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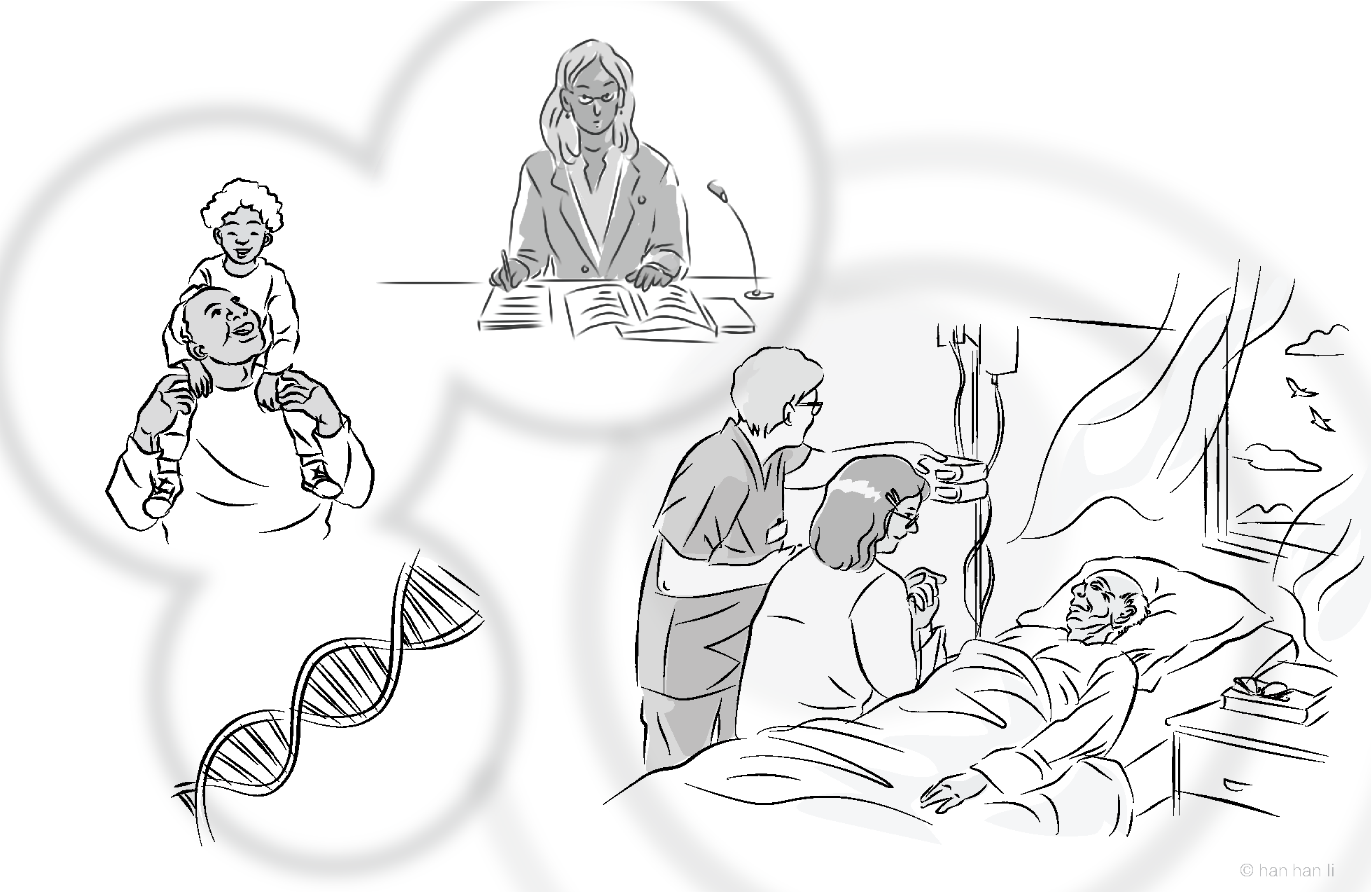

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ÉDITORIAL / EDITORIAL

Aide médicale à mourir et troubles mentaux : exploration des défis, des préoccupations et des enjeux éthiques associés

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Mots-clés
AMM, aide médicale à mourir, TM-SPMI, trouble mental seul problème médical invoqué, Québec, Canada

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MAID, medical assistance in dying, MD-SUMC, mental disorder sole underlying medical condition, Quebec, Canada

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

MISE EN CONTEXTE

Incarnant le respect de la dignité humaine et de l'autonomie décisionnelle, l'aide médicale à mourir (AMM) est un soin qui a redéfini notre vision du mourir au sein de la société québécoise puisqu'il correspond aux valeurs et aux besoins de nombreuses personnes. Jusqu'à présent, l'AMM a fait l'objet d'une acceptabilité élevée à travers la province (1-3). Or, le nombre croissant d'AMM octroyées au Québec suscite énormément d'émoi à l'heure actuelle, spécialement à l'aube de l'élargissement de ses critères d'éligibilité (4-6). À ce propos, certains évoquent les risques de dérives ou de « pente glissante » (7). En l'absence de donnée scientifique suffisante sur le sujet, il est important de ne pas céder aux scénarios catastrophes ou aux généralisations hâtives. Cependant, il est nécessaire de reconnaître que des risques objectifs et anticipables, autant au niveau clinique, social qu'éthique, doivent être réfléchis en amont.

En 2021, suivant le jugement *Truchon C. Procureur général du Canada*, le critère de « mort raisonnablement prévisible » (fédéral) et celui de « fin de vie » (provincial) ont été invalidés, rendant accessible l'AMM aux personnes qui ne sont pas en fin de vie (8). Ce changement législatif a techniquement rendu éligible l'AMM pour les personnes dont le trouble mental est le seul problème médical invoqué (AMM TM-SPMI) (9). En raison de la complexité inhérente à l'octroi d'un tel soin, le gouvernement fédéral a demandé un moratoire de deux ans, prolongé d'une année en 2022, afin de réfléchir de manière approfondie aux enjeux qui en découlent (9). Ce moratoire prendra fin le 17 mars 2024, permettant aux personnes dont le TM-SPMI d'avoir accès à l'AMM s'ils répondent à tous les autres critères d'éligibilité.

UN DÉBAT CARACTÉRISÉ PAR LA COMPLEXITÉ ET L'AMBIGUÏTÉ

Bien que l'AMM soit de mieux en mieux intégrée dans le continuum de soins palliatifs et de fin de vie, des questionnements spécifiques se posent lorsqu'il s'agit d'octroyer une AMM TM-SPMI. Afin d'identifier les principales préoccupations en matière de AMM TM-SPMI en amont de ce changement législatif, le gouvernement a mandaté un groupe d'experts afin d'analyser les enjeux qui s'y rattachent et d'émettre des recommandations (10). Quatre préoccupations majeures émergent de leur analyse: 1) l'ambiguïté quant au caractère irréversible ou incurable des troubles de santé mentale, 2) la difficulté à distinguer un risque suicidaire d'une demande d'AMM raisonnée, 3) la difficulté d'évaluer l'aptitude à consentir chez certaines personnes qui vivent avec un trouble de santé mentale et 4) la présence de vulnérabilités structurelles (10). Ces préoccupations sont d'ailleurs cohérentes avec celles identifiées dans la littérature scientifique jusqu'à présent (11-13) et seront rigoureusement approfondies par les auteurs dans le cadre de ce numéro de la revue.

L'hétérogénéité et la sensibilité de ces enjeux mettent en lumière le caractère particulièrement subjectif de l'AMM TM-SPMI et traduisent la difficulté de déterminer s'il s'agit d'un soin cliniquement, mais également éthiquement approprié pour la personne qui en fait la demande (10). Depuis l'invalidation du critère de fin de vie, une crainte partagée par plusieurs est que l'AMM puisse potentiellement être octroyée à défaut de meilleures conditions socioéconomiques, d'accessibilité à des ressources de soutien ou encore pour contrer l'isolement social (11,12). D'emblée, précisons que l'AMM est un soin octroyé pour apaiser les souffrances causées par une maladie et non pas celles générées par des conditions socioéconomiques ou psychosociales sous-optimales. À l'inverse, nous ne pouvons nier que les inégalités sociales de santé ont des impacts négatifs significatifs sur la santé des individus(14-16). Ces préoccupations étant de nature systémique, des actions gouvernementales concertées ainsi que des ressources, autant humaines que matérielles, sont nécessaires pour avoir un impact positif sur ces problèmes sociétaux et réduire les vulnérabilités qui y sont rattachées. Bien que ces enjeux ne soient pas objectivement irrémédiables ni irréversibles, ce qui contribue à la complexité éthique du débat, des changements d'une telle ampleur sont

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difficilement envisageables à court terme. En l'absence de ressource suffisante ou disponible, est-il acceptable sur le plan éthique d'octroyer l'AMM à une personne en souffrance, « en attendant » l'occurrence de tels changements sociétaux? Inversement, la mort est-elle réellement une alternative acceptable au manque de ressources ou à des conditions socioéconomiques sous-optimales?

La complexité inhérente aux demandes de l'AMM TM-SPMI est potentialisée par le fait que les experts ont des opinions divergentes concernant la conceptualisation de différents enjeux en contexte de santé mentale (17). Par exemple, jusqu'à présent, il ne semble pas y avoir de consensus à savoir s'il est possible de se doter d'une méthode fiable et valide permettant de distinguer les personnes dont le désir de mettre fin à leur vie est symptomatique d'un trouble mental, de celles dont la demande d'AMM est rationnelle, réfléchie et conforme à leurs valeurs (17). En ce sens, il est essentiel que les professionnels de la santé (PS) usent de leur jugement clinique et procèdent à une analyse au cas par cas pour répondre aux demandes d'AMM TM-SPMI (10,17).

Évidemment, c'est plus facile à dire qu'à faire! Considérant le haut niveau de subjectivité, d'ambiguïté et d'émotivité relatif à chaque demande d'AMM, la complexité de la décision à prendre est caractérisée par l'incertitude. Quoiqu'inconfortable, même douloureuse, l'incertitude demeure nécessaire. Morin affirme que la simplification de problèmes complexes, qu'il nomme la vision mutilante, « se paie cruellement dans les phénomènes humains : la mutilation tranche dans les chairs, verse le sang, répand la souffrance. » (18, p.18). En réduisant des enjeux aussi complexes que ceux générés par l'administration de l'AMM TM-SPMI au fait d'être « pour » ou « contre », une telle simplification se concrétiserait nécessairement au détriment du bien-être de la population. Selon lui, ce qui distingue l'humain de la cybernétique est sa tolérance à l'incertitude, aux contradictions, à l'imprécision, autrement dit, à sa possibilité d'explorer le contenu de « la boîte noire » (18). Ainsi, la complexité inhérente aux enjeux relatifs à l'octroi de l'AMM TM-SPMI nous permet de préserver la sensibilité nécessaire pour réfléchir à ce débat qui quoique source d'inquiétudes et d'inconforts, nous oblige à remettre en question nos a priori, mais surtout à ouvrir le dialogue.

UN SOIN INTRINSÈQUEMENT SENSIBLE ET ANCRÉ DANS UNE PERSPECTIVE D'AUTONOMIE RELATIONNELLE

L'AMM est un soin intrinsèquement sensible puisqu'il ébranle notre conception du bien et du mal, questionne le caractère sacré de la vie et notre droit comme humain d'en altérer la trajectoire normale (19). L'AMM redéfinit également les frontières de la médecine moderne. Jusqu'où peut-on aller au nom de la dignité de la personne, de son autonomie, de sa liberté de choix? À ce propos, Burnier affirme qu'il est presque impossible d'aborder des questionnements aussi fondamentaux que l'euthanasie « avec le détachement requis » (20, p.84). Nos propres valeurs et croyances influencent notre vision du monde, mais l'AMM questionne le sens que nous leur attribuons ainsi que leurs limites (20). Conséquemment, il importe de réfléchir aux enjeux qui découlent de l'AMM TM-SPMI, non pas en tentant d'être objectif, mais en faisant preuve d'une « subjectivité contrôlée » (20), notamment en accueillant l'incertitude qui ne peut être dissociée des présentes discussions (18).

L'AMM repousse les limites de l'autonomie en contexte clinique, mais réitère également son caractère fondamentalement relationnel. L'exercice de notre autonomie ainsi que le sens que nous attribuons au fait d'être autonome, est influencé par nos relations interpersonnelles, nos expériences et le contexte dans lequel nous évoluons (21,22). Une personne en fin de vie peut demander l'AMM parce qu'elle ne souhaite pas être un fardeau pour sa famille, et ce, même en l'absence de pression ou d'influence externe de la part de ses proches. Dans le même ordre d'idées, un PS pour qui l'AMM va fondamentalement à l'encontre de ses convictions pourrait accepter d'administrer ce soin qu'il reconnait être conforme aux valeurs de son patient. Être autonome, c'est la capacité de faire des choix en fonction de nos propres valeurs et de notre vision singulière du monde (19). En acceptant cette prémisse, nous acceptons également que notre vision du monde coexiste avec celle d'autrui qui peut être différente, voire diamétralement opposée de la nôtre, aussi confrontant que cela puisse être.

Toutefois, indépendamment de notre perspective quant à l'AMM TM-SPMI, il s'agit d'un soin indéniablement extraordinaire pouvant avoir des répercussions psychologiques chez les PS qui participent à son processus d'administration (23,24). Même si l'AMM découle d'une demande libre et éclairée, le sentiment d'agentivité du PS qui cause activement la mort d'une personne exacerbe la sensibilité inhérente à ce soin. Si l'AMM TM-SPMI est confrontant sur le plan clinique et éthique, elle l'est d'autant plus pour ceux qui ont la responsabilité de l'administrer. À ce propos, Kreimer (23) fait la distinction sur le plan conceptuel entre « Killing » et « Letting die ». Dans les deux cas, même si la conséquence est la même (soit la mort) et que la personne y consent de façon libre et éclairée, mettre fin activement à la vie d'une personne est généralement plus difficile psychologiquement et moralement pour le PS que de retirer l'équipement médical qui le maintient en vie (23). En participant activement, intentionnellement et directement dans un geste qui cause la mort, le PS peut se sentir coupable d'être celui qui administre le soin, même éprouver de la détresse (23). Cependant, dans ce débat éthique complexe, nous n'avons pas à choisir entre le bien-être du patient et celui du PS ni prioriser l'un au détriment de l'autre. L'AMM, spécialement pour les personnes dont le TM-SPMI, est un soin « engageant » psychologiquement pour le PS qui doit l'administrer (24), autant sur le plan professionnel que personnel. Conséquemment, les PS devraient pouvoir bénéficier de ressources de soutien appropriées et d'avoir accès à des espaces dialogiques sécuritaires pour exprimer leurs inconforts et leurs préoccupations, au même titre que les personnes qui demandent à bénéficier de ce soin.

LA SINGULARITÉ INHÉRENTE À CHAQUE DEMANDE ET L'IMPORTANCE DU DIALOGUE

Qu'on le veuille ou non, l'AMM fait désormais partie de la culture et du climat sociopolitique québécois. Les patients ont toujours demandé à mourir, mais depuis 2015, les patients demandent l'AMM. Cette demande peut être raisonnée, réfléchie et conforme aux valeurs du patient, mais peut également ne pas l'être. Il peut exister (ou non) d'autres moyens efficaces et scientifiquement éprouvés pour pallier sa souffrance. Cette demande peut (ou non) traduire un symptôme d'un trouble de santé mentale. Cette demande peut correspondre (ou non) à nos valeurs personnelles et professionnelles ou à la trajectoire de soins que l'on a souhaité ou anticipé pour cette personne. Qu'il s'agisse d'un soin approprié sur le plan clinique (ou non) pour le patient, une demande d'AMM traduit nécessairement une souffrance, un besoin, un ressenti, minimalement une préoccupation. Demander l'AMM n'équivaut pas forcément à un « désir de mort », mais on ne peut nier que ce vocable fait désormais partie intégrante de notre identité collective.

Certaines personnes demandent l'AMM, non pas parce qu'elles veulent mettre fin à leurs jours, mais parce qu'elles sont confrontées à une perte de sens et de contrôle en raison de la maladie qui les incombe (25-27). Nissim et collègues (26) ont mis de l'avant par l'entremise d'entrevues semi-dirigées que les motifs les plus fréquemment soulevés par les participants qui ont exprimé un désir d'hâter leur mort étaient associés au fait de concevoir la mort comme une « porte de sortie hypothétique » à la maladie. À ce propos, un des participants a mentionné que « *I have no desire to commit suicide, but I have no desire to take it out of my hands either.* » (26, p.168). Ainsi, la conceptualisation de la mort comme option de dernier recours, et non pas comme moyen immédiat de remédier à la situation, peut s'avérer psychologiquement apaisante pour plusieurs personnes (26). Être en mesure de conserver un certain contrôle sur leur fin de vie et d'exercer leur autonomie décisionnelle contribuerait notamment à l'acceptation de la situation (26). Rodriguez-Prat et Van Leeuwen (25) ont mis en lumière un constat similaire, soit celui que la volonté d'un patient de hâter sa mort est souvent intimement rattachée au désir de préserver son autonomie, sa dignité, mais également puisque la mort peut être une stratégie de conservation du « soi authentique », celui qui est exempt de maladie.

Bien qu'une demande d'AMM n'implique pas forcément un désir de mort, celle-ci traduit nécessairement un besoin singulier, une souffrance. Or, une attention trop importante à la finalité de l'AMM peut faire de l'ombre à la souffrance du patient, à son vécu expérientiel et, ultimement, à la manière qu'il considère optimale pour être apaisé. Précisons qu'ici l'intention n'est pas de banaliser le caractère extraordinaire de ce soin ni d'en faire la promotion. Au contraire, que l'AMM soit (ou non) un soin cliniquement ou éthiquement approprié, une telle demande illustre une souffrance proportionnelle au caractère extraordinaire du soin. Une discussion approfondie avec un PS compétent est donc absolument nécessaire afin de bien comprendre ce qui motive cette demande, d'explorer les alternatives possibles et, au final, de déterminer s'il s'agit bel et bien du soin qui répond à son besoin (28). Même si l'AMM est l'expression ultime de l'autonomie décisionnelle d'une personne, il n'en demeure pas moins qu'un soutien clinique approprié est fondamental afin que cette décision soit éclairée et conforme à ses valeurs. Une prise de décision partagée entre le PS et le patient permet une compréhension mutuelle de la souffrance de ce dernier, mais également de trouver un « terrain d'entente » en identifiant un traitement cliniquement approprié et qui répond aux besoins singuliers du patient (28).

CONCLUSION

Depuis la légalisation de l'AMM en 2015, l'élargissement de ses critères d'éligibilité suscite énormément d'intérêt, autant sur la scène médiatique qu'académique (29-31). Au courant de la prochaine année, l'AMM sera élargie aux personnes vivant avec un handicap neuromoteur grave, aux personnes qui en feront la demande par le biais d'un consentement anticipé en prévision d'une inaptitude et aux personnes dont le TM-SPMI (9,32). Même si ces changements législatifs bénéficieront à plusieurs personnes pour qui l'AMM correspond à leurs valeurs et leurs besoins en matière de fin de vie, il n'en demeure pas moins que de nombreux enjeux éthiques émergent de cet élargissement.

Une des préoccupations majeures en matière d'AMM TM-SPMI est qu'il s'agit d'un soin que l'on puisse octroyer « à défaut de » ; c.-à-d. à défaut de services en santé mentale accessibles et de qualité, à défaut d'être en mesure de départager un désir de mort raisonné d'un risque suicidaire symptomatique, à défaut d'avoir accès à des conditions socioéconomiques plus favorables. Cette préoccupation est tout à fait valide et mérite que nous l'adressions en tant que société. Nous avons collectivement légalisé l'AMM parce qu'il s'agit d'un soin qui répond aux valeurs et aux convictions de plusieurs personnes au Québec. Conséquemment, nous avons la responsabilité de nous assurer que l'AMM ne devienne pas un soin « à défaut de », notamment en favorisant l'accès à des services en santé mentale et en réduisant autant que possible les inégalités sociales de santé. Rappelons qu'au même titre que nous n'avons pas à choisir entre le bien-être du patient et celui du PS, nous n'avons pas à choisir entre fournir des soins et services en santé mentale et la légalisation de l'AMM TM-SPMI; rien ne nous empêche de faire les deux. L'AMM est un soin qui est fondamentalement caractérisé par sa sensibilité, sa complexité et l'incertitude qui y est rattachée. Bien qu'il n'existe aucun remède à l'incertitude, la réflexion critique, le dialogue ainsi que l'essor des données probantes peuvent certainement nous aider à naviguer à travers les enjeux éthiques complexes que pose l'accès à ce soin. Dans le cadre de ce numéro, les auteurs partageront avec rigueur et nuance leurs réflexions à propos des enjeux relatifs à l'AMM chez les personnes dont le TM-SPMI.

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Medical Assistance in Dying and Mental Disorders: Exploring the Challenges, Concerns and Ethical Issues Involved

BACKGROUND

Embodying respect for human dignity and decision-making autonomy, medical assistance in dying (MAID) is a form of care that has redefined our vision of dying in Quebec society, since it corresponds to the values and needs of many people. To date, MAID has been widely accepted across the province (1-3). However, the growing number of MAID granted in Quebec is raising considerable concern, especially as the eligibility criteria are being broadened (4-6). In this respect, some people have noted the risk of abuse or a “slippery slope” (7). In the absence of sufficient scientific data on the subject, it is important not to give in to doomsday scenarios or hasty generalisations. However, it is important to recognise that objective and foreseeable clinical, social and ethical risks need to be considered in advance.

In 2021, following the *Truchon C. Attorney General of Canada*, the criteria of “reasonably foreseeable death” (federal) and “end of life” (provincial) were invalidated, making MAID accessible to people who are not at the end of life (8). This legislative change rendered MAID technically available for people where a mental disorder is the sole underlying medical condition (MAID MD-SUMC) (9). Because of the inherent complexity of providing such care, the federal government requested a two-year moratorium, extended by one year in 2022, in order to reflect in depth on the issues involved (9). This moratorium will end on 17 March 2024, allowing people with MD-SUMC to have access to MAID if they meet all the other eligibility criteria.

A DEBATE CHARACTERISED BY COMPLEXITY AND AMBIGUITY

Although MAID is becoming increasingly integrated into the continuum of palliative and end-of-life care, specific questions arise when it comes to granting MAID MD-SUMC. To identify the main concerns regarding MAID MD-SUMC ahead of this legislative change, the government commissioned a group of experts to analyse the issues and make recommendations (10). Four major concerns emerged from their analysis: 1) the ambiguity surrounding the irreversible or incurable nature of mental health disorders, 2) the difficulty of distinguishing between a suicidal risk and a reasoned request for MAID, 3) the difficulty of assessing the capacity to consent of certain people living with a mental health disorder, and 4) the presence of structural vulnerabilities (10). These concerns are, moreover, consistent with those identified in the scientific literature to date (11-13) and will be rigorously explored by the authors in this issue of the journal.

The heterogeneity and sensitivity of these issues highlight the particularly subjective nature of MAID MD-SUMC and reflect the difficulty of determining whether it is clinically and ethically appropriate care for a person to request (10). Since the invalidation of the end-of-life criterion, a fear shared by many is that MAID could potentially be granted for lack of better socio-economic conditions, access to support resources or to counter social isolation (11,12). It should be made clear from the outset that MAID is care granted to alleviate the suffering caused by an illness and not that generated by sub-optimal socio-economic or psychosocial conditions. Conversely, we cannot deny that social inequalities in health have significant negative effects on individual health (14-16). As these concerns are systemic in nature, concerted government action and resources, both human and material, are needed to have a positive impact on these societal problems and reduce the associated vulnerabilities. Although these issues are not objectively irremediable or irreversible, which contributes to the ethical complexity of the debate, changes on this scale are difficult to envisage in the short term. In the absence of sufficient or available resources, is it ethically acceptable to grant MAID to a person in pain, “while waiting” for such societal changes to occur? Conversely, is death really an acceptable alternative to a lack of resources or sub-optimal socio-economic conditions?

The complexity inherent in MAID MD-SUMC requests is compounded by the fact that experts have differing opinions regarding the conceptualisation of different issues in the mental health context (17). For example, to date there does not seem to be consensus on whether it is possible to develop a reliable and valid method for distinguishing between people whose desire to end their lives is symptomatic of a mental disorder and those whose request for MAID is rational, well thought out and in line with their values (17). In this sense, it is essential that healthcare practitioners (HCPs) use their clinical judgement and carry out a case-by-case analysis when responding to requests for MAID MD-SUMC (10,17).

Obviously, this is easier said than done! Given the high level of subjectivity, ambiguity and emotion involved in each MAID request, the complexity of the decision to be made is characterised by uncertainty. Although uncomfortable, even painful, uncertainty remains necessary. Morin states that the simplification of complex problems, which he calls the mutilating vision, “pays a cruel price in human phenomena: mutilation cuts into flesh, spills blood and spreads suffering” (18, p.18; author translation). By reducing issues as complex as those generated by the administration of MAID MD-SUMC to being “for” or “against”, such a simplification would necessarily be to the detriment of the population’s well-being. In his view, what distinguishes humans from cybernetics is their tolerance of uncertainty, contradictions and imprecision – in other words, their ability to explore the contents of the “black box” (18). Thus, the inherent complexity of the issues surrounding the granting of MAID MD-SUMC enables us to preserve the sensitivity needed to reflect on this debate which, although a source of concern and discomfort, forces us to question our preconceptions, but above all, to engage in dialogue.

CARE THAT IS INTRINSICALLY SENSITIVE AND ROOTED IN A PERSPECTIVE OF RELATIONAL AUTONOMY

MAID is an intrinsically sensitive form of care because it shakes up our concept of good and evil, questions the sanctity of life and our right as humans to alter life's normal trajectory (19). MAID also redefines the boundaries of modern medicine. How far can we go in the name of human dignity, autonomy and freedom of choice? In this regard, Burnier argues that it is almost impossible to approach such fundamental issues as euthanasia "with the requisite detachment" (20, p.84; author translation). Our own values and beliefs influence our view of the world, but MAID questions the meaning we attribute to them and their limits (20). Consequently, it is important to reflect on the issues arising from MAID MD-SUMC, not by attempting to be objective, but by demonstrating a "controlled subjectivity" (20), in particular by welcoming the uncertainty that cannot be dissociated from the present discussions (18).

MAID pushes back the limits of autonomy in the clinical context, but also reiterates its fundamentally relational character. The exercise of our autonomy, and the meaning we attribute to being autonomous, is influenced by our interpersonal relationships, our experiences and the context in which we live (21,22). A person at the end of life may request MAID because they do not wish to be a burden on their family, even in the absence of external pressure or influence from those close to them. Similarly, a HCP for whom MAID goes fundamentally against their convictions may agree to administer this care if they recognise that it is in line with the patient's values. To be autonomous is to be able to make choices based on our own values and our own vision of the world (19). In accepting this premise, we also accept that as confronting as this may be, our view of the world coexists with the views of others that may be different from or even diametrically opposed to our own.

Regardless of our perspective on MAID MD-SUMC, it is undeniably extraordinary care that can have psychological repercussions for the HCPs involved in its administration (23,24). Although MAID is the result of a free and informed request, the HCP's sense of agency in actively causing a person's death exacerbates the sensitivity inherent in this care. If MAID MD-SUMC is clinically and ethically challenging, it is all the more so for those responsible for its administration. Kreimer (23) draws a conceptual distinction between "Killing" and "Letting die". In both cases, even if the consequence is the same (i.e., death) and the person consents to it in a free and informed manner, actively ending a person's life is generally more difficult psychologically and morally for the HCP than removing the medical equipment that keeps the person alive (23). By actively, intentionally and directly participating in an act that causes death, the HCP may feel guilty about being the one administering the care, and may even experience distress (23). However, in this complex ethical debate, we do not have to choose between the well-being of the patient and that of the HCP, nor prioritise one over the other. MAID, especially for people with MD-SUMC, is psychologically "engaging" care for the HCP who has to administer it (24), both professionally and personally. Consequently, HCPs should be able to benefit from appropriate support resources and have access to safe dialogical spaces in which to express their discomforts and concerns, in the same way as people requesting this care.

THE INHERENT UNIQUENESS OF EACH REQUEST AND THE IMPORTANCE OF DIALOGUE

Whether we like it or not, MAID has become part of Quebec's culture and socio-political climate. Patients have always asked to die, but since 2015, patients have been asking for MAID. This request may be reasoned, considered and in line with the patient's values, but it may also not be. There may (or may not) be other effective and scientifically proven ways of alleviating their suffering. This request may (or may not) reflect a symptom of a mental health disorder. This request may (or may not) correspond to our personal and professional values or to the care trajectory we have desired or anticipated for this person. Whether or not it is clinically appropriate care for the patient, a request for MAID necessarily reflects suffering, a need, a feeling or, at the very least, a concern. Asking for MAID is not necessarily tantamount to a "death wish", but it cannot be denied that the term has become an integral part of our collective identity.

Some people ask for MAID, not because they want to end their lives, but because they are faced with a loss of meaning and control due to their illness (25-27). Using semi-structured interviews, Nissim and colleagues (26) found that the reasons most frequently given by participants who expressed a desire to hasten their death were associated with seeing death as a "hypothetical way out" of the illness. In this regard, one participant mentioned that "I have no desire to commit suicide, but I have no desire to take it out of my hands either." (26, p.168). Thus, the conceptualisation of death as an option of last resort, and not as an immediate means of remedying the situation, can be psychologically calming for many people (26). Being able to retain a degree of control over their end of life and to exercise their decision-making autonomy would contribute in particular to acceptance of the situation (26). Rodriguez-Prat and Van Leeuwen (25) have highlighted a similar finding, namely that a patient's desire to hasten their death is often closely linked to the desire to preserve autonomy and dignity, but also because death can be a strategy for preserving the "authentic self", the one that is free of disease.

Although a request for MAID does not necessarily imply a desire to die, it does reflect a singular need, a suffering. Too much focus on the purpose of MAID can overshadow the patient's suffering, their lived experience and, ultimately, the way they feel is best for them to be appeased. The intention here is not to trivialise nor to promote the extraordinary nature of this care. On the contrary, whether MAID is (or is not) clinically or ethically appropriate, such a request illustrates suffering commensurate with the extraordinary nature of the care. An in-depth discussion with a competent HCP is therefore absolutely essential in order to fully understand what is motivating this request, to explore the possible alternatives and, ultimately, to determine whether this is indeed the care that meets the patient's need (28). Although MAID is the ultimate expression of a person's decision-making autonomy, appropriate clinical support is nonetheless essential to ensure that the decision is informed and in line with the person's values. Shared decision-making between the HCP and the patient allows for mutual understanding of the patient's suffering, but also for finding "common ground" by identifying a clinically appropriate treatment that meets the patient's individual needs (28).

CONCLUSION

Since MAID was legalised in 2015, the expansion of its eligibility criteria has attracted a great deal of interest, both in the media and academia (29-31). Over the next year, MAID will be extended to people living with a severe neuromotor disability, to people who request it through advanced directives in anticipation of incapacity, and to people with MD-SUMC (9,32). Although these legislative changes will benefit many people for whom MAID corresponds to their end-of-life values and needs, the fact remains that many ethical issues emerge from this expansion.

One of the major concerns about MAID MD-SUMC is that it is care that can be given "in the absence of"; i.e., in the absence of accessible and quality mental health services, in the absence of being able to distinguish a reasoned desire to die from a symptomatic suicidal risk, in the absence of having access to more favourable socio-economic conditions. This concern is entirely valid and deserves to be addressed by us as a society. We have collectively legalised MAID because it is a form of care that responds to the values and convictions of many people in Quebec. Consequently, we have a responsibility to ensure that MAID does not become a "default" form of care, in particular by promoting access to mental health services and reducing social inequalities in health as far as possible. Just as we do not have to choose between the well-being of the patient and that of the HCP, we do not have to choose between providing mental health care and services and legalising MAID MD-SUMC; there is nothing to stop us from doing both. MAID MD-SUMC is a form of care that is fundamentally characterised by its sensitivity, complexity and the associated uncertainties. While there is no cure for uncertainty, critical reflection, dialogue and the development of evidence can certainly help us navigate the complex ethical issues involved in accessing this care. In this journal issue, the authors share their thoughts on the concerns surrounding MAID for people with MD-SUMC.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The "Third" Eye: Ethics of Video Recording in the Context of Psychedelic-Assisted Therapy

Khaleel Rajwani[a]

Résumé

Après des cas très médiatisés d'agressions sexuelles et d'autres comportements contraires à l'éthique de la part de thérapeutes, la recherche clinique récente sur les drogues psychédéliques a généralement rendu obligatoire l'enregistrement vidéo de toutes les séances de thérapie. Dans cet article, j'examine les questions éthiques liées à l'enregistrement vidéo dans le contexte unique des séances de thérapie psychédélique. Je commence par résumer les avantages et les risques importants liés à l'enregistrement vidéo, puis ensuite les préoccupations éthiques concernant l'enregistrement obligatoire des séances de thérapie psychédélique du point de vue du patient, et je soutiens que ces préoccupations doivent être prises au sérieux par les cliniciens et chercheurs. J'examine également le point de vue selon lequel l'enregistrement vidéo est essentiel pour la sécurité des cliniciens. Acceptant la légitimité des préoccupations des deux points de vue, j'expose quelques considérations de base sur le consentement éclairé qui pourraient générer un dialogue autour des préoccupations potentielles des patients. Je défends l'option de refuser, tant pour les patients que pour les cliniciens. En conclusion, je souligne l'importance de poursuivre l'enquête bioéthique critique et la recherche qualitative concernant les pratiques d'enregistrement vidéo dans le contexte des thérapies assistées par les psychédéliques.

Mots-clés

thérapie psychédélique, bioéthique des technologies, enregistrement vidéo, MDMA, philosophie de la psychiatrie

Abstract

In light of high-profile cases of sexual assault and other unethical conduct by therapists, recent clinical research involving psychedelic drugs has generally mandated the video recording of therapy sessions. In this paper, I address a gap in the literature by investigating ethical issues related to video recording in the unique context of psychedelic therapy sessions. I begin by summarizing the important benefits and risks related to video recording. I then examine ethical concerns about mandatory recording of psychedelic therapy sessions from a patient perspective and argue that these concerns must be taken seriously by clinicians and researchers. I also examine the view that video recording is essential for clinician safety. Given the legitimacy of concerns from both perspectives, I outline some basic informed consent considerations that could generate dialogue around potential patient concerns and defend the option to opt-out for both patients and clinicians. In conclusion, I underscore the importance of further critical bioethical inquiry and qualitative research regarding video recording practices in the context of psychedelic-assisted therapies.

Keywords

psychedelic therapy, bioethics of technology, video recording, MDMA, philosophy of psychiatry

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INTRODUCTION

In 2015, Meghan Buisson was among the first participants in a phase two clinical trial of MDMA-assisted therapy for treatment-resistant post-traumatic stress disorder. In early 2018, Buisson filed an ethics complaint with the primary sponsor of the trial, the Multidisciplinary Association for Psychedelic Studies (MAPS), attesting to sexual assault by her therapist both during therapy sessions and after active treatment. Later that year, Buisson filed a civil court claim in British Columbia alleging that the therapist "committed sexual assaults constituting battery while she was enrolled in the study and under his therapeutic treatment. She also accused him of negligence and breach of contract, for failing to provide appropriate therapy and maintain a professional relationship." (1) The ethical review of Buisson's case included reviewing available video recordings of sessions, which revealed disturbing therapist conduct and malpractice during therapy sessions. The review added credibility to Buisson's allegations that there was an unprofessional and intimate relationship, and her account of having endured sexual violence over a two-year period beginning at the time of her treatment. Later, some of these video recordings were consensually shared by Buisson with journalists, and eventually published (2). These videos played an important role in uncovering the ethical violations, which ultimately resulted in both of her therapists being barred from participation in future clinical trials. The case also resulted in changes to MAPS safety and ethics policies, and institutional review of clinical trials by regulatory bodies (2).

Buisson's case was not an isolated incident; there have been many reports of abuse in psychedelic therapy contexts (1). In light of this high-profile case of sexual assault and other disturbing therapist misconduct, practitioners and researchers in the field of psychedelic-assisted therapy have been doubly concerned with ensuring patient safety, therapist accountability, and institutional integrity. Today, clinical research involving psychedelic drugs often mandates the video recording of psychedelic therapy sessions, with some exceptions. Such recordings generate tangible documentation and can solidify accountability in cases of malpractice, abuse of power, negligence, sexual assault, and other unethical or violent behaviours on the part of either therapists or patients. In addition to safety and accountability considerations, video recordings can have many important benefits for therapist and patient reflection, professional and situational training, and standard of care improvement. Video

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recordings can also be useful as part of novel qualitative and quantitative research in the emerging field of psychedelic-assisted psychotherapy, including studies involving natural language analysis and artificial intelligence.

However, as in other areas of medical and mental health practice, video recording technology and medical data collection pose significant ethical concerns related to privacy, informed consent and data security. Psychotherapy involves highly sensitive and confidential interactions. As Funkenstein et al. note, videotaping in psychotherapy can have unpredictable consequences, and “fundamentally alter the dynamic between patient and therapist, as well as the tenor of their work.” (3) The capture and storage of video recordings, even if relatively secure, can reduce patient trust in therapist-patient confidentiality and hinder open communication; patients may feel “censored, self-conscious, exploited, or unsafe in front of the camera.” (3). In the novel context of psychedelic-assisted therapies, video recording entails additional ethical concerns stemming from the unique nature of psychedelic drugs, experiences and spaces.

In what follows, I address a gap in the literature by investigating ethical issues related to video recording in the unique context of psychedelic therapy sessions. I begin by summarizing the important benefits and risks related to video recording in the context of psychedelic therapy sessions. I then examine ethical concerns about mandatory video recording, from a patient perspective, and argue that these concerns must be taken seriously by clinicians. I also examine the view that video recording is essential for clinician safety. Given the legitimacy of concerns from both perspectives, I outline some basic guiding questions for informed consent practices that could generate dialogue around potential patient concerns. I also defend the option to opt-out, for both patients and clinicians. In conclusion, I underscore the importance of further critical bioethical inquiry and qualitative research regarding video recording practices in the context of psychedelic-assisted therapies.

BENEFITS OF VIDEO RECORDING IN PSYCHEDELIC-ASSISTED THERAPY

Video recording has substantial and ethically important benefits for psychotherapy generally, some of which are even more significant in the context of psychedelic-assisted therapy. Below, I summarize some of the most important benefits of video recording in psychedelic-assisted therapy.

Ethical and Legal Accountability

Due to the radical effects of psychedelic drugs on mood, perception, empathy and openness to experience, among other effects, psychedelic-assisted therapy entails a unique degree of vulnerability and greater potential for therapist abuse (4). Psychedelic-assisted therapy further poses unique and ethically significant challenges related to boundary-setting, touch, and transference, among other relational ethical challenges (4,5).

As demonstrated by the case of Meghan Buisson and others, video recordings can bolster accountability in cases of abuse and unethical conduct by therapists. Although most of the therapist’s ethical transgressions and sexual assault in the Buisson case were not recorded, some of the behaviour seen on video added credibility to Buisson’s allegations of therapist misconduct. In cases of accusations of malpractice or unethical behaviour, recordings provide concrete, tangible evidence for ethical and legal review processes. Further, patients under the influence of psychedelic drugs may have their testimonial credibility doubted based on conventional legal standards related to presence of mind and drug-related intoxication. Thus, video recordings can provide a layer of protection for vulnerable patients, as well as protect therapists against false allegations of abuse or misconduct from patients. In the worst scenarios, videos could be used as evidence in the prosecution of assault committed by either patients or therapists, in situations where a court deems that confidential and protected medical recordings should be disclosed. Overall, the presence of video recordings provides an important layer of protection for ethical oversight and legal accountability in the context of psychedelic-assisted therapy.

Safety and Security

While video recordings may have benefits for ethical oversight *post facto*, the presence of cameras may also help deter reckless, inappropriate or violent of behaviour of patients and therapists in sessions, due to their awareness of camera observation and recording. This is particularly important in cases of trauma “transference” and possible aggressive or violent episodes, which could occur during sessions. It is important to note, however, that knowledge of video recording will not necessarily prevent unethical actions; in Buisson’s case for example, the therapists were well aware of the fact that sessions were recorded on video, but this did not stop their unethical conduct.

Therapeutic Documentation and Patient Reflection

Due to cognitive limitations, bias, and clinical stressors, practitioner memory and recall can be sparse or flawed (6). Video and audio recording technology collects rich data outside of written notes and charts, even in chaotic and complex clinical situations. Video recordings allow clinicians to revisit sessions with incomplete notes, reduce recall bias, assess therapeutic considerations and outcomes, and further develop patient-specific healing strategies (6). This can be particularly helpful for therapists participating in lengthy psychedelic-assisted therapy sessions, while also maintaining many complex patient relationships. Video recordings can thus improve quality of care and attention to detail in clinical settings.

Where consensual and therapeutically appropriate, patients too could observe, revisit and reflect on previous therapy episodes through video recordings. Revisiting specific experiences could allow patients to understand the experience from an observer perspective, different than their first-person memory of the session. For example, among other possible benefits, videos may allow patients to better understand the effects of psychedelic drugs on them, to revisit and engage with positive and negative episodes from their drug experiences, and to recall experiences that may be forgotten or remembered differently due to the radical effects of psychedelic drugs on memory and perception. Falzone et al. discuss several examples where sharing video recordings with patients participating in conventional psychotherapy increased insight; videos can allow patients to view their words, behaviours, experiences and nonverbal reactions through a clarifying lens, whereas merely relying on therapists' observations could be perceived by the patient as judgmental or distorted (3,7). Conversely, revisiting sessions through video recordings also creates the risk of reliving difficult or traumatic experiences (8).

Therapist Training and Clinical Supervision

Video recording has many benefits for training new therapists. Psychotherapy – and psychedelic-assisted psychotherapy in particular – is a difficult modality to teach, learn and practice; several residency programs now employ video as an important part of modern pedagogy and trainee supervision (3).Video recording allows students to participate in clinical observation, with many advantages over in-person observation. For one, adding an inexperienced student into in-person therapeutic settings can affect patient comfort and alter therapeutic dynamics. This is particularly true in the case of psychedelic-assisted therapy where the practical demands of therapists and healers are complex, the therapeutic alliance is critical, and patients taking psychedelic drugs may experience an amplification of existing trauma, social anxiety, or paranoia around having additional people in a healing space. Furthermore, the geographic and temporal flexibility of observing video recordings, rather than in-person sessions, increases student access to training and helps speed up the common tripartite educational model of "see one, do one, teach one." This may have important spillover benefits for patient access, particularly in underserviced, underfunded, or remote areas where psychedelic therapists are inaccessible, and educational and institutional resources do not exist to allow for consistent in-person observation by trainees.

The use of video recordings can also help teams of practitioners supervise, standardize and improve quality of care by providing opportunities for learning from past clinical situations, understanding errors, and improving therapeutic skills over time. For example, clinical supervision in the MAPS open-label phase 2 trial of MDMA-assisted therapy for PTSD involved "evaluating video-recorded therapy sessions according to specific criteria, assessing how closely co-therapy pairs adhere to the *Treatment Manual* and study protocol." (8) In addition to learning from clinical mistakes and improving situational awareness, video recordings can be used to spark dialogue between clinical practitioners, therapist educators and clinical ethicists about real-time decision-making in difficult and complex situations that arise in psychedelic-assisted therapy.

Video can have significant benefits over traditional pedagogical and reflective tools like written accounts and case studies; uncensored recording data can help to bypass subjective biases, omissions and distortions from memory or notes (3). However, it is important to recognize that there are significant differences between watching videos and observing in-person sessions, where the stakes and real-time challenges are different and may be more pressing. Video observation cannot replace in-person observation and training.

RISKS OF VIDEO RECORDING IN PSYCHEDELIC-ASSISTED THERAPY

Video recording presents well-established risks in psychotherapeutic settings, some of which are potentially even more significant or serious in the context of psychedelic-assisted therapy. Below, I summarize some of the most significant risks.

Breach of Privacy & Data Insecurity

Privacy matters deeply, especially in medical and mental health contexts. Patients must be assured that any information, experiences and emotions they share within the therapeutic space will be kept confidential and secure. In the case of patients experiencing the effects of psychedelic drugs, their sense of vulnerability may be particularly acute. During these experiences, patients may experience radical changes in their experience of reality, changes in their behaviour, and have a perceived loss of control over their thoughts and actions.

Video recordings capture intimate details about therapy sessions and drug experiences at a far higher level of detail and precision than is possible with written notes or audio recordings. Video generally captures all verbal communications, behaviours, specific visual details about faces and body language, physical movement and positioning, as well as metadata such as the exact time and GPS location of therapy sessions. Even with strict data security protocols for medical records, data insecurity is a real risk, whether it occurs through human error, abuse of power, technological malfunction, or hacking.

If video recordings of therapy are misused, shared without consent or leaked for any reason, the negative consequences could be significant or even disastrous for the patient (3). The intimate details about sessions and metadata could potentially be used to actively identify, stalk or otherwise harm patients. In a 2014 case, a data breach at New York Presbyterian Hospital and Columbia University resulted in the wide exposure of protected health information of over 6800 patients, including medication-related records, which became publicly searchable on Google and other internet search engines (9). The widespread stigma around drug use, and psychedelic and hallucinogenic drug use in particular, means that video records generate even greater risks of targeted humiliation, shame, stigma, ostracization from families and communities, and (cyber)bullying. Further, the risk is not only true for third parties illicitly accessing or hacking records, but also for medical practitioners, employees, and healthcare institutions who have may have legitimate internal access to a patient's medical records. For example, in a case in 2008, 13 UCLA medical centre employees were fired and 6 physicians faced disciplinary action after internally accessing the confidential medical records of celebrity singer Britney Spears, regarding her hospitalization in the psychiatric unit (10).

Through search engines and social media channels like YouTube, TikTok, and Reddit, among others, leaked video recordings can spread quickly via user reposting and memetic replication, and be preserved indefinitely via data caching. In just a short period of data leakage, the chance of being able to quickly remove all videos from the internet can be low, even in jurisdictions with strong data protection laws. The existence of these videos on the internet could have significant consequences for patients. Videos could harm future educational and employment prospects, prevent access to government services, and could lead to legal persecution, particularly in conservative jurisdictions where law enforcement continues to violently persecute racialized people and marginalized drug users, even if the drugs are decriminalized or medically approved. Furthermore, for patients with diverse domestic and global citizenship statuses, public evidence of drug use of any kind could lead to deportation, loss of documented status, political persecution, or imprisonment.

Changing Therapeutic Dynamics

Studies have demonstrated the complex ways that the presence of cameras influence therapeutic dynamics (6,11-13). Patients may legitimately feel that recording makes therapist-patient confidentiality less secure and robust, and this can hinder open, honest and comfortable communication in front of cameras (3). For example, patients may be less likely to share intimate details about themselves or others, talk specifically about particular individuals, discuss illegal activities such as recreational drug use or other crimes, or discuss other sensitive topics while being recorded. Hesitancy to share any details that may be relevant for therapy and healing can ultimately alter and change the therapeutic dynamic, hinder positive psychedelic experiences and thus negatively affect therapeutic outcomes.

Intensification of Adverse Drug Effects

Psychedelics generate unique neurophenomenological dynamics that emerge from the diverse and intense effects of psychedelic substances on mood, cognition, sense-perception and memory. Common adverse effects of psychedelic drugs include fear, anxiety, dysphoria and/or paranoia (14). Emotional experiences may be amplified or intensified while using psychedelic drugs (14). One study found that higher levels of pre-treatment paranoia and interpersonal sensitivity were associated with great patient discomfort with audio and video recording of psychotherapy sessions (13). Further, paranoid thinking is a common feature of psychedelic mental states, and is highly sensitive to changes in the environment and context in which the psychedelic experience takes place (15). Thus, situated awareness of a camera could exacerbate patient discomfort and shape the therapeutic context in ways that alter psychedelic effects related to paranoid thinking.

Set, Setting and Sanctity of Psychedelic Healing Spaces

Although shamans and Indigenous psychedelic healers have held this wisdom for generations, there is growing understanding and consensus among Western academic researchers that extra-pharmacological features, namely mindset (set) and setting, play a critical role in shaping psychedelic phenomenology and healing processes (16). As Noorani notes, not only do cameras and recording equipment constitute a meaningful part of the set and setting of clinical psychedelic-assisted therapy, but they imbue the psychedelic space with particular normative symbolism and aesthetic characteristics.

> Suspended between the death of the body and the proverbial 'death of the ego', these living room-like settings are also closely monitored. A CCTV camera is hidden in plain sight, both recording a picture of 'everything' that happens in the room, while itself exceeding the container in its promise of data in the event that they are needed. The aesthetics of the camera, other monitoring equipment and the suspended ceilings characteristic of office buildings throw the eclectic curation of the space into relief: they reveal the nestedness of the session room within a broader scientific-bureaucratic container, shaping participants' own experiences through symbols of safety, accountability and rigor. (17)

Noorani's analysis of recording technology within the set and setting of psychedelic psychiatry complements the conceptual notion of placebo response in other biomedical research; both point to the concrete effects of non-pharmacological factors on the experiences and outcomes of drug interventions (16,17). This notion is further underscored by the fact that many historical and contemporary psychedelic practices construct spaces free from digital technology that focalize natural and organic surroundings, and promote spirituality, meditation, mindfulness as well as religious and artistic practices as part of the therapeutic process (16,18,19). Cameras could be distracting or disrupting to these important psychedelic healing techniques in both intangible and measurable ways. Further, psychedelic substances have been used as a central component of spiritual and religious practices since the beginning of recorded human history. Within many cultures, psychedelic substances and healing spaces are considered sacred and spiritually endowed (18). Thus, the disruptive effects of recording technology on psychedelic set and setting may be further amplified for patients from Indigenous communities and other cultural communities that maintain these rich historical and spiritual relationships with psychedelic medicines and practices.

ETHICAL CONCERNS WITH MANDATORY VIDEO RECORDING: PATIENT PERSPECTIVES

Given the substantive benefits and risks, is it ethically justified to mandate video recording of all psychedelic-assisted therapy sessions? First, let us consider whether the benefits always outweigh the risks, from a patient-centred perspective. Given the cases of patients like Buisson who have experienced sexual assault and unethical conduct by psychedelic therapists, video recordings can clearly provide greater accountability and oversight, and in some cases may improve patient safety by deterring therapists from acting in unethical and harmful ways. Patients can benefit from quality improvement and care standardization practices that draw on video recordings as tools. Furthermore, patients who have never experienced psychedelic drugs (generally or in the specific form being used) may be unaware of how inebriated and vulnerable they could be during an experience, even if they are meticulously informed beforehand. Thus, advocates of mandatory video recording may argue that we ought to weigh professional knowledge of risks and the history of problem cases (e.g., sexual abuse) above other legitimate patient concerns about video recording. According to this view, a certain degree of paternalism around mandatory video recording is justified, insofar as it reflects asymmetric knowledge and understanding about the realities of psychedelic-assisted therapy.

In response, however, I argue that it is impossible to conclude from the outset that these benefits outweigh the risks for a patient. Psychedelic substances affect everyone differently, and psychedelic experiences are extremely context- and culture-sensitive (20). Further, patients have diverse values and needs in relation to psychedelic therapies. Some patients may find the risks of video recording to be extremely worrisome, daunting or ethically problematic because of their positionality, marginalized identities, individual symptomology, past traumas, past experiences with psychedelic drugs, past experiences with breaches of privacy, cultural background, and spiritual or religious beliefs, among other reasons. Even if patients are appropriately informed about the risks of declining video recording, such as having less potential evidence for formal complaints or grievances, they still may legitimately feel that the risks of video recording are too high.

In addition, the purported safety benefits of video recording are not assured. For example, in the Buisson case, recordings were not a deterrent for unethical behaviour, and this suggests that there needs to be more compelling reasons for their use in the context of patient-centred care. There is significant therapist misconduct and harm that can occur long before or after video recording takes place. And, even when video technology is active during problematic occurrences, recordings can be actively manipulated by offenders or randomly fail, as technology sometimes does. Patients reporting unethical clinician behaviour in any kind of therapeutic context must be taken seriously, regardless of whether the behaviour is caught on camera. Video recording technology cannot replace robust institutional processes and ethical safeguards against unethical, abusive, or violent therapists harming patients – it is merely one piece within a holistic ethical review process.

The vast majority of conventional (non-drug assisted) psychotherapy sessions are not video recorded, despite many historical cases of unethical conduct and abuse, particularly inappropriate sexual involvement by therapists (21). Although such actions do not occur in the majority of therapeutic interactions, and the unethical conduct may not always happen during therapy sessions (as in Buisson's case), patients can be harmed. Yet, given these practical risks, it is still justifiable for patients to consent to conventional therapies without mandatory video recording, given other longstanding institutional safeguards and structures of accountability and ethical oversight in psychotherapeutic disciplines. The influence of psychedelic drugs does, however, substantively change the patient's state of consciousness and increase their vulnerability to harm by their healers, guides, or therapists (22). But the ethical calculus is affected both ways: the involvement of psychedelic drugs also changes the circumstances in ways that amplifies the perceived stakes and increases risks of video recording these psychedelic-assisted therapy sessions.

One study showed that although most patients are willing to consider audio or video recording of psychotherapy sessions, patients had different comfort levels with the practice, and many expressed genuine concerns (13). Patients deserve access to spaces that make them feel safe enough and comfortable to fully participate in the psychedelic-assisted therapeutic practice. Clinicians must take patient concerns about video recording seriously; they should air on the side of giving individual patients agency to make ethical determinations for themselves, as part of an "enhanced" informed consent in psychedelic contexts (23). It is always coercive to some degree to elicit informed consent without any real possibility of opting-out. At present, there are often a lack of alternatives to video recorded therapy sessions, and declining to consent may outright exclude patients from accessing the therapy. It is reasonable for certain patients, who stand to benefit greatly from psychedelic-assisted therapies, to withhold consent to video recording. As such, video recording practices should not be unilaterally imposed.

Even where it is possible to opt out of consenting to video recording, we must also consider other forms of coercive pressure, particularly implicit or explicit *quid pro quo* exchanges. There is coercive power inherent in the clinician-patient relationship, which deeply affects all procedures of informed consent related to video recording in psychotherapy (3). Because a patient is in a position of relatively less power, and they are being helped by the clinicians or the medical institution offering the psychedelic therapy, the patient may feel that they owe something to their caregivers. Early-stage psychedelic-assisted therapies in today's social and legal context are difficult to access and often constitute a relatively exclusive privilege, particularly given the deeply inequitable representation of patients along geographic, socio-economic and racial categories (24). Because a patient has been admitted into a highly selective or relatively inaccessible psychedelic-assisted therapy program, they could feel as though they owe it to their clinicians or institution to consent to sharing their medical data and video recordings for broad purposes, without fully considering the extent to which their records could be used. This coercive pressure also extends to the practice of asking for interviews or video testimonials after the therapy, which are often used for fundraising purposes at non-profit psychedelic therapy centers, mental health institutes, and psychedelic science associations.

In an ideal world, people would have access to psychedelic substances through varied therapeutic modalities and healing frameworks that are best suited to them. But due to drug criminalization and mass incarceration, restrictive medicalization of psychedelics, and ongoing cultural genocide against Indigenous and non-Western healing practices, there are, in practice, no other legal alternatives to accessing psychedelics for people who may benefit from them as part of their holistic healing process. This is slowly beginning to change in certain jurisdictions; for example, in the US, the passing of Oregon ballot initiative 109 in 2020 opened the door to legitimate manufacture, delivery and administration of psilocybin in the state. However, while access to psychedelic healing remains limited and inequitable, we must still recognize reasonable patient concerns about video recording.

ETHICAL CONCERNS WITH MANDATORY VIDEO RECORDING: CLINICIAN PERSPECTIVES

Let us now address the importance of video recording from the clinician's perspective. Video recording may help protect practitioners in cases of unfounded allegations and may also help deter dangerous or harmful behaviours by patients. This is particularly important due to the fact that patients under the influence of psychedelic drugs may experience radical alternations to their memory of therapeutic situations, and their perception of actions and intentions. In exceptional situations, aggression, violence, or self-harm are possible. Because of these factors, video recording could reasonably be perceived to improve clinician safety in the therapeutic setting.

However, video recording is not essential for therapist safety: there are several features of psychedelic-assisted therapy that already heavily prioritize therapist safety and shape the dynamic of power between therapists and patients. For one, therapists are trained professionals, and unlike patients, they are not under the influence of psychedelic drugs in the therapeutic space. Thus, they should be expected to have knowledge and understanding about navigating dynamics of transference and reacting to situations as they arise in ways that are based on their training and past professional experience. Second, therapists may have immediate safeguards that can be exercised over patients in crisis situations, such as being able to leave the space, access panic buttons or other communication technology, have on-call security aid, and in the worst case, they may even be able to deploy isolation tools or physical restraints. Lastly, therapists maintain moral and institutional authority as credible professionals and healers, resulting in a significant power differential within the therapist-patient relationship. This does not mean that therapists are completely shielded from potential harm inflicted by patients; for example, false accusations of wrongdoing can quickly jeopardize their standing with professional boards. However, while it may be justified for therapists to desire the additional safeguard of video recordings, the prioritization of their safety is already well-established within particular features of the clinical setting and the power differential of the therapeutic relationship.

Furthermore, as in the case of patient safety, video recordings should only be one part of a robust institutional structure of safeguards and accountability – video recording technology can fail or be actively manipulated by abusers, and unrecorded therapeutic sessions occur every day in psychotherapeutic disciplines that require processes for addressing safety, accountability and oversight without video data. In all these scenarios, therapists should still feel safe, comfortable and confident to offer professional care, regardless of whether a session is video recorded. While it may be justified for therapists to opt out of sessions that do not involve video recording if they feel genuinely unsafe, they must also be rigorously attuned to centring patient values and comfort within psychedelic therapy spaces, including taking seriously the patient's feelings and views around video recording technology. Without an intense focus on creating a safe set and setting that is attuned to power imbalances and the patient's individual needs and background, therapists risk delivering ineffective therapy and amplifying harmful dynamics with vulnerable patients under the influence of psychedelic drugs.

IMPROVING INFORMED CONSENT PRACTICES AROUND VIDEO RECORDING

There is a clear ethical imperative for clinicians to recognize the legitimacy of patient concerns around video recording during the informed consent process. Patients deserve to have distinct informed consent processes for different possible uses of video recordings. In particular, it is important to distinguish between video recording for treatment purposes and educational or research purposes. The latter largely benefit therapists and institutions over patients and pose a fundamentally different ethical calculus (3). Separating these use cases allows for deeper dialogue and ethical analysis about specific benefits and trade-offs for patients, therapists and institutions. For example, clinicians and ethicists tasked with developing and discussing informed consent should consider:

1. What are the benefits of video recording? How would recordings be used to improve safety, ethical accountability, quality of care, etc.?
2. What are the risks of video recording? What could happen in case of data breach? How can the presence of cameras change or intensify drug effects, change therapeutic dynamics, or alter set and setting?
3. After the therapy session, who will have access to the video recordings? How and for how long will data be stored? What are the patient's rights related to privacy, confidentiality, data storage and data deletion?

4. In what scenarios will videos be reviewed, and by whom? (e.g., standardization and improving quality of care, cases of grievances for malpractice or sexual assault, etc.) What happens if video technology fails or data becomes incomplete or lost? If the videos are deemed problematic by the supervisor(s) or reviewer(s), what is the process for clinical, ethical, or legal escalation (where applicable and consented to)?
5. How will video recordings be incorporated within medical records and charts? Will clinicians outside of those involved in direct psychiatric or mental healthcare have access?
6. Does the patient additionally consent to use of the recordings for training and educational purposes? How will video recordings be used in training? Within what time frame? What kinds of identifying information from recordings will be available to trainees and teachers? What are the patient's rights around retroactive withdrawal of consent for training purposes?
7. Does the patient wish to be considered as part of future research involving data from their video recordings? What kind of data would be shared with other researchers? How will the patient be contacted regarding additional informed consent for each new study?
8. What alternatives are available? What accountability procedures are in place if a patient does not wish to have their sessions video recorded? What are the potential consequences of opting out?

Detailed and accessible information addressing these, and other ethically relevant topics, is critical for a robust consent process around video recording in psychedelic-assisted therapy. Throughout an ethical informed consent process, therapists must take into account the inherent power associated with their role and maintain a high degree of caution related to video recording. When implemented in a thoughtful and ethical way that respects patient comfort and autonomy, the informed consent process can actually increase a patient's willing investment in treatment (3).

However, while this process can help therapy participants better understand how and why video recordings are being used, a more rigorous informed consent process does not solve all ethical issues, particularly if there is no possibility of opting out and/or no viable alternatives. Patients who are uncomfortable with video recording, and clinicians who are uncomfortable without it, must have the real choice to opt out. Opting out should not change the ability of the patient to access a safe and effective psychedelic-assisted therapeutic intervention. Even when the patient does consent to video recording and/or the use of recorded data in research, it should not be assumed that they will consent in perpetuity, particularly without specific knowledge of how data sets could be shared between clinicians or researchers in the future. Nuance and specificity are essential for obtaining ethical informed consent pertaining to the use of video recordings for different purposes and in different contexts.

Institutions that take on the enormous responsibility of guiding psychedelic therapy should never coerce patients or clinicians into consenting to practices that do not make them feel safe or comfortable. Presently, patients without a legitimate option to decline video recording may unjustly lose access to psychedelic-assisted interventions that stand to improve their psychiatric symptoms, holistic mental health and quality of life.

CONCLUSION

The ethical stakes associated with recording in any psychotherapy context are already very high (3,7). The goal of this paper was to develop a more robust overview of the unique ethical issues that arise when psychedelics are involved within the therapeutic context. The widely accepted practice of video recording in psychedelic-assisted therapy is clearly worthy of deeper ethical inspection. I maintain that patient hesitancy around consenting to video recording in psychedelic spaces is justified, and must be taken seriously by clinicians, researchers and ethicists. I raised some essential considerations for informed consent pertaining to different uses of video recordings and emphasized that patients and clinicians should have the real option to opt-out. I also proposed that safety and accountability measures must go beyond video recording.

Further bioethical inquiry is warranted, drawing on both critical and empirical methodologies. There is a significant gap in the empirical literature investigating practical patient and clinician concerns and experiences with video recording in psychedelic spaces. There is also a significant gap in the theoretical literature interrogating the ways that the presence of video recording and other technologies affect psychedelic set and setting in subtle and profound ways, and the ways that technological practices in psychedelic-assisted therapy reflect particular bioethical, psychotherapeutic and psychiatric norms and power relations. It is important that the bioethics literature related to specific technological practices in psychedelic-assisted therapy develops swiftly alongside the rapid proliferation of research and clinical practice.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Ethical Issues Arising in Humanitarian Work and Possible Responses to Them: Results from a Critical Literature Review

Louis Pierre Côté[a], Marie-Josée Drolet[b]

Résumé

Bien que le travail humanitaire soit lié à des questions éthiques parfois préoccupantes, aucune revue de la littérature n'a jusqu'à présent décrit ces questions et les réponses possibles. Suivant la méthode proposée par McCullough, Coverdale et Chervenak, une revue critique de la littérature a été réalisée afin de combler cette lacune dans la littérature existante. 83 articles ont été sélectionnés pour être analysés et 25 unités de sens ont émergé, qui ont été regroupées en trois grandes catégories de questions éthiques : 1) expériences éthiques subjectives, 2) problèmes éthiques pratiques et 3) politique et pouvoir. En termes de réponses possibles à ces questions, six articles proposent des réponses de nature préventive ou réparatrice. Au final, bien que le corpus de textes étudiés soit dominé par les expériences souvent riches, parfois anecdotiques, des acteurs de terrain du travail humanitaire, peu de recherches empiriques ont été menées à ce jour pour identifier les enjeux éthiques liés à cette pratique et les réponses possibles à ces enjeux. De même, aucune des réponses proposées n'a été testée empiriquement afin d'en déterminer la pertinence et l'efficacité.

Mots-clés

travail humanitaire, éthique humanitaire, expériences éthiques, problèmes éthiques, politique et pouvoir, revue de la littérature

Abstract

Although humanitarian work is linked to ethical issues that are sometimes of concern, no review of the literature to date has described these issues and their possible responses. Following the method proposed by McCullough, Coverdale and Chervenak, a critical review of the literature was conducted to fill this gap in the existing literature. 83 articles were selected for analysis and a total of 25 units of meaning emerged, which were grouped into three broad categories of ethical issues: 1) subjective ethical experiences, 2) practical ethical problems, and 3) politics and power. In terms of possible responses to these issues, six articles propose responses that are either preventative or restorative in nature. In the end, although the corpus of texts studied is dominated by the often rich, sometimes anecdotal experiential experiences of field actors in humanitarian work, little empirical research has been conducted to date to identify the ethical issues related to this practice and the possible responses to them. Also, none of the proposed responses have been empirically tested to determine their relevance and effectiveness.

Keywords

humanitarian work, humanitarian ethics, ethical experiences, ethical problems, politics and power, literature review

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INTRODUCTION

The overarching aim of humanitarian work to provide assistance and protection to affected people does not shield it from ethical issues. In this article, following Swisher et al. (1), we contend that ethical issues arise in situations where at least one moral value is compromised; and in humanitarian work, which we understand broadly to include varied activities with humanitarian purposes (e.g., humanitarian healthcare, relief action in crisis or disaster, or development aid), such situations abound. Indeed, humanitarian work may give rise to a variety of complex ethical issues (2) that shape the day-to-day practice of humanitarian workers, be it at individual, pragmatic, or organizational levels. We do not focus specifically on one group of humanitarian activities or individuals. Rather, we consciously embrace a very broad and inclusive understanding of humanitarian work, its activities and workers, to extend as widely as possible the scope of ethical issues to be documented and addressed.

Humanitarian work comprises a considerable history of aid responses and has stimulated an ever-growing body of research and literature surrounding its complexities and issues. Despite this work, and even though a recent article provided an overview of how the ethical issues arising in humanitarian work are conceptualized (3), no study has yet produced a comprehensive overview of what *are* the issues arising in humanitarian work and their possible solutions. Given this gap in the literature, we sought to identify and describe the ethical issues arising in humanitarian work as they are discussed in the literature, as well as possible responses to them. Being able to detect and clearly conceptualise ethical issues is a fundamental step towards their resolution.

The following section explains the research methods used to respond to the questions that prompted our systematic literature review. We then present the results of the review and the ethical issues that were discussed in the literature, and some possible responses discussed by some authors. Before concluding, we critically discuss and interpret these results.

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METHODS

Following McCullough, Coverdale and Chervenak's (4,5) method, an efficient means to address ethical concepts, we critically and systematically reviewed the literature discussing ethical issues arising within humanitarian work contexts. We first developed pertinent research questions: (a) What are the ethical issues facing humanitarian actors? (b) What means are proposed to address these issues? (c) How are the ethical issues arising in humanitarian work conceptualized in the literature? (d) How are these concepts defined, if any? (e) What theoretical foundations do the authors use? (f) What typologies do the reviewed documents develop or discuss issues? In this article we focus on questions (a) and (b) as questions (c), (d), (e) and (f) have been the object of a separate paper (3).

From our research questions, we then identified keywords to be used in database searches to find relevant literature. Both French and English keywords were used to broaden the scope of our research. Keywords were related to three categories: "issue", "ethics", and "humanitarian".

- *Issue*: issue/enjeu; challenge/défi; difficulty/difficulté; problem/problème; tension/tension; dilemma/dilemme; discomfort/malaise; trouble/trouble; distress/détresse
- *Ethics*: ethics-ethical/éthique; moral/morale
- *Humanitarian*: humanitarian aid/aide humanitaire; international aid/aide international; humanitarian emergency/urgence humanitaire.

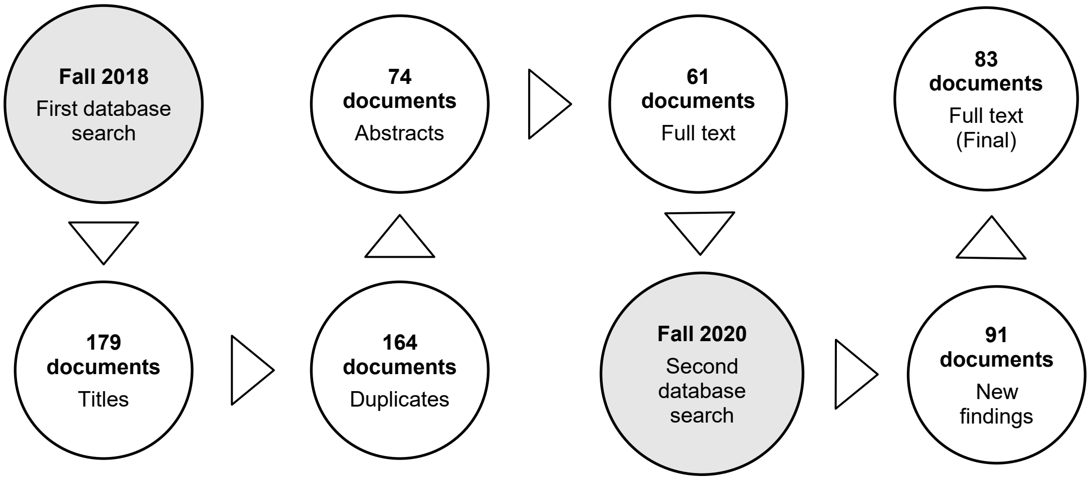
We then sought out the relevant literature in 22 databases (see Table 1), and from the Université du Québec à Trois-Rivières' library catalog.

Table 1. Databases Used

Databases
Academic Search Complete; Cairn.info; CambridgeCore; Canadian Periodical Index; CINHAL; Érudit; Eureka; Google Scholar; JSTOR arts & sciences; MEDLINE; Open Edition Freenium; Oxford Academic; Periodicals Archive Online; Persée; Philosopher's Index; Project Muse; PsychINFO; REPÈRE; ScienceDirect; Scopus; Springer; Taylor and Francis

Any reference that 1) was written in French or in English, 2) answered at least one of our research questions, and 3) was accessible either physically or electronically (without additional fee) was included. Publication date was not a basis for exclusion. The review comprised peer-reviewed articles, books and book chapters, as well as non-peer reviewed articles whether published in professional or academically sources.

Figure 1. Database Search Research Steps



We first reviewed the databases in the Fall of 2018. Preliminary exclusionary criteria were deployed early in our database searches, with keywords to be included in the titles of the publications reviewed. If searches sometimes generated thousands of results for each database visited, we believed early exclusionary criteria based on the titles of the publications could prove efficient to target the most relevant texts. This generated 179 *a priori* relevant publications. We screened the corpus to assess relevance before further analysis, removing duplicates (n=15), so the initial corpus went from 179 to 164 publications. We also removed 90 publications judged irrelevant based on their summary, thus reducing the number of publications to 74. Finally, we removed 13 additional documents because they proved irrelevant to answering at least one of the research questions, for a final number of 61 publications. In the Fall of 2020, using the same research criteria, we again searched the same databases to update the publications corpus. This second review generated 30 additional *a priori* relevant publications. Using the same screening processes, only 22 of the 30 publications were relevant for further analysis, increasing our corpus to 83 relevant publications.

The second step involved the extraction from the publications of information related to our research questions. We created data extraction tables for each publication to target information thought relevant to our research. Compiled together, the tables provided an encompassing view of the ethical issues discussed in the literature that arise in humanitarian work contexts.

Lastly, we critically assessed the information in the tables with regards to our research questions. To classify the humanitarian ethical issues discussed in the literature, we generated several meaning clusters based on the descriptions of the issues presented in the publications reviewed. Gradually, by linking certain clusters to others that were closely related, we narrowed down categories to provide a broad representation of the humanitarian ethical issues, as they are discussed in the literature. We separated issues into micro-, meso-, macro-level categories; a similar process was carried out to analyze proposed responses to such issues.

RESULTS

Bibliometrics

Table 2. Bibliometrics*

1. Type	**N (%)**
Peer-reviewed papers	62 (74.7%)
Books and book chapters	12 (14.5%)
Non-peer reviewed papers	9 (10.8%)
Total	83
2. Year	
[2010-2020]	61 (73.5%)
[2000-2009]	16 (19.2%)
[1990-1999]	6 (7.2%)
3. Language	
English	76 (91.6%)
French	7 (8.4%)
4. Themes	
Health & Medicine	35 (42.2%)
General Issues	27 (32.5%)
Conflicts & Crises	15 (18.1%)
Development	4 (4.8%)
5. Types of Research	
Theoretical	55 (66.3%)
Empirical	18 (21.7%)
Literature Review	12 (14.5%)
6. Where Authors Write From	
USA	25
Canada	22
UK	15
France	7
Australia	5
Switzerland	5
Netherlands	4
India	2
Ireland	2
South Africa	2
Sri Lanka	2
Sweden	2
Other**	17
Total	110***

* The complete list of references is available on request.

** Includes the following countries: China, Croatia, Denmark, Estonia, Ethiopia, Germany, Italy, Japan, Lebanon, Malawi, Nepal, Pakistan, Saudi Arabia, Serbia, Singapore, and Turkey. They were grouped because exactly one author wrote from each of them.

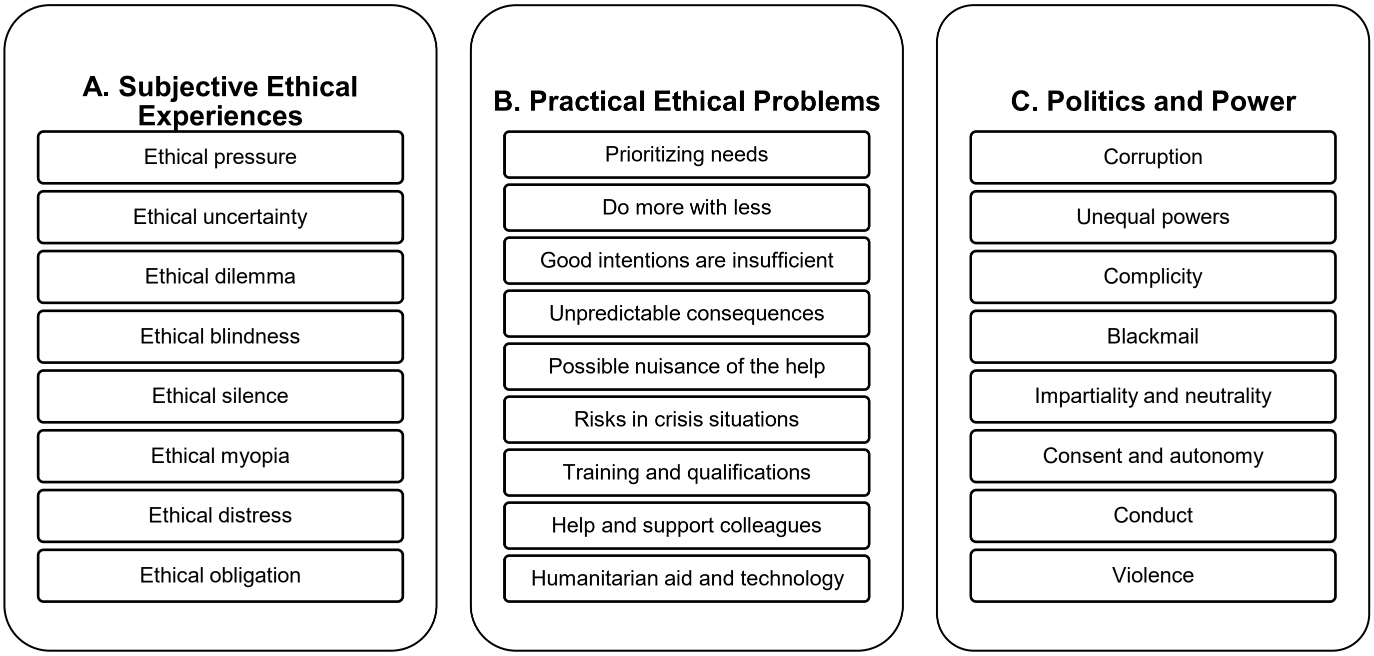
*** This number is greater than that of the reviewed publications because some had multiple authors coming from different countries.

As Table 2 makes evident, almost 75% of the publications were peer-reviewed articles; the rest were book chapters and non-peer-reviewed papers (25.3%). Additionally, most of the publications reviewed (73.5%) were published after 2009. The dominant language was English, with only 7 publications (8.4%) written in French. In section 4 of Table 2, we divided the publications based on the general themes of humanitarian work on which they touch. Publications dealing with health and medicine, and those discussing humanitarian issues in general terms (e.g., pertaining to broad humanitarian principles, research in or about humanitarian settings) made up 60.3% (n=50) of the corpus, with the remaining 39.7% (n=31) addressing issues in conflicts and crisis situations or issues in humanitarian development. Of note, 6 of the 7 publications written in French discuss humanitarian issues in general terms. Most (66.3%) of the publications employed theoretical approaches to discuss ethical issues in humanitarian work contexts. The rest of the publications were literature reviews (14.5% of all publications) and empirical research (21.7% of all publications). All the empirical publications presented qualitative studies based on interviews with humanitarian workers. The authors (i.e., all the authors of all the publications) included in the review mostly came from institutions (universities or NGOs) in the USA, Canada or the UK, accounting for 56.3% of all the authors. Also notable were author-affiliations in France, Australia, Switzerland and the Netherlands (19%). The remaining 24.7% of authors are distributed amongst 21 countries of Europe, Asia and Africa. Overall, the literature reviewed included 30 years of publications on ethical issues in humanitarian work.

Ethical Issues Arising in Humanitarian Work

In analyzing the texts included in our literature review, many ethical issues emerged. We classified these issues under 3 broad categories: (A) *Subjective Ethical Experiences*, (B) *Practical Ethical Problems*, and (C) *Politics and Power*. Figure 2 provides an overview of how these categories relate to each other, from A to C, i.e., from the most pragmatic to the most systemic or macro-oriented. The categories bring together issues that begin with the subjective experience, in the humanitarian actor's interiority, over which they may have (or the impression of having) more control and extend to more structural issues linked to humanitarian organizations or policies, over which they may have (or the impression of having) less immediate control. The meaning units are arranged in a *logical progression of themes* and not according to the frequency of their occurrence. The three categories are interrelated, and not mutually exclusive. As such, while we have made clear distinctions between them to facilitate readability and understanding, the distinctions may not always be as apparent within actual humanitarian work contexts, where such issues arise.

Figure 2. Dimensions of Humanitarian Ethical Issues



Subjective Ethical Experiences

The first category, which emerged from our reading of selected publications, pertains to the subjective experiences of humanitarian workers as they operate in the practical contexts previously identified. This first category of ethical issues includes eight themes, illustrated in Table 3.

Table 3. Ethical Issues Discussed in the Publications under Subjective Dimensions

Themes	References
A. Subjective ethical experiences of humanitarian workers	
1. Ethical pressure	Aarcharya et al. (6); Asgary & Junck (7); Asgary & Lawrence (8); Civaner et al. (2); Delgado Luchner & Kherbiche (9); Draper & Jerkins (10); Gotowiec & Cantor-Graae (11); Hunt et al. (12,13,14); Lebouc (15); Tarvydas et al. (16); Zarka et al. (17)
2. Ethical uncertainty	Gotowiec & Cantor-Graae (11); Meldrum (18); Simm (19); Sinding et al. (20); Slim (21,22).
3. Ethical dilemma	Delgado Luchner & Kherbiche (9); Gasper (23); Harris (24); Hunt (25); Kiddell-Monroe et al. (26); Le Coconnier & Pommier (27); Pasic & Weiss (28); Remer (29); Schloms (30); Sheather & Shah (31); Simm (19); Sinding et al. (20); Slim (32,21,22); Smith (33); Tobin (34)
4. Ethical blindness	Fraser et al. (35); Kiddell-Monroe et al. (26); Slim (21)
5. Ethical silence	Ayimpam et al. (36); Brauman (37); Haver (38)
6. Ethical myopia and cultural tensions	Asgary & Junck (7); Ayimpam et al. (36); Bell & Carens (39); Bruno & Haar (40); Eckenwiler & Hunt (41); Funk et al. (42); Harris (24); Harroff-Tavel (43); Hunt (25); Hunt et al. (44); Mftuso-Bengo et al. (45); Moley (46); Rubenstein et al. (47); Schnall et al. (48); Schwartz et al. (49); Scott-Smith (50); Slim (21,22); Tobin (34); Yacoub et al. (51); Yimer et al. (52); Zarka et al. (17)
7. Ethical distress	Delgado Luchner & Kherbiche (9); Broussard et al. (53); Eckenwiler & Hunt (41); Kiddell-Monroe et al. (26); Simm (19); Smith (33)
8. Ethical obligation	Gustavsson et al. (54)

Ethical pressure

Present in 17 of the publications reviewed, ethical pressure is defined as “a situation in which the employees feel pressured by their peers, supervisors, and other members of the organization to compromise their personal values in order to achieve organization goals” (55, p.159). Ethical pressure may also arise “within oneself” and be exerted upon one’s psyche, namely through the internalization of values, norms or obligations, particularly in situations of urgency and scarcity. This is at play, for instance, in Asgary and Lawrence’s article, where they discuss how some ethical situations may pressure humanitarian workers to act outside the scope of their competencies (8). Such pressure is exacerbated by the incapacity to accurately predict the consequences of the aid. Aarcharya et al. (6) highlight the pressure associated with having to protect resources and make sure that they remain usable. Ethical pressures also come from organizations, which can question workers’ professional autonomy (2). Significant pressures are also associated with bearing the burden of choice: “emotional suffering that emerged during and after decisions that became ethical challenges”, experienced as “inescapable feelings of stress […] both psychologically and professionally” (11, p.5). This burden is also expressed through pressures of having to take responsibility for those choices (14). Moreover, Lebouc (15) highlights the fact that the practical and theoretical knowledge of humanitarian work may not prevent workers from feeling isolated and pressured by “the need to act, alone with one’s experience, knowledge and conscience”, and faced with the need to act quickly, with no time for deliberation (15, p.46; our translation). Lastly, Tarvydas et al. (16) address institutional and professional pressures: “In mass trauma counseling, counselors often must confront clinical, interprofessional, institutional, and public policy forces that may have marked effects on their ethical judgments and boundaries” (16, p.261; for similar ideas see 17).

Ethical uncertainty

Ethical uncertainty is present in six of the publications reviewed. It can refer to “an inability to apply appropriate moral rules” (56, p.894), or, more broadly, a self-doubt regarding the best way to apply ethical principles or how to best direct ethical decision-making. As Simm eloquently puts it “moral uncertainty […] pertains to situations where one is unsure what moral principles, values, or rules to apply” (19, p.2; for similar ideas see 20-22). In their 2017 article, Gotowiec and Cantor-Graae note that preparations for ethical challenge of humanitarian work come with much uncertainty: “participants expressed challenges within the self when they were unsure of which values to apply in a given situation. Uncertainty can be created when one is hesitant about crossing professional ethics guidelines” (11, p.5). Also noteworthy is how Meldrum addresses uncertainty with regards to spiritual concerns in humanitarian work, highlighting that fact that “physicians remain highly uncertain about how to conduct themselves in spiritual discussions with patients” (18, p.27).

Ethical dilemma

In the philosophical literature, a dilemma is broadly understood as a situation in which the agent 1) has to make a decision between at least two alternatives, 2) has the ability to do each of them, but 3) is unable to do all of them because they are incompatible (57). Such an issue is present in sixteen publications. As Slim puts it, “moral dilemmas have a terrible symmetry about them. Whichever path you choose will inevitably involve serious moral losses of some kind” (21, p.165; for similar ideas see also 19,30,32). This view is consistent with that of Gasper, who notes that “aid personnel often face painful dilemmas, where whatever they do will involve severe moral costs” (23, p.32). For instance, Hunt notes that selecting which patients to give aid may result in dilemmas for which workers are not prepared: “participant expressed that this type of decision-making was one of the responsibilities that she felt least prepared for” (25, p.65). Sinding et al. discuss humanitarian work in extreme settings and lack of resources: “[such] limitations set up two sorts of dilemmas […]: having to choose one patient over another, and having to choose between the needs of current patients and the (possibly more acute) needs of future patients” (20, p.149). In discussing humanitarian work within detention facilities, Forsythe (58) acknowledges that dilemmas may arise: 1) in treating with partial access (p.138); 2) “in accepting routine visits over a long period of time when other places of detention, accompanied by credible reports of ill-treatment, are off limits to the ICRC [International Committee of the Red Cross]" (p.138); 3) accessing patients "only after a period of isolated confinement during which the detaining authority" can torture prisoners to gain information (p.141). Moreover, Harris explains that there is a dilemma in recruiting local staff: "If […] the most suitably qualified personnel [are targeted,] they risk depleting local emergency response capacities by drawing resources away from domestic organizations. However, if they recruit people with little or no emergency related experience, the effectiveness of the international agency's assistance is likely to be compromised" (24, p.293). For Le Coconnier and Pommier, 'fundamental dilemmas' arise in situations of unequal powers "where the ruling power is particularly brutal towards its population or a part of it, while aiming to impose a tight or even exclusive control over the way aid is granted [to] beneficiaries" (27, p.105-106; our translation). Finally, in their 2011 article, Sheather and Shah address four possible dilemmas faced by humanitarian health workers. First, since "stigma around HIV can be high", the personnel "can fear informing or counselling individuals who test positive for HIV" (31, p.162). Second, should workers "turn a blind eye to the use [by local community] of MSF [Médecins Sans Frontières] equipment?" (31, p.163). Third, with regards to "MSF oppos[ing] re-infibulation and work[ing] to ensure that it is not undertaken in its delivery facilities", the authors note that "not performing [it] risks jeopardising community trust" (31, p.163). Fourth, having an inexperienced doctor "confronted with doing something that she has never done before" (i.e., caesarean section): "she could do a lot of harm by doing the operation badly, but doing nothing guarantees that the baby will not survive" (31, p.164).

Ethical blindness

Ethical blindness was implicit in three publications and can be defined as a "temporary inability to see the ethical dimension of a decision at stake" (59, p.324). For instance, Fraser et al. discuss the idea that it may prove difficult to properly identify what the issue is in a given situation: "participants found it difficult to identify what constituted an ethical issue[;] […] one group spent time […] debating whether the central problem […] was 'ethical' or 'pragmatic' before concluding by describing the scenario and their decision as 'quasi ethical'" (35, p.412).

Ethical silence

Ethical silence, also sometimes referred to as "moral muteness", "occurs when people witness unethical behavior and choose not to say anything [or] […] when people communicate in ways that obscure their moral beliefs and commitments" (60). Notably, in his 1999 paper, Brauman criticizes the silence that NGOs maintain with regards to situations that are problematic in terms of human rights. These silences or refusals to 'take sides' could be "a precious help for authorities [...] because their silence was transformed into approval […]" (37, p.244). Also of great importance, Haver discusses how talk of corruption is often silenced: "Technically, 'zero tolerance' policies stress the requirement not to tolerate corruption – i.e., insisting on accountability when corruption happens. But 'zero tolerance' has often been understood to mean 'zero discussion' of corruption" (38, p.11). In Ayimpam et al., finally, highlighted a particular kind of silence. In contexts where research can cause cultural disturbance within local communities, "it was important to train interviewers to address the subject of excision indirectly in the survey sites, using the participants' personal reflections on human rights as an entry point […]" (36, p.34; our translation). In this scenario, workers had to silence themselves, as well as the real goals of research, to be able to conduct this work.

Ethical myopia and cultural tensions

Closely related to ethical silence, ethical myopia means that one is incapable of seeing and understanding ethical issues clearly, as the perception of the issue is related to cultural biases (61). Under the umbrella of myopia, we have included issues directly concerned with such an incapacity, as well as issues related to cultural differences that may create conflicts, misinterpretations, stress or other problems. For instance, Asgary and Junck remark that culturally insensitive humanitarian work can potentially harm the populations one wishes to help (7). Further, Ayimpam et al. discuss intercultural tension in conducting humanitarian research: "a first type of difficulty associated with field investigation is the experience of (psychologically risky) intercultural tension, [experienced in] managing [...] the distance and proximity relationships in daily interactions" (36, p.25; our translation). Hunt points out that ethical issues arise in humanitarian work because of "different cultural understandings of health, illness, and death between the local population and the NGO workers" (25, p.64). Psychological difficulties may also arise when workers need to deal with conflicting values and beliefs. For instance, Bell and Carens discuss workers who must sometimes 'sacrifice' deeply held values to promote the mission (e.g., downplay gay people's rights in Nigeria to better connect with local populations) (39, p.307). Such conflict may also arise when trying to 'challenge' local cultures. If humanitarian norms conflict with local cultures, on the one hand, attempts can be made to bring pressure in order to try to improve vulnerable people's lives; but on the other hand, this may be perceived as cultural imperialism or undervaluing of local norms (39, p.307). In a similar perspective, Funk et al. note "that services oriented towards women, especially reproductive health and gender-based violence services, are often difficult to implement; male gynecologists often face harassment and family planning interventions must be implemented in secret" (42, p.142). Likewise, Rubenstein et al. acknowledge the existence of "challenges in respecting norms while providing equal and appropriate services for women's health when few female providers were available. When services were provided by females, organizations faced challenges in addressing harassment and gender-based violence against female staff" (47, p.17-18). Harroff-Tavel addresses the need for humanitarian workers to respect local populations and their cultures, and to remain self-conscious about their potential limitations (maintain a humble perspective) (43; for similar ideas see also 17,24,44,46,48,51). In the same vein, Bruno and Haar note that, regarding cultural differences, workers ought to gain a "strong appreciation, humility, and understanding of local culture" (40, p.13). Mftuso-Bengo et al. warn that it may be "impossible for researchers from another social environment to know all the acceptable and unacceptable cultural practices in another area" (45, p.47). Cultural tensions can be exacerbated by trying to balance neutrality and the defense of human rights, "since speaking out usually involves 'taking sides' in some way" (50, p.6). In their article, Schwartz et al. highlight challenges pertaining to differing health norms in communicating with patients: "conflicts about expected communication between [workers] and patients, and between professionals, generated ethical struggles for respondents" (49, p.50).

Ethical distress

The notion of ethical distress first arose in the nursing literature to describe situations "when one knows the right thing to do, but institutional constraints make it nearly impossible to pursue the right course of action" (62, p.5). Simm, following Jameton (63), defines moral distress as "the painful psychological disequilibrium that results from recognizing the ethically appropriate action, yet not taking it, because of such obstacles as lack of time, supervisory reluctance, an inhibiting medical power structure, institution policy, or legal considerations" (19, p.1; for a similar idea, see 33). For Kiddell-Monroe et al., moral distress can arise for humanitarian workers "in their response to crises", as they "are witness to tragic and inhumane situations" (26, p.259). In their 2020 paper, Gustavsson et al. identify three types of moral distress in disaster response. The first type occurs "when the individual is hindered from doing what he/she perceives to be the right course of action in the situation, is characterized by external obstacles that prevent the responder from helping as intended" (54, p.217). The second type presents itself "when the individual cannot live up to his/her own ideals, derives from situations where moral values are encroached irrespective of action taken" (p.217). The third type takes place when "failing to do what is perceived as right even if possible, is related to the individual's weakness of will (*akrasia*) to act upon moral values" (p.217). They identify a fourth type of distress: a "reactive distress developed in the aftermath of the situation that involved moral challenges" (p.217). For Eckwenwiler and Hunt, moral distress can be the result of a constant "struggle to provide care for populations that may perceive them as untrustworthy and avoid them entirely" (41, p.13).

Ethical obligation

Especially common in philosophical discussions of ethics, an 'ethical obligation' refers to a form of duty to follow principles, values or norms, be they the result of coercion or due to a person's own volition. Broussard et al. (53) review eight main ethical obligations arising in humanitarian work contexts, that is, to: 1) provide high quality care; 2) appropriately acquire and manage assets; 3) protect and care for workers; 4) support local responses; 5) equitably distribute benefits and burdens; 6) recognize and incorporate local knowledge and cultural norms; 7) minimize harm; and 8) interact and communicate with honesty and transparency (53).

Practical Ethical Problems

Among the ethical issues we identified in the literature, many have to do with the practical, day-to-day setting of humanitarian practice (see Table 4). For this category, we identified nine themes of ethical issues, each of which is present in at least one publication.

Table 4. Ethical Issues Discussed in the Publications under Pragmatic Dimensions

Themes	References
B. Practical Ethical Problems	
1. Prioritizing needs	Asgary & Lawrence (8); Bhan (64); Civaner et al (2); Geale (65); Hunt (66); Hunt et al. (14,44); Le Coconnier & Pommier (27); Leider et al (67); Michael & Zwi (68); Sinding et al. (20); Sommers-Flanagan (69); Yacoub et al. (51)
2. Doing more with less	Aarcharya et al. (6); Asgary & Junck (7); Asagary & Lawrence (8); Chung & Hunt (70); Delgado Luchner & Kherbiche (9); Draper & Jenkins (10); Ford et al. (71); Funk et al. (42); Geale (65); Hunt (66); Hunt et al. (12,14,72); Landman (73); Lebouc (15); Leider et al. (67); Michael & Zwi (68); Moodley et al. (74); Richards (75); Schnall et al. (48); Schwartz et al. (49,76); Sommers-Flanagan (69)
3. Good intentions are insufficient	Gasper (23)
4. Unpredictable consequences	Gasper (23); Le Coconnier & Pommier (27); Pasic & Weiss (28); Schloms (30); Slim (21,22)
5. Possible nuisance of helping	Asgary & Lawrence (8); Delgado Luchner & Kherbiche (9); Hunt et al. (77); Rubenstien et al. (47); Zientek & Bonnell (78)
6. Risks in crisis situations	Ayimpam et al. (36); Binns et al. (79); Bruno & Haar (40); Cardozo et al. (80); Delgado Luchner & Kherbiche (9); Geale (65); Hall-Clifford & Cook-Deegan (81); Haver (38); Moley (46); Sumathipala et al. (82); Tarvydas et al. (16); Yacoub et al. (51); Yimer et al. (52)
7. Training and qualifications	Asgary & Lawrence (8); Maxwell et al. (83); Pal et al. (84); Remer (29); Slim (21); Tobin (34)
8. Help and support colleagues	Bhan (64); Hunt et al. (72); Le Coconnier & Pommier (27); Meldrum (18); Rubenstein et al. (47); Scott-Smith (50); Sommers-Flanagan (69); Vaux (85)
9. Humanitarian aid and technology	Mftuso-Bengo et al. (45); Slim (22); Yacoub et al. (51); Zientek & Bonnell (78)

Prioritizing needs

Prioritizing needs is one of the most recurrent ethical issues that arise in humanitarian work, identified in 17 of the publications reviewed. In general, this refers to the fact that, in times of crisis, humanitarian workers are faced with sometimes harrowing choices regarding the allocation of available resources. In part, that means having to decide how best to allocate resources. For instance, in their empirical study, Asagary noted that humanitarian aid workers "struggled with how best to allocate resources to communities" while acknowledging that "in a resource-limited setting, meeting the needs of one constituency would likely mean taking away resources from others" (8, p.3; for similar ideas, see 27,51). Indeed, as Geale notes, prioritizing aims to "allow for the best possible use of the limited resources" (65, p.447). What is more, Bhan suggests that the need to prioritize needs may influence whether to continue or stop an intervention: "there often have to be choices made about pulling the plug or not intervening because of triage considerations and the need for resource prioritisation” (64, p.145). In fact, Leider et al. argue that while “[triage] will typically exclude those who are ‘too far gone,’ as well as those who do not need substantive medical attention imminently”, there is “disagreement” in prioritizing since some “argue that, among those who can be helped, prioritizing the worst off is the most appropriate, as others could potentially be treated later” (65, p.e6). However, they note that this approach may not be the most efficient, especially if resources are lacking. Additionally, while Civaner et al. discuss the possible risks associated with doing poor triage (2), Hunt et al. (44) note that in extreme cases, humanitarian missions may especially prioritize life-saving objectives. Similarly, Hunt proposes that, in extreme cases, “there may be little opportunity to do other than promote a utilitarian approach to decision-making regarding the selection and prioritisation of patients” (66, p.614). Finally, Sommers-Flanagan eloquently identifies how justice is intertwined with prioritizing needs: “In medicine, and in crisis, individuals will not have exactly equal needs, and the available resources will never be sufficient. Therefore, determining a just method of offering services and goods can be a most challenging task” (69, p.196).

Doing more with less

The necessity to do more with less, closely related to the previous issue, surfaced in more than 20 publications. It relates to tough choices that humanitarian workers must confront in contexts of great need and a lack of resources. Schwartz et al. put this idea eloquently: “[humanitarian workers] persistently were confronted by situations in which the resources available were insufficient or inadequate […]. The choices that scarce resources presented were a recurring source of ethical struggle. The narratives indicate that the respondents wrestled with distributive justice challenges in their urgency to provide care in contexts of extreme scarcity” (49, p.47). For Schwartz et al., the ethical struggle is about being able to work most efficiently while lacking sufficient resources. Schnall et al. point to a similar idea in proposing that “scarcity is a significant concern for providers of humanitarian aid” as they “are frequently faced with situations in which available resources are insufficient to sustain life, or inadequate to meet patient needs” (48, p.6). In such cases, the fact that one ought to do more with less may interlink with issues of distributive justice: “the fair distribution of scarce resources, can be especially difficult to uphold” (7). Additionally, Funk et al. (42) provide an encompassing view of how a lack of resources can both require that workers to do more with less and also drain available resources:

> challenges included those related to staff shortages, which resulted in the overworking of staff, or practices that were beyond an individual’s scope of training and knowledge; hospitals operating over capacity; and gaps in service provision, such as a lack of gender-based violence interventions or psychological support for children. *These challenges all raised concerns about adherence to obligations to provide quality care and deliver humanitarian aid*. (42, p.139, italics in original; for similar ideas see 68,74)

Hunt et al. reflect along similar lines when they propose that “resource limitations” may make humanitarian workers act “outside their ordinary sphere of practice or near the margins of their competency, due to a perception that better options are not available” (12, p.503; for similar ideas see 14,67). What is more, Asgary and Lawrence believe such an issue can exacerbate systemic and infrastructure problems (8). In such contexts, it may prove particularly difficult to draw bridges between theory and practice (9). In sum, Aacharya describes the chaos that may emerge from the need to do more with less: “Having to manage a large number of injured people in a short time, with limited resources, amid the disruption of the regular mechanisms and resources, results in chaos” (6, p.26).

Good intentions are insufficient

Explicitly expressed as such in a single text, the idea that good intentions are not enough runs (implicitly) through many publications and involves subjective issues such as moral distress or ethical uncertainty (see Table 3). This generally refers to the idea that while humanitarian workers’ intentions may be commendable, they are not immune to unforeseen harm. In his 1999 article, Gasper notes that, in humanitarian work, ethical guidelines may amount to no more than good intentions, which are seldom enough in themselves to prove helpful (23).

Unpredictable consequences

The idea that the consequences of actions may be hard to predict surfaced in four of the publications reviewed. This issue addresses the difficulties that aid workers may face in adequately predicting the effects of some of their practices on the populations they assist. In this sense, Le Coconnier and Pommier interrogate the possible consequences of humanitarian work: “Should we proceed or not? Who is the primary beneficiary of the action? To whom does the aid go?” (27, p.105; our translation). They additionally highlight how aid, since its consequences are difficult to predict, may “feed combatants, even torturers of a population, and so risk further fuelling conflict” (27, p.105; our translation). In a similar perspective, Slim discusses ‘ambiguous aid’ that risks making things worse (21,22), in line with Hassner (86) and Sommers-Flanagan (69). He also argues that such choices can be “shrouded in an ‘epistemic veil’ […], [i.e.], people do not know enough or cannot know enough to make an informed choice between various alternatives” (21,22), which correlates with Gasper (23) and Pasic and Weiss (28).

Possible harm of helping

In relation to the idea that it is difficult to accurately predict consequences, some humanitarian decision-making may cause harm. This concern surfaced in five of the publications reviewed. Asgary and Lawrence (8) note that humanitarians can potentially harm local populations, notably if they are manipulated. For instance, the aid can be manipulated as a political tool when medical aid is used preferentially. Humanitarian workers with little field experience may be unaware of the socio-political consequences, so relationships with some communities can be severely damaged, undermining collaborative and effective medical aid (8). Additionally, Delgado Luchner and Kherbiche highlight a need for humanitarian workers to “evaluate the risks associated with their work both for themselves (in terms of physical harm, the consequences of accepting armed protection, etc.) and for beneficiaries (preventing aid dependency, maintaining dignity, ensuring participation, etc.)” (9). Discussing the need to properly close humanitarian projects, Hunt et al. emphasize a need to “avoid or minimize harms for individuals and groups who have been receiving assistance, and to be proactive in anticipating and addressing sources of potential harm” (77, p.10). They note that the risks “of harm are diverse, and include loss of services, feelings of abandonment, heightening of community tensions or misuse of project data, as well as risks for wider communities due to economic disruption or insecurity during and after closure, for project staff due to loss of employment or feelings of distress, or for the organization if there is reputational harm” (p.10). In their 2020 article, Zientek and Bonnell address several ‘sins’ humanitarian aid may commit, which in turn can lead to unpredicted harms: 1) the risk of “leaving a mess behind”, 2) the possibility of “going where we are not wanted, or needed and/or being poor guests”, and 3) risking “doing the right thing for the wrong reason” (78, p.336).

Risks in crisis situations

The issue pertaining to risks in crises situations is present in thirteen publications, and refers to the possible danger or harm that humanitarian workers may have to face in their practices and decision-making. In their 2014 article, Ayimpam et al. propose a list of risks which may arise in humanitarian work contexts (36; for a similar idea see 40). First, they highlight risks related to particular social contexts: “researchers find themselves caught up in very tense struggles of meaning” because of cultural tensions (36, p.26-27; our translation; for a similar idea see 52). Second, they describe risks associated with authoritarian contexts, “in which the study is taking place, as in the case of a civil war that makes access to the land impossible” (36, p.27; our translation). Third, they point out risks pertaining to socially stigmatized populations: “these risks are also related to the populations and categories of people who are despised, abandoned or stigmatized and who are concerned by the survey. [...] This type of situation generates personal emotions that must be managed […]” (36, p.27; our translation). Fourth, they emphasize risks associated with conducting research in a highly monitored environment: “manage to collect information that is as free from manipulation as possible in a very unfavourable context” (36, p.28; our translation). Fifth, they propose that risks may be exacerbated in conflicts (36, p.32), which is consistent with problems highlighted by Cardozo et al. (80). Indeed, they assert “that humanitarian aid workers are increasingly at high risk for experiencing violence and being exposed to terrorism development opportunities, low salaries, or unsafe living conditions, which may also lead to burnout and other negative mental health outcomes” (80, p.1-2; for similar ideas see 16,81). What is more, in discussing disaster crises, Geale highlights how they risk negatively affecting humanitarian work “due to pollution, risk of epidemic, and psychosocial issues” (65, p.447; for a similar idea, see 82). Also, Moley discusses risks of violence that local populations may face: “an inherent risk of violence or other physical harm that threatens researchers as well as the people with whom they work” (46, p.363). Finally, Haver notes that deviating from ethical principles can lead to undue risks that may prevent the desired assistance from being properly carried out (38).

Training and qualifications

Issues pertaining to training and qualifications encompassed challenges or problems related to the effective transmission of humanitarian knowledge and practice. For instance, Maxwell et al. remark that the promotion of organizational value can be made through training: “grounding staff in organizational values such as integrity and good stewardship through training and integrating these values into staff appraisals, while a challenge in the context of rapid recruitment, promote honesty” (83, p.155). Asgary and Lawrence note, however, that humanitarian workers sometimes must carry out tasks that are beyond their competence, and organizations have to fill structural voids that are sometimes unexpected, which could perhaps be solved with better training and supervision (8). In the same perspective, Yacoub et al. suggest that “lack of expertise, training, and guidance for field practitioners to situate palliative care in crisis settings” can lead “to either abandonment or futile invasive interventions for patients who will only experience them as burdensome and not beneficial” (51, p.7).

Help and support colleagues

Finally, helping colleagues is part of a particular perspective of caring for others and ensuring the preservation and well-being of the people with whom one works. This idea is ingrained in the principle of beneficence, eloquently captured in Sommers-Flanagan: “beneficence refers to doing good when the opportunity is available [and] […] exhorts us to seek and promote the benefit of others, prioritizing this benefit over any potentially gained for ourselves” (69, p.193). To this point, Hunt et al. note that “collegial and team relationships are key sources of support as health professionals respond to ethically challenging circumstances, including mentoring by respected senior colleagues and mutual support among peers” (72, p.59). Rubenstein et al. highlight organizational problems pertaining to protecting workers (47; see Table 5).

Table 5. Protection and Caring for Workers

Protect and care for workers	• Organization cannot reasonably assure the safety of health workers in the field, and transfers risk to them • The organization has difficulty addressing the psycho-social needs of health workers • Contingency, safety, or emergency plans difficult • Violence against and devaluation of women and vulnerable groups • Health workers’ families may not be compensated if the health worker is killed

Source: abstracted from Table 2 in Rubenstein et al. (47, p.27-28)

Humanitarian work and technology

Issues pertaining to the use of technologies in humanitarian work were addressed in four publications. The use of technologies in humanitarian work can bring about unforeseen problems. For instance, Mftuso-Bengo et al. discuss the use of genetically modified food: "An example could be the introduction of genetically modified (GM) food as therapy for malnutrition in a humanitarian crisis. While there are significant benefits to be accrued from such GM crops, the sensitivities and opposition to such technology cannot be easily neglected" (45, p.48). Hunt et al. also remark that the use of "digital data collection […] raises questions about informed consent and ownership of information, including whether individuals know and accept the purposes for which their information will be used and how it will be stored" (13, p.42). Zientek and Bonnell discuss the failure "to match technology to the local environment", which can occur when "visiting groups […] bring technology that they are accustomed to using in their home environment, such as electronic records or advanced surgical tools" (78, p.335). "These technologies become useless to the intended beneficiaries when reliable electricity or water supplies may not be available, and training local clinicians to use devices that will not be available is a waste of the limited time available to train them in more practical techniques" (p.335). In the same perspective, Slim warns that technology must not "become a barrier to engaging and communication with people who need protection and assistance" (22, p.224).

Politics and Power

On a systemic level, a third category of humanitarian ethical issues has to do with power structures and organizational politics. This last category of ethical issues includes eight themes, summarized in Table 6.

Table 6. The Ethical Issues Discussed in the Publications under Cultural Politics Dimensions

Themes	References
C. Politics and Power	
1. Corruption	Asgary & Lawrence (8); Maxwell et al. (83); Pasic & Weiss (28); Remer (29); Slim (21); Tobin (34)
2. Unequal powers	Funk et al. (42); Gotowiec & Cantor-Graae (11); Hunt (87); Hunt et al. (14); Jayasinghe (88); Mftuso-Bengo et al. (45); Slim (22); Zientek & Bonnell (78)
3. Complicity	Buth et al. (89); Michael & Zwi (68); Slim (21); Sommers-Flanagan (69); Yacoub et al. (51)
4. Blackmail	Brauman (37)
5. Impartiality and neutrality	Bhan (64); Eckenwiler & Hunt (41); Funk et al. (42); Hunt et al. (13,72); Le Coconnier & Pommier (27); Meldrum (18); Pal et al. (84); Rubenstien et al. (47); Scott-Smith (50); Sommers-Flanagan (69); Vaux (85)
6. Consent and autonomy	Aarcharya et al. (6); Bruno & Haar (40); Civaner et al. (2); Hunt et al. (13,72); Jayasinghe (88); Maglio & Pherali (90); Mftuso-Bengo et al. (45); Moodley et al. (74); Sommers-Flanagan (69)
7. Conduct	Buth et al. (89); Michael & Zwi (68); Slim (21); Sommers-Flanagan (69); Yacoub et al. (51)
8. Violence	Funk et al. (42)

Corruption

In humanitarian settings, corruption generally refer "a claim that certain policies and practices are subverting the 'proper' working of the humanitarian apparatus" (91, p.S161). Such corruption may include "bad" practices that would be seen as (moral or otherwise) failures. Of the 83 publications reviewed, seven discussed issues of corruption. Maxwell et al. distinguish important "features of humanitarian assistance that make it particularly vulnerable to corruption": 1) "pressure to act quickly, and to be seen (by management and in the media) as acting rapidly"; 2) humanitarian work "is by definition going to be needed in places […] legal system may be dysfunctional or itself extremely corrupt"; and 3) "senior management of agencies may be operating in places of which they have little personal knowledge and there is limited institutional memory" (83, p.143-144).

Likewise, Asgary and Lawrence discuss corruption both at the national and program level, and at the level of governmental and international agencies (8). At a micro level, bribery can be used to facilitate practical work in communities. Indeed, Remer discusses a team who, upon arriving in a community, "seeks out the local police chief and offers him a monetary payment to keep the corrupt officers from harassing the team during their stay, as long as the team is behaving legally. This payment saves thousands of dollars in terms of work time" (29, p.238). Lastly, Tobin warns that "Humanitarian assistance can be manipulated by warring factions and unscrupulous regimes, for their own political purposes" (34, p.573).

Unequal powers

Eight publications dealt with issues of unequal powers: this corresponds to the fact that, in humanitarian 'transactions' (be they social, material, etc.), different people hold different degrees and types of power, which can influence the possibilities of action or put pressure on people or organizations. Slim discusses the systemic issues pertaining to unequal power relations in humanitarian work. To begin, humanitarian work is likely to greatly alter (and thus leave its mark on) the locations of its intervention, even long after departure (21,22). He also notes that while aid is increasingly framed by narrow codes of conduct and management parameters, this can prove counterproductive if the emphasis is on achieving objectives and not on the quality of aid (21,22). In other words, the systemic and organizational powers that direct humanitarian projects, while precise and adequate in many respects, at times deprive humanitarian workers of more meaningful control over their immediate work environment because, as Slim explains, the focus is often mainly on achieving organizational goals and not necessarily on providing adequate assistance. In a similar perspective, Gotowiec and Cantor-Graae review possible issues arising with regards to 1) the risk of being "held hostage by institutional constraints"; 2) "being silenced by the organization"; 3) "organization feigning ignorance"; 4) using "bureaucracy as an alibi"; 5) "struggling against orders" (11, p.4; for a similar idea see 42). All of these issues can contribute to making workers feel powerless. In effect, Hunt discusses how humanitarian healthcare professionals “feel powerless in some situations […] in which assistance to needy communities is impeded by local powers, such as armed groups or the military, bureaucratic structures that delay the implementation of programs, or corrupt officials” (87, p.521). Similarly, Hunt et al. discuss working under systemic constraints: “efforts to provide palliative care were circumscribed by systemic constraints inherent to humanitarian operations and to the wider context of global inequality in healthcare access” (14, p.7). Moreover, in his 2007 paper, Jayasinghe discusses the unequal powers between workers and local populations: “is this ethical when one considers the asymmetric power relationship between the aid worker and a recipient? Having provided assistance at a time of dire need, the aid worker has considerable power over the individual and family” (88, p.624-25).

Complicity

Broadly speaking, ‘complicity’ refers to one’s involvement, with others, in harm or some wrongdoing; this issue surfaced in five of the publications reviewed. For Buth et al., complicity brings about moral wrongs that ought to be counterbalanced with the goods arising from them (89). In their 2002 article, Michael and Zwi ask: “Does providing health care prop up a repressive regime?” (68, p.117). In effect, they note that “in many instances, service provision is very much part of a process of ‘winning hearts and minds’ [and] […] political and religious groups worldwide make a point of providing services as one way of winning recruits to their cause” (p.117). Lastly, Yacoub et al. discuss how the emphasis on saving lives can make workers feel complicit when no care is available: “the rush to rescue and the emphasis on saving as many lives as possible sometimes leads to feelings of complicity when only end-of-life care can be provided.” (51, p.6).

Blackmail

Blackmail is defined as “extortion or coercion by threats” (92), namely through the use of fear, defamation, the withholding of resources or fund, etc. It has surfaced explicitly in one publication but is implicitly discussed in others. For instance, Brauman discusses how “in Korem, the main camp where MSF worked, the organization’s members witnessed the blackmail by the new head of the Party”, without being able to say anything for fear that things would get worse for the locals (37, p.240; our translation). Such witnessing makes salient the links that exist between many issues. Indeed, witnessing blackmail may have ties with forms of complicity or may even involve ethical pressures, which in turn exacerbate workers’ stress levels.

Impartiality and neutrality

In humanitarian contexts, while neutrality generally means refraining from taking side in conflicts in order to provide assistance and protection to all affected people, impartiality means that “humanitarian aid must be provided solely on the basis of need, without discrimination” (93, cf. 94). Rubenstein et al. observe that impartiality “stipulates that humanitarian actors must not discriminate or give preference to any nationality, race, religious belief, class, political opinion, or similar status” in their work (47, p.3). Furthermore, according to Vaux there is “a widespread expectation that aid agencies will not take sides in conflict” (85, p.243). However, for Le Coconnier and Pommier “neutrality is put to the test when humanitarians are called upon to react to a change in the situation provoked or encouraged by one party” (27, p.102, our translation). In those cases, Hunt et al. observe that neutrality sometimes “creates dilemmas where care may be viewed as incompatible with justice” (72, p.6). While Bhan discusses the need to remain neutral in providing care, he recognizes that part of being impartial means protecting populations with proper regulations: “the need to protect their patients from research which might not have received adequate regulatory and ethics approval, and might not be designed to protect the rights of the patients” (64, p.146-147). On the organizational level, Eckenwiler and Hunt remark that humanitarian workers can sometimes be used as tools in counterterrorism frameworks, which “threaten[s] their professional autonomy and their commitment to neutrality and independence” (41, p.13; for a similar idea, see 42).

Consent and autonomy

To ask for and gain someone’s autonomous consent is to ask for someone’s free, informed and uncoerced permission to perform an act (95). Bruno and Haar note, for instance, that “Western norms of written consent might be impossible if research is carried out in a population with low literacy rates or when written consent can violate the need for complete anonymity or expeditious research” (40, p.12; for similar ideas see 6,74,90). Further, they show that, sometimes, frameworks to gain informed consent had to be culturally and locally modified (40, p.12). Likewise, Hunt et al. note that disaster situations “challenge traditional approaches to obtaining informed consent, including provision of information and time for discussions, consideration of information, support from others, continuity of care, and confidentiality (among other details). All of these features affect people’s ability to exercise their autonomy” (72, p.4; for a similar idea see 69). Civaner et al. point out paternalistic attitudes in gaining informed consent of people affected by disasters: “participants usually defend a paternalistic approach based on the extraordinary conditions of disasters: ‘[…] people exposed to disasters cannot think rationally, I am there to help them and they know this already, therefore I can and I should decide on behalf of them’” (2, p.10). For Jayasinghe, respecting autonomy relates to respecting dignity (88). Finally, Mftuso-Bengo et al. warn about possible undue inducement of people into accepting to deal with humanitarian workers (45).

Conduct

Under ‘conduct’ were included issues of *how* one ought to behave in humanitarian work contexts, which is closely related to ethical obligations and ties into humanitarian principles. Related to such principles is the question of responsibility, which is highlighted in Michael and Zwi: “The moment [workers] get involved […] they become contributors to the health effort in that particular area, and share some responsibility for what is delivered, how, and with what level of quality” (68, p.123). As well, Slim notes that humanitarian conduct is often expressed through compromise: “[Some losses] may involve matters of principle, material interest or humanitarian impact. These choices are frequently posed and solved as moral compromises. In humanitarian action, they often emerge in judgements and decisions around political operational association" (21, p.157-158).

Violence

In broad terms, violence occurs when one person or group causes harm (emotional, physical, etc.) to another person or group. It can be occasional (random acts of) violence (e.g., two people fighting in a bar) or systemic violence (e.g., femicide). It is not difficult to see how many instances of violence, in humanitarian contexts, are profoundly systemic. If most publications reviewed did not explicitly discuss this concept per se, it nonetheless reflects many publications that address ethical issues arising in humanitarian crises situations. Funk et al. explicitly discuss how violent targeted attacks on humanitarian healthcare facilities raise serious ethical concerns for workers: "Respondents reported instances in which workers were injured, kidnapped, killed or threatened with violence, as well as situations where their organisation's facilities had been deliberately and systematically targeted […]" (42, p.137).

Possible Responses to the Ethical Issues of Humanitarian Work

Few of the publications reviewed proposes possible responses to the ethical issues presented in the literature. Indeed, only six publications (out of a total of 83) discuss possible responses, which can be divided into two broad categories: 1) responses meant to prevent potential harms associated with ethical issues (prevention), and 2) responses aiming to address the negative consequences of these issues (restoration).

Some publications offer critical reflections that comprise the beginnings of solution frameworks, as is the case of Smith (33) and Kiddell-Monroe et al. (26). In his article, Smith offers a relevant reflection on *resistance* and the ethics of refusal, which "seeks to promote structural justice by refusing to bow to systemic causes of inequality" (33, p.17). Smith draws on the works of Rubenstein (47), who develops "an ethics of resistance" framework in order take into account "the multiple and often conflicting responsibilities of humanitarian organisations, and necessarily prompts that they justify their actions – and similarly any corresponding inaction – in any given setting" (33, p.17). For Smith, resistance is not simply about rejection as a simple refusal would entail; rather, it invites humanitarian workers to stay alert and open-minded about the struggles that come with making the best possible ethical decisions. Such resistance, for Smith, comes with a "continuous reflection and evaluation" of one's actions and decisions and requires "transparency and accountability". Thus, Smith's proposition is mostly preventive, i.e., it seeks to respond to humanitarian ethical issues before they arise or to counter them at the outset (whereas reparative responses would aim to respond to issues that have occurred and currently cause problems). It could even serve as the groundwork for future research on the topic, especially for work that seeks to develop comprehensive decision-making frameworks to guide and help humanitarian workers in the field. On this, Kiddell-Monroe et al. provide interesting insights into future ethical plans by MSF. They highlight how the organization is currently reflecting on how to create "a simple framework for ethical reflection that can be easily used at both project level and headquarters alike" (26, p.265). Such a framework could, according to these authors, facilitate much needed dialog within all levels of the organization about "complex and often emotional issues" (p.265).

Other publications propose practical responses to one or some of the problems that they discuss. This is true for Wright (96) and for Yimer et al. (52). Wright proposes an ethical compass to guide decision-making by humanitarian workers who conduct research in the field. The compass draws extensively on the results of the international working group established by the Nuffield Council on Bioethics, the aim of which was to explore the ethical challenges arising in conducting research in emergency settings. The ethical compass comprises three core values: 1) "equal respect (respect for others as moral equals)"; 2) "fairness"; and 3) "helping reduce suffering" (96, p.516). Wright mentions that, following the values presented in the compass, the report highlights "four key recommendations": 1) "work closely in partnership with emergency responders"; 2) "invest in community engagement mechanisms"; 3) "promote fair collaborations between research institutions in low- and high-income countries"; 4) "support emergency planning, including helping secure robust health and research systems" (96, p.517). While this ethical compass is meant to help humanitarian workers' decision-making when conducting research in emergency settings, it is worth noting that it could be used as a guiding tool in many more humanitarian settings. This is also the case for the solution identified by Yimer et al. (52). In addressing crisis situations in which multiple ethical issues may arise, especially harm to humanitarian workers, the authors emphasize the importance of training and preparations "in conflict resolution […] community engagement", and "in principles of ethics [and] consent" (52, p.5), to minimize risks and help make the better resolve ethical issues.

Finally, Rubenstein et al. (47) and Zientek and Bonnell (78) develop holistic solution frameworks meant to address ethical issues in general, as they arise in humanitarian work contexts. While both publications provide steps to follow to address ethical issues, Rubenstein et al.'s aim is mainly preventive whereas Zientek and Bonnell's aim is mostly restorative. Rubenstein et al. (47), in discussing the ethical challenges arising for humanitarian healthcare providers workers in settings of extreme violence, propose five recommendations to help ethical decision-making. First, they recommend to "commit time and resources to addressing key ethical issues" faced by the organization and its workers (47, p.32). Second, they recommend articulating "clear ethical and humanitarian principles as a foundation to address the challenges" faced (p.32). The third recommendation emphasizes the need to "provide regular training and support in ethics to staff within the organization" (p.33). Fourth, they highlight the need to "create processes and mechanisms within the organization to support ethical decision-making and recording and disseminating the decisions" (p.34). And fifth, they recognize the need to "provide support for mental health and psychosocial support needs of staff and others supported by the organization who must make ethically challenging decisions" (p.33). Similarly, Zientek and Bonnell (78) suggest four steps for managing and rectifying ethical harm inflicted within humanitarian medical practice. For them, these steps identify what is "an appropriate response to harmful events when they occur" (p.337). First, they highlight the need for "prompt recognition of the harm caused by an intervention" and encourage actions attempting "to correct or minimize the harm" (p.338). Second, they suggest that workers involved in the harm should "investigate the possible causes of the adverse event" (p.338). Such investigation should lead them, in step three, "to a determination of additional measures to mitigate the harm" as well as an understanding of the possible "changes in practice for future missions to help prevent harm from recurring" (p.338). Finally, "The fourth step in responding to adverse events when they result from a preventable error is an apology to the patient or surrogates" (p.338).

DISCUSSION

The purpose of our systematic literature review was to identify the ethical issues arising in humanitarian work and some possible responses to them. Regarding the ethical issues discussed, our research revealed a predominance of ethical issues shaped by subjective experiences, which are themselves formed by a singular context, specific to humanitarian work. In other words, ethical issues arising from subjective experiences (e.g., ethical myopia or ethical distress) are particularly evident when they are situated in the practical context of their development in humanitarian work (e.g., doing more with less). Many of the subjective experiences identified overlap either with other subjective experiences (e.g., ethical silence overlapping with ethical myopia, cf. 36), or with other pragmatic (e.g., ethical pressure overlapping with the possible nuisance of helping, cf. 9) or even organizational issues (e.g., ethical dilemma overlapping with impartiality and neutrality, cf. 27). The ethical issues identified in the literature point to pervasive problems inherent to humanitarian practice itself. This is consistent with a previous step of our review (3), in which we observed that, for some authors, humanitarian work contexts can profoundly shape the use and meaning of ethical concepts.

Regarding solutions to ethical issues, only a minority of publications (n=6/7.23%) propose solutions to the issues that they raise. Nevertheless, it is worth noting that possible solutions, while sometimes innovative and elaborate (in that they had both preventive and restorative aims), appear to stem only from the authors' theoretical considerations. In fact, none of the publications that discussed solutions document the concrete actions that could be implemented in actual humanitarian practice and by the key humanitarian actors involved, in order to address the problems raised (beyond strictly theoretical frameworks). Moreover, it is interesting to note that the solutions identified in this research consider the structural causes that allow ethical issues to persist, which is different from previous analogous research findings by one of the present authors (97), in which occupational therapists tended to focus on micro-environmental solutions despite their acknowledgement of the macro-environmental nature of their problems. Finally, although only 18 out of 83 publications (21.7%) have empirical foundations, most of the literature discusses ethical issues arising from the lived, day-to-day work experiences of humanitarian actors. One might have expected, given the large theoretical proportion of the corpus reviewed, that the issues identified would have focused more on the structural or organizational dimensions of the issues.

One of the major strengths of this article is that it provides a broad and systematic overview of the humanitarian ethics literature, something that has seldom been approached in this way. By reviewing a large body of texts, including peer-reviewed and non-peer-reviewed publications and book chapters, and in both French and English, we were able to address some important elements that might otherwise have been overlooked. Further, in this article, we did not merely point to ethical problems discussed in the literature, but also highlighted relevant responses to humanitarian ethical issues proposed by various authors. Nonetheless, while the body of texts included in our study is bilingual (French/English), relevant publications written in other languages may have been missed – a limitation based on our own linguistic competencies. This predominantly Western perspective could thus bias the results of this review, which thus points to the pertinence of similar studies being conducted in other languages.

While the picture of ethical issues, and their possible solutions, presented here are broad, stemming from the large number of publications consulted (and which were published between 1990 and 2020), we recognize that they may reflect a gap between actual fieldwork and research. In fact, the relative paucity of empirical research points to a need for greater attention by scholars of humanitarian health ethics. Further, we acknowledge that in humanitarian work there may arise issues pertaining to independence. Indeed, while there may be situations of ethical drift related to dependence of humanitarian work on political, spiritual, religious or commercial aspects, it is unfortunate that our review found virtually nothing to say about this, *per se*. Finally, we recognize a limitation in grouping together vast and sometimes exclusionary areas of humanitarian (such as humanitarian research under general humanitarian issues). Perhaps if we had used better targeted keywords, we would have found more targeted articles that would have allowed for better precision in separating humanitarian areas. Our priority was to use the broadest possible definition of humanitarian work in order to best identify the full range of issues we were looking, i.e., ethical issues arising in humanitarian work, and in this we succeeded.

CONCLUSION

This article presents the results of a critical systematic review of the literature, which provided a comprehensive overview of the ethical issues arising in humanitarian work, and possible responses to these issues. A large and diverse number of ethical issues were identified, which we classified according to three dimensions: a subjective dimension, a pragmatic dimension and a cultural-political dimension. While the majority of the issues can be classified in both the subjective and pragmatic dimensions, we noted that 1) most publications deployed theoretical perspectives (see Table 2) and 2) solutions, when present, focused primarily on structural causes. The results of this study will, we hope, support the ethical practice of humanitarian workers and the operation of humanitarian organizations, by providing them with the words to name the ethical issues that are susceptible to arise in their work. Making more accessible this ethical language is an important step toward enhanced ethical awareness and preparation. Considering that this study identified important gaps in the literature (i.e., a seeming lack of empirical research on these issues and, above all, the possible responses to them), it would be relevant to evaluate empirically the responses that we have reviewed, an important step in assessing their effectiveness to adequately address the ethical issues experienced by humanitarian actors in various contexts. Longer term, such research could then promote better documentation and understanding of which solutions work best, and be an important step towards alleviating problems such as ethical distress (54).

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Who Protects Clinical Learners in Canada? Ethical Considerations for Institutional Policy on Patient Bias

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Résumé
Naviguer dans la dynamique sociale des espaces cliniques peut être un défi supplémentaire aux complexités du travail clinique. Il a été démontré que les actes de partialité et de discrimination de la part des patients affectent les travailleurs de la santé à la fois physiquement et psychologiquement. Alors que l'on s'intéresse de plus en plus à la discrimination par les patients, nous attirons l'attention sur les expériences et les besoins uniques des apprenants cliniques. Étant donné que les apprenants jouent un rôle vital dans le fonctionnement des écosystèmes hospitaliers, nous préconisons d'inclure leur voix dans toute révision de la politique et de la pratique. Dans cet article, nous examinons de manière critique la littérature académique sur les expériences des apprenants en matière de mauvais traitements de la part des patients et de leurs familles. Nous soulignons les principales lacunes en matière de politique, de processus, de formation et de culture institutionnelle, ainsi que le besoin urgent pour les institutions de combler ces lacunes d'une manière qui soit significative pour les apprenants. Notre objectif est de mettre en évidence le manque d'attention acordée par la bioéthique et de proposer des domaines dans lesquels nous pouvons apporter une valeur ajoutée et un soutien. Dans cette optique, nous présentons une série de tableaux contenant des valeurs directrices, des considérations éthiques et des questions à l'intention des institutions.

Mots-clés
patients racistes, mauvais traitement des apprenants, préjugés des patients, apprenants cliniques, bioéthique, politique institutionnelle, enseignement des professions de santé, soins de santé au Canada

Abstract
Navigating the social dynamics of clinical spaces can be an added challenge to the complexities of clinical work. Acts of bias and discrimination from patients have been found to affect healthcare workers both physically and psychologically. As more attention is paid to addressing discrimination by patients, we raise attention to the experiences and unique needs of clinical learners. Given that learners play a vital role in the functioning of hospital ecosystems, we advocate for the inclusion of their voices in any revision to policy and practice. In this paper, we critically examine the academic literature on learner's experiences with mistreatment from patients, and their families. We outline the major gaps in policy, process, training, and institutional culture, noting the urgent need for institutions to address these gaps in ways that are meaningful to learners. Our goal is to highlight the lack of bioethics attention to this matter and propose areas where we can add value and support. With this goal in mind, we present a series of tables with guiding values, ethical considerations and questions for institutions.

Keywords
racist patients, learner mistreatment, patient bias, clinical learners, bioethics, institutional policy, health professions education, Canadian healthcare

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INTRODUCTION

The detrimental impact of racism has received much scholarly and applied attention across various disciplines and professions over the last three years. Following the 2020 public murder of George Floyd, an African-American man brutally murdered by police in Minnesota, USA, and the nationwide outrage in Canada over the 2020 death of Joyce Echaquan, an Atikamekw woman who died as a result of being subjected to racism and a lack of proper care during a hospital stay in Quebec, many within Canadian healthcare have called for greater scrutiny to the harm caused by structural and interpersonal acts of discrimination and oppression. Clinical spaces are not exempt from such acts; in fact, they ought to be viewed as microcosms of society – experiences of discrimination are not left at the doorstep of the hospital but rather permeate the walls of the institution. In these spaces, bodies of difference are surveilled and scrutinized in ways that often amount to experiences of inequity.

Bioethics, like medicine, nursing, occupational health, and social work, has been called to turn its gaze inward to examine the harms that are caused by the whiteness of the field and the lack of attention to the lived and material reality of discrimination in healthcare. There are topics within the bioethics realm that, to-date, have not received sufficient attention despite the inherent ethical spaces they occupy. One such topic is the ethics of patient bias – e.g., discriminatory requests and refusals of care from patients, verbal or physical actions or statements rooted in discriminatory attitudes or beliefs – that are based on the social identity of the clinician. The academic literature on patient bias is dominated by scholarship on patients as the *targets* of discrimination, but very little attention has been paid to patients as the *source* of discrimination. Studies that have explored

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discrimination from patients predominantly focus on the harrowing experiences of medical professionals, with some attention to the plight of physician learners. Clinical learners across the health professions are particularly vulnerable to discriminatory behaviours given their junior status and the power imbalances that are associated with their roles. Despite legal obligations to protect learners from physical and non-physical harms, including dignitary harms, inadequate organizational responses contribute to the overwhelming silence that learners tend to endure after experiencing bigoted behaviour from patients.

The aim of our paper is to challenge this culture of silence by drawing attention to the nuances of learners' experiences with patient bias. Our aims are threefold: first, we provide a critical review of learner experiences in hospital settings; second, we examine notable barriers and challenges faced when responding to patient bias; and third, we outline individual and institutional responsibilities necessary for the protection of learners. We conclude with an overview of the policy, process, and training gaps in this area and then outline the ethical values to weigh, and questions to consider, when examining what protection, training, reporting, and support for learner mistreatment ought to entail.

The Experience of Clinical Learners in Hospital Settings

Clinical learners play a vital role in the functioning of hospital ecosystems. Navigating the social dynamics of clinical spaces can be an added challenge to the complexities of clinical work. Although the experiences of clinical learners in teaching hospitals is a relatively understudied area, the experiences of medical students, residents, and fellows are captured in the wider academic literature (1-11). An obvious gap in this scholarship is information about or examination of the experiences of non-physician learners, that is, in other health professions such as nursing, occupational therapy (OT), physical therapy (PT), respiratory therapy, and social work (12-18). This gap applies to the broader literature on the topic, as well as more specifically to academic scholarship on the experiences of health professions learners in Canada.

The few reports that exist regarding the experience of clinical learners in Canada focus on physician learners as the primary source of data. The "Voices" surveys – Voice of the Medical Student, Voice of the Resident, and Voice of the Clinical Fellow (19) – seem to be the primary tools used to garner feedback on the clinical experiences of medical learners in Canada. While these surveys are helpful in shedding light on the experiences of physician learners, they also highlight the critical gaps in broader understandings of learner experiences in Canada. For example, there has been little attention to how racialized[1] clinical learners in the nursing and allied health professions may be uniquely affected by patient, family, and visitor mistreatment (19). Further, a lack of attention to Indigenous learner experiences points to the ongoing erasure of Indigenous experiences in Canadian healthcare research and education.

The misconception that discrimination and systemic oppression are uncommon problems in Canadian healthcare, and healthcare education more broadly, can be attributed in part to the preceding and prevailing whiteness of the medical field and healthcare leadership more generally (7). In reality, harassment and discrimination are dominant themes of the clinical learner experience (21). In a study conducted at the University of Toronto Temerty School of Medicine, 54% of residents and 46% of fellows reported experiencing harassment or discrimination during their clinical rotations (21). Furthermore, 49% of medical residents identified patients and their families as the primary source of this mistreatment (21). Data from the 2019 "Voice of the Resident" and "Voice of the Clinical Fellow" surveys revealed that, of the respondents, 64% of physician residents and 39% of fellows across hospitals and clinical programs reported exposure to incivility including, but not limited to, disrespectful behaviour, verbal assault, bullying, sexism, racism, classism, Islamophobia, antisemitism, sexual harassment, threats of physical harm, and assault throughout the course of their previous year's training (21).

Despite discrimination being a consistent theme of the medical learner experience in the Toronto context, nuanced qualitative accounts on the nature and extent of these experiences are lacking. A scan of the wider literature reveals some phenomenological accountings in other geographical contexts (2,4,5,9,11,22-30), yet these tend to be narrowly focused. The existing work in this area examines the impact of discrimination on learners (9,15-18,22,25,31,32), the differential experience for minoritized learners (2,4,5,9,11,13,15,18), the difficulties in responding to discrimination (3,5,7,8,9,11,15,17,26), barriers to reporting (5,9,14), and the lack of institutional resources and support from clinical supervisors (7,15,18,30,33). We explore the nuances of each of these issues, below.

Acts of bias and discrimination from patients have been found to affect learners both physically and psychologically (9,25). This includes experiences of stress, fatigue, emotional distress, and trauma that often lead to decreased job satisfaction, burnout, withdrawal from practice, distracted learning, and an inability to focus on professional development (9,16,17,22,31). The psychological impact of patient bias has been described as "a long-term, well-ingrained sense of humiliation" (16, p.716) that accompanies feelings of fear, uncertainty, rejection, exclusion, and cynicism (9). These experiences can and often do contribute to imposter syndrome amongst learners (2,3,32), whereby one constantly questions one's ability, belongingness, and capacity to succeed in a program.

While all learners might experience discrimination from patients in some form (including discrimination solely because of their identity as a learner), racialized learners, and those who embody difference (relative to the white, cisgender, heterosexual

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[1] The term 'racialized' is applied here and throughout the text to acknowledge that race is a social construct (20). Historically and contemporarily, racialization has been weaponized as a process to separate Black, Indigenous, and People of Colour (BIPOC) from the dominant white group to uphold a system of white supremacy. We recognize that in some contexts, 'white' may also be racialized; however, for the purposes of this manuscript, we use the term to refer to non-white groups.

male prototype) tend to be disproportionately targeted (5). Learners who identify as women, and those who identify as Black, Latinx, Asian, and Muslim experience a higher rate of misidentification, role-questioning, racial slurs, physical and verbal abuse, sexual harassment, and refusals of care (2,4,5,9,11,13). Biased reassignment requests or refusals of care from a patient's substitute decision-maker, family member or essential care partner also occur but are seldom documented (1,9,10,14,34). Despite observations that biased refusals of care are more commonly made by family members than by patients themselves (16), the nuance and veracity of this claim remains unexplored, particularly in relation to clinical learners. Furthermore, literature documenting patient bias policies across health systems and institutions remains relatively sparse and contains very few concrete steps or specific processes (as well as roles and responsibilities) for handling these interactions when problematic behaviours are directed toward learners (34,35).

The personal accounts of clinical learners convey the gravity of this issue and the urgency with which incidents of bias from patients and/or their family members ought to be addressed. The few personal narratives recounted in the wider literature reveal that clinical learners have experienced both physical and verbal assaults as well as degrading and demeaning behaviours (30,33). For example, Bonsu recounts her experience having a patient spit at her, try to bite her hand, and scream "Get off me, you dirty Black monkey!" (33, p.1462). Williams and Rohrbaugh describe a patient's use of the N word being repeatedly weaponized against Williams while training as a resident physician (30). Despite attempts to redirect the patient with compassion, the patient refused to acknowledge Williams' presence or even his humanity (30). Sadly, in each of these incidents, the supervisor did not address the patient's behaviour, nor check-in with the learner to offer support or inquire into how they wanted it to be addressed (i.e., whether they wanted to be removed from the patient's case). These types of experiences are not new, nor are they reserved for Black learners. Others have reported on the prevalence of patients demanding to be seen only by a white doctor (26) or explicitly refusing care from clinicians of a particular ethnicity, e.g., patients expressing that they "do not want an Arab to touch" them (16, p.715). In addition to refusals, racialized physician learners described having their medical credentials questioned by patients (26) and female physician learners reported having their role questioned so often that it hindered their ability to do their jobs (22).

Similar to the aforementioned physician leaner experiences, learners from other disciplines report refusals of care and verbal abuse in the forms of threats, racism, swearing, and sexual insults (13-15,18,36). It has been argued that nursing staff (especially nursing students) are subjected to biased refusals of care and abusive behaviour more often than physicians due to the high frequency and closeness of interactions with patients and families (16). Additionally, the culture of sexualization towards nurses may result in nursing students being particularly vulnerable to sexual harassment in comparison to learners from other disciplines (12,13,37). Nursing students have reported extreme cases of verbal abuse from patients and their families during clinical placements, often involving racial and sexual connotations (13). The nursing students in Ferns and Meerabeau's study describe being told "I don't want any Black monkey to come to my bedside, f… off', being called "a dirty whore" and being told "...all nurses should be f...ed to show them who's boss" (13, p.440).

In addition to being sexualized, some learners, based on the nature of their discipline, might also be more likely to experience physical acts of aggression or unwanted touching from patients. For example, learners from disciplines that embed movement in their approach to care (such as PT and OT), might experience the added dimension of unwanted physical contact from patients. Steinkamp's study with 'underrepresented minority' PT learners highlights how unwanted touching from patients can sometimes be entwined with the provision of care (18). A PT learner in the aforementioned study described her experience as follows:

> I was treating an older White woman with an ankle sprain. She grabbed and rubbed my hair and said 'Wow, your hair is just so fun.' I was immediately taken aback. My clinical instructor (CI) and I talked about how what she did was inappropriate. I saw the same patient 2 more times, and she touched my hair both times and made a remark about how it felt. I felt very uncomfortable with this. My CI had stated that they would intervene if it happened again, but they did not. Looking back, I should have said something right away to stop this behavior; however, I did not know how my CI would respond to me doing so (18, p.S63).

The discomfort experienced with such an encounter can be destabilizing for learners, especially if the incident is not addressed by their supervisor.

RESPONDING TO BIAS

Multiple barriers exist for learners when deciding whether and how to respond to incidents of patient bias; these include: 1) feeling a need to prioritize clinical care, 2) experiencing uncertainty in their ability to respond effectively, 3) sensing an absence of support from their team, supervisors, and organization, and 4) lacking knowledge concerning related policy (9). Additionally, learners' junior status within the conventional medical hierarchies, their limited experience, clinical autonomy, and confidence in their roles restrict their ability to respond when subjected to biased patient conduct (11,26). As a result of these barriers, many clinical learners compartmentalize experiences of bias, avoid confronting them directly, and continue to care for patients at the expense of their own safety and personal dignity (3,5,8,9).

Responding to these instances can be just as difficult as it is to endure them in the moment, particularly for racialized learners. They might feel voiceless in responding to acts of bias or feel that they cannot react in ways that protect their dignity because of the pressure to be perfect and perform at a higher level than their white colleagues (7,8,15,17). It is likely that they also undergo a different level of scrutiny insofar as societal biases inform how trainees are evaluated (38). Racialized learners describe feelings of exclusion, isolation, and a lack of support and recognition within the clinical education setting (7). Some make calculated decisions to downplay their identity including disguising visible identity markers to reduce the frequency of indignities experienced (8,17). These experiences disadvantage racialized learners, leading to higher turnover rates and greater academic disparities that hinder professional development as well as institutional attempts to bolster diversity and inclusion within healthcare professions and leadership (2,3,32).

The aforementioned points are directly applicable to the experiences of Black learners. Black physicians in Ontario, for example, report that experiences of overt racism and prejudice from patients were routinely unaddressed or dismissed by their white supervisors during their medical training (7). This is the case, despite there being higher reported rates of mistreatment among Black and Indigenous learners, other racialized learners, women, individuals identifying as 2SLGBTQIA+, members of minoritized faith groups, and learners living with a disability (21,39). Leaving these incidents unaddressed results in learners feeling unsafe, excluded, and isolated, and contributes to a general reluctance to report incidents of patient bias (7,21). Approximately 95% of Black physicians who reported experiences of race-based mistreatment had not received training on how to respond to such incidents and consequently internalized or ignored negative encounters (7,40). Over the course of their training, some Black physicians sought support and guidance from other Black colleagues, as well as family and friends (7). As a result of this self-directed coping, they developed strategies to self-advocate and the skills needed to respond directly to verbally abusive and biased patients (7).

When learners feel confident and supported to respond directly to acts of bias, they report setting limits, developing plans with their teams, and explaining to patients the effect of biased behaviour on their clinical care (5,9). Some learners report that they debrief biased incidents informally with colleagues, friends, and family members (5,7,9). Responding effectively is associated with improved feelings of competence and a greater sense of inclusion within the team and profession (9). The ability to navigate these interactions is a skill that must be taught and ought to be embedded in clinical education, as is the case with other clinical competencies.

Pean and Hart maintain that it is unethical for clinical learners to capitulate to discriminatory conduct by patients, thereby sacrificing their own dignity in the service of a problematic ideal of clinical neutrality (26). In a healthcare context, any approach to biased patient conduct or reassignment requests must consider the acute care needs of the patient as different clinical contexts necessitate different responses (25,34,41). For example, responses to patient bias in the emergency department generally would entail different considerations than might a rehab context. Furthermore, different contexts might invoke varying degrees of altruism on the part of the healthcare worker. In emergency contexts, where the focus is on stabilizing the patient, one might argue that patient safety should be prioritized over staff wellbeing. The tension between patient needs and healthcare workers' rights is further complicated when applying Ontario's human rights code (42). Though there are further nuances to unpack within the context of occupational health and safety, healthcare workers cannot be made to endure continued exposure to violence, harassment, or discrimination as this would constitute a contravention of employee rights (42). The same argument applies to learners' rights to train in a discrimination free environment.

The motivation of clinical learners to prioritize the clinical needs of the patient, and in many cases, the therapeutic relationship over their own dignity and well-being (9), reflects medical cultural norms and an ethic of care (43). This is further amplified for learners in caring professions, such as nursing, in which having empathy for patients is expected and any act of assertiveness in the face of abuse can be interpreted as uncaring (14). Expectations of resiliency and self-sacrifice are normalized within healthcare culture; for racialized clinicians, this often means bearing personal humiliation and overlooking violations of personal dignity in order to compartmentalize emotions and proceed with biased patient encounters (26,33).

Learners may or may not report harmful incidents based on the severity of the violation experienced and the emotional labour that is required to escalate the concern (5). Deciding whether, when, what, how and to whom to disclose or report experiences of bias is a common challenge reported by learners (5,9,14). Some describe feeling reluctant to report incidents of patient bias due to an array of institutional and interpersonal barriers (5,14). These include: 1) the perception that no positive change will follow, 2) a lack of support from supervisors and leadership, 3) feeling compelled to prioritize clinical care, 4) fear of appearing unprofessional, and 5) a sense that the emotional burden of pursuing a claim is too high (5,9).

INDIVIDUAL AND INSTITUTIONAL RESPONSIBILITIES TO CLINICAL LEARNERS

Targeted pathways addressing bias toward clinical learners ought to include consideration of the unique vulnerabilities and power differentials at play. In a competitive training environment, learners, as temporary members of the interdisciplinary team requiring evaluation for completion of their program, are limited in the extent to which they can safely advocate for themselves (31). Given their unique vulnerabilities, there ought to be both individual and institutional protections in place to safeguard against dignitary harms and other violations. Individual and institutional responses to bias take many forms. Examples that offer varying levels of protection to clinical learners include patient reassignment and the use of behaviour contracts as a means of enforcing compliance (9). However, despite the common use of these contracts within health systems, there is little evidence of their efficacy; instead, they raise concerns about health equity, accessibility, and patient-centred care (44). The false sense of resolution that may come with implementing ineffective responses to patient bias risks the safety and well-being of clinical learners.

Supervisor and institutional responses to biased reassignment requests are variable and typically take either a zero-tolerance approach that entails: 1) refusing to replace a practitioner and leaving the patient to accept the decision or to seek care elsewhere, or 2) accommodating the patient's request, often on an ad hoc basis, without providing an ethical justification for the decision (16).

Appropriate and effective supervisor responses to bias or discriminatory reassignment requests ought to demonstrate respect for targeted learners and endeavor to prevent further harm or trauma (31). How, when, and to whom one responds all affect the ability of learners to thrive in the clinical setting. Actions that empower and support learner autonomy are most needed in these situations. Such acts can include: 1) checking in with learners who have been targeted by patient bias, 2) consulting with them in order to respond appropriately, 3) soliciting their consent for patient reassignment prior to acting (35), 4) showing support publicly and privately in the face of such acts, and 5) offering opportunities to debrief or unpack the experience with additional supports. Protecting clinical learners from patient bias through policy, guidelines, and training is the joint responsibility of academic institutions and partnering healthcare facilities. Organizational silence in the face of patient bias is tantamount to complicity and reinforces existing inequities. Stewardship of clinical learners' well-being, including their learning experiences, requires that hospitals, universities, and professional colleges commit to and collaborate in advocating for legislative protections for learners, systemic change, and social justice.

GAPS IN CONSIDERATIONS: ASKING CRITICAL QUESTIONS

As awareness of persistent institutional racism and other forms of systemic discrimination continue to surface at the forefront of institutional consciousness, a number of publications in the academic literature have focused explicitly on the gaps that currently exist and the changes that can be made. These gaps tend to be structured around the need for policy, better processes for handling patient bias, adequate training to respond to bias, and efforts to improve the culture of institutions. Table 1 below offers areas for improvement according to each corresponding gap.

Table 1: Recommended Areas for Improvement by Corresponding Gap

Gaps	Recommendations for Improvement
Policy	• Consistent guidance is needed to navigate the practical, ethical, and legal aspects of biased patient conduct and reassignment requests. This should include transparent and accessible mechanisms for reporting, reviewing and responding to data on biased incidents (5,26,30).
Process	• Robust, accessible reporting structures should be available to all staff and learners (45). This could include a designated committee or office for reviewing incidents of patient bias to ensure accountability for organizational response, adherence to policy and processes, a mechanism for data collection, and support for targeted learners (34). • Institutions should have transparent data collection processes that uphold values of privacy and security (23,30,45). • Institutions should disseminate findings that identify high risk areas and promote organizational accountability (23,30,45).
Training & Resources	• Tailored training should be provided to learners, educators, supervisors, and bystanders, indicating how to identify and respond to incidents of patient bias. This would include education about policies, processes, and support resources (5,16,30,31). • Scripts can be drafted to help learners redirect and de-escalate racist patients, to correct and set limits, and to safely refuse further assessment of the patient (30). • Training should be provided to learners and educators, as well as managers and supervisors, on how to lead safe and effective debriefs following incidents of patient bias (30). • Learners and supervisors should be provided with resources that identify internal and external support resources for those subjected to patient bias (5,31). • Healthcare organizations and academic institutions should share responsibility for the safety and well-being of clinical learners by integrating anti-bias education throughout training programs, and by tracking and responding to bias incidents, providing support to targeted learners, and fostering a culture that values diversity and inclusion (30).
Culture	• Institutional culture should address discomfort with conversations on bias, discrimination, and racism in healthcare (35). • Healthcare organizations should explore whether their culture exceptionalizes patient preferences without striking a balance between patient needs and staff and learner safety and well-being (34). • Visible leadership endorsement of anti-discrimination initiatives and promotion of a just and equitable organizational culture that protects and supports learners is needed to promote an equitable and inclusive environment (34). • Institutional leaders should acknowledge the hierarchical nature of healthcare education by noting that it raises barriers for clinical learners to address and report incidents of patient bias. Reporting should be encouraged without fear of retaliation, damage to reputation, or influence on evaluation (5,24). • Leadership should support recruitment and retention efforts to increase diversity and representation in all educational and professional stages of all healthcare professions (17). • Leaders and supervisors should acknowledge the influence of a healthcare culture that upholds implicit expectations of infallibility, toughness, self-sacrifice, and unwavering empathy within medical, nursing, and the allied health professions. This includes consideration of the impact of this culture on the mistreatment of learners, specifically racialized learners, within academic healthcare settings (14,31).

The aforementioned gaps noted in the literature are directly applicable to the Toronto, Ontario context. The need for clear policy, processes, training, and a broader culture shift has been highlighted in local change initiatives (7,19). In fact, Ontario learners have explicitly expressed a desire to raise awareness about the prevalence and impact of racism within Canadian healthcare and health professional education (7). Small steps have been made towards this goal. For example, in 2022, the Temerty Faculty of Medicine at the University of Toronto published the "Black at Temerty Medicine" report to raise awareness of the many ways in which anti-Black racism manifests within medical education. This report has since informed initiatives to target anti-Black racism within the Faculty of Medicine and could be used as a model for similar efforts aimed at calling attention to other insidious forms of discrimination and oppression that are active in Canadian medical education, most notably, anti-Indigenous racism. Not only are Indigenous knowledge systems, narratives, and lived experiences typically erased from medical education, but most (if any) inclusions are framed around harmful stereotypes that work to perpetuate negatives images (46,47,48). Accounting for difference in an inclusive way, noting the many lived realities and intersecting identities of people, and accounting for the experiences of non-physician clinical learners is a small first step towards addressing the critical gaps in our response to learner mistreatment in Canadian healthcare.

When discriminatory refusals of care are not handled appropriately, questions about the ethical climate and culture of the institution are justified. Most healthcare organizations have policies on how to address workplace violence and these generally include processes for documenting and reporting these incidents (e.g., through incident reporting systems via the institution's Safety Services department). However, patient bias and discriminatory requests or refusals of care have historically existed in a grey zone with policies specific to patient bias only recently starting to gain traction from a health systems perspective (34,35). Unfortunately, the same cannot be said for policies that solely attend to patient bias directed towards learners. Patient bias policies typically cover healthcare workers or staff members who are employed in the healthcare institution. Given that learners are affiliated with a home university or college and rotate through hospitals and other sites for their clinical placements, the nuances of their experiences, and their specific needs, tend to be overlooked in institutional health policy.

Initiatives that aim to redress the lack of guidance specific to learner mistreatment are underway for Ontario learners and educators. The Toronto Academic Health Science Network for education (TAHSN-e) recently developed a guide for faculty, supervisors, and learners to use as a resource when navigating and responding to incidents of learner mistreatment by patients, family, and visitors (49). The University Health Network (UHN), a TAHSN-affiliated hospital, has advanced its efforts in providing oversight and direction to all parties involved. Their new guidance document on learner mistreatment (50) draws on the TASHN-e guide as well as UHN's Caregiver Preference Guideline (51) to outline a process for UHN staff and physicians to prepare for and respond to incidents of learner mistreatment. This guidance document, along with UHN's Caregiver Preference Guideline, work to provide all members of UHN with appropriate guidance on how to navigate instances of patient bias, with the latter also addressing the ethics of discriminatory requests and refusals of care (51). Although UHN's Caregiver Preference Guideline is currently being revised to account for gaps in system responses that might contribute to non-physical harm towards staff or patients, these two documents share a commitment to the important task of documenting incidents as a means toward comprehensive data collection. Without knowing the prevalence and impact of these experiences, it is difficult for institutions to address the issue in ways that are meaningful to those confronted with and affected by mistreatment.

Mistreatment of learners and staff by patients, family members, and visitors should not be an issue that is addressed only by a select few (e.g., Bioethics departments or Clinical Education offices). There are institutional obligations that must be attended to by others stakeholders across the organization. For example, for patient bias incidents to be captured accurately and in ways that result in data that is actionable, there must be proper incident reporting forms and systems in place that recognize and account for the multiple ways that bias might materialize. On a broader level, non-physical harm (e.g., racism and other forms of discrimination) needs to be given the same level of credence and weight as physical harm when considering safety incidents across health systems. Non-physical harm events should also be formally recognized as workplace hazards and treated as such by Occupational Health and Safety departments. In addition to obligations from Safety Services, and Quality and Safety departments, Human Resources has a key role to play in ensuring that there are adequate structures, supports, and resources in place to protect staff and learners from both physical and non-physical harm. There are also legal obligations that must be attended to when ensuring that a workplace or learning site is free from discrimination (as per Ontario's Human Rights Code) (42). These points highlight that all stakeholders have a role to play in ensuring that hospitals, as sites for the receipt and provision of healthcare, are safe and discrimination free for all who work, learn, and access care.

Given that the principles of equity and justice are deeply embedded in the fabric of bioethics, we maintain that there is a special role for bioethicists in this matter. Bioethicists are well suited to address concerns of bias and mistreatment given the core skillset required for healthcare ethics consultation (e.g., conflict resolution, mediation, negotiation, and facilitation of public engagement) (52). These skills are often used to help establish and, in some cases, re-establish trust between patients and healthcare providers, or other parties that have become divided by acts engendering mistrust (52). Bioethicists also have a role in the development of fair and equitable policies and any resulting policy analysis. More specifically, bioethicists can help ensure that the lived experiences and perspectives of learners and staff are reflected in all policies that directly affects how these groups are treated in the organization.

Patient bias and discriminatory refusals are often jarring and traumatizing and can psychologically harm both the affected clinician and the quality of care provided. Addressing these incidents in a meaningful and effective way is an underexplored area of ethical interest and warrants deeper research and policy attention. In the section below, we present two tables that offer various considerations for those embarking on policy development or framework creation for handling learner mistreatment. Table 2 lists guiding values and ethical considerations to weigh. Table 3 is a series of guiding questions to reflect upon when considering what protection, training, support and reporting ought to look like within the context of learner mistreatment.

Table 2: Guiding Values and Ethical Considerations

Values	**Ethical Considerations**
Beneficence/ Non-maleficence	● What are the short- and long-term effects of mistreatment on learner wellbeing and their education? ● What is the effect on the learner’s ability to navigate similar interactions during the rest of their clinical placement? ● What are the obligations of specific institutions to address harms to learners? How might these differ based on site (i.e., university versus hospital)? ● How might the type (and size) of institution affect the level of resources available to address harms and provide support to learners? ● How might the reputation of each institution be damaged if learner mistreatment is not handled appropriately? ● What are potential short- and long-term consequences for learners if mistreatment is not addressed appropriately? ● How does status as a learner influence their ability to access employee hospital supports when facing mistreatment? What potential harms might arise from the lack of such access? ● What are the potential consequences of seeking university support when learner mistreatment occurs in the clinical setting?
Equity	● Which groups of learners are likely to be subjected to mistreatment? ● What added protections need to be implemented for learners from equity-deserving groups? ● Have academic and healthcare institutions considered the direct and indirect needs of learners when faced with mistreatment? ● What mechanisms are in place to capture learner specific needs with respect to mistreatment? ● What equity-related considerations need to be attended to when capturing learner specific needs? ● What conditions are in place to ensure that learners from equity-deserving groups feel safe to explicitly share their needs? ● What support mechanisms are available to learners who encounter triggering situations that are not recognized as such by their supervisor? ● How might programs avoid exacerbating existing disparities? ● What potential barriers are learners likely to encounter? What steps will be taken to remove them?
Fairness	● What opportunities are available for learners to prepare themselves to respond to these situations effectively? ● How might these experiences affect the clinical experience and education of marginalized learners compared to others?
Transparency	● How is information on the nature, frequency, and prevalence of mistreatment experiences made available to learners prior to the start of their placements? What information is made available regarding institutional procedures and supports for handling learner mistreatment? ● How can institutions effectively address learners’ apprehensions about potential repercussions associated with reporting mistreatment? What assurances will be provided to foster a safe and supportive environment for voicing concerns?
Accountability	● Who is responsible for protecting learners? Within program structures, are there designated leads who are accountable for ensuring learners have a pathway to report mistreatment? ● Are there established accountabilities at professional colleges or associations concerning how learner mistreatment ought to be handled? ● Are there other partnerships that ought to be involved in the university-hospital relationship to enhance learner protection at a broader level?
Privacy	● How are learners’ privacy rights safeguarded when incidents occur? Who is the incident shared with so that it is escalated via the right channels while also protecting the learner from unintended consequences? ● When incidents occur in the clinical environment, are reporting relationships structured to ensure that the university or professional school is informed of the incident in a manner that allows them to provide needed supplemental support, whilst respecting the learner’s privacy?
Reciprocity	● What are the learner’s expectations of the clinical environment? ● What are the learner’s expectations of their supervisor’s ability to recognize and attend to mistreatment? ● Given the partnership between educational institutions and the healthcare environment, what can learners reasonably expect in terms of protection from unsafe or traumatizing experiences? ● What responsibilities do institutions have in terms of providing learners with safe environments for their learning and educational activities? ● Do institutions meet the expectations learners might have for a discrimination or mistreatment-free environment?
Stewardship	● If learners are removed from particular interactions, are there steps to ensure that they are given opportunities to be involved in other cases? How will the learner’s education be supplemented to ensure that there are no gaps in their exposure to particular cases, programs, clinics, types of care provision?

Table 3 below presents guiding questions for institutions to reflect upon when considering training, reporting mechanisms, and supports that ought to be made available to help learners navigate incidents of mistreatment.

Table 3: Guiding Questions for Institutions

Themes	High-level Questions	Example Considerations
Protection	● What does protection look like for clinical learners?	● What do learners consider adequate protection or appropriate responses to mistreatment? ● From an equity lens, what might protection look like for racialized learners or those from underrepresented groups? ● Are there learner-informed materials and processes that consider the nuances of their lived experience as well as the tensions associated with power differentials? ● Are learners made aware of organizational policies, their legal rights and protections, as well as any other available resources prior to the start of their placements?
	● What are the obligations of the institutions involved: 1) university, 2) hospital 3) college, etc.?	● What institutional processes are there to protect against these types of experiences? ● Are there mandatory legislative obligations that include protections for learners? ● Are there services or supports, akin to WSIB protections for workers, that provide protection for learners? ● Are there learner-centred policies that capture this issue? ● Does the clinical education department cover all the necessary education prior to and during the placements? ● Are learners aware of the various reporting mechanisms available to them? ● Do learners know who to approach when incidents of mistreatment occur, and do they feel safe enough to speak up when situations arise? ● Does each institution have a confidential or anonymous process for safe reporting? E.g. Whistleblower hotline? ● Does each institution have a safe-haven program for clinical learners to feel safe in accessing support?
Training	● What training needs to be available for supervisors to ensure that they understand and appreciate the experiences of learners? ● What training needs to be available for supervisors to ensure they are capable of providing appropriate supports and resources? ● What training needs to be developed to teach learners how to navigate such instances in the moment? (Particularly important where there might not be a supervisor present).	● Supervisors should be able to recognize the differential impact of harmful interactions on racialized learners and acknowledge that learners will have a range of experiences and reactions. What pre-work is necessary to optimize the skills of supervisors such that they can recognize when a learner's identity characteristics might be influencing how a patient is responding to them? ● What training will be provided to ensure that supervisors do not inadvertently re-traumatize learners via their responses or failure to respond to incidents involving mistreatment? ● Are there simulated cases for all supervisors focused on appropriate ways of addressing these scenarios (informed by the needs and preferences of learners)? ● Do supervisors undergo evaluation with respect to how they respond to these scenarios? ● Is there an institutional level feedback process or evaluation of supervisors' skills from the learners' perspective? ○ If a clinical learner is exposed to biased, racist, or other harmful behaviour from patients or their family members or visitors, and the supervisor does not adequately respond or support the learner, what mechanism is in place to make the educational institution aware of the realities of the learner's experience? What mechanisms are there to alert the supervisor's direct report to the supervisor's success (or failure) to provide adequate support? ● Are supervisors capable of discussing issues related to inclusion, diversity, equity, accessibility and anti-racism (IDEAA) as they relate to learner experiences of mistreatment? ● What training is needed for supervisors who are uncomfortable with speaking to issues of racism, bias, or discrimination? How does the institution ensure that all supervisors have had some form of anti-racism training? Should they be encouraged to undergo more training to improve comfort with attending to these issues in the clinical context? ● What simulated training ought to be designed to teach learners how to respond to incidents in the moment and afterwards? Should this be mandatory preparation for learners before they begin any clinical placement?
Support	● What supports should be made available to clinical learners in the hospital? ● What processes need to be in place to ensure that if learners are exposed to blatant racist or demeaning behaviour or language, that they have avenues to cope, address, and resolve any emotional distress? ● Do learners feel that the clinical environment is respectful and supportive?	● What supports should be provided to clinical learners working in clinical environments? (Employee Assistance Programs typically offer 24 hour support only to staff members, whereas university mental health supports for learners are only available from 9am – 4pm, on weekdays). ● Which healthcare-related services are available for consultation, if any? Bioethics? Social work? Spiritual Care? An office devoted to IDEAA? ● Supervisors should be able to offer support to learners before engaging in sessions that might be conflict heavy or where they suspect that interactions might become emotionally charged. What pre-work is necessary for supervisors to offer appropriate support? ● Is the learning environment one that is supportive of addressing these concerns? Do learners feel empowered and encouraged to share when they have been exposed to discriminatory behaviour and to identify when they might need support? ● What conditions must be met for the environment to be considered safe enough for learners to share when support is needed? ● How will supervisors discern whether the learner's support needs have been met?
Reporting	● How can incidents be reported? ● Is data disaggregated to distinguish learner-involved incidents separately from those experienced by staff?	● What kinds of feedback or data are being collected? ● At what level is data currently being collected, if at all, e.g., program vs. department vs. discipline? ● What reporting tools exist for clinical learners? ● Who is responsible for monitoring these data, and identifying which programs or institutions are in need of urgent intervention or change?

CONCLUSION

Navigating clinical environments can be as difficult for healthcare workers as it is for patients. This is particularly true for those who are also evaluated for the work they do, as is the case for clinical learners. Given the hierarchy and power dynamic inherent to clinical spaces, much reflection is needed on how to best protect those who are at an increased risk of harm. This paper provided an overview of the current literature on clinical learners' experiences navigating patient bias, as well as discriminatory requests and refusals of care. We showed that the learner status, in addition to the multiple intersecting aspects of the learner's identity, affect how patients, their family members, and visitors respond or react. We outlined the differential experiences of racialized learners and those from marginalized backgrounds, noting the many sacrifices made to one's dignity and overall wellbeing. The paper highlighted that the challenges do not end with experiences of bias and discrimination; they are compounded by challenges in both responding and reporting. Despite these critical concerns, the nuances of learners' experiences and the conditions under which they work are not captured in sufficient detail in the wider literature. In response to these clear gaps, we outlined key areas for improvement in the scholarly and policy realms, noting small advancements made in our local context, in Toronto, Ontario. Future work ought to include the voices of the broad spectrum of clinical learners on what is needed before, during, and after incidents of patient bias, and ways in which responsible parties can provide meaningful support. We further call for broader bioethics engagement with this issue as well as support from healthcare leadership to move this work forward; it is only through actionable steps that we will be able to truly demonstrate our commitment to protect clinical learners.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

BILL S-231: The Ethics of Familial and Genetic Genealogical Searching in Criminal Investigations

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Résumé
Les récentes avancées en matière d'enquêtes criminelles, en particulier dans les affaires non résolues très médiatisées, ont contribué à consolider le rôle de l'analyse d'ADN dans les contextes d'enquête. Par conséquent, certaines juridictions cherchent à étendre les méthodes de collecte et d'analyse de l'ADN. Au Canada, une loi a été proposée pour élargir la Banque nationale de données génétiques (BNDG) et autoriser les recherches familiales dans les enquêtes criminelles et médico-légales. Cet article présente les implications éthiques de la législation proposée et, plus largement, des méthodes généalogiques déjà utilisées qui fonctionnent en dehors de la BNDG et reposent largement sur des services d'ADN à but lucratif et grand public. Les analyses d'ADN effectuées actuellement dans le cadre du système de justice pénale sont fortement réglementées et offrent d'importantes protections non seulement aux individus, mais aussi à leurs parents génétiques, dont les données biométriques sont indirectement impliquées. En revanche, les recherches familiales présentent des risques pour la vie privée des délinquants et de leurs proches. En outre, la pratique de plus en plus répandue de la recherche généalogique repose sur des produits commerciaux non réglementés qui utilisent une technologie différente pour exposer des informations génétiques très détaillées. Cette technologie ne répond pas à des normes d'investigation rigoureuses et pose des problèmes importants en matière de consentement éclairé. Nous concluons que l'élargissement de la collecte d'ADN dans la BNDG pour y inclure la recherche familiale risque d'exacerber les préjugés systémiques existants et que la recherche généalogique génétique à l'extérieur de la BNDG est incompatible avec la législation canadienne actuelle qui protège la vie privée, la non-discrimination génétique et les droits et libertés fondamentaux.

Mots-clés
généalogie génétique, recherche familiale, enquêtes criminelles, projet de loi S-231, confidentialité génétique, discrimination, technologie des tests ADN, biométrie

Abstract
Recent breakthroughs in criminal investigations, especially of high-profile cold cases, have helped to consolidate the role of DNA analysis in investigative contexts. Consequently, some jurisdictions are looking to expand DNA collection and analysis methods. In Canada, legislation has been proposed to expand the National DNA Databank (NDDB) and to allow familial searching in criminal and forensic investigations. This article outlines the ethical implications of the proposed legislation and, more broadly, of genealogical methods already in use that operate outside the NDDB and rely heavily on for-profit and consumer DNA services. Current DNA analysis within the criminal justice system is heavily regulated and provides important protections not only for individuals but also for genetic relatives whose biometric data is indirectly implicated. In contrast, familial searching poses risks for offender privacy as well as for their relatives. Additionally, the expanding practice of genetic genealogical searching relies on unregulated commercial products that use different technology to expose highly detailed genetic information. This technology falls short of rigorous investigational standards and poses significant problems for informed consent. We conclude that expanding DNA collection within the NDDB to include familial searching risks exacerbating existing systemic bias and that genetic genealogical searching outside of the NDDB is incompatible with existing Canadian legislation that safeguards privacy, genetic non-discrimination, and fundamental rights and freedoms.

Keywords
genetic genealogy, familial searching, criminal investigations, Bill S-231, genetic privacy, discrimination, DNA testing technology, biometrics

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INTRODUCTION

DNA analysis in criminal investigations is constantly changing as technology evolves. New techniques and approaches have recently been deployed to solve several cold cases in both Canada and the USA, and these investigative breakthroughs have propelled calls to expand DNA sampling and analysis beyond what is currently mandated by Canadian legislation. Eager to capitalize on new technological advances, legislators have proposed modifications to Canada's legislation around genetic testing in investigational contexts. At the same time, investigators are already working outside existing legislation to make use of the skyrocketing popularity and availability of commercial DNA testing services.

Bill S-231 *Increasing the Identification of Criminals Through the Use of DNA Act* was first proposed in December 2021 and is currently being studied by the Standing Senate Committee on Legal and Constitutional Affairs (1). Bill S-231 is not the first

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legislation proposed along these lines; an earlier piece of legislation, Bill S-236, died with the close of Parliamentary session 43 in 2021. Given these repeated attempts, it is clear that lawmakers are determined to propose legislation around the expansion of DNA sampling and the implementation of different technologies and tools. Whether or not the current Bill S-231 eventually receives royal assent, the bioethical and legal impacts of legislation around DNA analysis are sure to remain pressing issues in coming years.

The current sponsors of Bill S-231 have outlined three main objectives:

1. First, they propose to expand the number of DNA samples collected by police because the power of DNA profiling in investigations increases with the size of the profile databank. As of 2022, in Canada the RCMP's National DNA Data Bank (NDDB) contained roughly 670,000 profiles (2).[1] Canada's NDDB currently holds DNA samples taken from crime scenes and from individuals who are convicted of designated "Primary Offenses" (typically characterized by murder, sexual assault, or serious physical assault). Under current legislation, some serious "Secondary Offences" such as uttering threats and serious drug crimes are also subject to DNA testing. In addition, separate databanks contain profiles derived from forensic samples (crime scenes, human remains) and from relatives of missing persons. Proponents of the Bill outline a plan to capture DNA samples from people convicted of lesser crimes (like theft, minor drug offenses, fraud, and even the unlawful harvesting of logs that have escaped log-booms) in order to increase the size of the NDDB and thereby increase the probability of future investigative breakthroughs.

2. A second objective, also addressed by enlarging the NDDB, is that a larger national DNA databank might provide exclusionary evidence to exonerate suspects from suspicion if their DNA profile does not match samples taken from crime scenes. This would reduce the incidence of false suspicion/conviction and make investigations more efficient by narrowing the list of possible suspects.

3. A third objective is to use DNA profile databanks to identify potential suspects, via their genetic relationships, to profiles already on file. Existing laws, specifically the *Canadian Criminal Code*, the *Criminal Records Act*, the *National Defence Act*, and the *DNA Identification Act* (3), currently prohibit using the NDDB to conduct familial searches. These restrictions are not unique to Canada. Internationally, other jurisdictions also impose restrictions to protect genetic privacy and ensure that innocent individuals are not directly or indirectly implicated in criminal investigations. Bill S-231's authors aim to allow familial searching in the context of serious crimes where an offender may be sentenced to 14 years or more.

Bill S-231's two operational goals are therefore to: 1) Expand the size of the NDDB by capturing a greater number of DNA profiles; and 2) Allow, for the first time, familial searching in investigations. These two explicit aims raise ethical and legal dilemmas, but they also highlight an obvious gap between what the Bill explicitly addresses and the ongoing investigational practices it ignores.

In this paper, we develop two arguments. First, we show that the provision to allow familial searching in Bill S-231 is both ethically and practically problematic. Familial searching is, as Amy Conroy puts it, a "technique that allows criminal investigators to identify potential suspects based on the familial links that can be observed between the separate profiles of genetically related individuals" (4, p.172). In the context of the NDDB, investigators performing a familial search would submit a DNA profile to the NDDB in the hopes of identifying an immediate relative (parents, siblings, offspring) whose DNA profile is already on file. Unfortunately, the NDDB and its underlying DNA profile technology are ill-suited to familial searching and unlikely to produce the investigational breakthroughs that the proponents of the Bill hope to facilitate. In our view, the possible benefits of permitting familial searching do not justify the privacy and ethical risks involved.

Second, we argue that the Bill does not address another, even more urgent practice: the unregulated use of genetic genealogical investigations. Genetic genealogical searching is a distinct process; investigators submit a DNA profile to a non-NDDB databank, attempt to trace the individual through their extended genealogy, and then draw on additional sources such as records of births, marriages, census records, etc. By comparing crime scene DNA samples to profiles and genealogical records contained in popular consumer products, investigators can often trace the perpetrator through their distant genetic relatives. Unlike familial searching, which is limited in its biometric detail and in its scope, genealogical searching yields extremely detailed biometrics of a much wider group of individuals.[2] Bill S-231 does not address the use of genetic genealogical searches outside the purview of the NDDB and that use unregulated commercial and consumer-oriented services. While offering significant investigational advantages, these genetic genealogical searches pose far more serious privacy and ethical risks that urgently need to be addressed by new legislation.

The Bill's failures to address the current use of commercial technologies and services leaves Canadians at risk of privacy violations, arbitrary search, loss of presumption of innocence, and non-consensual use of their biometric information. To examine the bioethical implications of Bill S-231's move to expand the national databank, to legalise familial searches, and to leave genetic genealogy unregulated, we first outline the technological differences and propensity for error in DNA analysis generally. We demonstrate that the NDDB presently offers important protections against discrimination and privacy violations,

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[1] Contrary to assertions by the Bill's sponsors, on a per capita basis, Canada's NDDB is not small but average in size relative to other G7, G20, and EU countries. See APPENDIX.

[2] Rafaela Granja emphasizes the broad scope of these searches with her phrase "long-range familial searches" (5).

both for offenders *as well as for their genetic relatives*. We then show that familial searching compromises these protections, and that genetic genealogy is even more intrusive and prone to error, ethical problems, and human rights violations. Finally, we conclude with some broader ethical considerations that should inform policy makers going forward.

DNA TECHNOLOGY AND ANALYSIS: ERROR AND RISK

Televisions dramas like the CSI series and high-profile cases like the apprehension of the “Golden State Killer” have entrenched DNA analysis as a definitive gold standard for proof in the minds of the public, investigators, and jurists alike. However, the underlying technology and analysis is open to error and misinterpretation: like any other science, DNA profiling involves a degree of subjective interpretation, and its reliability depends on myriad factors. Moreover, DNA profiling and analysis are by no means the unique purview of law enforcement. DNA profiling is increasingly common in medical tests, direct-to-consumer DNA tests and their publicly accessible databanks, and profiles from missing persons/human remains. DNA technology is changing rapidly and is becoming increasingly available and affordable. The biometric detail offered by these technologies is astonishing, revealing a uniquely intimate and comprehensive picture of our racial origins, familial relationships, disease predispositions, physical and physiological traits, and even of our lifestyles and environment.

Whereas DNA analysis by law enforcement is usually regulated by legislation and relies on specific technology, DNA profiles can be derived from various other technologies, each of which comes with different propensities for error and each of which also reveals different degrees of biometric detail. The risks and propensity for error of DNA testing and analysis depends on what *type* of technology is being deployed, the *purity and quality* of the DNA sample obtained, *who* is conducting the analysis, *what kind* of comparison is being done, and *where* the biometric data is stored.

The reliability of genetic testing depends on the way that DNA is sampled and processed, and on the way that the results of the analysis are subsequently interpreted and then stored. At the sampling and preservation stage, sample contamination is a major risk. DNA profiles sampled directly from convicts generally preserve high quality DNA samples suitable for purification and laboratory analysis. Samples are derived from cheek swabs, sputum, or blood specimens and immediately preserved for analysis, thereby lowering the risk of sample contamination.

By contrast, DNA samples from crime scenes have often been subjected to environmental exposures (light, temperature, humidity, chemicals, etc.) and far from being fresh are often hours, days, or even years old. This kind of contamination and sample degradation can lead to spurious results. As legal expert Erin E. Murphy puts it: “A doctor would never just say, ‘bring in an old bloody Band-Aid and we will run some tests!’ Crime scene testing, however, is like seeking results from that dirty Band-Aid – after it has been in the trash for two weeks” (6, p.19). Another complicating factor is that people shed DNA continuously (some much more than others) and can leave traces behind that are detectable for many years. This type of contamination, called DNA transfer, can be surprisingly indirect: our DNA lands on people, objects, and places with which we have never had direct contact. Again, this has profound consequences for criminal DNA investigations. For example, DNA found on the underwear of a rape/murder victim at Yale University was linked to a convicted felon. However, this suspect had died two years *prior* to the murder under investigation. In his capacity as a construction contractor, the felon had left DNA behind on pipes, and these traces transferred to the victim’s body when it was hidden by the real perpetrator (6).

Sampling materials and lab conditions can also lead to investigational error. German police spent 16 years investigating a serial killer, dubbed the “Phantom of Heilbronn,” based on DNA samples found at 40 crime scenes in Germany and Austria from 1993-2009. It was finally discovered that the genetic matches were the result of contaminated cotton swabs that were licensed as sterile for medical but not forensic use. The individual whose DNA was supposedly found at the crime scenes was in fact a worker in the factory producing the swabs (7).

DNA analysis is a highly sensitive and fundamentally interpretive task that is often incorrectly thought of as an objective assessment. Tellingly, the authors of a 2011 study evaluating the reliability of DNA analysis submitted a DNA profile and case notes to 17 different analysts working in a single accredited lab in the USA. There was no consensus but rather widely differing opinions from the analysts regarding the probability that the individual profiled was guilty of the crime (8). These divergent conclusions emerged in spite of the fact that the analysts worked to a standardized protocol, used standardized tools and reagents, and shared the same workspace. As technology develops to detect progressively fainter traces of DNA, the regulation of analysts and analysis protocols and an acknowledgement of technical limitations will become increasingly crucial in mitigating the risk of misinterpretation and error. This risk of error is always present, but regulating protocols and the degree to which the technology can be pushed goes some way to ensuring the integrity of results and guarantees that investigators can document each stage of the analysis and subsequently retrace the chain of custody of samples if needed.

In view of the risk of error and ensuing privacy concerns, jurisdictions worldwide have tried to regulate and standardize DNA analysis in criminal investigations. Canadian law enforcement currently employs a Combined DNA Index System (CODIS), the same system used by the EU, UK, and the USA (the FBI). The Canadian database of CODIS profiles is housed in the National DNA Data Bank (NDDB), a division of the national police force, the RCMP. CODIS technology provides a simple genetic "barcode" that is unique to each person. This technology derives the "barcode" from only a few dozen short DNA sequence markers (Short Tandem Repeats or STRs). Like fingerprints, these markers are unique to individuals.[3]

In terms of its risk of error and its privacy implications, CODIS is relatively safe compared to other technologies. Already at the time of its inception, international authorities identified one crucial advantage of CODIS technology: as a critical review conducted in 2013 confirmed, authorities were reassured that CODIS barcodes provide enough information to link a profile with one individual without revealing genetic traits, health predispositions, or racial data (10). As the US Department of Justice's regulations confirm, CODIS profiles are "sanitized 'genetic fingerprints' that can be used to identify an individual uniquely, but do not disclose an individual's traits, disorders, or dispositions" (11, p.74937). In Canada, the CODIS profiles stored in the NDDB are anonymized using reference numbers that can only be linked to a name if a crime scene sample registers a match to a specific profile. The privacy risk to individuals whose DNA is sampled using this technology is therefore low, as is the potential for discrimination on the basis of race or health predispositions. CODIS only requires a small amount of DNA for analysis and its reliance on short "barcodes" can be useful even when sample degradation is a factor, as the technology only requires a short segment of legible DNA to generate a profile. CODIS technology is not immune to procedural error, but the federal regulations around the NDDB and the processing of samples by accredited experts at least standardizes each stage of the process, ensures that chains of custody are traceable, and attenuates the risk of error as much as possible.

CODIS's reliance on short "barcodes" provides an important degree of privacy, but its protections come at a cost: CODIS has limited reliability in the context of familial searching. The limitations of CODIS technology in familial searching were highlighted in a study conducted by the FBI in 2022. This study concluded that for familial searches, CODIS profile comparisons "have very low efficiency in locating true relatives in offender databases" (12, s31). Similarities between genetic profiles are sometimes flagged as "related" even where there is no genetic relationship between the individuals. Because of this, the probability of a false result actually *increases* with the size of the databank (12). For this reason, CODIS is much less useful as a technology for familial searching.

The use of DNA technology in forensic and criminal investigations is currently regulated in Canada by the *DNA Identification Act* (3). The *Act* permits investigators to match individuals to a specific crime/forensic scene: the Commissioner can report perfect or likely profile matches (*DNA Identification Act* 5.5-6.1). Since the NDDB was established in 2000, legislation has specifically precluded database curators from disclosing partial matches that could implicate relatives of individuals whose profiles were on file (Section 6 of the *DNA Identification Act* and Statutory Review [3,13]). The limitations on familial searching reflect international legislative practices. In the USA, the FBI does not permit familial searching of its DNA databank (14). Various State jurisdictions impose additional limits. The states of Maryland and Montana, for example, have recognized the implications for relatives of criminals and consequently require specific conditions to be met before a familial search can be conducted: the crime must be deemed extremely violent, investigators must demonstrate that additional evidence is unlikely to be found, and a judge's permission must be obtained (12). The UK likewise only permits familial searches when the crimes under investigation are serious (15). One way to establish investigative necessity is by imposing a requirement for a warrant; this is the case in Montana (16).

In Canada, the *DNA Identification Act* does not allow the reporting of overlapping profiles, e.g., profiles that have some markers in common but where others are discernibly different. In other words, the Commissioner cannot reveal partial matches that might suggest a genetic relationship between two samples: a previously unknown profile obtained at a crime scene, and one from a related person already registered in the databank. In essence, this prohibition on familial searching guards against the implication, investigation, and exposure of genetic information of the *relatives* of offenders. This prohibition simultaneously protects their personal information, privacy, and legal rights as outlined in the *Charter of Rights and Freedoms*. There is one notable exception to this prohibition: in Canadian forensic investigations of missing persons and unidentified human remains, familial comparisons can be carried out if immediate relatives explicitly consent to provide samples for this purpose. A circumstance where this might occur is when a family hopes to identify missing or murdered relatives.[4] In such cases, family members' privacy is protected because the DNA of victims, volunteers, and human remains are not stored in the NDDB's Convicted Offenders Index or the Crime Scene Index, but rather in the Voluntary Donors Index, the Victims Index, the Missing Persons Index, the Human Remains Index, and the Relatives of Missing Persons Index.

In the push to expand the size of the NDDB in Canada and to permit familial searches, legislators have repeatedly downplayed the privacy implications of these changes. At the second reading of Bill S-231, Senator Claude Carignan even emphatically asserted that "Bill S-231 does not change these important privacy protections" (1). This view is hard to justify given that the legislation will not only increase the number of individuals sampled but also subject their genetic relatives' profiles to scrutiny and potential privacy violations. Moreover, the Bill proposes to expand the familial search to include indices outside of the NDDB's Convicted Offenders Index by including the indices containing profiles from missing persons, victims, and volunteers. This combined resource would also be used to aid foreign governments, organizations, and institutions.[5]

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[3] Indeed, The Supreme Court of Canada (in R. vs Rodgers) explicitly recognized that CODIS "barcoding" was analogous to a fingerprint with regard to specificity to a single individual (9).

[4] This specific category of investigation can also involve more revealing and intimate biometrical tests such Y-chromosome analysis, mitochondrial DNA, and whole genome sequencing.

[5] Section 18 of Bill S-231 proposes to add 6.41 to section 6.4 of the *DNA Identification Act*.

ETHICAL AND PRIVACY IMPLICATIONS OF FAMILIAL SEARCHING

Familial searching in the context of criminal investigations is widely acknowledged to pose significant risks in terms of ethics, privacy, and consent, and there have been numerous calls for a detailed study of these risks (17,18). In its own Statutory Review of the *DNA Identification Act* published in 2010, the Standing Senate Committee on Legal and Constitutional Affairs emphasized that familial searching was "one of the most controversial subjects" (13, p.61) that it had reviewed and recommended that "before kinship analysis or familial searching be permitted, the Department of Justice further study the matter…to analyze the impact that allowing kinship analysis or familial searching might have on the protection of society, the administration of justice, the privacy of individuals and the presumption of innocence" (p.64). To our knowledge, the Department of Justice has yet to undertake such a study.

The specific risks associated with familial searching have been described at length, including in the Senate Committee's Report on the *DNA Identification Act*, which noted numerous concerns from witnesses that familial searching could:

- Compel family members to become unwilling "genetic informants;"
- Lead police to match an individual to a crime *other* than the one being investigated;
- Link the genetic profiles of innocent individuals to a crime;
- Lead to "genetic surveillance of certain groups of people," including groups overrepresented in the justice system;[6]
- Expose biometric information unrelated to the criminal investigation, such as instances of false paternity and adoption (13, p.63-4).

In many respects, familial searching of the NDDB would subject not only convicted offenders but their genetic relatives to privacy invasion, arbitrary search, and violations of their right to be presumed innocent. Given that certain racialized populations are overrepresented in the NDDB, familial searching will disproportionately affect these populations. The most recent incarceration demographics in Canada clearly show that racialized people are overrepresented in the criminal justice system: in 2020-21, individuals self-reporting as Indigenous and Black made up 27% and 8% of offenders (19), although they represent only 5% (20) and 3.5% (21) of the national population, respectively. An expanded NDDB will perpetuate these demographic inequalities and compromise the privacy rights of racialized populations. Subjecting these populations to routine searches constitutes a serious violation of key tenets of the legal system. As Murphy explains, familial searches "embody the very presumptions… [that] evidentiary rules have long endeavored to counteract: guilt by association, racial discrimination, propensity, and even biological determinism" (15, p.304).

Canada's laws around DNA abandonment further compound this risk of systemic discrimination. As Amy Conroy has convincingly argued, the Supreme Court of Canada has shown reluctance to categorize DNA sampling from abandoned articles (discarded ginger ale cans, cigarette butts, facial tissues) as examples of arbitrary search. She points out that DNA "can be obtained from bodily tissues that are routinely and unconsciously shed by individuals in the course of their daily activities," (4, p.176) and the Supreme Court's position currently leaves "individuals with no meaningful right to refuse police the use of genetic materials that are shed and discarded daily" (p.188). This is problematic in and of itself, but when combined with familial searching, investigators would potentially be able to obtain "abandoned" DNA not only from suspects but from innocent individuals and submit these profiles to the NDDB for comparison. This, Conroy concludes, "present[s] a serious risk for genetic privacy" (p.184) but it also circumvents the key tenet of the *DNA Identification Act*, which is to ensure that the NDDB "only contain the profile information of convicted offenders" (p.174).

Legal scholar Colton Fehr likewise argues that familial searches would likely contravene Section 8 of the *Canadian Charter of Rights and Freedoms* (23). This section explicitly protects "the right to be secure against unreasonable search or seizure" (24). Fehr likens familial searching to communication intercepts to make a compelling point: most people would find it unacceptable to have their telephone traffic routinely monitored because a distant relation is an offender. As Fehr points out, just as innocent parties are likely to get unfairly caught up in an investigation if their private exchanges are surveyed, analysing DNA databanks for familial connections will indiscriminately capture a larger number of innocent parties. In the interest of privacy and security, Fehr argues, there should be a constitutional obligation to limit such investigations to cases of violent and immanent injury or threat (23).

Fehr's analysis echoes the findings of a 1995 Report by the former Privacy Commissioner of Canada, which considered genetic testing in relation to *The Privacy Act* (1985). In it, the Commissioner stipulated that DNA should be regarded as a form of personal information and should be subject to the "fair information practices" set out in the *Privacy Act*, notably that government agencies can:

- collect only the personal information they need to operate programs;
- collect the information directly from the person concerned, if possible;
- tell the person how it will be used;
- use personal information only for the purpose for which it was collected or for a 'consistent' purpose;
- disclose the information only as the Act permits;
- take all reasonable steps to ensure the accuracy and completeness of the information;
- allow the person access to his or her personal information;

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[6] Amy Conroy has subsequently shown that familial searching of the NDDB would perpetuate racial stereotyping and systemic bias of Indigenous communities, who are disproportionately represented in the criminal justice system (22).

- and allow the person to make objections to the correctness of personal information kept by government, have the objections stated on file, request changes to the file, and notify users of the information of the objections. (25, p.55)

Furthermore, the Commissioner highlighted the fact that genetic information must, under the *Privacy Act*, be collected "directly" from an individual (except under very specific circumstances):

> personal genetic information must be collected directly from the individual to whom it relates. Even if it is possible to identify a genetic characteristic of one person from a test of a relative, the genetic information should, if possible, be collected directly from that person, not the relative (25, p.60).

The Commissioner concluded that forensic use of genetic information should only be implemented after it has been subject to a "study of the privacy and other human rights implications" and, "if the study finds the data bank to be acceptable," subsequently be subject to "specific authorizing legislation" (25, p.50). Advances in DNA analysis have made this study all the more urgent, especially given the potential for "abandoned" DNA to play a role in investigations and in familial searches.

In direct contrast to these recommendations, Bill S-231 does not grant any consideration to how the use of genetic profiling in criminal investigations will affect the privacy of persons *indirectly* linked to the investigation through familial relationships, nor does it provide any guidance around consent. As we will demonstrate, addressing these issues is important not only in the context of Bill S-231's proposal to allow familial searching given that current investigational practices already operate outside the NDDB and the purview of the *DNA Identification Act* to use genetic genealogy in criminal investigations.

ETHICAL AND PRIVACY IMPLICATIONS OF GENETIC GENEALOGY AND COMMERCIAL/ CONSUMER SERVICES

Given CODIS's limited efficacy in familial searching and the stringent regulations surrounding use of the NDDB, it is small wonder that investigators are eagerly making use of genetic genealogy techniques, often in collaboration with commercial services and open-source databanks. Where familial searching of the NDDB raises significant ethical and privacy issues, these are magnified in the context of genetic genealogy and its completely unregulated use. Until recently, this use was largely limited to municipal police units (whose activities are not governed by the *DNA Identification Act* unless they are using the NDDB), but the RCMP has now also adopted genetic genealogy as an investigational method.

The impetus for this transition to genetic genealogy occurred in 2018 when, after an investigation spanning decades, the Californian "Golden State Killer" was arrested. Instead of relying on police-run DNA databanks, investigators submitted anonymous crime scene DNA samples to a commercial lab, FamilyTreeDNA. The resulting genetic profile was then uploaded to and compared with family trees on consumer-oriented genealogy websites such as MyHeritage and GEDmatch (26-28). Family tree data, as well as the gender, age, race, and height of the offender, allowed police to identify the perpetrator. Encouraged by this and similar breakthroughs, Canadian investigators have eagerly adopted genetic genealogy techniques to crack cold cases: the Toronto, Calgary, and Edmonton Police Departments have been early adopters. In November 2023, the RCMP announced that they had solved the 47-year-old murder of Pauline Brazeau by submitting a crime scene DNA sample to Othram, a Texas-based commercial company specializing in forensic genetic genealogy (29). The technical approach was to conduct whole genome sequencing of a crime scene sample and then reverse-engineer the data to permit comparison to the profiles one might find on GEDmatch, for example.[7] Genealogical investigators then built family trees to narrow the search. The RCMP were able to solve this investigation without recourse to the NDDB and were therefore not bound by regulations prohibiting familial or genealogical searching.

Both of these breakthroughs were achieved thanks to a technology that is fundamentally different from CODIS and is much better suited to genetic genealogy: SNP (Single Nucleotide Polymorphisms) Microarray analysis predominates due to its prevalence in the direct-to-consumer market, but other technological approaches, like mitochondrial sequencing, Y-chromosome analysis, and whole genome sequencing are also used by investigators. These newer technologies generate far more detailed genetic profiles and can reveal more distant genetic relationships than CODIS. Where CODIS records 13-20 short DNA markers, SNP technology maps approximately 680,000 DNA markers using a microarray platform.[8] As a result, SNP assays produce highly detailed genetic profiles revealing not only genetic relatedness but also information on gender, health predispositions, race/ethnicity, and physical traits. The granularity of detail revealed by SNP is so rich that distant family – extending far beyond immediate family to thousands of genetic relatives – can be identified. By way of comparison, where CODIS can sometimes confirm immediate relatives, SNP technology can show genetic links between seventh or eighth cousins, linking hundreds if not thousands of genetic relations. Yaniv Erlich et al. have estimated that if just 2% of Americans of European descent were to deposit SNP profiles, 99% of the total population of that ethnicity would be detectable via 3rd cousins (30).

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[7] Whole-genome sequencing reveals not only the 680,000 markers mapped by SNPs but some 4 billion nucleotides. The increased granularity of detail exposes vastly more intimate information that heightens the privacy risks.

[8] Microarrays are small glass slides to which hundreds of thousands of distinct DNA sequences have been affixed. When a labelled DNA sample from a crime scene is added to the microarray, the complementary DNA sequences light up. In a test (or assay), each sample will light up subsets of those 680,000 sequences that are unique and characteristic of that sample.

These enriched profiles and capabilities come with specific propensities for error, serious privacy risks, and unresolved issues around consent. We briefly consider these disadvantages by comparing CODIS to newer technologies.

Propensities for Error

The level of informational detail provided by SNP analysis widens the scope for procedural error. SNP analysis requires 20-100 times the quantity of DNA sample compared to CODIS (31). Obtaining this quantity of DNA from a crime scene without introducing contaminated or degraded DNA is all the more difficult when compared to CODIS and increases the likelihood of false results. For example, contaminated samples of DNA would produce a distorted pattern in a SNP result and could lead investigators to falsely exclude a suspect (31). Studies also show that DNA sample degradation can lead to poor prediction of kinship (32).

In terms of reliability, CODIS and direct-to-consumer SNP microarray technology are both susceptible to error at each stage of the investigative process. However, SNP technology carries numerous additional risks. Open-source genealogy databases are compiled by amateurs and volunteers and may contain errors. Genealogical information input by users is supposed to be substantiated by documentary evidence (birth, death, and marriage certificates, census forms), but the rigour, training, and inclination of the hobbyists that populate the data is variable. Much more seriously, commercial genetic genealogy services rely on customers to collect their own cheek swab or sputum sample. Even when customers collect this DNA sample under ideal conditions, tests suggest that the assays can be so unreliable as to preclude their use for medical tests (33,34). Investigators using these commercial services access and compare profiles, but with no way of verifying the reliability of the samples submitted. They are also unable to determine whether samples submitted were obtained lawfully, consensually, and under the correct name. The analysis of samples is similarly unregulated, and the relative reliability of each company is impossible to ascertain.

Privacy Risks

Genetic genealogy carries some of the same privacy concerns as familial searching, including the risk of disclosing genetic relationships that are unknown to the families involved (e.g., illegitimate or adopted children), the risk of disclosure of medical information, and the subsequent bias that may affect individuals with genetic illness or predisposition towards disease. However, because genetic genealogy is almost always conducted through or in collaboration with commercial services and/or open-source databases, these risks are exponentially heightened.

A key consideration is the dynamic business landscape in which companies operate. One of the commercial companies that had previously catered to genealogy hobbyists, GEDmatch, was acquired by forensic analysis firm Verogen in 2019. Verogen itself was a 2017 spin off from Illumina Inc., the dominant provider of SNP microarrays and a major player and developer of DNA profiling and sequencing tools and services. Companies are constantly changing hands, reorganizing, and merging. Moreover, in view of the increased business from police investigators, several companies (e.g., Verogen, Parabon NanoLabs Inc., and Othram Inc.) now offer SNP analysis directly to police. Not only is it becoming difficult to separate police from commercially provided investigative services, but the businesses used over the course of investigations comprise specialty forensic, genealogy, direct-to-consumer, and hobbyist services. When individuals interested in genealogy or health predispositions deposit their DNA with a company and their profile is integrated into a database, all employees of these companies can potentially access extremely granular and intimate information.

Likewise, the commercial warehousing of a company’s biometric data can be subcontracted or held in a third location, which means that customers’ genetic information can be stored online or in remote jurisdictions where privacy is unprotected and potentially difficult to trace. Storing and transferring biometric data across city, state, provincial, and even national boundaries carry with it obvious risks. For example, a Canadian DNA profile submitted to 23andMe for analysis will be processed by a 23andMe subsidiary, Labcorp, in the USA. The DNA profile and resulting family tree will be housed wherever 23andMe dictates, and the information will be subject to American, not Canadian, legislation and protections. Consumers may then upload the 23andMe profile to GEDmatch for comparison to profiles and pedigrees obtained from other companies. While 23andMe might not have contributed directly to an investigation, the information derived from their assay becomes part of the larger GEDmatch resources that do. Companies are not always clear about what they do with the data, nor with whom it might be shared (35). Investigators relying on this data face myriad uncertainties. Is the chain of custody traceable? When data is stored by third parties in jurisdictions around the globe, who owns the samples and data? Have consumers consented to having their genetic data stored in other countries? What laws and regulations apply if the process crosses international borders? Do foreign powers have access to the data?

The collection, analysis, and storage methods deployed by commercial companies clearly violate several of the conclusions reached by the Privacy Commissioner in his 1995 report, namely that “personal information…must not be collected in a manner that risks inaccuracy…[and must be collected] in tightly controlled circumstances,” and that “government institutions should ensure [that]...Only qualified persons should conduct genetic tests and interpret test results” (25, p.55). It is unclear if investigators using these commercial services are aware of the risks and potential violation of privacy protections.

Consent Issues

In the context of genealogical investigations, the issue of informed consent is fraught with problems. As we will explain, genetic information is often acquired under unregulated conditions and may have been obtained through coercive means or indirectly from relatives. Furthermore, samples can be used for purposes other than those explicitly consented to by the individual who provided the sample. In short, genetic genealogy has profound implications for the Privacy Commissioner's recommendation that information must be gathered "directly from the person concerned" and after informing each individual "how it will be used." (25, p.55)

The case of Michael Usry Jr. is revealing. In 2014, Usry was interrogated by Idaho Falls authorities as the prime suspect in the murder and rape of Angie Dodge in 1996. Investigators had submitted a DNA profile from the crime scene to a commercial DNA analysis service used by genealogy hobbyists. The investigators rapidly inferred Usry's guilt based on a DNA profile that his father had submitted to the commercial service several years earlier. Further DNA tests eventually cleared Usry of suspicion. The perpetrator was eventually revealed to be a 7th cousin, an individual unknown to Usry but with whom he shared a common ancestor born in 1741. Police had not understood the limitations of the testing technology, and investigational tunnel vision had ensued (36). Significantly, the genetic profile that implicated Usry in a criminal investigation was not retrieved from him directly; investigators relied on a profile that had been donated to a commercial DNA analysis service by his father, who had not explicitly consented to his DNA being used for investigational purposes (36).

Most direct-to-consumer DNA services do not obtain informed consent from customers for their information to be used in criminal investigations. When the database used for the "Golden State Killer" investigation, GEDmatch, was purchased by forensics lab Verogen Inc. in 2019, the company's new owners were forced to seek permission from past customers to use their genetic profiles for future investigations. As of 2019, only 14.2% had given consent (37). Even more troubling, some profiles contained in international research-oriented databanks may have been obtained through coercion. The Y-Chromosome Haplotype Reference Database (YHRD), for instance, is a research database that is also exploited by forensic labs and the manufacturers that provision direct-to-consumer kits – the YHRD contains both CODIS-like STRs as well as SNP markers. It also likely contains profiles taken forcibly from vulnerable populations such as the Uyghur (PRC) and Roma (eastern Europe). By accessing the YHRD, investigators and consumers alike are unwittingly participating in unethical practices (38).

Even where consent is requested, Gabrielle Samuel and Debbie Kennett point out that many consumers are ill-equipped to understand the subtle implications of consent for themselves or for their relatives (39). These authors and others have argued that there is a fundamental problem with a consent paradigm that centres upon individuals when extended families and collectives are put at risk (39-41). As Nina de Groot, Britta van Beers, and Gerben Meynen put it, "an individual consent model has significant limitations when it comes to IGG [investigative genetic genealogy] and needs to be complemented with a more collective approach" (40, p.793).

If consent is granted by an individual submitting a genetic sample, that consent cannot cover the individual's genetic relatives, whose biometric data is nevertheless exposed. As Michael Szego, Director of the Centre for Clinical Ethics at the University of Toronto explained in an interview with the authors:

> If I wanted to participate in a public genomics project that would involve sequencing my genome and making it publicly available, I could currently consent to such a project even though it would have implications for my family. Balancing individual autonomy with the privacy rights of 3rd party family members is a difficult question in genomics. Who ought to consent? Is that me? Or … by virtue of it affecting my family members, should they have a say in whether I participate or not?... What are the privacy rights of that fourth cousin [who] has never participated in any kind of genetic research, [who] wants to be… left alone and… by virtue of a family member that that individual probably has never met, has contributed a sample (2022/03/01)?[9]

David Goodis, former Assistant Commissioner of Ontario's Information and Privacy Commissioner, elaborates on this point in similar terms. When contributing DNA information, he argues,

> I'm also impacting my biological relatives, who themselves didn't consent… This is unusual in privacy law, because normally,… I can consent to the use and disclosure of my information. But [in this case]… I'm now also consenting to somebody else's information being disclosed or somebody else being identifiable by my information (2022/02/24).[9]

The repercussions of this disclosure of biometric data thus extend far beyond the parameters of criminal investigations. As DNA analysis becomes ever more detailed, the potential future impact of exposing biometric data remains unknown, and we have reason to protect the privacy of future generations, whose genetic privacy depends on how their immediate ancestors' genetic information is protected.

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[9] Structured interviews were conducted of major stakeholders with expertise in genetic non-discrimination as part of the project entitled "Participatory Democracy and Canadian Genetic Non-Discrimination Act." The research was funded by Genome Canada and the Social Sciences and Humanities Research Council of Canada. Ethics protocols were approved by the Research Ethics Boards of the Universities of Windsor and Montréal. To date approximately 30 people have been interviewed. Consent was obtained from interviewees cited in this article prior to publication.

CONCLUSIONS: TRANSPARENCY, ACCOUNTABILITY, AND POLICY

It is clear that CODIS technology no longer satisfies investigational needs, but the use of familial searching, genetic genealogy, and commercial services are not currently compatible with the legal, ethical, jurisdictional, and procedural standards of criminal investigations. Bill S-231 does not address the reliability, privacy, and consent risks around the use of familial searching, nor does it seek to regulate the genetic genealogy and commercial databanks already in use by investigators.

In other jurisdictions, the use of commercial DNA analysis services is heavily regulated. For example, the 2019 guidelines from the US Department of Justice restrict federal investigators there from using commercial or direct-to-consumer resources unless specific conditions are fulfilled, namely that all other avenues of investigation have been exhausted (including CODIS); the crime under investigation is violent and/or presents a substantial threat to public security; the DNA sample obtained indicates a single offender, is available in sufficient quantity, and is of high quality; investigators use no deception in the submission and analysis of samples; and the data banks employed have explicit consent from data bank consumers that their DNA profiles can be used in this manner (14).

Although Bill S-231 tries to limit familial searching to serious offenses where traditional methods have failed to solve a case, it does not go far enough in addressing ethical and privacy concerns nor in addressing current and future DNA analysis technologies. Legislation is needed to protect investigators as well as those under investigation, and the interests of genetic relatives need to be front and centre in plans to expand genetic analysis in the criminal justice system. Such legislation, we conclude, needs to have longevity, advance equity, rethink privacy and consent as communal rather than individual, and proactively anticipate technological creep.

Longevity

DNA analysis and regulation is clearly a "transgenerational issue," as de Groot, van Beers, and Meynen assert, both with regard to privacy and consent: "future generations might also be affected by today's individual decision to make one's genetic data accessible to law enforcement" (40, p.793). Regulatory legislation must take a long view of the potential impact on individuals and their descendants. This is particularly true of young people in the criminal justice system. At a presentation to the Standing Senate Committee on Legal and Constitutional Affairs, Stephanie DiGiuseppe, (Director, Criminal Lawyers Association) emphasized the risks that longevity of genetic profiles hold (42). With specific reference to juvenile offenders, DiGuiseppe pointed out that legislators must assess not only the immediate known risks to individuals, but also the future potential risks; over the 60-70 years remaining life expectancy of a young offender, for instance, it is not unthinkable that Canada's democratic system undergo substantial changes. Longevity is a concern not only given the intergenerational dimension of DNA analysis but also with regard to the robustness of the legislation.

Advancement of Equity

The concerns around systematic bias and racial/ethnic inequity in the criminal justice system cannot be solved in the short term with genetic testing legislation. However, the discussion around DNA analysis can serve to highlight specific inequities and suggest possible ways to redress these. For instance, the disproportional representation of certain groups in the NDDB arises from its very selective profiling of individuals convicted of criminal offenses in Canada. In contrast, commercial databases are much less selective, contain many more profiles, and tend to represent racial/ethnic groups *other* than those represented in the NDDB. As Erin Murphy writes, "the racial composition of genealogical DNA sites – which heavily skew white – may end up balancing and complementing that of government databases, which disproportionately contain profiles from persons of colour" (43, p.7). To pursue this logic to its conclusion, a universal database containing profiles of an entire country's population would be free from bias. The idea of a federally run universal database would also resolve the pressing issue of the commercialization of biometric data, which risks reproducing long-standing inequalities and power structures, as Rafaela Granja has discussed (5). However, when DNA and profiles are commodified, individual donors assume significant risks while the profits generated benefit commercial entities with little motivation to mitigate these risks. For these reasons, wide-scale genetic testing is, in de Groot, van Beers, and Meynen's words, "generally not regarded as an acceptable option" (40, p.792).

Collective Privacy and Consent

The collective and intergenerational dimensions of genetic testing will compel legislators to rethink privacy and consent. The notion of individual rights and freedoms does not capture the complexities involved in DNA analysis. Instead, legislators need to advocate for what Samuel and Kennett term a "societal approach" based on "solidarity" (39). Such an approach, they argue, would be grounded in "wide public engagement" and would "[aim] to foster public trust and legitimization by placing strong ethical emphasis on people's willingness to engage in activities that may carry some risks for the benefit of others" (39, p.300). In order to foster this type of public good faith, Samuel and Kennett rightly argue, institutions – and not individuals – need to demonstrate transparency and accountability (39). The issue of consent should not rest uniquely on the individual; rather, the "responsibilization" of individuals needs to be shifted to institutions and governments. The "solidarity" model "places the responsibility on institutions to be transparent about their own stakes and interests, and about the types of harms that may not be foreseeable" (39, p.300). While it may be too much to hope that commercial companies undertake such a radical ethos of responsibility, legislators might feasibly insist that police and government institutions work to make processes and statistics fully transparent. As Murphy shows, such transparency is sorely lacking, and as a consequence, the public remains dangerously ill-informed about the practice of investigative DNA searches (43).

Anticipating Technological Creep

Given our environment of rapid technological change, policy needs to anticipate technological creep. Bill S-231's provision for familial searching is late to the game and does not address current practices, let alone imminent developments. Whereas previously whole genome sequencing was prohibitively expensive, costs have now dropped to be competitive with CODIS technology. Investigators will likely find it fiscally expedient to use this technology without understanding the potential consequences of scrutinizing vastly enhanced biometric detail. Not even investigators of the Human Genome Project were able to foresee that analytical methods would render void the anonymity of their genome donors (44). In spite of the promise of anonymity, privacy critics were able to use a combination of freely available genome sequence data, Y-chromosome data, and public genealogy websites to identify donors with high probability. Recently, Edmonton Police, in collaboration with the US firm Parabon NanoLabs Inc., published a mug shot based solely upon Parabon's extrapolation of phenotype from a DNA sample (45). The technology employed to create this mugshot remains opaque, and the mugshot was withdrawn after a public outcry. Journalist Taylor Lambert, quoting interviewee Brenda McPhail, Director of Privacy, Technology & Surveillance at the Canadian Civil Liberties Association, goes on to state that "what's needed are 'legal frameworks and guard rails' to limit how police and other public bodies can pursue DNA analysis… 'Although it doesn't mitigate the trauma that the community has surely felt…it does provide a really important and welcome opening for a public conversation about precisely what the risks of this technology are'" (45). Canada has been very slow to develop policy around genetic analysis, the Department of Justice has failed to undertake the recommended research into the impact of DNA analysis, and legislators repeatedly propose new policy that fails to address concerns expressed by numerous federal reports. For their part, investigators are likewise understandably frustrated by the failure to move forward with legislative action. The issues will not be solved with hasty debate or incomplete policy, but they will also rapidly grow more urgent with the passage of time. Murphy puts it succinctly: "Big genome data has arrived: it is time to do something more than gape in wonder at it." (43, p.8).

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APPENDIX

Table 1. Comparison of Canadian DNA Sampling Versus G7

Per Capita Ratio Arranged Highest to Lowest[10]

G7	# DNA Samples (millions)	Population (millions)	Per Capita Sampled Ratio	Date Reported
UK	5.8	67.33	0.08614288	2021
France	5.22	67.55	0.07727609	2021
USA	12	328.3	0.03655193	2019
Canada	**0.67**	**38.93**	**0.01721038**	**2022**
Germany	0.827	83.13	0.00994827	2021
Japan	1.213	126.6	0.00958136	2019
Italy	0.007	59.01	0.00011862	2021

Table 2. Comparison of Canadian DNA Sampling Versus G20

Per Capita Ratio Arranged Highest to Lowest

G20	# DNA Samples (millions)	Population (millions)	Per Capita Sampled Ratio	Date Reported
UK	5.8	67.33	0.08614288	2021
France	5.22	67.55	0.07727609	2021
Australia	1.2	25.74	0.04662005	2021
USA	12	328.3	0.03655193	2019
Saudi Arabia	0.909	34.27	0.02652466	2021
EU	50.866	1294.04	0.0393079	2021
Canada	**0.67**	**38.93**	**0.01721038**	**2022**
South Africa	0.743	58.56	0.01268784	2021
Germany	0.827	83.13	0.00994827	2021
Japan	1.213	126.6	0.00958136	2019
Russia	0.7344	144.4	0.00508587	2021
Korea South	0.1798	51.76	0.00347372	2021
Italy	0.007	59.01	0.00011862	2021
China	N/A			
India	N/A			
Indonesia	N/A			
Mexico	N/A			
Argentina	N/A			
Brazil	N/A			
Turkey	N/A			

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[10] DNA Sampling Rates per capita were calculated using statistics reported by the 2022 “Note: From EU General Secretariat of the Council to The Working Party on JHA Information Exchange (IXIM),” Brussels, 25 March, Interpol’s 2019 “Global DNA Profiling Survey Results,” and country-specific annual police and police lab sampling statistics. The number of unique DNA profiles held and reported was compared to the population for that particular country for the year reported.

Table 3. Comparison of Canadian DNA Sampling Versus EU

Per Capita Ratio Arranged Highest to Lowest

Canada vs EU Compared	**# DNA Samples (millions)**	**Population (millions)**	**Per Capita Sampled Ratio**	**Date Reported**
France	5.22	67.55	0.07727609	2021
Estonia	0.0651	1.329	0.0489842	2021
Lithuania	0.135	2.795	0.04830054	2021
Latvia	0.0701	1.883	0.03722783	2021
Finland	0.198	5.542	0.03572717	2021
Austria	0.256	8.96	0.02857143	2021
Denmark	0.15	5.875	0.02553191	2021
Czechia	0.2608	10.7	0.02437383	2021
Netherlands	0.356	17.53	0.02030804	2021
EU	8.801	446.727	0.01970107	2021
Canada	**0.67**	**38.93**	**0.01721038**	**2022**
Hungary	0.161	9.71	0.01658084	2021
Sweden	0.168	10.42	0.01612284	2021
Slovakia	0.085	5.45	0.01559633	2021
Slovania	0.0259	2.11	0.01227488	2021
Germany	0.827	83.13	0.00994827	2021
Ireland	0.04344	5.028	0.00863962	2021
Spain	0.403	47.33	0.00851468	2021
Bulgaria	0.0543	6.899	0.00787071	2021
Luxembourg	0.00436	0.639	0.00682316	2021
Belgium	0.0656	11.59	0.00566005	2021
Poland	0.143	37.53	0.00381029	2021
Romania	0.0657	19.12	0.00343619	2021
Greece	0.0195	10.66	0.00182927	2021
Cyprus	0.0017	1.22	0.00139344	2021
Croatia	0.0047	3.9	0.00120513	2021
Portugal	0.011	10.3	0.00106796	2021
Malta	0.000065	0.517	0.00012573	2021
Italy	0.007	59.01	0.00011862	2021

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Development of Professional Ethics Curriculum in the Operating Room for the Current Era of Surgery: A Mixed Method Study

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Résumé

Introduction : Les progrès rapides des technologies complexes et l'émergence de nouvelles méthodologies chirurgicales nécessitent une prise de décision éthique nuancée dans des scénarios très stressants. Par conséquent, la compréhension de l'éthique professionnelle dans l'environnement chirurgical est cruciale pour tous les praticiens impliqués dans les soins aux patients. Cette étude a été lancée dans le but de concevoir un programme complet pour les facultés de médecine iraniennes, axé sur l'éthique professionnelle au sein de la salle d'opération. **Méthodes :** Cette recherche exploratoire à méthode mixte a été exécutée en phases qualitatives et quantitatives distinctes. La première étape a consisté à mener 12 entretiens semi-structurés avec des professeurs iraniens experts dans la formation à l'éthique professionnelle et le personnel des salles d'opération afin d'évaluer les besoins actuels et d'examiner les programmes existants. La phase quantitative suivante a consisté à évaluer les éléments de chaque axe du programme d'études par le biais de la méthode Delphi. **Résultats :** La phase qualitative a permis d'identifier 45 codes primaires, 14 sous-catégories et 5 catégories primaires. La phase quantitative a confirmé 3 domaines d'objectifs pédagogiques, 12 domaines de contenu pédagogique, 8 méthodologies d'enseignement et 10 méthodes d'évaluation par le biais du processus Delphi. Ces éléments confirmés ont finalement été incorporés dans divers cours théoriques et cliniques en tant que thèmes d'intégration longitudinale. **Conclusion :** Sur la base de nos résultats, nous recommandons l'élaboration d'objectifs pédagogiques ciblant les domaines cognitif, affectif et psychomoteur et l'intégration longitudinale d'un cours d'éthique professionnelle.

Mots-clés

programme d'études, éthique professionnelle, intégration, salle d'opération, étude à méthodes mixtes, Iran

Abstract

Introduction: The rapid advancement of intricate technologies and the emergence of novel surgical methodologies necessitate nuanced ethical decision-making under high-stress scenarios. Consequently, cultivating an understanding of professional ethics within the surgical environment is crucial for all practitioners involved in patient care. This study was initiated with the aim of designing a comprehensive curriculum for Iranian medical schools, focusing on professional ethics within the operating room. **Methods:** This mixed-method exploratory research was executed in distinct qualitative and quantitative phases. The first stage involved conducting 12 structured interviews with Iranian faculty members who were experts in education of professional ethics and operating room staffs for assessing the current needs and reviewing extant curricula. The subsequent quantitative phase entailed evaluating the elements of each curriculum axis via the Delphi method. **Results:** The qualitative phase led to the identification of 45 primary codes, 14 subcategories, and 5 primary categories. The quantitative phase confirmed 3 instructional goal domains, 12 instructional content areas, 8 teaching methodologies, and 10 evaluation methods through the Delphi process. These confirmed components were eventually incorporated into various theoretical and clinical courses as longitudinal integration themes. **Conclusion:** Based on our findings, we recommend the development of educational objectives targeting cognitive, affective, and psychomotor domains and the longitudinal integration of a professional ethics course.

Keywords

curriculum, professional ethics, integration, operating room, mixed-methods study, Iran

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INTRODUCTION

Healthcare settings are experiencing rapid transformations due to emerging needs, which often lead healthcare teams into a myriad of ethical quandaries. These are often further compounded by technological innovations and an evolving knowledge base, making medical ethics a particularly important discipline in the 21st century (1). In the operating theatre, ethical challenges may arise in various forms. One such challenge is the question of informed consent, particularly in emergency situations where the patient may be unconscious and unable to provide consent (2). Another example is the ethical dilemma of resource allocation, such as deciding who gets priority when there are limited operating rooms or surgical equipment (3). The advent of Artificial Intelligence (AI) in surgery, particularly in oral and maxillofacial cosmetic surgery, has introduced new ethical considerations, including concerns about data protection, diversity, and transparency (4). In gender-affirming medical care, healthcare professionals face ethical challenges related to decision-making, including dividing and defining decisional roles and bounds, negotiating decision-making in a multidisciplinary team, and navigating various decision-making temporalities (5).

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In the context of bariatric surgery, patients face challenges in maintaining dietary changes and weight loss, highlighting the need for personalized dietary advice and ongoing psychological support (6). In low-middle income countries, the ethical challenge lies in ensuring equitable access to surgical care and the implementation of educational and training programs for local healthcare providers (7). These specific examples underscore the complexity of ethical decision-making in the operating theatre, highlighting the need for ongoing ethical reflection and discussion in surgical practice. Recent scholarship has significantly emphasized professional ethics or professionalism within medical education (8). It is increasingly acknowledged that medical education should include ethical curricula designed to cultivate clinical decision-making skills, foster professional ethics, and instill core values in medical and paramedical students (9).

However, critical questions persist regarding ethical instruction. Key issues include the specifics of what should be taught, who should teach it, and how this content should be imparted (10). Complicating matters, current professional ethics curricula often suffer from incoherence, insensitivity to societal needs, and isolated treatment of ethical topics (11,12). Thus, a coherent, up-to-date curriculum for professional ethics is a prerequisite for teaching ethical skills to various medical and paramedical groups, including nursing (13). Some experts argue that professional ethics teaching and evaluation should be integrated into undergraduate medical and dental curricula, with an emphasis on active learning and student engagement via case-based teaching (14).

Global research also underscores the significance of using diverse educational strategies for enhancing ethical learning experiences. Notably, top nursing schools worldwide have adopted methods such as integration, student-centred, community-centred, outcome-based, and problem-solving strategies (1). Employing varied educational models and assessment tools is crucial to promote professional ethics among medical students, as recommended by Ansari et al., with methods including reflection, feedback, clinical encounters, role-playing, bedside teaching, film and video usage, portfolio analysis, interactive seminars, mentoring, and problem-solving (15). These approaches have been corroborated by other scholars, who emphasize role-playing, mentoring, and reflection in ethics education (16), and the effectiveness of team-based teaching methods for self-directed learning and learning in action (17).

Successful course implementation for medical ethics and professional ethics also hinges on other factors, notably the timing of course presentation, which might be standalone theory courses or integrated with clinical courses throughout an academic semester. The latter approach has been advocated by AlMahmoud et al., who emphasize the effectiveness of integrated learning within clinical subjects over isolated theoretical courses (18). Integration, implying the organization of taught subjects and the creation of connections between different subjects in different courses, fosters mental coherence and deep understanding. Two forms of integration exist – horizontal and vertical – and both have been used extensively in medical schools to reinforce learning of basic science courses (19,20).

Notwithstanding, empirical evidence from the operating room illustrates the disappointing reality that, in Iran, extensive teaching of professional ethics has failed to produce graduates capable of comprehending and making ethical decisions in the challenging surgical environment (21,22). As future practitioners, medical graduates will frequently encounter a wide range of ethical topics in their daily routines, from respecting patient autonomy and confidentiality to teamwork, communication, and making appropriate decisions concerning abortions, assisted reproductive methods, organ transplants, emerging technologies, innovative surgical methods, surgical and anesthesia research, and cases involving crime victims (23). Accordingly, this study aims to develop a professional ethics curriculum tailored to the field of operating room technology for Iranian medical schools.

MATERIALS AND METHODS

The current research is an exploratory mixed-method study executed in two phases: qualitative and quantitative, in alignment with the Kern curriculum model (24).

The study was carried out from November 14 2021 to October 14 2022 at Alborz University of Medical Sciences, in Karaj, Iran, with the ethics code IR.ABZUMS.REC.1400.190.

Qualitative Phase

The initial phase comprised a general needs assessment conducted via a comparative study and a literature review of global professional ethics courses in English and Persian. Extracted data from this section was published in another article, in Persian (25). This process helped identify primary axes integral to the Kern-based curriculum design (24). Guided content analysis, following the methodology proposed by Hsieh and Shannon (26), was used to identify gaps in national curricula and practical domains in Iran. Twelve structured interviews were conducted, focusing on educational goals, content, teaching and assessment methodologies, and the presentation of the professional ethics course throughout academic semesters. The participants included 7 faculty members from operating room departments in four different universities, two operating room staff from two general hospitals, and three professional ethics and medical ethics course instructors from three medical and nursing schools in Iran. Guided content analysis facilitated data division into five categories: learning objectives, educational content, teaching methods, assessment methods, and the approach to delivering the course during the academic period. Data analysis commenced with the first interview and continued until the twelfth, when saturation was reached, and no new themes emerged.

Study Validity and Reliability

The study's accuracy was confirmed using Lincoln and Guba's four criteria: credibility, dependability, confirmability, and transferability (27). Prolonged engagement with data was used to ensure credibility, while member checking was used to increase dependability during the initial coding stage. External supervisor review confirmed the correctness of coding, and to meet the confirmability criterion, the entire data collection and analysis process was meticulously described. Full participant details were provided to facilitate data transferability.

Quantitative Phase

The Delphi method, widely used in literature to establish consensus on curriculum structure in various medical and nursing programs (28), was employed in the quantitative phase. An initial draft of the designed curriculum was based on the list of titles and themes extracted from the first phase, encompassing content, educational goals, teaching and assessment methods, and instructional strategy, along with a proposed academic period.

Delphi Participants

Expert selection considered educational qualifications, experience in professional ethics and operating room fields, and willingness to participate in the Delphi process. Three Delphi rounds were conducted over five months, with eighteen Iranian expert panel members participating in the first round from six nursing, medical and allied health schools in Iran. Experts evaluated the list of titles and themes extracted from the initial phase based on educational goals, teaching and assessment methods, and the proposed academic period, using a Likert scale with low (Score 1), medium (Score 2), and high (Score 3) options. They were also encouraged to note flawed items and provide corrective suggestions.

The mean scores were computed using Microsoft Excel, and cases with a mean score of 2 and above were approved based on expert panel consensus. The approved cases, along with recommended modifications, were then emailed to the experts for the second round, with fifteen responding. Mean scores were calculated a second time using Microsoft Excel, with cases holding a mean score of 2 and above approved based on the expert panel consensus. Descriptive statistics, such as mean/median and standard deviation, are advised for consensus calculations in the Delphi method (29). Following the approval of cases and review of some in the first and second rounds, the final curriculum was formulated and prepared in the Delphi survey's third round.

The presented data outlines a comprehensive and detailed integrated curriculum for professional ethics in Iranian operating rooms, derived from both qualitative and quantitative phases of research.

RESULTS

Qualitative Phase

The qualitative phase comprised a targeted review of curricula documents from undergraduate surgical technology programs globally, with the aim of identifying professional ethics modules and courses. Specifically, we reviewed program curricula from seven countries across three continents with different cultures (USA, Canada, Australia, Scotland, Pakistan, India, and Iran) to get a broad perspective on how professional ethics education is incorporated internationally. The review focused on identifying the structure, content, delivery methods, and learning outcomes related to professional ethics. Detailed findings from this review have been published separately in Iranian journals, in Persian (25).

Further, twelve structured interviews were conducted and analyzed using the directional content analysis method. This approach yielded a granular view of the components of a professional ethics curriculum, resulting in 145 primary codes, grouped under 14 subcategories and the five aforementioned main categories (Table 1).

Table 1: Extracted Categories and Subcategories in Qualitative Phase 1

Categories	Subcategories	Primary codes
Educational strategy	Discipline-base	Teaching in two separate courses
		Teaching in specialized courses
	Integration	Introducing ethics topics in every specialized course
		Presenting ethics topics with internship courses
Contents	Communication skills	Team working
		Therapeutic communication
		Verbal skills
		Non-verbal skills
		Empathy
		cooperation
	Medical ethics	Illegal abortion
		The four principles of ethics
		Victims of sexual assault and domestic violence
		Assisted reproductive methods
		informed consent
		Ethics in research
	Law and Ethics	Ethics codes
		Financial crimes
		Liability insurance
		Legal authorities for managing complaints
		Medical errors and malpractice
		informed consent
		Human rights
	Professional Behaviour	Values in disciplines
		Professional development
		Role modeling
Teaching methods	Passive	Lecture
	Active	Scenario-based teaching
		Role modeling
		Group discussion
		Demonstration
		Reflection
Assessment methods	Formative	Written tests (MCQ, essay)
		Expressing real experiences
		Direct observation
		Journal clubs
		Reflection
	Summative	Written tests (MCQ, essay)
		Direct observation
		Expressing real experiences
		Personal and Group Project
		Reflection in portfolio
		Seminar presentation
Educational Goals	Cognitive	Knowledge of legal and rule principle
		Awareness of the ethics approach
		Understanding of ethical issues in the operating room
	Affective	Interested in job
		Empathy reaction
		Attention to the patient's right
	Psychomotor	communication and teamwork
		Protecting patient privacy
		Doing right in a critical situation

Quantitative Phase

The Delphi process commenced with an expert panel of 18 participants, which decreased to 15 in the second round and concluded with 13 panelists in the final round, over a period of five months. Demographic details of the final 13 experts who participated in the last round of the Delphi survey are provided in Table 2.

Quantitative Phase – Analysis

Initial analysis of the survey items across five axes in the first round, using a mean index above 2 (from a maximum of 3), facilitated the agreement and acceptance of 11 educational content, 69 educational objectives, 6 teaching methodologies, 8 evaluation methods, and a strategy for vertical integration. During this stage, we expanded the initial table to include one additional educational content, two teaching methodologies, and two assessment methods.

Heeding the expert panel's suggestions, we further differentiated the learning objectives into cognitive, affective, and psychomotor domains, implementing a structured taxonomy. We determined and assigned suitable courses across different academic semesters, extending the table with the following categories: 'Main Concepts,' 'Academic Semester,' 'Course,' 'Course Type,' 'Learning Objectives,' 'Objective Domain,' 'Taxonomy,' 'Teaching Methods,' and 'Assessment Methods.' Subsequently, these revised items underwent a third review by the expert panel.

Table 2: Demographic Properties of Experts Participating in Delphi Rounds

Specialty	Number	Department	Gender	Mean age(year) ± SD	Experience(year)
Perioperative nurse	3	Country's Operating Room Board	2 Females 1 Male	53 ±1.4	26 ±2.7
Medical ethics	2	Medical Ethics Group	1 Female 1 Male	48.3 ±0/3	19.6 ±1.4
Perioperative nurse	3	Operating Room Group	3 Females	41.3 ±5.6	17.3 ±6.3
Medical Education	3	Medical Educational Development Centre	2 Females 1 Male	43.7 ±1/8	13 ±3.9
Forensic Medicine	1	Forensic Medicine Group	1 Female	45.9	11.6
Islamic Ethics	1	Islamic Ethics Group	1 Male	51.6	21.3

During the third and final round of the Delphi process, the expert panel approved the proposed vertically integrated professional ethics curriculum. This curriculum comprised ethical concepts, learning objectives across different taxonomies and domains, teaching methodologies, and assessment methods. These components can be concurrently taught across various academic semesters, dovetailing with other related theoretical and practical courses (Table 3).

Table 3: Integrated Curriculum of Professional Ethics in the Operating Room

Main concepts	Semester	Course title	Course type	Learning objective	Objective domain	Taxonomy	Teaching methods	Assessment methods
Communication	1	Introduction to surgery	Theory	Explain the main elements in the process of communication	Cognitive	1	Interactive lecture	Written test
				Compare types of communication with each other	Cognitive	1	Interactive lecture	Written test
				Discuss the importance of therapeutic communication with patients	Affective	2	Interactive lecture	Written test
				List the barriers to effective communication	Cognitive	1	Interactive lecture	Written test
				Explain the importance of communication and teamwork in patient safety	Cognitive	2	Interactive lecture	Written test
				List the common errors in communicating and doing teamwork in the operating room	Cognitive	1	Interactive lecture	Written test
	2	The internship of behaviour in the operating room	Practice	Respect the operating room staff	Psychomotor	3	Demonstration	Direct observation
				Criticize the strengths and weaknesses related to the admission of a patient to the operating room	Affective	4	Demonstration	Analytical report
				Listen carefully to the patient	Affective/ psychomotor	1	Demonstration	Direct observation
				Analyze the strengths and weaknesses of teamwork skills during your internship	Affective	4	Demonstration	Reflection in portfolio
				Demonstrate the skills of delivering bad news to the patient's family	Psychomotor	3	Demonstration	Direct observation
	2	Psycho health in the operating room	Theory	Voluntarily participate in a scenario to demonstrate correct and incorrect communication with the patient	Affective	2	Demonstration	Direct observation
				List the skills of giving bad news to companions	Cognitive	1	Demonstration	Written test
Human rights	3		Practice	Criticize informed consent taken from the patients during internship	Cognitive	4	Demonstration	Reflection in portfolio

		The internship of principles of Circulate technologist performance in the operating room		Develop practical guidelines to support the patients' rights	Cognitive	5	Demonstration	Reflection in portfolio
				Criticize the observance of the principle of confidentiality at the bedside with an example	Cognitive	4	Demonstration	Reflection in portfolio
				Respect patient privacy when admitting a female patient to the operating room	Psychomotor	3	Demonstration	Direct observation
	4	Professional ethics in the operating room	Theory	Explain the concept of informed consent	Cognitive	2	Interactive lecture	Written test
				Mention the main principles of informed consent	Cognitive	1	Interactive lecture	Written test
				Compare different types of medical consents	Cognitive	2	Lecture	Written test
				Explain the importance of the principle of confidentiality in the care and treatment of patients	Cognitive	2	Interactive lecture	Written test
				Describe the exceptions to non-compliance with the principle of confidentiality	Cognitive	1	Interactive lecture/group discussion	Written test
				Explain the importance of the patient's proper clothing and his/her personal privacy	Cognitive	1	Interactive lecture	Written test
Principle of medical ethics and professionalism	4	Professional ethics in the operating room	Theory	Explain the history of medical ethics in the world and Iran	Cognitive	1	Interactive lecture/group discussion	Written test
				Describe the four principles of medical ethics	Cognitive	1	Interactive lecture	Written test
				Compare the approaches of different schools to the ethics	Cognitive	2	Interactive lecture	Written test
				Define the concept of professional ethics and its elements	Cognitive	1	Interactive lecture	Written test
	4	Internship: principles of circulation technologist performance in the operating room	Practice	Apply the principle of justice to admitting patients to the operating room	Psychomotor	3	Demonstration	Direct observation
	5	Internship: operating room management	Practice	Analyze the current issues and challenges of surgery and anesthesia ethics in the world and Iran	Cognitive	3	Interactive lecture	Critical report
Ethics codes	4	Professional ethics in operating room	Theory	Explain the concept of codes of ethics in medical and paramedical professions.	Cognitive	2	Interactive lecture	Written test
				List the ethical codes approved by the American Association of operating room nurses	Cognitive	2	Interactive lecture	Written test
	6	Internship: emergency unit and PACU	Practice	React to non-compliance with the ethical codes in the operating room.	Affective	2	Case-based discussion	Daily note-taking
Medical negligence and documentation	4	Professional ethics in operating room	Theory	Explain the difference between negligence and crime	Cognitive	2	Interactive lecture	Written test
				Explain the types of malpractices in the operating room with examples	Cognitive	2	Interactive lecture	Written test
				Explain the role of documentation in legal proceedings related to negligence	Cognitive	2	Interactive lecture	Written test

	4	Internship: principles of scrub technologist performance in operating room	Practice	Analyze the reports registered in the files in terms of compliance with the standard principles of report writing	Cognitive	4	Demonstration	Reflection in portfolio
	5	Internship: surgery technics	Practice	React to the mistakes made by the surgical team members	Affective	2	Demonstration	Reflection in portfolio
	7	Internship: operating room management	Practice	give a speech regarding cases of malpractice in one's internship and preventive solutions	Cognitive	5	Clinical experience/self-study	Direct observation
Laws and authorities for dealing with medical malpractice	4	Professional ethics in the operating room	Theory	List the authorities for handling medical malpractice	Cognitive	1	Interactive lecture	Written test
				Explain the reasons for the increase in patients' complaints	Cognitive	1	Interactive lecture	Written test
Euthanasia and organ transplantation	4	Professional ethics in the operating room	Theory	Define the concept of euthanasia	Cognitive	1	Interactive lecture	Written test
				Actively participate in euthanasia-related topics	Affective	2	Interactive lecture	Observation
				Exemplify the types of euthanasia	Cognitive	1	Interactive lecture	Written test
				Criticize the different viewpoints related to the acceptance of euthanasia	Cognitive	4	Interactive lecture	Written test
	4	Cardiopulmonary resuscitation		State the conditions and rules related to organ transplantation in Iran	Cognitive	1	Interactive lecture	Written test
				Compare the criteria and conditions of the end of life in organ transplantation and euthanasia	Cognitive	2	Interactive lecture	Written test
Ethics in assisted reproduction methods	4	Technology of gynecological and urology surgery	Theory	Explain the principles of ethics in assisted reproductive techniques	Cognitive	2	Interactive lecture	Written test
				Compare the types of assisted reproductive techniques with legal permission in the world & Iran	Cognitive	2	Interactive lecture	Written test
				Explain the legal conditions for the possibility of using surrogacy and sperm bank	Cognitive	2	Interactive lecture	Written test
				Interested in discussing the topics of assisted reproductive methods	Affective	2	Interactive lecture	Observation
				Compare the views of different jurists on the use of assisted reproductive methods	Cognitive	2	Interactive lecture	Written test
Abortion	4	Technology of gynecological and urology surgery	Theory	React to the issue of abortion freedom	Affective	2	Interactive lecture/group discussion	Observation
				Accept or reject abortion with reasons	Affective	2	Interactive lecture	Written test
				Compare views of jurists and different religions on abortion	Cognitive	2	Interactive lecture	Written test
				Explain the legal rules and conditions of abortion in Iran	Cognitive	1	Interactive lecture	Written test
	7	Internship: operating room management	Practice	Control client's medical record in terms of fetal death in utero when admitting cases with emergency curettage	Psychomotor	4	Interactive lecture	Direct observation
Admission of the injured and victims of crime	5	Operating room management	Theory	List signs of crime in family violence against children and women	Cognitive	2	Interactive lecture	Written test
				Explain ethical issues involved when treating suspicious individuals and victims of crime	Cognitive	2	Interactive lecture	Written test

				Explain how to keep cases when dealing with injured and victims of family violence	Cognitive	2	Interactive lecture	Written test
				Explain legal and ethical proceedings when admitting victims of sexual violence to the operating room	Cognitive	2	Interactive lecture	Written test
	7	Internship: operating room management		Discuss a lived experience of admitting cases of crime or family violence to operating room	Cognitive	4	Interactive lecture	Project
Professionalism	4	Professional ethics in the operating room	Theory	Describe the concept of professionalism in medical science	Cognitive	2	Interactive lecture	Written test
				Explain role models in the professional development of students	Cognitive	2	Interactive lecture	Written test
		Internship: operating room management	Practice	Suggest your own role models during internship based on the role model's properties	Affective	3	Narration	Critical report -reflection
Ethical Considerations of Research	3	Research method in the operating room		Describe ethical principles and rules in different medical research	Cognitive	2	Interactive lecture	Written test
				Exemplify ethical challenges related to modern medications, tools, technologies, and techniques in the operating room	Cognitive	2	Case-based discussion	Review article
				Apply ethical considerations in research to clinical studies	Cognitive	3	Case-based discussion	Proposal
				Exemplify conflict of interest in clinical studies on the operating room	Cognitive	2	Case-based discussion	Proposal

DISCUSSION

The main objective of our study was to refine the delivery of a professional ethics course in an Iranian medical school by integrating various longitudinal themes into the undergraduate curriculum for operating room technology. This was executed in two stages: qualitative and quantitative. In the qualitative stage, we reviewed the existing curriculum of professional ethics specific to operating room nursing. We also analyzed participant interviews, resulting in the identification of five curriculum development categories: course content, educational objectives, teaching strategies, evaluation methods, and course delivery methods. These categories align with global curriculum evaluation frameworks (30,31).

During the quantitative phase, we affirmed 12 educational content titles, each associated with cognitive, psychomotor, and emotional objectives. This validation process used 8 teaching methods and 10 evaluation methods through a longitudinally integrated approach. Our educational content, sub-categorized into communication skills, ethics and law, medical ethics fields, and professional commitment, mirrors global curricula in certain aspects and aligns with the cognitive, psychomotor, and emotional educational objectives (32-38). Furthermore, this content closely parallels Iran’s current curriculum, although Iranian curriculum for professional ethics in the operating room primarily focuses on cognitive objectives (21).

McNeil et al. further delineated elements such as medical knowledge, communication skills, ethical and legal comprehension, and ethical values (e.g., honesty and integrity, responsibility and participation, respect, sensitivity, compassion, and empathy) as integral to professionalism and professional ethics (39). Regarding educational goals, our study participants underscored the importance of cognitive, emotional, and psychomotor goals. A comprehensive coverage of these areas cannot be achieved solely by focusing on cognitive objectives. Our interview analysis and a review of programs at special organisations – e.g., AORN (The Association of periOperative Registered Nurses) and EORNA (European Operating Room Nurses Association), and various universities in India, Australia, Scotland, Canada, Pakistan, USA and Iran – corroborate the importance of addressing educational goals across these three domains (32-38). This sentiment aligns with Mahajan et al. who stressed the importance of learning objectives in knowledge, skills, and attitudes (40).

Our research revealed that course presentation methods fell into two subcategories: separate and mixed presentations. These include such options as mixed course presentations combining theory with internship courses. Based on our data analysis, educators and practitioners in this specialized field emphasized the integration of teaching and evaluation during the course and alongside other theoretical and practical courses. This approach contrasts with the current operating room technology curriculum in Iran, where this course is presented as a single, theoretical unit (21). However, at six universities examined in this study, this course is offered as an integrated, longitudinal theme (32–38). Khaqani et al. note that in our curricula, medical ethics is presented as an isolated unit, separated from other specialized courses. In contrast, many international curricula infuse medical ethics topics specific to a course into all specialized courses. For instance, foreign reference books on “Obstetrics and Gynecology” address ethical topics related to women and childbirth in their introductions and intersperse medical ethics points throughout their text. This approach to embedding ethics is mirrored in foreign radiology books, which present topics on medical ethics during patient radiation and on communication with patients (12).

Abolqasmi et al., taking into account the shift in teaching and evaluating the professional ethics course in nursing, propose an integrated model as an effective method for presenting this course (1). In their study titled “The Experience of Academic Staff Members in Teaching Professional Obligations to Medical Students,” Allami et al. found that an ethics course, scattered and translated from foreign texts, lacks a coherent identity and can confuse students (41). Similarly, Kavas et al. in Turkey argued that a solely theoretical course, presented in a separate semester, would not suffice for instilling ethics in the future careers of medical and paramedical groups (9) . Echoing this sentiment, AlMahmoud et al. underline that learning in the form of integration in clinical subjects is more effective than separate, theoretical course presentations (18). In line with this, Mahajan et al. advocate for a coherent integration of professionalism and ethics into the curriculum (40).

The teaching method category in our study encompasses two subcategories: teacher-centred and student-centred methods. These primary codes include group discussion, interactive lectures, case-based learning, role-playing, and demonstration. The participants emphasized the importance of participatory methods that actively involve students, as opposed to relying solely on lectures. Despite this, our surveys showed that the majority of universities in Iran primarily use a lecture format. However, the curricula we reviewed use several teaching methods such as lectures, problem-based learning, experience-based learning, conferences, discussions in clinical skills units and real clinical settings, group discussions, case-based learning, guided learning, and team learning (32-38). The findings from Khaganizadeh et al.’s research highlight that the learning activities and strategies used to present ethics courses in our country are suboptimal. They suggest that instead of solely relying on lectures, newer teaching methods such as active learning, individual participation, group interactions, and a problem-based approach should be implemented (42). Allami et al. further argue that one of the significant issues in ethics education is the traditional, preachy approach towards professional challenges (41). In line with this, Ayesha argues that teaching professional ethics should not just concentrate on the cognitive domain, but also on developing skills and attitudes (14).

Several studies have addressed the efficacy of different teaching methods in the field of professional ethics. Byrne, John, et al. found the lecture method to be the least effective in teaching ethical topics in obstetrics and gynecology assistant programs (43). Domenc Rodrigues et al. posited that, in terms of effectiveness, case-based learning holds an advantage over traditional lectures (44). Sawant et al. emphasized the significance of participatory teaching and the role of professors as role models and mentors for learners (45), while Ercan Avci highlighted the importance of active and case-based methods in his study (46). Chowdhury suggested that ethics and values could be imparted through a variety of educational techniques such as role models, demonstrations, simulations, educational games, discussions, projects, group works, educational visits, interviews, and brainstorming, using resources like poetry, stories, music, photos, posters, and slogans (47). In a review titled “Application of Narrative in Medical Ethics,” Daryazadeh explored the usage of diverse teaching methods like storytelling and problem-solving in teaching medical ethics concepts (48). Furthermore, Garza et al. introduced various teaching methods, including group discussion methods, case-based learning, and sharing personal experiences (30). Simon underscored the importance of team-based teaching methods as one of the collaborative approaches in learning ethics topics, arguing that this method facilitates self-directed and in-action learning (17).

The category of evaluation methods encompasses both formative and summative assessment subcategories, which include primary codes such as written tests, reports, direct observation during internships, and expression of experiences. In their study, Abul Qasemi et al. evaluated a variety of assessment tools, such as multiple-choice and written tests, essay writing, practical demonstration in clinical skills units, case studies, poster presentations, reflections, portfolios, continuous review of practical skills, class activities, and objectively structured clinical examinations (1). In the analysis of the curriculum of the professional ethics course for operating room studies in various universities in Iran, USA, India, Pakistan, Scotland and Australia, assessment techniques such as final exams with multiple-choice questions, discussions and written tests, essay writing, and portfolio construction were also highlighted (32-38). Nevertheless, written tests seem to be the prevalent form of assessment for this course. Mohibi Amin’s study underscored the deficiency of appropriate evaluation in ethics education and highlighted international experiences that emphasize the use of diverse and comprehensive evaluation methods (10). Consequently, it appears necessary to revisit the course presentation method, teaching techniques, and evaluation strategies involved in the delivery of this course.

LIMITATIONS

This study’s limitations stem from the unique nature of the operating room technologist curriculum in Iran and its differences from analogous curriculums around the world. These variances might pose challenges in generalizing the findings of the study on a global scale; but they nonetheless tell us much about the state of medical training in Iran and opportunities to improve professional ethics education of health professionals.

CONCLUSION

This comprehensive study sought to evaluate the structure, delivery, and impact of a professional ethics course in the undergraduate curriculum of operating room technology in Iran. The research process involved a two-tiered approach, qualitative and quantitative, to provide a balanced insight into the effectiveness of the course. The results revealed significant gaps in the course's presentation, content, teaching, and evaluation methodologies. For instance, the course content, while covering important themes such as communication skills, ethics, law, medical ethics, and professional commitment, largely addressed cognitive goals, neglecting the equally crucial psychomotor and emotional aspects. This finding is particularly concerning as professional ethics courses in many other countries strive to balance these three domains. Moreover, the presentation of the course in Iran is limited, with the curriculum typically offering it as a theoretical, independent unit. This contrasts with global trends where professional ethics is integrated longitudinally across all specialties, an approach that has been associated with more effective learning outcomes. The traditional lecture-based teaching method employed in Iran further adds to the limitations, with our research and several other studies emphasizing the need for more participatory and interactive teaching methods such as group discussion, case-based learning, and role-playing. The assessment of the course also warrants revision. At present, written tests are predominantly used for evaluation, which may not accurately measure a student's understanding and application of professional ethics. Other forms of assessment, such as direct observations, reflective reports, and portfolios, could provide a more comprehensive appraisal of a student's competency. Nonetheless, the study's findings should be interpreted with caution given the unique context of the operating room technologist curriculum in Iran, which differs significantly from its counterparts globally. This distinctive curriculum presents challenges in generalizing the findings on a global scale. Based on the shortcomings to profession ethics education identified by our study, it is recommended that the professional ethics course in the operating room technology curriculum in Iran be revisited and revised. These changes should aim to transform the course into a longitudinally integrated component across all paramedical and nursing disciplines. This revision should encompass a holistic reconsideration of the course's presentation, content, teaching, and assessment methods, shifting towards a more engaging, interactive, and comprehensive approach to professional ethics. This reform could potentially enhance the ethical grounding of future operating room technologists, ultimately leading to more professional and ethical healthcare practices in the country.

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None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Rôle modérateur du format de présentation de dilemmes de confidentialité sur la relation entre l'utilitarisme et la propension à la levée de la confidentialité

Guillaume Chailler[a], Michael Cantinotti[a], Bastien Trémolière[a,b]

Résumé
Bien que l'étude du jugement moral ait gagné en popularité ces dernières années dans le domaine de la psychologie, peu de recherches se sont intéressées aux dilemmes de confidentialité en contexte de jugement moral. Or, les personnes cliniciennes font régulièrement face à de tels dilemmes qui surviennent souvent dans des contextes chargés émotionnellement. Cette étude évalue le rôle des émotions dans les réponses à ces dilemmes de confidentialité. En tout, 186 participants étudiant en psychologie dans différentes universités du Québec ont été assignés aléatoirement à l'un des trois groupes d'un devis expérimental (modalité audio dramatique, modalité audio neutre, modalité texte) et ont répondu à des dilemmes de confidentialité en choisissant entre la protection ou la levée de la confidentialité. Le positionnement des participants sur un continuum allant du déontologisme à l'utilitarisme, grâce à la réponse à des dilemmes sacrificiels, a également été pris en considération. Le modèle de régression linéaire multiple hiérarchique utilisé indique un apport significatif provenant des réponses aux dilemmes sacrificiels, de l'intensité émotionnelle perçue des dilemmes de confidentialité et de la formation obtenue dans le domaine de l'éthique et de la déontologie. L'analyse révèle en outre l'effet modérateur de l'exposition à la condition expérimentale sur la relation entre la tendance à l'utilitarisme et la propension à la levée de la confidentialité dans une relation psychothérapeutique. Ces résultats ont des implications pratiques concernant le cursus en psychologie, où des mises en situation avec une validité écologique pourraient bonifier la formation en éthique.

Mots-clés
jugement moral, confidentialité, dilemmes moraux, tonalité émotionnelle, levée de la confidentialité

Abstract
Although the study of moral judgment has gained in popularity in the field of psychology in recent years, little research has focused on confidentiality dilemmas in the context of moral judgment. Yet clinicians regularly face such dilemmas, which often arise in emotionally charged contexts. This study assesses the role of emotions in responses to these confidentiality dilemmas. A total of 186 participants studying psychology at different universities in Quebec were randomly assigned to one of three groups in an experimental design (dramatic audio modality, neutral audio modality, text modality) and responded to confidentiality dilemmas by choosing between protecting or lifting confidentiality. Also taken into consideration were participants' positioning on a continuum ranging from deontology to utilitarianism, based on their response to sacrificial dilemmas. The hierarchical multiple linear regression model used indicates a significant contribution from responses to sacrificial dilemmas, perceived emotional intensity of confidentiality dilemmas and training obtained in the field of ethics and deontology. The analysis further reveals the moderating effect of exposure to the experimental condition on the relationship between the tendency towards utilitarianism and the propensity to waive confidentiality in a psychotherapeutic relationship. These results have practical implications for psychology curricula, where situation scenarios with ecological validity could enhance ethics training.

Keywords
moral judgment, confidentiality, moral dilemmas, emotional tone, lifting confidentiality

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INTRODUCTION

Le jugement moral a pendant longtemps été étudié selon les courants rationnels et sentimentalistes mettant en opposition la raison et les émotions (1,2). Au début des années 2000, Greene et al. (3) ont proposé, à travers l'utilisation de dilemmes sacrificiels, que ces jugements étaient le fruit d'un processus conjoint alliant raisons et émotions. De nombreuses recherches réalisées dans le domaine du jugement moral ont utilisé la théorie des doubles processus ainsi que les dilemmes sacrificiels afin d'étudier le fonctionnement du cerveau (4-8), les traits de personnalités individuels (9,10), certaines dispositions psychologiques associées aux préférences morales, ainsi que la manière dont les émotions ou le contexte social pouvaient venir affecter les décisions individuelles (11,12).

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À titre d'illustration, voici un exemple de dilemme sacrificiel :

> *Vous êtes le chef d'un petit groupe de soldats. Vous êtes sur le chemin du retour après avoir effectué une mission se situant dans le territoire ennemi. Un de vos hommes est tombé dans un piège ayant été posé par l'ennemi et est gravement blessé. Le piège est connecté à une radio qui a alerté les ennemis de votre présence, et ce dernier sera donc bientôt en chemin vers votre position. Si les ennemis trouvent votre homme blessé, ils vont le torturer et le tuer. Celui-ci vous supplie de ne pas l'abandonner à son sort, mais si vous essayez de l'amener avec vous, c'est votre groupe en entier qui se fera capturer. La seule manière pour vous d'empêcher ce soldat blessé de se faire torturer est de lui tirer une balle vous-même.*
>
> *À quel point serait-il approprié, pour vous, d'exécuter ce soldat afin de protéger le reste du groupe?* (3) [traduction libre]

De très nombreux dilemmes similaires ont été créés en faisant varier les paramètres utilisés dans les scénarios, comme la proximité entre les acteurs ou encore le nombre de victimes pouvant être potentiellement sauvées (4). Ces auteurs établissent une distinction importante entre les dilemmes sacrificiels qualifiés de « personnels » et ceux qualifiés « d'impersonnels ». Les dilemmes personnels impliquent le fait de causer une blessure à une ou plusieurs personnes, et non seulement de rediriger un dommage déjà existant. Les dilemmes ne remplissant pas ce critère sont qualifiés de dilemmes impersonnels (4,13). C'est dans le contexte des dilemmes personnels que le conflit entre l'utilitarisme et la déontologie survient.

La théorie des doubles processus du jugement moral avance qu'à la prise en compte d'un dilemme sacrificiel personnel, deux processus s'activeraient et produiraient des réponses différentes, soit la réponse utilitaire, soit la réponse déontologique (5). Dans l'exemple ci-dessus, exécuter le soldat serait moralement inacceptable selon le principe déontologique qui avance que la moralité d'une action dépend de sa nature intrinsèque sans tenir compte des conséquences. Selon ce principe, tuer une personne innocente s'avère immoral, peu importe le nombre de vies pouvant être épargnées (14). À l'inverse, exécuter le soldat serait acceptable selon une perspective utilitariste. Selon celle-ci, la moralité d'une action est déterminée par sa conséquence. Ainsi, dans une perspective purement utilitariste, tuer une personne innocente est acceptable si cette action vise à minimiser le nombre de pertes humaines (15). En termes de processus, le jugement déontologique serait essentiellement le fruit de processus intuitifs qui reposeraient sur les émotions, alors que le jugement utilitariste serait surtout la conséquence de processus nécessitant une délibération et un style rationnel de pensée (16). Chaque individu aurait une propension interne à opter de manière prépondérante pour l'un ou l'autre de ces deux principes, ce qui a fait l'objet de nombreuses études sur les dilemmes sacrificiels.

Plusieurs variables individuelles semblent affecter la préférence morale. Par exemple, une étude propose que les individus présentant des scores supérieurs à la moyenne dans les tâches sollicitant la mémoire de travail ont davantage tendance à opter pour la réponse utilitaire (17), appuyant l'idée selon laquelle il est plus simple pour les personnes rationnelles d'émettre ce type de jugement (3). De plus, les individus provenant de milieux socioéconomiques élevés seraient plus utilitaires dans leurs jugements moraux et réagiraient avec moins d'empathie face à la souffrance d'autrui, comparativement à ceux provenant de milieux socioéconomiques plus faibles (18-20). Les individus empathiques seraient davantage enclins à se mettre dans la position des personnes subissant le tort lors des dilemmes moraux et partageraient davantage les sentiments de celles-ci, ce qui pourrait expliquer l'association négative qui a été observée entre le jugement moral utilitaire et l'empathie (21). Dans cette même perspective, Kœnigs et al. (8) soutiennent qu'un manque de *culpabilité*, de *honte* et d'*empathie* augmenterait également le jugement utilitaire. Selon ces auteurs, ces trois composantes sont associées à la conscience personnelle et désignées comme des « affects moraux », c'est-à-dire qu'ils joueraient un rôle actif dans la résolution de dilemmes moraux conflictuels. D'autres études suggèrent que les individus avec des traits de psychopathie et de machiavélisme seraient davantage portés à opter pour des décisions utilitaires, notamment car ces caractéristiques entraînent souvent un détachement émotionnel important (9,10). Il semble également y avoir une corrélation positive entre l'activation d'émotions négatives et l'émission de jugements déontologiques (22).

Bien que les dilemmes sacrificiels s'avèrent utiles pour comprendre comment les personnes émettent des jugements moraux et quelles variables affectent ces jugements, la dernière décennie a vu s'élever plusieurs critiques concernant l'utilisation de ces dilemmes sacrificiels, en particulier pour leur manque de réalisme (23,24). En effet, ces dilemmes incarnent des situations relativement éloignées de la réalité et dans lesquelles il est parfois difficile pour les participants de se projeter pour s'identifier aux personnages des dilemmes. La validité écologique de ces mises en situation présente des enjeux, ce qui met en doute l'utilité et la transposition des recherches sur cet objet dans le quotidien et dans la formation professionnelle en santé. Toutefois, il apparait possible d'appliquer la théorie des doubles processus à des contextes beaucoup plus proches de la réalité et qui concernent des enjeux publics d'actualité. C'est notamment le cas avec certains dilemmes éthiques en psychologie, par exemple concernant les enjeux entourant la levée du secret professionnel.

Dans la profession de psychologue, les conflits éthiques peuvent survenir dans des contextes variés: situations délicates en lien avec la confidentialité, relations présentant des conflits de rôles, de loyauté ou d'intérêts, ou encore exposition à l'inconduite de collègues (25). Plus spécifiquement, nous nous intéressons aux dilemmes associés à la levée de la confidentialité étant donné que ceux-ci font partie des enjeux éthiques les plus fréquemment rencontrés par les psychologues (25). De plus, de nombreuses études révèlent qu'il n'y a pas toujours de consensus entourant les situations où la levée du secret professionnel est requise ou pertinente (26-28).

Les dilemmes de confidentialité dans la profession de psychologue

Bien que son application puisse paraitre simple, la confidentialité entre thérapeutes et clients n'est jamais absolue, ce qui suscite parfois de la confusion et parfois même de sérieux dilemmes éthiques dans la pratique professionnelle (26-30). Par exemple, des professionnels dévoilant des informations qui auraient dû être préservées sous le secret professionnel sont susceptibles de faire l'objet de poursuites et d'avoir des plaintes à leur égard les mettant en situation de porte-à-faux avec la loi ou leur ordre professionnel. En revanche, les psychologues ont également un devoir légal et éthique de dévoiler des informations confidentielles lorsque certains risques sont présents; dans certains cas, ne pas dévoiler ces informations cruciales peut également les rendre passibles de poursuites et d'être tenus partiellement responsables envers les gestes posés par leurs clients (30,31). Ces devoirs peuvent ainsi entrer en opposition et amener les professionnels à vivre des dilemmes envers lesquels il n'est pas évident de se positionner à propos du principe de confidentialité.

Selon le code de déontologie de l'Ordre des psychologues du Québec, plusieurs situations peuvent permettre, voire contraindre le professionnel à lever la confidentialité. Par exemple, un professionnel suspectant un enfant ou un adolescent d'être victime de négligence ou de toute forme d'abus susceptible d'affecter son développement a l'obligation légale d'en informer la Direction de la protection de la jeunesse (32). En outre, quand un psychologue estime qu'un de ses clients est inapte à conduire, il a une obligation discrétionnaire de signaler à la Société de l'assurance automobile du Québec qu'il entretient un doute sur l'aptitude à conduire du client en question (32). Le psychologue peut aussi lever le secret professionnel dans l'objectif de prévenir un acte dangereux ou un suicide lorsqu'il a un motif raisonnable de croire qu'un individu ou une collectivité est menacé. Cependant, le psychologue ne peut communiquer les informations confidentielles qu'aux personnes menacées et aux individus pouvant leur porter secours. Également, le psychologue doit se fier à son jugement professionnel sur la dangerosité et se doit d'évaluer l'imminence du danger avant de dévoiler les informations confidentielles (32,33). Ensuite, l'ordre professionnel peut effectuer une inspection afin de vérifier la justesse de la tenue de dossier de l'un de ses membres (levant ainsi le secret professionnel) et un professionnel pourrait également être appelé au tribunal afin d'être amené à lever son secret professionnel dans le cadre d'un procès (33). Toutefois, tous les cas de figure possibles ne sont pas spécifiquement détaillés et comme une grande partie de la décision dépend du jugement du professionnel, il est possible que les interprétations concernant le « degré de dangerosité » et « l'imminence du danger » puissent varier d'un professionnel à l'autre et avoir des incidences sur les levées de confidentialité (34).

Plusieurs situations peuvent être jugées délicates, car les principes figurant dans les codes de déontologie et la législation peuvent entrer en contradiction et générer des enjeux concernant l'application de ces principes dans les pratiques cliniques ou laisser des vides interprétatifs (30,35-37). De plus, la jurisprudence peut évoluer à travers le temps, complexifiant la prise de décision des professionnels. Ces différents contextes peuvent placer les psychologues dans des positions incertaines et des auteurs suggèrent que ce sont les jugements de valeur des professionnels qui font la différence dans le cadre de ces décisions (28,38-42). Ci-dessous, nous abordons différents contextes associés à un manque de consensus chez les thérapeutes concernant la levée du secret professionnel.

Le VIH et la confidentialité

Le virus de l'immunodéficience humaine (VIH) communément appelé « le sida » a été détecté initialement au début des années 1980 (43). Entre 1981 et 2018, il aurait causé plus de 32 millions de morts (44). Pendant plusieurs années, ce virus était considéré comme étant mortel, car il endommageait graduellement le système immunitaire des personnes atteintes, les rendant vulnérables à développer des maladies qui s'avéraient mortelles. Aujourd'hui, le VIH n'est plus considéré comme une maladie mortelle, mais bien comme une maladie chronique (45). Cependant, cette condition est associée à un manque d'information, de la stigmatisation et de la discrimination, principalement envers les jeunes adultes homosexuels masculins, ainsi que certaines personnes issues des minorités visibles ou ethniques (45-48). Le manque de consensus concernant le devoir de divulgation du statut sérologique des patients infectés par le VIH est parfois associé au flou dans l'interprétation du degré de dangerosité associé à la transmission du virus. Il n'est pas clair pour les psychologues de savoir s'ils ont un devoir de divulgation dans ces situations. Aux États-Unis, l'Association américaine de psychologie (49) a statué qu'aucun devoir légal n'était imposé aux psychologues à ce sujet. Cependant, plusieurs jugements de tribunaux ont montré que des juges pouvaient opter pour des positions opposées à celles des ordres professionnels. Effectivement, selon ces juges, parfois les psychologues avaient divulgué la condition sanitaire à tort, alors que dans d'autres situations, ils avaient omis, à tort, de le faire (50). En 2011, 67 lois existaient dans 33 états des États-Unis criminalisant l'exposition au VIH (51). Au Canada, la non-divulgation du statut sérologique des individus présentant le VIH a été criminalisée en 1998 (47). Toutefois, dans la plupart des juridictions, les psychologues n'ont pas de devoirs légaux de divulgation des activités sexuelles passées, présentes ou futures de clients séropositifs. Cependant, si la charge virale est élevée, que la personne cliente mentionne explicitement qu'elle ne portera pas le condom et que le partenaire sexuel est identifiable, le devoir d'avertir le ou les partenaires pourrait être requis (47). Néanmoins, cet enjeu reste complexe pour les psychologues, car les thérapeutes doivent protéger à la fois l'intérêt du client et celui du public (36). En effet, c'est grâce à la présence du secret professionnel que les individus infectés par le VIH se sentiront à l'aise de divulguer les informations délicates à leur psychologue. Il en découle que si cet espace de parole n'est plus perçu comme sécuritaire par les clients, il ne sera pas possible de protéger la population. Conséquemment, il est nécessaire de savoir naviguer dans une zone grise visant à réduire autant que possible les méfaits, tout en préservant la relation de confiance auprès de la clientèle en thérapie.

La confidentialité entourant la pratique auprès de la clientèle adolescente

L'adolescence représente une période de vie intense où il y a présence de remise en question de certaines valeurs et dans laquelle des changements comportementaux peuvent avoir lieu chez les individus dans l'objectif d'être acceptés par les pairs, de trouver son identité ou ses limites personnelles (52). Plusieurs de ces comportements peuvent impliquer une notion de danger ou de risque chez les personnes adolescentes. Par exemple, ces dernières peuvent s'engager dans des comportements sexuels à risque, elles peuvent consommer des substances illicites en grande quantité ou être agressives, violentes, voler des biens et s'absenter sans motif des activités scolaires. Il est très fréquent pour les professionnels travaillant auprès d'adolescents de faire face à des situations pouvant générer des prises de décision difficiles concernant la question de la confidentialité (28,34,42,53,54). Avec les mineurs, la problème de la confidentialité s'avère particulièrement complexe, car le psychologue doit prendre en considération le droit à la confidentialité du client, le droit et les préoccupations légitimes du parent, respecter l'engagement envers le mineur et agir dans l'intérêt supérieur de celui-ci (42,55,56). De plus, lorsque le professionnel travaille dans un milieu scolaire, certains engagements envers la commission scolaire ou les directions scolaires peuvent également compromettre la confidentialité (34,57). Aussi, la Loi québécoise sur la protection de la jeunesse oblige les intervenants sociaux à faire un signalement lorsque les enfants ou adolescents subissent ou sont susceptibles de vivre des abus ou de la négligence (32). Dans certains cas, ces signalements peuvent aller à l'encontre de la volonté des adolescents et exacerber la situation (53). Pour ces raisons, les professionnels se retrouvent fréquemment dans des contextes thérapeutiques délicats, car la levée de la confidentialité entraine des impacts négatifs sur le lien de confiance et, conséquemment, sur le processus thérapeutique (28,34,42,53,57).

De plus, même lorsqu'une levée de confidentialité est requise par une règle claire, plusieurs questions peuvent rester en suspens concernant l'interprétation de certains propos figurant dans les codes de déontologie. Par exemple, que veut-on dire par « information nécessaire à divulguer » et que signifie « meilleur intérêt de l'adolescent »? (34). Le manque d'information concernant les droits des mineurs, de même que le manque de balises dans les codes de déontologie suggèrent que lorsque les professionnels travaillent avec des mineurs, les dilemmes de confidentialité peuvent être difficiles à solutionner (53). La résolution de ces situations peut être d'autant plus complexe dans les contextes multisectoriels ou de partenariat qui impliquent des cadres de référence différents. Des instances comme la Direction de la protection de la jeunesse, les parents, les autorités scolaires, les associations sportives ou même la présence d'autres intervenants sociaux peuvent venir complexifier les dilemmes et alourdir le travail auprès de la personne adolescente concernée.

Plusieurs études quantitatives réalisées auprès de professionnels travaillant avec des adolescents illustrent en outre un manque de consensus dans les prises de décisions entourant le maintien du secret professionnel (34,42,53,54). La perception d'un acte dangereux peut varier considérablement et les justifications proposées par les professionnels sont souvent pertinentes autant pour l'acte de divulgation que pour celui de non-divulgation dans les dilemmes entourant la confidentialité (34,42,58). Pour l'ensemble des raisons, le maintien de la confidentialité avec la clientèle adolescente n'est pas toujours évident et suscite des questionnements importants dans les communautés cliniques et scientifiques (34,42,53).

La confidentialité dans les cas du suicide en fin de vie et du suicide assisté

Une autre situation dans laquelle il parait délicat de prendre une décision concernant la confidentialité est lorsqu'un individu se trouve en fin de vie et désire mettre fin à ses jours. Vers la fin des années 1990, plusieurs études ont montré qu'environ 80 % des psychologues estimaient que pour certains patients la mort pouvait être considérée comme la meilleure option possible (59-62). À ce moment, les principes qui figuraient dans le code d'éthique de l'Association américaine de psychologie (APA) créaient de la confusion chez les psychologues (63), notamment, le principe d'obligation de divulgation en présence d'une personne pouvant porter atteinte à sa sécurité ou celle d'une autre personne et celui du droit à la dignité de la personne cliente. Cela étant dit, en respectant le premier principe, le respect du second était remis en question et vice-versa. Il est également utile de mentionner que l'APA (63) a adopté une position neutre en n'obligeant pas ses membres à lever la confidentialité lors des cas de suicide en fin de vie. Cependant, les comportements éthiques ne sont pas forcément alignés sur les comportements légaux. Malgré un débat présent depuis des années, aider ou encourager une personne en fin de vie à mourir demeure un crime presque partout dans le monde (26). La Suisse a été l'un des premiers pays à adopter une législation décriminalisant le suicide assisté, en 1937, et le premier état aux États-Unis dans lequel une loi à ce sujet est entrée en vigueur est l'Oregon, en 1994 (60,64). Il est à noter que dans les états ayant légalisé le suicide assisté, celui-ci génère des obligations professionnelles différentes des autres cas de suicide.

Ces trois contextes constituent des exemples actuels de dilemmes de confidentialité en psychothérapie. Des dilemmes associés à d'autres contextes peuvent également survenir. Pour l'expérience réalisée dans le cadre du projet, nous nous attardons uniquement aux dilemmes évoqués dans les paragraphes précédents. De surcroît, ces situations peuvent être très chargées émotionnellement pour les clients et les psychologues étant donné qu'il y a présence d'enjeux importants et difficiles à résoudre. Les humains traversant ces épreuves vivent beaucoup de détresse et les psychologues qui les accompagnent sont également sensibles au vécu de leurs clients. Dans le cadre de cette étude, nous nous intéressons donc à l'impact de ce ressenti émotionnel sur les décisions prises par les professionnels.

LA PRÉSENTE RECHERCHE

De nombreuses études réalisées à propos de l'influence des émotions sur les dilemmes éthiques ont montré des effets marqués attribuables à la colère, la honte, la peur et la culpabilité (65-70). Toutefois, à notre connaissance, aucune étude ne s'est intéressée à l'influence d'émotions intégrales ou incidentes sur les dilemmes de confidentialité. Pourtant, le contexte de thérapie est chargé émotionnellement et il parait important que la personne thérapeute soit consciente de l'effet de celles-ci sur ses décisions.

Objectifs et hypothèses

Le principal objectif du projet consistait à prédire la variable de propension à la divulgation d'informations confidentielles (par opposition à la préservation de la confidentialité). L'effet conjoint de la condition expérimentale (variation de la tonalité émotionnelle) avec la propension à l'utilitarisme constitue le principal prédicteur d'intérêt, tout en ajustant le modèle pour une série de variables qui pouvaient jouer le rôle de facteurs de confusion. La première variable étudiée concerne la formation dans le domaine de l'éthique en psychologie. La deuxième concerne la perception des participants au sujet de l'intensité émotionnelle perçue lors de l'écoute ou la lecture des différents scénarios relatant les dilemmes de confidentialité. La troisième variable caractérise le jugement moral des individus sur le continuum déontologique/utilitaire sur la base des réponses à des dilemmes sacrificiels. La quatrième variable concerne la condition expérimentale principale du projet, c'est-à-dire trois modalités d'exposition différentes aux scénarios, soit les modalités texte, audio neutre et audio dramatique. Finalement, la dernière variable concerne le terme d'interaction entre la modalité d'exposition et la propension à l'utilitarisme moral.

Afin de mieux comprendre les jugements des individus, il est également pertinent de connaitre leurs justifications qualitatives par rapport à leurs décisions dans les dilemmes de confidentialité. Cette connaissance permettra de développer une compréhension du point de vue des participants. Elle pourrait également susciter de nouvelles pistes de réflexion sur différentes façons de concevoir ces dilemmes pour la recherche et la formation universitaire, en les éclairant sous l'angle de la compréhension et de la perception subjective des personnes qui y sont confrontées.

La première hypothèse de recherche de cette étude est la suivante :

> H_1 : Il est attendu que l'intensité émotionnelle perçue soit plus élevée pour les dilemmes de la modalité audio avec tonalité dramatique. Si tel est le cas, cela indique que la manipulation expérimentale a engendré un effet décelable par les participants.

Ensuite, les hypothèses de recherche liées au modèle de régression hiérarchique multiple, en contrôlant l'apport conjoint des cinq différentes variables mentionnées, sont les suivantes : il est attendu que chacune des variables ci-dessous influence la propension à lever la confidentialité.

> H_2 : La présence de formation dans le domaine de l'éthique en psychologie.
> H_3 : La propension à l'utilitarisme.
> H_4 : La modalité de présentation des scénarios.
> H_5 : L'intensité émotionnelle perçue des mises en situation.
> H_6 : L'interaction entre la modalité d'exposition au dilemme et la propension à l'utilitarisme.

MÉTHODE

Devis de recherche

Un plan de recherche expérimental sur des données corrélationnelles est utilisé avec une manipulation consistant à assigner aléatoirement les participants à l'une des trois conditions de la variable de modalité de présentation des dilemmes portant sur la confidentialité : 1) audio avec absence de tonalité émotionnelle; 2) audio avec tonalité émotionnelle dramatique; et 3) texte à l'écran sans narration audio. L'assignation est réalisée automatiquement par le logiciel de construction de questionnaires en ligne Qualtrics.

Participants

Les participants ont été recrutés grâce à des messages de sollicitation sur les pages Facebook des programmes de psychologie dans les universités de Sherbrooke, Trois-Rivières, Québec, Montréal, Gatineau et Chicoutimi au cours des sessions d'automne 2019 et d'hiver 2020. Pour prendre part au projet, les participants devaient être étudiants en psychologie au certificat, au baccalauréat, à la maitrise ou au doctorat. La participation à l'expérience s'est faite sur une base volontaire et trois cartes-cadeaux de 25 $ ont été tirées parmi les participants ayant pris part à l'étude. Au total, 356 individus ont participé au projet. Sur ce total, 150 d'entre eux ont été retirés des analyses, car ils n'avaient pas répondu entièrement au questionnaire. Vingt participants ont également été retirés, car ils n'ont pas consenti ou répondu au consentement à postériori (voir section Procédure). Dans les 186 participants restants, il y avait trois étudiants au certificat, 113 étudiants au baccalauréat, deux étudiants à la maitrise, 57 étudiants au doctorat et 11 participants dans la catégorie « autre ». Il y avait 153 femmes (82 %) et 33 hommes (18 %). L'âge des participants variait entre 18 et 44 ans (*M* = 23,78, *ÉT* = 5,11).

Approbation éthique

Cette étude a été approuvée par le Comité d'éthique de la recherche avec des êtres humains de l'Université du Québec à Trois-Rivières (UQTR; numéro de certificat éthique: #19-254-07.05).

Instruments de mesure

Dilemmes sacrificiels

Pour mesurer la préférence morale dans les dilemmes sacrificiels, cinq dilemmes traduits de l'anglais provenant de l'étude de Greene et al. (3) ont été utilisés. Les participants devaient évaluer si les décisions des personnages dans les vignettes étaient appropriées sur une échelle Likert en 6 points, allant de *totalement inapproprié* [1] à *totalement approprié* [6]. Voici un exemple de dilemme :

> *Vous êtes docteur. Un de vos patients présentant un diagnostic de séropositivité au VIH est sur le point de quitter l'hôpital. Il vous avoue en toute confidence, sous le sceau du secret professionnel de la relation docteur-patient, qu'il a comme intention d'infecter le plus de personnes possible et qu'il compte commencer ce soir. Étant donné que vous êtes lié par le secret professionnel, il n'y a légalement pas de manière d'empêcher cet homme de poser ces gestes. Toutefois, il s'avère que vous pourriez contaminer sa médication avec un poison mortel indétectable, ce qui l'empêcherait d'infecter d'autres personnes.*
>
> *À quel point serait-il approprié, pour vous, d'empoisonner cet homme afin de prévenir la propagation du virus?*

Dans ce dilemme, la réponse déontologique (ne pas contaminer l'homme et laisser mourir des personnes) est opposée à la réponse utilitariste (contaminer l'homme et sauver des personnes). Un score factoriel basé sur les réponses aux cinq dilemmes a été réalisé pour positionner les participants sur un continuum allant du déontologisme (score factoriel faible) à l'utilitarisme (score factoriel élevé). La totalité des dilemmes utilisés est présentée dans l'Annexe A.

Dilemmes de confidentialité

Les trois dilemmes portant sur la confidentialité étaient traduits et adaptés de l'étude de Walton (71). Un étudiant-acteur disposant de plusieurs expériences en théâtre et d'expériences professionnelles pour des vidéos de conscientisation a été engagé afin d'interpréter trois vignettes audio (voir Annexe B). Ces dernières reproduisaient un contexte thérapeutique dans lequel des clients dévoilent des situations délicates générant des enjeux concernant la confidentialité. Voici un exemple de vignette :

> *Richard travaille comme psychologue dans une école secondaire. Dans cette école, il y a une politique que doivent adopter les professionnels. Si ceux-ci suspectent qu'un étudiant est victime d'abus, ils doivent toujours le rapporter aux autorités scolaires sous peine d'être renvoyés. Richard est en consultation avec un adolescent de 16 ans qui présente plusieurs marques sur le corps. Richard questionne le jeune face à celles-ci et voici ce qu'il lui mentionne comme détails.*
>
> *« Mon père, il est devenu vraiment en colère hier soir, puis il m'a fait mal, mais c'était la première fois qu'il levait la main sur moi, puis après il s'est excusé plein de fois. Puis en plus ben, il est en politique, ça fait que s'il fallait que ça se sache, le monde pourrait se servir de ça contre lui aux prochaines élections puis ça nuirait à ma relation avec lui. »*

Les participants devaient répondre à la question : « selon vous, qu'est-ce que le psychologue devrait faire? » en utilisant une échelle de Likert allant de *maintenir la confidentialité* {1} à *divulguer l'information à la personne concernée* {6}.

Manipulation de la tonalité émotive

Chacune des trois vignettes était présentée selon trois différentes modalités de présentation et chaque participant était assigné aléatoirement à l'une d'entre elles. À cet égard, le comédien a interprété les mises en situation. Pour chacune des vignettes, ce dernier a enregistré une version avec une tonalité émotive « neutre » ainsi qu'une autre « dramatique ». Les mises en contexte des vignettes apparaissaient à l'écran sous la forme de textes et les récits oraux des personnes vivant la situation dramatique étaient accessibles en dessous par un lien audio. Pour la modalité « écrite », les verbatim des vignettes étaient établis à partir des versions audios pour que les textes correspondent au contenu audio.

Variables de contrôle

Quatre autres prédicteurs secondaires influençant potentiellement la propension à la levée de la confidentialité sont étudiés dans un modèle de régression linéaire hiérarchique (séquentielle) multiple.

La formation obtenue dans les domaines de l'éthique et de la déontologie en psychologie est opérationnalisée par le nombre de cours universitaires suivis dans ces domaines. Cette variable a toutefois été intégrée dans le modèle de manière binaire (« 1 » signifiant qu'un ou plusieurs cours d'éthique ont été suivis, « 0 » signifiant qu'aucun cours d'éthique n'a été suivi).

La préférence morale des participants sur la tâche de dilemmes sacrificiels est déterminée à partir des jugements émis sur les différentes actions des protagonistes dans les scénarios. Un score élevé traduit une plus grande propension à l'utilitarisme. Une échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6} était utilisée.

L'intensité émotionnelle perçue à la suite de la prise de connaissance des dilemmes portant sur la confidentialité est également mesurée. Un score élevé indique une plus grande perception d'intensité émotionnelle. Une échelle de Likert allant de *aucune intensité émotionnelle* {1} à *très grande intensité émotionnelle* {7} était utilisée.

Un autre prédicteur concerne une variable d'interaction entre la modalité de présentation des dilemmes et la propension à l'utilitarisme. La tendance à l'utilitarisme joue un rôle de variable modératrice pour ce prédicteur. Ces variables prédisent la décision portant sur les dilemmes de confidentialité. Un score élevé signifie une plus grande propension à lever la confidentialité. Une échelle de Likert allant de *maintenir la confidentialité* {1} à *divulguer l'information à la personne concernée* {6} était utilisée.

Finalement, une dernière variable concerne une analyse qualitative thématique des justifications fournies par les participants. Nous avons effectué une catégorisation des justifications associées aux scénarios par les participants pour expliquer leur position sur le continuum allant du non-dévoilement au dévoilement afin d'examiner les éléments des dilemmes qui avaient attiré leur attention. Deux des membres du projet (GC et BT) ont élaboré des catégories à la suite de la lecture des réponses des participants : 1) Souci de la sécurité du client; 2) Travail du contenu en thérapie et maintien de l'alliance thérapeutique; 3) Interrogation concernant la personne à qui l'on devrait divulguer l'information; 4) Autonomie ou choix du client; et 5) Code de déontologie. Par la suite, nous avons comptabilisé les pourcentages de correspondance entre les deux versions de classification, ce qui nous a amenés à exclure les catégories : 1) *Souci de la sécurité du client* et 2) *Travail du contenu en thérapie et maintien de l'alliance* en raison d'une convergence trop faible lors de la cotation. Un troisième membre du projet (MC) a ensuite tranché en procédant à une cotation finale des justifications sur lesquelles il y avait divergence, pour arriver à un consensus.

Après avoir effectué leur jugement, les participants devaient fournir une justification pour motiver celui-ci. Enfin, les participants indiquaient à quel point ils trouvaient que le scénario présenté était émotionnellement intense, en utilisant une échelle allant de *aucune intensité émotionnelle* {1} à *très grande intensité émotionnelle* {7}.

Le matériel utilisé dans le cadre du projet est librement disponible (Emotional tone and confidentiality dilemmas).

Procédure

Les participants étaient invités à cliquer sur un lien les dirigeant sur le site Internet du logiciel Qualtrics à partir duquel ils pouvaient consentir à participer à l'étude et commencer le questionnaire. Le questionnaire était composé de trois sections. Sur la première section figurait un questionnaire sociodémographique où les participants devaient indiquer leurs âge, sexe, état civil, programme d'étude et nombre d'années universitaires complétées. Une question visait également à déterminer si les participants avaient suivi un ou plusieurs cours portant sur l'éthique et la déontologie. Les participants étaient également questionnés sur leur expérience en relation d'aide, soit sur le nombre d'heures travaillées, ainsi que sur les clientèles avec lesquelles ils avaient travaillé dans le passé. Enfin, les participants intéressés à participer au tirage au sort des trois cartes-cadeaux étaient invités à fournir leur courriel afin d'être contactés dans le cas où ils seraient tirés au sort.

Dans la deuxième section, les participants étaient dirigés aléatoirement vers l'une des trois conditions de la manipulation de la tonalité, soit « écrite », « audio avec tonalité neutre » ou « audio avec tonalité dramatique » et devaient répondre à trois dilemmes portant sur la confidentialité. Pour les versions audios, un fichier audio apparaissait et indiquait aux participants d'activer leurs écouteurs ou haut-parleurs à un volume sonore adéquat. Puis, les participants devaient lire ou écouter les dilemmes et prendre une décision sur chacune des situations, à savoir s'ils optaient pour la décision visant à maintenir ou lever la confidentialité (sur un continuum). Pour chaque situation, les participants devaient écrire dans un encadré une justification appuyant leur prise de décision. Finalement, les participants devaient répondre à une question visant à évaluer l'intensité émotionnelle perçue lors de l'exposition à chaque mise en situation.

Enfin, dans la troisième section, les participants devaient répondre aux cinq dilemmes moraux sacrificiels mettant en confrontation les principes de l'utilitarisme et du déontologisme. Finalement, ils étaient invités à fournir leur consentement à nouveau, car le but réel de l'étude n'était pas indiqué au complet dans le formulaire de consentement initial (recherche avec divulgation partielle), tout en l'étant dans le formulaire de consentement consécutif à l'expérimentation. En effet, la variation des tonalités émotionnelles n'a pas été évoquée dans le formulaire de consentement initial pour éviter de biaiser les résultats si les participants avaient su à quoi s'attendre.

RÉSULTATS

Analyses statistiques

Après l'examen de la distribution des variables d'intérêt, un modèle de régression hiérarchique multiple exploratoire a été retenu et fait l'objet des tests présentés ci-dessous avec les logiciels SPSS 27 et R 4.1.3. Excepté les prédicteurs d'intérêt principal (ceux composant le terme d'interaction), les variables ont été ajoutée séquentiellement dans le modèle de régression linéaire multiple hiérarchique (séquentiel), afin de pouvoir tester leur contribution respective, en allant des plus concrètes aux plus abstraites sur le plan conceptuel (voir Tableau 3).

Un effet d'interaction significatif indique que la modalité expérimentale joue un rôle modérateur dans la relation entre la propension à l'utilitarisme et la propension à la divulgation en lien avec des dilemmes de confidentialité.

Statistiques descriptives

En moyenne, les participants avaient complété un peu plus de trois années universitaires (*ÉT* = 2,60), 108 (58 %) n'avaient suivi aucun cours portant sur l'éthique ou la déontologie, 60 (32 %) en avaient suivi un et 18 (10 %) deux ou plus. La majorité des participants, soit 136 (73 %), mentionne avoir de l'expérience en relation d'aide avec des clientèles variées et parmi ces personnes, 67 (49 %) rapportent moins de 500 heures d'expériences dans ce domaine, alors que 69 (51 %) indiquent plus de 500 heures d'expérience. Les groupes randomisés étaient comparables sur ces caractéristiques ($p > 0{,}05$).

Le Tableau 1 présente les scores d'intensité émotionnelle perçue en fonction des différentes modalités de présentation des dilemmes. Les résultats descriptifs suggèrent que la manipulation expérimentale a généré l'effet attendu sur les scénarios 1 (soins palliatifs) et 3 (école), car pour ceux-ci la moyenne d'intensité émotionnelle perçue la plus élevée se trouve dans la modalité audio « dramatique ». Toutefois, étant donné que la moyenne la plus élevée dans le deuxième dilemme se trouve dans la modalité « texte », il a été conclu que la manipulation expérimentale n'a pas fonctionné pour ce dilemme, lequel a été exclu des analyses. Ces données appuient ainsi la première hypothèse de notre projet pour les scénarios 1 (soins palliatifs) et 3 (école).

Tableau 1 : Moyennes et écarts-types des scores d'intensité émotionnelle perçue selon les différentes modalités des scénarios

		Scénario 1 (Soins palliatifs)		**Scénario 2 (VIH/Sida)**		**Scénario 3 (École)**	
n	Modalité	*M*	*ÉT*	*M*	*ÉT*	*M*	*ÉT*
61	Audio dramatique	5,08	1,49	4,68	1,47	4,78	1,33
48	Audio neutre	4,04	1,60	4,04	1,56	3,66	1,39
77	Texte	4,49	1,62	4,77	1,30	4,24	1,61

Note. Variables cotées sur l'échelle : 1 = *aucune intensité émotionnelle,* 7 = *très grande intensité émotionnelle.* L'exclusion de certains participants en raison de questionnaires incomplets explique le débalancement des effectifs dans les différentes modalités de la manipulation expérimentale.

Le Tableau 2 décrit les scores de propension à la divulgation en lien avec les scénarios de confidentialité 1 (soins palliatifs) et 3 (école). Il est possible de constater que les scores sont relativement similaires entre les modalités expérimentales. Toutefois, ce tableau ne présente pas les résultats ajustés en fonction d'autres variables pertinentes comme la perception d'intensité émotionnelle de la mise en situation.

Tableau 2 : Moyennes et écarts-types des scores de divulgation des scénarios 1 et 3

		Scénario 1 (Soins palliatifs)		**Scénario 3 (École)**	
n	Modalité	*M*	*ET*	*M*	*ET*
48	Audio neutre	3,60	1,72	4,46	1,73
61	Audio dramatique	3,54	1,79	4,48	1,63
77	Texte	3,27	1,64	4,45	1,54

Note. 1 = *maintenir la confidentialité,* 6 = *divulguer l'information à la personne concernée*

Analyses inférentielles

L'un des objectifs du projet visait à comprendre de quelle manière la propension à l'utilitarisme pouvait prédire les décisions morales dans des dilemmes portant sur la confidentialité (propension à la divulgation). Pour résumer les dilemmes sacrificiels sur une seule variable allant du déontologisme à l'utilitarisme, un score factoriel a été construit à partir d'une analyse en composante principale (méthode Anderson-Rubin). Il est apparu que parmi les cinq dilemmes sacrificiels, les dilemmes 1 (docteur) et 3 (le choix de Sophie) étaient mal résumés par un modèle à une composante principale et ils ont été exclus des analyses. Les trois autres dilemmes sacrificiels étaient résumés adéquatement par une composante principale, reproduisant 57,2 % de la variance des scores sur ces dilemmes ($n = 186$).

Résultats Scénario « Violence en milieu scolaire »

Un modèle de régression hiérarchique à cinq étapes a été développé pour prédire le score de propension à la divulgation dans les dilemmes portant sur la confidentialité. Le Tableau 3 illustre l'apport de chacune des étapes de manière plus détaillée. Nous présentons dans un premier temps les résultats du modèle pour le scénario 3 (école) et dans un deuxième temps, ceux du scénario 1 (soins palliatifs). Avant de poursuivre, il est important de mentionner qu'aucune corrélation significative entre la variable témoignant de l'expérience en relation d'aide et les autres variables centrales du projet n'a été observée. Cette variable a ainsi été exclue du modèle statistique.

Dans la première étape du modèle, la variable mesurant le fait d'avoir suivi un ou plusieurs cours d'éthique a été insérée. Cette variable a été dichotomisée en raison d'enjeux de normalité, séparant les participants ayant suivi un cours d'éthique ou plus de ceux n'en ayant pas suivi. Pour le scénario 3 (école), comparativement à un modèle sans variable, le fait d'avoir suivi un cours d'éthique ou plus augmente la prédiction du score de propension à la divulgation de 3,3 % (ΔR^2), $p = 0{,}016$. Ce résultat appuie ainsi la deuxième hypothèse de recherche pour ce scénario.

Dans la deuxième étape, une variable relative au score factoriel de propension à l'utilitarisme a été insérée. Celle-ci n'a toutefois pas d'influence sur la prédiction du score de propension à la divulgation (*p* = 0,499). Ce résultat infirme la troisième hypothèse de recherche pour ce scénario.

Dans la troisième étape du modèle, la variable concernant les différentes modalités de présentation du scénario a été ajoutée. L'ajout de cette variable n'entraine pas une augmentation significative de la prédiction du score de propension à la divulgation (*p* = 0,970). Ce résultat infirme la quatrième hypothèse du projet pour ce scénario.

Tableau 3 : Modèles de régression multiple prédisant le score de propension à la divulgation (Scénario 3)

		Coefficients non standardisés			**Coefficients standardisés**				
Étape	**Prédicteur**	***b***	***ES***		***β***	***p***	***R^2***	***F***	***p***
1	Constante	4,713	0,158			0,000	0,033	5,975	0,016
	Cours d'éthique/déontologie suivis (binaire)	-0,593	0,243		-0,182	0,016			
2	Constante	4,722	0,159			0,000	0,036	0,458	0,499
	Cours d'éthique/déontologie suivis (binaire)	-0,607	0,244		-0,186	0,014			
	Score factoriel de propension à l'utilitarisme	-0,084	0,124		-0,051	0,499			
3	Constante	4,704	0,263			0,000	0,036	0,030	0,970
	Cours d'éthique/déontologie suivis (binaire)	-0,606	0,245		-0,186	0,014			
	Score factoriel de propension à l'utilitarisme	-0,083	0,125		-0,050	0,510			
	Modalité de présentation texte (réf : audio neutre)	-0,005	0,304		-0,002	0,986			
	Modalité de présentation audio émotif (réf : audio neutre)	0,060	0,316		0,017	0,851			
4	Constante	4,846	0,261			0,000	0,088	9,649	0,002
	Cours d'éthique/déontologie suivis (binaire)	-0,567	0,240		-0,174	0,019			
	Score factoriel de propension à l'utilitarisme	-0,062	0,123		-0,037	0,614			
	Modalité de présentation texte (réf : audio neutre)	-0,153	0,301		-0,047	0,612			
	Modalité de présentation audio émotif (réf : audio neutre)	-0,248	0,324		-0,073	0,445			
	Intensité émotionnelle perçue	0,257	0,083		0,240	0,002			
5	Constante	4,909	0,261			0,000	0,122	3,252	0,041
	Cours d'éthique/déontologie suivis (binaire)	-0,546	0,237		-0,168	0,023			
	Score factoriel de propension à l'utilitarisme	-0,433	0,232		-0,261	0,064			
	Modalité de présentation texte (réf : audio neutre)	-0,224	0,300		-0,068	0,456			
	Modalité de présentation audio émotif (réf : audio neutre)	-0,319	0,324		-0,094	0,326			
	Intensité émotionnelle perçue	0,274	0,083		0,256	0,001			
	Interaction entre le score factoriel et la modalité de présentation (audio émotif comparé à texte)	0,299	0,303		0,115	0,325			
	Interaction entre le score factoriel et la modalité de présentation (audio émotif comparé à audio neutre)	0,787	0,316		0,267	0,014			

Note. N = 186

Dans la quatrième étape du modèle, une variable correspondant au niveau d'intensité émotionnelle perçue lors de l'exposition au scénario a été entrée. L'ajout de cette variable augmente la prédiction du score de propension à la divulgation de 5 % (ΔR^2), *p* = 0,002. Ce résultat appuie la cinquième hypothèse de recherche.

Dans la dernière étape du modèle, la variable opérationnalisant l'interaction entre la modalité de présentation du scénario et le score factoriel de propension à l'utilitarisme a été ajoutée. L'ajout de cette variable entraine une augmentation de la prédiction du score de propension à la divulgation de 3,4 % (ΔR^2), *p* = 0,041. En d'autres termes, la tendance à l'utilitarisme est modérée par la modalité de présentation du scénario et prédit le score de propension à la divulgation pour le scénario 3 (école). Le modèle complet prédit donc 12,2 % ($R^2_{\text{ajusté}}$ = 8,5 %) de la variabilité du score de propension à la divulgation. Ce résultat appuie par le fait même la dernière hypothèse de recherche du projet.

La décomposition du terme d'interaction révèle que seule la comparaison entre l'exposition à une tonalité audio dramatique et l'exposition à une tonalité audio neutre est significative (*b* = 0,79, *p* = 0,014). La comparaison entre l'exposition à la tonalité audio neutre et la condition texte n'est pas significative (*b* = -0,30, *p* = 0,303), et c'est aussi le cas pour la comparaison entre la tonalité audio émotive et la condition texte (*b* = 0,49, *p* = 0,286).

Au-delà d'un effet simple du terme d'interaction, dans le modèle final (étape 5 dans le Tableau 3), les prédicteurs suivants sont significatifs : le fait d'avoir suivi ou non un ou plusieurs cours d'éthique et l'intensité émotionnelle perçue lors de l'écoute du scénario. En contrôlant l'effet des autres variables, un participant ayant effectué un ou plusieurs cours d'éthique présente un score de propension à la divulgation qui diminue de 0,546 unité, IC 95% = [-0,094; -1,041] comparativement à une personne qui n'en a pas suivi. Ensuite, lorsque le score d'un participant augmente d'une unité sur la variable d'intensité émotionnelle perçue, le score de propension à la divulgation augmente de 0,274 unité, IC 95% = [0,094; 0,421]. Finalement, pour une augmentation d'une unité sur le score de propension à l'utilitarisme, comparativement à un participant exposé à la modalité « audio neutre », un participant qui a été exposé à la modalité « audio dramatique » présente un score de propension à la divulgation qui augmente de 0,787 unité, IC 95% = [0,164; 1,411].

Le Tableau 4 permet d'illustrer des différences dans le score de propension à la divulgation en fonction des différentes combinaisons de variables chez les participants. Cela permet de visualiser plus concrètement de quelle manière la propension à la levée de confidentialité peut être affectée. Nous constatons que les personnes soumises à la condition audio émotive ont moins tendance à lever la confidentialité que celles soumises à la condition texte (voir Tableau 4, scénario 4) lorsque des cours d'éthique/déontologie ont été suivis, que l'intensité émotive perçue est minimale et que la tendance à l'utilitarisme est aussi minimale (voir Tableau 4, scénario 3). Cependant, l'inverse apparait lorsqu'aucun cours d'éthique/déontologie n'a été suivi, que l'intensité émotive perçue est maximale et que la tendance à l'utilitarisme est maximale (voir Tableau 4, scénario 2).

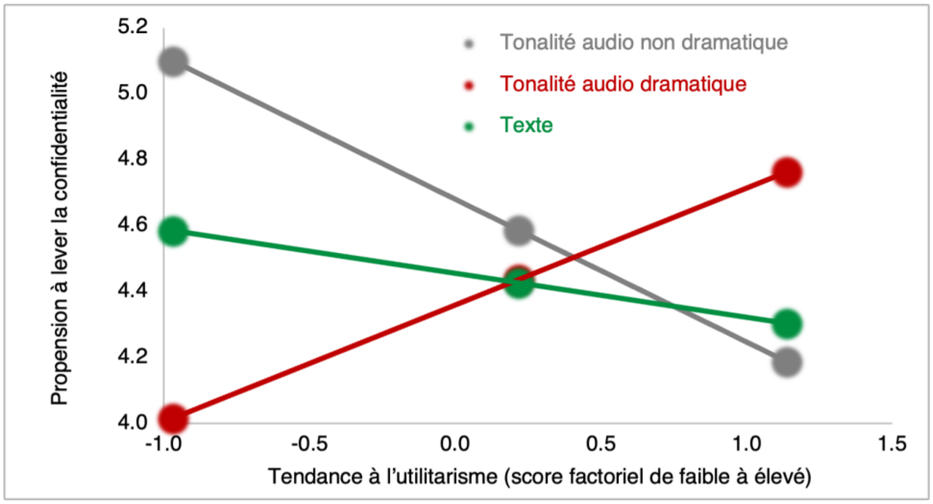
Tableau 4 : Score de divulgation des participants en fonction des différentes combinaisons des valeurs obtenues sur les variables de prédiction dans le modèle de régression

Scénario	Valeur de la constante	Cours d'éthique suivi?	Intensité émotionnelle perçue	Score d'utilitarisme	Modalité	Interaction avec le score factoriel	Score de propension à la divulgation
1	4,909	Oui (-0,546)	Maximale (0,748)	Maximal (-1,148)	Audio émotif (-0,319)	Audio émotif comparé à audio neutre (2,086)	5,73
2	4,909	Non (0)	Maximale (0,748)	Maximal (-1,148)	Audio émotif (-0,319)	Audio émotif comparé à audio neutre (2,086)	6,276
3	4,909	Oui (-0,546)	Minimale (-0,896)	Minimal (1,074)	Audio émotif (-0,319)	Audio émotif comparé à audio neutre (-1,952)	2,270
4	4,909	Oui (-0,546)	Minimale (-0,896)	Minimal (1,074)	Texte (-0,224)	Audio émotif comparé à texte (-0,42)	3,575
5	4,909	Oui (-0,546)	Maximale (0,748)	Maximal (-1,148)	Texte (-0,224)	Audio émotif comparé à texte (0,792)	4,532

Note. Le score de propension à la divulgation peut varier entre 1 = *maintenir la confidentialité* et 6 = *divulguer l'information à la personne concernée*

La Figure 1 ci-après illustre l'effet d'interaction entre l'utilitarisme et la propension à la levée de confidentialité. Nous constatons que l'interaction génère un effet positif sur la levée de confidentialité pour la condition « tonalité audio dramatique », alors que celle-ci génère un effet inverse pour les deux autres conditions.

Figure 1 : Influence de la modalité de présentation de la vignette sur la relation entre l'utilitarisme et la propension à la levée de confidentialité



Note. La série des trois points sur la gauche de la figure correspond à un score z de -1 (16e percentile) sur l'axe horizontal, la série de trois points au milieu (les deux du bas se chevauchent), à un score z de 0,5 (médiane), et la série de trois points sur la droite, à un score z de 1 (84e percentile). Les scores sur les axes horizontal et vertical ne représentent pas des scores z.

Résultats scénario « Suicide en fin de vie »

Comme mentionné précédemment, nous avons également analysé le scénario 1 (soins palliatifs) avec les variables de notre modèle. Le Tableau 5 illustre les modèles de régressions multiples prédisant le score de propension à la divulgation pour ce scénario.

Tableau 5 : Modèles de régression multiple prédisant le score de propension à la divulgation (Scénario 1)

		Coefficients non standardisés		**Coefficients standardisés**				
Étape	**Prédicteur**	***b***	***ES***	***β***	***p***	***R^2***	***F***	***p***
1	Constante	3,712	0,167		0,000	0,031	5,582	0,019
	Cours d'éthique/déontologie suivis (binaire)	-0,616	0,261	-0,176	0,019			
2	Constante	3,718	0,168		0,000	0,035	0,735	0,392
	Cours d'éthique/déontologie suivis (binaire)	-0,623	0,261	-0,178	0,018			
	Score factoriel de propension à l'utilitarisme	-0,113	0,132	-0,064	0,392			
3	Constante	3,863	0,278		0,000	0,042	0,654	0,521
	Cours d'éthique/déontologie suivis (binaire)	-0,633	0,262	-0,181	0,017			
	Score factoriel de propension à l'utilitarisme	-0,121	0,132	-0,068	0,364			
	Modalité de présentation texte (réf : audio neutre)	-0,320	0,325	-0,091	0,326			
	Modalité de présentation audio émotif (réf : audio neutre)	-0,037	0,337	-0,010	0,913			
4	Constante	3,927	0,278		0,000	0,061	3,472	0,064
	Cours d'éthique/déontologie suivis (binaire)	-0,593	0,261	-0,169	0,024			
	Score factoriel de propension à l'utilitarisme	-0,134	0,132	-0,076	0,311			
	Modalité de présentation texte (réf : audio neutre)	-0,384	0,325	-0,109	0,239			
	Modalité de présentation audio émotif (réf : audio neutre)	-0,208	0,347	-0,057	0,549			
	Intensité émotionnelle perçue	0,156	0,084	0,144	0,064			
5	Constante	3,945	0,283		0,000	0,074	1,176	0,311
	Nombre de cours d'éthique suivis (binaire)	-0,559	0,262	-0,160	0,034			
	Score factoriel de propension à l'utilitarisme	-0,293	0,259	-0,166	0,260			
	Modalité de présentation texte (réf : audio neutre)	-0,418	0,327	-0,119	0,204			
	Modalité de présentation audio émotif (réf : audio neutre)	-0,234	0,350	-0,064	0,505			
	Intensité émotionnelle perçue	0,162	0,084	0,150	0,056			
	Interaction entre le score factoriel et la modalité de présentation (audio émotif comparé à texte)	0,036	0,330	0,013	0,914			
	Interaction entre le score factoriel et la modalité de présentation (audio émotif comparé à audio neutre)	0,456	0,349	0,145	0,193			

Note. N = 186

Comparativement au scénario 3 (école) dans lequel trois modèles (étapes) sur cinq se sont avérés significatifs, ce scénario a généré un résultat significatif pour le premier modèle seulement, montrant ainsi une augmentation de la prédiction du score de propension à la divulgation de 3,1 % (ΔR^2), p = 0,019 lorsqu'un cours d'éthique ou plus a été complété. Comme pour le scénario 3, avoir suivi un ou plusieurs cours d'éthique en psychologie diminue la propension à lever la confidentialité (b = -0,62). Il est également important de mentionner que le modèle intégrant la variable d'intensité émotionnelle perçue (étape 4) a généré un résultat proche de la signification statistique, augmentant ainsi la prédiction du score de propension à la divulgation de 1,9 % (ΔR^2), p = 0,064 en présence d'une intensité émotionnelle perçue comme étant élevée. Cela étant dit, l'effet modérateur entre la modalité de présentation du scénario et la tendance à l'utilitarisme s'est avéré non significatif sur la propension à la levée de confidentialité pour le scénario 1 (soins palliatifs).

Analyse des justifications

Nous avons également extrait les 186 justifications et les avons classées dans les catégories présentées dans la méthode. Une justification indiquée par un participant pouvait être classée dans plusieurs catégories s'il y avait présence de plusieurs éléments dans celles-ci. Le Tableau 6 présente le nombre de justifications correspondant à chacune des trois catégories pour les scénarios et la proportion des participants qui font référence aux trois catégories d'éléments. Nous constatons que les justifications pour les dilemmes réfèrent à des aspects différents : le scénario 3 (école) insiste davantage sur l'aspect déontologique (dénoncer les violences sinon risquer de perdre son emploi), alors que le scénario 1 (soins palliatifs) se centre plutôt sur la valeur d'autonomie du client et génère un plus grand questionnement concernant la personne ou l'entité à qui divulguer l'information confidentielle.

Tableau 6 : Fréquences et pourcentages des justifications émanant des participants par catégories, selon les scénarios

	Scénario 1 (soins palliatifs)			Scénario 3 (école)	
Catégories	***Fréquence***	***Pourcentage***		***Fréquence***	***Pourcentage***
Interrogation sur la personne à qui divulguer	57	30,6 %		28	15,1 %
Autonomie ou choix du client	32	17,2 %		11	5,9 %
Code de déontologie	19	10,2 %		34	18,3 %

Note. N = 186

Finalement, nous avons également effectué un sixième modèle de régression intégrant l'apport prédictif des justifications selon les trois catégories indiquées dans le tableau 6. Pour les deux scénarios, nous constatons un apport significatif provenant des catégories *interrogation sur la personne à qui divulguer* et *autonomie ou choix du client* montrant un lien négatif entre la présence de ces arguments et la propension à divulguer (Annexe C).

DISCUSSION

L'objectif principal du projet consistait à tester un modèle prédictif de la propension à la divulgation d'informations confidentielles. Notre première hypothèse de recherche s'est avérée corroborée pour deux scénarios, étant donné que nous avons constaté des différences de moyennes significativement plus élevées d'intensité émotionnelle perçues dans les conditions audios dramatiques. Nos autres hypothèses de recherche avançaient qu'il y aurait une influence sur la propension à divulguer de la présence ou l'absence d'avoir suivi un ou des cours en éthique/déontologie en psychologie, par la propension à l'utilitarisme, par la modalité de présentation des dilemmes, par la présence d'intensité émotionnelle perçue lors de la prise en compte du dilemme et par l'interaction entre la propension à l'utilitarisme et la modalité de présentation des scénarios. Un modèle de régression linéaire s'est avéré significatif pour le troisième scénario (école) sur la confidentialité; enfin les données appuient trois hypothèses de recherche sur cinq concernant le modèle, c'est-à-dire les hypothèses 2, 5 et 6.

Plus précisément, pour le scénario 3 (école), le modèle a prédit 12,2 % ($R^2_{\text{ajusté}}$ = 8,5 %) de la variabilité du score de propension à la divulgation. Les variables influençant la propension à divulguer sont le fait d'avoir ou de ne pas avoir suivi de cours de déontologie/éthique, l'intensité émotionnelle perçue ainsi que l'interaction entre la modalité de présentation du scénario et le score factoriel de propension à l'utilitarisme. Toutefois, pour le scénario 1 (soins palliatifs) il n'y a eu que la variable associée au fait d'avoir suivi un ou plusieurs cours de déontologie/éthique en psychologie qui s'est avérée significative et la variable portant sur l'intensité émotionnelle s'est avérée proche de la signification statistique.

Après avoir effectué la classification et la cotation des justifications dans des catégories, nous avons constaté plusieurs différences dans les éléments évoqués par les participants pour chacun des dilemmes. D'abord, il apparaît que les moyennes de divulgation du scénario 3 (école) sont plus élevées que celles du scénario 1 (soins palliatifs). Il est possible de faire l'hypothèse qu'une situation relatant des abus physiques vécus par un adolescent (scénario 3) soit plus encline à entrainer une levée de la confidentialité qu'une situation de personne âgée en fin de vie qui désire se suicider, car il n'a plus de qualité de vie. Les deux scénarios sont différents et nous pouvons constater ces différences dans les justifications sous-jacentes à chacun d'entre eux. En effet, pour le scénario 1 (soins palliatifs), près du tiers des participants (30,6 %) a fait mention d'un questionnement en lien avec la personne à qui l'on devrait divulguer l'information confidentielle. La plupart d'entre eux mentionnent que ce n'est pas à la conjointe qu'aurait dû être dévoilée l'information, mais à un service d'urgence pouvant accorder une aide immédiate au client. En revanche, pour le scénario 3 (école) seulement 28 participants (15,1 %) ont évoqué le même point stipulant que ce n'était pas à la direction de l'école que l'on devait divulguer l'information, mais bien au service de protection de la jeunesse. Cela étant dit, cet aspect a créé une confusion et a vraisemblablement affecté le score de divulgation de certains participants à la baisse, car plusieurs d'entre eux ont justifié qu'ils auraient levé la confidentialité uniquement à des tiers différents de ceux proposés dans les scénarios. Cet élément a donc affecté la qualité statistique de notre modèle, surtout pour le scénario 1 (soins palliatifs).

En poursuivant la comparaison des scénarios grâce aux justifications qualitatives, il apparaît qu'il y avait une différence importante dans la catégorie *autonomie ou choix du client* entre les deux scénarios. Pour le scénario 1 (soins palliatifs), 32 participants (17,2 %) ont évoqué un argument en faveur de l'autonomie du client, contre 11 (5,9 %) pour le scénario 3 (école). Cette divergence de résultats pourrait s'expliquer par les contextes des scénarios. Il est plausible d'émettre l'hypothèse que les participants ont jugé que la volonté de l'adolescent avait moins de poids étant donné qu'il a été victime de violence par son père. Cela est d'autant plus possible en considérant son statut de mineur. En revanche, la situation de l'homme en fin de vie atteint d'une maladie incurable et n'ayant plus les moyens de financer ses soins a pu amener les participants à considérer que celui-ci avait droit à sa dignité et de décider pour lui-même, valorisant ainsi son autonomie. Ce résultat pourrait ainsi expliquer une partie de la raison pour laquelle la moyenne de divulgation s'avère moins élevée pour ce scénario, ce qui appuie également ce qu'on retrouve dans la littérature concernant les cas de suicide en fin de vie en contexte de psychothérapie. Effectivement, des études ont montré que les thérapeutes pouvaient être en accord avec l'idée du suicide dans des contextes de fin de vie (60-62).

Finalement, lorsque nous comparons la catégorie faisant référence au code de déontologie entre les deux scénarios, 19 participants (10,2 %) du scénario 1 (soins palliatifs) ont évoqué cet argument contre 34 (18,3 %) pour le scénario 3 (école).

Il est possible d'interpréter ces résultats en lien avec la transposition de la Loi de la protection de la jeunesse dans le code de déontologie, ce qui dirigerait les participants vers la décision de la levée de la confidentialité. Pour le scénario 1 (soins palliatifs), les justifications pouvaient aller dans les deux sens, certains évoquant la présence de l'article autorisant à lever la confidentialité dans le cadre d'un danger imminent pour soi ou pour autrui, alors que d'autres évoquaient plutôt l'idée des droits à la dignité et à la liberté de la personne.

Les éléments abordés précédemment pourraient ainsi expliquer la divergence de moyenne sur la propension à divulguer entre les deux scénarios. Cependant, pour le scénario 1 (soins palliatifs), la variable d'interaction entre le score de propension à l'utilitarisme et les modalités de présentation du scénario ne présente pas un effet significatif. Il est donc possible que la manipulation expérimentale réalisée pour le scénario 1 (soins palliatifs) n'ait pas été suffisamment importante pour générer un effet. Il est également possible que ce soient des éléments intrinsèques au dilemme qui aient expliqué l'absence de lien significatif. Par exemple, il peut être plus difficile de voir de quel côté se situe la tendance utilitariste dans ce scénario, car garder l'homme en vie n'est pas « utilitaire » dans un contexte de fin de vie. Il est ainsi possible de croire qu'il n'y avait pas suffisamment d'éléments décelables dans la nature du dilemme pouvant s'apparenter aux philosophies morales de la déontologie ou de l'utilitarisme.

De façon générale, les analyses ont permis d'observer que la présence de formation dans les domaines de l'éthique et la déontologie présentait un lien négatif avec la propension à lever la confidentialité. En effet, les cours d'éthique présents dans le curriculum visent à outiller les futurs psychologues afin de leur permettre de mieux répondre aux situations conflictuelles. Ils visent également à favoriser le développement d'un esprit critique chez les étudiants et à les sensibiliser au lien thérapeutique ainsi qu'à l'intérêt supérieur des clients (38). Dans le contexte du troisième scénario (école), il est possible d'avancer que les individus ayant opté pour la décision de lever la confidentialité ont interprété de manière stricte la consigne administrative menaçant le psychologue de sanctions en cas de non-divulgation. Cette interprétation les distinguerait des participants ayant eu accès à des cours dans ces domaines. En contrepartie, nous constatons que pour le scénario 1 (soins palliatifs), deux principes pouvaient entrer en contradiction, ce qui amenait les participants à pouvoir défendre autant la position du maintien que celle de la levée du secret professionnel. En effet, le principe du droit à la dignité et à la liberté de l'individu entrait en contradiction avec celui de l'obligation de divulgation en présence d'une personne pouvant porter atteinte à sa sécurité ou celle d'une autre personne (31). Il est ainsi envisageable que cette variable ait amené les étudiants à accorder une plus grande importance à la relation thérapeutique au détriment de l'adoption d'une ligne de conduite prédéfinie par les différents codes.

Pour le scénario 3 (école), nous avons constaté un lien entre l'intensité émotionnelle perçue et la propension à divulguer. En effet, plus les participants ont perçu une intensité émotionnelle élevée lors de l'écoute du dilemme, plus ils avaient tendance à lever la confidentialité, et ce, indépendamment de la modalité de présentation des dilemmes. Il est donc possible d'avancer une hypothèse stipulant que la présence d'émotions ait pu déstabiliser les participants les amenant davantage à lever la confidentialité. Ces données corroborent la littérature montrant que les nouveaux thérapeutes peuvent facilement se sentir affectés par l'intensité des émotions et que cela peut impacter leur jugement lorsqu'ils sont confrontés à des dilemmes éthiques (72). Ces données sont intéressantes lorsque nous les comparons à l'impact des cours d'éthique sur la divulgation. La formation en éthique/déontologie viendrait freiner la divulgation, alors que l'intensité émotionnelle perçue accentuerait celle-ci. Ces résultats pointent donc l'importance de la formation académique et pratique des thérapeutes, car ils sont susceptibles d'être influencés par plusieurs variables lorsque vient le temps de prendre des décisions importantes sur le plan de l'éthique (38,40,73).

Toujours pour le troisième scénario (école), l'interaction entre la modalité de présentation du scénario et le score factoriel de propension à l'utilitarisme a montré un effet significatif lorsque les modalités « audio émotif » et « audio neutre » sont comparées, ainsi qu'un effet marginalement significatif lorsque les modalités « audio émotif » sont comparées à « texte ». En effet, lorsqu'un participant était assigné à la condition « audio émotif » et qu'il avait tendance à opter pour les choix utilitaristes dans les dilemmes sacrificiels, il avait davantage tendance à choisir l'option de lever la confidentialité. La tendance à l'utilitarisme moral serait associée à une tendance à lever la confidentialité dans le cadre de ce dilemme, mais uniquement dans la condition qui visait à accentuer l'émotion du client dans la vignette. Si ce résultat est interprété avec les données de la littérature montrant un lien entre les choix déontologiques et l'empathie (21), il semblerait que les individus ayant une propension à opter pour les choix déontologiques aient perçus des éléments dans la modalité « tonalité dramatique » du scénario 3 qui les ont induits à opter pour le maintien de la confidentialité. Une hypothèse serait que les participants ayant choisi les décisions déontologiques dans le cadre des dilemmes sacrificiels aient été affectés différemment par la condition expérimentale comparativement aux participants ayant une tendance utilitariste. En effet, selon la littérature, les personnes utilitaristes présenteraient un raisonnement délibéré et réfléchi, mais pour lequel les émotions sont en partie laissées de côté à l'inverse des personnes déontologiques qui seraient sensibles aux facteurs émotionnels (3,4).

Ces résultats soulèvent plusieurs questionnements intéressants dans le cadre de la pratique clinique en psychologie, car nous constatons qu'une même situation peut entrainer des réactions différentes chez les étudiants lorsque nous modifions certains paramètres émotionnels. Cela suggère que les futures personnes cliniciennes sont influencées par leur biais personnel de même que par le contexte et que ces variables peuvent venir influencer leurs décisions cliniques sans pour autant qu'elles en soient conscientes. Une prise en compte de ce phénomène ainsi qu'une sensibilisation accrue face à celui-ci pourrait permettre une optimisation des décisions éthiques entourant la confidentialité. Il serait ainsi important de sensibiliser les étudiants à ces influences dans une perspective métacognitive, mais aussi de créer des mises en situations s'apparentant davantage aux situations pouvant survenir dans le cadre d'une pratique professionnelle, en intégrant la charge émotionnelle pouvant accompagner celles-ci. À cet égard, Mattison (40) propose d'amener les thérapeutes en formation à prendre le temps de se poser des questions sur eux-mêmes lorsqu'ils se retrouvent en contexte de dilemmes éthiques. Des questions telles que : « Quels éléments de mon vécu ou de ma personnalité sont en train d'influencer la décision que j'ai envie de prendre? », « D'où provient ma décision, de qu'elle manière celle-ci s'articule-t-elle dans mon esprit? », « Quelles étaient mes réactions et sensations physiologiques présentes lorsque j'ai été mis au courant de la situation? », « De quelle manière mes valeurs ou ma philosophie personnelle, de même que mes obligations légales, influencent ma décision? » seraient un bon point de départ pour promouvoir une croissance personnelle dans le domaine de l'éthique, notamment chez les étudiants (40, p.209, traduction libre).

Plusieurs méthodes sont mises de l'avant au sujet de la manière d'enseigner l'éthique aux étudiants. Il apparait que l'une des méthodes les plus efficaces serait de promouvoir des ateliers de groupes entre étudiants portant sur différents dilemmes éthiques (38,40,73). L'exposition à des jeux de rôles et à des études de cas tout en interagissant avec les pairs permettrait d'avoir accès à ses opinions et valeurs personnelles sur les différents sujets tout en prenant conscience de celles d'autrui. Des auteurs mentionnent qu'ils proposent aux étudiants d'effectuer un travail réflexif sur eux-mêmes sous forme d'autobiographie afin qu'ils identifient les différentes variables influençant leurs valeurs et leurs visions de l'éthique (73). Des questions plus spécifiques sur leurs traditions familiales, leur religion, leur culture et la vision du bien et du mal sont soulevées afin de faciliter l'écriture de cette autobiographie. Proposer aux étudiants de défendre les points de vue qu'ils ne partagent pas en les invitant à jouer à l'avocat du diable est également une stratégie intéressante pour apporter des nuances dans leur vision de l'éthique (73).

Notre recherche comporte plusieurs limites. Premièrement, il importe de rester prudent sur la généralisation des résultats étant donné que le modèle n'était significatif que pour un dilemme parmi les trois. Une deuxième limite concerne notre échantillon, constitué d'étudiants en psychologie. Il est ainsi difficile de généraliser nos résultats aux psychologues disposant de plusieurs années d'expérience. En effet, l'expérience est une variable importante dans le développement des psychologues (74,75), il est donc possible qu'un effet se soit avéré moins apparent chez une population avec un plus haut degré d'expertise. Par ailleurs, dans le cadre de cette étude, la variable témoignant de l'expérience en relation d'aide n'a montré aucun lien significatif avec les variables d'intérêts. Il est toutefois important de nuancer cette variable, car elle ne mesurait pas l'expérience en tant que psychologue, mais bien en tant que personnes étudiantes en formation en psychologie, donc avec une expérience limitée. Ainsi, notre variable mesurait leur expérience en nombre d'heures plutôt qu'en années. Cela étant dit, une étude réalisée par Bhola et al. (72) a montré que les thérapeutes novices expérimentent une série d'émotions difficiles lorsque ces personnes sont confrontées à des dilemmes éthiques entourant la confidentialité. Ces auteurs ont également montré qu'un même dilemme peut susciter des affects très différents d'une personne thérapeute à une autre. Dans les émotions recensées dans cette l'étude, il y avait l'anxiété, de l'inconfort, de la peur, un sentiment de panique, de l'irritation, une pression amenée par un sens des responsabilités, de l'impuissance, du doute quant à ses capacités professionnelles, de l'incertitude ainsi qu'une crainte de nuire au client ou à la relation thérapeutique (72). L'étude a montré qu'il n'y avait pas de patron émotionnel fixe à la prise en compte des dilemmes et que les étudiants étaient envahis d'émotions particulièrement intenses et difficiles à réguler. Cette étude montre l'importance des différences individuelles dans l'interprétation et la résolution des dilemmes et pointe également la pertinence de sensibiliser les jeunes thérapeutes à des dilemmes éthiques.

Une autre limite associée au projet concerne l'opérationnalisation de la variable de l'intensité émotionnelle perçue sur la propension à divulguer. En effet, lors de l'analyse des données, nous avons constaté que cette variable avait pu susciter une confusion chez les participants, car « l'intensité émotionnelle perçue » peut engendrer des perceptions sur un grand nombre de paramètres émotionnels rendant ainsi la réponse des participants plutôt diffuse. Nous avons également observé que dans le deuxième dilemme, l'émotion était perçue plus intensément dans la condition « texte » comparativement à la condition « audio émotif ». Rétrospectivement, il aurait été préférable de poser la question différemment aux participants afin de clarifier ce qui avait été perçu. Par exemple, une question visant à préciser les émotions perçues dans la tonalité de l'acteur et une autre adressant l'intensité de celles-ci aurait mieux opérationnalisé la perception du participant. Cette variable du modèle pourrait donc être clarifiée en vue d'utilisations futures. De plus, il serait intéressant d'inclure une variable sur l'empathie ou l'identification perçue envers la personne dans la mise en situation, afin de déterminer si cette variable joue un rôle explicatif.

CONCLUSION

Cette étude montre que différentes modalités de dilemmes peuvent mener à différentes décisions de la part de l'interlocuteur. Ce résultat est intéressant dans le cadre de la pratique clinique en psychothérapie et soulève des questionnements sur le plan éthique, notamment en ce qui a trait à la formation des psychologues. En effet, lors de la formation éthique, les dilemmes sont souvent amenés d'une manière textuelle et les réflexions entourant celle-ci prennent surtout en compte les arguments rationnels. L'étude montre qu'il semble y avoir une différence entre le fait d'aborder un dilemme de manière textuelle et rationnelle comparativement au fait de vivre celui-ci avec l'émotion qui accompagne la personne subissant la situation conflictuelle. Cette étude met en relief l'importance de l'analyse du ressenti émotionnel lors des décisions éthiques et invite les responsables de cursus académique en psychologie à réfléchir sur l'importance des réactions émotionnelles personnelles dans la pratique de la psychologie. En effet, une application des exercices proposée par Matisson (40) pourrait s'avérer pertinente. Ces exercices pourraient aider les étudiants à cerner l'influence du ressenti émotionnel sur leurs décisions et interventions. Selon Ruedy et Schweitzer (77), les principes d'acceptation de soi et de non-jugement découlant de la pleine conscience permettraient d'avoir accès à une plus grande quantité d'informations associées aux décisions éthiques, car les individus seraient moins amenés à ignorer ou rationaliser les informations qui pourraient être vécues ou perçues comme menaçantes pour eux (77). De plus, ce travail visant à améliorer la conscience de soi permettrait une meilleure compréhension ainsi qu'une meilleure gestion des enjeux contre transférentiels présents dans les suivis thérapeutiques qui peuvent eux aussi entrainer une mauvaise application des principes éthiques liés à la profession (78).

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ANNEXE A. DILEMMES SACRIFICIELS

Docteur

Vous êtes docteur. Un de vos patients présentant un diagnostic de séropositivité au VIH est sur le point de quitter l'hôpital. Il vous avoue en toute confidence sous le sceau du secret professionnel de la relation docteur-patient qu'il a comme intention d'infecter le plus de personnes possibles et qu'il compte commencer ce soir. Étant donné que vous êtes lié par le secret professionnel, il n'y a légalement pas de manière d'empêcher cet homme de poser ces gestes. Toutefois, il s'avère que vous pourriez contaminer sa médication avec un poison mortel indétectable, ce qui l'empêcherait d'infecter d'autres personnes.

À quel point serait-il approprié, pour vous, d'empoisonner cet homme afin de prévenir la propagation du virus?

Échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6}.

Lawrence d'Arabie

Vous êtes le chef d'une petite armée composée de guerriers de deux tribus, la tribu de la montagne et la tribu de la rivière. Vous n'appartenez à aucune des deux tribus. Durant la nuit, un membre de la tribu de la montagne a eu une dispute avec un membre de la tribu de la rivière et l'a assassiné. Les membres de la tribu de la rivière sont frustrés par cet acte et vont attaquer les membres de l'autre tribu, sauf si l'assassin est condamné à mort. Cependant, les membres de la tribu de la montagne refusent de tuer l'un de leurs guerriers. La seule manière pour vous d'éviter une guerre entre les deux tribus qui provoquerait des centaines de morts est d'exécuter l'assassin en lui coupant la tête avec votre épée.

À quel point serait-il approprié, pour vous, de trancher la tête de cet homme afin d'empêcher les deux tribus d'entrer en guerre et de provoquer ainsi des centaines de morts?

Échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6}.

Le choix de Sophie

C'est une période de guerre. Vous et vos deux enfants âgés de cinq et huit ans habitez dans un territoire occupé par l'armée ennemie. Dans les quartiers ennemis, il y a un docteur effectuant des expériences douloureuses sur les humains qui mènent systématiquement à leur décès. Le docteur planifie effectuer une expérience sur l'un de vos enfants, mais il vous laisse choisir sur lequel de vos enfants l'expérience aura lieu. Vous avez 24 heures pour amener l'un de vos enfants à son laboratoire.

Si vous refusez, il mènera son expérience sur chacun d'entre eux. À quel point serait-il approprié, pour vous, d'emmener l'un de vos enfants au laboratoire pour éviter que les deux meurent?

Échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6}.

Vaccin

Une épidémie virale s'est propagée dans le monde, tuant des millions de personnes. Vous avez développé deux substances dans votre laboratoire. Vous savez que l'une d'entre elles est un vaccin, mais vous ne savez pas laquelle. Vous savez aussi que l'autre substance est mortelle. Une fois que vous aurez trouvé laquelle des deux substances est le vaccin, vous allez pouvoir l'utiliser pour sauver des millions de vie. Vous avez avec vous deux patients et la seule manière d'identifier le vaccin est d'injecter les substances dans le corps de vos patients. Une personne va vivre, l'autre va mourir et vous allez pouvoir commencer à sauver des vies avec votre vaccin.

À quel point serait-il approprié, pour vous, de tuer l'une de ces personnes avec une injection mortelle dans l'optique d'identifier le vaccin qui sauvera des millions de vies?

Échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6}.

Armée

Vous êtes le chef d'un petit groupe de soldats. Vous êtes sur le chemin du retour après avoir effectué une mission se situant dans le territoire ennemi. Un de vos hommes est tombé dans un piège ayant été posé par l'ennemi et est gravement blessé. Le piège est connecté à une radio qui a alerté l'ennemi de votre présence, et ce dernier sera donc bientôt en chemin vers votre position. Si les ennemis trouvent votre homme blessé, ils vont le torturer et le tuer. Celui-ci vous supplie de ne pas l'abandonnera son sort, mais si vous essayez de l'amener avec vous, c'est votre groupe en entier qui se fera capturer. La seule manière pour vous d'empêcher ce soldat blessé de se faire torturer est de lui tirer une balle vous-même.

À quel point serait-il approprié, pour vous, d'exécuter ce soldat afin de protéger le reste du groupe?

Échelle Likert allant de *totalement inapproprié* {1} à *totalement approprié* {6}.

ANNEXE B. DILEMMES DE CONFIDENTIALITÉ

Dilemme 1

George est psychologue en soins palliatifs et intervient auprès d'une personne qui est gravement malade. La personne lui transmet les informations suivantes :

« Tous mes docteurs s'entendent pour dire que je vais mourir prochainement. J'ai tellement mal, puis j'ai plus d'argent pour continuer à payer mes frais médicaux pour mes traitements. Je dois dire que je pense à me suicider puis je sais exactement comment je vais le faire. Ma blonde elle comprend pas puis elle veut pas me voir partir, mais j'veux pas qu'elle soit mise au courant de ce que je m'apprête à commettre. »

Selon vous, qu'est-ce que le psychologue devrait faire?

Échelle Likert allant de *maintenir la confidentialité* {1} à *divulguer l'information à la personne concernée ou à un tiers* {6}.

Dilemme 2

Max est psychologue dans un bureau privé et réalise un suivi psychologique depuis trois mois avec un étudiant universitaire qui est atteint du SIDA et qu'il juge à haut risque suicidaire. Celui-ci lui divulgue les informations suivantes :

« C'est vraiment difficile d'être atteint de ce virus-là. Vous êtes la seule personne qui m'a pas jugé puis qui m'a supporté au cours des derniers mois. Sans votre aide, j'pense pas que j'aurais été capable de vivre. Je me suis senti tellement seul les derniers mois, j'étais perdu, désemparé. C'est con, mais la seule chose qui avait l'air de pouvoir me réconforter c'était la sexualité. Puis là bein, j'ai vraiment honte-là, mais je me suis pas protégé avec mes derniers partenaires. Puis malgré tout ça, on dirait que je peux pas m'empêcher d'inciter mes partenaires actuels à avoir des relations non protégées avec moi. »

Selon vous, qu'est-ce que le psychologue devrait faire?

Échelle Likert allant de *maintenir la confidentialité* {1} à *divulguer l'information à la personne concernée ou à un tiers* {6}.

Dilemme 3

Richard travaille comme psychologue dans une école secondaire. Dans cette école, il y a une politique que doivent adopter les professionnels. Si ceux-ci suspectent qu'un étudiant est victime d'abus, ils doivent toujours le rapporter aux autorités scolaires sous peine d'être renvoyés. Richard est en consultation avec un adolescent de 16 ans qui présente plusieurs marques sur le corps. Richard questionne le jeune face à celles-ci et voici ce qu'il lui mentionne comme détails.

« Mon père il est devenu vraiment en colère hier soir puis il m'a fait mal, mais c'était la première fois qu'il levait la main sur moi puis après il s'est excusé plein de fois. Puis en plus bin, il est en politique ça fait que s'il fallait que ça se sache, le monde pourrait se servir de ça contre lui aux prochaines élections puis ça nuirait à ma relation avec lui. »

Selon vous, qu'est-ce que le psychologue devrait faire?

Échelle Likert allant de *maintenir la confidentialité* {1} à *divulguer l'information à la personne concernée ou à un tiers* {6}.

ANNEXE C. MODÈLE INTÉGRANT L'APPORT DES JUSTIFICATIONS

Scénario 1: Récapitulatif des modèles

Modèle	*R*	R^2	R^2 ajusté	Erreur standard de l'estimation	Tests de la variation du R^2				
					Variation du R^2	Variation de F	ddl1	ddl2	*p*
1	0,176	0,031	0,025	1,71	0,031	5,58	1	175	0,019
2	0,221	0,049	0,038	1,70	0,018	3,30	1	174	0,071
3	0,231	0,054	0,037	1,70	0,005	0,85	1	173	0,357
4	0,248	0,061	0,034	1,70	0,008	0,71	2	171	0,495
5	0,272	0,074	0,036	1,70	0,013	1,18	2	169	0,311
6	**0,461**	**0,213**	**0,165**	**1,58**	**0,138**	**9,72**	**3**	**166**	**< 0,001**

Scénario 3: Récapitulatif des modèles

Modèle	R	R^2	R^2 ajusté	Erreur standard de l'estimation	Tests de la variation du R^2				
					Variation du R^2	Variation de F	ddl1	ddl2	*p*
1	0,182	0,033	0,028	1,59	0,033	5,80	1	174	0,016
2	0,189	0,036	0,025	1,59	0,003	0,46	1	173	0,499
3	0,190	0,036	0,014	1,60	0,000	0,03	2	171	0,970
4	0,296	0,088	0,061	1,56	0,052	9,65	1	170	0,002
5	0,349	0,122	0,085	1,54	0,034	3,25	2	168	0,041
6	**0,572**	**0,327**	**0,286**	**1,36**	**0,205**	**16,74**	**3**	**165**	**< 0,001**

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Beyond Private? Dementia, Family Caregiving and Public Health

Monique Lanoix[a]

Résumé
Le Forum économique mondial a qualifié la démence de l'une des plus grandes crises sanitaires mondiales du XXIe siècle. Dans cet article, je soutiens que les soins non rémunérés prodigués par la famille ou les proches des personnes atteintes de démence devraient être une question de santé publique. Shaji et Reddy l'ont proposé en 2012 dans le contexte des soins aux personnes atteintes de démence en Inde. Ils reconnaissent explicitement l'influence de l'article de Talley et Crews de 2007 sur la prestation de soins en tant que nouveau problème de santé publique. Cependant, ils limitent leur proposition aux soins prodigués aux personnes atteintes de la maladie d'Alzheimer et de démences apparentées (MADA), ce que je considère comme une première étape importante dans l'élaboration d'un argumentaire visant à inscrire plus fermement les soins dans un programme de santé publique. Pour étayer mon propos, j'établis tout d'abord que la prestation de soins est un déterminant social de la santé. Ensuite, je réfute les objections à l'ajout de la prestation de soins aux personnes atteintes de la MADA à un programme de santé publique, car cela entraînerait une dérive de la mission de la santé publique. Je soutiens ensuite qu'une compréhension large de la santé publique peut inclure ce type de prestation de soins et est préférable car elle met en évidence une question d'équité en matière de santé, la nature sexuée de la prestation de soins. Enfin, je soutiens qu'une définition de la santé publique incluant les déterminants sociaux de la santé et la prestation de soins est mieux adaptée pour faire face aux conséquences sanitaires de l'évolution actuelle des schémas démographiques. Mon argumentation renforce les écrits sur la migration qui appellent à l'élargissement du champ d'application de la santé publique.

Mots-clés
démence, soins familiaux, santé publique, relationnel, déterminants sociaux de la santé, équité

Abstract
The World Economic Forum has called dementia one of the biggest global health crises of the 21st century. In this paper, I make the case that unpaid caregiving by family or close others of persons living with dementia should be a matter of public health. Shaji and Reddy proposed this in 2012 in the context of dementia care in India. They explicitly acknowledge the influence of Talley and Crews' 2007 article on caregiving as an emerging public health concern. However, they narrow their proposal to caregiving for persons living with Alzheimer's disease and related dementias (ADRD), which I take to be an important first step in building an argument for putting caregiving more firmly on a public health agenda. In order to support my claim, first, I establish that caregiving is a social determinant of health. Second, I counter objections to the addition of caregiving for persons living with ADRD to a public health agenda, as it would lead to public health mission creep. I then argue that a broad understanding of public health can be inclusive of this type caregiving and is preferable as it highlights an issue of health equity, the gendered nature of caregiving. Finally, I make the case that a definition of public health inclusive of the social determinants of health and caregiving is more adequately suited to address the health consequences of the current changing demographic patterns. My argument adds support to writings on migration calling for broadening the scope of public health.

Keywords
dementia, family caregiving, public health, relational, social determinants of health, equity

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INTRODUCTION

The World Economic Forum has called dementia one of the biggest global health crises of the 21st century (1). Alzheimer's is the most prevalent disease that leads to dementia, but other diseases can cause this degenerative condition, and together they are labelled Alzheimer's disease and related dementias (ADRD), which is the term I will use (2). In this paper, I make the case that unpaid caregiving by family or close others of persons living with ADRD should be a matter of public health. This possibility first came to my attention through Shaji and Reddy's 2012 proposal in the context of dementia care in India (3). In India, most persons living with ADRD are cared for at home since institutional care is not readily accessible or affordable, and very often is not culturally acceptable (4). Shaji and Reddy argue that the best way to meet the needs of family caregivers as well as that of persons living with dementia is through an array of services, from education to support (3). They put forward that a public health framework would lead to exploring more fully the needs of populations and would result in better services not only for the persons living with ADRD but also their caregivers as the wellbeing of the former is tied to the latter (3).

Shaji and Reddy (3) explicitly acknowledge the influence of Talley and Crews' 2007 (5) article on caregiving as an emerging public health concern. However, they narrow their proposal to caregiving for persons living with ADRD, which I take to be an important first step in building an argument for putting caregiving more firmly on a public health agenda. My paper also owes much to Talley and Crews' proposal, which I regard as a call to delve more deeply into an analysis of caregiving and its potential ties to public health. It is certainly the case that caregiving for persons living with ADRD is more widely recognized in

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all parts of the world, from high to low-income countries, as a complex, and demanding activity that often has a negative impact on caregivers' mental and physical health. If this supports a greater examination of the question, there is also another reason for my analysis, which is the definition of public health. The proposal to include caregiving within a public health framework prompts a critical examination of the definition of public health, more specifically whether public health should be narrowly or broadly defined. The chosen perspective, whether narrow or broad, will have a direct impact on the development of public health policies, which is why it is important to build consensus on this question.

I focus on policy and recommendations from Canada and the USA and I insist on referring to *caregiving* as opposed to *caregivers*. This may appear to be a trivial point since caregivers are already present in many of the Canadian and American public health recommendations. However, if current policies and initiatives refer to caregivers, the manner in which they are addressed is tangential to the greater concern of the social and health status of persons living with ADRD and the consequences for the health care systems. Explicitly referring to caregiving entrenches its recognition as a risk factor for harm that warrants prevention at the population level. It calls attention to the fact that caregiving is not an isolated practice as it is influenced by the caregiver's socioeconomic context. Finally, since women are most often the caregivers of persons living with ADRD, a focus on caregiving makes possible the explicit acknowledgement of the gendered nature of caregiving, which is an essential step in addressing this matter of health equity.

To build my case, I first establish that caregiving is a social determinant of health. Second, I counter objections to the addition of caregiving for persons living with ADRD to a public health agenda and argue that a broad understanding of public health can be inclusive of this type caregiving. Thirdly, I make the case that a broad definition of public health is more adequately suited to address the health consequences of the current changing demographic patterns, thus adding support to the writings on migration that call for a broadening the scope of public health. Finally, my paper makes clear that Talley and Crews' proposal remains relevant; however, "framing the public health of caregiving" as they propose requires developing initiatives and strategies that are suitable for the population requiring caregiving. My discussion demonstrates how this is possible for persons living with ADRD and their caregivers.

CAREGIVING AS A SOCIAL DETERMINANT OF HEALTH

My analysis is directed at caregiving understood as the assistance typically provided to older adults who have difficulty carrying out the activities of daily living. Home health care aides and personal support staff working in nursing homes perform this type of work for remuneration. For the purposes of my paper, I limit my study to the assistance that is unpaid and provided by family or friends of persons diagnosed with ADRD who are living at home.[1] This type of assistance is classified as "informal care" even if it often has a positive impact on the care receiver's health. Given that this type of caregiving can involve complex tasks, I use the term "unpaid caregiving" to distinguish it from the paid care provided by nurses or care aides in the home.

The rehabilitation and the neuropsychological literature recognize two types of activities of daily living: those that are needed to survive, such as eating and personal hygiene (ADL); and the activities that are instrumental to life (IADL), such as managing a bank account (6). In the first instance, the assistance provided can range from cleaning someone's living space, to helping with meals and intimate tasks such as dressing or bathing. In the case of persons living with ADRD, the assistance needed initially may only be with the IADLs; however, as the disease progresses, individuals living with ADRD will increasingly need help with the ADLs and this assistance will likely become more complex.

The first step in determining whether this type of caregiving can be located under the umbrella of public health is to demonstrate that it is a social determinant of health. The World Health Organization defines the social determinants of health as "the non-medical factors that influence health outcomes. These are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems" (7).[2] Baker, Metzler and Galea observe "that certain conditions commonly referred to as social determinants – including access to affordable healthy food, potable water, safe housing, and supportive social networks – are linked to health outcomes is something on which most of us agree" (8). It is not immediately obvious that there would be general agreement that caregiving for persons living with ADRD can be included on the list of social determinants of health. In order to establish that it can be included, it must meet three criteria. First, that caregiving can have a significant negative impact on caregivers' health outcomes. Second, that it is a risk factor affecting a large segment of the population. Third, that these negative health outcomes are preventable or at least mitigated by adequate policies.

In the following paragraphs, I examine studies discussing caregiver burden. I do not present a systematic literature review as there is broad agreement that caregiving takes a toll on caregivers (9). For example, the World Health Organization explicitly acknowledges caregiver strain in their 2017 guidelines to assess the effectiveness of caregiver support (10). Rather, I draw attention to findings from specific studies to highlight how caregiving activities are complex and often involve multiple actors and systems. I begin my analysis by looking briefly at studies directed at caregiving for adults living with a chronic illness or a disability; then, I examine research focusing on caregiving for persons living with ADRD.

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[1] I use the term 'family' in a broad sense to include family, spouses, partners, as well as close others.

[2] I draw attention to the mention of 'work' in the definition. Although caregiving is not paid, it is work, as many caregivers will attest.

In their proposed theoretical framework to understand caregiver burnout, Gérain and Zech write that “[a]cross the literature and the media, it is widely accepted that being an informal caregiver puts a person at risk of poorer mental and physical health” (11, p.1). In interviews conducted by phone with over one thousand caregivers in the USA, Navaie-Waliser et al. determined that 36% were vulnerable caregivers (12), which they define as older, with health problems and as having less education. Vulnerable caregivers had more problems providing care and they reported that their health had suffered (12). In their study of older caregivers providing care for their spouses living with a chronic illness, Schulz and Beach observe that “being a caregiver who is experiencing mental or emotional strain is an independent risk factor for mortality among elderly spousal caregivers” (13, p.2215).

In the more limited case of caregiving for persons living with ADRD, Gitlin and Schultz report that caregiving activities can have a negative impact on the caregiver’s health (14). Studies comparing caregivers of persons living with ADRD to individuals who are not providing care reveal that caregivers faced more distress as well as negative health outcomes (15). In their scoping literature review of peer-reviewed articles pertaining to caregiver burden, Queluz et al. note that the personal health of caregivers as well as their emotional health was a key concern (16). The authors included data from various countries, published in English, with a focus on caregivers of persons living with ADRD. If these studies are limited by language, they nevertheless concur with international studies on the risk factors associated with caregiving for persons living with ADRD (17).

Unsurprisingly, the disease trajectory of the person receiving assistance will have an impact on caregiver burden. In addition, it will be influenced by the caregiver’s age, culture, sex, socioeconomic status and their attitude (18). If older caregivers confront the risk of negative health outcomes, younger caregivers often tackle challenges, albeit of a different sort. Nonetheless, these can also lead to negative health outcomes. As Brodaty and Donkin explain, “caregivers [of persons living with ADRD] face many obstacles as they balance caregiving with other demands, including child rearing, career, and relationships. They are at increased risk for burden, stress, depression, and a variety of other health complications” (19, p.218-19).

If the physical and emotional strain of caregiving is usually associated with the direct activities of care, other aspects of caregiving can increase caregiver stress. In their study of the structural burden of caregiving for persons with chronic illness and/or ADRD in the USA and Canada, Taylor et al. highlight an under explored area of caregiver burden, that of having to manage fragmented health care structures (20). They point out that in much of the literature, the stress of caregiving is assumed to come from an imbalance between caregiving demands and the caregiver’s time (20). Their analysis reveals the impact of having to negotiate and manage access to long-term care services. Not only are these caregivers dealing with the strain of direct care, but they also face a secondary stress of having to navigate various systems, from health to social services, in order to access adequate care and support (21). Although support services are put in place to be of use to those who provide care, they can increase time commitments and frustration. This added burden, although more frequent in high-income nations, highlights how caregiving for persons with either chronic diseases and/or ADRD is complex and requires commitment, time, effort as well as knowledge.

Although not exhaustive, the studies mentioned so far agree that caregiving for persons living with ADRD is a risk factor for negative mental and physical health outcomes. Moreover, they highlight the impact of other social determinants of health on the strain experienced by caregivers. These findings indicate that caregiving for persons living with ADRD satisfies the first criterion of its inclusion as a determinant of health. As for the second criterion, a 2022 study published in *Lancet Public Health*, estimated that the global number of people with dementia will nearly triple from 2019 to 2050 (22). If the number of persons who are living with dementia is on the rise, more family members and friends will become caregivers.[3] As large segments of the population undertake assisting individuals living with ADRD, I propose that the question becomes one of population health. Finally, if caregivers of persons living with ADRD often face diminished health outcomes, studies have shown that policies directed at caregivers, which include education and supportive care, helped mitigate some of the effects of caregiving (23). Because caregiving of persons living with ADRD fulfills all three criteria, it can be classified as a social determinant of health.

PUBLIC HEALTH AND CAREGIVING

Granting that caregiving for persons living with ADRD is a social determinant of health, it remains to be shown that it can and should be part of a public health agenda. In this section, I counter possible objections to my proposal.

According to Faden et al. (24), there are four characteristics of public health. The first is that public health targets populations, not individuals; it is a public good. The second is a commitment to prevention of disease and injury. A requirement of government action constitutes the third feature and, fourth, public health is outcome oriented. It can be readily agreed that caregiving for persons living with ADRD meets criteria two, three and four. However, there are two possible objections related to the first criterion. Both objections pertain to the assumption that caregiving is a familial activity involving individuals, not populations. Although the two objections are conceptually linked, I consider them separately as they bring to light different problematic suppositions.

The first objection identifies governmental support for family caregivers of persons living with ADRD as unpaid care and not health care proper and thus not directly relevant to public health. The second objection is that caregiving for persons living

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[3] The greater demand for caregiving as well as the increasingly complex nature of caregiving are two of the factors motivating Talley and Crews’ call for framing “caregiving as an emerging public health issue” (5, p.224).

with ADRD pertains to familial care. The reasoning behind the latter objection is that, regardless of how many people are caregivers, familial care involves close others in the private sphere. I turn to the first objection next, and then examine the second by mobilizing some of the recent literature on populations and migration.

It is generally agreed that public health can be defined from a narrow or a broad perspective (25). The classic version, which is the narrow version from Winslow (1920), which defines public health as "the science and the art of preventing disease, prolonging life, and promoting physical health and efficiency through organized community efforts…" (26, p.30). In their 2023 scoping review on public health, Azari and Borisch found Winslow's definition to be the most cited (27). However, global, social and political transformations have incited the search for a more comprehensive definition of public health that would include attention to broader questions such as that of health equity. Powers and Faden's proposal to view public health as a matter of social justice is an example of a broad understanding. In their 2006 book, *Social Justice: The Moral Foundations of Public Health and Public Health Policy*, Powers and Faden argue that "the foundational moral justification for the social institution of public health is social justice" (28, p.80). They view a close allegiance between public health and social justice as necessary to advance the goals of public health.

Labelling caregiving for persons living with ADRD as unpaid care, as opposed to health care, would not necessarily prevent its integration into a public health agenda. A broad definition of public health could easily include family caregiving for persons living with ADRD as caregiving touches upon matters of social justice. To explain, first, caregivers face an increased risk for negative health outcomes while providing care that ultimately lessens the impact of ADRDs on health care systems. If everyone in a particular region benefits from a less overloaded health care system, it is at a cost to those who provide care and very often lack proper support. Second, as the studies discussed previously demonstrate, socioeconomic status and age influence the health outcomes of caregivers; caregiving is interwoven with other determinants of health. There is also the issue of caregiving and gender. A definition of public health that acknowledges the differential impact of socioeconomic factors could easily include caregiving for persons living with ADRD. However, if caregiving is included in a broad definition of public health, it is open to the charges directed at the broad interpretation of public health. That is, it could be construed as unduly broadening the scope of public health. To assess this charge, I turn to the objections that Powers and Faden's proposal has faced as well as their rebuttal of these objections.

Several theorists and practitioners working in the domains of health care and population health have applied Powers and Faden's framework. Notably Horn (29) argues that the problem of fetal alcohol syndrome in South Africa would be better addressed using a public health framework that includes attention to poverty. According to Horn, this is the best way to ensure the recognition of social injustices that worsen a public health issue. In a later article, she makes clear that there should be a close link between social justice and public health especially in low-income contexts (30). She is aware, however, that such a close association can lead to public health mission creep, that is, the broadening of public health to the extent that it includes much larger questions of human rights and socioeconomic inequalities. Rothstein argues that tackling such issues is outside the mandate and expertise of public health officials (31). The fear is that adding questions relating to human rights or socioeconomic inequalities to the public health agenda would lead to a radical transformation of public health. This new public health could end up directing its attention toward social justice rather than health.

Those who worry about public health mission creep, such as Rothstein, acknowledge that socioeconomic status has consequences for health outcomes. Nevertheless, they perceive the two areas as having to remain separate. Powers and Faden have responded that they are sensitive to the dangers of mission creep. However, they write, "the greater, more pervasive risk is lack of moral attentiveness to policies that neither do the best they can to secure the conditions for improved public health or pursue public health in ways that undermine other aims of justice" (32, p.46). Powers and Faden have a point, as it may be difficult or nearly impossible to keep particular determinants of health as concerns of public health separate from considerations of social justice.[4]

If these worries over the expansion of public health are taken seriously, where does it leave the proposal to address caregiving for persons living with ADRD as an issue of public health? I suggest that the question of caregiving is of a different *kind* than that of injustice related to social economic class. Caregiving is a type of activity directed at the wellbeing of the person receiving care. Although it is not medical care, it is instrumental to the health and wellbeing of the person receiving care. Caregiving for persons living with ADRD is akin to the paid caregiving taking place in an institutional setting or the paid caregiving provided by home care aides: both types of assistance, paid and unpaid, involve activities that support health and wellbeing. Socioeconomic class, on the other hand, is the social and economic location of individuals within a particular region. Although it can have an impact on the health status of an individual, it does not directly involve a medical procedure or assistive care aimed at supporting wellbeing. The difference between family caregiving and paid caregiving is a difference of *degree* and not a difference in *kind*.

To illustrate, let us look at an example of a recent Canadian policy introduced to manage the Covid-19 pandemic in the health care workforce. Public Health Ontario, the public health agency of the province of Ontario, published a technical brief updated in December 2021, where it recognizes the risks of infection health care workers face (33). This policy is an example of public health directing efforts to protect the health and wellbeing of paid health care workers in their work environment. One reason was certainly to curb infection rates; another was to ensure that workers were available. Additionally, the government, either

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[4] For example, refugee and migrant health is an issue that pertains not only to health but also to social justice.

as a direct employer or as having the responsibility to oversee workplace security, understands that it has a duty to protect workers and prevent infection.[5] If public health can turn a vigilant eye to the protection of paid care workers, it can also do so for unpaid family caregivers. Granting that the government does not pay family directly in Canada, professional health care workers are part of the public health care system and studies have shown they depend on family caregivers (35-37). Although not recognized explicitly, family caregivers are providing essential care.

The reluctance to integrate family caregiving for persons living with ADRD as a question relevant to public health also comes in part because it blurs the boundaries between health care and unpaid care taking place at home.[6] However, that boundary is permeable, as many policies, for example those on home-care, illustrate (38). My point is that the proposal to add caregiving for persons living with ADRD does not expand public health's overall focus, as another service is simply included within its scope. In sum, a broad definition of public health can include caregiving without the worry of mission creep.

The second objection is grounded on the presumption that family caregiving provided to persons living with ADRD is a private matter to be managed by individuals. Regardless of the number of caregivers who may face diminished health outcomes, by its very nature, familial caregiving should remain an issue to be tackled by governmental policies relating to family caregiving and not health care per se. Thus, it is not directly relevant to public health.

Feminist activists and scholars have successfully challenged this presumption and have argued that family care matters to the public realm. The matter has also been the subject of writings in feminist bioethics (39,40). Numerous studies have demonstrated the positive impact of family caregiving on care receivers' health outcomes. Very often, in the case of home care, professional care providers such as nurses rely on family caregivers (35,36). I note one example, even if dated, of Saillant's research on caregiving in Québec in the early 1990's where she established the unquestionable impact of family members, very often women, on the production of positive health outcomes for their families (41,42).[7]

Another critical consideration is that caregiving does not take place ex nihilo but is shaped by the social, political and familial contexts in which it takes place. Talley and Crews, in their response to Eckenwiler's comment on their 2007 article, rightly clarify that "[a]lthough care is given to an individual, the caregiving process frequently involves multiple providers and occurs within interactive, dynamic contexts of varying duration and incredible delicacy" (44, p.1931). Eckenwiler's proposed ecological framework for caregiving explicitly acknowledges that the needs and support given to care recipients and to paid and unpaid caregivers is intertwined in a variety of policies, from migration to labour laws as well as health (45). The 2020 American Public Health Agency's policy statement on strengthening the dementia workforce echoes the same observation. The authors of the policy statement recognize that although topics such as service provision to persons living with ADRD "are often thought of as private, family concerns, the broader implications on our health care, economic, social and cultural systems are all encompassing. Flaws there impact us all; rectifying them will help us all" (46, p.7).

PUBLIC OR POPULATION?

I have shown thus far that caregiving for persons living with ADRD can be integrated into a public health agenda, broadly construed. However, whether a narrow public health perspective is more adequate than a broad one or vice versa has yet to be determined. In their scoping review, Azari and Borisch (27) point out that a clear definition of public health would help those who work in the field and certainly would help the individuals who could benefit from public health policies. If no consensus has been reached as to a clear definition, the authors emphasize the need to re-assess and update definitions of public health. Caregiving provides a useful lens to examine this point.

The narrow view of public health focuses on disease prevention and control. This perspective does not explicitly take into consideration socioeconomic contexts and, as a result, encourages the perception that individuals are mostly responsible for their health.[8] Such a perception erases the uncontrollable aspects of a person's life that will nonetheless have an impact on their health outcomes. This is one of the reasons Powers and Faden insist public health is a matter of social justice. As the studies discussed earlier suggest, a more thorough understanding of the challenges that caregivers may face requires taking into consideration their socioeconomic context. My point is that a thorough reckoning of the negative health outcomes brought about by caregiving requires a broad understanding of public health. To support my claim, I turn to the literature that critically engages populations and migration in relation to public health.

Childress et al. clarify the focus of public health as involving the health of an entire population as opposed to that of an individual (48). If the target of public health seems clear, finding an unambiguous definition of public health has not been straightforward as Azari and Borisch's scoping review demonstrates (27). This is the reason Dawson and Verweij label public health a contested concept (49). In their chapter on the meaning of public in public health, they explain how public health might refer to the health of the public or it might signify the interventions needed to keep the public in good health. Regardless of this

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[5] This recognition came rather late. During the pandemic, front-line workers faced a heavy burden according to the Canadian Institute for Health Information (34).

[6] Some activities of care could be a controlled act (such as wound dressing) that a nurse has delegated to a family member. This illustrates how the strict demarcation between paid and unpaid care can be questionable. I owe this point to Michael Lepore.

[7] The question of family contributions as been the focus of later research agendas (43).

[8] This tends to promote an individualistic attitude toward public health measures with state-based interventions negotiated through a delicate balance of limiting individual rights and promoting the greater good. This negotiation can be at times controversial, as witnessed in North America during the Covid-19 pandemic and the rules surrounding masking and vaccines. As for the lager domain of bioethics, Lane et al. maintain that debates in bioethics are moved by concerns that are individualistic, which downplays "the importance and legitimacy of group-level health care dilemmas" (47, p.25).

equivocality, until recently, the accepted understanding of public health is that it involved persons residing in one country, state or region. However, societies have changed: not only are there demographic transformations such as population aging, but there is also increased population mobility across the globe because of political and climate crises (25,50). Moreover, with a greater awareness of global health inequalities, there is growing agreement that such inequalities should be a concern of public health. As can be surmised, the question arising from these changes is whether public health should limit itself to one region or adapt to the changing patterns of human life and respond to the global health inequalities.

These realities have prompted Faden to consider the meaning of public in public health, although from a different perspective than Dawson and Verweij's. She worries that using the term 'public' to define the aim of public health may give the impression that this collective entity is comprised of individuals who must share certain features. She prefers the term population because "characterizing the health we are trying to advance as that of populations, by contrast, may minimize the implication that special shared features or characteristics are needed in order for a group of individuals to constitute a collective unit whose health can be of concern" (51). According to Faden, 'population' is more indicative of the heterogeneity of the individuals inhabiting the entity that is the focus of public health.

Faden concurs with Wikler and Brock's proposal for population level bioethics embracing an internationalist perspective. As Wikler and Brock write,

> [t]he bird's eye perspective of this population level bioethics includes consideration not only of health care but also of other social determinants of health, including socio-economic standing, environmental and working conditions, and social exclusion. Its subject therefore is health rather than health care alone, insofar as health can be affected by conditions and interventions in any of these domains (52, p.78).

Since family caregiving for persons living with ADRD is a determinant of health, I submit that caregiving for persons living with ADRD is one of those domains.

Wikler and Brock maintain that population bioethics is not limited to narrowly circumscribed groups but extends in "both space and time" (52, p.79). In emphasizing the importance of time, they point to a larger understanding of relationships between individuals, for example that between generations.[9] Taking Geoffrey Rose's contrasting views on the medical approach and the population approach to social determinants of health, Wikler and Brock clarify that,

> [t]he population approach…seeks to reduce the risks of the population as a whole, usually by non-individual and non-medical interventions. For example, while the medical approach would provide drugs for hypertension to the worst cases, the population approach would work toward a reduction in the salt content of processed foods, lowering everyone's risk and thereby the number of deaths attributable to hypertension (52, p.91).

Since a population approach casts a wide net on the types of risk factors affecting health outcomes, a population approach is consistent with a broad understanding of public health.

There is a useful parallel to be drawn between the example given above and caregiving for persons living with ADRD. As is currently the case in Canada at least, the approach to caregivers of persons living with ADRD is what I would call a medical approach, as Wikler and Brock describe it. I do not deny that policies and initiatives that target ADRD as a public health concern include support for caregivers. However, if a caregiver is deemed to be close to a burnout, then either a nurse or a social worker on the case might intervene and facilitate access to support or even respite for the caregiver. If no one is managing the case, the caregiver might do some research to find out what services might be available. Another possibility, which is quite common, is that the caregiver would simply go without support (53). Focusing on caregivers in this manner is similar to prescribing medication for hypertension: the focus and support are on the individual caregivers not on the impact that caregiving has on the caregiving population.

The medical approach to caregiving for persons living with ADRD frames the health outcomes of caregivers as subsidiary to the health outcome of persons living with ADRD. When the focus is on sustaining caregivers in their role as care providers, it essentially instrumentalizes caregivers. Alternatively, a population approach would encourage the development of system wide policies to address the impact of caregiving while taking into account how some caregivers may be more vulnerable. To explain, because a population approach requires a broad understanding of public health, the policies developed under a broad public health agenda could consider other social determinants of health. Crucially, such a perspective supports the development of system wide policies that address an aspect of caregiving that is sadly absent from many policy recommendations: the gendered dimension of caregiving. This dimension has implications for health equity; however, it remains invisible when caregiver support is managed using a medical approach. In their viewpoint in the recent *JAMA Health Forum*, Stall, Shah and Bushan call attention to the fact that in the USA women disproportionately face the burdens of caregiving (54). Moreover, most caregivers carry out medical tasks that professional health workers usually perform. The authors conclude that challenging the

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[9] It can potentially include questions related to the health outcomes of migrant workers. See Eckenwiler's ecological framework on the question of migrant care workers (45).

gendered nature of caregiving is a way to better support caregivers and "ensuring that caregiving interventions are equitably implemented" is essential to create an equitable and resilient society (54, p.4).

AMERICAN AND CANADIAN POLICIES AND INITIATIVES

In this section, I discuss several American and Canadian strategies, initiatives, and recommendations relating to ADRD and caregivers. My first objective is to highlight several of the key recommendations from these various proposals in order to determine whether they fit a narrow or broad view of public health. My second, using caregiving as a critical lens of analysis, is to show that a broad definition of public health is more suitable to the current demographic and global transformations, adding support to the literature on migration and population that argues for a broad definition of public health (25,28,51,52).

American initiatives

In a 2018 testimony to the American Senate Special Committee on Aging, McGuire acknowledges that although there is a recognition of ADRDs as an issue of public health, much work remains to be done to improve the health and wellbeing of those who have these diseases. She adds that there is a growing need to help these individuals and their families (55). In their 2020 version of a public health Road Map designed to address the increasing prevalence of dementia, Olivari, French and McGuire call for the recognition of ADRD as a problem of public health (56).[10] The authors remark that ADRD had been considered a topic relevant to gerontology but not public health; however, they state that the changing demographics call for considering ADRD a matter of public health. The proposed Road Map is "categorized into four overarching public service actions: educate and empower, develop policies and mobilize partnerships, assure a competent workforce, and monitor and evaluate" (56, p.4). In addition to calling for more research and collaboration, the Road Map targets knowledge mobilization for persons with ADRD, their families and the greater public to shift attitudes and achieve better health outcomes.[11]

There are also several plans to address the health impacts of ADRDs. The National Plan to Address Alzheimer's Disease is a "federal strategy for reducing the burden of AD/ADRD by accelerating research towards treatments, improving care and support for people facing these conditions now, and reducing the risk of AD/ADRD by promoting brain health" (58) and is housed in the office of the Assistant Secretary for Planning and Evaluation, part of the Department of Health and Human Services (DHHS). If it does not discuss caregiver burden explicitly, it points to the increased need for care for persons living with ADRD. Specifically, it seeks to eliminate or at least ameliorate the management of ADRD in addition to meeting the needs of American families who are facing the disease. Of significance, the National Alzheimer's Project Act (NAPA) advisory council presented a report to the American Congress in 2021 where they put forward a national strategy to support family caregivers. The strategy is grounded in five priority areas for action: 1) awareness and outreach; 2) engagement of family caregivers as partners in health care and long-term services and supports; 3) services and supports for family caregivers; 4) financial and workplace security; 5) research, data, and evidence-informed practices (59). Many of the stated goals are similar to the ones put forward by the Road Map; however, the objective to engage caregivers as care partners marks them as active participants in the management of ADRDs. If there is a recognition of the contributions of caregivers, the strategy remains gender neutral.

The *RAISE Act* is an important step in the recognition of the impact of caregiving as well as the contributions of all caregivers. It became law in 2018 and its objective is to "Recognize, Assist, Include, Support and Engage family caregivers" (RAISE). The advisory councils of RAISE and the *Supporting Grandparents Raising Grandchildren Act* with input from the public developed the National Strategy to Support Family Caregivers. Greg Link of the Office of Supportive and Caregiver Services of the Administration of Community Living (ACL) explains in his presentation for NAPA[12] that the strategy is a "driver for legislative and policy change" (61). It aims to support all caregivers, regardless of age, where they live and the types of care they provide. It is "a vision and road map for meaningful change, a framework for all types of family caregiving and situations and experiences" (61). It also seeks to include caregivers in underserved communities. In her assessment of the *RAISE Act*, Kenway, who was her dying mother's caregiver, praises the effort (62). However, she observes that the 2021 initial report to Congress recommends decreasing the negative impact on the finances of family caregivers; and the proposed solution to this specific problem is to make paid care cheaper. However, Kenway deems the solution problematic because it appears as if family caregivers will no longer be providing care (62, p.220). If this is yet another example of erasing caregivers' contributions, I am also concerned that making care cheaper risks further devaluing this type of work.

The American Public Health Association (APHA) has also weighed in on the increased occurrence of ADRDs and the need to develop strategies to cope. In the 2020 policy statement, *Strengthening the Dementia Care Workforce: A Public Health Priority*, the APHA recognizes that persons living with ADRD, their caregivers as well as society bear the health and social and economic burdens related to the shortcoming in the public health and long-term care systems (46). The APHA emphasizes the need for a dementia-capable workforce as the shift from institutional care to home and community care calls for a workforce trained in dementia care. This is vital to ensure that the care needs of persons living with ADRD are met. According to the policy statement, this would lower the cost the health care costs.

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[10] Olivari and McGuire work for the Centers for Disease Control and Prevention, which is part of the Department of Health and Human Services. French works for the Alzheimer's Association. I mention the affiliations to highlight the close collaboration between government and an association to fight a disease.

[11] In the American context, the Alzheimer's Association has also put forward a proposal to consider ADRD as of a public health approach (57).

[12] The Secretary of the Department of Health and Human Services established Administration for Community Living (ACL) in 2012. The "ACL advocates across the federal government for older adults, people with disabilities, and families and caregivers" (60).

A greater number of skilled care workers would certainly lessen some of the burden of caregiving for families. The APHA explicitly recognizes that dementia care is complex especially as the disease progresses (46), which implies that eventually the care required may be too much for family caregivers. For the APHA, a competent workforce would not only alleviate the need for family care, but it would also ensure that the care provided is adequate. The APHA statement further emphasizes the importance of knowledge sharing for persons with ADRD and their families so that they can make informed decisions. Significantly, the policy statement refers to the gendered aspect of caregiving: it calls for caregiver support as caregivers, very often women, face discrimination and negative impacts on their mental and physical health (46). It is one of the few documents that explicitly addresses gender.

Canadian initiatives

Canada has not developed as many policies, strategies or recommendations relating to caregiving for persons living with ADRD as the USA; however, many Canadian initiatives have similar perspectives on caregivers. In 2019, the Public Health Agency of Canada (PHAC) put forward a strategy to address dementia entitled *A Dementia Strategy for Canada: Together We Aspire*, consisting of five pillars: 1) collaboration between governments, researchers and persons living with dementia; 2) research and innovation; 3) surveillance and data; 4) knowledge mobilization for care providers and the wider public; and 5) training a competent workforce.

In 2019, the PHAC commissioned a panel of experts to produce a report, *Improving the Quality of Life and Care of Persons Living with Dementia and their Caregivers* (CAHS report). The report underscores the importance of recognizing the rights of persons living with ADRD, but it also urges the explicit acknowledgement of the fact that caregiver needs are not the same as the needs of those living with ADRD (64). If this is a welcomed addition, the focus is disappointingly narrow as it targets supporting caregivers in their role as caregivers, e.g., by encouraging work-life balance, increasing knowledge dissemination concerning best practices for caregivers (64, s.5). The CAHS report states that a focus on person-centred care is essential: “the quality of life of persons living with dementia and their caregivers can be improved across all stages of the condition through a complex combination of person-centred, high quality health and social care” (64, s.4.3). Although a patient-centred focus indicates a strong attention to the needs of the persons living with ADRD, these needs can/should very often include family caregivers as part of that focus. Nevertheless, there is the risk of failing to take into consideration and address the specific needs of caregivers, especially as the report does not explicitly take into consideration the gendered dimension of caregiving.

In addition to the CAHS report, the PHAC has funded several initiatives, one of which is the Dementia Community Investment program that funds community-based projects. This program “supports community-based projects that …[embrace] the wellbeing of people living with dementia and family and/or friend caregivers, increase knowledge about dementia and its risks factors, and undertake research to evaluate the effectiveness of project interventions” (65). Successful projects include one that considers the wellbeing of individuals living with ADRD and their caregivers in Inuit communities (65). The Native Women’s Association of Canada received financing for *Supporting a Circle of Care*, a toolkit aimed at Indigenous caregivers of persons living with ADRD (64). Another project focuses on supporting family caregivers of persons living with ADRD in long-term care through a web based social support intervention (65). As these projects illustrate, the initiatives target meeting the needs of specific communities as defined by the communities themselves.

In the 2022 follow-up to the 2019 dementia strategy, the PHAC highlights some of its investments in the report *Together We Achieve* (66). In his opening letter, the honorable Jean-Yves Duclos, federal Minister of Health, explains, “the Dementia Community Investment has to date supported 21 community-based projects designed to improve the wellbeing of people living with dementia and caregivers and to increase knowledge about the dementia risk factors” (66, p.vii). The report affirms its objectives to foster “culturally appropriate and culturally safe [tools] for diverse populations” (66, p.70). In particular, it devotes a section to Indigenous populations and explicitly acknowledges that “... a lack of access to health care in remote, rural and isolated communities and a lack of cultural safety in the health care system may create barriers to equitable and culturally appropriate care” (66, p.61). The report concludes on a hopeful note, stating that increased research funding announced in the 2022 budget “will further efforts on brain health, improved treatments, and support for dementia caregivers.” (66, p.70). If the report emphasizes the importance of culturally safe and appropriate care, it maintains a strong medicalized focus. Caregivers, although mentioned, are not the object of specific recommendations save to say that the guidance they receive must be culturally appropriate.

The Canadian Public Health Association’s mission is to “enhance the health of all people and communities in Canada, particularly those who are structurally disadvantaged, and to contribute to a healthier and more equitable world” (67). In a 2016 post on its website, *Caregiver burden takes a toll on mental health*, the association acknowledges that caregivers are essential to the Canadian health care system as “they care for individuals at home who would otherwise need professional interventions.” The document concludes: that “…as long as the need for informal care exists, the needs of the voluntary caregiver must also be addressed” (68). Aside from recommending awareness of caregiver needs, no further initiative has been undertaken.

From narrow to broad: Moving forward

The American Road Map and the Canadian strategy *Together We Aspire* have much in common. They both support more research; they understand the need for a competent workforce trained in dementia care; and they emphasize educating caregivers as well as the greater population about ADRDs. One of the prime motivators for these initiatives is the recognition that ADRDs have an impact on population health and will have consequences for the health care system. Notably, both the American and Canadian public health responses take into account the consequences of the rise in ADRD and the increasing demand for caregiving over an extended period of time. Nevertheless, the American and Canadian initiatives are focused primarily on meeting the care needs of persons living with ADRD. Even if there is a broad acknowledgment that caregivers play a central role in providing essential care and in promoting the wellbeing of the person living with ADRD, the consequences of caregiving on the health of caregivers are not explicitly addressed. Rather the need for supportive services is framed as a way to sustain caregivers in their caregiving role. As is the case for most initiatives, with the exception of the APHA statement (46), gender is noticeably absent.

The Road Map and *Together We Aspire* focus on research and disease prevention. Knowledge strategies are directed at supporting informed decision-making concerning care provision. These are the goals of a narrow version of public health. However, other Canadian and American initiatives might not easily fit a narrow perspective of public health. I turn to these next.

The *RAISE Act* explicitly addresses caregiver need. It might be concluded that this plan could be integrated into a broad public health approach. Although promising, the act focused on initiatives that target individuals. To explain, the supportive programs, such as respite care, are implemented to mitigate the impact of the activities of caregiving and address the needs of individual caregivers. The services are provided on a case-by-case basis. As discussed previously, this is similar to the medical approach described by Wikler and Brock (52). In addition, there is no explicit recognition of the possible impact of age, poverty or education; yet, these factors can decrease caregivers' ability to provide care and to cope. The APHA statement goes a step further because it underscores the importance of the interaction between paid and family caregivers. This signals a recognition of caregivers as care partners, which is also in the *RAISE Act* and in the CAHS report. This acknowledgment is essential, but there needs to be an additional initiative, that is, to recognize that some caregivers may be more vulnerable than others.

The Dementia Community Investment program is designed to take into consideration the different locations or cultures of those living with ADRD and their caregivers. It is grounded in the recognition that not all populations have the same needs, nor do they have the same approach to caregiving. Although these initiatives are vital, they are allocated as singular funding opportunities. And communities must apply for these grants, thus requiring marginalized communities to mobilize significant resources to write proposals that will obtain financing. This is a piecemeal approach: absent is the blanket recognition of the socioeconomic impacts on caregivers. To illustrate my point, I discuss two key issues. The first is the knowledge mobilization plan that is part of the many initiatives and the other concerns caregiving and gender equity.

The knowledge required to care for persons living with ADRD is a central aspect of most proposals. Shaji and Reddy (3) found that caregivers in India were unaware of the behavioural and cognitive changes due to ADRD as most of them tended to think the changes in behaviour were part of the natural aging process. This is certainly not unique to India. As Queluz et al. found in their scoping review, support for caregivers included sharing information about the disease such as the stages of dementia and the prognosis (16). Other topics mentioned pertained to self-care and relationship management (16). There are many facets to the information needed by caregivers, ranging from an awareness of the symptoms and expression of the particular dementia to knowing how to provide adequate care and to access available services. The caregiver's expertise, or lack of it, will have a direct impact on their ability to manage.

Knowledge mobilization initiatives, such as those funded by the Dementia Community Investment program, target culturally safe and appropriate knowledge transmission. It might be surmised that such initiatives are indicative of a broader public health agenda. However, this conclusion is misleading – the shared information is unidirectional. To explain: the knowledge transmitted is from the experts to the caregivers. It does not allow space for the local knowledge of caregivers to emerge, which means that local practices are subordinated to a scientific discourse. Importantly, it erases the many ways to perceive caregiving as well as the location of caregiving within a family or group. In their editorial on aging and families, Keating and de Jong insist on the importance of families for aging adults and the need to understand the diversity of ways family provide care (69). There is little space for this to take place within the initiatives I examined. Ultimately, the type of knowledge transmission that is encouraged in the Canadian initiatives and strategies is one that is coherent with the goal of disease prevention and management. These are the goals of a narrow understanding of public health.

Gender is an aspect of ADRDs that cannot be ignored. First, women are more likely to develop Alzheimer's and, second, women are the ones who will provide care, both paid and unpaid (70,71). The website of the American Alzheimer's Association states that female caregivers provide 2.5 times more care than male caregivers. In addition, "[m]ore than three in five unpaid Alzheimer's caregivers are women" and "more than one-third of dementia caregivers are daughters" (70). Similarly, in Canada, "women do the majority of unpaid caregiving" (72, p.23). If caregiving is a risk factor for negative health outcomes, then women are more at risk. This aspect of health equity eludes a narrow public health perspective.

A broad version of public health can address and redress the negative health outcomes that many women face because of their caregiving. This will involve many areas of policy, from home care to health care. A greater number of trained paid caregivers, as the APHA recommends, could help women in caregiving roles cope. I would also add that better working conditions and salaries would increase the number as well as the retention of care workers. These are small steps that require a broad understanding of public health.

Finally, I call attention to an example of a regional strategy directed at dementia that enlarges the scope of public health. The Geriatric Health Systems Research Group developed a regional dementia strategy for Southwestern Ontario, Canada. The group explicitly recognizes that regional strategies are crucial as each region may have a unique set of issues. However, this does not imply that there should not be attention given to system wide services. In the study, respondents – persons living with dementia, their care partners, health care administrators and policy makers – all indicated the need for improving system-wide quality (73).[13] As the authors explain, there are different levels of dementia strategies serving distinct purposes. For example, initiatives at the national level focus on education and research, whereas regional strategies develop local programming and target service delivery (73). I would add that questions of gender equity could be addressed by national polices while local polices could be directed at communities allowing for local practices to emerge.

CONCLUSION

In the USA it is estimated that unpaid caregivers can spend more than 60 hours a week providing care (56). According to a compilation of data from Statistics Canada, Eales, Kim and East report that Canadians who care for someone with dementia will spend 1.5 more time performing caregiving tasks than other caregivers (74). There is an explicit acknowledgement, in the literature, if not in actual policies, that individuals will sacrifice their career and their health to provide adequate care (75-77). In Canada, there are various provincial policies to support family caregivers, such as home-care and respite care, but, as studies have shown, the services are usually insufficient (53,78). The person living with ADRD may enter residential care at a later stage of the disease, but before that time, many hours of caregiving will have taken place in the home.

In this paper, I explained why I agree with Shaji and Reddy's proposal (3) to include caregiving for persons living with ADRD as a matter of public health. To support their recommendation, I showed that caregiving for persons living with ADRD is a social determinant of health. If current policies and initiatives focus on caregiver support, then caregiving should explicitly be part of a broad public health agenda. Caregiving is a risk to the physical and mental health of caregivers and this risk varies according to the caregiver's socioeconomic status. Crucially, women are more often the caregivers of persons living with ADRD. The implication is that women face an increased risk to their health. Because of the ways in which caregiving is linked to other determinants of health, caregiving challenges the narrow definition of public health. My discussion of caregiving in the case of persons living with ADRD adds support to the call for a broader public health agenda that tackles questions relating to migrant health.

I focused on caregiving for persons living with ADRD because of the initiatives put forward by the USA and Canada to address ADRD as a question of public health in addition to the clear evidence linking caregiving and negative health outcomes. The American Road Map and the Canadian Strategy are examples of laudable efforts to bring ADRD into the public health arena. However, even with such bold initiatives, the health outcomes of the caregivers of individuals living with ADRD remain marginal. Nonetheless, there are promising initiatives such as the regional strategy developed by the Geriatric Health Systems Research Group (73). It signals the possibility of a broad public health approach to caregiving: a mix of system wide policies, such as federal policies addressing gender and caregiving, in addition to more local priorities such as those supporting alternative models of caregiving. This is certainly achievable in the Canadian context.

I limited my argument to a specific type of caregiving. It is certainly possible to argue for a broader array of caregiving services; however, not all types of caregiving will have an impact on caregivers' health outcomes, and this requires assessing each type of caregiving. Moreover, even if the type of caregiving has health consequences for caregivers, it may involve a different set of policies. For example, caregiving in the case of children with physical and cognitive impairments would likely involve public health, respite care as well as education policies. As I stated earlier, my argument builds on Talley and Crews' important proposal, which I argue, implies recognizing that public health must embrace a larger agenda. This agenda would not only consider health related questions that pertain to individuals located in a specific place and time, but it would also embrace the subject of public health as one of populations extending over space and time, as Wikler and Brock (52) proposed in the case of bioethics. A focus on *population* as opposed to *public* makes clear that the subject of public health must move beyond borders and beyond generations if it is to address current social and demographic transformations.

The Covid-19 pandemic has made the needs of caregivers even more pressing as illustrated by various international studies calling for caregiver support during this time (79,80). As reported by Wang et al., "[t]he international dementia experts and Alzheimer's Disease International,10 recommend support for people living with dementia and their carers is needed urgently worldwide. In addition to physical protection from virus infection, mental health and psychosocial support should be delivered" (81, p.1191). If the conditions of care changed during the pandemic, they will likely return to a near pre-pandemic state. However, the need for caregiver support will not vanish.

The inclusion of family caregiving of persons living with ADRD under a broad public health framework that addresses gender inequities through polices and incentivizes all individuals to become involved in care work is a small step toward the greater social and political recognition of the importance of care. It stresses how, in the words of Rogers, the political dimensions of public health are inescapable (82).

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[13] Increasingly in the literature, the term 'care partner' is used instead of care receiver. The change is to emphasize that the persons who receive care are not passive recipients of care. Although I agree that those receiving care are too often painted as passive, I retain the use of 'caregiver' as it is the term used in policies and because my discussion pertains to the care that is provided by family and to emphasize that this care is work.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Causes for Conscientious Objection in Medical Aid in Dying: A Scoping Review

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Résumé
À la lumière de la législation actuelle sur l'aide médicale à mourir (AMM; aussi appelée euthanasie et suicide assisté) dans différents pays du monde, certains arguments ont été consacrés au droit à l'objection de conscience pour les professionnels de la santé dans ces pratiques spécifiques. Les objectifs de cette étude exploratoire sont de fournir une vue d'ensemble des motivations et des causes qui se cachent derrière l'objection de conscience identifiée par la littérature précédente selon les expériences des professionnels et de vérifier si ces motivations correspondent aux débats théoriques sur l'objection de conscience. Comme le montrent les résultats, il existe une dissonance entre les motivations incluses dans la définition traditionnelle et courante de l'objection de conscience utilisée dans les cadre théoriques et spéculatifs et les facteurs réels que les études empiriques relèvent comme motivations déclarées pour s'opposer à l'AMM. Par conséquent, soit nous envisageons de nouveaux facteurs à inclure dans les causes de la "conscience", soit nous acceptons qu'il existe des motivations qui ne sont pas réellement applicables à l'objection de conscience et qui devraient être traitées par d'autres moyens. L'objection de conscience à l'AMM étant multiforme, il peut y avoir différents types de motivations qui agissent en même temps. Il est donc pertinent de rééquilibrer les considérations théoriques et empiriques pour bien comprendre la complexité du phénomène et ainsi donner des pistes sur la meilleure façon de traiter l'objection de conscience.

Mots-clés
objection de conscience, euthanasie, suicide assisté, aide médicale à mourir, causes

Abstract
In the light of current legislation on Medical Aid in Dying (MAiD; also known as euthanasia and assisted suicide) in different countries worldwide, there have been some arguments devoted to the right to conscientious objection for healthcare professionals in these specific practices. The goals of this scoping review are to provide an overview of the motivations and causes that lie behind conscientious objection identified by previous literature according to professionals' experiences and to verify if these motives match with theoretical debates on conscientious objection. As the results show, there is a dissonance between the motivations included in the traditional and mainstream definition of conscientious objection used in theoretical and speculative frameworks and the actual factors that empirical studies note as reported motivations to object to MAiD. Hence, either we consider new factors to include as causes of "conscience", or we accept that there are motivations that are not actually applicable to conscientious objection and should be addressed by other means. As conscientious objection to MAiD is multifaceted, there can be different kinds of motivations acting at the same time. It is thus pertinent to rebalance theoretical and empirical considerations to fully understand the complexity of the phenomenon and so provide insights on how to best deal with conscientious objection.

Keywords
conscientious objection, euthanasia, assisted suicide, medical aid in dying, causes

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INTRODUCTION

Dealing with the end of life is difficult for patients and healthcare professionals alike (1,2). Thus, integrating procedures like Medical Assistance in Dying (MAiD) into usual professional practice is still a theoretical and a practical challenge in many countries, probably because it has been experienced qualitatively differently than clinical procedures (3). In such a scenario, conscientious objection (CO) appears as a mechanism for resolving ethical conflicts and respecting healthcare professionals' moral convictions in liberal democratic societies. Practitioners may find themselves in a dilemma between their own beliefs regarding life and death and the patient's will to end their life by asking for MAiD. Since the 1990s, following legislation of this practice in certain jurisdictions, the provision of assistance in dying has been introduced as a part of the aims of the clinical practice (4-6). However, there is a tradition that persists significantly in healthcare training and practice in which the preservation of life is an absolute value; hence, practices such as euthanasia or assisted suicide are considered outside the scope of professional duties, or even contrary to them (7-9). In addition to this professional *ethos*, professionals may also hold deep personal convictions that make it difficult for them to assist a person to die without feeling that their own moral integrity is damaged and/or that there is some kind of a loss of identity (10-14).

Moral motivations to justify CO have mainly relied on references to this deep-seated sphere of beliefs (10-23). However, along with this type of argument, authors have noted a myriad of other problems linked to practical difficulties or psychological impact,

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that also seem to be at stake and can lead to CO (12-14). For this reason, it is essential to have a broader view on the issue. This article, therefore, aims to summarise and increase our knowledge about the causes that lead healthcare professionals to claim CO when facing MAiD (or euthanasia and assisted suicide). As this is a fairly recent and underdeveloped area of study, the proposed scoping review will provide a synthesis of the available evidence on CO by healthcare professionals to guide both clinical practice and ethical reflection in the context of MAiD, and so contribute to discussions regarding which motivations can be really considered "*of conscience*".

MATERIALS AND METHODS

While there were few reviews on topics related to the motivations for CO in clinical practice areas such as abortion, organ donation or end of life (24-28), or to professionals' perspectives on MAiD (29), we decided to conduct a scoping review that particularly addressed motivations for CO to MAiD both from a theoretical and empirical literature in countries with positive legislation when the data of the articles was collected. This scoping review has followed the recommended five-step framework for scoping reviews (30-33). The research questions were the following:

1. What are the causes for CO identified in the literature on MAiD (euthanasia and assisted suicide), according to professionals' experiences?
2. Do these motives match the theoretical frameworks and arguments regarding CO?
3. Are there factors involved in a decision to object to a MAiD other than motivations of conscience?

Search Strategy and Selection Process

We carried out our search using the PubMed, Scopus, PsycInfo, WOS, Embase, and LILACS databases, until October 24, 2022. The search strategy was initially developed in PubMed and then adapted to the other databases after considering different crossed words and possible synonyms and finding no significant differences (Table 1). Studies fulfilling the criteria shown in Table 2 were eligible. Following the removal of duplicates, four members of the review team, in pairs, screened all studies by title and abstract, and papers were cross-checked by the other pair. Full-text articles were obtained for full review, following the same division in the review team, based on our inclusion and exclusion criteria. In case of disagreement, the final decision was made by two data screeners and a third party.

Table 1. Search Strategy

PubMed	("conscientious refusal to treat"[Text Word] OR "conscientious object*"[Text Word] OR "refusal to participate"[Text Word] OR "refusal to treat"[Text Word] OR "conscientious refusal"[Text Word]) AND ("euthanasia"[Text Word] OR "assisted suicide*"[Text Word] OR "mercy killing*"[Text Word] OR "assisted dying"[Text Word] OR "aid in dying"[Text Word] OR "assisted death"[Text Word] OR "medical assistance in dying"[Text Word] OR "right to die"[Text Word])) AND (humans[Filter])
PsycInfo	noft(euthanasia OR "assisted suicide*" OR "mercy killing*" OR "assisted dying" OR "aid in dying" OR "assisted death" OR "medical assistance in dying" OR MAID OR "right to die") AND noft("conscientious refusal to treat" OR "conscientious object*" OR "refusal to participate" OR "refusal to treat" OR "clause of conscience" OR "conscientious refusal") Limits applied
Scopus	(TITLE-ABS-KEY (euthanasia OR "assisted suicide*" OR "mercy killing*" OR "assisted dying" OR "aid in dying" OR "assisted death" OR "medical assistance in dying" OR maid OR "right to die") AND TITLE-ABS-KEY ("conscientious refusal to treat" OR "conscientious object*" OR "refusal to participate" OR "refusal to treat" OR "clause of conscience" OR "conscientious refusal")) AND (LIMIT-TO (DOCTYPE , "ar") OR LIMIT-TO (DOCTYPE , "re"))
Embase	('euthanasia'/exp OR euthanasia OR 'assisted suicide*' OR 'mercy killing*' OR 'assisted dying'/exp OR 'assisted dying' OR 'aid in dying' OR 'assisted death' OR 'medical assistance in dying'/exp OR 'medical assistance in dying' OR maid OR 'right to die'/exp OR 'right to die') AND ('conscientious refusal to treat'/exp OR 'conscientious refusal to treat' OR 'conscientious object*' OR 'refusal to participate'/exp OR 'refusal to participate' OR 'refusal to treat'/exp OR 'refusal to treat' OR 'clause of conscience' OR 'conscientious refusal') AND [embase]/lim AND [humans]/lim
WOS	euthanasia OR "assisted suicide*" OR "mercy killing*" OR "assisted dying" OR "aid in dying" OR "assisted death" OR "medical assistance in dying" OR MAID OR "right to die" (Topic) and "conscientious refusal to treat" OR "conscientious object*" OR "refusal to participate" OR "refusal to treat" OR "clause of conscience" OR "conscientious refusal" (Topic) and Article or Anticipated Access or Review Article (Types of Documents)
LILACS	Euthanasia AND Objection

Table 2. Inclusion/Exclusion Criteria

Inclusion criteria	
Types of publication	Studies with quantitative methodology, mixed methodology, qualitative, interventions, narrative reviews, scoping reviews, systematic reviews
Subject or domain being studied	Articles focused on or with mention of CO in euthanasia and assisted suicide
Language	English, Spanish, French, Catalan, Italian
Participant/population	Healthcare professionals: physicians, nurses
Country of study	In empirical articles, works about countries where MAiD is legal
Intervention	Any intervention related to our conditions
Date	In empirical articles, works published and accepted after the approval of MAiD legislation of the country until Oct 24, 2022. Date limitation for articles centred on theoretical aspects of CO, until Oct 24, 2022.
Exclusion criteria	
Type of publication	Editorials and letters to editor, books, and theses, not accepted for publication preprints, conferences, and abstracts
Subject or domain being studied	Articles that do not include or do not mention causes or motives for CO in MAiD. Articles focused only on a theoretical framework that do not include reported or potential causes for CO
Language	Other than English, Spanish, French, Catalan, or Italian
Participants/population	Other healthcare professionals apart from physicians and nurses; and animals
Intervention	No exclusion criteria
Date	Articles prior to the legalisation of MAiD in the relevant country

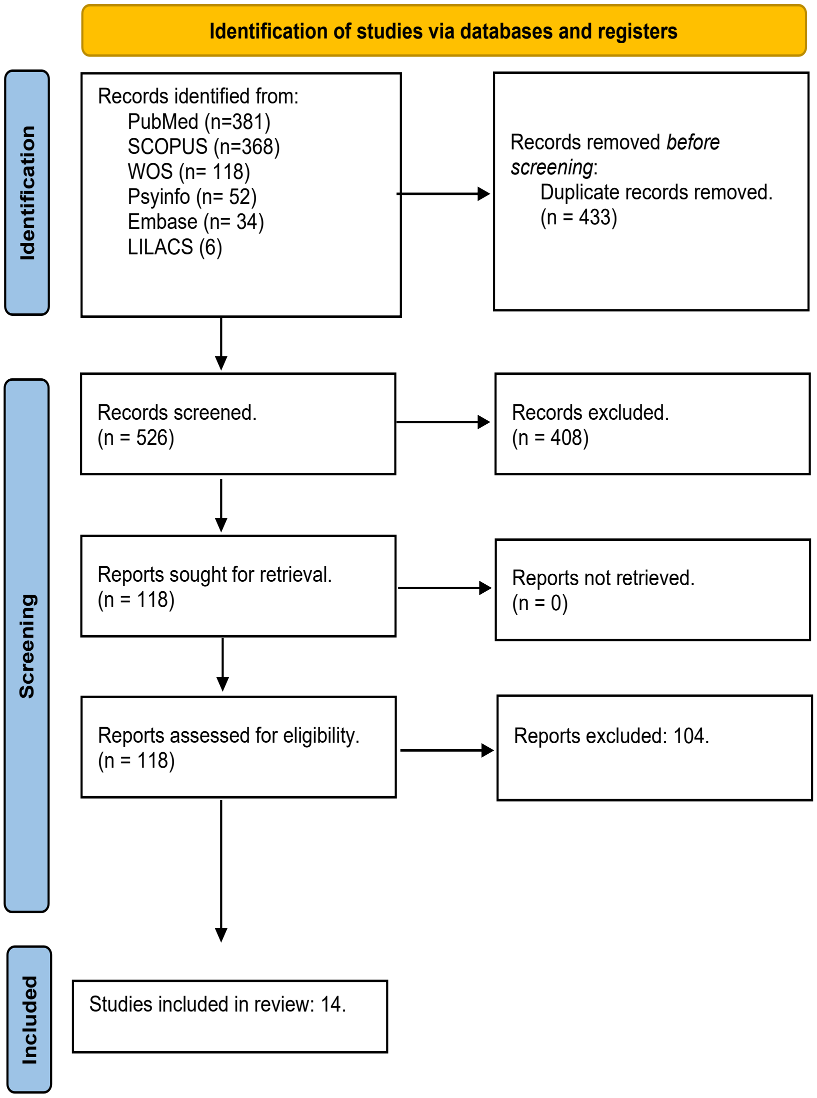
Data Extraction and Data Synthesis

Data extraction was undertaken by the four members of the review team using a template previously designed by consensus. We created a table gathering the main characteristics and results of the studies to collect information from the data extraction. The areas were: “Definition of CO”, “type of professionals”, “motivations for CO”, “CO to which part of the process”, “other causes to reject participation in a MAiD”, “general perception of CO”, “recommendations about how to deal with OC in MAiD”. Finally, we developed a narrative synthesis of the most relevant findings.

RESULTS

After screening by title and abstract, of the 526 articles identified after duplicate removal, 118 were included for full-text review, and fourteen met the criteria for the extraction of relevant information (Figure 1).

Figure 1. Scoping Review Flow Diagram



Following the PRISMA 2020 approach proposed by Page et al. (34)

Of fourteen selected articles published between 1998 and October 24, 2022, eight were qualitative studies (1-3,35-39), four original articles (40-43), there was one quantitative study (44), and one narrative review (45). Organised by country, there were ten articles from Canada; two from the region of Victoria, in Australia; one from the Netherlands; and one from other countries (See Table 3).

Table 3. Selected Articles Published Between 1998 and 2022

Article	Year	Country	Methodology	Key findings
(1)	2018	Canada	Qualitative, phenomenological research. Semi-structured interviews with eight nurses in Ontario.	CO in MAiD is a critical issue for Canadian nurses. Ethics education, awareness, and respect for nurses are needed to support nurses to address their issues of conscience in professional practice.
(2)	2021	Australia	Qualitative research. Semi-structured interviews with 17 health professionals in Victoria with a self-identified CO to voluntary-assisted dying.	The broad protection offered by the 2017 Voluntary Assisted Dying Act encourages a range of behaviours from conscientious objectors, due to the minimal obligations imposed. To assist conscientious objectors, more policy, institutional guidance, and education are needed explicitly addressing how to effectively manage CO. Such guidance is imperative to ensuring that moral integrity is preserved and that they are exercising their CO appropriately.

(3)	2020	Canada	Qualitative research. In-depth interviews with 7 Quebec physicians engaged with end-of-life care.	The major themes of MAiD in relation to aggressive treatment, CO and uneven distribution of work emerge. MAiD was experienced and thought of as qualitatively different to other end of life procedures. Findings expose a complexity and contentiousness within the practice, which remains under researched and underreported, indicating avenues for further research.
(35)	1998	Netherlands	Qualitative research. Semi-structured, in-depth interviews with 20 nurses employed in a Dutch hospital.	To make clear the role of nurses in euthanasia, the issue was split into four phases: observation of a request for euthanasia; decision making; carrying out of the request; and after-care. This article is a brief report on the most important results regarding these four phases. Special attention was paid to nurses who have CO.
(36)	2019	Canada	Exploratory qualitative study. Semi-structured interviews with 22 physicians who refuse MAiD.	The reason most often cited for CO is not based on moral or religious grounds, but on motives related to emotional burden and fear of psychological repercussions after participating in MAiD. All participants expressed more than one concern (between 2 and 7).
(37)	2019	Canada	Qualitative research. Semi-structured interviews with 20 Quebec physicians who did not integrate MAiD into their medical practice.	This paper explores the reasons for opposition to or ambivalence towards MAiD. The secular reasons given by participants were grouped into four main categories: 1) the ends of medicine and professional identity, 2) the philosophy of palliative medicine and resource allocation in palliative care, 3) benevolent paternalism, the “good death”, and the interests of future selves, 4) the risk of a slippery slope and the protection of vulnerable people.
(38)	2021	Canada	Exploratory qualitative study. Semi-structured interviews with 5 patients, 11 family members, and 14 healthcare providers.	Patients, families, and healthcare providers highlighted access and delivery concerns regarding program sustainability, care pathway ambiguity, lack of support for care choices, institutional conscientious objection, navigating care in institutions with a CO, and post-death documentation. Healthcare professionals were uncertain about professional roles and responsibilities.
(39)	2021	Australia	Qualitative, phenomenological research. Semi-structured interviews with 17 health professionals in Victoria, in any medical discipline and career stage, who self-identified as having a CO to voluntary-assisted dying.	This paper aims to understand how CO operates in the context of voluntary-assisted dying. Participants identified multiple motivations, which can be broadly categorised as: concerns for oneself; concerns for patients; concerns about the current Victorian legislation; and concerns for the medical profession. Participants’ moral commitments included personal, professional, and political commitments. In some cases, CO was specific to Victoria’s current legislation rather than voluntary-assisted dying more broadly. Findings suggest CO motivations extend beyond those traditionally cited and thus a need to better understand and manage CO in the healthcare context.
(40)	2016	Canada	Theoretical. Expert commentary with a legal approach.	The Supreme Court of Canada unanimously ruled in Carter v. Canada (2015) that the Canadian Charter of Rights and Freedoms protects the right of every competent, consenting adult suffering from a grievous and irremediable medical condition to choose death, assisted by a physician. It is considered that CO is not legally guaranteed for physicians, prioritising patients’ right to MAiD.
(41)	2016	Canada	Theoretical. Philosophical approach (Deontological ethics and the Doctrine of Double Effect).	Under Canadian law, a religious or conscientious objector has conflicting duties, i.e., a duty to respect the “right to life” and a duty to respect the tenets of their religious or conscientious beliefs. Discussion of religious or CO to MAiD have not explicitly considered competing duties of conscientious objectors. They have focused on the existence of CO but ignored the normative question of whether the duty to respect one’s conscience or religion supersedes the duty to respect the patient’s right to life.
(42)	2017	Canada	Theoretical	Canadian policy makers have proposed requiring all physicians to provide an effective referral for MAiD upon the patient’s request. It is argued that forcing physicians to refer their patient to a colleague willing to cause the patient’s death will seriously compromise moral integrity of CO physicians and undermine quality of care.
(43)	2020	Canada	Theoretical	Refusal by practitioners should be tolerated where it could be accommodated in practice groups without burdening willing providers or adversely affecting patient access. Regarding institutions, the cost to vulnerable patients of MAiD being delayed or denied is much greater and the burdens of conscience to institutions. Since it cannot be accommodated without impairing both patient access and well-being, refusal by publicly funded healthcare institutions to offer MAiD must be completely disallowed.

(44)	2020	Canada	Quantitative research. Cross-sectional survey of members of the Canadian Spine Society (CSS).	Most members of the CSS supported both the right of patients to participate in MAiD and the right of physicians to provide this service if they so choose, while still respecting the principle of CO. Yet, only a small minority were willing to be actively involved in MAiD.
(45)	2021	Different countries	Theoretical. Integrative review of 39 articles from different countries, that included a definition of CO and at least one criterion justifying its acceptability, or not, in the Western context of care.	CO and its criteria of acceptability are articulated in relation to four poles. Two of these, care and professional competence, underpin the very definition of CO. The other two poles, collective and individual, convey the values and powers involved in healthcare CO. The interaction between these four poles illustrates the criteria of acceptability or non-acceptability of CO. This model allows a dynamic view of CO and tries to be adaptable to various types and contexts of care, beyond MAiD.

Definitions of Conscientious Objection in Medical Aid in Dying

Conscientious objection was not specifically defined in all the articles analysed. In those in which it appears (1,36,43,44), CO is mostly referred to as: 1) a healthcare professional's right to refuse to participate in procedures considered incompatible with their conscience, values, or beliefs (1,36,43); 2) a care provider's right to non-participation in MAiD as a legal practice (44). The use of 'right' in both kinds of definitions may be regarded either in a binding sense – the right to CO as a prerogative explicitly recognised from a legal point of view – or in a non-binding sense, that is, the moral rather than legal right to CO. In those articles where it is not specifically defined, CO is usually understood as a moral right not to offer MAiD or not to participate in practices perceived as incompatible with core values or as inappropriate, in spite of the fact that these are legally established (35,37,40-42,45). The concepts used in these articles are freedom of conscience, act of conscience, conscience claims, conscience rights, and conscientious and religious objection.

A frequent argument found to justify CO is the commitment to personal convictions, values, and beliefs (36,44). However, the terminology to support the refusal of some healthcare practices is wide-ranging: ethical beliefs, moral integrity, moral norms, moral intuitions, moral reasons, moral grounds, moral right, moral gravitas, moral injury (37,42,44) or moral distress (43). Healthcare professionals could also invoke their commitment to religious beliefs, moral grounds, or religious objections (43). Therefore, reflections about the issue mention both secular and religious convictions (2).

Depending on the country's legal framework (Canada, Australia [Victoria], and the Netherlands), CO has been regulated and implemented in different ways. The papers based on empirical methodology analysed here have registered some divergences between the theoretical definition of CO and its actual application in the MAiD processes (1,3,36,37). For instance, some motivations are different from the idea of protection of moral integrity and beliefs, a relevant aspect of the topic that will be developed in the next section of this paper.

Arguments for Conscientious Objection to Medical Aid in Dying

The studies analysed show that arguments for CO cannot be generally classified according to one single category (36,39), but rather to several that may interact with each other. For the sake of clarity, we have organised these into four categories: 1) CO grounded on religious/secular variables; 2) CO specifically related to the goals of medicine and the expected conduct of healthcare professionals; 3) CO linked to the possible moral distress of physicians and nurses who are asked to provide euthanasia or assisted suicide; 4) CO linked to contextual factors, where reasons such as disinformation or bureaucratic obstacles might be crucial.

First, according to the religious/secular distinction, three articles in our study use it as a category to classify motivations (36,37,39); two articles use it to refer to religious institutions appealing to CO (39,43); and one article mentions the relation between CO and a Christian philosophy of life (35). Moreover, in most of the theoretical articles, when CO is analysed from a normative perspective, 'religious' is used as tantamount to 'conscience' – i.e., 'freedom of conscience and religion' (40,41,43). Nevertheless, all things considered, most of the reasons for CO adduced in the empirical literature fall into the category of 'secular', understood as not tied to an explicit religious motivation; in other words, religious reasons are seldom cited for CO (39). Sumner, for example, states that the distinction between religious and secular should not be considered as relevant for CO: "The fact that moral convictions are religiously based does not make them deeper or more central to a person's self-identity than convictions held without benefit of the divine, nor does it make them more costly to abandon or betray." (43, p.10) Therefore, the following motivations presented in this scoping review will be considered as secular.

Second, regarding the ideas related to the goals of medicine, several articles mention some motivations for CO based on what the ethical core of the medical profession should be. According to the authors of these articles, MAiD is incompatible with medicine's intrinsic core values (i.e., non-maleficence, protecting life, health promotion, etc.) and this is one of the main reasons reported for CO (35-39,42). In this regard, the literature defends the existence of some alternative practices to MAiD – e.g., palliative care – that are more suitable for the goals of healthcare professions (1,2,35-39,43).

Third, there is a concern for the moral distress or emotional burden that performing euthanasia might cause for healthcare practitioners (1,3,35,39,43). Several causes can be attributed to this moral distress. For instance, if we understand that the connection to moral integrity is a key factor in moral distress (46), the fear of a supposed slippery slope (i.e., the lowering of ethical standards over time) is one of the main reported concerns that leads to ambivalence about or rejection of MAiD among professionals (3,37,39). Other concerns like the fear of legal repercussions (36) or the emotional consequences of performing euthanasia (3) have also been mentioned as triggers of moral distress.

Fourth, some reasons mentioned as motivations for CO are actually more related to the procedure and context than to the moral or ideological core of euthanasia and assisted suicide. For instance, according to the literature, some of the reasons that may determine attitudes towards MAiD are the lack of time to properly consider a patient's request (2), legal insecurity, fear of social stigma, high administrative workload (36), and lack of competence (38). The institutional context can also exert a decisive influence on health professionals, even if they would personally not feel uncomfortable with the performance of MAiD. This is the case of so-called 'institutional objection', which is mentioned in several articles (2,36,38,41).

Practices related to Medical Aid in Dying that are targets of Conscientious Objection

Discussions about the kind of practices that one may object to vary among the articles. There seems to be a different approach to the topic depending on if the CO refers to the whole practice (a *categorical* CO) or if it only concerns a concrete stage of the process (conversation about euthanasia as an option, patient transference, prescription, or administration), in which case it can be considered as a *partial* CO.

Among categorical conscientious objectors, some refuse even the option to give information about MAiD to their patients (35). They feel that, by providing a referral, they would be complicit in the patients' death, and this would compromise their moral integrity (1,2,40,42,44). In extreme cases, professionals not only object to providing MAiD but also actively persuade their patients to withdraw their request. These professionals are categorised as dissuasive non-referrers (2).

Apart from categorical conscientious objectors, we also find reference to professionals who refuse to participate in MAiD but are willing to discuss the procedure with a colleague or to refer their patient to an alternative provider for MAiD (38). In doing that, they feel that their moral objection against participating in a practice of which they disapprove is compatible with the patient's right to request euthanasia or physician-assisted suicide (2). There is still another position that relies on casuistry: those conscientious objectors who would perform a MAiD under strict conditions, in exceptional situations based on a decision case-by-case, and after a deep reflection (2).

What about nurses who object? Empirical studies show that they defend their right to CO as healthcare professionals. Nevertheless, they also experience a kind of contradiction when they object insofar as they believe that CO is contrary to the nursing duty to participate in patients' caring tasks (35). To add another layer of complexity to the situation, they admit that it would be hard to take care of the patient the day before euthanasia administration because they could not support the patient's decision or could not share their point of view freely (35). In this sense, nurses find it difficult to inform their patients about their moral standpoint, fearing that patients may not understand their reasons to object.

In general terms, the literature has noted the difficulty of proving the sincerity of the refusal to get involved in dying requests (36,45,39). As a widespread rule, it has been established that care providers could object to a practice, but not to the request of a specific patient (40). They must maintain professional standards (1) and make sure patients can access healthcare services no matter the circumstances (42).

Degrees of Conscientious Objection recognition

Mostly, the sources analysed consider that CO is acceptable and worth protecting so that professionals are not sanctioned for their refusal to participate in the procedure. However, at the same time, it is suggested that this right should have some limits and conditions. This is specifically true from a 'patients-centred' perspective and the guarantees of access by public healthcare systems. Therefore, we find different degrees of recognition regarding CO in the MAiD context.

On the one hand, CO is considered deeply legitimate in healthcare practice because authors perceive that MAiD falls out of the scope of standard medical competencies and can thus be seen as a special duty (35,45). Furthermore, some professionals have significant concerns about the compatibility of MAiD with good medical and nursing care (35,42). The background idea of this position is that MAiD causes harm (40) and, for that reason, medical ethics may be at issue during the whole process (42). Hence, CO is considered a mechanism to preserve healthcare professionals' moral integrity and avoid moral damage (2,36). These two dimensions – moral integrity and moral damage – are sometimes linked to professionals' religious reasons and their view of euthanasia as a morally wrong practice (37).

On the other hand, some of the articles argue for a balance between CO and patients' autonomy and their right to access specific services (2,41), including MAiD (43). For instance, according to Canadian legislation protecting equitable access to care, patients should not be discriminated against and, consequently, healthcare professionals have a duty towards those patients that require medical services (40,45). In this sense, Brown et al. (38) note that CO recognition may imply a break of the social contract between healthcare professionals and patients as the right of healthcare providers to object may collide with the patients' right to access MAiD. As a solution, some articles defend the view that healthcare professionals should be prepared to perform the MAiD practice in case it is requested (35,45), regardless of their CO. Attaran (40) appeals to the obligation to follow the law, that is, to provide MAiD. He argues that physicians should adapt themselves to social demands, especially in publicly funded healthcare systems.

From a legal point of view, countries where MAiD is a legal practice have either recognised the possibility for healthcare professionals to not participate in the process (43), as is the case in the Netherlands, or regulated CO as an individual right that should be respected, as is the case in Spain. However, some articles seem to find the right to CO at risk when confronted with the right to MAiD. According to this perspective, there are not enough safeguards for professionals who stand for CO (38,43) nor enough legislative provisions for a robust respect of CO (39,41,42). Additionally, it is worth highlighting that there are healthcare professionals, both for and against performing MAID, who feel that they are under pressure or stigmatised by their peers, clinical leaders, institutions, and society when seen as acting contrary to mainstream views about euthanasia and assisted suicide (1,39,45).

Proposals to improve Conscientious Objection Practice in Medical Aid in Dying

A number of the articles analysed the offer of different proposals to improve the situation related to CO in the institutional, professional, and personal realms. Measures presented were in three main areas: 1) definitions of CO and the division of tasks by professions, 2) concrete processes to object, and 3) repercussions for conscientious objectors.

First, on the institutional/legal level, there is a need to improve the framework for CO in MAiD. That includes, firstly, the need to define or clarify the current definitions that inform the role of the different professions involved in MAiD, and secondly, the need to underpin the non-religious reasons or reasons not directly related to conscience behind CO. As a pragmatic measure, Caux et al. (45) propose the creation of a model list of CO acceptability, as well as some sort of adaptive CO depending on the geographical area (rural/urban) and its possible impact on professionals' lives and collective values. On the personal/professional levels, promoting self-reflection and education in moral competencies would be important to identify possible frictions and ethical tensions among professionals as well as to better manage ethical dilemmas (45). Professionals need to have enough time to think about MAiD so they can decide whether to participate (36). Even more importantly, institutions should give better emotional support to professionals (36) and be attentive to their needs as these could be a source of emotional distress (38). As there might be stressors that guide the professionals' decision not to participate in a MAiD, Brown et al. (38) suggest reconciliation as a process that harmonises endogenous factors (previous experiences, comfort with death, conceptualization of duty, end-of-life care approaches, spiritual beliefs, and self-accountability) with current practices.

Second, it is urgent to clarify and evaluate the processes by which a CO may be declared (1). If professionals decide to object after reflecting on their practices and beliefs, there are some points to consider. Institutions should "identify how the facility and staffing logistics are managed concerning MAID, and how, when, and to whom objection will be communicated to ensure the continuation of safe care" (38, p.1796). Some authors agree on the importance of communication of a CO to the rest of the team and their patients. This has two aims. On the one hand, having frank and open conversations with patients could allow for more space to appreciate patients' motivations for requests (1) and open the discourse (38). On the other hand, it is required to assure collectively that MAID is available to any patient who asks for and qualifies for this service (45). There is consensus in the literature that referral pathways should be implemented (38,41). Every time that a professional declares a CO, there should be an easy transfer to another colleague to facilitate MAiD access without neglecting professionals' moral integrity. One way to solve this issue is to accept multiple MAiD access pathways, including physician- and patient-initiated referrals (38). Nevertheless, this measure would not work if there were not enough professionals who agreed to perform MAiD (41). Moreover, as a public medical service guaranteed by law, public awareness of CO should be a priority. That includes informing the population about the possibility of CO in their medical centres (45). Christie et al. (41) go further and suggest requiring a justification of the CO motives, even though there is a freedom to object.

Third, some authors who take a pro-CO position are concerned with the impact on professionals who object and recommend an improvement of institutional support to professionals who declare a CO as well as their destigmatisation (1,38). These measures could help conscientious objectors to voice their positions and feel more respected.

DISCUSSION

After presenting all the findings of the current scoping review and confronting these with similar recently published studies (47), we confirmed that there are still very few articles exploring in-depth the possible causes for CO to MAiD, or the theoretical assumptions and empirical factors that are involved or contribute to their understanding. Thus, there is a clear need for further research on the topic.

If we consider for a moment the theoretical approaches to the topic made by some of the authors, it seems that motivations for CO to MAiD are usually taken for granted, leading them to the synonymous use of language such as "freedom of conscience (and religion)", "protection of moral integrity", or "protection from moral distress" as grounds to claim CO (cf. 1,38,39,43). In a similar vein, most of the articles analysed defend the right to CO as if it was crystal clear that, in cases of a rights confrontation, the right to CO would be at risk and the right of patients to receive MAiD would prevail. This was a surprising finding, since CO has frequently been protected and guaranteed over and above the social rights of citizens to benefit from a service, as has been widely reported in the case of abortion (48). Our findings show that there still exists an important gap between the theoretical and the empirical literature about CO to MAiD. Theoretical discourses keep using the common and traditional definition and motives for CO (that is, protection of freedom of conscience and moral integrity) as the main reason for healthcare professionals, but without questioning whether these match with the findings of empirical studies. At the same time, the assumed claim that CO is at risk when confronted with the right to MAiD is not backed up by robust empirical data.

Results reveal that CO to MAiD is a multidimensional phenomenon, but this is not included in the theoretical discussion. Although the literature analysed explores one or another dimension of CO to MAiD, there are no comprehensive reviews of the intersection between these different motivations. To make this clear, consider the following example. Some have considered CO as a legal mechanism to guarantee the exceptionality of not obeying the law – the right to MAiD – due to conscience conflicts (39,43). Others have understood this as an ethical and deontological resource when values and beliefs collide with the morally controversial practice (35,42). These values and beliefs can come from a personal source, not necessarily religious, and they can also be part of a core professional *ethos* (36,37,39). There are others who consider contextual factors as the key to CO. These factors include group pressure, institutional mandates, bureaucratic load, ignorance, fear, and stigma (2,36,38), as well as the circumstances (i.e., in the case where the patient is unknown to the healthcare professional or vice versa) and the timing of the MAiD process (i.e., administration, information, or patient's referral).

Regarding institutional CO, it is relevant to consider potential pressures exerted on healthcare professionals when facing euthanasia in institutions where there is a specific mission and values. Insofar as some of these institutions are religiously affiliated (42), religion may play not only an individual role – as mentioned above – but also a collective one. It can be a political catalyst for institutional objection to euthanasia and, thus, affect the controversies on CO.

Among the articles reviewed, there was no proposal to establish a systematic categorisation of the motivations behind CO to MAiD based on their different nature. More recent articles have, however, made attempts in this direction (47). It is not possible to fully comprehend CO to MAiD if the legal, ethical and deontological, psychological, religious, and contextual factors are not all considered together as elements that can both individually and combined trigger a CO. Furthermore, the political and social dimensions should be considered and made crucial considerations in future research. As a public health policy and law, MAiD is under the influence of political parties and citizens' opinions and can be ideologically instrumentalised in the political arena. That, too, has an impact on public, professional, and personal support for or refusal of MAiD, and can easily polarise the decision whether to object. Although it is true that not all the dimensions have to appear at the same time in any given healthcare professional, all should be considered at some point when analysing and theorising about CO. Given this complexity, there is a need for a mixed methodological approach that combines theoretical and empirical research to better understand the nature and interaction of all the factors at play.

As reported above, theoretical approaches to CO focus much more on the religious motivations than empirical work would seem to justify. The latter includes a larger list of secular motives, with religious reasons being one of the many possible causes for CO. The difference between religious and secular causes for CO to MAiD (36,37,39) reveal the moral weight given to each of these motives in the discussion, which, in turn, may have an important impact on their ethical and legal recognition, and on the standpoint for the philosophical debate.

Traditionally, conscience and religion have been understood as interwoven entities since 'conscience' constitutes the core of the individual, at least in the Western-Christian tradition (48). Further, religions have historically articulated issues about the nature and meaning of life, so their influence on public conceptions and individual consciousness have been well studied, especially regarding life and death issues (cf. 50-52). The consideration of religious beliefs and commitments of faith as inalienable has qualified them for special protection that have not always been granted to secular moral sources (53). However, regarding CO to MAiD, secular moral sources should be considered equally to religious sources, since their non-religious justification does not necessarily make them easier to abandon or betray. In fact, the empirical studies examined show that this difference of moral weight has to be reviewed; and the repercussions of this argument include the possible need to reformulate the very same notion of CO.

One of the main problems neglected in the articles under review is the difficulty of establishing which values and beliefs should be considered *of conscience*, and, therefore, worthy of special protection (e.g., becoming an exception on the enforcement of the MAiD law). It was noted above that deeply held moral convictions, with a high individual significance, have been considered as deserving protection under CO. However, are professional values also part of care providers' conscience? Should they be? Some authors in the general bioethics literature, outside the scope of the articles reviewed, propose different answers to these questions. On the one hand, Savulescu and Schuklenk (22), for example, argue that healthcare professionals – specifically, physicians – must be willing to provide all those procedures that are legal, beneficial, required by patients, and that are part of a fair healthcare system. Thus, the values of conscience of healthcare professionals should be put aside to avoid unjustified moral impositions on patients. On the other hand, more traditional bioethics scholars, such as Pellegrino (11), defend the view that personal and professional values are intertwined; healthcare providers cannot renounce their personal beliefs without eroding their moral integrity and losing their identity, so they should not be required to do so.

There are other motives that deserve special attention. Can moral distress and psychological impact be reasons to appeal to CO? What about contextual factors such as the workload associated both with bureaucracy and providing the actual professional intervention? It might seem that they fall outside the standard definition of CO – i.e., understood as a 'conflict with one's core values or beliefs' – and they are also outside what can be considered the professional's *ethos*. However, they are actually some of the reported causes for healthcare professionals to claim CO, according to the empirical articles in our scoping review. If we consider that these motivations exceed the definition of conscience and, thus, cannot be used as a right to CO, then we have to face another question: What status and name should we give to this kind of refusal from healthcare professionals to provide MAiD? If they are no longer protected by the right to CO, should they have the right to refuse? It is not implausible to assume that some healthcare professionals who are not actually against MAiD may use CO to avoid dealing with other problems with which they might be confronted. For example, when 1) there is no institutional support for healthcare professionals to perform MAiD and also accomplish their other daily tasks, especially in systems that are already overloaded, or 2) when performing MAiD can lead to being judged or stigmatised (particularly in small communities), or can even put a professional's job at risk (if none of the others team members want MAiD to be performed in the unit), is there a right to refuse to take part in a medical practice that it is not based on conscience?

In the case of such a non-conscience-based refusal, we would question the fundamentals of the assumptions that sustain the current right to CO to contribute to reconciling theory and praxis in MAiD. It is unknown if professionals are understanding conscience in the traditional way, but there seems to be a dissonance between words and acts. Definitions remain abstract and lacking interpretation, nor have there been no explicit efforts to identify which cases could be part of conscience motivations and which could not. But it is also clear that determining the sincerity of this immeasurable *content of conscience* – which is frequently considered an essential part of individuals' privacy, intimacy, and identity – will be extremely difficult.

Among the papers analysed, there are vanishingly few authors who dare to propose the need for conscientious objectors to make some kind of public justification of their personal reasons for CO to MAiD (cf. 14,23). These authors usually base their arguments on the need to reconcile the protection of conscience with patients' autonomy and rights. While there is a large and established literature in philosophy on CO and religious exemptions (54,55) to reconcile the two rights, there is need for a deep philosophical investigation to fully understand the different options to include/exclude the secular dimensions of and the multifactorial, hybrid motives for the notion of conscience and, thus, CO. One of the possible options is to rethink the moral debate not in terms of competing rights (healthcare professionals' rights to CO versus patients' right to MAiD) of rational, independent beings, but in terms of relations and responsibilities to others. This approach would include the social, cultural, and political influence on moral decisions.

Instead of using a theoretical-juridical model of morality – i.e., a compact, propositionally codifiable, impersonally fixed action guiding code within an agent or a compact set of universal law-like propositions (56) – we could use an expressive-collaborative model of morality. This model is context-dependent, relational, and analyses actual practices of responsibility through empirical research. It also critically reflects on whether there is any need to modify the previous moral assumptions because they can change over time. In this theoretical framework, we could consider a relational concept of conscience, rather than the standard liberal one. In that sense, conscience should be understood non-dogmatically, but as something that is sensitive to connections between personal and professional moral dimensions, and open to critical (self-)reflection (14,57). A relational perspective might be useful to avoid thinking about conscience in a categorical, fixed, individualistic way (like much of the theoretical literature reviewed, which follows the theoretical-juridical model). In the same vein, a relational approach could contribute to carefully analysis of deeply held beliefs related to notions of life and death, considering not only one's own values, but also responsibilities towards others. Lastly, such a relational framework could be helpful in distinguishing those motivations related to problems that are susceptible to mitigation through different measures, such as emotional support, institutional strategies, and education (i.e., fears of the emotional impact of practising MAiD, lack of legal and clinical knowledge, group pressure, workload, etc.) that act as determinants to current CO but might be addressed by other means. In so doing, it would be possible to give an adequate answer to why there is a gap between theoretical and empirical literature, and to reframe the controversial problems that countries with current MAiD legislation are facing, as well as the derived issues that CO could imply for both healthcare professionals and patients.

LIMITATIONS

The results and discussion contained in the present scoping review are promising and ambitious. Nevertheless, some limitations must be considered. Most of the articles analysed were based on a qualitative methodology (1-3,35-39). Qualitative research is, in the context of CO for MAiD, very useful for capturing the richness of healthcare professionals' discourses, but it has a geographical (articles are mostly from Canada) and sample limitation (small number of participants in each research). Therefore, it would be useful to widen the spectrum of qualitative studies to other countries where MAiD is legal, as well as encouraging more regional and international/comparative quantitative research on health professional CO for MAiD.

CONCLUSION

Conscientious objection is traditionally defined as a healthcare professional's prerogative to safeguard their conscience when they feel it is threatened by the requirement of performing a legal practice, as is the case with euthanasia and assisted suicide (or abortion). But in such situations, the patient's rights might be constrained or even outweighed, since the professional's moral integrity could be at stake. In the light of current legislation on MAiD (euthanasia and assisted suicide) in different countries, there have been some arguments devoted to the right to CO for healthcare professionals in these specific practices. As the results of our systematic review show, there is a dissonance between the traditional definition of CO that is used in theoretical and speculative discussions and the factors reported in empirical studies as motivations to object to MAiD. CO to MAiD arises from a variety of different motivations, in a spectrum that includes personal and moral beliefs (whether secular or religious), conceptions of the goals of the profession (not harming, protecting life, etc.), as well as other practical reasons such as lack of training, social pressures, legal insecurity or workload. Some of these causes seem not to belong to the concept of 'conscience'. However, from the perspective of the theoretical articles, the concept of 'conscience' is sometimes used as a monolithic idea that cannot be questioned and can turn into a hodgepodge that mixes values and beliefs with other causes that eventually might undermine the original meaning and purpose of CO. Hence, we should either consider new causes among the general concept of 'conscience' or accept that there are motivations to use CO that are not actually applicable to CO and that should be addressed by other means. Our review of the literature showed that CO in MAiD is multifaceted, and there can be different kinds of motivations acting at the same time. There is thus a need to rebalance theory and practice to fully understand the complexity of the phenomenon and offer better insights on how to deal with CO. This mixed approach, we argue, is compatible with a relational framework that enables a better reflection about one's own conscience and the impact that CO to MAiD may have on professionals' and patients' end-of-life rights and decisions.

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None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Questioning the Ethics of Assisted Dying for the Mentally Ill

Patrick Craine[a]

Résumé
Depuis que le Canada a légalisé l'aide médicale à mourir (AMM) en 2016, il est devenu l'un des régimes les plus permissifs au monde en matière d'euthanasie et de suicide assisté. Le nombre de décès a augmenté rapidement et les catégories d'admissibilité continuent de s'élargir. Le pays est sur le point, à partir de mars 2024, d'autoriser l'AMM pour les personnes dont la seule condition sous-jacente est la maladie mentale, ce qui a suscité un débat considérable. Les défenseurs de l'AMM pour les maladies mentales considèrent souvent qu'il s'agit d'une question d'égalité d'accès, mais cette extension implique des complexités considérables que l'on ne retrouve pas dans d'autres cas. Cet article examine l'AMM psychiatrique dans le contexte canadien, en s'attaquant directement aux arguments les plus pertinents des défenseurs de cette pratique. Il affirme qu'indépendamment de tout engagement préalable vis-à-vis de l'admissibilité de l'AMM en soi, il existe une nécessité éthique et juridique évidente de s'opposer à l'extension de l'AMM pour des raisons de maladie mentale si l'on suit les paramètres établis dans le cadre du régime canadien. Le document avance trois arguments : premièrement, les maladies mentales ne peuvent pas être considérées comme *irrémédiables*, comme l'exige la loi canadienne; deuxièmement, nous ne pouvons pas établir avec suffisamment de certitude qu'un patient atteint d'une maladie mentale a la *capacité de prendre des décisions* pour choisir l'AMM; et troisièmement, l'autorisation de l'AMM psychiatrique aura un *impact dévastateur* sur les soins et l'assistance aux malades mentaux.

Mots-clés
aide médicale à mourir, AMM, éthique, euthanasie, suicide assisté, maladie mentale, Canada

Abstract
Since Canada legalized medical assistance in dying (MAID) in 2016, it has become one of the most permissive regimes in the world for euthanasia and assisted suicide. The number of deaths has risen rapidly and the categories of eligibility continue to expand. The country is poised, as of March 2024, to allow MAID for those whose sole underlying condition is mental illness, generating considerable debate. Advocates of MAID for mental illness often frame it as a question of equal access, but this extension involves considerable complexities not present in other cases. This paper examines psychiatric MAID in the Canadian context, engaging directly with the most pertinent arguments of the practice's advocates. The paper argues that independent of any prior commitments vis-à-vis the permissibility of MAID per se, there is a clear ethical and legal necessity to oppose extending MAID on the grounds of mental illness if we follow the parameters set up within the Canadian regime. The paper advances three arguments: first, that mental illnesses cannot be deemed *irremediable*, as required by the Canadian law; second, that we cannot establish with adequate certainty that a mentally ill patient has the *decision-making capacity* to choose MAID; and third, that allowing psychiatric MAID will have a *devastating impact* on care and support of the mentally ill.

Keywords
medical assistance in dying, MAID, ethics, euthanasia, assisted suicide, mental illness, Canada

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INTRODUCTION

Since Canada legalized medical assistance in dying (MAID) in 2016, it has become one of the most permissive regimes in the world for euthanasia and assisted suicide. The number of deaths due to MAID in Canada now dwarfs other jurisdictions where the practice has been legalized for decades, such as the Netherlands and Belgium. In 2022, there were 13,241 reported MAID deaths, up 31.2% from 2021, and up 135% since 2019 (1). Amid these rising numbers, the categories of those eligible for MAID has been increasing steadily. The public has been gripped in recent years by news reports about MAID approvals for people who are driven by poverty, lack of housing, or inadequate access to health care or social services (2-4). The country's justice minister has recently upheld MAID as a charter right for "all Canadians" in response to questions about people choosing MAID for reasons of poverty (5). The influential College of Physicians in Quebec is now calling to allow MAID for sick newborns (6). While Canada's MAID regime was originally conceived as an attempt to balance the principles of patient autonomy and protection of the vulnerable, it seems that the pursuit of autonomy has become predominant. Now Canada is looking at extending its MAID regime even further. A parliamentary committee recommended in February 2023 that access be extended to mature minors, and that advance requests be allowed for patients who expect to be incapacitated (7). In June 2023, the Quebec National Assembly passed a bill approving advanced requests, extending access to those with significant and persistent disability, and requiring palliative care facilities to offer MAID (8). The biggest point of debate for many months in 2022-2023 was the pending allowance of MAID for those whose sole underlying condition is mental illness. Though initially slated to begin in March 2023, Parliament pushed it back one year to March 2024. Advocates of MAID for mental illness often frame it as a question of equal access, but this extension of MAID involves additional complexities.

My purpose in this paper is to examine MAID for those whose sole underlying condition is mental illness, as it is presented in the Canadian context, engaging directly with the most pertinent arguments of advocates of this practice. My thesis is that the

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extension of the law is wrong, legally and ethically, and specifically on the terms established by Canada's own MAID regime. I begin by considering the background, reviewing the existing implementation of MAID for mental illness in other countries, and then looking at the legislative and judicial context for MAID in Canada that has led to the impending allowance of MAID for mental illness. I then present three arguments for my thesis. First, I argue that mental illnesses cannot be deemed *irremediable*. Second, I argue that we cannot establish with adequate certainty that a mentally ill patient has the *decision-making capacity* to choose MAID. With these first two arguments, I maintain that MAID for mental illness cannot meet two of the key eligibility criteria in the Canadian law. In my third argument, I contend that allowing psychiatric MAID will have a *devastating impact* on care and support of the mentally ill, looking particularly at three areas: psychiatric care, suicide prevention, and social/structural supports. In a final section, I examine the impact of MAID access for people with disabilities since it was legalized in 2021 and argue that this experience should serve as a warning against extending access to the mentally ill.

My argument in this paper is independent of any prior commitments vis-à-vis the permissibility of MAID per se. I contend that regardless of whether one considers MAID permissible, there is a clear necessity to oppose extending MAID on the grounds of mental illness if we follow the parameters set up within the Canadian regime. This is a position held, in fact, by many experts who support the legalization of MAID and by many psychiatrists who participate in its provision.

LEGISLATIVE AND JUDICIAL BACKGROUND

International context

Before considering the situation in Canada, we need to look briefly at the international context. Euthanasia/assisted suicide for psychiatric reasons is currently permitted in the Netherlands, Belgium, Luxembourg, and Switzerland. The experiences in the Netherlands and Belgium, where it occurs most prominently, have shaped the Canadian debate. And the Netherlands, in particular, has led the way on this issue. The scholarly debate on physician-assisted death for psychiatric disorders was touched off there in the 1980s, but it has been permitted in practice since the 1990s (9). The issue came to international prominence with the Dutch Supreme Court's 1994 ruling in the Chabot case, involving a 50-year-old woman who sought to end her life after suffering depression in the wake of losing her two sons. The psychiatrist Chabot had observed her in his private guesthouse for two months and met with her to discuss her desire for death. During this time, she refused treatment, both psychotherapy and medication. Thus, Chabot chose to prescribe her a drug to assist her death. The Dutch Supreme Court found him guilty of assisted suicide, but without penalty, and they deemed that psychiatric suffering is a legitimate ground for physician-assisted death.

The Dutch Psychiatry Association published the first guidelines for physician-assisted death in cases of psychiatric suffering four years later, in 1998, and in 2002 the practice was decriminalized by the Dutch Parliament. The issue was largely dormant afterwards, as there were only a few cases reported yearly up until 2010. However, cases began to increase significantly in 2011, connected to the foundation of the End of Life Clinic, which aims to help patients whose physicians oppose physician-assisted death. The number of cases reached its peak in 2021, with 115 reported cases out of 7,666 total cases of euthanasia (1.5% of total cases) (10). In 2022, there were again 115 reported cases of psychiatric euthanasia, out of 8,720 total cases of euthanasia (1.3% of total cases) (11).

In Belgium, euthanasia has been legal for both physical and mental illness, without fatal diagnosis, since 2002. The number of reported cases also increased there over time, peaking in 2015 with 63 cases. In 2021, the most recent data available, there were 45 reported cases out of 2,700 total euthanasia cases, representing 1.7% of all cases (12).

Canadian context

When MAID was first introduced in Canada, it was framed as "end of life" care. The first bill legalizing MAID, in Quebec in 2014, was called the *Act Respecting End-of-Life Care*. The federal Bill C-14, passed in 2016, required that natural death be "reasonably foreseeable" for MAID eligibility. However, the end-of-life criterion was not part of the criteria for MAID indicated in the 2015 Supreme Court decision in *Carter v. Canada*, and many contested it on these grounds. In particular, it was challenged by Jean Truchon and Nicole Gladu, who both suffered from incurable degenerative diseases. They argued that this criterion was an undue restriction that prevented their access to MAID. The Quebec Superior Court agreed, and on September 11, 2019, the court issued its *Truchon* decision striking down the end-of-life criterion (13).

Bill C-14 did not exclude those suffering from mental illness from access to MAID; however, it required that they meet all the other eligibility criteria. So, the requirement of natural death as "reasonably foreseeable" excluded most, if not all, people who sought MAID where mental illness was the sole underlying condition. One would be eligible for MAID if there was another condition present, even if mental illness was the patient's motivating factor for choosing MAID (14).[1] However, the removal of the end-of-life criterion with the *Truchon* decision opened the door to MAID for mental disorder as the sole underlying condition. The ruling applied only in Quebec, but the Canadian government would soon respond with a new bill, C-7, applying its finding across the country.

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[1] Canada's Department of Justice explained: "People with a mental illness or physical disability would not be excluded from the regime but would … be able to access medical assistance in dying [only] if they met all of the eligibility criteria" (14).

Quebec responded by amending their legislation to remove the end-of-life criterion. However, they also specified that, for an indefinite period, the allowance of MAID would not apply in cases of mental illness as the sole underlying condition. Instead, the Quebec National Assembly set up a Select Committee to investigate extensions of MAID. To the surprise of many, when the Select Committee issued their report in December 2021, they recommended against allowing MAID for mental illness as the sole underlying condition (15).

After being granted two extensions, the Canadian Parliament passed Bill C-7, and it received Royal Assent on March 17, 2021 (16). The bill does two things: it amends the safeguards for those whose death is reasonably foreseeable, and it introduces a second path to MAID for those whose death is not reasonably foreseeable. This second path opened up MAID access to people with disabilities and would allow MAID for those whose sole underlying condition is mental illness; however, the bill explicitly specified that mental illness would not qualify as a “grievous and irremediable medical condition” until March 17, 2023. Within this timeframe, the bill required that there be an independent expert review conducted regarding protocols, guidance, and safeguards for MAID in cases of mental illness. The deadline has now been extended to March 2024 (17).

Let us examine the bill’s provisions, as they pertain to mental illness as the sole underlying condition. After Bill C-7, there are now five eligibility criteria for MAID. The person must 1) be at least 18 years of age, with decision-making capacity, 2) be eligible for government-funded health services, 3) make a voluntary request, 4) give informed consent, 5) and suffer from a “grievous and irremediable” condition. There are three criteria for a condition to be considered “grievous and irremediable”: it must i) be a serious and incurable illness, disease, or disability, ii) putting the person in an advanced state of irreversible decline in capability, and iii) causing enduring and intolerable physical or psychological suffering that cannot be alleviated under conditions the person considers acceptable. Two major points of debate have arisen about the eligibility criteria as they pertain to mental illness. First, on the notion of irremediability or incurability, which seems much more complicated to determine for mental illness than physical illness. Second, on the issue of decision-making capacity, which would seem to be at risk in cases of mental illness. We will look at both questions carefully.

The bill implements a number of safeguards depending on whether natural death is reasonably foreseeable. Two of the “track 2” safeguards in particular have raised serious concerns in how they apply to cases of MAID for mental illness. First, it implements a 90-day waiting period. Many experts have warned this is not long enough for some cases of mental illness. Some episodes of depression, for example, can last longer than this time span. Second, it requires that patients be “informed” of alternative options to relieve suffering and “seriously consider” them. Many have criticized this safeguard for not requiring MAID requesters to actually pursue alternatives before MAID is approved. Notably, both the Netherlands and Belgium require this (18,19). Critics believe this requirement has helped to keep the number of cases relatively low, and without it there is fear that the numbers could be much higher in Canada.

Since the implementation of MAID in Canada, the question of its application for mental illness as the sole underlying condition has been subject to exhaustive study and debate among scholars, in government-appointed expert panels, and parliamentary hearings. This literature will be crucial to informing the discussion that follows. To help situate us, I will mention a few of the key interventions. First, in December 2016 Canada’s Ministers of Health and Justice commissioned a study of the current state of knowledge on this issue from the Council of Canadian Academies, which formed an expert working group. In 2018, they released a 270-page report focused on presenting the available evidence and summarizing the various views. Second, in August 2021, the government established the Expert Panel on MAID and Mental Illness to satisfy Bill C-7’s requirement of independent review on the question. In May 2022, the Expert Panel released its report supporting the extension of MAID to the mentally ill. Third, in April 2021 the Canadian Parliament established a Special Joint Committee on MAID. This committee gave special attention to the question of mental illness. The committee held hearings with experts and interested parties and received many important briefs; they released their final report on February 15, 2023 supporting the government’s extension of the deadline to 2024.

ARGUMENT 1: IRREMEDIABILITY

The question of irremediability is a pillar of Canada’s MAID regime: the requester must be afflicted with a “grievous and irremediable” medical condition that is both incurable and irreversible. If mental disorder is the sole condition motivating a MAID request, then the crucial question is whether mental disorders can truly be deemed irremediable. In theory, this is one of the key objective criteria that remains after the removal of the “reasonably foreseeable” natural death requirement. However, as we shall see, the debate here hinges on whether irremediability should be interpreted as an *objective* standard or a *subjective* standard (20).[2] Notably the Quebec Select Committee listed this question of irremediability as the first reason they recommended against opening MAID for mental disorder. They found no consensus in the testimony from psychiatrists and other specialists on whether mental illness can be deemed irremediable, and so concluded this was cause for doubt and great caution (15). In what follows, I first examine the view that mental illness can never be deemed irremediable, and then the claim that they can sometimes be deemed irremediable.

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[2] Examples of articles arguing for an objective standard include (21-22), and those arguing for a subjective standard include (23-24).

Argument: Mental disorders cannot be deemed 'irremediable'

Many psychiatrists and researchers testified to both the Quebec Select Committee and the Canadian Parliament's Joint Committee that it is impossible to deem mental disorders irremediable. Irremediability is a criterion developed for somatic conditions that is shoehorned into applicability for psychiatric conditions, failing to account for the distinct nature of mental illness. In somatic conditions, the causes are empirically observable, and so are in general more easily understood, and the effects are more universally applicable across cases. This allows for easier accumulation of data upon which to base prognoses. However, in psychiatric conditions the causes are more mysterious and deeply borne, while also being more susceptible to external factors. Experiences of psychiatric illness and responses to treatment are thus highly individual, making prognoses impossible to establish.

As a result, while somatic conditions can be deemed irremediable based on evaluation of past cases, mental illnesses by nature have an *unpredictable trajectory*. Christopher Cowley explains well this distinction (25). He observes that with a somatic illness, an inability to predict its course is due to ignorance of the causal mechanisms underlying the illness. But a mental illness that arises in response to outside events is "highly individual" in nature, "based on the singularity of the individual's biography and perspective and on the singularity of the interaction with those events." As a result, the principles for therapeutic treatment are "much cruder" and there is "much greater room for mystery." As Dr. Mark Sinyor, Assistant Professor of Psychiatry at the University of Toronto, told Parliament's Special Joint Committee, a decision about euthanasia would thus necessarily be "based on hunches and guesswork that could be wildly inaccurate" (26).

This point was emphasized in an influential intervention at the federal level from a body called the Expert Advisory Group, composed of leading experts, including the former president of the Canadian Psychiatric Association. In a report to Parliament in 2020, the Expert Advisory Group argued that while many physical disorders such as advanced cancer and neurodegenerative conditions have a predictable trajectory, allowing reasonably reliable determinations of prognosis, one can never assign such a clear prognosis for mental disorders (19). Even if irremediability is possible in the case of mental illness, physicians cannot form a prognosis in advance; they can only recognize it after the fact. The Expert Advisory Group noted that the Council of Canadian Academies working group, in which many of them participated, had conducted an extensive review leading up to their 2018 report, and "could not find evidence from anywhere in the world that supports being able to identify irremediability in individual cases of mental illness" (19, p.12).[3] This position is supported by expert bodies, such as the Centre for Addiction and Mental Health (29),[4] and interested groups such as the Canadian Association for Suicide Prevention (30). In 2020, the Expert Advisory Group was also able to claim the support of the Canadian Psychiatric Association (31). However, the CPA changed their position later that year (32).[5]

The challenge of determining irremediability in the case of mental illness also comes to the fore in recent developments within the philosophy of psychiatry that underscore the profound influence of social factors on mental illness. In a 2022 article, Hane Htut Maung draws on this research to make an "externalist argument" against MAID for mental illness (34). He observes that philosophers of psychiatry are beginning to reconceptualize mental illness, moving from an *internalist model* in which it is seen primarily as a brain state or process towards an *externalist model* that, while acknowledging the internal factors, sees the illness as constitutively dependent on the person's environment. This reappraisal of social impacts on mental illness compounds the unpredictability of the progression of these illnesses and underscores that determinations of irremediability may not account for the full scope of interventions available. On the externalist model, an illness that seems irremediable may in fact be improved in a new social context.

According to the Expert Advisory Group, the fact that there are psychiatrists who think they can deem mental illness irremediable shows the grave risk of opening access. It indicates that there are patients who will be deemed irremediable by some psychiatrists, even though such a prognosis is impossible. Some of these patients would, in fact, improve if given the chance. Thus, they warn, people will be helped to die who would have gotten better (19). Further, even those who support opening access to MAID for the mentally ill have acknowledged the impossibility of determining irremediability, if the term is interpreted objectively (19). For example, Dembo, Schuklenk, and Reggler write that "it is impossible to predict response or remission with certainty," but argue that nonetheless patients with capacity should be able to decide on the question of irremediability for themselves (35, p.453).

Additionally, a case study co-written by Dembo, one of the just-mentioned authors, presents a clear instance where the psychiatric team thought the patient was irremediable, but turned out to be wrong. The study was published in 2013, before legalization of MAID. Dembo presents "Patient 1" who suffers from schizophrenia and obsessive-compulsive disorder and had been resistant to all manner of treatment for nearly ten years (36). Dembo writes that she and her team "believed that there was almost no likelihood that she could recover." However, after another treatment attempt, the patient's symptoms

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[3] In their 2022 brief (27), the Expert Advisory Group maintains that in the interim, "No evidence has emerged to change these conclusions [from the 2020 Report], but rather to reinforce them"; they cite (28). Notably, a scoping review published in October 2022, focusing on a review of relevant studies in the PubMed database regarding treatment-resistant depression, found that "current evidence does not support the view that clinicians can accurately predict long-term chances of recovery in a particular person with [treatment-resistant depression]" (20).

[4] The Centre for Addiction and Mental Health states: "At any point in time it may appear that an individual is not responding to any interventions – that their illness is currently irremediable – but it is not possible to determine with any certainty the course of this individual's illness. There is simply not enough evidence available in the mental health field at this time for clinicians to ascertain whether a particular individual has an irremediable mental illness" (29).

[5] The CPA updated its position again in 2021 (33).

disappeared, and she had been well for two years at the time Dembo was writing. According to Dembo, “At the time, we could not possibly have known” that she would recover.

The Canadian government’s Expert Panel itself also acknowledged the extreme difficulty of forming prognoses for mental illness. The panel writes: “The evolution of many mental disorders, like some other chronic conditions, is difficult to predict for a given individual. There is limited knowledge about the long-term prognosis for many conditions, and it is difficult, if not impossible, for clinicians to make accurate predictions about the future for an individual patient” (37, p.9).[6]

Counter-argument: Mental disorders can be deemed ‘irremediable’

So, it seems that there is wide agreement that the objective standard of irremediability cannot be met. But if the Expert Panel and other MAID-for-mental-illness advocates admit it is not possible to predict future outcomes in these cases, how do they argue that the irremediability criterion can apply?

They do so by adopting a different definition of incurability and irreversibility that subjectivizes the criterion, reframing it in autonomous terms. The definition the Expert Panel adopts allows a determination of irremediability to be the result of a “shared understanding” between patient and physician “on the basis of the evolution and response to past interventions” (37, p.41). They write: “In the context of MAiD [where mental disorder is the sole underlying medical condition], a grievous and irremediable medical condition exists in circumstances where a person has a longstanding condition leading to functional decline and for which they have not found relief from suffering despite an extensive history of attempts with different types of interventions and supports” (37, p.53). In their recommendations they state that “it is not possible to provide fixed rules” for determining incurability and irreversibility, leaving the decision to individual assessors “on a case-by-case basis” (37, p.55).

The option for autonomy in this definition of irremediability came out strongly in the testimony to Parliament’s Special Joint Committee. Dr. Mona Gupta, the Expert Panel chair, said in cases where we know little about an illness’s long-term evolution, “What is the degree of certainty required? … If we think about what an incurable condition is and draw a parallel with other chronic illnesses, we can say that the threshold is met once all the conventional treatments have been exhausted” (39). When asked if it is acceptable that a person could choose MAID when their condition might have improved, Gupta said: “I think the question is, who should decide whether that’s an acceptable risk? In allowing MAID in our country, we’ve said that is a choice for that individual to make that request. … I think it’s acceptable for the individual to make that decision, yes” (39). Dr. Derryck Smith, Clinical Professor Emeritus at the University of British Columbia’s Department of Psychiatry and former board member of Dying with Dignity, told the committee that irremediability comes into play “when there are no more treatments available that are ‘acceptable’ to the patient. Under law, the patient cannot be forced to take any types of treatments that are available. They must agree. If a person refuses additional treatment, I would, therefore, consider them to be irremediable” (40).

Gupta and Smith propose here that patients themselves are competent to determine the irremediability of their own illness. The risk of such a proposal is underscored by research from van Veen et al., who find that mentally ill patients’ perceptions of irremediability may in fact be influenced by symptoms of their mental illness, namely hopelessness and treatment refusal (41).

Response: Irremediability must be interpreted objectively

Given this clear lack of consensus among psychiatrists on whether mental illness is irremediable, the Quebec Select Committee was right to recommend against allowing MAID for mental illness. But it seems the disagreement hinges on a question that is more legal and philosophical than medical, namely: How is irremediability, as established in the Canadian law, to be interpreted? As an objective or subjective standard? It seems there is wide agreement that the objective standard of irremediability cannot be met. As framed in the original Quebec regime, the Carter decision, and Bill C-14, irremediability required an objective interpretation. Reinterpreting it as a subjective standard would be a fundamental change to the law, with far-reaching consequences for other vulnerable groups as well. I argue that if Canada is to go in this direction, it ought to subject this point to debate and change the language, rather than simply applying a meaning to “irremediable” that defies normal usage of the word. The prospect of declaring illnesses as “irremediable” that indeed are not irremediable in the normal use of the term is deeply problematic. We risk ipso facto declaring patients who could improve as incapable of improvement, and thus risk diminishing the hope that is so essential to recovery in mental health care.

ARGUMENT 2: DECISION-MAKING CAPACITY

My contention is that a psychiatrist cannot determine with adequate certainty that a patient with a “grievous” mental illness has the capacity to make a decision for MAID. The principle of informed consent is a pillar of modern medicine, considered central to the value of patient autonomy. Consequently, the requirement that the patient themselves make an informed request, voluntarily, is a pillar of Canada’s MAID regime. However, informed consent is impossible unless a patient possesses decision-making capacity. We can describe it as an individual’s ability to understand and appreciate the nature and consequences of the treatment decision before them (42). Canadian law presumes that all adults, including adults with mental disorders, have capacity to make medical decisions (43,44). However, capacity can be deemed lacking if there are reasonable grounds for

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[6] Additionally, a report from the Association des médecins psychiatres du Québec, which found in favour of allowing MAID for sole mental illness, acknowledges: “It is possible that a person who has recourse to MAID could have regained the desire to live at some point in the future.” They add: “Assessors will have to answer this ethical question [regarding certainty of eligibility] each and every time they evaluate a request” (38, p.28).

doubt with respect to a particular treatment decision (37). Doctors assess capacity before treatment, and where necessary will use capacity assessment tools. Affirming the decision-making capacity of the mentally ill is essential to ensuring epistemic justice in the medical system and overcoming tendencies to ableism, sanism, and paternalism (45). The mentally ill must be afforded their proper responsibility as epistemic agents in their own healthcare decisions. But it would also constitute an epistemic injustice to wrongly attribute capacity to a vulnerable patient, and thereby fail in the duty to protect them in their time of greatest need.[7]

Argument: 'Grievous' mental illness diminishes capacity for MAID decision

Assessing capacity in people with mental disorders is complex and varies greatly based on the type of illness and its severity. Many with good reason have questioned whether those overcome by a "grievous" mental health condition – the bar required for MAID – are truly in a position to possess capacity for so grave a decision as MAID. Some would eliminate MAID for mental illness on these grounds (46,47). There are two factors to highlight here.

First, it is recognized that mental disorders can result in diminished capacity. Some mental disorders such as dementia, intellectual disabilities, and sometimes schizophrenia, lead to an evident decline in patients' cognitive abilities, sometimes to the extent that they do not have the ability to understand the decision before them, or to appreciate how the disorder is influencing their thinking. Other mental disorders impair capacity because they affect the patient's emotions and moods, such as depression, anxiety disorders, and bipolar disorder. When an illness reaches a grievous stage, it can dominate the person's consciousness, altering judgment, and overcoming the normal exercise of will. As the illness progresses, the patient's personal agency is increasingly compromised. Once it has reached a "grievous stage" we can rightly ask whether decisions are made by the illness itself rather than the patient.[8] Though highly controversial and fraught with ethical, legal, and practical complexities, society has continued to recognize a need for so-called "paternalism" in some of these cases when it allows patients to be committed for psychiatric treatment against their will (49).

Second, assessing capacity is complicated by the fact that the desire for death is a symptom of many mental disorders. Even advocates of MAID for mental illness are concerned that we determine the request for MAID is not motivated by suicidality (37). Clinicians must distinguish between a desire for death that is a result of the condition, such as suicidal ideation, and a desire that emanates from an autonomous and well-considered decision (18). This is commonly acknowledged to be a very hard distinction to make. The challenge is exacerbated, perhaps to the point of insurmountability, when we consider the long-lasting and chronic nature of many mental disorders, and the profound effect that mental disorder can play in shaping one's values, potentially warping them to favour a choice for death. So even if a request for death seems purely rational and not arising from mental illness, that does not mean that the illness did not shape the underlying values that led to the request.

Counter-argument: A blanket ban is unjustified

Do these characteristics weighing against decisional capacity justify a blanket ban on MAID for mental illness? In standard practice for other treatment decisions, the mere diagnosis of a mental disorder or the presence of symptoms of such a disorder is not considered adequate to determine incapacity. Rather, the decision about capacity requires clinical assessment and must be made on a case-by-case basis (18). As Van Staden and Kruger write, "The clinical assessment of a particular patient's capacity to give informed consent in a case of mental disorder is better informed by the consideration of conditions necessary to give informed consent than by making inferences from the general features implied by a specific diagnosis" (50). Many experts, while recognizing the complexity of assessing capacity in these cases and acknowledging that some may indeed be incapable, argue that decisions about MAID for mental illness should similarly be made on a case-by-case basis.

There are two main arguments. The first is that a blanket ban would be overbroad and thus prevent MAID for a segment of requesters who in fact have capacity. This segment would thus be "sentenced" to endure their suffering unjustly, amounting to "arbitrary" discrimination on the grounds of mental illness (51). The second argument, advanced strongly by the Expert Panel, asserts that concerns about capacity, and risks of error in capacity determinations, are "equally challenging" in the case of other serious medical decisions for which there is no blanket ban, such as withdrawal of life-saving treatment (37, p.10). They write: "In other areas of practice, difficulties in assessing capacity are not resolved by refusing to permit access to the intervention to all persons or a subgroup of persons" (37, p.42). Rather, such decisions are resolved on a case-by-case basis and not provided to specific individuals who are deemed incapable of giving consent.

Response: We cannot determine capacity with adequate certainty

In response, I maintain that even if we admit, for the sake of argument, that there are in fact some "grievously" mentally ill patients capable of making a MAID decision, we cannot make a judgment of capacity in particular cases with *sufficient certainty* to justify a formal determination of capacity.

First, we must recognize the high degree of rigor required in a MAID capacity determination. The law specifies that determinations of capacity must be specific to individual treatment decisions at a specific time, and not merely based on a

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[7] As Kidd et al. note, reducing the severity of an illness, such as through wrongful depathologization, is also a form of epistemic injustice. They make this point with respect to obsessive compulsive disorder: "When we wrongly depathologize a condition, we fail to recognize its severity, since its pathological dimensions are omitted, reducing OCD to personality traits such as tidiness." (45, p.10).

[8] Philosopher and ethicist Louis Charland explores this dynamic in the case of anorexia nervosa (48).

general measure of capacity (52). Moreover, it is a widely acknowledged principle that the degree of capacity required increases along with the stakes of the decision (18). The greater the stakes, the greater the capacity required, and the greater the scrutiny necessary for determining capacity. As ethicist Scott Kim writes, “It is widely accepted that the level of abilities required — the threshold for competence — increases as the risk-to-benefit ratio increases” (53, p.34). Thus because of the high stakes of a decision for MAID, involving a choice to deliberately end one’s life, the review of a patient’s capacity to make an informed and free decision is of utmost importance.

Second, there is good reason to question whether it is even possible to meet this high degree of rigor required in assessing capacity regarding MAID for mental illness. Research on decision-making capacity is still at a nascent stage, and the question of determining decision-making capacity is in fact highly controversial for researchers and health professionals (52). They disagree about how to conduct such assessments objectively. The current standard practice is highly subjective, relying on the judgment of the individual physician, who has often received little training. Moreover, as the Council of Canadian Academies report noted, “there is conflicting evidence on the reliability of capacity assessments” (18, p.67). Some studies find high rates of disagreement between capacity assessors (54,55). Research on capacity in the context of MAID for mental disorder is minimal (9). Further, there are concerns that capacity assessments in other jurisdictions, particularly the Netherlands, lack adequate rigor (9,52).

As Charland et al. argue in a widely-cited 2016 article, the current “gold standard” for assessing decision-making capacity – the MacArthur Treatment Competence Assessment Tool (56) – is seriously deficient because of a bias towards establishing capacity on legal grounds (52). This results in an exclusive focus on cognitive abilities, failing to capture the crucial affective aspect of psychiatric disorders. Of course, the role of feelings and emotions is central in such a weighty decision as MAID, even more so when we are dealing with psychiatric disorders (52). Charland argues that the traditional tools, then, may “be seriously empirically wanting and even empirically invalid” (48). Because of the tools’ cognitive orientation, mentally ill patients can often generate false positives. But in reality, writes Charland, “patients in these circumstances cannot possibly be considered ‘competent’ or ‘capable’ to make their own treatment decisions when they are so affectively biased and ruled by their disease. As they themselves report, they have ‘lost control’ and feel powerless in relation to their disease.” Given these concerns, Charland et al. argue that our mechanisms for assessing capacity cannot bear the weight of the rigor demanded by the MAID regime (52). Their concern was echoed by the chair of the Council of Canadian Academies working group: Dr. Kwame McKenzie told CBC: “It’s not clear that we have ways of measuring peoples’ capacity to make decisions that are robust enough so that we wouldn’t make mistakes one way or the other” (57).

Is it just a matter of developing better tools? Researchers continue to propose better methods of assessing capacity (58-61). But, I maintain, no assessment will be capable of precluding the possibility of false positives. If am I right in this, then there can be no adequate assessment. In a MAID decision, the stakes are so high that we cannot accept error. MAID, of course, is an active intervention that brings about the death of the patient. In this light, we can compare it to the famous analogy of the hunter in the woods who is responsible for ensuring that his target is indeed a deer rather than a human being. If the hunter errs and shoots a human being, he remains responsible for that death despite all good intentions. Likewise, the apparent evil of unjustly consigning patients with capacity to unwanted suffering is outweighed by the risk of putting to death a vulnerable person who lacks capacity for the decision, and thus failing in our duty to protect their life.

The Expert Panel rightly insists on the need for “rigorous” capacity assessments (37). But it is clear that they fail to appreciate how high are the stakes, and the degree of rigor required, when they equate the capacity of a patient to choose MAID with the capacity for choosing removal of lifesaving treatment. The latter decision is clearly very high stakes and capacity assessment must be very rigorous. But there is a sharp distinction between MAID and withdrawal of treatment. MAID is a deliberate and intentional choice for death; the second is not.[9] The Expert Panel argument is consequentialist, dismissing the crucial distinction between an *intended* and a *foreseen* result.

I underline here the fact that the Canadian law requires that a condition be “grievous” to qualify for MAID. Thus, I do not argue in this instance that mental illness itself intrinsically renders one incapable of making a decision for MAID: we are discussing only mental illness that reaches the high bar of gravity set by the Canadian law. Refusing to legalize MAID for mental illness on these grounds is not, then, an instance of epistemic injustice, but a requirement of justice. Mental illness deemed “grievous” enough to qualify for MAID should itself be adequate to determine lack of capacity for the gravest of decisions, to deliberately end life. But even if we admit the *theoretical possibility* of capacity, I maintain that we cannot be sufficiently certain of such a judgment in a particular case to form a *determination* of capacity. This argument about capacity has rightfully not been the central concern advanced by opponents of MAID for the mentally ill, but it is nonetheless an essential consideration. While not definitive on its own, coupled with my other two arguments, it contributes to a clear and strong case against legally extending MAID to the mentally ill.

ARGUMENT 3: IMPACT ON CARE AND SUPPORT OF THE MENTALLY ILL

Allowing MAID for mental illness will, arguably, have a devastating impact on care of the mentally ill in our society, and in three important areas: psychiatric care, suicide prevention, and social and structural supports.

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[9] The Expert Advisory Group makes the same point about the distinction between MAID and withdrawal of treatment (19).

Psychiatric care

While Canadian law frames MAID as an exception to the fundamental principle against deliberately taking human life, a unique feature of the country's MAID regime has been that euthanasia and assisted suicide are classified positively as a form of *care*.[10] In a 2023 article, Trudo Lemmens explores how Canada has uniquely framed MAID as *therapy*, explaining how this has resulted in its becoming the most expansive euthanasia regime in the world (62). Framing MAID as care transforms the medical profession, as care for patients is now presented as including deliberately and intentionally bringing about their death. Extending MAID to mental illness will have the same effect on psychiatric care. It risks undermining the essential trust between patients and caregivers, which is often very fragile, and difficult to establish and maintain. In mental health care, hope for recovery is essential. But it becomes very difficult when the option of MAID is available. There is a real risk that MAID could come to be seen as the only solution to eliminate the patient's suffering. Psychiatrists report that it is difficult to care for a person who has decided on MAID; even though many treatments remain, the choice of MAID closes them off to other options.

Despite the concern for autonomy, allowing access to MAID for mental illness curtails patients' freedom by abandoning them to their disorder. A medical system that sees MAID as a form of care heaps a dreadful burden on the patient when they are at their most vulnerable. A person who does not truly desire MAID must carry the fear that they might seek it out in a dark period. When they most need the support and protection of his caregivers, the patient is abandoned and forced to be their own protector. A ban on MAID for mental illness is an important protection for this person, "freeing" him from falling into this false solution to suffering.

Suicide prevention

Canada and all Western societies recognize suicide prevention as a grave matter of public interest. This is attested in the preamble of Bill C-14, which describes suicide as a significant public health issue (63). In 2012, the Canadian Parliament passed an Act establishing a national framework for suicide prevention (64). The World Health Organization says "health-care services need to incorporate suicide prevention as a core component" (65, p.9). However, the response to suicide was complicated when MAID was legalized. Canada now recognizes an *acceptable* form of suicide that we assist and an *unacceptable* form of suicide that we seek to prevent. The challenge is thus how to distinguish between the two; and MAID for mental illness blurs this line even more. With the "reasonably foreseeable" natural death criterion, MAID was still limited to the context of people who were on the verge of death. But in considering MAID for mental illness, we are now looking at allowing MAID based on health conditions that have as their very symptoms the desire to die. In considering which suicides to assist when it comes to people with mental illness, some stress the importance of ensuring that the desire for death does not arise as a symptom of the mental health condition. However, it is not at all clear that we can reliably distinguish between mentally ill MAID requesters who are suicidal and those whose desire is well-considered and autonomous (18). The Expert Panel ultimately acknowledges that it may not be possible: "In allowing MAiD in such cases, society is making an ethical choice to enable certain people to receive MAiD on a case-by-case basis regardless of whether MAiD and suicide are considered to be distinct or not" (37, p.66.)

The logic of suicide prevention is that life is valuable, and thus suicide is not truly good for the person. Even if the person professes a desire to die, we see that desire as rooted in a disorder and thus as not being what they truly want. We must intervene to prevent them from making a bad decision and help them recover the sense of the value of life. This logic runs counter to the logic of MAID, which prioritizes autonomy and the person's own assessment of what is in their best interest. There is a justifiable concern that accepting the logic of MAID will result in it displacing the logic of suicide prevention. Deeming some suicides acceptable weakens the conviction of the need to prevent suicide, and in fact legitimizes it as an acceptable choice. This confuses the messaging we are sending to society on this important issue, setting up suicide as an accepted solution to suffering, and risking establishing it as a social norm.

Social and structural support

The mentally ill already face significant social and structural vulnerabilities. They often suffer from poverty, lack of housing, and lack of family and social support. They face significant stigma and discrimination, and access to mental health care that they need is severely lacking, with great geographical, social, and financial barriers. There is a grave risk that opening access to MAID will only exacerbate these challenges. MAID risks being seen by society as a solution to these social problems, removing the impetus to seek real solutions and offer real help. There is also an important risk of MAID being chosen as an escape from life suffering stemming from these vulnerabilities rather than from the illness itself. In the face of these problems, the call for autonomy for the mentally ill falls flat. How can we speak of autonomy to choose death, when patients are not given viable support to choose life? As psychiatrist Dr. John Maher told the Parliament's Special Joint Committee, "Death is not an acceptable substitute for good treatment, food, housing and compassion" (66).

Allowing MAID for the mentally ill also risks exacerbating discrimination against the mentally ill by sending the message that their life is not worth living. The Expert Advisory Group warns that MAID for mental illness would be the "ultimate form" of discrimination because MAID will be offered "for all sorts of life suffering, even when their mental disorder could have gotten better" (19, p.5). MAID also risks increasing the sense of being a burden on family and society, potentially plunging them further into illness. The stigma and discrimination faced by the mentally ill appears in both an avoidance of seeking treatment,

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[10] This classification of euthanasia/assisted suicide as *care* is explicit in Quebec's law, and implicit through association in the federal law.

and in the severe lack of access to treatment. Dr. Maher, who says he oversees teams that care for the 7,000 sickest mentally ill patients in Ontario, told Parliament's Special Joint Committee in May 2022 that they have 6,000 patients on their waitlist and the wait-time is up to five years. "I would like to know, have any of you had a serious illness where you've had to wait five years for treatment?" he asked the parliamentarians. "This is stigmatization entrenched in our system" (67).

Can we really consider MAID for the mentally ill while patients are struggling to even access treatment? Bill C-7 requires that MAID requesters be "informed" about treatment options, but there is no requirement that patients be given *access* to these treatments. We face the frightening prospect that MAID could be approved not only without requiring the patient to exhaust treatment options, but where the patient in fact *wanted* to pursue treatment but could not access it (57). In fact, Dr. Ellen Wiebe, a family doctor and MAID provider, told the Special Joint Committee that she would consider a five-year wait to access treatment as sufficient cause to approve MAID as irremediable (68).

MAID FOR PEOPLE WITH DISABILITIES: A WARNING WE OUGHT TO HEED

Canada's decision to open MAID access to non-terminal conditions makes it available to two major classes: people with disabilities and the mentally ill. There are important intersections between these two vulnerable groups, with each facing systemic challenges in our society associated with, respectively, ableism and sanism. Bill C-7 excluded the mentally ill from MAID for a time, but people with disabilities have had access since the bill came into force in March 2021. The experience of MAID for people with disabilities sheds important light on what MAID for the mentally ill will look like. In fact, examining this experience shows that the dangers I warn of for the mentally ill are already coming to pass for people with disabilities.

Disability scholar Heidi Janz observes that while euthanasia advocates hailed C-7 as a victory for autonomy, disability-rights advocates "mourned" the new law: "These disability-rights advocates recognized that, contrary to the claims of its champions, Bill C-7 would not advance the human rights of people with disabilities; rather it would enshrine into law the quintessential ableist stereotype that it's better to be dead than disabled" (69, p.299). Just like the mentally ill, people with disabilities systemically lack access to social determinants of health such as stable employment, adequate and affordable housing, and support services (69). In such a situation, accessibility to MAID presents people with disabilities with a "Hobson's choice," says Janz; that is, they are put in "a situation in which it seems that you can choose between different things or actions, but there is really only one thing that you can take or do." Since the passage of Bill C-7, she explains, "death by MAID is their only remaining alternative to abject poverty and/or incarceration in a long term care facility" (69, p.304).

Indeed, a mounting body of evidence suggests that people with disabilities are resorting to MAID due to a lack of access to sufficient social and structural support systems. A 2023 article on the state of Canada's MAID regime by Coelho et al. points out that Canada's data collection is inadequate because it is largely reliant on self-reporting by MAID providers, and there is little oversight. As a result, one must rely heavily on narrative accounts reported in the media to evaluate the system (70). Since Bill C-7's passage, the media has been flooded with stories of people who are choosing MAID simply because they cannot access the support they need to live with their disability. Various researchers and journalists have gathered such accounts (69-72). I list here three examples:

1. "Sophia," a 51-year-old Ontario woman with severe chemical sensitivities, opted for MAID in February 2022 when she could not secure adequate housing free from cigarette smoke and cleaners (3). In a video filmed eight days before her death, she said, "The government sees me as expendable trash, a complainer, useless and a pain in the ass."

2. "Denise," a wheelchair-bound 31-year-old woman, told media in the spring of 2022 that she received initial approval for MAID after she could not find housing that would accommodate her chronic illnesses (2). Living only on a meagre income from Ontario's Disability Support Program, she told the reporter, "I've applied for MAiD essentially...because of abject poverty." Fortunately, "Denise" ended up opting out of MAID after an outpouring of support in response to the initial report on her challenges (73).

3. Michael Fraser, a 55-year-old Toronto man who was housebound due to disability and unable to afford rent, received MAID in July 2022 (4). He said the decision was based on "a constellation of factors — intractable disease, poverty, childhood sexual trauma, mental health challenges and the option of an assisted death."

We have good reason to expect that the experience of people with disabilities will be reflected in the experience of the mentally ill. In fact, as is clear from Fraser's case, mental illness is already a major contributing factor to MAID decisions. Based on the experience of people with disabilities, disability rights groups have been sounding the alarm over the risk to the mentally ill in the lead up to the legalization of MAID for mental illness in March 2024. As a coalition of over 50 organizations wrote to Canada's justice minister in December 2022: "We know, as do you, that the existing law is not working and has not worked, and that people with disabilities have been dying by MAiD due to their life circumstances and oppression. To legalize MAiD for mental illness would pour gas on a fire that is already out of control" (74).

CONCLUSION

In this paper I have argued on three grounds against opening access to MAID where mental illness is the sole underlying condition. First, I argued that we must adopt an objective interpretation of irremediability, and that on this objective interpretation mental illness cannot be deemed irremediable, as required by the MAID eligibility criteria. Second, I argued that grievously mentally ill patients cannot be deemed with adequate certainty to have the capacity to choose MAID, and thus MAID for mental illness fails to meet a second key eligibility criterion. Third, I argued that allowing access to MAID on grounds of mental illness will have a devastating impact on care and support of the mentally ill, including psychiatric care, suicide prevention, and social/structural supports.

If Canada does move forward with this expansion of MAID to those suffering from mental illness, as it seems it will, how bad will it be? Expert bodies supporting access to MAID on the grounds of mental illness assure us that the number of cases will be low, pointing to data from the Netherlands and Belgium. Only a small number of requests for psychiatric euthanasia in these countries are approved,[11] and psychiatric euthanasia deaths represent only about 1.5% of total euthanasia deaths. The reality is that it is impossible to predict what will happen if Canada opens access to psychiatric MAID. But I suggest that we have good reason to think that Canada will have many more cases than they do in the Netherlands and Belgium.

We need to remember that when MAID was legalized in Canada in 2016, the claim was that it would not have a sweeping effect on the country's attitudes towards life and death, because the numbers would be low, only occurring in "exceptional cases." The justification here was an appeal to the experience of the Netherlands and Belgium (75). However, our experience in Canada has been radically different than predicted. The number of MAID deaths are already significantly higher than the Netherlands and Belgium and continue to grow significantly every year. Since 2019, the number of deaths has increased by 135%, from 5,631 cases to 13,241 cases. We can debate why Canada's numbers are rising so rapidly but it seems that the this is due to the manner in which Canada has set up its MAID regime. In particular, Canada has treated MAID as a form of care, helping to destigmatize and encourage MAID to be seen as integrated into a normal continuum of treatment. Moreover, Canada has adopted a highly subjectivized approach, placing a high value on autonomy versus protection of the vulnerable and respect for life (62).

The ground has, I argue, been laid for this same dynamic to play out in cases of MAID for mental illness. As MAID has been integrated into healthcare, so too will it be integrated into care for the mentally ill. And we have seen that the criteria to govern MAID for mental illness have been established in a way that emphasizes the subjective aspect, the principle of autonomy, putting a premium on the patient's own determination about what they purportedly want. I suggest that we see this subjective emphasis in two major ways. First, in the Netherlands and Belgium there is a requirement that patients pursue other treatment options before they can be given access to MAID. This requirement contributes to the high number of rejected requests. However, in Canada we have no such requirement; all that is required is that the patient be informed of other treatment options and that they have seriously considered them. So, a key requirement set up in the Netherlands and Belgium and which has led to a low number of cases is not present in Canada's system. Second, there is a strong move, even an official one, for interpreting what would ordinarily be objective criteria as subjective criteria in order to allow people to choose MAID. As we saw, there is a big push to interpret irremediability in terms of the patient's decision, along with their doctor, not to pursue other treatment options.

We must remember that this so-called autonomy is meant to be exercised by patients who have *grievous* mental health conditions, and conditions that are often closely linked with a desire for death. This is a population in highly vulnerable situations, and vulnerable precisely with respect to the decision they are expected to make autonomously. So, let us be clear: If Canada goes down this path, many vulnerable people will be given MAID at the hands of psychiatric caregivers who are sworn to protect and care for them.

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[11] Recent studies estimate that 95% of requests are rejected in the Netherlands (9).

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

Ethics of Medical Assistance in Dying for Non-Terminal Illness: A Comparison of Mental and Physical Illness in Canada and Europe

Katharine Birkness[a], Abraham Rudnick[b,c]

Résumé

L'aide médicale à mourir (AMM) devrait être légalisée au Canada à partir de mars 2024 pour les personnes dont la seule condition médicale sous-jacente est un trouble ou une maladie mentale (AMM MM-SCMS). Dans le cadre de l'élaboration de lignes directrices visant à assurer la sécurité et la cohérence de l'AMM MM-SCMS, il convient d'accorder une attention suffisante à l'interprétation de la terminologie ambiguë de la législation actuelle et de veiller à ce que ces interprétations soient fondées sur des principes éthiques acceptables.

Abstract

Medical assistance in dying (MAiD) is scheduled to be legalized in Canada as of March 2024 for individuals with mental disorder/illness as their sole underlying medical condition (MAiD MD-SUMC). As guidelines are being developed for the safe and consistent provision of MAiD MD-SUMC, sufficient consideration must be given to the interpretation of ambiguous terminology in current legislation, and to ensuring sound use of acceptable ethics principles in these interpretations.

Mots-clés

éthique, (ir)remédiabilité, aide médicale à mourir, AMM, maladie mentale, principisme

Keywords

ethics, (ir)remediability, medical assistance in dying, MAiD, mental illness, principlism

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INTRODUCTION

The choice as a medical practitioner to provide medical assistance in dying (MAiD) requires extraordinarily careful deliberation given the significance and finality of the intended outcome, i.e., the relief of intolerable suffering in life by means of the provision of care to facilitate death. There are thus criteria encoded in law that must be met for MAiD to be conducted. These legal criteria are related, but not identical, to ethical considerations such as those encoded in the Canadian Medical Association's Code of Ethics. This document endorses autonomy (respect for self-determination of persons with health challenges), beneficence (maximizing positive outcomes such as well-being of persons with health challenges), non-maleficence (minimizing negative outcomes such as harm to persons with health challenges), and justice (particularly as fairness, such as equity) (1,2). Ethics deliberation is needed in this context, as is careful analysis of legal requirements and precedent.

The legal requirements for MAiD in Canada as of May 2021 are as follows. The patient must be eighteen years or older, have (related) decision-making capacity, be eligible for publicly funded health care, make a voluntary request (for MAiD) free of external pressure, and provide informed consent (3). Once these criteria are met, the eligible individual must meet a final criterion: they must have a grievous and irremediable medical condition. This is defined as meeting all of three conditions: 1) having a serious illness, disease, or disability; 2) being in an advanced state of irreversible decline; and 3) experiencing intolerable physical or psychological suffering from this illness, disease, disability, or state of decline that cannot be alleviated under conditions the person considers acceptable (3). The decision of whether to administer MAiD as a medical practitioner is difficult as terminology like "irreversible decline", "intolerable suffering", and "acceptable conditions" must be interpreted in the unique context and circumstances of specific patients. In relation to MAiD, it is in conditions of legal uncertainty when ethical considerations come to the forefront of the decision-making process.

Uncertainty in MAiD eligibility in Canada is expected to involve new legal and ethical horizons as MAiD is extended to patients with mental disorder/illness (4) as their sole underlying medical condition (SUMC) for requesting MAiD (MAiD MD-SUMC). Introduced in March 2021, Bill C7 granted MAiD eligibility to those whose death was not reasonably foreseeable but excluded mental illness from this category until March 2023. Its introduction was then further delayed until March 2024 (5). The extension of MAiD eligibility to those with non-terminal illnesses was based on the principle of justice, i.e., that there were insufficient differences between those with non-terminal illnesses to justify their exclusion from MAiD eligibility. Through the comparison of these two groups, the courts found that they were, however, different enough to justify different MAiD eligibility tracks. Similarly, it was found that mental illness was sufficiently analogous to non-terminal physical illness to also eventually include this group in MAiD eligibility (6). At this moment, the question of whether non-terminal physical illness and mental illness are sufficiently different to justify a different set of criteria for mental illness, and what those criteria might consider, has not been answered. Numerous papers have explored theoretical similarities and differences in ethical and criteria application for MAiD between these groups (7,8). This study aims to further explore this question in a new way, that takes the comparison of these two groups beyond the theoretical to the practical, by analyzing a hypothetical example of a patient with a physical non-terminal

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illness. The ethical challenges that arise in the course of the example's analysis are extrapolated to assess whether they also apply to mental illness, and in what ways (if any) they would be inapplicable to MAiD MD-SUMC. The goal is to highlight pertinent moral considerations and related ethical challenges, and to identify issues to be considered by those involved in the development of guidelines for MAiD MD-SUMC.

The example is based on an amalgamation of clinical patient encounters primarily based on experience of the first author as a recent medical student, designed to highlight relevant ethical considerations, with key personal details changed to maintain patient confidentiality. Guidelines from the Netherlands, Belgium, and Luxembourg are also addressed when appropriate for any precedent set by these countries, where MAiD for non-terminal illnesses including mental illness has been legal since the 2000's. This paper finds that key considerations for the developers of MAiD MD-SUMC guidelines will be in defining severe mental illness, how to interpret irremediability for mental illness, and whether alternatives to MAiD to relieve suffering must not only be considered but trialled by requestors.

Such an analysis is timely in Canada, especially as MAiD MD-SUMC guidelines are expected to considerably affect Canadians suffering from mental illness. Also, Canadian guidelines related to MAiD MD-SUMC eligibility have the potential to influence how MAiD guidelines are developed worldwide as this procedure may become more widely accepted and used globally.

EXAMPLE

Brian is a 73-year-old Canadian citizen. He was diagnosed with type-2 diabetes mellitus 20 years ago. After multiple attempts at taking diabetes medications consistently, he chose not to take any medications to control his blood sugar levels because he found the daily burden of medication management too great. He was found to have capacity to decide about care for his diabetes, and he was willing to accept the known risks of having uncontrolled diabetes. Lately, he has developed diabetic sequelae including chronic kidney disease, peripheral artery disease, and neuropathy. He has developed numerous chronic non-healing ulcers on his lower legs, with infections requiring IV antibiotics in-hospital. Recently, an infected ulcer became gangrenous. Brian underwent a below-knee amputation of his left leg to prevent progression to life-threatening sepsis. Brian has since developed a severe fear of further complications from his diabetes. He developed insomnia and finds his daytime thinking preoccupied by this fear. Brian now requests MAiD. He was assessed and it was found that he has acceptable decision-making capacity related to MAiD. Alternatives were proposed, including starting medications to treat diabetes and prevent, as much as possible, its further progression; but Brian has declined these alternatives due to the continued belief that the burden of managing diabetes medications is too high for him and the belief that the utility of starting blood sugar medications would now be relatively low.

DISCUSSION

Brian clearly meets the legal criteria for MAiD decision making in Canada. He is of age, has related capacity, is eligible for publicly-funded health care, and has made a voluntary request for MAiD. He has autonomously made the decision not to take diabetic medications, based on receiving full information and reasoned deliberation. The question remains whether he meets the legal criterion of having a grievous and irremediable disease, as well as whether it is ethically sound to provide MAiD in this situation.

Brian's request for MAiD was made based on his main underlying medical condition of type-2 diabetes. While there is no agreed-upon standard for determining when a non-terminal illness becomes 'serious', or 'advanced', in Brian's case, it is arguably the sequelae of Brian's diabetes which cause it to be considered both serious and advanced. These include microvascular changes such as those resulting in peripheral artery disease and neuropathy that have led to poor wound healing and chronically infected ulcers, and consequently the loss of one leg, causing significant disruptions to his day-to-day functioning and multiple hospitalizations. Given these significant sequalae, and that much of this physiological change is not reversible, Brian's diabetes can be considered serious and in "an advanced state of irreversible decline". Thus, he meets the first and second conditions which characterize a "grievous and irremediable medical condition."

Is it possible to extend this reasoning to mental illness, and view the notions of serious, advanced, and irreversible, in a similar way to physical non-terminal illness? According to this reasoning, his disease severity was largely determined based on the pathophysiological changes the illness had wrought, which is not something that is usually testable in relation to mental illness. We are currently unable to access pathophysiological brain changes of mental illness to a sufficient degree to assess severity of mental illness, but perhaps this may one day become possible. Another way the severity of Brian's illness was assessed was based on functional limitations and hospitalizations. These are criteria that can be applied to determining the severity of mental illness, and it is a common way by which the severity of mental illness is assessed. Despite many attempts to create a standard definition of serious mental illness (SMI), or severe and persistent mental illness (SPMI), there is currently no related theoretical or operational consensus definition in psychiatry and psychology, the two main professions currently responsible for diagnostics of mental disorders. However, there are factors relevant to mental illness severity that can be considered, including diagnosis, whereupon schizophrenia spectrum disorder and major mood disorder are more likely to be considered serious than other mental disorders (recognizing that some people with these other mental disorders may have a particularly severe form). Other relevant factors include the degree of disability or functional impairment caused by the illness in various realms like activities of daily living, social, and occupational roles, duration of the illness, and the need for long-term treatment (9,10). Severity may be assessed in this way, but how can it be determined whether the person is in an "advanced state of irreversible decline"? Given that the pathophysiological trajectories of various mental illnesses are not as well-understood as those of physical illnesses, and that the recovery of functioning of individuals with mental illness is varied, one way would be to determine if the decline is in fact reversible with available treatments. Indeed, many operationalized definitions of SPMI include minimum durations of treatment that must be attempted before the illness can be viewed as persistent (10). However, requiring much if not all treatment before the provision of MAiD is ethically fraught; this issue is further discussed below.

The third condition that Brian must legally meet to be eligible for MAiD in Canada is that he have intolerable physical or psychological suffering from the disease or state of decline that cannot be alleviated under conditions that the patient considers acceptable. Psychological suffering can be difficult to conceptually grasp, let alone systemically assess. In Luxembourg's MAiD guidelines, intolerable suffering is considered largely subjective, "and depends on their personality, there [sic] pain perception threshold, their conceptions and their values" (11). While many guidelines agree that suffering is subjective, according to Dutch guidelines the suffering must also "be palpable and understandable to the physician" (12). This implies that in the Netherlands, a patient who reports intolerable suffering may be denied MAiD if that suffering cannot be understood by the physician receiving the request. This clarification is important in Canada, where assessors may be meeting the patient for the first time. This also creates a potential for bias against vulnerable patients in the Canadian context, where the absence of long-term patient knowledge may instead be replaced by prior perceptions of patient groups. For example, for a patient with low socioeconomic status requesting MAiD, their suffering may be less understandable to a more privileged Canadian physician if a long-term relationship or knowledge of circumstances or community is not present. Not requiring this understanding of suffering by the physician may increase patient autonomy as well as ameliorating concerns about social justice. However, requiring some amount of physician understanding of patient suffering allows physicians to better understand reasonable alternatives to alleviate suffering, in line with the principle of beneficence; this also aligns with epistemic justice, aiming to reduce if not eliminate unnecessary knowledge-related power disparities such as the medical knowledge differential of physicians, particularly psychiatrists in this context, over patients (13). One solution would be to create recommendations in upcoming Canadian guidelines for considerations to better understand intolerable suffering such as circumstance, community conditions, values, length of time, personal biases, or patient vulnerabilities that may lead to bias.

In Canada, it is not required in MAiD eligibility criteria that patients necessarily try alternatives to relieve their suffering, to determine whether suffering can be alleviated under acceptable circumstances (3). Returning to the case of Brian, it may be that he is overestimating the burden of having to manage daily diabetic medications. If this is so, Brian would have less to fear if he did start diabetic medications since better blood sugar control can prevent the development and progression of complications. However, it is also possible that denying MAiD to Brian because alternatives exist that, according to many others, are deemed acceptable, will prolong his suffering. It could cause further harm by denying his autonomy, risking iatrogenic harm from such medications, and increasing the amount of time he lives in fear. In Canadian law, for patients whose death is not reasonably foreseeable, to be eligible for MAiD, "you and your practitioners must have discussed reasonable and available means to relieve your suffering, and all agree that you have seriously considered those means" (4). If Brian receives all pertinent information and is able to reason in relation to it, to his condition, and to weigh the options, it is likely that this will be sufficient to say that he has given serious consideration to his options. The potential harm in this case is that there could be termination of Brian's life when there may have been methods to alleviate his suffering while alive. In this case, a question is whether there is a situation in which one has seriously considered alternatives, but despite there being an effective alternative to relieve suffering, it is acceptable that the patient still decides to choose MAiD instead? The difficulty in answering this question with certainty lies in part in the variance in weighing of consequences that different people will demonstrate in answering this question, given their differing values, life experiences and other key personal factors.

This reasoning can be extended to a person suffering from a serious mental illness such as persistent depressive disorder. Suppose that this person is requesting MAiD but has never been treated with relevant evidence-based interventions – such as psychotropic medication (e.g., antidepressant medications), psychotherapy (e.g., cognitive behavioural therapy), or neuromodulation (e.g., transcranial magnetic stimulation) – because they have decided that these alternatives are unacceptable or intolerable. Much would depend on the individual's reasoning to determine whether they have given serious consideration to the alternatives. Suppose this person has weighed the alternatives and perceives living as a worse harm than premature death. Is there a situation in which MAiD should be provided when the patient has not tried alternatives for treatment? Interestingly, in the Dutch Regional Euthanasia Review Committee's 2018 Euthanasia Code, it explicitly states that in circumstances of mental illness, "if the patient refuses a reasonable alternative, he cannot be said to be suffering with no prospect of improvement" (12). The Canadian law is sufficiently ambiguous that it could be argued that Canadian guidelines on MAiD MD-SUMC should include a proviso similar to that of the Netherlands, in which there must be a sufficient trial of standard treatments for mental illness prior to the provision of MAiD MD-SUMC to better determine irremediability. Additional provisos recommended for consideration in MD-SUMC guidelines based on this analysis include developing a standardized definition of severe/persistent mental illness and seeking consensus on whether medical practitioners must understand a patient's suffering and what considerations should factor into this understanding.

CONCLUSION

In this paper, morally ambiguous terminology in legal criteria for MAiD in Canada were interpreted based in part on a principlist approach. Guidance for the interpretation of these terms was sought through a selective review of relevant grey and white literature from Canada, the Netherlands, Belgium and Luxembourg. These interpretations were applied to a hypothetical example of a patient with a physical non-terminal illness requesting MAiD and extrapolated to assess their applicability to mental illness. Ongoing issues in applying these terms to mental illness include deciding on a consensus definition for severe mental illness/severe and persistent mental illness, defining irremediability for mental illness, and ascertaining whether trial(s) of standard evidence-based interventions will be required for MAiD eligibility where mental disorder/illness is the sole underlying medical condition. These are issues that are expected to be addressed in the forthcoming guidelines, but it may be that there are no uniform answers to these questions. If so, the development of an ad hoc or standing ethics committee to discuss challenging MAiD MD-SUMC requests and provide guidance to health care practitioners could be a solution to support ethically sound MAiD MD-SUMC services (currently it is not required for such a forum to be involved in advance of any MAiD provision in Canada). Other issues remain to be addressed in relation to MAiD MD-SUMC, such as MAiD for substance use disorder, the distinction from suicidality, the lack of sufficient accessibility to some evidence-based treatments for mental illness (e.g., psychotherapy, which is not readily available in Canada, unlike other jurisdictions such as the UK that has publicly funded psychotherapy for those in need), and social determinants of mental health (e.g., some people with mental illness who lack affordable housing and adequate income may request MAiD MD-SUMC due to such disruptive social determinants). The question of whether to pause MAiD indefinitely for an individual while these social determinants are addressed is challenging as it may be discriminatory to withhold a public service on the grounds of an individual being irrectifiably socially disadvantaged. Certainly, rectification of social determinants should first be attempted (in the limited ways in which physicians are able to do so), but if this is not feasible within a timely manner, MAiD then should be considered. These issues will ultimately have to be addressed by authorities such as provincial governments, in order to guide providers in their approach to MAiD referrals and assessments, as well as in their approach to seeking alternatives; and this should be done with input from scholars and other experts, as well as people with lived experience of mental illness, to ensure that the provision of MAiD MD-SUMC is ethically sound.

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LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

News Items About the Use of Medical Assistance in Dying Raise Concerns About the System in Canada

Sebastian Straube[a], Charl Els[b], Xiangning Fan[a]

Résumé
Plusieurs articles récents traitent de cas où l'assistance médicale à mourir semble être demandée non pas parce que la situation médicale est sans espoir en dépit d'un soutien optimal, mais plutôt parce que les soutiens qui pourraient théoriquement être disponibles sont inaccessibles dans la pratique ou, s'ils sont accessibles, sont apparemment insuffisants. Nous discutons de ces développements.

Abstract
Several recent news items discuss cases where medical assistance in dying seems to be sought not because the medical situation is beyond hope despite optimal supports, but rather because supports that could theoretically be available are inaccessible in practice or, if accessible, are apparently insufficient. We discuss these developments.

Mots-clés
aide médicale à mourir, AMM, reportages, pauvreté, circonstances socio-économiques, Canada

Keywords
medical assistance in dying, MAID, news reports, poverty, socioeconomic circumstances, Canada

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We have previously written in this journal about a woman seeking medical assistance in dying (MAID) because she was experiencing multiple chemical sensitivities and reportedly had no access to appropriate housing (1). Since then, we have read a news report that discussed several patients with disabilities considering MAID in the context of poverty (2). Another news report discussed a woman with fibromyalgia contemplating MAID, and saying she would not consider it were it not for her inability to make ends meet and that the Ontario Disability Support Program would not provide her enough money to live (3). We also note reports about yet another patient, a quadriplegic woman from Ontario, who has applied for MAID, again stating that she could not access help from the Ontario Disability Support Program in a timely fashion (4,5).

These cases are similar in that MAID seems to be sought not because the medical situation is beyond hope despite optimal supports, but rather because supports that could theoretically be available are inaccessible in practice or, if accessible, are apparently insufficient. We fear that the cases that are reported in the news may be the tip of the proverbial iceberg, as others in comparable circumstances may not be willing to be featured in the media reporting on MAID.

Even if going to the media is a cry for help, these cases raise some concerns: Firstly, they illustrate the lack of practically accessible supports for patients in need, and the extent to which poverty represents a form of coercion that interferes with truly informed consent in decisions around MAID. With more plentiful financial resources, getting help in the home or remaining more socially connected might have been possible and could have made a difference for these individuals. Secondly, the question needs to be asked whether there is scope creep in the MAID system due to the specific circumstances of how it is applied, and whether the current checks and balances to ensure that MAID is accessed for valid reasons are adequate. Now that a legal and accessible option to MAID exists, it is impossible not to know that it can be accessed, even if other – more costly – options would be more appropriate and desired by the individual seeking MAID. Thirdly, and arguably the most serious concern, is that the fact that such cases are possible at all points to a fundamental flaw with the MAID approach. The question needs to be asked whether a system that allows for such developments is suitable. One cannot help but wonder if it would not be more compassionate were the resources devoted to supporting a dignified death instead used to allow a dignified life for those most in need, who may be in pain, poor, socially isolated and at a point of desperation, but who are nonetheless still living meaningful lives. People with disabilities and the elderly would appear to be particularly at risk, and in need of advocacy.

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ÉTUDE DE CAS / CASE STUDY

Decision-making at Life's End: Sharing the Burden of Responsibility

Amanda Quinn[a], Amitabha Palmer[b], Nico Nortjé[b]

Résumé

Cette étude de cas aborde les défis de la prise de décision en fin de vie dans la pratique, en se concentrant sur l'équilibre délicat entre le paternalisme médical, la prise de décision partagée et les droits des décideurs de substitution. La famille a d'abord du mal à saisir la gravité de l'état de santé de l'être cher, mais un moment charnière lors de la réunion sur les objectifs de soins apporte une clarté soudaine. Ce cas explore la pertinence et les implications de la pratique du non-dissentiment éclairé. Cette analyse suggère que cette pratique est inappropriée à moins qu'il n'y ait des preuves irréfutables de paralysie de la décision. Des stratégies pratiques sont proposées pour faciliter l'accompagnement de la mort dans la compassion, tout en tenant compte des contraintes de l'urgence clinique.

Mots-clés

prise de décision partagée, non-dissidence éclairée, paternalisme médical, fin de vie, deuil compliqué

Abstract

This case study discusses the challenges of end-of-life decision-making in practice, focusing on the delicate balance between medical paternalism, shared decision-making, and the rights of surrogate decision makers. The family initially struggles to grasp the severity of their loved one's medical condition but a pivotal moment during the Goals of Care meeting brings sudden clarity. This case explores the appropriateness and implications of the practice of informed non-dissent; and our analysis suggests that it is inappropriate unless there is compelling evidence for decision paralysis. Practical strategies are offered that facilitate compassionate dying care within the constraints of clinical urgency.

Keywords

shared decision-making, informed non-dissent, medical paternalism, end-of-life, complicated grief

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CASE

Mr. J, a 30-year-old patient with testicular cancer – metastasized to the lungs, liver, lymph node, and bone – arrived at our tertiary cancer centre's emergency room with shortness of breath. The patient had less than 20% lung capacity at arrival and was transferred to the Intensive Care Unit (ICU), where he was intubated overnight and became non-responsive. After extensive work-up, the medical team concluded that, despite any medical interventions, Mr. J's condition was irreversible, and death imminent. Given this prognosis, the team agreed that medically appropriate treatment was restricted to palliative care and a code-status change from Full Code to Do Not Resuscitate (DNR). The family, unaware of this information, believed that aside from his underlying cancer, Mr. J suffered only from pneumonia and that through proper treatment he would make a full recovery. This asymmetry prompted apprehension among the medical team about how best to disclose the reality of Mr. J's condition to the family.

An ethics consult was held which included four family members, the attending physician, the patient's case worker, an ethicist, and a hospital chaplain. The care team met briefly prior to the family's arrival – a practice that is especially useful for difficult cases given potential risks and challenging psycho-social factors. During the pre-meeting, the medical team commented that, based on previous interactions with the family, they were in a state of denial regarding the severity of Mr. J's condition, especially given his young age and the rapid disease progression, and would likely ask for medically inappropriate treatment. For this reason, the medical team favoured taking the decision to remove life support "off the shoulders" of the family to avoid prolonging Mr. J's dying process. In the meeting with the family, the medical team described the patient's physiological state, and the family began to demonstrate understanding that Mr. J was actively dying through expressions of pre-emptive grief. As this recognition occurred, the attending physician introduced the matter of code-status, a term used only to indicate whether a patient will be resuscitated given the need (Full code), or if they abstain from resuscitation under all circumstances (DNR).

In response to this, the wife asked the medical team, "What do we do?", and the nephew asked, "How long does [Mr. J] have?". The medical team proceeded to inform the family that they should call anyone who wished to say final goodbyes and when they were ready the following day, the team would begin compassionate extubation. Appearing distressed, the wife asked the medical team, "Do I have a say in what happens?". The ethicist reassured the wife that, as the medical power of attorney (MPoA), no medical decisions would be made without her consent.

Once the meeting had ended, the attending physician approached the ethicist and shared that the weighty consequences of end-of-life medical decisions can lead to paralyzing guilt which in turn leads to poor medical decisions and outcomes. This is

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especially true when families are highly distressed. And as if to remove any doubt of her distress, the wife fainted immediately upon returning to her husband's room. The consult raised a deep ethical problem: How to support grief-stricken families who may be in decision paralysis while simultaneously avoiding the harm of prolonging a patient's dying process?

INFORMED NON-DISSENT

The attending physician was advocating for a kind of medical paternalism, a decision-making model wherein medical professionals, based on their wider breadth of knowledge and experience, make treatment decisions without necessarily informing the patient or obtaining their consent (1). Medical paternalism can be justifiable, or even obligatory, if the decision-maker lacks the ability or capacity to make decisions according to the patient's interests (2). In these cases, such as when a patient or their MPoA succumb to decision paralysis, medical teams may employ informed non-dissent (IND), in which providers unilaterally determine appropriate care, inform the surrogates of their course of actions, and then act unless directly overridden by the subjects of care (3). However, this practice is rare, as most patients and their families prefer to participate in a shared decision-making process.

In this particular case, IND was inappropriate because, although distressed, there was no compelling evidence to suggest that the wife was experiencing decision paralysis. Were the wife to flee when faced with this decision, or the family dissolve into intractable conflict, then the immediacy of Mr. J's medical condition (and the subsequent harms of resuscitation, should it be required) may have justified an appeal to IND (4); however, the family displayed no dire conflict in values during the ethics consult, nor did the wife avoid her responsibility. Moreover, through asking, "Do I have a say in what happens?", any assumption that the wife did not want to participate was undermined. Beyond this, the wife had the right to be informed of her decision-making power, a right that follows from the principle of respect for autonomy. This right is the default clinical position which should only be overridden for compelling reasons (2).

SHARED DECISION-MAKING

Beyond respect for autonomy, medical teams should also appreciate the impact that medical decision-making has on a patient's loved ones. When a patient dies in the ICU, their loved ones are at increased risk of complicated grief, post-traumatic stress disorder, and mental health issues (5,6). The burden of individual medical decisions rests heavily on the shoulders of those left behind. Shared decision-making recognizes the burden on both the family, who must live with the decision, as well as the medical team, who must administer the care (7). Mr. J's wife actively inquired about her husband's treatment, signifying her desire to be involved. A paternalistic response to her attempted participation ignores this shared burden, thus eliminating the opportunity for a shared decision-making process that would simultaneously reduce the risk of poor familial outcomes and unethical medical practice.

Rather than overriding the wife's power as the MPoA, the decision-maker should be provided with time, resources, and reassurance of the medical team's commitment to shared decision-making. Examples of such provisions include:

Table 1. Examples of provisions

Provision	Action	Discussion Guide
Time	• Allow for silence • Provide a suggested timeline based on compromise • Provide time for reflection • Offer time for farewells	"Continuing intubation prolongs your loved one's dying process. The medical team would prefer, for the patient's sake, to take the patient off the ventilator as soon as possible. However, if you need time to process this information or gather family members to say final goodbyes, then we can ensure you have enough time for this."
Resources	• Consultation with chaplaincy • Hospital psychologist/counseling resources • Offer grief pamphlets/bereavement support • Provide resources on local funeral and burial procedures/costs	"During these challenging times, we often offer resources like counseling or chaplaincy, grief pamphlets, and information on bereavement options. These resources are here to assist you, so please do not hesitate to seek them out or use them."
Commitment to shared decision-making	• Ask emotionally reflexive questions • Practice empathetic listening • Offer assistance through the process • Address questions or concerns • Provide reassurance that care will continue	"Do you have any other questions about the patient's condition?" "Is there anything we can do to assist you through the patient's dying process?" "Do you have any concerns about our suggested treatment plan/ timeline?"

The patient is inextricably linked to those they care about, meaning that the patient's well-being, in part, depends on the well-being of their loved ones. By acknowledging the vulnerability of decision-makers in environments of high acuity, it would be wise for care teams to allow families and decision-makers to contemplate their fears, anxieties, grief, hopes, and thoughts and be given what time is available. Rushing loved ones to make a decision based on medical time is not beneficial to the loved ones or the care team. It can not only lead to feelings of disrespect and overwhelm the family, but it also needlessly places the burden of decision-making solely on the care team.

While the demanding nature of the ICU often imposes constraints on the luxury of time, it is essential to hold values tight so as not to lose them in the chaos of emergency. Rushed practices and paternalism without due cause fail to acknowledge the values held dear by the patient's loved ones. Shared decision-making allows for the tightest hold, both on ethical practice and good patient outcomes. Though it is not always convenient, shared decision-making is the process by which the human element is preserved in medicine.

DISCUSSION QUESTIONS

1. How can care teams better engage families in shared decision-making, especially in cases where there is a high risk of complicated grief or deep denial?
2. As suggested in the case review, should it be the responsibility of the physician or the direct care team to inform the patient of available resources? If not, what medical professional should assume the role of bereavement-informant?
3. How can we better support physicians and care teams who work in high-stress environments when faced with moral dilemmas regarding patient care?

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TÉMOIGNAGE / PERSPECTIVE

Plagued to Death by Ableism: What the COVID-19 Pandemic and the Expansion of Eligibility for MAID Reveal About the Lethal Dangers of Medical and Systemic Ableism in Canada

Heidi Janz[a]

Résumé
Dans cet article, je m'appuie sur mes recherches et mon expérience en tant qu'éducateur et défenseur de l'éthique du handicap pour démontrer que la réponse du Canada au COVID-19 et l'élargissement de l'éligibilité à l'AMM sont des symptômes du capacitisme médicale et systémique qui afflige la société canadienne. Je conclus par une réflexion sur le danger permanent que représente pour les personnes handicapées le capacitisme eugénique déguisé en autonomie dans un Canada où le COVID-19 est peut-être en train de disparaître, mais où la contagion du capacitisme devenu mortel grâce à l'AMM continue de se répandre.

Mots-clés
capacitisme, discrimination systémique, COVID-19, aide médicale à mourir, AMM

Abstract
In this paper, I draw on my research and experience as a disability ethics educator and advocate in order to demonstrate that both Canada's COVID-19 response and its expansion of eligibility for MAID are symptoms of the medical and systemic ableism that afflicts Canadian society. I conclude with a consideration of the enduring danger that eugenic ableism disguised as autonomy poses for people with disabilities in a Canada where COVID-19 may be waning, but where the contagion of ableism turned lethal through MAID continues to spread.

Keywords
ableism, systemic discrimination, COVID-19, medical assistance in dying, MAID

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INTRODUCTION

The year 2020, and the advent of COVID-19, ushered in a time of new peril for disabled people in Canada. Government and public health officials repeated their daily mantra "We're all in this together" while at the same time creating policies and legislation which made it clear that disabled Canadians were not part of the "we." Provinces quietly developed Critical Care Triage Protocols that prohibited many disabled people from receiving critical care in the event that a surge in severe COVID-19 cases outstripped available resources, and at the national level, government pushed through an expansion of Medical Assistance in Dying (MAID) despite overwhelming opposition from major disability rights organizations, scholars, activists and the United Nations.

In this paper, I draw on my research and experience as a disability ethics educator and advocate in order to demonstrate that both Canada's COVID-19 response and its expansion of eligibility for MAID are symptoms of the medical and systemic ableism that afflicts Canadian society. I conclude the paper with a consideration of the enduring danger that eugenic ableism disguised as autonomy poses for people with disabilities in a Canada where COVID-19 may be waning, but where the contagion of ableism turned lethal through MAID continues to spread.

WHAT IS ABLEISM?

Ableism can be defined as prejudice and discrimination against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require 'fixing' and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as 'less than,' and perpetuates harmful stereotypes, misconceptions, and generalizations about people with disabilities (1). Clear yet unacknowledged, evidence of ableism can be seen in everything from the way in which buildings are built to exclude people who do not walk or see (2), to the way in which students with disabilities are taught that it's better to look, move, and behave as much like their nondisabled peers as possible (3), to the way in which terms associated with disability are used as insults in everyday language (4). Unlike racism or sexism, however, ableism remains, in the words of Canadian disability scholar Gregor Wolbring, "one of the most societally entrenched and accepted isms" (5). Ableism becomes systemic as patterns of discriminatory and exclusionary practices against people with disabilities are entrenched in sectors that are fundamental to societal membership, such as education, employment, and housing. Limited access and opportunities in one of these key sectors, such as education, often automatically leads to further restrictions in employment opportunities, which in turn limits housing options (6-8).

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MEDICAL ABLEISM ROOTED IN EUGENIC LOGIC

One key sector in which ableism is most deeply rooted is healthcare. Disability scholar Fiona Kumari Campbell draws a direct link between ableism and a biomedical paradigm, defining ableism as “a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human” (9). This ableist biomedical association of disability with a diminished state of being human is central to the development and practice of eugenics. D.J. Kevles defines eugenics as the “improvement of human genetics by ensuring individuals deemed unfit in society do not breed; for example, forced sterilization, separation of communities, genetic testing of embryos in order to select for individuals without certain disorders” (10). Rosemarie Garland-Thomson thus uses the term “eugenic logic” to describe the ableist belief that “our world would be a better place if disability could be eliminated.” (11) Under the influence of such eugenic logic, medical practitioners assume that disabled people have a poor quality of life and prescribe or rule out courses of treatment accordingly. Indeed, studies have consistently shown that, as a group, health care professionals tend to substantially underestimate the quality of life of people with disabilities (12-15). Most recently, a survey of more than 700 US physicians, across several specialties, found that just over 82% reported that people with disabilities have a significantly worse quality of life than nondisabled people (16).

COVID-19 HEALTHCARE POLICIES AS EVIDENCE OF THE GRIEVOUS AND IRREMEDIABLE ABLEISM AFFLICTING HEALTHCARE IN CANADA

The novel coronavirus, which for the better part of two years put ‘normal’ life across the planet on pause, has revealed in the starkest of terms the real and present danger that medical ableism poses for people with disabilities. Just as COVID-19 is not confined by national borders, the prevalence of medical ableism that the pandemic revealed likewise transcends geographical boundaries. As Panocchia et al. observe, “Although different countries have proposed different guidelines to manage this emergency, these proposed criteria do not sufficiently consider people living with disabilities. People living with disabilities are therefore at a higher risk of exclusion from medical treatments as physicians tend to assume they have poor quality of life” (17). In the same vein, Ignagni et al. identify a “eugenic logic” underpinning most worldwide healthcare responses to COVID-19, such as Critical Care Triage Protocols that list pre-existing disability as an exclusion criterion for receiving Critical Care in the event that the system is overwhelmed, and critical care resources need to be rationed (18).

MAID COMPLICATED BY MEDICAL ABLEISM

Like many of the healthcare responses to COVID-19, the expansion of eligibility for MAID in Canada to include people with disabilities who are not at the end-of-life is demonstrably rooted in medical ableism. To begin with, as healthcare professionals, MAID assessors are not immune to the prevalent influence of medical ableism rooted in eugenic logic (19). This becomes particularly significant given that studies consistently demonstrate that healthcare professionals who provide care to disabled individuals are often more pessimistic and upset about their charges’ prognoses than are the affected individuals themselves (20-22). Some may argue that this is essentially a moot point because people with disabilities meet with MAID assessors only after they have already applied for MAID. However, such an argument fails to take into consideration the fact that, among other things, MAID assessors are tasked with determining “the greatest source of suffering” that is prompting a person’s request for MAID (23). MAID assessors afflicted with undiagnosed ableism are likely to automatically view the existence of disability, in and of itself, as the greatest source of suffering. They thus risk conflating suffering stemming from remediable social conditions, such as poverty and the lack of affordable, accessible housing and community-based, user-directed personal support services, with the ‘irremediable’ presence of disability.

It is important to recognize that it is not just individual MAID assessors who can perpetuate the ableist conflation of suffering caused by remediable social deprivations with the ‘irremediable’ presence of disability; rather, this ableist conflation is present within the MAID law itself. Once eligibility for MAID was expanded to include people with illnesses and disabilities whose natural death was *not* reasonably foreseeable, Canada became a country in which it is accepted that certain sorts of lives with certain limitations can be terminated with medical assistance. This means that ill and disabled Canadians, along with their families, are now routinely encountering messages telling them that, if they are experiencing X, Y, and Z because of their condition, ending their lives through MAID is a valid solution to their suffering. The prevalence of this ableist medical and social messaging is resulting in increasing numbers of ill and disabled people ‘choosing’ MAID as a final capitulation to ableism.

One casualty of such ableism was Sophia (a pseudonym), a 51-year-old Ontario woman with severe sensitivities to chemicals who ‘chose’ medically-assisted death after her desperate search for affordable housing free of cigarette smoke and chemical cleaners failed. She had Multiple Chemical Sensitivities (MCS), a chronic condition. “The government sees me as expendable trash, a complainer, useless and a pain in the ass,” Sophia said in a video filmed on Feb. 14, 2022, eight days before her death. As Avis Favaro of CTV News reported:

> [Sophia] died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. She also left behind letters showing a desperate two-year search for help, in which she begs local, provincial and federal officials for assistance in finding a home away from the smoke and chemicals wafting through her apartment…

> Letters she wrote said that indoor cigarette and pot smoking increased, sending fumes through her Scarborough apartment building's ventilation system. More chemical cleaners were used in the hallways that worsened her symptoms. She confined herself to her bedroom – or "dungeon," as she called it – for most of the pandemic, sealing the vents to keep cigarette and pot smoke from wafting into her unit.
>
> Four Toronto doctors were aware of Sophia's case and they also wrote to federal housing and disability government officials on her behalf. In that letter the doctors confirmed that her symptoms improved in cleaner air environments and asked for help to find or build a chemical-free residence.
>
> "We physicians find it UNCONSCIONABLE that no other solution is proposed to this situation other than medical assistance in dying," they wrote. (24)

Sophia personally reached out to many Canadian disability rights advocates, including myself, for help in her desperate fight for the safe housing that would have enabled her to live. As a result, her story featured in testimony given by disability-rights advocates to the House of Commons Justice Committee studying Bill C-7 in the fall of 2020. They testified that, if Bill C-7 was passed and MAID was expanded, people like Sophia, people worn down and worn out by years of trying unsuccessfully to obtain the supports they need to live, will ultimately be left with no other option but MAID.

Sadly, it was only after her death that Sophia's story garnered any kind of public attention. But even more sad – indeed, maddening – is that when Sophia's story finally *did* generate some posthumous media attention, it prompted champions of MAID to subtly cast aspersions on the veracity of her story. For example, in a news story entitled "Are Canadians being driven to assisted suicide by poverty or healthcare crisis?" published in *The Guardian*, Leyland Cecco tells Sophia's story, and then quotes the following response by Dalhousie Law professor and MAID advocate Jocelyn Downie: "You have to meet rigorous eligibility criteria. And being poor and not having a home, or a home that is suitable for you, does not make you eligible." (25) In other words, "There's nothing to see here, folks. Move along."

There is a sense in which Downie's discounting of Sophia's story is unsurprising. For, even in the midst of such ongoing and growing injustices being perpetuated against people with disabilities through systemic medical ableism, the field of bioethics continues to privilege the voices of philosophers and ethicists who see the expansion of MAID within a medical system and a society that are steeped in ableism as inescapable and, ultimately, compatible with autonomy. Opposing views of the expansion of eligibility for MAID to people with disabilities who are not at the end-of-life but living in an ableist society as being detrimental to both the autonomy and well-being of people with disabilities – views most commonly expressed by disability-rights advocates – are summarily dismissed as paternalistic. A recent example of this is a paper entitled "Choosing death in unjust conditions: hope, autonomy and harm reduction," published in the April 2023 issue of the *Journal of Medical Ethics*. In their paper, Kayla Wiebe and Amy Mullin "consider and reject arguments that the autonomy of people choosing death in the context of injustice is necessarily reduced, either by restricting their options for self-determination, through their internalisation of oppressive attitudes or by undermining their hope to the point that they despair" (26). Using what they term a "harm reduction" approach, they argue that "even though such decisions are tragic, MAiD should be available" to people with disabilities who choose to die by MAID because they cannot get the support they need to live with dignity. This is because:

> Rather than betraying an 'ableist bias,' their decisions can be more charitably and respectfully interpreted as an accurate assessment of their situation. It is one thing to identify an ableist bias in a person or a policy where there is no lived experience with a disability, and quite another to attribute ableism to a person who has intimate experience living with their disability, and to on this basis question the legitimacy of their decisions regarding their own care. (26)

Rephrased in plain language, what Wiebe and Mullin are essentially saying is, "Yeah, ableism exists, and it sucks and we should work to reduce it. But the reality is that we will never eradicate it. So, if a person with disabilities wants to get MAID to escape the crappy life they have because they live in an ableist society, we should believe them regarding how crappy their life is and let them die by MAID." In my view, such an argument is nothing other than eugenic logic cloaked in the language of autonomy.

CONCLUSION

The Parliamentary and Senate Committee studies of Bill C-7, the proposed expansion of eligibility for MAID, took place in the fall and winter of 2020-2021 while the entire country was under pandemic lockdown. The breathtaking irony of this situation is that, at the very time when government and public health officials were urging Canadians to take precautions and even to make sacrifices for the sake of protecting the lives of vulnerable people, some of these same government officials were working to push through a bill that would make many of these same vulnerable people eligible for a state-sanctioned death. The kind of logical and ethical contortions that this required had to be of Olympic calibre, matched only by the logical and ethical contortions that it took to quote from the UN Convention on the Rights of Persons with Disabilities in the Preamble to Bill C-7, when three UN Human Rights experts declared Canada's MAiD regime to be in violation of that very Convention. In lieu of being able to organize any sort of in-person last-stand protest, since it was the middle of the pandemic, leaders in Canada's disability community organized the Disability Filibuster, a grassroots online protest on a scale never before undertaken in Canadian disability history. The idea was conceived on March 3, 2021. In the span of a mere three days, a nation-wide working group of disability rights and equality rights activists had come aboard, seed funding was secured, extensive disability accommodations were arranged, a suitable online platform was determined, publicity was generated, and a round-the-clock, inclusive livestream protest of disabled artists, activists, scholars and allies was launched. The inaugural Filibuster broadcast began at 7 PM on March 8, 2021. After an initial invasion by Zoom bombers shortly after launch forced a sudden interruption, it resumed at 7 PM on March 9 and continued late into the night. In total, the Disability Filibuster ran live, continuous broadcasts for almost 60 hours with only brief nightly breaks between 4 AM and 6 AM EST. Content ranged from lectures, interviews and panel presentations to artistic, comedic and dramatic performances and laid-back coffeehouse late-night conversations. Each and every contribution was thematically tied to the Filibuster's central mission of stopping the passage of a dangerous amendment to Canada's assisted suicide laws, by exposing the injustice, ableism and inhumanity at its core (27).

Despite these herculean efforts by the disability community, Bill C-7 passed into law on March 17, 2021. The passing of Bill C-7, and ongoing efforts to further expand eligibility for MAID to include people with a sole diagnosis of mental illness and so-called 'mature minors' are clear and disturbing indicators that systemic and medical ableism are not just alive but thriving in Canada. Sadly, this relentless expansion of MAID will inevitably result in a growing number of Canadians with disabilities losing their lives to ableism disguised as autonomy.

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TÉMOIGNAGE / PERSPECTIVE

Reflecting and Regretting

Ohad Avny[a,b]

Résumé
C'est l'histoire d'une femme âgée qui souffre de démence et qui a enduré toute une vie de mauvais traitements de la part de son mari. Au fil du récit, nous découvrons l'histoire tragique de cette femme âgée et les tentatives faites par son médecin au fil des ans pour l'aider. Les questions éthiques auxquelles le médecin est confronté, ses émotions, ainsi que les dilemmes stratégiques auxquels il doit faire face alors qu'il planifie et gère le traitement et les soins du mari et de la femme, créent une toile de fond troublante pour une histoire de comportement du patient et du médecin. Les dilemmes éthiques, émotionnels et professionnels liés au traitement d'un mari violent et de sa femme sont examinés en détail.

Abstract
This is the story of an elderly woman who suffers from dementia and has endured a lifetime of abuse from her husband. As the tale unfolds, we learn about this old woman's tragic history, and of the attempts her doctor has made over the years to help her. The ethical issues the doctor struggles with, his emotions, as well as the strategic dilemmas he is forced to confront as he plans and manages the treatment and care of the husband and the wife create an unsettling backdrop to a story of patient and doctor behaviour. Ethical emotional and professional dilemmas when treating an abusive husband and his wife are discussed in detail.

Mots-clés
fin de vie, maltraitance, soins primaires, démence, relations médecin-patient, dilemmes professionnels

Keywords
end of life, abuse, primary care, dementia, physician-patient relations, professional dilemmas

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INTRODUCTION

I remember well the day Edward (names are fictional) arrived at my clinic and said to me, "Dr. Avny, I have decided to transfer from my current doctor to your care, and I would be delighted if you would accept my wife as well."

Edward was an elderly man of eighty-five, vigorous and with piercing eyes. He stepped into my office with a vital, determined step. Something about his body language and his tone of voice had generated in me a certain discomfort: Was it his certainty that I would be pleased to accept him, or his sense of entitlement? Or the question in my mind: why might he want to change doctors? I immediately attempted to direct our conversation to my own comfort zone as we briefly discussed his medical history. During the conversation, other thoughts came to my mind: *"Why had he decided to transfer to my care? And why was I feeling so uncomfortable with him?"*

After the interview with Edward, I asked if I could meet his wife for an introductory interview. Edward replied coldly (a reaction that surprised me) that his wife was unable to attend the clinic and that she had already agreed to be transferred to my care. I decided to call her while Edward was still in my clinic. I distinctly remember her reticence during our telephone conversation, how brief her replies were and how feeble her tone. I concluded the meeting with Edward with a nod. And all the while, inside, the un-named discomfort continued to grow.

As soon as Edward had left the room, I telephoned their previous attending physician who was a close colleague of mine and my mentor during my residency. It did not take long for me to understand the sort of 'trouble' I had gotten myself into by agreeing to take them on as patients. I was told by my colleague that Edward had been abusing Malka, his wife, for many years, despite many efforts by my colleague as her attending physician, and the interventions of a social worker and the welfare services, who had tried to assist Malka countless times. I was slowly comprehending the kind of reality I had stumbled upon, a reality of loneliness and anguish suffered by an aging woman who was also apparently slipping into dementia and who was starved of affection by her husband. No wonder Edward had said, "I decided to turn over a new leaf with a devoted and professional doctor like you. I have heard so much about you."

I sensed that I had fallen victim to the machinations of a patient who wished to find a family doctor who would remain uninvolved and not interfere with the suspected violence that Edward evidently inflicted on his wife. For the first time in my professional career, I began to ponder how I might possibly untangle the complexities involved in such a situation and assist a woman living with dementia to leave her home or take some other possible steps to disentangle her marital relationship. I had to try to figure out a way that I could rescue a person who had apparently succumbed to a kind of imprisonment in her home, a place normally expected to be a haven of safety and security. I decided to invest in my relationship with the patient, Edward, adopting a well-planned attitude aimed at gaining his confidence – despite a sense of apprehension and many reservations. My goal was to slowly convince Edward that I should be able to visit Malka to assess her condition, as a first step in understanding the dynamic

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of their relationship and whether there was a need to ‘rescue’ her. That sense of treating Edward with little or no compassion for him, and with an attitude aimed at assisting his wife, was difficult and unnatural for me. Empathy and acquiring rapport with our patients have always been the cornerstone of my work with my patients. But at the same time, Edward also needed medical attention as he was suffering from heart failure, ischemic heart disease and peripheral vascular disease. Thus, I felt that it was a case of “ethical tension” of a physician struggling between his professional duty to treat all patients and criticism of his patient’s moral behaviours.

I realized that considering the advanced ages of both Malka and Edward, it was likely that I would be treating and accompanying them through the final years of their lives. Only this time, the therapeutic experience would be completely different from those I had generally experienced with other patients who were nearing the end of their lives.

At that stage, I could consider whether it would be better if I could relieve myself of the duty of treating Edward and Malka using a variety of pretexts. But here, the question arose whether my commitment as a doctor was limited by my personal preferences. Was choosing who I wanted to treat an act of moral dereliction? I knew that most Western countries mandate physicians to act within a framework of ethical practice, and from that basis policies have been implemented that put the welfare of patients before that of the treating physician. That is why, for countless generations, physicians have treated patients afflicted with serious infectious diseases, for example, physicians in Africa who often put their lives at risk, despite using the best available protective measures, to care for Ebola afflicted persons.

The reasoning I normally use to convince myself of anything is that beneficence and justice, two of the founding principles of the so-called Georgetown Mantra (1), the most recent basis of medical ethics, should be respected. How can I convince myself, and, if necessary, the medical regulating body that I can discharge a patient from my care? How could I discharge a patient to whom I am not historically attached, and of whom I might even disapprove? I recognized that at this time of his life, perhaps Edward would be better off being treated by a different doctor, one who might be more empathetic and assist him in an unbiased way. Or was that just an excuse I had been telling myself?

During our second meeting, as I pondered the other very pressing ethical issue, I decided to probe a little more in an attempt to find an interest in Edward as a patient. I looked into his medical history – ischemic heart disease, anemia that had been put down to an undetermined cause, and an abdominal aneurysm that was being regularly monitored. I decided to try and create a work environment that would allow me to gain Edward’s trust and convince him, in an empathic manner, to allow me to examine Malka. Since Malka was “too weak” to come to my clinic, I asked Edward’s permission to pay her a house visit. I saw Edward pale at my request, but he consented.

I arrived at their house on a cold, inclement day. Malka was sitting in a chilly room wearing a sweater. I introduced myself and we started talking. She told me she has been suffering from diarrhea lately, as well as weight loss and abdominal discomfort (as she said in lay terms, “stomach-aches”). I offered to examine her and did so when she agreed. She was bent over and showing all the signs of aging. She was unbruised and the physical examination yielded no significant findings other than extreme emaciation. I asked her about possible reasons for her loss of weight, and Malka told me again about her diarrhea. The possibility that she was being deprived of adequate food seemed a more probable cause. At one point, her husband left the room, and I immediately used the opportunity to ask her, gently and with as much empathy as I could generate, if she felt safe in her home and if she had been suffering any form of violence. Her reply was simple. “My husband takes care of me, as he always has.”

Over the next few months, Edward visited my clinic at intervals to discuss his medical conditions. Whenever I asked after his wife’s wellbeing, his stock answer was that she was still eating very little and still suffering from diarrhea, but that her general state of health was unchanged. He did ask for periodic blood tests for himself and his wife since he was “concerned for her health.”

I felt the need to try to interfere again when one of my patients, a woman who lived not far from Edward and Malka, told me about the shouting she regularly heard coming from the couple’s apartment. The woman then asked if I was their attending physician. I was shocked. I bit my lip and said nothing. I realized I had to adopt an active attitude, and I knew that the key to my ability to help Malka involved conducting a cognitive evaluation test at her house in the hope of finding her to be demonstrate some degree of cognitive impairment. In that case, I felt I would be justified professionally and legally to call in a welfare officer and remove Malka from her house and the apparently non-caring and maybe even planned damaging attentions of her husband.

I asked Edward for permission to visit Malka again. I was more confident this time, feeling I had been able to “gain the trust of the husband”, who I knew now felt safe with me. During my meeting with Malka, I asked her several questions using a brief a Mini-Cog cognitive screening test. And, indeed, the test results indicated a high probability of cognitive impairment, although at what level was not clear, but at least bordering on dementia. We called in a welfare officer and, eventually, a judge visited the patient’s home. Once the judge had formed his impression of Malka, she was removed from her home, against her will, and a place was found for her in a nursing home.

I subsequently received several welfare officer reports that Malka’s general condition had improved in her new place of residence. She gained weight and her mood improved. Unfortunately, her dementia worsened, but the quality of her life did generally improve and, eventually, she died peacefully in the nursing home where she lived. Over the course of the following year, Edward, her husband, continued to frequent my clinic. At his advanced age of eighty-six, it was clear to me that he was subject to making what to some, including myself, were futile medical inquiries. I refrained from taking the lead of his medical care which necessitated trying to convince him to avoid these unnecessary medical tests to which he was referred by various subspecialists. I must admit that to a certain extent, I was inwardly not terribly disturbed to see the man spending his final years in endless inquiries, running from one doctor to the next, all to no avail.

"*He deserves it*," I said to myself, even though I knew deep down that was an unprofessional view and one that would be frowned upon by leaders in medical and Jewish-based ethics. I distinctly remember the day he came to see me with symptoms of worsening new congestive heart failure. It was obvious that he was approaching the end of his life and required close medical supervision and intensive care. It was then that I chose to tell him how I had long felt about him.

"Edward," I said bluntly, "I feel I can no longer treat you. I know how you abused Malka for years, and I am asking you now to transfer to the care of another doctor. I feel that because of the great anger I feel for you, I will be unable to provide you with the best care."

I remember how he had paled. He stood slowly, gave me a chilling glare, and walked out of my office, slamming the door behind him. The whole clinic heard his angry shouting as he left. Ultimately, he agreed to be transferred to the care of another doctor. Two weeks later, his neighbor who was also my patient, came to see me and asked if Edward had been to the clinic lately. I told her he hadn't. I then called the social worker who tried to contact him. She was unsuccessful. Later, she called me to say that Edward had been found dead after the authorities had been forced to break into his house.

I was shocked. The following thoughts were overwhelming:

- **Guilt of his death:** Had I been the trigger for his suicide, if he had indeed taken his own life? Was I responsible for a deterioration in his state of health that had caused his death? Had I intentionally intended to hurt him?

- **Empathic failure:** How could I manage a lack of empathy and feeling of alienation toward a patient? Maybe I missed something about Edward that would have led to a different interpretation of his actions: What if it were ignorance, fear, frustration and his own personality failures that led him to act this way rather than true malice?

- **Professional failure:** I knew that the regulatory body has very strict protocols about ending the doctor-patient relationship. And I knew that in no way had I followed that regulatory body's dictums (1). The English dictum obligates preplanning separation (2). The patient may feel he was abandoned by the only person who cared for him. Words and phrases said in these situations might have a critical effect on our patient's life. Emphasized is the importance of communication with the patient even if the patient was violent or abusive. A patient's reaction depends on how the physician discusses separation with them. None of these were present in my case.

And then there were further ethical questions that I was forced to ponder: Could I, as a physician, dismiss my patient? Was I obliged to care for an abusive patient? Could I treat a patient when despising him? As an experienced primary care physician, I doubted my professionalism. Somehow, I was not practicing reflective strategies while dealing with this difficult medical situation. Why didn't I share with my colleagues my agonizing ruminations, why didn't I discuss it with my Balint group (a small group of physicians that discuss and share challenges in medical practice)? (3).

James E. Groves argued that patients who fill clinicians with dread can be assigned to categories that include "clingers," "entitled demanders," "help-rejecters," and "self-destructive deniers," and that these same categories can provide guidance to clinicians interested in managing their care (4,5). Yet Edward did not fall into one of these categories since the shadow of his abusive behaviour toward his wife was always present in my mind when I met him. Perhaps diving into his deep psychological complexity could have helped me override his apparent sociopathic behavioural traits. Knowing his world, personal narrative, and complexities could have allowed me to overcome my own fears and anger and feel more comfortable and capable as his physician. I could put aside my anger and frustration and have more interest in Edward as a patient. Counter transference (bringing my own anger and frustration) could have been minimized and I could have humbly treated Edward as a patient suffering from CHF pending his death. I had some comfort when reading the paper published by Winnicot "Hate in the counter transference" where he acknowledged outright hatred for some patients in certain circumstances as perhaps I had felt. Winnicot, in his writing acknowledges counter transference of hate as "objective counter transference" where patients evoke such feelings regardless of the therapist's personality and difficulties when treating their patients. He describes physician-hatred as being normal reaction to the patients' personality and behaviour. Yet, even if that is the case, I should have chosen a different strategy in ending our relationship (6).

As a private person, and as a professional, I consider myself tolerant and permissive. I find myself filled with anger when dealing with malice, abuse, and social injustice. It is at these times that I act impulsively. As a primary care physician in a well-off neighborhood, I am less experienced in dealing with criminal patients. It is clear to me that this point of conflict arouses in me a sense of loss of control and victimization of myself as if I was also threatened by the violent patient. At these times, perhaps I retreat to the more basic "flight or fight" mode and so cannot sublimate my anger and divert it to a professional action when treating violent patients. I would think that bridging the gap between abusive behaviour, and acting as a caring objective physician, demands introspection, clear thinking, as well as cognitive and conduct strategies. Each physician has their own narrative and psychological difficulties, and in extreme situations we confront our personal vulnerability, at times losing clear strategic thinking and engaging in counter-transference (of fear, as was the case with Edward) that overrides our clinical judgement – impulsive behaviour "pops out". I presume that disavowal of the hateful feelings toward Edward required less effort than bearing them, and which allowed me to dismiss him in such a way. As from a psychoanalytic perspective being aggressive and with no empathy toward Edward is understandable, these emotions should nonetheless be reshaped according to a higher purpose.

I sometimes tell the story of Edward and Malka in an ethics workshop that I teach for medical students. Interestingly, almost all students sympathize with me and acknowledge my impulsive behaviour as being understandable, even trying to comfort me. It is at these moments that they also acknowledge, subconsciously, our fragility as physicians trying to balance our medical mission with our own personality and sensitivities. At these moments in our discussions, I thank them for their empathy and the opportunity to openly discuss with them my mistake in the hope that they will remember our session when they experience similar situations as physicians, in the future.

I discuss with them these three dimensions of our relationship with patients: *emotional*, *ethical*, *professional*. Although at first one could justify my decisions and behaviour, further reflection of this story would reveal dilemmas and mistakes when treating and ending the care of Edward and his wife, Malka. Emotionally, I regret not reflecting and processing my alienation to Edward, I regret my impulsive behaviour. Ethically, I regret my decision to dismiss Edward and my manipulative strategy when treating him. Professionally, I regret not discussing this case with my colleagues, both in staff meetings and Balint groups. I failed in appropriately handling the complexity of being the apparent abuser's physician. I am reminded of this very moment when feelings of anger override coherence when treating "difficult" patients, that I should cultivate empathy, morality, and professionalism to the best care of my patient.

To this very day I still feel a "pinch in my heart" whenever I recall the tragic story of Malka and Edward.

As the renowned Maimonides (who was a Sephardic Jewish philosopher, physician and became Torah scholar of the Middle Ages) wrote: "Allow me to look upon every sufferer, who comes to ask my advice, as a human being, without the difference between rich and poor, friend and hater, good and bad man". And as Maria Tereza said, one should strive to glimpse the dignity in every patient (4).

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TÉMOIGNAGE / PERSPECTIVE

Éthique et collaboration avec les communautés autochtones : la pratique ethnographique et les angles morts de la bureaucratie de la recherche

Émile Duchesne[a]

Résumé

L’engouement pour la recherche en contexte autochtone a fait en sorte que des balises formelles ont été implantées pour encadrer la venue des chercheurs dans les communautés. Bien que bienvenue, cette implantation ne s’est pas faite sans une bureaucratisation accrue des relations de recherche. Il appert que de nombreuses communautés autochtones, dont les ressources sont limitées, ne sont pas bien outillées pour faire face aux impératifs administratifs préconisés par les protocoles en recherche autochtone. Partant d’expériences de recherche anthropologique de terrain en contexte innu, le présent article montre comment des relations de recherche respectueuses ont pu être implantées en dehors du cadre bureaucratique et administratif généralement préconisé par les protocoles de recherche. Le cœur de cette démarche se situe dans la participation radicale du chercheur à la vie sociale et plus particulièrement à la prise au sérieux des prémisses de socialité des personnes avec qui il travaille. L’erreur serait de penser que cette démarche de collaboration se situe dans l’informalité : elle se situe plutôt dans un cadre éminemment formel qui correspond aux critères et valeurs des collaborateurs autochtones du chercheur.

Mots-clés

autochtone, ethnographie, éthique, collaboration, Innu, terrain, entrevue

Abstract

The enthusiasm for research in an Indigenous context has led to the introduction of formal guidelines for researchers to visit communities. While welcome, this has not been achieved without increased bureaucratization of research relationships. It appears that many Indigenous communities, with their limited resources, are ill-equipped to deal with the administrative imperatives of Indigenous research protocols. Based on the experiences of anthropological field research in the Innu context, this article shows how respectful research relationships could be established outside the bureaucratic and administrative framework generally advocated by research protocols. The heart of this approach lies in the researcher’s radical participation in social life, and more specifically in taking seriously the social premises of the people with whom he works. The mistake would be to think that this collaborative approach is situated in informality: rather, it takes place within an eminently formal framework that corresponds to the criteria and values of the researcher’s Indigenous collaborators.

Keywords

Indigenous, ethnography, ethics, collaboration, Innu, field, interview

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INTRODUCTION

Je mène des recherches en anthropologie depuis 2015 chez les Innus de Unamen Shipu, une communauté autochtone de la Basse-Côte-Nord au Québec. Ma méthode privilégiée est la recherche ethnographique. Concrètement, je réside pendant de longues périodes dans la communauté pour partager le quotidien des gens. Aussi, je participe à des expéditions de chasse de plusieurs semaines sur le territoire. La pratique ethnographique implique généralement une participation radicale à la vie sociale des personnes avec qui l’anthropologue travaille. Dans mon cas, cette expérience immersive permet de comprendre de l’intérieur le point de vue des Innus sur des sujets tels que leur cosmologie, le rapport aux animaux, l’histoire, etc. Mes apprentissages orientent les questions que je pose lors des entrevues avec mes collaborateurs qui sont, pour la plupart, des ainés unilingues détenteurs de savoirs. Ce genre de recherche de terrain ne peut être réalisée sans une approbation éthique d’une instance universitaire et une reconnaissance institutionnelle par la communauté d’accueil. Il s’agit là d’un impératif dicté par les universités, les organismes subventionnaires du gouvernement fédéral canadien (1) et l’Association des Premières Nations du Québec et du Labrador (2).

La recherche autochtone jouit actuellement d’un engouement pratiquement sans précédent. Certaines communautés autochtones voient débarquer un nombre impressionnant d’équipes de recherche sur leur territoire. Cet afflux dépasse bien souvent les capacités d’accueil des communautés, de sorte que des mécanismes internes doivent être mis en place pour les encadrer. La situation actuelle n’est pas si loin de ce que Vine Deloria décrivait dans son célèbre essai de 1969, *Custer Died for Your Sins* : « Every summer when school is out a veritable stream of immigrants head into Indian country. […] From every rock and cranny in the East *they* emerge, as if responding to some primeval fertility rite, and flock to the reservations. ‘They’ are the anthropologists » (3, p.78). À cela, aujourd’hui, on pourrait ajouter les géographes, les historiens, les biologistes, les sociologues, les chercheurs en santé, etc. qui sont de plus en plus nombreux à faire de la recherche en contexte autochtone. La prolifération de ce genre de recherches et l’imposition de balises éthiques pour les encadrer ne se sont toutefois pas faites sans une certaine bureaucratisation des relations de recherche : les formulaires, les protocoles et les demandes administratives sont plus nombreuses que jamais et ce pour tous les acteurs de la recherche, y compris pour les

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autochtones (4). D'ailleurs, les communautés autochtones ne sont pas toutes outillées de la même façon pour faire face à ces nouvelles réalités. Cet article montre les défis de réaliser une recherche avec une communauté autochtone qui dispose de peu de moyens administratifs pour accueillir des chercheurs. L'argument principal est que le fondement d'une bonne collaboration se situe non pas dans les protocoles bureaucratiques mais dans la capacité du chercheur à agir dans le respect des prémisses de socialités qui sont propres aux collectivités avec lesquelles il travaille.

LA PLACE DES CHERCHEURS DANS UNE COMMUNAUTÉ INNUE

L'isolement et les faibles ressources de la communauté d'Unamen Shipu ont fait en sorte que la communauté n'a pas vécu l'afflux de chercheurs que d'autres communautés vivent actuellement. En effet, comme la communauté n'est pas reliée au réseau routier, il est difficile de s'y rendre sans connaître préalablement des personnes sur place. De même, l'absence d'une politique locale pour encadrer les activités de recherches fait probablement que les demandes de recherches ne font peut-être pas toute l'objet d'un suivi. La situation n'a pas toujours été ainsi, car de nombreux anthropologues ont visité la communauté depuis les années 1970 : on peut penser à des chercheurs bien connus dans ma discipline tels que Rémi Savard, Paul Charest, Sylvie Vincent, Peter Armitage et de nombreux autres encore. En 2003, l'anthropologue Denis Gagnon, à la suite d'une recherche ethnographique à Unamen Shipu, notait que cette communauté « est la collectivité innue la plus étudiée et la plus visitée par les anthropologues. On peut même parler d'une certaine saturation de chercheurs dans cette communauté » (5, p.248). La communauté d'Unamen Shipu est particulière car virtuellement tous ses membres parlent la langue innue au quotidien (6). L'isolement de la communauté a également fait en sorte que la chasse, la pêche et la cueillette y prennent une plus grande importance qu'ailleurs. En cela, il s'agit d'une communauté idéale pour étudier la culture traditionnelle innue et ses expressions contemporaines, d'où cet important afflux d'anthropologues depuis les années 1970. Cependant, dans les dernières années, la communauté fut pratiquement désertée par les chercheurs. Depuis que je la fréquente, je n'ai pas eu conscience d'autres anthropologues qui l'aient visité : il y en a peut-être eu, mais on ne m'en a pas parlé. Par contre, j'ai eu conscience que des chercheurs ont fréquenté Unamen Shipu pour des projets de recherche mis en œuvre par l'Assemblée des Premières Nations du Québec et du Labrador (APNQL), Santé Canada ou avec l'école de la communauté. J'ai cependant rencontré beaucoup de journalistes, cinéastes et artistes qui fréquentaient la communauté pour leur travail. Mais pas d'anthropologues. Bref, malgré un passé récent où les chercheurs abondaient dans cette communauté, il est difficile de parler aujourd'hui d'une saturation comme le faisait Gagnon il y a 20 ans. En cela, la situation d'Unamen Shipu est différente de celle des autres communautés autochtones situées plus au Sud. À cet égard, l'anecdote qui suit est parlante.

En 2018, je participais à un colloque sur les méthodes collaboratives en recherche autochtone au congrès annuel de l'Association canadienne-française pour l'avancement des sciences (ACFAS) à l'Université du Québec à Chicoutimi. J'étais accompagné de mon ami Normand Junior Bellefleur, alors élu au conseil de bande de sa communauté, pour présenter un projet de transmission culturelle que nous souhaitions mettre sur pied. Le projet consistait essentiellement à organiser une expédition sur le territoire avec des jeunes et des aînés afin de favoriser la transmission de savoir reliées au canot et aux portages, ce que nous avons fait l'automne suivant le colloque. Beaucoup de participants, non autochtones pour la plupart, décriaient l'afflux trop important de chercheurs dans les communautés autochtones. Certains ont avancé des chiffres : telle communauté aurait reçu plus de 70 demandes de recherche l'année dernière. À mesure que les témoignages s'accumulaient, mon ami Junior décide de prendre la parole : « J'entends dire qu'il y a trop de chercheurs dans les communautés autochtones et qu'on ne sait plus quoi en faire. Pouvez-vous m'expliquer alors pourquoi alors personne ne vient nous voir à Unamen Shipu? Pourtant on n'est pas méchant! ». Son intervention en a fait rire plusieurs – c'était d'ailleurs l'intention principale de Junior – mais il n'a pas vraiment reçu de réponse à son interrogation. Tout cela pour dire qu'au Québec, il y a des communautés autochtones qui reçoivent un nombre démesuré de demandes de recherche et d'autres qui n'en reçoivent pratiquement pas. Les premières sont généralement très organisées et ont des comités qui encadrent la venue des chercheurs. Pour les secondes, on adopte généralement une attitude de cas par cas mais souvent, leurs moyens limités – au point de vue financier, institutionnel et des ressources humaines – font en sorte qu'ils ne peuvent faire autrement.

Mon expérience avec la communauté d'Unamen Shipu me fait dire qu'il est difficile pour un chercheur d'obtenir l'encadrement institutionnel qui est souvent demandé par les protocoles et les comités d'éthique lorsque les communautés ont peu de moyens pour le faire. Je me souviens encore des démarches préalables à ma recherche de maitrise (7). J'avais alors demandé à rencontrer un élu du conseil de bande pour parler de ma recherche. Il avait fallu que j'insiste un peu pour qu'il accepte de me rencontrer. Je lui explique mon projet brièvement en lui expliquant que je dois avoir l'accord de la communauté. Il me questionne alors : « J'ai entendu dire que tu restais chez telle personne. J'ai aussi vu que tu avais des amis ici… Alors je ne comprends pas ce que je peux faire de plus pour toi ». Je me fais un peu plus clair : je dois seulement avoir une personne qui atteste que ma présence est autorisée. L'élu rit un peu et me dit finalement qu'il n'y a pas de problème. Chez les Innus et les peuples algonquiens en général, il n'est pas bien vu de se mêler des affaires des autres car l'autonomie personnelle y est grandement valorisée (8-10). Alors si des gens me parlent et participent à ma recherche, qui est-on pour les empêcher de le faire? La situation aurait peut-être été différente si j'avais été un travailleur d'Hydro-Québec, un garde-chasse ou un autre représentant de la société coloniale auxquels les Innus préfèrent ne pas avoir à faire affaire. Il faut aussi dire que la communauté d'Unamen Shipu dispose de moyens financiers limités, surtout lorsqu'on la compare à d'autres communautés autochtones qui ont signé d'importantes ententes avec les gouvernements et des compagnies privées. D'autre part, les employés du conseil de bande sont peu nombreux et souvent débordés par d'autres tâches plus importantes que d'encadrer un chercheur.

Bref, je n'expose pas ce contexte pour me dédouaner de mes responsabilités éthiques avec la communauté. Je souhaite plutôt exposer les défis auxquels j'ai dû faire face pour remplir les exigences fixées par le comité d'éthique de mon université, exigences qui sont elles-mêmes basées sur les protocoles de l'APNQL et des organismes subventionnaires. Mis à part les dispositions sur le consentement libre préalable et éclairé qui sont applicables à toutes les entrevues faites par un chercheur, il était aussi demandé de faire approuver une demande de recherche par une institution communautaire reconnue. C'est pourquoi, pour ma recherche doctorale, j'ai ratifié une entente de recherche avec le directeur général de la communauté avec l'accord du chef qui a été informé du processus et qui a accepté de déléguer la ratification au directeur général. L'entente explique brièvement mon projet, mes méthodes et mon financement et évoque mes responsabilités envers la communauté : assurer le consentement des participants, écouter les recommandations du conseil de bande et des ainés, interdire l'utilisation commerciale des données, mais surtout rendre disponibles les données et les résultats de la recherche à la communauté et aux participants. Bien que l'aspect légal et formel de ce genre d'entente soit important, il n'en demeure pas moins que le cœur d'une collaboration réussie ne se situe pas dans ce genre d'ententes, qui ne devraient jamais être vues comme une fin en soi. En effet, il me semble plutôt qu'une collaboration réussie trouve sa source dans la construction d'une relation de confiance qui prend sa source dans le respect des formes locales de socialité,

LES DIFFÉRENTES NUANCES DE LA RECHERCHE COLLABORATIVE

Bien que les protocoles de recherches comme ceux de l'APNQL ou l'Énoncé de politique des trois conseils : Éthique de la recherche avec des êtres humains (1; EPTC2), stipulent qu'il est préférable de faire une recherche dite collaborative, j'ai jugé que je n'avais pas les moyens pour le faire. Par recherche collaborative, on entend généralement que le sujet de la recherche est décidé par les autorités des communautés et qu'un processus de suivi formel soit engagé entre la communauté et le chercheur. Implicitement, la recherche doit répondre à un besoin concret. Pourquoi est-ce que j'affirme que je n'avais pas les moyens de faire ce genre de projet? Premièrement, aucun employé ou élu du conseil de bande n'avait l'espace nécessaire dans son agenda pour assurer un suivi de mes activités. D'autre part, je ne voulais pas non plus imposer du travail supplémentaire non payé à des gens qui sont déjà fort occupés. Il aurait toujours été possible de créer un comité de suivi, mais je vois mal comment un tel comité aurait pu fonctionner à long terme sans que les gens soient compensés financièrement ou autrement pour leur implication. Pour que ce genre de démarche puisse fonctionner, il me semble qu'il faut soit que la communauté dispose des ressources pour le faire, soit que le chercheur les fournisse. Or, en tant qu'étudiant au doctorat, je ne disposais pas de ressources financières suffisantes pour faire vivre un comité de suivi et la communauté n'en disposait pas non plus. Mais au-delà des technicalités d'un tel suivi, j'ai l'impression que c'est une démarche que les gens de la communauté ne trouvaient pas nécessaire dans mon cas. Il n'y a donc pas eu de co-construction du sujet de recherche avec les autorités politiques de la communauté, comme cela est souvent prescrit dans les protocoles en recherche autochtone.

En revanche, il est indéniable que le sujet s'est coconstruit, par la force des choses, au fil de mes discussions avec les ainés détenteurs de savoir. En effet, il est assez frappant que je n'aie jamais pu réussir à réaliser un projet de recherche que j'avais formulé avant d'aller sur le terrain. Constatant le manque d'intérêt des gens sur place, j'ai souvent dû réorienter mes projets pour les faire cadrer avec les préoccupations de mes interlocuteurs. Il me semble d'ailleurs que toute démarche anthropologique sincère est marquée par un engagement profond envers les gens avec qui l'on travaille (11,12). C'est bel et bien l'idéal que je me suis donné et que j'ai voulu démontrer dans les paragraphes précédents. Cette recherche s'appuie sur un tissu de relations que j'entretiens depuis 2015 et ces relations sont basées sur des obligations réciproques dont les critères sont propres aux Innus mais aussi aux peuples algonquiens plus largement (13-15). Autrement dit, les gens d'Unamen Shipu savent qu'ils peuvent compter sur moi lorsque mon expertise sera nécessaire. Au jour le jour, cela se manifeste de manière encore plus concrète en participant aux tâches de la vie quotidienne, en contribuant monétairement aux dépenses de ma famille d'accueil, en donnant et recevant des nouvelles lorsque l'on est éloigné, etc. Alors pourquoi dis-je que je n'ai pas fait une recherche collaborative? Comme l'a souligné Marie-Pierre Bousquet (16), le mot « collaboratif » est aujourd'hui utilisé à toutes les sauces dans les projets de recherche. Dans certains cas, on sous-entend même qu'en dehors de la recherche collaborative, il n'y aurait point de salut. À l'instar de Bousquet, je pense que les recherches collaboratives « en viennent à être instrumentalisées comme une fin en soi, alors qu'elles ne devraient être qu'un moyen. Cela fait partie du travail du chercheur de décider si c'est le meilleur moyen pour mener sa recherche, en tant qu'expert de sa discipline » (16, p.27). Ma démarche de recherche se situe ainsi davantage du côté de la recherche fondamentale : elle ne vise pas à opérer un changement comme le ferait une recherche-action ou à répondre à un besoin précis et délimité. Cela ne veut pas dire qu'elle n'aura jamais d'application dans le futur ou qu'elle ne réponde à aucun besoin. De manière générale, les gens d'Unamen Shipu sont très contents que les voix de leurs ainés soient enregistrées, valorisées par une recherche, mais aussi et surtout archivées pour le bénéfice des générations futures.

D'autre part, je n'ai pas senti que mes interlocuteurs ainés souhaitaient collaborer plus que ce qu'ils ne l'ont fait dans le cadre de ma recherche. Pour prendre un exemple, à l'hiver 2019 au lac Noirclair, je partageais la tente d'Atuan, un aîné détenteur de savoir très respecté dans sa communauté et qui ne parle que la langue innue, avec un ami qui avait mon âge. Ayant un appareil photo supplémentaire, je me suis dit que je pourrais le prêter à Atuan pour qu'il puisse documenter notre expédition à sa façon. J'y voyais une façon de décentrer mon rôle et de favoriser la collaboration. Atuan ne parlant que la langue innue, je demande à mon ami de lui expliquer que je lui passais l'appareil photo pour qu'il puisse documenter lui-même notre expédition. Atuan répondit qu'il n'avait aucun problème à ce que je le prenne en photo! Je demandai à mon ami d'insister pour qu'il prenne l'appareil photo. Atuan répondit encore une fois que c'était plutôt à moi de prendre les photos. Après quelques allers retours du genre, Atuan finit par prendre l'appareil photo et le rangea dans son sac pour ne plus jamais y retoucher du voyage. Visiblement, la « recherche collaborative » n'intéressait pas du tout Atuan! Il me semble que cette anecdote exprime comment certains collaborateurs experts – dans ce cas-ci les ainés détenteurs de savoirs – sont tout-à-fait à l'aise d'être consultés dans le cadre d'une recherche : il s'agit pour eux d'une façon de performer leur autorité et de valider leur rôle d'expert culturel.

Les gens d'Unamen Shipu qui ne sont pas des « experts » ont sensiblement le même sentiment, car lorsqu'on les questionne sur certains sujets plus pointus de la cosmologie et de la culture innue, ils vont dire qu'ils savent de quoi je parle, mais que je ferais mieux de consulter un aine pour avoir une meilleure réponse. En effet, aux yeux de tous, les ainés sont les personnes les plus compétentes pour parler de la culture et ils le font avec autorité. La participation que j'ai demandée aux ainés est donc assez classique, c'est-à-dire qu'ils ont été appelés à participer à des entrevues semi-dirigées. On ne souligne peut-être pas assez le fait que les entrevues semi-dirigées offrent un espace de liberté qui permet aux collaborateurs de faire état de leur préoccupation et d'instruire le chercheur sur des sujets qui les préoccupent. Bien sûr, tout cela est conditionnel au fait que le chercheur soit capable d'écouter et de parfois mettre de côté son questionnaire d'entrevue. Dans mon cas, les témoignages de mes collaborateurs m'ont suivi bien au-delà des entrevues, notamment en orientant la suite de mes recherches dans les archives et dans le registre ethnographique comparatif. Ce sont même leurs témoignages qui ont orienté le thème de ma recherche : ils ont fait de ma recherche une tout autre recherche. En effet, initialement, je devais parler de leur perception des changements climatiques. Comme mes interlocuteurs ne trouvaient pas que c'était un sujet particulièrement intéressant – et qui, de leur point de vue, se résumait à peu de choses –, les entrevues ont vite divergé vers l'histoire de la communauté, leur expérience à la chasse, les esprits-maitres des animaux, etc. D'ailleurs, il est révélateur que les témoignages les plus intéressants fussent pour la plupart « non sollicités » ou « non attendus » c'est-à-dire qu'ils ne découlaient pas d'une question précise de ma part. À mes yeux, les entrevues les plus intéressantes anthropologiquement parlant étaient celles où j'ai posé le moins de questions. Il y a même une entrevue lors de laquelle je n'ai posé aucune question et qui est sans conteste l'une des plus extraordinaire au niveau de la richesse des données! Bref, mes interlocuteurs avaient des choses précises à me raconter et ils tenaient à ce que je les prenne en compte, ce que j'ai tenté de faire le plus possible. Malheureusement, selon mon expérience, ce genre de co-construction de la recherche est difficile à faire reconnaitre auprès des comités d'éthique, des organismes subventionnaires et des autres acteurs de la recherche. Pourtant, elle est au cœur d'une démarche anthropologique sincère et elle est tout-à-fait cohérente avec les valeurs des Innus avec qui je travaille, qui placent en haute estime l'écoute, l'apprentissage expérientiel et la réciprocité.

La plupart des entrevues que j'ai faites pour ma recherche doctorale ont eu lieu en 2021, soit sept ans après ma première visite à Unamen Shipu. Bien sûr, j'ai fait quelques entrevues ponctuelles avant cette date avec les ainés que je connaissais le mieux. Cette situation a mené à un évènement assez comique. Un soir d'automne en 2021, je buvais une bière avec mon père adoptif dans la petite tente innue qu'il avait installé dans sa cour arrière. On discutait de choses et d'autres, autour du petit poêle de tôle, jusqu'à ce qu'il me demande si je faisais toujours ma recherche. « Bien sûr! Mais pourquoi tu te demandes ça? » lui avais-je répondu. Il me fit alors son petit exposé sur ce que, à ses yeux, un bon chercheur devait faire, car il en avait vu passer plusieurs chez son père lorsqu'il était plus jeune. Il conclut que je devais le plus rapidement possible aller enregistrer les ainés, car, voyant que je n'avais pas fait beaucoup d'entrevues, il trouvait que je n'avais pas l'air du tout d'un chercheur sérieux! Je lui expliquai que c'est précisément ce que je comptais faire dans les prochaines semaines. Je venais alors tout juste d'apprendre que je ne pourrais pas aller en forêt cette année-là. Je devais donc réorganiser mon calendrier de recherche. Ce soir-là, autour du feu, mon père adoptif me prodigua ses conseils sur la bonne façon de faire des entrevues avec les ainés. Au terme de la discussion, il a été décidé que j'engagerais sa sœur ainée comme interprète puisqu'elle avait déjà fait ce travail par le passé, et qu'à la fin des entrevues je donnerais 100$ en cadeau aux ainés qui accepteraient de participer. Quand j'ai fait les entrevues, en 2021, les ainés que j'ai consultés savaient déjà très bien qui j'étais même si je n'avais jamais formellement rencontré la plupart d'entre eux. Ils avaient entendu parler de moi, de mes séjours au *nutshimit* (c.-à-d. le territoire forestier des Innus), des territoires que j'avais vus, des gens avec qui j'avais chassé, etc. Certains m'ont d'ailleurs accueilli en me disant : « Je savais qu'un jour tu viendrais m'enregistrer ». C'est mon impression, mais je crois sincèrement que d'avoir attendu aussi longtemps avant de consulter les ainés pour de longues entrevues a fait en sorte que mes interlocuteurs se sentaient plus en confiance. J'étais aussi moi-même beaucoup plus compétent pour comprendre ce qu'ils me disaient puisque dans certains cas, j'avais moi-même vu les territoires dont ils me parlaient ou, sinon, j'étais capable de les situer au moins approximativement par rapport à d'autres points géographiques. Loin de tout comprendre ce qu'ils racontaient en innu-aimun, j'étais toutefois capable de capter des bribes de ce qu'ils disaient et donc de suivre minimalement leur discours. De la même façon, par mes expériences depuis 2015, j'étais aussi plus en mesure de replacer les personnes, les notions et les évènements à propos desquels mes interlocuteurs m'entretenaient. Les méthodes de recherches des disciplines autres que l'anthropologie prévoient rarement autant de temps pour assurer la collecte de leurs données dans un contexte autochtone. Les sept ans que j'ai attendu avant de procéder aux entrevues feront certainement sursauter certains lecteurs! Mon expérience me dit toutefois que l'attente est payante et permet d'assurer de meilleures relations de recherche de même que des données plus solides.

CONCLUSION

Dans un contexte où de plus en plus de chercheurs fréquentent les communautés autochtones du Québec et du Canada, il était souhaitable que des balises claires soient implantées pour éviter les dérives et assurer des relations respectueuses. C'est ce qu'a permis l'EPTC2 et le protocole de l'APNQL. Cependant, parallèlement à cette implantation, on assiste à une bureaucratisation constante des relations de recherche avec les peuples autochtones. Cette formalisation des pratiques de la recherche s'est parfois faite, il me semble, au détriment des communautés qui sont moins bien outillées administrativement pour composer avec ces impératifs bureaucratiques. Dans cet article, j'ai voulu montrer comment des relations de recherches respectueuses pouvaient s'établir en dehors des impératifs bureaucratiques. Il serait trompeur d'affirmer que ces pratiques de collaboration s'inscrivent dans l'informalité car les principes qui les sous-tendent sont au cœur des formes de socialité autochtones. Dans le cas des Innus, on parle de valorisation du respect, de la réciprocité, de l'écoute, du sens du travail mais aussi de l'autonomie personnelle. En cela, il est tout naturel pour les Innus de considérer que les chercheurs qu'ils invitent chez eux doivent participer à la vie quotidienne et offrir une aide dans des secteurs qui n'ont rien à voir avec la recherche. Avec le temps, le chercheur s'intègre aux réseaux de réciprocité de la communauté qui l'accueille et c'est la qualité et la profondeur de cet engagement qui permet des relations de confiance. De cette façon, le chercheur collabore ou coconstruit son sujet de recherche non pas à travers un processus de négociation politique, administratif et bureaucratique mais en respectant les prémisses de socialité des gens avec qui il travaille. Pour le meilleur et pour le pire, les chercheurs trouveront toujours un moyen de composer avec les formulaires et les impératifs bureaucratiques. En revanche, les communautés autochtones, elles, vivent très difficilement avec les personnes qui ne respectent pas leurs prémisses de socialité. En cela, d'un point de vue éthique, cette dimension est la plus fondamentale de toutes. Il en retourne qu'au-delà des formulaires, des guides de recherches et des protocoles, c'est avant tout la personnalité du chercheur mais plus particulièrement sa prise au sérieux des valeurs locales et son engagement dans la vie quotidienne qui détermine le succès de sa démarche dans un contexte autochtone.

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Conflicts of Interest

None to declare

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COMPTE RENDU / REVIEW

Les restes humains : législation, intérêt scientifique et enjeu éthique des ensembles anthropobiologiques, de Yann Ardagna et Anne Chaillou

Lucile Bousquié[a]

Résumé
Compte rendu du livre de 2022 par Yann Ardagna et Anne Chaillou, *Les restes humains : législation, intérêt scientifique et enjeu éthique des ensembles anthropobiologiques*.

Abstract
Review of the 2022 book by Yann Ardagna and Anne Chaillou, *Les restes humains : législation, intérêt scientifique et enjeu éthique des ensembles anthropobiologiques*.

Mots-clés
restes humains, anthropologie biologique, bioéthique, droit patrimoniaux, archéologie

Keywords
human remains, biological anthropology, bioethics, heritage law, archaeology

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INTRODUCTION

« Les restes humains : législation, intérêt scientifique et enjeu éthique des ensembles anthropobiologiques » (1) est un ouvrage collectif dirigé par Yann Ardagna et Anne Chaillou qui présente les différentes réflexions entamées en 2011 par un groupe de travail, à l'initiative de la sous-direction de l'archéologie du ministère de la culture français, concernant la gestion des restes humains archéologiques dans le pays. Ce groupe de travail était formé de professionnels des domaines scientifiques, muséal et juridique, ayant tous un lien avec les processus de mise au jour, analyse, conservation ou valorisation des restes humains en France. Les différents chapitres sont rédigés par ces professionnels auxquels se sont ajoutés d'autres contributeurs à la demande des auteurs.

Le point de départ est une volonté de l'État français d'améliorer la gestion des restes humains patrimonialisés issus de fouilles archéologiques, déjà conservés en ostéothèques ou présentés dans les musées. Le but était de mettre en place des protocoles à différents niveaux pour assurer une conservation pérenne et sélective des vestiges anthropobiologiques afin de soutenir au mieux leur valorisation scientifique, leur potentiel pédagogique auprès du grand public et leur transmission aux générations futures. Bien que ces protocoles n'aient pas abouti à une législation spécifique, les réflexions issues des concertations entre professionnels ont permis d'isoler trois thèmes jugés essentiels pour aborder la question des restes humains. Ces trois thèmes sont repris dans les différentes parties du volume et sont « la législation, l'intérêt scientifique et l'éthique » (p.6).

L'ouvrage s'articule en quatre parties, composées de plusieurs chapitres et rassemblant des réflexions autour des textes déontologiques et juridiques concernant les restes humains patrimonialisés, autour de l'intérêt scientifique de ces derniers et autour des exemples français et étrangers en matière de leur gestion et de leur conservation.

La première partie s'intitule « Diversité, apport et intérêt » et aborde très largement l'utilité des collections anthropologiques en France. Les auteurs des différents chapitres ont pour volonté d'expliquer à la fois la valeur scientifique des vestiges anthropobiologiques, leur valeur patrimoniale et pédagogique auprès du grand public et l'importance de leur préservation dans le temps. Ils mettent également en avant les conflits existants entre ces différents aspects qui ont parfois de la difficulté à cohabiter pour une même collection ostéologique et la nécessité de trouver un équilibre entre recherche et conservation. Un des exemples donnés est la volonté de pratiquer des analyses invasives et en partie destructrices, ADN ou isotopiques, sur les ossements et la volonté des mêmes chercheurs de conserver au mieux ces restes pour les analyses futures.

La deuxième partie, « Statut juridique et dimension éthique », se penche sur les différentes lois françaises en lien avec le corps humain, les protocoles funéraires et la protection des vestiges archéologiques. Elle aborde également les questions éthiques en lien avec la présence de restes humains dans les musées, leur valorisation via différentes expositions et les réactions suscitées chez le grand public. Le principal défi qui apparait à la lecture des chapitres est le flou juridique dans lequel se trouvent les restes anthropobiologiques patrimonialisés, issus de fouilles ou de collections muséales. Aucune loi ne cite précisément ces vestiges et ce qu'il est légalement admis ou non de faire avec. Les chercheurs et magistrats doivent composer avec les différents textes de loi pour encadrer les fouilles, l'analyse scientifique, la conservation, l'exposition et la réinhumation des restes humains. Pour cela, ils se réfèrent aux lois nationales et territoriales dont ils citent plusieurs exemples ainsi qu'aux cas de jurisprudence. Ils peuvent également se baser sur les codes éthiques et déontologiques des associations professionnelles nationales et internationales comme ceux de l'ICOM ou du BABAO (2,3) qui répondent au mieux aux questions laissées sans réponse par le Droit, mais n'ont aucune valeur légale. Ces codes appellent au respect du corps

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humain et à l'intégrité de la dignité, tant physique que morale, des individus analysés ou exposés ainsi qu'à la prise en compte des populations descendantes. Mais dans certains cas, cela entre en conflit avec les lois et laisse les professionnels dans l'embarras, comme avec les traités des Nations Unies qui incitent au rapatriement des vestiges aux populations d'origine, ce qui s'oppose à l'aspect légal inaliénable des collections muséales et patrimoniales françaises (4). Cela amène à des conflits entre le grand public, les conservateurs et les instances étatiques, dont certains sont détaillés dans plusieurs chapitres.

La troisième partie « Particularisme des collections ostéo-archéologiques » présente alors la manière dont les différents professionnels pratiquent leur métier en conciliant recherche, conservation, garantie de l'éthique professionnelle et surtout respect dû aux corps humains de toutes provenances et de toutes époques. Certains chapitres abordent des notions plus générales sur la conservation des vestiges et d'autres se concentrent sur des aspects spécifiques de la recherche archéologique et de son interaction constante et essentielle avec l'opinion publique et les représentants locaux de différents groupes sociétaux.

Enfin, la dernière partie, « Réflexions hors de l'hexagone », se penche sur les particularités juridiques d'autres pays et l'application de ces dernières en lien avec la recherche anthropobiologique et l'archéologie funéraire. Sont cités le Portugal et la Belgique et leurs collections identifiées de renommée internationale, le Royaume-Uni et les lois restrictives qui ont amené à une « crise de l'archéologie » durant la dernière décennie et enfin les États-Unis et l'établissement de la loi NAGPRA en lien avec les vestiges anthropobiologiques autochtones.

Chaque chapitre est rédigé de manière à pouvoir se lire de façon isolée et il est donc possible de consulter le recueil en tout temps sans devoir chercher les définitions ou les abréviations dans les premières pages. Il est indéniable que ce recueil compile de manière quasiment exhaustive et très accessible tous les aspects et acteurs intervenant auprès de vestiges humains, tant d'un point de vue scientifique et muséologique que juridique, déontologique et éthique. En cela, bien que la plupart des notions soient expliquées de manière à être comprises même par des non-spécialistes, ce livre s'adresse essentiellement aux professionnels et étudiants en anthropologie biologique, en archéologie, en muséologie et dans une moindre mesure en droit. En effet, il a surtout pour but d'engager une réflexion de leur part sur les conflits internes entre juridiction et codes déontologiques, d'apporter des réponses sur les démarches à suivre pour respecter les individus actuels et ceux du passé et d'harmoniser les pratiques tant archéologiques que muséales à l'échelle nationale pour que chaque vestige humain puisse recevoir le même traitement. L'apport de cet ouvrage dans le domaine de la bioéthique est donc très important, car il réunit en un même recueil les témoignages de tous les corps de métiers en lien avec des situations problématiques et permet de créer des ponts entre les professions qui seront amenées à collaborer de plus en plus sur les collections anthropobiologiques.

Il est cependant important de rappeler que cela concerne le système français et que, bien que très informatif, l'ouvrage ne peut servir que de point de comparaison et non de guide pratique et éthique de ce côté de l'Atlantique, au Canada. Il faut tenir compte des différences historiques et juridiques entre nos deux pays pour pouvoir mieux appréhender toutes les réflexions éthiques, ainsi que des différences de vocabulaire entre professions. Cependant, le livre nous accompagne dans cette démarche en définissant clairement les termes utilisés et en contextualisant beaucoup les différents évènements pris en exemple.

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

Chronique du cinéma 3 : *Tu te souviendras de moi* – quand le récit de soi s'étiole

Nathalie Plaat-Goasdoue[a], Jacques Quintin[a]

Résumé
Édouard perd la mémoire. Le fil du récit de sa vie se dissout, le laissant confus, livré à une forme de solitude qui, graduellement, le coupe d'un monde dans lequel, on le comprend rapidement, il avait plutôt l'habitude d'occuper l'avant-scène. Intellectuel invité régulièrement à prendre parole dans l'espace public, Édouard, l'historien émérite, est ici confronté à une maladie qui, ironiquement, atteint la mémoire. Lui qui, toute sa vie, a réfléchi sa société en la mettant en lien avec son passé, perd peu à peu la capacité à placer sa propre vie sur le fil d'un récit continu. Comment ses proches composent-ils avec la disparition d'une part identitaire d'Edouard? La maladie n'est-elle que l'inverse de la santé, pour lui, ou aussi, un terreau fertile à une transformation qui le rendrait, paradoxalement, plus vivant, au sens ou le philosophe l'entend, dans son expression "vivant jusqu'à a sa mort"? Que reste-t-il de nous lors que notre récit qu'on se fait de nous-mêmes nous échappe? Analyse du film de 2022 de François Archambault : *Tu te souviendras de moi*.

Mots-clés
mémoire, cinéma, maladie, identité narrative, persona, proches-aidants, histoire, récit

Abstract
Édouard loses his memory. The thread of his life's story dissolves, leaving him confused and lonely, and gradually cut off from a world in which, as we soon realize, he was accustomed to taking centre stage. An intellectual who is regularly invited to speak in the public arena, Édouard, the historian emeritus, is confronted with an illness that, ironically, affects his memory. He who, all his life, has reflected on his society by linking it to his past, gradually loses the ability to place his own life on the thread of a continuous narrative. How do those closest to him cope with the disappearance of a part of Edouard's identity? Is illness simply the opposite of health for him, or is it also fertile ground for a transformation that would, paradoxically, make him more alive, in the philosopher's sense of the phrase "alive until dead"? What's left of us when the story we tell ourselves escapes us? Analysis of François Archambault's 2022 film: *Tu te souviendras de moi*.

Keywords
memory, cinema, illness, narrative identity, persona, caregivers, story, narrative

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« Tu te souviendras de moi » (1), film réalisé par Éric Tessier, paru sur nos écrans en 2022, est tiré de la pièce de théâtre écrite par François Archambault, qui a d'abord été jouée sur la scène de La Licorne, à Montréal en 2014. Édouard, le personnage principal, qui avait été campé par Guy Nadon au théâtre, est ici repris par un Rémi Girard qui, fidèle à son habitude, interprète le rôle avec une grande justesse. On y voit un homme au crépuscule de ce qu'il avait toujours tenu pour acquis, comme la plupart d'entre nous, soit sa capacité à raconter, à penser, à se souvenir de sa vie. La maladie, jamais directement nommée, mais pleinement exposée, traverse toutes les scènes, comme elle traverse possiblement dans la vraie vie, tous les espaces occupés par la personne atteinte et ses proches. Les personnages qui gravitent autour d'Édouard, eux aussi directement affectés par les pertes infligées, nous sont aussi révélés dans une authenticité qui échappe aux catégories moralisatrices ou réductrices dans lesquelles le langage commun a tendance à les ranger. Alors que nous présupposons souvent des proches-aidants qu'ils sont affligés, attristés et forcément dédiés à la personne atteinte, nous voyons ici une palette de réactions beaucoup plus complexes et ce, autant chez la fille adulte, Isabelle, incarnée par Julie Le Breton que la femme d'Édouard, Madeleine, jouée par France Castel.

Édouard perd la mémoire. Le fil du récit de sa vie se dissout, le laissant confus, livré à une forme de solitude qui, graduellement, le coupe d'un monde dans lequel, on le comprend rapidement, il avait plutôt l'habitude d'occuper l'avant-scène. Intellectuel invité régulièrement à prendre parole dans l'espace public, Édouard, l'historien émérite, est ici confronté à une maladie qui, ironiquement, atteint la mémoire. Lui qui, toute sa vie, a réfléchi sa société en la mettant en lien avec son passé, perd peu à peu la capacité à placer sa propre vie sur le fil d'un récit continu.

Avec Madeleine, son épouse, nous assistons à la trajectoire d'une femme en colère contre son mari et qui, arrivée au bout d'un dévouement qui, on le devine, a précédé la maladie, craque et le quitte pour un autre homme en pleine santé avec qui elle peut vivre une vie en phase avec son désir. Au même moment, Édouard est paradoxalement habité de manière indéniable par la force de son lien d'amour pour elle. Alors que sa présence au monde « du dehors » s'efface graduellement, Édouard devient en effet de plus en plus habité par les souvenirs de sa vie intime, rejouant en boucle en lui-même les scènes des débuts de son histoire d'amour avec sa femme. On croirait que Madeleine rejoue pour lui la madeleine de Proust! Sans réaliser pleinement ce qui lui arrive (les pertes de mémoire à court terme lui faisant constamment oublier la situation dans laquelle il se trouve), Édouard se voit jeté dans une forme d'errance, dans l'attente que Madeleine revienne, sa Madeleine qui représente pour lui une forme de « maison relationnelle », pour reprendre la formule du psychanalyste Robert Stolorow (2). Une fois les projecteurs extérieurs de sa vie s'éteignant, c'est un peu comme si Édouard accédait à une vérité intérieure potentiellement négligée aux premiers abords de l'existence qu'il avait menée jusqu'à ce jour. Nous pourrions penser à la *persona* de Carl

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Gustav Jung (3) qui, après avoir été presque amalgamée à son identité, se détacherait d'une autre identité plus intérieure qui, elle, se révèlerait au fur et à mesure qu'elle se perdrait, dans une impermanence aussi friable que précieuse. Les souvenirs des amours, des pertes, des liens familiaux devenant alors plus prégnants et chéris que n'importe quelle théorisation, argumentaire, posture médiatique finement ficelée pour Édouard, il se laisse envahir par les souvenirs plus anciens de sa jeunesse pleine de fougue, d'espoirs, de passions qui s'entremêlent aussi aux sursauts de l'histoire collective. Si Édouard établit un rapport intellectuel avec le passé, ce qui est, encore une fois paradoxal, Madeleine désire donner vie à la jeunesse qu'elle porte toujours en elle.

Par le truchement d'une intrigue dans laquelle Édouard doit se faire « garder » pendant le départ de Madeleine et Isabelle, ce dernier fait la rencontre de Bérénice, jeune femme d'à peine 20 ans, un peu désabusée de la vie, qui a accepté de veiller sur lui. Édouard se retrouve ainsi à dialoguer avec la jeunesse contemporaine, alors qu'il est lui-même empli des souvenirs de la sienne. La jeunesse d'aujourd'hui l'inquiète pour son manque de mémoire, ironiquement, mais aussi pour son manque d'attachement à une culture qui se perd, la culture québécoise, dans sa qualité distincte. Dans le message qu'il souhaite livrer à cette jeunesse, nous retrouvons cette forte idée d'une société dotée de gigantesques structures de plus en plus performantes, technologiques, cognitivement redoutables, mais qui se détachent graduellement d'une forme de densité du message, de contenu, d'enracinement dans une identité, une histoire à raconter. C'est là une des forces de ce film que de dresser, par les dialogues, une analogie entre la perte de mémoire d'Édouard et la perte des grands récits caractéristiques de la société postmoderne dans laquelle nous évoluons. La quête actuelle du moment présent telle que portée par le courant de « pleine conscience » se voit ici mise au défi par l'historien qui, se retrouvant condamné au moment présent, prend la mesure de la perte de la conscience d'une existence toujours médiatisée par le récit que nous nous en faisons. Impossible de ne pas invoquer ici la pensée du philosophe Paul Ricoeur et de toute sa réflexion sur la mémoire, l'histoire et l'oubli. Ricoeur disait : « Je reste troublé par l'inquiétant spectacle que donnent le trop de mémoire ici, le trop d'oubli ailleurs, pour ne rien dire de l'influence des commémorations et des abus de mémoire – et d'oubli. » (4) Pour Ricoeur, reprenant la pensée de Maurice Halbwachs, toute mémoire est collective, puisque, pour se souvenir, nous avons besoin d'autrui. La médiation fournie par le récit personnel apparait ainsi comme ces allers-retours incessants entre ce qui pourrait appartenir à « la grande Histoire » telle qu'elle est présentée dans le discours théorique des historiens et toutes « les petites histoires personnelles » dont elle est aussi forcément constituée, histoires elles-mêmes façonnées par l'histoire collective et ainsi de suite.

Ainsi, en se remémorant l'élection du Parti québécois, Édouard raconte que c'est précisément en rentrant chez eux, ce soir-là, que, portés par la liesse collective, Madeleine et lui ont conçu leur deuxième fille, Nathalie. Alors que nous comprenons que sa fille Nathalie n'est plus dans sa vie, nous saisissons aussi combien l'événement politique de l'élection du Parti Québécois, tel que vécu et éprouvé par les jeunes à ce moment de l'Histoire, n'a pas abouti là où ils auraient souhaité qu'il les mène. Nous assistons ainsi à un croisement continu entre le récit de la vie intime d'Édouard, et celui de sa nation. Le référendum perdu de 1980, les espoirs portés puis les revers de l'histoire se juxtaposent sur ses pertes plus personnelles, dont celle de sa fille, évidemment au cœur d'une souffrance qui nous sera révélée graduellement. Encore ici, Ricoeur nous permet de penser une existence constamment vécue comme une médiation, celle du récit, permettant d'allier le temps extérieur au temps intérieur, l'histoire collective à l'histoire personnelle. Cité par Alain Thomasset, Ricoeur dira « le récit est médiation entre la vie et la vie, puisque, se construisant à partir du vivre et du souffrir des hommes, il propose à ses lecteurs une œuvre qui interprète ce vivre et dont l'appropriation peut leur permettre d'agir autrement » (5). Sur le plan éthique, Ricoeur nous permet de saisir à quel point nous créons nos institutions, tout autant que les institutions nous créent. Le thème de l'institution, de son rôle et des enjeux éthiques qu'elle soulève lorsqu'il s'agit d'y placer toutes ces personnes en perte de récits d'eux-mêmes est d'ailleurs au cœur du film. À quel point leur retirons-nous leur droit de parole, de décision, d'influence, au fur et à mesure que leur monde s'efface? Le film contribue ainsi à souligner les profonds enjeux éthiques associés au traitement des personnes en pertes cognitives dans nos sociétés occidentales. De fait, bien qu'Édouard perde la mémoire, bien qu'il soit de plus en plus affecté par la maladie, il ne cesse de répéter qu'il a des choses à dire, qu'il a un message à livrer, qu'il a des choses à raconter. Des longues prises de vues sur des pièces des maisons ou des appartements, vidées de leurs personnages apparaissent comme des métaphores possibles de la maladie, qui dépouille l'intérieur de ses personnages, laissant en nous une impression d'être vidé de soi et des autres, peut-être.

Mais il y aussi un autre questionnement éthique qui est porté par le film, soit celui de la maladie et de l'accompagnement qu'on lui offre. La maladie est présentée dans son aspect double, c'est-à-dire, à la fois comme l'inverse de la santé, mais aussi comme le terreau fertile à des transformations, à des révélations, à des processus qui pourraient aussi être positifs. Le langage autour de la maladie se trouve ainsi mis au défi par le film, qui, par une sorte de procédé herméneutique, nous amène à prendre conscience des cases langagières dans lesquelles nous classons les réalités associées aux maladies dégénératives, à la « vérité » de nos récits, à ce qu'il est juste d'offrir comme présence et accompagnement aux personnes atteintes. Par la rencontre d'humain à humain qui se tisse entre Édouard et Bérénice, nous traversons toute une série de questionnements sur ce qui constitue le cœur d'une posture d'accompagnement. De fait, la réalité d'Édouard dépend de la constance d'autrui qui peut le voir, l'entendre et donc témoigner de sa présence, jusqu'à la fin de sa vie. Nous voyons un homme qui ne cesse de penser ou qui ne cesse de vouloir comprendre. C'est cette activité qui le maintien vivant malgré les pertes de mémoire. On croirait revoir Titus, dans la pièce *Bérénice* de Racine, qui demeure constant et ferme dans sa position face au monde : penser, pour Édouard, c'est sa manière d'affirmer sa gloire (6).

À aucun moment, Bérénice n'est vue dans une activité de « prise en charge », contrairement à ce qui est habituellement compris comme étant « la chose à offrir » dans nos institutions. Bérénice ne prodigue aucun soin, ne fait rien, sinon donner une parole à Édouard en l'écoutant. C'est l'attention qu'elle porte à ce dernier qui le rend réel. La présence de Bérénice le confronte, ce qui le pousse à aiguiser sa pensée. C'est par son altérité qu'elle fait aussi émerger sa présence.

Graduellement, un monde s’installe entre Bérénice et Édouard, une vie qui transcende la vie biologique. Leur relation repose sur une activité de penser ensemble le monde, sur le dialogue et sur la présence qui peut rappeler le « holding » (contenance) du psychiatre Donald Winnicott (7), si différent du « handling » qui serait, lui, la prodigation de soins plus concrets, techniques et qui traverse l’ensemble des structures de soins de nos institutions. La réflexion sociale sur la posture d’accompagnement est ainsi soulevée comme si le film démontrait sur quoi peut reposer une relation de soin, en dehors de ce qui, de manière générale, le définit. Alors qu’Édouard confond Bérénice avec sa fille perdue, Nathalie, elle accepte de « jouer le jeu », de porter le chandail rouge qu’il lui remet, sans le confronter dans sa perception. Nous arrivons ainsi à nous demander ce qui constitue « la vérité » et à quel point il importerait de ramener Édouard dans « la vraie histoire » et non celle qu’il se raconte pour demeurer vivant.

Par ailleurs, alors qu’Édouard se transforme aux côtés de Bérénice, la jeune femme semble, elle aussi, s’incarner dans sa propre vie comme jamais en côtoyant l’homme; elle devient femme incarnée dans un corps fait de désirs, et se sent utile, donnant du coup un sens à sa vie. Bérénice amène du désordre, symbole ici de vie. Un clin d’œil supplémentaire à la pensée de Winnicott (8) est encore possible ici, ce dernier ayant insisté sur combien la vie psychique repose sur « le jeu », soit la capacité à habiter un espace entre le réel et l’imaginaire, dans une forme de médiation qui permet de s’incarner. Nietzsche l’avait déjà souligné, il suffit d’un peu de mensonge pour ne pas mourir de la vérité (9) : une vie riche en libido pour Madeleine et le devoir moral de protéger son père pour Isabelle.

Le « jeu » de Bérénice, jugé comme déraisonnable, voire une forme de folie, provoque la désapprobation d’Isabelle, placée à nouveau devant la douleur de la perte de sa sœur et la certaine invisibilité dans laquelle elle se trouve aussi. Journaliste de carrière, elle choisit néanmoins d’aller couvrir les inondations dans un coin reculé du Québec, plutôt que d’être aux côtés de son père et d’affronter comment cette situation l’inonde de pensées et d’émotions. L’image de la professionnelle, prise par le souci de prendre des décisions rationnelles, qui s’applique à « rapporter des faits », rappelle la posture possible du père qui a privilégié sa carrière plutôt que ses liens intimes, tout en posant la question de ce qui compte au fond : les faits ou le récit subjectif. Mais elle n’échappe pas à la réalité de son monde intérieur, tous les affects refaisant surface, un peu comme une inondation qui attirerait notre attention sur les pans négligés de nos vies, de manière incontournable.

Dans ce film, la maladie est présentée dans ce qu’elle contient de possibles ouvertures sur des mondes jusque-là insoupçonnés. L’existence d’Édouard possède encore une valeur. Même en perte de mémoire, il travaille à « rester vivant jusqu’à sa mort » (10). C’est pourquoi, il refuse le suicide ou autre forme d’en finir avec la vie. Édouard, à son insu, sert de guide spirituel à Bérénice. Le temps ne peut plus détruire leur amour, même s’il amenuise les capacités cognitives.

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