'équipe d'encadrement. Si certaines universités ont organisé des processus pour gérer ces conflits depuis quelques années, d'autres n'ont pas encore statué. Cette étude de cas adapte plusieurs situations réelles pour montrer les défis d'une telle gestion des conflits d'intérêts dans la constitution d'un jury de thèse de doctorat.

Mots clés
thèse, conflits d'intérêt, éthique, évaluation

Abstract
A researcher or university professor is often required to be a member of a thesis jury. This is part of their scientific activities. However, in an increasingly specialized academic world, it is sometimes difficult to create a thesis jury without being confronted with conflicts of interest between the members and the supervisory team. While in recent years some universities have organized processes to manage these conflicts, others have not yet decided. This case study adapts several real-life situations to show the challenges of such conflict of interest management in setting up a doctoral thesis jury.

Keywords
thesis, conflicts of interest, ethics, evaluation

Introduction

L'une des tâches importantes pour un professeur ou un chercheur dans le milieu universitaire est de soutenir les étudiants dans leur processus doctoral, mais aussi d'évaluer les thèses d'autres étudiants. Cependant, dans certains domaines scientifiques, notamment depuis que les chercheurs sont de plus en plus hyper spécialisés et les objets très précis, il est délicat de trouver des examinateurs externes qui ne connaissent pas, ou n'ont pas eu des relations de travail ou amicales, avec l'étudiant et son équipe d'encadrement. La gestion des conflits d'intérêts[1] dans la constitution de la liste des membres d'un jury de thèse est donc une tâche bien délicate [2,3]. Certaines universités sont très en avance et disposent de normes et de guides très rigoureux pour les gérer, les membres devant signer des déclarations explicites, tandis que d'autres n'ont pas encore véritablement statué sur la question, laissant libre cours à certaines pratiques et un flou parfois artistique.

Cas fictif inspiré de deux histoires réelles récentes

Dans un comité de thèse d'un de vos amis

Au début des années 1990, nous avons encore vu dans un pays du Nord une personne soutenir une thèse de sciences de gestion et système de santé concernant un pays du Sud alors que sa sœur était membre du jury. Elles n'avaient pas le même nom, mais il était notoire qu'elles étaient de la même famille. Les pratiques ont changé puisque dans la plupart des pays cela ne serait plus possible aujourd'hui, mais peut-être pas partout.

Vous êtes un expert mondial dans le domaine de l'histoire de la santé publique en Asie. Un de vos collègues, très réputés depuis 30 ans dans ce domaine et avec qui vous avez commencé à collaborer pour comprendre l'histoire de la médecine traditionnelle au Myamar, vous demande d'être membre d'un jury de thèse. Vous connaissez l'étudiant du Myamar, car il a fait sa thèse dans le programme de recherche que vous avez codirigé avec ce collègue. Cet étudiant ne vous a jamais impressionné. La plupart de ses rapports de recherche étaient peu novateurs et manquaient de rigueur. La qualité de la langue faisait souvent défaut et la majeure partie des commentaires que vous lui faisiez pour les améliorer n'étaient jamais pris en compte. Cependant, puisque vous appréciez ce collègue depuis des lustres, vous acceptez d'être membre du jury, un voyage à Canberra en Australie[2] où cet étudiant est inscrit et ce collègue professeur vous intéresse aussi, car vous ne connaissez pas la région.

Mais lorsque vous recevez la thèse, vous comprenez que rien n'a changé depuis les rapports que vous commentiez. Le document reste médiocre et vous ne comprenez pas pourquoi ce collègue de renom accepte que l'étudiant défende sa thèse. Vous lui demandez et il vous répond « *oui je sais, mais vraiment je n'en peux plus, cela fait trop longtemps que je traîne cet étudiant, je l'ai amené au maximum qu'il pouvait et je veux en finir. Il sera quasiment le premier de son pays à soutenir une thèse tant ce pays a été dans l'obscurité ces 30 dernières années* ». Vous rédigez alors votre rapport de cinq pages

[1] Pour en savoir plus sur ce sujet et notamment sa définition, voire l'excellent site : www.interets.umontreal.ca; ainsi que la référence [1]
[2] Ce pays est évidemment utilisé ici au hasard pour rendre le cas plus réel et ne présage en rien l'absence de gestion de conflit d'intérêt dans ses universités. Au contraire, l'University of Western Australia dispose d'une procédure intéressante par exemple.

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d'évaluation de la thèse en tant qu'évaluateur externe. Bien que vous restiez courtois, vous mettez l'accent sur les carences de la thèse et, qui sait lire entre les lignes, s'étonnera qu'il soit finalement décidé que la soutenance soit organisée.

En novembre 2016, vous faites finalement le voyage à Canberra pour la soutenance de thèse. Et là votre surprise est encore plus grande quand vous découvrez que votre position d'examinateur externe, bien que proche du directeur de thèse, reste la plus éloignée… En effet, les trois autres examinateurs de la thèse ainsi que le président du jury sont des amis de 20 ans du directeur. Ils se connaissent parfaitement, ont signé de très nombreux articles ensemble, dirigés des projets de recherche et des étudiants. L'un deux a même dirigé la thèse de la femme de l'autre, originaire elle aussi du Myamar. Vous apprenez plus tard qu'un autre est le mari de la sœur du directeur. La soutenance se déroule tranquillement, tous les membres du jury posent des questions qui montrent clairement qu'ils mettent en doute la qualité de la thèse, mais elle termine par être acceptée. L'étudiant reçoit la mention la moins élevée possible, mais devient docteur en histoire.

Questions

1. Quels enjeux éthiques cette étude de cas met-elle au jour?
2. Quels conflits d'intérêts pourriez-vous identifier?
3. Comment comprenez-vous les décisions du directeur de thèse?
4. Qu'auriez-vous fait à la place de l'examinateur externe?

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ÉTUDE DE CAS / CASE STUDY

Utilisation de données secondaires et signature scientifique lors de l'évaluation d'une intervention en santé mondiale

Valéry Ridde[1,2]

Résumé
Dans le domaine de la santé mondiale, les bailleurs de fonds internationaux financent de nombreuses interventions dont ils souhaitent l'efficacité. Ils financent ainsi parfois des évaluations externes, le plus souvent menées par des chercheurs du Nord, pour en faire la démonstration. En outre, il existe de multiples bases de données, souvent collectées par les chercheurs du Sud, utiles pour réaliser ce type d'études. Mais cette multiplicité d'acteurs, de collaboration, d'enjeux et de potentiels conflits d'intérêts pose des défis importants sur le plan de l'utilisation de données secondaires et de la signature scientifiques des publications qui peuvent en découler. Cette étude de cas propose une réflexion à cet égard.

Mots clés
santé mondiale, recherche évaluative, données secondaires, enjeux éthiques, signature scientifique

Abstract
In the area of global health, international donors fund many interventions that they want to be effective. They sometimes fund external evaluations, most often conducted by northern researchers, to demonstrate effectiveness. In addition, there are multiple databases, often collected by researchers from the South, useful for this type of study. But the multiplicity of actors, collaborations, issues and potential conflicts of interest pose significant challenges in terms of the use of secondary data and the scientific authorship of publications that may result. This case study offers some thought in this regard.

Keywords
global health, evaluative research, secondary data, ethical issues, scientific authorship

Introduction

Dans le domaine de la santé mondiale, de multiples interventions sont mises en œuvre dans les pays du Sud dont le financement provient largement de bailleurs de fonds du Nord. Elles sont organisées par des intervenants et des experts des pays concernés, parfois appuyés par des experts du Nord. Afin de rendre des comptes aux contribuables du Nord, mais aussi pour s'interroger sur l'efficacité des solutions proposées, ces mêmes bailleurs de fonds financent aussi des évaluations de ces interventions. La réalisation de ces évaluations est recommandée, par exemple, par le Comité d'aide au développement de l'OCDE. Au-delà des évaluations internes et autre suivi que les intervenants réalisent pour améliorer leurs interventions [1], ils commandent aussi, souvent, des évaluations externes. Ainsi, la distance à l'objet et la rigueur de l'analyse sont essentielles à la qualité et la probité des résultats présentés lors d'une évaluation d'impact [2]. Mais cette distance peut aussi faire en sorte de ne pas comprendre en détail comment l'intervention fonctionne et pourquoi elle a produit ces impacts, ou pas [3]. Évidemment, comme ces bailleurs financent tant l'intervention que l'évaluation, les enjeux autour des conflits d'intérêts peuvent être importants, même en faisant appel à des personnes non impliquées dans les actions. Les exemples sont nombreux en santé mondiale à cet égard [4]. En outre, la réalisation de ces évaluations d'impacts pose des soucis d'ordre méthodologique majeur [2]. En effet, rares sont ces interventions où l'utilisation d'une démarche expérimentale est possible, ou souhaitable, où des données empiriques auraient été collectées avant et sans les actions envisagées. Les chercheurs évaluateurs, qui sont le plus souvent du Nord, doivent donc se retourner vers des approches de type quasi-expérimentales [2] et utiliser des données secondaires [5], autrement dit, des données collectées par d'autres équipes, souvent du Sud, dans le cadre d'autres projets. C'est dans ce contexte que nous présentons cette étude de cas fictive inspirée de plusieurs histoires réelles.

Une étude de cas dans un pays de l'Asie du Sud-Est

La Banque Internationale de l'Urgence (BIU) souhaite analyser les effets de son intervention humanitaire dans les camps de réfugiés de Baboye, une région d'un pays du Sud-Est asiatique. Cela fait plus de 10 ans qu'ils interviennent dans ces camps, plus de 12 millions de dollars y ont été dépensés pour améliorer la santé des populations et notamment réduire la présence des maladies diarrhéiques des enfants. En 2008, cinq ans après son intervention, la BIU avait commandé une évaluation à un consultant australien. Ce dernier, expert en évaluation de programme, mais ne disposant pas de compétences poussées en épidémiologie, a effectué cette analyse. Son rapport affirme que l'intervention humanitaire a été efficace, mais la méthode qu'il a employée n'est pas solide. Elle est entachée de nombreux biais. Malgré cela, puisque le rapport est positif, la Banque a poursuivi son investissement dans cette intervention pendant plus de six ans encore. Cependant, la BIU a besoin de preuves encore plus solides, car de plus en plus de ses fonctionnaires s'interrogent sur l'efficacité de cette aide. Ainsi, ils savent que vous êtes l'un des grands experts internationaux de l'évaluation d'impact. Vous êtes professeur à l'université de Cambridge en Angleterre, mais vous n'êtes jamais allé dans ce pays. Profitant de la disponibilité de nouvelles bases de données populationnelles, grâce à plusieurs enquêtes réalisées par des ONG auprès d'une population représentative de celles vivant dans les camps de réfugiés, la BIU vous contacte. Aucun appel d'offres n'est lancé, il s'agit d'un contrat négocié de gré à gré. La BIU vous donne ainsi un contrat de 35 000$ ainsi que l'accès à huit bases de données provenant d'ONG du pays. Elles

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Les éditeurs suivront les recommandations et les procédures décrites dans le Code of Conduct and Best Practice Guidelines for Journal Editors de COPE. Plus précisément, ils travaillent pour s'assurer des plus hautes normes éthiques de la publication, y compris l'identification et la gestion des conflits d'intérêts (pour les éditeurs et pour les auteurs), la juste évaluation des manuscrits et la publication de manuscrits qui répondent aux normes d'excellence de la revue.

The editors follow the recommendations and procedures outlined in the COPE Code of Conduct and Best Practice Guidelines for Journal Editors. Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

ont donné l'autorisation par écrit de leur exploitation. Vous avez recruté un chercheur postdoctoral et une étudiante au doctorat pour vous aider dans le nettoyage de la base de données et les analyses subséquentes.

La personne qui pilote cette évaluation de l'intervention humanitaire au sein de la BIU est une jeune qui vient de terminer son doctorat en éducation, mais qui n'a pas obtenu de poste universitaire pour le moment. C'est elle qui a négocié les termes du contrat avec vous et qui est chargée par la BIU d'en suivre la mise en œuvre et de vous soutenir en cas de besoin, notamment dans l'accès aux soins. Cependant, vous restez le responsable scientifique de l'évaluation. Cette jeune personne est cependant une experte de certaines méthodes d'évaluation. Ainsi, au cours du mandat, il se trouve qu'elle discute très souvent de vos choix méthodologiques, parfois pour vous proposer des améliorations et parfois pour remettre en cause vos compétences et vos décisions techniques. Mais vous continuez vos analyses de données secondaires, car vous en avez l'expérience depuis 30 ans.

Cependant, il vous manque encore quelques données contextuelles et vous voulez en savoir un peu plus sur ce qui se passe sur place. Ainsi, le chercheur postdoctoral fait une mission de 10 jours sur place pour mieux comprendre l'intervention et confirme que la BIU est très impliquée dans sa mise en œuvre et sa défense. Elle a dépensé beaucoup d'argent dans ce projet et souhaite qu'il montre des preuves d'efficacité. Malheureusement, après plusieurs mois de travail, de multiples analyses, les résultats ne sont pas probants. Les données montrent que l'intervention n'a pas été efficace, l'état de santé des populations et le niveau des maladies diarrhéiques n'ont jamais baissé après plus de 10 ans d'actions et d'investissements. La personne de la BIU devient de plus en plus pressante, elle vous suggère toujours plus de méthodes et d'analyses différentes pour tenter de trouver des résultats positifs… mais rien n'y fait, globalement, l'intervention n'a apporté aucun changement. Finalement, même si les différentes présentations des résultats dans le pays et au siège de la Banque sont souvent tendues, cette dernière finit par accepter les analyses et le rapport. Le solde du contrat est payé.

En tant que chercheur, vous souhaitez évidemment publier les résultats dans une revue savante renommée. Vous souhaitez que votre jeune collègue chercheur postdoctoral évoque cette question pendant la dernière réunion avec la personne en charge du dossier au sein de la BIU. Il revient et vous explique « *Je reviens de la réunion de restitution. Ça s'est bien passé. Bons échanges. Ils sont satisfaits de la qualité du travail, un peu moins des résultats, mais ça se comprend. Pour l'article, ils souhaitent que nous proposions à des chercheurs du pays de participer*. » Vous êtes évidemment surpris, car lors de la négociation de départ du contrat, cette question n'avait jamais été évoquée et l'ensemble des analyses a été fait par vous et votre équipe, donc aucune personne du pays. Il s'agit d'analyse de données secondaires. La BIU, qui finance l'intervention depuis 10 ans, mais aussi cette évaluation finale, souhaite que l'article de présentation des résultats dans une revue scientifique internationale soit écrit avec la participation (signature) d'une personne du pays.

Questions

- Quels sont les différents enjeux éthiques soulevés par ce cas?
- Quels sont les enjeux liés à un processus d'évaluation à distance et d'utilisation de données secondaires pour comprendre une intervention?
- Quels enjeux concernant la paternité de la signature de l'article sont posés dans ce cas?
- Comment auriez-vous réagi et qu'auriez-vous fait pour répondre à cette demande du financeur?

Conflit d'intérêts
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ÉTUDE DE CAS / CASE STUDY

Partager et renforcer les capacités d'enseignement au Sud : les défis déontologiques des droits d'auteurs

Valéry Ridde[1,2]

Résumé
Dans le domaine de la coopération internationale et notamment en santé mondiale, depuis très longtemps, des enseignants du Nord se rendent dans des institutions du Sud pour participer au renforcement des capacités de leurs collègues. Ainsi, il arrive bien souvent que des enseignants-chercheurs du Nord et du Sud collaborent pour préparer des recherches ou donner des formations, avec souvent l'objectif que ces processus permettent aux premiers de partager leurs expertises spécifiques au second. Dans ce contexte particulier, souvent empreint d'enjeux de pouvoir et d'accès aux ressources, des défis éthiques et déontologiques se posent. Dans cette étude de cas fictive fondée sur des expériences réelles, nous mettons notamment en avant les enjeux concernant les droits d'auteurs associés à la production de protocoles de recherche ou de matériel pédagogique dans ce contexte de collaboration pour le renforcement des capacités.

Mots clés
santé mondiale, formation, déontologie, intégrité, renforcement des capacités, droits d'auteurs

Abstract
In the field of international cooperation, particularly in global health, educators from the North have for a long time been visiting institutions in the South to help build the capacities of their colleagues. Thus, it often happens that educator-researchers from the North and the South collaborate to prepare research or training, often with the aim that these processes allow the former to share their specific expertise with the latter. In this particular context, often marked by issues of power and access to resources, there are ethical and deontological challenges. In this fictional case study, based on real-world experiences, I highlight, among other things, the copyright issues associated with the production of research protocols or educational materials in this collaborative context for capacity building.

Keywords
global health, training, ethics, integrity, capacity building, copyright

Introduction

Dans le discours (et la pratique) international de l'aide publique au développement, on continue d'entendre le besoin de renforcer les capacités des professionnels, étudiants et chercheurs au Sud. En effet, l'un des 17 objectifs du développement durable (ODD) concerne le besoin de renforcer les partenariats pour atteindre les 16 autres ODD à l'horizon de 2030. Ainsi, il subsiste de nombreux projets visant à envoyer en Afrique par exemple, des experts du Nord pour organiser des cours universitaires, des formations courtes ou encore des missions médicales dont la pertinence et la preuve de leur efficacité restent à démontrer [1]. Mais cela peut aussi se concrétiser, à l'image des co-encadrements d'étudiants [2], par des collaborations en binômes où des experts du Nord donnent des cours avec des experts du Sud tout en profitant de ce processus pour partager leurs connaissances didactiques ou sur l'objet. C'est ce que l'on nomme parfois les missions d'enseignements, par exemple aussi anciennes que dans les années 1970 entre la France et le Vietnam [3]. Il arrive évidemment, mais c'est plus rare, que des experts du Sud enseignent aux étudiants du Nord lors de leurs missions ou que des échanges Sud-Sud soient organisés [4]. Dans le contexte de ce type de partenariat [3,5], certains évoquent le besoin d'un « partenariat scientifique juste […notamment par le] renforcement des communautés scientifiques locales par la formation » [6] et de renforcer la « solidarité scientifique » [7] pour soutenir la course aux ODD. Ce type de collaboration n'est évidemment pas sans enjeux, notamment en santé mondiale où les relations de pouvoir et d'accès aux ressources peuvent engendrer des défis déontologiques particuliers, notamment dans les contextes où les enseignants-chercheurs en Afrique réalisent de nombreuses consultations pour compenser leurs conditions de travail difficiles [3,8,9].

L'histoire d'un cas fictif[1] fondé sur trois expériences réelles

Vous êtes un expert, professeur dans une université canadienne, dans le domaine de l'évaluation des apprentissages et notamment de la formation par compétences. Or, suivant les développements au Nord, les pays du Sud se sont aussi engagés dans des processus de réformes de leurs enseignements universitaires et doivent transformer tous leurs programmes pour qu'ils identifient, non seulement des savoirs, mais aussi des compétences à acquérir. La coopération canadienne (ancienne ACDI) vous sollicite pour réaliser deux missions. La première est pour évaluer un programme qu'elle a financé pour la réforme de l'enseignement au Gondwana et la seconde pour donner une série de cours (cinq jours par an pendant trois ans) à l'université d'État du Gondwana dans le département d'éducation à la santé.

Pour la première mission, vous décidez de répondre à la demande de l'ACDI en collaborant avec un évaluateur du Gondwana, qu'un collègue vous a suggéré. C'est en effet essentiel de travailler avec une personne qui maitrise parfaitement le contexte.

[1] Évidemment, il s'agit d'un cas fictif associé à mon expérience du Nord vers le Sud, mais un enseignant du Sud (au sens de l'institution de rattachement) pourrait avoir vécu la même expérience utile pour construire une autre étude de cas.

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The editors follow the recommendations and procedures outlined in the COPE Code of Conduct and Best Practice Guidelines for Journal Editors. Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

Vous rédigez un plan d'évaluation, précisant les détails de la méthode que vous proposez. Ce collègue n'est pas un expert en évaluation, mais en didactique, il ne fait donc quasiment aucun commentaire sur le plan proposé. Finalement, votre proposition est retenue par l'ACDI, un budget de 40 000$ vous ait octroyé et vous réalisez cette recherche évaluative durant deux mois avec cette personne. Trois mois après, un de vos amis qui coordonne un projet d'une ONG d'éducation au Gondwana vous appelle. En effet, il vient de lancer un appel d'offres pour évaluer son projet et a reçu un document, un plan d'évaluation dont l'évaluateur unique est la personne avec qui vous venez de terminer le rapport pour l'ACDI. Il vous demande si vous êtes au courant, ce qui n'est pas le cas. Mais ce n'est pas un souci, dites-vous, car cette personne est un consultant indépendant, il a donc bien le droit de répondre à cet appel sans vous en parler et donc de gagner sa vie avec cela. Intrigué, vous demandez quand même à votre ami s'il est possible de recevoir le plan proposé par le collègue. Il hésite, mais vous fait confiance et vous envoie le document. Vous constatez que ce document est une reproduction presque à l'identique de votre plan d'évaluation pour l'ACDI. Vous reconnaissez vos mots et expressions, ce qui n'est pas difficile, car votre collège ne connaît absolument pas ces démarches méthodologiques.

Pour la seconde mission, l'ACDI vous propose de donner des cours, mais vous impose de le faire avec un enseignant du Gondwana qu'elle a déjà identifié, car il fait partie d'un programme de coopération universitaire entre votre institution et l'université d'État. L'idée est de créer un binôme afin de former le collègue au fur et à mesure des années, ce dernier pourra ainsi donner les cours seuls par la suite. L'idée est séduisante et vous vous y engagez pleinement. Vous n'avez cependant aucune connaissance de cette nouvelle personne avec qui vous allez devoir collaborer pendant trois ans. Vous préparez la totalité du matériel pédagogique sur la base des cours que vous donnez dans votre université canadienne. Avant d'arriver sur place, vous avez échangé avec le collègue enseignant et réfléchi ensemble au contenu possible du cours. Mais comme c'est un sujet très nouveau pour lui, les discussions ont été limitées. La première année vous donnez le cours seul, l'enseignant du Gondwana n'intervient que pour animer quelques travaux de groupe et donner des exemples tirés du contexte local. Il est cependant présent lors de tous les enseignements. La seconde année, vous partagez la dispensation des cours à moitié et vous lui proposez quelques recommandations pour renforcer son enseignement. La dernière année, vous assistez aux cours donnés par votre collègue avec votre matériel, qu'il n'a presque pas fait évoluer, et agissez surtout en lui donnant quelques conseils sur le contenu et la pédagogie, mais peu, car c'est un excellent enseignant. L'expérience est enrichissante et vous pensez que votre collègue pourra poursuivre les cours sans votre aide maintenant. Quatre années plus tard, un étudiant du Gondwana vient vous rencontrer au Canada pour vous demander de superviser sa thèse de doctorat en éducation. Il vient de terminer une maitrise en éducation au Gondwana et vous annonce qu'il a suivi les cours de votre ancien collègue. Petit monde, comme le romançait parfaitement David Lodge [10] pour caricaturer l'interconnaissance du milieu universitaire, vous êtes agréablement surpris. Vous demandez à l'étudiant de vous envoyer les diapositives que le professeur a utilisées pendant son cours et partagées avec les étudiants. Nouvelle surprise ! Vous constatez que 80% des diapositives sont exactement celles que vous aviez préparées lors de la première année de vos cours, il y a bien longtemps. Aucune ligne ou mot supplémentaire n'a été ajouté, aucune mise à jour des nouvelles recherches, rien n'a changé… sauf la présence de votre nom qui n'est plus sur aucune diapositive. De plus, vous apprenez que ce même professeur ne donne pas ces cours gratuitement à l'université, mais, dans le cadre d'une coopération avec le Brésil et d'un nouveau projet de renforcement des (mêmes) capacités, il reçoit des honoraires de 300$ par cours.

Questions

1. Quels enjeux éthiques et déontologiques sont mis au jour dans cette étude de cas?
2. Les problèmes particuliers à chaque cas sont-ils différents?
3. Que devrait faire cet expert en éducation? Comment aurait-il pu prévenir la situation et éviter cette découverte?
4. À qui appartient le matériel pédagogique de l'expert canadien? Quels défis pour les droits d'auteurs se posent dans ce contexte particulier?

Conflit d'intérêts
Aucun déclaré

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None to declare

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TRAVAIL CRÉATIF / CREATIVE WORK

Haiku, Spiritual Exercises, and Bioethics

James Dwyer[1]

Résumé
Pierre Hadot a discuté des liens profonds entre l'ancienne philosophie occidentale et les exercices spirituels. L'auteur apprécie ces liens, mais il explique pourquoi il a exploré une voie différente. Il a commencé à écrire le haïku comme une forme de pratique spirituelle. Il voulait utiliser ces courts versets pour devenir plus attentif, présent et réactif – dans sa vie et dans son travail en bioéthique. Après avoir comparé le haïku traditionnel et le haïku moderne, l'auteur offre quelques exemples à partir de sources antiques. Ensuite, il envisage comment la lecture et l'écriture du haïku pourraient aider la bioéthique à moins se concentrer sur la délibération et le choix, et plus sur l'attention et la perception. Le haïku pourrait aider la bioéthique à s'intéresser aux contextes, aux conditions de vie et aux mondes vécus qui façonnent et situent la vie des gens. Ces poèmes courts pourraient même éclairer certaines des origines et des fondements existentiels de la vie éthique. Finalement, l'auteur présente quelques haïkus qu'il a écrits sur la vie moderne, les jeunes enfants, les personnes âgées, la maladie, la médecine et la mort.

Mots clés
haïku, exercices spirituels, bioéthique, habiter et percevoir, contextes

Abstract
Pierre Hadot has discussed the deep connections between ancient Western philosophy and spiritual exercises. The author appreciates these connections, but he explains why he explored a different path. He began to write haiku as a form of spiritual practice. He wanted to use these short verses to become more mindful, present, and responsive – in his life and in his work in bioethics. After comparing traditional haiku and modern haiku, the author gives some examples from classical sources. Then he considers how reading and writing haiku might help bioethics to focus less on deliberation and choice, and more on attention and perception. Haiku might help bioethics to attend to the contexts, life conditions, and lifeworlds that shape and situate people's lives. These short poems might even illuminate some of the backgrounds and existential grounds of ethical life. At the end, the author presents some haiku that he wrote about modern life, young children, older adults, illness, medicine, and death.

Keywords
haiku, spiritual exercises, bioethics, inhabit and perceive, contexts

I was busy. I had ethics consults to do, classes to teach, administrative work to handle, an article to write, and my own health problems to deal with. Often I wasn't mindful of the present moment and activity. Too often I was thinking ahead to the next thing on my list. So I began to write haiku as a form of spiritual practice. I wanted to be more mindful, present, and responsive.

Both the East and the West have long traditions of spiritual practice, and I could have taken a different path. I've always admired the work of the French philosopher Pierre Hadot (1922-2010). He was a distinguished academic philosopher and historian of philosophy. He knew many languages, understood historical contexts, and read texts with the utmost care. He also championed a view of philosophy that connected it to exercises and practices. One of his books was even titled *Exercices spirituels et philosophie antique* [1]. Another book, *What is Ancient Philosophy* [2], sums up the view that he developed and championed:

> It would take a large volume to tell the entire history of the reception of ancient philosophy by medieval and modern philosophy. I have chosen to concentrate on a few major figures: Montaigne, Descartes, Kant. We might mention many other thinkers – as different as Rousseau, Shaftesbury, Schopenhauer, Emerson, Thoreau, Kierkegaard, Marx, Nietzsche, William James, Bergson, Wittgenstein, Merleau-Ponty, and still others. All, in one way or another, were influenced by the model of ancient philosophy, and conceived of philosophy not only as a concrete, practical activity but also as a transformation of our way of inhabiting and perceiving the world [2].

I wanted to transform my "way of inhabiting and perceiving the world," but I also wanted to change the world in certain ways. With these ethical aims in mind, I could have taken a Western philosophical path, but I was busy, so I began with haiku.

Traditional Japanese haiku comprise 17 syllables, in a 5-7-5 pattern, with a cutting word (*kireji*) that divides the poem, and a seasonal word (*kigo*) that indicates the time of year. These short poems embody a Zen spirit: a focus on the moment, an emphasis on concrete perceptions, a coupling of nature and human nature, and a deep sense of the impermanence of life. Good haiku are often detached and touching, commonplace and insightful, serious and playful – all at the same time.

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Since the 17-syllable requirement does not work well in European languages like English and French, the journal *Modern Haiku* [3] gives the following gloss of this poem:

> Haiku is a brief verse that epitomizes a single moment. It uses the juxtaposition of two concrete images, often a universal condition of nature and a particular aspect of human experience, in a way that prompts the reader to make an insightful connection between the two. The best haiku allude to the appropriate season of the year. Good haiku avoid subjectivity; intrusions of the poet's ego, views, or values; and displays of intellect, wit, and facility with words [3].

I was happy to be freed from the 17-syllable requirement, but the rest of the guidelines proved difficult. Although I tried to focus on the concrete, my lifeworld is filled with abstractions: ideas about solidarity and justice, problems about futility and technology, and shortcomings in structures and systems. I was reluctant to give up all abstractions because some of them are useful tools in certain contexts. The American philosopher John Dewey (1859-1952) observed, "abstraction deliberately selects from the subject matter of former experiences that which is thought helpful in dealing with the new. It signifies conscious transfer of a meaning embedded in past experience for use in a new one." [4] Although I tried to keep the seasons in mind, much of my environment tries to keep the seasons out: hospitals and flu shots, grocery stores and imported fruit, parking lots and snowplows. Although I tried to quiet my ego, I am often asked to explain my views and values. Indeed, ethics consults often involve articulating views and values.

To begin, I read about and from the great Japanese masters of haiku: Basho, Buson, and Issa. I admired how Basho (1644-1694) transformed the witty and courtly linked verses of his time into the form and spirit we now call haiku. I read about how he spent the last nine years of his life on a spiritual pilgrimage across Japan. His travel journals (*haibun*) from this period combine prose and poetry. Here is one haiku that shows his keen perception [5]:

> Early fall –
> the sea and rice fields
> all one green.

This haiku almost overcomes the dualism of perceiving subject and perceived object.

Buson (1716-1784) was a great poet and painter. I admired his clarity of perception and his luminous sense of common things. He urged his students to "use the commonplace to escape the commonplace." [5] While his commonplace included a lot of trees, birds, and snow, my commonplace includes a lot of email reminders, hospital policies, and educational bureaucracies. Clearly, I had work to do, but this little verse shows what might be gained [5]:

> I go
> you stay;
> two autumns.

So powerful, clear, and brief!

Issa (1763-1828) was my favorite haiku poet. I admired his compassion for insects, birds, horses, young children, and old adults. I admired his disregard for social status and social hierarchies. And I admired how he maintained an awareness of suffering and a deep sense of justice, without becoming weary of the world. This haiku shows his attention to communal life [5]:

> The snow is melting
> and the village is flooded
> with children.

This haiku recognizes concern and connection [5]:

> Her row veering off,
> the peasant woman plants
> toward her crying child.

This haiku focuses on nature and human values [5]:

> Were it sweet,
> it'd be my dew,
> his dew.

And this haiku shows how much death is a part of life [5]:

> The moon tonight –
> I even miss
> her grumbling.

Issa provided me with many examples and lessons.

Using haiku as a spiritual practice is very promising, but how might this practice help bioethics? The discipline of bioethics has tended to focus on two aspects of ethical life: deliberation and choice. Of course, we need to deliberate well and choose wisely when dealing with treatment options, ethics consults, health policies, and all the issues of bioethics. But attention and perception are also important aspects of ethical life. We need to attend widely and perceive clearly. We need to attend to the contexts, life conditions, and lifeworlds that often shape and situate people's lives, including their choices. Haiku might help us to perceive the natural, social, and built environments that are often in the background of modern life and medicine. These poems might even do something more. They might illuminate existential grounds of ethical life.

So I began to write haiku. Every day I wrote a haiku, in my notebook or on an index card. By looking for and writing haiku, I became a bit more mindful and present. I was able to attend to the contexts, life conditions, and lifeworlds in which other people and I live our lives. Sometimes I had a glimpse of different ways of being in or inhabiting the world. I don't really know whether I became more responsive, but I kept writing. At the end of each month, I edited and saved a few of my haiku. After a while, I tried to arrange the saved poems according to the seasons: from the beginning of spring, through summer and fall, into the heart of winter. But that didn't work. So I arranged them into the following categories: modern life, young and old, illness, medical world, and death.

Modern Life

the Milky Way:
billions of stars
obscured by city lights

I take
half a pastry –
twice

the sun sets
through the window –
the meeting goes on

cars exiting
the church lot –
still in a hurry

a Turkish beach
a refugee child
washes ashore

Young and Old

children blowing
on dandelion puffs –
coevolution

adults
irritated with the child
for playing like a child

children helping
their mother –
dig through the dumpster

planting a fruit tree
on her eightieth birthday –
justice between generations

every birthday
restaurant music
gets worse

bent pines –
a picnic bench
with bent men

Illness

living alone:
small splinter
big problem

I'll be okay –
it's only raining
in the puddles

every morning
good sleep or bad
birds chirping

cancer center:
today a visitor
tomorrow snow

outlines of
leaves blown away –
Alzheimer's

Medical World

waiting room TV
with Fox News –
sick twice

he winces
at the stitches
and the copay

hospital meal –
hard to remember
to say grace

cutting off
the hospital bracelet –
cicadas buzzing

a second opinion:
it is a
world of dew

Death

red highlights
in maple leaves –
my mother's hair

my footprints
in the snow
mere dimples now

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

An Alternative to Medical Assistance in Dying? The Legal Status of Voluntary Stopping Eating and Drinking (VSED)

Jocelyn Downie[1]

Résumé
L'assistance médicale à mourir (AMM) a reçu beaucoup d'attention de la part de nombreux acteurs dans le domaine de la bioéthique. Des philosophes, des théologiens, des avocats et des cliniciens de toutes sortes ont abordé de nombreux aspects difficiles de cette question. Le débat public, la politique publique et la loi ont été renforcés par des analyses disciplinaires variées. Avec la légalisation du AMM au Canada, on s'intéresse maintenant à des questions qui ont toujours été éclipsées par le débat sur l'autorisation de l'AMM. Un de ces problèmes est l'arrêt volontaire de manger et boire (AVMB) comme une alternative à l'AMM. Dans cet article, je vais appliquer une perspective légale à la question. Une compréhension des aspects légaux de l'AVMB permet d'établir les fondements d'une réflexion éthique au sujet de son autorisation. Est-il permis pour ceux qui préfèrent l'AVMB à l'AMM? Est-il permis pour ceux qui ne sont pas admissibles à l'AMM en vertu de notre législation actuelle – pour ceux qui n'ont pas de maladie grave et irrémédiable, pour les mineurs matures, pour les personnes dont la seule condition médicale sous-jacente est un trouble mental et qui ne rencontrent pas les critères d'admissibilité, et pour les personnes ayant perdu leur capacité, mais ayant rempli une directive préalable?

Mots clés
aide médicale à mourir, arrêt volontaire de manger et de boire, nutrition orale et hydratation

Abstract
Medical assistance in dying (MAiD) has received considerable attention from many in the field of bioethics. Philosophers, theologians, lawyers, and clinicians of all sorts have engaged with many challenging aspects of this issue. Public debate, public policy, and the law have been enhanced by the varied disciplinary analyses. With the legalization of MAiD in Canada, some attention is now being turned to issues that have historically been overshadowed by the debate about whether to permit MAiD. One such issue is voluntary stopping eating and drinking (VSED) as an alternative to MAiD. In this paper, I will apply a legal lens to the issue. An understanding of whether VSED is legal provides a foundation for ethical reflection on whether it ought to be permitted. Is it permitted for those who prefer VSED to MAiD? Is it permitted for those who do not qualify for MAiD under our current legislation – for those who do not have a grievous and irremediable medical condition, for mature minors, for individuals whose sole underlying medical condition is a mental disorder and who do not otherwise meet the eligibility criteria, and for individuals who have lost capacity but had completed an advance directive?

Keywords
medical assistance in dying, voluntary stopping eating and drinking, oral nutrition and hydration

Introduction

Medical assistance in dying (MAiD) has received considerable attention from many in the field of bioethics. Philosophers, theologians, lawyers, and clinicians of all sorts have engaged with many challenging aspects of this issue. Public debate, public policy, and the law have been enhanced by the varied disciplinary analyses. With the legalization of MAiD in Canada, some attention is now being turned to issues that have historically been overshadowed by the debate about whether to permit MAiD. One such issue is the use of voluntary stopping eating and drinking (VSED) as an alternative to MAiD. In this paper, I will apply a legal lens to the issue [1-3]. An understanding of whether VSED is legal provides a foundation for ethical reflection on whether it ought to be permitted. Is it permitted for those who prefer VSED to MAiD? Is it permitted for those who do not qualify for MAiD under our current legislation – for those who do not have a grievous and irremediable medical condition, for mature minors, for individuals whose sole underlying medical condition is a mental disorder and who do not otherwise meet the eligibility criteria, and for individuals who have lost capacity but had completed an advance directive?

The Canadian federal legislation regulating MAiD came into force on June 17, 2016. This legislation establishes the eligibility criteria and procedural safeguards for MAiD under the Canadian *Criminal Code*. Notably, it allows access only to individuals who meet the following conditions:

- Are eligible for health services funded by government in Canada (or would be but for a minimum period of residence or a waiting period);
- Are at least 18 years old;
- Are capable of making decisions with respect to their health;
- Made a voluntary request;
- Gave informed consent to receive MAiD after having been informed of means available to relieve suffering, including palliative care;
- Have a grievous and irremediable medical condition meaning:
    - they have a serious and incurable illness, disease or disability;
    - they are in an advanced state of irreversible decline in capability;
    - that illness, disease, or disability, or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

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    - 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.
- Have waited ten days between the day their formal request for MAiD was signed and day MAiD is provided (unless this waiting period has been abbreviated due to imminent death or imminent loss of capacity);
- Have given explicit consent immediately before the provision of MAiD.

The cumulative effect of these requirements is that there are individuals who are experiencing enduring and intolerable suffering who are, or are going to be, ineligible for access to MAiD and so are seeking an alternative path to end their suffering. For example:

- A patient with Alzheimer's disease who, by the time their state of decline is advanced and suffering is intolerable, will no longer have decision-making capacity;
- A patient who has had a debilitating stroke but for whom natural death is not "reasonably foreseeable";
- A patient with an intractable mental illness causing enduring and intolerable suffering but for whom natural death is not "reasonably foreseeable";
- A patient with severe and debilitating chronic pain who is experiencing enduring and intolerable suffering but for whom natural death is not "reasonably foreseeable."

There are also individuals who are experiencing enduring and intolerable suffering and could meet the eligibility criteria for MAiD, but who would not have access to it (e.g., because there are no willing providers or institutions where they live, and they are unable to travel) or who would not choose it (e.g., because it is contrary to their religion or conscience). Of course, every effort should be made to offer such individuals access to resources and interventions that might alleviate their suffering without ending their lives. Palliative care is an obvious example of such an intervention. However, there are times when these resources and interventions are not able to alleviate the person's suffering. There are also times when such resources and interventions are not accessible or acceptable to the person who is suffering. It is in the face of such circumstances that the issue of Voluntary Stopping Eating and Drinking (VSED) arises.[1]

For the purposes of this paper, VSED involves either: 1) a competent individual stopping eating and drinking and indicating that, when they become incompetent (because of having stopped drinking), they do not want to be given oral or artificial nutrition and hydration; or 2) a previously competent individual refusing oral and artificial nutrition and hydration through a prior capable expressed wish.

In this paper, I will address a number of legal questions that can be asked about VSED:

- Is a competent person legally permitted to cause their own death through VSED (either through a refusal while competent or through a refusal made in advance of loss of capacity)?
- Must health care providers respect a previously competent person's prior expressed wishes not to be offered or given oral or artificial nutrition or hydration after losing capacity?
- What are health care providers' legal obligations to a previously competent person who, when capable, expressed a desire not to be offered or given oral or artificial nutrition or hydration, and then, once incapable, requests oral or artificial nutrition or hydration?
- Is a health care provider legally permitted to tell patients about VSED as a possible pathway to death?

I seek to answer these questions using Nova Scotia as the case study.[2] I also provide, in Annex 1, a template institutional policy developed on the bases of the analysis presented in this paper.

Three additional questions fall outside the scope of this paper. *First*: what are the legal implications if an individual seeking MAiD plays a role in their death's reasonable foreseeability? In other words, can an individual whose medical circumstances do not make their natural death reasonably foreseeable commence VSED as a way of causing their natural death to *become* reasonably foreseeable? [5,6] This paper focuses solely on individuals pursuing VSED all the way to death (i.e., not as a way to access MAiD). The question of VSED as a path to eligibility for MAiD is the subject of a separate paper. *Second*: are mature minors legally permitted to cause their own deaths through VSED? Space constraints preclude adequately representing the nuances of statutory differences between provinces and territories with respect to the role of a best interests analysis when considering mature minors' decision-making authority [7]. *Third*: is a health care provider legally permitted to help patients to cause their own death through VSED? This question is addressed in a separate paper [8].

[1] This is also sometimes referred to as Voluntary Refusal of Food and Fluids (VRFF) [4].
[2] The full analysis must be done on a provincial/territorial level because, while there are some common law principles that operate at the national level, there are also provincial/territorial statutes that must be considered. Conclusions about other provinces and territories can be drawn following an analysis of the significance of any differences in provincial or territorial consent to treatment, substitute decision-making, and advance directives legislation.

Is a person legally permitted to cause their own death through VSED?

Common law

It is very clear that competent adult patients have a legal right to refuse any or all *medical treatment* even where the consequence of the refusal is or may be death:

> The law has long protected patient autonomy in medical decision-making. In *A.C. v. Manitoba (Director of Child and Family Services)*, 2009 SCC 30 (CanLII), [2009] 2 S.C.R. 181, a majority of this Court, per Abella J. (the dissent not disagreeing on this point), endorsed the "tenacious relevance in our legal system of the principle that competent individuals are — and should be — free to make decisions about their bodily integrity" (para. 39). This right to "decide one's own fate" entitles adults to direct the course of their own medical care (para. 40): it is this principle that underlies the concept of "informed consent" and is protected by s. 7's guarantee of liberty and security of the person (para. 100; see also *R. v. Parker* (2000), 2000 CanLII 5762 (ON CA), 49 O.R. (3d) 481 (C.A.)). As noted in *Fleming v. Reid* (1991), 1991 CanLII 2728 (ON CA), 4 O.R. (3d) 74 (C.A.), *the right of medical self-determination is not vitiated by the fact that serious risks or consequences, including death, may flow from the patient's decision. It is this same principle that is at work in the cases dealing with the right to refuse consent to medical treatment, or to demand that treatment be withdrawn or discontinued*: see, e.g., *Ciarlariello v. Schacter*, 1993 CanLII 138 (SCC), [1993] 2 S.C.R. 119; *Malette v. Shulman* (1990), 1990 CanLII 6868 (ON CA), 72 O.R. (2d) 417 (C.A.); and *Nancy B. v. Hôtel-Dieu de Québec* (1992), 1992 CanLII 8511 (QC CS), 86 D.L.R. (4th) 385 (Que. Sup. Ct.). [9]

While we do not have any Supreme Court of Canada decisions turning on the issue of the right to refuse oral or artificial nutrition and hydration, it is reasonable to extrapolate from their discussions of the right to refuse medical treatment. There is no reason to believe that the Supreme Court of Canada, presented with a case turning on the issue of the right to refuse oral or artificial nutrition and hydration, would do anything other than point, yet again, to its commitment to the principle of bodily integrity and respect for autonomy and conclude that competent adult patients have a legal right to refuse oral or artificial nutrition and hydration, even where a potential or certain consequence of the refusal is death.

This conclusion is supported by comments made about the right to refuse *oral or artificial* nutrition and hydration in some lower, albeit not binding, court decisions. As noted by Justice Smith in *Carter v Canada*:

> To summarize, 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. [10][3]

Again in *Carter*, Justice Smith noted that 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*'." [9] Justice Smith did not take issue with this submission; indeed, she relied upon it in her argument against the absolute ban on assisted dying. 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* nutrition and hydration]" [12][4]:

> [T]here 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. For consent to personal care to be meaningful, the decision must be made by someone who is capable of understanding the proposed care and who is free from undue influence or coercion. [12][5]

[3] See also [11]
[4] It is important to note that the BCCA in *Bentley* agreed with the trial judge that Margot Bentley was making a presently competent decision so this was not, in the end, a case of a presently *incompetent* vs. previously *competent* person. Rather, it was a case of presently competent vs. previously competent person. Thus, the common law principles expressed above were endorsed in Bentley even though the result in the case was that Bentley continued to receive oral nutrition and hydration. See [13].
[5] Of course this is a trial level decision in one province and so is not a binding authority. It does, however, accurately reflect the Supreme Court of Canada's position on the philosophy underlying the common law position re: bodily integrity and autonomy.

It is also clear that *previously competent* adult patients have a common law right, through prior expressed wishes, to refuse any or all *medical treatment* even where a potential or certain consequence of the refusal is death. The philosophy underlying this principle is, as the Ontario Court of Appeal stated in *Fleming v Reid* (and the Supreme Court of Canada endorsed in *Rodriguez v British Columbia* [14] and *Carter* [9]):

> A patient, in anticipation of circumstances wherein he or she may be unconscious or otherwise incapacitated and thus unable to contemporaneously express his or her wishes about a particular form of medical treatment, may specify in advance his or her refusal to consent to the proposed treatment. A doctor is not free to disregard such advance instructions, even in an emergency. The patient's right to forgo treatment, in the absence of some overriding societal interest, is paramount to the doctor's obligation to provide medical care. This right must be honoured, even though the treatment may be beneficial or necessary to preserve the patient's life or health, and regardless of how ill-advised the patient's decision may appear to others. [15]

Again, we do not have any Supreme Court of Canada decisions turning on the issue of the right to refuse oral or artificial nutrition and hydration through prior expressed wishes. However, it is reasonable to extrapolate from their discussions of the right of a competent adult to refuse treatment and conclude that, presented with a case turning on the issue of the right to refuse oral or artificial nutrition and hydration through a prior express wish, the Supreme Court of Canada would point to its commitment to the principle of bodily integrity and respect for autonomy.

Thus it can be concluded that competent adults and previously competent adults whose prior capable informed expressed wishes are known, have a *common law* right to refuse oral and artificial nutrition or hydration.

Nova Scotia legislation

Under the *Hospitals Act* [16], no patient in a hospital shall be treated without consent to such treatment. If a patient is incapable of consenting to treatment, consent may be given or refused by a substitute decision-maker. Substitute decision-makers must make decisions "in relation to specified medical treatment" on behalf of the person according to the person's "prior capable expressed wishes." [16, s 54A(a)] If these are not known, then the decision must be made "in accordance with what the substitute decision-maker believes the wishes of the patient would be based on what the substitute decision-maker knows of the values and beliefs of the patient and from any other written or oral instructions." [16, s 54A(b)] If these are also not known, then the decision must be made "in accordance with what the substitute decision-maker believes to be in the best interest of the patient." [16, s 54A(c)]

It must be noted here that the *Hospitals Act* likely does not authorize substitute decision-makers to refuse care as opposed to treatment. The definition of "substitute decision-maker" is "a person who is given the authority to make admission, care or treatment decisions on behalf of a patient under this Act or a voluntary patient." [16, s 2(w)] However, the subsequent provisions dealing with the authority and basis for substitute decision-making do not make reference to care but rather only treatment. It seems reasonable to interpret the *Hospitals Act* as covering artificial hydration and nutrition (as treatment) but not oral nutrition and hydration (as care). Further, under the *Personal Directives Act*, a person may name a delegate to make decisions on her behalf about health and personal care (when she has lost decision-making capacity) [17]. There is no reason to believe that health care does not include artificial nutrition and hydration and personal care explicitly includes oral nutrition and hydration [17].

Thus, it can be concluded that competent adults have a statutory right to refuse artificial nutrition or hydration.[6] Previously competent adults have a statutory right to refuse oral and artificial nutrition and hydration through a personal directive.

Must health care providers respect a previously competent person's prior capable expressed wish not to be offered or given oral and artificial nutrition or hydration after losing capacity?

Health care providers have a duty to respect patient refusals. Physicians are required by law to respect such refusals. For example, to touch a person against the person's wishes would constitute battery[7] or assault [18]. Therefore, health care providers risk civil and criminal liability for forcing artificial nutrition or hydration against a competent adult's wishes, a valid personal directive, or a substitute decision-maker basing a refusal of consent on prior capable informed expressed wishes of a previously competent adult. Health care providers also risk civil and criminal liability should they force oral nutrition or hydration against a competent adult's wishes or a valid personal directive of a previously competent adult.

It must be noted here that some have suggested that, in the context of VSED, failure to provide oral or artificial nutrition or hydration could constitute the *Criminal Code* offence of "failure to provide the necessaries of life." [12] However, this fails to

[6] There is one somewhat bizarre exception to this general conclusion in Nova Scotia as the *Involuntary Psychiatric Treatment Act*, SNS 2005, c 42, s 39 establishes that an advance directive made by a person while capable but now an involuntary patient, can be made in accordance with the substitute decision-maker's belief in the person's best interests "if following the patient's prior capable informed expressed wish would endanger the physical or mental health or safety of the patient or another person, in accordance with what the substitute decision-maker believes to be in the patient's best interests." Many people have argued that this provision is unconstitutional (violating s 15 of the *Charter*) but to this day it remains the law.

[7] The Supreme Court of Canada has clearly endorsed the view that the common law concept of bodily integrity requires that health care providers not touch patients without their consent. Starting or continuing treatment would be considered touching and, if done against a patient's wishes, would be considered tortious battery. See, for example, *Ciarlariello v Schacter* [1993] 2 SCR 119.

recognize two things: 1) there is a duty to provide the necessaries of life only where the patient (directly or through their substitute decision-maker) is unable to remove themself from the physician's charge and is unable to provide themself with the necessaries of life; and 2) there is an offence only where the health care provider is under a duty and fails without legal excuse to perform that duty [18].

I would argue that, when a person or their substitute decision-maker has the decision-making capacity and legal authority to refuse oral nutrition or hydration and is refusing it, then that person will not be under the charge of the physician. Being "under the charge of" entails "the exercise of an element of control by one person and a dependency on the part of the other." [19, at 42]. It does not make sense to consider a person to be under the control of a physician in relation to the unwanted provision of treatment when the physician is legally prohibited from touching them without their consent or to consider someone to be dependent on a physician for nutrition and hydration that they do not want (and that they or their proxy have the legal authority to refuse). In such a case, there is no duty to provide the necessaries of life.

I would also argue that, even assuming for the sake of argument there is a duty, a valid refusal in a VSED case constitutes a lawful excuse for not meeting that duty because administering oral or artificial nutrition or hydration in the circumstances of a valid refusal would constitute tortious battery and criminal assault, and because provincial/territorial consent legislation across Canada allows patients or substitute decision-makers to refuse consent to treatment (covering artificial nutrition and hydration) [20-22].

It can therefore be concluded that health care providers have a legal obligation to respect a previously competent person's prior capable informed expressed wishes not to be offered or given oral or artificial nutrition or hydration after losing capacity.

What are health care providers' legal obligations if a previously competent person, when capable, expressed a desire not to be offered or given oral or artificial nutrition or hydration, and then, once incapable, requests oral or artificial nutrition or hydration?

Under the *Hospitals Act*, the incompetent person's substitute decision-maker must make the decision about whether to give consent to the provision of artificial nutrition or hydration:

> (a) in accordance with the patient's prior capable informed expressed wishes unless
> (i) technological changes or medical advances make the prior expressed wishes inappropriate in a way that is contrary to the intentions of the patient, or
> (ii) circumstances exist that would have caused the patient to set out different instructions had the circumstances been known based on what the substitute decision-maker knows of the values and beliefs of the patient and from any other written or oral instructions [16, s 54A].

Therefore, if subsections (i) or (ii) are not met, the substitute decision-maker must, despite the request from the incompetent person, refuse consent to artificial nutrition or hydration in accordance with that person's prior capable expressed wishes; further, the health care providers must respect that refusal [17, s 15(2)(a)].[8]

Under the *Personal Directives Act*, the substitute decision-maker ("delegate") is required to act in accordance with instructions in a personal directive unless:

> (i) there were expressions of a contrary wish made subsequently by the maker who had capacity,
> (ii) technological changes or medical advances make the instruction inappropriate in a way that is contrary to the intentions of the maker, or
> (iii) circumstances exist that would have caused the maker to set out different instructions had the circumstances been known based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions. [17, s 15(2)(a)]

In turn, a court may "vary, confirm or rescind a personal-care decision, in whole or in part, made by a delegate or statutory decision-maker" [17, s 31(1)(d)] or "order that all or part of a personal directive ceases to have effect." [17, s 31(1)(i)] However, this power is limited by the fact that "the court may not add to or alter the intent of an instruction contained in a personal directive unless the court is satisfied that the maker's instruction or wishes changed subsequent to the making of the instruction." [17, s 31(3)] Again, if the exceptions are not met, the delegate must, despite the request from the incompetent person, refuse consent to oral or artificial nutrition or hydration, the court must not intervene, and the health care providers must respect that refusal.

Finally, under the common law, an express refusal of oral or artificial nutrition and hydration made by an individual while competent overrides a request for oral or artificial nutrition and hydration made while incompetent unless there is a basis for concluding that the person had changed their views while they were still competent [23].

[8] It is possible that (iii) might be met in some circumstances – if, for example, the substitute decision-maker believes the process of dying by starvation or dehydration is different than the person anticipated and that, had the person known what it would be like, they would not have refused nutrition and hydration.

Is a health care provider legally permitted to tell patients about VSED as a possible pathway to death?

To answer this question, we must determine whether death by VSED is suicide and, if so, whether telling patients about VSED as a possible pathway to death constitutes counselling, abetting, or aiding suicide under the *Criminal Code*.

The *Criminal Code* establishes the following:

> 241 (1) Everyone is guilty of an indictable offence and liable to imprisonment for a term of not more than 14 years who, whether suicide ensues or not,
> (a) counsels a person to die by suicide or abets a person in dying by suicide; or
> (b) aids a person to die by suicide.

Is death by VSED suicide?

It is unclear whether death by VSED is always, sometimes, or ever to be considered suicide. A detailed discussion of this issue is available in "The legal status of deep and continuous palliative sedation without artificial nutrition and hydration" [8] and "Is refusing care a legal pathway to medical assistance in dying?" [24] The conclusion drawn, based on a review of the case law as well as a review of instructions for and practices with respect to the completion of medical certificates of death (including when the manner of death is to be certified "suicide"), is that we cannot in all cases confidently state whether or when death by VSED is suicide. In the face of such uncertainty and in light of the seriousness of the possible consequences of criminal charges, it seems prudent to assume for the sake of argument that death by VSED is suicide and therefore to explore whether telling patients about VSED as a possible pathway to death constitutes counselling, abetting, or aiding suicide under the *Criminal Code*.

Counselling

There are no Supreme Court of Canada decisions on the meaning of "counselling" in the context of s.241(1) of the *Criminal Code*. Based on the available lower court decisions in this context and other court decisions about counselling in other contexts, it seems very unlikely that a health care provider would be convicted of counselling suicide for telling a patient about VSED as a possible pathway to death or for advising them on how to follow this pathway *unless*:

- the health care provider wanted to induce the patient to stop eating and drinking as a means of committing suicide.
- the health care provider wanted to use her influence to induce the patient to pursue death through VSED.
- the health care provider sought to convince or persuade the patient to pursue death through VSED.

As concluded by Justice Christine Gosselin of the Court of Quebec (QCCQ) in *R v Morin*, after summarizing the relevant Supreme Court of Canada (SCC) jurisprudence, "counselling" for the purposes of s.241(1) "concerns speech that, assessed objectively, aims to induce, persuade or convince a person to commit suicide." [25][9] Health care providers in the context of VSED would be telling a patient about VSED as a possible pathway to death because they have an obligation to disclose all treatment options and alternatives; VSED is an alternative. They would not be wanting to induce, influence, convince, or persuade the patient to follow VSED. Therefore, they should not face criminal liability for counselling suicide.

Abetting

Abetting suicide likely requires "encouraging, instigating, promoting or procuring the crime to be committed." [30][10] Again, as with counselling, health care providers in the context of VSED would not be aiming to encourage, instigate, promote or procure suicide. Therefore, they should not face criminal liability for abetting suicide.

Aiding

Aiding suicide likely requires that the accused assist or help the person who commits suicide. A health care provider who merely tells a patient about VSED as a pathway to death is not assisting or helping the patient to follow that path. Therefore, they should not face criminal liability for aiding suicide.

Conclusion

It can be concluded that VSED is a legal pathway to a hastened death. As noted earlier, it may be of particular interest for those individuals who would not qualify for MAiD or who are experiencing enduring and intolerable suffering and could meet the eligibility criteria for MAiD, but who would not have access to it (e.g., because there are no willing providers where they live and they are unable to travel) or who would not choose it (e.g., because it is contrary to their religion or conscience). Individuals can: 1) refuse oral and artificial nutrition and hydration while capable; and 2) state a very clear informed refusal of oral and artificial nutrition and hydration through a prior capable expressed wish. These refusals must, in almost all

[9] See also [26-29].

[10] "The *actus reus* of aiding or abetting is doing (or, in some circumstances, omitting to do) something that assists or encourages the perpetrator to commit the offence. While it is common to speak of aiding and abetting together, the two concepts are distinct, and liability can flow from either one. Broadly speaking, "[t]o aid under s. 21(1)(*b*) means to assist or help the actor. . . . To abet within the meaning of s. 21(1)(*c*) includes encouraging, instigating, promoting or procuring the crime to be committed": *R v Greyeyes*, 1997 CanLII 313 (SCC), [1997] 2 SCR 825, at para 26."

circumstances,[11] be respected. It can also be concluded that health care providers are legally permitted to inform patients about VSED as a pathway to death.[12]

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25. R v Morin, 2014 QCCQ 1609.

[11] The exceptions being when there is good reason to believe that the presently incompetent patient changed their mind while competent or would have come to a different conclusion while competent had they had the information available to substitute decision-makers, health care providers, and judges in the present.
[12] Institutions wishing to reflect these conclusions in policy are directed to Annex 1.

26. Mugesera v Canada (Minister of Citizenship and Immigration), 2005 SCC 40 (CanLII), [2005] 2 SCR 100.
27. R v Déry, 2006 SCC 53 (CanLII), [2006] 2 SCR 669.
28. R v Hamilton, 2005 SCC 47 (CanLII), [2005] 2 SCR 432.
29. R v Sharpe, 2001 SCC 2 (CanLII), [2001] 1 SCR 45.
30. R v Briscoe, 2010 SCC 13, [2010] 1 SCR 411.

Annex 1.

TEMPLATE INSTITUTIONAL POLICY ON VOLUNTARY STOPPING EATING AND DRINKING (Nova Scotia version)[13]

Purpose

The purpose of this policy is to provide guidance to health care providers, their patients, and others involved with decisions about stopping oral nutrition and hydration when individuals or their delegates refuse oral nutrition and hydration. It describes the legal context for stopping oral nutrition and hydration in such circumstances and sets out the institutional commitments as well as the process that must be followed when such a decision is being made about stopping oral nutrition and hydration.

Limitations on scope

A choice to stop oral nutrition and hydration is legally distinct from medical assistance in dying (MAiD).[14] For policy and procedure on how to respond to a request for MAiD, see [insert link to institution's MAiD policy and procedure].

Withholding or withdrawal of artificial nutrition and hydration falls within the well-settled legal right of patients and their substitute decision-makers to refuse health care. For policy and procedure on how to respond to a refusal of artificial nutrition and hydration, see [insert link to institution's withholding and withdrawal of treatment policy and procedure].

Terminology

"capacity" means the ability to understand information that is relevant to the making of a personal-care decision and the ability to appreciate the reasonably foreseeable consequences of a decision or lack of a decision;

"delegate" means a person authorized under a personal directive to make, on the maker's behalf, decisions concerning the maker's personal care;

"health care provider" includes a person licensed or registered under Provincial legislation to provide health care;

"nearest relative" means, with respect to any person, the relative of that person first listed in the following subclauses:
(i) spouse,
(ii) child,
(iii) parent,
(iv) person standing in loco parentis,
(v) sibling,
(vi) grandparent,
(vii) grandchild,
(viii) aunt or uncle,
(ix) niece or nephew,
(x) other relative,
who, except in the case of a minor spouse, is of the age of majority;

"personal care" includes, but is not limited to, health care, **nutrition, hydration**, shelter, residence, clothing, hygiene, safety, comfort, recreation, social activities, support services and any other personal matter that is prescribed by the regulations; [emphasis added]

"spouse" means, with respect to any person, a person who is cohabiting with that person in a conjugal relationship as married spouse, registered domestic partner or common-law partner;

"statutory decision-maker" means a nearest relative or the Public Trustee authorized under Section 14 of the Personal Directives Act.

Legal context

- Patients/delegates can refuse oral nutrition and hydration

[13] This policy was developed by the author based on the analysis presented in this paper.
[14] "***medical assistance in dying*** means
(a) the administering by a medical practitioner or nurse practitioner of a substance to a person, at their request, that causes their death; or
(b) the prescribing or providing by a medical practitioner or nurse practitioner of a substance to a person, at their request, so that they may self-administer the substance and in doing so cause their own death. (*aide médicale à mourir*)" s.241.1 *Criminal Code*

- Health care professionals and institutions must respect decisions about oral nutrition and hydration made by capable patients (directly or through valid personal directives when the maker becomes incapable) or incapable patients' delegates except where the delegate is acting outside their authority. [15]

Institutional commitments

It is central to the philosophy of [institution name] that its staff shall identify, assess, and respond to each patient's situation in a manner consistent with the patient's wishes and best practices.

[Institution name] recognizes the right of patients to exercise their autonomy by making decisions regarding their care at the end of life, including decisions to stop oral nutrition and hydration. Such decisions may be made at the time of the proposed provision or through a personal directive in advance of loss of capacity.

[Institution name] also recognizes the obligation of an incapable patient's delegate to make decisions on behalf of the patient according to the patient's prior expressed wishes (if any) or values and beliefs relevant to the specific decision (if known), or best interests (if wishes, values, and beliefs relevant to the specific decision are not known). This includes decisions to stop oral nutrition and hydration. The exception to this rule comes when there is good reason to believe that a presently incapable patient changed their mind while capable or would have come to a different conclusion while capable had they had the information available to their delegate.

[Institution name] also recognizes that health care providers have an obligation to respect refusals of oral nutrition and hydration (from capable patients or through instructions in previously capable patients' valid personal directives or through instructions given by patients' delegates). An exception to this rule comes when there is good reason to believe that a delegate is acting outside their authority in which case the health care providers should make an application to the Supreme Court of Nova Scotia.

[Institution name] also recognizes that health care providers have a right to refuse to participate in the stopping of oral nutrition and hydration so long as this refusal is expressed in a way that does not harm the patient and alternative health care providers can be provided by the institution.

Process

1. Realize there is a decision to be made about continuation of oral nutrition and hydration

2. Assess decision-making capacity of patient to make decision re: oral nutrition and hydration
    a. If patient is capable, ensure decision is free and informed
        i. If free and informed, respect the patient's decision
        ii. If not informed, inform the patient and then respect the patient's decision
        iii. If not free, take steps needed to remove undue inducement/coercion and then respect the patient's decision

    b. If patient is not capable, determine whether there is a valid personal directive with instructions that apply in the circumstances[16]
        i. If there is a valid personal directive with instructions that apply in the circumstances, follow the instructions
        ii. If there is no valid personal directive with instructions that apply in the circumstances, determine whether there is a valid personal directive appointing a delegate
            1. If there is a valid personal directive appointing a delegate, respect the decision of the delegate unless they are acting outside their authority[17]

[15] In making any decision, a delegate shall
(a) follow any instructions in a personal directive unless
(i) there were expressions of a contrary wish made subsequently by the maker who had capacity,
(ii) technological changes or medical advances make the instruction inappropriate in a way that is contrary to the intentions of the maker, or
(iii) circumstances exist that would have caused the maker to set out different instructions had the circumstances been known based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions;

(b) in the absence of instructions, act according to what the delegate believes the wishes of the maker would be based on what the delegate knows of the values and beliefs of the maker and from any other written or oral instructions; and

(c) where the delegate does not know the wishes, values and beliefs of the maker, make the personal-care decision that the delegate believes would be in the best interests of the maker.

[16] "applies in the circumstances" means provides clear direction as to the patient's wishes and there is no good reason to believe that the presently incapable patient changed their mind while capable or would have come to a different conclusion while capable had they had the information available to delegates, health care providers, and judges in the present.

[17] "acting outside their authority" means the delegate is not acting in accordance with the patient's prior expressed wishes, beliefs, or values or, if those are not known, is not acting in the best interests of the patient.

a. If the delegate is acting outside their authority, make an application to the Supreme Court of Nova Scotia[18]

3. Provide high quality care to the patient making them as comfortable and safe as possible within any constraints of the decision made.

Special Notes
It is essential to remember that the determination of decision-making capacity must be made relative to the decision to be made. Where the patient is refusing oral nutrition and hydration, capacity to make that decision includes the ability to understand and appreciate that this will result in death.

It is essential that health care providers assessing whether a decision is free have an understanding of the ways in which responding to offers of oral nutrition and hydration (e.g., a spoon being placed on lip) can be a reflex rather than a sign of a free decision.

It is essential that all those advising patients about end of life decision-making advise them that if they want someone to be able to decline oral nutrition and hydration on their behalf should they become incapable, they need to appoint a delegate. They should be advised that statutory decision-makers do not have the authority to decline oral nutrition and hydration (although they do have the authority to consent to or refuse artificial nutrition and hydration).

It is essential that all those advising patients on completion of personal directives advise them on the need to be as clear and specific as possible. Patients should be encouraged to reflect on the potential future decision of whether to have oral nutrition and hydration and, if someone knows that they want to decline oral nutrition and hydration even in the face of the consequence of death, they should be encouraged to state that clearly and explicitly.

It may be psychologically difficult for staff and patients' families to observe a patient not being given oral nutrition and hydration. Resources are available to support staff and patients' families [insert link to institutional supports].

[18] 31(1) The court may, on hearing an application under Section 29, do any one or more of the following:
(a) where a court is satisfied that a writing embodies the intentions of the maker, the court may, notwithstanding that the writing was not executed in compliance with the requirements of this Act, order that the writing is valid and fully effective as a personal directive as if it had been executed in compliance with the requirements of this Act;

(b) make a determination of capacity of the maker or person represented or a delegate or statutory decision-maker after considering a report made under subsection (2)(b);

(c) determine the validity of a personal directive or any part of it;

(d) based on instructions contained in a personal directive or other evidence of the maker's instructions or wishes made while the maker had capacity, vary, confirm or rescind a personal-care decision, in whole or in part, made by a delegate or statutory decision-maker;

(e) determine the authority of a delegate or statutory decision-maker;

(f) provide advice and directions;

(g) stay a decision of a delegate or statutory decision-maker;

(h) substitute another person as delegate;

(i) order that all or part of a personal directive ceases to have effect;

(j) order that costs of the proceeding be paid from the estate of the maker or person represented;

(k) make any other order that the court considers appropriate.

(2) For the purpose of assisting the court in making a decision under subsection (1), the court may
(a) require a delegate or statutory decision-maker to provide to the court a report of personal-care decisions made by the delegate or statutory decision-maker; or

(b) order that a report on the capacity of a maker or person represented or a delegate or statutory decision-maker be prepared.

(3) In making a decision under subsection (1), the court may not add to or alter the intent of an instruction contained in a personal directive unless the court is satisfied that the maker's instruction or wishes changed subsequent to the making of the instruction. *2008, c. 8, s. 31*.

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

"What Is PER?" Patient Engagement in Research as a Hit

Jean-Christophe Bélisle-Pipon[1,2], Claudio Del Grande[3,4], Geneviève Rouleau[4,5]

Résumé
Impliquer les patients dans la conduite de la recherche et dans l'établissement des agendas de recherche est de plus en plus considéré comme un impératif éthique de même qu'un moyen de transcender la vision classique des patients en tant que sujets passifs en favorisant leur autonomisation. Cependant, l'engagement des patients en recherche est encore une approche émergente avec des cadres définitionnels et opérationnels débattus. Cette chanson aborde la rencontre parfois difficile et l'insaisissabilité de la compréhension mutuelle entre chercheurs et patients. « What is PER? » est une illustration impressive des défis et enjeux rencontrés dans l'univers de l'engagement du patient en recherche.

Mots clés
engagement des patients, travail artistique fondé sur la recherche, savoir expérientiel, autonomisation des patients, recherche axée sur les patients, résultats centrés sur les patients, implication des patients

Abstract
Engaging patients in research conduct and agenda setting is increasingly considered as an ethical imperative, and a way to transcend views of patients as passive subjects by fostering their empowerment. However, patient engagement in research (PER) is still an emerging approach with debated definitional and operational frameworks. This song addresses the sometimes difficult encounter and elusive mutual understanding between researchers and patients. "What is PER?" is an impressionistic illustration of the challenges and issues that can be found in the universe of patient engagement in research.

Keywords
patient engagement, research-based artistic work, experiential knowledge, patient empowerment, patient-oriented research, patient-centered outcomes, patient involvement

[Researcher]	What is PER? Patients explain me, explain me Once more	
[Researcher]	Patients explain me, explain me Once more	
	What is PER? Hey Hey	
		[Patients' back vocals] *Whoa ooh whoa ooh*
[Patients]	I don't know why you're not fair I give you my insights, but you don't bear So, am I right? What is wrong? Gimme a plea	
[Patients]	What is PER? Researchers explain me, explain me Once more	
[Patients]	What is PER? Researchers explain me, explain me Once more	
		[Researchers' back vocals] *Whoa ooh whoa ooh whoa ooh whoa oh oh ooh whoa ooh whoa oh oh oh oh (Bis)*
[Patients] *[Researcher]* *[Both]* *[Researcher]*	Oh, I can help, what can I do? I'm applying for grants and I need you I know we're a team, me and all of you I can't press *Send*	
[Researcher]	What is PER? Funders explain me, explain me Once more	
[Researcher]	What is PER? Funders explain me, explain me Once more	

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		[Researchers' back vocals] *Whoa ooh whoa ooh whoa ooh whoa oh* *oh ooh whoa ooh whoa oh oh oh oh (Bis)*
[Researcher]	What is PER?	
		[Researchers' back vocals] *Whoo ooh whoo ooh whoo ooh*
	What is PER?	
		[Researchers' back vocals] *Whoo ooh who ooh whoo ooh*
	What is PER?	
[Both]	No one can tell me, can tell me At once	
[Researcher]	Explain me	
[Researcher]	Just tell me	
[Patients]	I want no other,	
[Researcher]	no other advisor	
[Patients]	This is our care	
[Researcher]	Our affair	
[Both]	We are together, I need you forever Is it PER…	
[Both]	What is PER? Won't you explain me, explain me Once more	
	What is PER? Funders explain me, explain me Once more	
	Hey Hey	*[Patients' back vocal]* *Whoa ooh whoa ooh whoa ooh whoa oh* *oh ooh whoa ooh whoa oh oh oh oh (Bis)*
	What is PER? Patients explain me, explain me Once more	*[Researchers' back vocal]* *Whoa ooh whoa ooh whoa ooh whoa oh* *oh ooh whoa ooh whoa oh oh oh oh (Bis)*
	What is PER? Researchers explain me, explain me Once more	
	What is PER?	

Afterword

Patient engagement in research (PER) is increasingly recognized and considered as an ethical imperative, based on the predication that research must serve those on whom and for whom it is conducted [1]. Seeking to transcend a paternalistic view of the involvement of patients in research (as objects and subjects of research), PER's objective is to value their knowledge and their experiences as being able to guide and orient research conduct and priority setting, so that it is more relevant and of greater impact [2]. Historically, researcher-patient relationships were not easily qualified as being founded on comradeship, equality and inclusivity [3]. Therefore, such a new approach to health research is laudable and likely necessary, but not without difficulty. PER requires, to some extent, the transformation of relationships between the various parties involved. An important change of culture and mentalities is needed to allow patients to join research teams and to be considered as important and valued partners [4].

"What is PER?"

This song – pastiche of the highly successful hit "What Is Love" performed by Haddaway in the 90s'[1] – addresses themes related to PER operationalization as well as the obstacles and pitfalls in rebalancing the researcher-patient relationship; one of its critical obstacles being the meaningful and effective involvement of patients in research. "What Is PER" returns to the root of this concept and questions its foundations and implications based on both patients' and researchers' perspectives. The

[1] The song was released in 1993 on the label Coconut. Written and produced by Dee Dee Halligan and Junior Torello (https://www.youtube.com/watch?v=HEXWRTEbj1I).

song focuses on the challenges to reach a genuine, mutually beneficial researcher-patient relationship. But, achieving mutual understanding is not easy. On the one hand, research carries its share of imperatives and constraints (e.g., never-ending quest for funds and publications) that can easily escape patients. On the other hand, patients' realities and experiences with their disease, the health care system and research endeavour may sometimes seem trivial or biased (uncontrolled experiences vs. controlled experiments) to researchers. Too often, patients and researchers live in parallel realities. This is evoked by the repetition of the same questions and incessant requests to get an explanation of what PER really is and what actually goes wrong. Both are seeking to have a common understanding of what unites them, of the terms of their relationship.

PER, as a (new) research approach [5], seeks to intermingle patients and researchers, particularly by valuing patients as partners, and their experiential knowledge as complementary to scholarly knowledge. The choir of patients stress that they want to contribute to research and share their perspective that forms a "communal body of knowledge exceed[ing] the boundaries of individual experiences" [6]. However, in the song, researchers are only involving them superficially – minutes before submitting a grant application – leaving patients dissatisfied with their involvement: "I don't know why you're not fair. I give you my insights, but you don't bear". Researchers also are dissatisfied with and puzzled by funder expectations regarding their involvement of patient partners in research. In essence, "What is PER" focuses on miscommunication and Augean expectations between patients, researchers and funders. The song evokes a need for a frank and open dialogue within the research community, including patients, researchers, funders and so on.

Towards answering the question "What is PER?"

Whether in the context of patient-oriented research (Canadian model, established by the Canadian Institutes of Health Research, CIHR) [7], patient-centred outcomes research (American model as defined by the Patient-Centered Outcomes Research Institute, PCORI) [8], or public involvement in research (British model championed by INVOLVE, funded by the National Institute for Health Research, NIHR) [9], engaging patients in research is complex. It requires researchers to balance their expertise and quest for evidence-based knowledge with the perspectives and the subjectivity of patients. It entails recognizing that patients have experiential knowledge that can potentially increase the relevance and validity (both internal and external) of research projects. To achieve this, it is necessary to have a common vision of PER as well as a clear understanding of respective expectations and limitations.

As some funding opportunities (and increasingly scientific journals[2]) are now requiring the involvement of patients, this nudges researchers to engage in PER approaches. The instrumentalization of patients to gain access to these funds is real and represents a pressing ethical issue [1], yet even well-intentioned researchers are facing difficulties in authentically conducting PER. The song conveys that researchers' and patients' narratives are still tangential, highlighting that these communities have not yet established the necessary dialogue [13]. The terms of their relationship (or of their *affair*) are not yet established, nor has agreement been reached on what they should expect from each other; this is potentially one of the most pressing operational dimensions of PER.

Much remains to be done to address the issues of communication and genuine and mutually beneficial relationships. When researchers and patients ask each other and research funding agencies what PER entails, the answers they receive – the back vocals in the song – are heartfelt but remain elusive. It is as if the words are lacking for them to truly understand each other at this early stage of their new partnership. Making them still wonder what PER is.

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JCBP is cofounder and former Executive Editor of *BioéthiqueOnline*, and is member of the *Canadian Journal of Bioethics* Editorial Advisory Board. CDG and GR have nothing to declare.

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[2] The number of journals explicitly welcoming articles about PER is growing. For instance, the British Medical Journal (BMJ) and the Canadian Medical Association Journal (CMAJ) both seek to publish scholarship about PER [10,11]. The BMJ (since 2015) and BMJ Open (since 2018) now require that articles submitted be accompanied by a patient and public involvement statement describing whether and how patients were involved in the research [12].

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

More Than a Biological Condition: The Heteronormative Framing of Infertility

Erika Maxwell[1], Maria Mathews[1], Shree Mulay[1]

Résumé
L'infertilité est souvent abordée du point de vue des couples hétérosexuels, le groupe de patients utilisant majoritairement les technologies de reproduction. Cependant, il existe de nombreux types de patients qui bénéficient de traitements de fertilité et ces patients sont souvent négligés dans les politiques, la planification, la prestation de services et la recherche. Ce commentaire démontre la nécessité d'approfondir la recherche sur les sous-groupes LGBT, lesquels se situent souvent en dehors des discours sur l'infertilité et sont donc particulièrement désavantagés par les structures actuelles des politiques et des services de fécondité.

Mots clés
hétéronormativité, infertilité, services de fertilité, LGBT, obstacles aux soins

Abstract
Infertility is often framed from the perspective of heterosexual couples, the dominant patient group using reproductive technologies. However, there are many types of patients availing of fertility treatments and those patients are often overlooked in policy, planning, service provision, and research. This commentary demonstrates the need for further research into LGBT subgroups, who frequently fall outside of infertility discourses, and are therefore especially disadvantaged by current policy and fertility service structures.

Keywords
heteronormativity, infertility, fertility services, LGBT, barriers to care

Introduction

When it comes to infertility and the right to reproduce, financially stable, heterosexual couples often have the loudest voices [1], resulting in the heteronormative framing of infertility research. This heteronormativity obscures the experiences of people using fertility services who fall outside the traditional infertility definition, such as lesbian, gay, bisexual, transgender (LGBT), and other sexual and gender minorities [1,2]. Using a critical theory lens, we can examine political, economic, social, and cultural factors to gain insight into the reasons for inequality [3]. We argue that the definition of infertility, and its social construction, leads to an exclusion and oppression of LGBT individuals and call for more research on LGBT experiences with infertility and fertility services to inform services and policy.

Definition

Infertility can be defined as both a medical and social condition. The increased availability of fertility services has contributed to the perception that infertility, a natural part of life for some people, is a medical condition requiring medical treatment [1]. In fact, the World Health Organization defines infertility as "a disease of the reproductive system defined by the failure to achieve a clinical pregnancy [(diagnosed by ultrasonographic visualization of one or more gestational sacs or definitive clinical signs of pregnancy)] after 12 months or more of regular unprotected sexual intercourse" [4]. This definition is inarguably framed in heteronormative terms. Many studies frame infertility from the perspective of heterosexual couples [5-9] and neglect other groups. The heteronormative definition is restrictive and means that the concerns and therapeutic goals of other patient groups are often overlooked. This definition should be broadened to include more perspectives, specifically those from LGBT subgroups experiencing social infertility (or involuntary childlessness).

Social Construction of Infertility

The belief that the right to reproduce is inalienable is influenced, to some extent, by the social construction of motherhood and the importance of biological parenting. Although infertility is most commonly defined and recognized as a medical condition, it can be argued that it is also a social condition, as women often feel societal pressure to be mothers [8,10]. This pressure is derived from the social construction of gender and gender roles [11]. For women, motherhood is a role perpetuated by social, cultural, and patriarchal values [11]. In some cultures, women may be ostracized because of their inability to conceive [8]. Interviews with Indian women found that women experienced social exclusion for not being able to have children, even if it was the result of their husband's infertility [8]. In an American study, questionnaires used to assess perceived infertility-related stress amongst male and female patients found that women experienced greater stress than men from infertility-related social concerns, sexual concerns, and the need for parenthood [9]. Nonetheless, men also experience pressure to become fathers and similarly feel stress from infertility and societal expectations of fatherhood [9,12]. Their experiences may be hidden and stigmatized, particularly when fertility is equated with masculinity [13].

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The need for parenthood described above demonstrates the constructed ideals surrounding parenting, as society defines parenthood in terms of the “biological parent” and assigns value to individuals based on their ability to have biological children. Biological parents are considered more legitimate than step or adoptive parents [14]. The nature of infertility as a social condition (and the social obligation to be a parent) means that it is not only experienced by heterosexual couples, but also by LGBT individuals and couples. The social constructions of infertility, motherhood, and biological parenting are important concepts to understanding how policy-makers, health care teams, and fertility patients define infertility. Research needs to explore how LGBT subgroups perceive and experience these infertility related issues.

Exclusion from Research

LGBT individuals are under-represented in infertility-related research. Although infertility research is beginning to examine this population, several studies noted that heterosexual couples are generally thought of as the main, if not the only, group using fertility services [1,15]. One researcher interviewed 17 heterosexual women of high socioeconomic status and 95 individuals from non-dominant groups using fertility services, including women of low socio-economic status, men, and women in same-sex relationships, to gain a better understanding of the medicalization of infertility [1]. The study found that the medicalization of infertility contributes to the misconception that infertility disproportionately affects white, wealthy, heterosexual women and excludes other individuals from proper access to reproductive care [1].

When LGBT subgroups are included in research, key information is lacking. For example, in studies that have examined the experiences of transgender individuals, there seem to be issues with the low level of service uptake, but little discussion of why this might be the case. Retrospective chart reviews of all transgender patients who had been seen for fertility preservation consultations at a Canadian clinic between November 2011 and March 2014 showed that nine of 11 male-to-female transgender patients and zero of three female-to-male transgender patients used cryopreservation services [16]. For transgender patients, fertility preservation services seem to be underutilized [17], especially for female-to-male patients [16,18], who must undergo more expensive and invasive procedures. It must be noted, however, that the underutilization of services by female-to-male patients may be a consequence of these patients not identifying with typical gender roles attributed to women, like motherhood [11]. Additionally, the limited service uptake by transgender patients may be associated with the substantial difficulties faced by LGBT subgroups, including limited financial resources, discrimination, and poorly-educated health professionals [1,2,15,19,20]. Further research is needed to examine utilization of fertility services in LGBT subgroups, specifically transgender individuals, to substantiate these deductions.

Exclusion from Service

LGBT individuals regularly face exclusion from fertility services. For example, a review of fertility centre websites found that patient education was heavily focused on heterosexual couples and did not provide similar information for same-sex couples [15]. Moreover, lesbian mothers and lesbians attempting to become mothers experience stigma and discrimination [19,21,22], in addition to the typical challenges associated with infertility and motherhood [2]. In England, lesbians using donor insemination were subjected to heteronormatively structured protocols and underwent additional screening to ensure suitability as parents [19]. Australian lesbian mothers who had used fertility services also experienced various forms of discrimination when accessing health services and by health professionals, including inappropriate questioning, heterosexual assumption, and refusal to provide care [2]. In the Australian study, researchers called for equitable access to service through more inclusive policy, sensitive to non-heteronormatively structured families, such as the use of gender inclusive language, health promotional materials, and health assessment forms, as well as staff education on the specific needs of this patient population [2]. These patient experiences demonstrate the subtle micro-inequities that exist due to the heteronormative framing of infertility, such as health assessment forms catering to heterosexual couples, as well as more blatant acts of discrimination like refusal of care.

Exclusion from Policy

When discussing policies related to reproductive technologies and procreation, it is important to be aware that they have been, and still are, largely designed from a heteronormative perspective [20,23]. An example of this can be seen through the discriminatory federal tax incentive for procreation offered by the Internal Revenue Service in the U.S., which allows a tax deduction for medical expenses, including IVF and other assisted reproductive technologies [20]. The way the law is written may result in heterosexual couples and same-sex couples being treated differently in qualifying for the deduction. The deduction may not be available to same-sex couples, even if one or both partners are infertile, because the law stipulates that it is only available to (medically diagnosed) infertile couples who would otherwise be able to reproduce naturally (i.e., heterosexual couples) [20]. Policies such as these reinforce systemic discrimination that perpetuates heteronormativity, and thus contributes to the further disadvantage of LGBT individuals.

Conclusion

This commentary demonstrates that there is a need for a body of evidence related to infertility issues experienced by LGBT subgroups. Research on fertility care for the LGBT community offers an opportunity to gain a better understanding of

infertility, as well as the social, political, and economic factors that surround it. Among other topics, research must explore the social construction of fertility from the LGBT perspective, develop a more inclusive definition of fertility, and describe barriers (and facilitators) experienced by LGBT individuals who seek fertility services. Research and the ensuing evidence base are needed to support inclusive policy and patient-centred models of care.

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Canadian Journal of Bioethics
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RÉPONSE À - ARTICLES / RESPONSE TO - ARTICLES

Effective Referral and the "Consumer Model of Medicine"

Elyse Platt[1]

Résumé
Des philosophes tels que Roger Trigg ont contesté la politique de référence efficace du Collège des médecins et chirurgiens de l'Ontario, soutenant qu'il s'agit d'un exemple de culture de consommation en médecine. Dans cet article, je conteste cette position et soutiens plutôt que les médecins qui ne parviennent pas à référer efficacement abusent plutôt de leur pouvoir en tant que gardiens des soins de santé.

Mots clés
référence efficace, modèle de consommation médicale, contrôle d'accès, aide médicale à mourir

Abstract
Philosophers such as Roger Trigg have taken issue with the College of Physicians and Surgeons of Ontario policy on effective referral arguing that it is an example of a culture of consumerism in medicine. In this paper, I take issue with this position and instead argue that physicians who fail to effective refer are instead misusing their power as gatekeepers to healthcare.

Keywords
effective referral, consumer model of medicine, gatekeeping, medical assistance in dying

In his recent paper *Conscientious Objection and 'Effective Referral'* [1], Roger Trigg argues that physicians ought to be respected in their decision to conscientiously object to the policy of the College of Physicians and Surgeons of Ontario (CPSO) on effective referral [2]. An argument put forward by Trigg to support this claim is that the CPSO policy succumbs to a "consumer model of medicine" that undermines the physician's expertise. In this response, I will argue that Trigg is mistaken in his characterization of the policy as an example of the consumer model of medicine, and that this mistake rests on a confusion about the kind of expertise that is relevant to disagreements over effective referral.

In 2015, the CPSO issued a new policy on effective referral in health care. The policy states: "Where physicians are unwilling to provide certain elements of care for reasons of conscience or religion, an effective referral to another health-care provider must be provided to the patient. An effective referral means a referral made in good faith, to a non-objecting, available, and accessible physician, other health-care professional, or agency." [2] Trigg takes issue with this policy because of concerns that it disregards the physician's moral point of view. He argues that the policy does not sufficiently recognize the physician's reasons for objecting to particular procedures, such as abortion or Medical Assistance In Dying (MAiD), and thereby subscribes to what he calls a "consumer model of medicine" privileging the desires of patients over their physician's ethics. He writes: "…if a mere consumer-oriented view arises that the patient's autonomy and right to choose overrides everything else, the ethical judgement of physicians, in this case all of them, is being put aside" [1]. He worries that this approach wrongly assumes that "the patient's judgements and preferences are all that matters" in health care [1], and argues that a policy of deferral to the patient's wishes represents a model of medicine in which the physician's expertise is disregarded for the sake of the patient's desires.

However, I'm not convinced that the CPSO policy rests on or promotes a consumer model of medicine, since its effective referral clause is not directed at physicians' *medical* expertise. Rather, it applies to situations where a patient's request for a medical service is incompatible with a physician's moral beliefs, and that for reasons of conscience, the physician is unable to provide. To illustrate my point, it is helpful to think about a case which more straightforwardly embodies a consumer model of medicine. Imagine that a patient walks into her doctor's office with a viral infection such as a seasonal flu. She demands of her doctor that she be prescribed antibiotics. Her doctor explains to her that antibiotics will not help with the viral infection because antibiotics can only treat bacterial infections. Unsatisfied, the patient threatens to file a complaint with the CPSO for neglect and medical misconduct if she does not get the "treatment she deserves." In this case, the patient is clearly reasoning on the basis of a consumer model of medicine; she is disregarding the knowledge of her physician related to existing scientific evidence about the effective use of antibiotics, and treating the physician as a mere vendor of a chosen pharmaceutical product. Here, the physician's medical expertise is being disregarded for the sake of the patient's misplaced desire for antibiotics.

In cases of effective referrals covered by the CPSO policy, however, there is no distinctively medical expertise being over-ridden or ignored. It is important not to conflate medical and ethical epistemologies, and to remember that there is nothing in being a physician that implies conferring them with a superior moral epistemic value than patients' for judging the ethical acceptability of medical procedures such as abortion or MAiD. In their paper *Gatekeeping and Personal Values Misuses of Professional Role* [3], Hester and colleagues address an analogous situation in which emergency contraception (EC) is being denied to women by pharmacists because of moral disagreement. They argue that "pharmacists and physicians who deny emergency contraception to women misuse their role as gatekeepers because EC is safer than many [over the counter] meds, and therefore does not require particular skill or application of special knowledge" [3]. Indeed, gatekeeping is inappropriate when there is no special knowledge or skill to legitimize the role of gatekeepers granted to a group of individuals. In cases covered by the CPSO policy on effective referral, the physician does not hold any special knowledge or

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skill that the patient lacks, and which would justify a refusal to provide a referral. The reason why the physician's resistance in this case is inappropriate is that the reasons the physician has for refusing to provide the service are moral, and not medical. The physician is inappropriately gatekeeping access to health services because of personal moral beliefs. The CPSO policy has nothing to do with a consumer-model of medicine, because it is not the physician's medical expertise that is being over-ridden but her personal view of the good life, and for instance in cases of abortion and MAiD, about lives worth living.

In their article *Conscientious Objection to Sexual and Reproductive Health Services* [4], Zampas and Ximena argue that the inappropriate use of conscientious objection clauses to protect clinicians' beliefs is widespread "…often in European countries conscientious objection clauses are being applied too broadly and sometimes even abused. The lack of adequate legal and policy framework to regulate the practice and prevent abuse results in serious violations of women's right to access quality sexual and reproductive health services with potentially detrimental impact on their health and lives." [4] They stress the need to have adequate policy to regulate the practice, and to develop safeguards against inappropriate mobilization of medical authority that may undermine some of patients' access to medical services.

Trigg is worried about the physician's perspective not being sufficiently valued. I am worried that physicians misuse their position of power as gatekeepers to services, building on justifications from a different domain, ethics, into which their expertise does not extend.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

L'humour macabre : un mécanisme de défense acceptable en soins critiques?

Alexandra Fortin[1], Charles Dupras[2]

Résumé
Les professionnels de la santé affectés aux soins critiques (urgence, soins intensifs, réanimation et soins coronariens) sont confrontés au quotidien à des situations particulièrement éprouvantes sur le plan émotionnel. Leurs conditions de travail difficiles peuvent devenir anxiogènes, se répercuter sur leur condition physique et/ou psychologique, diminuer leur performance et augmenter leur taux d'absentéisme au travail. Pour faire face à ce contexte stressant et parfois même déprimant, certains professionnels ont recours à l'*humour macabre* (ou « gallows humour »), une forme d'humour noir à connotation morbide, dont le contenu est susceptible de choquer certaines personnes. Bien que très répandue, l'utilisation de l'humour macabre en soins critiques est extrêmement controversée et la plupart du temps réprimandée par les ordres professionnels. Prenant appui sur les codes déontologiques qui les régissent, les ordres professionnels supposent que l'humour macabre enfreint les devoirs et les responsabilités de leurs membres envers leurs patients, rejetant alors son utilisation d'emblée. Dans cet article, nous contestons le rejet catégorique de l'humour macabre en soins critiques. Nous adoptons une perspective conséquentialiste, axée sur l'étude de la littérature scientifique portant sur les bienfaits de l'utilisation de l'humour en milieu de travail, pour défendre son acceptabilité éthique. En permettant d'être mieux disposés à prodiguer des soins malgré les événements tragiques vécus par les professionnels, nous verrons comment l'utilisation de l'humour macabre peut ultimement avoir des retombées positives sur les patients. L'éthique conséquentialiste n'est pas intéressée seulement par la maximisation des bienfaits de l'humour macabre, mais également par la réduction des risques de préjudices à autrui associés à son utilisation. Ce critère important nous conduira donc à définir les termes et à proposer certaines conditions devant être respectées pour une utilisation éthique de ce mécanisme de défense important par les professionnels de la santé en soins critiques.

Mots clés
humour macabre, soins critiques, professionnels de la santé, mécanisme de défense, éthique

Abstract
Health care professionals assigned to critical care (emergency, intensive care, reanimation) are confronted on a daily basis with particularly trying situations. Their hard work conditions can become anxiety-provoking, affect their physical and/or psychological condition, decrease their performance and increase their absenteeism rate at work. To face this particularly stressful and sometimes depressing context, some professionals fall back on "gallows humour", a sort of black humour with a morbid overtone, which is likely to shock certain people. Although gallows humour is very widespread, its use in critical care is extremely controversial and most of the time reprimanded by professional orders. Based on the codes of ethics that govern them, professional orders assume that gallows humour violates the duties and responsibilities of their members towards their patients, rejecting its use straightaway. In this article, we contest the categorical rejection of gallows humour in critical care. We adopt a consequentialist perspective based on the study of scientific literature on the benefits of using humour in the workplace, to defend its ethical acceptability. By enabling us to be better prepared to provide care despite the tragic events experienced by professionals, we will see how the use of gallows humour can ultimately have a positive effect on patients. A consequentialist ethics is not only interested in maximizing the benefits of gallows humour but also in reducing the risk of harm to others related to its use. This important criterion will therefore lead us to define the terms and suggest certain conditions that must be respected for an ethical use of this important defense mechanism by health care professionals in critical care.

Keywords
gallows humour, critical care, health professionals, defense mechanism, ethics

Introduction

Les infirmières et les médecins travaillant en soins critiques sont constamment confrontés à des situations stressantes. Plusieurs patients s'y présentent avec un pronostic sérieux, parfois même vital. La souffrance et la mort font donc partie intégrante du travail de ces professionnels de la santé. Dans un tel contexte de travail, souvent exténuant et potentiellement déprimant, certains collègues font appel à l'humour pour détendre l'atmosphère dans les moments les plus tendus. Ils espèrent ainsi améliorer le climat et l'état d'esprit dans l'équipe soignante et optimiser l'aptitude à prodiguer des soins dans des conditions de travail non idéales.

La pratique de l'humour en soins critiques est toutefois controversée. Certains la perçoivent comme un manque de professionnalisme, voire une atteinte à la déontologie médicale. Dans la littérature anglophone, aux États-Unis principalement, ce sujet sensible a été abordé de façon constructive sous l'appellation « gallows humor » (humour de la potence). Ces analyses ont permis de faire la lumière sur un phénomène répandu et complexe, puis de proposer quelques pistes de réflexion pour faire face aux enjeux éthiques qu'il soulève et aux conflits moraux qu'il peut générer chez certains travailleurs.

Jusqu'à présent la contribution de la littérature francophone à ce débat important est demeurée très modeste, si bien qu'il n'existe pas, à ce jour, de traduction française satisfaisante pour décrire cette pratique et ses implications. Dans cet article, nous nous pencherons donc sur les enjeux éthiques associés à l'utilisation de ce que nous appellerons l'*humour macabre*, c'est-à-dire l'humour à connotation morbide pratiquée à l'égard d'un patient en fin de vie, dans un état de santé critique ou décédé. L'objectif est de rapporter les discussions en cours à propos de l'humour macabre en bioéthique, puis de proposer quelques critères et conditions pouvant favoriser son utilisation éthique.

Selon nous, les approches éthiques qui refusent de façon catégorique tout appel à l'humour macabre, comme l'approche déontologique, ne prennent pas suffisamment en considération les conséquences positives qu'elle peut avoir sur la santé

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mentale et la productivité des professionnels, et de façon indirecte, sur le bien-être des patients admis sur l'unité de soins. En réponse aux lacunes de cadres éthiques trop intransigeants, axés de façon prioritaire sur les devoirs et obligations des codes professionnels, nous offrirons une perspective conséquentialiste sur la question, ayant pour axiome principal la *maximisation du bien-être général.*

En nous appuyant sur plusieurs études scientifiques démontrant les nombreux avantages de l'humour en milieu de travail, nous défendrons l'idée d'une pratique consciencieuse et responsable de l'humour macabre en soins critiques. Ainsi, nous concevrons l'humour macabre, non pas comme un manque de respect envers la dignité du patient, mais comme un mécanisme de défense mature utile aux professionnels de la santé confrontés à un milieu de travail anxiogène dans nos institutions de soins.

Soins critiques : un terreau fertile pour l'humour macabre

Un patient de 78 ans, souffrant d'une maladie pulmonaire obstructive chronique, se présente à l'urgence en pleine détresse respiratoire. La dyspnée dont il souffre est connue pour provoquer un sentiment de perte de contrôle, qui se manifeste la plupart du temps par un niveau d'anxiété élevé chez le patient [1]. Elle requiert une prise en charge immédiate, le plus souvent en réanimation par les infirmières, les inhalothérapeutes et les médecins, dont la présence et le soutien favorisent un climat de confiance envers l'intervention et permettent de réduire l'anxiété du patient. Une fois son état respiratoire stabilisé, le patient est transféré dans un autre secteur de l'urgence.

Quelques heures plus tard, le patient demande à une infirmière de l'aider à se rendre à la salle de bain. N'ayant plus besoin d'oxygène et ne présentant aucun signe de dyspnée, l'infirmière accompagne celui-ci jusqu'à la salle de bain et lui montre la cloche d'appel à utiliser si un besoin d'assistance est ressenti. Dix minutes passent. L'infirmière frappe à la porte pour s'assurer que tout va bien. N'obtenant malheureusement aucune réponse de la part du patient, elle décide alors d'ouvrir la porte, pour y retrouver son patient gisant sans vie. Aucune tentative de réanimation n'est entamée puisqu'une consigne claire à son dossier le proscrit en cas d'arrêt cardiorespiratoire. Cette scène morbide inattendue bouleverse, non seulement l'infirmière responsable, mais toute l'équipe soignante.

Une fois avisé, le médecin se rend au chevet du patient afin de constater le décès. À son arrivée, il demande à voix haute et d'un air sérieux : « Où est donc le coupable? » D'abord déstabilisés par la question, les membres de l'équipe soignante comprennent, lorsque le médecin se penche vers la cuvette de la toilette et répète « où est donc le coupable? », que le médecin ne s'adresse pas véritablement à eux, mais bien aux fèces de la victime, principal suspect, ayant de toute évidence pris la fuite par le réseau d'aqueduc… Malgré le caractère pour le moins audacieux, sur le plan éthique, de l'utilisation de l'humour dans une situation si accablante, les fous rires éclatent et crèvent aussitôt la tension palpable qui s'était installée au sein de l'équipe. Par le biais d'un humour discutable, la responsabilité de la mort du patient est déplacée, d'une certaine façon, du personnel en charge au cours naturel des choses. Les infirmières retournent à leur poste respectif, le sourire en coin et l'âme plus légère, prêtes à prodiguer les meilleurs soins possible au prochain arrivant.

Être émotionnellement, intellectuellement et physiquement disposé à prodiguer à tout moment des soins rapides et adéquats aux patients est crucial pour les professionnels de la santé en soins critiques. Au sein de ces départements, que ce soit à l'urgence ou aux soins intensifs, les travailleurs sont particulièrement à risque de vivre des expériences traumatisantes menant à une détresse psychologique en raison de l'état physique, de la souffrance et du pronostic souvent peu encourageant des patients qui y sont pris en charge [2].

L'Association des médecins d'urgence du Québec (AMUQ) observe depuis déjà plusieurs années que les soignants se sentent trop souvent dépassés par la multiplication de leurs tâches et de leurs responsabilités, ainsi que par la complexité croissante des cas cliniques admis à l'urgence. L'instabilité des équipes et le manque de personnel d'expérience contribueraient aussi, selon l'AMUQ, à créer un contexte de travail extrêmement difficile dans ces unités, où la rapidité d'exécution et la précision des interventions sont parfois déterminantes pour la survie des patients [3]. En médecine d'urgence, les professionnels de la santé sont aussi régulièrement victimes de violence physique et verbale [4]. En janvier 2016, un documentaire intitulé « Des soins aux poings », réalisé par la journaliste Karina Marceau, mit en lumière la problématique de la violence dans le réseau de santé québécois. On y rapportait que plus de 40% des demandes relatives à un arrêt de travail reçues par la *Commission des normes, de l'équité, de la santé et de la sécurité du travail* (CNESST) découlaient d'une agression dans le réseau de la santé [5]. Côtoyer la violence au quotidien peut avoir pour effet de miner l'enthousiasme, la motivation et le courage de professionnels au départ dévoués pour leur fonction. Plusieurs d'entre eux vont même jusqu'à quitter leur emploi de façon définitive.

La pratique du « gallows humour » dans le contexte de soins critiques, ou *humour macabre*, consiste en l'utilisation d'un humour noir et satirique entourant ou s'inspirant de situations éprouvantes et/ou de sujets délicats [6]. La détresse psychiatrique du patient, les pathologies associées aux mauvaises habitudes de vie et la mortalité sont des exemples de sujets fréquemment abordés par l'humour macabre [7]. Si l'humour permet de détendre l'atmosphère et devient du même coup un remède efficace contre la détresse psychologique au travail, nous croyons que son usage est défendable sur le plan éthique. Même s'il semble parfois inacceptable, par exemple lorsqu'accessible aux oreilles de la famille en deuil, nous avançons qu'il peut être légitime – voire même globalement bénéfique – lorsqu'il respecte certains critères et conditions. Afin de poser les

assises de l'analyse éthique que nous proposons, il importe de souligner, tout d'abord, quelques distinctions fondamentales entre les théories déontologiques et conséquentialistes, pouvant toutes deux inspirer la réflexion critique et stimuler la discussion sur la pratique des professionnels de la santé.

L'éthique déontologique : gardienne de la dignité humaine

Les approches éthiques de type déontologique sont pour la plupart dérivées de la philosophie d'Emmanuel Kant (1724-1804). Elles accordent une place prépondérante à l'aspect universalisable de l'action moralement bonne, peu importent les circonstances, ainsi qu'au respect de la dignité humaine [8]. Le terme « déontologie » provient du grec « deon-deontos », qui signifie *devoir* [9]. La morale déontologique fait donc référence à un ensemble d'obligations strictes, parfois qualifiées de « catégoriques ». De ces obligations, comme dire la vérité ou encore ne pas tuer, nous ne devrions, sous aucun prétexte et en aucune circonstance, être dispensés.

Inspirés en partie par la conception du devoir moral de la philosophie kantienne, les *codes de déontologie* élaborés par les ordres professionnels ont pour objectif de faire respecter un certain nombre de principes et de normes que les travailleurs doivent respecter pour répondre aux exigences de la bonne pratique de leurs professions respectives [10]. Ces codes offrent des balises formelles permettant de guider l'action. Bien que les codes déontologiques laissent de l'espace pour le jugement du praticien dans les situations complexes, ils prescrivent la plupart du temps des règles claires qui dictent les devoirs éthiques et la conduite responsable des professionnels de la santé de manière à protéger à la fois le public et la profession, un peu comme le faisait le Serment d'Hippocrate dans la Grèce Antique.

Selon l'éthique déontologique, il n'est pas acceptable de manquer de respect envers la dignité d'autrui. Pour les professionnels de la santé, protéger la dignité des patients est un devoir fondamental. Ce devoir est d'ailleurs inscrit de façon explicite dans le *Code de déontologie des infirmières et infirmiers du Québec* (CIIQ) à l'article 3.1 : « L'infirmière ou l'infirmier doit prendre les moyens nécessaires pour assurer le respect de la dignité, de la liberté et de l'intégrité du client » [11]. Il en est de même à l'article 4 du *Code de déontologie de médecins*, mais aussi à l'article 58, qui, de façon plus spécifique, souligne que: « Le médecin doit agir de telle sorte que le décès d'un patient qui lui paraît inévitable survienne dans la dignité » [12]. La protection de la dignité humaine implique donc le respect du corps inanimé et la protection de la réputation de la personne décédée. Pour les partisans de l'éthique déontologique, qui accordent préséance à la dignité, l'utilisation de l'humour macabre en soins critiques peut paraître moralement inacceptable. Pour ceux-ci, le médecin qui, comme dans l'exemple présenté plus haut, formule une plaisanterie à l'égard de son patient, faillit à ses obligations morales, et du même coup, trahit la confiance du public et l'ensemble de sa profession.

L'interdiction catégorique et absolue d'employer l'humour macabre sous prétexte de protection de la dignité humaine exclut toute possibilité de gestion bien pesée des bénéfices et des risques associés à une pratique répandue. Ainsi, une approche exclusivement déontologique préconisant l'*arrêt* de toute forme d'humour macabre en contexte de soins critiques priverait les professionnels des effets bénéfiques que l'humour peut apporter en situation tendue. Selon ce cadre strict, aucune amélioration de l'utilisation ne serait envisageable. Par contre, une approche conséquentialiste permettrait d'admettre que l'humour macabre peut être bénéfique et autoriserait la proposition de repères pour guider les professionnels de la santé à *mieux utiliser* l'humour dans leur pratique quotidienne. Selon nous, une approche conséquentialiste axée sur la préservation de la vie, la minimisation des souffrances et la maximisation du bien-être pourrait être mise à profit pour améliorer l'impact positif global de l'utilisation de l'humour macabre en soins critiques. Dans la section qui suit, nous suggèrerons que proscrire, condamner ou punir toute utilisation de l'humour macabre en soins critiques n'est ni raisonnable ni souhaitable.

L'éthique conséquentialiste au secours de l'humour macabre

Le conséquentialisme est un courant de la philosophie morale qui émerge au cours du XIXe siècle, grâce aux travaux de John Stuart Mill et Jeremy Bentham. Cette approche de l'éthique s'intéresse avant tout aux conséquences avérées ou probables d'une action sur le bien-être générale, dans le but de déterminer si celle-ci est moralement acceptable. Les conséquentialistes considèrent une action bonne et souhaitable lorsqu'elle *maximise le bonheur et minimise les répercussions indésirables pour le plus grand nombre de personnes* [13]. Ce courant se distingue de l'approche déontologique, notamment, parce qu'il prête une attention toute spéciale aux circonstances entourant l'action. Alors que Kant définissait la bonne action comme étant *celle qui l'est toujours*, peu importe la situation (critère d'universalité), Bentham et Mill désiraient mettre en lumière l'importance de prendre en considération *les particularités de la situation* dans laquelle se trouve la personne qui agit [14].

Pour les professionnels de la santé, l'éthique conséquentialiste se traduit donc en un impératif moral consistant à maximiser le bien-être et à minimiser la souffrance des patients et de leur entourage [9, p.364]. Pour répondre à cette exigence éthique, ils se doivent d'évaluer et de réévaluer constamment ce qui est dans le meilleur intérêt de leurs patients. Ils doivent par ailleurs être en mesure de prioriser l'action la plus bénéfique parmi les alternatives disponibles. Toutefois, la santé physique et mentale des travailleurs eux-mêmes peut elle aussi être menacée. En soins critiques, notamment, « les médecins épuisés sont dysphoriques, dénigrent leur propre performance, se sentent coupables et craignent les erreurs. Ils perdent le sentiment de réalisation de soi, se désengagent de la relation avec le patient et sont insatisfaits de leur vie sociale et familiale. Le burn-out peut ainsi aboutir à une détérioration sérieuse de la santé qui se manifeste par de l'angoisse, des toxicomanies et des idées

suicidaires » [15, p.572]. À cette liste, l'AMUQ ajoute une diminution notable de la productivité au travail et une hausse considérable du taux d'absentéisme [16].

En plus de nuire au bien-être des soignants, les conditions de travail propre aux unités de soins critiques peuvent compromettre leur capacité à maximiser le bonheur général des patients et de la famille qui les accompagne : « en ne réagissant pas avec compassion à leur propre détresse, [les soignants] risquent de diminuer leur capacité à répondre à la souffrance et à la détresse d'autrui » [17, p.31]. Dans ces circonstances, avoir recours à des mécanismes de défense efficaces, qui soient aussi moralement et juridiquement acceptables, devient crucial pour les professionnels en soins critiques.

L'humour : un mécanisme de défense reconnu

Les mécanismes de défense se définissent comme une « révolte du moi contre des représentations et des affects pénibles ou insupportables » [18, p.41]. Cette révolte du moi se manifeste souvent de manière inconsciente et involontaire [18]. Il existe cinq niveaux de défense, classés en ordre croissant d'efficience : la dysrégulation défensive, l'action, la distorsion majeure de l'image, la formation de compromis et la défense mature [19,20]. Selon Vaillant, l'usage de mécanismes de défense matures favorise une meilleure santé mentale, de meilleures relations interpersonnelles et le succès [21]. Les mécanismes de défense mature sont l'altruisme, la sublimation, la suppression, l'anticipation et l'humour [19]. En 1905, Freud caractérisait déjà l'humour comme « la manifestation la plus élevée [des] réactions de défense » [22, p.204]. En effet, contrairement au refoulement, qui ne permet pas l'extériorisation des tourments, l'humour favorise le retour à un équilibre psychologique en amoindrissant les affects pénibles [22].

Depuis les années 1980, plusieurs études ont aidé à mieux comprendre les bienfaits physiques et psychosociaux de l'humour. Le rire provoquerait des réactions physiologiques ayant des effets favorables au niveau des systèmes cardiovasculaire, musculosquelettique, endocrinien et immunologique [23-25]. Les épisodes de rire diminuent la concentration sérique d'hormones de stress, comme le cortisol, et auraient du même coup un effet favorable sur le système immunitaire [24]. Le fou rire, en stimulant le système nerveux sympathique et en libérant des catécholamines [25], provoque une hausse de la pression artérielle et du rythme cardiaque, ainsi que des contractions musculaires [26]. Cette réaction systémique est suivie, un peu comme après l'exercice physique, d'une période de relaxation agréable générée par le système nerveux parasympathique. Cet état de béatitude coïncide avec une libération accrue d'endorphine, communément appelée l'hormone du plaisir [23].

Le sens de l'humour est un trait de personnalité qui reflète de la joie, du bonheur et de l'amusement. Il se manifeste par le désir de faire rire autrui et de créer des situations amusantes [27]. Contrairement aux épisodes de fous rires, le sens de l'humour n'entraîne pas forcément des réactions physiologiques systémiques. Il aurait néanmoins des répercussions psychosociales positives au sein d'un groupe. Par exemple, en réduisant le stress des employés, l'humour permettrait à ceux-ci une meilleure gestion de soi [28]. Sur le plan individuel, cela se traduirait par une amélioration de leur concentration et de leur mémorisation [29]. Sur le plan collectif, l'humour faciliterait la communication lorsque le climat de travail est tendu, en permettant « d'exprimer l'insatisfaction d'une façon socialement acceptable » [30, p.107]. Une ambiance humoristique en milieu de travail favoriserait les échanges entre collègues et renforcerait les liens de confiance [27], créant ainsi un environnement agréable et une satisfaction à l'emploi, souvent accompagnés d'une diminution notable du taux d'absentéisme [29]. L'humour améliorerait également la qualité du travail accompli, ainsi que la performance générale des employés dans des conditions de travail difficiles et stressantes [28].

Miser sur les bienfaits de l'humour en soins critiques

L'environnement de travail oppressant et le taux élevé de mortalité sont des raisons pour lesquelles les soignants en soins critiques sont particulièrement à risque de détresse morale et d'épuisement professionnel [4,16]. Ces conditions de travail sont des exemples « d'affects pénibles ou insupportables » auxquels les soignants doivent faire face. Pour cette raison, l'humour est un mécanisme de défense fréquemment employé entre soignants [31,32]. Y avoir recours facilite les échanges lorsque le climat de communication est perturbé par un état de détresse émotionnelle [33]. L'humour macabre, plus spécifiquement, est souvent utilisé en milieux hospitaliers, puisque les soignants s'inspirent instinctivement du langage médical, de leur environnement de travail et des situations vécues pour formuler leurs plaisanteries [34, 35].

Certains auteurs dénoncent l'humour macabre en précisant que des séances de débriefing seraient plus appropriées en termes de professionnalisme et d'efficacité [36,37]. Or, ces séances de débriefing exigent du temps, de l'organisation et de l'initiative afin de regrouper le personnel. Malheureusement, l'horaire atypique des employés et la quantité élevée de soins à prodiguer durant leur quart de travail [4] ne favorisent pas la coordination et la tenue de telles séances. L'humour, qui représente pour sa part une ouverture à la communication, offre un compromis astucieux entre le silence et les séances de discussion planifiées.

Minimiser les risques de l'humour macabre

Les mécanismes de défense matures se mettent en action de manière inconsciente et involontaire. Cela signifie, par exemple, qu'un soignant ne réalise pas d'emblée que l'utilisation de l'humour macabre lui permet de diminuer son niveau de stress. Il ne faudrait toutefois pas en conclure que les plaisanteries sont formulées de manière totalement irréfléchie. Au contraire, les soignants semblent connaître et respecter la plupart du temps un ensemble de règles informelles (Tableau 1).

Tableau 1 Quelques critères pour un humour macabre acceptable

Conditions	Justifications / Recommandations
Identifier un **contenu acceptable**	• Éviter les sujets considérés plus délicats, susceptibles de blesser et/ou d'offenser l'audience (ex. : les avortements spontanés, les cancers et la pédiatrie)
Choisir le **bon moment**	• Attendre que l'épisode de crise situationnelle soit dissipé
Être à un **endroit approprié**	• Éviter les lieux à proximité des patients et des familles
Anticiper la **réception** et la vérifier ensuite	• Reconnaitre les émotions vécues par soi-même et par autrui pour ne pas créer de tensions supplémentaires
Faire preuve de **respect**	• Reconnaître l'aspect subjectif de l'humour et la diversité des besoins psychosociaux • Ne pas imposer l'humour macabre aux jeunes professionnels de la santé et aux tiers vulnérables
Régler les problèmes en amont lorsque possible	• Identifier des solutions alternatives comprenant moins de risques • Éviter d'avoir recours aux mécanismes de défense de manière abusive

Une étude réalisée en Ohio auprès d'étudiants en médecine s'est intéressée à la perception des futurs médecins de l'utilisation de l'humour macabre en milieu hospitalier [7]. Dr Wear et son équipe ont rapporté plusieurs thèmes considérés non propices à l'humour par ces étudiants, comprenant entre autres les avortements spontanés, les cancers et la pédiatrie. Ils ont également observé le slogan: « Never in the elevator » (jamais dans l'ascenseur). La préoccupation implicite derrière cette maxime éthique partagée est que l'humour macabre ne devrait jamais se faire dans un environnement où des personnes autres que les soignants sont susceptibles d'en être témoin – et ultimement d'en être choqués ou blessés.

Trois critères supplémentaires permettent d'évaluer l'acceptabilité de l'humour dans une situation donnée : le moment opportun, la réception et le contenu [34]. De manière générale, il semble préférable d'employer l'humour une fois l'épisode de crise situationnelle dissipé. Il est important de reconnaître les émotions vécues au cours de celui-ci avant d'initier une plaisanterie, sans quoi elle pourrait engendrer des tensions supplémentaires. Il est d'ailleurs pertinent d'identifier l'audience présente, afin d'anticiper la réception de l'humour macabre, qui peut varier d'une personne à une autre, ou d'une culture à l'autre. En effet, le contenu acceptable – tout comme la prévision de la réception – sont des critères qui s'évaluent en grande partie de manière subjective. Il est donc important de reconnaître la diversité des perceptions de l'humour et des besoins psychosociaux exprimés par les membres d'une équipe de soins.

Les jeunes professionnels de la santé, par exemple, sont généralement plus sensibles à l'humour macabre [7,37]. Puisque cette pratique ne correspond pas aux valeurs professionnelles et aux standards enseignés, ces derniers peuvent se sentir désillusionnés par la réalité de leur nouveau métier et éprouver des symptômes de détresse morale [38,39]. Les médecins, les infirmières-chefs ou tout autre professionnel de la santé avec plus d'expérience sont responsables de l'intégration des jeunes employés [36]. En ce sens, ils ne doivent pas de leur imposer l'humour macabre sans avertissement ou sans transition préalable. Ils doivent plutôt les soutenir afin de les décomplexer progressivement face à cette pratique couramment employée en soins critiques.

Ces exigences morales, attentives aux particularités de la situation, s'inscrivent dans la philosophie morale de type conséquentialiste, qui rappelons-le, s'intéresse en premier lieu à la maximisation du bien-être général et à la minimisation des souffrances [13]. Les conditions proposées précédemment pour l'utilisation acceptable de l'humour macabre permettent non seulement de créer un environnement de travail agréable, un besoin criant en milieu hospitalier, mais permettent aussi de réduire les torts qu'elle pourrait causer à la famille des patients ou encore aux travailleurs moins disposés à approuver ou bénéficier d'un tel humour. C'est d'une telle prudence que devraient faire preuve les soignants lorsqu'ils utilisent l'humour macabre pour se protéger des répercussions négatives engendrées par leur métier. Ainsi, les risques de conséquences négatives seront minimisés à leur plus simple expression et l'utilisation de l'humour macabre aux bénéfices des soignants et de l'ensemble des patients admis en soins critiques pourra être considérée éthiquement acceptable.

Conclusions

Dans cet article, nous nous sommes appuyés sur l'approche conséquentialiste pour mettre en lumière les bienfaits potentiels, pour les professionnels et les patients, de l'humour macabre en soins critiques. L'humour est un mécanisme de défense reconnu, dont l'ampleur des conséquences positives globales peut justifier son utilisation, et ce même si elle semble parfois faire un pied de nez à la dignité des patients, ou encore représenter un certain risque pour la crédibilité de la profession. Une approche strictement déontologique nous a d'abord semblé insuffisante pour l'analyse du cas présenté initialement, puisqu'elle priorisait par principe la dignité du corps inanimé, et ne tenait aucunement compte du climat dans l'unité de soins et du bien-être des personnes qui y travaillent et des effets (ou conséquences) qu'ils ont sur la capacité des professionnels à offrir des soins de qualité. D'un point de vue conséquentialiste, l'humour macabre peut permettre de favoriser « le plus grand bonheur du plus grand nombre de personnes » [8] en ayant un impact positif non seulement comme mécanisme de défense mature pour les soignants, mais ultimement, en favorisant des soins médicaux adéquats aux patients.

Les études citées indiquent que les soignants s'imposent des règles et des limites informelles protégeant leurs patients de possibles préjudices. L'humour agit comme une défense mature reconnue pour être employée de manière inconsciente et involontaire. Désapprouver de façon prématurée les intentions des soignants et présumer que l'utilisation d'humour est un manque de professionnalisme parce qu'il « déshumanise » les soins de santé de façon générale ne nous semble pas raisonnable. La relation en apparence un peu froide, que peuvent entretenir les soignants en situation de détresse émotionnelle avec certains patients, ne devrait pas être perçue comme une « déhumanisation » des soins, mais plutôt comme une « distanciation » favorable au bon état d'esprit du personnel en soins critiques [15]. C'est entre autres parce qu'ils désirent prodiguer des soins de qualité à leurs patients, que les soignants se mettent autant de pression et qu'ils ressentent parfois le besoin de se distancer de ceux-ci [40]. En s'attaquant à leurs mécanismes de défense, on fait peser sur les épaules des professionnels de la santé un lot de stress excédentaire ultimement nuisible à tous.

Malgré l'utilité démontrée des mécanismes de défense matures, observer une augmentation marquée de leur emploi devrait être un indice d'une situation préoccupante. Devoir se défendre constamment contre la récurrence « d'affects pénibles » ou encore l'inefficacité du mécanisme de défense choisi [18], peut à l'occasion indiquer un problème en amont. Ces deux scénarios requièrent une attention particulière en soins critiques, puisque la présence de situations stressantes est omniprésente et croissante. L'utilisation abusive de l'humour macabre peut être un indice de la précarité des conditions de travail et de l'insuffisance des ressources psychosociales à la disposition des soignants. En outre, Claudiane Poisson et son équipe expliquent, dans un article portant sur la détresse morale, que « l'utilisation récurrente de stratégies de défense peut avoir pour inconvénient d'empêcher le travailleur de percevoir sa souffrance, de penser à ce qui le fait souffrir et de s'investir pour tenter de transformer la source de souffrance de manière à ce qu'elle n'en soit plus une » [39, p.70]. Ces aspects ne devraient d'aucune façon être négligés, puisqu'ils peuvent être précurseurs d'épuisement professionnel [37] et qu'ils peuvent nuire à la qualité des soins prodigués aux patients. Malgré ses bienfaits potentiels, l'humour macabre ne doit pas être perçu comme une échappatoire aux lacunes et aux difficultés de notre système de santé, mais bien comme une solution d'urgence à utiliser avec prudence et parcimonie par les professionnels de la santé pour pallier les conditions de travail anxiogènes auxquelles ils sont confrontés.

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COMPTE RENDU / REVIEW

Review of: Hébert, P. (2016) *Good Medicine: The Art of Ethical Care in Canada*

Massimo Orsini[1]

Mots clés
éthique, soins de santé, médecin, Canada

Keywords
ethics, health care, physician, Canada

Good Medicine: The Art of Ethical Care in Canada [1] is a collection of true stories that implore the reader to consider and challenge the appropriate boundaries between medical *treatment* and medical *care*. These stories are shared from the perspective of Dr. Philip Hébert, Professor Emeritus at the University of Toronto's Department of Family and Community Medicine. Drawing on his experiences as a physician, a patient, and an educator, Hébert's *Good Medicine* advocates the importance of empathic care in medical practice, emphasizing the primacy of good communication at every stage of the patient-physician relationship.

The book explores a variety of topics faced by practitioners, ethicists, jurists and patients alike: consent to medical treatment, the boundaries of informed consent, capacity, end of life care, assisted dying, and more broadly, the patient-physician relationship. Each of these topics are addressed through the lived experiences of the author as well as his patients, each meriting their own chapters. The book reads easily and eloquently, and is appropriate for general public. While *Good Medicine* is accessible to the average reader in ways dissimilar to most texts in the field of medical ethics, the practical value of this book to clinicians and patients should not be underestimated. Traditional educational texts are seldomly capable of capturing the ambiguous realities of medical practices. Relying on lived experiences, Hébert captures these realities effectively, displaying the real-world ambiguities incumbent upon a physician navigating the healthcare system as an institution, while also managing patient expectations and unprofessional personal biases.

Within his book, Hébert suggests that the practice of the eponymous "good medicine" entails more than a steadfast endeavour to treat illness. It requires a careful, curious, and holistic approach, placing credence upon the patient's experience and wishes. The stories told by the author exemplify the value of communication and active listening in the medical practice. Absent such communication, the author argues, the practice of medicine is at best frustrating for the patient, and at worst, the source of negligent outcomes. These stories include that of a patient whose dermatological symptoms were but a red herring for more insidious ailments, overlooked by dismissive physicians for want of more careful examination. They include the story of the author's own father, who lived most of his life mortally aware of an arterial-venous malformation that could one day claim his life, and the value of advanced directives for when such a day would come. At the crossroads of personal convictions, religion, and resource allocation, the book also tells the infamous story of Hassan Rasouli, and the plight of his family before the medical system and even the Supreme Court in their efforts to secure life support for a patient deemed to be beyond the realm of recovery.

Using stories as allegorical vehicles to impart important lessons, Hébert's *Good Medicine* succeeds in highlighting the human element of medicine, placing emphatic care on the same footing as technical expertise. His stories are as poignant as they are enjoyable to read. Though secondary sources and citations are lacking, Hébert's use of a passive voice in *Good Medicine* makes it accessible for a wide audience. The book deserves a space on the bookshelves of aspiring and practicing physicians, lawyers, ethicists, and merits the attention of the public at large.

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None to declare

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1. Hébert P. Good Medicine: The Art of Ethical Care in Canada, Toronto, Doubleday Canada, 2016.

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COMPTE RENDU / REVIEW

Review of: Zlotnik Shaul, R. (ed.) (2014) *Paediatric Patient and Family-Centred Care: Ethical and Legal Issues*

Marla Sharp[1]

Mots clés
pédiatrie, patient, centré sur la famille, soins, éthique, droit

Keywords
paediatric, patient, family-centred, care, ethics, law

Paediatric Patient and Family-Centred Care: Ethical and Legal Issues [1] introduces readers to a collaborative approach to patient care that is quickly gaining acceptance and support across various levels of the healthcare spectrum – one in which members of the patient's family are also recognized as care recipients, and thus care is planned around the entire family unit. This type of care requires healthcare teams to respect and respond to the specific needs, values, and desires of the patient and family and to ensure that these principles and factors have a functional role in all clinical decisions.

The text provides readers with a wide range of relevant and engaging works, written by knowledgeable Canadian experts from various fields, including bioethics, law, medicine, health policy, nursing, philosophy, and social work, among others. Sections and chapters are intuitively organized in such a way that facilitates a cohesive understanding, despite a relative lack of definitional unity across fields of practice compared to more traditional care models. This work provides an inclusive and enthusiastic approach to this topic, and its approach differs from that of other published works in the area of paediatric patient and family-centred care models insofar as it features significant discussion of both ethical and legal deliberations rather than one or the other. Furthermore, the authors' frequent use of case studies makes for informed understanding of the contemporary, real-world benefits and challenges that arise when implementing variations of this type of care model.

Some of the most notable advantages of Patient and Family-Centred Care (P&FCC) approaches include greater patient and family satisfaction, better overall health outcomes, fewer lawsuits, and reductions in rehospitalizations and referrals to specialists [2]. However, there remain some substantial issues, some of the most problematic pertaining to resource allocation [2], physician concerns about losing their role as primary healthcare providers and the practicality of involving family members in care planning [3], and difficulties determining who makes up the family unit [4]. The articles within this text come together to provide a strong explanation and analysis of P&FCC in paediatric care settings; one that would be particularly useful for organizations or institutions (and for the professionals that work within them) that are interested in learning more about this care model when considering whether or not to implement it into their current care practices, or conversely, for those that may have already begun to implement these types of 'synergistic' [3] approaches to care and are seeking insight for optimization purposes.

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COMPTE RENDU / REVIEW

Review of: Cooper, D.B. (ed.) (2017) *Ethics in Mental Health-Substance Use*

Zoe Bernatsky[1]

Mots clés
santé mentale, toxicomanie, éthique

Keywords
mental health, substance use, ethics

Research demonstrates that approximately 50% of American adults who experience mental health or substance-use issues face *both* mental health and substance use challenges [1]. *Ethics in Mental Health-Substance Use* [2] employs a multi-disciplinary and holistic method to explore challenges that affect the lives of individuals with mental health and substance use issues and those who love and care for them. The authors, which include nurses, physicians, psychologists, ethicists and lawyers, outline challenges such as the assessment of capacity for treatment in "high-stakes" treatment choices such as electroconvulsive therapy or medical assistance in dying, since mental health conditions and substance use can impact the capacity to confer consent for such treatment. Principles related to contemporary issues such as harm reduction and respect for boundaries within dual relationships are introduced, making this book a particularly useful guide for practitioners and ethicists new to this field of practice.

The book is set up in a concise format with case studies, interactive exercises, and guiding questions for self-assessment. Chapters 1-3 introduce ethical frameworks to guide professional practice. These include reflective approaches, such as virtue and care ethics, and instrumental approaches, such as the utilitarian, deontological or four principles approach. Cases are used to underscore that in some situations, the 'best' option is not readily obvious or achievable. Chapters 4-7 highlight the need for practitioners to acquire skills and dispositions such as cultural sensitivity, compassion, respect, and dignity, in order to be effective in their work with these often vulnerable and stigmatized individuals. I was particularly impressed by Chapter 8 which explores a way forward, using a virtue framework. Here, practitioners are encouraged to exercise practical wisdom arising from moral skill (rooted in experience and reflection) and moral will (based in doing what is right for the right reasons) as they encounter persons with complex stories and multifaceted challenges. Chapters 9-15 focus on challenges related to policy development which include human rights issues such as informed consent, abstinence vs. harm reduction approaches, the importance of gender sensitive services, and difficulties employing "gold-standard" research techniques. The critical challenge of evaluation of capacity for consent and self-determination are central matters of ethical concern, particularly when there is a threat to self or others, or when the benefits of treatment are uncertain and the burdens significant (e.g., the use of electroconvulsive therapy). Finally, chapters 16-21 relate to the special concerns of younger and older individuals, high-risk sexual behaviour, cannabis use, palliative care and assisted death.

Ethics in Mental Health-Substance Use is a must read for those who work in the field of mental health and substance use, especially for professionals new to this area. The use of realistic case studies provides an opportunity to better understand ethical principles and frameworks and how they can be employed in the pursuit of holistic health of individuals with mental health and substance use challenges. Reflective exercises are also well-suited for professional development. Senior leadership and policy developers who have mental health and substance use within a larger portfolio and whose responsibility it is to be informed about ethical concerns related to research and practice, will also find this book helpful. Limitations include the fact that no patient was a chapter author and proficient practitioners might already be familiar with the content, however, the multi-disciplinary patient-centred approach is refreshing and makes the text a very helpful addition to the Mental Health-Substance Use series. Cooper and his colleagues make an important contribution to the field of mental health, substance use and ethics by surveying the field and outlining the most critical themes in the field today.

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COMPTE RENDU / REVIEW

Review of: Austin, W. et al. (2013) *Lying Down in the Ever-Falling Snow: Canadian Health Professionals' Experience of Compassion Fatigue*

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

Nipa Chauhan[1]

Mots clés
usure de compassion, soins de santé, professionnel de la santé, Canada

Keywords
compassion fatigue, healthcare, health professional, Canada

Published in 2013, *Lying Down in the Ever-Falling Snow* by Wendy Austin et al. [1] is a compilation of essays written by various Canadian healthcare professionals about their experiences managing compassion fatigue. Utilizing the Canadian metaphor of endless winter as their guide, the authors contribute to the concept of compassion fatigue by providing anecdotes that can potentially uncover a more focused definition of it. The order in which the book is laid out is practical in that it exhibits an emotional strategy – the book becomes increasingly emotional/sentimental/distressing as the chapters progress. After the philosophical concept of human compassion is introduced and explored, the authors explain how they chose to approach such an emotional experience through hermeneutic phenomenological research; they gather four essays that illustrate how compassion fatigue affects the body, time, space, and relations. After the intimate anecdotes from healthcare professionals are told, the book moves on to texts that are meant to evoke hope and survival, which they believe are the most logical and emotionally important steps to take when one finds oneself directly affected by compassion fatigue. In this work, the authors successfully illustrate their experiences with compassion fatigue as it affects the body, time, space, and relations, while contributing to the research of understanding the concept itself.

Breaking down compassion fatigue's effects into four simple relational concepts proved to be a huge advantage in understanding the crippling nature of such an experience. Starting with the body, "The Cold Heart" chapter describes the numbing effect that healthcare workers may experience and an alarming feeling of self-awareness that commonly follows. The next chapter, "The Endless Winter", describes the seemingly never ending temporal experience of compassion fatigue, further tiring the healthcare worker as they attempt their routines. The chapter entitled "Lost and Alone in a Prairie Blizzard" describes the space in which the health worker finds themself as the workplace becomes a source of dread and extreme stress. With more illustrative and emotional anecdotes, the chapter "An Icy Wall (Within and Between)"' is where the authors share how relationships between clinicians and their patients develop despite the experiences of each party. Small interactions, like running into patients in grocery stores, proves to have much more of an impact on clinicians than they are comfortable with. Trying to answer questions that clinicians do not necessarily have answers to can be quite an exhausting routine.

It is recommended to read this book in installments, as the content within the book may elicit a lesser but significant response of compassion fatigue for the reader. The experiences told within the book are heart-wrenching, but they meet the goal of helping the reader understand how and why clinicians experience such weariness and why compassion fatigue needs to be attended to more fully in the healthcare setting.

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COMPTE RENDU / REVIEW

Review of: Greenberg R.A., Goldberg A.M., Rodríguez-Arias D. (eds.) (2016) *Ethical Issues in Pediatric Organ Transplantation*

Josée Bonneau[1]

Mots clés
pédiatrie, transplantation d'organes, éthique, droit

Keywords
pediatric, organ transplantation, ethics, law

In their work, Greenberg, Goldberg and Rodriguez-Arias [1] explore the many complex ethical issues related to pediatric organ transplantation. Topics such as: children as living donors, deceased donation, newborn as potential donors, emerging challenges related to organ donation and organ allocation are some of the delicate themes that are thoroughly discussed. The authors shed light on many of the ethical dilemmas related to pediatric organ transplantation and provide readers the opportunity to deepen their knowledge and engage in reflection.

This book brings together a multitude of ethical issues related to pediatric organ transplantation. The authors have brought together the work of national and international experts to provide readers with a global and thorough body of knowledge regarding pediatric organ transplantation. This book is an excellent cross-section of the varied legal and ethical issues that arise in the context of caring for children in need of an organ transplantation.

Each chapter of the book offers an in-depth analysis of a precise ethical issue that occurs in pediatric organ transplantation. Explicit examples allow the reader the opportunity to deepen their knowledge and reflect critically. A deeper understanding the uniqueness of these issues is extremely important thus making this book an excellent resource for all practitioners. Many perspectives are offered by experts in the field for each of the topics presented. This allows readers the possibility to explore situations from different aspects. The clinical nature of the issues presented as well as the health provider, child and family perspectives also allow for application to practice.

Greenberg, Goldberg and Rodriguez-Arias have successfully provided readers with the opportunity to gain knowledge and insight into the many ethical issues surrounding pediatric organ transplantation. They have brought together experts from across Canada as well as international practitioners and scholars who together provide the foundation for this unique body of knowledge. This book is a valuable resource and has truly allowed me to explore the many different ethical issues related to pediatric organ transplantation.

As we know, pediatric and adult issues are very different. Legal and ethical perspectives vary when we are caring for a pediatric population. Issues of vulnerability, of best interest and of consent can be further complicated. This book allows for a better understanding of these complex issues by exploring organ transplantation from a pediatric perspective. This is truly a unique and inspiring book that has empowered me to have the knowledge and language to address ethical issues in pediatric organ transplantation.

Many thanks to the authors for their unique contribution to pediatric ethics.

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COMPTE RENDU / REVIEW

Diversity and Context in Health Ethics: The Case for Rural Health

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

Yasmina Mashmoushi[1], Mitan Mzouri[1]

Résumé
Ce compte rendu soutient que le livre *Repenser l'éthique de la santé rurale* est une lecture essentielle pour les fournisseurs de soins de santé en milieu rural, les décideurs en matière de santé rurale et les éthiciens en santé rurale, parce qu'il révèle les inadéquations fondamentales du cadre traditionnel en éthique de la santé, centré sur les milieux urbains, avec la santé en milieu rural, et formule les bases pour une éthique plus viable et distinctive en santé rurale. Ce compte rendu soutient, en outre, que ce livre a des implications profondes et solides sur l'importance d'incorporer la diversité et le contexte dans les délibérations éthiques à l'intérieur du domaine plus large qu'est l'éthique de la santé, et ce à tous les niveaux de l'analyse éthique (c.-à-d. micro, méso et macro), servant ainsi d'influence résonante et judicieuse pour les éthiciens de la santé de tous domaines.

Mots clés
éthique de santé rurale, éthique rurale, politique de santé rurale, biais urbain, théorie féministe, diversité bioéthique

Abstract
This review maintains that the book, *Rethinking Rural Health Ethics*, is essential reading for rural health providers, rural health policy makers, and rural health ethicists because it uncovers the fundamental inadequacies of the traditional, urban-centric health ethics framework with respect to the rural health setting and formulates the basis for a more viable and distinctive rural health ethics. This review further maintains that this book possesses far-reaching, robust implications on the importance of incorporating diversity and context into ethical deliberations within the broader field of health ethics and in all levels of ethical analysis (i.e., micro, meso, and macro), thus serving as a resonating and sage influence for health ethicists in all fields.

Keywords
rural health ethics, rural bioethics, rural health policy, urban bias, feminist theory, diversity bioethics

In *Rethinking Rural Health Ethics* [1], Christy Simpson and Fiona McDonald argue that the traditional, urban-centric health ethics framework fails to take into account the distinctiveness of the rural context, often resulting in flawed ethical analysis within that setting. They reconceptualize what a viable rural health ethics framework might look like, while arguing that the diversity, richness, and complexity inherent in the rural health setting has much to offer the broader field of health ethics. Overall, this book provides rural health providers, ethicists, and policy makers with a strong and clear foundation for a viable rural health ethics and possesses robust, far-reaching implications on the importance of incorporating diversity and context into ethical deliberations within the broader field of health ethics.

The book is composed of two principal sections. In the first section, the authors argue that the traditional, mainstream approach to health ethics is urban-centric and possesses biased and ill-informed assumptions and stereotypes about the nature of rurality and life and work in rural settings (e.g., the deficit perspective inherently problematizes the rural context and impedes the strive for change). They highlight how urban norms and a sense of "othering" pervade ethical deliberations. They do not dismiss all the insights that the traditional health ethics framework can provide the rural context, but stress that there is a need to reassess what is and is not relevant, how what is still relevant must be further nuanced to fit the rural health context specifically, and what novel considerations must be formulated for this context. The authors use a mix of population research, survey, and anecdotal evidence from rural health providers, patients, and residents to demonstrate the inapplicability of the traditional health ethics framework to rural health and the clear need to formulate a distinctive rural health ethics. For the reader, this strong melange of evidence creates a convincing and holistic view of the distinctiveness of the rural health context and its ethical relevance. The authors also emphasize the importance of moving beyond the commonly addressed micro-level bedside issues that pervade the rural health ethics literature to entertain more complex and important meso and macro levels analyses of rural health. In so doing, they thoroughly 'deconstruct' the existing rural health ethics framework.

In the second section of the book, the authors 'reconstruct' the basis for a viable rural health ethics. In response to the dearth of meso and macro level analysis in the literature, they employ an organizational ethics framework and systems analysis framework and effectively demonstrate their applicability to the rural context. Taking a value-based approach to health ethics, they conceptualize three distinct ethical values (place, community, and relationships) that they argue are underdeveloped in both the rural and broader health ethics literatures. These three values significantly impact rural residents' health care decisions and experiences with receiving care; for example, rural patients may choose to be discharged early despite medical advice in order to return to their community or, alternatively, to receive treatment locally despite higher operative mortality risks. Thus, the authors stress that these values must be given appropriate weight in ethical deliberations, both within and outside the rural health setting (e.g., tightknit, inner-city ethnic communities). They argue that it is imperative that we consider them as three standalone values because they carry discrete ethical nuances and only by considering them separately can they each be given appropriate ethical weight. However, it remains an open question for the reader whether these values should truly stand alone. It may be argued that these values should be encompassed within the broader ethical values of beneficence and nonmaleficence, in that the best possible patient care inherently requires that we appropriately situate patients. Alternatively, these values can be meshed into a single, overarching 'value of context' – which may be especially fitting given the significant overlap that exists between them.

The authors consistently lay down the philosophical principles from which they work, giving readers a very clear sense of their starting points for analysis. At the heart of this book's argument is a feminist approach to health ethics. Three key feminist theories resonate throughout the book: standpoint theory, perspectives on power, and relational autonomy. The authors use

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standpoint theory, the idea that all our knowledge and values are situated, to emphasize that ethical frameworks must be revised to incorporate perspectives of non-dominant groups. They also bring to our attention the power relationships that exist among the multiplicity of actors that play a role in health care delivery and policy making. Furthermore, since relationships in rural communities have an intensity and visibility that does not often characterize relationships in urban environments, they stress the importance of employing the concept of relational autonomy in the rural context, which emphasizes that individuals are situated within a complex web of interpersonal relationships that affect their decision-making. The authors move beyond standard notions of relational autonomy (i.e., the interpersonal) to relationships with places and communities, emphasizing that they too affect individuals' decision-making. Ultimately, they use a feminist perspective to contest the more pervading neo-liberalist approach to health ethics which views health services as a good rather than a right, individuals as autonomous and rational agents devoid of context, and health care as being provided primarily by and to strangers. Through these thoughtful philosophical deliberations, the authors create a strong and sound argument for a distinct rural health ethics framework.

The authors use an approach that is equally informed by both abstract philosophical principles and concrete practical considerations. In each chapter, they apply theory to a number of renowned issues in rural health care, demonstrating practical viability (e.g., the recruitment and retention of rural health providers, professional boundaries and dual or multiple relationships, uniform standards of care, roles of rural health facilities, resource allocation, issues of access versus quality, centralized versus local governance models). Thus, although much of their analysis is conceptual, the authors maintain a keen eye on what may work in practice. This is another major strength of the book, ensuring that any proposed theoretical considerations are not too far removed from the context within which they are meant to be applied and considered.

Rethinking Rural Health Ethics [1] is valuable reading for rural health providers, rural health policy makers, and rural health ethicists because it establishes the clear need for a distinctive rural health ethics framework and formulates the basis for such a framework. This book possesses profound insights beyond the rural health ethics literature, emphasizing that to strive towards patient-centered care and firmly adhere to the principles of beneficence and nonmaleficence requires that we also fully situate and contextualize individual patients. Thus, this book serves as a resonating, sage influence for health ethicists in all fields of health ethics.

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

Au-delà de la bureaucratie obligatoire : comment bien travailler avec des comités d'éthique de la recherche

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Résumé
Les comités d'éthique de la recherche (CÉR) universitaire, même s'ils sont bien établis en Amérique du Nord depuis les années 1980, ont encore parfois mauvaise réputation au sein des chercheurs. Parfois, ils sont vus par les membres de la communauté scientifique comme un système bureaucratique voué à empêcher ou à ralentir la recherche et ne comprenant pas la réalité des chercheurs. Cette vision négative relève souvent de la mécompréhension du mandat d'un CÉR et de la façon dont il doit fonctionner, par les chercheurs comme par certains CÉR. Fondée sur l'expérience d'une présidente d'un CÉR et d'un bioéthicien, cette foire aux questions vise à démystifier l'éthique de la recherche pour que les chercheurs et les CÉR puissent collaborer dans l'avancement des connaissances, tout en assurant une conduite de recherche éthique et responsable.

Mots clés
éthique de la recherche, CÉR, comité d'éthique de la recherche, université, vision négative, mandat, chercheur

Abstract
University research ethics boards (REBs), although well established in North American since the 1980s, sometimes still have a poor reputation among researchers. They may be seen by members of the academic community as a bureaucratic system designed to prevent or slow down research, and one that does not understand the reality of researchers. This negative view is often the result of misunderstanding by 1) researchers and 2) some REBs about what an REB's mandate is and how it should work. Based on the experience of an REB President and a bioethicist, these Frequently Asked Questions aim to demystify research ethics so that researchers and REBs can collaborate in the advancement of knowledge, while ensuring the ethical and responsible conduct of research.

Keywords
research ethics, REB, research ethics board, university, negative view, mandate, researcher

Introduction

« Zut, il faut que je demande un certificat d'éthique… ». Les comités d'éthique de la recherche (CÉR), chargés d'encadrer la pratique des chercheurs et d'assurer une conduite éthique de la recherche, ont parfois mauvaise réputation en Amérique du Nord [1-3]. Ainsi, il arrive que des membres de la communauté scientifique les voient encore comme un système bureaucratique voué à empêcher ou ralentir la recherche : « c'est juste de la paperasse qui a été créée pour nous compliquer la vie ». Les CÉR douteraient-ils de l'intégrité des chercheurs? Pire, certains peuvent penser que les CÉR ne comprennent pas la réalité des chercheurs : « faut-il vraiment faire signer un papier à mes participants alors qu'ils sont analphabètes, ou qu'ils voient les papiers comme un contrat ou un manque de confiance dans leur parole »? Il peut dès lors arriver que certains chercheurs « arrangent la vérité » pour obtenir leur certificat d'éthique parce qu'ils pensent qu'il faut dire ce que le CÉR a envie d'entendre. Et puis, à quoi sert un CÉR? Si son travail est seulement d'évaluer les risques, « je les connais, ces risques, et je peux les gérer, ça fait plus d'un siècle que ma discipline existe ».

Cette vision relève souvent de la mécompréhension d'abord de la part des chercheurs, ensuite de certains CÉR et institutions, sur ce qu'est le mandat d'un CÉR et la façon dont il doit fonctionner. Un CÉR sert à faire des évaluations éthiques de projets impliquant des participants humains. L'évaluation éthique a pour but de s'assurer du respect de la dignité humaine, articulée à travers les trois principes que sont le respect des personnes, la préoccupation pour le bien-être et la justice [4]. Elle ne devrait pas être un simple processus bureaucratique de vérification de documents – notamment les formulaires de consentement – soumis par les chercheurs, ni une application simpliste et sans nuance de « règles éthiques » sans égard pour le contexte particulier dans laquelle la recherche se fait. Un élément important, mais pas unique, est l'identification, l'évaluation et la gestion des risques encourus par les participants, qui tombent sous « la préoccupation pour le bien-être ». Par ailleurs, les règles de l'art en recherche ne se limitent pas qu'aux seuls critères scientifiques, mais englobent également les notions d'éthique et de conduite responsable [5,6].

Dans un monde idéal, un CÉR accomplit son mandat de protection des participants de recherche en soutenant et en accompagnant les chercheurs pour les aider à rencontrer leurs obligations et responsabilités envers les participants de recherche. Dans la vraie vie, les CÉR sont des structures imparfaites, qui font partie de systèmes bureaucratiques plus ou moins souples et qui encore trop souvent ne disposent pas de toutes les ressources humaines et financières nécessaires pour bien remplir leurs responsabilités. Ils sont hébergés dans des institutions qui reconnaissent plus ou moins l'importance de l'éthique de la recherche et doivent donc composer avec des contextes de travail qui peuvent rendre leurs relations avec les chercheurs plus ou moins fonctionnelles. Fondée sur l'expérience d'une présidente d'un CÉR et d'un bioéthicien, cette foire aux questions vise à démystifier l'éthique de la recherche pour que les chercheurs et les CÉR puissent collaborer dans l'avancement des connaissances, tout en assurant une conduite de recherche éthique et responsable.

Questions pour les professeurs

1. Les membres des CÉR sont-ils « juste des bureaucrates »?

On entend souvent cette idée fausse circuler. Les membres des CÉR ne sont pas des bureaucrates et ne devraient pas agir de façon bureaucratique ou dogmatique dans leurs analyses éthiques des projets ou dans leurs relations avec les chercheurs. Que ce soit dans une université, un hôpital ou tout autre lieu de recherche, il est obligatoire d'avoir des CÉR, qui doivent suivre

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les principes et les valeurs d'un cadre normatif international (ex. Déclaration d'Helsinki), fédéral (ex. : *Énoncé de politique des trois Conseils : Éthique de la recherche avec des êtres humains*, EPTC2 [4]) et provincial (ex. Code civil du Québec). En majorité, les CÉR sont composés de vos collègues qui siègent en tant qu'experts méthodologiques : ils ont l'expérience de faire de la recherche de diverses façons et ensemble, ils doivent pouvoir évaluer un éventail de projets. Au Canada, un CÉR, de façon statutaire, doit comprendre au moins cinq personnes, hommes et femmes : au minimum deux chercheurs, un membre versé en éthique, un membre versé en droit et au moins un représentant du public [art. 6.4, ÉPTC2]. Le nombre de membres dépend du nombre de projets que le CÉR doit analyser par année, de la nature de ces projets, de la taille de l'institution, etc. À part le membre versé en éthique, qui a une expertise en éthique de la recherche, les autres membres ne sont pas des éthiciens. Mais ils doivent tous avoir une bonne connaissance des documents normatifs tel que, au Canada, l'ÉPTC2 [7]. Ils travaillent en comité à faire l'analyse éthique des projets de recherche soumis à leur CÉR.

Un CÉR est souvent accompagné par un membre du personnel professionnel qui est de plus en plus un conseiller spécialisé et formé en éthique de la recherche. Son rôle est de soutenir le CÉR : gérer les dossiers, répondre aux questions des chercheurs et des étudiants, former les membres des CÉR, etc.

2. Dois-je obligatoirement faire signer un formulaire de consentement écrit?

Un consentement écrit est la norme, mais il n'est pas obligatoire. Ce qui est obligatoire est de recueillir le consentement libre, éclairé et continu : le participant doit comprendre le projet, la nature des risques et des bénéfices qu'il encourt et l'usage des données qu'il fournit. Si le participant ne signe pas de formulaire, le chercheur a l'obligation de consigner par écrit la façon dont il a recueilli ce consentement [art. 3.12, ÉPTC2]. Dans le cas d'un projet prévoyant un consentement oral, il faut fournir une justification au CÉR qui explique les raisons pour lesquelles un consentement écrit serait problématique dans le contexte du projet. Sur le terrain, vous devez vous assurer que les participants comprennent et consentent à participer, qu'ils en saisissent les implications pratiques (risques encourus, bénéfices possibles, efforts exigés, temps, publication, etc.). Normalement, vous devez aussi laisser une trace écrite là où vous travaillez, dans la langue locale, indiquant les champs obligatoires d'un formulaire de consentement (résumé vulgarisé du projet, contacts au CÉR, etc.), mais des exceptions sont possibles, notamment si cela met en danger le participant [8,9].

3. Dois-je obligatoirement détruire mes données au bout de 5 ou 7 ans?

Il s'agit d'une règle générale administrative imposée par de nombreuses universités à des fins de vérification scientifique, aussi encadrée par d'autres organismes régulateurs; ces règles n'émanent des cadres en éthique tel que l'EPTC2. Les chercheurs doivent fournir au CÉR des précisions sur les mesures de protection prévues pour toute la durée utile des renseignements. Sont ainsi visées la collecte, l'utilisation, la diffusion, la conservation et la suppression éventuelle de ces renseignements [art. 5.3, ÉPTC2]. La confidentialité des données personnalisées doit être protégée et le chercheur doit garantir que les données ne seront pas utilisées à des fins autres que celles pour lesquelles le participant a donné son consentement.

Dans son évaluation du caractère adéquat des mesures de protection proposées pour l'ensemble de la durée utile des renseignements, le CÉR ne doit pas imposer au chercheur l'obligation de détruire les données de recherche : le chercheur a simplement besoin d'expliquer les raisons pour lesquelles il veut conserver ses données. L'information conservée peut servir à d'autres fins, par exemple dans le cas de recherches longitudinales, ce que le chercheur doit expliquer aux participants lors du consentement. Les périodes appropriées de conservation des données varient selon la discipline, l'objet de la recherche et la nature des données.

4. Dois-je obligatoirement rendre anonymes mes participants?

Comme moyen de protéger les participants, la norme est de les rendre anonymes, notamment contre de possibles atteintes à leur vie privée ou autres répercussions négatives de leur participation. Mais il ne s'agit pas d'une obligation. Certains participants peuvent même exiger que leurs noms soient associés à leurs paroles, ou cités en général. Pour certains, enlever le nom est un manque flagrant de respect, voire un vol de données. Pour d'autres, être nommé et cité peut être une marque de reconnaissance [10]. Dans certains cas, comme la recherche avec les personnages publics, il est impossible qu'ils ne soient pas identifiés, surtout quand leur participation dans la recherche est vue comme un acte public, dans le sens où ils s'expriment avec le chercheur comme s'ils se prononçaient en public. Mais vous avez l'obligation de réfléchir en amont, puis de discuter avec les participants au sujet des implications du processus de la recherche, de la collecte jusqu'à la publication, et aux impacts potentiels de la divulgation de leur identité sur leur vie personnelle ou professionnelle.

5. Quels sont mes devoirs de chercheur vis-à-vis des participants qui peuvent être en détresse?

En tant que chercheur, votre but principal est de collecter des données que vous allez analyser. À l'exception de certains domaines de recherche – ex. : recherches-action visant à réduire un problème dans un milieu – le rôle des chercheurs n'est pas de pratiquer des interventions sociales ou de fournir des thérapies. Cependant, vous devez être conscient que la recherche peut causer des traumatismes psychologiques ou de la détresse morale. Vous pouvez être empathique et fournir un soutien moral, à la mesure de vos compétences, à quelqu'un en détresse (arrêter l'entrevue, offrir des mouchoirs). Si vous êtes un professionnel de la santé, rappelez-vous que, dans le cadre de vos recherches, vous n'établissez pas une relation thérapeutique. Néanmoins, vous conservez un devoir d'agir, proportionnel à vos compétences.

Vous avez l'obligation de prévoir les risques potentiels, connaître les ressources disponibles et appropriées et les transmettre aux participants s'ils en ont besoin, par exemple en offrant des références à des personnes-ressources, ou en communiquant avec un membre de la famille). Vous ne pouvez pas bouleverser quelqu'un avec vos questions qui remuent de mauvais souvenirs et le laisser seul avec sa détresse ensuite. En outre, il existe des situations où le chercheur peut être interpelé en tant que professionnel ou simple citoyen et être obligé d'agir, notamment pour les risques de blessures graves, de mort pour soi ou pour autrui, de maltraitance d'enfants [11]. Il est important de reconnaître ses responsabilités en tant que chercheur et les limites de celles-ci.

6. Pourquoi dois-je présenter tout le projet alors que je suis le meilleur spécialiste?

Le CÉR doit avoir accès à tout votre projet, y compris les outils de collecte de données et tous les documents destinés aux participants. Avec cette documentation, le CÉR est en mesure d'évaluer la portée et la nature des risques associés au projet, ainsi que de prodiguer des conseils. Avoir le point de vue de collègues qui sont experts dans d'autres domaines et qui ont des expériences différentes permet d'identifier des éléments que le chercheur n'a pas prévu ou imaginé. Ainsi, l'analyse d'un document de recrutement par le CÉR peut permettre de relever du vocabulaire d'un niveau de langage non accessible ou non adapté aux participants visés. Les CÉR sont pluridisciplinaires : même s'ils ont une diversité d'expertises, ils n'ont pas forcément des connaissances fines sur votre domaine de recherche spécifique. Le comité doit avoir une bonne compréhension du projet pour l'évaluer. Sinon, il doit s'adjoindre cette expertise pour procéder à l'évaluation [art. 6.4 et 6.5, ÉPTC2].

Il vous appartient de fournir à votre CÉR tout ce dont il a besoin pour comprendre la particularité de votre situation. S'il n'a pas en mains toutes les informations et tous les documents, il ne sera pas en mesure de vous aider. Ne prenez pas cela à la légère, ne rendez pas votre dossier à la dernière minute (les CÉR sont, le plus souvent, très occupés!); un dossier bien structuré, avec tout le contenu et les explications nécessaires, sera bien évalué et dans un délai raisonnable.

7. Ai-je besoin d'une approbation éthique locale quand je travaille à l'international?

Oui, quand c'est possible. S'il y a un CÉR local, on doit respecter sa capacité à évaluer les risques et les bénéfices de la recherche sur les participants [12]. De plus en plus de pays se dotent de CÉR : ils peuvent être, dans certains cas, régionaux, institutionnels ou nationaux. Mais la plupart, en dehors de l'Amérique du Nord, se restreignent à la recherche en santé. Les CÉR locaux peuvent être incompétents dans plusieurs domaines (ex. : dans les sciences sociales) et manquer cruellement de ressources pour porter des évaluations éthiques étoffées et dans un délai raisonnable. Cela fait partie des défis de la recherche à l'international [13]. Quel que soit le CÉR local par lequel vous pourriez être amené à passer, vous êtes également tenu de passer par un CÉR canadien, dans votre institution, et de suivre les principes énoncés dans l'ÉPTC2.

8. Quelles sont les responsabilités des professeurs vis-à-vis des projets de leurs étudiants?

Vous êtes responsable de la bonne conduite de la recherche de vos étudiants. C'est à vous de les conseiller, de leur montrer comment bien faire de la recherche, de leur expliquer comment fonctionne un CÉR et de les accompagner dans la constitution du dossier qu'ils déposeront au CÉR. Il est important que vous relisiez attentivement les projets de vos étudiants avant de les signer. En les approuvant, vous vous en portez garant.

9. La recherche doit-elle être bénéfique pour les participants?

Plusieurs projets de recherche n'offrent pas de bénéfices directs pour les participants et comportent plutôt des retombées générales pour l'avancement des connaissances. En matière de bénéfices, le caractère acceptable d'une recherche pour les participants doit être évalué à l'aune des risques encourus, dans la poursuite d'un équilibre entre les bénéfices potentiels et lesdits risques. Ainsi, il est justifiable de conduire une recherche qui n'a aucun bénéfice direct pour les participants si le projet est jugé sans risques conséquents pour eux. Inversement, un projet à risques plus importants, mais dont on aurait réduit au maximum les risques inutiles et évitables, pourrait être jugé acceptable s'il comporte des bénéfices potentiels importants pour les participants. Il importe dans l'étude de cet équilibre risques-bénéfices de prendre en compte l'opinion de la population à l'étude.

Quand la recherche offre des bénéfices directs, comme l'accès à des services qui sont autrement inaccessibles (par exemple des soins de santé ou des thérapies), il est important de s'assurer qu'ils ne représentent pas une influence indue qui pourrait miner le caractère libre du consentement du participant [14].

Questions pour les CÉR

10. Pourquoi faut-il lire et comprendre le sens de l'ÉPTC2?

L'ÉPTC2 est le document normatif qui encadre toute recherche conduite avec des êtres humains au Canada dans des institutions qui reçoivent des financements gouvernementaux. Ce document, en constante évolution pour répondre aux besoins des innovations en recherche et aux questions émergentes, énonce des principes ainsi que des modalités d'application pour guider l'analyse éthique dans une diversité de situations. L'ÉPTC2 n'est pas un règlement, mais un cadre normatif pour guider à la fois la façon dont la recherche est conduite éthiquement et la façon dont elle est évaluée par les

CÉR. Les chercheurs qui ont besoin de précisions ou de conseils particuliers devraient en premier lieu contacter leur CÉR. Les CÉR qui butent sur des questions d'interprétation des normes éthiques et légales en vigueur, ou des enjeux qui ne sont pas suffisamment bien abordés dans l'ÉPTC2 (ex. recherche sur Internet, recherche épidémiologique par rapport à la surveillance populationnelle) peuvent contacter leur bureau de conduite responsable en recherche s'il existe dans leur institution, ainsi que le Groupe consultatif interorganisme en éthique de la recherche.

11. C'est légal, donc c'est éthique?

Un CÉR doit examiner le volet éthique ainsi que les implications légales d'un projet. En règle générale, les lois et les cadres normatifs sont fondés sur des principes communs, qui reflètent les valeurs partagées dans les sociétés démocratiques. Les chercheurs ont, par exemple, des obligations formelles envers les participants qui sont explicitées à la fois dans des lois provinciales et fédérales et dans les cadres normatifs comme l'ÉPTC2 : protection des participants; consentement libre, éclairé et continu; propriété intellectuelle; divulgation de cas d'abus envers des enfants [Principes directeurs, ÉPTC2]. Mais il faut distinguer les obligations légales du chercheur du sujet de sa recherche en tant que tel : il est possible de mener des recherches sur des comportements illégaux tout en conduisant une recherche parfaitement éthique. Inversement, ce n'est pas parce que c'est permis que c'est éthique et que cela ne cause pas de tort moral aux participants, à leur entourage, voire à leur communauté. Il existe plusieurs exemples où des compagnies ou des gouvernements ont tenté de forcer des chercheurs à divulguer les noms de leurs participants, en les assignant en justice [15]. Rappelons ici l'importance de bien protéger la confidentialité des données : dans le cas de recherches hyper-sensibles, les chercheurs peuvent être amenés à crypter leurs données et à détruire tout moyen d'identification des participants, même par eux-mêmes. Dans une situation de conflit entre ce qui est légal et ce qui est éthique, il est fortement recommandé d'en discuter avec des collègues, d'en parler à votre CÉR et de chercher les meilleurs conseils, notamment juridiques.

12. Les CÉR sont-ils compétents dans l'évaluation de tous les domaines de recherche?

Un CÉR a l'obligation de s'assurer d'être compétent dans l'évaluation des dossiers qui lui sont soumis. Pour cela, il doit chercher l'expertise nécessaire, de façon ponctuelle pour une évaluation particulière, ou de façon régulière en ajoutant un membre versé dans un domaine spécifique, pour garantir que l'évaluation sera de qualité et appropriée [art. 6.4 et 6.5, ÉPTC2]. Le CÉR peut également vous inviter à venir parler directement aux membres. En principe, il doit être possible de rencontrer les membres de son CÉR pour expliquer la spécificité de son domaine de recherche, les choix parfois singuliers (méthodologiques ou autres) du projet et justifier son approche, dans un esprit de dialogue et de collaboration.

13. Toute recherche comporte-t-elle des risques?

Les risques existent dans presque tous les projets : ils peuvent être minimes ou majeurs; physiques, psychologiques, sociaux, culturels, etc. Les CÉR doivent reconnaître que, selon les domaines de recherche et les méthodologies utilisées, les risques ne sont pas tous de la même portée et de la même nature. Un des risques qui pose souvent des problèmes dans les CÉR a trait aux « populations vulnérables » [16]. Une personne dite vulnérable ne l'est pas forcément dans toutes les circonstances : le risque peut être relatif selon la personne d'une part, selon le contexte d'autre part. En outre, même les personnes en position d'autorité peuvent, dans certaines situations, être vulnérables.

Le rôle d'un CÉR est d'appliquer un principe de proportionnalité dans l'évaluation du projet. Les protections mises en place doivent donc être proportionnelles au niveau de risque [art 6.12, ÉPTC2]. L'appréciation des risques (probabilités, conséquences) et des moyens de gestion appropriés est un exercice interprétatif complexe fondé sur l'expérience du comité, les nombreux cas de figure rencontrés dans des projets passés et enrichi par l'apport du chercheur qui connaît bien son milieu de recherche.

Un projet à risque minimal ne veut pas dire qu'on peut substituer son jugement à celui du participant : le principe de respect des personnes implique de respecter ses choix, ses valeurs, et qu'il revient au participant de décider si la participation au projet est bonne pour lui ou non. La participation à la recherche doit être volontaire et informée, et le participant doit pouvoir changer d'avis à tout moment.

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Conflit d'intérêts
Marie-Pierre Bousquet est professeure titulaire et présidente du Comité d'éthique de la recherche – Société et culture (CÉR-SC) à l'Université de Montréal; elle est mariée à Bryn Williams-Jones. Bryn Williams-Jones est professeur titulaire, membre versé en éthique du Comité universitaire d'éthique de la recherche (CUÉR) de l'Université de Montréal et éditeur en chef de la revue. Les opinions exprimées ici sont celles des auteurs et ne reflètent pas forcément les positions de l'institution ou des deux comités dont les auteurs sont membres.

Conflicts of Interest
Marie-Pierre Bousquet is Full professor and President of the Society and Culture Research Ethics Board (CÉR-SC) at the Université de Montréal; she is married to Bryn Williams-Jones. Bryn Williams-Jones is Full professor, member specialised in ethics at the University Research Ethics Board (CUÉR) of the Université de Montréal, and Editor-in-chief of the journal. The views expressed here are those of the authors, and do not necessarily reflect the positions of the Institution or the two committees in which the authors are members.

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Canadian Journal of Bioethics
Revue canadienne de bioéthique

ÉTUDE DE CAS / CASE STUDY

Helping Surrogate Decision-Makers Through Difficult Conversations

Nico Nortjé[1]

Résumé
Les discussions complexes dans les services de soins intensifs sont souvent perçues comme un processus permettant d'amener un mandataire à prendre une décision de fin de vie. Toutefois, le fait de permettre au mandataire de devenir narrateur peut atténuer la tâche ardue qui l'attend.

Mots clés
mandataire, service de soins intensifs, décisions de fin de vie, narrateur

Abstract
Difficult conversations in the ICU are often seen as ones of getting a surrogate decision-maker to make an end-of-life decision. However, allowing the surrogate decision-maker to become a narrator can alleviate the daunting task lying ahead.

Keywords
surrogate decision-maker, ICU, end-of-life decisions, narrator

Introduction

It is estimated [1] that less than 20% of adults who are admitted to the intensive care unit (ICU) have discussed their wishes about end-of-life treatment with their loved ones. This often leads to surrogate decision makers having to make high-stakes decisions about life-sustaining critical care, under conditions of heightened psychological stress and uncertainty [1]. This uncertainty is often tied with the fact that the surrogates themselves are unprepared for the role abruptly bestowed upon them. Making sense of the circumstances, prognosis and values of the individual for whom they need to make decisions of great importantance as this will alleviate depression, anxiety and maladaptive reasoning [2,3].

The following case will illustrate the turmoil that surrogate decision makers often face when they are left to make decisions without prior knowledge of the patient's choices.

Case study

John was in his early 20s when he was diagnosed with cancer to the bone, which quickly spread to the lungs. Unfortunately, John kept his diagnosis to himself and for the next few months he did not keep to his appointments and the result was that he was rushed to the Emergency Room with impending respiratory failure. Unfortunately, John's cancer, together with all the metastases, progressed so much that he was not a candidate for any kind of treatment. As time lapsed, John became progressively unresponsive and eventually lost capacity to make decisions. His mother, as his appointed medical power of attorney, stepped in to make decisions on his behalf. Mrs. B was very distraught, as can be expected, and she kept focussing on the fact that she did not know about his prognosis, that he was so young, and how he still wanted to do so many things in his life. Mrs. B was by no means ready to change the code status of her son and transition him to comfort care. She wanted to keep on fighting and pursue treatment.

Framing Effect

The aforementioned case is not uncommon in many ICU's; often the surrogate decision maker is caught off guard and forced to make tough decisions for which they themselves feel ill-prepared, given the circumstances. This stress, as well as the onset of the grief process, often result in surrogate decision makers wanting heroic treatment, even if it is against medical advice. Given the fact that the practice of medicine has developed to encapsulate patient autonomy and rights, healthcare teams are often left despondent when they know what the prognosis is, but also need to follow the instructions of the patient or as in this case, the surrogate decision maker. It is in cases like these that healthcare teams often reach out to an ethicist to be a bridge between the patient (and family) and the health care team.

Consequently, the ethicist was consulted and after reviewing the medical records of the patient, and the notes from the different team members, a family meeting was organized to discuss goals of care with the surrogate decision maker. In this case the ethicist drew on the seminal work of Tversky and Kahneman [4] which focus on the psychology of choices and how the framing of decisions can be greatly beneficial to use. The authors argue that choices that individuals make are framed by the formulation of the problem. In ICUs, the problem is often framed as one of end-of-life decisions that need to be made. Patients (and or families) will use this framework in a context where the consequence of not trying (death) outweighs the gains (prolongation of life, regardless of quality), and so it would be beneficial to keep on trying. Tversky and Kahneman [4] argue that it is best to use alternative frames for a decision problem. These different frames do not necessarily mean that one does not pay attention to the end-of-life issue at hand (because that would be ignoring the elephant in the room), but rather change the focus of the conversation from doing everything to keeping the patient alive to having a VALUE conversation (explained below) as proposed by Curtis and White [5]. The ethicist in this case found that if the focus of the conversation could be shifted away from making a life altering decision, to instead focussing on the surrogate decision maker's position to tell a story as a narrator, an alternative frame could be provided and hence given rise to the usefulness of the faming effect.

ISSN 2561-4665

VALUE conversation

Unfortunately, the first goals of care conversation were unsuccessful in this case as the surrogate decision maker was insistent on pursuing medically inappropriate care. The ethicist met with the surrogate decision maker the following day and focussed on having a VALUE conversation. The contraction VALUE stands for 1) **V**alue the surrogate's statements; 2) **A**cknowledge his/her emotions; 3) **L**isten to him/her without interruptions; 4) try and **U**nderstand the patient as a person. What did he/she do; what gave him/her pleasure in life; what were the highlights in his/her life?; 5) **E**licit any questions from the surrogate and get accurate feedback for him/her.

In this case as in others, as the ethicist engaged with the team and the surrogate in situations like these to help ascertain the best way forward and to respect the patient's values, the VALUE conversations do not happen in one day but over the course of a few days. Once the ethicist gained the surrogate's confidence the next phase of the conversation was to focus on what the surrogate wished for the patient. Most surrogates, approximately 87% [6], wish for their loved ones not to die in pain and to be comfortable.

When Mrs. B was given the opportunity to be the narrator and tell her story about her son and the person he was, and not necessarily the cancer patient, she was able to come to a resolution. Mrs. B changed her son's code status and transitioned him to comfort care. The patient passed away two days later with his whole family at his bedside.

When narrators tell a story, they give 'narrative form' to experience. This narrative form often gives insight to the personal experiences of the surrogate decision maker. They position characters in space and time and, in a very broad sense, give order to and make sense of what has happened. Often a cancer diagnosis, and especially end-of-life decisions, are unexpected and the person who hears it/needs to make a decision has not had time to internalise the facts and the reality. Thus, it can be argued that narratives provide a way to explain or normalize what has occurred; they lay out why things are the way they are or have become the way they are. Narrators then have the freedom to finish the chapter of the story.

Questions to consider

1. What resources exist or does your institution have available to assist surrogate decision makers in this time when they need to make end-of-life decisions?
2. What is the role of the ethicist to assist in normalizing end-of-life conversations?

Conflit d'intérêts
L'auteur est éditeur de la *Revue canadienne de bioéthique*.

Conflicts of Interest
The author is an editor at the *Canadian Journal of Bioethics*.

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Canadian Journal of Bioethics
Revue canadienne de bioéthique

ÉTUDE DE CAS / CASE STUDY

Rapport de pouvoir entre enseignante et doctorante : utilisation de données de recherche et signature scientifique

Séverine Carillon[1], Valéry Ridde[1,2]

Résumé
Enchâssée dans un rapport de pouvoir, cette étude de cas fictive met en évidence différentes pratiques d'utilisation de données de recherche dans le cadre d'une collaboration entre enseignante-chercheure et doctorante. Elle vise à mettre au jour les difficultés et enjeux éthiques d'une telle collaboration et particulièrement les défis liés à la signature scientifique et à l'utilisation des données à l'issue de la recherche.

Mots clés
collaboration, rapport de pouvoir, utilisation des données de recherche, éthique, signature scientifique

Abstract
Embedded in a power relationship, this fictional case study highlights different practices of using research data in a collaboration between professor-researcher and doctoral student. It aims to highlight the difficulties and ethical issues of such collaboration, particularly the challenges related to scientific authorship and the use of data at the end of the research.

Keywords
collaboration, power relationship, use of research data, ethics, scientific authorship

Introduction

Dans le domaine du développement, des institutions internationales et des agences de coopération sollicitent parfois l'expertise de chercheurs ou d'enseignants-chercheurs universitaires du Nord ou du Sud. Les mandats proposés sont essentiellement des évaluations de projets ou des recherches appliquées. Certains chercheurs et enseignants-chercheurs se voient ainsi confier des missions d'expertise de plusieurs semaines, voire plusieurs mois dans des pays du Sud. Ils font alors parfois appel à de jeunes diplômés ou doctorants recrutés ponctuellement pour assurer tout ou partie de la mission d'expertise, sous leur supervision. Cette configuration implique un rapport de pouvoir entre des individus dont les statuts socioprofessionnels et académiques diffèrent. Elle pose des enjeux éthiques de collaborations, d'utilisation des données collectées et de signature scientifique, peu développés dans la littérature et rarement discutés dans les équipes de recherche en dépit de leur importance [1-4]. Les données existantes portent essentiellement sur les enjeux éthiques des partenariats entre des équipes du Nord et du Sud (tels que la propriété des données, la répartition des pouvoirs entre les équipes) [5-9] mais peu sur ceux liés aux rapports de pouvoir entre des individus qui travaillent au sein d'une même équipe au Nord dans le contexte de ces relations Nord-Sud.

L'étude de cas proposée ici est inspirée de plusieurs situations réelles. Elle vise à mettre en évidence les difficultés et enjeux éthiques d'une collaboration entre des individus dont la relation est d'emblée asymétrique[1], l'un, plus expérimenté, employant et supervisant l'autre, mais qui sont engagés dans une mission scientifique commune au Sud.

Cas d'étude

La division sociale du travail de recherche

Mme D., enseignante-chercheure reconnue, travaille dans une université belge[2]. Elle a obtenu un financement d'une institution internationale pour conduire une recherche sur l'expérience de l'andropause chez les hommes au Mozambique. Pour mener à bien ce projet, elle recrute une de ces anciennes étudiantes tout juste diplômée d'un master, et potentiellement future doctorante (la demande de financement de la thèse sous sa direction est alors en cours). La jeune chargée d'étude est recrutée pour une durée de six mois. Elle doit assurer la construction des outils d'enquête, la collecte des données sur le terrain, l'analyse, la rédaction du rapport et la valorisation des résultats de l'étude. Ce travail se fait sous la supervision de Mme D. à qui il revient la responsabilité scientifique et administrative du projet en tant que principale investigatrice. À ce titre, elle rédige le protocole de recherche, révise et valide les documents produits et s'assure du bon déroulement de la recherche.

L'implication de la jeune collaboratrice, indispensable à la mise en œuvre du projet, constitue une opportunité pour Mme D. de voir étudier un terrain qu'elle ne peut elle-même explorer compte tenu de ses engagements à l'université en Belgique, et qui lui permettra d'étendre son domaine de recherche. La jeune recrue saisit, quant à elle, cette expérience pour renforcer sa propre capacité de recherche. L'étude s'inscrit ainsi dans une relation pédagogique, somme toute assez classique [1,2,10], à la fois d'échange, « donnant-donnant », et de pouvoir entre une chercheure statutaire et expérimentée, et une chargée d'étude « juniore » recrutée temporairement et poursuivant ainsi son apprentissage de la recherche.

En tant que cheffe du projet, Mme D., se rend sur le terrain pour lancer l'étude avec sa jeune collaboratrice. Une fois les contacts pris sur place, les partenaires rencontrés et l'étude de terrain démarrée, Mme D. rentre reprendre ses activités en Belgique. Sa collaboratrice poursuit le travail de terrain durant 10 semaines. Elle fait part régulièrement de ses avancées à Mme D. Elle développe un réseau de connaissances particulièrement propice au déroulement de la recherche. Elle clôture sa

[1] Nous n'aborderons pas ici la question du genre dans cette relation. Cette question pourrait faire l'objet d'une étude de cas à part entière.
[2] Le choix du pays est bien évidemment aléatoire

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mission avec des données de qualité. À son retour, elle travaille sur les données pendant trois mois pour en faire une analyse détaillée. Elle partage spontanément les données empiriques – entretiens, observations, littérature grise collectée sur place – avec Mme D. qui a ainsi accès à la totalité des données collectées. Mme D. participe à l'élaboration et à l'écriture du rapport final via des discussions avec sa collaboratrice sur le contenu des analyses, la construction du plan du rapport, et la révision du rapport. Enfin, Mme D. assure, en tant que responsable du projet, la mission de restitution sur le terrain à l'issue de l'étude avec sa collaboratrice.

Tout au long de ce processus, aucune politique de publication – qui écrit et signe quoi? – et d'utilisation et de partage des données – qui a le droit de les réutiliser et sous quelles modalités, avec quel accord ou contribution de qui? – n'a été discutée.

Défis liés à la signature scientifique

À l'issue de cette recherche, la chargée d'étude – devenue doctorante sous la direction de Mme D. – écrit un article pour la revue *Andropause* dans le cadre d'un numéro spécial sur les représentations sociales de l'andropause. Elle est première auteure et Mme D., co-auteure. Cette répartition des auteures fait *à priori* consensus. Les auteures sont ainsi classiquement nommées par ordre décroissant selon l'importance de leur contribution à la recherche [4]. L'article suit ensuite le processus d'évaluation ordinaire – relectures, remarques, modifications… – pendant lequel la correspondance s'établit, comme c'est d'usage, entre les coordinatrices du numéro de la revue et la première auteure de l'article.

Lors de la soumission de la version finale de l'article, Mme D. demande à sa collaboratrice de passer première auteure. Après tout, n'est-elle pas la cheffe du projet de recherche? Elle a également besoin de publier pour l'avancée de sa carrière, argument qu'elle mobilisera explicitement. La jeune collaboratrice, bien qu'ayant fourni la majeure partie du travail, laisse faire le changement de position des auteures. Comment refuser cette demande venant de sa – désormais – directrice de thèse? C'était sans compter les coordinatrices du numéro qui ne comprennent pas ce changement, le contestent pour des raisons déontologiques et proposent de maintenir la jeune collaboratrice première auteure. Mme D. ne conteste pas la proposition de ses pairs. L'article est publié ainsi.

Quelques mois après la parution de l'article, le résumé et les références sont mis en ligne sur un site en libre accès. L'article n'y est cependant pas joint. Mme D. figure sur ce résumé en tant que première auteure. Elle figure également sur le site comme la personne qui a fourni les informations mentionnées sur cette page. Sa jeune collaboratrice n'est pas informée de cette mise en ligne ni de l'échange de l'ordre des auteures. Elle le découvrira de façon fortuite quelques années plus tard.

Défis liés à l'utilisation secondaire des données de recherche

La jeune collaboratrice n'est pas au bout de ses découvertes. Quelle n'est pas sa surprise de découvrir, dans un ouvrage collectif, un chapitre sur l'andropause des hommes au Mozambique, essentiellement basé sur les données qu'elle a même collectées et analysées. Ce chapitre fait apparaître comme unique auteure Mme D. Sa jeune collaboratrice, certes citée dans le texte, n'a été informée ni de l'utilisation secondaire de ses données, ni de l'écriture du chapitre, ni de la parution de l'ouvrage.

Questions à considérer

- Qu'auriez-vous fait à la place de la jeune collaboratrice?
- Quelles sont les solutions à envisager face à ce type de situation?
- Quels préalables dans l'élaboration d'un projet peut-on mettre en place pour éviter de telles situations dans cette forme de collaboration?
- Comment comprenez-vous les agissements de Mme D.?

Conflit d'intérêts
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Canadian Journal of Bioethics
Revue canadienne de bioéthique

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

Access to Personal Information for Public Health Research: Transparency Should Always Be Mandatory

Louise Ringuette[1,2], Jean-Christophe Bélisle-Pipon[3,4], Victoria Doudenkova[1,2], Bryn Williams-Jones[1,2]

Résumé
Au Québec, la *Loi sur l'accès aux documents des organismes publics et sur la protection des renseignements personnels* offre une exception en matière de transparence à la plupart des institutions publiques où la recherche en santé publique est menée en leur permettant de ne pas divulguer leurs utilisations de données à caractère personnel (souvent collectées sans le consentement des personnes étudiées). Cette exception est éthiquement problématique en raison de préoccupations importantes (ex. : la protection de la vie privée et les inconvénients potentiels des utilisations secondaires de données) et nous soutenons que tous ceux qui mènent des recherches doivent être transparents et responsables du travail qu'ils accomplissent dans l'intérêt public.

Mots clés
accès aux données, données personnelles, vie privée, transparence, loi, intérêt public

Abstract
In Québec, the *Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information* provides an exception to transparency to most public institutions where public health research is conducted by allowing them to not disclose their uses of personal data (often collected without the consent of those being studied). This exceptionalism is ethically problematic due to important concerns (e.g., protection of privacy and potential harms of secondary uses of data) and we argue that all those who conduct research should be transparent and accountable for the work they do in the public interest.

Keywords
data access, personal data, privacy, transparency, law, public interest

Introduction

Public health surveillance activities (e.g., of communicable diseases, cancers) and public health research requires access to a wide variety of personal data, often without the consent of citizens or research participants. Access to population data is crucial for evidence-based decision-making and the development of informed public policy and interventions [1]. With recent advances in data collection and analysis (and "Big Data"), there is enormous potential for public health research to help address many of the most challenging problems facing society. But even when conducted with a clear public interest in mind (i.e., to promote public health and prevent disease and disability), public health research can raise important concerns about the protection of privacy, the validity of individual consent and potential harms of secondary use of personal data [2-4].

It is widely accepted that research participants have a fundamental right to give free and informed consent to participate in research. Normative guidelines in Europe and North America provide robust safeguards to ensure that research participants are protected against the potential harms of unregulated and unrestricted data access and sharing [5-9]. But while these norms are clear for health and social research involving human participants, there is ambiguity for public health research. This is especially the case when public health researchers and surveillance teams involve the same colleagues using the same datasets that stem from other projects and designed for other purposes. It is unclear that normative research ethics frameworks are adapted to current (e.g., epidemiological) and future (e.g., Big Data) public health research, particularly with regards to the protection of individual information and transparency about what research is being conducted, by whom and for what purposes.

In Québec, the *Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information* [10] (hereafter, the Access Act) provides a good example of this problem. This law governs access to information and the protection of personal information and privacy, a fundamental right in the Province of Québec, Canada, as is clearly proclaimed in Chapter 1 of the Québec Charter of Human Rights and Freedoms [11, Art. 5]. While most governmental organizations and agencies are legally required to disclose, on an institutional website, an inventory of all personal information files held [10], an exception is made for the very places where most public health research is conducted, that is, universities, hospitals and public health research centres. These concerns are particularly problematic when we consider that most personal data collected by public health institutions in Québec is allowed by public health legislation, with little or no public awareness [12]. Without real transparency about the use of citizens' medical data and other personal information, there is no way for the Québec population to ensure that their data are used properly, and ultimately, to know that their trust in actors of the state is well placed.

In the last few years, there has been a push, from both the scientific [13] and political [14] community, to revise data access provisions and processes. In response, a reform of the Access Act was presented by the government to the National Assembly in May 2018 [15]. Bill 179 focused on allowing more access to personal health data for population-based research, unfortunately, but it did not include any provisions for more transparency regarding the uses of personal health data (especially for public health research). While this Bill died on the order paper [16], we argue that there is a window of opportunity for adding provisions in a revision of the Access Act to address an exceptionalism (granted to certain institutions) that is detrimental to the public interest.

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An Inequitable Transparency Requirement

A growing number of personal information files (PIF) are stored on the servers of universities, hospitals and public health research centres. This information is collected for public health activities, such as the surveillance of cancers or infectious diseases [17] or for research purposes [18], sometimes with and at other times without individual consent [8,10,12,19]. In Québec, public health stakeholders or researchers may have access to personal information without individual consent, with permission granted by institutional actors such as the Director of Professional Services of a hospital [20, Art. 19.2] or the Québec Access to Information Commission [10, Art. 67 to 68.1 and 125]. These authorizations may be granted following specific conditions: 1) individual consent is unfeasible (e.g., epidemiologic studies with large populations), 2) intended use is necessary to accomplish a public health mandate or for research purposes, 3) purposes pursued cannot be achieved unless the information is communicated in a form allowing persons to be identified, and 4) personal data will be used in a manner that will ensure its confidentiality [10,20,21].

The Québec law specifies that public bodies regulated by the Access Act are required to disseminate on a website an inventory of their PIF, as well as "studies, research or statistical reports produced by or for the public body, whose distribution is of interest for the purposes of public information" [22, Art. 4]. As prescribed by the Access Act [Art. 76], PIF inventories must be kept up-to-date, disseminated and must include:

> (1) the title of each file, the classes of information it contains, the purposes for which the information is kept and the method used to manage each file;
> (2) the source of the information entered in each file;
> (3) the categories of persons to whom the information entered in each file relates;
> (4) the categories of persons who have access to each file in carrying out their duties; and
> (5) the security measures taken to ensure the protection of personal information. [10, Art. 76][1]

The inventory includes the list of all PIF that have been communicated under the application of a law, a mandate or a service contract [10]. For example, the Quebec Breast Cancer Screening Program contains personal identifiers, health data and demographic data (classes of information) on women between 50 and 69 years of age (categories of persons). Access to this file is restricted to some professionals (categories of persons) of the *Institut national de santé publique du Québec* (INSPQ), a public health organization that has a mandate from the Québec Ministry of Health and Social Services (MSSS) for this program[2].

Interestingly, unlike government organizations regulated by the Access Act, universities and hospitals are not required to comply with the Access Act's regulation, i.e., *Regulation Respecting the Distribution of Information and the Protection of Personal Information* [22] (hereafter Regulation). Also, public health research centres (e.g., *Institut national d'excellence en santé et services sociaux du Québec*) that have access to significant amounts of personal information to carry out mandates entrusted by government organizations (e.g., Ministry of Health) [23], including public health research, do not have to comply with some parts of the Access Act and its Regulation. Specifically, these institutions do not need to disseminate on their websites information regarding their PIF inventories or publish the list of studies using PIF, which may include information extracted from patient medical records. Public health research centres usually disseminate on their websites information regarding studies, research or statistical reports but they do not publish their PIF inventories [24,25]. As a result, there is no way for the Québec population to know what institutions are currently using their personal information without their consent.

Respect of Privacy and Transparency as Crucial Ethical Norms

The current asymmetry between legal requirements and the exemption enjoyed by the very centres where most public health research is conducted raises important ethical issues. The exemption comes without any binding, accessible and long-lasting evaluation mechanisms that could enable the general public or research participants to ensure that public health stakeholders or researchers are compliant with expected ethical obligations, including respect for privacy and the protection of confidential information. Public health research centres are thus exempted from an important legal requirement and ethical responsibility. Even if research ethics boards (REB) in Québec normally assess research data management plans when reviewing protocols, their oversight is limited to particular projects. Further, they are rarely equipped to do long-term surveillance of data management practices [8], and they and their institutions do not normally make publicly available the list of studies being conducted. Also, the line between data collection for public health surveillance activities (not requiring research ethics review) and the secondary use of the same data for public health research (normally requiring ethics review) can be a source of some confusion for public health researchers [26,27]. Finally, the role and responsibilities of REBs in evaluating public health

[1] The Access Act does not define the terms 'classes of information' or 'categories of persons'. Based on the information available on the website of the Ministry of Health and Social Services in Québec (MSSS), these terms are related to the type of data (e.g., health, education, personal identification), the persons concerned by these data (e.g., client, employee, citizen), and the persons who have mandated access to these data (e.g., authorized employees). For examples, see the MSSS webpage Diffusion de l'information et protection des renseignements personnels.

[2] Information available on the MSSS webpage Diffusion de l'information et protection des renseignements personnels, Programme québécois de dépistage du cancer du sein (PQDCS).

research needs further examination. For example, while REBs are now ubiquitous in universities and hospital research centres, they are not well established into public health centres[3] [12, Art. 36].

The Canadian *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) [8] applies the principle of respect for autonomy to all participants in research, including "those who are participants because their data…are used in research". More generally, it also includes "a commitment to accountability and transparency in the ethical conduct of research" [8]. But what means are available to the general public or research participants to ensure compliance with their consent and protection of their privacy when it may be exceedingly difficult, if not impossible, to inventory PIF or even the number of studies performed? In the absence of inventories, it is not possible to independently assess the appropriateness of the use of citizen or participant information or appreciate the number of studies for which an REB has approved secondary use of data. Participants cannot exercise their right to withdraw from a study or to be informed of its findings, if they are unaware that their data is being used. While the TCPS2 highlights the importance of transparency and accountability when it comes to clinical trials [8], more public transparency regarding the use of personal data in public health research is also needed.

The Québec case is interesting because it highlights an asymmetry in data use accountability by various institutions. Current trends in data use add an extra dimension to the complexity of the case and a paradoxical situation for individuals. On the one hand, more and more personal data are collected which is making it easier to re-identify individuals simply by crossing certain datasets. On the other hand, it is more difficult than ever for a person who wishes to revoke their consent to ask for data withdrawal; whereas data is widely shared and stored on servers that are accessible to various institutions and individuals (i.e., less under the control of a single entity having full authority over its use), it is difficult (if not impossible) to ensure that a person's data will be removed. In such a situation, it is necessary both to rethink the very notion of consent to the use of personal data for various purposes (e.g., research, public health), but also to raise awareness of the fact that personal data is more accessible than ever and that it is difficult to control access to data and to remove datasets. In such a context, transparency is key to enabling individuals to better understand the (potential) uses that are made of their data.

As proposed by the Québec *Commission d'accès à l'information* in 2016 (14), legislation should evolve to ensure uniformization of the requirements for data use (i.e., all institutions should be subject to the same conditions) and take into account the potency of new data use practises and the impact on the expression of individual consent (implicit or explicit). Exceptionalism for some is not in the public interest; data access and usage should always entail high levels of transparency and accountability. There is a growing pressure to revise the Access Act, especially to ease and speed up data access processes [14,28,29]. Whether it is through a new version of Bill 179 or any future attempts to revise the Access Act, it is imperative that transparency and accountability be *sine qua non* values for data access and usage.

Conclusion

If privacy "refers to an individual's right to be free from intrusion or interference by others [and] is a fundamental right in a free and democratic society" [8 p.57], then the obligation to disseminate PIF inventories and results obtained from their use in universities, hospitals and public health research centres should also apply to these institutions. Attention to transparency is an important way to ensure the implementation of efficient management mechanisms – such as laws, regulations, REB review and oversight, self-regulation – which together can help restore a balance between researchers' pursuit of knowledge and participants' right to privacy [30]. There is no *right* to conduct research, but there is still a right to privacy [19 Art. 3]. Researchers should only collect and access the information needed for their research, and not simply collect *everything they can* [2,31], especially if they agree with the importance of protecting privacy as a fundamental right [11]. Institutions must ensure that public health research is conducted in an ethical and responsible manner, and that good research does not come at the expense of the protection of privacy. In so doing, by being transparent, institutions demonstrate that they are accountable and working in the public interest; they are trustworthy because they demonstrate that they have nothing to hide [32].

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[3] In Québec, the Public Health Ethics Committee, by law, is responsible for the evaluation of surveillance plans, but the legislation does not say anything about follow-up of surveillance plans or ethical evaluation of research using data collected for surveillance purposes.

Conflits d'intérêts
Ringuette est étudiante au doctorat à l'Université de Montréal et analyste à la *Commission d'accès à l'information du Québec* (en congé sans solde pour terminer ses études de doctorat), le bureau du commissaire à la protection de la vie privée de la province de Québec. Le contenu de cet article reflète les opinions des auteurs et non celles d'une organisation ou d'une institution. Tous les auteurs déclarent ne pas avoir de conflits d'intérêts en relation avec ce manuscrit. Ringuette est éditrice de la *Revue canadienne de bioéthique* (RCB; anciennement *BioéthiqueOnline*), Bélisle-Pipon est cofondateur et ancien éditeur exécutif de *BioéthiqueOnline* et est membre du Conseil consultatif de rédaction de CJB. Williams-Jones est l'éditeur en chef de CJB. Aucun des auteurs n'a participé au processus de révision éditoriale.

Conflicts of Interest
Ringuette is PhD student at Université de Montréal and analyst at the *Commission d'accès à l'information du Québec* (on leave without pay to complete her PhD studies), the office of the privacy commissioner in the Province of Québec. The content of this article reflects the opinions of the authors and not those of any organization or institution. All the authors declare that they have no conflicts of interest related to this manuscript. Ringuette is an Editor of the *Canadian Journal of Bioethics* (CJB; formerly *BioéthiqueOnline*), Bélisle-Pipon is cofounder and former Executive Editor of *BioéthiqueOnline*, and is a member of CJB Editorial Advisory Board. Williams-Jones is the Editor-in-Chief of CJB. None of the authors were involved in any part of the editorial review process.

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