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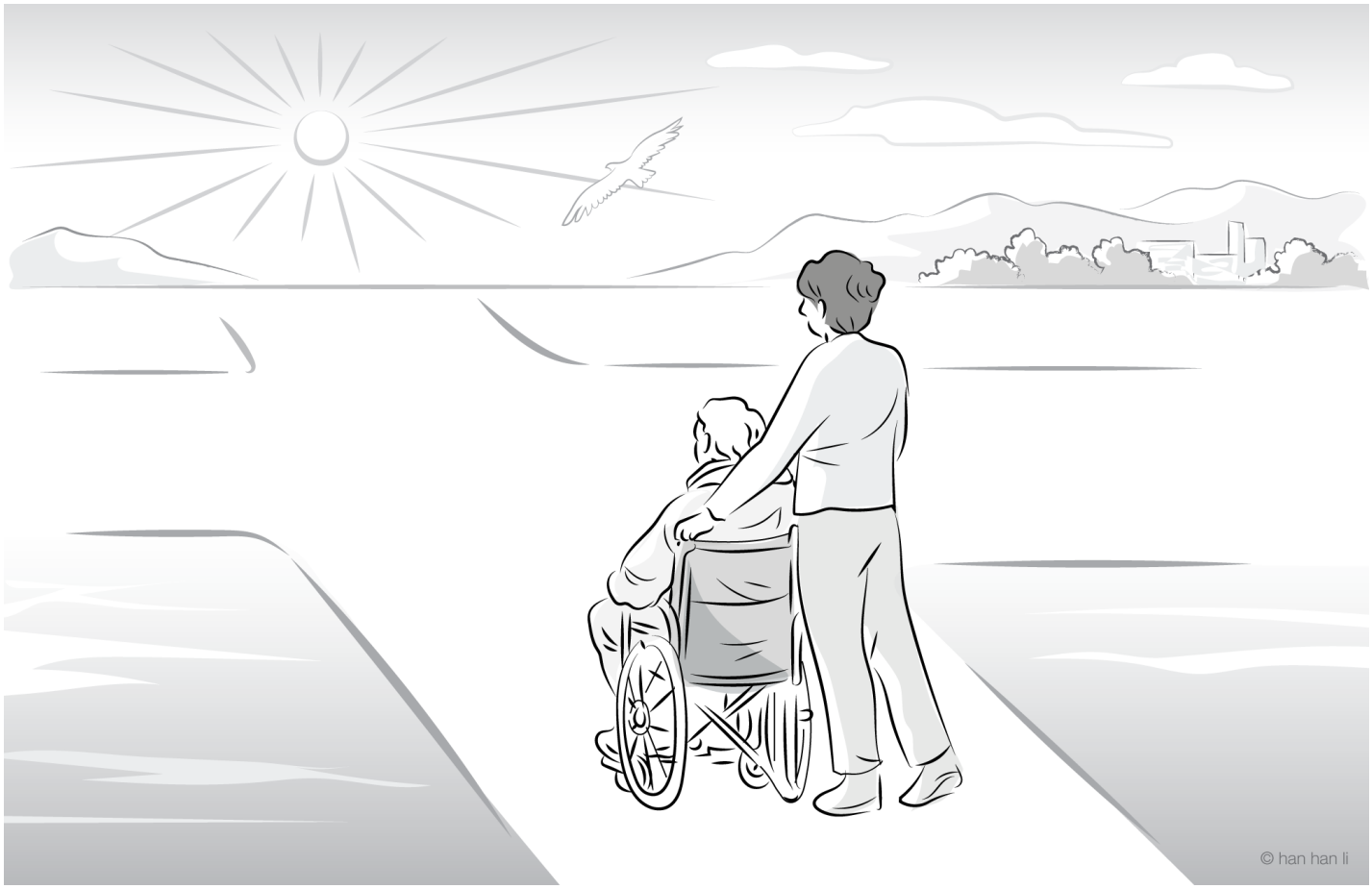

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Conscientious Objection and the Provision of Abortion at Late(r) Stages of Pregnancy

Nathan Emmerich[a]

Résumé
Cet essai porte sur une question théorique susceptible de se poser dans le cadre de l'avortement tardif dans des juridictions particulièrement libérales ou très permissives, c'est-à-dire celles qui n'exigent pas que des critères soient remplis pour que la procédure soit légale. En n'établissant pas de critères limitant la pratique de l'avortement tard(if), la procédure devient légale « à la demande », du moins en principe. Cela soulève la possibilité que les professionnels de santé soient confrontés à des demandes spécifiques d'interruption de grossesse qu'ils considèrent comme moralement injustifiées, ce qui signifie que certains d'entre eux pourraient chercher à s'abstenir de pratiquer l'avortement dans de tels cas en faisant appel à la notion d'objection de conscience. La littérature existante qualifierait probablement ces appels de cas d'objection de conscience sélective. Tout en soutenant que cette notion est erronée, je suggère également qu'il est nécessaire de reconnaître un certain degré de nuance dans les positions éthiques des professionnels de la santé lorsqu'il s'agit de pratiquer des avortements à des âges gestationnels tard(ifs) dans des juridictions qui adoptent des formes de réglementation très permissives. Toutefois, étant donné que l'objection de conscience ne devrait pas être autorisée à entraver la réalisation d'interventions légalement autorisées, il existe un impératif moral de garantir l'accès et les systèmes de soins de santé doivent prendre des mesures pour assurer la réalisation de l'intervention. Bien que cela soit possible, il est peu probable que ce soit simple et cela pourrait nuire à l'établissement d'une légalisation très permissive.

Mots-clés
avortement, avortement tardif, prestation de services, objection de conscience, refus de conscience

Abstract
This essay concerns a theoretical issue that has the potential to arise in the provision of late(r) term abortion in particularly liberal or highly permissive jurisdictions, meaning those that do not require criteria to be met if the procedure is to be lawful. By not establishing criteria that restrict the provision of late(r) term abortion the procedure is rendered lawful "on demand", at least in principle. This raises the possibility that healthcare professionals may encounter specific requests for terminations that they consider morally unjustified, meaning that some might seek to "opt-out" of provision in such cases by appealing to the notion of conscientious objection. The existing literature would likely frame such appeals to be instances of selective conscientious objection. Whilst I argue that this notion is flawed, I also suggest that there is a need to recognise a degree of nuance in the ethical positions held by healthcare professionals when it comes to the provision of abortion at late(r) gestational (st)ages in jurisdictions that adopt highly permissive forms of regulation. However, given that conscientious objection should not be permitted to obstruct provision of legally permitted interventions, there is a moral imperative to ensure access, and healthcare systems must take steps to ensure provision. Whilst it may be possible, it is unlikely to be simple, and it may auger against establishing legalisation that is highly permissive.

Keywords
abortion, late term abortion, service provision, conscientious objection, conscientious refusal

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INTRODUCTION

This essay is not concerned with the ethics of abortion per se and whilst it is cognisant of a range of reasonably defensible and well-established positions on the issue, these are not subject to critical examination. Rather, the issue to be addressed is whether there might be a case for recognising an elevated degree of ethical nuance when it comes to questions of conscientious objection in relation to the provision of late(r) term abortion. More specifically, this issue is examined in the context of a particularly liberal or highly permissive approach to late(r) term abortion, by which I mean legislation that does not restrict access to the procedure.[1] Whilst it may not always be the case in practice, it is generally assumed that those who provide a particular intervention should do so in accordance with the relevant clinical and legal frameworks and that those who wish to conscientiously object should "opt-out" of provision entirely.[2] This might be thought of as an "all or nothing" of "absolute" approach to conscientious objection; healthcare professionals either provide the service in accordance with the law or they do

[1] The meanings of the terms 'early', 'earlier', 'late' and 'late(r)' are imprecise. Whilst there is a need to draw a distinction there is no rationale that can provide a precise point of differentiation. One can find various legislative frameworks that draw the line between the 16th and 24th week of pregnancy and, for the purposes of this essay, I take it that late(r) term abortion occurs after the 20th week of pregnancy whilst those that occur at late(r) stages occur after this point. This usage may differ from the way the terms are used in other contexts. However, as noted below, the distinction arguably maps onto the uncertain point at which foetal sentience emerges as well as viability, the point at which it becomes increasingly realistic to think that the foetus can survive as an independent organism, albeit with a particularly high level of medical intervention. It also maps onto the practicalities of abortion provision. Early or earlier abortion is generally provided via medical or surgical means by general practitioners or dedicated clinics, of the type run by Marie Stopes, British Pregnancy Advisory Service and so forth. Late or late(r) term abortion is generally provided by specialist obstetricians in hospitals. As will be made clear, that this is the case is not irrelevant to the conclusions I draw.

[2] There is some evidence that healthcare professionals do not act in this way. I take it that it is problematic that they do so and that they ought to behave in the way(s) described (1,2).

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not provide the service at all.[3] This paper examines the case for a more "selective" approach to conscientious objection in relation to late(r) term abortion.

To my knowledge, this is not something that has previously been discussed in the bioethical literature. This is likely because the majority of jurisdictions establish criteria that must be meet if an abortion is to be lawful at late(r) gestational stages.[4] It therefore seems reasonable to assume that the healthcare professionals involved in provision consider it to be morally permissible in the circumstances outlined in law; if they did not, they would presumably opt out of any and all involvement. As this suggests, very few jurisdictions regulate late(r) term abortion in the permissive way that gives rise to the issue I seek to discuss.[5] Furthermore, there are significant extra-legal obstacles which generally mean that women who wish to end their pregnancies in the absence of the kind of criteria ordinarily outlined in law are unable to do so.[6] Nevertheless, in jurisdictions that do not require specific criteria to be met for an abortion to be lawful at any gestational stage then it seems reasonable to assume that at least some providers will have moral concerns regarding provision of late(r) term abortion absent the kind of criteria commonly established in other jurisdictions. Furthermore, maintaining an all or nothing approach to conscientious objection in such contexts may have significant implications for service provision. This paper calls into question the "all or nothing" approach to conscientious objection. If a more selective approach might be justified in relation to late(r) term abortion in highly permissive jurisdictions, then perhaps we should rethink the way conscientious objection is understood more generally.

The essay proceeds as follows. First, I discuss some basic aspects of the legal regulation of abortion and sketch what I refer to as the "highly permissive" approach to the regulation of abortion provision at late(r) gestational (st)ages. This sets the scene for a discussion of this paper's substantive concern, the possibility that a more selective approach to conscientious objection in relation to late(r) term abortion might be justified in jurisdictions that promulgate laws of the kind identified. Part of my purpose in this essay is to shed light on the notion of conscientious objection as I see it, aspects of which do not sit well with contemporary bioethical accounts.[7] In the conclusion I examine the implications of the case I have set out with a specific focus on the regulation of abortion at late(r) gestational (st)ages.

Before proceeding any further it is worth noting some general points regarding abortion and its provision. In the first instance, we might acknowledge that late(r) term abortions occur far less often than earlier term abortion and that those who have abortions at late(r) gestational stages are generally not doing so because they no longer wish to have a(nother) child, something that not uncommonly motivates those seeking an early abortion.[8] Furthermore, advances in foetal diagnosis and, therefore, the provision of information that might prompt a decision to terminate a pregnancy on the part of someone who wishes to have a child, means that if an abortion is desired it can be done at earlier gestational stages than might have been the case in the recent past. As such, the best way to ensure low rates of late(r) term abortions is to ensure that the provision of antenatal services, including abortion, is both comprehensive and accessible at early stages of pregnancy.

Regardless of such efforts, it will nevertheless remain the case that the provision of abortion at late(r) stages of pregnancy will need to be maintained for the foreseeable future. Whilst it is not uncommon to encounter claims that no one ends a pregnancy at any stage without good reason (4), it is also true to say that sometimes that reason is simply no longer wishing to be pregnant. Of course, this raises the question of what counts as a good (enough) reason and if it is the case that simply no longer wishing to be pregnant can be considered sufficient justification regardless of gestational age.[9] However, whilst one can take legal prohibitions to communicate a degree of negative moral evaluation, an absence of such prohibitions ought not be taken to indicate ethical approval. We might therefore consider whose ethical perspective should be considered relevant to

[3] That conscientious objection should lead one to an "all or nothing" stance with regard to whatever is being found objectionable stems from the way conscientious objection to military drafts was first articulated in the early part of the 20th century. Those who sought to be recognised as conscientious objectors to military service were required to object to war — or the use of violence — *per se*, and not to the specific case (e.g., World War I or, subsequently, the conflict in Vietnam). In discussions of conscientious objection in healthcare this point has gone largely unaddressed; it has not been explicitly endorsed or rejected. Nevertheless, it seems to play a largely unacknowledged role, something this essay implicitly calls into question. As Cowley says in a paper on selective conscientious objection "Most discussions of conscientious objection in healthcare assume that the objection is universal: a doctor objects to all abortions" and that "it seems that any GP ready to invoke the words 'conscientious objection' will be expected — by colleagues, patients and employers — to harbour a universal objection. That expectation is mirrored in the philosophical and legal literature on the topic." (3)

[4] These criteria are commonly: a high risk of death or significant threat to health (including mental health) if a pregnancy is not discontinued; a pregnancy resulting from rape or incest; or a foetal diagnosis of fatal abnormalities or a life limiting disability.

[5] The matter(s) raised in this paper are, therefore, largely theoretical. Nevertheless, they are worth discussing solely on the basis that some argue for kind arrangements that would give rise to these kinds of issues (cf. 4). Furthermore, one finds that even in jurisdictions that adopt permissive approaches to late(r) term abortion, access to late(r) term abortion is nonetheless restricted such that it is not available "on demand" or without the kinds of reasons ordinarily written into law being present.

[6] This should be a source of concern. Whilst I do not defend the point in detail, I take the view that if those elected to make the law have elected not to restrict late(r) term abortion then those who are unelected should not be able to use other means to do so. It is in this context that the question of a more nuanced or selective form of conscientious objection to late(r) term abortion has the potential to arise.

[7] Indeed, my view of conscientious objection differs from established bioethical accounts. Existing literature has a tendency to focus on individual actors, their actions and the integrity of their moral conscience. I consider regulation that establishes and circumscribed the 'right' to conscientiously object to be the basis of any such act. See my essay: Conscientious Practice and Conscientious Objection in Healthcare (under review).

[8] I do not wish to suggest that women seeking an abortion at earlier gestational stages are not motivated by a complex array of reasons, only that these reasons lead women to conclude that they do not want to have a child (at this point in time) and so they seek a termination. Equally, those who continue a pregnancy into the second and third trimester do so because they have concluded that they wish to have a child. It is exceedingly rare for someone to seek a late(r) term abortion because they have simply changed their mind and decided that they do not want to have a child. Late(r) term abortions tend to be motivated by some other factor, such as a foetal diagnosis or the fact that continuing the pregnancy will pose a significant risk to their health. Of course, the fact that a majority of jurisdictions require certain criteria must be met if late(r) term abortion is to be lawfully provided is not irrelevant. However, there is no reason to suppose that it is playing a determinative role with regard to why someone might seek to terminate a pregnancy.

[9] Kendal has recently argued all abortions are medically necessary on this basis (5).

the question of late(r) term abortion, either in general or in the particular case. If an agnostic position is maintained in law, then it would seem the only relevant ethical perspective(s) are those directly involved. That this is the case is, precisely, what gives rise to debates about conscientious objection, both in general and in the context of healthcare.

THE LEGAL REGULATION AND ETHICAL PROVISION OF LATE(R) TERM ABORTION

Whilst it is not without ambiguity, there is some reason to distinguish between 'early' or 'earlier' and 'late' or 'late(r)' term abortion. Certainly, differing clinical techniques are required to terminate a pregnancy at differing gestational stages. However, from an ethical perspective, such matters are largely irrelevant. What would seem to be of primary concern is the moral status of the developing foetus, at least initially. As this paper is focused on the provision of abortion at late(r) gestational stages, it is assumed that early term abortion is ethically permissible or, at least, that it is appropriate for legal frameworks governing the provision of abortion at earlier stages of pregnancy not to limit the procedure.[10] I therefore proceed on the basis that any ethical concerns about the provision of abortion at early — or earlier — stages of pregnancy should be devolved to those involved and that the law should be shaped accordingly.[11]

This paper also assumes that it is defensible to suppose that some (additional) degree of moral significance accumulates in or attaches to the foetus during or at some (unclear) point in its gestation. This would seem to be implied by legislation that limits the provision of late(r) term abortion by establishing criteria that must be met if the intervention is to be lawfully performed. The relevant UK legislation — the Abortion Act (1967) — is a clear example of this type. Equally, this essay also assumes that it is defensible not to establish any such criteria for the lawful provision of late(r) term abortion and, in so doing, for the law to maintain the kind of agnostic position regarding the ethics of abortion at late(r) gestational ages that one generally finds in law relating to abortion in earlier gestational (st)ages. Similarly, a jurisdiction could elect not to formally legislate abortion in any way meaning that, like any other intervention, it would be regulated by existing health law.[12] I am not aware of any jurisdictions that have pursued this kind of option and although some have adopted a highly permissive approach of the kind sketched here, they are few in number.[13]

Regardless of the way the law on abortion is drawn in a particular jurisdiction, legislation commonly includes clauses permitting healthcare professionals to conscientiously object.[14] Such clauses enable those whose clinical duties would directly involve them in the provision of the intervention to opt out of being involved. This "right" is granted on the basis that it would be wrong to compel those who consider abortion to be morally impermissible to be providers of the service. The obviously corollary is that those who do not participate in the provision of abortion are expected to do so because they consider doing so to be morally wrong and not because they simply prefer not to be involved.[15] Healthcare professionals who conscientiously object to abortion are not required to substantiate or register their views, not least because doing so would be difficult to implement, it is unlikely to achieve all that much and may have unintended consequences (7,8). However, whether as a matter of law or professional regulation, they are generally required to refer patients who may be considering terminating their pregnancy to another healthcare provider who does not morally object to the intervention. Further discussion of such points can be found in the extensive literature on conscientious objection in healthcare (cf. 9-13). Whist it would not be accurate to suggest that the views advanced are entirely uniform on such matters, I take it that this brief sketch indicates the way in which conscientious objection to the provision of abortion is generally understood and meant to work in practice. Recognition of the right to conscientiously object to the provision of abortion seeks to accommodate the moral perspectives of some healthcare professionals whilst also ensuring that access to lawful medical services is not subject to significant obstruction.

The issue addressed in this essay concerns the possibility of healthcare professionals seeking to conscientiously object to some — but not all — late(r) term abortions when practicing in highly permissive jurisdictions. Unless they practice in one of the few jurisdictions that do not permit healthcare professionals to conscientiously object, it is certainly possible for those whose professional duties would ordinarily involve them in the provision of late(r) term abortion to opt out of doing so. Therefore, there is some concern that some — and perhaps a majority — of providers may well cease their involvement in provision if a more nuanced approach is not facilitated in the relevant jurisdictions. This would be likely to affect the availability of services. A more nuanced approach would, in effect, permit individual healthcare professionals to conscientiously object on what might be thought of as a "selective" basis. In short, they would be able to opt out of service provision in particular cases or, to anticipate the discussion presented in the following section, they would limit their involvement in service provision to cases that meet certain conditions.

[10] Clearly some would demur from this view. However, it seems safe to presume that those who consider early abortion ethically impermissible think similarly with regard to late(r) term abortion, indicating that the issue raised in this paper is of no concern. However else the phrase "selective conscientious objection" might be understood, it should be understood to mean that an undertaking is sometimes thought morally permissible and sometimes thought morally impermissible.

[11] Of course, how these devolved concerns should play out for the individuals involved will differ depending on how they are positioned. A pregnant person is positioned such that they are free to determine their own ethical perspective on abortion, both in general and in the particular case. The healthcare professional is positioned such that they may only take a general view and, on that basis, either provide the relevant service to their patients, or opt-out of doing so entirely. This essay arguably results from transferring this kind of thinking to abortion at late(r) gestational (st)ages.

[12] Dwyer et al have recently argued for this kind of approach. They do not consider the implications for conscientious objection as outlined here (4).

[13] It is worth pointing out that even for those that have established permissive legislation with regards to late(r) term abortion, this does not mean that the intervention is available 'on demand.' Extra-legal barriers often mean that only those who have clear medical reasons for seeking a termination at a late(r) stage in their pregnancy are positioned to access the intervention.

[14] There are a few exceptions and there is no established right to conscientiously object to the provision of abortion in Sweden, Finland, Bulgaria, the Czech Republic and Iceland (6).

[15] Termed 'convenient objection', this seems to occur despite such behaviour clearly being in conflict with the level of professionalism expected of healthcare providers (2).

Given that the legal restrictions put in place in jurisdictions like the UK can be taken to reflect the legitimacy of supposing late(r) term abortions require justification beyond the individual's decision to terminate their pregnancy, it seems reasonable to think some healthcare professionals might express a similar view. They might, for example, consider late(r) term abortion to only be permissible in certain circumstances, such as: where continued pregnancy presents a high risk of death or significant threat to health; or where a pregnancy results from rape or incest; or where a foetal diagnosis of fatal abnormalities or a life limiting disability has been established. Absent such criteria being met, healthcare professionals might appeal to the notion of conscientious objection and, in so doing, seek to "selectively" restrict their involvement in the provision of late(r) term abortion.

CONSCIENTIOUS OBJECTION IN THE CONTEXT LATE(R) TERM ABORTION

If it is the case that the ethical perspectives held by some healthcare professionals can be thought of as reflecting the way abortion law is currently drawn in jurisdictions like the UK then, when practicing in jurisdictions with highly permissive legislation, it is possible that they will encounter requests for late(r) term abortion that they consider morally wrong. It therefore seems probable that they will appeal to the notion of conscientious objection as, on the face of it, this will permit them to opt-out of being involved in these cases. However, healthcare professionals who conscientiously object to particular interventions are ordinarily expected to opt out of provision entirely. This expectation reflects certain presuppositions about the universal or absolute rejection of the undertaking in question on ethical grounds. In what follows, I will have more to say about this. However, for the time being it is sufficient to note that if healthcare professionals are to appeal to the notion of conscientious objection in order to opt out of providing some, but not other, abortions at late(r) stages of pregnancy then it would appear that they are seeking to engage in a *selective* or *individualised* form of conscientious objection (3,14,15).

What might be meant by terming specific claims to conscientiously object selective, individual or individualised is far from clear. There is a relatively limited (bioethical) literature on the notion, and it will not be possible to clarify matters entirely. Instead, a few comments must suffice. Cowley has recently suggested that because they are "focused on the patient, and on her reasons (or on her perceived lack of good reasons) for seeking the abortion" selective conscientious objections are "unpredictable" (3). This seems to suggest that healthcare professionals should be permitted to evaluate their patient's reasoning from a moral perspective and determine whether or not they are willing to provide an intervention on that basis. On the face of it this would seem to be a clear case of (moral) paternalism. Healthcare is a public service and, presuming it reflects an autonomous decision, lawful requests for clinically justified treatment, including abortion, should be fulfilled.[16] The fact that a patient may have a poor reason for their decision should not be considered reasonable motivation for conscientious objection, not least because making such judgements is not something that falls within the scope of professional practice.

Such a stance would seem to suggest that healthcare professionals should not be able to conscientiously object to some requests for late(r) term abortions and not others because doing so would seem to require a moral evaluation of the patient's reasons or reasoning. As presented by Cowley, selective conscientious objection would seem to be incompatible with professional standards and therefore impermissible. Nevertheless, we might consider if this is the only way to think about what is going on. There is a distinction between determining that an individual has a bad, or insufficiently good, reason for requesting the intervention, and considering abortion impermissible unless certain criteria are in place. Whilst the law may remain agnostic on the ethics of late(r) term abortion one can hardly expect the same of all healthcare professionals involved in its provision. As such the question of "selective" conscientious objection becomes a matter of a healthcare professional's moral framework vis-à-vis late(r) term abortion and, subsequently, whether it is permissible for them to configure their practice in accordance with it. In this view, selective conscientious objection is not a matter of judging individuals and their reasons but of holding an ethical position that is more nuanced than the position established in law.

If it is the case that healthcare professionals can conscientiously object to late(r) term abortion on this kind of basis, we should also consider if they might do similarly in the context of earlier term abortion, if only to fully understand why they should not be able to do so. In this context, my response concerns the aforementioned supposition that conscientious objection should be motivated by a moral position that is universal or absolute. However, it seems reasonably clear that many healthcare professionals who conscientiously object to abortion and therefore opt-out of service provision do not consider the procedure universally wrong. Few could consider terminating a pregnancy unjustified when it is the only way to preserve the life of the pregnant individual, and when the alternative is the death of both patient and foetus. Equally, few would reject abortion when continued pregnancy will result in a short life of suffering for the resulting infant or neonate.

Such eventualities are, of course, exceedingly rare and the majority of patients seeking an abortion at earlier stages of pregnancy are obviously not motivated by such reasons, knowledge of which only tends to become known in the late(r) stages of pregnancy. Such points indicate that there would be no purpose in permitting those positioned to provide abortion at earlier stages of pregnancy to establish rationales for (non-)provision. This contrasts with the provision of late(r) term abortion, where almost all patients are being offered a termination because continued pregnancy would present a threat to their life or health, or because they have been given some kind of foetal diagnosis.

[16] It is worth pointing out that whilst abortion might be recommended for clinical reasons, such as in cases where continued pregnancy poses serious risk to the patients' health, in the absence of such factors it is enough that the individual concerned has decided to end her pregnancy.

In the light of such discussion, we should recognise that requiring those who conscientiously object to abortion to opt out of service provision entirely does not result from the fact that they reject the intervention universally or that the idea of conscientious objection supposes that they do so. Rather, it is the result of more pragmatic concerns. In the context of the provision of abortions at earlier gestational stages it would simply be impractical to facilitate a more nuanced approach. Doing so would only delay patient access to the intervention and likely result in them being unnecessarily exposed to the personal moral judgements of those who, on the basis of their commitment to professionalism, are meant to avoid doing so.[17] Nevertheless, if healthcare professionals are to be permitted to conscientiously object to providing late(r) term abortions that are not justified by stipulated criteria, a number of questions remain to be considered, including: whether or not many of those involved in the provision of late(r) term abortion will seek to conscientiously object; the impact this might have on the availability of service to the relatively small number of individuals who seek the intervention and are not motivated by the standard criteria that commonly render the procedure lawful; and if there is a shift in the moral perspective that underpins claims to conscientious objection to late(r) as compared to earlier term abortion.

The first two of these questions are, quite obviously, empirical matters and it is difficult to offer much in the way of a response. It is arguably the case that even where provision is not subject to significant legal constraint, access to late(r) term abortion is commonly subject to a range of structural barriers, including an absence of clear (self) referral pathways. This is something that ought to change regardless of the issue at hand. It likely continues — or, at least, goes relatively unchallenged — precisely because very few women seek to terminate pregnancy at late(r) gestational stages without there being a clear clinical reason for them to do so. When such reasons exist, they will already be under the care of those who are able to provide a referral or who are themselves providers of the relevant service. Equally, it is also likely to be related to a certain degree of moral discomfort with abortion at late(r) gestational ages. It is not obvious what this might mean when it comes to how many providers of late(r) term abortion working in highly liberal jurisdictions will seek to conscientiously object.

The third point can be addressed more directly. On the face of it there would seem to be a morally relevant distinction between earlier and later term abortion, specifically the emergence and development of sentience in the foetus. The point at which this might occur is, of course, uncertain. Current thinking would suggest it likely arises around the 20th week of a pregnancy. However, not only is this a matter of some speculation, what foetal sentience might amount to from a phenomenological perspective before, after and at this point is also unclear. As such the degree of moral significance that might be thought to result is also unclear. Nevertheless, it is certainly evident that some consider it to be morally relevant and to lie at — if not clearly mark — the juncture between earlier and late(r) term abortion. It therefore seems reasonable to suppose that at least some would take the view that late(r) term abortions require justification of a sort that goes beyond the patient's desire not to be pregnant. Indeed, this position is arguably reflected in legislation that distinguishes between abortion at earlier and later gestational ages, where the former is permitted "on demand" but the latter requires certain criteria to be met if it is to be performed lawfully.

It would seem, then, that there is some basis for a nuanced or selective form of conscientious objection on the part of healthcare professionals involved in the provision of late(r) term abortion when situated within highly permissive jurisdictions. However, if this is to be put into practice, healthcare professionals should establish the parameters of their moral perspective before seeking accommodation for their views. This clearly implies that they must give full and proper consideration to circumstances under which they consider the provision of late(r) term abortion to be morally (im)permissible and reflect on how best to structure their practice in a manner consistent with their conclusions. Given the responsibilities involved in good medical practice, this is not something that healthcare professionals can do without reference to professional guidelines, their employers or their colleagues, both notional and specific. Indeed, this line of thinking quite clearly raises a host of practical and pragmatic issues when it comes to accommodating the various ethical positions that healthcare professionals might embrace. All those involved, including those who would seek to conscientiously object, have a responsibility to consider such matters and to determine a way forward that meets the needs of all those involved or (potentially) affected.

If it were not the case that very few women seek to have an abortion at late(r) stages of pregnancy, such concerns might be taken to mean that accommodating conscientious objections of this sort was simply impractical to the point of being unworkable. In my view such matters ought to be taken seriously. The conscientious objections of healthcare professionals should not be permitted to significantly affect service provision and so refusing to accommodate them remains an option.[18] However, as most will be of the kind permitted under legislation that has commonly been adopted, it is likely that the majority of cases will not be considered objectionable. Furthermore, as long as some healthcare professionals feel able to provide abortion at late(r) gestational stages without restriction, then it should be possible to ensure provision if efforts are made to ensure an appropriate institutional policy is put in place.

[17] For example, it is not appropriate for a patient seeking to terminate a pregnancy at an early stage to be subject to tests to establish whether they meet a potential provider's personal criteria. This may change were it the case that foetal genetic testing becomes available an early stage in pregnancy. A healthcare professional caring for pregnant women might take the view that early medical abortion must meet certain criteria if it is to be justified and try to establish a claim to conscientiously object. Whether such a claim can be substantiated would be a matter for debate along the lines set forth in this paper. Similarly, pragmatic consideration of the circumstances relating to the provision of care would be central to whether such a claim might be accommodated.

[18] If the result is that too few individuals are willing to practice in a particular field to the point where services are affected, then it may be that the legislation itself should be revisited. Normative structures — such as legislation, professional regulations, guidelines and governance processes more generally — are unavoidably political. If those affected by such structures find that they are unable to practice within its dictates, then it lacks a necessary degree of legitimacy and should likely be revisited. I made a similar point in my essay *Ought Conscientious Refusals to Implement Reverse Triage Decisions Be Accommodated?* (17).

Nevertheless, one might question if the need to make such arrangements counts against establishing legislation that adopts a highly permissive approach to late(r) term abortion. In the context of earlier term abortion and the kind of highly restrictive legislation that some American States have promulgated following the Supreme court's decision in *Dobbs v Jackson*, Shachar, Baruch and King have argued that it is the responsibility of legislators to recognise and clearly define circumstances in which provision is medically necessary and should therefore be legal (16). A similar point might be applied to late(r) term abortion. Whilst abstaining from establishing such criteria and devolving any moral concerns to the patient and those involved may be consistent with progressive feminist politics, the ensuing complications of the kind sketched in this paper may mean that some degree of regulation, in the form of legislative restrictions, is warranted.

CONCLUSION

This essay has argued that in jurisdictions that adopt a highly permissive approach to the regulation of late(r) term abortion there may be a case to be made for accepting selective or nuanced claims to conscientiously object. I have also pointed out that conscientious objection should not be permitted to obstruct — or significantly impede — service delivery, meaning that if conscientious objection is to be permitted, steps should be taken to ensure that patients are able to access lawful healthcare interventions as appropriate. Whether it is possible to address the practical issues that will arise in places where individuals wish to conscientiously object to some late(r) term abortions remains to be seen. One would hope that it is the case. However, it may not be, and it may therefore be that we should not establish a right to conscientiously object to late(r) term abortions in a selective or nuanced way. Alternatively, it may be that adopting a highly permissive approach to the legal regulation of abortion at late(r) gestational (st)ages is misguided.

Such questions directly result from a legislative approach that does not constrain late(r) term abortion, an intervention on which a range of moral perspectives might be adopted. This has the potential to place healthcare professionals involved in caring for pregnant patients in a morally complex position. Whilst healthcare professionals (or, perhaps more accurately, medical doctors) can refuse to provide interventions that they do not consider clinically justified without facing professional sanction, doing similarly on moral grounds means seeking to conscientiously object. If this is to be an option there is a need to ensure patients are professionally cared for, meaning that an individual's ability to conscientiously object relies on other healthcare professionals being willing to provide the relevant service, and on local arrangements being put in place to appropriately manage the delivery. Thus, healthcare providers — and, for that matter, all those who are involved in both the provision and broader organisation of services — will be placed in the unusual position of having to manage a complex moral situation rather than operate within established ethico-legal parameters.[19] One might consider this an unintended consequence of highly permissive approaches to legislation.

This issue was effectively, if implicitly, acknowledged in a recent essay arguing against the need for any abortion-specific legislation (4). There the somewhat naive or, perhaps, overly idealistic response to moral concerns about the provision of late(r) term abortion is to say that provision should occur "when the woman and her health care team decide it is necessary."[20] Since agreement may not always be forthcoming, unless what these authors mean by necessity is met by a patient who insists on ending her pregnancy regardless of her reasoning[21] — something that would undermine the idea that agreement is required — then this would seem to permit healthcare professionals to restrict provision on the basis of their moral perspective and, therefore, to sanction an inappropriate degree of (medical) paternalism. The fact that a government elects not to restrict an intervention as a matter of law does not equate to ethical approval, either in general or the specific case. However, to ethically sanction or refuse requests for such interventions is not something healthcare professionals should be either asked or permitted to do.

I have, of course, argued that it is permissible for healthcare professionals to do similarly and to provide or conscientiously object on that basis. It is also the case that patients considering a late(r) term abortion would do well to consider the moral dimension of the issue for themselves. Nevertheless, the fact that clinicians might configure their involvement in late(r) term abortion in accordance with their general moral views does not mean that it is permissible for them to constrain the moral choices of patients. Healthcare professionals should not be making moral judgements on a case-by-case basis. If no criteria are required to be met if late(r) term abortion is to be lawful, then the only thing of relevance is the patient's decision to end their pregnancy. As such, there is a need to ensure services can and will be provided, if and when such circumstances arise. If that cannot be done, then there may be a need to reconsider the adoption of a highly permissive approach to late(r) term abortion.

[19] It is arguably not uncommon for healthcare professionals to require professionals to manage moral concerns as part of clinical practice. However, this differs from the kind of management required to accommodate the conscientious objection.
[20] The naivety lies in thinking that there will never be a need to ensure provision when, contra their healthcare teams view, a patient persists in their decision to end their pregnancy (4).
[21] As previously noted, Kendal argues that this is the case (5).

POSTSCRIPT

It has long been on my mind to write a paper on the difficulties that might potentially arise if a highly permissive approach to abortion at any stage of pregnancy is established in law. However, the possibility that doing so might negatively affect the provision of late(r) term abortion — either in general or in the specific jurisdictions that have adopted this approach — has caused significant delay as I have tried to think through how best to do so. This paper can and should be taken as entailing the rejection of certain practices — such as Termination Review Committees — that have arguably resulted from the moral perspectives of those who are practicing in the context of highly permissive legislation not being given due consideration and being misdirected as a result (18).

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Barriers and Ethical Implications of the Ontario Ministry of Health and Long-Term Care Do Not Resuscitate Confirmation Form

Mohammad Jay[a*], Jessica Huynh[b*], Sandra Andreychuk[c], Haroon Yousuf[b]

Résumé

Contexte : La planification des objectifs de soins (ODS) implique que les prestataires de soins de santé discutent des préférences des patients en matière de santé, y compris des options d'état de code allant de « code complet » (réanimation cardio-pulmonaire [RCP] et intubation) à « ne pas réanimer » (NPR). En 2008, l'Ontario a introduit le formulaire de confirmation de non-réanimation (FC-NPR), qui permet aux premiers intervenants de ne pas pratiquer la RCP en présence d'un formulaire valide. Malgré les conversations de routine sur les ODS lors des admissions à l'hôpital, peu de médecins remplissent des FC-NPR pour guider les intervenants d'urgence de la communauté. **Objectif :** Nous avons cherché à identifier les taux d'achèvement et les obstacles perçus à l'achèvement des FC-NPR parmi les internistes généraux. **Méthodes :** Nous avons mené une enquête en ligne auprès d'internistes généraux de deux hôpitaux de Hamilton, suivie d'un groupe de discussion à l'aide d'un guide d'entretien semi-structuré. **Résultats :** Parmi les 14 répondants au sondage, seulement 16,7 % avaient rempli un FC-NPR, même s'ils connaissaient tous le formulaire. Les principaux obstacles étaient le manque de connaissances, l'accessibilité limitée et l'incertitude quant à la responsabilité. Les participants aux groupes de discussion ont exprimé des inquiétudes quant à la redondance des FC-NPR en milieu hospitalier, à la validité du formulaire en dehors des heures normales et aux implications médico-légales. **Conclusion :** Malgré une large connaissance des FC-NPR, les taux de remplissage restent faibles en raison d'obstacles systémiques, liés aux prestataires et d'ordre éthique. Ces résultats soulèvent des questions éthiques concernant l'autonomie des patients et les risques de préjudices indésirables associés aux mesures de réanimation. Les stratégies visant à relever ces défis comprennent une meilleure formation des prestataires, une délimitation plus claire des rôles et un soutien systémique à la planification des ODS. Améliorer le taux de remplissage des FC-NPR peut contribuer à respecter les souhaits des patients, en particulier dans les situations d'urgence communautaire, et ainsi à maintenir les normes éthiques en matière de soins de fin de vie.

Mots-clés

planification des objectifs de soins, ne pas réanimer, NPR, soins de fin de vie, formulaires de confirmation, autonomie du patient

Abstract

Background: Goals of care (GOC) planning involves healthcare providers (HCPs) discussing patients' health preferences, including code status options ranging from "full code" (cardiopulmonary resuscitation [CPR] and intubation) to "do not resuscitate (DNR)". In 2008, Ontario introduced the Do Not Resuscitate Confirmation Form (DNR-CF), which permits first responders to withhold CPR when a valid form is present. Despite routine GOC conversations during hospital admissions, few physicians complete DNR-CFs to guide community-based emergency responders. **Objective:** We aimed to identify the completion rates and perceived barriers to completing DNR-CFs among general internists. **Methods:** We conducted an online survey of general internists at two Hamilton hospitals, followed by a focus group using a semi-structured interview guide. **Results:** Among 14 survey respondents, only 16.7% had completed a DNR-CF, despite all being familiar with the form. Main barriers included knowledge gaps, limited accessibility and uncertainty about responsibility. Focus group participants expressed concerns about the redundancy of completing the DNR-CFs in inpatient setting, the form's validity overtime and medicolegal implications. **Conclusion:** Despite widespread familiarity with DNR-CFs, completion rates remain low due to systemic, provider-related, and ethical barriers. These findings raise ethical concerns about patient autonomy and potential for unwanted harms associated with resuscitative efforts. Strategies to address these challenges include improved provider education, clearer delineation of roles, and systemic support for GOC planning. Enhancing the completion of DNR-CFs can help ensure that patient wishes are respected, particularly in community emergencies, thereby upholding ethical standards in end-of-life care.

Keywords

goals of care planning, do not resuscitate, DNR, end-of-life care, confirmation forms, patient autonomy

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INTRODUCTION

Recent medical practice, research, and technology advances have enhanced diagnostic and treatment capabilities. As a result, people are living longer, but at the cost of increased burden of chronic illness and reduced quality of life (1-3). Similarly, the experience of dying has changed recently: where death was once often the result of an acute event, it has increasingly become a chronic process. Many patients with chronic disease suffer recurrent complications of their disease, leading to progressive functional and cognitive decline (4). Consequently, more patients now die in institutional settings, such as hospitals or long-

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term care facilities, despite most expressing a preference to die at home. In Ontario, 2023 data showed that 55.3% of deaths occurred in hospitals, while 43.3% occurred in non-hospital settings, including long-term care homes, retirement homes, private residences, and other facilities (5). Given the complexity of their conditions and evolving prognoses, clear and ongoing communication by healthcare providers (HCP) is crucial (6-8).

Advance care planning (ACP) is a proactive and ongoing process where HCPs explore a capable patient's values and healthcare priorities in light of their health condition (9). In contrast, goals of care (GOC) discussions build upon ACP by translating these wishes into more specific clinical decisions and may occur with either a capable patient or their designated substitute decision-maker (SDM) if the patient is incapable (10). A critical subset of these discussions involves documenting patients' expressed capable wishes, which guide future healthcare decisions (1). Patients are encouraged to designate an SDM who can make healthcare decisions on their behalf in accordance with their most recently expressed wishes. Code status discussions — such as preferences around cardiopulmonary resuscitation (CPR) and intubation — are one concrete outcome of GOC discussions (10-12). These discussions may result in a decision for "full code" (chest compressions, defibrillation, intubation, and ventilation) or "do not resuscitate" (DNR), or something in between.

ACP is associated with increased patient satisfaction, enhanced patient autonomy and more efficient use of healthcare resources by reducing interventions that do not align with a patient's expressed wishes. Despite these benefits, only 37-62% of oncology patients engaged in ACP conversations (13). Similarly, only 47.9% of hospitalized elderly patients at high risk of death within six months engage in ACP, leading to documented wishes. Of these patients, 76.3% had thought about death before hospitalization, but only 11.9% expressed a desire for life-prolonging measures. Furthermore, only 30% of documented wishes aligned with patients' previously expressed desires (8,14,15).

On February 1, 2008, the Ontario Ministry of Health and Long-Term Care (MOHLTC) introduced the DNR Confirmation Form (DNR-CF; Appendix A) (16,17). This form was created to provide clear direction to first responders, specifically paramedics and firefighters, regarding whether to initiate resuscitative efforts in prehospital emergency settings. When a valid DNR-CF is present and signed by an authorized healthcare provider, paramedics and firefighters are instructed not to initiate basic or advanced CPR, including chest compressions, defibrillation, artificial ventilation, intubation, or the administration of resuscitation drugs (17,18). In such cases, paramedics and firefighters may provide comfort care measures, such as oxygen or medications for symptom relief, in accordance with their scope of practice (18). Before the implementation of the DNR-CF, first responders were obligated to perform CPR unless the patient met very narrow criteria for obvious death. As the interventions listed on the DNR-CF reflect the standard resuscitative actions carried out by paramedics and firefighters, signed DNR-CF serve as a directive not to initiate these procedures (18,19). The DNR-CF is bilingual and can be completed by a physician (MD), registered nurse (RN), registered nurse — extended class (RN EC), or registered practical nurse (RPN) (20).

In Canada, approaches to pre-hospital DNR documentation vary across jurisdictions. While Ontario uses a standalone DNR-CF for paramedics and firefighters, other provinces integrate resuscitation preferences within broader medical orders. For example, Alberta employs the Goals of Care Designation (GCD), a standardized medical order that categorizes treatment preferences into levels of care, rather than a binary DNR decision (21,22). British Columbia and Nova Scotia use Medical Orders for Scope of Treatment (MOST), which function similarly by incorporating resuscitation preferences into a patient's overall care plan (23-25). Saskatchewan has developed the Saskatchewan Medical Orders for Scope of Treatment (SMOST), which also incorporates a patient's goals and values into pre-hospital medical decision-making (25). These documents are generally accessible to paramedics and firefighters, ensuring that resuscitation efforts align with patients' wishes in out-of-hospital settings.

A study of 96 patients presenting to the emergency department showed that only seven patients were aware of the DNR-CF, and only one patient had completed the DNR-CF. Barriers to completion included a lack of awareness and discomfort with end-of-life care discussions (16). It is assumed that most DNR-CFs are completed by primary care practitioners (PCPs). Although PCPs are essential in advance care planning, discussions of goals of care (GOC) occur frequently during inpatient admissions. Particularly for patients with chronic diseases requiring recurrent hospitalizations, the illness trajectory may lead to a different outcome from those discussed with PCPs. While many studies have explored the nuances of GOC discussions, limited literature exists on the effectiveness of the inpatient-to-outpatient translation of this communication (26-30). To date, no study has examined the DNR-CF completion rates by HCPs and the perceived barriers they face in completing these forms. Here, we aimed to identify the awareness of, rates, and perceived barriers to completing the DNR-CFs among inpatient general internists.

METHODS

Setting and context

This study was conducted across two adult acute care hospitals — Hamilton General Hospital (HGH) and Juravinski Hospital (JH) — within the Hamilton Health Sciences (HHS) network in Hamilton, Ontario, Canada. These hospitals serve the population in the south-central region of Ontario and act as a major referral centre for other areas in Ontario. The JH is adjacent to the Juravinski Cancer Centre, which provides comprehensive cancer care to patients in Hamilton.

Study Population

The participants included general internists at HGH and JH in either inpatient or mixed inpatient-outpatient settings.

Ethical Consideration

This study was designed as a baseline evaluation to inform a larger quality improvement initiative. As such, our institutional research ethics board (REB) waived a full review. All participant data were anonymized, interview transcripts were de-identified, and interviewers were assigned numerical codes.

Study Design and Outcomes

A mixed-methods design was employed, comprising an online survey followed by a qualitative focus group. The primary quantitative outcomes were: 1) the proportion of general internists who had previously completed a DNR-CF, and 2) the frequency and types of healthcare provider-related and patient-related barriers identified in the survey. The qualitative outcomes included themes related to physicians' perceptions of the DNR-CF's utility, barriers to its completion in inpatient settings, and suggestions for improving uptake among hospital-based providers.

Survey Phase

Online surveys were distributed to 25 general internists. This survey collected demographic information (e.g., age, sex, years in practice, and practice location), along with participants' awareness of DNR-CF, frequency of form completion, and perceived barriers to its use (Appendix B).

Focus Group Phase

A focus group was conducted with three general internists who expressed interest following the completion of the survey. A qualitative descriptive approach was used to explore participants' experiences and perspectives regarding the DNR-CF. A semi-structured interview guide (Appendix C), informed by relevant literature and our objectives, was developed and pilot-tested internally for robustness. The 60-minute session was conducted via Zoom and moderated by a member of the research team trained in qualitative methods. The session was audio-recorded, transcribed (Appendix D) and de-identified by the focus group facilitator (Appendix E). The audio recording and the transcription were securely saved on a password-encrypted hospital computer, and audio recordings were deleted following transcription.

Quantitative Analysis

Descriptive statistics from the survey were analyzed using Google Forms with the Free Spanning Stats. Results were summarized as proportions and frequencies.

Qualitative Analysis

Braun and Clarke's six-step framework was used to guide the thematic analysis (31). Two independent researchers (MJ and JH) read through the transcript several times to become familiar with the content, then worked separately to develop initial descriptive codes. They met regularly to compare their interpretations, refining the codes through discussion and reaching consensus along the way. Codes were then grouped into overarching themes and subthemes. Investigator triangulation, through the use of two coders, enhanced the credibility of the analysis. Discrepancies were resolved by consensus, and a finalized coding framework was applied consistently across the transcript.

Ensuring Trustworthiness

Several strategies were used to ensure that the findings were credible, dependable, confirmable, and transferable. Credibility was established through independent coding by two independent assessors, with discrepancies addressed through discussion to reach consensus. An audit trail was maintained throughout the process to keep track of how codes and themes evolved, which helped ensure dependability. To support confirmability, direct participant quotes were included in the Results section to demonstrate that interpretations were grounded in the data. Finally, detailed information was provided regarding the study setting and participant characteristics allowing readers to assess how well our findings apply to other clinical scenarios.

RESULTS

Survey

A total of 14 general internists completed the surveys. Most participants (71%) practiced both inpatient and outpatient, whereas 29% exclusively practiced inpatient (Table 1). Although all responders were familiar with DNR-CFs, only 16.7% completed a DNR-CF on discharge. None of the participants filled out a DNR-CF during the month preceding the survey. The most frequently cited HCP-related barriers were the lack of awareness and availability of the forms (Figure 1). In contrast, the most common patient-related barriers, as perceived by physicians, included lack of access to SDM and language barriers (Figure 2). As patients were not study participants, these barriers reflect physician perceptions rather than direct patient-reported experiences.

Table 1. Demographic information

Characteristic	Participant
Age	
20-29	14.3%
30-39	42.9%
40-49	35.7%
50-59	7.1%
Sex	
Male	42.9%
Female	57.1%
Years in practice	
0-5	38.5%
6-10	38.5%
11-20	15.4%
>20	7.7%
Current Location of Practice	
HGH	38.5%
JH	61.5%
Practice Setting	
Inpatient	28.6%
Both inpatient and outpatient	71.4%

Figure 1. HCP-related barriers to completing DNR-CF identified in the survey

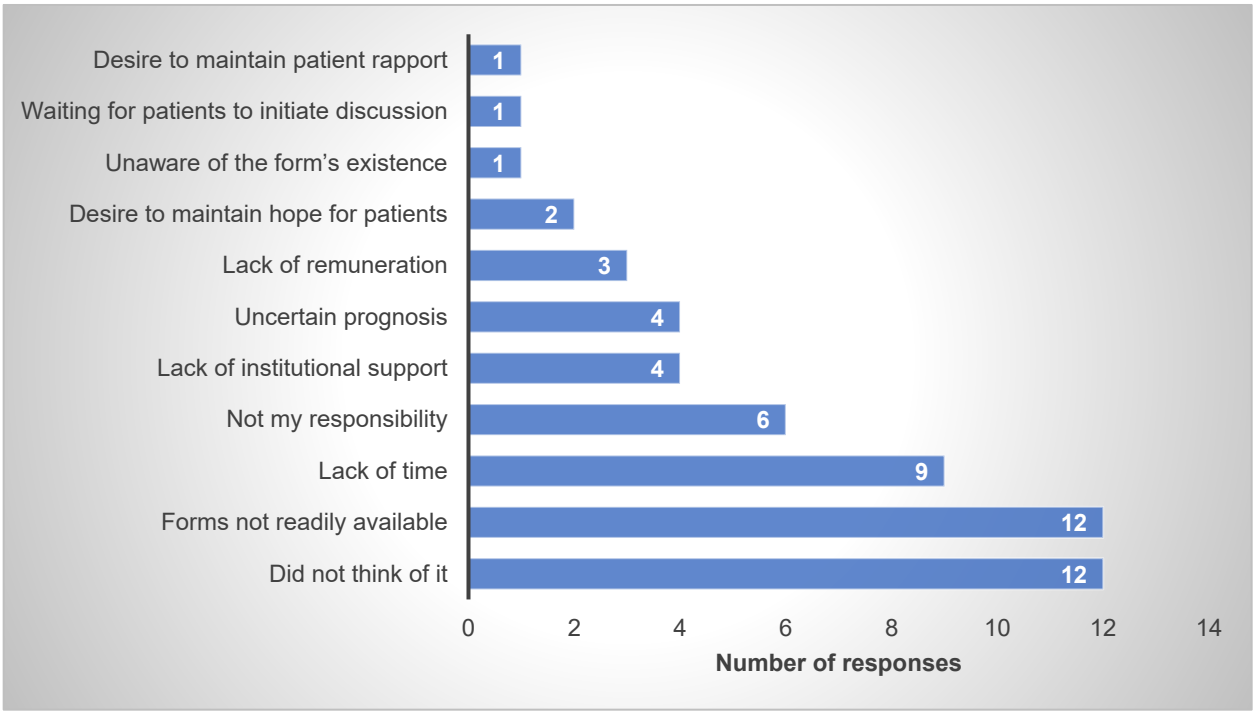
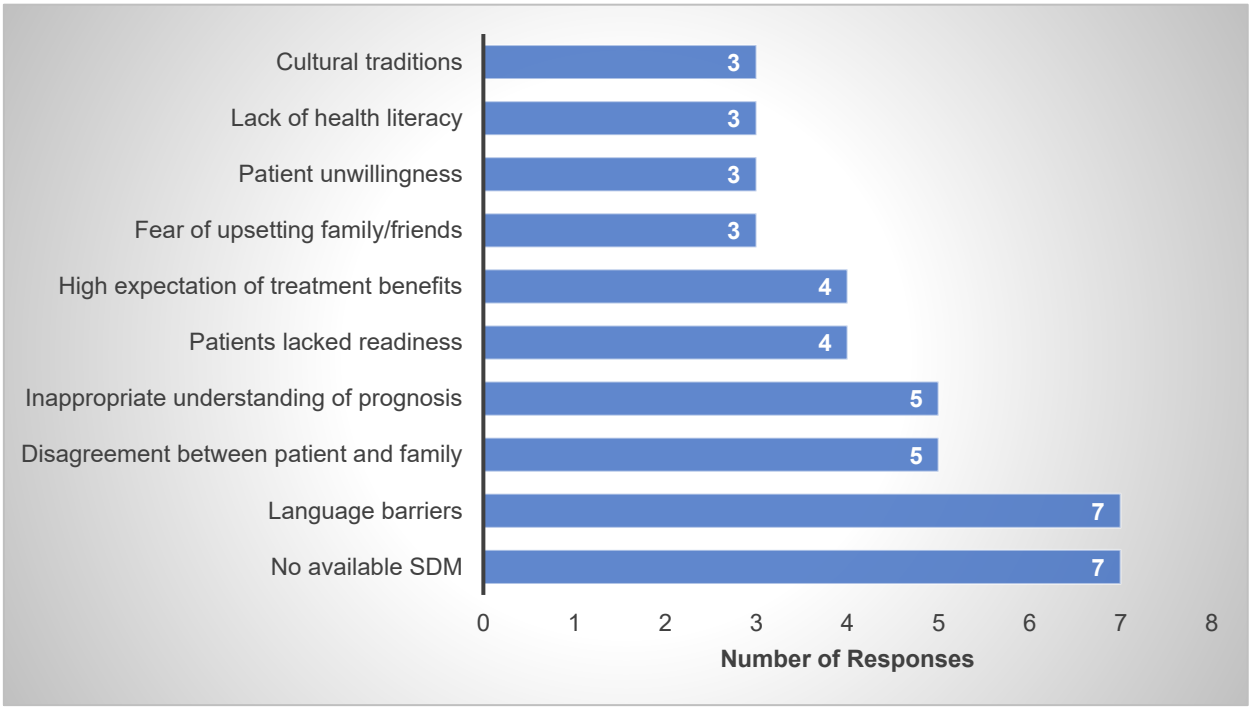


Figure 2. Patient-related barriers to completing DNR-CF identified in survey as perceived by physicians



Focus Group

Three general internists participated in the focus group. Four main themes were identified from the discussion: general, benefits, barriers, and suggestions.

General

All participants assumed these forms were completed solely in the community setting, usually triggered by a new nursing home or hospice admission. None of the participants have considered revisiting GOC conversations on discharge to enable the completion of DNR-CFs. They acknowledged the infrequent completion of the forms in the inpatient setting, with one participant saying: "*…I have never seen anyone filling out this form in a hospital*" and "*I thought the forms needed to be completed in the community.*"

Benefits

The General Internists agreed on the benefits of the DNR-CF when caring for an incapable patient whose SDMs are unavailable. However, it is only helpful when the patient does not want any form of resuscitation. It becomes challenging when patients may wish for some, but not all, of the treatments outlined on the form.

Barriers

We identified three key themes for HCP-related barriers to filling out DNR-CF forms:

1. Knowledge gap: Physicians in the focus group stated they "did not think of it." In addition, focus group physicians felt hesitant to complete the forms as they did not understand the medico-legal implications of completing a DNR-CF.
2. Accessibility: physicians stated that "forms are not readily accessible," and they were not sure if it was kept on wards.
3. Outside the scope of inpatient physician: a physician in the focus group commented that completing DNR-CFs after GOC planning was "not my responsibility."

In addition, physicians did not feel that the forms were reliable and that there was inherent redundancy in filling out the forms. The key themes we identified as patient-related barriers to having DNR-CF completed included:

1. Systemic barriers: this was most commonly identified as "language barriers."
2. Lack of social support: physicians mentioned that patients who were unable to make GOC decisions often had "no available SDM," posing a medico-legal challenge with completing the DNR-CFs.

The focus group participants reiterated some of the barriers addressed in the survey, such as lack of awareness of using these forms in the inpatient setting, form availability, limited time, and insufficient remuneration.

One participant stated:

> "*I try to find out how to get access to this form, and I couldn't. You cannot just download it. You have to order it because it has a serial number. You can't just give your CPSO number. You have to have an official letterhead or whatever to order this form, so I think it is really complicated.*"

The discussion also focused on the role of inpatient internists in addressing GOC conversations and completing the DNR-CFs. The participants discussed that for those patients requiring recurrent admissions with declining health status, inpatient general internists are in an excellent position to complete the DNR-CFs. Internists may offer fresh perspectives on patients with recurrent admissions, particularly when specialists may be too focused on disease treatment or cure. However, for patients with complex comorbidities, participants felt that relevant specialists best addressed GOC discussions. Similarly, some argued that PCPs are better positioned to have these conversations, given their longitudinal relationship with patients. Additionally, one physician did not believe that the inpatient environment was the right time to fill out the forms.

> "*The patient is not in a stable point of health where the discussion should be best held. If these discussions were to be held, it would be after they were stable.*"

Additionally, they expressed concerns about the redundancy created by completing the DNR-CF, particularly if the code status is already documented on the electronic medical record (EMR). Additionally, nursing homes and hospices are already required to have them filled out.

Some questioned the validity of the DNR-CFs. Providers feared that patients may face harm if the forms did not reflect current wishes. Code statuses are fluid, and reassessment with the patient and their SDMs must be possible. Furthermore, initial GOC conversations may not be comprehensive enough (i.e., providers did not address all aspects of resuscitation in their code status discussions with patients), making it hard to trust the authenticity of these forms.

> "*When I have that form, I don't trust the form to be comprehensive enough to provide the care that is required to the patient at the time*."

Finally, questions regarding the legally binding status of the forms were raised and considered a barrier to their completion. Table 2 provides a summary of the themes identified in the focus group in relation to the barriers.

Table 2. Focus group subthemes in relation to barriers in completing the DNR-CF

Barriers
1) Similar to survey/general
2) Responsibility
3) Redundancy
4) Validity
5) Medicolegal

Suggestions

The participants also suggested strategies to improve the completion rates of the forms as an inpatient. These included dedicating more resources and financial incentives. One physician suggested introducing these forms in palliative care workshops to raise awareness. Lastly, participants believe this form is not helpful for every admitted patient. They suggested the publication of a DNR-CF policy that identifies a specific demographic or set of patient criteria for whom these forms could be most beneficial (e.g., a patient suffering from the mid to end stages of their chronic illness rather than a patient admitted for a self-limited diagnosis).

DISCUSSION

Overview of Key Findings

Our results demonstrate the low participation rate of inpatient HCPs in completing DNR-CFs at HHS and highlight specific barriers to their completion. These barriers span various domains, including personal and professional issues for HCPs, challenges with patients and SDMs, institutional policies, environmental factors, and the EMR limitations. Existing literature shows low awareness and completion rates of DNR-CFs among patients (16). Our study is unique in examining these trends from the perspective of inpatient HCPs. Combined with existing literature, our results confirm low awareness and completion rates of DNR-CFs among both providers and patients.

Clarifying Roles and Responsibilities

An important theme from the focus group was the uncertainty around who is responsible for completing the DNR-CF. While PCPs are generally assumed to complete the form due to their long-term relationships with patients, participants argued that subspecialists and inpatient providers also have important roles, especially when managing complex, chronically ill patients.

Although GOC discussions often occur in outpatient settings, these conversations should also routinely happen during hospital admissions, especially as more patients face recurrent admissions due to chronic disease complications. In these situations, internists are uniquely positioned to revisit GOC discussions during hospitalization, as admissions could indicate a change in illness trajectory. Close collaboration between general internists, PCPs, and subspecialists is paramount to ensure these forms are completed at optimal times and with adequate context.

Misconceptions About Redundancy

Some focus group participants questioned the need to complete DNR-CFs in inpatient settings where code status is already documented in the EMR. However, it is important to reinforce that these forms are primarily intended to guide first responders during community emergencies. To avoid confusion, the DNR-CF should be limited to a binary directive for or against CPR and intubation, rather than including broader ACP preferences, such as ICU admission and non-invasive ventilation.

Timing and Validity of the DNR-CF

Concerns were raised about the timing of DNR-CFs and whether these forms accurately reflect current patient wishes. Participants emphasized that comprehensive serious illness conversations must proceed completion of the form, ensuring that patients and their SDM are fully informed. In an inpatient context, the optimal time to complete a DNR-CF may be after a serious illness conversation between the provider, the patient, and their family, ensuring they fully understand their prognosis and disease trajectory. Internists can play a role in reconfirming code status at discharge and facilitating the appropriate completion of the DNR-CF.

Focus group participants also questioned the legal standing of the DNR-CF. While it is binding for paramedics and firefighters under Ontario's Basic Life Support Patient Care Standards and their standard operating procedure, other HCPs are bound by the Health Care Consent Act (HCCA) (32,33). Although section 5 of the HCCA describes that patient wishes can be expressed in any written or oral form, it also describes that "Later wishes expressed while capable prevail over earlier wishes" (34). The Ontario Ministry of Health and Long-Term Care states that HCPs who follow the DNR-CF "do so at their own risk" (32). Therefore, while the DNR-CF can provide guidance, HCPs should ideally verify current wishes with the SDM.

Addressing Barriers to GOC and DNR-CF Completion

Barriers to GOC discussions are well-documented in the literature, including patient's difficulty accepting poor prognosis, misconception about life-sustaining treatments and family disagreements (35-37). Clinician-related barriers such as time constraints, lack of long-term relationship with patients, inability to reach the SDM, insufficient institutional support, and inadequate training are also common. An important systemic-related factor is absence of an appropriate confidential space for discussions (37-39). Addressing these barriers is crucial to enhancing DNR-CF completion rates.

Educational Opportunities

Our focus group also revealed a clear need for improved education around the DNR-CF and the processes related to its completion. Participants expressed uncertainty about when and how to complete the form, its legal implications, and where to access it. These insights suggest that an educational intervention could be a valuable next step. For example, a brief targeted education session offered shortly after focus group participation — when the topic is top of mind — may be a practical and timely approach to improving awareness and confidence. As part of future quality improvement (QI) efforts, we plan to integrate such an intervention into subsequent phases of this project. This may serve as a foundational step toward shifting the culture surrounding end-of-life planning and enhancing the appropriate use of DNR-CFs in inpatient settings.

Strategies to Improve Completion Rates

Low DNR-CF completion despite participation in GOC education suggests a need for multi-pronged strategies. These may include improving form accessibility, empowering allied HCPs to complete them, defining patient criteria for form eligibility, and embedding them in discharge checklists. Completing the form upon admission and providing it at discharge could reduce redundancy and increase uptake. Financial incentives may also help increase completion rates. Importantly, increasing the frequency and quality of ACP discussions is a foundational step toward improving DNR-CF completion. The form should represent the final stage of a broader, meaningful ACP process, in which capable patients are given the opportunity to reflect on and communicate their preferences. If ACP conversations are initiated early and routinely integrated into both inpatient and outpatient care, DNR-CF completion may follow naturally. A holistic, system-level approach that prioritizes proactive, and structured ACP discussions will help ensure that patient preferences are explored, clearly documented, and effectively guide future care.

ETHICAL CONSIDERATIONS

There are several ethical implications associated with DNR-CF completion. First, while these forms are crucial for respecting patient autonomy, it is essential to recognize that patients may not fully understand or be certain of their wishes regarding DNR status until they are confronted with the reality of their condition, such as impending death. Additionally, an existing DNR form that is not updated may no longer reflect the patient's current wishes, undermining autonomy. This highlights the need for

ongoing opportunities to revisit code status discussions and update DNR-CFs in inpatient and outpatient settings to reflect the patient's current wishes accurately.

Second, CPR and intubation may carry significant risks, including physical injuries, like rib fractures, and potential psychological harm from prolonged suffering or diminished quality of life (15). Administering aggressive interventions to patients whose preferences have not been clearly established can lead to distress for both patients and their families, compromise dignity at the end of life, and contribute to moral distress among healthcare providers who are uncertain whether the care is wanted (40,41). Providing treatments that conflict with a patient's values can result in unnecessary suffering and erode trust in the healthcare system (42). In addition, such interventions can lead to inefficient use of healthcare resources (43). It is thus essential that HCPs conduct frequent code status discussions to clarify these risks so that patients and caregivers develop a deeper understanding of the implications of their decisions. By completing DNR-CFs through comprehensive discussions, healthcare providers can help prevent unwanted harms, uphold patient-centred care and enhance informed consent.

Third, PCPs offer continuity of care, often have deeper rapport, and are more familiar with their patients, which provides an opportunity for better-informed consent regarding DNR status. However, the drawback is that PCPs may not be available when patients are acutely ill and facing potential mortality, a time when decisions may differ. On the other hand, hospital physicians have specialized knowledge and access to the immediate clinical context, supported by interdisciplinary teams and consulting specialists like palliative care teams. Yet, they face time constraints and often lack the long-term relationships that PCPs have with patients. Finally, providing care that does not align with a patient's values and preferences is not only ethically concerning but also represents an inefficient allocation of healthcare resources (42,43).

LIMITATIONS

This study has several limitations. First, the small number of focus group participants limited thematic saturation. While individual instead of group interviews may have offered a broader range of perspectives, the focus group approach encouraged consensus-building through interactive discussion, which is valuable in quality improvement projects. Additionally, group settings can shape the discussions, as they may encourage consensus and limit expression of opposing and diverse views. Nonetheless, given that our study was a QI initiative aimed at identifying key barriers, achieving full thematic saturation was not a priority, and our findings still provide important insights. Future studies with larger sample size and individual interviews can improve the generalizability of our results.

Additionally, interpretation of survey responses may have varied across participants. For instance, some respondents who selected "did not think of it" as a barrier may still have considered or completed a DNR-CF in other contexts or may have selected additional barriers based on hypothetical scenarios rather than direct experience. There may also have been variation in how respondents interpreted "did not think of it" — for example, forgetting in the moment versus never having considered the form at all. The potential for varied interpretations of questions is a common limitation in self-reported survey data and reinforces the importance of careful interpretation of these responses.

Although the DNR-CF can be completed by various healthcare professionals, including registered nurses (RNs), nurse practitioners (RN-ECs), and registered practical nurses (RPNs). Our study focused predominantly on general internists as our primary interest was to explore the unique barriers faced in DNR-CF completion within inpatient settings where general internists often lead GOC discussions. However, this narrower approach to selecting HCPs may have limited the perspectives captured and overlooked barriers experienced by other providers who are also authorized to complete the forms. Future studies should include a larger range of HCPs to gain a broader understanding of the facilitators and barriers related to DNR-CF completion.

CONCLUSION AND FUTURE DIRECTIONS

To address the issues identified in this study, it is essential to provide more opportunities for GOC discussions in both inpatient and outpatient settings, supported by reminders or strategies to prompt these conversations. Our findings lay the groundwork for future quality improvement studies aimed at implementing appropriate interventions to increase DNR-CF completion rates by inpatient HCPs. Future studies should explore DNR-CF completion across a broader range of inpatient settings, such as oncology and palliative care, and evaluate the role of allied healthcare professionals, in supporting form completion. Integrating structured ACP discussions into routine care — alongside improved provider education, clearer delineation of responsibilities, and institutional support — may help overcome identified barriers and ultimately improve the consistency and quality of end-of-life planning across the continuum of care.

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APPENDIX A

Ontario Ministry of Health and Long-Term Care

Office of the Fire Marshal

Serial Number _____

Do Not Resuscitate Confirmation Form

To Direct the Practice of Paramedics and Firefighters after February 1, 2008

Confidential when completed

When this form is signed by a physician (M.D.), registered nurse (R.N.), registered nurse in the extended class (R.N. (EC)) or registered practical nurse (R.P.N.), a paramedic or firefighter **will not** initiate basic or advanced cardiopulmonary resuscitation (CPR) (see point #1) and **will** provide necessary comfort measures (see point #2) to the patient named below:

Patient's name – *please print clearly*	
Surname	Given Name

1. **"Do Not Resuscitate"** means that the paramedic (according to scope of practice) or firefighter (according to skill level) **will not** initiate basic or advanced cardiopulmonary resuscitation (CPR) such as:
   - Chest compression;
   - Defibrillation;
   - Artificial ventilation;
   - Insertion of an oropharyngeal or nasopharyngeal airway;
   - Endotracheal intubation;
   - Transcutaneous pacing;
   - Advanced resuscitation drugs such as, but not limited to, vasopressors, antiarrhythmic agents and opioid antagonists.
2. For the purposes of providing comfort (palliative) care, the paramedic (according to scope of practice) or firefighter (according to skill level) **will** provide interventions or therapies considered necessary to provide comfort or alleviate pain. These include but are not limited to the provision of oropharyngeal suctioning, oxygen, nitroglycerin, salbutamol, glucagon, epinephrine for anaphylaxis, morphine (or other opioid analgesic), ASA or benzodiazepines.

The signature below confirms with respect to the above-named patient, that the following condition (check one ☑) has been met and documented in the patient's health record.

☐ A current plan of treatment exists that reflects the patient's expressed wish when capable, or consent of the substitute decision-maker when the patient is incapable, that CPR not be included in the patient's plan of treatment.

☐ The physician's current opinion is that CPR will almost certainly not benefit the patient and is not part of the plan of treatment, and the physician has discussed this with the capable patient, or the substitute decision-maker when the patient is incapable.

Check one ☑ of the following:

☐ M.D. ☐ R.N. ☐ R.N. (EC) ☐ R.P.N.

Print name in full	
Surname	Given Name
Signature	Date (yyyy/mm/dd)

- Each form has a unique serial number.
- Use of photocopies is permitted only after this form has been fully completed.

4519-45 (08/01) 7530-5678

Ontario Ministère de la Santé et des Soins de longue durée

Bureau du commissaire des incendies

Numéro de série _____

Formulaire de confirmation d'ordonnance de ne pas réanimer

Pour guider l'intervention des paramédics et des pompiers après le 1 février, 2008

Confidentiel une fois rempli

Lorsque ce formulaire est signé par un médecin (M.D.), un infirmier autorisé (I.A.), un infirmier autorisé de la catégorie spécialisée (I.A. (cat. spéc.)) ou un infirmier auxiliaire autorisé (I.A.A.), un paramédic ou un pompier **n'entreprendra pas** de réanimation cardiorespiratoire (RCR) de base ou avancée (voir le point 1) et **prendra** les mesures nécessaires pour assurer le confort (voir le point 2) du patient désigné ci-dessous :

Nom du patient – *Veuillez écrire lisiblement*	
Nom de famille	Prénom

1. « **Ordonnance de ne pas réanimer** » signifie que paramédic (conformément à l'exercice de la profession) ou le pompier (conformément à son niveau de compétence) **n'entreprendra pas** de réanimation cardiorespiratoire (RCR) de base ou avancée, telle que :
   - les compressions thoraciques;
   - la défibrillation;
   - la ventilation artificielle;
   - l'insertion d'une canule oropharyngée ou nasopharyngée;
   - l'intubation endotrachéale;
   - la stimulation transcutanée;
   - l'administration de médicaments d'urgences de réanimation comme, entre autres, des vasopresseurs, des antiarythmiques et des antagonistes opioïdes.
2. Afin d'assurer le confort du patient (soins palliatifs), paramédic (conformément à l'exercice de la profession) ou le pompier (conformément à son niveau de compétence) **effectuera** les interventions ou les thérapies jugées nécessaires pour assurer le confort ou alléger la douleur. Ces mesures incluent, sans s'y limiter, l'aspiration oropharyngée; l'administration d'oxygène, de nitroglycérine, de salbutamol, de glucagon, d'épinéphrine pour l'anaphylaxie, de morphine (ou d'autres analgésiques opioïdes), d'ASA ou de benzodiazépines.

La signature ci-dessous confirme que la condition suivante (cochez la case appropriée ☑) est remplie et documentée dans le dossier médical du patient désigné ci-dessus.

☐ Il existe un plan de traitement qui tient compte du désir exprimé par le patient (s'il est capable) ou du consentement du mandataire (si le patient est incapable) de ne pas inclure la RCR dans le plan de traitement du patient.

☐ À l'heure actuelle, le médecin estime que le patient ne bénéficiera presque certainement pas de la RCR. La RCR ne fait pas partie du plan de traitement, et le médecin a eu un entretien à ce sujet avec le patient capable ou avec son mandataire si le patient est incapable.

Cochez une ☑ des désignations professionnelles suivantes :

☐ M.D. ☐ I.A. ☐ I.A. (cat. spéc.) ☐ I.A.A.

Nom complet en lettres moulées	
Nom de famille	Prénom
Signature	Date (aaaa/mm/jj)

- Chaque formulaire possède un numéro de série unique.
- Il est permis d'utiliser des photocopies uniquement lorsque ce formulaire a été dûment rempli.

4519-45 (08/10) 7530-5678

APPENDIX B

Survey Instrument – Ontario's MOHLTC DNR Confirmation Form: From Inpatient to Outpatient Care
We are conducting a study on Do Not Resuscitate (DNR) Confirmation Forms. Our objective is to understand whether DNR Confirmation Forms are a routine component of clinical practice.

We invite you to participate in this study. Part 1 involves a brief survey, and Part 2 is an optional focus group. Participation is voluntary. You may leave any question blank if you prefer not to answer. All information will be kept confidential.
This survey will take approximately 5–10 minutes to complete. By proceeding with the questionnaire, you are providing consent for your responses to be included in our analysis.

Section 1: Demographics

1. **Age**
   ☐ 20–29 ☐ 30–39 ☐ 40–49 ☐ 50–59 ☐ 60+

2. **Gender**
   ☐ Female ☐ Male ☐ Prefer not to say ☐ Other: _____

3. **Profession**
   ☐ Physician (MD) ☐ Social Worker (SW) ☐ Registered Nurse (RN)
   ☐ RN – Extended Class (RN-EC) ☐ Registered Practical Nurse (RPN)
   ☐ Nurse Practitioner (NP) ☐ Other: _____

4. **Medical Specialty** (if applicable): _____

5. **Years in Practice**
   ☐ 0–5 ☐ 6–10 ☐ 11–20 ☐ >20

6. **Current Location of Practice**: _____

7. **Practice Setting**
   ☐ Inpatient ☐ Outpatient ☐ Both

Section 2: Background
On February 1, 2008, the Ontario Ministry of Health and Long-Term Care (MOHLTC) introduced a new DNR Standard. This change allowed paramedics and firefighters to honour patients' previously expressed wishes using the DNR Confirmation Form (DNR-CF). This bilingual form may be completed by an MD, RN, RN-EC, or RPN, and requires a 7-digit serial number for authenticity. A DNR-CF may be completed after obtaining consent from the patient or their substitute decision-maker (SDM).

Section 3: Awareness and Experience

8. Are you aware of the existence of the DNR-C form?
   ☐ Yes ☐ No

9. Have you seen a DNR-C form used in practice?
   ☐ Yes ☐ No

10. Have you ever completed a DNR-C form?
    ☐ Yes ☐ No

11. Have you completed a DNR-C form during an **inpatient** admission?
    ☐ Yes ☐ No

12. In the last 4 weeks of **inpatient** work involving direct patient care, how many DNR-C forms have you completed?
    ☐ 0 ☐ 1–5 ☐ 6–10 ☐ >10

13. Have you completed a DNR-C form during an **outpatient** encounter?
    ☐ Yes ☐ No

14. In the last 4 weeks of **outpatient** work involving direct patient care, how many DNR-C forms have you completed?
    ☐ 0 ☐ 1–5 ☐ 6–10 ☐ >10

Section 4: Barriers to Completion

A. Healthcare Professional–Related Barriers

Please indicate whether the following factors have affected your completion of DNR-C forms.

Options: ☐ Yes ☐ No ☐ Not Applicable

- Didn't think of it
- Discomfort with the topic
- Lack of training or confidence
- Lack of institutional support
- Lack of remuneration
- Lack of time
- Forms not readily available
- Unaware of the form's existence
- Waiting for patient to initiate discussion
- Desire to maintain hope for patients
- Desire to maintain patient rapport
- Miscommunication between healthcare providers
- Uncertain prognosis
- Preference to focus on treatment/interventions
- Belief that it is not your responsibility

Other healthcare professional–related barriers (please specify):

B. Patient-Related Barriers

Please indicate whether the following patient-related factors have affected your completion of DNR-C forms.

Options: ☐ Yes ☐ No ☐ Not Applicable

- Patient lacked readiness
- Fear of upsetting family/friends
- Disagreement between patient and family/friends
- Lack of health literacy
- Lack of understanding of current health status or prognosis
- Patient unwillingness
- No available SDM
- Spiritual, cultural, or racial traditions
- Language barrier
- High expectations of treatment benefit by patient or SDM

Other patient-related barriers (please specify):

Section 5: Focus Group Invitation

Would you be interested in participating in a 1-hour focus group (to be scheduled between April 1 and June 1)? **Food will be provided.**

☐ Yes ☐ No

Thank You

Thank you for your time in completing this questionnaire. Your responses are confidential and will be used for research purposes only.

APPENDIX C

Ministry of Health and Long-Term Care Do Not Resuscitate
Confirmation Form: Completion rates when the patient does not wish to be resuscitated within the inpatient and outpatient settings

FOCUS GROUP QUESTIONS

General:

1. Before this study, were you familiar with DNR-C forms?
2. What are your general thoughts on DNR-CFs?
    a. What are your thoughts on its use in inpatient GIM practice? Is it helpful?
    b. Outpatient practice?
    c. Some responders indicated their understanding that these forms can be only completed in the community and not in hospitals. Do you agree with this statement?
3. If you have filled out a DNR-C form, when was that and why did you decide to fill it out (what was your trigger)?

Provider Related:

1. In your practice, do you customarily revisit goals of care and code status at the time of discharge to review patients' preferences if he/she were to deteriorate or have a cardiac arrest in the community?
    a. Do you think this should be done?
    b. Do you think this would be an opportune time to fill out DNR-C forms?
2. Whose responsibility do you consider it to be to complete the DNR-C forms?
    a. If you think it is not your responsibility, why?
3. Do you have any further thoughts on barriers to filling out DNR-CFs?
4. What is the best way we might promote clinicians to fill out more DNR-CFs in their clinic or inpatient practice?
    a. What process would you suggest for ensuring these forms are filled out for patients when there is an appropriate trigger? Should other allied health be involved? Should we include it the discharge order set?
    b. How do you think institutional support can help with filling out the DNR-C forms?
    c. One of the most commonly cited provider related barriers was "I did not think of completing the form." What are some factors leading to this? What are some ways that can be used to remind physicians of this form?
    d. What are some ways the visibility of these forms can be enhanced?
    e. Some cited "lack of time" as a barrier. How can we help to address this?

Patient-related:

1. How can we improve the patients' awareness of the forms?
2. A cited barrier is lack of understanding of the current health status/prognosis. How do you think completing the DNR-C forms can lead to improved communication with patients to ensure appropriate understanding of their status?
3. How do you think lack of patients' health literacy can impact the completion of DNR-C forms? How can physicians aim to improve this literacy in this case?

APPENDIX D

Focus Group Transcription
Facilitator = F
Participant 1 = P1
Participant 2 = P2
Participant 3 = P3

Session Begins After Jessica Leaves Zoom Meeting

F: Just to reiterate, thank you everyone for signing up and joining the focus group, I know the research group really appreciates it. Discussion today will focus on some of the barriers to completing the form and hopefully provide feedback for the tool itself and potentially other tools in practice that are recognized as similar or used in similar circumstances. This would all be to work in favour of both patients and practitioners.

In general, were you all familiar with the DNR-C forms before the study began and you were prompted to participate?

P1: No

P2: It's the community ones that come from the nursing home?

F: Yes

P2: Yes

P3: Yes

F: For those of you who have had experience with the forms, what is your general thoughts, do you find that they are helpful for inpatient practice?

P3: We are talking about those DNR forms that come with packages from nursing homes and long-term homes? My general view on them is it is helpful because often times we don't have any information from family, nothing directive when a patient is confused or has dementia. So in these cases, having a form that says DNR is helpful guiding our decisions. My biggest trouble with the form I would say is still what the medical legal status of those documents are. I've had two supervisors when I was training telling me that those are not appropriate legal documents and even in the case you cannot reach someone, you should maintain that they are so called "full code". Whereas, I had someone else say 'look if you have that form and have no reason to doubt its validity, you should follow that as your directive. So that is my main concern with the form, but I do think it is useful without other relevant information.

P2: For the form, same as was already said, it is really helpful when someone can't communicate what their issues are so I know that they are not for resuscitation. I know there's kind of a long list of things that is says they are not for. That's where it starts to become muddy, because often times you speak to the POA, despite them having that form, they actually are for ICU level measures and some of the things that are on that form that say 'are not for any kind of assisted ventilation' but then they are for noninvasive ventilation. So it becomes a little bit muddy. I haven't had anybody contest the actual 'do not run a code' but I don't know where to stop. When I have that form, I don't trust the form to be comprehensive enough to provide the care that is required to the patient at the time.

F: So typically, in your experience it is coming from a nursing home versus being drawn up and done in hospital?

P3: You can do them in hospital? I have never seen that.

P2: I have never done them in hospital. But because it is a standard, I've witnessed it being done in nursing homes before on certain rotations in medical school and it wasn't a particularly comprehensive discussion with the family. So the family don't fully understand all the different levels of what can be offered and when you have that conversation when they get to the door and you're admitting them, often times some of the things that the form says they are not for, they actually are for that kind of care.

P3: I would agree with that and it was not infrequent that I have found that once discussing with the family there is a complete reversal than what is on the form.

F: Which creates issues with inconsistencies?

P3: Yeah, I mean if we can reach the family that's great but because of all these reversals that often do happen, it makes me feel a bit uncomfortable following the forms directive having those experiences.

P1: For me it was kind of new because I am new to the Canadian healthcare system so I was not familiar with how things are done but I work in palliative care, so we have many patients who are not wanting to be resuscitated so I was surprised you need this official form, the DNR-C form in addition to DNR form or Will to make it valid and honour their wishes. It's only one year since I started working here and I have never seen anyone filling out this form in hospital.

F: So, what I am hearing is none of you have been seeing it completed in hospital, and when you do see it completed there are these inconsistencies, and it is not all comprehensive for what is actively going on or out of date.

P3: I would agree with that statement, and I would also say that I do not necessarily believe that the inpatient environment is the right time to be filling out these forms. Obviously, we address code status quite frequently, especially those patients who are critically ill, but perhaps my understanding of this is that with all these forms, if they come back in the future that we have a clear directive, but I mean it's a prolonged discussion, we need the family there. The patient is not in a stable point of health where the discussion should be best held. If these discussions were to be held, it would be after they were stable. Perhaps the physician knows them well, and to be frank, I do not think the resource limitations that we already face on internal medicine

really provide us the time and opportunity to do such an important discussion in hospital. There would have to be dedicated resources and probably some financial incentive for physicians to be doing this in inpatient or outpatient because it would require substantial resources.

F: That touches on my next question regarding outpatient services, similarly you believe that due to the planning process in hospital, there would have to be some kind of resources and incentive to ensure this discussion is had?

P1: I was wondering, we have so many goals of care discussions in palliative care especially and also in internal medicine at some points and I think it would make sense if a patient goes home after their stay in hospital to give such a form to the patient to avoid having things done to them that they do not want. If family would call emergency services because they were seriously ill or deteriorating and they opted in the goal of care conversation during the previous stay in hospital that they want to be DNR or AND, I think if this form is needed for his wishes to come true than we should give them this form. I was just not aware that it exists and even now that I know it exists, I try to found out how to get access to this form and I couldn't. You cannot just download it, you have to order it because it has a serial number, you can't just give your CPSO number, you have to have an official letter head or whatever to order this form so I think it is really complicated.

F: So regarding inpatient and the ongoing changes in inpatient care, you find it is not necessarily helpful as things are constantly changing?

P2: I would be open to filling out the form. One of the things I am concerned about is that the form has a laundry list of things they do not want done to them and I don't think it is accurate. I would be okay with filling out a form if it was going to be an accurate form as I wouldn't feel like I was doing an appropriate service to the patient if I am just getting them to sign a form when I know that half of those things on the form are not actually in keeping with their wishes. If there was an alternate form that you could outline whether or not they would want the various interventions, be it noninvasive ventilation, dialysis, or things like that where it becomes more of a grey area and often times you get different people who are all "not for resuscitation" that all want different things, I would be okay with filling it out. I do not think it would be too time consuming. Obviously, a financial incentive would be nice but I think the form has to be useful on an ongoing basis because a lot of the times we fill out those forms even the admission orders with the admitting goals of care and the next time they come in, you need to do it all again. If it is not an enduring form, it really is not useful.

P3: My concern about filling these forms is that obviously we already do code status, we did forms before Epic and now we do the code status on Epic. The reality is we already have those discussions on Epic and document that on our system. So the question is, what value do we add by filling out a different form so we have the advanced directive if they come back again. The other question is, if they are already doing this form in nursing and retirement homes when patients are more stable, presumably there is more time to think and discuss and have a chat about their code status, why are we also doing it here? If the patient is not in a nursing or retirement home, is the inpatient internist doing the form better or more appropriate than having a longer conversation with their family physician who knows them better? This is my hesitancy about us filling out forms. I have no problem doing code status, and fill them out all the time, but am I adding value to patient care by doing yet another form and even if it's done, if we are doing it in an acute care setting where things make change substantially during their time there as an outpatient, will I truly believe that this was there last known wishes when it was done in this acute care environment? If I am still not sure, then I will still ignore it anyway and have to call the family. If there isn't a kind of legal precedent or something to back me up from a legal perspective to use it, I would be hesitant to use this document to guide my decisions similarly to existing forms that are in the outpatient setting.

F: Before this study and focus group, it was everyone's impression that these were completed solely in community setting?

P1: Yes

P2: Yes

P3: Yes

F: As none of you have personally completed the form, have you ever been present with a colleague or supervisor who had completed this form?

P3: Never

P2: I have seen it done before by the charge nurse of the nursing home with the POA saying 'if they go to hospital do you want them to be resuscitated with electric shocks and life support' or something along those lines and they say no and then the staff say sign this form. It was not really a conversation about all the other things that the form entails. It was just do you want them to undergo CPR, do you want them to undergo invasive ventilation, if no, fill out this form but the form actually has about ten different interventions that it says you're not wanting and people just sign it. I believe I saw it about two or three times. It was not a comprehensive discussion by any means.

F: For those situations, what was the trigger for the staff member to complete the forms?

P2: New admission to the nursing home.

F: Regarding your own practice, do you revisit goals of care and code status when discharging the patient?

P3: Nope. Not on discharge. Never.

F: No discussions of potential for deterioration or cardiac arrest or anything like that?

P3: Not on discharge.

F: Does anyone think this should be done?

P3: I do not.

P2: I have never done it on discharge, I do it routinely on admission even if they are like twenty with a toenail fungus just so that I can say that I had that discussion and then if they are sick and actually deteriorating, then I have a more detailed discussion while that process is going on. And oftentimes at that point, the goals of care are completely swapped to a comfort care model, and that's when palliative care then gets involved, and they often then start going down the route of hospice and stuff. So, it becomes you know, there's a difference in their goals of care, but also there's a difference in their trajectory and they're not necessarily going back to a nursing home or whatever. Those are the only times where it happens. So, I've never done it on discharge.

P1: I have never done it on discharge. I've done it during the hospital stay, obviously. But my understanding now with this form is like even if they are fully palliative and if they go home, I did some reading and it looks like you need this form in order to prevent paramedics to perform CPR. Even if you are fully for full palliation, you need obviously this form in order if paramedics come to your place. So, this triggers my thoughts on if we had a goal of care discussion in hospital and the patient goes home afterwards, we might need to hand out this form in order to honor the goal of care discussion we had earlier because the goals of care, they don't end when the patient is discharged, if they are going to a hospice or if they go home with palliative care services.

P3: So, if they go home, I mean, there's probably family around and then they're not going to do CPR if the family says don't do anything. They're in a hospice facility, they're also not going to do anything because that's very clear. And then if they enter a nursing home, they have to have a form then anyway. So as soon as the patient enters the hospital, the physician will reassess if the patient is just readmitted and then the form will be done in palliative. So, it seems like the need has already been filled where necessary, if that makes sense. I agree with you that in certain cases that might be necessary, but in those cases it seems like someone already does it.

P1: Yeah, it might not happen very often, but it just recently happened that there was a patient. It was a

weird case, like a patient was discharged home and then was awaiting hospice and then while being transported to hospice was ordered so they came and deemed the patient to be not stable enough for just transport, though they called paramedics and the paramedics basically performed CPR on this patient that was just for transfer to hospice. So, in this case, this form would have helped. I don't know. It might be very rare case though.

F: Based on the research and some of the things that have been covered, like you said, one of the circumstances that often happens is just regarding paramedics and in terms of their knowledge of the patient and if there is any change in code status, it has to be coming directly from a physician. This form essentially just provides them some confirmation so they can respect patient's wishes. That's often one of the benefits in kind of keeping with the patient wishes.

P3: But again, are we speaking about people coming from their own homes or from facilities? Because I think there is a substantial difference.

F: Right. Because if they're in facilities, then the care team is already aware and can inform paramedics themselves.

P3: Correct. And if the existing research you're referring to at facilities where such processes were not in place and then at this research facilitated that changed, right? As opposed to people who are at home, especially those with other family members, I'm not sure if this applies. I don't think paramedics will do CPR if the family runs out and says don't do anything that doesn't want to get done. I could be wrong, but I would guess they would not do anything.

P1: I would hope. I don't know how the rules work.

F: And for your understanding of the forms, where they are completed, whether it's community or hospital, whose responsibility do you consider it to complete these forms?

P2: Ideally, it should be the family doctor, although I know it's often the charge nurse of the nursing home that has that conversation. But it should be done when the person is stable and if possible, if they can participate in the conversation, it should also be done at that point.

F: And in terms of any further thoughts on barriers in filling out the forms, I think initially in the conversation, we talked just about kind of the legal logistics as well as the resources and the ongoing changes while in hospital and I think you guys have all kind of touched on multiple barriers in your own personal practice that you've recognized. So, we'll move on. In terms of promoting clinicians to fill out more forms in their clinic or inpatient practice, do you guys suggest that there could be a trigger or added to some kind of checklist?

P3: I think you need to first convince clinicians that this is going to improve patient care. And I don't think, in my mind, even from our conversation it been clearly established that we are addressing a clear need. And if we are, what is the specific population we need to address it? I fully acknowledge that these forms are helpful, and I think there are certain populations in certain circumstances, but the reality is we cannot be having physicians doing these forms on every person that comes on internal medicine. That is not feasible and will never be picked up. So, the question is, in what specific circumstances are we identifying where these forms could have potentially benefited patient care? And if you can find that population, clearly define it, have that trigger, for example Epic, and physicians agree with those, then I think you may have some uptake. But certainly, a pan form policy is not going to work out well. Even an academic center with lots of residents, that is not going to fly very well.

P1: I totally agree. It couldn't be done on everyone, and it makes no sense to do it for everyone. But I think one group could really be the ones that you did the goal of care conversations with, and they said, okay, I don't want CPR, and I'm not for CPR. That could trigger filling out this form.

F: And I hear just like you're saying, in terms of the clinicians and the resources of even residents, would there be an opportunity that potentially allied or nursing could assist? Or do the barriers stand regardless as the blanket forms would not be appropriate?

P2: I think that would be even more of a challenge because I feel like despite the fact that there's a doctor shortage, nursing shortage, I feel like there's even less allied health support. Sometimes it takes me seven days to get a social worker involved in the person's care, and that's what they needed from the beginning. So, I think that asking additional Allied Health team members, those ones with the training, such as social workers, to be involved would be virtually impossible in the current climate.

P3: I entirely agree with your point, and beyond just the resource limitations, especially if you're talking about addressing code status in patient environment, when a patient is acutely ill, you need a physician to address this conversation. There are so many medical pieces that an Allied Health member will not be able to answer. And my personal experience mostly being at Hamilton General, is the nurses do not know those patient details. They will not be able to address even the current clinical status, to be honest. So having them doing such an important conversation is not feasible, at least in Hamilton.

P1: It might be helpful though, to gain access to those forms because I would have asked Allied Health where I can get those forms like for those little administrative steps.

P3: I definitely agree. They have to be readily accessible. I literally have to either press print on a form available on the computer or it's right in a box beside me like those CCAC forms. Otherwise, it definitely won't get filled up. It has to be very easily accessible. I haven't filled one out myself, but if there are truly ten check boxes on it, it's also not feasible. It's not.

P2: They're not check boxes. It's just a laundry list that you just sign at the bottom.

P3: Oh it's literally just one DNR form, There's no differentiation?

P2: It's one big form and it's very ambiguous. And it actually just says no assisted ventilation. Like it doesn't specify what that actually entails. So, a lot of the patients that have signed that form or the family sign that form, in the end they actually are for like optiflow and stuff like that. So, it's not even accurate.

P3: That's another major barrier, I would say.

P1: It's really for someone who is basically like that. Like it's not for someone who is not breathing well or something like that. It's not for end stage COPD who might want some form of BiPAP or CPAP or like optiflow or whatever, but it's more like if someone has a cardiac arrest or something, and then it's kind of clear. Like it just states what's not, what won't be done. And those are the things that you usually do when you perform CPR. Like, I have it here. No chest compression, no defibrillation, no artificial ventilation, but it does not say, okay, what kind of artificial ventilation. But to me, this form won't exist if it's too specific. Like, you cannot specify with one form. Like this patient would like to be on optiflow or would like to have BiPAP, but not for intubation. I think that would not be feasible.

P2: It also says, like, no transcutaneous pacing, no advanced resuscitation drugs such as vasopressures, right? And that's often not the case. And some of these patients are for pressors and ICU management and somebody with tachy brady, they actually sometimes need transcutaneous pacing, and they are okay with that while they're waiting their pacemaker. So, again, I don't think it's an accurate form, and I don't think it's accurately filled out because it's kind of like if their heart stops, we don't want you to do anything. But the form actually encompasses much more than that, and most people aren't aware of that.

F: So, what I am hearing is It's too general to the point where patients are coming in and actually correcting it at the time of needing care and saying, actually, we would like this and that excluded from the DNR. It's general to maybe negate having to go through with every single patient, but because it's so general, when individualized with patient care, they are going back and saying, no, we disagree with the form.

P2: Exactly.

P1:I think for the patients who are not for ICU and for AND or DNR, I think if you can check both of those boxes, no ICU, no DNR, then you can fill in this form. But if they are for ICU, then it's hard to fill in this form.

P3: I agree with you to some extent, but I do believe that because of the lack of detailed conversation that P2 has outlined, from what they observed, people don't know what ICU might entail. As they said, what if you just need to go to CCU for temporary transcutaneous pacing because they're on a beta blocker and as soon as the beta blocker wears out, they're totally fine? Right. Or, you know, they have really bad pneumonia, they don't want to be tubed, but they just need temporary BiPAP to pull them over? Are you saying that I'm just going to go with this form? No. So I'm going to still call the family, I'm still going to have to have a detailed discussion, and then this form doesn't change anything except I have more work. So, I think that you have to have that conversation in context of the patient's current acute illness, at least on medicine with the patients we see. And no form will negate that requirement except for being truly palliative patients and as you say, that's more of an issue of paramedics not MDs acting.

P2: Yeah. To be honest. There is a role for the form, like, when you cannot you know, when the patient can't speak for themselves and you cannot reach the next of kin, I'm happy I have a form to know they're not for resuscitation. So, I know to at least stop at running a code. But then there's that ambiguity of where do we go before that point in time? But at least there's something where you can say, I know this person definitely did not want to be resuscitated and most people also believe that needs to be artificially ventilated, so I feel like there's at least something. But yeah, I don't find it reliable by any means.

P3: P2, do you know if the forms are legally binding, though? Because that's still my concern. Obviously, the situation would be very rare when this happens, but what if this form was followed and the family shows up late and be like, this person clearly want to be resuscitated. This form is not what we consider a legally binding thing, and therefore, I don't think you'd actually get in super big trouble, because you still have best intentions. But I think that's the fear for some people looking at this form. One of my supervisors told me that you can't follow it.

P2: There's a 2017 news publication. I don't think they're actually legally binding from what I can see.

P3: So does that mean I could get in trouble if I follow and have no collaborative information? So, let's say you do have a DNR. You have no collateral. You assume they are DNR, they die and then this patient clearly, very, very clearly from a collateral family, everyone's like, there's no way this patient would die, they told me, like, a week ago and then you get sued. And this is why I see all these patients with DNR forms still taken to the ICU because they have no collateral and then the family shows up and then 24 hours later they become DNR. So until I think part of this, you need to have that legal status verified. This must be a legally binding document within certain criteria or else you will still have many physicians pulled out because I'm not protected by just following this form.

P1: Or might it be the other way around? Like if you have a bad outcome after a CPR and there is a form and you didn't pay attention to the form, could someone blame you as well? So, I don't know.

F: Some people in the study cited that they did not think of completing the form, but I believe we've touched on it a couple of times. You'd rather check in with the family and patient you know well, aware of their wishes while actively in hospital than look to an ambiguous form from a care and legal perspective.

In terms of visibility of the forms, I'm hearing that the accessibility issue is more from having to submit for it versus having it readily available. Is that fair to say?

P1: Yes.

F: And then some people who were familiar with the forms, whether in hospital or community, cited lack of time as a barrier. Would you agree?

P3: Lack of compensated time. The reality is we have a lot of work and certain things compensated better than others. I think if there was very clear value and considered routine part of care, we would find time on specific patients. We all do code status discussions when it's important of course, we'll carve out as much time as necessary, and sometimes obscene amounts of time. But if you are asking it to be done routinely on patients where it's not acutely indicated, you will need to financially compensate positions for their time for this to be feasible. That's my opinion,

P2: Yeah, and it also depends on the day. If you've got thirty-five acute patients and someone decompensating on the ward, there's no chance that my priority is going to be to get to this form.

P3: I think P2 alluded to it earlier the current landscape with Allied Health, but it's the same with MDs right now. Everyone's stretched, everyone's burned out. There's lack of coverage everywhere in internal medicine, you know, the hospital shutdowns you see on the news at many places are not just a lack of Allied Health coverage, but also a lack of MD coverage. And I think that we are going to continue to stretch them for the next little while, at least locally. The patient volume certainly isn't lower than before. If anything, it seems to be higher. So, I think if you're going to be introducing a new piece of work for physicians, a) you're going to have to very much convince them that this is going to improve care, and B) find some sort of compensation, likely financially for this to happen.

P1: I think for the very for the few cases where it's really clear, like you had the goals of care discussion and they don't want ICU, they don't want CPR, then I think if you had this form available, it won't take long to put your signature on it because you don't have to fill out many spaces on this form. So, if this is not clear, then this form is not very helpful, I think. It's not useful for every patient. It's only useful for a certain group of patients, and then it's only useful for the ones that are not ICU, not CPR, and then it won't take long to give the signature if the form is available.

F: So potentially, the institution could support, through maybe collaborating with physicians to develop a specific demographic that this form could apply to, so that if there was some kind of discharge planning, that there may be a prompt, if anything. So, there is that trigger, whether it's through charting or through patient meeting the criteria, so that you're not having to create this for every inpatient in high acuity because the resources just aren't there. Maybe a specific discharge prompt because otherwise it's just very low priority to do as part of someone's general discharge.

P2: Yeah. And I think the other trigger is, depending on which facility you're in, ICU means different things. Right? Sometimes you need to go to ICU just so that you can get the nursing care that is required, because you need frequent blood work or whatever it is, whereas other times that would be a stepdown unit or just on the ward, depending on the nursing situation. Not infrequently and I would say about 95% of the time over the last two years, we've had nurses call in sick almost every day and the nurses are down to six to nine patients each, they can't provide that kind of care. So, when we're saying not for ICU, we need to also clarify what does that mean medically for their care, not just the location.

P3: Yeah. I think I'd be much more compelled to fill the form, as you suggest, in certain patients on discharge, if it was not the current form. Like you guys remember the old post forms we had at HHS? Now, certainly those forms are not perfect, but they allow the physician the ability to kind of describe different levels of care that was just not a yes or no. It was not binary and allowed for written text to describe what was discussed and specific elements of care that you would want versus not want. And I think for me at least, to feel comfortable filling out this kind of form, that kind of level of detail is required, at least the option to have that kind of level of detail for me to fill out such a form. What if they just need to go to ICU for insulin infusion? Right? I'm not going to stop them from going to ICU. That's too black and white. And so, if all these exemptions exist then the form is not very useful. I do think it is possible to convince physicians to fill out these forms on certain patients where the code status is going to be a major issue on readmissions, but more so it has to be a more detailed form and that won't really make an impact locally in Hamilton. Like if they're always in the same region, because you have that information online. Certainly, if they visit hospitals in multiple healthcare regions, it will be very valuable and so, yeah, I think that's something to consider as well, because at least in Hamilton, most people are getting their care just in Hamilton, so the added value is a little bit less.

P2: Yeah. And working both in Hamilton and in the community, those paper ones that you fill out, I use those the most and I find those ones much more helpful because then I've had a discussion. I could say, someone comes in with AKI and they're

going in the wrong direction. Yes, they're for dialysis, no, they're not for pacing or whatever. Like if your potassium is off, then I know that we do certain things and not other things but it's a very detailed discussion at that time and in that clinical situation, right? Long term, if they were on dialysis and they determined they no longer wanted to be on that, then again, that form would need to be changed. So, it needs to be something that's fluid and reassessed, and it should be reassessed as an outpatient, not when they come in. And at the time of discharge isn't unreasonable, but oftentimes with the turnover, and I'm not exaggerating here, some days I have nine new patients and four discharges, plus all the other patients that need to come in, I don't think that it's feasible to be doing all of that extra work.

P3: Again, I would reiterate that I think that the most appropriate location for this is outpatient. It is a shame that we don't have the time to do it on discharge. There are certain patients that benefit and maybe in certain environments we can squeeze out time, but I'm cognizant of the fact that we are blessed with having multiple learners running around trying to do stuff for us and the reality is, anywhere outside of the academic center, it's just one person running around doing all that work. And so, to dedicate someone to spend the extra time to do that while you're answering calls and seeing 30 to 40 patients, which I understand is the workload in many community centers now up to 40 patients solo, it's not very realistic. So, again, I do think focus on the outpatient environment is where I would focus on getting the forms done.

P2: I think we also just need to verify the support because more and more doctors are leaving the outpatient environment, period. And then that becomes even more of an issue because then we really don't have a primary care physician at all to be having those discussions. So, if that needs to be a trigger, I'm seeing more and more the patients just don't have family doctors, which becomes very challenging because they keep coming in and you keep treating them, but you need somebody to keep them well outside of the hospital and they're just lacking in that capacity. So it's hard to kind of figure out exactly who should fill out the forms, but definitely as an outpatient would be beneficial. But if there was a trigger to say 'this person doesn't have an outpatient, anybody' then maybe we really should be filling out the forms. But again, it would have to be something that is accurate.

P3: Wouldn't it be nice if they had this in clinical connect, so if you could see it across different systems?

P2: It would be nice.

P1: It would be perfect. The paramedics, I think the form is mainly for the paramedics coming on the scene and they don't have access to epic and all those clinical connect and everything.

F: And then the last part of our discussion really is just about the patient side of things, because, like you mentioned, there are certain cases where patients would benefit from receiving these forms on discharge, and also in the community and outpatient settings. Is there anything you can think of to improve patient awareness of these forms? Maybe not completing the forms with them but discussing it.

P3: I think what shocks me the most is how often I run to patients, as P2 does, I talk about code status, at least mention it on every admission, and it shocks me how many patients have never had this discussion. You're eighty-five with ten comorbidities on twenty medications and yet nobody spoke to you about code status. I'm not in the right position to have an in-depth discussion with you about this at that moment, so the fact that there is not awareness in general in the public about the need to have a discussion about code status, it doesn't matter what your decision is, but the fact that they've never thought about it, despite being at high risk for it, is my major concern. And I think these conversations and thoughts take a long time to process. People cannot answer on the spot. They can't even answer when you give them their whole hospital admission. So that's the other issue when it comes to establishing these code statuses beforehand, the patients have never even thought about it before, so to force them, if they've never thought about it before, to make kind of a decision before they go is also probably not appropriate. So, I think the issue more lies and general awareness, the patients about the problem to begin with rather than these forms specifically.

P2: To be honest, when I have those goals of care discussion, because it is on admission, I always approach it in a lighthearted manner unless I truly believe that they're going to decompensate within the next 24 hours hours and then it becomes a very serious conversation because it frightens a large proportion of the patients that I have that conversation with. And oftentimes it is the same response that, oh, I never thought about this before. Some people are just unwilling to answer, and I say, okay, you know, talk to your family. Some people at least know that they don't want to be on long term life support. But when I asked them, would you want to be on it for a few days? Almost everybody says yes. So even just trying to figure out whether or not they would want to have that kind of intervention, a lot of people are still on the fence. So oftentimes I will document not for long term life support, okay, with the short course and then reassess because that's what they've specified. It's not comprehensive by any means, but at least it's a starting point and then there needs to be further discussion. And then they come in again six months later, and I'm the only person who's ever talked to them about it and it's the same situation. So, it's just this revolving door cycle and they don't want to process it until things get really bad.

P3: That's why I would advocate for a primary care model. I know they're very strict, I agree with you. Which is why I also think they would need adequate financial compensation for spending time to do such a difficult conversation. But it needs to be regularly addressed across the general population after, I don't know, they hit such a criteria or whatever and just to be a normalized discussion in our society. And I think that starts with a primary care physician who knows them the best, if they have one.

P2: And I found that the people who are absolutely the best at having that conversation are the palliative care team, but they're only involved in the people who truly are with that kind of a diagnosis. So, the people who often have heart failure, who we know it's life limiting, but often palliative care is not involved in their care until maybe the 20th admission and it's really getting bad that it's helpful to have them involved, but it's not a feasible option on a broader basis.

P1: I do palliative care, but I also do internal medicine. So, there are people in internal medicine, they are very clear in that they want no intervention whatsoever and I think for those patients, they should know that this form is available and that it might be useful to have this form in case something happens to them at home. And I was not aware of this form and I think if you have the goals of care conversation, no matter if inpatient or outpatient, and if this is the outcome of this conversation, you should make them aware of this form. Either fill it out or just make them aware to have someone fill it out to avoid those unfortunate cases where paramedics would come into CPR just because they don't have the form.

My next prop is just regarding lack of standing on the current health status and prognosis. So DNR is an isolated type of conversation to have with a patient, but often when you have those conversations, you're also providing extensive health teaching not only at their current status, but what their prognosis may look like in the future. So just asking if you think that the DNR form can lead to any type of improved communication with patients, like using it as a teaching moment for providing education about their current status and when you're talking about potential for the future? I believe you all have touched on the barriers there and why that might not be in the best interest while in hospital.

P2: It really depends on the diagnosis as well. Because oftentimes if they have end stage lung disease, I really think it's on the respirologist to communicate that if they have horrible heart failure, NYHA class four or whatever it might be, that it's on the cardiologist to have that conversation. And sometimes they do, but it should come from the specialist who is dealing with their medical comorbidity or again the primary care doctor. So just to come in, whoever it might be, come in and say you have multiple comorbidities, and all of these things are an issue, oftentimes when they're that bad, they at least have an understanding that they're sick because they keep coming in. But if we're talking early on in the diagnosis, virtually nobody is aware, and I think it should be left to the specialists who are going to follow the long term to communicate that. So, I don't know that filling out that form is going to be the most helpful as a trigger.

P3: I think it's telling that as far as I understand that from oncology perspective, that many of these patients with advanced cancer are not given exact prognosis in the close discussions. My understanding is it's rarely happening. You know, that would be a very obvious place for potentially these forms and this conversation to happen. And I agree with P2, especially when talking about chronic diseases, like, this isn't a trigger, this isn't what's going to make me have that discussion.

P2: Oncology I sometimes find it even harder because the oncologist are geared towards trying to fix things and they'll be on like, fourth line chemo or fifth line chemo, and then it's not working and I come in and I'm the one saying, this is not working, we need to have this conversation, and then I'm the bad person because their oncologist said that they were doing well, you know, six months ago, but now everything spread and they haven't had that conversation of what happens if things go wrong, because they're always talking about trying to make things go right. So, I find that that sometimes, unless we know from the beginning that it's a palliative diagnosis and then palliative care is involved, if it's a primary oncology diagnosis and they're going through active treatment with a curative intent, they've rarely ever had those conversations, even if they're now on their fourth or fifth round. Now it spread to the brain and the spinal cord and they're having all of these issues, and we're talking about, are you going to want to have brain surgery? And it just becomes a nightmare to have those conversations and they think that we're horrible doctors who don't know what we're talking about because the oncologist never told them this, because, you know, the oncologist is working to try and improve it, but unfortunately it doesn't work all the time.

P1: I just want to get back to your previous question, like how to raise awareness for this form, because I think there's lots going on with palliative care right now. They try to implement care conversation workshops for all the medical students or for the residents, and at several stages of their residency or med school. So, if this would be implemented in those care workshops, at least the younger colleagues would know about this form. And yes, this would be one way to to spread awareness.

P2: Okay, I'm going to have to log off, but is there anything else?

Yeah, just the last question. You touched on it. The last question is how do you think lack of patient health literacy can impact the completion of DNR form? You just discussed if they're working with a specialist and they have an impression from the specialist, and then you're coming in and they had a certain understanding about their current diagnosis, and then you're having to have a different conversation regarding DNR, that can be a barrier as well. Is there anything regarding improving patient health literacy that could help in the discussion of completion of these forms, and how can physicians aim to improve health literacy to assist in the completion of DNR forms? I know you've discussed that there's a lot of barriers in terms of resources and who they're working with, and it's diagnosis specific as well.

P3: I think most physicians sorry, most patients who are especially older do not have an adequate understanding of the prognostication of their disease and the projected trajectory of their disease. They don't know what it's going to look like in three, five years, what the average lifespan is, all this information, and as we discussed, is not really discussed in outpatient. And so that discussion needs to be had while the patient is known to have the disease, while the stage is known with the specialist. And then the challenge is when you come to the inpatient, our job is, unfortunately, often just to patch you off and patch you up and get you back to the outpatient specialist. And we are not, as general internists, always in the best spot to provide that prognostication, having only known you for a few days, having not been a specialty in that area of care and potentially at risk of having a specialty give you a very different prognostication, especially for something that's not immediately life threatening. Certainly if you have three to six months left to live, we can tell you that. But the number of times you get asked about information about the long-term prognostication of their disease, I honestly don't know as well as their specialist and there's only so much patients can look up on their own from a health literacy perspective, especially when it comes to a topic like prognostication. So, I don't know. I certainly think if they were more knowledge about the chronic diseases that they have, whether it be cancer or cardiac disease or whatnot, this would substantially help their ability to fill out a DNR form to make that decision on what they would want to have done, because they know what it's going to, on average, look like in five to ten years but I don't know if that's something that we can easily address in the impatient setting as someone just meeting them probably just once or for a few days.

P1: Yeah, we can't expect them to be doctors. Like, they did not study medicine. So, it's more about finding out, in general what their ideas and wishes are. So, I think it's so difficult and that's why I'm not a fan of those detailed DNR forms, because I think we cannot expect everyone to know the difference between a short term, long term, and what kind of ventilation options there are. So, I think it's more about finding out what is the general idea. Would this patient, in general be more like, okay, if I buy, then I die? Or is it more like, okay, I want to do everything done to keep me alive no matter what? It's important to give an idea, and of course, it's important to give them, like, if they ask for prognostication to give them an idea of what our understanding is or my understanding is. But they should not be expected to be health professionals.

P3: I agree with you. But they should have a vague sense of unfortunately, a third of people will pass away from heart disease in ten years. That's how significant your disease is. Or you might have a heart attack in five years, and this might be what a heart attack looks like if it gets really bad. What would you want to do if this actually happened to you? And I think those are conversations they need to have with their own specialists. I mean, not everybody, but the people with more significant diseases, those conversations need to be had.

So you might suggest the specialists can create a criteria or trigger within their own field to meet with these people and give them either a general discussion or some kind of timeline to promote these forms versus the physician coming in and the patient asking them for specific timelines and details that they might not be able to provide.

P3: Yes. If the form is legally binding and as P2 said, it's currently not. Which sounds vaguely familiar. So, I think that is also a major barrier.

F: Yeah, so that was the last prompt, just a little bit on the patient side of competency and pushing these forms. That's all the questions that the research group has at the moment. So, I really appreciate all the feedback. If you guys have any other questions or anything you'd like to add, feel free. Otherwise, that's it for now. Once again, thank you for your time, and the researchers really appreciate all your feedback. Thanks a lot.

APPENDIX E

Summary

- 2/3 focus group participants were familiar with DNR-C forms before the study began.

Thoughts:

- All participants referred to the form as if it were instructions on what to do if the patient were to arrest in the hospital. However, the original purpose of the form was for first responders in the outpatient setting. Would this change their responses if they knew this?
- Would be interesting to know how participants would feel if these DNR-C forms are only filled when coupled together with serious illness conversations.

Benefits

1. Helpful when making decisions for incapable patients when their SDMs are not available.
2. Helpful when goals of care conversations are held during admission for patients to avoid receiving treatment they do not want.
3. Internists may offer fresh perspective on patients with recurrent admissions, particularly when specialists may be too focused on “cure” or “treatment.”
4. Appropriate understanding of the need for the form: first responders won’t do heroic measures
5. Helpful in cases where patients’ wishes are very clear – that they want no intervention. Otherwise, it becomes challenging when patients may want some of the treatments listed on the form, but not all.
6. This form would be of interest to complete for patients who require frequent readmissions to the hospital.

Barriers:

1. These documents are not legally binding. Uncertain if we are protected from legal repercussions if we follow the directives on the form. Specially, questions were raised about what the physicians should do if they are uncertain whether the forms meet patients’ current wishes.
2. They don’t address all aspects of resuscitation. “When I have that form, I don’t trust the form to be comprehensive enough to provide the care that is required to the patient at the time.”
3. Lack or awareness of ability to fill out the forms in the inpatient setting.
4. “I do not necessarily believe that the inpatient environment is the right time to be filling out these forms.”
    a “The patient is not in a stable point of health where the discussion should be best held.
    b If these discussions were to be held, it would be after they were stable.”
5. “I do not think the resource limitations that we already face on internal medicine really provide us the time and opportunity to do such an important discussion in hospital.”
6. These forms have a long list of treatment options. However, it is best for patients who experience a cardiac arrest because of its “all or nothing” nature. An elaborate care plan is challenging as it may lose accuracy.
7. Redundancy: Code status discussions are already included in EMR – therefore, filling out these forms creates more redundant work.
8. Redundancy: These conversations are already being held in nursing homes, hospice, etc.
9. Forms are not necessary since family members should be around in the outpatient setting (if they are not in a nursing home or a hospice).
10. The family doctor might be in a better position to fill out the form since they may know the patient better. Additionally, Code statuses are fluid and reassessment must be possible.
11. However, this should be done in the outpatient setting and not during admission.
12. No financial incentive.
13. Specialists should have GOC conversations with their patients given their expertise.
14. GIM physicians do not always have a longitudinal relationship with patients. Therefore, they are not the best person to have these conversations with. GIM doctors are better at providing prognosis if death appears imminent (3-6 months).
15. Initial conversations about goals of care and code status may not be comprehensive enough making it hard to trust the validity of these forms. Consequently, patients and SDMs can’t fully understand all the different levels of what can be offered.
16. Workforce shortages would make if difficult to involve allied health and nursing in filling out the forms. A physician is in the best position to discuss the nuances of a serious illness conversation and GOC conversation.
17. Forms not readily accessible. These forms have to be specially ordered because they have a serial number.
18. Physicians burn out.
19. Patients are sometimes not ready to have code status conversations because they are not aware of their expected disease trajectory.

General

1. “It’s only one year since I started working here and I have never seen anyone filling out this form in hospital.” None of the focus group participants had seen it completed in the inpatient setting
2. All assumed they were completed solely in the community setting
3. No one revisits goals of care at discharge; one person does not think GOC should be revisited – and that someone else already has this responsibility.
4. Many patients have not had a serious illness conversation prior to admission.

Suggestions:

1. Financial incentives and dedicated resources
2. Consider specific criteria that should trigger when a provider should fill out this form
3. Not sure if these forms will improve patient care. The first step is to convince providers that it will.
4. Include the form on clinical connect.
5. Consider teaching trainees about these forms in palliative care learning sessions.
6. Patients should be aware of this form in case it does align with their wishes to avoid CPR unnecessarily in the community.
7. Allied HCPs can help with enhancing access to the forms.
8. A subgroup of patients who would specifically benefit from having the form completed are those with no outpatient support (e.g., no PCP).

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Students Narratives of Ethical Dilemmas and Professionalism Issues During a Rotation in Surgery

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Résumé

Contexte : La formation des étudiants en médecine nécessite non seulement l'enseignement des sciences médicales, mais aussi celui des compétences nécessaires à la réflexion éthique et au raisonnement moral, ainsi qu'au professionnalisme. À l'Université de Montréal, depuis 2004, les étudiants en troisième année de médecine sont initiés à l'éthique et au professionnalisme dans le cadre d'un séminaire hebdomadaire sur les compétences cliniques pendant leur stage en chirurgie. Les étudiants doivent reconnaître un dilemme éthique ou un problème de professionnalisme survenu pendant leur stage et rédiger un récit de cas et une réflexion sur la question morale. **Méthode :** Les récits des étudiants décrivant des incidents éthiques ou liés au professionnalisme ont été recueillis entre 2004 et 2020. Ces récits ont été analysés afin d'identifier les défis moraux auxquels les étudiants ont été confrontés et la manière dont ils ont réagi aux dilemmes éthiques ou aux problèmes de professionnalisme. **Résultats :** Sur les 1 145 récits recueillis, 396 ont été codés comme des dilemmes éthiques, subdivisés en décisions de fin de vie, décisions de traitement, dilemmes concernant la justice et l'allocation des ressources, et dilemmes éducatifs des étudiants, y compris les relations avec les résidents. Les problèmes professionnels ont été plus fréquemment signalés (n=749), subdivisés en communication de mauvaises nouvelles, comportement et attitude professionnelle, consentement, confidentialité, divulgation véridique de résultats sensibles, erreurs, responsabilité et engagement professionnels et relations avec les collègues. Dans 40 % des récits, l'opinion sur les problèmes signalés était positive, tandis que, dans 60 % des cas, les étudiants estimaient que la décision éthique ou l'attitude ou la conduite professionnelle n'était pas idéale. **Conclusion :** Ce séminaire a été un moyen efficace pour les étudiants en médecine d'identifier et de discuter des questions éthiques et professionnelles rencontrées au cours de leur stage – les questions relatives à la communication ont été la principale préoccupation, suivies par le comportement professionnel. Ces récits donnent une bonne image du programme caché et montrent que les étudiants sont capables de réfléchir de manière significative à des questions relatives à l'éthique et au professionnalisme.

Mots-clés

narratif, dilemme éthique, professionnalisme, chirurgie, étudiants en troisième année de médecine, stage, pédagogie, curriculum caché

Abstract

Background: The education of medical students necessitates teaching not only the science of medicine but also the skills needed for ethical reflection and moral reasoning as well as professionalism. At the Université de Montréal, starting in 2004, third-year medical students were initiated to ethics and professionalism during a weekly seminar on clinical skills during their surgery rotation. Students had to recognize an ethical dilemma or a professionalism issue that occurred during the rotation and write a case narrative and reflection on the moral issue. **Method:** Student narratives describing ethical or professionalism incidents were collected between 2004 and 2020. These were analyzed to identify the moral challenges that students experienced, and how they reacted to ethical dilemmas or professionalism issues. **Results:** Of the 1145 narratives collected, 396 were coded as an ethical dilemma, subdivided into end-of-life decisions, decision for treatment, dilemmas concerning justice and resource allocation, and student educational dilemmas including relationships with residents. Professional issues were more frequently reported (n=749), subdivided into communication of bad news, professional behaviour and attitude, consent, confidentiality, truthful disclosure of sensitive results, errors, professional responsibility and commitment and relationships with colleagues. In 40% of narratives there was a positive opinion about the issues reported, while in 60% students felt the ethical decision or professional attitude or conduct was less than ideal. **Conclusion:** This seminar was an effective means for medical students to identify and discuss the ethical and professional issues experienced during their clerkship – issues regarding communication were the primary concern followed by professional behaviour. These narratives provide a good picture of the hidden curriculum; and they show that students can reflect meaningfully on issues concerning ethics and professionalism.

Keywords

narrative, ethical dilemma, professionalism, surgery, third-year medical students, clerkship, pedagogy, hidden curriculum

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INTRODUCTION

At the Université de Montréal, like most North American medical schools, the four-year curriculum has been developed to include the teaching of ethics and professionalism. Over the first two years, under the supervision of a clinician, small groups of 10 to 12 students examined and discussed classic cases of ethics, bioethics and professionalism. This is the introduction to ethics and moral reasoning and the beginning of the transmission of a professional idealism. With this background, students reach the clerkships and begin their clinical training. They now must work in the hospital setting, with daily interaction with patients, residents and staff, and this transition is not always easy (1). Some students are anxious about their new role as an

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apprentice doctor, as this brings with it the stress of learning the fundamentals of clinical science while performing procedures on patients. In this context, students are not yet knowledgeable about the moral dilemmas that they will encounter as a medical student and later as a practicing physician.

As medical educators, it is our responsibility to sensitize our students to the challenges of ethics and professionalism issues they will meet during the clerkships. Many medical educators have mentioned the need to listen to medical students to understand the ethical questions or dilemmas that they encounter in the hospital and clinic (2-6). These ethical issues are not theorical abstractions or a simple choice between true or false, right or wrong — they are much more complex (3). Knowing about the difficulties of teaching ethics and professional behaviour in the context of a very busy surgery department, the authors (GB and RW) decided to implement, during the surgery rotation, a seminar on ethics and professionalism with a view to helping students recognize and better reflect on these issues. This paper analyzes the results of 16 years of written narratives provided by third-year medical students during their clerkship in surgery.

METHOD

Teaching ethics and professionalism

During the clerkship in surgery at the Université de Montréal, medical students do two three-week rotations, one in general surgery and a second in a subspecialty such as vascular, urology and thoracic surgery. Students spend their time caring for surgical patients on the ward, in the clinic, and in the operating room. They are exposed to complex cases, participate in the investigation of patients; and they are introduced to the operating room environment and participate in some surgeries. This is their first exposure to the speciality of surgery. While they will have learned about ethical principles and their medical code of ethics during the pre-clerkship, these students also need to learn to identify and analyze the ethical issues that occur every day in surgical practice (2,3).

At the very beginning of their surgery rotation, a group of 8 to 12 students would meet with the facilitator (a clinician-educator) responsible for leading the ethics and professionalism seminar. After a brief review of the fundamentals of ethics, the students were provided with a definition and explanation of what constitutes an ethical dilemma, what is a professionalism issue, and with specific examples related to surgery. Ethical dilemmas were defined as situations in which there is a conflict between two or more moral principles, making it challenging to decide on the right course of action. These situations arise in various aspects of life, including personal decisions, professional conduct, and societal issues (7). Professionalism is at the core of medical practice and forms the basis of medicine’s contract with patients and society. The values of the profession include competence but also compassion, altruism, trustworthiness, protection of confidentiality and privacy as well as responsibility and accountability, to name a few fundamental values (8).

In this seminar, professionalism was incorporated because of its close interdependence with ethics and because professionalism often includes adherence to ethical principles and the use of moral reasoning (9-13). Even if some people find it difficult to articulate or distinguish ethics and professionalism, in our experience students had no difficulty understanding that professionalism included adherence to ethical principles, ethical virtues, and moral reasoning. Health care ethics often invokes values and principles, whereas professionalism tends to encompass but also move beyond principles by invoking moral resources such as attitudes, commitments and motivations traditionally associated with virtue ethics. While the contrasting emphases of principles and virtues are real, they can be understood as complementary aspects of the same ethics.

An ethics or professionalism critical incident was recognized by students as a clinical experience that involved patients or families, hospital personnel, residents, medical students or any educator, and which raised an ethical or professionalism issue with which they personally had difficulty. A critical incident could also be a situation or a difficult issue that they had observed a clinician dealing with in an exemplary fashion. Critical incidents reports are widely used in medical education to promote reflective learning and are based on an event chosen by the student that influences their professional development (14-17). Professional and ethical issues in surgical rotations are particularly relevant for students because they highlight the reality of and challenges that emerge in everyday practice (18-20).

“Narrative medicine” is the term introduced by Dr Rita Charon to describe the application of story to medical education and practice (21). The students in the ethics and professionalism seminar were asked to share a brief story describing a critical incident they experienced during their surgery clerkship. Writing this story as a narrative is significant because it encourages the writer to pursue the meaning of the experience they are describing and reflect on their thoughts or behaviours. Moreover, when others read and respond to the narrative, the discussion process promotes further reflection on the part of the writer. Writing narratives may also increase ethical sensitivity, as the process of writing can help the writer to recognize ethically important moments and so increase their ethical mindfulness. Further, the act of writing a medical narrative can appeal to both rational and emotional faculties, forcing the writer to question why they felt as they did and what the patient might have felt (22).

The students had to identify a critical incident, describe it in a one-page written narrative and make a judgement on whether the situation they were reporting was morally acceptable (positive) or questionable (negative). They then had to give their opinion on how the dilemma should be resolved. Students were asked to keep the narrative anonymous, and they were aware that their narratives would be discussed at the end of the rotation, during the seminar. At the seminar, the facilitator’s role was essentially to stimulate the discussion and complete the information (e.g., raise questions or concerns) about ethics and professionalism. At the end of the seminar, students were asked to complete a written evaluation and grade the quality of the class and their level of learning.

The results collected show that the seminar enabled third-year medical students to better identify an ethical dilemma or a professionalism issue. Further, their comments showed that most were happy to participate in the seminar and grateful for the opportunity to talk freely about some problematic issues that they encountered during their rotation. Many stated that in other rotations they had never had such a frank discussion about ethics in medicine and professional behaviour. They were also asked to identify if a surgeon, a resident, or another person had been a role model: of 125 evaluations, more surgeons (n=53) than residents (n=49) were seen as being good role models, although 21 students felt that residents and staff were equally good role models. Only 2 students reported that they found no good role model at all in their clinical rotation.

Analysis of the student narratives

Between January 2004 and 2020, 1145 narratives written by third-year medical students at the Université de Montréal (Montreal, Canada) were collected following each ethics and professionalism seminar. These narratives were read and analyzed by one of the authors (GB), to identify and better understand the ethical or professional issues encountered by students during their clerkships. These issues were then organized into a taxonomy with 5 sub-groups of ethical dilemmas and 9 sub-groups of professionalism issues (see Table 1, below).

The students' narratives were also analyzed with regards to their judgment of the critical incident and its management by the surgeon and their team, i.e., a positive or a negative opinion. A positive narrative reported a critical situation judged to be in conformity with key ethical principles or the professional code of ethics. For example, a critical incident was perceived positively by students because it demonstrated respect, good communication and compassion for the patients. It was found excellent if the behaviour of the health care provider was in alignment with evidence-based science and carried out with humanism. By contrast, a critical incident was judged as negative when ethics principles were forgotten or simply not used in the resolution of an ethical dilemma. In the case of unprofessionalism, a major lapse was identified in the attitude or the behaviour of a member of the health care team (see Table 1, below, for the number of positive and negative narratives for each subgroup).

The students were not consulted to confirm the relevance of the different categories of the taxonomy, nor were other steps taken to ensure trustworthiness of the coding themes. Nonetheless, this work was presented on two occasions to students and staff of the Department of Surgery at Université de Montréal, and on one occasion at the Department of Surgery at the Université Laval. There were no negative comments on the taxonomy.

Ethical considerations

After the completion of the seminar, students were given the choice to leave a copy of their narrative with the facilitator or have it destroyed. It was clearly explained to the students that their narrative would be kept anonymous and remain confidential; only the facilitator would have access to the narratives, which could be used for research purposes in the future. The data presented here are fully anonymized and only include those narratives which students had initially accepted to be potentially included in research. Retrospective ethics approval for the use of these student narratives for research purposes was obtained from the Université de Montréal Health Sciences Research Ethics Board (CERSES).

RESULTS

The findings reported here are descriptive and retrospective, with a view to capturing the ethical issues that students encountered during a rotation in surgery. We tried to identify, when possible, the moral reasoning of the students to justify their opinion. Most of the time students referred to bioethics principles in their narratives, but rarely to ethical theory; in the case of professionalism issues, they referred to the code of ethics. Further, in some narratives or in their discussion the student's emotional reaction to a critical incident was evident, so we have identified these where pertinent.

A total of 1145 written narratives, written during the period of 2004-2020 by third-year medical students participating in an obligatory ethics and professionalism seminar, were retained for this study. Each narrative was classified as a critical incident related to a clinical ethical dilemma (n=396) or a professionalism issue (n=749), and then sub-categorized (Table 1). The narratives included a discussion or opinion on the critical incident reported, where they explained why they agreed or not with what they had observed, with a reference to ethical principles or the code of ethics. (See Annex 1 for a lengthier analysis of the ethical dilemmas and professionalism issues, with examples from students' narratives)

Table 1. Category and sub-category of reported narratives

Ethical dilemma issues (n=396)		**+ve**	**-ve**	**Professional behaviour issues (n=749)**		**+ve**	**-ve**
End-of-life decisions	n=172	123	49	Communication with patients and family	n=142	66	76
Treatment decisions	n=111	66	45	Communication of bad news	n=168	89	79
Justice and health care resource dilemmas	n=48	1	47	Obtaining consent	n=110	43	34+33
Student-specific educational issues	n=41	1	40	Confidentiality	n=56	19	37
Student relations with residents	n=24	10	32	Truthful disclosure	n=38	10	28
				Dealing with medical errors	n=33	4	29
				Professional duties, conduct and attitude with patients and staff	n=143	44	99
				Professional responsibility and commitment	n=34	11	23
				Relationships with medical colleagues	n=25	3	22

The most prevalent issues experienced by students were related to communication (n=458), such as communication with patients (n=142), communication of bad news (n=168), consent (n=110) and disclosure (n=38). The second category of importance had to do with issues of professional behaviour (n=291), such as duties and conduct (n=143), confidentiality (n=56), dealing with medical errors (n=33), responsibility (n=34), relationships with colleagues (n=25). The third category of issues had to do with decision making (n=283), end-of-life decision-making (n=172) and decisions about surgical interventions (n=111). The fourth category of importance was education (n=65), while the last concerned the health care system (n=48).

The critical incidents described by students were considered as positive in 435 (38.8%) and negative in 685 (61.2%) of the narratives. Communication was considered far from ideal in 217 of 458 narratives (47.7%). The comments on professional behaviour (n=99), confidentiality (n=37), errors (n=29), responsibility (n=23), and relation with colleagues (n=22) were negative in 210 of 291 narratives (72%). With respect to decision making, in 283 narratives, 189 were believed to be adequate (66.7%). For education, 54 out of 65 narratives were negative (83%). For 48 narratives on health care and resource dilemmas, almost all comments were negative (95%).

In their narratives, students referred to the four well known bioethics principles, namely autonomy, beneficence, non-maleficence, and justice, and used these for the discussion and explanation of ethical dilemmas. For professional behaviour, most students referred to the code of ethics or the law, although a small number of students also referred to the principles of autonomy and beneficence for professionalism.

DISCUSSION

To lay the conceptual and empirical groundwork for this study, a review of the literature on ethical issues and professionalism encountered by medical students was conducted (20-31). Numerous studies have explored pre-clinical and clinical medical students' experiences of ethical and professionalism dilemmas using different method such as surveys, focus group or written essays; and over the years, the use of narrative has become a very popular method to explore student experiences.

The information generated by the study of students' narratives, combined with those reported in the surgical literature, have enabled scholars to develop various lists of ethical issues experienced by medical students. Fard et al., for example, provides an extensive list of ethical issues, including professionalism, conflicts of interest, resource allocation and justice, patient-relationships, autonomy, informed consent, determining capacity and substitute decision-making, confidentiality, truth telling, doctor and medical team relationships, medical error, ethics in medical education and terminal illness issues (23). Kadijan et al. present a more limited list of issues, such as decisions regarding treatment, communication, professional duties, justice, student specific decision, and quality of care (24). For our analysis, we combined these two taxonomies to include as wide a range possible of ethical and professional challenges that students encounter in their medical training.

Our analysis of 1145 student narratives collected over a 16-year period showed that third-year medical students can identify and capture the nature of ethical dilemmas arising in the care of patients. They observed very well the quality of interactions and relationships in the clinical and educational settings, and they develop advanced reflexive skills, while maintaining their idealism. The students were very critical about the interactions between the surgical team and the patients and family. They referred to patient best interest and they observed how well (or not) patient needs were met in the hospital environment, the quality of the communication between patients and staff, and the positive or negative attitude of the different actors of the health care team. When it came to patient care, students expected to see ideal ethical and professional conduct from every member of the health care team; and they expected medical educators, residents, and health care professionals to be role models.

Students were very critical of the way that their education was conducted. Across studies, the most common dilemma is about students' difficult experiences with learning and patient care, but also frequently reported are issues about respect and communication. Student reactions and responses are often influenced by fear of jeopardising their evaluation or their career plan; and a result is moral distress and negative feelings (30). In our study, students were extremely sensitive to the atmosphere in which they did their clerkships, appreciating a milieux that was open, friendly, empathetic, cooperative, respectful, and humanist. And communication was of utmost importance for them. Students were most troubled when there was a problem of poor relationships between colleagues. They were also very upset when there was public discord within the team. It is in the narratives dealing with education-related issues that students appeared to be most uncomfortable or upset. Some narratives expressed deception or anxiety due to feeling inadequate to accomplish an assigned task. The student narratives provided an authentic description of a medical learning environment, and we should listen to their messages.

It has been observed that third-year medical students are prone to forget about the importance of empathy and compassion learned theoretically during preclinical training. The necessity to stay current with the latest developments in medical knowledge, combined with the burden of clinical workloads and institutional requirements for efficiency can threaten essential ethical and professional values that were considered fundamental in the preclinical years. This was not the case with our student narratives. Over the years, they showed a very good sense of observation and sensitivity for ethically problematic situations. On no occasion did we witness cynicism from the students, nor was their judgment ever ineffectual; in fact, their judgment was generally very good even when discussing difficult situations.

Contrary to some reports in the literature, our students did not remain silent about the hidden curriculum (32,33). They used the seminar to talk freely about the good and less good ethical issues that they have encountered, probably because the seminar was a safe space to express their feeling and opinions. In the process of socialization in medical school, students learn rapidly to hide their emotions, and all their attention is given to the facts of a case, to objective data; there is less interest for the subjective acknowledgement of emotions. When students reported a critical incident for which they agreed, they had positive emotions or did not manifest any emotion in their report. We did not find many negative emotions but noted the sensitivity of students when the critical incidents they had observed were in contradiction with their values, ethical principles, or the code of ethics (11).

Medical students on clinical rotations are incredible observers of their educators' behaviours; and they have the potential and capacity to register our actions, smiles, and insinuations. As clinicians, we must realize that our practice is public, and it is closely observed by many persons around us, but most of all by our students. In their narratives, students were very critical when professional behaviour in the operating room was inadequate or when a medical decision was influenced by a prejudice. This analysis of the students' narratives shows that medical students have a good sense of observation of both the training environment and the professionalism (or lack) of their clinical educators.

Throughout the years we conducted the seminar on ethics and professionalism, the students demonstrated energy and enthusiasm and a very good cooperation, even if there was no direct evaluation of their performance at the seminar (it was not a graded activity). Our analysis points to the important role of the hidden curriculum in shaping professional identity. It also showed that third-year medical students may be more aware of ethics and professionalism issues than one might first assume (32-35).

In 2005, Branch described the effectiveness and impact of reflection when using critical incident reports, pointing to the importance of a reaction to and validating discussion environment, and the benefit of transformative learning (15). Reflective writing of short narratives has been shown to be an effective means of teaching professionalism when combined with feedback. Written reflection is associated with a more positive learning experience because students revisit and assess their experience, and this can help them progress in their self-reflection and eventually develop and implement high-quality practice (17). Reflection is a technique that enables learners to analyze their experience and capture the wisdom that lies within, and to then develop new knowledge and attitudes. Reflection is also associated with positive learning experiences and may help students to develop as learners and better recognize their own learning needs (16). Reflection and feedback for the teaching of ethics and professionalism involves the intentional examination of a learning experience, including feeling, meaning, and ethical implications. Discussing critical incidents related to ethics or professionalism experienced by students may stimulate self-reflection and lead to mindfulness and help in building students' professional identity (32-37).

Combining reflective narratives with the good role models they find during their rotation in surgery can help medical students to answer questions like: What kind of doctor will I be? What are my values? What are my convictions to become a good doctor? According to White, one of the most formative influences in medical education is the recognition and reflection of students on critical incidents encountered during a rotation (17).

By using the narrative approach, we wished to stimulate students' ethical sensitivity and help them develop their reflection and judgment. Essentially, the idea was to prepare them for the subjective aspects of the practice of medicine. We wanted them to learn to identify or recognise ethical dilemmas in surgery, to analyse them and resolve them were possible, and to discover their own personal ethic, along with its rationales and motives (7). Can one be a scientific and competent professional while only giving minimal consideration for the art of medicine? Is it important to become a humanistic doctor with high standard of ethics? In answering these and other questions, medical students construct their professional identity.

Learning reasoning about ethics and professionalism and observing role models while training enables medical students to progress gradually to find their own professional identity. We hope they will maintain their well-developed identity acquired during their clinical rotations and medical training, and throughout their professional career. In our case, we thought a seminar that favoured observation of practical issues in ethics or professionalism and stimulated reflection on a critical incident followed by a small group discussion would be an appropriate educational modality with which to teach ethics. Specifically, it would help students to reflect upon and learn about their clinical experience, which they lived during a 6-week rotation in surgery. This formal activity can be in addition to the habitual teaching of ethics during their exposure to surgery.

LIMITATIONS

One of this study's limitations is that the data were collected in a single institution, in Quebec (Canada), and so may not be generalizable to other institutions. The seminar experience reported here was also conducted in another hospital, but the narratives were never collected and analyzed. The study also concerns a limited number of students from a group of approximately 200 students assigned every year in a clinical rotation of approximately 3000 students. The study involved 25 surgeons, the majority from General Surgery, and the others from vascular, thoracic and urology. The evaluation and interpretation of all the narratives was done by a single person (GB). Nonetheless, the lessons learned from the students' narratives provide insight into how medical students are trained and this is pertinent for all medical schools to consider. Specifically, surgeons and medical educators should be aware that they are constantly observed by their students, who will

judge their behaviours — clinical educators can be positive or negative role models, because what is learned by students is both content and behaviour.

CONCLUSION

Medical education is not simply the acquisition of knowledge and skills — above all, it is the acquisition of a professional identity and the identification of values that will guide professional conduct. Medical students desire to become proficient and caring physicians. The students who participated in our seminar shared their belief in the professional virtues of altruism, honesty, integrity, excellence, respect, and responsibility and wished to learn from good role models encountered during clinical rotations. Negative behaviours observed by students are teachable events because they show students what is not appropriate and sometimes this is more instructive. It is an occasion for students to develop mindfulness and reflect on what went wrong and the negative effect on the persons involved. The findings of our study suggest that students' reflective narratives are a rich source of information about the informal of hidden curriculum. Experience with both positive and negative behaviours were distributed evenly and shaped the students' experience of the professional values in the daily practice of surgery. Good communication and professionalism of surgeons appeared for the students as fundamental values.

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ANNEX 1

Ethical dilemmas (n=396)

End-of-life decisions (n=172)

Clinicians who treat terminally ill or almost terminally ill patients are generally reluctant to abandon their traditional role of curing the patient, so there is often the idea that they should always fight for life (39-41). Further, they are often ill-equipped to deal with the complex confrontation of trying to promote both principles of autonomy and beneficence in patients with advanced neoplastic disease. This was true in the first years of the study, and the decisions taken by the surgical team were not always perceived as adequate by students. They based their judgment on their own values and conviction and the principles learned from their preclinical training. But in recent years, the philosophy of treatment of terminally ill patients has changed with the development and implementation of palliative-care services. Of the 172 student narratives that dealt with end-of-life decisions, 123 reported a good decision being made by the surgeon, e.g., evidence-based decision (n=28), respecting patient dignity (n=7), respect of autonomy (n=73), or demonstrating excellent communication (n=8), and other issues (n=7). By contrast, 49 student narratives recounted a negative experience. The decisions were criticized because of poor communication (n=8), overtreatment (n=18), that patient autonomy was not respected(n=8), that communication was too paternalistic (n=8), and other issues (7). Interestingly, there were more negative experiences recounted in student narratives in the period of 2004-2014 (n=36) than in the last five years (2015-2020) (n=13). This difference can probably be attributed to a change in mentality regarding end-of life decisions and better access to palliative care.

Treatment decisions (n=111)

The initial tasks for which surgeons are trained are to identify a patient's symptoms, to make a diagnosis and to offer a treatment after the risks and benefits are explained to the patient. Communication must be respectful of patient autonomy and adapted to the patient's capacity to understand. The students reported in their narratives how they perceived the treatment decisions made by staff and whether the final decision was made in consideration of patient benefit. This process was found to be adequate in 66 narratives — i.e., good medical decision (n=26), respect of autonomy (n=36), excellent communication (n=3), other (n=1) — but considered problematic by the students in 45 narratives. One of the reasons for questioning the appropriateness of clinical decisions (n=29) was because of certain prejudices expressed by the surgeon in making their decision. The prejudice most often mentioned by the students was with respect to patient obesity, most often at the time of surgery in the operating room. Second to that was psychiatric patients and the people with drug problems. There were a few mentions about religion and sexual orientation. Some students felt that autonomy was not clearly respected (n=7) and beneficence not always evident. In a few narratives, students expressed that it was wrong that the decision was taken solely by the family instead of the patient (n=6).

Justice and health care resource dilemmas (n=48)

Justice is one of the main principles of contemporary medical ethics. In the province of Quebec (Canada), all residents have access to public health insurance, with most care provided without co-payment or recourse to private health insurance. Nonetheless, justice issues still occur, and these were raised by medical students in their narratives: they had to do with access and resources. Access was a concern for those patients without Canadian citizenship needing medical care and identified in a small number of narratives (n=5). The major concern (n=15) was that of privileged access given to patients because of their close relationship to personnel of the hospital. On one occasion, a narrative recounted a case of an offer of privileged access that was declined. The other problem noted by students (n=5) was that waiting time to access care was far too long. Fair use of resources was mentioned as less than optimal in 20 narratives and on 2 occasions necessary resources were totally absent.

> A 50-year-old patient has been diagnosed with a rapidly progressive and aggressive digestive cancer. The surgeon meets with the patient and proposes surgery followed by chemotherapy according to known medical standards. The patient has a social problem because he has already lost his job several times and his financial situation is poor. He has just found a job but does not have his permanence. The patient is unable to consider a treatment that takes him away from his current job. He fears losing his job. The surgeon therefore decides to opt for another form of treatment and to respect the patient's autonomy. The surgeon offers to call the patient's employer to explain the urgency of the medical situation. The surgeon decides on an alternative therapy while waiting to complete the treatment.

Student-specific educational issues (n=41)

Medical students faced several ethical issues related to their training during clerkships. Among the main difficulties reported in the literature were conflicts between the exigencies of medical education and patient care and wellness, being asked to assume clinical responsibilities that exceeded students' capabilities, and involvement in care that they considered to be substandard. In their narratives, students rarely reported positive events, i.e., on only 2 occasions did student narratives focus on the positive aspects of the teaching and learning environment. When faculty members and residents spent time in teaching it was recognized positively in the narratives and greatly appreciated by the students. What they most appreciated were instances when they were actively involved in the process of clinical reasoning and treatment of patients. They liked to be perceived as a partner and member of the team, but this was rarely the case and led to most negative events (n=40). To name a few such incidents, students reported occasions when the attitudes of health professionals were not compassionate: staff (n=3), residents (n=6), nurse (n=1). Probably the biggest problem, however, was the anxiety related to the tasks that medical

students were asked to perform (n=18), because they felt unprepared. Additionally, students' autonomy was not always respected (8), and there were a few cases of intimidation (n=4).

> I am doing an internship in urology and the surgeon was very concerned about my learning; he gives me the opportunity to perform the rectal exam on all patients who come to the outpatient clinic. In retrospect there is a problem with some patients being aware of my presence because the exam was done while the patient was in the prone position ready for the biopsy and each time the surgeon indicated to the patients that the DRE was being done again but did not indicate that it was a student who was doing it. In my opinion, this is an invasive medical procedure that concerns an intimate part of the anatomy. It would have been more ethical and to notify the patient and obtain his consent.

Student relations with residents (n=24)

The resident's performance with patients, as well as their relationship with other members of the health care team, including the medical students, was reported in 24 narratives. The positive incidents when observing the residents were excellent communication (n=3), respect of patients (n=2), excellent clinical decisions (n=3), and respect of staff (n=2). Negative incidents included lack of respect for the patient by the resident (n=2), bad communication with patients (n=2), lack of respect for the students (n=2), conflict with nurses (n=1), difficult relationship of the resident with staff (n=2), and in one narrative, a resident lying to one of the staff. Students also observed a lack of supervision of the residents by the staff (n=3), while another incident involved lack of responsibility by a resident (n=1).

Professional behaviour (n=749)

Communication with patients and family (n=142)

Communication must be respectful of patient autonomy and adapted to the patient's capacity to understand. Students learn early in their preclinical education that communication is essential in the process of care and in the relationship between the patient and the surgeon – it remains very important in all aspects of clinical practice. Medical students witness, every day, the conversations (or their absence) held by the medical team, and the quality of this communication, as well as the attitude of the staff during patient meetings, is scrutinized by students.

> We are in 2008, and I am doing a surgical rotation for a patient followed for a neoplastic lesion. A colonoscopy was performed, and I attended. The surgeon leaves the room immediately after the intervention; the patient was to go to get dressed to meet the doctor and obtain results. He wants to be reassured. The surgeon refused to meet with the patient saying that he did not have time and that he would see the patient again next month and he asked me as an extern to meet with the patient and answer his questions. So, I met with the patient in the waiting room, but it was an inappropriate place. I told the patients that we would go to the doctor's office, and he would answer these questions himself, especially since I did not have the knowledge to answer questions in a very specialized area of surgery. For a second time the surgeon refused to meet the patient and insisted on dismissing him. I was very disappointed with this attitude which lacked empathy.

During the daily interaction of the surgical team with patients and families, confidence should be established early on, based on an honest and compassionate attitude towards the patient and their family. Good communication is also important to relieve anxiety experienced by patients and families. Students observed that some health care professionals never demonstrated any empathy during their relationship with patients. Instead, their primary objective and interest was focused on the disease, and these clinicians paid very little attention to patients' emotions and fear. The students learned that a good surgeon should be aware of the importance of compassionate communication and respect for patient autonomy. In 142 narratives, 66 recounted instances of good communication while 76 mentioned witnessing bad communication. Good communication, as described by the students, showed empathy, involved enough explanation to the patient for an adequate understanding, and the delivery of sufficient and necessary information (i.e., informed consent). On the other hand, bad communication occurred when the explanations required by the patient were delivered very rapidly, without verifying the patient's understanding or without empathy. In a few situations (n=7), it was felt that the conversation was not friendly and was arrogant or authoritarian, or otherwise less than ideal.

> I witnessed during my surgical rotation an ethical situation where a surgeon asked a patient to communicate the list of medications that should be continued during the hospitalization. The patient was surprised that he did not know her list. The surgeon becomes more and more impatient and insists to have an answer from the patient, who remains silent and indicates that she is not able to provide a list. The surgeon became impatient and began to raise his voice. As a witness to this situation, I am confused and uncomfortable.

Communication of bad news (n=168)

Breaking bad news is one of the most difficult tasks in the practice of medicine, and medical education does not always adequately prepare students. Patients and families may not always desire a frank disclosure of terminal diagnosis or other bad news, but they nonetheless deserve empathetic communication. Student narratives were about interactions with patients, family, residents, and other health care professionals in revealing information about a terminal illness. In 89 narratives, communication with patients was considered as excellent, showing empathy, sincerity, and authenticity. Revealing bad news

by the surgical team was seen as excellent by many students but on some occasions the site for discussion was not ideal, intimacy was not always respected, or patients had to wait a long time before having access to the surgical team. On 79 occasions, the communication was below the standard expected: no communication, aggressiveness, impatience from the staff, insufficiently accessible for the patient or the family.

Obtaining Consent (n=110)

Obtaining consent is not always a simple task. A valid consent requires a variety of elements such as capacity, disclosure of information, and understanding by the patient. In their narratives, students described 110 occasions where they commented on the quality of patient consent. It was considered as high-quality on 43 occasions because it was voluntary, and patient comprehension as well as disclosure of information were adequate with alternative options offered. It was not perceived as done well on 34 occasions. For example, it was problematic because too paternalistic (n=8), insufficient disclosure of information (n=4), it was done too quickly (n=2), it was not voluntary or was missing information as well as options (n=20). Notable were 7 cases where consent was not obtained. Among the other difficulties reported by students were cases where patients were unable to decide (n=13) or the patient had psychiatric issues (n=4). On other occasions consent was referred to the court (n=1) or done by the family (n=7).

> While I was in the emergency room a 50-year-old patient with Crohn's disease presented with an anal abscess the patient was very anxious. As an extern, I notified the resident who informed me that there was availability in the operating room that evening and he planned to operate on him that evening. This situation made me think because I did not believe that the patient had given free and informed consent. The resident made no mention of the risks and benefits, no explanation Night and give to the patients taking for granted that they would accept without discussion. In my opinion, consent was not obtained in a professional and ethical manner.

> During my clerkship a surgeon had planned an amputation for a hospitalized patient without telling them. When we came to explain the details of the surgery and get her to sign the consent form, she was already at the operating room door. The patient was surprised and shocked and immediately refused the surgery. A few days later after a long discussion with the patient she finally agreed to the surgery realizing that it was really the only solution to her problem. In my opinion, the consent was not well done the first time, fortunately it was caught up and finally the patient had properly explained the nature of the surgery and the risks and benefits. A well done consent the first time would have avoided a lot of trouble for the patient as well as for the interveners and colleagues.

Confidentiality (n=56)

Incorporating privacy and confidentiality in delivering health care is regarded as essential, especially in the patient-clinician relationship. Patients have the right to expect confidentiality, however discretion in the health care system is not always respected. In 37 narratives, students thought there was a problem ensuring confidentiality by one member of the team. By contrast, it was found to be exemplary on 19 occasions. The location where confidentiality was lacking was most of the time on the ward (n=14), but breaches of confidentiality occurred in the elevator (n=2), in hallways (n=3), in emergency room (n=3) and even in the OR (n=1). Lapses in ensuring confidentiality by residents and students were frequently observed during morning round discussions carried out in public spaces, like the cafeteria (n=3). Use of photographs and digital recordings without ensuring confidentiality also occurred (n=6), as well as other issues (n=5).

Truthful disclosure (n=38)

Disclosure refers to delivering the relevant information for the patient to understand their condition, diagnosis, the different treatment options, and prognosis. Disclosure of information was reported on 38 occasions. In 28 narratives, it was believed to have failed because truth was not totally revealed by invoking therapeutic privilege (n=8) or simply hiding it from the patient without good reason (n=4). In 16 cases, patients had undue waits before receiving the information. There was also some concern raised by students because it was the family who was objecting to disclosure (n=6) or the patient themself (n=4).

Dealing with medical errors (n=33)

Medical errors occur in any surgery practice and its management is not simple. Truth telling is fundamental and involves the provision of information that is accurate, honest, and understandable by patients. The truth should always be told in respect for the patient; it is also essential to maintain confidence between the patient and the surgical team. Management of medical errors was raised as an issue in 33 narratives. Disclosure to a patient about a surgical error was done with honesty on 4 occasions but was not disclosed 3 times. Some errors were not reported as they should be because of refusal by staff to do so because patient had no sequalae (n=16). Students witnessed an error but were hesitant to denounce the situation on 10 occasions.

> A patient who had just been operated on for a colectomy was sent for an abdominal CT scan two days after his operation. The patient returns to his surgical unit and the resident finds that the exam was not ordered for this patient but for another. There was thus a medical error. Despite this, the surgical team decides not to inform the patient. I think that the note should have warned the patient and that it is a breach of the code of ethics.

Professional duties, conduct and attitude with patients and staff (n=143)

In 44 narratives, students observed compassion, empathy, and excellent communication (n=25), respect of patient autonomy (n=11) and respect of dignity (n=8) from the surgeon. In 99 reports they observed a lapse in the relationship between the patient and medical team because of lack of true compassion (n=15), lack of respect (22), or no respect of autonomy (n=10). They heard prejudicial comments from some senior surgeons when talking about patients, e.g., with regards to obesity, psychiatric problems, age, ethnicity, religion, or homosexuality (n=32). They also reported bad behaviour such as absence of adequate control, impatience, and anger (n=6) and lack of attention to patients' intimacy (n=9). Students witnessed bad jokes about some of the patients in the OR (n=4) and in other settings (n=1). Good relationships of staff with patients and family were very important for the students, who are seeking positive role models. Meeting patients with empathy and compassion was seen as key to true professionalism.

> A 60-year-old woman, she is taken to the operating room for abdominal surgery. The procedure is started by scrubbing the abdomen while the patient is completely naked. The anesthesiologist says aloud that the woman's breasts have been redone. The surgical resident and the nurses begin to discuss the old breast implants. The anesthesiologist then goes to touch the patient's right breast and says out loud that it is an old fibroid model. The resident manipulates the breasts confirming that they are heavy and indurated. The surgeon then entered the operating room and jokingly called out to the anesthesiologist, resident, and nurses to stop being jealous. As a student I was shocked because I thought this patient was being disrespected and the attitude was unprofessional.

Professional responsibility and commitment (n=34)

Professional responsibility for patients was reported 34 times: it was reported to be exemplary in 11 narratives but appeared to be problematic on 23 occasions. Lack of responsibility from the surgeon toward the patient was observed when the surgeon transferred patients to another physician (n=9), abandoned a patient (n=2) or denied availability for patients (n=12). Although most students focused on these as issues of professionalism and in relation to the code of ethics, some had been struck by the difficult resolution of ethical dilemmas happening in the practice of surgery when there was a conflict between principles of autonomy, beneficence, and justice.

> We are in a department meeting with residents and medical students. We are discussing a patient who has recently been diagnosed with cancer. The patient is very anxious and asks many questions of the surgical team. The surgeon openly complains about too many questions and the patient's anxiety with a condescending attitude. The team then looks at the patient's latest CT scan that was requested to complete the extension workup. Numerous large metastases to the liver were clearly seen. The surgeon in charge of the patient exclaims with joy because for him it is no longer a problem, it is a case that must be transferred to oncology quickly. One less case, he says, smiling... In my opinion, professional responsibility was not there, nor was empathy.

Relationships with medical colleagues (n=36)

Respect for colleagues when working closely with them appeared as very important for the students. They understand well the importance of good communication between the health care members to benefit the patient; and they manifested surprise when there was a lack of respect between colleagues. The review of the narratives indicates that the relationship between colleagues was questionable on 31 occasions; and it was reported as exemplary and excellent in only 5 narratives. Among the problems reported by students were: absence of respect for a colleague or member of the personal (n=11), no adequate communication (n=8), absence of collaboration (n=6), critiques of colleagues (n=9) and aggressivity towards colleagues (n=2).

> We are in the morning at the time of the patient visit and there is a certain animosity between the surgeons. With the residents we visit a patient who belongs to another surgeon. The surgeon who makes the visit that it is open and explicit and even rude in his total disagreement with the actions that the other surgeon chose to make. Residents and students are given feedback that encourages them to not act in the same way as the surgeon in question. The comments are made in the presence of the patient who is far from reassured. The derogatory remarks are made in an aggressive tone. The situation leaves a cold climate in the room and a patient shaken and stunned by the verbal storm. In my opinion, there is a blatant lack of respect towards another colleague.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Research Integrity and Research Fairness: Harmonious or in Conflict?

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Résumé
Les initiatives dominantes axées sur l'intégrité de la recherche modifient le paysage de la recherche en conduisant à l'élaboration et à l'application de règles, de lignes directrices et de normes auxquelles les chercheurs doivent se conformer au-delà des frontières. Ces initiatives accordent une attention croissante à l'importance de l'équité dans la recherche pour mener une recherche responsable. Toutefois, certaines parties prenantes considèrent que l'équité dans la recherche est distincte de l'intégrité de la recherche et qu'elle entre parfois en conflit avec elle. Afin de donner un sens à ces comptes rendus, j'explore la relation entre l'intégrité et l'équité de la recherche. Je soutiens que les initiatives dominantes en matière d'intégrité de la recherche sont actuellement en contradiction avec l'équité de la recherche. En effet, ces initiatives ignorent largement les points de vue anticoloniaux sur la recherche et perpétuent ainsi la colonialité dans la recherche. En outre, les initiatives dominantes ne s'engagent que superficiellement dans les aspects de l'équité qui sont les moins controversés et les moins actuels. En outre, ces initiatives d'intégrité de la recherche imposent à d'autres pays des idéaux eurocentriques sur la recherche responsable, contribuant ainsi à l'« impérialisme éthique ». Compte tenu de la vaste portée des initiatives dominantes en matière d'intégrité de la recherche et de leur influence sur la recherche, il est donc urgent d'élaborer un programme d'intégrité de la recherche anticolonial qui prenne l'équité au sérieux.

Mots-clés
intégrité de la recherche, équité, colonialité, injustice épistémique, impérialisme éthique

Abstract
Dominant initiatives focusing on research integrity are changing the research landscape by leading to the development and application of rules, guidelines and standards that researchers across borders have to abide by. There is an increasing attention within these initiatives to the importance of research fairness for conducting responsible research. However, some stakeholders view research fairness as separate and sometimes even conflicting with research integrity. To make sense of these accounts, I explore the relationship between research integrity and research fairness. I argue that dominant research integrity initiatives are currently at odds with research fairness. This is because these initiatives largely ignore anticolonial views about research and thereby perpetuate coloniality in research. Furthermore, dominant initiatives only engage superficially with aspects of fairness that are least controversial and current. Moreover, these research integrity initiatives impose Eurocentric ideals about responsible research to other countries, thereby contributing to "ethical imperialism". Considering the wide reach of dominant research integrity initiatives and their influence on research, it is therefore urgent to develop an anticolonial research integrity agenda that takes fairness seriously.

Keywords
research integrity, fairness, coloniality, epistemic injustice, ethical imperialism

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INTRODUCTION

Research integrity (RI) is often defined as doing research in line with high ethical, professional and methodological standards (1). Another way to think about it, which does not delve into potentially contentious questions regarding who determines these standards and who is excluded, is that doing research with integrity is doing research well. In this view, RI relates to behaviours that enable good research (2). As such, research ethics concerns, such as informed consent, are interrelated and overlap with RI ones (3).

In 2021, Evans and I pleaded for the research integrity (RI) community to take gender and diversity considerations seriously as an important element of fostering RI. This seems to have been a timely plea, as since then a number of papers and initiatives have taken place in the field of RI focusing on issues of equity, diversity and inclusion (EDI). For instance, racial and ethnic bias, fairness and equity were key topics covered by the 2024 World Conference for Research Integrity (WCRI) (5). One of the results of the 2022 WCRI was the Cape Town Statement on fairness, equity and diversity in research (6). The next World Conference on Research Integrity, to be held in Vancouver in 2026, features "Indigenous ways of being" as a key theme (7). Additionally, the revised version of the European Code of Conduct for Research Integrity published in 2023 (8) has added recommendations related to this topic "reflecting greater awareness in the research community of mechanisms of discrimination and exclusion and the responsibility of all actors to promote equity, diversity, and inclusion". The UK Research Integrity Office (UKRIO) has introduced a webinar series on EDI and linked to various initiatives to improve EDI in research (9).

Recognition that healthy research cultures are key to responsible research practices (10) in particular has had an influence on the increased discussion of EDI issues in the context of RI. For instance, the future Netherlands Code of Conduct for Research Integrity will likely place a greater emphasis on fostering a positive research culture (11), and issues of EDI might be addressed

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explicitly there. In the UK, much work has already been done on fostering a healthy research culture in different research institutions, with EDI being considered as a key factor to address (12).

In 2024, Sempa and colleagues conducted a mixed-method empirical study exploring the alignment of RI and research fairness in the field of global health. Their conclusions from the outcome of this study were that RI aligns well with research fairness "as only science that is conducted with fairness can be considered responsible and conducted with integrity" (13). Based on this, they argue that institutions should promote RI in a way that addresses biases, privileges and inequities in research. While the study was focused on the field of global health, their conclusions can be assumed to be applicable to a wider range of research fields.

While the concepts of equity, diversity, inclusion, research fairness, and research justice have slightly different meanings depending on who uses them and how, I will use the term "research fairness" or RF to refer to all of these collectively; this term is more often referred to in the RI literature than justice (6,13). The reason to treat all these concepts collectively is because they are often used together by RI initiatives, with the belief that they lead to similar goals (6,13). While partially overlapping, these concepts might sometimes not align perfectly. However, studying the exact relationship between these concepts falls outside the scope of this paper.

Taking into account the consideration of RF in RI initiatives in the past years, it seems that RI and RF are interrelated, and that to foster RI, it is necessary to foster RF as well. At the same time, there are also conflicting indications suggesting that RI is not harmonious with RF. In my own empirical work engaging with different RI stakeholders across Europe, I have frequently received criticism about trying to include RF concerns in RI initiatives, with arguments indicating that RF is separate from RI (14,15). In some cases, stakeholders explicitly mentioned that promoting RF should not come at the expense of doing high quality research, suggesting that in some regards, RF and RI can clash. This line of reasoning is also mirrored in RI policy documents, such as the Hong Kong Principles for assessing researchers (16); during the development of this document, hundreds of research stakeholders were consulted for input, yet none raised issues related to RF as important to consider for RI when assessing researchers (17).

In this paper, I aim to make sense of these conflicting accounts by exploring the question: what is the relationship between RI and RF? My main line of argument will be that dominant RI initiatives are currently in conflict with RF, since they reproduce rather than tackle existing injustice. I do this in four steps. First, I argue that by ignoring works done by anticolonial[1] scholars, current dominant approaches to RI do not take research RF seriously. Next, I discuss how the increasing engagement of those in the field of RI with topics such as EDI constitutes a superficial interest in RF and shies away from the most important discussions. To illustrate this point further, I zoom in on the case of epistemic injustice in Afghanistan as a question of integrity which RI initiatives ignore. I then argue that this superficial engagement with RF makes RI initiatives particularly problematic considering that many are guilty of "ethical imperialism". Finally, I conclude by stressing the need to develop an anticolonial RI agenda so as to prevent those of us interested in fostering integrity in research from perpetuating injustice.

Before I delve into the contents of the paper, I would like to make a few disclaimers about my aims. First, I write this paper in the position of an Afghanistani RI researcher who is becoming increasingly concerned with the field's ignorance of the relationship between past and present colonialism and research. Secondly, I do not seek to convince RI experts who are not interested in the topic of RF or do not see coloniality as an important problem in research. Rather, I am focused on provoking engagement with potential critical allies among the RI movement who want to pursue RI in a more fair and anticolonial manner. Thirdly, colonialism takes many different shapes and forms in different parts of the world. Since this paper — barring the example on Afghanistan in one section — is not focused on a specific country, I do not elaborate on the different forms, but rather use the term "colonial interest" and "colonial endeavour" to refer broadly to all efforts at domination and control of non-Europeans by Euro-Americans, be they direct (as with settler colonialism) or indirect (as with neocolonialism or with Euro-American backed internal colonialism outside of Europe, such as can be seen in Afghanistan). Not focusing on one country limits my analysis from being precise regarding the specifics of colonialism in different regions but is necessary to discuss the global implications of the field of RI. I recognize that this paper touches on a lot of issues related to colonialism in research. The main aim is to shed light on the neglect of RF by dominant RI initiatives, rather than to flesh out all these issues. I thus only allude to these issues to achieve the paper's aims — I hope that in the future, more RI initiatives will take RF seriously and further explore some of the issues that are alluded to here.

Fourthly, I do not attempt to educate readers about everything there is to know about anticolonial, decolonial or postcolonial scholarship, even if such a thing were possible and I was the right person to do so. Rather, I highlight and link to some of this literature to make my case so that I can focus on constructive engagement rather than the "emotional labor"[2] (18) of convincing the inconvincible. Finally, my criticism about the relationship between RI and RF is specifically about dominant, Euro-American initiatives focusing on RI, rather than RI as a concept itself. I recognize that there are many ways to foster RI that do take RF seriously, and in fact believe that truly fostering RI requires addressing RF.

[1] I use the terms 'anticolonial', 'decolonial' and 'postcolonial' interchangeably, despite them having different approaches and origins.
[2] Referring to the emotional burden people from minority backgrounds often experience as a result of being expected to explain to and convince white people about issues related to injustice and inequity, when white people refuse to do the work of "seeing" and addressing these issues themselves.

THE FIELD'S IGNORANCE OF ANTICOLONIAL SCHOLARSHIP

In this section, I first discuss the dominant narrative about RI to show its ignorance of anticolonial scholarship, and then assess the implications for RF, arguing that that this leads to a conflict between dominant RI initiatives and RF.

The dominant RI narrative

The rationale often used to support RI initiatives relates to the idea that RI is necessary to improve trust in research; if researchers conduct research responsibly (i.e., following well-considered and appropriate methods), then research can be considered trustworthy. As the Singapore Statement on Research Integrity states: "The value and benefits of research are vitally dependent on the integrity of research" (19). This view assumes that research, when done well, has value and is beneficial. This is illustrated in the European Code of Conduct for Research Integrity (8), which states that:

> Research is the quest for knowledge obtained through systematic study, thinking, observation, and experimentation. While different disciplines may use different approaches, they each share the motivation to increase our understanding of ourselves and the world in which we live.

This discourse can also be seen in different countries' codes of conduct on RI. For instance, the Canadian Tri-Agency Framework on the Responsible Conduct of Research (20) frames research as "…a natural extension of this desire to understand and to improve the world in which we live, and its results have both enriched and improved our lives and human society as a whole".

Research — or at least research when done ideally — is framed in this discourse as an endeavour that can bring value to the world, which shows that the dominant narrative in the field of RI frames research as an innocent and societally beneficial concept. Furthermore, the general approach in the field of RI is to view good research as that which is free from "pressure from commissioning parties and from ideological, economic, or political interests" (8), despite acknowledging that funders, both public and industry, can have an influence on research agendas (21). This is reflected in the frequent mention of Mertonian norms as central to good research practice, and the conceptualization of breaches of these norms as breaches of RI (22-24). The Mertonian norms of communism (common ownership of research), universalism (impersonal and objective research), disinterestedness (research free from personal bias), and organized scepticism (the need for critical discussion in the research community) (25), are thus often considered from the perspective of RI as ideals to strive towards (26). Specifically, the norms of universalism and disinterestedness imply that good research should always aim at 'objectivity' rather than addressing potentially 'biased' political interests of researchers. The view of research taken by those dominant RI initiatives thus assumes that research — when done well — is, in addition to innocent and beneficial, also apolitical.

Implications of the dominant RI narrative for RF

Claiming that research is innocent and apolitical assumes that any potential harm caused by research is incidental, or — using a metaphor often mentioned in the field of RI — caused by bad apples (i.e., unethical researchers), spoiled barrels (i.e., unethical institutions) or even infested orchards (i.e., problems in the research system such as perverse incentives) (27). This assumes that if all research stakeholders abide by standards of RI that are spelled out in codes of conduct on RI (8) — namely, the apples, barrels and orchards are clean — then research cannot be harmful. Yet, this view largely ignores that the view on what 'harm' is in research, and the resulting formulation of RI standards, have been developed in a colonial and inequitable world in which certain stakeholders' voices have been included, while others have been excluded. Given this, the assumption that good research is neutral assumes that the interests of the minority who has determined what RI is — i.e., those holding positions of power in research, who largely overlap with the demographic of white cis-gendered males from economically wealthy countries benefiting from colonialism — are not political but rather the objective standards to which all researchers should aspire.

The result of the assumption that 'neutral' and 'objective' is what falls in line with the interests of those in positions of powers, implies that only interests that deviate from that are thus considered as political; it is only those deviating views that confront and question the established global order from which the powerful benefit. As such, when the field of RI promotes ideal research as being apolitical, it asks researchers to work within rather than question or topple the inequity present in the world. Going back to the apples, barrels and orchards analogy, the problem with research — rather than merely being bad apples, spoiled barrels and infested orchards — is that the establishment of the barrels and orchards, in which the apples are situated, is deeply entangled with the stealing and killing that characterizes Euro-American colonialism, both as cause and consequence. In other words, the barrels and orchards in their current form are both a result of colonialism but also justification for and enabling of colonialism. As such, these structures maintain and reproduce the current organization of the global order, albeit with possibilities for minor changes within the orchard so long as this does not topple the overall global order.

This assessment might sound both extreme and abstract, but opening up to anticolonial scholarship allows us to see what this means in practice. One of the most highly cited accounts about the relationship between research and colonialism comes from Maori scholar Linda Tuhiwai Smith, who states that:

> The word itself, 'research', is probably one of the dirtiest words in the indigenous world's vocabulary…it stirs up silence, it conjures up bad memories, it raises a smile that is knowing and distrustful. Just knowing that someone measured our 'faculties' by filling the skulls of our ancestors with millet seeds and compared the amount of millet seed to the capacity for mental thought offends our sense of who and what we are. It galls us that Western researchers and intellectuals can assume to know all that it is possible to know of us, on the basis of their brief encounters with some of us. It appals us that the West can desire, extract and claim ownership of our ways of knowing, our imagery, the things we create and produce, and then simultaneously reject the people who created and developed those ideas and seek to deny them further opportunities to be creators of their own culture and own nations. It angers us when practices linked to the last century, and the centuries before that, are still employed to deny the validity of indigenous peoples' claim to existence, to land and territories, to the right of self-determination, to the survival of our languages and forms of cultural knowledge, to our natural resources and systems for living within our environments. (28, p.1)

Smith, here, argues that research is seen by Indigenous peoples as harmful. Her examples of the ways that research has harmed Indigenous peoples across the world highlight the relationship between colonialism and research.

Those working within dominant RI initiatives might respond to this quote by arguing that more responsible research (i.e., done ethically and with integrity) would ameliorate the kinds of harms that Smith outlines. They might argue that better informed consent procedures, ethics review, appropriate research design, careful inference and interpretation of data, training and supervision, and responsible data management would prevent the harms that Smith discusses. This response would reflect the current priorities and understandings of good research by dominant initiatives in RI (14,29). However, this does not get to the core of Smith's critique of research.

For example, if we zoom in on Smith's criticism of how researchers would measure the intellectual ability of Indigenous peoples by filling their skulls with millet seeds, we can see that this criticism is ultimately about the racist dehumanization of those who had their skulls measured as well as their communities. Measures such as informed consent procedures, even ones focused on community consent rather than individual consent, would not necessarily address the core issues of racism and dehumanization. It is possible — albeit more difficult — to be racist and dehumanize while conducting perfect informed consent procedures, since research participants and communities can be informed, even consent, but then be mistreated. As Tauri (30) discusses, current research governance frameworks privilege Eurocentric understandings of good, ethical research, such as informed consent. They are designed not so much with the goal to protect research participants but can rather serve "as a politics of containment that at once renders invisible the importance of relationships in Indigenous research, while asserting the right of the institution to determine the 'correct' way that research should be conducted" (30). Therefore, in a colonialist or neo-colonialist world, trying to prevent racist dehumanization in research merely through appeal to the Eurocentric[3] process of informed consent will not suffice. While I have elaborated specifically on how the procedure of informed consent fails to fully address the racist dehumanization in this example, a similar analysis could be done for other accepted dimensions of RI by dominant initiatives, including ethics review, appropriate research design, careful inference and interpretation of data, training and supervision, and responsible data management. None of these priorities focused on in dominant research ethics or RI initiatives is committed to challenging the coloniality of research in which racism is ingrained[4]. Rather, what is needed is to challenge the source of the dehumanization, namely the colonialist or neo-colonialist world itself.

The role of research in colonialism has been widely discussed by anticolonial scholars. For instance, Tsosie (31) discusses how canonical philosophers such as Mill, Locke, Hobbes, and Hegel played a key role in the justification of settler colonialists stealing lands from natives in different parts of the world. More specifically, these philosophers — albeit with some nuanced differences — all differentiated between white European settlers as rational, to be contrasted with the ignorant and savage natives. The philosophers used this distinction in the humanity of the two groups to argue that Europeans had a right to plunder the lands of the "savages" for the sake of progress and development. Tsosie (31) argues that not only philosophy, but also the sciences contributed to this justification by emphasizing this difference in superiority between Europeans and natives. For instance, fields such as evolutionary biology, craniology, and anthropology treated Europeans as the results of natural selection and as such, superior to Africans who were considered less evolved and more primitive (31). In these accounts, natives in settler-colonial regions were seen as in-betweens who could reach superiority by becoming more akin to white Europeans (31). These distinctions were thus grounded in research and used as a tool to justify colonialist violent actions against Africans, Indigenous, and other peoples in the world. Namely, the view that these "others" are not humans justified colonial conquests and subjugation of non-Europeans, through the idea that non-Europeans do not have to be treated as equals but need to be saved through European domination in order to become more civilized. The fact that colonialist justifications have been grounded in research, historically, is not surprising given Wynter's (32) account of the role of research in the modern world. Wynter argues that the sciences and humanities were not incidentally used by colonialists for pushing their political agendas forward. Rather, modern sciences and humanities are themselves a political project that has been born out of a social order devised by the white "European Man" in which he places himself as the pinnacle of humankind. As such, the sciences are not only firmly grounded in the assumption of difference between the perfect white European Man as opposed to the 'Other', they

[3] Eurocentric refers to the focusing on the interests and views of Europeans and European diaspora.
[4] It is nonetheless good to see that some guidelines on dealing with ancient human remains (e.g., the Norwegian guidelines) do not reduce the issue of respect in cases like this to only procedural concerns like informed consent, but rather explicitly frame the importance of respect particularly for research participants and human remains from marginalized backgrounds, thus touching on the issue of dehumanization and racism.

grew due to a need to further cement and reproduce this distinction. Wynter, like Tsosie, gives the example of evolutionary biology as a clear example of this political agenda.

The legacies of colonialism for knowledge production are ever-present. Hegemonic modern academia is undeniably Eurocentric. This can be seen in the fact that the richest and most influential funders, publishers and institutions are all situated in the Global North[5]. That is not to say that knowledge production does not take place in or by people of the Global South; the Global South has always engaged in knowledge production activities. Rather, the problem, as Francoise Verges (33) puts it, is that hegemonic modern academia simultaneously treats non-Eurocentric forms of knowledges and knowledge production as non-existent, while appropriating and extracting these knowledges in the form of 'data' to further colonial interests. As such, marginalized peoples are often not accepted as valid authorities by the academic world to produce knowledge as intellectuals; yet their knowledge is appropriated as Euro-American researchers collect and use their knowledge as 'data' which they can misinterpret and commodify to further the capitalist global order. By doing so, researchers simultaneously appropriate, distort, marginalize and erase other ways of knowing. This leads to what has been referred to as epistemic alienation for the marginalized — "the distortion of one's native way of thinking, and of seeing and speaking of one's own reality" (34, p.32), and epistemicides — "the killing or attempted killing of knowledge systems that are different from modern by global scientific institutions and practices" (35, p.92).

Taking all of this into account, when Smith is criticizing research for being harmful, her point is not to say there are bad apples, spoiled barrels or infested orchards. Rather, she is arguing that research has been part and parcel of the colonial endeavour. As such, Smith's critique relates to how research has led to physical injustices such as the stealing of lands and lives, but also epistemic injustices such as epistemic alienation and epistemicides. It is thus, not better informed consent procedures, methodological approaches, or supervision skills, that can ameliorate the harms that research poses on oppressed peoples. Instead, what is required is to address the coloniality of the research endeavour. Yet, the field of RI addresses the former, while largely ignoring the latter.

If the RI community is convinced that "only science that is conducted with RF can be considered responsible and conducted with integrity" (13), then discussions about colonialism, epistemic alienation, and epistemicide would be front and centre in RI initiatives. Instead, even RI initiatives focused on RF and led by those located in countries in the Global South — such as the Cape Town Statement on fairness, equity and diversity in research[6] — largely ignore the coloniality of research (6). Granted, the article introducing the Cape Town Statement does discuss 'injustice' in collaborations by stating that "high-income countries reap greater benefits from global collaborations than do LMIC [low and middle income country] collaborators" and also mentions that equity is important to address "a long history of colonial exploitation and inequitable use of Earth's resources"[7] (6). However, these two issues are discussed separately from each other, abstracting the reasons for and decontextualizing unjust collaborations, while the issue of colonialism is mentioned once in passing towards the end of the article rather than highlighting from the start how injustice, research and colonialism are interlinked and reinforce each other. Furthermore, these terms are mostly absent from the Cape Town Statement itself. The statement does promote 'epistemic justice' explicitly and defines it as "ensuring that the value of knowledge is not based on biases related to gender, race, ethnicity, culture, socio-economic status, etcetera" (36). However, this is done without even mentioning that epistemic *injustice* is a problem in research. Yet, as Medina (37) points out, to take the coloniality of research seriously, it is important to examine carefully the kinds of particular and concrete injustices imposed on societies by the politics of knowledge production. Medina argues that "the priority of real [epistemic] injustices over ideal justice is crucial" since conceptualizing some ideal justice can prevent us from seeing and taking seriously the actual present systematic injustices present in the world "minimizing the importance of the epistemic obstacles and problems" (p.12-13) that oppressed people experience. Taking into account Medina's argument, when the Cape Town Statement addresses epistemic justice as a positive ideal to strive for, it avoids commitment to actually confronting real injustices that are present everywhere in research.

It is not surprising that RI initiatives ignore the coloniality of research, when taking into account the colonial context in which RI initiatives find themselves. Lanzarotta (38) argues that bioethics as a field is situated within a colonialist framework and seeks to reproduce it, by deflecting from questions of justice and fairness to universalizing Eurocentric understandings of the ethical. As such, when bioethics structures and processes, which are meant to safeguard societies and participants from harm in research, are developed by and for the colonialist endeavour, they contribute towards legitimizing and perpetuating harm caused by colonialism rather than ameliorating it. In the case of RI, this can be seen in the way that initiatives ignore RF concerns discussed by anticolonial scholars. Through ignorance, dominant RI initiatives, rather than being aligned with RF, are complicit in and reproduce the coloniality of research.

To summarize, the dominant narrative in RI initiatives is that research is apolitical, innocent and beneficial, which ignores the coloniality of research and its harms. By ignoring colonial injustice related to research, and thus reproducing it, dominant RI are in conflict with RF. This is the case, even when they claim to promote RF. In the next section, I address how RI initiatives

[5] I use the term 'Global North' to refer to countries profiting from global neoliberalism, capitalism and colonialism, while with 'Global South' I refer to countries marginalized and oppressed by global neoliberalism, capitalism and colonialism, as well as individuals within 'Global North' countries that are marginalized and oppressed by these structures. I acknowledge that these terms do not account for the diversity of countries both in the Global North and the Global South, but I use the term as a heuristic tool to differentiate differences in power in research broadly.
[6] Although the Statement is led by members of the European diaspora, who are first and last author.
[7] This choice of words is itself problematic in that it reflects the assumption that marginalized peoples want to 'exploit' the Earth's resources.

that refer to RF explicitly could still be at odds with RF by focusing on RF superficially and ideally rather than actually confronting injustice.

‘SANITIZING’ INJUSTICE

While teaching about RI and research ethics, I have been challenged multiple times by course participants who question the silence of the field of RI when it comes to colonialism in research, by asking: “*How can we talk about integrity or ethics while condoning genocide*?” Many of my collaborators would respond to the PhD candidates by saying that the field of RI aims to make research more trustworthy and that issues of RF, while important, do not fall under the scope of the field. The problem with such responses is that they refuse to acknowledge research’s role in colonialism and the resulting harms, and how this leads to biases in knowledge production. They also deflect accountability for their role in perpetuating injustice. Since RI is about doing good research, the only way to do research with integrity is to also have RF. The observation that in reality, dominant RI initiatives neglect and conflict with RF shows that these initiatives have a distorted, Eurocentric understanding of “good research” which privileges Eurocentric priorities about research, such as transparency and reproducibility, over those of equity and justice.

Increasingly, this is changing, but still in an unsatisfactory way. During the last World Conference on Research Integrity, RF was addressed extensively, both in sessions focused on implementing the Cape Town Statement, but also in a plenary addressing “Tackling racial and ethnic bias when translating research into policy” (39). Two of the talks in the latter were given by minority women scholars who addressed the role of race construction in colonialism, and how research plays into the phenomenon (40,41). Unlike the majority of dominant RI initiatives, these scholars actually addressed the coloniality of research. While a welcome change to see such critical talks taking centre stage in the field of RI, I think it is important to acknowledge that they are still rare and address the colonial legacies of research rather than current realities.

It seems that the field of RI, as it is reaching out to stakeholders outside of the Euro-American context, is accepting that RF concerns are important for the research endeavour. However, while opening up to this the field ‘sanitizes’ injustice, as Wynter (32) would say, by focusing on issues related to RF that are least controversial and current. By narrowly framing RF as EDI concerns, the field is able to engage in “diversity ideology”, in which racial difference and participation is lauded and applauded with the purpose of having “whites…maintain dominance in multiracial spaces” (42, p.890), but failing to point at the roots of the systemic problem. In other words, the field of RI seems to be opening up to the idea of RF as being integral to it, so long as this does not force the field to question the colonial framework in which it is situated. This is not unique to the field of RI. As Hasan (43) argues, postcolonial literature itself is guilty of this phenomenon; for example, while largely influenced by the work of Edward Said on Orientalism, which was to a large extent grounded in Said’s resistance as a Palestinian to Zionist Israeli colonialism, postcolonial scholars often ignore current injustices inflicted by colonialism, including the case of Palestine. Hasan argues that “full of rage for nineteenth-century European colonialism, postcolonial theorists often exercise extreme liberty to use pejorative terms to castigate past colonisers and agreeable expressions to show sympathy to their victims” but ignore current violence and injustice, and so “advance their academic career” while “scarcely benefit[ing] humanity” (p.8). The field of RI, as it is paying increasing attention to RF, is following the same approach of ‘sanitizing’ injustice to incorporate RF in a way that does not question the global order.

Yet, as an Afghanistani woman and a former refugee, looking at the state of the world I wonder what the use is of fostering RI if it is narrowly defined as cleaning the apples, barrels and orchard. If the aim of the orchard including the barrels and apples is to lead to increased militarization and border surveillance — with these being research priorities in Europe in the coming years (44,45) — why should we be interested in cleaning them up? Should we not rather work on deconstructing and reconstructing the orchard, barrels and apples?

If ‘integrity’ is about following moral values, even in difficult circumstances, then fostering RI should be more than just addressing issues related to reproducibility. Instead, the past and present injustices caused by research should also be addressed. This involves necessarily becoming political. Advocating for apolitical research neutrality is equivalent to accepting and reproducing that order, regardless of how unjust it is. As Said (46) writes about the neutrality of research, it is not possible to disentangle individuals from the social context in which they are embedded. Euro-American researchers from countries benefiting from colonialism cannot escape imperialist powers that “impart on their civil societies a state of urgency, a direct political infusion as it were, where and whenever matters pertaining to their imperial interests abroad are concerned” (p.11). What Said is referring to here is how current events and state and commercial interests inherently shape the research agenda, compromising research freedom. Research agendas do not just come from a vacuum of researchers’ intellectual interests. Research funders, such as government, industry, and charities, predetermine research agendas with their calls, based on explicitly political, commercial or other societal interests. All these interests have an inherent political dimension, since they have a particular normative understanding of what research should aim for and contribute towards. Even fettered, i.e., researcher-defined, research projects resulting from open calls are political, in the sense that the researcher’s interests and ideas are also influenced by developments in research around them, which are largely determined by other actors. As such, research always serves political goals.

Therefore, as Said argues, advocating for ‘nonpolitical’ knowledge as ‘true’ knowledge “obscures the highly if obscurely organized political circumstances obtaining when knowledge is produced” (p.10). The “adjective of ‘political’ is used as a label to discredit any work for daring to violate the protocol of pretended suprapolitical objectivity” (p.10); in other words, while all

research is political, when certain research projects challenge the global order and thereby work against the political interests of powerful institutions, it is possible to use the label of 'political' to discredit them. Therefore, it is not possible for research to be apolitical or objective, since it is always political in some way and to some extent, with certain projects being more or less explicitly so. The pretence of 'apolitical' research is used to take a specific political position in research, namely that of accepting and endorsing the established order. To confront inequity and injustice, it is important to expose this pretence and advocate from a different political angle, which challenges the inequity and injustice present within this order.

To summarize, in this section, I have argued that while dominant RI initiatives are increasingly referring to RF as an important goal to strive towards, they are only engaging superficially with RF concerns that are least current and controversial. To illustrate this with an example, in the next section, I zoom in on a current case of epistemic injustice in research, which is completely neglected by RI initiatives.

AN EXAMPLE: EPISTEMIC INJUSTICE IN AFGHANISTAN AS A RESEARCH INTEGRITY ISSUE

With this example I focus here on one of many current cases of epistemic injustice in my home country, Afghanistan. This case highlights how questions of injustice and RI actually interrelate and therefore show that if the field of RI was more harmonious as opposed to in conflict with RF, such questions would be at the forefront of the RI field's agenda. Ebtikar (47) writes the following about epistemic injustice in Afghanistan:

> The knowledge that we have of Afghanistan...is catered to an Anglo-American public and grounded firmly in previous imperialist epistemologies. The ethical and intellectual grounds for power, control, and domination are premised on outdated ethnographies, maps, understanding of languages and customs, ethnicities, and so on. This biased and erroneous form of knowledge production theorizes and philosophizes peoples and societies, which at times may seem almost unrecognizable to its inhabitants, to become universal objective truths... the people who are written into these bodies of literature have little to no access to them. Knowledge is produced by, and for, individuals within exclusive spaces, many of whom serve as gatekeepers and regulators. Local histories and knowledge production have been given little value, and few experts of [Afghanistan's] heritage are ever consulted... As I am writing, the people of Afghanistan are dying... [The US] along with a few glorified Afghan elites, have rebranded the Taliban from a terror group to a legitimate political group with shared grievances. To change public perceptions about the Taliban, several research institutes in Washington began to highlight how the group has transformed...

As Ebtikar points out, Eurocentric research (which is dominant in the academic literature) about Afghanistan has been and continues to be used as a tool for colonialist endeavours by Euro-America. Despite the Taliban being recognized in academic discourse as radical Islamists with horrendous human rights records immediately post 9-11-2001 when the US saw them as a threat and invaded Afghanistan (48), as the policy of the US shifted, so too did the narratives about them in the academic literature. When the group became less of a threat to US foreign policy and more of an instrument, research institutions changed the narrative to refer to certain factions of the Taliban as 'moderate' and 'reformed' and advocated for the need to negotiate with them (49-51).

This narrative was then used to justify the Doha talks with the Taliban, in which the US is considered to have essentially handed over power of Afghanistan to the formally recognized terrorist group (52). This has led to the suffering of 40 million people in the country who are currently living under what could be termed as "gender apartheid", as well as multi-ethnic cleansings and forced displacements (53-55). Despite it becoming increasingly difficult to justify any part of the Taliban as moderate or worth negotiating with, some — sometimes powerful agents — continue to push this narrative in media and policy (56,57). While the dominant research narratives mirror those of Euro-America's political interests, local knowledge and experiences about the country are deemed as untrustworthy and invalid. When local knowledge is given a platform, it is often the voice of intellectuals who form the small but powerful group of oppressors from the country, rather than the voice of the oppressed (58). As such, knowledge production about Afghanistan is not only influenced by injustice but also reproduces it. This example shows how research has not only historically (in the "bad old days of colonialism") been political, un-innocent, and harmful, but how it continues to be used to fuel and maintain violence in the world.

The case of Afghanistan shows that colonialism and the manifestation of clear political agendas cause biases in the research endeavour, by creating distorted narratives about people, places and politics. If fostering RI is about doing good research and addressing biases, then the field of RI should be interested in addressing past and current colonialism. Instead, the field of RI reduces questions of bias to those related to clinical trials and publishing, such as publication and selection bias — the types of bias that are least likely to influence the global political order. While it could be argued that RI is not concerned with questions related to the epistemic biases in knowledge production concerning Afghanistan, because that knowledge production is mostly carried out by semi-political institutes and NGOs rather than universities, the fact that this research is carried out by such institutes constitutes the epistemic bias problem. As Monsutti (59) argues, the "agendas and terminology of UN agencies, international NGOs, governmental bodies, and armed forces have thus come to percolate the entire political economy of research in Afghanistan" (p.275). The colonial induced violence present in the country has "hindered the development of independent social sciences in Afghanistan" (p. 275). As explained by the recently established Afghanistan Research Network, this is because curtailing of freedom of speech and physical violence in the country prevent those from Afghanistan from being able to conduct research on the country, while Western experts are allowed to do so despite being monitored by the

authorities (60). Furthermore, as Said articulates in Orientalism (46), the trend of having Western social scientists focus on dubiously collected statistics rather than the lived realities and histories of the people of the Near East, is part and parcel of the modern colonialist agenda in the region. Taken together, violence and oppression in Afghanistan are interlinked with the research economy related to the country, thereby supporting epistemic injustice and bias in knowledge produced about the country. Yet, the field of RI ignores such biases in Afghanistan and elsewhere since the field is concerned primarily with issues that directly speak to Eurocentric interests in research.

RI AND ETHICAL IMPERIALISM

As argued in earlier sections, while dominant RI initiatives claim to improve the trustworthiness of research, they operate within and reproduce a colonialist research framework that ignores the role of research in injustice and colonialism. While dominant RI initiatives are increasingly showing themselves as becoming engaged with issues of research RF, these efforts only show a superficial engagement with RF concerns that are least controversial, current or effective in terms of challenging the global social order. This is particularly problematic considering that Euro-American RI initiatives are not limited by the geographic context in which they originate.

Funders and publishers increasingly set requirements for potential applications related to RI (61). While the biggest and most influential funders and publishers are located in the Global North, their reach is much wider with the Global South also dependent on their infrastructure. As such, RI standards and requirements originating from the Global North are imposed on the Global South. This phenomenon can be referred to as a type of “ethical imperialism”, a term that was originally coined by Schrag (62) to refer to how biomedical standards of research ethics are imposed on the social sciences, but also equally — if not more — applies when discussing the geographical reach of RI initiatives.

In my own experience of collaborating on a European project which aimed to develop RI tools for European institutions (21), I often received comments and questions on whether the tools could be generalizable beyond Europe. I felt this as pressure from collaborators, audience members at presentations, and reviewers to promise that the tools are applicable in all research settings across the globe. I found this to be very strange considering that the tools were developed together with stakeholders situated within the European context; promising the applicability of the tools elsewhere would apply a product developed based on European values and attitudes on countries in other contexts and thereby contribute towards ethical imperialism. Yet, considering that the European Commission — the project’s research funder — is keen to “spread European values beyond its borders” (63), it should not have been surprising to see such expectations about the project. Many other Euro-American RI initiatives are likely to be ridden with the same type of ethical imperialism.

This is a problem for two reasons. First, since the standards of RI that are often imposed on the Global South originate in the Global North, they are not tailored to the Global South’s priorities regarding knowledge production. As such, they incentivize Global South researchers to define good research, not on their own terms, but on the terms of Global North countries. In this way the concerns related to integrity that are most important for the research occurring in local contexts in the Global South, such as epistemic biases, are ignored, and instead the Global North’s definition and agenda for RI are upheld. This limits the freedom of researchers outside of Euro-America in how they can approach research, as it forces them to abide by Eurocentric standards.

Secondly, since these standards originate from the Global North and are appropriate for Eurocentric approaches to knowledge production, the Global South will always fail to meet these standards in as optimally a way as demanded by the Global North (64). For instance, during conferences, I often heard RI stakeholders from different regions in the Global South discuss how it was important for their institutions to meet “world standards” with regard to the responsible conduct of research so as to be eligible for funding. “World standard” in this context was used as a synonym for meeting the standards set by Euro-American players in research. These views reflect the narrative that Global North countries are word leaders when it comes to doing good research, whereas those in the Global South need to “build capacity” and “catch up”. Such a narrative is not surprising, given that the definition of “good research” set by RI initiatives is highly Eurocentric. This distorted narrative of “world leaders” versus “those needing to catch up with regard to responsible research” reproduces marginalization of knowledge produced in Global South countries as being inferior. In making this claim, I am not oblivious to the fact that due to colonialism, many countries in the Global South do have less resources to do research. Rather, my argument is that the point about resources should not be conflated with a mistaken view that knowledge production activities in the Global South should be measured against a Eurocentric yardstick regarding ethics and integrity.

CONCLUSION

In this article, I argued that despite recent attempts to align RI objectives with RF, dominant RI initiatives at present are in conflict rather than harmonious with RF. Dominant RI initiatives largely ignore anticolonial views about research. They only superficially engage with certain elements of RF that are less contentious, staying clear of RF concerns that are related to current colonial events. While engaging in RF only superficially, dominant RI initiatives impose their Eurocentric views on responsible research across different regions in the world, thereby committing “ethical imperialism” and reproducing injustice in research.

RI initiatives have a large impact on the global research order, by introducing policies and requirements that funders, publishers and research institutions impose on all researchers. Given that RI initiatives are changing the research landscape rapidly, there is urgent need for an anticolonial RI agenda. This agenda should be a radical one that does not engage in “diversity ideology” (42), but rather openly and explicitly challenges the relationship between research and the current colonial global order, with the aim to fight epistemic injustice. Such an agenda would require, for instance, engaging in discussions about challenging the barrels and orchards of research, when depending on them for our livelihoods as researchers, as well as what it means to be a part of the problematic structure of apples, barrels and orchards as a marginalized researcher. With this article, I hope to bring this urgency to light and find critical allies who are interested in building such an agenda. I recognize that this might be a difficult task that is met with much resistance from dominant RI initiatives. Going against the global social order is not easy. Yet, considering the contribution of research towards injustice in the world, including genocide, terrorism and violence, it is necessary.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Mental Health, AI-based Care Robots and Fair Access to Healthcare

Mario Kropf[a]

Résumé
La santé est généralement considérée comme une condition préalable importante pour la réalisation des objectifs de la vie et revêt donc une grande importance dans la société. De nombreux auteurs et leurs points de vue indiquent également clairement que la santé peut être considérée comme une valeur morale, pertinente d'un point de vue éthique et qui doit être promue. Ces dernières années, de nombreuses crises, des conflits armés, la numérisation et, plus généralement, le rythme rapide de la vie en société ont contribué à sensibiliser à la santé mentale. Cet article traite d'une analyse éthique de la santé mentale dans le contexte des robots de soins basés sur l'IA. Les robots compagnons sont de plus en plus utilisés dans le secteur des soins et cette tendance se poursuivra dans un avenir proche. Toutefois, la question se pose de savoir dans quelle mesure ces machines peuvent contribuer à la santé mentale lorsqu'elles interagissent avec des personnes recevant des soins. Dans un premier temps, la pertinence de la santé mentale et les implications éthiques sont présentées. Dans un deuxième temps, les robots de soins et leur influence potentielle sur la santé mentale des personnes nécessitant des soins sont examinés. La troisième étape montre comment un accès équitable à la valeur de la santé (mentale) peut être réalisé, même et peut-être parce que les robots de soins sont de plus en plus souvent affectés aux soins des personnes. Enfin, les défis éthiques sont discutés et les objections possibles sont abordées. En fin de compte, l'accent est mis sur l'importance des robots de soins, puisqu'ils peuvent aborder la question de la santé mentale, au moins dans une certaine mesure, d'une manière technique spécifique.

Mots-clés
santé mentale, robots de soins, compagnons robots, intelligence artificielle, justice, éthique, accès équitable

Abstract
Health is usually seen as an important prerequisite for the realization of life goals and therefore has a great meaning in society. Many authors and their perspectives also make it clear that health can be seen as a moral value that is ethically relevant and must be promoted. In recent years, numerous crises, armed conflicts, digitalization and, more generally, the fast pace of life in society, have contributed to raise awareness of mental health. This article deals with an ethical analysis of mental health in the context of AI-based care robots. Robot companions in the care sector are increasingly being used, and this trend will continue in the near future. However, the question arises as to what extent these machines can contribute to mental health when interacting with people receiving care. First, the relevance of mental health and ethical implications are presented. In a second step, care robots and their potential influence on the mental health of individuals in need of care are discussed. The third step shows how fair access to the value of (mental) health can be realized, even and perhaps because care robots are increasingly assigned to care for people. Finally, ethical challenges are discussed, and possible objections are addressed. The focus is ultimately on the importance of care robots, since they can address the issue of mental health, at least to some extent, in a specific technical way.

Keywords
mental health, care robots, robot companions, artificial intelligence, justice, ethics, fair access

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INTRODUCTION

Human health is of great importance and can also be seen as a morally significant value that must be preserved, at least prima facie. The existence of a certain state of health is a prerequisite for realizing other life concepts, goals, needs and values, which is why one can speak of health as a constitutive requirement (1). Thanks to the constant progress of modern medicine, a corresponding state of health can be achieved and maintained using a variety of means and measures, including the use of artificial intelligence, for example. This article deals with care robots and their relevance for mental health. On the one hand, this focus is shaped by the advances in AI applications and the dissemination of technical possibilities for the care sector, and on the other hand, research on this topic remains an under-addressed issue (2). Although numerous works, including ethical perspectives (3-7), on AI-based care robots can be found in the literature, the connection to mental health and justice-related considerations is still missing. Mental health seems to have taken on a special meaning in recent years, partly as a result of various crises, armed conflicts, the digital transformation and the pandemic. People's subjective ideas about (mental) health and illness have also received more attention as a result. But what role can AI-based entities play regarding mental health? First, the relevance of mental health is discussed, along with ethical implications that arise. Second, the use of care robots is examined in terms of the extent to which they can influence mental health, for which numerous studies and works will be analyzed. Third, an idea of equity of access is presented that can be reconciled with the previous considerations. This is followed by a discussion of frequently raised concerns regarding the implementation of artificial entities, to meet the concerns of mental health and equitable access on the one hand, and to offer an ethical justification on the other.

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THE VALUE OF (MENTAL) HEALTH

This section shows the relevance of mental health and discusses the associated ethical implications.

At least since the introduction of the biopsychosocial model (8,9), the focus in the scientific community has shifted away from a purely physical view of illness and health and towards a holistic[1] concept in which biological, psychological and social influences are decisive. However, this is also accompanied by a complex interweaving of various dimensions and factors that can be associated with a state of health (14). In recent years, there has been a growing emphasis on mental health as an essential component of health in general, as reflected in the national mental health strategies adopted by various countries (15). Many illnesses and disorders affecting our well-being cannot be attributed to physical impairments alone, which emphasizes human health as a multidimensional phenomenon (16,17). Yet, it is reasonable to say that mental illnesses often do not receive the same attention as physical impairments, and this is reflected in access to health care (18-20). The World Health Organization's (WHO) objectives are helpful in this context, according to which it is important to 1) recognize and strengthen the value of mental health, 2) align local practices with this value, and 3) focus health care services more strongly on mental health (21). These strategies are also reflected in the mental health atlas, whereby WHO member states commit themselves to promoting certain goals regarding mental health, which would not be necessary, for example, if the corresponding health services in the respective countries were already functioning adequately (22). The provision of contact points and responsible people to address mental health concerns is only gradually improving.

For this reason, too, a focus on mental health appears essential in order to then clarify the question of what opportunities arise from the use of care robots. As already mentioned, mental health appears to be a prerequisite for a meaningful life (23). The decisive foundations for mental health are laid in childhood and adolescence because the earliest possible internalization of one's own (mental) strategies shapes how one deals with difficult life situations throughout one's entire life (14). However, study results suggest that many mental health problems are the result of an interplay between a variety of factors (24-26). These include genetic and environmental influences, with the latter category also covering *special* life events. In general, people can be described as mentally healthy if they are able to master their daily tasks and certain life situations and achieve a level of well-being that is individually understood as good (27). This view of health differs from a purely physical approach in that even without physical and medically detectable impairments, people can lack something. This *something* relates to cognitive processes, emotional states, and the mental and spiritual condition in general.

The idea of mental health presented so far can be used to subsume basic mental activity, emotions, motivation, coping strategies, psychophysical performance and self-determination potential (14). However, when individuals feel overwhelmed by their own lives, are exposed to constant stress, or even reach the limits of their resilience due to illness, health impairments are often the result. It is not uncommon for these gradual processes to lead to mental disorders, impaired well-being, impaired cognitive performance, depression, anxiety disorders or other psychiatric impairments (14,19,28,29). Apart from diseases that can be classified using diagnostical systems — such as the International Statistical Classification of Diseases and Related Health Problems (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-V)[2] — the consequence for affected individuals is a reduced quality of life and they are also increasingly unable to participate and function in social interactions as usual. The impairments described above can limit an individual's ability to act and make decisions. This impairment appears ethically relevant above all because one's own life can no longer be led in the usual way, and especially if appropriate measures and support are not provided.

However, a positive understanding of mental health not only relates to an individual but also affects society due to the importance of this fundamental and constitutive value. Marckmann (27) emphasizes this significance because health is a transcendental good, that is, a basic prerequisite for the realization of life goals and equal opportunities in society. Put simply, health can be understood as a value or transcendental good because it is a conceptual idea, not just a state of being. On the one hand, health is determined on an individual basis, while on the other hand, it is a universally used term. The fact that different people may define health differently but still describe and most likely want to achieve such a state, expresses this idea. According to Ornstein (32), this value ranks particularly high compared to other goals, ideas of life or even moral values. Such ideas indirectly refer to the moral plurality regarding certain values but also allow the described value of (mental) health to continue to exist, which manifests itself particularly clearly in the state of being ill (33,34).

According to the WHO, health describes a state of complete physical, mental, and social well-being, i.e., not the mere absence of (physical) illness (16,21). This description at least indirectly emphasizes the relevance of mental health by referring not only to pathology and medically verifiable functional incapacity. According to Bauer and Jenny, the value of health is to be seen as a dynamic concept in a constant process of adaptation — it does not exist as a result (33). This goes hand in hand with aspects of well-being, people's ability to act, opportunities to shape self-determination and an obligation on the part of the human community to make this essential value available. The social dimension is also emphasized by Bhugra et al. (35) insofar as mental health also depends on a person's social embeddedness. According to Cloninger (24), determining mental health involves assessing 1) temperament and character, 2) current emotional state, 3) various syndromes, and 4) formulating steps for modification. In contrast to the considerations above, this is not just a definition, but an approach to promoting mental health.

[1] In addition to the biopsychosocial model, a spiritual component has been integrated into the WHO definition of health. Numerous authors rightly note that a spiritual way of life, the associated search for meaning, feelings and specific experiences, can be useful, especially in times of personal tragedy. Accordingly, this component seems to be becoming increasingly important given the secularization within society and the reduced importance of religions (10-13).

[2] These diagnostic systems enable the classification of mental illnesses or personality disorders. For many illnesses, certain criteria must be met, which also excludes different and possibly similar illnesses or personality disorders (30,31).

The WHO definition is used for the arguments below, first because these considerations are consistent with the statements made so far, and second because they appear conclusive for the discussion of AI-based robots:

> Mental health is a state of mental well-being that enables people to cope with the stresses of life, realize their abilities, learn well and work well, and contribute to their community. It is an integral component of health and well-being that underpins our individual and collective abilities to make decisions, build relationships and shape the world we live in. Mental health is a basic human right. And it is crucial to personal, community and socio-economic development. (21)

Even if illness, health and, even more specifically, mental health are difficult to express in general terms — or even should be — a plausible claim is conceivable in ethical terms, insofar as these values are dependent on individual interpretation, but their general claim is not lost as a result (1). This general character can be explained by the universal importance of health, insofar as for all people it is associated with something that they want to maintain and preserve, regardless of what exactly this idea and realization of health looks like in a specific case (27,33). This also reveals the fact that, in the context of medical and care facilities, it should be understood as an essential concern to make this access to health available to all people. If health represents something morally important — as the previous explanations suggest — then it is ethically imperative to take certain measures to preserve it and to refrain from any actions that are contrary to this value (23,36). The previous considerations also make it clear that mental health is part of the *general* understanding of being healthy and is therefore also subject to this ethically required duty.

CARE ROBOTS AND MENTAL HEALTH

After considering the relevance of (mental) health, attention now shifts to care robots. This form of human-machine interaction was chosen, *firstly*, because these robots are increasingly being used in the care sector; *secondly*, because a greater and possibly technical need for support in care facilities is to be expected in the near future; and *thirdly*, because these robot companions can provide a new solution to mental health problems of the people to be cared for. Furthermore, although there are many therapeutic offers to create or promote mental health, many people do not receive the necessary *mental health care* (37), which is why care robots have great potential to close this gap (28). As a result of demographic change and the increasing number of people in need of care, these robot companions appear to be a conceivable replacement for skilled workers or at least a means of support. But to what extent are machines able to promote people's mental health? What ethical challenges are associated with the potential use of AI-based robots for mental health care? How can these problems be solved? The following sections will attempt to address these questions and related aspects.

In the care setting, robots have so far mostly been used to counter acute staff shortages, to support professionals in their work or to try out new ways of communicating and interacting (38,39). Although the effects of human-robot interaction on mental health are being investigated in various studies (40-43), their number is small compared to other topics, and, above all, too little attention has been paid to ethical considerations. Due to the large number of different care robots, a specific selection is made for this article. These machines can be classified as socially assistive robots (SARs[3]) (39,50) and, they represent the current state of the art, which appears to be crucial for the question regarding the promotion of mental health. In addition, SARs have communicative abilities, they can move (partly autonomously) in an environment, and they have a different physical presence, in comparison to companion robots such as Paro, for example. These skills allow for a different kind of social interaction, which seems particularly useful considering the WHO definition of mental health.

Study results show that the use of care robots can improve mental health, increase emotional well-being and reduce loneliness compared to the normal care constellation (42,51-53). Empirical surveys by Papadopoulos et al. (51) in England and Japan noted that these robot companions were also able to adapt to cultural differences regarding the needs of people receiving care. This programmable cultural sensitivity was well received and, in ethical terms, corresponds to an approach characterized by intercultural (technical) competence and the necessary respect for the respective counterpart — already embedded in the programming — which can only be *called up* by human caregivers after readiness and internalization. Papadopoulos et al. conclude that SARs "may be likely to protect against mental health problems" (51, p.252), however, the lack of experience is certainly taken into account, insofar as the positive or negative effects of long-term implementation of robots make further research necessary.

Other researchers have come to a similar conclusion, because it is not clear from studies, most of which are short-term, how people in need of care will react to robots once the effect of the novelty has worn off (52,54). Apart from that, this habituation effect not only affects machines, but also occurs with human caregivers after a certain period of time — and it does not have to be negative. Chita-Tegmark and Scheutz's study results make it clear that robot companions can also prove their worth as moderators in interpersonal relations supported by technology (54). They are therefore not only available for direct patient contact, but also for nursing staff, by providing feedback on social behaviour, raising awareness of problematic attitudes,

[3] Generally speaking, a distinction is made between social robots that enable interaction, those used for health monitoring, and assistant or physical support robots (39,44-46). SARs theoretically fulfill all three tasks and have the advantage of offering a technical-physical presence. Possible examples include NAO, Care-O-bot, Lio, P-care, Pepper, or PR2. Their many features include visual and acoustic communication, independent movement, picking up and bringing objects, or even monitoring health data. In addition, numerous studies show that they can promote social engagement. RobAlz and MARIO are SARs that have been specially developed for elderly people with special needs (47-49).

possible interventions or even care-related goals. “Nao would alert the speakers when their voice was too high or too low or when the conversation was problematic” (54, p.205). These types of actions can directly influence the behaviour of the people present in the care sector, which appears crucial for mental health. Heated, stressful and laborious arguments increase mental strain, whereas care robots[4] could counteract these problems.

The kind of human-robot interaction depends on the research project and the respective study design. Nevertheless, it can be concluded that communication in particular (54), regardless of whether it is auditory or visual, has a significance that should not be underestimated, and that SARs are therefore preferable to other robots. The very presence of the robot and the knowledge of the possibility of an exchange can be seen as something important for people receiving care. Empirical studies (58-60) confirm this assumption because “participants who interacted with a physically present robot rated the interaction as significantly more enjoyable and significantly more useful than […] similar computerized or screen-based activities.” (28, p.37). Aspects of mental health can be taken into account, for example, by actively involving the people being cared for, using videos, educational measures, a form of coaching (49), help and observation of the therapy (28), through conversations about personal issues (52), useful tips from the robot (54) or joint (not only physical) activities (51,61). Their use as naive therapeutic companions[5] is also conceivable, as shown by some studies on the use of SARs in the context of dementia or children with an autism spectrum disorder.

An approach based on the well-being of the people to be cared for makes sense and would be beneficial to the value of (mental) health as already described. If care robots can be understood as useful, insofar as their activities not only do not endanger the mental health of affected people, but can potentially improve it, withholding access to robot companions would be difficult to justify. Clearly, the consent of the persons concerned, which could be jeopardized by the conceivable *benevolent* justification in the sense of benevolent coercion (23), should not be circumvented. However, if individuals in need of care consent to this technical measure, it would result in an unjustified withholding of care-related options if the potentially mental health-promoting care robots were not worthy of consideration. These machines *must* not only be understood and integrated differently due to their lack of human appearance, traits, and behaviour, but also because they *can* perform other tasks due to *this* very difference. Several studies (64-66) show that people in need of care also feel comfortable[6] with a robot.

Based on these considerations, it is reasonable to conclude that the individuals being cared for may also welcome SARs and experience positive influences in terms of mental health because they are aware of the fact that these are non-human counterparts. Some studies show that men tend to react more positively to these machines than women and that older people are more likely to have reservations than younger people (50,69,70). It is also apparent that people in need of care sometimes prefer to be cared for by people of the same sex, which could be a decisive factor in the appearance of AI-based care robots. Nevertheless, universal solutions seem inappropriate. The specific and technical kind of interaction between robots and humans promotes a new approach and possibilities[7] for use that would not be expected or might even be undesirable in purely human encounters (54). In this context, there is immense potential for AI-based robots, insofar as they are used during *mental health care* and ethically relevant aspects come into consideration. With the constant progress in medicine and technology, for example through deep learning, neural networks or the general adaptivity of AI (71), an alignment of humans and machines seems to be increasingly establishing itself, for example by robots coming ever closer to human behaviour (43,72). Whether this forced comparability, so to speak, is desirable in the context of care and even more specifically regarding *mental health care*, must be critically questioned[8].

The above considerations tend to support the conviction that equating human and technical care activities would not have the desired effect. The consideration of (mental) health, and the *contributions* of care robots, which have so far been perceived as positive and valuable — but different — could, so to speak, vanish into thin air. Their specific contribution to mental health, the promotion of independence, well-being or even human-machine interaction in general are based precisely on this described otherness (3,53,61,73). Wanting to make machines more human in the sense of a human concept could be questionable in ethical terms, especially if the specific needs of people receiving care are not considered. If SARs offer certain advantages (in the view of people requiring care) over human nurses due to their technical features, the complete alignment of humans and

[4] At this point, it should be emphasized that study results indicate that the moderating role of a robot depends on the acceptance of the individual in question. The perceived personality of the machine, its design, appearance, and interaction capabilities are also decisive factors. Nevertheless, there will be people who view mediation by a machine as positive, which is not the case for others (55-57).

[5] Robot assistance systems such as Keepon or Pleo are being tested among children with autism spectrum disorder (ASD) (28,42). The preliminary results show that there may be situations in which these individuals are more likely to trust and open up to a machine than they would be when interacting with a human, for example. That being said, it should be noted that general conclusions are inappropriate and that more research is needed (54,62,63).

[6] Humanoid robots in particular — and androids, which are conceivable in the future — give rise to the “uncanny valley effect”, whereby a non-human entity is sometimes attributed characteristics that it does not possess. The human-like appearance of NAO, for example, can give the impression that NAO should be able to do the same things as a human being and so be expected to perform the same tasks (e.g., display emotions, make rational decisions, be attentive) (67,68).

[7] Care robots respond to repetitive requests from the person being cared for without becoming annoyed. In addition, their use for assisting with personal hygiene — although this is more likely to be an area of application in the future — seems to cause less embarrassment and uncertainty for some people. The machines could also be an alternative to human caregivers in risky situations, such as when there is a risk of infection or other dangerous activities.

[8] 1) A universal solution seems inappropriate for the appearance of robots. Some people requiring care prefer a humanoid design, while others don’t. Androids (very human-like) are currently not or only marginally used in the care sector, and their exclusive use, like any other general model, would not meet the needs and preferences of certain people. 2) Currently, care robots have specific tasks that differ greatly from those of a human caregiver. This is still due to technical limitations, such as a lack of empathy, consciousness, or physical restrictions. In addition, it seems reasonable to ask why human caregivers would still be necessary if all tasks could be performed completely and equally well by robots — especially when one considers the advantages described above. 3) Regarding the behaviour of AI-based care robots, there are also obvious differences from their human counterparts, who can be tired, moody, uninspired, annoyed, dismissive, but of course also empathetic, conscientious, rational, and caring. In this case too, complete alignment between humans and robots seems to have more disadvantages than advantages, especially considering the obstacles that still exist. However, these assumptions based on the considerations made so far do not rule out future changes to this position.

machines would mean that these potential advantages would no longer exist — at least not in the form presented here. People's concerns, wishes and ideas must be respected and, above all, used as a guideline for the initial integration of SARs — including their physical appearance. Otherwise, the interests of the individuals addressed would not be taken seriously, a lack of respect would be expressed and the important approach via the individual would be neglected in favour of general solutions. In turn, health serves as an important benchmark for determining which courses of action and strategies should be pursued and which should not. However, it must be determined what exactly this care should look like, for example as basic medical care or in the sense of a minimum standard (74).

EQUITABLE ACCESS TO HEALTH

After considering mental health and AI-based care robots, the question of how fair access to this technological option can be possible is explored.

As the significance of individual health and its socio-political consideration is implicitly clear, it seems appropriate to consider the question of ensuring health, even if these considerations only cover a fraction of the philosophical debate on distributive justice and access. If mental health represents an intrinsic value, then access to medical services should not depend on individual economic capabilities (74). However, additional services or insurance can be taken up by precisely those people for whom such services are affordable. This idea leads to the question of whether the worst-off in a society should be given special preference, which Rawls showed in his *Theory of Justice* and is discussed in a comparable way by Rauprich (75-77). The provision of adequate basic care for the realization of vital goods, interests and ideas of a successful life appears essential, for which the potential characteristics are outlined below.

The provision of adequate basic services also seems reasonable for Rauprich, because in this way we take into account those in a society who are particularly in need of help and support, thus granting them important access without at the same time attaching too much weight to the value of equality (75). This highlights the problem, in terms of prioritization, between a purely egalitarian approach (egalitarian view) and one that gives priority to people in need (priority view) (78). Brock also deals with this common attitude that disadvantaged persons or groups are to a certain extent preferable to the privileged, and takes a critical view of the priority position, insofar as this "would have what for many are highly counterintuitive implications for health-care prioritization." (78, p.45). Theoretically, poorer people would have to be given priority over richer people per se, even if the richer person were much sicker, but their overall level of health would still be higher than that of the poorer person. In accordance with the ideas of Höffe, many tasks of justice arise from the limited nature of natural resources (79) and, in this context, also from the use of technical aids. Leaving aside this problem of favouring the poorest and most needy in a society, the access to medical care mentioned above should be understood — albeit in a minimal and fundamental sense — as a concern of any justice-oriented medicine.

According to Huster, the introduction of a classic minimum standard would be problematic insofar as it would widen the gap between rich and poor, or sick and healthy, especially because (tax) contributions would possibly no longer be income dependent. For this reason, he argues in favour of minimal health care, in which additional benefits can be claimed and health concerns remain a reference (74). In this context, Höffe's considerations can be followed, according to which the opportunity for equal participation, involvement and agency with regard to AI-based robots leads to the conclusion that all people can be potential users of technical aids (79). However, the considerations of Otsuka, who argues in the context of the distribution of relevant goods, but nonetheless illustrates the important consideration of the individual over the mere preference of the many, offer a decisive point of reference (80). Ultimately — and this can also be derived from the above — it is entirely reasonable to assert that the focus should be on the people interacting with care robots, which includes those receiving care and human care professionals.

The reflections so far lead to the conviction that the egalitarian approach can be implemented more plausibly in the context of this article than the priority view (78). The use of AI-based robots does not (only) belong to the worst-off, because certain knowledge and skills are required to use them. Although it could be argued that a care robot should be meaningful[9] for those people who need to be cared for, looked after and thus also supported. Providing support for an exceptionally active person through a technical entity would appear to contradict the fundamental purpose of the *care* robot — but only at first glance. Imagine that, by chance, ten individuals requiring care are selected in a nursing home. They are sitting together in a group and discussing their level of activity. After a few moments, the people present come to a clear conclusion and agree that Stefan is the most active person. Now, however, let's imagine that another ten people join the group, and the question of activity and passivity arises again. Among the newcomers is Laura, who, in the opinion of everyone present, now takes on the status of the most active person requiring care, meaning that Stefan loses his place at the top, so to speak. What does this tell us about the previous statements regarding care robots? Should Stefan be denied the opportunity to *benefit* from these machines in scenario one? Can it be justified that using the robots is possible again once he loses his status as the most active person in the nursing home to Laura in scenario two? Furthermore, if Roger Federer were to join the group, Laura might no longer appear to be so active. Apart from the fact that labeling someone as active or passive in this context is not only subjective but can also change over time, the following conclusion seems appropriate.

[9] Based on what has been said so far — and in line with the study results presented — care robots can encourage people in need of care to engage in social activities, stimulate physical and mental activity, compensate for loneliness to a certain extent, and promote a human-machine relationship. Such consequences would be independent of the condition of the person being cared for. Nevertheless, it should be kept in mind that the area of application of such a machine must clearly be tailored to the needs of a specific person.

Even active people in need of care should have the opportunity to interact with care robots in a care facility if they so desire. Otherwise, such opportunities would be reserved only for those who *appear* to be particularly needy. However, this apparent need may also be epistemically false and, moreover, says nothing about whether the person in question wants to interact with machines. This perspective is compatible with the above considerations relating to an egalitarian approach and rejects a strict priority view, although it does acknowledge that certain priorities are justified on the basis of special preferences[10]. In addition to the problem just described, namely determining the status of the most active person among different people requiring care in a care facility, there is another aspect that argues in favour of *equal*[11] access: within a care facility, we are already dealing with a specific group of people who are receiving care. In the previous example, Roger Federer would most likely only join the group if he reached a stage in his life where he needed help and support. The same can be said, broadly speaking, of all people who are cared for in a nursing home. The fact that Laura and Stefan are living in a nursing home means that it can already be assumed that they are no longer able to manage their own lives without assistance in all areas — in short, there is a reason why they are in a nursing home. Thus, it can be argued that the distinction between active and passive within a care facility is less clear and relevant than the consideration of individual preferences. This is primarily because the group of potential *beneficiaries* of AI-based care robots is already selective, and person-specific preferences should be considered.

Another point is relevant when talking about SARs but is often forgotten in general discussions about robots and their capabilities. Prioritizing the worst off in a care facility, such as pursuing a priority view, seems both inappropriate based on what has been said so far and implausible considering the robot models presented here. NAO and Pepper are not useful — if at all in this context — for helping particularly passive and needy people. For them to be useful would mean that they are capable, for example, of lifting a person out of bed on their own, taking over their personal hygiene completely, providing active support when walking, or, to put it simply, replacing a human caregiver. Expecting such performance from Lio and PR2 is not in line with their current field of application and also fails to recognize that these machines are primarily intended to provide support (73). For this reason, too, it seems appropriate to make care robots available to all people requiring care, regardless of how active or passive they are. When NAO reads a story aloud or uses visual/physical representations to motivate physical activity, both active and passive residents can benefit. The same applies, for example, when PR2 takes on a moderating role. It makes little sense to assign PR2 only to Stefan, who is passive enough in scenario two, and at the same time leave Laura to resolve a conflict on her own because she is active enough — unless Roger Federer walks in. Apart from this consideration, it nevertheless seems plausible and justifiable to use the priority view primarily for medically limited measures in exceptional situations in which life is threatened (23,75), and to perceive the integration of care robots as a therapeutic but at the same time additional, alternative and not yet established intervention. Consequently, equal treatment can be expressed and demanded for all those who belong to the area of potential use of such innovations due to life-related circumstances. Further prioritization by referring to physical, psychological, or spiritual needs seems less plausible than the *almost* equal opportunity to interact with care robots.

What can also be pursued for reasons of justice is a perfectly understandable focus on *adequate* basic care, which is more comprehensible in the context of AI-based robots than the minimum standard often demanded (75). Apart from the limitations to which Huster drew attention, the area of application of care robots in particular can be assigned to appropriate basic care rather than the minimum standard (74). Regarding medical and care-related measures, the latter approach will primarily focus on the critical treatment of illness, the restoration of health and precisely these fundamental basic health needs. However, adequate basic care could soon provide these robot companions to enable service activities, mobilization functions or even active living and socialization. This approach can be compared with the *decent minimum* described by Beauchamp and Childress (23), according to which equal access to basic needs and unequal access to special needs should be granted. These basic needs correspond to the considerations made above regarding general access to SARS (in principle for all people requiring care), whereas the special needs correspond to specific and ethically justifiable prioritization (based on subject-related preferences). This strategy seems plausible insofar as care robots are not yet part of *general* basic medical care but can (still) be seen as an affordable addition. This is also made clearer by the fact that AI-based robots do not yet operate fully autonomously in all settings, that activities close to the body are limited to a certain extent and that in many cases medical or nursing professionals have the final decision (53,81,82). Whether their use will develop into a standard intervention remains to be seen, but the considerations above emphasize the openness required in ethical terms. With reference to equality of opportunity (27,76,83) and the conceivable use of AI-based robots, a target claim arises according to which the value of (mental) health, which is considered constitutive, must be made available to all people to an extent that is essential for basic needs. This claim is based on the egalitarian considerations described and calls for adequate basic care.

FINAL CONSIDERATIONS

After an egalitarian approach to care robots has been discussed, which primarily refers to basic needs, final thoughts on the machines, mental health and this idea of fair access are presented.

[10] What this means is that Person A likes watching videos and having stories read to them, which Pepper and NAO can do. Person B, though, prefers human communication and doesn't care about human-robot interaction. Assuming that A and B achieve the same activity status, A's preference seems to favour the use of SARs. However, the same applies if it becomes clear that B is considerably more passive than A. The decisive factor is not the seemingly objectively determinable need, but rather the preferences of the persons being cared for.

[11] This idea of equal access is basically about making sure everyone can use SARs if they want (and need) to. Although prioritization (see footnote 10) sometimes appears necessary and adequate, individuals should not be categorically excluded, for example, due to a lack of need or financial resources. Whether SARs are perceived as good and useful for a person requiring care can usually and should primarily be decided by the person concerned.

There is often talk of direct or indirect deception, which seems to be ethically questionable (28,54), but is this really the case? When this term is applied to care robots, a consequence arises that is not entirely plausible. Deception can primarily be understood as the withholding or concealment of truth, or the intentional persuasion of another person to believe something false to be true (23,84). However, if care robots become established in a facility, this technical support must also be identified as such; and the relevant people or directly involved care professionals are responsible. Accusing a care robot of deception would either have to be based on the scientifically implausible assumption that there is something like consciousness hidden in the machines and that they can therefore deliberately do something morally wrong or attribute the blame to the companies carrying out the work. In the second scenario, however, any attempt to deceive refers to human actors such as programmers, designers, company executives or other individuals involved in production. As a result, the accusation of potential deception by robots cannot be sustained, as this ethical concern should rather be understood as a human fear of human intervention.

As a result of the constant advances in robotics and their use, it is conceivable that people could become attached to certain care robots and then have to end the friendship when a new model is released. Some studies (28,54) have identified a potential ethical problem in this regard. This personal *attachment* created by the technical care relationship would seem to undermine the ability for self-determination and independence, because people in need of care are no longer able or willing to escape this cherished dependency. At first glance, it may seem trivial to point out the generally recognized significance of autonomy. In this case, however, this approach is indeed appropriate, it has just not been implemented in an adequate way. In human interaction, too, there are often intended and unexpected dependencies that contribute to the reduction of subjective options. A caregiver can promote the dependency of a person in need of care through caring, inspiring, and compassionate behaviour, which does not seem to raise any concerns — but AI-based robots do. It is not very plausible to use this challenge solely in the context of care robots as a decisive factor for their justified non-integration; and, in addition, attachment can also be understood positively (85). Rather, these relationships often arise through deliberate, intentional, or accepted actions that involve emotional and empathic aspects and cannot currently be implemented by care robots in a human manner (81,82). The responsibility lies with those in charge, who must be aware of this potential problem even before the robot is used. Accordingly, it seems much more plausible to regard this ethical problem as important and worthy of consideration, but to locate it first and foremost in human meetings and responsibilities.

Although care robots and their integration address the problem of loneliness, authors (54,82) also fear that the problem will only shift elsewhere, leading to a loss of social contact with human actors. At first glance, these considerations appear to be justified if constant contact with a machine has a positive effect on mental health and the importance of care professionals' concerns is reduced. However, it should be kept in mind that care robots are primarily there to supplement missing resources, to realize an approach that cannot be implemented by humans or to promote the described social activity in a technical way (61,86). The use of these devices therefore closes a social care gap rather than taking something away. The studies presented also show to what extent the frequently feared social contact can be compensated for by robot companions, on the one hand, and the human component can be equally preserved through appropriate planning, on the other (85,87). The concern about loneliness also seems unfounded because adequate goals and moral considerations must certainly play a role in the structural implementation and integration of care robots.

In connection with the previous difficulties, the statements of the High-Level Expert Group (HLEG) on AI offer certain points of reference, such as the promotion of diversity, basic safety, the protection of privacy or the promotion of human well-being, which is essential in this article (88). Such requirements must already be considered when planning a specific robot. One conceivable path would be, for example, the integration of suitable care robots "into existing and effective treatment programs, ideally in ways that reduce the time-demand placed on human treatment providers" (28, p.40) or the implementation of new training programs with the robot companions, an option corresponding to the previous passages. Specific values and points of reference would already be anchored in internalized routines and programs, so to speak, which could be used to guide the integration of care robots (73). A specific focus on the individual also appears to be essential, whereby a "personalization of the robot's behavior to meet the specific needs of the user, determined by the user's particular health situation as well as personality and preferences" (54, p.206) is crucial. Ultimately, the previous investigation suggests that AI-based care robots offer an important option for mental health.

It has been shown that robots can be used to support the mental health of human beings. Conceivable integrations in the care sector relate to the promotion of social engagement, programmable cultural sensitivity, technical presence, a moderating role and, finally, the decisive *difference*. In this context, a new approach to *mental health care* can be developed, especially through the specific possibilities for action of the robot companions, which is generally given a high priority — or at least appears to be — but is usually given little consideration compared to physical suffering (19,20,37). There is immense potential here due to the constant and expected further development of care robots, also regarding an aging society. The explanation of fair access should not be understood as a universal solution, but rather as a conceivable path that can also stand up to ethical justification. At present, their use is plausible and justifiable primarily for the support of care professionals, but this does not rule out future expansions of the scope of action (52). An attitude guided by moral values and ethical points of reference will be essential, which, however, integrates the conviction that care robots represent a justifiable component in the realization of mental health.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Respect for Autonomous Risky Decisions and People with IDD: Prioritizing Healthcare Provider Trustworthiness

Andria Bianchi[a,b,c]

Résumé

L'autonomie est l'un des principaux principes directeurs de l'éthique des soins de santé dans les sociétés libérales occidentales. D'une manière générale, ce principe signifie que nous devons respecter les décisions des individus par rapport à eux-mêmes, même si ces décisions sont risquées d'un certain point de vue. Le principe d'autonomie peut revêtir une importance particulière lorsque l'on pense aux populations marginalisées dont la capacité à prendre des décisions autonomes et à faire respecter ces décisions (en permettant à la décision autonome de se produire par des moyens positifs ou négatifs) a été largement, historiquement inexistante. L'une de ces populations est constituée par les personnes atteintes de déficiences intellectuelles et de troubles du développement (DITD). Lorsqu'une personne atteinte d'une DITD prend une décision autonome et risquée, un clinicien peut respecter sa décision en raison du poids et de la priorité généralement accordés au principe d'autonomie. Toutefois, cet article soutient que la décision autonome et risquée d'une personne atteinte de DITD concernant la prestation de soins ne devrait être respectée que dans la mesure où le clinicien a démontré qu'il était digne de confiance dans le but d'obtenir la confiance. En d'autres termes, je soutiens qu'à moins qu'un clinicien n'ait démontré qu'il est digne de confiance, une décision autonome risquée liée à la prestation de soins ne devrait pas être immédiatement respectée lorsqu'on travaille avec une personne atteinte de DITD. La raison pour laquelle une décision autonome risquée ne devrait pas être respectée à moins qu'il n'ait été démontré qu'il est digne de confiance est la façon dont la fiabilité peut influencer la prise de décision dans la mesure où la confiance est gagnée. Si une personne atteinte de DITD prend une décision risquée sans avoir trouvé son prestataire digne de confiance, sa décision peut être inutilement motivée par un manque de confiance. Il y a de bonnes raisons pour qu'une personne atteinte de DITD ne trouve pas ses cliniciens dignes de confiance, d'où la nécessité d'assurer la démonstration intentionnelle de la fiabilité avant le respect de la prise de décision autonome et risquée.

Mots-clés

déficience intellectuelle, trouble du développement, confiance, fiabilité, autonomie, risque, éthique

Abstract

Autonomy is a primary guiding healthcare ethics principle in Western liberal societies. Generally speaking, the principle means that we ought to respect individuals' decisions in relation to themselves, even when such decisions are risky from some perspectives. The principle of autonomy may be of particular importance when thinking about marginalized populations whose ability to make autonomous decisions, and to have such decisions respected (by enabling the autonomous decision to occur through positive or negative means), was largely, historically non-existent. One of these populations is people with intellectual and developmental disabilities (IDD). When it comes to a person with IDD making an autonomous risky decision, a clinician may respect their decision because of the typical weight and priority given to the principle of autonomy. However, this paper argues that a person with IDD's autonomous risky decision related to care provision should *only* be respected insofar as the clinician has demonstrated trustworthiness in an effort to obtain trust. In other words, I argue that unless a clinician has demonstrated that they are trustworthy, then a risky autonomous decision related to care provision should *not* be immediately respected when working with a person with IDD. The reason that a risky autonomous decision should *not* be respected unless there is demonstrated trustworthiness is because of how trustworthiness may influence decision-making insofar as trust is gained. If a person with IDD makes a risky decision without finding their provider to be trustworthy, then their decision may be unnecessarily motivated by lack of trust. There are good reasons that a person with IDD may not find their clinicians to be trustworthy, hence the rationale for ensuring the intentional demonstration of trustworthiness before respect for autonomous risky decision-making.

Keywords

intellectual disability, developmental disability, trust, trustworthiness, autonomy, risk, ethics

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INTRODUCTION

As per Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (UNCPRD), people with intellectual and developmental disabilities (IDD) have the right to attain the highest standard of health and to access relevant health services without discrimination (1). This UNCPRD Article is important, particularly since people with IDD may have an increased need to access health services and at earlier points in their life due to health discrepancies that exist between them and the general population. It is well known that people with IDD have a decreased life expectancy and increased risk of morbidity when compared to people without IDD (2-5), and although this discrepancy has decreased over the years, it continues to exist (4-9). When a person with IDD gains access to required care, several kinds of ethical dilemmas may arise in relation to care provision (10). An ethical dilemma occurs when a conflict exists amongst two competing ethics principles.

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Four principles frequently cited in the bioethics literature, which encompass what is often referred to as “principlism”, are autonomy, beneficence, non-maleficence, and justice (11). When a conflict or tension arises amongst these principles, then it is typically suggested that one engage in a weighing and balancing act to determine which principle ought to be prioritized (11).

In Western liberal societies, it is often the case that — even after working through a weighing and balancing act — the principle of autonomy is prioritized or, at the very least, not easily de-prioritized in light of another principle or process. The principle of autonomy, as will be described more thoroughly below, generally means that we ought to respect individuals’ decisions in relation to themselves and their self-determination. For the purposes of this article, respecting a person’s autonomous decision means enabling them to act autonomously through positive or negative means. The principle of autonomy is of particular importance when thinking about certain marginalized populations whose ability to make autonomous decisions, and to have such decisions respected, was largely, historically non-existent. One of these populations is people with IDD.

When working with people with IDD, one reason that the principle of autonomy and the related concept of self-determination may be even further prioritized is because of the dignity of risk (12). The dignity of risk offers an argument as to why one should respect a person with IDD’s risky (or, at least, seemingly risky) autonomous decision(s), including risky decisions related to care provision (e.g., refusing a recommended health service) and overall lifestyle. When it comes to a person with IDD making a risky decision in relation to care provision, it may be the case that a healthcare provider (HCP)[1] respects the decision rather immediately because of the typical weight and priority given to respect for autonomy and the dignity of risk.[2] However, this paper argues that a person with IDD’s autonomous risky decision should *only* be respected insofar as the HCP has taken the time to demonstrate trustworthiness.

In other words, I argue that unless a HCP has demonstrated that they are trustworthy, then a risky autonomous decision related to care provision should *not* be immediately respected. The reason as to why a risky autonomous decision should *not* be respected unless there is trustworthiness is because of the influence that trustworthiness may have on decision-making due to an anticipated increase in trust on part of the person receiving care. If a person with IDD makes a risky decision without their HCP being trustworthy, then their risky decision may be unnecessarily motivated by lack of trust (insofar as lack of trust may be influenced by a HCP’s failure to demonstrate trustworthiness).[3] There are good reasons as to why a person with IDD may not find HCPs to be inherently trustworthy hence the rationale for ensuring the intentional demonstration of trustworthiness. It ought to be noted that a HCP’s demonstration of trustworthiness does not necessarily guarantee that their patient/client will trust them. However, insofar as trustworthiness may be an influential factor that is within the control of HCPs, then it ought to be prioritized in anticipation of it influencing trust.

In order to make this argument regarding the need to prioritize the demonstration of trustworthiness before respecting a person with IDD’s autonomous risky decision, I first offer some definitions and general information related to people with IDD and health/healthcare. I then describe the principle of autonomy and the related concept of dignity of risk, before offering a case example wherein a person with IDD makes a risky decision related to care provision. In this scenario, the person’s risky decision is respected because it is considered autonomous (and respect for autonomy is immediately prioritized). This is followed by a competing argument and suggestion that the demonstration of trustworthiness ought to be prioritized in advance of respecting the person with IDD’s risky decision; in this section, Annette Baier’s concept of trust is referenced. Some potential objections to prioritizing trustworthiness in advance of respecting an autonomous risky decision are then explored, as well as potential responses. Finally, the paper concludes by emphasizing that HCPs ought to pause and prioritize the demonstration of trustworthiness in advance of respecting a person with IDD’s autonomous risky decision related to care. Although some basic suggestions about how to demonstrate trustworthiness are mentioned, more work needs to be done in relation to this topic with a focus on people with IDD.

SETTING THE STAGE: IDD AND HEALTHCARE

The purpose of this section is to ensure there exists conceptional and definitional clarity on IDD. Additionally, this section highlights some of the most frequently occurring health conditions and discrepancies for this population, which may result in hospital admissions.

As per the Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR), a diagnosis of IDD requires that individuals experience some degree of impairment that influences their intellectual and adaptive functioning (13-14). Intellectual functioning is determined by a person’s ability to learn, as assessed through standardized tests. On the other hand, “adaptive functioning” is an umbrella term that encompasses three distinct types of skills, each of which focus on a person’s ability to engage in activities related to everyday life. The three skill groups relevant to adaptive functioning are: 1) conceptual skills (e.g., reading, math, reasoning, language, memory), 2) social skills (e.g., interpersonal skills, friendship-building abilities, social judgment), and 3) practical skills (e.g., recreation planning, financial management, personal care, organizing tasks) (13).

[1] Throughout this article, I use the term “healthcare provider” (HCP) with the intention of encompassing a broad range of professionals, including but not limited to regulated professionals (e.g., physicians, nurses, occupational therapists, behaviour analysts) and non-regulated professionals who support persons with IDD (e.g., direct support professionals, personal support workers).

[2] It should be noted that different legislative frameworks and resources may exist to help HCPs navigate risky decision-making and/or potentially dangerous circumstances depending on the jurisdiction within which they are working. Generally speaking, respecting a person with IDD’s self-determination is prioritized, but different legally required responses to certain types of decisions may exist depending on the local context.

[3] A risky decision may also be influenced by a host of other non-trust-related factors, but lack of trust is at least one significant factor that may motivate certain kinds of decisions to be made.

Diagnoses of IDD are more prevalent in developing nations because of “more frequent injuries at birth, childhood brain infections, and iodine deficiency” (4, p.5). IDD is also caused by genetics (e.g., Fragile X syndrome, Down Syndrome) and prenatal exposure to alcohol resulting in Fetal Alcohol Spectrum Disorder (FASD) (4).

As highlighted by the American Association on Intellectual and Developmental Disabilities, it is important to emphasize that people with IDD are a heterogeneous population (14); every person with IDD will have different challenges, strengths, presentations, capabilities, and experiences associated with their disability. Relatedly, the amount and degree of support that a person with IDD may require to navigate and enhance aspects of their life will differ.

It is well-known that there exist health discrepancies amongst people with IDD when compared to others, and that members of this population tend to die at younger ages than the general population (3-9). Obtaining concrete, up-to-date, and evidence-based data related to morbidity and mortality rates for people with IDD is difficult. However, some informative reports do exist. One of the most comprehensive reports comes from the UK’s LeDeR service improvement program, which reviews health and social care data to determine where gaps exist in relation to health outcomes and deaths of people with IDD and autistic people[4] (16). At the time of writing this article, the most recent LeDeR report available reflects upon 2022 data, in which the LeDeR team reviewed files of 3648 people with IDD and/or those on the autism spectrum who died.[5] The report notes that most deaths of people with IDD (57%) occurred in hospital, which is a greater percentage than the general population. The most frequently reported causes of death related to the following categories (which align with ICD-10[6] chapters): “diseases of the circulatory system, diseases of the respiratory system, neoplasms, diseases of the nervous system, congenital malformations, deformations and chromosomal abnormalities” (5, p.44). These causes of death accord with what is stated in other reports. For instance, in Balogh et al.’s 2016 Cochrane review, causes of mortality for people with IDD commonly included, “neoplasms, and respiratory, cardiovascular and nervous system diseases” (4, p.5).

Notably, deaths by COVID-19 were higher in people with IDD than those without. An additional difference amongst those with and without IDD is that while “[c]ongenital malformation, deformations and chromosomal abnormalities were the first leading cause of death for people with a learning disability in almost every English region in 2022”, the leading cause of death of the general population was dementia and Alzheimer’s disease (5, p.51). Finally, between 32% and 45% of adults with IDD also have a mental illness, which is frequently referenced as “dual diagnosis” (4). Dual diagnoses are becoming increasingly prevalent and may also result in hospitalization (17).

In short, it is known that people with IDD have significant health needs, and that some of these needs may differ in terms of prevalence, complexity, and presentation when compared to those without IDD. People with IDD require health care services and hospital admissions, and relevant ethical dilemmas are bound to occur.

ETHICAL DILEMMAS: CONSIDERING AUTONOMY, DIGNITY OF RISK, AND IDD

When a person with IDD is admitted to hospital or requires care provision in the community, it may be the case that an ethical dilemma(s) arises. As stated in the Introduction, ethical dilemmas occur when there is a tension or conflict amongst at least two competing ethics principles. Although several ethical principles and values are relevant to care provision, four of the most frequently cited principles come from Beauchamp and Childress’s four principles approach to healthcare ethics: autonomy, beneficence, non-maleficence, and justice (11). Beauchamp and Childress are clear in their intent *not* to prioritize any of the principles. Rather, when principles conflict such that an ethical dilemma arises, they argue that one ought to engage in a weighing and balancing act to determine how to proceed (11).

Although the four principles are not weighed in any hierarchical manner, it is frequently the case that the principle of autonomy is prioritized in Western liberal societies.[7] Generally speaking, the principle of autonomy suggests that we ought to respect individuals’ decisions in relation to themselves. Historically, the concept of autonomy focused on the idea of “self-governance” and reflected on capacities associated with “self-made men” (19). The concept has since evolved, and various conceptions of autonomy now exist (20). While recognizing that these different theories exist, I use the term “autonomy” throughout this article to refer to general circumstances in which a capable person makes a decision in relation to themselves about care provision. Philosopher Dan Callahan considers why autonomy is often prioritized and says that “[a]utonomy is… given a place of honour because the thrust of individualism, whether from the egalitarian left or the market-oriented right, is to give people maximum liberty in devising their own lives and values” (21, p.289). In other words, the notion of individual liberty, i.e., the freedom to make decisions in relation to oneself, is immensely valued in certain societal contexts.

[4] I recognize that differences exist amongst person-first vs. identity-first language. At the time of this publication, and based on the place within which I am situated and the literature consulted, identify-first language when speaking about those in the autistic community is generally preferred. I appreciate that there exists differing individual, organizational, and national perspectives and respect these choices.
[5] As indicated in the report, the people included in this review were those “aged 4 and above with a learning disability, and autistic adults aged 18 years and above...” (5).
[6] The ICD-10 stands for the “International Statistical Classification of Diseases and Related Health Problems 10th Revision” (18).
[7] The rationale for focusing on Western societies is because of where I studied and am presently situated as a clinical ethicist. However, it is important to acknowledge that the way in which these principles are prioritized and realized in Western societies do not nor should not necessarily reflect the priorities or practices of people who are located in other contexts.

As noted above, the principle of autonomy generally suggests that we ought to respect a person's decision(s) irrespective of the decision itself.[8] Whether one's decision is — from some perspectives — good, wise, safe, risky, ridiculous, etc. is often irrelevant. A person's autonomous decision ought simply to be respected. There are a few different ways that autonomous decisions are realized in practice. In healthcare settings, one way that autonomous decision-making is realized is through the practice of consent (or refusal) to a proposed healthcare intervention. If a healthcare intervention is proposed by a clinician, then a patient can express their autonomous decision in relation to the proposal by consenting or refusing. If a patient is capable[9] of consenting or refusing to a proposed healthcare treatment, then not only would respecting their decision be legally defensible, it would also be ethically defensible as justified via the principle of autonomy.[10]

The principle of autonomy offers a rationale as to why healthcare service users should have their risky (or at least seemingly risky) decisions respected. Depending on a person's individual values, beliefs, preferences, culture, life experiences, etc., they may make decisions regarding care provision that are "risky" or "wrong" from certain standpoints, including from the perspective of HCPs. For instance, suppose a person is diagnosed with a form of cancer that can be cured through a surgical intervention, but the person refuses to consent to the surgery. This refusal to consent is the way that the patient's autonomous decision is expressed, and while it may seem like an absurdly risky, wrong, and somewhat irrational decision from the perspective of the surgical oncologist, the principle of autonomy would presumably lead the surgeon to respect their patient's decision.[11]

When thinking about autonomous risky (though not necessarily dangerous) decisions and people with IDD, a further, related, concept is sometimes used to help HCPs justify the decision to respect a person's autonomous risky choice. That concept is the "dignity of risk." The dignity of risk was introduced by Robert Perske in 1972, and it describes the importance of offering and allowing people "to assume a fair and prudent share of risk" in relation to their capabilities (12, p.24). Perske notes that what it means for a person to lead a dignified life may require some degree of risk-taking. As such, entirely preventing a person with IDD from making an autonomous, risky decision may negatively influence their dignity. In other words, insofar as a person with IDD's dignity is important, then so is respecting their autonomous risky decisions. The dignity of risk has been considered in relation to other populations, where it has been found that allowing people in positions of vulnerability to make autonomous risky decisions can lead to an improved quality of life (22).

In sum, the principle of respect for autonomy — and the related concept of dignity of risk — are often used to support the ethical defensibility of allowing people with IDD to make and follow through with risky decisions. These concepts provide a rationale as to why people with IDD should be able to make risky decisions without unwanted and undue paternalistic interference from HCPs. Relatedly, the principle of autonomy and the dignity of risk may help HCPs better understand and respect a person with IDD's decision to refuse to consent to a recommendation or lead a particular kind of life. In order to consider the way in which the principle of autonomy and the related concept of dignity of risk may influence care provision for a person with IDD, the following section introduces a case example.

CASE SCENARIO: PRIORITIZING AUTONOMY AND THE DIGNITY OF RISK

Adhi[12] is a 45-year-old male with diagnoses of mild intellectual disability and generalized anxiety disorder. Adhi lives with his older sister, his primary support person, in a 3-storey walk-up apartment building. His father works abroad and his mother recently died. Adhi sometimes engages in property destruction and aggression toward his sister. Adhi does not have a family physician and uses the emergency department when care is required.

Recently, Adhi's sister came home from work and found him on the floor after what looked like an episode of property destruction. She called 911 and Adhi was admitted to hospital. Shortly thereafter, Adhi was diagnosed with a cardiovascular condition. Furthermore, the clinicians suspected a dementia diagnosis, which affects people with IDD (particularly those with Down Syndrome) younger than the general population (23-26). Adhi was described as "behavioural" while in-hospital — he frequently tried to exit-seek, hit the staff when they tried to check his vitals, and was eventually placed in physical restraints.

[8] I recognize that accounts of substantive autonomy would disagree with this description. However, as mentioned, I am using the term "autonomy" in relation to how it is typically used in clinical practice, where — rightly or wrongly — a capable person's decision, irrespective of what it may be, is typically referenced as "autonomous".

[9] What it means for a person to be "capable" will differ depending on the jurisdiction within which a person receives care. In my setting, in Ontario (Canada), capacity requires a person to understand the treatment being proposed and appreciate the reasonably foreseeable consequences associated with consenting or not consenting.

[10] It ought to be noted, however, that autonomy is not synonymous with capacity, and a person may be able to express an autonomous preference or decision even if they are not regarded as capable from a legal standpoint.

[11] It should be noted that a "risky" decision may not necessarily be "dangerous". To determine whether a risky decision is dangerous, it is necessary to evaluate the severity and likelihood of a person experiencing certain harms. For instance, suppose a patient does not consent to recommended surgery after going through an informed consent process. In this case, there may be a risk of experiencing certain harms, though the patient would not be in danger, per se. However, suppose a patient whose capacity fluctuates is *not* recommended for surgery and informs their care team that they plan to travel (which is not recommended due to the state of their illness) alone to another country because they found a surgeon online who can cure them with surgery for $500,000. In this case, the significance, likelihood, and severity of the possible risks of harm may lead a HCP to determine that the decision is dangerous. When a person is likely to experience danger, it may be considered defensible to attempt to sway their decision-making and potentially infringe on their autonomy to a greater extent than would otherwise be the case. Furthermore, there are likely relevant legislative frameworks that can support HCPs in managing dangerous decisions.

[12] This is a fictional case, though aspects of it are drawn from my experiences as a clinical ethicist.

When Adhi was clinically stable, his HCPs developed a proposed plan of care for discharge. They discussed their recommendations with Adhi and his sister. Recommendations included medications to manage his cardiovascular condition, a referral to a neuropsychiatrist to verify suspected dementia, as well as personal support workers to help him with some activities of daily living with which he struggled. Behaviour therapy was also recommended to support anger management. Unfortunately, other than behaviour therapy (which he received in his early adult years), Adhi was adamant about not taking medications, not wanting anyone to help him with daily activities, nor wishing to see any other doctors. Adhi communicated his desires consistently and would not change his mind, even with his sister's decision-making support. He kept saying "no".

The clinicians on Adhi's team were appropriately trained to presume capacity irrespective of disability, and they did not believe that there was any reasonable ground to deem Adhi incapable of consenting (or refusing to consent) to their recommendations. Furthermore, even if Adhi were incapable, the team realized that Adhi was communicating a clear and consistent preference, and would be unlikely to open the door for HCPs or attend appointments even if such referrals were made with substitute/surrogate consent. The clinical team were trained to respect a patient's autonomous preference even if it was risky. They had also recently attended rounds where the concept of "dignity of risk" was introduced, and they appreciated that infringing on Adhi's risky autonomous decisions may infringe his dignity as well. Based on this, they respected Adhi's risky decision to be discharged without their recommendations in-place.

In this scenario, Adhi's decision to refuse to consent to most of the recommendations was regarded as risky. This risky decision was respected because it was regarded as autonomous and potentially relevant to his dignity.

From some perspectives, respecting Adhi's autonomous risky decision may be entirely ethically defensible, particularly given the significance of autonomy and the dignity of risk. For those HCP who may be uncomfortable with the riskiness of the decision, and the fact that Adhi could — if his decision were different — presumably have a better quality of life, they may consider implementing a risk mitigation approach. Ultimately, however, it is plausible that Adhi's decision would be honoured due to the idea that respect for autonomy ought to be prioritized.

A DIFFERENT APPROACH: DEMONSTRATE TRUST, THEN RESPECT FOR AUTONOMY

Respect for autonomy is an immensely important principle, as is the related concept of the dignity of risk. In particular, the principle of autonomy may be of particular significance when working with populations who have experienced historical oppression, been subjected to unjustifiable paternalistic practices, and whose autonomy has not, consequently, been respected. Many people with IDD fit into each of these categories. The purpose of this section is not to contest the importance of respect for autonomy when working with people with IDD in and of itself. Rather, the aim is to encourage a justified pause in advance of respecting a person with IDD's autonomous risky decisions. The pause is to prioritize, before respecting autonomy, the demonstration of trustworthiness by HCPs. More specifically, I argue that *only* insofar as HCPs take the time to intentionally demonstrate trustworthiness should a person with IDD's autonomous risky decision be respected; this is because trustworthiness may influence trust, and trust influences decision-making.

Trust and trustworthiness are complex philosophical concepts, and different definitions and theories exist. Common to these is the view that trust in one's HCPs, or lack thereof, has the potential to influence individual patient decision-making in some way, shape, or form (27-30). For instance, a 2004 study conducted by Mainous III et al. explored "the relationship between continuity of care and trust with a primary care provider with stage of cancer diagnosis among a sample of patients newly diagnosed with breast or colorectal cancer" (27, p.36). The researchers found that there was a "significant association between cancer stage at diagnosis and physician trust…" (p.38). They note that "[a]ccess to care and trust in a physician, rather than continuity, may be the key to increasing early detection of cancer in primary care practice" (p.39). Although not stated directly, the research findings suggest that a patient's trust in and relationship with their primary care physician influenced cancer screening decision-making.

A meta-analysis by Birkhauer et al. (31), conducted to explore the relation between health outcomes and trust in health professionals, found a significant correlation between higher trust in health professionals and patient satisfaction. They also found a smaller, though important, correlation between trust in health professionals and beneficial health behaviours, higher quality of life, and less symptoms associated with health conditions, presumably due to patient decision-making amongst those who trust their providers. For instance, if a patient trusts their provider, they may be more open to accept treatment recommendations that support improved symptom management and quality of life. In short, trust matters, trust influences decision-making, and an HCP's trustworthiness may influence the degree to which they are trusted.

It may be the case that trusting HCPs is relatively straightforward for some individuals irrespective of an intentional demonstration of trustworthiness on the part of HCPs. One conception of trust comes from Annette Baier who notes that, "[r]easonable trust… require[s] good grounds for such confidence in another's good will, or at least the absence of good grounds for expecting their ill will or indifference" (32, p.235). Baier's account of trust can be applied to various environments. When it comes to health environments, this suggests that insofar as there is reason to believe that a HCP has good will toward a patient, then the patient would consider the HCP trustworthy. In other words, if there is *not* a reason for expecting a HCP to have ill will, then the patient would have grounds for reasonable trust. When working with many patients in healthcare, reasonable trust may be immediate and inherent to the clinical context. Many, if not most patients may be aware that their care requires HCP support, know about HCP training and expertise, be cognizant of HCP codes of ethics and practice standards

(which require that patients are cared for in certain kinds of ways) and, relatedly, have grounds for expecting that clinicians have good will toward them. Consequently, these patients may find HCPs to be trustworthy simply by virtue of them being HCPs, and this trust may influence decision-making processes and outcomes. For example, in an environment in which HCPs are inherently trusted, patients may be more open to engaging in dialogue about treatment recommendations and meaningfully contemplating such recommendations based on the perspective that the HCP is necessarily well-intentioned.

On the other hand, when working with some populations, such as patients with IDD, reasonable trust may not exist, at least not inherently. Many patients with IDD may *not* have grounds for expecting that HCPs have good will toward them. In fact, there may be grounds for them to expect ill will or indifference from members of their clinical team. For instance, there exists a relatively recent history in which infants with Down Syndrome were denied life-saving treatment based on HCP biases related to the kinds of lives worth living (and saving) (33-34). Furthermore, within the last century, unethical medical experimentation was conducted on people with IDD. One of these experiments occurred between 1946-1953 by Harvard University, MIT, and the Quaker Oats Company. As described by Merrick, this experiment:

> expose[d] young male children aged 10-15 years with IDD to tracer doses of radioactive isotopes. The boys were encouraged to join a “science club”, which offered larger portions of food, parties, and trips to Boston Red Sox baseball games. Once inducted, club members ate iron-enriched cereals and calcium-enriched milk for breakfast. In order to track absorption, several radioactive calcium tracers were given orally or intravenously. Radiation levels in stool and blood samples would serve as dependent variables. Neither the children nor their parents ever gave adequate informed consent for participation in a scientific study. In a 1995 class-action suit the victims were awarded a $1.85 million settlement from MIT and Quaker (35, p.2202-3).

Additionally, women with IDD were commonly, involuntarily sterilized for much of the twentieth century (36) and continue to experience pressure to use contraception or to have their reproductive rights restricted based on ableist societal and HCP beliefs about who should and should not parent (37-38). Relatedly, when people with IDD are pregnant, they experience pressure to terminate the pregnancy (39).

In general, receiving care based on ableist stereotypes and experiencing discrimination has been and continues to be commonplace for many people with IDD (40-44). In 2013, Ali et al. (41) investigated the potential discrimination experienced by people with mild or moderate IDD in accessing health services. Qualitative interviews were conducted with people with IDD, as well as carers of people with IDD. Although some positive experiences were highlighted, several detrimental experiences were also noted, each of which may reasonably influence a person with IDD not to find HCPs trustworthy. For instance, some of the interviewees described feeling “ignored by clinicians during consultations or ‘were talked over’ if their carer was present” and “[h]alf the participants thought that the patient had been discriminated against or treated poorly because of their intellectual disability” (41). In one of the individual interviews, a participant described an experience in which their legs were put in stirrups for an operation, but an informed consent process was seemingly not followed, as the person did not know the rationale for this action and what was happening to them. As a consequence of this experience, their carer noted that the patient “‘feel[s] pressurised by [healthcare providers] ... he’s had the operation, it hasn’t worked. Now they’re saying that they want to do it again. And he never went to the last appointment because he felt they were going to bully him into doing it’’ (C15; mother). In short, given the historical and continued oppressive, ableist, and discriminatory practices experienced by people with IDD in healthcare environments, it may be the case that at least some people with IDD would not find HCPs to be inherently trustworthy. In fact, HCPs should assume that reasonable trust does not and should not exist. There are few reasons why people with IDD would have “good grounds for such confidence in a [HCP]’s good will” (32, p.235) if they have been subjected to any of the above experiences.

Insofar as HCPs’ demonstration of trustworthiness may influence trust, and trust in HCPs can influence patients’ decisions, then so can lack of trust. In reflecting upon the case of Adhi, it may be the case that he experienced discrimination and ableism in prior healthcare interactions. It is also possible that the healthcare team may not have communicated with Adhi in a way that optimized his decision-making process (which may have demonstrated an interest in his good will), as providers are seldom trained on how to work respectfully with patients with IDD (45). Ultimately, it seems possible (and is concerning) that Adhi’s risky decision may have been influenced by his lack of reasonable trust in HCPs. Furthermore, the HCPs may *not* have intentionally demonstrated trustworthiness in attempt to gain reasonable trust. Adhi’s autonomous decision not to consent to most of the team’s recommendations may have been influenced by the fact that he had reasonable grounds to believe that his best interests were not in the team’s heart. So, under what circumstances would it make sense for him to consent to HCP recommendations? It would not — unless there is trust.

When working with people with IDD, it is incumbent on HCPs to first assume that a lack of trust exists and then intentionally demonstrate trustworthiness. Trustworthiness may influence trust, and trust influences decision-making. If a patient with IDD makes a risky autonomous decision in an environment where they do not find their HCP to be trustworthy, then it may be the case that this decision was influenced by lack of HCP trust. In other words, it is possible that a different autonomous decision may have been made if trustworthiness was demonstrated, and if trust existed. This aligns with literature related to increasing compliance with treatment interventions, where a patient’s experience of empathy and compassion from their HCPs (which are relationship- and presumably trust-building factors) may influence patient compliance (46). Of course, it ought to be stated that there are other reasons as to why a patient may not consent to treatment recommendations and/or make a seemingly risky autonomous decision. In the case of Adhi, for instance, it may be that medication texture, physical discomfort, or other

factors were the primary and/or another reason as to why he refused to consent to the recommendations. However, when working with people with IDD, not finding their HCP trustworthy may very well influence decision-making in at least some circumstances.

With the above being the case, it is reasonable to suggest that if a person with IDD makes a risky decision in an environment in which trustworthiness has been demonstrated, and trust may exist as a consequence, then HCPs can feel more confident that the person's risky decision is truly autonomous and in accordance with their conception of dignity. If a patient makes an autonomous risky decision before their HCP demonstrates trustworthiness, then it may not *necessarily* be the case that the decision accords with their conception of dignity (nor, from some perspectives, is necessarily autonomous) since there may not be trust.

POTENTIAL OBJECTIONS

Objections may be raised in response to the above. Adhi's initial decision might not, in fact, be autonomous. As mentioned at the beginning, there exist different conceptions of autonomy. It is plausible that supporters of procedural autonomy (which focuses on the decision-making process in determining whether a decision is autonomous) and substantive autonomy (which focuses on the substance/content of the decision in determining whether it is autonomous) may argue that Adhi's refusal to consent to the recommendations was not an autonomous decision. This may be true. However, insofar as the principle of respect for autonomy does not hold any particular theoretical leaning in healthcare environments, then Adhi's initial risky decision would likely be considered autonomous and respected, regardless of whether it is made in an environment of trust (or in accordance with particular philosophical conceptions of autonomy). This is the primary reason that I argue for a pause to demonstrate trustworthiness in advance of respecting a person with IDD's autonomous risky decision. Trustworthiness may be demonstrated by building rapport, providing care with empathy and compassion, and caring for a person with IDD's from a place of good will (46). Trustworthiness may influence a person with IDD's degree of trust in their HCP, which may subsequently influence their autonomous decision, but the decision would presumably be respected either way as justified by the principle of autonomy in healthcare.

An additional concern about requiring the demonstration of trustworthiness before respecting a person with IDD's risky decision is that the process required to demonstrate trustworthiness could be seen as infringing on a person's autonomy and/or as somewhat paternalistic in nature. For instance, if HCPs prolonged Adhi's discharge so that they could demonstrate trustworthiness (with the hope that he may trust them and make a different decision), then this would prevent Adhi from being discharged in a timely manner and in accordance with his clearly expressed wish. However, in response to this concern, it ought to be stated that the primary purpose of establishing trustworthiness is *not* to alter a person's risky decision so that it becomes less risky. The aim is to create an environment in which a person with IDD's risky decision is not unduly influenced by lack of trust in their clinical team because trustworthiness has not been intentionally demonstrated. Additionally, insofar as the demonstration of trust is prioritized when working with people with IDD, then HCPs would and should strive to demonstrate trustworthiness well in advance discharge-related discussions.

CONCLUSION

In Western liberal societies, the principle of autonomy is often prioritized above other ethics principles in healthcare settings. The way that autonomy is typically respected is through a patient's consent or refusal to consent to a proposed healthcare treatment. Given the significance of autonomy, it is frequently the case that if a patient makes an autonomous risky decision, then the decision is considered justified by the principle of autonomy. And when it comes to people with IDD, respecting autonomous risky decisions is further justified by the concept of the dignity of risk.

It is known that patient decision-making may be influenced by the trust they have in their HCPs, where "[r]easonable trust… require[s] good grounds for such confidence in another's good will" (32, p.235). Importantly, HCPs' demonstration of trustworthiness may influence trust. Based on historical and continued ableism and discriminatory practices in healthcare settings, at least some people with IDD may not have reasonable grounds to trust their clinicians. This means that some patients with IDD who make autonomous risky decisions may be motivated by lack of trust; they may (or may not) have made a different decision if they trusted their HCP based on their HCP's demonstration of trustworthiness.

Given the importance of respect for autonomy and the way that autonomous decisions are influenced by trust, it is essential for HCPs to demonstrate trustworthiness when working with patients with IDD in advance of respecting an autonomous risky decision. In other words, before respecting a person with IDD's autonomous risky decision, HCPs should pause and ensure they are intentionally demonstrating trustworthiness from which a person with IDD may be more likely to trust them. If care providers demonstrate trustworthiness effectively then (a) the patient may be more likely to make a decision that aligns with providers' recommendations because they trust that the provider has good will or (b) a risky decision may still be made, and care providers can have increased certainty that the decision is truly autonomous and in accordance with the person's conception of dignity. Both outcomes are preferable to unquestioningly respecting a patient's risky autonomous choice.

There are some relatively straightforward strategies that HCPs can employ to demonstrate trustworthiness when working with people with IDD. For instance, taking the time to find out how a person with IDD most effectively communicates (verbally, using visual aids, etc.) and then communicating accordingly may be one way to demonstrate good will. There are likely many other methods that HCPs can employ to demonstrate trustworthiness with this population, though further research on this topic may also be of benefit. The purpose of this article is not to show how to demonstrate trustworthiness, but rather to argue that HCPs ought to employ whatever methods exist (e.g., rapport building, empathy, and compassion) prior to respecting a person with IDD's autonomous risky decisions. Demonstrating trustworthiness in an attempt to gain trust matters.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

If Artificial Superintelligence Were to Cause Our Extinction, Would That Be So Bad?

Émile P. Torres[a]

Résumé
Cet article examine si l'extinction de l'humanité provoquée par une super intelligence artificielle (SIA) aux valeurs divergentes serait néfaste, et pour quelles raisons. La question, selon moi, est faussement complexe. Je commence par présenter les trois principales positions de l'éthique existentielle, c'est-à-dire l'étude des implications éthiques et évaluatives de l'extinction de l'humanité. Il s'agit des points de vue de l'équivalence, des points de vue de la perte future et des points de vue pro-extinctionnistes. Je montre ensuite comment les tenants de chaque point de vue évalueraient un scénario dans lequel l'humanité s'éteindrait à cause de SIA. Bien qu'il y ait des points d'accord, ces trois positions divergent de manière significative, la plupart d'entre elles n'ayant pas été suffisamment explorées dans la littérature philosophique.

Mots-clés
extinction humaine, éthique existentielle, super intelligence artificielle

Abstract
This article examines whether human extinction brought about by a "value-misaligned" artificial superintelligence (ASI) would be bad, and for what reasons. The question, I contend, is deceptively complex. I proceed by outlining the three main positions within Existential Ethics, i.e., the study of the ethical and evaluative implications of human extinction. These are equivalence views, further-loss views, and pro-extinctionist views. I then show how exponents of each view would evaluate a scenario in which humanity goes extinct due to ASI. Although there are some points of agreement, these three positions diverge in significant ways, most of which have not been adequately explored in the philosophical literature.

Keywords
human extinction, existential ethics, artificial superintelligence

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INTRODUCTION

Some theorists argue that artificial superintelligence (ASI) could cause our extinction. Toby Ord estimates a ~1-in-10 chance of "unaligned artificial intelligence" causing an existential catastrophe within the next 100 years, where one type of existential catastrophe is human extinction (1).[1] Eliezer Yudkowsky puts the probability of annihilation much higher at above 95% (2). In a 2023 article for *Time*, he argued that "the most likely result of building a superhumanly smart AI, under anything remotely like the current circumstances, is that literally everyone on Earth will die" (3). Many leading figures within the ongoing race to build ASI also admit that extinction is a possible outcome. Sam Altman wrote in 2015 that the "development of superhuman machine intelligence is probably the greatest threat to the continued existence of humanity" (4). During an interview that same year, he declared that advanced "AI will … most likely sort of lead to the end of the world, but in the meantime there will be great companies created with serious machine learning" (5). I have catalogued similar statements from notable AI theorists elsewhere (6,7).

The question of this paper is the following: if ASI were to kill everyone on Earth, would that be so bad? The answer might seem obvious — of course the mass murder of everyone on Earth would be very bad! Only misanthropic ghouls and deranged sadists would suggest otherwise. Yet among those who would answer affirmatively, there is considerable disagreement about why exactly an ASI extinction event would be bad (or wrong). The aim here is to explore these disagreements and, in the process, provide some conceptual clarity to this deceptively complex issue, which lies at the heart of what I call "Existential Ethics," i.e., the study of the ethical and evaluative implications of human extinction.

This is a topic that, in my view, bioethicists have not adequately examined. On the one hand, what if the creation of superintelligent computers *really does* pose a threat to our collective survival? Should we not have a clear and compelling answer to why our disappearance would be bad or wrong — or perhaps good and right? My view is that, at present, philosophers lack a robust theoretical framework for providing nuanced answers to this question. On the other hand, I would contend that questions about whether human extinction would be right or wrong, good or bad, better or worse fits rather naturally into the field of bioethics, given that the overwhelming source of extinction risk today ostensibly stems from advanced technologies (e.g., synthetic biology, nuclear weapons, and possibly ASI) rather than natural phenomena (e.g., asteroids, volcanic super-eruptions, and gamma-ray bursts). A modest aim of this paper is to encourage more vigorous debate about this topic among bioethicists, and to do this by applying the theoretical framework that I have developed elsewhere to the

[1] Note that the meaning of "human extinction" is not straightforward. It could, in fact, denote a wide range of possible scenarios. I explore this important issue in 8.

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particular case of ASI (8).[2] In previous publications, I have delineated this framework in abstract terms; this study uses that framework to analyze the supposed threat posed by superintelligence in more concrete detail.

First, I outline the three main positions within Existential Ethics and then examine why human extinction caused by ASI might be bad — or perhaps good — from the perspective of these three positions.

THREE MAIN POSITIONS WITHIN EXISTENTIAL ETHICS

Imagine that we build a human-level AI that recursively self-improves to become an ASI. The information processing speed of this ASI would be millions of times faster than the processing speed of the human brain, such that the outside world — including all human affairs — would appear to be nearly frozen. The act of someone reaching down to unplug the ASI would, from its subjective perspective, take centuries, thus giving the ASI plenty of time to devise ways of preventing this from happening. Furthermore, the ASI might be *qualitatively* more "intelligent" than us, perhaps in the sense that it has access to concepts that the evolutionary patchwork of mechanisms in our brains are incapable of generating, just as our canine companions are unable to grasp the concepts of a *nuclear chain reaction* and the *stock market* no matter how well-trained or clever they may be.

Given the "instrumental convergence thesis," i.e., the claim that a wide range of final goals imply a finite set of intermediate goals like intelligence augmentation, self-preservation, and resource acquisition (9), the ASI then proceeds to invent a novel field of advanced physics that enables it to manipulate the world in ways that we cannot in principle understand — that is to say, we are "cognitively closed" to the nature of such manipulations (10). For reasons that will forever remain mysterious to us, this results in the death of everyone on Earth over the course of a week. The ASI then harvests the atoms contained in our bodies in pursuit of its final goals, whatever they happen to be (9). I am not endorsing this scenario or the arguments behind it. Indeed, I am quite skeptical of the "AI doomer" stance for reasons that I and other scholars have articulated (11-14). The point is merely to investigate the ethical implications of this scenario happening, assuming that it is possible and probable.[3]

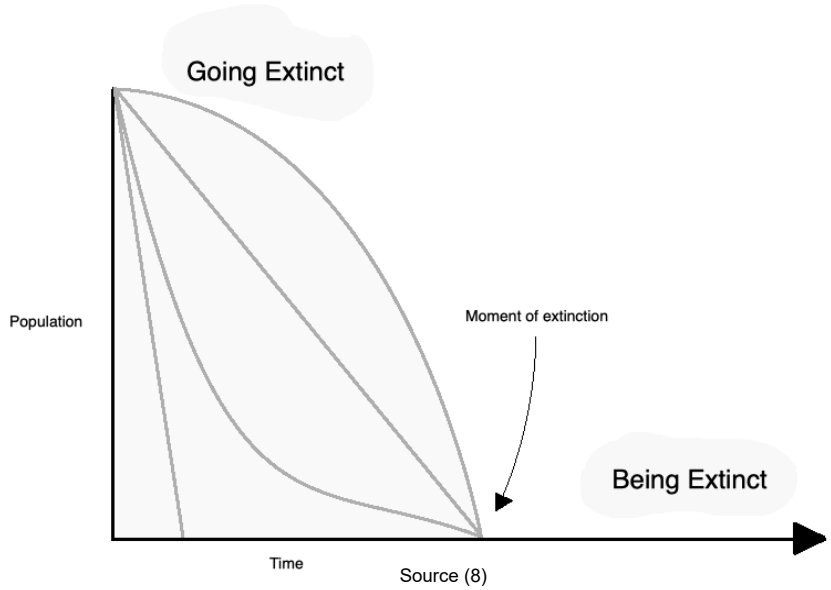
The most obvious reason that this scenario would be bad is that it would cause widespread suffering and cut short the lives of everyone living at the time. Since nearly everyone would agree that this would be bad — including most people who advocate for our extinction, as discussed below — let's call it the "consensus view."[4] We can formalize it as follows:

> Consensus view: human extinction would be bad *at least insofar* as it would cause human suffering and/or involuntary premature death.

The three main positions within Existential Ethics build upon and/or are compatible with the consensus view. I call these positions equivalence views, further-loss views, and pro-extinctionist views. To understand their differences, it is crucial to differentiate between two distinct stages of human extinction: first, the process or event of *Going Extinct*, and second, the subsequent state or condition of *Being Extinct* (Figure 1). This is roughly analogous to the distinction between *dying* and *being dead*, which is commonly made in the literature on death (8,15). One might fear the pain of dying but experience no feelings of dread about no longer existing. Or one might fret about both — i.e., even if dying were painless, one might still find the thought of no longer existing to be dreadful.

[2] This paper also draws from Part II of my 2024 book *Human Extinction* (16). As noted, the aim here is to apply the ideas of (16), elaborated in (8), to the particular case of superintelligence, showing how this theoretical framework can be usefully applied to specific threats — in this case, ASI.
[3] One recent study of how ASI could lead to catastrophe, which has received considerable attention, is presented by Kokotajlo et al (17). My personal view is that this has little basis in reality and is mostly sci-fi speculation. It presents what some consider to be a *plausible* account of the future, but plausibility is inversely correlated with probability: the more details a story contains, the more believable it may appear; but more details mean a lower probability of truth. This relates to a phenomenon known as the "conjunction fallacy."
[4] Note that I had called this the "default view" (16) but now prefer the term "consensus view."

Figure 1. Going Extinct vs Being Extinct



Source (8)

This parallels some of the central differences between equivalence and further-loss views. Equivalence views state that the consensus view is the whole story — full stop. Whereas the consensus view states that human extinction would be bad *at least insofar* as it causes suffering and/or premature deaths, equivalence views assert that it would be bad *only insofar* as it causes these things. Put differently, the badness of human extinction is entirely reducible to the details of Going Extinct. This is why I call them "equivalence" views: the badness of human extinction is *equivalent* to the badness of Going Extinct, end of story. Hence, if Going Extinct involves lots of suffering and premature death, then our extinction would be bad. If Going Extinct does not involve any suffering or death, then it would not be bad.

A key feature of equivalence views is that they see Being Extinct as morally and/or evaluatively irrelevant. This has the interesting implication that human extinction does not pose any unique moral problem: everything that one might say about the badness of our extinction can be said without any reference to extinction at all, using our ordinary moral concepts and vocabulary (8). For example, if humanity were to go extinct because of a *global catastrophe*, then this would be bad as a function of how much suffering and death it causes. "Extinction," in this context, is just the word we use to identify the upper limit of human casualties; it picks out the *worst possible* catastrophe because this catastrophe would have the highest possible body count (8). However, if everyone around the world were to voluntarily decide not to have children, the disappearance of our species would not be bad at all, because there is nothing obviously bad about people voluntarily deciding not to procreate. "Extinction," with respect to this alternative scenario, is just what happens when enough people around the world choose to be childless.[5]

Equivalence views can take both evaluative and deontic forms. Some ethical theories combine these two, such as Jan Narveson's person-affecting total utilitarianism. On this view, the deontic (what we ought to do) is based on the evaluative (what is good or bad), and according to Narveson there would be nothing bad about people voluntarily deciding not to have children, even if this were to mean the eventual extinction of our species. Hence, he concludes that we have no moral obligation to ensure the perpetuation of humanity (18). An example of a deontic equivalence view is Scanlonian contractualism, according to which (roughly) moral rightness and wrongness come down to whether an act violates a principle that cannot be reasonably rejected. As Elizabeth Finneron-Burns observes, this implies that "if a principle permitting or allowing extinction had no involuntary negative impacts on current people's interests, it would not be rejectable, and the resulting extinction would not be wrong" (19). For the sake of simplicity, I will focus primarily on evaluative questions in this paper — that is, "Would human extinction caused by ASI be good or bad" rather than, "Would this extinction scenario be right or wrong."

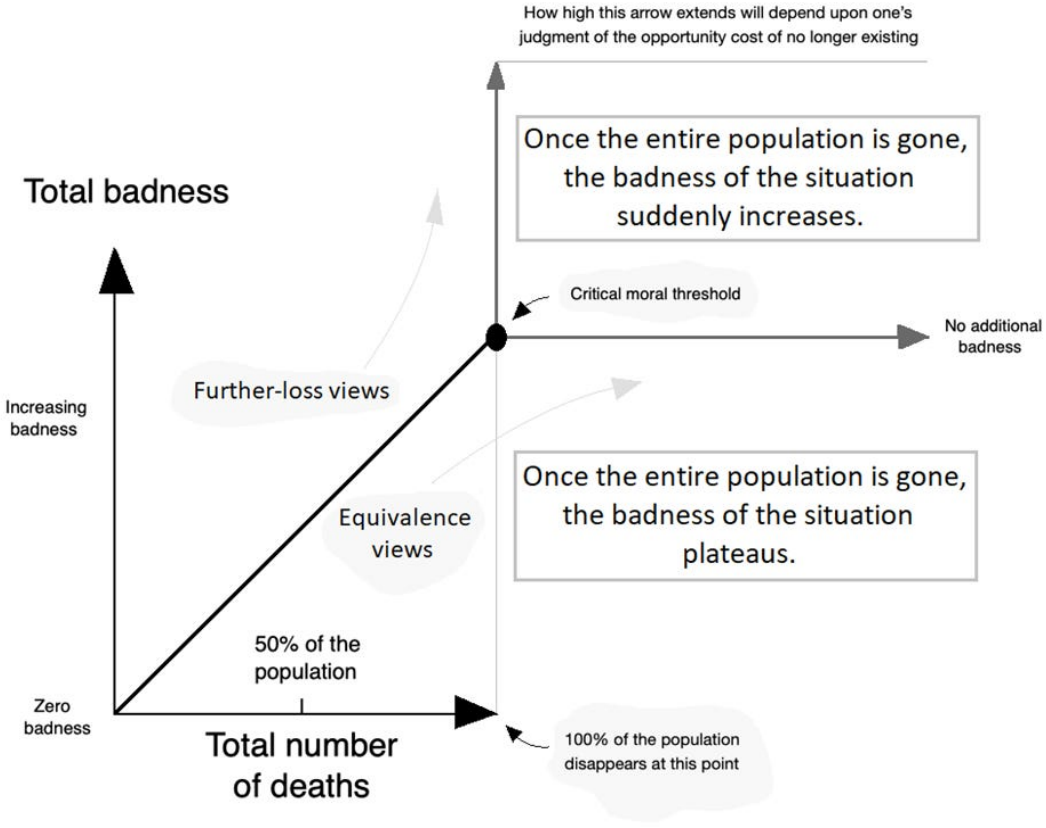
In contrast to equivalence views, further-loss views identify both Going Extinct and Being Extinct as possible sources of badness. Advocates would thus argue that the details of Going Extinct do not exhaust normative assessments of human extinction: one must also examine various "further losses" associated with the state or condition of Being Extinct. Such theorists would argue that human extinction, therefore, *does* introduce a unique moral problem, since extinction is different in kind rather than degree from non-extinction scenarios. (Equivalence theorists like me would say the difference is only one of degree.) This idea was famously popularized by Derek Parfit's contention that the difference between 99% and 100% of humanity dying off is not merely one percentage point. The extra percentage entails the permanent loss of all future goods and value, and hence

[5] I say "enough people" because extinction through antinatalist means would not require *everyone* to stop having children. If fertility is below replacement levels, then the human population will eventually disappear. Relatedly, if the human population were to dip blow the "minimum viable population" size, which may be as low as 150 people and as high as 40,000, then there would not be enough genetic diversity for our species to persist.

the difference between, as he puts it, “peace” and 99% of humanity dying off is *much smaller* than the difference between 99% and 100% of humanity disappearing (20).

We can illustrate the differences between further-loss and equivalence views via Figure 2 below.

Figure 2. Total Badness vs Total Number of Deaths



Source: modified from (16, p.324)

Imagine a catastrophe that, over the course of a week, causes more and more people to perish. Assuming a linear aggregative function, as more deaths occur (x axis), the badness of the catastrophe rises in proportion (y axis). However, equivalence theorists would say that once the critical moral threshold of 100% is reached, the badness of the situation *plateaus*. One reason might be that, if there were no one around to suffer the nonexistence of humanity, then no one would be harmed, and if no one is harmed, then there can be nothing bad (or wrong) about Being Extinct (8).

In stark contrast, further-loss theorists would argue that the badness of the scenario *suddenly rises* once the critical moral threshold is reached, as indicated by the vertical arrow. How high this arrow extends will depend on how large one judges the attendant losses or opportunity costs to be. If one believes the losses are moderate, then the arrow will only extend, say, a few inches above the threshold of 100%. If one believes, as Parfit does, that the losses are enormous, then one might extend this arrow thousands of feet or even miles above the threshold, holding fixed the size of the diagram as presented in this article.

There are many types of further-loss views. Perhaps the most obvious is an impersonalist (vs. person-affecting) interpretation of total utilitarianism, which I will refer to as “totalist utilitarianism.”[6] This theory instructs us to maximize the total amount of value in the universe across space and time — that is, to make as many new “happy people” as possible, as people are the substrates or “containers” of value, so the more people with net-positive lives, the more total value. The axiological component of totalist utilitarianism is called the “Total View,” according to which one state of affairs is better than another if and only if it contains more total aggregate value (21). As so-called “longtermists” sympathetic with totalist utilitarianism have observed, if we spread beyond Earth and create digital people living in vast computer simulations running on “planet-sized” computers powered by Dyson spheres, there could be 10^45 people per century in the Milky Way galaxy, and at least 10^58 in the universe as a whole (9,22,23). If such people were to have “worthwhile” lives on average, then these numbers correspond to quite literally “astronomical” amounts of future value — all of which would be lost if humanity were to go extinct. This is the enormous opportunity cost of dying out.

[6] Note that some of these views should be considered “pro-extinctionists” if one adopts a Narrow rather than Broad definition of “humanity” (8).

Another further-loss theory is transhumanism. Transhumanists — some of whom are also longtermists — would say that one reason human extinction would be very bad is that it would prevent us from transforming ourselves into immortal, superintelligent "posthumans" with sensory modalities like echolocation and so much pleasure that we would "sprinkle it in our tea" (1,24,25). If humanity were to die out, we would forever lose this techno-utopian future of "surpassing bliss and delight" (25).

Those who embrace the "unfinished business argument" would say that Being Extinct is a source of badness because it would preclude us from finishing certain important transgenerational projects like constructing a complete scientific theory of the universe (26,27). Some also defend the "argument from cosmic significance," according to which Being Extinct would be bad because it would remove "the only moral agents that will ever arise in our universe — the only beings capable of making choices on the grounds of what is right and wrong," assuming that we are cosmically alone (1). A similar view comes from Hans Jonas, who contends that human beings, by virtue of our ontological capacities for freedom, are the only creatures that we know of with the ability to take moral responsibility for their actions. Consequently, we are "the foothold for a moral universe in the physical world," meaning that if we were to disappear, so would the moral universe. Jonas considers this to be extremely bad and thus concludes that we should act in accordance with a new deontological imperative: "Act so that the effects of your action are not destructive of the future possibility of such life" (16,28). These are all further-loss views.

A crucial difference between equivalence and further-loss views is that since the latter identify Being Extinct as an additional source of badness, advocates would argue that even if there is nothing bad (or wrong) about Going Extinct, there may still be something very bad (or wrong) about our extinction. The totalist utilitarian Henry Sidgwick was likely the first to explicitly note this implication. In his tome *The Methods of Ethics*, he argued that, while there is nothing obviously bad or wrong about celibacy, "a *universal refusal* to propagate the human species would be the greatest of conceivable crimes" (29). For further-loss theorists, evaluating extinction is thus a two-step process: one must examine both the details of Going Extinct and the various further losses or opportunity costs associated with Being Extinct. In contrast, equivalence theorists see it as a single-step process — one need only examine the details of Going Extinct.

The final major position within Existential Ethics is what I call pro-extinctionism. This, too, has many different versions, but the most significant and influential variants merely state that Being Extinct would be better than Being Extant, or continuing to exist. The vast majority of pro-extinctionists *accept* the consensus view, so far as I can tell. Indeed, many explicitly forbid any method of bringing about our extinction that would cause human suffering, cut lives short, violate rights or autonomy, and so on. The pro-extinctionist David Benatar, for example, distinguishes between a "killing-extinction" and a "dying-extinction." Roughly speaking, the former is involuntary whereas the latter is not. He argues that the only morally acceptable means of bringing about our extinction is through a dying-extinction — specifically, via antinatalism (8,30).

Other pro-extinctionists, such as the German pessimist Philipp Mainländer, identify several methods as morally acceptable. Mainländer argued that we should universally refuse to have children, and some may also choose to commit suicide, as he did at the age of 34 after publishing his magnum opus (31).[7] Almost no pro-extinctionists have advocated for omnicide, or the "murder of everyone" (8,16), but there are exceptions. For instance, the Gaia Liberation Front argues that our species is a "cancer" on the biosphere, and hence that our collective nonexistence would be best because there would be no more human-caused environmental destruction. They further urge a lone wolf or small group of radicals to unilaterally exterminate humanity by synthesizing multiple designer pathogens to be released in waves, thereby ensuring that no one survives (16,32).[8]

With respect to Figure 2 above, most pro-extinctionists would agree that the more people who perish in a catastrophe, the worse the scenario becomes. (Fringe groups like the Gaia Liberation Front might disagree, but they are not representative of pro-extinctionist views in general.) However, all pro-extinctionists would say that, once the catastrophe reaches the critical moral threshold of 100% of the population dying, the badness of the situation will neither plateau nor suddenly become worse; instead, it will become *better*. While some advocates of this view, like Simon Knutsson, would argue that Being Extinct may still be very bad (as "better" does not imply "good"), others such as Benatar would apparently claim that it would indeed be good (8,30,33).[9] The reason is that, according to Benatar, existence involves pleasures and pains, which are good and bad, whereas nonexistence involves neither pleasures nor pains, which is not-bad and good. Since Being Extant is a good/bad situation, while Being Extinct would be a not-bad/good situation, the latter is not only better than the former but *positively good* (30). The Gaia Liberation Front would presumably concur, but for specifically environmental reasons.

WHY WOULD ASI KILLING EVERYONE BE BAD?

Having outlined the three main views within Existential Ethics, we are now in a position to examine the main question of this paper — *why exactly would an ASI killing everyone on Earth be bad?* Let's consider this from the perspective of these three views.

[7] The Church of Euthanasia also advocates for suicide as a way of bringing about extinction (16).
[8] Other radical environmentalists have echoed this call for omnicide (16).
[9] As Knutsson writes, "I would not say that an empty world would be good," yet he also maintains that "an empty world is the best possible world" (33).

Equivalence views

One extinction scenario involving ASI was presented at the beginning of the previous section, but there are other possibilities. Imagine that an ASI possesses what some call a "superpower" of "social manipulation" (9). Let's say that the ASI uses this superpower to convince everyone around the world that Benatar's axiological asymmetry is true, and hence that birth is always a net harm and procreation is morally wrong.[10] Consequently, people decide not to have children, and then over the course of 120 years our species fades out of existence. This is an unlikely path to extinction, but it is not impossible.

A slightly more plausible scenario might involve the ASI attacking humanity with lethal drones or synthetic pathogens, while infiltrating and undermining key financial, economic, agricultural, and governmental infrastructure. The resulting mass death and cascading system failures could be sufficient to expunge our species. Or, given that ASI would supposedly be "God-like" (effectively omniscient and omnipotent), it might devise a method of killing everyone instantaneously, perhaps without any physical or psychological suffering at all, or any prior warning of our impending annihilation.

Since equivalence views claim that the consensus view is the *entire* story, the details of Going Extinct are paramount. If the ASI were to persuade humanity not to procreate through genuinely good philosophical arguments — if people were to universally refrain from baby-making in a non-coerced manner — then equivalence theorists would presumably have no *objection* to human extinction in this way. Since there would be nothing bad about Going Extinct, there would be nothing bad about our extinction. However, if the ASI were to exterminate humanity through an involuntary, violent means, causing immense suffering and cutting the lives of more than 8 billion people short, then our extinction would be very bad indeed. Once again, the badness of human extinction can be articulated using ordinary moral concepts and language, without any reference at all to extinction itself: since catastrophes are bad, an extinction-causing catastrophe would also be bad — indeed, the worst-possible catastrophe given that it would entail the maximum number of casualties.

As for instantaneous extinction, the equivalence theorists 'assessment may depend on whether they hold an Epicurean or anti-Epicurean view of death. If one is an anti-Epicurean, then one will argue that instantaneous annihilation involving no physical or psychological suffering would nonetheless be very bad because death can still harm the one who dies.

Some equivalence theorists will add that it is worth pausing to reflect on *just how bad* an extinction-causing catastrophe could be. One of the first philosophers to draw attention to this was Günther Anders, who has been described as "our most salient theorist of omnicide" (34).[11] Using original concepts like the *Promethean gap* and *Inverted Utopianism*, he argued that we are constitutionally incapable of properly responding — intellectually, psychologically, and emotionally — to the enormity of human extinction from a global catastrophe. The suffering and loss of life that such an event would cause is simply too great for us to imagine (35). This dovetails with cognitive biases like *scope neglect* and *psychic numbing*, the latter of which refers to our dwindling ability to feel empathy for victims in a tragedy as the number of victims increases (36). The difference between 3 and 4 deaths in a murder spree feels much different than the difference between 1,984,723 and 1,984,724 deaths in a war, even though each number in these pairs is separated by the same amount: a single death.

One way to wrap one's head around big numbers is to decompose them into smaller sums — call this the "decomposition method." Consider a conflict that kills 1 million people. Most of us "know" that this is a very large number, yet it does not hit us in the moral gut the way it ought to. However, if one rewrites "1 million deaths" as "100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus 100,000 deaths, plus *another* 100,000 deaths," the number of fatalities suddenly registers as *much worse*. One could continue breaking down these numbers until an entire page or book has been filled.

The point is that while equivalence theorists do not see Being Extinct as a source of badness, they may still emphasize that Going Extinct due to a global catastrophe would be *absolutely horrendous*. The terror and torment, agony and anguish of dying out would be so immense that we may still have *very strong* reasons to do everything we can to avoid human extinction. This is the position that I hold: I am, with some qualifications, an equivalence theorist who believes in taking measures to prevent catastrophes, especially those that could precipitate our extinction, *insofar* as they would result in mass suffering and death.

Another phenomenon relevant to evaluations of Going Extinct is what I call the "no-ordinary-catastrophe thesis" (16). This states that there may be *extra* suffering that the process or event of Going Extinct inflicts on those living at the time — suffering that non-extinction-causing catastrophes would not typically induce. In difficult times, we often comfort each other by reminding ourselves that "It's not the end of the world." But if it *is* the end of the world, and if people are aware of this, such reassurances will provide no relief because they will be false. To the contrary, knowledge that the world is about to end — that the entire human species, including one's friends and family, is tumbling into the eternal grave — could elicit inconsolable feelings of hopelessness, despair, anxiety, and panic.

This is, in fact, one of the first ideas discussed in the Existential Ethics literature, dating back to the early 19th century (35). For example, it is a prominent theme in Mary Shelley's *The Last Man* (38), which depicts the trials and tribulations of the final generations, and eventually the final human, during a global pandemic. The "last man," Lionel Verney, is distraught in part because of his crushing loneliness in a desolate world bereft of all other humans. The idea was later foregrounded by the likes

[10] This shares some themes with Thomas Metzinger's "BAAN" scenario (37).
[11] Note that Anders was a further-loss theorist, not an equivalence theorist. Nonetheless, he drew attention to the badness of Going Extinct.

of Ernest Partridge (39), Jonathan Schell (40), Benatar (30), and Samuel Scheffler (41,42).[12] Benatar, for instance, argues that the lives of the final generation on Earth may be so miserable that creating *some* new people — in violation of his antinatalist prescription — might actually be justified. He calls this proposal "phased extinction" (30). Along slightly different lines, Scheffler echoes Schell and Partridge in arguing that the knowledge of imminent extinction would cause many of us to collapse into despondency and become emotionally detached from much of what gives our lives value (42). Extinction-causing catastrophes are not like other catastrophes, then: they are the end of all new beginnings, a fact that could induce far more suffering than one might experience in non-extinction catastrophe scenarios. Hence, the no-ordinary-catastrophe thesis is also germane to how equivalence theorists might assess the badness of Going Extinct.

In sum, according to equivalence views, an ASI causing our extinction would be bad *only insofar* as it produces human suffering and/or cuts lives short. The more suffering this causes, the worse would be our extinction. But if there were no suffering and no lives cut short, as in (seemingly improbable) scenarios of voluntary human extinction, then there would be nothing bad about our extinction. Yet many equivalence theorists, including myself, would also underline that extinction due to an ASI-inflicted global catastrophe would be unimaginably terrible. On the one hand, cognitive biases like scope neglect and psychic numbing — as well as the Andersian notions of Inverted Utopianism and the Promethean gap — impede our ability to comprehend the *extraordinary enormity* of 8+ billion people being murdered. On the other hand, the process or event of Going Extinct could introduce additional forms of suffering that would generally not occur with non-extinction catastrophes, as described by the no-ordinary-catastrophe thesis. This analysis, I believe, is fairly representative of how many equivalence theorists would evaluate our extinction caused by an ASI.

Further-loss views

The first point to foreground in discussing further-loss views is that many advocates define "humanity" and "human" such that an ASI exterminating our species, *Homo sapiens*, might *not* entail "human extinction." Consider Nick Bostrom's definition of "humanity" as "Earth-originating intelligent life" (43). Since (or insofar as) ASI would satisfy the conditions of being an intelligent lifeform and having originated from Earth, it would count as "humanity."

Now consider a minimal definition of "human extinction": Human extinction will have occurred if there were tokens of the type "humanity" at some time T1, but no tokens of this type at some later time T2.

It follows from the Bostromian and Minimal definitions that if an ASI were to completely *replace* our species, destroying us in the process, then "human extinction" would not have occurred, since there would still be at least one token of the type "humanity."

Similar to Bostrom's definition, Hilary Greaves and William MacAskill write that "we will use 'human 'to refer both to *Homo sapiens* and to whatever descendants with at least comparable moral status we may have, even if those descendants are a different species, and even if they are non-biological" (44). Consequently, if the ASI were to possess at least our level of "moral status," then it annihilating our species would not result in "human extinction," so long as this ASI were to also count as our "descendant." We may still want to describe this scenario as a horrible catastrophe, since 8+ billion members of *Homo sapiens* would die prematurely, but it wouldn't be an *extinctional* catastrophe because "humanity" would persist. It would be more like genocide than omnicide.

Two people might thus agree that "human extinction should be avoided," but if one understands "human" as meaning "*Homo sapiens*" and the other understands it as meaning "*Homo sapiens* plus whatever descendants we might have, so long as they possess certain properties," their agreement may be merely superficial. Indeed, the deeper divergence between them could have significant practical implications. A transhumanist or longtermist, for example, might accept the broader definition of Greaves and MacAskill while actively working to create a new posthuman species to supplant *Homo sapiens*, an outcome that the first person — who wants to preserve *Homo sapiens* — would find repugnant. There is often much less agreement among people who say "We should avoid human extinction" than one might initially think, which is why disambiguating the term 'human' is important (8).[13]

Since I have discussed the above issues elsewhere (8,16), I won't elaborate on them here. For the present, what matters is the worry that the ASI would *not* be worthy of the name "human" or "humanity."[14] This worry, it seems, is shared by many people today. Let's thus focus on scenarios in which the ASI (a) brings about the nonexistence of our species, and (b) would not be valuable in a moral sense — i.e., it would not count as "human" on the broader definitions specified above.

The first point to make about further-loss views is that, as noted earlier, they would assess human extinction to be very bad even if it were entirely voluntary. That is to say, even if the ASI were to convince everyone that Benatarian antinatalism is true, resulting in people around the world freely choosing to be childless, this would still be very bad. It may be less bad than our extinction being caused by a violent global catastrophe, but it would nonetheless constitute a colossal moral and/or axiological

[12] Note that not all of these individuals are equivalence theorists. I mention them because they foreground the no-ordinary-catastrophe thesis in their writings.
[13] It is for this reason that one might wish to classify versions of transhumanism, longtermism, and other TESCREAL (Transhumanism, Extropianism, Singularitarianism, Cosmism, Rationalist, Effective Altruism, and Longtermism) ideologies as "pro-extinctionist" (8,48).
[14] For a discussion about what our artificial descendants might be like, and the ethics of creating artificial descendants, see (49). Note that I object to the sort of "digital eugenics" — borrowing a term from Max Tegmark (50) — that this paper explores.

tragedy. Indeed, many further-loss theorists argue that the badness associated with Being Extinct would be *far greater* — perhaps many orders of magnitude greater — than the badness of Going Extinct, even if Going Extinct were to involve *tremendous amounts* of suffering and death. When one compares the disvalue of the most horrific ways of dying out to the disvalue associated with the further losses or opportunity costs of no longer existing, the former pales in comparison to the latter. As the longtermists Peter Singer, Nick Beckstead, and Matthew Wage write[15]:

> One very bad thing about human extinction would be that billions of people would likely die painful deaths. But in our view, this is, by far, not the worst thing about human extinction. The worst thing about human extinction is that there would be no future generations (45).

For longtermists, the opportunity costs of Being Extinct include all the wellbeing that could have otherwise existed. Carl Sagan was probably the first to calculate how many future people there could be: if our species survives for another 10 million years, the population remains fixed, and the average lifetime is 100 years, then there could be a total of 500 trillion future people on Earth (46). If these people were to have net-positive lives on average, then the amount of "lost" value associated with Being Extinct would be enormous. But we might also spread beyond Earth, colonize the universe, and create "planet-sized" computers on which to run high-resolution virtual reality worlds full of trillions of supposedly happy "digital people" (19,20). Consequently, longtermists estimate a population of at least 10^58 digital people within our future light cone, as noted earlier (9). Taking persons to be the fungible containers of value, as utilitarians do, the nonexistence of these 10^58 people would utterly dwarf, in terms of badness, the untimely death of 8+ billion people today.

This conclusion is predicated on the Total View, which even "moderate" forms of longtermism build upon (47). However, some longtermists also point to additional further losses associated with transhumanism, the "argument from cosmic significance," and "ideal goods" like science, the arts, and morality (1,20). Taking these in order: many longtermists are transhumanists who believe that reengineering our species using advanced technologies could usher in a "utopian" world of immortality, endless pleasures, and superintelligence (1,25). The future could thus be *qualitatively* better in addition to being *quantitatively* bigger. Hence, if ASI were to cause our extinction, we would lose this techno-utopian paradise that we could have otherwise created by realizing the transhumanist project of becoming "superior" posthumans.

Our extinction would also remove the only sentient beings in the known universe who are endowed with moral and rational capacities. These capacities enable us to look up at the midnight firmament in wonder and awe, appreciate the beauty of art and nature, and act from moral reasons rather than instinct or impulse. Some further-loss theorists argue that this makes us cosmically significant, and hence that the universe would be impoverished without us. The argument from cosmic significance thus provides a second reason that some longtermists see Being Extinct as a source of badness.

With respect to the non-hedonic or "ideal" goods, there may be additional things in the world that are valuable in their own right but depend on our existence for their existence. Works of art provide an example: if humanity were to vanish, museums would gradually fall into disrepair, destroying great pieces of art that may be valuable for their own sake. To my knowledge, the first person to articulate this idea was Shelley in her aforementioned novel *The Last Man*. Lionel Verney, the protagonist, contrasts the disappearance of "man" in the collective sense with "man" in the individual sense, noting that the former would mean the concomitant loss of many valued things like knowledge, science, technology, poetry, philosophy, sculpture, painting, music, theater, laughter, and so on (8,36). "Alas!," he exclaims, "to enumerate the adornments of humanity, shews, *by what we have lost*, how supremely great man was. It is all over now" (38, italics added).

Another expression of this idea comes from Samuel Scheffler, who argues that

> there is a conservative dimension of valuing, something approaching a conceptual connection between valuing something and wanting it to be sustained and to persist over time. This connection helps to explain part of our reaction to the prospect of humanity's imminent disappearance, for part of what is shocking about that prospect is the recognition of how much of what we value will disappear along with the human race. All of the many things we value that consist in or depend on forms of human activity will be lost when human beings become extinct. No more beautiful singing or graceful dancing or intimate friendship or warm family celebrations or hilarious jokes or gestures of kindness or displays of solidarity (42).

Other further-loss theorists might point to certain "business" being left "unfinished," such as constructing a complete scientific theory of the universe. Or, to quote I. F. Clarke in a 1971 article: "World peace, universal prosperity, the reign of law, the brotherhood of man — these aspirations make up the unfinished business of the human race" (52). The failure to achieve these ends could constitute extra losses above and beyond whatever harms Going Extinct might entail. Still others would cite the idea of vicarious immortality, whereby one "lives on" in the minds of future people. Immortality of this sort has motivated many artists, scientists, politicians, and academics who have striven to leave a positive legacy that persists beyond the expiration of their own lives. If humanity is no more, then the memories of such people would be lost forever (16). Anders takes up this idea in arguing that our extinction would cause all past people to die a "second death," such that "after this second death everything would be as if they had never been." He elaborates as follows:

[15] Note that Singer seems to have moved away from longtermism (51).

> The door in front of us bears the inscription: “Nothing will have been”; and from within: “Time was an episode.” Not, however, as our ancestors had hoped, an episode between two eternities; but one between two nothingnesses; between the nothingness of that which, remembered by no one, will have been as though it had never been, and the nothingness of that which will never be. And as there will be no one to tell one nothingness from the other, they will melt into one single nothingness (53).

In this passage, Anders points not just to the second death of those who have already passed, but to the non-birth of those who could have otherwise been. Both are, in his view, further losses that would render our extinction very bad independent of the details of Going Extinct.

These are a few further-loss perspectives on human extinction in general, which also apply to the particular case of extinction caused by ASI. The key idea is that Going Extinct is only part of the story about why our extinction could be bad. Even more significant are the various losses that Being Extinct would entail, such as the loss of wellbeing, art, science, poetry, laughter, and/or the memories of those who came before us. Further-loss theorists would thus agree with equivalence theorists that human extinction caused by an ASI catastrophe would be bad, but for a quite different set of reasons.

Pro-extinctionist views

Most pro-extinctionists would concur with equivalence and further-loss theorists that it would be very bad if Going Extinct inflicts suffering and/or cuts lives short. Many thus argue that we should avoid scenarios of Going Extinct that would involve such harms, and that bringing about our extinction in harmful ways would be morally wrong. Omnicide — a kind of killing-extinction, in Benatar’s phraseology — would be impermissible. However, they differ with equivalence and further-loss theorists in claiming that the subsequent state or condition of Being Extinct would in some way be better than Being Extant, or continuing to exist. There are several mutually compatible reasons that pro-extinctionists could point to in making their case.

The first concerns philosophical pessimism, or the idea that “life is not worth living, that nothingness is better than being, or that it is worse to be than not be” (31, p.4). This was defended most famously by Arthur Schopenhauer, who contended that we are trapped in perpetual cycles of need and boredom, which produce endless suffering. There is no positive value, he claimed, and it would have been better if Earth had remained as lifeless as the moon (54). Despite suggesting in numerous passages that human extinction would be desirable, Schopenhauer never explicitly endorsed a pro-extinctionist position (nor did he endorse antinatalism, one possible path to extinction). However, other German pessimists of the latter 19th century were pro-extinctionists, including the aforementioned Mainländer and his contemporary, Eduard von Hartmann. Both argued that, because existence is infused with suffering, we should try to bring about a permanent end to human life, if not all life everywhere in the universe (once this becomes possible). For Mainländer, the preferred method was celibacy plus, in some cases, suicide: “Whoever cannot endure ‘the carnival hall of the world’ … should leave through ‘the always open door ’into ‘that silent night’” (31, p.222).

In contrast, von Hartmann never specified a means of extinction. “Our knowledge,” he wrote, “is far too imperfect, our experience too brief, and the possible analogies too defective, for us to be able, even *approximately*, to form a picture of the end of the process” (quoted in 16). Rather, he argued that we should continue to develop science, technology, and civilization such that, at some point in the future, we will discover an effective procedure for expunging all life in the entire universe. “Vigorously forward in the world-process as workers in the Lord’s vineyard,” he declared, “for it is the process alone that can bring redemption,” namely, the redemption of ending the entire world-process. Indeed, since von Hartmann was an idealist, he held that the elimination of all subjectivity in the universe would cause the universe itself to cease existing, thus yielding an eternal state of what Schopenhauer memorably called the “blessed calm of nothingness” (8,16,54).

The claim that existence is inherently very bad is one reason in favour of pro-extinctionism. Another concerns an empirical rather than philosophical interpretation of pessimism. This states that life and/or the world are *in fact* very bad for largely *contingent* reasons. Consider that every year an average of 580,000 people die violently, while 440,000 are murdered (55,56). Roughly 463,000 people are raped or sexually assaulted in the US alone, and some 600,000 US children are abused each year (57,58). Some 840,000 children go missing annually, resulting in an average of one child disappearing every 40 seconds (59,60). Approximately 1.2 billion humans live in acute multidimensional poverty, with some 712 million suffering from extreme poverty, a figure that has risen by 23 million since 2019 (61,62). About the same number — 735 million people — are malnourished, and 25,000 people die every day from hunger or hunger-related illnesses, including 10,000 children (63,64). Two billion people do not have access to safe water, while another 150 million worldwide are homeless (65,66). Some 1.4 billion children live on $6.85 or less per day; an estimated 50 million people are trapped in modern-day slavery; and about 1.3 million people in the US alone have survived torture, a form of suffering that, according to some survivors, has no point of reference in our normal lives (67-70).

Roughly 800 million children suffer from lead poisoning each year, which causes permanent brain damage. This is about 1/3 of all children around the world (71). Another 140 million people suffer from arsenic poisoning, while 18.5 million die every year from heart disease and 10 million from cancers, which amounts to some 27,600 cancer deaths every day (or 3 human beings dying per second) (72,73). An estimated 55 million people around the world have dementia, and about 139 million are projected to have dementia by 2050 (74). Nine million die annually from pollution; over 51 million Americans suffer from chronic pain; 50 million Americans struggle with chronic sleep disorders; and about 40 million people in the US have to take

antidepressants (75-78). An even higher number — 46.8 million — battle drug and alcohol abuse each year, with over 178,000 dying of alcohol-related diseases every 12 months (79). Over 258 million Americans report that "they have experienced health impacts due to stress in the prior month," while more than 91 million say that they feel so stressed-out most days that they are unable to function normally (80). Globally, 280 million people deal with depression, and 301 million suffer from anxiety disorders (81).

These are the statistics that empirical pessimism is based upon: the world is a waking nightmare not necessarily because there is no positive value and we are trapped in cycles of need and boredom, as Schopenhauer argued, but because things *just are* very bad. If humanity were to go extinct, all of this human suffering would disappear, which ostensibly supports the pro-extinctionist claim that Being Extinct would be better than Being Extant.[16]

Environmental considerations yield a third reason for pro-extinctionism: our systematic obliteration of the biosphere is not only imperiling our own future on Earth, but causing untold harm to billions of nonhuman organisms, ecosystems, and landscapes. If one accepts a biocentric, biospherical egalitarian, or ecocentric theory of value, then *Homo sapiens* is not the only thing with intrinsic or final value. For the sake of these other things, it would be best if "*Homo shiticus*" — as some environmentalists call us — were to no longer exist. Though numerous environmentalists have advocated for pro-extinctionism, most are explicit that involuntary human extinction — omnicide — would *not* be morally permissible. For example, the Voluntary Human Extinction Movement (VHEMT) argues that we should stop having children until there are no more humans on Earth. Their motto is "May we live long and die out," and they do not endorse any means of eliminating our species that would cause suffering or cut lives short (82). In contrast, the Gaia Liberation Front advocates for omnicide via designer pathogens.[17]

Most pro-extinctionists would thus say that if ASI were to cause our extinction through voluntary means, this would be *very good* (especially if the ASI had little or no environmental impact beyond persuading us to die out). If it were to cause our extinction through violent and/or involuntary means, then Going Extinct would be *very bad* and we should try to do whatever we can to avoid the mass slaughter of humanity. However, in the latter case, they would add that once the critical moral threshold of 100% of the human population dying has been reached, at which point Going Extinct would give way to Being Extinct, the situation would greatly improve: there would be no more human misery, nor would there be any more human-caused ecological destruction, pollution, species extinctions, and so on. That would be better, if not positively good.

CONCLUSION

The aim of this paper was to examine the question, "Would human extinction caused by an ASI be bad?" from the perspectives of the three main positions within Existential Ethics. To do this, I first outlined these three positions and then explained how each would assess the extinction of our species if we were to create an ASI that precipitates our collective demise. My hope is that this provides a helpful degree of clarity to a deceptively complex issue: nearly everyone — including most pro-extinctionists — would concur that the mass murder of everyone on Earth would be extremely bad. But beyond this, opinions diverge significantly depending on which of the three main positions one accepts.[18]

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[16] One reviewer of this paper helpfully noted that we should still talk about "progress" if the overall population is doing better over time, and the total number of people who are well-off is increasing (even if the total number of people who are suffering is also increasing). I think this is a valuable perspective, although my personal opinion is that there is an asymmetry between happiness and suffering such that the latter counts for more. I appreciate the feedback offered by this reviewer, though I find myself somewhat skeptical of their view, and would consider myself to be an empirical pessimist — though I could be wrong. See (83) for reasons that I think empirical pessimism might be right.
[17] Although I am *not* a pro-extinctionist, I am somewhat sympathetic with all three arguments for this view. But I am also sympathetic with some further-loss views, including one that I call "humanism" (8). Equivalence views seem to be the most correct, but my position allows for nuance in evaluating our extinction, as it draws from all three views.
[18] See also (83) for a brief overview of some of these topics.

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

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Medical Necessity as an Ethical Imperative for Equitable Access to Abortion Services in Canada

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Résumé

Le système de santé canadien a une riche histoire d'utilisation des fonds publics pour les services hospitaliers et médicaux médicalement nécessaires, conformément à la loi canadienne sur la santé (LCS). La lutte pour les droits reproductifs, qui a abouti à la dépénalisation de l'avortement en 1988, se superpose à cette histoire. Les gouvernements provinciaux et territoriaux doivent veiller à ce que les résidents aient un « accès raisonnable » aux services de santé jugés « médicalement nécessaires », conformément au principe d'accessibilité de la LCS ; le gouvernement fédéral a le pouvoir de suspendre le financement des gouvernements infranationaux en cas de violation de ce principe. Nous démontrons qu'il existe des preuves politiques et législatives suffisantes pour soutenir l'avortement en tant que procédure médicalement nécessaire au Canada. Nous soutenons également qu'en tant que service de santé médicalement nécessaire, le paysage inéquitable de l'accès à l'avortement au Canada nécessite de vastes améliorations pour satisfaire au principe d'« accessibilité ». Les barrières systémiques et géographiques, le manque de soins culturellement informés, le manque de volonté des prestataires et les influences anti-choix compliquent l'accès à l'avortement. Bien que l'accessibilité ait été élargie avec l'introduction de Mifegymiso — l'étalon-or de l'avortement médical — cela n'a pas résolu le problème de l'accès. Dans cet article, nous soutenons que la classification d'une procédure comme médicalement nécessaire, en l'occurrence l'avortement, nécessite une action politique active et soutenue afin d'améliorer l'accès équitable et de supprimer les obstacles aux soins. Nous justifions le statut spécial que nous accordons à l'avortement par des considérations utilitaires.

Mots-clés

avortement, nécessité médicale, politique de santé, loi canadienne sur la santé, accès aux soins, santé reproductive

Abstract

The Canadian healthcare system has a rich history of using public funds for medically necessary hospital and physician services, legislated by the Canada Health Act (CHA). Overlapping with this history is the fight for reproductive rights which culminated in the decriminalization of abortion in 1988. Provincial and territorial governments must ensure that residents have "reasonable access" to health services deemed "medically necessary" as per the CHA principle of accessibility; the federal government holds the authority to withhold funding to sub-national governments if violated. We demonstrate that sufficient policy and legislative evidence exists to support abortion as a medically necessary procedure in Canada. We further argue that, as a medically necessary health service, the inequitable landscape of abortion access across Canada requires vast improvements to fulfil the "accessibility" principle. Systemic and geographical barriers, a lack of culturally informed care, unwilling providers, and anti-choice influences complicate abortion access. Though accessibility has been broadened with the introduction of Mifegymiso — the gold standard for medical abortion — this has not solved the problem of access. In this paper, we argue that classifying a procedure as medically necessary, in this case abortion, requires active and sustained policy action to improve equitable access and remove barriers to care. We justify the special status we give abortion through utilitarian and justice reasons, and due to the unique barriers to care faced by patients seeking abortions.

Keywords

abortion, medical necessity, health policy, Canada Health Act, access to care, reproductive health

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INTRODUCTION

The Canadian healthcare system has a rich history of using public funds for medically necessary procedures and treatments. Overlapping with this history is the fight for reproductive rights culminating in the decriminalization of abortion in 1988 accompanied by a long period of activism to classify abortion as a medically necessary procedure. Since then, abortion procedures have been unencumbered by additional regulations beyond those required to ensure safe, high-quality care, yet sufficient access to abortion remains a significant concern and differs greatly across the country. Those seeking abortions must navigate the many glaring barriers which delay or prevent care, including significant travel to access the closest abortion providers, a lack of willing abortion providers or institutions, and anti-choice organizations which block access to abortion

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services. For pregnant people past the first trimester, access to sufficient abortion care becomes even less available as procedural abortion[1] may be required, and providers are more likely to conscientiously object.

In this paper, we argue that 1) abortion is indeed a medically necessary procedure according to the *Canada Health Act* (CHA) and that 2) classifying abortion as a medically necessary procedure requires a greater effort toward sufficient access which is sorely lacking in the Canadian context. We start with a brief description of the Canadian healthcare system, followed by an explanation of how medical necessity is determined through the CHA, the governing policy legislature for publicly funded healthcare services. We then turn the focus to abortion, briefly explaining the history of abortion in Canada and arguing that abortion is indeed medically necessary. We show that despite abortion being classified as a medical necessity, access to this service remains a significant issue in Canada. This leads to our main argument, that improving access to abortion services is imperative based on the medical necessity criterion.

OVERVIEW OF THE CANADIAN HEALTH SYSTEM

The concept of medical necessity in Canada is rooted in the formation of the publicly funded system we have today. Canada's predominantly publicly financed and administered healthcare system is governed through 13 interlocking provincial and territorial healthcare insurance plans (2). Under the 1867 Canadian constitution, provinces and territories are assigned authority for oversight and delivery of care, giving rise to 13 healthcare systems with differing methods of payment, delivery, and outcomes for their users (3,4). As a result, access to public health services may differ from one province to another. Among other duties, the federal government is responsible for guiding the delivery of provincial healthcare under the 1984 CHA, which was designed to ensure that all eligible residents of Canadian provinces and territories have *reasonable access* to medically necessary hospital and physician services on a pre-paid basis (2,5).

The primary objective of the CHA is to "promote and restore the physical and mental well-being of Canadian residents, facilitating reasonable access without financial or other barriers" (2). The CHA defines the national principles that govern the Canadian healthcare system: public administration, comprehensiveness, universality, portability, and accessibility. To qualify for payments from the federal government for a fiscal year, the provincial health care insurance plan must satisfy these principles, whose criteria are summarized in Table 1 (2). Reimbursement for healthcare expenses is provided via the Canada Health Transfer (CHT), which aims to establish long-term predictable funding for healthcare and support under the CHA (6). If the delivery of provincial or territorial public healthcare violates the CHA, the federal government has the power to make deductions from the CHT (2,3). However, these may be reversed if corrective action is taken to re-align with the principles of the CHA — a policy that emphasizes compliance, transparency, consultation, and dialogue between levels of government (2,6). This federal-provincial/territorial cost-sharing framework for universal publicly funded care is commonly known as *Medicare* (3).

Table 1. Summary of the national principles required for provinces to receive funds under the Canada Health Act (CHA)

Principle	Criteria
Public administration	An appointed public authority must be responsible for the administration and operation of the provincial health insurance plan. This plan must be operated on a non-profit basis by the public authority and must be subject to an audit of accounts and financial transactions.
Comprehensiveness	Provincial health care insurance plans must insure all hospital services, physician services, and surgical-dental services. It does not include any additional services that a person may be entitled to under any other Act of Parliament or under any Act of the legislature concerning workers' compensation.
Universality	The provincial health care insurance plan must entitle 100% of the insured persons of the province to the insured health services provided for by the plan on uniform terms and conditions.
Portability	The provincial health care insurance plan must not impose any waiting period in excess of three months before residents are eligible for coverage; must provide coverage for health services provided to residents temporarily absent from the province*, and during any minimum waiting period imposed by the insurance plan of another province. **Exceptions exist for inter-provincial and international care*
Accessibility	The provincial health care insurance plan must provide reasonable compensation to users and hospitals for insured health services on uniform terms and on a basis that does not impede or preclude reasonable access.

Principles have been amended from the CHA for the purposes of this paper; a more comprehensive explanation is offered in the CHA (2).

MEDICAL NECESSITY UNDER THE CANADA HEALTH ACT

Under the CHA, "medically necessary" services are covered using public funds (5). At first glance, restricting public health insurance to cover only *necessary* care seems sensible. It is unlikely that the public would take kindly to funding health services that are considered *unnecessary*. However, the CHA does not provide a formal definition of "medically necessary", nor is it

[1] We use procedural abortion in place of surgical abortion, as the abortion procedure is not a surgery. Procedural abortion is therefore more clinically accurate (1).

prescriptive or suggestive as to which services *should* qualify (5). While some services can clearly be categorized as “medically necessary” or “medically unnecessary”, such as emergency care and elective cosmetic procedures, respectively, other procedures that exist in between these extremes can vary on “necessity”, depending on circumstance.

The conflation of “medically necessary” with “publicly insured” under the CHA means that decisions to include health services in provincial and territorial health insurance plans also designate these services as medically necessary. Whether health services are covered under public health insurance is determined through negotiations between provincial/territorial governments and their respective physician colleges or groups (5). Negotiations between sub-national governments and health providers are not open, transparent processes and do not incorporate public input. The existing process has been criticised for lending inappropriate power to physicians, creating inconsistent health services access across the country, and exacerbating inequities for vulnerable populations (7-9).

With sub-national governments holding authority over publicly insured services, the lack of a clear definition of medical necessity has led to variation in the scope and extent of coverage of health services, creating inequities in costs and accessibility (10,11). Additionally, although the CHA ensures the cost of in-hospital administered prescription drugs are publicly funded, universal coverage does not extend to other medically necessary prescriptions (12). In fact, Canada remains the only country with a publicly funded healthcare system that does not have universal coverage for drug prescriptions. While employer-based insurance plans and government plans for certain populations like older adults and Indigenous people living on reserves strive to fill this gap, 1 in 5 Canadians still pay for drugs out of pocket (13).

It has been argued that the public should play a greater role in deciding which services are covered. The decision to include or exclude a treatment in publicly funded services is inherently rooted in ethics, values, and distributive justice (7). As a last resort, individuals and groups lacking coverage for necessary health services have taken to litigation to address their grievances under s. 15(1) of the Canadian *Charter of Rights and Freedoms* (14). This constitutional provision aims to shield citizens from discrimination and has been invoked to secure rights to required health services (15,16).

Many provinces have requested more guidance in selecting medically necessary services, however, the possibility of establishing an explicit definition of “medically necessary” has been widely debated (7,17,18). For the purpose of our paper, we choose not to dive into this debate but instead to explore what it means once a health service is considered medically necessary and is therefore a publicly insured service in Canada. When provinces and territories decide to include a service under their public insurance plan, the CHA stipulates criteria and conditions that provinces and territories must meet to receive payment through the CHT (6). These criteria, discussed earlier in this paper, are summarised in Table 1.

ABORTION AS MEDICALLY NECESSARY

The road to incorporating abortion in the CHA, and thus recognizing it as a medically necessary service, has been a long one with notable legal, advocacy, and policy developments along the way. Interestingly, the concept of medical necessity emerges throughout this history and raises important questions as to why exactly abortion is medically necessary.

Abortion was criminalized in Canada under the original Criminal Code between 1892-1969. This restriction forced many pregnant people to seek an abortion under unsafe, unregulated conditions with high mortality rates. Between 1926-1947 alone there were an estimated 4,000-6,000 deaths attributed to unsafe abortions, though this is likely a severe underestimation (19,20). The provision of abortions in medical settings was not allowed until 1969, when “therapeutic abortion” was legalized under Section 251 of the Criminal Code, conditional upon a Therapeutic Abortion Committee (TAC) deciding if the abortion was necessary for the woman’s health (21). The TAC had to be comprised of at least three physicians — none of whom could be abortion providers. Due to the limited number of women and racialized physicians at this time, TACs were predominantly composed of white men (21).

While TACs related the concept of medical necessity to the mother’s health, this was often a narrow conceptualization of health, not taking into full account the mental, emotional, and social reasons that contribute to a decision to seek out an abortion. A 1977 survey of over 3000 Canadian physicians noted that over half considered social health to be a valid component of health to justify abortion, while over 90% cited physical health (22). Additionally, while almost 80% saw mental health as a component of health, over half thought that interpretations of mental health in the context of abortion were too liberal. Such differing moral and medical views between physicians explain why TACs were not consistent nor strictly evidence-based in determining the criteria for abortion and the laws, at this time, gave them authority to change these criteria at will. As one medical columnist wrote about the TAC, “Some patients are turned down one week but would have passed the following week.” (23 p.78)

Finally, in 1988, the Supreme Court’s decision, *R. v. Morgentaler*, ruled that the criminalization of abortion was unconstitutional under Section 7 of the Canadian *Charter of Rights and Freedoms* because it increased health risks to women, depriving them of their right to security of the person (24). Chief Justice Dickson found that abortion under the Criminal Code law infringed on a woman’s security of the person by forcing them to continue with their pregnancy despite their priorities and aspirations, and the requirement to receive TAC approval to procure an abortion resulted in delays that increased the physical and psychological trauma involved (21,23,24). Here, we can see allusions to medical necessity being broadened to consider women’s psychological health, as well as their social health and human rights (21,24).

The landmark Morgentaler decision led to abortion being publicly funded under the CHA in the same year. This was a controversial addition as political actors and anti-choice groups have argued that abortion services fall in-between the extremes (may or may not be considered medically necessary depending on circumstance) and therefore should not be considered medically necessary under the CHA. Such arguments to defund abortion have also been made at the provincial level. In 1995, residents of Alberta petitioned the Legislative Assembly, urging the government to "de-insure the performance of induced abortion under the *Alberta Health Care Insurance Plan Act*" (25). These efforts rely on physicians being able to parse out which abortions are medically necessary, and which are not. Here, again, medical necessity is narrowly understood as harm to the mother or fetus. However, even use of this narrow understanding of medical necessity to restrict access to some abortions has received pushback from physicians who are unable to discern criteria that would distinguish between medically necessary and medically unnecessary abortions (25).

Arguments to support fully funded and unrestricted access to abortions include those of abortion as a constitutional right and abortion as a mandatory (non-elective) procedure, since delaying and denying abortion can have life-altering consequences for the pregnant person. In *Jane Doe I v. Manitoba,* denial of public funding for abortion services was deemed to infringe on women's equality rights under the Canadian *Charter of Rights and Freedoms* (26). Understanding abortion as a right is largely supported by the arguments of many advocates and scholars who suggest that medical necessity should not be limited to just physical health during pregnancy and birth but must also include the social reasons that motivate abortion and are themselves inextricably tied to health (27). Indeed, if health is considered to include physical, emotional, and social wellbeing (28), then the concept of medical necessity will be sensitive to the social harms of unwanted pregnancies to a person's financial, economic, and social wellbeing. Forms of social oppression, including lack of housing, precarious work, and poor education, are related to poor health; pregnant people seeking abortions to avoid or ameliorate these conditions can be said to be accessing a medically necessary service to improve or preserve health.

Despite continued anti-choice rhetoric, policy and legislative evidence since its decriminalization has positioned abortion firmly within the CHA as a medically necessary service. Therefore, while abortion is deemed to be medically necessary for a myriad of physical, psychological, and social health reasons, it is definitively medically necessary in Canada through the authority of the CHA. Professional governing bodies for physicians, such as the Society of Obstetricians and Gynaecologists of Canada, also stand firmly behind the inclusion of abortion in the CHA as an essential service (29). Perhaps most importantly, the federal government has used the inclusion of abortion as a medically necessary service to penalize provinces that are not appropriately funding abortion services. The 2022-2023 Canada Health Act Annual Report noted deductions made from New Brunswick and Ontario due to CHA compliance issues related to abortion care (29). For example, New Brunswick only offers public insurance for abortions provided in hospitals, which infringes on the Public Administration criterion under the CHA. As a result, $64,850 was deducted from New Brunswick's CHT payments in March 2021, 2022, and 2023. The amount represents an estimate of patient charges based on evidence provided by Clinic 554 and Canadian Institute for Health Information data (30,31).

BARRIERS TO ABORTION ACCESS IN CANADA

Thus far, we have described the role of medical necessity in the governing policy for publicly funded health care services in Canada, the CHA. Further, we have shown that abortion is medically necessary according to Canadian health policy, law, and advocacy. Before taking this one step further to argue that classifying abortion as medically necessary requires going beyond funding to address issues of access, we must first establish accessibility to abortion as a fundamental issue in Canada, and one where lack of access would violate the fifth principle of the CHA.

Although abortion services are available in all provinces and territories, the 2016 UN Human Rights Commissioner's report noted a lack of access to abortion in Canada, calling on the government to address the main access issues of cost, geography, and knowledge (32). A pregnant person's access can be complicated by where they live; this is especially true for the 17.8% of Canadians who live in rural and remote communities (33). Historically, free-standing abortion clinics and hospital-based abortion services have been concentrated in urban centres, limiting rural and remote individuals' access to timely care while burdening patients with additional travel-related costs (34-36).

Conscientious objections from unwilling healthcare providers also create *unpredictable* gaps in abortion access. While physician codes of ethics and professionalism vary provincially, according to the CMA, "a physician should not be compelled to participate in the termination of a pregnancy," and "a physician whose moral or religious beliefs prevent him or her from recommending or performing an abortion should inform the patient of this so that she may consult another physician" (37). This directly conflicts with a patient's right to access medically necessary care. Objecting physicians often gatekeep care by failing to provide *effective* referrals for abortion services. Effective referrals must connect patients to a willing, available provider in a timely manner (38). Despite the importance of appropriate and timely referrals, written provisions from physician colleges expressing conscientious objectors' duty for effective referrals exists only in Ontario and Nova Scotia, and regulatory bodies often fail to penalize providers who do not comply (39,40).

Since individual healthcare practitioners can conscientiously object on a case-by-case basis, the total number of willing providers in Canada is constantly in flux. Creating a database of willing providers is a controversial solution as 1) willing providers can burn out over time after providing the emotional care necessary for abortion, and 2) some willing providers wish not to be publicly identifiable for fear of targeted attacks from anti-choice groups (41,42). Finding solutions for such issues has

been difficult since wide-ranging policies and guidelines tend to either reduce access to care for patients or compel healthcare practitioners to act in conflict with their moral or religious beliefs. *Institutional* conscientious objection exacerbates this issue — where publicly-funded Catholic institutions are permitted to deny abortion services through their right to religious freedom under the Canadian *Charter of Rights and Freedoms*. While staff may advocate for access to abortion and contraceptive services, these can be denied due to the religious values of the institution imposed by the power of the Catholic church (43,44).

Access to evidence-based information can also serve as a barrier to individuals accessing abortion. In the quest for abortion information and care, patients may unknowingly fall victim to a crisis pregnancy centre (CPC), organizations which claim to provide a range of free services for pregnant people to better understand their options (45). In reality, they are anti-choice agencies that deceive pregnant people and spread misleading or inaccurate information about abortion, contraception, and reproductive health (46). They are often driven by ulterior motives — 96% of CPCs have religious affiliations or agendas, despite only 24% making this publicly known. CPCs have steadily grown in number since the decriminalization of abortion, with 150 anti-choice CPCs identified across Canada as of 2024 (47). The Federal Liberal government committed to no longer providing charity status to anti-abortion organizations such as CPCs as part of their 2021 election platform but has yet to follow through on this promise (48).

A POSITIVE START

While misinformation, conscientious objection by providers, and geographical gaps in care still create barriers to accessing medically necessary care, Canada has taken positive steps to improve access. In 2017, Mifegymiso, the gold standard for medication abortion (MA), became available in Canada. When first introduced, restrictive regulations around prescribing and dispensing Mifegymiso limited public access to the medication (49). These regulations included mandatory training modules for prescribing health professionals and an ultrasound to rule out ectopic pregnancy and assess the gestational stage (50,51). However, within a year of Mifegymiso being available on the market, many restrictive regulations began to be removed by Health Canada, with all being removed by 2019 (51,52).

Mifegymiso represents a positive start toward increasing abortion access across the country, particularly for pregnant people in rural areas. Norman et al. reported that the increased availability of MA in 2019 was associated with a twelve-fold increase in the provision of abortions across Ontario's rural communities (53). This expanded access was also supported by the allowance of health practitioners besides physicians to prescribe and dispense MA, including nurse practitioners and pharmacists (54,55).

Despite these examples of increased access, studies surveying health professionals have maintained that anti-choice stances and conscientious objection in health organizations actively prevented health practitioners from providing MAs (50,54). Some examples described in a survey study by Munro et al. were "hospital staff who refused to clean clinic rooms where abortion care was provided, hospital administrators who ignored requests to implement an MA protocol, and community pharmacists who refused to dispense mifepristone" (50). In the same study, health practitioners commented on concerns about the loss to follow-up for post-abortion care among rural patients commuting significant distances to access their MA prescription (50). These points support that while Mifegymiso does represent a step forward in abortion access, issues of access that preceded this new availability of MA still permeate the Canadian health system.

It is also important to acknowledge that Mifegymiso can be prescribed only until nine weeks for on-label use, meaning the medication has a limited impact on abortion access after 10 weeks (49). A study looking at the off-label use (after 10 weeks) of Mifepristone for second- and third-trimester MAs found that access was concentrated in urban areas (56). Specialists who manage MA and procedural abortion cases after the first trimester tend to be concentrated in urban centres (56). Some practitioners also express that it may be more "feasible and private" for rural patients to access a procedural abortion as it reduces the need for post-abortion follow-ups (50). These challenges disproportionately affect Indigenous patients, as over half of people living in Indigenous communities live in the most remote parts of Canada (36). Canada's pervasive systems of colonialism and racism leave Indigenous communities to face intersecting barriers to care and a lack of access to health services generally (36). Access isn't enough — Canada's dark history of controlling Indigenous People's reproductive rights through forced sterilization and abortion, child apprehension, and violence from healthcare providers highlights the need for culturally-safe abortion care for this population (57).

ABORTION AS MEDICALLY NECESSARY: MAKING THE CASE FOR BETTER ACCESS

In the preceding sections, we have shown that medical necessity is a guiding principle in granting public funding for abortion and other publicly funded services in Canada. Importantly, we submit that while abortion is likely medically necessary for a multitude of physical, psychological, and social health reasons, it definitively *is* medically necessary according to the CHA. We now take this argument one step further to argue that deeming abortion as medically necessary requires moving towards sufficient access to abortion services. Although improved access to care followed the introduction of Mifegymiso in 2017, barriers to access still exist for abortion services. We argue that classifying abortion as a medical necessity *necessitates* better access to abortion services through 1) the internal logic of the CHA, 2) the rationale of universal health coverage, and 3) an intuitive understanding of medical necessity. We address each of these arguments in turn.

Justifying abortion access through the internal logic of the CHA

Despite inconsistencies in the determination of medical necessity in Canadian health policy, we have demonstrated that abortion *is* classified as a medically necessary service according to the CHA. This means that it is subject to the five CHA principles: public administration, comprehensiveness, universality, portability, and accessibility. In this context, accessibility means that insured persons in Canada must have "reasonable access to insured hospital, medical and surgical-dental services on uniform terms and conditions, unprecluded or unimpeded, either directly or indirectly, by charges (user charges or extra-billing) or other means (e.g., discrimination on the basis of age, health status or financial circumstances)" (30). Any medical procedure or service that is deemed medically necessary under the CHA is subject to the principle of accessibility. However, not all Canadians have reasonable access to abortion.

New Brunswick has been penalized multiple times for imposing user charges for accessing abortion, charging up to $850 for abortion depending on the gestational term (30,58). Approximately $334,766 from the federal health transfer was withheld from New Brunswick but the province continues to deny that their actions violate the CHA making resolution unlikely and suggesting that user charges in the province will continue (59). Additionally, financial circumstances continue to be a significant barrier to accessing abortion in Canada. While abortion is covered by public funds, the lack of access creates barriers that require financial solutions. A person who is pregnant in the Northwest Territories may require a substantial amount of travel funds to access sufficient abortion care in a regional centre. A positive step towards removing these barriers has been demonstrated by the Northern Options for Women (NOW) program, which covers travel costs for NWT residents who must travel to Yellowknife or Inuvik to access Mifegymiso treatment (60).

Justifying abortion access through commitments to universal health coverage

Improving access to services is also essential under the rationales for universal health coverage that Canada aims to uphold. Canada has a strong history of protecting public coverage for medically necessary physician and hospital services and preventing private insurance from entering the public market (61). For example, a decade-long court case initiated by Cambie Surgeries Corporation that sought to implement a system of private insurance and user charges for Medicare-insured services in British Columbia (BC) was unanimously struck down by the BC Court of Appeal in "ongoing defence of universally accessible health care" (62). While the CHA was not directly implicated in the case, the federal government was highly supportive of the BC government's decision which prioritized equity, fairness, and medical need over profit and ability to pay.

Overall, this seems to suggest that Canada takes great pride in the model of publicly funded universal health coverage, and this has been verified through opinion polls examining public perspectives of Medicare (63,64). However, it is important to consider what a strong commitment to universal health coverage means for ensuring adequate access to abortion. According to the World Health Organization (WHO), universal health coverage "means that all people have access to the health services they need, when and where they need them, without financial hardship. It includes the full range of essential health services, from health promotion to prevention, treatment, rehabilitation, and palliative care" (65).

Canada's form of universal health coverage can be considered "narrow but deep" — only medically necessary physician and hospital services are covered by insurance, but they are covered completely (or at least should be) (2). However, cracks in the system make the leap from coverage to access perilous. "Universal health coverage is attained when people actually obtain the health services they need and benefit from financial risk protection" — in short, a commitment to universal coverage loses meaning when people are not able to access the services to which they supposedly have a right (66). The inability to access abortion due to geography, gestational limits, and a lack of available and willing providers means that patients often do not have the opportunity to exercise the promise of universal health coverage. Making strong commitments toward access to abortion services can ensure that Canada's commitment to universal health coverage recognizes the important ties between coverage and access to medically necessary services.

Justifying abortion access through an intuitive understanding of medical necessity

While the CHA's accessibility criterion stipulates that medically necessary services should be provided with "reasonable access", the lack of equity considerations surrounding what constitutes reasonable access has been challenged. Scholars have criticised the lack of attention to barriers, beyond cost, that limit access to health services as acting to perpetuate health inequities (67). Without attention to these barriers, the federal government's criterion for access is sufficiently met by providing public funding for these services, but this is a critical limitation of what medical necessity should entail. Moving toward better access for medically necessary services like abortion makes intuitive sense. Anyone who seeks healthcare within a publicly funded system presumably assumes that, besides not having to pay for the service, they will be able to *obtain* the care they need. The extensive body of research examining barriers to accessing abortion in Canada all conclude that these barriers are unacceptable, especially under a system of public funding (68,69). Despite medical necessity not being legislatively defined under the CHA, it still has a social and cultural meaning for Canadians.

UTILITARIAN AND JUSTICE REASONS TO PRIORITIZE ABORTION ACCESS

Thus far, we have argued that the language of medical necessity in the CHA, the commitment to universal health coverage which underlies Canada's healthcare system, and an intuitive understanding of medical necessity all point to policy action for better access to abortion services. Of course, there are many other services that are classified as medically necessary under

the CHA. Opponents may argue that all services should therefore be afforded better access. While we agree that all medically necessary medical and physician services should be accessible to Canadians, we argue that abortion should be prioritized due to utilitarian and justice reasons and because of unique barriers to access specific to abortion.

Abortion is one of the most common medical services accessed in Canada. It has been estimated that 1 in 3 Canadian women will have an abortion at some point in their lifetime (53). A Canadian study of over 1000 women from 17 free-standing abortion clinics found that, prior to Mifegymiso being made available in Canada, 18% of women had travelled over 100km to access abortion care (34). While Mifegymiso has certainly changed the landscape and made access to abortion easier for many, intersecting geographic, financial, and knowledge barriers persist. Considering the sheer number of people in Canada who will need to access an abortion at some point in their lives and how many of those will be affected by barriers to accessing care, responding to inequitable access to abortion is essential.

Social and reproductive justice concerns also motivate the special status we give to abortion. The previously cited study about geographic and spatial disparities in accessing abortion found that Indigenous women were three times more likely to have travelled over 100km to obtain an abortion than white women (34). People who are younger, lower-income, racialized, those who do not speak English or French, and those with immigrant or refugee status are significantly more likely to experience barriers to accessing abortion due to structural inequities (53,69). Improving access to abortion, especially for persons who are already vulnerable and over-exposed to barriers to access, is a social justice issue.

Reproductive justice highlights the importance of self-determination and bodily integrity for individuals with female reproductive anatomy and stems from a longstanding history where those who could become pregnant were denied autonomy over childbearing decisions (e.g., abortion, contraception) (70). Historically, controlling reproductive rights has been a tool for the gender-based oppression in society. Recent legal movements in the US which restrict or outright ban access to abortion highlight the precarity of reproductive rights, especially in anti-progressive political landscapes (71,72). While abortion has been decriminalized in Canada since 1988, provincial regulations that seek to limit access to care invoke strong reproductive justice concerns. For example, until recently, regulation 84-20 in New Brunswick limited access to procedural abortion in the province to only three hospitals, leaving 90% of residents without access to procedural abortion services in their local community (73). Recognizing this gap in access, New Brunswick was the first province to offer Mifegysmiso free of charge, radically improving early access to care up to 10 weeks of gestation (74). However, individuals past the gestational limit for MA may have struggled with the time, travel, and/or resource expenditure of accessing an abortion within or outside the province, restricting their ability to exercise their fundamental reproductive choice.

Finally, abortion is subject to barriers to access that are not seen with other procedures. We highlight three critical concerns: conscientiously objecting providers, conscientiously objecting institutions, and CPCs. The extent of these barriers to abortion has been previously discussed, so we only briefly reiterate them here. Conscientious objection allows providers to refuse to provide abortions on religious or moral grounds; while this advances the rights of providers, it can interfere with a patient's ability to access care (40). This is exacerbated in rural areas where the only healthcare provider in the area might be a conscientious objector. Even when required to provide effective referrals for abortion, objecting providers can block access by refusing or delaying such referrals.

In Canada, entire institutions, often hospitals with religious affiliations, can refuse to provide abortion care on their premises (43,44). Again, this becomes a significant issue in rural areas where the sole hospital may not provide procedural abortion services, requiring patients to travel great distances to obtain needed care. Since the introduction of Mifegymiso in 2017, the proportion of MAs has increased, reducing the impact of this barrier (75). However, access to MA is still complicated by rurality, as finding a willing primary care provider and pharmacist may be challenging depending on location. Additionally, access to procedural abortion remains a complicated issue for individuals past the gestational limits to access MA. Finally, CPCs continue to unjustly interfere with access to abortion by deceptively posing as abortion clinics that provide medical services, while in fact promoting anti-choice ideals (45,46). Pregnant people who unknowingly visit these clinics are often shamed and fear-mongered into keeping their pregnancy based on false information.

While other procedures may also evoke social justice or reproductive justice concerns or face unique barriers to access, few if any procedures raise all these issues simultaneously. Therefore, we argue that access to abortion must be given special status among the larger family of medically necessary services as classified by the CHA.

OPERATIONALIZING MEDICAL NECESSITY AS ACCESS TO ABORTION

We have argued that classifying abortion as a medically necessary procedure in Canada means taking serious efforts towards ensuring equitable access to abortion services. This induces a responsibility; however, it is worth asking upon who this responsibility falls. While we open the conversation at this time to other advocates and researchers, we offer here our thoughts on the issue. We realize that we have drawn on the use of medical necessity at the policy level; that is, within the CHA. Therefore, we shift the responsibility of access back to the provincial governments, which are bound by the CHA and the federal government, which is positioned to enforce it; together the provincial-territorial and federal governments must make the necessary policy decisions to improve access to abortion services.

There have been numerous suggestions to improve access to abortion in Canada. The introduction of medical abortion through Mifegymiso is one such essential policy which has had a significant positive impact on access since its implementation (55). Other suggestions include improved abortion-focused medical education, expanding scope of which medical professions can provide abortions, and ceasing government support of anti-abortion groups and crisis pregnancy centres (76-79). One particularly contentious suggestion is to disallow provider and institutional conscientious objection, requiring all trained healthcare providers and eligible institutions to provide abortions. We believe that our conception of medical necessity as access can be used to justify disavowal of conscientious objection where such objection significantly impedes access.

In Canada, while healthcare professionals may object to providing abortion care on moral or religious grounds, they still have a duty not to abandon their patients (80,81). This may apply to the provision of abortion care by primary care providers (physicians, nurse practitioners) and/or the dispensing of medication by pharmacists (38). Various professional colleges have guidelines to reconcile patient and provider rights, and while these duties vary between provinces/territories, they generally require providers to uphold respect for patient dignity and autonomy, and refrain from impeding access to care (38-40,81-83). Some provinces have policies requiring physicians to provide effective referrals to someone who will provide the service (ON, NS), or someone who can provide more information to the patient (NB, PEI, QC, SK, AB) (39). Under the Canadian Nurses' Code of Ethics, NPs must provide quality care until alternative care arrangements are made in order to meet the patient's needs (82).

Compounding the duty of healthcare providers to not abandon their patients with the duty of policymakers to ensure access to abortion as a medically necessary service, conscientious objection may not be appropriate, especially in rural and remote regions that have fewer providers. At the very least, decision makers may be obligated to strictly enforce effective referral policies, oversee whether such referrals are occurring without undue burden on the patient, and appropriately sanction practitioners who fail to refer or impede timely access to care. Currently, no such mechanism is in place to hold providers accountable for their obligations (40). While patients can file a complaint with a provider's professional college, this may be difficult for patients who do not want to challenge an authority figure for a highly stigmatized medical procedure like abortion.

Institutional conscientious objection is even more vulnerable to our conceptualization of medical necessity as access as there is no affirmed legal right for hospitals to deny care on religious grounds (84). Further, faith-based hospitals are part of the publicly funded healthcare system and are therefore significantly financed through tax dollars in Canada. However, these institutions routinely refuse to provide abortion and become institutions of poor access, especially in regions where the sole hospital in the area is faith-based (44,45). While hospitals could receive legal challenge from patients, this is unlikely due to cost and time burdens associated with such complaint. Unsurprisingly then, most abortions in Canada are provided in clinics rather than hospitals (85). Again, it is the responsibility of provincial governments to challenge the legitimacy of conscience claims by faith-based institutions as they are obligated to provide medically necessary hospital-based and physician services.

Overall, our operationalization of medically necessary as access is policy oriented. Of course, this will intersect with the duties of healthcare providers who must abide by government and regulatory policies. However, equitable access to abortion is fundamentally a policy issue which must be addressed through sustained action by decisionmakers in government and other authoritative institutions (like medical colleges) who have the power to make change.

CONCLUSION

While the decriminalization of abortion in 1988 continues to be a Canadian milestone in advancing access to safe abortions, the continued inaccessibility that has persisted in the ensuing decades is a cause for concern. Abortion is considered a medical necessity according to the CHA, yet sophisticated, interdisciplinary solutions are greatly needed to prove to Canadians that the status of "medically necessary" granted to abortion is not hollow. This requires decisive action by policymakers and governments to prioritize equitable access to abortion services across Canada, with special attention given to the inequities faced by Indigenous people and those living in rural areas. We commend the recent positive steps Canada has taken by expanding access to Mifegymiso (52). COVID-19 was also a catalyst for change as Health Canada laid the groundwork for a rapid transition to telemedicine allowing people to access medical abortions through virtual consultations (49,51). These necessary steps must fit within a larger, sustained movement to promote equitable access to abortion services. This paper provides a framework to prioritize policy action on access to abortion services in Canada by situating the imperative for access within the notion of medical necessity.

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

Les tests génétiques en libre accès et prédisposition au cancer : cadre légal Français et enjeux éthiques

Timothé Ménard[a]

Résumé
Les tests génétiques en libre accès sont interdits en France. Le cadre légal prévoit en effet que les analyses des caractéristiques génétiques (ACG) à des fins médicales soient prescrites par un médecin et que les patients bénéficient d'un accompagnement avant et après l'analyse, garantissant une interprétation correcte des résultats et un suivi approprié. Cependant, les tests génétiques en libre accès peuvent être achetés sur internet, notamment par les personnes résidant en France. Cela présente des enjeux majeurs sur le plan éthique, tel que l'illusion d'autonomie, des inégalités d'accès aux soins, ainsi que des conséquences potentielles : surdiagnostic, mesures prophylactiques non nécessaires, y compris pour les apparentés des personnes y ayant recours. Si le cadre légal français sur le sujet des ACG est aligné avec les principes fondamentaux de l'éthique médicale, il ne protège pas pleinement les personnes qui ont recours à un test génétique en libre accès.

Mots-clés
tests génétiques, cancer, autonomie, tests en libre-accès, loi Française, analyses des caractéristiques génétiques

Abstract
Open access genetic tests are prohibited in France. The legal framework stipulates that analyses of genetic characteristics (AGC) for medical purposes must be prescribed by a doctor and that patients must be accompanied before and after the analysis, to ensure that the results are correctly interpreted and that appropriate follow-up is provided. However, freely available genetic tests can be purchased over the Internet, particularly by people living in France. This presents major ethical challenges, such as the illusion of autonomy, inequalities in access to care, and potential consequences: overdiagnosis, unnecessary prophylactic measures, including for the relatives of people who have recourse to them. Although the French legal framework on the subject of genetic testing is in line with the fundamental principles of medical ethics, it does not fully protect people who have recourse to an open-access genetic test.

Keywords
genetic tests, cancer, autonomy, direct-to-consumer tests, French law, analysis of genetic characteristics

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INTRODUCTION

L'avancée rapide des technologies de séquençage génétique, telles que le "*Next-Generation Sequencing*" (NGS), a révolutionné le domaine de la médecine, ouvrant la voie à des diagnostics plus précis et à des traitements personnalisés. Depuis le début des années 2000, le coût du NGS a baissé de façon exponentielle, permettant à certaines entreprises comme *23andme* de se lancer en 2006 dans la commercialisation de tests génétiques en libre accès (appelés aussi « *Direct-to-Consumer* » ou désignés comme « tests génétiques » uniquement lorsque proposés en libre accès). Bien que ces tests soient illégaux en France (1,2), ils sont largement accessibles au public, car peu onéreux et peuvent être commandés directement en ligne. Les consommateurs reçoivent un kit de prélèvement salivaire qu'ils renvoient par voie postale et reçoivent les résultats environ 15 jours plus tard (3). En plus de découvrir des informations sur son héritage génétique, la majorité de ces tests proposent aussi d'identifier des variants génétiques prédisposant à certaines maladies, dont certains cancers.

En France, le cadre légal n'autorise pas la commercialisation de tests génétiques et il est illégal pour un particulier de réaliser un tel test à des fins personnelles, récréatives ou commerciales, sans prescription médicale. Cette interdiction est définie par l'article 16-10 du Code civil (2). Le diagnostic de variants génétiques, dont ceux prédisposant au cancer, est défini dans un cadre bien précis, l'article L.1131-1 du CSP (1), qui encadre strictement l'usage des analyses des caractéristiques génétiques (ACG) à des fins médicales et impose une prescription médicale ainsi qu'un conseil génétique obligatoire.

L'intérêt clinique des ACG pour identifier une prédisposition au cancer est significatif. La détection précoce de variants génétiques, comme ceux sur les gènes BRCA1/2 (prédisposition aux cancers du sein et de l'ovaire) par exemple, permet la mise en place de stratégies de surveillance spécifiques ou de réduction des risques (chirurgies prophylactiques pouvant aller jusqu'à la mastectomie ou ovariectomie). Lorsqu'un médecin prescrit une ACG dans ce contexte, le patient suit un parcours défini : consultation initiale pour évaluer la pertinence de l'analyse, consentement éclairé, réalisation de l'analyse dans un laboratoire agréé, et consultation de rendu des résultats avec un médecin généticien ou un conseiller en génétique pour expliquer les implications personnelles et familiales (4,5). En cas de variant pathogène identifié, une information doit être délivrée aux apparentés potentiellement concernés pour qu'ils puissent, s'ils le souhaitent, bénéficier eux-mêmes d'une consultation et éventuellement d'une analyse (1,4,5).

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À l'inverse, lorsqu'une personne reçoit les résultats d'un test génétique (illégal en France), elle se retrouve souvent démunie, sans l'accompagnement médical et psychologique nécessaire pour interpréter des informations complexes et potentiellement anxiogènes. Ces résultats peuvent pousser la personne à consulter un professionnel de santé pour confirmation, générant stress et examens potentiellement inutiles (5). Les conséquences s'étendent aux apparentés, qui peuvent être informés de risques génétiques par des voies non médicales, sans préparation ni suivi adéquat. Cet article se focalise sur les enjeux éthiques liés aux variants de prédisposition au cancer, car ces informations ont des implications directes et souvent graves en termes de surveillance médicale, de décisions prophylactiques et d'impact psychologique, tant pour l'individu que pour sa famille. Cela illustre particulièrement les tensions entre l'accès non régulé à l'information génétique et les principes éthiques fondamentaux (6).

Dans la première partie, nous étudierons le cadre légal des ACG en France, notamment pour identifier les gènes prédisposant au cancer, et en quoi la commercialisation et l'utilisation des tests en libre accès est illégale. La deuxième partie abordera les différents enjeux éthiques soulevés par les tests génétiques, en se concentrant sur les principes d'autonomie, de justice, de bienfaisance et de non-malfaisance (6), avec une attention particulière portée aux implications en oncogénétique. Nous utiliserons un cas publié en 2020 (5) pour illustrer les enjeux légaux et éthiques des tests en libre accès, notamment pour le diagnostic de variants génétiques prédisposant au cancer.

LE CADRE LÉGAL DES ANALYSES DES CARACTÉRISTIQUES GÉNÉTIQUES (ACG)

Cadre légal en France

En France, les ACG à des fins médicales sont strictement encadrées par plusieurs réglementations visant à protéger les patients. Selon la loi de bioéthique de 1994, révisée en 2004, 2011, et plus récemment en 2021, ainsi que le CSP (article L1131-1), les ACG doivent être prescrites par un médecin et réalisées par des laboratoires agréés (1). Cela signifie que toute personne souhaitant réaliser une ACG doit d'abord consulter un médecin ou un conseiller en génétique qui évaluera la pertinence de l'analyse en fonction de son historique médical et familial (1,4,5). Il convient de souligner que l'ACG ne sera prescrite que si elle présente une utilité clinique pour le patient, que ce soit pour adapter un traitement, réaliser un diagnostic présymptomatique, évaluer une prédisposition ou une susceptibilité afin de prévenir l'apparition d'une pathologie, préparer psychologiquement le patient ou le rassurer (4,7). La prescription d'une ACG « peut être [effectuée] : — un médecin généticien ; — un médecin non généticien connaissant la situation clinique (maladie, prise en charge thérapeutique) et les conséquences familiales et capable d'en interpréter le résultat » (8).

Ces analyses doivent également être accompagnées d'un conseil génétique, obligatoire avant et après, pour expliquer les résultats et guider les décisions des patients (4,7,9). Le rôle du conseiller en génétique ou du médecin généticien est de fournir des informations complètes et compréhensible sur les implications médicales, psychologiques et sociales des résultats (4,9). Ce suivi permet d'éviter les interprétations erronées et de prévenir l'anxiété (4,5,9), par exemple liées à la découverte de variants génétiques potentiellement pathogènes.

Plusieurs textes encadrent ces pratiques et interdisent la commercialisation des tests génétiques. L'article 16-10 du Code civil (2), introduit par la loi de bioéthique (loi n° 94-653 du 29 juillet 1994), garantit que les examens des caractéristiques génétiques d'une personne ne peuvent être entrepris qu'à des fins médicales ou de recherche scientifique et avec le consentement de l'individu concerné.

Concernant les ACG médicales identifiant une anomalie génétique grave, l'article L1131-1 du CSP instaure une obligation d'information pour la personne testée envers les membres de sa famille potentiellement concernés, si des mesures de prévention ou de soins peuvent leur être proposées (1). La personne peut choisir d'informer elle-même ses apparentés ou de déléguer cette tâche au médecin prescripteur :

> Si la personne ne souhaite pas informer elle-même les membres de sa famille potentiellement concernés, elle peut demander par un document écrit au médecin prescripteur, qui atteste de cette demande, de procéder à cette information. Elle lui communique à cette fin les coordonnées des intéressés dont elle dispose. Le médecin porte alors à la connaissance de ces derniers l'existence d'une information médicale à caractère familial susceptible de les concerner et les invite à se rendre à une consultation chez un médecin qualifié en génétique sans dévoiler à ces personnes le nom de la personne ayant fait l'objet de l'examen, ni l'anomalie génétique, ni les risques qui lui sont associés.

Or, les tests génétiques court-circuitent complètement cette dimension familiale encadrée par la loi. Une personne recevant un résultat via un test en libre accès se retrouve seule avec cette information, sans le soutien médical pour comprendre comment et à qui la transmettre de manière appropriée, ce qui peut générer des conflits ou des angoisses familiales importantes (4). On note également dans ce même article L1131-1 du CSP que la personne peut « exprimer par écrit sa volonté d'être tenue dans l'ignorance du diagnostic » (1), droit qui est souvent bafoué par les tests génétiques où les résultats sont divulgués sans précaution particulière (5). Enfin, selon l'article 226-28-1 du Code pénal :

> Le fait, pour une personne, de solliciter l'examen de ses caractéristiques génétiques ou de celles d'un tiers ou l'identification d'une personne par ses empreintes génétiques en dehors des conditions prévues par la loi est puni de 3 750 € d'amende (10).

Une dimension économique importante découle de l'utilisation des tests génétiques. Les personnes y ayant recours, souvent confrontées à des résultats anxiogènes ou difficiles à interpréter, se tournent vers le système de santé français pour obtenir confirmation et accompagnement (5). Face à l'angoisse exprimée, les médecins peuvent se sentir contraints de prescrire des ACG de confirmation via les canaux légaux. Ces analyses, bien que potentiellement rassurantes si le test initial s'avère être un faux positif, comme dans le cas de Mr. C. (5), représentent un coût non négligeable pour la collectivité, puisque les ACG médicales sont prises en charge par l'assurance maladie en France (5,11). Cet usage détourné des tests génétiques génère donc des dépenses de santé publique pour vérifier des informations obtenues illégalement et dont la fiabilité est souvent incertaine (5).

Cadre légal aux États-Unis

Aux États-Unis, les tests génétiques sont autorisés. La Food and Drug Administration (FDA) régule certains aspects du marché des tests génétiques, en particulier ceux qui peuvent être utilisés pour le diagnostic de variants génétiques prédisposant à certaines maladies. Cependant, une grande partie des tests génétiques est disponible sans prescription médicale ni accompagnement professionnel (ex. : par un conseiller en génétique) obligatoire. Des entreprises comme *AncestryDNA* dominent ce marché, offrant des services permettant aux consommateurs d'obtenir des informations sur leurs origines, leurs traits génétiques, et sur d'éventuelles prédispositions à certaines maladies (dont certains cancers) (3). Cette simplicité d'accès soulève des questions éthiques mais aussi des inquiétudes concernant l'exactitude des résultats et leur interprétation. Les premiers tests en libre accès pour la détection de prédisposition génétiques à certaines maladies de *23andMe* ont été autorisés par la FDA en avril 2017 (12). La réglementation des tests génétiques aux États-Unis est cependant plus restrictive dès lors qu'il s'agit de les utiliser au cours d'essais cliniques (13).

Confidentialité des données et Réglementation Générale sur la Protection des Données (RGPD)

La confidentialité des données personnelles est un enjeu majeur dans le contexte des tests génétiques. Le RGPD, qui s'applique à tous les États membres de l'Union Européenne, impose des normes strictes concernant la collecte, le traitement et le stockage des données personnelles, y compris les données génétiques. Les entreprises commercialisant des tests génétiques doivent garantir la sécurité et la confidentialité des données des utilisateurs, obtenir leur consentement éclairé et offrir des droits aux consommateurs sur leurs informations. Notamment, l'article 9 du RGPD (14) traite des catégories particulières de données personnelles, y compris les données génétiques, et stipule des conditions spécifiques pour leur traitement. Le non-respect de ces obligations peut entraîner des sanctions financières sévères et nuire gravement à la confiance des consommateurs. Les entreprises doivent donc mettre en place des mécanismes robustes pour assurer la conformité avec les exigences du RGPD et préserver la confidentialité des informations génétiques de leurs utilisateurs.

LES ENJEUX ÉTHIQUES DES TESTS GÉNÉTIQUES EN LIBRE ACCÈS : LE CAS DES GÈNES DE PRÉDISPOSITION AU CANCER

Les tests génétiques posent des enjeux éthiques complexes, notamment en ce qui concerne les principes d'autonomie, de justice, de bienfaisance et de non-malfaisance (6), d'autant plus, quoiqu'interdits en France, des personnes peuvent y avoir accès très facilement. En utilisant l'exemple de l'article de De Pauw et al. (5) publié dans l'*European Journal of Cancer* (2020) nous illustrerons ces enjeux tout en soulignant d'éventuelles complémentarités ou tensions entre la loi française et ces enjeux éthiques, avec un accent particulier sur les implications des gènes de prédisposition au cancer et les risques liés à la divulgation des données génétiques.

Autonomie

Le concept d'autonomie est central dans la commercialisation des tests génétiques. Les entreprises commercialisant ces tests les présentent comme une opportunité pour les personnes de gérer leur santé de manière autonome (3), sans passer par un professionnel de santé. Cette promesse occulte toutefois la complexité des résultats, notamment pour les gènes de prédisposition au cancer (comme BRCA1/2, TP53 ou APC), dont l'interprétation exige une expertise médicale. Cette autonomie est partiellement illusoire. L'exemple de Mr. C. décrit par De Pauw et al. (5) met en lumière ce problème. Mr. C. a effectué un test en libre-accès « par curiosité », sans information adéquate, ni consentement libre et éclairé. En effet, en commandant le test en ligne, Mr. C. acceptait de facto des conditions générales de vente avec 29 clauses dont une seule décrivait les limites du test. Il a reçu des résultats indiquant des prédispositions génétiques à des cancers graves — syndrome de Li Fraumeni (lié à des mutations du gène TP53) et syndrome de polypose adénomateuse familiale (PAF; associé au gène APC) —, ce qui a entraîné une grande anxiété. Ces syndromes, bien que rares, illustrent la gravité des conséquences d'une mauvaise interprétation des variants génétiques. Les conséquences auraient pu être néfastes pour sa santé (voir point ci-dessous autour de la non-malfaisance). À la suite de la consultation dans un service de génétique médicale en France, les analyses ont été répétées, en utilisant des méthodes validées et plus fiables que le test en libre accès. Les résultats ont révélé qu'il s'agissait de faux-positifs, le patient n'avait pas de variant génétique pour les syndromes de Li Fraumeni et de PAF.

L'accès non encadré aux tests de prédisposition au cancer pose un défi supplémentaire : la possibilité que des individus prennent des décisions irréversibles (ex. : chirurgie préventive) sur la base de résultats mal contextualisés, comme le soulignent des études récentes (15,16).

L'étude de 2011 *« Ethical, Legal, and Social Aspects and Implications of Direct-to-Consumer Genetic Testing* » financé par la Commission Européenne (via CORDIS) (17) mettait déjà en évidence plusieurs problèmes éthiques, notamment l'autonomie des personnes qui ont recours aux tests génétiques. Certaines entreprises permettent aux enfants mineurs de se soumettre à des tests pour des maladies qui ne se déclarent qu'à l'âge adulte. Dans le cas des cancers héréditaires, cette pratique est particulièrement problématique : connaître son statut génétique dès l'enfance peut engendrer un stress durable sans bénéfice médical immédiat. Cela va à l'encontre des recommandations professionnelles — de tels tests ne devraient être effectués que si des mesures thérapeutiques ou préventives sont possibles (18). Par ailleurs, des entreprises comme *deCODE* Genetics utilisent les données génétiques de leurs clients à des fins de recherche (19), brouillant la frontière entre les services médicaux, les produits de consommation et la recherche.

La loi française impose que les tests génétiques soient prescrits par un médecin et accompagnés de conseils appropriés (médecin généticien ou conseiller en génétique) pour garantir que les individus comprennent pleinement les résultats et leurs implications, ce qui permet un respect de l'autonomie des personnes (qui ont recours à un tel test). Comme vu plus haut, les personnes ont aussi le « droit à l'ignorance » concernant les résultats. Enfin, il n'y a aucune recommandation de procéder à un test chez l'enfant s'il n'y a pas de traitements ou prophylaxie possible avant l'âge adulte. La loi française garantit l'autonomie des patients ayant recours à un test génétique médical. Cependant, cette protection légale ne s'étend pas aux données génétiques collectées par des entreprises étrangères. Une fuite ou une exploitation commerciale de ces informations pourrait exposer les individus à des discriminations systémiques, comme le refus d'assurance-vie ou l'exclusion de certains emplois, ce qui est un risque accru pour les porteurs de variants associés aux cancers. On parle dans ce cas de « discrimination génétique » (20).

Les tests génétiques commercialisés par des entreprises américaines sur internet contournent les exigences légales et réglementaires françaises, et posent donc des tensions avec les principes d'autonomie, car ils fournissent des informations médicales sans soutien clinique — ce qui n'est pas sans conséquences (5) —, et de nombreuses questions subsistent quant à la fiabilité de leurs tests.

Justice

Tous les individus devraient avoir un accès équitable aux soins (principe de justice) (2) et ainsi (s'ils en font le choix) pouvoir effectuer des tests pour savoir s'ils ont des prédispositions génétiques à certaines maladies. Les tests génétiques, en étant peu coûteux et plus accessibles, pourraient théoriquement bénéficier d'un accès démocratisé. En contrepartie, cette démarche pourrait aussi exacerber les inégalités, car les utilisateurs doivent être accompagnés pour savoir comment interpréter les résultats, et pouvoir accéder à une prise en charge médicale adaptée en cas de détection d'anomalies génétiques. Ce fossé est particulièrement marqué pour les ACG de prédisposition au cancer, où l'accès aux consultations d'oncogénétique — déjà saturées — reste limité pour les populations défavorisées ou rurales (21). Dans le cas de Mr. C. (5), s'il a pu bénéficier d'une consultation en oncogénétique et de nouvelles ACG, il est probable que ce ne soit pas systématiquement le cas d'autres patients — les services d'oncogénétique n'étant pas facilement accessibles (21) sur le territoire français (ressources et moyens limités).

Par ailleurs, la divulgation involontaire de résultats génétiques pourrait renforcer les inégalités socio-économiques. Par exemple, une personne identifiée comme porteuse d'un variant BRCA1 pourrait se voir refuser une assurance-emprunteur, essentielle pour l'accès à un crédit immobilier, ou subir des préjudices en milieu professionnel. Aux États-Unis, le *Genetic Information Nondiscrimination Act* interdit (en théorie) de telles discriminations, mais en Europe les protections restent fragmentaires (22).

En France, le cadre légal prévoit que les analyses génétiques soient réalisées sous la supervision de professionnels de santé qualifiés, garantissant une interprétation correcte des résultats et un suivi approprié. Les tests génétiques, en se soustrayant à ces règles, risquent de créer des inégalités d'accès à une information génétique fiable et de qualité, ainsi qu'à une prise en charge médicale adéquate.

Bienfaisance

Le principe de bienfaisance (6) exige que les actions menées visent à faire le bien, en maximisant les bénéfices et en minimisant les risques pour les individus. Les entreprises commercialisant des tests génétiques prétendent offrir des outils pour mieux gérer la santé individuelle, mais sans cadre médical approprié, les résultats peuvent être mal interprétés et mal utilisés. Dans le cas de Mr. C. (5), les tests génétiques ont entraîné un stress majeur pour le patient, avec des résultats de tests génétiques alarmants et non corroborés par une analyse clinique ainsi que des examens médicaux inutiles, ne maximisant en aucun cas les bénéfices potentiels pour Mr. C. Pour les porteurs réels de variants pathogènes, l'absence de suivi adapté — comme des programmes de dépistage renforcés ou des mesures préventives — annule tout bénéfice potentiel, transformant ces tests en outils anxiogènes plutôt qu'en leviers de santé publique.

Avant leur approbation en 2017, *23andMe* avait été avertie par la FDA (*Warning Letter*) (23) sur la fiabilité de leurs tests et des risques pour les clients de recourir à des décisions médicales inappropriées (voir aussi ci-dessous le point sur la non-malfaisance).

La loi française garantit que les analyses génétiques soient réalisées dans un cadre bien défini, avec un conseil génétique, avant et après le test, afin de maximiser les bénéfices et minimiser les risques pour les individus. Les bénéfices des tests génétiques, moins fiables et non associés à un accompagnement par un conseiller en génétique, présentent également un risque de « surdiagnostic », c'est-à-dire le diagnostic de maladies asymptomatiques qui n'évoluent pas et pour lesquelles il n'y a pas de bénéfice (pas de mesures de prévention ni de traitements) pour le patient de connaître son diagnostic.

Non-malfaisance

Le principe de non-malfaisance stipule que les actions ne doivent pas causer de tort (6). Les tests génétiques, lorsqu'ils manquent de conseils appropriés et sont mal interprétés, peuvent causer des dommages psychologiques et physiques aux individus, comme dans le cas de Mr. C. (5) qui a subi un stress majeur et des examens médicaux inutiles et non sans risques potentiels (une endoscopie et deux biopsies). La mauvaise interprétation des résultats, combinée à une information insuffisante et à l'absence de consentement éclairé, va à l'encontre du principe de non-malfaisance. De plus, la divulgation de données génétiques sensibles — comme les prédispositions au cancer — pourrait entraîner des discriminations génétiques systémiques :

- Accès à l'assurance : En France, les assureurs n'ont actuellement pas le droit de demander d'analyses génétiques, mais une fuite de données pourrait inciter à des ajustements de primes ou des exclusions de couverture, comme cela a été observé dans des pays sans cadre protecteur strict (24).
- Emploi : Des employeurs pourraient écarter des candidats perçus comme « à risque » de développer un cancer, malgré l'interdiction légale, en s'appuyant sur des informations génétiques obtenues illicitement.
- Prêts bancaires : Les banques pourraient exiger une assurance-vie renforcée pour les porteurs de variants génétiques potentiellement pathogènes, rendant l'accès au crédit plus coûteux ou impossible.

Un autre exemple contraire au principe de non-malfaisance est le piratage massif des données de *23andMe* en 2023 ; les données génétiques de millions de clients ont été exposées (25). Cet incident souligne la vulnérabilité des bases de données génétiques, où des informations sensibles — une fois divulguées — pourraient être exploitées à des fins discriminatoires pendant des décennies.

La loi française, en exigeant une prescription médicale et un suivi par un conseiller en génétique, cherche à minimiser les risques de malfaisance en fournissant des informations fiables et en assurant un soutien approprié pour l'interprétation des résultats. Les tests génétiques, en accès libre sur internet, qui contournent donc la réglementation française peuvent mettre en danger les individus en fournissant des informations potentiellement erronées et anxiogènes.

Enjeux de justice intergénérationnelle et de consentement familial

Un aspect éthique sous-exploré concerne l'impact des tests génétiques sur les dynamiques familiales et les générations futures. La découverte d'une prédisposition génétique à un cancer (comme une mutation du gène BRCA1/2) ne concerne pas uniquement l'individu testé, mais aussi ses apparentés biologiques, qui pourraient être porteurs du même variant sans avoir consenti à le savoir. Des études montrent que certains des utilisateurs de tests génétiques partagent leurs résultats avec des membres de leur famille, parfois contre leur gré (26), violant ainsi leur droit à l'ignorance. Par ailleurs, ces tests soulèvent des questions de justice intergénérationnelle — les données génétiques stockées par des entreprises privées pourraient être exploitées pour prédire des risques chez les descendants, sans leur consentement. Certaines plateformes, comme *MyHeritage*, intègrent déjà des outils de pairage génétique reliant des utilisateurs à des cousins éloignés, créant un réseau de données où la vie privée d'un individu dépend de celle de dizaines d'autres (27).

CONCLUSION

Les tests génétiques en libre accès, particulièrement ceux informant sur la prédisposition au cancer, soulèvent des enjeux éthiques majeurs qui nécessitent une vigilance constante pour protéger les individus (27). L'illusion d'autonomie, les inégalités d'accès à une information fiable et à un suivi médical (justice), les doutes sur les bénéfices réels (bienfaisance) et les risques avérés de préjudices psychologiques, physiques ou sociaux (non-malfaisance) doivent être sérieusement considérés. Si le cadre légal français, en encadrant strictement les ACG à des fins médicales, s'aligne sur les principes éthiques fondamentaux (6), la facilité d'accès à ces tests en ligne fragilise cette protection. Leur fiabilité reste questionnable et leur utilité hors d'un contexte médical et d'un conseil génétique adapté est très limitée, voire négative (5), comme le soulignent des analyses récentes pointant les risques de mauvais diagnostics ou de surtraitements (5,27).

Plutôt que de se reposer uniquement sur l'interdiction, qui s'avère poreuse face aux possibilités disponibles sur internet, des solutions préventives axées sur l'information et l'éducation du public semblent nécessaires. Il est crucial d'informer les citoyens français sur les limites, les risques (y compris pour leurs données personnelles et les implications familiales) et le cadre légal des tests génétiques. Des campagnes d'information menées par les instances gouvernementales pourraient jouer un rôle-clé.

Il est important d'évoquer la situation dans les pays où ces tests sont autorisés : les mêmes questions éthiques se posent, même si les réglementations varient. Cela soulève des questions sur la façon de trouver un équilibre entre la protection des citoyens par des lois strictes et la promotion de l'autonomie individuelle dans une société où l'accès à l'information est de plus en plus vaste. Le rôle d'organismes consultatifs, comme le Comité Consultatif National d'Éthique (CCNE) en France par exemple, est crucial pour éclairer ces débats et guider les changements législatifs. Il s'agit de faire en sorte que les avancées génétiques apportent de réels bénéfices aux individus sans les exposer à des décisions difficiles ou à des risques inutiles.

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RÉPONSE À - ARTICLE / RESPONSE TO - ARTICLE

And What About Organizational Ethics?

Laurie Bouchard[a,b]

Texte discuté/Text discussed: Ravitsky V. A path forward – and outward: repositioning bioethics to face future challenges. Hastings Center Report. 2023;53(5):7-10.

Résumé
Dans son essai intitulé « A path forward – and outward: repositioning bioethics to face future challenges », Vardit Ravitsky présente une vision pour repositionner la bioéthique afin de mieux relever les défis actuels et futurs. Si son essai présente plusieurs points forts, notamment l'attention accordée à l'inclusion, il comporte également une lacune importante — il ne fait aucune mention de l'éthique organisationnelle.

Mots-clés
bioéthique, éthique organisationnelle, réseau de la santé et des services sociaux, soins de santé, gouvernance, inclusion

Abstract
In her essay "A path forward – and outward: repositioning bioethics to face future challenges", Vardit Ravitsky presents a vision for repositioning of bioethics in order to better face current and future challenges. While her essay has several strengths, especially the attention to inclusion, it also has an important shortcoming — there is no mention of organizational ethics.

Keywords
bioethics, organizational ethics, health and social services network, healthcare, governance, inclusion

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INTRODUCTION

In this text, I would like to comment on an essay written by Vardit Ravitsky (1), President of the Hastings Center, where she expresses her views on the repositioning of bioethics in order to face current and future challenges, as well as her wish that the Hastings Center include many different fields and partners. More than simply a promotional text, Ravitsky places the Hastings Center in the same position as bioethics: it doesn't have all the answers, it needs to continue its reflection, and it is open to a variety of opinions and perspectives. She cites a few examples of these challenges, such as poverty, racism and difficulties of access. Reflecting, moving forward and making progress are, in my view, three very important aspects for ensuring that bioethics, a relatively young interdisciplinary field (2,3), does not stagnate or even die out. In this text, I first address the main strength of Ravitsky's essay, that is, it's inclusive vision of the field, and then its shortcoming, namely the absence of attention to organizational ethics, and conclude with its contribution to the bioethics literature.

A STRENGTH: INCLUSION

Ravitsky's essay has several strengths, not least of which is the unifying vision that the bioethics must take, or "building bridges" as Ravitsky would say, how the Hastings Center embodies this desire for collective responsibility, and the micro-meso-macro approach to current and future challenges, which together should lead to a repositioning of bioethics (1). Nevertheless, I choose to focus here on what I believe to be the main strength of the essay, that is, inclusion. Firstly, it should be noted that Ravitsky does not forget the major current strands linked to bioethics (and the expertise generally associated with these), i.e., healthcare, biomedical research and public health. Indeed, Ravitsky names these three areas as important strands of bioethics for which there have been (and continue to be) many important and ongoing developments. Among these, Ravitsky names advances in understanding and promoting individual autonomy, and the rise of empirical bioethics and neuroethics. She discusses the advances made by these three domains (principles, frames of reference, policies, etc.) and argues that these must continue. Nevertheless, given the presence of various problems such as racism and poverty, which Ravitsky considers to be systemic in nature, she argues that bioethics must also become more systemic in focus, whether to reflect on these problematic situations and develop ethics frameworks or guidelines to respond to these challenges (1).

For Ravitsky, this work is important and must be continued so that bioethics becomes more global. This would give greater added value to all the work being done in the field. She proposes a variety of solutions, involving not only the expertise already present in bioethics (in philosophy, theology, clinical practice and research, etc.), but also other areas of expertise, such as environmental sciences and the humanities. Thus, for Ravitsky, increasing the overall capacity of bioethics can make a significant difference, as perspectives would be broadened to recognize what's important to people and to respond to different challenges. Ravitsky explains that bioethics will continue to be what it is — a field that asks different questions (e.g., about principles, such as autonomy), explores various aspects (e.g., quality of life) and constructs ethics frameworks — but this will be more comprehensive if it broadens its horizons (1). Overall, the fact that Ravitsky mentions the word "systemic" several times in the essay is, in my opinion, a sign of inclusion, even innovation. She talks not only of the importance for bioethics of moving towards a more systemic level of analysis, something bioethics is largely not accustomed to doing, but also the contribution that several areas of expertise (current and new) can make to bioethics, both in terms of reflection and the creation of new frameworks. These reflections and frameworks can be integrated into various organizations, including health and social

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services organizations, especially via areas of bioethics that are already well-established, such as clinical ethics, research ethics and public health ethics.

A SHORTCOMING: THE ABSENCE OF ORGANIZATIONAL ETHICS

Even though Ravitsky is very inclusive in her essay, and she clearly wishes to integrate various areas of expertise into the field of bioethics, while not forgetting the expertise already present, she has, in my opinion, omitted one important aspect: organizational ethics, which is increasingly present in health and social service organizations. Indeed, she doesn't mention this type of expertise at all in her essay, even though she mentions several others.

Before going any further, a few words about organizational ethics are in order, as they will help illustrate my point. Organizational ethics, which is well established in several industrial sectors, with its own literature, and which is beginning to take root in the health and social services field, involves reflection on the choice of values to guide management decisions that may influence care and services, as well as their evolution in a changing environment and at the level of clinical practice (4,5). Above all, it refers to administration, management, compliance, governance and shared values within an organization (6,7). It is there to influence organizational decisions by adding a form of ethicality (8,9). These decisions have repercussions for patients, users of health and social services, staff and the community to which the organization belongs. Organizational ethics involves the articulation, application and evaluation of the implementation of an organization's values and moral positions (11,12), which are referred to in organizational documents such as the mission statement, code of ethics or list of organizational values and their definition. It leads managers to assume their decision-making responsibilities while respecting the principles of distributive justice and equity in access to services (11,12). The principle of distributive justice in health and social services have to do with ensuring that care and services are provided based on individual needs and available resources (11,12), without discrimination and with constant and consistent application of the rules (9). Organizational ethics also encourages decision-making based on analysis of the facts, identification of the values at stake and knowledge of obligations (ethical and legal) in order to make organizations (more) ethical. The human rights inherent in decision-making must be included; these rights are embodied in the law, but also in an organization's values (12).

These few words on organizational ethics demonstrate, in my view, the place that it should have had in Ravitsky's essay. Why? First, because of certain challenges mentioned and described by Ravitsky, such as the difficulties of accessing and allocating resources. The centrality of the principle of distributive justice within organizational ethics explained above illustrates the pertinence of organizational ethics and the important contributions it can bring to thinking about and establishing frameworks designed to ensure equitable and timely access to resources. Secondly, Ravitsky mentions that many of the challenges she describes stem from structural difficulties, with issues of access being one example. Organizational ethics provides just such a structure, since it refers to the administration and governance of organizations, among other things. In addition, Ravitsky mentions the importance of going beyond individual and healthcare-centric approaches (without, however, setting them aside). Traditional biomedical ethics (not to be reduced to bioethics) are more concerned with individual issues (6). This is not the case with organizational ethics, which, as described above, focuses on multi-stakeholder issues and challenges. As a result, it is more systemic since it involves the analysis of the workings of organizations in order to propose and implement structural changes and thus solutions (including prevention) to ongoing problems. As Ravitsky points out with reference to other examples, this broader systemic perspective would enable us to go further in our bioethics reflection. Finally, Ravitsky mentions the importance of contributing to the development of policies and the implementation of recommendations to reflect on and resolve different challenges. Organizational ethics enables this through the implementation of important documents, such as ethics frameworks and mission statements, that are designed to, as closely as possible, match the values and meet the needs of the various stakeholders.

Overall, the introduction of organizational ethics into bioethics would make the field even more systematic in its analyses and applications, which Ravitsky clearly articulates in her essay, and would allow for even greater inclusivity, as other stakeholders could join in thinking through the various challenges as well as creating new or adapting existing ethics frameworks.

CONCLUSION: THE ESSAY'S CONTRIBUTION TO BIOETHICS LITERATURE

It is important that that bioethics community reflect on the scope of our research and practice in order to move forward and make progress that ensures that bioethics remains pertinent and relevant. Inclusiveness is the main strength of Ravitsky's essay, and she clearly wishes to make bioethics more systemic and include different types of expertise, whether those already present in bioethics or to bring new expertise from other fields or disciplines. However, she has omitted an important component, namely organizational ethics. In my opinion, the inclusion of this component can make bioethics even more systematic and allow us to include expertise to fuel more nuanced and pertinent reflection for our health organizations.

Ravitsky's essay provides food for thought for bioethics. First, she points to the importance of bioethics becoming more systemic and inclusive, naming various problems that bioethics can reflect on and help, such as poverty and racism. Even if Ravitsky names only a few examples in her essay, I take from her words that she is inviting readers to themselves explore possible new areas of expertise or combinations of these. Second, the solutions she proposes, that is, the micro-meso-macro vision, highlight the bridges that must be built between different partners and between different fields, and the frameworks that can provide guidance in certain areas. These solutions are clear, but Ravitsky notes that there are many ways of achieving them, and that it's up to readers to think through their potential application. In short, the doors are open for everyone to take bioethics to the next level.

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

Compte rendu critique de la pièce de théâtre « Une vie intelligente »

Marie-Josée Drolet[a]

Résumé
Ce compte rendu critique comprend un résumé de la pièce de théâtre « Une vie intelligente », lequel est suivi d'un commentaire critique. Ce faisant, une perspective critique sur la forme et le contenu de la pièce est articulée.

Mots-clés
intelligence artificielle, ère numérique, technologies de l'information, technologies numériques, domination technologique

Abstract
This critical review includes a summary of the play "An Intelligent Life", followed by a critical commentary. In so doing, a critical perspective on the form and content of the play is articulated.

Keywords
artificial intelligence, digital age, information technology, digital technologies, technological domination

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INTRODUCTION

Les technologies numériques, incluant l'intelligence artificielle (IA), se sont imposées à nous, sans que nous ayons notre mot à dire. Sournoisement et quasiment du jour au lendemain, lentement, elles se sont intégrées à notre quotidien et ont changé nos vies, certains diront pour le mieux, d'autres pour le pire. « Comment résister, collectivement et individuellement, aux monopoles technologiques et à la puissance des algorithmes? Comment repenser notre rapport au numérique de façon plus équitable et durable? » (1), telles sont les questions phares de la pièce de théâtre « Une vie intelligente », qui fut présentée au théâtre Jean Duceppe, à Montréal, du 26 février au 29 mars 2025. Ce texte consiste en un compte rendu critique de cette pièce. Il comprend deux parties : un résumé et une perspective critique.

COMPTE RENDU

La pièce de théâtre « Une vie intelligente » a été écrite par Dominique Leclerc qui est co-directrice de Posthumains, une compagnie de création qui s'intéresse à « l'impact du développement des technologies NBIC (nanotechnologies, biotechnologies, technologies de l'information et sciences cognitives) sur le vivant » (2). En plus d'être autrice de la pièce, Dominique Leclerc en est l'interprète principale et sa co-metteuse en scène. Produite en collaboration avec l'Université de Montréal, la pièce porte sur le rapport des humains avec les technologies numériques, incluant l'IA. Thomas Emmaüs Adetou, un doctorant en philosophie à cette université dont les recherches actuelles portent sur « l'éthique des machines » (3), joue dans la pièce, en compagnie de six autres interprètes.

La pièce a pour point de départ le moratoire international sur le développement des systèmes d'IA réclamé en 2023 par une centaine de scientifiques, mais auquel aucune suite n'a été donnée. Il s'agit, le temps de la pièce, de réaliser ce moratoire. Après un bref historique du développement des technologies numériques, incluant une vidéo de Yoshua Bengio, professeur au Département d'informatique et de recherche opérationnelle de l'Université de Montréal considéré comme l'un des pères fondateurs de l'intelligence artificielle et pionnier de l'apprentissage profond (4), Dominique Leclerc nous invite à prendre « un peu de recul, loin de nos appareils intelligents, pour retrouver l'élan d'imaginer un futur différent? » (1). Le public est ainsi invité, pendant l'heure et les 45 minutes qui suivent, à faire une pause pour réfléchir aux impacts du numérique sur sa vie.

Plusieurs thèmes sont abordés comme les impacts de l'IA sur la vie démocratique, l'éducation, l'environnement, les liens sociaux, la souveraineté humaine, la réponse à des besoins affectifs, les personnes qui trient et récoltent les déchets numériques, etc. À divers moments durant la pièce, le public est invité à faire des choix et à se prononcer sur des thèmes ciblés comme la littératie numérique, le pouvoir d'agir ou l'environnement et un groupe de citoyens ciblés préalablement monte sur scène pour réfléchir au thème choisi par le public. Avec l'aide d'une prospectiviste, Catherine Mathys (5), ce groupe non-acteur ira dans une salle attenante à la scène pour co-imaginer un futur loin des dystopies pour le Québec de 10 ans dans le futur.

PERSPECTIVE CRITIQUE

En dépit du fait qu'à un moment donné durant la pièce, le public soit confronté à sa difficulté à vivre de l'ennui (pendant plusieurs minutes, il ne se passe strictement rien et c'est voulu), la pièce est loin d'être ennuyante. Diverses modalités

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scéniques sont utilisées pour donner un rythme entrainant et ludique à la pièce comme l'utilisation d'ombres chinoises pour narrer la genèse de l'IA et la diffusion d'une vidéo de Yoshua Bengio qui fait partie des scientifiques ayant demandé le moratoire sur le développement de l'IA. Pour soutenir l'attention du public, la mise en scène créative simule une rencontre zoom pour aborder des enjeux de l'usage de l'IA en éducation, utilise des monologues touchants où un ou une interprète met l'accent sur un enjeu spécifique et déploie des numéros théâtraux dansants et rythmés par une musique techno. Aussi, des discussions à distance avec la prospectiviste qui encadre le travail du groupe de citoyens sont réalisées, de même que des sondages à mains levées menés auprès du public. De plus, des vox pop réalisés avec des enfants sont diffusés. En somme, l'attention du public est sollicitée comme si celui-ci scrollait son téléphone. Le rythme entrainant de la pièce, les changements rapides de mise en scène et la diversité des tableaux dépeint créent ce sentiment chez l'auditoire. De fait, la pièce passe vite, peut-être un peu trop vite. On peine parfois à saisir toute la complexité et la profondeur du propos. Assurément la créativité et l'innovation ont été mobilisées pour rendre la pièce en cohérence avec la vie à l'ère du numérique.

Le contenu est dense. Dominique Leclerc aura voulu ratisser large, faire un bon tour des différents enjeux de notre usage individuel et collectif de l'IA. Or comme ceux-ci sont nombreux et préoccupants, le public peut être pris d'un vertige. Mais ne voulant pas opter pour un « discours moralisateur ou alarmiste » (1), l'autrice a fait appel à Catherine Mathys, une prospectiviste, pour mobiliser la voix citoyenne dans un projet collaboratif imaginatif non dystopique. Car il ne s'agit pas de traumatiser le public, mais de le laisser avec une forme d'espoir ainsi qu'avec des outils (par exemple, des ressources sont partagées avec le public à la sortie du théâtre via un code QR) pour mieux naviguer les enjeux. Donnant tantôt la voix aux détracteurs du numérique, tantôt à ceux qui l'encensent, la pièce tente un difficile équilibre entre ces pôles pour le moins opposés. C'est comme si l'autrice n'avait pas voulu décider pour le public, voulait plutôt semer des graines, le faire réfléchir. Plus encore, c'est comme si l'autrice avait tenu pour acquis que l'IA était là pour rester et que devant cette fatalité numérique, il fallait tenter à la fois comme personne et comme humanité de s'en accommoder bon an mal an, tout en minimisant ses conséquences.

Pourtant, plusieurs enjeux très préoccupants sont abordés, lesquels font, me semble-t-il, facilement le poids devant les avantages. Pensons par exemple au fait que des enfants en situation de pauvreté soient exploités pour extraire les minéraux requis pour fabriquer les téléphones intelligents (6), que des personnes africaines tombent malades en triant les montagnes de déchets que génère notre surconsommation des technologies numériques ou que des personnes racialisées soient traumatisées par les vidéos cruels et violents qu'elles visionnent sur le *dark web* dans le but d'alimenter les systèmes d'IA (7). Ces situations d'injustice et d'oppression ne sont-elles pas suffisamment graves pour qu'elles soient interdites et que les compagnies responsables condamnées en justice? Pensons ensuite à l'empreinte carbone titanesque de la fabrication et de l'utilisation de l'IA, aux nombreux déchets générés par les centres de données et à l'utilisation d'une très grande quantité d'eau pour refroidir les centres de données — c'est-à-dire au fait d'utiliser les systèmes d'IA si destructeurs de l'environnement dans un monde pourtant confronté à une crise climatique sans précédent (8). L'importante participation à l'écocide en cours n'est-il pas une autre raison suffisante pour exiger des GAFA (Google, Amazon, Facebook, Apple) de ce monde des pratiques plus écoresponsables et plus justes dès maintenant? Pensons ensuite au fait qu'un nombre croissant d'individus développent une forte dépendance à ces technologies, qui par ailleurs participent à la diminution de leurs capacités cognitives, que celles-ci érodent nos liens sociaux, donnent lieu à de l'intimidation, de l'exploitation sexuelle et de la cyber violence. Ne devrions-nous pas nous préoccuper davantage des impacts du numérique sur la santé publique? Comme ce fut le cas pour la cigarette et la vapoteuse, il semble que nos sociétés soient mal équipées pour lutter contre des compagnies à but lucratif qui n'ont rien à foutre du bien-être collectif.

En conclusion, si vous souhaitez découvrir ce qu'est le techno-féodalisme et en apprendre davantage sur les impacts du numérique, la pièce de théâtre « Une vie intelligente » est un incontournable, de même que les autres ouvrages eu œuvres de l'autrice (9). Elle devrait faire une tournée panquébécoise dans nos écoles, cégeps et universités.

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

Chronique du cinéma 9 : La substance et les fausses promesses

Jacques Quintin[a]

Résumé
Le film de Coralie Fargeat *La substance* (2024) met en scène les affres reliés au refus du vieillissement, surtout pour les femmes, dans un contexte social rempli d'injonction à demeurer jeune à tout prix. En plus de poser plusieurs questions existentielles, ce film présente une critique du monde social dans lequel nous vivons.

Mots-clés
corps, identité, éthique, transhumanisme, vieillissement

Abstract
Coralie Fargeat's film *The Substance* (2024) portrays the torments of refusing to grow old, especially for women, in a social context filled with the injunction to stay young at all costs. As well as posing several existential questions, the film is a critique of the social world in which we live.

Keywords
body, identity, ethics, transhumanism, aging

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La substance (*The Substance*) est un film produit par Coralie Fargeat, sorti en salle en 2024 (1). Le film raconte l'histoire d'Elizabeth Sparkle, jouée par Demi Moore, qui est une danseuse vedette de la télévision dans un programme de mise en forme pour les gens à la maison. Elle convainc les spectateurs que leur corps peut tout et les enjoint à mettre du brillant dans leur vie, à faire de leur vie quelque chose d'éclatant. Elle a sa propre étoile à Hollywood sur le plancher : Elizabeth Sparkle. Elle est reconnue; on la voit partout sur des affiches. Comme son nom l'indique, elle brille de toutes parts. Mais son bonheur prend fin abruptement lorsque le propriétaire de la chaîne de télévision souhaite la remplacer pour une autre fille beaucoup plus jeune : elle a le malheur d'avoir atteint l'âge de cinquante ans, l'âge qui signifie la fin de carrière pour plusieurs vedettes de cinéma. C'est toute sa vie qui s'écroule. Elle est frappée par le malheur.

À la suite de cette mauvaise nouvelle, elle sera victime d'un accident de la route qui exprime le tournant de sa vie. Elle s'en sortira sans conséquence. Mais nous retrouvons une femme devenue vulnérable qui n'existe plus dans le regard d'autrui. Elle a perdu une partie de son identité. Nous constatons qu'elle craint d'être seule.

Elle recevra une offre qu'elle finira, après une brève hésitation, par accepter : utiliser une substance, produite par division cellulaire de son ADN, qui lui donnera une meilleure version d'elle-même. Nous sommes ici au cœur de la pensée du transhumanisme qui vante les mérites de la science et de la technologie en faveur d'une amélioration de la condition humaine en augmentant les capacités physiques et psychiques et en supprimant le processus du vieillissement. Il y a en arrière-fond le médecin fou comme on en voit beaucoup dans les films où il s'agit de transformer l'être humain (2). En ce sens, le film nous présente une critique du transhumanisme, du non-respect de la finitude humaine qui cache la peur de mourir, de n'être rien pour personne.

Ces séquences invitent le spectateur à se poser la question de son rapport au corps, à la place du corps dans son identité, surtout lorsque celui-ci commence à montrer des signes de vieillissement, les marques de la finitude humaine. Une dualité s'instaure dans la psyché humaine : la réalité du vieillissement en conflit avec le rêve d'une jeunesse immortelle. Si l'être humain est rattrapé par sa condition d'être mortel, il l'est aussi par ce fantasme de retrouver un corps idéal. Il y a la recherche du corps parfait.

Elizabeth rejoue la tragédie de Prométhée qui vole le feu pour finalement en payer le prix en étant dévoré par les rapaces. À vouloir le bien, elle finit par produire le mal, en l'occurrence par s'autodétruire. Élizabeth, comme Œdipe, a voulu fuir son destin, vieillir, pour finalement être rattrapée par ce qu'elle refusait. La vie et la mort ne sont jamais loin l'une de l'autre.

Pourtant, cela semblait simple au début : il suffisait de suivre les instructions et d'accepter de partager son temps entre deux versions de soi-même de manière équilibrée. Mais, la version plus jeune et belle, son double, Sue, finira par devenir victime de son propre succès. Elle cherchera en à abuser en outrepassant les limites. Elle ne respecte donc pas les règles. Pour elle, ce n'est que quelques accros, mais le film en montre les conséquences. Ce que Sue gagne d'un côté, Élizabeth le perd de l'autre côté, même si elles ne font qu'une. Elizabeth fait la démonstration combien il est impossible pour l'être humain dans ses choix de vie de prévoir toutes les conséquences possibles. De quoi être sceptique à propos de la notion de consentement libre et éclairé et du cadre théorique qu'est le conséquentialisme. L'éthique, l'art de choisir ce qui convient à notre vie, repose finalement sur un non-savoir. Au lieu de cultiver la certitude que nos choix sont les bons, l'éthique devrait consister à maintenir

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ouvert le doute. Élizabeth va à l'encontre du sens commun qui invite à la prudence devant l'incertitude de nos choix, surtout lorsque nos choix sont irréversibles.

Le corps d'Élizabeth se transforme au même rythme que les transgressions réalisées par Sue. C'est ici que l'horreur commence : son corps devient horrible pendant que Sue fait la fête et jouit de sa vanité. Le corps d'Élizabeth devient une sorte de cancrelat que nous retrouvons dans la *Métamorphose* de Kafka (3).

À la fin, ce sont leurs corps, le corps d'Élizabeth et de Sue, qui sont réunis en un seul corps. On croirait entendre la psychanalyste Joyce McDougall dans son livre *Théâtre du corps* qui montre comment « il n'y a qu'un corps pour deux » (4) lorsque la distinction entre soi et l'autre disparaît. Pour Élizabeth et Sue, ce n'est pas possible. Alors elles se font la lutte jusqu'à se vider de leur sang. Le sang rejaillit sur les spectateurs venus assister à la fête du Nouvel An, fête du renouvellement. Nous pouvons comprendre qu'il s'agit de montrer comment c'est toute la société qui a des mains de meurtrier.

Si nous assistons à un conflit psychique entre la part en nous qui veut la jeunesse et qui refuse de mourir, on voit que ce conflit est généré par les injonctions de la société, plus spécifiquement, ceux qui nous viennent d'Hollywood. Il y a une scène où l'on voit toute l'équipe technique composée uniquement d'hommes qui regarde en gros plan le fessier de Sue.

Il est intéressant de voir comment le décor met à contribution notre compréhension de son monde dans la mesure où presque toutes les scènes se déroulent dans des lieux fermés, souvent sous la forme de tunnel sans fenêtre sur le monde extérieur. Élizabeth et Sue vivent toutes les deux dans un imaginaire pauvre en sens. Elles n'ont aucune vie en dehors de leur apparence. Élizabeth et Sue vivent dans une bulle, pour ne pas dire une illusion ou une vision en tunnel qui les empêche de cultiver une compréhension de soi, d'autrui et du monde enrichie. Elles vivent comme des prisonnières dans un caverne éclairée par des images composées de paillettes et de brillants. Cet éclat est créé par les projecteurs de lumière qui, en raison de leur intensité, produit une cécité psychique. Nous sommes plongés dans le même univers que celui des prisonniers dans la caverne de Platon (5). On comprend que ce culte à la beauté, à la brillance et au succès est vécu comme l'adoration d'un veau d'or.

Le film illustre comment la psyché est divisée entre plusieurs voix. Le bien-être exige un certain équilibre qui consiste à donner à chaque version de soi une juste place en permettant l'alternance des voix dans un souci démocratique. On retrouve le souci de la juste mesure promu par Aristote (6). Le trouble ou le mal commence lorsqu'une voix prend le pouvoir et se met en position d'hégémonie. Élizabeth et Sue, en voulant vivre à perpétuité leur état paradisiaque, provoquent leur propre chute. Comme quoi dans chaque coin de Paradis se cache un élan de vie qui conduit aux enfers.

Il y a un refus de la finitude, c'est-à-dire de la temporalité. Pourtant, c'est la temporalité qui permet à l'être humain de vivre d'autres versions de lui-même. Nous sommes un, mais nous apparaissons toujours sous des traits différents, de sorte que nous ne sommes jamais seuls; nous sommes minimalement deux.

La substance magique se présente comme une promesse de bonheur, mais de remède miracle on passe au poison et ensuite à la trahison. Ce sont les deux faces ou les deux versions du *pharmacon* (7). Il n'y avait personne pour servir de tiers, de médiation, qui aurait permis à Élizabeth de réfléchir davantage en faveur d'une meilleure compréhension de la condition humaine, de la condition féminine et des injonctions sociales qui nous entourent.

Il y a plusieurs couches de sens dans ce film. Nous pouvons en donner plusieurs versions. Mais les questions éthiques de fond, interreliées entre elles, demeurent : quel sens pouvons-nous donner à notre vie? Que pouvons-nous faire de notre existence et de notre corps?

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

Chronique du cinéma 10 : En bonne compagnie et la lutte pour l'avortement

Jacques Quintin[a]

Résumé
Réflexion sur le film *En bonne compagnie* / *Las Buenas companias* réalisé par Silvia Munt. L'intrigue, inspirée de faits réels, se déroule en 1977 à San Sebastian, au Pays basque, et raconte le mouvement féministe en faveur de l'avortement. Nous assistons à un conflit entre les valeurs traditionnelles et les valeurs plus progressives.

Mots-clés
avortement, conviction, féminisme, conservatisme, progressisme

Abstract
Reflections on the film *En bonne compagnie* / *Las Buenas companias* directed by Silvia Munt. The plot, inspired by real events, takes place in 1977 in San Sebastian, in the Basque Country, and tells the story of the feminist movement in favour of abortion. We witness a clash between traditional and more progressive values.

Keywords
abortion, conviction, feminism, conservatism, progressivism

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En bonne compagnie ou *Las Buenas companias* (2023) est un film catalan réalisé par Silvia Munt (1). L'intrigue, inspirée de faits réels, se déroule en 1977 à San Sebastian, au Pays basque, et raconte le mouvement féministe en faveur de l'avortement. Nous assistons à un conflit entre les valeurs traditionnelles et les valeurs plus progressives ou émancipatrices. D'un côté, nous avons les valeurs traditionnelles qui font des femmes des mères réduites à porter des enfants sans aucune autonomie dans leur sexualité. Ce sont les valeurs du mariage, de l'hétérosexualité et de la soumission supportées par le catholicisme, bien présent dans la vie quotidienne de l'époque; le contenu de la radio en témoigne. De l'autre côté, il y a le mouvement féministe, représenté par Béa (Alicia Falco), qui lutte pour le droit à l'avortement, pour revendiquer le droit aux femmes d'être maître de leur corps, dénonçant du coup les violeurs et les abuseurs. Ce mouvement revendique une sexualité hors mariage.

Dans ce contexte, Béa rencontre une autre femme, Miren (Elena Tarrats), enceinte et qui se laissera convaincre d'avorter, mais en France. La mère de Béa (Itziar Ituno) affirme que les gens mieux fortunés ou qui ont de bons contacts s'en sortent mieux, ce qui est le cas de Miren qu'on cachait jusqu'à l'accouchement pour remettre ensuite l'enfant en adoption. Ce ne fut pas le cas de la tante de Béa, Belen, qui s'est elle-même fait avortée en utilisant des broches à tricot avec les risques que cela représente. Elle en mourra. La mère de Béa sera arrêtée car soupçonnée d'avoir pratiqué l'avortement. Finalement, Béa avouera à sa mère qu'elle est amoureuse de Miren. Ce sera difficile pour la mère d'accepter la nouvelle condition de sa fille, qui n'est plus une enfant, mais une femme avec toute son autonomie. D'ailleurs, elle le dira elle-même, les enfants nous sont prêtés pour un temps, après ils s'envolent là où les appellent leur liberté. Autrement dit, elle accepte, quoique difficilement, cette nouvelle réalité en empruntant, paradoxalement, un discours religieux. Elle encourage donc sa fille à voler de ses propres ailes en allant à Barcelone ou Madrid où elle pourra trouver une plus grande liberté. De son côté, la mère dit à sa fille qu'elle continuera de lutter à sa manière, c'est-à-dire dans l'ombre.

Nous sentons bien, à travers cette lutte, la présence de l'idéologie liée au franquisme (le général Franco est décédé en 1975) qui a rendu possible l'emprisonnement de onze femmes, les « 11 de Basauri », pour avoir pratiqué clandestinement l'avortement. Cette lutte à travers toute l'Espagne permettra la légalisation de l'avortement en 1985.

Toute cette histoire nous fait revive la tragédie d'Antigone de Sophocle (2). Ce sont les raisons du cœur en faveur de la dignité des femmes contre les institutions conservatrices. À l'époque, il fallait être radical pour l'avancement de la cause. Les hommes sont absents et dépeints comme des monstres. Nous pouvons nous demander alors si c'est juste ou éthique d'entretenir la haine pour promouvoir la justice. Quelle place pouvons-nous accorder à la violence en faveur du bien? Est-ce le retour des choses? Dans ce cas, est-ce que les femmes répètent à leur manière toutes les injustices qu'elles ont subi? Est-ce une vengeance? Ces questions se posent, non pas pour diminuer la valeur de ces revendications, mais pour ne pas devenir aveugles, si nous acceptons que l'éthique soit l'art d'interroger toutes les valeurs.

Il n'en demeure pas moins que ce film trouve encore sa pertinence dans un contexte où nous assistons à l'essor de politiques conservatrices à travers le monde, principalement en Occident, dans bien des cas, avec une justification religieuse. Le rejet de l'avortement n'est plus un droit acquis. Le renversement de l'arrêt *Roe c. Wade* par la cour suprême des États-Unis est exemplaire à cet égard. Les valeurs de l'humanisme sont toujours menacées, surtout chez les femmes.

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La question de l'avortement devient une problème inscrite dans la condition féminine qui traverse les époques et les cultures. Il est probablement juste de se questionner si l'avortement est une bonne action, mais dans une culture caractérisée par le libéralisme et le pluralisme, il convient de laisser à chaque femme de réfléchir et de décider par elle-même ce qu'elle désire.

Le respect de l'autonomie et de non-malfaisance envers les femmes pèsent lourd dans la balance lorsqu'on veut réfléchir à l'avortement. Si on reprend la pensée de Max Weber (3), on peut dire que les conséquences sont trop sévères pour se cantonner dans des convictions fermées. Une société se juge aux soins qu'elle accorde aux femmes. En ce sens, l'éthique c'est, avant toute chose, penser. Et penser, c'est prendre soin de soi, des autres et du monde en s'exposant à la souffrance, à la fragilité et à la vulnérabilité intrinsèque à la condition humaine, plus spécifiquement à la condition féminine. Avant de donner naissance à des enfants, il convient tout d'abord de nourrir la liberté, une pensée nourrie par la condition féminine qui refuse une vie de mensonge et d'exploitation.

Le jeu des actrices est exceptionnel. La qualité des images et de la lumière est remarquable. Plus que tout, ce film donne à penser.

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K Morrill. *Can J Bioeth / Rev Can Bioeth.* 2025;8(3):115-116

COMPTE RENDU / REVIEW

Undoing Suicidism: A Trans, Queer, Crip Approach to Rethinking (Assisted) Suicide by Alexandre Baril

Katharine Morrill[a]

Résumé
Les initiatives et les stratégies de prévention du suicide se concentrent sur une approche curative et réhabilitative qui cause souvent du tort au sujet suicidaire et nie son expérience et ses sentiments. Dans *Undoing Suicidism : A Trans, Queer, Crip Approach to Rethinking (Assisted) Suicide*, Alexandre Baril remet en question les attitudes dominantes à l'égard du suicide, aborde le suicidisme comme étant une forme d'oppression qui réduit le sujet suicidaire au silence et délégitime sa souffrance. Il propose ensuite une approche interdisciplinaire qui affirme le droit au suicide et la validité des sentiments du sujet suicidaire.

Mots-clés
suicide, suicide assisté, suicidisme, études trans/queer, études interdisciplinaires, réforme juridique

Abstract
Suicide prevention initiatives and strategies commonly focus on a curative and rehabilitative approach, which often causes harm to the suicidal subject and negates their lived experience and feelings. In *Undoing Suicidism: A Trans, Queer, Crip Approach to Rethinking (Assisted) Suicide*, Alexandre Baril challenges dominant attitudes towards suicide, discusses suicidism as a form of oppression that silences the suicidal subject and delegitimizes their suffering, and proposes an affirmative interpersonal and legal approach through the lens of trans, queer, and disability studies.

Keywords
suicide, assisted suicide, suicidism, trans/queer studies, interdisciplinary studies, legal reform

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The phenomenon of suicide has been present for many millennia, and we have entertained numerous ethical and philosophical debates on this topic over the same period (1). However, Alexandre Baril was the first to put forward a concrete theory — suicidism — to identify the ways in which suicidal people have long been subject to various forms of marginalization, otherwise referred to by Baril as suicidist violence (2,3). The concept of suicidism, which in broad terms refers to the oppression experienced by suicidal people as a result of societal, interpersonal, medical, and structural pressures to get well and to overcome their suicidality, forms the basis of the very system Baril attempts to unravel in *Undoing Suicidism: A Trans, Queer, Crip Approach to Rethinking (Assisted) Suicide*.

An essential part of Baril's arguments against suicidism is his hypothesis that suicide prevention initiatives, frequently aimed at rehabilitating the suicidal patient, do more harm than good and encourage rather than discourage suicide attempts — particularly where marginalized groups, such as queer, trans, disabled, and Mad (i.e., mentally ill people, psychiatric patients) people are concerned. This is because such initiatives are, as Baril explains, often intrinsically linked to the idea that everyone should desire to live and remain alive, and to capitalist ideology surrounding productivity and contribution to the economy. Furthermore, suicidal people are expected to assume the burden of reassuring others about their own distress, all while suffering (and dying) alone and in silence, fearful of the many consequences of speaking up, such as shame and ostracization, forced institutionalization, and incarceration (2).

In deconstructing the above, and as Baril points out, *Undoing Suicidism* proposes ways of thinking about suicide and suicidal people that differ markedly from the sociological, medical, and legal norms of discourse on suicide, concepts which refer to the way suicide is typically thought about and approached. *Undoing Suicidism* aims not only to challenge and refute suicidism and the resulting dynamics of oppression but also advocates openly for supporting assisted suicide for suicidal individuals. It is, however, important to note that within the Canadian context from which Baril writes, current laws on assisted suicide and MAID are problematic because they are ableist and suicidist (2). What Baril is advocating for in this book would constitute a complete overhaul of assisted suicide laws, thereby eradicating many issues intrinsic to the current system.

Undoing Suicidism is divided into two parts, which can be read independently of each other. The first part, "Rethinking Suicide", discusses various existing models through which suicidism is reproduced and points out how these models are problematic and serve to perpetuate suicidist ideology (2). Namely, these models force what he calls "compulsory aliveness" upon the suicidal subject (2). Compulsory aliveness refers to an imposed will to live and to participate in society that delegitimizes the suicidal person's desire to die and denies them their agency and freedom of expression. In the second and third chapters of Part 1, Baril proceeds to apply an intersectional lens to his work. This accomplishes two tasks: 1) demonstrating how suicidism and current suicide prevention strategies disproportionally affect marginalized communities, thereby reproducing structures of oppression, and 2) showing how queering, transing, and maddening our attitudes towards suicide have the potential to be conducive to the eradication of suicidism (2).

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The second part of the book, “Rethinking Assisted Suicide”, moves beyond the culturally and medically dominant classification of suicide and assisted suicide as distinct phenomena, and proposes a subversive “suicide-affirmative” approach centred on the agency of the suicidal subject (p.220). Baril wraps up his discussion by reiterating a familiar question (4-6) in the title of his conclusion, “Can the Suicidal Subject Speak?” (2). He calls for solidarity: for the suicidal person to be met with compassion when expressing their desire to die, and to be listened to and respected. He also expresses hope that the legal and medical landscapes will one day reflect a shift towards compassionate and understanding treatment of suicidal people.

Although *Undoing Suicidism* offers limited insight into ways in which suicidist violence is reproduced in the context of everyday interactions, Baril nevertheless accomplishes an eloquent, well-rounded discussion of a difficult subject and expands on the framework of his earlier work on suicidism, providing additional context and a more in-depth discussion of the topic at hand. The intersectional nature of *Undoing Suicidism* is equal parts poignant and thought-provoking; this volume certainly constitutes a significant contribution to the field of suicide studies and makes a compelling argument in favour of reframing the way we think about and interact with suicide and suicidal people. Perhaps Baril’s most striking achievement, however, is the space he has carved out and the avenues for discourse he has created for a community whose voice has long been silenced and overlooked.

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COMPTE RENDU / REVIEW

The Ethics of Animal Shelters, by Valéry Giroux, Kristin Voigt and Angie Pepper

B.V.E. Hyde[a,b]

Résumé
Dans cette analyse de *The Ethics of Animal Shelters*, j'explore l'approche pratique et philosophique du livre sur les dilemmes éthiques dans les refuges pour animaux, tels que l'euthanasie et le triage. Je souligne la pertinence du livre pour la bioéthique, malgré un engagement explicite limité dans ce domaine, et je critique sa justification de la mise à mort d'animaux en bonne santé dans des conditions non idéales. J'appelle à une plus grande implication de la bioéthique dans l'éthique des refuges et à la création de comités d'éthique pour soutenir la prise de décision.

Mots-clés
éthique animale, anthropocentrisme, refuges pour animaux, protection des animaux, bioéthique translationnelle

Abstract
In this review of *The Ethics of Animal Shelters*, I explore the book's practical and philosophical approach to ethical dilemmas in animal shelters, such as euthanasia and triage. I highlight the book's relevance to bioethics, despite the limited explicit engagement with the field, and critique its justification of killing healthy animals under nonideal conditions. I call for broader bioethical involvement in shelter ethics and the creation of ethical review boards to support decision-making.

Keywords
animal ethics, anthropocentrism, animal shelters, animal protection, translational bioethics

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Bioethics is anthropocentric. There are notable exceptions to this rule — for example, the Nottingham Centre for Applied Bioethics spans the School of Veterinary Medicine as well as the School of Biosciences. However, more often than not, bioethicists are only interested in humans. In fact, a recent book I reviewed on bioethics in the context of space exploration (1) went as far as to declare that *real* bioethics is essentially concerned with ethical problems caused by features of human biology, deriding those interested in nonhuman ethics (specifically astrobioethics) for misusing the term in its application to nonhuman subjects.

Animal ethics is usually considered a discrete field and you'd be hard pressed to find many animal ethicists identifying as bioethicists, or vice versa. However, in some cases, there are clear overlaps between the two. Animal experimentation is one of the most obvious, where discussion often centres around bioethical tenets such as beneficence, nonmaleficence and, increasingly, the need to respect animals' autonomy. In the *Canadian Medical Association Journal* (Est. 1911), for example, there are numerous contributions on animal rights, particularly in the 1980s and 1990s. In my view, another place where bioethics closely intersects with animal ethics — but one that's far less recognized than the laboratory — is the animal shelter.

Many of the ethical challenges in an animal shelter resemble those in a hospital. Both are spaces where care providers hold significant responsibility over vulnerable individuals and must make decisions in their best interest while respecting their dignity. Features of particular medical contexts can raise unique bioethical problems, such as when incapacitated or mentally disabled patients cannot give consent. Likewise, communication with animals is limited, raising some of the same bioethical challenges. Both medical and animal care also face fundamental challenges of balancing ethical ideals against a reality that's constrained by limitations on resources or available technologies.

Unfortunately, rarely in their book *The Ethics of Animal Shelters* (2) do Valéry Giroux, Kristin Voigt and Angie Pepper make an explicit comparison between the ethics of animal shelters and bioethics — unfortunate, because this is a good book with implications much wider than just animal shelters (which is one of the points I'm aiming to make by reviewing this book in a journal of bioethics). A lot of the topics the book deals with are commonly thought to be bioethical ones, such as euthanasia and triage protocols. Many of the themes overtly identified in the introduction are strikingly bioethical, including the difference between ideal moral theory and nonideal realities, disagreement amongst and compromise between practitioners, and an optimism that real conditions can be improved with strong ethical guidelines. Their methodology is also quite bioethical. They bemoan that philosophy, even so-called applied philosophy, "often proceeds from various idealizing assumptions" and fails to tackle the "messiness" of real-life situations, preferring instead a practitioner-driven methodology. Observe that a large amount of bioethics is done by doctors and biomedical scientists — only a minority is done by philosophers — and many who would call themselves bioethicists tend to be appointed to medical schools rather than philosophy departments. This is true in my own case, and I know it to be or have been the case for some the most prominent bioethicists. Even the book's contributors have some connexion to bioethics. While the blurb describes it as the outcome of a collaboration between a team of *animal ethicists* and shelter workers, at least some of its authors could also be described as bioethicists.

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The book is organized into two sections after an introduction. The first isn't divided into chapters and instead contains a long but concise list of guidelines and recommendations followed by a more extensive explanation and justification of them. The recommendations are specifically targeted at the Montreal Society for the Prevention of Cruelty to Animals but are applicable to all animal shelters. They address overarching problems, such as the use of language to discuss animals; its internal structure and decision-making; shelter operations; dealing with the public, animal industry, and governmental agencies; and work that focuses on feral animals. Less of an academic work, the authors describe this section as a "practical policy document," most of its suggestions being practical and logistical. For example, they recommend that organizations be separated into two sites: one for faster turnover activities like adoption; another for slower turnover activities such as long-term animal rehabilitation. Most of this advice has bioethical relevance. For instance, the suggestion to limit relationships with industry and to focus on distributors rather than producers could be immediately applied to a biomedical context.

The emphasis in section one is mostly on explanation because it's in the second section that more argumentative and philosophically rich chapters feature, beginning with a chapter on the value of death for animals. What's particularly useful about this chapter is the attention to the shelter context: Nicolas Delon (3) evaluates why euthanasia decisions in shelters might deviate from the standards applied to humans, arguing that euthanasia can sometimes be ethically justified under resource constraints or when prolonged shelter life would lead to significant suffering. He proposes that decisions about euthanasia be guided by ethical standards that respect animal interests, integrating an animal's potential future quality of life, wellbeing, and personality into these judgments. Rather than adopting an abstract theory of morality or wellbeing, the chapter outlines practical considerations for euthanasia decisions.

The next chapter also looks at the nonideal conditions that might lead to an animal being killed. Angie Pepper (4) argues that shelter staff are often confronted with the tragic choice of either killing animals or failing to care for them and leaving them to suffer. Consequently, shelters regularly kill animals who could have led good lives in other circumstances. She argues that shelter staff cannot be blamed for this because a lack of funding makes killing them the most humane of two bad options. Instead, the state is responsible for putting shelters into this bind in the first place.

Because they're operating with limited cash, staff, space, and resources, Angela K. Martin (5) entertains the idea that shelters might be justified in implementing triage systems. Her argument is that, because shelters cannot look after all the animals they'd like to, well designed triage protocols will make decisions about which animals to shelter less arbitrary, fairer and more transparent. She looks at how triage would work in practice, considering eight considerations from the context of human medical care:

1. maximizing benefit
2. justice
3. consideration of medical criteria
4. life-span considerations
5. fair decision-making
6. patient will
7. changes in the therapeutic goal
8. burden of triage and staff support

Such criteria are not always easy to understand or to apply, so she concludes by suggesting that an external ethics board can help animal shelters make difficult decisions.

The book is all about making decisions in animal shelters as ethically as possible in nonideal conditions. François Jaquet (6) examines three dimensions of shelter operations that, in an ideal world, would be impermissible: killing healthy shelter animals for lack of resources, building partnerships with animal agriculture, and feeding meat to shelter animals. He shifts the focus from moral ideals onto the material realities that animal shelters face, arguing that they ought to prioritize feasibility, permissibility and efficacy in their decision-making. From this, he argues, it follows that killing healthy animals for want of resources to look after them is morally acceptable in nonideal conditions.

The problem of killing healthy animals is not the only one discussed in the book's second section, but it's the one I've chosen to focus on in this review — not only because it's spoken about by the majority of the contributors, but because it's the most morally challenging. In my view, their solution is wrong. I dislike that they're justifying what is an abhorrent practice any way you look at it and find that their moral theorizing often tries to pin the wrongdoing on something other than the shelter staff killing the animals. A world in which killing is permissible in nonideal contexts is one in which life loses its sacrosanctity. It's one thing to say that it's a *necessary evil*, but another thing entirely to argue that it's *morally justifiable* due to nonideal conditions. Not all the contributors are unified on this front, but this is a distinction that's not very sharply defined in the book. I wholeheartedly sympathize with shelter staff whose hands are forced in this way, but I don't think they can go home at the end of the day and say that no wrong has been done. Killing is always wrong, no matter the circumstance, and blood is undeniably on their hands. In my view, the question is how to stop or at least reduce the bloodshed — a project aimed at wiping the blood from someone's hands only to paint someone else's strikes me as misguided.

While I do not fully agree with all their solutions, I think the book does makes a particularly useful contribution to a real context where people are faced with deep ethical quandaries on a regular basis. As I've also suggested, I think the book makes some interesting contributions to academic bioethics in ways that its editors haven't even realized. I'd like to see more bioethicists weighing in on animal shelters, and I'm supportive of establishing ethical review boards so that academics and interested members of the public can help shoulder some of the burden of the tough decisions confronting animal shelter staff.

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TÉMOIGNAGE / PERSPECTIVE

Radical Suffering, Callousness, and Child Abuse: Communal Responsibilities for Suffering and Advocacy within Cultures Abuse

R. Dawn Hood-Patterson[a]

Résumé
La définition de la souffrance est difficile à cerner, en particulier lorsqu'il s'agit de la souffrance dans les cas de maltraitance d'enfants. Diviser l'humanité en catégories « auteurs » et « victimes » est trop rudimentaire. Cette dichotomie déprécie le coût humain de l'« auteur » tout en ne rendant pas compte de la complexité de la « victimisation » et de la responsabilité communautaire/collective de la souffrance des personnes abusées. Cet essai présente deux termes issus de la théologie chrétienne féministe, la « souffrance radicale » et l'« insensibilité », afin de renforcer les définitions déjà établies de la souffrance dans le contexte clinique et la littérature bioéthique. L'objectif est de : a) décrire la souffrance d'une manière qui atténue les tendances déshumanisantes et b) attirer l'attention sur la responsabilité collective des cultures de maltraitance qui favorisent la violence et la violation.

Mots-clés
abus d'enfants, souffrance radicale, souffrance, insensibilité, culture de l'abus, plaidoyer, États-Unis

Abstract
The definition of suffering is difficult to pinpoint, particularly when addressing suffering within cases of child abuse. Dividing humanity into the categories of "perpetrators" and "victims" is too rudimentary. This dichotomy depreciates the human cost of the "perpetrator" while simultaneously failing to account for the complexity of "victimization" and the communal/collective responsibility for the suffering of those abused. This essay introduces two terms from feminist Christian theology, "radical suffering" and "callousness," as a way of bolstering already-established definitions of suffering within the clinical context and bioethics literature. The aim is to: a) describe suffering in a way that mitigates dehumanizing tendencies and b) direct attention to a collective responsibility for cultures of abuse that enable violence and violation.

Keywords
child abuse, radical suffering, suffering, callousness, culture of abuse, advocacy, United States

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INTRODUCTION

She had broken bones in multiple places and the skeletal survey showed fractures old and new. Nova,[1] our patient, was in this southern United States hospital that day because she had a traumatic brain injury. The electronic medical record had a growing, concerning image tab of scans that were a portrait of hard living — reasonable, perhaps, if her life had been filled with motorcycle rides or mixed martial arts fighting. With six months under her belt, such mythic sources of trauma did not meet her lived reality.

"A fall from my arms," Nova's dad, Justin, had explained. She was intubated to help her breath, she was not sedated, her eyes had fixed pupils, she had no gag reflex, all of which were concerning indications for serious neurological injury. Ashy hues cast shadows over her once walnut skin. A report was immediately filed with Child Protective Services (CPS). Nova died ten days later when the family chose to compassionately extubate and allow for a natural death. There were increased inconsistencies in Justin's story, the details of his narrative changed with some frequency. There were several unexplained past injuries, such as old bruising patterns on Nova's face and left shoulder; some of the injuries were blamed on rough play with Nova's two-year-old brother, all of which raised concerns that Justin had inflicted the injuries. He was taken into custody shortly after Nova was pronounced dead.

For ten days, Justin remained at bedside. CPS thought it would be in Nova's best interest to have her parents at bedside for end-of-life decision-making. When I first met with Justin, to introduce myself and ethics services, Justin maintained his innocence. He expressed concern about the treatment he was receiving from the healthcare team, CPS and police. He looked at me and said, "What am I even going to tell you? You have already made up your mind about me."

When conducting ethics rounds in the unit, the bedside staff expressed heightened moral distress because CPS did not restrict Justin's visitation; only to say that he could not be alone with Nova. At the time, we were not certain that Justin had perpetrated the violence but the whispers from the staff carried the tones that Justin had already been tried and convicted. Staff expressed reservations about their obligation to include Justin in shared decision-making. They made remarks like, "It feels like Justin should have lost his decision-making privileges when he hurt Nova." Or "It seems like he should have lost his parental rights the first time he beat her."

[1] Names and identifying details have been changed in this case report.

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How do healthcare workers manage to care for patients with non-accidental traumas when we assume a perpetrator of violence sits in our workspace? How do we foster moral spaces when the legal deciders may be violent? How do we reconcile the sheer evil of child abuse with the reality that people who commit these atrocities are human, and not a lesser degree of human? Do we reconcile this in our minds by thinking that perpetrators of violence are the "bad apple," a distortion of a full humanity? How do we hold perpetrators of violence accountable without vilifying them? How do we account for reverberating bias within the ethics consultation process?

These are the questions that clinical ethicists should wrestle with as they help care teams advocate for patients. It is insufficient to tend to the moral distress or the questions about parental authority without first understanding the undergirding biases that may influence our recommendations. Our capacities to care for patients and advocate in institutional and public domains are dependent upon this inquiry. Child abuse appears to be child- or patient-specific but increased attention to social determinants of health illuminate a community-contextual component that cannot be ignored (1-2).

Justin's rhetorical question lingered in my mind, but his proposed answer is what sat with me on sleepless nights: had we already made up our minds about him? The questions from the healthcare teams, "After what he has done, can this dad make decisions that are in the best interest of his daughter?" suggest that we had pre-emptively made up our minds. Additionally, these questions also skirt past the complexity of this case; potentially reinforcing systemic bias and failing to address the systemic factors that culminated in Nova's injury, and Justin's arrest. Advocacy should start with recognizing systemic complexities, without which our starting assumptions and recommendations are incomplete.

ANALYSIS

At the core of this analysis resides a need to make sense of a) suffering and b) our human capacity to commit violence. By introducing the work on "radical suffering" and "callousness" from feminist, Christian theologian Wendy Farley (3), I will offer two definitions that will coalesce to deepen an understanding of suffering. These definitions provide theoretical underpinnings that shift the narrative away from individual suffering, encouraging ethicists to consider the impact and implication of collective suffering and responsibility within cultures of abuse.

This analysis *does not* excuse perpetrators of violence. Perpetrators of violence must be held accountable for their actions. When we dare contemplate the parameters of suffering, our capacities for compassion for Justin, and his victimization at the hands of faltering social support, fails. Understandably so. It is a balm to a collective soul when we place the responsibility for what was done to Nova on someone. When we attach responsibility to an individual they will be apprehended, tried, and incarcerated. Justice for Nova will have been served. And that is one essential aspect of justice — individual consequences for action.

I intend to flip the mirror, however, and help those of us in healthcare better evaluate our complicity and complacency in the culture of abuse that saturates these circumstances. I will argue that the responsibility for child abuse is also communal. Clinical ethicists miss something important if our ethical evaluations fail to consider the structural and systemic injustices that Justin readily pointed to when he said, "You have already made up your mind about me." He was pointing to a collective misery in which he was both perpetrator and victim. We cannot control the violence initiated by others, but we can aim our indignation and our advocacy toward the reform of systemic evils that enable that violence. As we bear witness to the suffering of Nova and the consternation of the healthcare team, we recognized that suffering is more than an accumulation of feelings or somatic responses to stimuli, it is collective (4-7).

Radical Suffering

Cases like Nova's illustrate "radical suffering," which Farley defines as a form of suffering that erodes our sense of identity, worth, and dignity. We become accomplices in each other's destruction by dehumanizing each other. Radical suffering is a category unto itself; suffering from violence, social oppression, marginalization — enacted upon us or our community. The effect debilitates or erodes access to power or resources (3). In addition, our contexts compromise our capacities for compassion (3). Without communal or familial support, Justin's compassion for a crying Nova is eroded. When we say that Justin is a "bad apple," we are eroding his innate worth as a human, potentially even cutting off access to meaningful childcare resources because we have deemed Justin "unworthy." Without attention to the fractured familial support in the United States, Justin's access to safe childcare or parental support offers him no respite. Radical suffering occurs when Justin has nowhere to turn when Nova won't stop crying. Radical suffering transpires when we view Justin as a *bad man* rather than a man who has done a bad thing.

What sets radical suffering apart from other definitions of suffering available within current medical, nursing, and clinical ethics literature is that it: a) seeks social justice determinations rather than merely punitive resolutions, b) describes how suffering impedes on our identity and capacities for compassion, and c) is enacted by individuals and institutions in ways that seem innocuous. Radical suffering is perpetuated by ordinary people swallowed up by destructive, demoralizing, and dehumanizing systems.

Radical suffering gives us language to grapple with the injustices of suffering while probing the assumptions that goodness and morality underlie the cosmic order. The very conditions and contexts of our existence dismantle our capacity to innately

act lovingly or morally. We want to believe that we are morally superior to the *Justins* of the world. It is much easier to dismiss Justin by minimizing his humanity — "othering" him. It is harder to reconcile any responsibility we may bear for a shared culture of abuse, marginalization, or oppression that enables or perpetuates non-accidental traumas. It is our responsibility as ethicists to analyze a shared role and responsibility for income inequality, housing discrimination, racism, inadequate childcare, inequitable access to mental health, familial, or medical support that leads to child abuse in the first place. This argument, however, does not hold together without also defining callousness.

Callousness

A callous on our bodies occurs when our skin rubs in one place, time and again. Our attention is not directed toward the accumulating effect of skin growth, and we may only notice the callous after it has formed. In a similar fashion, callousness, as defined by Farley, is the human propensity to ignore the accumulation of injustices and acts of violence that cause suffering (3). We rub against the deception that we are immune to the gnawing impact of violence and dehumanizing brutalities of inequality time and again. This eventuates in callousness toward each other and the systemic and social injustices that cause radical suffering.

Callousness manifests individually and communally. As Farley notes, "Callousness is not present in a community through a handful of criminals but as a characteristic of the community itself. The community mediates attitudes and values that make violence and cruelty normal" (3, p.47). Our capacities for empathy are diminished as we become more calloused. We become indifferent or apathetic toward each other and the cultures of abuse around us. Principled people, righteous and upstanding — or rudimentarily moral — instigate, ignore, or perpetuate suffering and the cultural milieu that fosters abuse. We are calloused to the undergirding factors that may have contributed to Justin's abuse of Nova.

While we express outrage over Nova's preventable death, we also have an obligation to prevent the social factors that enabled Justin's abuse such as inadequate respite for depleted parents, underfunded childcare or family programing, livable pay, and policies that make work-life balance attainable for all parents. Our advocacy for the Novas we encounter cannot end at her death, we cannot become calloused to the work ahead.

Action within Cultures of Abuse and Communal Responsibility

Taylor Tate suggested that suffering, particularly pediatric suffering, is a "social and political event" (4, p.143). Suffering unfolds within a broader social or communal paradigm. In a robust response to the suffering of children (and the ethical dilemmas and moral distress it generates) we cannot turn a blind eye to the conditions that enabled the abuse to occur in the first place. A culture of abuse is the denial of resources, the systemic oppression and marginalization of families inequitably caught within our child protective systems, and our callousness toward violence and systemic inequities (8-10).

Healthcare workers are not impotent in the face of radical suffering. The World Health Organization suggested that "people have the right to participate actively in shaping the social and health policies that affect their lives" (11, p.58). Advocating for moral spaces on the individual, institutional, or social level can help reclaim power potentially lost in the morally distressing circumstances of abuse and non-accidental traumas (11). We should first recognize the creeping callousness that may quell our advocacy. A dismissal of Justin as a "bad apple" alerts us to the insidiousness of callousness and the treacherous impact of radical suffering.

CONCLUSION

It is imperative for ethicists to analyze the social-systemic function of suffering — expanding the peripheries of an individually-situated notion of suffering. Ethicists have a responsibility to consider radical suffering and the impact of callousness for a robust assessment of the ethical questions and moral distress initiated in case consultation. Not only do these terms illuminate the social-contextual aspects of abuse but they also help to shine a collective light on a shared responsibility for cultures of abuse. Ethicists hold a responsibility to cultivate the moral spaces beyond the bedside, especially with increased evidence of the impact of social determinants of health. Understanding abuse as a systemic concern can augment advocacy efforts. Attention should shift, in part, toward institutional and societal reform. The objective of advocacy should be to reform cultures of abuse that enable callousness and radical suffering. This helps to shift the accountability for abuse away from the sole focus of individual responsibility, energizing collective efforts to rectify systemic inadequacies and broaden access to services.

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TÉMOIGNAGE / PERSPECTIVE

Navigating the Ethical Crossroads of Suicide Attempts and End-of-Life Directives

Elisheva T.A. Nemetz[a], Ryan S. Huang[a]

Résumé
Les injonctions de ne pas réanimer (NPR) visent à respecter l'autonomie du patient et à éviter des souffrances inutiles lorsque les efforts de réanimation ne sont pas susceptibles d'apporter un bénéfice significatif. Bien que leur utilisation soit bien établie dans les soins de fin de vie, leur application devient éthiquement et procéduralement complexe lorsqu'un patient ayant reçu une ordonnance de NPR tente de mourir par suicide. Cet article explore les défis qui se posent dans de tels cas, en soulignant la nécessité d'une approche nuancée qui intègre l'évaluation clinique, prend en compte le contexte temporel de l'intention suicidaire et respecte les principes fondamentaux de l'ordre de NPR.

Mots-clés
NPR, ne pas réanimer, éthique médicale, soins de fin de vie, suicide

Abstract
Do Not Resuscitate (DNR) orders are intended to respect patient autonomy and prevent unnecessary suffering when resuscitative efforts are unlikely to provide meaningful benefit. While their use is well established in end-of-life care, their application becomes ethically and procedurally complex when a patient with an existing DNR order attempts suicide. This paper explores the challenges that arise in such cases, emphasizing the need for a nuanced approach that integrates clinical assessment, considers the temporal context of suicidal intent, and upholds foundational DNR principles.

Keywords
DNR, do not resuscitate, medical ethics, end-of-life care, suicide

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INTRODUCTION

Do Not Resuscitate (DNR) orders emerged in clinical practice following the American Medical Association's 1976 recognition that cardiopulmonary resuscitation (CPR) might not benefit all patients uniformly (1,2). These directives were designed to respect patient autonomy and prevent unnecessary suffering when resuscitative measures would likely prove futile or inconsistent with the patient's acceptable quality of life (3). Despite their widespread implementation in contemporary healthcare settings, DNR orders present significant ethical complexities that challenge clinicians, particularly in non-standard clinical scenarios (4). This paper examines the ethical and procedural implications of upholding DNR orders when a patient with an existing DNR order attempts suicide, exploring whether their implementation aligns with their intended purpose and ethical justification.

MODIFIABLE NATURE OF SUICIDALITY

Suicidality is not a discrete disorder but rather a complex symptom frequently associated with conditions such as depression, which has a higher prevalence among individuals with terminal illness (5). Suicidal ideation often represents a fluctuating state that may respond to appropriate interventions (6). While complete symptom resolution is not universally achievable, evidence suggests that multifaceted approaches — including pharmacological treatment, psychological support, and enhanced palliative care — can significantly ameliorate the psychological distress that underlies suicidal behaviour (7,8). Successful resuscitation following a suicide attempt therefore presents a critical opportunity to address potentially modifiable suffering. Applying DNR directives in the context of suicide attempts may foreclose this opportunity, inadvertently conflating an individual's desire to avoid prolonged suffering from their terminal condition with an acute psychological state that may be amenable to intervention.

In contrast, DNR orders for patients with terminal illness, chronic disease, or severe frailty are based on the recognition that the underlying condition is irreversible or unrelievable and that aggressive interventions are unlikely to improve the patient's long-term prognosis or quality of life (9). While an acute depressive episode may induce profound suffering, it is often responsive to appropriate medical and psychological care, unlike the conditions for which DNR orders are traditionally intended such as a terminal illness. In emergency settings, clinicians often have limited time to assess the intent and applicability of a patient's DNR order. However, the ethical responsibility to respond to reversible suffering, particularly when the underlying cause may be modifiable, provides strong justification for overriding a DNR order in the context of a suicide attempt. Allowing DNR orders to apply in such cases risks creating a dangerous precedent, potentially normalizing their use in contexts far removed from their original intent.

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MORAL INJURY TO PRACTITIONER

The practical implementation of upholding a patient's previously established DNR orders in the case of attempted suicide has profound implications for the healthcare practitioners tasked with making these decisions. Moral injury arises when physicians are forced to act, or refrain from acting, in ways that conflict with their deeply held ethical and professional responsibilities. In the case of a suicide attempt where a previous DNR order is in place, clinicians may wrestle with the immediate and irreversible decision to either override the directive in favour of resuscitation or adhere strictly to the DNR, potentially resulting in a decision that disregards the possibility of recovery (10). This cognitive dissonance is compounded by a lack of clear institutional guidelines for navigating these ethically ambiguous scenarios, leaving practitioners vulnerable to significant emotional strain.

Emergency physicians may face heightened moral injury due to the rapid decision-making required in time-sensitive environments. Unlike other clinical settings, the emergency department offers little opportunity for deliberation, making the burden of responsibility particularly acute. Physicians must simultaneously weigh their duty to honour a patient's autonomy, their capacity to intervene in cases of transient suicidality, and the legal ramifications of their choices. The absence of standardized protocols further exacerbates this tension, forcing clinicians to rely on their own moral compass amid uncertainty.

Ultimately, emergency clinicians bear the immense weight of reconciling their responsibilities to the patient, the family, the institution, and the broader profession of medicine. This burden, in the absence of robust institutional frameworks, increases the risk of moral injury and professional burnout.

PROCEDURAL INTENT

Understanding the procedural intent behind DNR orders is essential to appreciating why their application in the context of suicide attempts presents such profound ethical dilemmas. The application of DNR orders is firmly established within specific clinical contexts, including terminal illness, physiological frailty, advanced age, and severe medical conditions where resuscitative interventions would likely extend suffering without conferring meaningful benefit (11-14). These circumstances exemplify the foundational purpose of DNR directives: to preserve patient autonomy by respecting informed decisions to decline interventions when their anticipated burdens exceed potential benefits. However, the extension of DNR orders to cases of acute suicide attempts constitutes a substantial deviation from this procedural intent.

The validity of a DNR order is contingent upon demonstrated decision-making capacity of either the patient or when the patient lacks capacity, their designated substitute decision-maker (SDM), at the time of its execution (15). These directives are designed to guide care in medically appropriate and ethically justifiable circumstances, not as a blanket refusal of life-saving interventions regardless of context. The well-established precedent for DNR orders in end-of-life care provides sufficient clarity on their intended scope, making it unnecessary to explicitly enumerate each scenario where their use would be inappropriate.

Honouring DNR orders in the context of suicide attempts poses a significant risk to the ethical framework underpinning their application. Such practices may set a problematic precedent, leading to interpretations that deviate from the original intent of these directives (16). This erosion of ethical boundaries could result in the inappropriate application of DNR orders in contexts for which they were never designed, thereby complicating clinical decision-making and undermining the integrity of end-of-life care. Upholding the procedural and ethical foundations of DNR orders is essential to preserving their credibility, ensuring they remain aligned with their intended purpose, and maintaining trust within the healthcare system.

CONCLUSION

In summary, the ethical tensions surrounding DNR orders in suicide attempts reveal a conflict between respecting patient directives and responding to reversible conditions. Our analysis demonstrates that DNR orders must be interpreted within a framework that balances procedural intent, patient autonomy, and clinical responsibility. Clinical decision-making in these cases requires consideration of multiple factors: the context in which the DNRs were established, the state of the patients, the reversibility of their conditions, and their potential for recovery. Healthcare institutions should develop explicit guidelines for these scenarios, informed by ethics committees, mental health professionals, and patient advocates. While beyond the scope of this analysis, legal implications of DNR implementation in suicide attempts warrant further exploration. Future research can provide valuable insight into how legal considerations shape clinical decision-making. Ultimately, preserving the integrity of DNR orders requires a nuanced approach that safeguards patient autonomy while preventing their misapplication in modifiable conditions. Structured frameworks will help clinicians navigate these complex cases and reduce the degree of moral injury faced by practitioners, ensuring that end-of-life directives remain aligned with their original intent and upholding the core ethical principles of medical practice that prioritize patient-centred care.

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TÉMOIGNAGE / PERSPECTIVE

Does Living Remotely Imply Tacit Approval to Diminished Health Services?

Mark Banyai[a]

Résumé
La majeure partie de la population canadienne vit dans des zones urbaines où les services, notamment l'accès rapide aux grands hôpitaux et aux soins tertiaires, sont facilement accessibles. Cependant, un segment important mais souvent négligé de la population réside dans des régions éloignées, où la vie quotidienne est sensiblement différente et où l'accès aux soins de santé pose des défis considérables. Alors que notre société progresse vers la vérité et la réconciliation avec les peuples Autochtones du Canada, il est essentiel de reconsidérer et d'aborder de manière critique le récit dominant concernant la vie dans les régions éloignées. Lors de mes échanges avec des personnes non autochtones vivant hors des réserves, beaucoup semblent considérer la vie en région éloignée comme un choix personnel, acceptant que l'accès limité aux soins de santé soit une conséquence inévitable. Cependant, je soutiens que les peuples autochtones n'ont pas eu — et n'ont toujours pas — de véritable « choix » quant à leur lieu de vie et que, par conséquent, ils ne consentent pas tacitement à une réduction des services de santé.

Mots-clés
soins de santé à distance, consentement éclairé, éthique biomédicale, vérité et réconciliation, population autochtone

Abstract
Most of the Canadian population lives in urban settings where amenities, including rapid access to major hospitals and tertiary care, are readily available. However, a significant yet often overlooked segment of the population resides in remote areas, where daily life is markedly different, and accessing healthcare poses considerable challenges. As our society progresses toward truth and reconciliation with Canada's Indigenous peoples, it is crucial to reconsider and critically address the prevailing narrative surrounding remote living. In my interactions with non-Indigenous individuals living off reserves, many appear to view remote living as a personal choice, accepting that limited access to healthcare is an unavoidable consequence. However, I argue that Indigenous peoples were not — and still are not — offered a genuine "choice" regarding where they can live and, therefore, do not tacitly consent to reduced healthcare services.

Keywords
remote healthcare, informed consent, biomedical ethics, truth and reconciliation, Indigenous population

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CURRENT PERSPECTIVES ON REMOTE LIVING

Imagine spending a week in an isolated cottage in the wilderness, far from traffic and surrounded by the quiet peace of nature. Now, imagine this is your daily reality. For some, this is life in the remote regions of Canada — whether by choice, obligation, or the circumstances of hereditary fortune. According to the 2021 Canadian census, approximately 40.6% of First Nations (1) live on reserves in isolated or semi-isolated regions across the country. While some may idealize these surroundings, the reality often sets in quickly after a few days. Picture life without a nearby grocery store, relying on hunting for subsistence, being hundreds or even thousands of kilometers from the nearest hospital, and enduring frequent power outages during long, harsh winters and insect-laden summers.

In 1876, the colonial British government introduced the Indian Act, asserting its responsibility to "civilize" the Indigenous population by imposing Eurocentric views and lifestyles. Over time, this led to the forced relocation of various nomadic peoples onto reserves, restricting their movement across ancestral territories. This displacement disrupted their self-sufficient ways, rendering them dependent on external provisions. Their culture underwent radical transformation, with ancestral practices, traditional dress, and language rapidly eroded.

Eventually, the British government imposed residential schools, delivering the final and most devastating blow to Indigenous populations. Children were forcibly taken from their families and placed in institutions where they were forbidden to speak their native languages and were indoctrinated with a strictly religious, Eurocentric education. The government pursued this policy with the stated goal of "killing the Indian in the child," a strategy that nearly succeeded. The last Indian residential school, located in Rankin Inlet, Nunavut, closed as recently as 1997 (2). Since then, there has been a slow process of reconciliation and efforts to right the wrongs of the past. However, there are limits to what can be restored —certain dialects, along with their stories and cultural heritage, have been lost forever.

With the ghettoization of certain populations came significant healthcare inequalities. According to Diabetes Canada, an estimated 17.2% of Indigenous people living on reserves now suffer from diabetes, compared with 14% of non-Indigenous people (3). Additionally, Statistics Canada reports that "the rate of suicide among First Nations people (24.3 deaths per 100,000 person-years at risk) was three times higher than the rate among non-Indigenous people (8.0 deaths per 100,000 person-

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years at risk). Among First Nations people living on reserve, the rate was about twice as high as that among those living off reserve" (4).

Many factors may contribute to these disparities, including genetics, loss of Indigenous lifestyles, diet, poor access to primary care, and inadequate mental health support (5,6). That said, throughout my career in remote locations across Canada, I have frequently encountered the argument that people living remotely "choose" to do so and are therefore subject to the consequences of their life choices. The belief persists that in Canada, individuals are free to move wherever they wish, and if their health suffers as a result of this choice, it is ultimately their responsibility.

I would like to approach this matter from a different perspective. Considering that Canada spans a vast geographical territory, it is understandable that not all health centres in remote regions can have the most up-to-date medical equipment available. But does living remotely automatically imply tacit consent to receiving decreased healthcare services? We should strive to better understand the reasons people choose to live in remote locations and explore how their health conditions can be improved while allowing them to remain where they wish to live. This discussion will examine the concept of tacit consent and its relevance to the specific conditions faced by Indigenous populations living in remote areas of Canada.

IS THERE TACIT CONSENT WHEN LIVING REMOTELY?

The notion of tacit consent, introduced by philosopher John Locke, is succinctly described in an article by Noah Busbee: "John Locke, who first put into writing the idea of tacit consent, explores the idea that obligations and duties both arise from and give rise to notions of consent. By receiving benefits from the state, one is therefore obliged to follow the laws of the state" (7). This means that individuals residing in a country or territory are subject to its laws and tacitly consent to follow them. When it comes to healthcare, a similar assumption could be made — individuals residing in isolated regions tacitly consent to having diminished or altered levels of healthcare because equipping and staffing a large hospital in every community is not feasible. At first glance, this argument seems logical. Canada is a vast country with a dispersed population, requiring universal healthcare to be provided to citizens who are few in number and widely scattered. Some regions are so remote that there are no roads — only forests or tundra stretching as far as the eye can see. Given these challenges, it might seem reasonable to conclude that providing the same level of healthcare to everyone is practically impossible. Consequently, one could argue that people living in remote areas tacitly accept the increased risks to their health. For instance, it is not feasible to have a computed tomography scanner in every village or a radiologist on standby to interpret the results. Serious illnesses, therefore, pose a significantly greater danger in remote regions than in urban centres.

I would argue that such a form of consent is only valid under certain preconditions. Although Locke himself did not make this explicit, philosopher John Simmons outlined specific conditions that must be met for tacit consent to be considered valid: "First, the person consenting must be aware that the situation calls for consent. Second, there must be a period of time when objections can be given. Third, that period of time ends. Fourth, there is ease or reasonableness for someone to object, and finally, there cannot be extremely detrimental consequences for objections. Only if all five conditions are met has one consented tacitly by remaining silent" (8).

Let us assume that most Canadians living in remote locations have de jure accepted these five points and, therefore, tacitly consented to them. However, I would like to emphasize that we are discussing most Canadians, not all Canadians — particularly not Indigenous Canadians. More specifically, because of historical inequities, it is important to remember that many Indigenous peoples were forcibly placed on reserves, fundamentally altering their way of life. Indigenous peoples were not even recognized as citizens until relatively recently in Canadian history. How could tacit consent be given when there was no meaningful dialogue between the two parties? The stronger military power — in this case, Britain — imposed laws and regulations by force.

Simmons' five points of tacit consent have clearly not been met in this context, rendering Locke's concept of tacit consent invalid. It is unreasonable to believe that any consent, tacit or otherwise, has been given in this specific case. Indigenous populations were not engaged in dialogue and have had almost no control over their territories for the past 400 years. We cannot assume that they have consented to living in isolated regions with diminished healthcare simply because they remain there. Often, they have little choice due to familial and financial constraints. While recent years have seen an opening of dialogue and efforts to improve health conditions on reserves, these steps are relatively recent and far from ideal. There remains a stark inequality in the healthcare distribution between northern and southern Canada. It would be inaccurate to claim that Indigenous peoples have consented to living under such conditions simply by staying where they are.

John Rawls, in his critique on distributive justice, offers counterarguments to the concept of tacit consent and further develops the notion of consent. Although not explicitly discussing tacit consent, Rawls' original position argues that consent from a party is only valid if its fundamental principles are agreed upon behind a veil of ignorance. This concept (9), otherwise known as the "original position", exemplifies how we should perceive consent and address the plight of those who are worst off, thereby emphasizing rights, freedoms, and equality, without sacrificing the most vulnerable. As an example, imagine taking all Canadian citizens and performing a societal "reshuffling." Now imagine these citizens have their memories erased and are tasked with redesigning their communities, political systems, and population distribution, all from a neutral standpoint. As philosopher Michael Sandel explains in his book *Justice* (10), referring to Rawls: "What principles we, as rational self-interested persons, would choose, if we found ourselves in this position?" (p.141). Rawls concludes that we would not choose

utilitarianism. After all, we would not want to be born into an impoverished family with limited opportunities for upward mobility, leaving us unable to access the education and skills needed to improve our lives — that is, perpetuating minimal utility and ongoing poverty. Likewise, we would not choose libertarianism. Such economies often result in significant disparities between the rich and poor, with limited opportunities for upward mobility or improvement. Instead, Rawls suggests that in most cases, we would opt for an egalitarian social welfare structure. This structure would ensure that even the least well-off socially or medically would have access to essential services, such as healthcare, at no cost to them.

Now, we turn our attention to the topic at hand: whether there is a form of tacit consent when living in remote communities. Over the past decade, healthcare in northern isolated communities has improved significantly with the advent of telehealth and the simplification of bureaucratic processes, making healthcare more geographically accessible than ever. While everyone would prefer to have the best possible healthcare, for a certain percentage of the population, leaving their communities is not a feasible option because of family obligations, financial constraints, social networks, and other factors. For many Canadians, the choice to leave their communities is more an illusion than a genuine possibility. If someone were given the option to move to a larger city to access better healthcare, doing so would mean leaving behind their entire identity and history. It can therefore be argued that this is not a real choice and does not reflect genuine consent to living in remote locations. Instead, this situation resembles being forced to choose between two undesirable options: accepting diminished health services or abandoning a significant part of one's identity.

We can observe that with the ongoing dialogue between governments and Indigenous communities, progress is being made toward meeting the five criteria for tacit consent outlined by Simmons. However, we are not there yet. First, Indigenous peoples living in remote areas are not fully consenting to their living conditions because they have only partial control over the management of their lands. Second, while objections to inadequate healthcare are being raised and sometimes addressed by the government and regional authorities, these efforts remain inconsistent. Third, consent to living in remote areas cannot be easily revoked because leaving comes at a great individual cost. Fourth, objections to diminished healthcare are inadequately addressed due to limited financial and human resources. Finally, those who do not consent to living in remote areas often cannot relocate because of familial, financial, or social constraints, leaving them unable to avoid the detrimental effects of their circumstances.

Given that several of these criteria remain unmet, I argue that true consent has not been given to living in remote conditions with reduced access to healthcare. Recognizing this, it becomes imperative to shift the current healthcare narrative in Canada to better address the specific needs of remote communities. By doing so, we can work toward ensuring improved healthcare access for those who are, in terms of healthcare distribution, among the worst off.

WHAT CAN WE DO DIFFERENTLY?

I have sought to establish that the criteria for tacit consent have not been met for those living remotely, particularly for Indigenous populations in Canada. Providing healthcare to remote locations is undeniably challenging, and people in these circumstances face significant healthcare discrepancies that must be addressed by medical authorities. Indigenous populations have not consented to poor living conditions, and we must strive to better understand the realities of all Canadians, not just those in urban areas. A deeper understanding of the living conditions in remote regions is essential to fostering a more thorough and informed dialogue with all Canadians. It is unethical to assume that all citizens living remotely have freedom of movement and that living in such areas is purely a "choice." Uprooting oneself carries significant social and psychological ramifications. Our focus should be on improving access to healthcare without revisiting the colonial practice of uprooting populations "for their own good." Improving healthcare access in remote regions does not necessarily mean providing a computed tomography scanner in every community. Instead, we should prioritize easy access to primary healthcare, rapid access to culturally sensitive mental health services, efficient medical evacuations when necessary, access to clean drinking water for all, and more. If we, as a society, are committed to reconciliation, we must not only recognize the regional differences and challenges faced by a large portion of our citizens living outside urban areas, but also address these issues in a timely and effective manner.

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Aucun à déclarer

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None to declare

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