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Han Han Li

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Enjeux éthiques à l'utilisation éventuelle de prédictors des préférences du patient pour soutenir la prise de décision substituée

Gina Bravo^{a,b}, Louise Bernier^{c,d}

Résumé

En 2010, Annette Rid et David Wendler proposaient que soient développés des prédictors des préférences du patient (PPP) pour guider les décisions de soins pour une personne inapte dont les volontés sont inconnues. Un PPP serait construit à partir des corrélations observées entre les préférences de soins et les caractéristiques sociodémographiques de répondants à un sondage. Il serait ensuite utilisé pour prédire les volontés inconnues du patient sur la base de ses propres caractéristiques. Un PPP pourrait améliorer la capacité à fournir aux patients incapables des soins qui correspondent à leurs préférences, en plus d'atténuer la détresse que ressentent de nombreux décideurs substitués en raison de l'incertitude quant aux volontés du patient. Malgré ces attraits, de nombreuses objections au PPP ont été formulées au cours des 15 dernières années. Nous souhaitons mieux comprendre le débat éthique entourant ces outils d'aide à la décision, afin de déterminer s'il est opportun d'en entreprendre le développement. S'appuyant sur un modèle conceptuel de la prise de décision en contexte de démence, nous avons analysé 65 publications traitant d'enjeux éthiques associés au PPP. Les enjeux relevés ont été catégorisés selon le principe éthique auquel ils se rattachent. Nous concluons en faveur du développement de PPP, en autant qu'ils servent à soutenir, et non à remplacer, les décisions humaines. Nous soulignons ensuite le besoin d'évaluer leur acceptabilité sociale et leur performance réelle sur le terrain. Enfin, nous proposons des mesures susceptibles de réduire les risques associés à leur utilisation et de renforcer la confiance des utilisateurs.

Mots-clés

prise de décision, soins de fin de vie, inaptitude décisionnelle, consentement substitué, principlisme, autonomie relationnelle, bienfaisance/non-malfaisance, justice

Abstract

In 2010, Annette Rid and David Wendler proposed the development of patient preference predictors (PPPs) to guide care decisions for incapacitated individuals whose wishes are unknown. A PPP would be built using observed correlations between care preferences and the sociodemographic characteristics of survey respondents. It would then be used to predict a patient's unknown wishes based on their own characteristics. A PPP could improve the ability to provide incapacitated patients with care that aligns with their preferences, while also alleviating the distress experienced by many surrogate decision-makers due to uncertainty about the patient's wishes. Despite these advantages, numerous objections to PPPs have been raised over the past 15 years. We sought to better understand the ethical debate surrounding these decision-support tools in order to determine whether their development is appropriate. Drawing on a conceptual model of decision-making in the context of dementia, we analyzed 65 publications addressing ethical issues associated with PPPs. The identified issues were categorized according to the ethical principles to which they relate. We conclude in favour of developing PPPs, provided they are used to support rather than replace human decision-making. We then highlight the need to assess their social acceptability and real-world performance. Finally, we propose measures that could reduce the risks associated with their use and strengthen users' trust.

Keywords

decision-making, end-of-life care, decisional incapacity, substitute decision-making, principlism, relational autonomy, beneficence/non-maleficence, justice

Affiliations

^a Faculté de médecine et des sciences de la santé, Université de Sherbrooke, Sherbrooke, Québec, Canada

^b Centre de recherche sur le vieillissement, CIUSSS de l'Estrie – CHUS, Sherbrooke, Québec, Canada

^c Faculté de droit, Université de Sherbrooke, Sherbrooke, Québec, Canada

^d Centre de recherche sur la régulation et le droit de la gouvernance, Université de Sherbrooke, Sherbrooke, Québec, Canada

Correspondance / Correspondence: Gina Bravo, Gina.Bravo@USherbrooke.ca

INTRODUCTION

Le nombre de personnes qui vivent avec un trouble neurocognitif, communément appelé démence, est en croissance au Canada en raison du vieillissement de la population et de l'absence de traitement efficace. D'ici 2050, 1,7 million de Canadiens pourraient en être atteints (1). Aux premiers stades du trouble, la personne atteinte requiert peu d'aide pour accomplir ses activités quotidiennes et elle conserve l'aptitude à exprimer ses valeurs et préférences (2). Toutefois, à mesure que les symptômes s'aggravent, la personne perd progressivement ses capacités fonctionnelles et cognitives, dont celle de prendre des décisions qui la concernent. Lorsqu'un problème de santé survient alors que le patient ne peut plus communiquer ses volontés, un proche est généralement appelé à décider en son nom (3). Ce sera notamment le cas lorsque le patient n'aura pas laissé de directives écrites quant à la manière dont il souhaite être soigné advenant son incapacité.

Le souhait que ses préférences de soins soient respectées en cas d'incapacité est largement répandu (4-6). Des dispositifs existent pour indiquer d'avance ses préférences, comme les directives médicales anticipées (DMA) introduites au Québec par la Loi concernant les soins de fin de vie (7). Ces dispositifs sont toutefois peu utilisés (8,9)¹ et comportent des faiblesses qui limitent leur potentiel réel à prolonger l'autonomie décisionnelle de l'auteur (10-13). À titre d'exemple, les DMA étant limitées à quelques interventions et situations de fin de vie, elles ne couvrent pas l'éventail de décisions susceptibles d'être prises pour un patient inapte. En l'absence d'indications claires des volontés du patient, la pratique clinique actuelle demande d'abord au décideur substitut – un proche le plus souvent – de tenter de prendre la décision que le patient aurait prise lui-même, soit d'appliquer la norme du jugement substitué; s'il s'en dit incapable, on l'invitera plutôt à appliquer la norme du meilleur intérêt (14,15). Or, des études révèlent : 1) que les proches peinent à prendre des décisions conformes aux volontés du patient (16-18); 2) qu'il n'est pas toujours possible pour l'équipe soignante d'identifier l'option thérapeutique qui promeut le mieux les intérêts cliniques du patient (19,20); et 3) que la prise de décision substituée est génératrice de stress et d'anxiété pour les proches (21). Comment, alors, maximiser la probabilité que le patient soit pris en charge comme il l'aurait souhaité, tout en réduisant le fardeau de ses proches?

En réponse à cette question, Annette Rid et David Wendler proposent de bonifier le processus décisionnel actuel en y intégrant le résultat d'un prédicteur des préférences du patient (PPP) (19,22,23). Un PPP est un algorithme pour prédire comment un patient donné souhaiterait être soigné, à partir de la façon dont d'autres personnes possédant les mêmes caractéristiques sociodémographiques que lui souhaiteraient être soignées si elles se trouvaient un jour dans des circonstances similaires à celles du patient. Par exemple, un PPP pourrait révéler que 75 % des femmes de 80 à 90 ans, qui détiennent un diplôme de premier cycle universitaire, ne souhaiteraient pas être alimentées artificiellement si elles souffraient de dysphagie (difficulté à avaler) alors qu'elles auraient définitivement perdu l'aptitude à consentir aux soins.

Trois études révèlent que de rendre ce type d'information accessible aux personnes impliquées dans le processus décisionnel pourrait augmenter la chance que le patient inapte soit soigné comme il l'aurait souhaité, en plus d'atténuer le fardeau des proches appelés à décider en son nom (24-26). Trois autres études suggèrent que les patients, les décideurs substituts et les soignants pourraient approuver l'utilisation d'algorithmes prédictifs pour soutenir la prise de décision substituée dans laquelle ils sont personnellement impliqués (27-29). Or, malgré ses bénéfices escomptés et l'accueil favorable qu'il a reçu de la part d'utilisateurs potentiels, aucun PPP n'a encore été développé (30,31). Serait-ce dû aux enjeux éthiques que soulève l'utilisation éventuelle de PPP en clinique (30-33)? Cet outil d'aide à la décision fait l'objet de débat dans la littérature scientifique depuis près de 15 ans. À notre connaissance, aucune synthèse des arguments émis par ses partisans et ses opposants n'a été produite à ce jour. Il demeure ainsi difficile de se prononcer sur l'opportunité de développer des PPP pour les déployer ensuite dans le réseau de la santé.

La présente étude cherchait à mieux comprendre le débat éthique autour des outils prédictifs des préférences de soins, en dressant un inventaire structuré des arguments pour ou contre leur utilisation (34,35). La question de recherche se lit comme suit : *Chez les patients inaptes à consentir aux soins en raison d'une démence avancée, qui n'ont pas laissé de directives claires susceptibles d'orienter le décideur substitut et l'équipe soignante vers l'option thérapeutique souhaitée, l'intégration du résultat d'un PPP au processus décisionnel est-elle souhaitable compte tenu des enjeux éthiques associés?* En fournissant un premier relevé des principaux obstacles à l'utilisation de PPP, l'étude contribue à l'avancement des connaissances sur un nouveau mode de prise de décision qui ne fait pas l'unanimité actuellement. Elle met par ailleurs en lumière le potentiel de ces algorithmes à mieux servir les intérêts de patients fragilisés par l'incapacité et à décharger les proches d'une partie du poids décisionnel qu'ils doivent porter.

L'article comprend quatre sections principales. La première explicite le concept de PPP, tandis que la deuxième présente le modèle conceptuel mobilisé pour répondre à la question de recherche. Le cadre méthodologique est ensuite exposé, suivi des résultats. Partant des constats qui se dégagent de la documentation analysée, la discussion présente différentes justifications pour développer puis implanter des outils prédictifs de préférences de soins. Des moyens susceptibles d'apaiser certaines inquiétudes liées à leur utilisation et des pistes de recherche future sont finalement proposés.

LE PRÉDICTEUR DES PRÉFÉRENCES DU PATIENT : DE QUOI S'AGIT-IL?

C'est en 2010 que Rid et Wendler (19) introduisent l'idée de recourir à un prédicteur des préférences du patient (PPP) pour soutenir la prise de décision substituée. Leur proposition s'inscrivait dans le contexte où le patient, devenu inapte, n'a pas laissé de directives quant à la manière dont il souhaiterait être traité en cas d'incapacité – ou pas de directives claires pour la situation clinique dans laquelle il se trouve – et où l'équipe soignante peine à déterminer l'option thérapeutique qui est dans son meilleur intérêt. Pensons, par exemple, à une personne atteinte de démence avancée qui contracte une grave pneumonie : Devrait-on lui administrer des antibiotiques par voie intraveineuse? L'intuber temporairement si elle respire avec difficultés?

Un PPP est un algorithme qui permettrait de prédire, avec une certaine précision, ce que le patient aurait voulu dans les circonstances – par exemple, de recevoir ou non des antibiotiques – à partir des préférences exprimées par des personnes

¹ Par exemple, au 31 mars 2024, 149 143 Québécois avaient enregistré des DMA, soit 2,1 % des personnes majeures. Données obtenues le 23 avril 2024 du MSSS par Louise Bernier à la suite d'une demande d'accès à l'information.

possédant les mêmes caractéristiques à l'occasion d'un sondage conçu à cette fin (19,22,23). Il s'agit donc d'une méthode actuarielle qui consisterait à mesurer les caractéristiques d'un ensemble de personnes et leur volonté de subir ou non différentes interventions de prolongation de la vie dans un contexte (hypothétique) d'incapacité. L'analyse statistique des données produirait une équation mathématique liant les caractéristiques aux préférences. Devant un patient inapte dont la situation clinique est complexe et teintée d'incertitudes, le médecin entrerait dans l'équation des informations connues sur le patient (son âge, son niveau d'éducation, etc.) pour en extraire la probabilité qu'il ait accepté ou refusé une intervention donnée s'il avait été en mesure de communiquer. Par exemple, le PPP pourrait prédire, sur la base de la situation clinique et des caractéristiques du patient, qu'il y a de fortes chances qu'il souhaite recevoir des antibiotiques intraveineux pour soigner une pneumonie qui menace sa vie. Dans un autre cas, le résultat pourrait suggérer que le patient ne souhaite probablement pas être ventilé artificiellement.

Conceptuellement, un PPP s'apparente à un algorithme créé par apprentissage automatique (*machine learning*). Les algorithmes développés pour la médecine par intelligence artificielle reposent sur une multitude de variables provenant de milliers de dossiers cliniques informatisés. Ce n'est pas tout à fait ce qu'envisagent Rid et Wendler, mais l'objectif est le même, soit d'obtenir une prédiction qui soit la plus fiable possible. Une distinction mérite toutefois d'être soulignée entre les deux approches : celle de Rid et Wendler reposerait sur des préférences exprimées en contexte hypothétique, tandis qu'un algorithme construit à partir de dossiers médicaux utilise des informations liées aux traitements que des patients ont réellement reçus.

Inquiets du rythme avec lequel l'intelligence artificielle se développe, des spécialistes exhortent les élus à légiférer rapidement dans le domaine afin de contrer les risques associés à cette technologie émergente (36,37). D'autres experts, en revanche, y voient un moyen prometteur pour améliorer la prise de décision substituée (30,38-40). Pourvu que les lois en vigueur l'autorisent, que des mesures de protection soient mises en place et que les permissions nécessaires aient été obtenues, certains commentateurs proposent même d'exploiter tout le corpus de texte produit par une personne (ses courriels, billets de blog, publications sur les réseaux sociaux), en plus de ses réponses à un sondage et des données contenues dans son dossier médical, pour inférer ses préférences de soins avec un haut degré de précision (31,41). L'algorithme ainsi obtenu serait alors personnalisé, plutôt que basé sur des données populationnelles; il permettrait de découvrir ce que la personne elle-même aurait voulu, plutôt que ce qu'auraient voulu des personnes comme elle.

Que l'algorithme origine d'un sondage ou d'autres sources, Rid et Wendler (22,42) soutiennent que d'intégrer le résultat qu'il génère au processus décisionnel permettrait mieux de respecter les principes qui devraient guider la prise de décision substituée que ne le fait la pratique clinique actuelle. Ils identifient six principes :

1. Promouvoir les intérêts cliniques du patient;
2. Permettre au patient de contrôler la manière dont il est traité;
3. Offrir un traitement conforme aux préférences et aux valeurs du patient;
4. Respecter la façon dont le patient souhaite que les décisions soient prises;
5. Soutenir les proches du patient; et
6. Favoriser une prise de décision rapide.

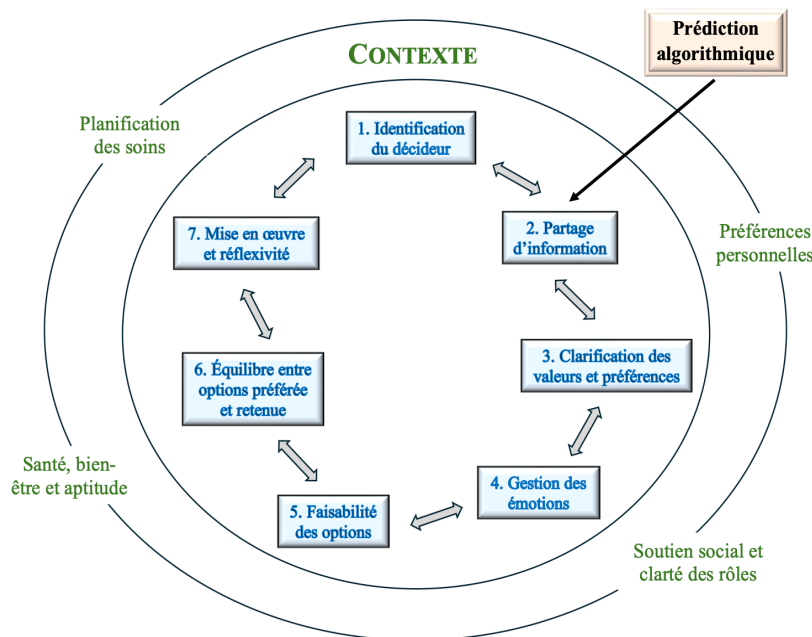
Des données préliminaires suggèrent en effet que des prédictions algorithmiques hautement individualisées des préférences de soins pourraient être plus précises que celles des décideurs substitués, tout en réduisant leur détresse émotionnelle (24-26). En outre, de telles prédictions pourraient contribuer à réduire la fréquence de conflits intrafamiliaux sur la manière de soigner un proche en fin de vie (43), favorisant une prise de décision plus rapide et un deuil plus serein si la décision entraînait le décès du patient (44).

Ces considérations incitent à développer des algorithmes prédictifs de préférences de soins pour les implanter ensuite en clinique. Mais au préalable, il importe d'avoir une vision d'ensemble des enjeux éthiques que cela soulève. Le modèle conceptuel mobilisé à cette fin, dans lequel notre objet d'étude – le PPP – s'insère naturellement, est présenté ci-dessous.

MODÈLE CONCEPTUEL

Reproduit à la figure 1, le modèle de Davies et al. (45) rend compte de la complexité du processus de prise de décision lorsqu'il concerne une personne atteinte de démence. Inspiré du *Interprofessional Shared Decision Making Model* (IP-SDM) de Légaré et al. (46), il a été développé à partir d'entretiens semi-dirigés réalisés auprès de 21 proches aidants et de 11 personnes atteintes de démence mais toujours aptes à s'exprimer. Les entretiens visaient à mieux comprendre le processus décisionnel et à identifier les facteurs contextuels susceptibles d'influencer les décisions qui sont prises.

Figure 1 : Modèle conceptuel de la prise de décision de soins en contexte de démence, adapté à l'étude des enjeux éthiques associés aux algorithmes prédictifs de préférences de soins



Le modèle de Davies et al. intègre quatre facteurs contextuels d'influence majeure :

- Les préférences personnelles, y compris celle de ne pas discuter de ses volontés de fin de vie;
- La planification préalable des soins, laquelle peut comprendre la désignation d'un représentant;
- La perception de la santé physique, du bien-être psychologique et de l'aptitude décisionnelle de la personne atteinte de démence;
- Le soutien de l'entourage et la clarté des rôles.

Il décompose ensuite le processus décisionnel en sept étapes interdépendantes :

1. Identification du décideur et des autres personnes impliquées dans la décision (membres de la famille, soignants et la personne atteinte tant que cela est encore possible);
2. Partage d'information;
3. Clarification des valeurs et des préférences de chacun;
4. Gestion des émotions (celles de la personne atteinte, du décideur substitut et des autres personnes impliquées);
5. Examen de la faisabilité des options, en tenant compte de leurs impacts possibles sur le bien-être physique et émotionnel des proches;
6. Recherche d'un équilibre entre l'option préférée et celle retenue;
7. Mise en œuvre de la décision et réflexion quant à ses implications.

Plusieurs raisons motivent notre préférence pour ce modèle. Il est spécifique au contexte de la démence et couvre tant les situations où la personne atteinte peut encore participer aux décisions entourant ses soins, que celles où elle n'a pas communiqué ses préférences de soins avant de devenir inapte. Il convient à un éventail de décisions, y compris celles relatives aux soins de fin de vie. Adapté d'un modèle bien établi, il combine le point de vue de proches aidants et de personnes atteintes de démence à celui de professionnels de la santé. En outre, comparé au IP-SDM qui a été développé pour les soins primaires, le modèle de Davies et al. s'applique tout autant en milieu de soins prolongés où les personnes atteintes de démence avancée terminent généralement leur vie. Enfin, il ajoute au IP-SDM une étape de prise en compte de l'impact des décisions sur l'ensemble des personnes impliquées, reconnaissant ainsi la dimension relationnelle de l'autonomie (47-50) et le désir presque universel des patients de ne pas nuire à leurs proches (51).

À ces motifs s'ajoute la possibilité qu'offre ce modèle d'y intégrer le PPP, à l'étape du partage d'information. Aux acteurs traditionnellement au cœur de la prise de décision partagée (le patient, ses proches et des soignants), se greffe ainsi un quatrième acteur potentiel – la société (dont la perspective est captée par le PPP) – qui pourrait jouer un rôle utile en cas d'impasse thérapeutique.

MÉTHODOLOGIE

Nous avons mené une analyse de contenu des écrits scientifiques publiés depuis 2010 qui traitent d'aspects éthiques liés aux prédictors des préférences du patient (PPP). Les publications analysées ont été repérées dans les banques de données bibliographiques (PubMed principalement) au moyen des mots-clés *patient preference predictor*, *algorithm ou prediction rule croisés avec end-of-life care*, *dementia/Alzheimer's disease/neurocognitive disorder* ou *incapacitated/incompetent*. Une recherche par auteurs (Annette Rid et David Wendler) a également été effectuée. La première recherche bibliographique a été effectuée à l'été 2023. La liste des références des publications sélectionnées a été parcourue pour y repérer d'éventuels articles manqués. Les requêtes ont été relancées le 1^{er} avril 2025 afin de retracer les derniers documents publiés sur le PPP. Les publications retenues ont été téléchargées et regroupées dans un répertoire dédié pour en faciliter la gestion et le codage.

Le codage a débuté avec une série de quatre codes principaux (de premier niveau) déterminés *a priori* en fonction de la grille d'analyse décrite ci-dessous. Graduellement, des codes secondaires (de second niveau) ont émergé, générés de façon inductive après une lecture répétée de chaque document. Les codes étaient accompagnés de leur définition respective qui, elle aussi, a évolué au fil de l'analyse. Des extraits tirés du corpus analysé serviront plus loin à les illustrer.

Grille d'analyse

Le principisme de Tom Beauchamp et James Childress (52) a été mobilisé pour relever dans la documentation assemblée, puis catégoriser, les enjeux éthiques que soulève l'intégration de PPP au processus décisionnel. D'inspiration à la fois utilitariste et kantienne, ce cadre de référence est constitué de quatre principes généraux mais abstraits : le respect de l'autonomie (l'obligation de respecter les capacités décisionnelles des personnes autonomes), la bienfaisance (un ensemble d'obligations visant à maximiser les bénéfices par rapport aux risques), la non-malfaisance (l'obligation d'éviter de nuire) et la justice (un ensemble d'obligations visant à répartir équitablement les bénéfices, les fardeaux et les risques). Ces principes servent de points de départ à la résolution d'un dilemme éthique. Dans leur application concrète à une situation donnée, ils nécessitent d'être spécifiés en les reliant aux circonstances particulières de la situation (une impasse thérapeutique, par exemple) et ils devront être arbitrés s'ils entrent en conflit les uns avec les autres.

Le processus de spécification vise à réduire le caractère indéterminé des principes en clarifiant quand, où, pourquoi, comment, sur qui et par qui l'action doit être effectuée ou évitée. Il consiste en l'ajout de contenus descriptifs et de règles qui donneront aux principes une capacité accrue de guider l'action tout en conservant l'engagement moral envers les normes originales. On pourrait, par exemple, spécifier le principe du respect de l'autonomie en exigeant que la directive anticipée d'un patient devenu inapte soit suivie lorsqu'elle s'applique clairement à sa situation clinique actuelle. Comme autre exemple, le principe de justice pourrait être spécifié en adoptant une règle qui interdit la distribution de ressources médicales en fonction de l'origine ethnique.

Par ailleurs, les principes n'étant pas classés *a priori* en fonction de leur importance, l'un peut primer sur les autres ou être surpassé par d'autres dans des circonstances particulières. Un arbitrage est nécessaire lorsqu'ils sont en conflit. Des conflits peuvent survenir, par exemple, entre la bienfaisance dans le traitement d'un patient particulier et le respect de ses choix autonomes (pensons au refus d'une transfusion sanguine par un témoin de Jéhovah), ou encore, entre la protection des informations médicales concernant un patient atteint d'une maladie contagieuse grave et la bienfaisance envers des tiers à risque d'être infectés. Le processus d'arbitrage vise à déterminer la force relative de normes morales conflictuelles dans des cas particuliers, afin d'identifier le principe à prioriser. Ainsi, si un patient doit être traité pour rester en vie mais refuse toute intervention, l'équipe soignante qui se baserait exclusivement sur le principisme devrait déterminer si la bienfaisance ou le respect de l'autonomie est l'obligation prédominante².

En résumé, les processus de spécification et d'arbitrage qui s'opèrent au sein du principisme cherchent à atténuer l'indétermination et d'éventuels conflits entre les quatre principes de base dans le but d'accroître la cohérence morale de la solution choisie. Très utilisé en médecine où il domine largement (54,55), le principisme est aussi utilisé en santé publique (56), pour encadrer la recherche avec des êtres humains (57) ou pour comprendre des phénomènes sociaux aussi variés que le don d'organes et le partage de seringues entre toxicomanes (58)³.

Concept-clé en bioéthique contemporaine, l'autonomie est classiquement comprise comme la capacité de prendre des décisions par soi-même, pleinement éclairées et sans pression externe. Une décision est autonome lorsqu'elle est authentiquement intentionnelle, libre de toute interférence de la part des professionnels de la santé, des proches ou de la société en général, et prise par un agent apte et suffisamment informé (47). Cette interprétation individualiste de l'autonomie a été critiquée pour ne pas reconnaître la nature profondément sociale et relationnelle des personnes (63). La nécessité de reconceptualiser la notion d'autonomie en termes relationnels émane aussi d'études empiriques ayant montré qu'une approche décisionnelle exclusivement centrée sur l'exercice individuel de l'autonomie ne reflète pas adéquatement les préférences et les expériences de soins des patients, notamment en fin de vie (48).

² L'application très directe du droit québécois, et en particulier des articles 3 et 11 du Code civil du Québec, imposerait plutôt une seule avenue : de respecter le refus de traitement après s'être assuré que le patient est bien apte à consentir et que son refus est bien libre et éclairé (53).

³ Pour d'autres exemples d'application du principisme à l'analyse éthique de questions controversées, voir Meslin, Sutherland, Lavery et Till (59), Quinn, Stearsman, Campo-Engelstein et Murphy (60), Hall et Smithard (61), ou encore, Monteverde (62).

Reconnaître une dimension relationnelle à l'autonomie est particulièrement pertinent lorsque la prise de décision médicale se déroule en contexte de démence. Parce que la personne atteinte perd inéluctablement ses fonctions cognitives, une transition vers une plus grande implication des proches dans le processus décisionnel est nécessaire (50). Les problèmes de mémoire, par exemple, sont souvent portés à l'attention d'un médecin par des proches plutôt que par les patients eux-mêmes. Les informations qu'ils fournissent aident alors le médecin à établir le diagnostic et le plan de soins. Mais les proches fournissent également des informations sur la façon dont, eux-mêmes, vivent la démence du patient et sur les contre coups qu'ils subissent (49). Les besoins et les intérêts des proches s'entremêlent ainsi à ceux du patient lors de la rencontre clinique. Certes, l'équipe soignante doit rester vigilante et s'assurer que les souhaits des proches ne vont pas à l'encontre des intérêts du patient. Par exemple, une famille pourrait demander l'interruption de traitements vitaux parce qu'elle bénéficiera financièrement du décès du patient (64,65). Une autre insistera au contraire pour que toutes les mesures soient déployées afin de prolonger la vie du patient, incapable de se résoudre à le laisser partir (66). Les professionnels de la santé ressentent généralement une certaine responsabilité envers les besoins du patient et de la famille mais, dans les cas où ceux-ci entrent en conflit, la priorité doit être accordée au patient (47,64,66-68). Ils devront alors prêter une attention particulière aux signes potentiels d'abus et de négligence, comme le refus explicite de la famille de prendre en compte le bien-être du patient (69).

Cela dit, promouvoir l'autonomie relationnelle du patient dans la prise de décision clinique nécessite de considérer sérieusement les intérêts de ses proches (68,69). De nombreux patients se soucient profondément de l'impact des décisions qui seront prises sur ceux avec qui ils ont développé des relations significatives au fil du temps (65,70,71). Le bien-être des proches et leur niveau de confort avec le plan de soins proposé constituent d'importantes préoccupations pour la plupart des patients et ces éléments font partie de leurs réflexions et décisions de soins individuelles. D'ailleurs, nombreuses sont les personnes en fin de vie, mais toujours aptes à décider par elles-mêmes, qui changent leurs préférences de soins pour accommoder celles de leurs proches et alléger ainsi leur détresse (65-73). En reconnaissant qu'ils prennent des décisions de soins en étant construits et habités par ces relations humaines significatives, ils incarnent le principe d'autonomie relationnelle. Par exemple, un patient qui refuse initialement toutes interventions de prolongation de la vie, optant plutôt pour des soins palliatifs, pourra changer d'idée et accepter de subir des traitements agressifs devant la difficulté de ses proches à reconnaître l'imminence du décès. Un autre pourra refuser une sédation palliative continue à l'insistance de sa famille qui souhaite pouvoir interagir avec lui le plus longtemps possible (72). Des analgésiques continueraient alors à lui être administrés pour apaiser ses souffrances, mais pas à des doses susceptibles de provoquer une baisse de conscience (68). Les soignants peuvent être troublés par un patient qui choisit de poursuivre son traitement malgré un mauvais pronostic dans l'unique but d'alléger le fardeau émotionnel de ses proches (66,71). Le cas échéant, ils doivent néanmoins s'abstenir de présumer que le patient est manipulé ou victime de coercition; il est peut-être simplement en train d'exercer son autonomie relationnelle en toute liberté et cohérence avec ses valeurs. Dans la plupart des cas, l'intention de la famille n'est pas de causer du tort; ses demandes témoignent plutôt du chagrin qu'elle ressent à l'idée de perdre un être cher (68,69).

Une préoccupation pour le bien-être des proches s'observe également chez les personnes qui rédigent des directives anticipées. Bien que certaines veulent que leurs directives soient strictement suivies, plusieurs autres souhaitent accorder une certaine latitude à ceux qui décideront en leur nom (70). L'octroi d'une marge de manœuvre au décideur substitut ne doit pas être considéré comme une révocation du pouvoir décisionnelle (64); il témoigne plutôt de l'intérêt de la personne pour ceux à qui elle a confié une lourde responsabilité (11,63,70,74,75).

L'intégration dans le processus décisionnel de l'intérêt réel que porte un patient au bien-être de ses proches est plus complexe dans la situation qui nous occupe, soit celle d'un patient inapte dont on ne connaît pas les volontés à cet égard. En décidant pour un tiers, un décideur substitut pourrait défendre ses propres intérêts, traitant injustement un patient inapte qui, s'il était apte, choisirait d'ignorer les intérêts des membres de sa famille. Comme le souligne Jeffrey Berger (70), cette situation est particulièrement troublante dans le contexte où les intérêts des patients et ceux de ses proches sont considérés comme distincts et concurrents. Écarter l'importance que les patients accordent généralement au bien-être de leurs proches en raison de préoccupations concernant un éventuel comportement inapproprié de la famille déforme la probabilité de préjudice et entre en conflit avec le postulat qui sous-tend la prise de décision substituée en médecine, à savoir que les familles sont généralement dignes de confiance.

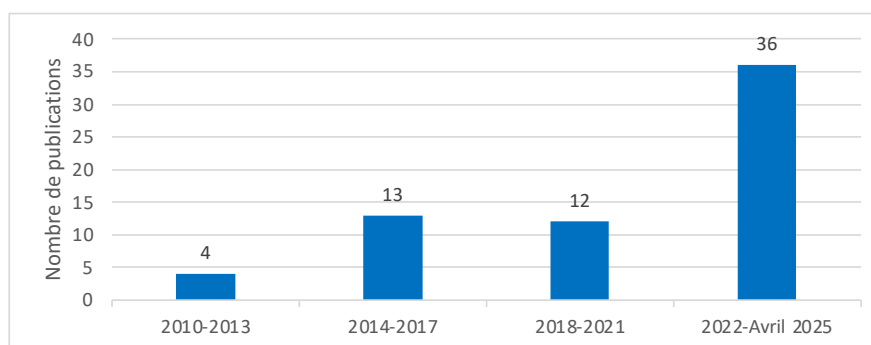
Reconnaître les situations de comportements familiaux inappropriés demeure néanmoins un défi, surtout lorsque les soignants n'ont pas eu l'occasion de rencontrer le patient avant qu'il devienne inapte et qu'ils ignorent comment se prennent les décisions au sein de la famille, ses valeurs culturelles et autres facteurs qui influent sur le processus décisionnel (69,73). Il pourra alors être nécessaire d'établir un dialogue avec la famille pour d'abord découvrir ses préoccupations et motivations profondes, clarifier ses attentes et corriger toutes perceptions erronées relatives au pronostic du patient, à sa qualité de vie et à son espérance de vie. L'équipe soignante pourra ensuite explorer avec la famille les différentes options qui peuvent promouvoir les intérêts de toutes les parties impliquées (66,68,69,73). Les proches du patient pourront alors accepter plus facilement, par exemple, de ne pas prolonger la mort en imposant un traitement qui ne modifierait pas l'issue ni n'améliorerait la qualité de vie du patient à ce stade avancé de sa maladie (67,73).

En résumé, du fait qu'elle reflète mieux la réalité sociale de la prise de décision pour un patient inapte, la perspective relationnelle de l'autonomie nécessite donc d'élargir la conception dyadique de la relation clinique pour y inclure les proches du patient. Pour analyser les enjeux éthiques associés au PPP, nous avons donc considéré la dimension relationnelle de l'autonomie, sans toutefois écarter totalement la perspective individuelle. Dit autrement, notre adhésion au concept d'autonomie relationnelle n'est pas un rejet de l'individualité de chaque patient (64). L'entourage du patient a aussi été pris en compte dans l'analyse des autres principes éthiques, notamment de la bienfaisance et de la non-malfaisance. Cet élargissement de la perspective s'arrime parfaitement avec le modèle conceptuel que nous avons adopté, qui reconnaît le rôle grandissant des proches dans la prise de décision pour une personne qui perdra progressivement la capacité à décider par elle-même.

RÉSULTATS

Au total, 65 articles ont été analysés, publiés majoritairement dans le *Journal of Medical Ethics* (n=19), l'*American Journal of Bioethics* (n=10) et le *Journal of Medicine and Philosophy* (n=9). Les auteurs de correspondance étaient principalement affiliés à des institutions situées aux États-Unis (n=35), au Royaume-Uni (n=12), en Allemagne (n=4) ou en Suisse (n=4). Comme le montre la figure 2, les enjeux éthiques associés au recours à des algorithmes pour soutenir la prise de décision substituée continuent de susciter l'intérêt de la communauté scientifique depuis la publication initiale de Rid et Wendler en 2010 (19).

Figure 2 : Nombre de publications traitant d'enjeux éthiques liés aux algorithmes prédictifs de préférences de soins (2010 – Avril 2025)



La grille d'analyse des enjeux relevés dans ces publications a permis de les classer selon le principe éthique auquel ils se rattachent : le respect de l'autonomie, la bienfaisance, la non-malfaisance ou la justice⁴. Ayant constaté que les rubriques *bienfaisance* et *non-malfaisance* étaient pour l'essentiel composées des mêmes arguments, nous les avons regroupés dans la présentation qui suit afin d'éviter les redites.

Respect de l'autonomie

L'intégration d'algorithmes prédictifs dans le processus décisionnel fournirait au décideur substitut des informations sur ce que souhaitent des personnes placées dans des circonstances semblables, lui permettant ainsi de prédire empiriquement ce que le patient voudrait (19). Cela rendrait plus probable que ce dernier reçoive les traitements qu'il préfère et évite ceux qu'il ne souhaite pas recevoir, que si la personne appelée à décider en son nom ne disposait pas de ces informations. Sachant que l'incertitude entourant les traitements souhaités par les patients inaptes est une importante source de stress pour les décideurs substitués, cette approche pourrait également réduire leur fardeau décisionnel. Les patients ne veulent généralement pas surcharger leur famille. Or, les décisions de soins de fin de vie s'accompagnent souvent d'une charge émotive significative, comme le soulignent Wasserman et Wendler (76, p.581) : « *Deciding whether a loved one is kept alive by aggressive and sometimes painful treatments based on a very low chance of recovery, or is kept comfortable and permitted to die, can pose an enormous burden* »⁵. Si les attentes envers des outils d'aide à la décision comme le PPP étaient rencontrées, ils fourniraient une façon épistémiquement puissante de prendre des décisions de soins pour des patients inaptes (77).

Le respect de l'autonomie du patient devenu inapte commande certes de tenter de le soigner comme il l'aurait souhaité et de contribuer au mieux-être de personnes qui lui sont chères. Comme explicité aux paragraphes qui suivent, des commentateurs contestent toutefois cette conception étroite de la notion d'autonomie. Ils remettent en question les hypothèses conceptuelles et normatives sur lesquelles est basée l'idée de recourir à des algorithmes prédictifs de préférences de soins, soutenant qu'elle repose sur une conception erronée du rôle du décideur substitut. Selon certains, ce rôle ne devrait pas se limiter à mettre en

⁴ Ces principes ne sont pas mutuellement exclusifs. Par conséquent, un argument pouvait être classé dans plus d'une rubrique si, par exemple, il soutenait à la fois le respect de l'autonomie et la bienfaisance.

⁵ Les citations ont été laissées dans leur langue d'origine, par souci d'intégrité et afin d'éviter de trahir par inadvertance la pensée des auteurs.

œuvre les préférences du patient, surtout si elles vont à l'encontre de son bien-être. En outre, le décideur substitut devrait tenter de suivre le chemin délibératif qu'aurait emprunté le patient pour faire son choix.

Dan Brock (78), par exemple, remet en question le poids accordé à l'autonomie décisionnelle du patient lorsqu'un décideur substitut, et non le patient lui-même, décide; il plaide pour que le bien-être du patient soit aussi considéré. L'autonomie, explique-t-il, ne peut être pleinement réalisée que lorsqu'un patient apte prend une décision de soins qui est éclairée, volontaire et reflète ses valeurs personnelles. Il s'agira souvent d'une décision qui sert au mieux ses intérêts. En revanche, la sauvegarde de l'autonomie d'un patient inapte ne peut être réalisée que partiellement et indirectement par un décideur substitut. Comme Collin O'Neil (79), Brock se demande si l'on ne devrait pas accorder moins d'importance à l'autonomie décisionnelle du patient dans la prise de décision substituée. L'incapacité des décideurs substituts à prédire correctement ce que le patient aurait choisi serait alors moins problématique, du moins lorsque la décision prise contribue au mieux-être du patient.

Comme d'autres (80-82), Brock défend également que la capacité d'un proche à prédire ses préférences de soins n'est pas la raison première qui motive une personne à le choisir comme décideur substitut. Lindemann et Lindemann Nelson expriment ainsi cette idée : « *when people envisage themselves as helpless patients, their thoughts turn to their families for reasons that go far beyond how good they are at matching a guess* » (81, p.167). Les familles constituent des unités sociales au sein desquelles se développent une confiance mutuelle et un sens profond de responsabilité envers les autres membres. Leurs responsabilités doivent s'accompagner d'une certaine latitude quant à la nature des soins à prodiguer à un proche. En outre, l'adhésion stricte à la norme du jugement substitué ne tient pas compte des impacts qu'auront les décisions qui seront prises sur les familles et les prestataires de soins. Ignorer les multiples ramifications de la prise de décision substituée va à l'encontre de la conception relationnelle de l'autonomie selon laquelle les décisions résultent d'une négociation entre les personnes affectées (49,83). Dit autrement, l'autorité morale des décideurs substituts ne dépend pas uniquement de leur capacité à prédire avec succès les souhaits du patient, mais découle de considérations familiales et sociales plus larges.

A contrario, les tenants du PPP soutiennent (20,32,42,76), étudies à l'appui (4-6,84), que la capacité prédictive est un élément déterminant dans le choix que fait une personne de son décideur substitut. Selon Sulmasy et al., la réalité est plus nuancée : « *a substantial body of work has shown that, despite ethical theory and law, most patients do not want pure substituted judgment should they lose decisional capacity* » (85, p.456). À titre d'exemple, ils citent une étude (86) dans laquelle 22 % seulement des patients en phase terminale souhaitaient que leurs proches effectuent un jugement purement substitué s'ils ne pouvaient plus décider par eux-mêmes. La plupart préférerait un mode mixte de prise de décision qui combine leurs préférences de soins à l'opinion des proches et du médecin traitant. La prémisse sur laquelle repose le PPP, à l'effet que les patients souhaitent que leurs préférences soient strictement respectées, ne fait donc pas consensus autant que le prétendent ses promoteurs.

Néanmoins, nombreux sont les patients pour qui il importe que la décision substituée corresponde à celle qu'ils auraient prise eux-mêmes. Pour certains auteurs (81,82,87-89), cela ne suffit pas pour respecter l'autonomie du patient et sa capacité de délibération rationnelle; encore faudrait-il que la décision découle des raisons que le patient aurait lui-même données. Pour Stephen John, une bonne décision substituée est fondée sur des raisons que le patient endosserait lui-même s'il était apte : « *that certain categories are predictively powerful is not a sufficient reason for using those categories if they do not relate to endorsable reasons* » (87, p.175). Une personne pourrait accepter, par exemple, que ses préférences de soins soient déduites de ses croyances religieuses, mais pas de son origine ethnique (ou vice versa). Nathaniel Sharadin (90) ajoute qu'il faudrait aussi exclure des algorithmes toutes fausses croyances qui s'avèrent corrélées aux préférences de soins. Il donne comme exemple les victimes de violence conjugale qui pourraient ne pas souhaiter recevoir des soins palliatifs en fin de vie parce qu'elles ont internalisé l'idée qu'elles méritent de souffrir : « *you can't derive a correct normative verdict regarding how you ought to treat a patient [...] from that patient's preference grounded in a manifestly false normative belief* » (90, p.E569).

Une conception élargie du respect de l'autonomie pourrait donc imposer des limites aux variables qu'un PPP devrait utiliser (33). Pour pleinement respecter l'autonomie du patient, sa souveraineté et son authenticité (3,76,78,91), il faudrait donc savoir s'il aurait souhaité qu'un PPP soit utilisé pour prendre des décisions en son nom et, le cas échéant, quelles caractéristiques il considère acceptables d'inclure dans le modèle prédictif. De telles exigences nous semblent réduire considérablement l'attrait du PPP pour la pratique clinique. De savoir si le patient souhaite que le résultat d'un PPP soit pris en compte constitue déjà un défi, considérant la faible proportion de personnes qui choisit d'exprimer d'avance ses préférences de soins. D'exiger, en plus, de connaître les caractéristiques qu'un patient souhaiterait prises en compte nous semble peu réaliste. Cette exigence n'est pas non plus compatible avec le concept même de PPP, qui se veut utile à la prise de décision en tirant partie de la connaissance des préférences d'une population, mais au prix d'une approche évidemment moins personnalisée. En outre, rien n'assure que les proches fondent leurs décisions substituées sur les raisons que le patient aurait lui-même données (33).

Sharadin souligne que le recours à un PPP pourrait être perçu comme une atteinte à l'autonomie du patient, parce que c'est sur la base de son appartenance à un groupe (d'âge, de genre, etc.) que serait déterminée sa volonté de recevoir ou non un traitement, comme si ses caractéristiques (son âge, son genre, etc.) déterminaient ou causaient ses préférences : « *Such reliance seems to involve a normatively objectionable treatment of an agent as having preferences that are non-autonomously*

formed » (77, p.862). Dressant un parallèle entre l'utilisation d'un PPP en médecine et le problème du « *Blue Bus* » familier aux juristes (92), il rappelle le consensus en droit à l'effet qu'une donnée purement statistique ne suffit pas pour franchir le seuil de la prépondérance et conclure à la responsabilité du défendeur : « *something more must be added to the evidentiary base in order to meet the burden of proof. [...] some kind of individualised or non-statistical evidence* » (77, p.859). Fervente défenseuse des « *living wills* », Laurel Mast (93) ajoute qu'il est hautement improbable que le moyen le plus efficace pour promouvoir l'autodétermination du patient n'emploie aucune information fournie par le patient lui-même.

À ces détracteurs, Jardas, Wasserman et Wendler (32) rétorquent que la plupart des patients priorise recevoir les traitements qu'ils préfèrent (ce que Jakob Mainz (94) appelle des préférences de premier ordre), et non le processus par lequel les décisions sont prises en leur nom (une préférence de second ordre). Ils ajoutent que le PPP ne repose pas sur le postulat que les caractéristiques d'un patient *déterminent* ou *causent* ses préférences, mais seulement qu'elles y sont associées (statistiquement). Le but d'un PPP n'est pas d'identifier les causes d'une préférence, mais de la prédire aussi précisément que possible. Il n'a pas non plus pour but de raisonner comme le ferait le patient ou d'identifier les raisons qui sous-tendent ses préférences de soins.

Quant à l'attente de certains auteurs à l'effet que les algorithmes prédictifs, pour être éthiquement acceptables, devraient révéler les raisons derrière leurs recommandations, Earp et al. répondent que ces outils d'aide à la décision ne devraient pas être soumis à des normes éthiques plus élevées que celles actuellement imposées aux décideurs substitués : « *We should be wary of a potential double standard whereby a [predictive algorithm] would be required to explain its predictions to a greater level of detail than a similarly situated human surrogate* » (31, p.20). Ils jugent cette attente irréaliste, sachant que les patients eux-mêmes parviennent rarement à expliquer leurs préférences de soins (39). Néanmoins, l'idée que des décisions de vie ou de mort puissent reposer sur des modèles mathématiques suscite un certain inconfort chez plusieurs commentateurs qui considèrent le processus déshumanisant (80,87,88,95-97). Parmi ceux-ci, Klugman et Gerke (96) soulignent que la prise de décision algorithmique sera toujours dépourvue de compassion, d'empathie et de solidarité, dont seuls peuvent faire preuve des décideurs substitués *humains*.

En résumé, le recours au PPP pourrait sauvegarder l'autonomie du patient inapte en lui permettant de recevoir les traitements qu'il préfère et en allégeant le fardeau de ses proches appelés à décider en son nom. En revanche, cette pratique pourrait miner l'autonomie en priorisant la précision des prédictions au détriment du bien-être du patient inapte et de la valeur qu'il accorde à l'opinion de ses proches. En outre, le PPP n'assure pas que la décision prise le soit pour les bonnes raisons; il réduit la décision à des corrélations statistiques et n'a pas la capacité d'agir avec empathie.

Ayant présenté les enjeux liés au respect de l'autonomie que soulève l'utilisation éventuelle de PPP en clinique, voyons maintenant ceux qui se rattachent aux principes de bienfaisance et de non-malfaisance. Rappelons que ces deux rubriques ont été regroupées afin d'atténuer la redondance.

Bienfaisance et non-malfaisance

Comme déjà mentionné, l'utilisation du PPP vise à prolonger l'autonomie du patient en périodes d'incapacité décisionnelle, en lui proposant des soins susceptibles de correspondre davantage à ses préférences. Du coup, cela contribue à son bien-être parce que les soins désirés par une personne sont, le plus souvent, dans son intérêt.

Un autre argument en faveur des algorithmes prédictifs a trait à la possibilité qu'ils facilitent le processus décisionnel substitué (28,29), une expérience souvent difficile pour les proches. La donnée générée par un algorithme permettrait aux décideurs substitués de découvrir ce que d'autres personnes avec qui le patient partage certaines caractéristiques souhaiteraient dans une situation similaire, rendant la décision plus facile à accepter au final. Ils pourraient se sentir moins seuls devant la décision à prendre, sachant que de nombreux volontaires ont contribué au développement du PPP (par leurs réponses au sondage, par exemple) dans l'unique but d'aider des décideurs substitués confrontés à des décisions complexes. L'utilisation d'un PPP pourrait aussi aider le médecin à expliquer au décideur substitut comment remplir efficacement son rôle. Il est souvent ardu pour une personne de faire abstraction de ses croyances et valeurs personnelles au moment de décider pour un tiers (33). En attirant l'attention du décideur substitut sur les déterminants d'une préférence de soins, le PPP permettrait d'éviter qu'il substitue ses propres préférences à celles du patient.

Les défenseurs du PPP croient que cet outil pourrait réduire la tension émotionnelle que vivent les décideurs substitués en leur donnant confiance que la décision qu'ils ont prise respecte fort probablement les volontés du patient (3,19,22,28,38). Le cas échéant, cela constituerait un bénéfice pour les nombreux patients qui souhaitent alléger le fardeau de leurs proches (4-6,98). Des effets inverses sont toutefois à prévoir si la prédiction générée par l'algorithme surprend le décideur substitut, l'amène à questionner son jugement ou l'écarte de la décision (23,30,33,81,97). Écarter les proches du processus décisionnel ne respecterait pas la position morale importante qu'ils occupent dans la vie des patients et ne serait pas bénéfique pour la majorité d'entre eux qui souhaite que leur famille soit impliquée (4,83,98). Être confrontés à des prédictions qu'ils croient erronées pour leur proche augmenterait probablement aussi le stress des décideurs substitués, tout comme la difficulté à fournir les informations nécessaires pour alimenter le PPP dans une situation hautement émotionnelle (80).

Questionner son jugement peut conduire au biais d'automatisation (*automation bias*) qui dénote la tendance à faire davantage confiance à une machine qu'à un être humain : « *humans using an AI [artificial intelligence] tend to believe in the infallibility of the AI and to doubt their own reasoning* » (96, p.36). À mesure que les algorithmes gagnent en autorité épistémique, ce biais pourrait aussi affecter les professionnels de la santé (55,96,99,100), limitant le développement de la sensibilité éthique (101) acquise à force d'être confronté à des situations complexes. Meier et al. illustrent ainsi ce phénomène de perte de compétence (*deskilling*) : « *like a muscle that atrophies when not being used, people's ethical competence [...] could deteriorate as a consequence of automation* » (102, p.W4). Diaz Milian et Bhattacharyya (103) ainsi que Ferrario, Gloeckler et Biller-Andorno (104) craignent que l'utilisation d'algorithmes pour prédire les préférences de soins incite à la fois les cliniciens et les décideurs substitués à transférer le fardeau de la prise de décisions complexes à une machine si on leur en donne l'occasion. Une nouvelle forme de paternalisme, induite par l'intelligence artificielle, pourrait alors s'instaurer.

A contrario, Meier et al. (102) se demandent si travailler avec de tels outils ne pourrait pas renforcer les compétences éthiques et accroître la transparence du processus décisionnel. Ils soulignent que la qualité de la prise de décision humaine est souvent altérée par des évaluations subjectives, des jugements intuitifs et des facteurs contextuels tels que le stress et les contraintes de temps. Le recours à un PPP rend les facteurs d'influence d'une préférence de soins explicites aux utilisateurs. Connaître la recommandation de l'algorithme et les informations sur lesquelles elle repose pourrait leur permettre d'élucider leur propre raisonnement, qu'ils soient d'accord ou non avec la recommandation.

Brock (78) soulève la question de savoir si le recours à un PPP pourrait miner le rôle des décideurs substitués, ce à quoi il répond que non pour autant que l'information générée soit fournie pour considération, au même titre que d'autres informations. Après tout, fait-il valoir, la recommandation d'un médecin et les raisons qui la motivent sont probablement elles aussi basées sur des données provenant de patients confrontés à des choix de traitement similaires, rencontrés en clinique ou lors d'activités de recherche. Dit autrement, la participation des proches à la prise de décision et l'utilisation de la donnée générée par un PPP ne sont pas mutuellement exclusives (33).

D'autres commentateurs reprochent au PPP d'être un outil de profilage social, parce qu'il imposerait à un patient spécifique la préférence de soins d'un groupe d'individus, n'accordant qu'une attention partielle à sa situation clinique particulière (80,90). À cela, Rid et Wendler (19,22) répondent que le PPP pourrait contrer le profilage si le médecin et le décideur substitut croient que le patient, étant donné son âge ou son origine ethnique par exemple, refuserait le traitement alors que l'algorithme suggère le contraire, corrigeant les idées préconçues. Néanmoins, un décideur substitut pourrait mal réagir à l'idée de devoir renoncer à un traitement de prolongation de la vie pour un proche, sur la base de son origine ethnique par exemple (80).

Rid et Wendler (23) admettent que le PPP pourrait être manipulé par le décideur substitut, le médecin ou des gestionnaires de l'établissement pour justifier des décisions qui favorisent leurs propres intérêts. Cette *tentation éthique* (101) pourrait être contrée par la création d'un organisme indépendant de surveillance.

Enfin, Rebecca Dresser (105) se dit préoccupée par l'idée que des personnes aux fonctions cognitives suffisamment préservées pour participer à un sondage détermineraient le devenir de patients inaptes dont les intérêts pourraient différer de ceux des répondants. L'utilisation d'un PPP causerait alors du tort à des patients particulièrement vulnérables. Le sondage à la base d'un PPP collecterait des informations sur ce que des personnes aptes pensent qu'elles préféreraient dans diverses situations hypothétiques alors qu'elles seraient inaptes. Ces informations refléteraient leur jugement sur ce qui constitue une qualité de vie acceptable dans ces circonstances. Parce que les patients inaptes mais conscients peuvent ressentir les bienfaits et les inconvénients des traitements qui leurs sont administrés, Dresser souligne l'importance que leurs intérêts expérientiels soient pris en compte. La démence compte parmi les problèmes de santé les plus redoutés. En raison de ces craintes et, plus largement, de la façon dont les patients atteints de démence sont perçus, traités et pris en charge dans un contexte socio-politique donné (106), il est probable qu'une proportion significative des répondants au sondage considère qu'une vie en contexte de démence avancée ne vaut pas la peine d'être vécue. Les propos de Dresser, qui font également écho à la dimension relationnelle de l'autonomie, reflètent son inquiétude qu'une majorité de répondants dévalue, pour diverses raisons personnelles et sociétales, la qualité de vie en situation d'incapacité et refuse, en raison de ces motifs, des traitements qu'une personne inapte aurait peut-être souhaité recevoir.

L'intégration d'un PPP à la prise de décision substituée se justifie donc par les bénéfices que pourraient en tirer les patients et leurs proches, dont des traitements mieux alignés aux préférences et un processus décisionnel moins chargé émotionnellement. Des effets négatifs pourraient cependant en résulter, si cette pratique sème le doute chez les proches qui croyaient connaître les volontés du patient, introduit une nouvelle forme de paternalisme dans le processus décisionnel, diminue la qualité du raisonnement éthique des professionnels de la santé et repose sur une dévaluation étendue de la qualité de vie des patients inaptes. Le risque d'une utilisation abusive de cet outil par des parties prenantes, et le phénomène de profilage social qu'il tend à reproduire, constituent deux autres arguments liés aux principes de bienfaisance et de non-malfaisance qui militent contre le recours au PPP.

Les autres arguments de nature éthique relevés dans la littérature scientifique, en faveur ou contre le recours éventuel à des algorithmes prédictifs de préférences de soins, ont été classés dans la rubrique *justice*. Objet de la dernière sous-section, ces arguments sont tous liés aux inégalités sociales que l'utilisation d'algorithmes pourrait atténuer ou amplifier.

Justice

Les considérations de justice sont primordiales dans le secteur de la santé, comme nous l'a rappelé la crise sociosanitaire engendrée par la pandémie de COVID-19 (107). Pourtant, peu d'arguments relatifs à la justice ont été formulés en faveur ou contre l'utilisation éventuelle de PPP. Cette rareté pourrait s'expliquer par la pluralité des théories de la justice distributive et l'absence de consensus quant à celle qui devrait guider la répartition des ressources médicales dans la société (102,108,109). Les arguments liés à des considérations de justice distributive sont de ce fait moins généralisables que ceux rattachés aux trois autres principes éthiques, considérés plus universels (109). En outre, les États dotés d'un système de santé universel comme le Canada adhèrent à des idéaux égalitaires, ce qui rend les considérations de justice distributive moins centrales au débat entourant les PPP. Ces outils visent à soutenir une prise de décision pour un patient inapte particulier. Or, les considérations plus sociétales interviennent rarement au niveau individuel.

Il existe, cependant, une autre dimension de la justice à laquelle il faut prêter attention lorsque l'on envisage d'utiliser des algorithmes prédictifs : la justice procédurale. Celle-ci concerne l'équité du processus qui mène à la décision (109,110). Mehrabi et al. définissent ainsi l'équité d'un algorithme (*fairness*) : « *the absence of any prejudice or favoritism toward an individual or group based on the inherent or acquired characteristics* » (111, p.1). Le principal défi est alors de garantir que la recommandation générée par un algorithme ne sera pas discriminatoire. Cela dépendra en partie des données utilisées pour le construire, lesquelles ne devront ni amplifier les biais existants ni en introduire de nouveaux (111,112).

Si des auteurs sont d'avis que les algorithmes prédictifs pourraient soutenir une prise de décision médicale plus juste et équitable (29,30,38,113,114), d'autres craignent que leur utilisation reflète simplement les stéréotypes et préjugés existants, et ainsi perpétue les injustices sociales (87,108,115-117). Certains algorithmes introduits dans des domaines non médicaux sont connus pour générer des résultats trompeurs en raison des biais inhérents aux données sur lesquelles ils sont construits (116). Par exemple, l'algorithme COMPAS (*Correctional Offender Management Profiling for Alternative Sanctions*), largement utilisé par les cours pénales américaines pour prédire le risque de récidive d'un accusé (118), manifeste une propension troublante à la discrimination raciale (119,120).

La discrimination, qu'elle soit raciale ou liée à d'autres caractéristiques personnelles (101), pourrait aussi s'infiltrer dans les algorithmes visant à soutenir la prise de décision médicale (121). Ce risque menace tout particulièrement les algorithmes construits à partir de dossiers médicaux, en raison des biais implicites (ou préjugés inconscients) présents chez certains professionnels de la santé. Un biais implicite conduit à juger une personne sur la base de caractéristiques non pertinentes telles que l'âge, l'origine ethnique, l'identité de genre ou le niveau socioéconomique (101,122,123). Il affecte le jugement et la démarche clinique du professionnel (ex. : le diagnostic posé, le nombre de tests demandés) et, par conséquent, l'accès aux soins de santé et la qualité des soins prodigués (113,122-125). Un algorithme bâti à partir des traitements reçus tendra alors à reproduire ces inégalités.

Mais le risque de perpétuer les inégalités sociales pourrait aussi affecter les algorithmes dont la source de données est un sondage (87,88). La préférence de soins prédite pour une personne appartenant à un groupe minoritaire sera moins fiable que pour un représentant de la majorité, du fait de sa sous-représentation dans l'échantillon (28,111). Par ailleurs, un algorithme pourrait prédire avec succès les préférences des patients, mais uniquement parce que les préférences elles-mêmes sont le résultat de circonstances injustes. Par exemple, les Afro-Américains tendent à préférer des soins agressifs en fin de vie, parce qu'ils doutent que le personnel médical prendra toutes les mesures nécessaires pour les soulager s'ils optent pour des soins palliatifs (28,111). En outre, certaines corrélations entre la classe socioéconomique et la volonté de recevoir ou non un traitement donné sont simplement le reflet d'injustices découlant de l'inaccessibilité de certains traitements coûteux (87,88,90). Lors d'un sondage, une personne défavorisée économiquement ou isolée socialement pourrait refuser les traitements de prolongation de la vie, non pas parce qu'elle ne souhaite pas que l'on tente de la maintenir en vie, mais plutôt parce qu'elle considère ne pas avoir les ressources (financières, humaines) nécessaires à sa survie. Cela dit, la pratique actuelle soulève les mêmes préoccupations puisque ce type de biais peut aussi affecter le traitement que choisit un patient ou un décideur substitut.

En somme, le recours à un PPP pourrait perpétuer les inégalités d'accès au système de santé dont sont déjà victimes certains groupes sociaux, et cela, que l'outil prédictif soit construit à partir de dossiers médicaux ou d'informations colligées par sondage. Avant d'écarter pour cette raison l'idée d'intégrer des PPP au processus décisionnel, un retour s'impose sur l'ensemble des enjeux que nous avons relevés dans les documents analysés. La discussion qui suit fait état des principaux constats qui s'en dégagent et des conclusions à en tirer.

DISCUSSION

Nous vivons à l'ère de l'algorithme. Des décisions qui affectent nos vies sont aujourd'hui prises par des modèles mathématiques. Des algorithmes servent à décider si un prêt hypothécaire nous sera accordé, à trier des *curriculum vitae* en vue de combler un poste vacant, à cibler des électeurs avec l'intention d'influencer leur vote et à surveiller notre santé (36). Pour Alain Supiot, « le rêve cybernétique d'une mise en pilotage automatique des affaires humaines est devenu réalité » (126, p.170). Des spécialistes de l'intelligence artificielle prédisent même qu'avec l'augmentation de la puissance des ordinateurs, les algorithmes dicteront une grande partie de nos activités quotidiennes (127). Progressivement, l'algocratie⁶ remplace la numérocraie (gouvernance par les nombres) dont la puissance dogmatique fait déjà craindre des dérapages (126).

En théorie, le recours à des modèles mathématiques pour rendre des décisions devrait conduire à une plus grande équité s'ils sont bien construits à la base : tous sont jugés selon les mêmes règles et les préjugés sont éliminés. Utilisés en médecine, ils ont le potentiel d'optimiser les soins offerts, en fournissant aux cliniciens des informations d'une grande précision pour guider leurs décisions (129).

Dans la présente étude, nous nous sommes intéressées au prédicteur des préférences du patient (PPP), un algorithme qui pourrait faciliter la prise de décision pour une personne inapte à consentir dont les préférences de soins sont inconnues. Plus spécifiquement, nous voulions établir s'il serait souhaitable de recourir à des PPP pour décider des soins à donner à un patient dont l'inaptitude résulte d'un trouble neurocognitif évolutif. À cette fin, nous avons recensé les enjeux éthiques que soulève cette pratique encore hypothétique. Avant d'exposer nos principaux constats, il convient de revenir brièvement sur les assises du PPP.

Dit simplement, un PPP prendrait ce que nous savons du patient pour prédire, par modélisation statistique, ce que nous ne savons pas. Il serait construit à partir des préférences de soins que des personnes auraient exprimées lors d'un sondage, en s'imaginant incapables à consentir en raison d'une démence avancée. Pour certains (80,82,93,130), la difficulté de se projeter dans un état jamais expérimenté (i.e., une démence avancée) rend cet exercice futile. Terri Fried (51) rappelle que les patients changent d'avis sur les traitements désirés lorsqu'ils sont confrontés à une maladie grave. Ce paradoxe du handicap (131,132) remet en question, dit-elle, la possibilité pour les individus de prédéfinir leurs préférences en matière de soins de fin de vie. Le *Groupe d'experts sur la question de l'inaptitude et l'aide médicale à mourir* soulignait lui aussi la tendance répandue à sous-estimer nos capacités d'adaptation à la maladie et le défi de se projeter dans un avenir lointain de manière réaliste : « Notre faculté à imaginer nos intérêts futurs est fortement faillible. » (133, p.95)

Cet argument mérite certes d'être pris en compte. Mais rejeter l'idée du PPP parce qu'il est difficile de prédire ce que l'on voudra une fois inapte, impliquerait, logiquement, de rejeter aussi toute modalité d'expression anticipée des volontés. Si des doutes persistent quant à l'efficacité réelle de ces dispositifs à diriger l'entourage vers les soins désirés (10-13), il nous semble illusoire de croire que le mouvement en faveur de la planification préalable des soins s'arrêtera. Sa finalité est suffisamment louable pour espérer que la recherche effectuée dans ce domaine (134,135) permettra d'en améliorer significativement l'efficacité.

Qui plus est, écarter le PPP de la prise de décision substituée en raison de la difficulté à se projeter dans un état inconnu priverait le décideur substitut d'informations certes imparfaites mais néanmoins susceptibles de sauvegarder dans une certaine mesure l'autonomie du patient – en rendant plus probable qu'il soit soigné comme il l'aurait souhaité – et d'alléger le fardeau du décideur substitut. Le recours aux PPP pourrait même bénéficier à la société dans son ensemble, en contrant le surtraitement, réduisant ainsi la pression économique sur un système de santé déjà surchargé (38,136). Lorsque les familles ne savent pas ce que leur proche aurait voulu, elles optent souvent pour des soins agressifs, plus coûteux que les soins de confort (137).

Revenons maintenant à la question au cœur de notre étude, à savoir si les enjeux éthiques que soulève le PPP sont suffisamment nombreux et sérieux pour justifier de ne pas investir dans le développement de ces outils destinés à soutenir la prise de décision substituée.

Deux principaux constats

Notre premier constat est à l'effet que les arguments de nature éthique en lien avec le PPP sont, bien que tous crédibles, souvent contradictoires, pointant dans des directions opposées. De tels outils pourraient : soutenir l'autonomie décisionnelle du patient ou l'affaiblir; alléger la charge émotive des proches ou l'alourdir; augmenter ou diminuer leur confiance dans la décision qu'ils ont prise; amplifier les biais cognitifs et les injustices sociales ou les atténuer; et ainsi de suite. Ces contradictions reflètent la nature spéculative des raisons données par les partisans et les opposants au PPP, que nous attribuons au manque d'études sur les effets réels (positifs et négatifs) d'y recourir pour décider de la manière de prendre soin

⁶ Terme formé de la fusion de l'apocope « algo », pour algorithme, et du mot « kratos », désignant le pouvoir. Dans une algocratie, les décisions sont basées sur des données et des statistiques plutôt que sur des opinions ou des institutions humaines (128).

d'une personne inapte. Le fait que les arguments soient toujours formulés au conditionnel (pourrait, *might*) témoigne de l'incertitude qui entoure ces effets. Un argumentaire composé uniquement d'éléments distincts (ex. : le recours au PPP pourrait soutenir l'autonomie décisionnelle du patient devenu inapte mais alourdir le fardeau de ses proches) aurait nécessité de soupeser des valeurs qui s'opposent : doit-on prioriser l'autonomie du patient ou le fardeau imposé à ses proches? Cette pondération de valeurs ne semble pas indiquée lorsqu'un même type d'argument (lié à l'autonomie, par exemple) sert aux uns à défendre l'idée du PPP, et aux autres, à la rejeter.

Notre second constat est à l'effet que plusieurs objections au PPP reflètent l'omission de distinguer une prédiction algorithmique d'une *décision* algorithmique concernant l'option thérapeutique à mettre en œuvre (33). Rebecca Dresser (105), par exemple, s'inquiète du fait que les préférences de personnes aptes à prendre des décisions détermineraient les soins à donner à des patients inaptes. Les promoteurs du PPP ne défendent pas l'idée que son résultat devrait *déterminer* les soins à donner au patient. Ils ne proposent pas qu'il soit utilisé comme seul déterminant d'un choix, mais plutôt comme une source d'information sur les tendances de préférences individuelles pour éclairer la prise de décision. La prédiction peut alors être intégrée au processus décisionnel, avec un éventail d'autres considérations pertinentes.

Un décideur substitut peut prendre en compte diverses informations avant de prendre une décision. Aucune raison ne semble justifier de restreindre le type d'informations dont il devrait disposer (32,33,78,108). Toute donnée susceptible d'éclairer les préférences du patient peut être considérée (138), y compris la prédiction générée par le PPP si elle est jugée suffisamment valide et pertinente. Muni d'une compréhension adéquate de l'origine de la prédiction, de la méthode employée pour le construire et des prédicteurs sur lesquels elle repose, le décideur substitut pourrait décider de l'ignorer s'il juge qu'elle ne tient pas suffisamment compte de la singularité de son proche (32,99). Dans le cas contraire, la perspective de personnes similaires au patient pourrait l'aider à identifier la meilleure option thérapeutique dans les circonstances.

On l'aura compris, nous ne soutenons pas l'idée de remettre le pouvoir de décider à un algorithme. Si une majorité de patients s'est dit favorable à ce qu'un PPP soit utilisé pour décider de leurs soins en cas d'inaptitude (27), encore plus nombreux sont ceux qui désirent que leur famille soit impliquée dans la prise de décision les concernant (4-6,84). Les PPP ne devraient pas remplacer les décisions humaines. Compte tenu des limites des algorithmes (fortement dépendants de la qualité des données utilisées pour les construire), du caractère hautement personnel des décisions de soins de fin de vie et de leurs conséquences, les prédictions algorithmiques devraient être utilisées pour soutenir, et non pour remplacer, le jugement humain. Elles pourraient alors déclencher la conversation avec l'équipe soignante, permettant à la famille de faire valoir, par exemple, que les valeurs et les préférences du patient ont changé au fil du temps (139). Les patients qui partagent des caractéristiques telles que l'âge et le genre n'ont pas nécessairement des préférences identiques. L'algorithme ne prédira pas parfaitement les préférences de soins, d'où l'importance de ne pas suivre aveuglément sa recommandation. Le décideur substitut doit pouvoir prendre en considération d'autres facteurs pertinents dans la vie du patient qui ne sont pas captés par les données analysées, et cela, même si les preuves s'accumulent à l'effet que les prédictions algorithmiques sont plus précises que ce qu'un humain aurait prédit. La précision n'est pas la seule considération pertinente. Respecter l'autonomie du patient commande d'honorer son désir qu'un proche détermine, ultimement, ce qui est dans son intérêt (33,82,83).

Jusqu'ici, notre examen des enjeux éthiques liés à l'intégration de PPP dans le processus décisionnel se situait dans le contexte où le patient n'a pas laissé de directives claires quant à la façon dont il souhaite être soigné s'il devient inapte. Mais le recours à des PPP n'est pas incompatible avec l'existence de telles directives. L'utilisation simultanée de deux instruments, même imparfaits, pourrait éclairer davantage la prise de décision que ne le ferait un seul d'entre eux. Si le patient a donné des directives pour guider ses soins futurs, l'idéal serait qu'il ait spécifié, non seulement quelles interventions il souhaite recevoir ou non, mais aussi comment les décisions doivent être prises : Souhaite-t-il que le décideur substitut soit informé du résultat du PPP? Dans l'affirmative, quel poids devrait-il lui accorder dans la prise de décision? A-t-il des restrictions quant aux variables qui peuvent être utilisées pour prédire ses préférences? Certes, tous ne veulent pas contrôler les décisions futures relatives à leurs soins de santé. Pour ceux qui n'ont pas d'opinion bien arrêtée sur la manière dont leurs préférences de soins devraient être prédites, c'est au décideur substitut que devrait revenir le choix d'être informé ou non de la recommandation du PPP. Le décideur substitut est généralement un proche du patient qui a ses intérêts à cœur. Il est légitime de présumer qu'il est le mieux placé pour juger si la recommandation de l'algorithme sert les intérêts en jeu.

Quelques mesures de sauvegarde

Dans l'éventualité où l'État décidait que des algorithmes prédictifs des préférences de soins seront intégrés au système de santé, des balises devront être élaborées pour minimiser les risques d'erreurs et d'utilisation abusive de ces nouveaux outils (29,39,103,121). Un devoir de vigilance s'impose à leur égard, compte tenu des conséquences de leur utilisation pour le patient, ses proches et l'équipe soignante. L'organisme responsable de développer des PPP devrait rendre accessible, sur son site web par exemple, en langage clair, une description de la manière dont ces outils ont été construits et mènent à une prédiction, de leur usage en clinique et des mesures prises pour atténuer les risques de préjudices et de résultats biaisés qui pourraient avoir une incidence sur les individus. Un système de règles soigneusement conçu et surveillé, qui impose des limites à l'utilisation de PPP, pourrait offrir les garanties nécessaires pour protéger les personnes vulnérables contre les erreurs et les abus. En outre, un cadre réglementaire solide est nécessaire pour renforcer la confiance du public dans l'utilisation de technologies émergentes (140).

Les mesures de sauvegarde devraient inclure l'obligation d'obtenir au préalable le consentement du patient à l'utilisation générale de PPP pour guider ses soins futurs, autorisation qu'il pourrait avoir donnée dans une directive anticipée. On pourrait exiger la consultation préalable d'un professionnel de la santé, dont le rôle serait de s'assurer que la personne a une compréhension suffisante des avantages et des limites de ces outils d'aide à la décision. La personne pourrait même être encouragée à expliquer pourquoi elle souhaite ou non que des PPP interviennent. Si la personne est bien informée, son désir clairement exprimé que le résultat d'un PPP soit considéré pour décider de ses soins (*opt-in*) ou non (*opt-out*) devrait être respecté. S'il n'a fourni aucune indication à cet effet, le consentement du décideur substitut devrait demeurer nécessaire.

L'ajout d'algorithmes au processus décisionnel pourrait créer des occasions supplémentaires de conflit. Des mécanismes de résolution de conflit devraient être prévus, et pourraient inclure la consultation du service ou du comité d'éthique clinique de l'établissement.

Une fois les algorithmes rendus accessibles dans le réseau de la santé, un organisme de contrôle devrait être mandaté pour surveiller le respect des règles mises en place. Chaque fois qu'un PPP est utilisé, des renseignements pourraient lui être transmis concernant le patient, les autres personnes impliquées et la décision prise. À l'image de la *Commission sur les soins de fin de vie*, cette entité serait chargée d'analyser ces données pour évaluer la qualité de la pratique, suivre son évolution dans le temps et s'assurer que des personnes vulnérables n'en sont pas victimes. Des rapports annuels accessibles publiquement, qui rendent compte de ses principales conclusions et identifient les améliorations qui s'imposent, contribueraient à rehausser la transparence du processus et à entretenir la confiance des citoyens. Cela dit, le nombre d'intervenants qui utiliseraient un PPP pour soutenir la prise de décision pourrait rendre la tâche d'un organisme de contrôle provincial insurmontable, compte tenu de la quantité de décisions de fin de vie qui se prennent annuellement (72). La collecte et l'analyse des données relatives à l'utilisation de ce nouvel outil pourraient peut-être alors être confiées à une instance locale. Chose certaine, toute innovation implantée dans le système de santé devrait faire l'objet d'une évaluation rigoureuse, d'autant plus celles qui pourraient avoir une incidence sur la durée de vie d'un patient (33).

Le déploiement de PPP dans le réseau de la santé pourrait transformer la façon dont sont prises les décisions substituées. Une approche participative devrait être privilégiée tout au long du processus de développement et d'implantation des algorithmes, offrant à des représentants des parties prenantes – concepteurs, gestionnaires d'établissement, soignants, patients, éthiciens, décideurs politiques et le grand public – l'occasion de faire valoir leurs intérêts, d'exprimer leurs inquiétudes et de débattre démocratiquement de la mesure dans laquelle les coûts et les risques associés à ces outils se justifient par les avantages qu'ils pourraient procurer aux patients, à leurs proches et à la société dans son ensemble. La question des ressources financières vraisemblablement importantes qui seront nécessaires pour développer, déployer et maintenir à jour les algorithmes mériterait d'être débattue à la table délibérative, considérant que les sommes à investir dans les PPP pourraient plutôt être utilisées pour améliorer la qualité des soins offerts aux personnes atteintes de démence.

Des campagnes d'information destinées au grand public, diversifiées sur le plan linguistique et culturel, devraient être diffusées sur le rôle des PPP dans la prise de décision substituée, leurs forces et leurs limites. Ces campagnes pourraient souligner la pertinence d'informer son entourage de sa volonté que de tels outils soient utilisés ou non pour guider les soins en cas d'incapacité.

Enfin, de la formation et des guides de pratique devraient être conçus à l'intention des professionnels de la santé pour les guider dans la manière d'intégrer ces nouveaux outils dans leur communication avec les proches. En plus de couvrir les aspects techniques liés au développement et à l'usage de PPP, le matériel pédagogique devrait rappeler aux professionnels leur droit, voire leur obligation, à bien évaluer la pertinence et la valeur ajoutée de recourir au PPP et aborder les situations plus délicates qu'ils pourraient rencontrer, dont des dynamiques intrafamiliales complexes.

Pistes de recherche futures

Des études supplémentaires sont nécessaires sur les PPP, à la fois *avant* que ne soit prise la décision de les intégrer au système de santé, et *après* s'il en était décidé ainsi. Un nombre considérable d'articles ont été publiés sur le PPP (voir figure 2), mais ils sont majoritairement théoriques. Il y a un manque d'études empiriques sur le sujet, tant quantitatives que qualitatives.

Les PPP augmentent-ils réellement l'exactitude de la prédiction des préférences de soins? Les preuves à cet égard sont encore préliminaires. Leur performance varie-t-elle selon les groupes de patients, menant parfois à des conclusions biaisées et discriminatoires? Les algorithmes peuvent avoir une grande précision dans l'ensemble, mais mal performer pour certains groupes. Comme toute nouvelle technologie, ils doivent être rigoureusement validés avant d'être utilisés (33). Des études sont aussi nécessaires pour déterminer comment aider les intervenants à reconnaître une utilisation abusive de PPP par l'entourage d'un patient (47,71). À notre connaissance, il n'existe qu'une seule étude de l'acceptabilité du PPP parmi les professionnels de la santé (29), à laquelle 11 personnes seulement ont participé. Il en faut davantage. Ultiment, l'utilité des PPP dépendra, non pas tant de leur performance prédictive, que de leur acceptabilité sociale et de leur adoption en milieu clinique.

Des études d'impact devront être réalisées après l'implantation de PPP dans le réseau de la santé, si telle était la décision, afin d'évaluer leur utilité réelle. Le recours à ce type d'algorithmes réduit-il significativement le fardeau des décideurs substituts? Améliore-t-il leur satisfaction à l'égard du processus décisionnel et celle des cliniciens impliqués? Somme toute, l'expérience de y recourir a-t-elle été plutôt positive ou négative? Pour quelles raisons? Comme ces études d'impact viseraient à établir des relations causales, elles devront employer des devis comparatifs, idéalement randomisés, lesquels soulèvent leurs propres problèmes éthiques (141).

Forces et limites de cette étude

Quelques forces méritent d'être soulignées, dont l'étendue de notre démarche pour repérer les enjeux, l'utilisation d'un cadre de référence bien établi pour les catégoriser et le recours à un modèle conceptuel spécifique à la prise de décision en contexte de démence. En outre, notre objet d'étude est d'actualité, considérant la vitesse avec laquelle les algorithmes s'infiltrent dans la pratique médicale. En revanche, nul ne peut garantir l'exhaustivité des sources documentaires analysées. Des enjeux éthiques ont pu nous échapper. L'analyse de contenu étant subjective dans une certaine mesure et, en l'occurrence, non soumise à un exercice de co-codage, l'identification des enjeux, leur catégorisation selon le principe éthique auquel ils se rattachent et leur interprétation peuvent ne pas être totalement reproductibles. Plus important encore, les enjeux relevés sont pour la plupart théoriques. D'autres pourraient surgir dans le futur advenant la décision de rendre des algorithmes prédictifs de préférences de soins accessibles dans le réseau de la santé.

CONCLUSION

Notre analyse nous amène à conclure que les algorithmes prédictifs de préférences de soins ont un certain potentiel informatif. Y recourir pourrait offrir aux patients inaptes, aux décideurs substituts et au personnel soignant plus d'avantages que d'inconvénients lorsque les volontés du patient sont inconnues. Intégrés au processus décisionnel, ces outils pourraient légitimer une décision complexifiée par l'inaptitude du patient et l'incertitude quant à l'option thérapeutique qui sert au mieux ses intérêts. Ils pourraient aussi rendre la décision plus facile à accepter pour les proches. Le recours à des algorithmes prédictifs pourrait même s'étendre aux situations où le patient avait documenté ses volontés alors qu'il était encore apte à le faire, sachant que la planification préalable des soins n'est pas une panacée.

Il existe des risques à l'utilisation d'algorithmes pour décider des soins à donner à un patient inapte (ex. : emploi abusif, décisions discriminatoires, paternalisme). Leur usage devra donc être encadré par des balises strictes, idéalement établies par consensus entre les parties prenantes. Parmi les balises proposées, nous réitérons l'importance que les décisions de soins ne soient pas prises par des algorithmes, mais demeurent entre les mains des décideurs substituts dont la plupart ont à cœur le bien-être de leur proche.

Dans l'éventualité où des PPP seraient implantés dans le système de santé, les décideurs substituts devront indiquer à l'équipe soignante s'ils souhaitent ou non être soutenus dans leur rôle par des algorithmes prédictifs. Si le patient avait indiqué son désir que de tels outils guident ou non ses soins futurs, sa volonté devrait être respectée. Certaines personnes ne souhaitent pas contrôler leur fin de vie; elles préfèrent laisser les décisions de soins à leurs proches, peut-être sans réaliser le fardeau qu'ils pourraient avoir à porter. Quant aux personnes qui se soucient de la manière dont les décisions seront prises en leur nom si elles deviennent inaptes, n'est-il pas de leur responsabilité d'informer leur entourage de leurs volontés, avant de perdre la capacité à communiquer? À qui veulent-elles confier cette lourde tâche? Souhaitent-elles que cette personne soit informée de la recommandation de l'algorithme? Dans l'affirmative, comment devrait-elle utiliser cette information?

Un long chemin reste à parcourir avant que des PPP puissent, un jour, soutenir la prise de décision de soins pour le nombre croissant de personnes qui perdront la capacité de décider par elles-mêmes. Ce chemin est semé d'embûches dues, entre autres, au manque de données probantes relatives au développement et à l'adoption de ces nouveaux outils. Le dialogue entre l'ensemble des parties prenantes, nourri par l'acquisition de nouvelles connaissances, pourrait permettre de lever les obstacles déjà identifiés et ceux qui pourraient survenir dans le futur.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

“The Death of Medicine as an Art of Humanity”. Multi-Level Ethical Implications of Integrating Mortality Prediction Algorithms in End-of-Life Care

Jad Brake^a, Kelly Newton-Mari^b, Alice Virani^{c,d}, Anita Ho^{e,f,g,h}

Résumé

Des algorithmes de prédiction de la mortalité (APM) basés sur l'intelligence artificielle ont été développés pour estimer l'espérance de vie d'un patient, dans l'espoir que les résultats fournis par ces algorithmes aident les professionnels de santé à déterminer le moment optimal pour entamer des discussions sur la fin de vie, afin d'améliorer la prise en charge conforme aux objectifs du patient. Cette étude qualitative, menée en Colombie-Britannique (C.-B.), au Canada, examine le point de vue des professionnels de santé sur les implications éthiques de l'utilisation des APM basés sur l'IA dans les soins de fin de vie. Cet article examine comment les APM soulèvent des questions éthiques familières mais aussi nouvelles, à plusieurs niveaux, concernant l'utilisation de l'analyse prédictive en médecine clinique. Ces préoccupations et considérations éthiques s'étendent sur quatre niveaux : individuel, professionnel, organisationnel et sociétal. Notre analyse de ces niveaux interconnectés révèle trois enseignements clés qui se recoupent : 1) la nécessité de redéfinir les rôles des cliniciens dans un paysage techno-thérapeutique en mutation; 2) le défi de gérer l'espoir en fin de vie dans le contexte de l'émergence d'outils prédictifs; et 3) l'importance de favoriser une approche équilibrée et holistique des soins de fin de vie face aux progrès rapides de l'intelligence artificielle. En mettant en lumière la complexité des implications éthiques de l'utilisation des APM dans le contexte sensible et vulnérable des dernières étapes de la vie d'une personne, ce travail fournit un cadre à plusieurs niveaux pouvant éclairer les meilleures pratiques. Il souligne également une vision globale des soins et insiste sur la nécessité de disposer de cadres éthiques, de lignes directrices, d'une collaboration interdisciplinaire et de formations pour guider la conception et la mise en œuvre des APM dans les soins de fin de vie.

Mots-clés

éthique, intelligence artificielle, algorithmes prédictifs, soins de fin de vie, mortalité

Abstract

Artificial intelligence-powered mortality predictive algorithms (MPAs) have been developed to predict a patient's life expectancy, with the hope that algorithmic outputs will help providers to find an optimal time to initiate end-of-life (EoL) conversations to enhance goal-concordant care. This qualitative research, conducted in British Columbia (BC), Canada, examines health care providers' perspectives on ethical implications of using AI-powered MPAs in EoL care. This paper discusses how MPAs raise familiar but also new multi-level ethical issues regarding the use of predictive analytics in clinical medicine. These ethical concerns and considerations span four levels: individual, professional, organizational, and societal. Our analysis of these interconnected levels reveals three key and overlapping insights: 1) the need to redefine clinicians' roles within a changing techno-therapeutic landscape; 2) the challenge of navigating EoL hope in the context of emerging predictive tools; and 3) the importance of fostering a balanced and holistic approach to EoL care amid rapid advances in AI. By uncovering the complexity of ethical implications of using MPAs in the sensitive and vulnerable context of the final stages of a person's life, this work provides a multi-level framework that can inform best practices. It also underscores a holistic view of care and stresses the need for ethical frameworks, guidelines, interdisciplinary collaboration and education to inform the design and implementation of MPAs in EoL care.

Keywords

ethics, artificial intelligence, predictive algorithms, end-of-life care, mortality

Affiliations

^a School of Nursing, University of British Columbia, Vancouver, British Columbia, Canada

^b Health Quality Program, Queen's University, Kingston, Ontario, Canada

^c Clinical Ethics and Spiritual Care Service, Provincial Health Services Authority, Vancouver, British Columbia, Canada

^d Department of Medical Genetics, University of British Columbia, Vancouver, British Columbia, Canada

^e Applied Ethics/School of Population and Public Health, University of British Columbia, Vancouver, British Columbia, Canada

^f Institute for Health and Aging, UCSF, San Francisco, California, United States

^g Ethics, CommonSpirit Health (California Region), California, United States

^h Centre for Advancing Health Outcomes, St. Paul's Hospital, Vancouver, British Columbia, Canada

Correspondance / Correspondence: Jad Brake, jadbrek@gmail.com

INTRODUCTION

The World Health Organization (WHO) estimates that 56.8 million people require palliative care each year (1), emphasizing that palliative and end-of-life services are essential elements of healthcare systems (2). As computational capability, data sources, and machine and deep learning (DL) models continue to expand, there has been a growing interest in integrating artificial intelligence (AI) into health care (3). AI-based tools have been used in medicine for wide range of purposes, including mortality predictions, prognosis, diagnosis, disease detection, clinical decision-making (4), treatment, patient engagement, and

administrative activities (3). Research has shown that AI-driven technologies have a potential to support the healthcare system by enhancing clinical efficiency and patient outcomes, improving the use of resources, and reducing workload burden (1,3).

For this paper, we focus on the implementation of mortality predictive algorithms (MPAs) developed using DL techniques. Several MPAs have been developed in various medical areas (5-12), including for end-of-life (EoL) care (13), with some of these tools showing to have a higher accuracy than that of experienced clinicians (10,13-15). Based on these promising results, enthusiasts hope that well-designed algorithms that incorporate a patient's clinical and broader context may assist healthcare professionals (HCPs) with making more accurate predictions of a patient's lifespan. This may in turn help HCPs better time their EoL conversations and promote goals-concordant care (13,16). By identifying those in-need of palliative services early, HCPs can better support patients and families in establishing proactive personal care plans and treatments (17). Proponents are optimistic that these technologies will enhance EoL care by better identifying the optimal therapeutic window for initiating goals of care conversations about patients' goals and wishes, thereby promoting autonomy and more personalized care while also decreasing costs and minimizing ineffective interventions (16).

Existing studies of HCPs' views regarding MPAs reveal that while clinicians mostly support integrating MPAs in medicine, they have ethical concerns regarding their use. Concerns include issues of bias and representation (18,19), data misuse and privacy (1,20), validity and implementation (21), AI ability to replace human skills of communication and empathy (22), diminished human connection between clinicians and patients (19) and the lack of transparency for "black-box" models (23). For example, Ahmad et al. (24) examined the views of palliative care professionals in England on the use of AI in palliative care. Participants viewed AI positively for identifying palliative care needs, but also expressed ethical concerns over data governance, confidentiality, and consent. Krishnamurthy et al. (25) examined multidisciplinary clinician perceptions on mortality prediction tools applied in cancer patients. Their study uncovered similar results, where clinicians described potential benefits of AI predictive models, including optimizing referral for early care and early conversations, better prognosis, and reducing distress and burnout. Concurrently, they raised concerns about accuracy, as well as uncertainties around patients' reactions to mortality predictions. Oncologists in Parikh et al.'s study (19) also highlighted improved prognostication as a potential utility of mortality risks algorithms for patients with cancer. Nonetheless, participants expressed doubts about algorithm accuracy and ethical concerns, such as over-reliance on AI predictions and automation biases, disclosure of an algorithm prediction, and losing the human connection in the patient-clinician relationship. Other studies discuss how even AI-driven tools that surpass humans in prognostic and diagnostic accuracy cannot replace the human element of care, including empathy and sensitivity to people's values and needs (13). Postill et al.'s study (19) with Canadian family medicine residents on AI-based survival estimation models in primary care revealed that care requires more than only mortality estimation, and that clinicians have lingering concerns around bias, privacy, and the lack of knowledge and confidence around these models and their use. Other studies cautioned similar concerns as potential barriers for successful integration of such technologies (20,21,26,27). Many researchers thus suggest a balanced approach between integrating AI and human aspects of care for successful implementation of AI-driven tools (1,28,29).

The relative novelty of clinical AI and the lack of clear evidence about the outcomes and consequences of its integration highlight the ethical complexities for using such tools in EoL care (28,30). Some researchers and institutions have proposed guidelines and strategies for ensuring ethical implementation of AI in sensitive health contexts including palliative care (28,31,32). Nonetheless, as Tyskbo and Nygren describe, AI mortality algorithms generate new epistemic, actionable, and ethical uncertainties (26), confirming an urgent need for ethical guidance, training, and education to ensure their ethical use in healthcare (1,22,33,34).

Despite the previously discussed studies, to the best of our knowledge there is no research specifically on Canadian HCPs' perspectives on the ethics of MPAs in EoL care. This qualitative study thus seeks to fill an important gap. Specifically, we explore HCPs' (physicians and nurse practitioners) views and attitudes on the ethical dimensions of implementing MPAs and the potential consequences for clinicians, patients and their families, health systems, and therapeutic relationships.

DATA AND METHODS

Study Design

This qualitative research was conducted in British Columbia (BC), Canada. The purpose of the study was to gain an in-depth understanding of HCPs' perspectives on the ethical dimensions and multi-level considerations of integrating AI-based MPAs into EoL care. Qualitative research offers the opportunity to interpret participants' perceptions and experiences (35). Accordingly, we employed semi-structured interviews, following a phenomenological approach, to enable in-depth analysis of individual interviews (36). Given the lack of empirical data and research specifically examining providers' perceptions of implementing AI algorithms in EoL care, this qualitative approach provides rich insights that can inform future studies (37). Before starting data collection, participants provided written consent and completed a demographic questionnaire. The study received ethics approval from The University of British Columbia Research Ethics Board (Application number H24-00711).

Sampling and Recruitment

Following a purposive sampling technique, the study included physicians (n=10) and nurse practitioners (n=5) with different demographic backgrounds (see Tables 1 and 2) and from different locations in BC, including Metro Vancouver (n=9), Fraser Valley (n=1), Vancouver Island (n=2), Northern BC (n=1), and the Southern Interior (n=2). Participants were selected based on the criterion of having active involvement in EoL care or were experienced in discussing prognosis and life expectancies with patients.¹ Further, to capture diverse experiences within the targeted research population, the study included participants from various of medical specialties, such as palliative care, oncology, emergency, pediatric care, geriatrics, cardiology, primary, internal, and family medicine. Recruitment used several strategies: distribution of flyers and information sheets about the study to local health institutions and authorities; and snowball sampling and mobilization of community health professionals to help identify and refer potential participants through word of mouth. Potential participants who expressed desire to participate were emailed a consent form and an invitation to participate in an online video interview.

Table 1: Characteristics of Participants

Characteristics	Participants N (%)
Total sample	15 (100.0%)
<i>Age</i>	-----
25-34	3 (20%)
35-44	5 (33.33%)
45-54	2 (13.33%)
55-64	5 (33.3%)
<i>Gender (self-identify)</i>	-----
Male	6 (40%)
Female	9 (60%)
<i>Ethnicity or cultural background (self-identify)</i>	-----
Caucasian/White	10 (66.67%)
Chinese Canadian	3 (20%)
Southeast Asian	1 (6.67%)
Mixed European Japanese	1 (6.67%)
<i>Place of birth</i>	-----
Canada	11 (73.33%)
Outside Canada	4 (26.67%)
<i>Highest level of education</i>	-----
Professional or Postgraduate Academic Degree (e.g. RN, MD, PhD)	10 (66.67%)
Master's degree or equivalent	5 (33.33%)
<i>Years in profession</i>	-----
1-5 years	3 (20%)
6-10 years	4 (26.67%)
More than 10 years	8 (53.33%)

Table 2: Participant Role: Physicians/Nurse Practitioner

Participant	Role
P1, P2, P4, P5, P6, P7, P8, P9, P11, P13	Physician
P3, P10, P12, P14, P15	Nurse Practitioner

Data Collection

Semi-structured interviews (n=15) were carried out between April 2024 and March 2025 by the first (JB) and third (AV) authors. All interviews were conducted online using Zoom, audio-recorded, and ranged from 31-52 minutes (average 41 minutes long). Interview questions focused on participants' perspectives on the effect that potential implementation of MPAs in EoL may have on the clinical practice, patients' experiences, and provider-patient relationships. The interview guide was developed following a literature review and the research team's knowledge and prior research experience. A mock interview was conducted, and the interview questions were modified accordingly to ensure clear wording and smooth flow between questions (see Appendix 1). Reflections and notes for observations (analytic memos) were taken right after each interview session. Data collection was continued until thematic saturation was achieved (no new themes emerged after interview number 13).

Data Analysis

All interviews were transcribed verbatim and anonymized by assigning a number to each participant. The first author transcribed (via Zoom) and checked all interviews for accuracy. This process constituted part of data familiarization, an initial,

¹ As nurse practitioners often provide a more advanced patient care and may have more experience in discussing prognosis and life expectancies with patients compared to nurses, they were selected to participate in the study.

but essential, stage of analysis that involves repeated reading of, and listening to, the collected data (35). After transcribing all interviews, the transcripts, memos, and demographic questionnaire results were imported into the NVivo 14 software, which we used to organize and code the data.

Given the lack of empirical data on HCPs' perceptions of implementing AI predictive algorithms in EoL care, we adopted an inductive thematic analysis approach that allowed us identify themes in the qualitative data and enabled an in-depth exploration of participants' accounts (35). We began inductive analysis with the initial data and constantly compared indicators, concepts, and categories as themes emerged. An initial cycle of coding was completed after the first (JB) and the last (AH) authors independently coded the first two interviews. Codes were compared, discussed, and modified to ensure intercoder reliability and coding accuracy and to arrive at a consensus codebook. Once the codebook was finalized and agreed upon by all team members, the JB independently completed the coding process for all remaining interviews. Guided by inductive reasoning, all codes were collapsed under themes and subthemes which were discussed and agreed upon by the team.

FINDINGS

The analysis revealed various ethical concerns and considerations across four levels: *individual*, *professional*, *organizational*, and *societal* (38). Within each level, several recurring themes and notable findings emerged. The findings also demonstrate interconnectedness of the multiple levels. This intersection offers a key perspective for understanding the complex interrelated layers of concerns and challenges related to the implementation of MPAs in EoL care as they are perceived by HCPs.

Table 3: Themes and Subthemes

Individual Level Considerations	Themes	Subthemes
	Personal sentiment and attitudes towards MPAs vary	• Optimism: MPAs as potentially beneficial • Caution and skepticism
	Implementation of AI prognostic tools	• AI as one tool among many • Need for evidence, knowledge, and experience
	Communication of AI prognostic information	• Prognostic conversations are complex • Preserving hope through communication
	Emotional readiness and consent	• Clinicians', patients' and families' readiness for the use of MPAs
Professional Level Considerations	Themes	Subthemes
	Potential professional benefits	• Enhance prognostication
	Professional concerns	• Shifting roles and responsibilities • Reduced professional judgment and clinical skills • AI replacing clinicians • Relational aspects of care: Reduced human element in therapeutic relationship • Team readiness
	Need for a balanced approach	• MPAs augment, do not replace clinicians' work
Organizational Level Considerations	Themes	Subthemes
	Potential organizational benefits	• Efficiency, cost savings, coordination
	Implementation: organizational constraints	• Lack of readiness, training, and oversight
	Changing work environment	• Workflow integration: overwhelming work, burnout and moral distress
	Potential conflicts	• Clinician autonomy vs organizational decisions
Social Level Considerations	Themes	Subthemes
	Implementation: social and systemic constraints	• Adaptation to rapid technological advancement • Limitations of existing healthcare systems and infrastructure
	Bias, inequity, misuse	• Representation, inequality, resource allocation • Misuse for cost-cutting or rationing
	Cultural implications	• Cultural, religious, and spiritual meaning around life and death • Cultural and religious conflicts • Culturally informed approach is needed

Individual Level Considerations

Participants conveyed a complex range of responses related to personally using AI-based tools, and particularly MPAs, in clinical care. For some participants, MPAs were perceived as beneficial tools with the potential to significantly advance their clinical practice and their patients' outcomes. Specifically, optimism about using this technology was often related to its perceived ability for analyzing large amounts of data and consequently improving prognostic accuracy:

I think that they [AI tools] can process a significant amount of data much faster and without bias. So, I do think that there is some benefit of processing a ton, more information, patient history, and presentations and diagnostics... as humans, I don't think we can necessarily do that kind of work. (P12)

Considering their own practice, participants described improving prognostic accuracy as particularly valuable in EoL as it can help with them hold timely and informed conversations about goals of care:

Particularly in end-of-life care, I think it [MPAs] can be quite helpful to inform goals of care discussions, to inform prognosis, or to have support. (P3)

In line with this concern, a common perspective that emerged from participant responses was that they would not fully rely on AI prognostic tools but may use them as “another tool in the toolkit” (P14). For example, one participant reflected that AI prognostic tools are “never a replacement” but instead “a small piece of the pie that you now have one extra tool on your tool belt on how to predict what's gonna happen with this patient” (P6). The same participant elaborated further, stating:

I would not completely rely on it, because I don't think I would fully trust an AI model to give me a clear prognosis, but it would just be one more piece of data that I integrate into my own clinical impression. (P6)

Additionally, some participants stressed the idea that data generated by AI should be treated as just one part of the clinical data and information to look at, amongst the broader context of the patient's experience and clinical presentation:

We look at the patients, clinical factors, that various test results, and attempt to come up with an estimate of a prognosis...and I think AI would be one extra piece of information that would be added into that. (P9)

One participant hoped for a balanced approach, one that combines the use of MPAs as additional clinical aids with human clinical practice and judgment, without the latter being diminished:

I would use it (MPAs) as a stimulus tool and then require my human clinical assessment and perspective on who the patient is, and who the family is, and things like that, in order to combine those two, actually inform my next steps, or, like, the actual care that I provide. (P12)

Another common theme was the need for evidence and experience to support the use of AI-enabled prognostic tools in clinical care. Participants frequently emphasized that they would trust these tools more if they could see data confirming their effectiveness:

I think with any new intervention, I always, I am a little cautious until I see a little more evidence come out. (P9)

Others expressed that they would like to test out the usefulness of these tools themselves in order to trust them:

I would need a period of testing it to see how accurate it really is in my own practice. (P6)

In addition to questioning their own readiness to adopt AI-based tools, clinicians also reported concerns about patients' and families' readiness for the use of MPAs in their care or the effectiveness of specific models. They questioned both AI models' capability of predicting or assessing patient's readiness for palliative care as well as identifying patient's emotional preparedness to hear prognostic information:

I think that's probably where we would need some patient and family data to sort of evaluate these tools to see, did they want to hear that this is potentially a chance that they might die in like a few months? Did they want to hear that at that point in time? Are they ready to hear that? Those types of things. (P3)

While many participants described prognostic accuracy as a major benefit and goal of MPAs, they raised questions around the value of predicting mortality, specifically patients' willingness to know their life expectancy. Based on personal experience, clinicians described this issue as being complex and proposed that the desire for hearing prognostic estimates is highly individualized:

I think they help certain kinds of patients who want to know more and who want to be advanced planners... but it doesn't help a lot of patients who don't think about their lives in this way and are just living day by day and aren't always planning for the future. (P6)

In that regard, participants noted communication of AI prognostic information with patients and families as a major concern. For example, participants worried that the use of precise numerical predictions might be detrimental to some patients, possibly increasing emotional distress. Participants generally preferred using broad timeframes when communicating with patients to avoid causing harm:

If we ever have these tools, I don't think we should change the way we deliver ... this information, which is right now in terms of ranges in time rather than specific numbers. (P2)

In addition, numerous participants expressed concern that AI's ability to increase accuracy in predicting life expectancy could inadvertently lead to diminished patient hope or even loss of hope:

When things are uncertain people sometimes have more hope, and when there's more certainty, people may have less hope. So, I guess I worry about unintended consequences just because we can be more accurate doesn't mean the patient will feel better as a result. (P5)

Others believed that realistic prognostic information could help patients find new forms of hope, if provided in the right way:

I don't think that AI would necessarily take away from people's hope, if its information given to people in a way that is allowing them to continue to have it. (P14)

In fact, HCPs' testimonies reflected a non-dichotomous understanding of hope and illustrated the complexity of this issue in EoL care. The theme of reframing hope, as the last quote demonstrates, was central to many participants' reflections. Hope in the EoL care context was described as often shifting from cure and survival to comfort and control over one's remaining time:

I think that's where a lot of the barriers to involving palliative care come from, people feel like involving palliative care change, or will decrease somebody's hope or take away their hope. But I think one of the biggest things that I advocate for is reframing hope. (P7)

In other words, rather than viewing hope as either present or absent, participants expressed a more dynamic understanding of hope as something that can coexist with prognostic awareness and be strengthened by constructive conversations. Knowing one's prognosis, for instance, was described as a way to support patients in planning and prioritizing meaningful experiences, and to redefine what they are hoping for:

It can change what that hope means for someone or what they're hoping for...for example, you had a younger patient recently who is given a poor prognosis, and she'd hope to kind of go here, there, and everywhere, and travel the rest of the year. And I think when, you know, she was given that information, it kind of helped her decide how she wanted to spend that remaining time. (P3)

Other concerns were shared about when and how to use MPAs while ensuring patients' and clinicians' rights are respected and protected. In addition to emphasizing the importance of providing clinicians the flexibility and right to choose whether or when to use MPAs, which should be treated like any "medical procedure that should not be enforced" (P5) as one clinician described it, participants also suggested that whether to use an AI prognostic tool should be based on the particular patient's needs or desires:

I think choosing to not use it or use it is always going to be dependent on the person in front of you, because I can know all the things I know, and I can use all the tools I want. But if someone is adamant on something, then it doesn't really matter. (P14)

Most participants viewed patient consent as an important ethical requirement in using AI prognostic tools. A few wondered whether a separate consent should be required for the use of AI predictive models, given that other predictive models (non-AI based) are already used by clinicians. Following this stance, some maintained that if MPAs are treated as "one more tool in the toolkit" (P14) then the consent should be about sharing predictive results with the patient and not the use of the model itself. Still, most participants claimed that an appropriate consent process is necessary for patients to be informed of potential benefits and more importantly, the potential risks associated with AI prognostic tools:

I think the patient has to have really informed consent about what are the impacts of this, the harmful impacts of this. Perhaps, you know, they would know what the potential benefits were, but what are the potential harms to having this information? (P8)

Several HCPs related the need for proper consent to the vagueness and uncertainty surrounding AI prognostic tools and their outcomes, and the fact that they are not yet clinically proven:

... we should inform patients and perhaps have their consent, at least until that longer term data is available. (P9)

Professional Level Considerations

At the intersection of individual-level considerations, participants articulated a combination of optimistic expectations and professional-level ethical concerns. Several acknowledged that prognostication is currently a weak spot in clinical practice, describing it as “*more of an art than a science*” (P7) and pointing to the difficulties of prognostication with current tools. This recognition resulted in participants’ optimism about the potential contribution of AI prognostic tools to their professional work:

... prognostication is probably one of the things that we struggle with the most as clinicians, and where there’s often not a clear gold standard...I can see why AI could particularly be useful in that regard. (P9)

Another participant reflected on this issue in relation to mortality prediction specifically:

I think AI would probably be considerably more accurate, because I mean, current clinician judgment is notoriously inaccurate for production of mortality. People often live much longer or much shorter than what we would guess. (P5)

Other participants explained the potential contribution of mortality prediction tools to EoL care:

Speaking specifically about end of life, predictive tools...would improve our working experience. Because it would be able to give us more accurate information that we can talk to patients with and help them make decisions with. I guess I’m optimistic in that sense. (P4)

In addition, some participants mentioned that AI prognostic tools could enhance professional clinical care by facilitating more coordinated work among different care providers:

... it’s very challenging for people [patients] to understand what their life is going to look like when they have experts in different areas only working on one thing [disease/medical condition] and not the whole overall picture... I think AI could take those kinds of things. (P14)

Nonetheless, numerous participants raised concerns that clinicians may worry that using AI in prognostication will change the traditional boundaries and responsibilities of HCPs’ roles:

Physicians are hesitant of change, because change is scary, and the status quo is easier, and I think artificial intelligence is a huge change in paradigm of how we approach clinical care. (P1)

While clinicians described AI as a supportive tool, they also worried that MPAs might devalue professional judgment or lead to reduced clinical skills. As one participant explained:

What if we rely on AI and we lose our ability to be clinicians? We don’t need doctors anymore. You can just [use] doctor Google, right?... And Dr. Google could probably, with all its little different AI machines, tell you when you need an X-ray when you don’t need an X-ray, when you need blood work, when you need a urine test, right? Like you don’t need to examine a patient anymore and I’m like, this is dangerous, medicine is going to die. (P8)

Describing the integration of AI in healthcare as “*the death of medicine as an art of humanity*” (P8), another participant provided a common concern:

I have a real sense of this being a very bad thing for medicine generally... we lose our ability to be clinicians? (P8)

Similarly, other participants also described the process of including AI tools in healthcare as “taking out all human aspects of medicine” (P6) and pointed to similar concerns about overreliance on AI tools:

My concern would be that if there were physicians who did that and who stop using their own brain and stop thinking and just relied on AI to give this number and to just, like, take that and just come to a patient and be like, the computer says you have a 50% chance of dying within the next 6 months.... That's a, just a future where we've really taken out all human aspects of medicine. (P6)

Participants also emphasized the emerging responsibilities of clinicians as evaluators, and the crucial and necessary role of humans in critically analyzing AI-generated information, which the felt would always be necessary:

I think part of my worry, too, is if clinicians who don't have good foundational critical thinking of the whole scenario, rely on that (MPAs) to make their decisions. I think it should inform decisions, but it should not be making decisions... I mean, it's a human factor that will be the reality of using a technology like this that I don't know if there's an answer to it. (P12)

Also, several participants pointed out the irreplicable role of the human element in therapeutic relationships, especially in EoL care, and described the challenge that AI may pose. Among some there was a consensus that the adoption of AI into clinical practice would negatively affect relational aspects of care, resulting from reducing humanness or even “losing connection with human life” (P8). Affirming the same stance, another participant explained:

Medicine is heading towards more of an algorithmic type of practice, and that takes away from the art of practice and the human, the humanness of humanity, of medical practice. And the more and more we head towards extremely data driven approaches, we're losing something in the process. (P6)

Given the potential benefits that AI tools may bring, most participants expressed hope for a balanced approach, one that maintains the human element while integrating AI into clinical practice. AI-based predictive tools were seen as tools to augment and complement clinicians' abilities in decision-making, prognostication, and patient care, without replacing them or diminishing the human-to-human connection.

Furthermore, some participants questioned the readiness of clinicians and healthcare teams to adopt AI-enabled tools. Reflecting on this issue, they expressed uncertainty and confusion about how these tools would be implemented along with a lack of understanding about their design, a sentiment that was shared by nearly all participants in the study:

... one of the factors would really consider is how ready is the team? Is the team ready to sort of be trained to deliver this information in an appropriate way? (P3)

Organizational Level Considerations

Several participants referenced the possible benefits that AI-powered prognostic tools could have at the organizational level. These include cost savings, resource planning and utilization, improved coordinated work and sharing of knowledge/clinical data among different care units and providers. The following quotes demonstrated some of these perceived advantages:

From an institutional level. I mean, you can kind of already see what the cost savings would be. (P7)

I do think there might be some operational advantages. Because if you have a sense of which patients on your panel as a clinic, as a department, as a facility, as a multi facility program. If you have a sense of how many patients in a certain category you have, it might help you plan for care, because we know people in the last year of life, you know, resource utilization is particularly heavy. (P11)

Yet, concerns about organizational adoption were also a prominent theme among participants. One recurring concern shared was the questionable readiness of healthcare systems to implement AI technologies due to the widespread lack of knowledge on MPAs among clinicians, including their design and use. Participants emphasized the need for organizational efforts to increase education, training and support:

All tools work better when there's adequate training on the tool. So, I think again, if clinicians are trained on how to use it... it's likely to be good. (P5)

Another participant emphasized that education and training should be approached as a carefully planned “*change management exercise*” (P11) with a clear orientation process as well as ongoing evaluation after implementation:

Before you introduce such a thing, you really do need to orient all the teams involved. Here's what's coming, here's why we're doing it, here's what is an effective response... Make sure people have the training to deal with the information appropriately. And then monitor how it goes, right? (P11)

One participant even suggested that patients may also need training before AI prognostic tools are integrated into their care:

If I were launching this in my institution, I would say, okay, here's the education modules the clinician has to do. And here's the education module that the patient has to do prior to implementing this, so that I know patients really understand what they're getting themselves into. (P5)

Given the lack of knowledge and experience with MPAs and their unanticipated outcomes, the need for organizations to take their time when carefully integrating AI prognostic tools was presented as essential:

You can't rush it. You can't, just, you know, cut corners and just do it, right? And so that's always the worry I have with any new technologies, it'll just be rammed down our throats, and then it just will do more harm than good. But I think if you follow the right steps, orient the staff, have the teams ready, do education, and, you know, do proper QI and change management, it should be okay. (P11)

Worries regarding the implementation of MPAs without adequate human oversight and supervision to ensure safe and effective implementation were shared:

I think if a hospital says, okay, now, we're going to use this AI model, I hope that there's humans behind evaluating it. (P10)

Moreover, participants described the need for healthcare organizations to integrate AI prognostic tools into workflows in a strategic way that considers current realities and resource constraints. Several participants referenced “flag fatigue” (notifications) in EMRs, stressing the importance of acknowledging current practice conditions:

We may have so many flags. You know not just mortality, but for any number of reasons in healthcare, and already our EMRs are very busy with a lot of data and a lot of flags, and I worry about just being bombarded with this. (P6)

Echoing such concern, some participants highlighted the stress AI prognostic tools could place on clinicians. They assumed that introducing these tools without providing necessary support could create an overwhelming work environment and contribute to clinicians’ burnout and moral distress “*in a field that is already at a high risk of burnout*” as one clinician phrased it (P1). Another participant maintained:

So, it might be nice to have this data, but I struggle to see how we best actually incorporate it into practice, and I worry that it would just add to more stress and burden on us to have to address that. The AI said this about this patient, now you have to deal with it. Yeah, what you're gonna do with it? (P6)

Discussing the potential harmful consequences for HCPs (stress, burnout etc.) of using MPAs in EoL care brought up concerns related to values of autonomy and conscientious objection in clinical work. One clinician argued:

... just because the institution provides it [MPAs], like, I don't think they [clinicians] should do it. Like, with all things in medicine, if you have a moral objection to something, I don't think you personally have to participate in that. (P13)

Other participants also expressed repeatedly that “*AI should not be an automatic tool*” (P2) or that “*it should be up to the individual practitioner whether to use a tool or not*” (P6), endorsing the shared call among most participants to preserve clinicians’ rights to determine when and how to use MPAs in their work. To reduce or deal with conflicts and disagreements that can arise between clinicians and their colleagues or between clinicians and their institutions, participants highlighted the need for a “*protocolized and institutional approach*” (P9) regarding the use and operation of these tools.

Societal Level Considerations

Some of the societal level concerns that emerged from the data, which intersect with organizational-, professional- and individual level considerations, were associated with current system constraints that do not allow the adoption of AI prognostic tools. This primarily focused on the mismatch between the high speed of AI advancement and the ability of the healthcare industry to adapt:

I think there's a bit of a disconnect with how quickly AI is moving and how historically slow the healthcare system is to incorporate new protocols, new approaches. (P9)

Another participant also described the significant limitations of the existing healthcare systems and infrastructure that will pose a challenge for the implementation of advanced technologies and large data sets. The following statement illustrated this systematic constraint:

I think some of the barriers will be that, like my health authority doesn't even use a lot of our EMR. I still use paper chart. ... it [EMR] would not be able to capture a lot of the data that might need to be fed into it, or that it'd be cumbersome to then have to or put in. (P14)

Some emphasized that MPAs' potential ability to provide more accurate prognostic results is expected to not only help with clinical decision-making regarding treatments and interventions but also with resource allocation practices:

If we have a very active tool to predict prognosis, then I think it will probably then help us allocate patients more appropriately to where they should be and using our resources in that way more appropriately. (P2)

However, multiple participants also noted the use of AI prognostic tools by institutions or systems to restrict access to care or justify resource-based decisions that do not always align with patients' best interests. Giving up suggesting or trying new treatments following MPAs' certainty about results was a major worry that some clinicians had around its consequences on public and individual's health:

Eventually you may get to the point where you say, okay, according to your AI predictor, you've got 3 months, so therefore we won't offer you this treatment. (P5)

In relation to the same issue, another participant expressed the strong conviction that AI generally, and MPAs specifically, will guide how funds are allocated and wondered about the value of this possibility:

We know that hospital administrators and the fund holders will start to rely more on AI data and mortality predictions to fund services. And is that right? (P8)

Discussions on treatments, resource allocation, and funding also speak to a broader ethical concern of misuse, or inappropriate use, of healthcare data and advanced technologies. This issue frequently emerged in participants' narratives through a range of examples as discussed at different levels throughout this article:

My concern is that it might be misused by the public, might be misused by those that don't have good moral ethics. (P15)

Furthermore, while reflecting on the design and validity of AI predictive models, other societal concerns were mentioned. Among these are the potential of AI to reinforce discrimination and maintain social inequalities. This bias, which some viewed as inherent to AI-based tools, was not only ethically and morally troubling but also interpreted by some as a flaw that may reduce clinicians' and public trust in MPAs and their results. While one participant voiced that AI models are "more objective" in analyzing patient data compared to humans who "all come with their own perspectives and biases" (P12), more voices questioned the validity of the models, highlighting a broader worry about how algorithms can reinforce and perpetuate inherent biases:

If a model is generated to do something like predict mortality for a certain population in certain circumstances, then I think that would be very interesting to look at, if that is applicable to the population that I'm seeing, which is a big question. And if it's trained on data that is appropriate. (P4)

Another participant expressed skepticism around model validity or generalizing results for different populations:

Yeah, number one would be patient selection, number 2 would be limitations to the program. I mean, you wanna know which patient population this has been tested on. And does this population that has been tested, is it similar to my population? And I guess I worry about broad adoption of a tool to populations that have not been specifically tested using the tool, like, if there's been no validation in, say, some rare tumor, then you shouldn't be using the tool for that. (P5)

Moreover, it appears from the data that the general sense of ambiguity around MPAs and their design, and the doubt about even the possibility of knowing which data were used or selected, adds to what seems as conditional and cautious trust in MPAs. The following quote represented such sentiments among clinicians:

So, I'd want to know more about where the program came from and what population they used to put this data together. And I don't know if that's even available. (P15)

On a global level, however, a few participants framed AI prognostic tools as a helpful way to acknowledge disparities between countries in relation to resourcing for EoL care:

From a global health perspective, I think it can be a powerful tool to get organizations to do better... maybe a kick in the pants about the inequities. (P10)

Some participants raised concerns surrounding social and cultural implications of the integration or implementation of MPAs in healthcare. Specifically, participants' descriptions and testimonies regarding communication with patients highlighted how the use of MPAs intersects with cultural values, religious beliefs, and spiritual meaning. A few participants noted that their patients' religious belief may change the way they think about AI tools:

You're gonna have people that gonna say 'I don't want to hear what AI says.' It's in God's hands. And actually, you're being arrogant and the computers are being arrogant to plan my child's death, right? So, there's cultures, religious scripture, many things that we have to consider when we share information. (P10)

In other words, in addition to respecting and acknowledging each individual's personal needs, being aware of cultural aspects and context is practically helpful in supporting effective clinician-patient communication, ultimately leading to a successful implementation of MPAs in EoL care. Therefore, a culturally sensitive and culturally informed approach is needed when designing and implementing MPAs in EoL care:

I think it kind of comes back to, like, the team being trained to have these conversations. But also a culturally sensitive way, right? from a lens of cultural humility. And also like, assessing what is the culture of this patient and this family? What have they understood so far? (P3)

Participants agreed that using MPAs in EoL care may add challenges to clinician-patient communication. Predictive algorithms "would certainly sort of complicate the discussion" in EoL care given that "certain cultures and backgrounds act differently at the end of life than others" (P4), one clinician assumed. At the same time, using MPAs in EoL care could ease the burden on clinicians when discussing life expectancy with patients, allowing them to avoid being blamed as "discrediting their religious beliefs" (P10):

I think that having AI can help, it's not me trying to say 'I want the bed for someone else.' It's not me saying 'I discredit your religious beliefs.' It's not me saying anything. This is just, you know, when we look at the AI algorithm, it says this, and it's just information and people will choose to use that or not in their decision making. (P10)

Briefly, the discussion of concerns on the broader societal level reflects participants' view that society has a collective responsibility to ensure that AI tools serve the public good, working in the best interest of patients and families while remaining attentive to their cultural and spiritual needs.

DISCUSSION

While other studies have explored HCPs' views on using AI for various conditions including palliative care (18,20-22,25,39), there remains a paucity of qualitative studies exploring HCPs' ethical considerations of integrating AI into EoL care. Existing literature on implementing predictive analytic technologies in various areas of medicine focuses on increasing model robustness, reducing bias, and improving diagnostic capability (7,16,20,28,39-45); there is relatively little attention on the ethics of using AI models to assist with clinical practice in the sensitive context of the final stages of a patient's life (4). As AI algorithms are increasingly developed and promoted as resources to enhance care that may change health care delivery, our study provides a multi-level framework that can inform best practices.

Our interviews with physicians and nurse practitioners regarding their perspectives on the ethical dimension of integrating AI-enabled prognostic tools in EoL care revealed a consistent but nuanced tension related to using this emerging technology in a deeply sensitive area of care. Consistent with previous studies (18,45,46), many clinicians viewed AI prognostic tools as holding potential to enhance care through improved predictive accuracy and resource planning. However, this optimism was juxtaposed against concerns about the transparency, reliability, applicability, and implementation of these models in real-world settings. Skepticism, a sentiment that was also expressed by clinicians in prior research (20,21), was based on potential technical limitations (e.g., data representation, accuracy, bias) as well as moral and relational questions about whether AI can (or should) support human prognostication in the evolving therapeutic and socio-technological space.

As participants discussed their optimism and caution about broader relational, interprofessional, organizational, and societal implications of increasingly relying on AI for EoL care, a unifying theme emerged: regardless of its promise, AI cannot and should not replace the human relational components needed in providing and organizing EoL care. Communication strategies around prognosis remain deeply personal, and over-reliance or over-confidence on AI might erode the value of clinical intuition and relational aspects of empathetic engagement. These findings echo concerns reported in previous research about diminished human clinical judgment and human-to-human interaction from over-relying on AI tools, and support the existing argument that AI, including MPAs, cannot and should not replace but augment the human connection (15,28,29,47). In addition, concerns were raised about the intersection between MPAs and system- or institution-level drivers (e.g., cost-saving imperatives, funding arrangements), and how these may influence implementation practices across health institutions, with downstream implications for patients and care quality. For example, MPAs have been designed and used by health systems to decrease healthcare expenses. These include pinpointing high-cost patients, lowering readmission rates, and forecasting worsening patient's condition (decompensation) (48-50). These institutional priorities of improving organizations' financial performance, including the possibility of denying treatments and services based on mortality predictions as some participants mentioned, may be non-transparent to patients and families. They may conflict with patients' and families' interests and goals, or restructure EoL care and how we evaluate quality of care. Therefore, there is an urgent need for regulatory oversight to address and deal with this clear tension, ensuring patients' interests are always protected. We also need more attention to the political economy of MPAs, by recognizing that different stakeholders may have divergent interests and unequal access to resources and power in the delivery of EOL care, and intentionally addressing or preventing such inequities.

The multiple interconnecting layers of individual, professional, organizational and societal concerns provide a helpful framework to understand clinicians' perspectives of developing and implementing life expectancy algorithms in EoL care. In particular, we highlight three key and overlapping observations brought on by our findings: 1) Redefining clinicians' role in the evolving techno-therapeutic environment; 2) Navigating EoL hope in the age of predictive tools; and 3) Promoting a balanced and holistic approach to EoL care in the rapidly evolving AI space.

Redefining the Clinician's Role in the Evolving Techno-Therapeutic Environment

A significant theme underlying all interviews centred on whether or how AI predictive models may affect clinicians' roles and responsibilities in EoL care. There is a general concern within healthcare about the use of AI potentially leading to the abrogation of the patient-clinician relationship. While these issues are not unique to mortality predictions, they may be especially salient in the final stages of life, when patients are often at their most vulnerable. On the one hand, participants suggested that AI outputs may simply provide more comprehensive or accurate information to enhance rather than alter clinicians' humanistic roles (51-53). Even though participants expected and wanted AI predictive tools to provide additional and accurate clinical insights, they considered these models as supplementary or complementary informational tools. They were not a replacement for their own expert judgment and therapeutic responsibilities of assessing their patients' emotional readiness or preferred ways to receive such information and communicating such information with sensitivity and compassion. Life expectancy models may nudge goals of care conversations, but they are not themselves communication tools that can address multifaceted concerns for patients or families facing weighty decisions in an existentially vulnerable time. Clinicians still need to engage with their patients in balancing various priorities and clinical realities to determine the most appropriate care plan (54).

However, participants' concerns about clinician readiness and education gaps in both AI and EoL conversations point to an important limitation. If clinicians have not already been trained to engage in these conversations in sensitive and respectful ways, AI prognostication tools that present quantifiable predictions may not, on their own, address patients' qualitative experience or enhance compassionate conversations about their hopes, expectations, worries, and goals, and sources of comfort as they weigh different care options in a distressing time. These tools also do not address underlying concerns that many health systems do not provide necessary time and space for therapeutic presence and relational support for those who are facing anticipatory grief and existential angst as they potentially approach the end of their natural life. Worse yet, EoL discussions are often emotionally challenging for clinicians. This raises the concern that some may refrain from initiating goals-of-care discussions until prompted by the AI algorithm, even when other signs suggest that the patient could benefit from such conversations. These signs might include the patient talking about family members' illness experiences, or expressing fears about their own health decline (54). Indeed, clinicians in other studies expressed concerns about clinician readiness, especially a lack of education, training and even knowledge about clinical AI (18,21,34). There are also broader philosophical concerns about epistemic injustice. If quantifiable data are presumed to override physicians' broader qualitative judgment, as well as patients' own subjective embodied experience, AI outputs may be granted more credibility than they deserve. This may also downplay the significance of patients' and families' contextual and phenomenological experiences when considering how to support patients and their loved ones in existentially sensitive times (54).

As AI models of variable performance become more prevalent in health care, participants also questioned if AI prognostic tools might alter or redefine their roles and responsibilities in other ways, positioning clinicians more as interpreters, mediators, and stewards of prognostic information rather than therapeutic partners. While participants advocated for thoughtful implementation and integration of AI with human oversight to minimize bias, inaccuracy, or unintended harms, some reported a low level of familiarity with AI health tools. As there continues to be a lack of education for HCPs on how various types of AI models work

(1,18,34), questions about regarding who should provide such oversight at the point of care, or how clinicians who are unfamiliar with AI models' analytical process or performance may support or educate patients or families regarding algorithmic outputs. Moreover, AI models are increasingly being presented as epistemically equal, or even superior, to human clinicians, particularly in predictive and diagnostic ability (10,13,14). Participants also voiced concerns about erosion of clinical skills as reliance on AI expands. Together these concerns raise epistemic and institutional questions about whether clinicians should trust their own judgment rather than follow machine recommendations in situations of prognostic disagreement, and what guidelines health care institutions should provide for these scenarios. This question becomes more critical given the possibility of AI-based tools perpetuating biases in palliative care (55) or even misleading HCPs (56). Although it is recommended that clinicians treat AI tools as a supplement to rather than replacement of their judgment (4), there is a risk that some clinician will rely unquestioningly on MPA results. This concern becomes increasingly relevant given that some clinicians may be prone to automation bias, accepting erroneous machine decisions over their judgment and interpretation (57), or follow their recommendations even when they contradict the clinician's initial impressions (56).

Navigating EoL Hope in the Age of Predictive Tools

These findings intersect with broader questions about how HCPs' roles may evolve as AI becomes more integrated into clinical care (20,47). They also show how the dominant focus on model accuracy and fairness in AI ethics discourse misses other important humanistic elements of EoL care and communication. These include the need to reinforce therapeutic alliance, uphold hope, and provide a healing presence in the face of a grim prognosis (58-60). Repeating similar calls in other studies where both clinicians and patients questioned AI tools' validity and asked for more evidence (21,61), several participants explained that trust in AI required seeing sustained evidence of clinical benefit. However, clinical benefits of prognostication are not simply about algorithmic accuracy of a patient's life expectancy based on clinical criteria. Indeed, participants expressed varying views about what would generally provide a more "truthful" result. Some pointed to AI models that promise to approximate a ground truth through large-scale data analysis. Others emphasized human clinicians, whose prognostic assessments are grounded in expert judgment shaped by bedside observation, patient context, and intuition. Many described elements of prognosis as being unquantifiable, and that attention to the qualitative and biopsychosocial dimensions of death and dying is necessary to promote a more holistic, patient-centred approach to EoL care (28,62,63). Some participants also expressed a need for epistemic humility for both humans and machines even in the face of striving for better accuracy, acknowledging the inherent uncertainty of predicting death.

Recognizing the complex interplay between clinical, spiritual, and relational dimensions of EoL experience and expectations, participants reflected thoughtfully on how AI-guided prognostic information — even if highly accurate — might affect patient hope, underscoring the highly individualized nature in which AI tools should be deployed in EoL care. While some had concerns that AI prognostication could eliminate hope, others thought these tools may help patients reframe hope. Participants emphasized that how information is communicated is just as important as what is shared (60). A thoughtful, compassionate approach was described as a way to preserve a patient's sense of agency and hope, even in the face of a difficult prognosis. Our findings illuminate hope as a dynamic and multifaceted aspect of patient wellbeing, that is shaped by socio-relational context, timing, clinician/patient readiness, and communication style. How the prognostication prediction is reached, considered alongside other individual and institutional factors, and communicated by clinicians may affect the therapeutic alliance and patients' care experience (64). While prognostication algorithms may provide additional data to support goal-concordant care plans, mortality prediction and associated communication may alter the patients' and families' identity and hope narrative (59), as well as clinicians' approach to, and view of, the significance and meaning of hope for terminally ill patients (65). These findings highlight the important role clinicians have when interpreting and conveying prognostic data from AI tools so that hope can be preserved or reimagined in ways that align with patients' needs.

Promoting a Balanced and Holistic Approach to EoL Care in the Evolving AI Space

An overarching finding of this study is the need for a balanced, carefully thought-out approach to integrating AI prognostic tools to promote benefits and minimize harm for patients and their families. Ideally, this approach would maintain the human element at the centre of care, brought forth by thoughtful implementation at the institutional level to support patients, families, and clinicians who must collaborate in determining and providing the most appropriate EoL care plan. This conclusion supports calls in previous studies for a balanced approach between AI-assisted tools and human aspects, an approach described as key for successful implementation of such tools, especially in palliative care (1,28,29).

Much of the research on AI-assisted predictive models in healthcare, and reviews of AI integration and use in palliative care specifically, focus on technical aspects such as efficiency and accuracy. While efficiency and accuracy are helpful, they are inadequate to provide high quality care (4,15,28). AI tools must be integrated within a holistic system that considers the complexity of patient experiences and therapeutic relationships in the changing AI landscape. Cultural and religious diversity, as well as different worldviews and metaphysical frameworks, shape how patients and families understand whether the timing of death can and should be calculated, quantified, or made transparent. These differences add further ethical dimensions to the pursuit of equitable, humanistic, and respectful care as technologies continue to mediate clinical practice. They also

underscore the need for patient-specific approaches to integrating AI prognostic tools in EoL care (1).² In other words, this paper argues for moving beyond a focus on mortality estimations to look at the complexity of patients' experiences in EoL, while being attentive to their personal needs, values, and preferences (14,28). Further, participants described an appropriate implementation process as one that includes education for both clinicians and patients, clear organizational policies (such as around consent processes) and workflow integration that is mindful of existing system constraints. These reflections echo what has been highlighted in the literature about the necessity of training and education about AI prognostic tools and their use in healthcare (1,34).

Participants' discussions about consent reflect a broader concern of whether valid and informed consent can be obtained from patients when MPAs with varying and uncertain levels of accuracies are used in EoL care. Indeed, the integration of AI-driven technologies in healthcare raise questions about whether current approaches and frameworks are even suitable (66,67). The "black box" nature of AI systems, their lack of explainability, clinicians' limited understanding of AI technologies and how these technologies work, and uncertainty about potential outcomes all constrain clinicians' ability to inform patients adequately. These constraints are especially significant when clinicians must explain the risks and implications of AI-driven medical decisions. Further, they complicate the application of traditional consent processes and standard disclosures of information in medicine, raising concerns about ethical and legal compliance of current consent forms (66,68). A shift is needed in understanding of and approaches to consent, anchored in a more suitable ethical framework that is aligned with and applicable to the rapidly evolving applications of AI in healthcare (66-68). Examples of initial steps that could help clinicians convey complex AI information to patients and obtain proper informed consent are: personalized consent forms, visual aids, and using plain language (66,67). Additionally, comprehensive training programs for HCPs on how AI systems work and how to interpret their outputs and communicate their findings, were also suggested to assist with obtaining consent and increasing patients' trust in decisions and results of AI models generally (66,68). As AI involvement in medicine becomes the new normal, as many believe (69), it is realistic to assume that providing care will involve AI. Thus, it may be more practical to train HCPs to explain, in general terms, how AI models work, rather than requiring them to provide detailed explanations of prediction results in each case. At the same time, institutions must ensure that any AI tool used in clinical care meets applicable ethical and legal standards (69).

Organizational readiness emerged as a critical factor: leadership commitment and approaching the integration of AI tools as part of a broader change-management process are key to ensuring these tools support, rather than burden, clinicians. Our findings highlight the pressing need for clear ethical guidelines, robust regulatory frameworks, and interdisciplinary collaboration to ensure the ethical and effective implementation of MPAs in EoL care, aligning treatment with patients' goals (15,20,70).

Canada's publicly funded healthcare system provides important context for interpreting these findings. As Canadian patients generally do not need to consider out-of-pocket costs when receiving treatment, decision-making around EoL care is more often shaped by factors beyond financial pressure. This differs from countries with different funding models, such as the United States, where insurance coverage and personal expenses have a major influence over HCPs' treatment recommendations and an individual's decision to access palliative care. Consequently, the implications of our findings must be considered within a system that prioritizes equitable access to care and operates largely independent of an individual's ability to pay. Yet while the financial burden of care may not play a large role in a patient's decision-making process, the shortage of palliative care services across Canada remains a significant challenge. According to the Palliative Care Coalition of Canada (71), only 58% of Canadians who could benefit from palliative care are able to access it, which is particularly relevant to the integration of MPAs. While MPAs have the potential to promote earlier identification of patients who may benefit from palliative care, they also highlight a tension between the identified need for care and the ability to provide it in a resource-constrained system. Situating the findings of this study within this context underscores the importance of developing approaches that align with the realities of palliative care delivery in Canada.

LIMITATIONS AND FUTURE DIRECTIONS

The current study has some limitations. First, the sample includes a relatively small number of participants which limits the generalizability of results. This exploratory empirical research sought to explore ethical aspects of MPAs use in EoL through in-depth understanding of research participants' perspectives and narrative. It is not intended to generalize or represent the perspectives of all clinicians, but to serve as a first step to informing future research on this topic. Such research should include a wider variety of clinicians with different backgrounds, expertise, and from other geographic locations inside and outside of Canada. Second, our study did not include patients and families. Exploring those experiences and perspectives of MPA use in EoL is crucial for gaining a deeper understanding of this topic. Third, a thorough philosophical discussion of the phenomenology of serious illness and metaphysical frameworks around the knowability of death was beyond the scope of this empirical paper. Additional research in these areas could provide insight into how MPAs represent not simply a technological but also metaphysical shift in EoL care.

² We thank a reviewer's insightful reminder of these considerations.

CONCLUSIONS

Algorithms and AI models now exist to aid clinicians in more accurately predicting mortality. This article examined HCPs' perceptions and attitudes towards the use of these technologies in EoL care. Our findings demonstrated that clinicians have both positive attitudes and concerns around integrating MPAs in medicine. They raised important questions about how MPAs should be designed and implemented, including the goals of these technologies, their potential outcomes, and whether improving accuracy is enough for improving quality of care. Our study demonstrated that mortality prediction and related tools can influence patients' and families' experiences, reshape HCPs' roles and daily practices, and affect healthcare systems and services. By analyzing HCPs' perspectives and perceptions of the ethical dimensions and multi-level considerations, our study provided a holistic view that reflects the complex needs and experiences of patients in EoL care, and highlights the need to move beyond focusing on mortality estimations and accurate predictions. MPAs have a potential to support HCPs and the healthcare system in managing EoL care. However, ethical implications at the individual, professional, organizational, and societal levels must be considered for successful integration and implementation of these tools. Further, considering these intersecting multi-level ethical dimensions is key for ensuring best clinical practices that align with both patients' goals and values as well as clinicians' concerns and needs. Maintaining human clinical judgment and the human element in therapeutic relationships, and preserving hope, are also essential for enhancing quality of care in the sensitive context of the final stages of a patient's life. Drawing on this holistic and multi-level perspective can help in developing ethical frameworks for ensuring ethical integration of AI in sensitive health contexts such as EoL care.

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Conflicts of Interest

None to declare

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APPENDIX 1: CLINICAL PROVIDERS' PERSPECTIVES ON THE ETHICAL IMPLICATIONS OF UTILIZING MORTALITY PREDICTION ALGORITHMS IN END-OF-LIFE CARE

Semi-Structured Interview Guide

Introduction

Thank you for being interested in our study on clinical providers' perspectives on using predictive algorithms in end-of-life care. There are already some algorithms out there that claim to be able to accurately predict the likelihood that a patient will die within 6-12 months by scouring over a patient's electronic medical record. For our interview study, we want to think about life expectancy prognostication algorithms in general. We will start by getting your initial thoughts on using AI algorithms to predict life expectancy for seriously ill patients, and then more specifically about what you think are potential benefits and concerns. You may share how you think the use of these types of algorithms may affect individual patients, your professional practice, or end-of-life care in general. Do you have any questions before we begin?

Interview Questions

1. Have you used any predictive algorithms in your medical practice? (If yes, please explain/elaborate.)
2. When you hear about AI mortality prediction algorithms, what are your initial thoughts about using these types of technology in end-of-life care?
 - a. How do you think they differ from other clinical decision algorithms you are familiar with? (e.g., APACHE scores)
 - b. Are you aware of your institution or other institutions using AI mortality predictive algorithms? (If yes, please explain/elaborate.)
3. In end-of-life care, when do you think AI mortality predictive algorithms might be most useful? Least useful or most concerning?
 - a. Institutional, operational, and individual patient levels
4. What factors would you consider in determining whether to use AI mortality predictive algorithms in your clinical work?
 - a. How might you use the information from these algorithms in patient care?
 - b. How might these algorithms affect your clinical practice or end-of-life care?
5. Suppose your hospital or clinic is using AI mortality prediction algorithms.
 - a. What should institutions and clinicians disclose to patients/surrogates regarding the use of these algorithms?
 - b. What would be ethical ways to disclose or share information about the use of AI and the AI predictions to patients or their surrogate decision makers?
6. What ethical concerns do you have regarding using mortality prediction algorithms in end-of-life care?
 - a. E.g., bias, accuracy, self-fulfilling prophecy.
 - b. Any other concerns?
7. (If not yet discussed in Q6) How do you think clinicians should deal with conflicts that may arise from using these algorithms?
 - a. Clinicians disagreeing with their institution's expectations to use these algorithms.
 - b. Clinicians questioning algorithmic predictions.
 - c. Patients/surrogates disagreeing with algorithmic predictions.
8. Assuming that these algorithms are accurate, how do you think various stakeholders may think about them being used in direct patient care?
 - a. Patients/families
 - b. Clinics/hospitals
 - c. Health authorities
 - d. Health/Life insurance companies

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Disordered Wrongdoing, Freedom, and Compassion

Benjamin Campbell^a

Résumé

On parle d'« infraction liée à un trouble mental » pour désigner un comportement ayant un lien de causalité avec le trouble mental de son auteur. Une conception courante à l'égard de ce type de délit est que le trouble constitue une « explication » mais non une « excuse ». On considère toutefois souvent que les troubles mentaux sont des conditions qui limitent la liberté d'une personne à choisir d'autres lignes de conduite. En philosophie éthique et dans les systèmes judiciaires démocratiques, ce type de contraintes pesant sur la liberté est considéré comme réduisant considérablement la responsabilité morale d'une personne face à un acte répréhensible, voire comme l'éliminant complètement dans de nombreux cas. Plutôt que de m'attarder sur cette interprétation juridique de la responsabilité, je m'intéresserai au contexte éthique « global » qui régit la manière dont nous traitons les délinquants atteints de troubles mentaux : notre comportement éthique. Je soutiens que notre attitude fondamentale envers les malfaiteurs déséquilibrés, compte tenu de ces contraintes pesant sur leur liberté, devrait être empreinte de compassion. Je m'attache tout particulièrement à la notion de compassion en tant qu'elle renvoie à l'obligation morale de faire preuve de compréhension envers les raisons qui poussent ces malfaiteurs déséquilibrés à agir comme ils le font.

Mots-clés

santé mentale, liberté, libre arbitre, comportement éthique, responsabilité morale, compassion, trouble obsessionnel-compulsif, troubles du spectre autistique, schizophrénie, syndrome de Gilles de La Tourette

Abstract

Disordered wrongdoing describes behaviour that is causally connected to a wrongdoer's mental disorder. A common attitude toward such wrongdoing is that the disorder is an "explanation" but not an "excuse". Mental disorders, though, are often thought to be conditions that limit one's freedom to choose alternative courses of action. These sorts of constraints on freedom are taken in ethical philosophy and democratic judicial systems to strongly reduce one's moral responsibility for a wrong act, if not remove it altogether in many cases. Rather than focusing on this legal interpretation of responsibility, I will focus on the "holistic" ethical context of how we treat disordered wrongdoers: our ethical comportment. I argue that our basic attitude toward disordered wrongdoers, on account of these constraints in freedom, should be compassionate. I explicitly focus on the meaning of compassion as it relates to a moral obligation to be understanding toward the reasons disordered wrongdoers have for their actions.

Keywords

mental health, freedom, free will, ethical comportment, moral responsibility, compassion, obsessive-compulsive disorder, autism spectrum disorder, schizophrenia, Tourette syndrome

Affiliations

^a Center for Global Health Ethics, Duquesne University, Pittsburgh, PA, USA

Correspondance / Correspondence: Benjamin Campbell, campbellb5@duq.edu

INTRODUCTION

How should we approach wrongdoing in the mentally disordered? It is no secret that mental disorders can sometimes manifest in antisocial and problematic ways. A common aspect of mental disorder is that the way the subject experiences the world is abnormal and estranged from the dominant community. As such, it is hard for the mentally healthy to know what to do when disordered people do bad things. I first provide an account of what disordered wrongdoing consists in and why it is important, focusing on the connection between mental disorders and unfreedom. I then focus on describing a basic principle of a theory of ethical comportment toward disordered wrongdoers.

WHAT IS DISORDERED WRONGDOING AND WHY IS IT IMPORTANT?

Introducing Disordered Wrongdoing and Building Blocks

To begin, we must delineate the concept of "disordered wrongdoing". It is not any wrongdoing performed by a person who is the victim of a mental disorder, but that which is significantly and relevantly causally connected to the wrongdoer's mental disorder. For example, suppose that a schizophrenic person, Robert, robs a bank because he has positive hallucinations that command him to do so. This is a case of disordered wrongdoing because his behaviour is intimately tied to his schizophrenia in a way that cannot be ignored. Suppose Robert robs a bank again, even though he lacks any disordered thinking, hallucinatory commands, or psychopathological feelings that motivate him to do so — this time, he is lucid. Even though he is still the subject of a mental disorder, this is not relevantly or significantly causally related to his wrongdoing, so it does not count as disordered wrongdoing.

What makes disordered wrongdoing interesting? Why should we care if a wrong act is committed because of a mental disorder? Bodily disorders, like cancer, may spur antisocial or risky behaviour. In such cases, we may be more tolerant or patient with wrongdoing given how the person may feel, but our interpretive stance toward them is broadly the same: they are

still rational, free agents who can choose to do right or wrong acts. But this stance is sometimes modified when the disorder becomes mental. When mentally healthy and financially stable, Robert appears, simply, to be greedy and so we pass some level of condemnatory judgment. When he is schizophrenically commanded, it seems like we may have a sense of sympathy or understanding toward Robert. The dividing line, here, seems to be that *mental disorders can sometimes interfere with a person's freedom, such that we are inclined to regard them and their relation to their wrongdoing in a less critical light*.

Despite our intuitive sense that mental disorders can interfere with one's freedom, it is exceedingly common to pass hostile judgment upon the disordered person and punish them for disordered wrongdoing. A slogan that has gained a good amount of currency is that mental disorders are explanations, but not "excuses" for wrongdoing (1). In other words, I may understand why your mental disorder is causally related to some bad act you have done, but I still regard you with disapproval. Though I may be personally empathetic with your plight, my behaviour will not be altered with respect to how I treat you.

This approach, in its strong form that precludes nuance or sensitivity to degrees of freedom, is incompatible with the approach employed by democratic judicial systems. For example, in the United States, major historical rules governing pleas of "not guilty by reason of insanity" (NGRI) all in some way make reference to the possibility that a mental disorder renders a person unfree: whether it is the superseded *Durham* rule,¹ the irresistible impulse test,² the Model Penal Code test³ or the M'Naghten rule,⁴ it is clear that democratic judicial systems have taken seriously the relationship between disorderment and freedom (2). Further, mental illness continues to be an important factor in determining sentence terms and length, as it is a common mitigating factor. While existing standards and sentencing guidelines, in my opinion, leave much to be desired — namely, because they almost uniformly undervalue the significance of mental illness and developmental history — the inflexible and callous approach expressed in the pithy catchphrase, "explanations but not excuses," seems to be *completely* unconcerned with the question of freedom. Given the historical-cultural importance of this subject, it seems that a deeper appraisal of the relationship is in order. Before we continue, though, two overarching clarificatory notes should be made.

First, the conception of freedom I employ is intended to be minimal and nonpartisan between broader views in the free will debate. Outside of the context of this project, I endorse a hard determinist and source incompatibilist position. But there is something to be said in ethical discussions for more measured and practical conceptions of free will, including those originating from compatibilist analyses. In the following, I adopt an understanding of freedom that involves the ability to choose otherwise in a practical and psychologically realistic way. Employing definitions like this function especially well in contexts surrounding questions of compassion and responsibility and can satisfy many with more moderate expectations as to what freedom involves. This view of freedom should accordingly be understood as provisional and restricted in its use. Nothing about the following should be taken to indicate any substantive statement on what the proper view is in broader debates surrounding the metaphysics of free will or responsibility.

The second clarification is about the conceptualization of mental disorder. The project of defining mental disorder in any adequate way is such a significant task that it would be unrealistic to expect to resolve it here. The subject of how to define mental disorder is highly controversial and includes debates surrounding the meaning of dysfunction, distress, harm, social construction, vagueness and boundaries, symptoms, the relevance of biological etiology, phenomenology, and much more. Rather than attempt to offer a satisfactory and exhaustive account of mental disorders as a class, I will merely identify and discuss particular disorders. A non-negotiable, however, is realism about mental disorders since their real instantiation in a given person is what deprives them of freedom.

Beyond difficulties in defining 'mental disorder,' there have been a range of developments in the metaphysics of mental disorders that could conceivably affect the success of my argument. A major current in the last fifty years is the growth of anti-realist approaches to mental disorderment, most notably represented by the work of Thomas Szasz. Additionally, a number of social movements have developed, including the "Mad Pride" movement, as well as the neurodiversity movement, both of which often focus on reframing mental disorders (and/or neurodevelopmental conditions) not as disorders, but as de-pathologized, diverse, and sometimes adaptive or beneficial ways of being. To be clear, each movement has a somewhat different, but potentially allied perspective about what matters (3). I have criticisms of disorder anti-realism and some aspects of the aforementioned social movements, but I set those aside for the purposes of the present analysis.

Finally, I want to make clear my aims in the following section as regards freedom and the conceptualization of mental disorder. I am not arguing that a mental disorder *must* impair freedom in every single case of wrongdoing nor that it impairs freedom in

¹ The *Durham* rule refers to a principle established in *Durham vs. United States* (1954), in which a person can be found NGRI if the criminal act was the product of a mental defect or disorder. The *Durham* rule was only ever applied in a select number of jurisdictions, but has been influential on the debate surrounding NGRI standards. Presumably, the *Durham* rule is based on the premise that a person is not free and thus culpable if their criminal conduct was caused by a disorder.

² The irresistible impulse test was established in the Alabama Supreme Court case of *Parsons v. State* (1887). Essentially, if a person *cannot* control their criminal behaviour due to a mental disorder, they must be found NGRI. Most jurisdictions that at one point allowed affirmative defenses on the basis of an irresistible impulse no longer do.

³ The Model Penal Code (MPC) test requires either a substantial deficit in the ability to recognize the wrongfulness of one's criminal behaviour or to control one's behaviour as a result of a mental disorder. This test is less demanding than the irresistible impulse test, since it does not require a total inability to control one's behaviour. Further, it has weak cognitive standards, only requiring that one substantially suffers in their ability to understand that their behavior is illegal or wrong (if this horn of the defense is taken up). The MPC test is a common test applied for NGRI pleas.

⁴ The M'Naghten rule is a historically significant rule still applied in a significant number of jurisdictions in the United States, which specifies that a person is NGRI if a mental disorder causes them not to understand the moral or criminal nature of the act they are performing, or the nature of the act itself.

all aspects of a disordered wrongdoer's life. Even more important is that I am not offering freedom-limitation as a definition of mental disorder. Rather, I am arguing that mental disorders are *real* and *harmful* configurations of mental systems and that they *often* impair freedom through their symptomatology. Beyond that minimal framing, I am content to leave any precise conceptual detailing aside, since for the present argument, we only require a fuzzy understanding of mental disorderment.

These clarifications are an attempt to make this analysis relatively moderate and free from at least some conceptual disagreement, since I take it that the argument and conclusion is plausible from a large range of perspectives — though certainly this does not mean all. I seek to disengage from questions surrounding the metaphysically “deep” meaning of freedom and mental disorder, and instead rely on more everyday notions of the two.

Freedom and Mental Disorders

Freedom, as I use it here, is the ability to choose otherwise. This “ability” is not a metaphysical ability (indeed, one may always be metaphysically able to do *x* or *y*), but an ability grounded in the factual constitution of a person, including one's psychological makeup. While I am, for instance, perhaps metaphysically able to run when someone holds a gun to my head, the fact of the gun being held to my head constrains, practically and psychologically, the sorts of choices I can make. Not only is it impractical to make any decision which might anger the gun-holder, because it will thwart any ends I am working toward (namely, because I would be dead), but I may also experience an overwhelming psychological compulsion to make one or another decision. Even if I could generate good reasons to ignore the demands of the gun-holder, everything in my mind and body would cry out to *just listen to them*. The “gun-against-the-head” trope is an example of an external constraint where a decision is made under duress — but not all such factual and practical constraints are external. Mental disorderment is often construed as a paradigm of an internal constraint on freedom (4). O'Connor, for example, argues that experiencing a traumatic event places serious limits on “what is psychologically possible” (5, p.123). In other words, experiencing a severe traumatic event may impair one's ability to choose a course of action other than the one they do end up choosing. The possibilities that are realistically open to their choice are limited by their condition.

The ability to choose otherwise, in this sense, is not binary — it is not an on/off switch where one suddenly has the ability or one does not. Rather, just as one can be said to “more or less” have the ability to understand a concept, or can “more or less” have the ability to do a somersault, so too can we “more or less” have the ability to choose otherwise. There are times when I can choose otherwise quite fully: I can take other options seriously, weigh them, review my beliefs and see how my values interact with them. But there are situations where I cannot choose otherwise in such a full manner — when the gun is to my head, my ability to really take alternatives seriously crumbles because my psychology *propels* me toward the answer. I am, as it were, not really in the driver's seat when I make a decision under those circumstances. When I am “forced” into an option, whether by internal or external constraints, we accordingly say that I was more or less free in whatever choice I make.

The relevance of free will discussions to psychopathology is clear. Compare a mentally healthy person who is, as a matter of disposition, angry, with someone who has intermittent explosive disorder (IED), a disorder marked by devastating bursts of almost uncontrollable anger. Suppose the mentally healthy person engages in a hit-and-run because of palpable but not pathological levels of anger. This person can still reasonably consider other options, even if their anger makes the wrong act enticing. Now, suppose the person with IED engages in a hit-and-run out of a burst of excessive, jaw-dropping anger. This person's experience of their options, their ability to consciously decide one or another, is washed out by the extent of their anger. Deciding *not* to engage in some aggressive act is a nonstarter, if it even shows up on their radar at all. This is not to say that there is a lack of variation in non-clinical populations, in particular, variation that can produce meaningful differences in levels of freedom. It is that mental disorders, in a wide range of cases, can undermine one's level of freedom far beyond normal psychological variation, and the level of responsibility we assign to that person should accordingly fall. Some may reject this analysis because making sense of or operationalizing the notion of a “degree of freedom” is difficult, or they think perhaps the idea is incoherent. But such a rejection would need to explain why such intuitions exist in the first place and why they can exert compelling persuasive power on the general population, attorneys and judges, and, indeed, philosophers. There are countless ways that mental disorders can impair freedom owing to the diversity of their features. I will now examine a few important and exemplary ways that disorders do so.

To begin with, consider the role of delusions and hallucinations in impairing freedom. Imagine a schizophrenic person who murders their neighbour because they have a delusion that the neighbour is poisoning them, perhaps with hallucinatory features commanding them to do so or false visual experiences of the neighbour dropping arsenic in their food or water supply. To many, it seems obvious that the schizophrenic person is not free in making such a decision. What makes them unfree is an epistemic deficiency: they do not really know what they are doing as regards the shared, intersubjective world. Their world, the one that they have information about, information that provides them with reasons and motivation for action, is one in which their neighbour is trying to kill them. The decision they make in the disordered world does not closely correlate to what happens in the world in which the rest of us live. They choose one course of action in their subjective world, and they are meaningfully severed from the “real” course of action and its consequences. How *could* they really choose otherwise? Hence, such a person would be unfree.

Next, mental disorders may restrict freedom through a kind of affective coercion. Take for instance a person with obsessive-compulsive disorder (OCD). OCD is characterized by the presence of obsessions (sticky, distressing thoughts that constantly

occupy a person's attention) that cause a person to perform compulsions (actions that are intended to make such thoughts less distressing or altogether eliminate them). Unfortunately, the performance of compulsions causes the person with OCD to become negatively reinforced to rely on them, so they enter an endless, self-perpetuating cycle of *scary thought-act-scary thought-act* (6). Imagine I am a person who has an obsession about stepping on a crack. I have thoughts that swarm my mind whenever I am walking, that direct my attention to the possibility that if I step on a crack, everyone I know will die. I may rationally recognize that nothing bad will actually happen if I step on a crack, but anxiety, discomfort, fear, or a "not-just-right-feeling" push me to be highly aware of where potential cracks are and to avoid them at all costs. Levy views the performance of compulsions as often "mechanically dictated" — as though the person with OCD were a robot, apprehending some threat and automatically trying to extinguish it. He concludes that OCD is a "malady of free will" (7, p.214). Not all compulsions are like those Levy describes. Some are highly cognitively involved and deliberative — a person with OCD may agonize over whether to perform a compulsion. What is relevant for our purposes, regardless of its automaticity (that being said, automaticity does serve as a good reason to consider a given act less freely chosen) is the intense affective weight that props up the compulsive cycle. Not performing a compulsion can feel like torture. This affective quality *pushes* me to perform the compulsion, often against my higher-order wishes. The intensity of the internal demand to perform a compulsion varies between individuals — so too, then, does the amount of freedom a person has in performing the compulsive act. The more powerful the demand, the less I can choose otherwise. OCD is quite revealing of the role of emotional coercion in the performance of a wide range of acts found in mental disorders: whether it be the decision to stay home from a friend's birthday party because one is in the thralls of agoraphobia's terror, the decision to lay in bed all day because the feeling to not do anything at all is so oppressive in major depression, or the intensity of some urge or desire over and against self-control mechanisms in impulse-control disorders. These sorts of internal pressures and demands constrain the psychological ability of a disordered person to choose otherwise.

Neurodevelopmental and neurological conditions often have a foot in both camps of "neurodivergence" and "mental disorder." The concerns raised here about free will and moral responsibility often apply to these conditions. I will not feign neutrality on the question of whether such conditions can, in some cases, count as mental disorders, and that some actions performed under the influence of these disorders can count as disordered wrongdoing. A useful example is Tourette Syndrome because it vividly highlights the complex nature of volition under the conditions of disorderment. Performing tics is annoying and can be exhausting. Depending on the intensity of the tic and how widespread it is, it can be temporarily disabling (or, when in a tic episode, the set of tics can be disabling for longer periods of time). The basic feeling of the premonitory urge, the sensation that precedes and motivates the performance of tics, is aversive and uncomfortable (8). Further, the phenomenology and neurobiology of Tourette's overlaps significantly with recognized mental disorders like OCD; the two are highly comorbid, and an "intermediate" disorder construct, "Touretic OCD" has been proposed (9). We know quite confidently that Tourette's is at least hanging out in the neighborhood of mental disorders. But I claim more than that: there are good reasons for a significant number of cases to believe that having Tourette's makes one worse off and that the cause of this being worse off is a set of mental symptoms. We should consider those cases to fall under the label, "neuropsychiatric disorder." Of course, even if this reasoning is not persuasive and one absolutely insists that Tourette's could, under no circumstances, be counted as a mental disorder, one would have to answer to the fact that Tourette's, autism (specifically autism spectrum disorder, or, ASD), and ADHD all feature in the DSM-5TR as mental disorders.⁵ The reason I argue that Tourette's (and, *mutatis mutandis*, other neurodevelopmental disorders) can count as a mental disorder is precisely to show that disordered wrongdoing can emerge from it, and further, that such wrongdoing *is* not performed totally freely. The person with Tourette's, in the vast majority of cases, does seem to choose with at least some amount of freedom to perform the tic. Leckman, Walker, and Cohen (11) found that 92% of participants with Tourette's reported having *some* volition over the performance of their tics. However, their agency is nonetheless impaired by the condition — asking a person with Tourette's not to tic is like asking someone who stubbed their toe not to wince. The feeling generated by stubbing your toe is so intense that it is exceedingly difficult to *not* wince, so too for premonitory urges and tics. Tourette's is a case of a neurological condition that is simultaneously a mental disorder. For the majority of people with it, the central act following from the disorder, ticcing, is at least partially unfree. When a person suffering from coprolalic tics shouts a racial slur, or a person punches another individual due to a tic, it is intuitively unjust to hold them to account in the same way one would a person who does not have Tourette's. Namely, because it is incredibly difficult for a person with Tourette's to inhibit the tic for any length of time, such that we would say they "didn't have a choice."

In all the above examples, the ability of the disordered person to choose otherwise is impaired by their disorder. We should therefore recast the definition of disordered wrongdoing as wrongdoing that is committed out of some degree of unfreedom related to mental disorderment. Accordingly, the level of moral responsibility conferred on the person for the performance of some wrong action should likewise be diminished. If the argument thus far is persuasive, and mental disorders can impose constraints on one's moral responsibility in the performance of wrongdoing, then how ought we act toward the wrongdoer in cases of disordered wrongdoing?

⁵ At multiple points in the DSM-5TR, neurodevelopmental disorders are referenced as mental disorders. For example, in their preliminary description of neurodevelopmental disorders, the authors say that "neurodevelopmental disorders also frequently co-occur with other mental and behavioral disorders with onset in childhood" (10, p.35). Note that "other," here, means that neurodevelopmental disorders *themselves* are mental disorders. We need not, however, rely on this sort of semantic analysis. Elsewhere, the authors explicitly give neurodevelopmental disorders as examples of mental disorders (10, p.374).

ETHICAL COMPORTMENT TOWARD DISORDERED WRONGDOERS

Disordered wrongdoing — as in, the act — is not itself exempt from criticism. The wrongdoing is *still* wrongdoing, regardless of its origins. As such, all the feelings and frustrations that respond to the wrongdoing (according to the severity of the offense) are fitting. It is not at all wrong for a person whose mother is murdered because of a schizophrenic delusion to be sad, shocked, frustrated, angry, and whatever other emotions are present. The question we face is how we should respond to disordered wrongdoers — the perpetrators of disordered wrongdoing.

Answers to this question are typically posed in terms of punishment — how much and what kind. There is often a legalistic flair to discussions about disordered wrongdoing. But our ethical orientation toward disordered wrongdoing exceeds just the question of punishment. It involves issues of how we should evaluate the person themselves as “good” or “bad,” how we ought to talk to them, with what tone, in what contexts, whether we want to avoid them, whether they should be excluded from the community, and whether one wants to have a relationship with that person at all. When we stand in relation to each other as members of an ethical community, there is an overarching character and attitude to how we treat others that integrates not only the dramatic or obvious ethical foreground — verbally expressed ethical judgments and condemnations, punishments, argumentation and rigorous ethical reasoning — but also the ethical background of everyday acts, that is, the way we look at people, smile or frown, move around them or avoid them, and so on. This is one’s *ethical comportment*. It includes the “prereflective” (12, p.77) and the reflective, and the dramatic (putting someone to death because of some wrong act) and mundane moments (frowning at a person because they did something wrong) of moral existence.

I argue that the mode of ethical comportment we ought to bear toward disordered wrongdoers is compassion. But what is compassion? Compassion is a somewhat analogical notion. In Strauss et al. (13), the authors summarized and reviewed eight “major” definitions of compassion, each with distinct features and components. Three major components, though, were generally accepted by these diverse perspectives: awareness of another’s suffering, resonating with that suffering emotionally and/or cognitively, and feeling motivated to alleviate or help the suffering person (13). When it comes to the contributions of the compassion literature, I think this is a fair composite model, but it misses the broader sense in which people tend to use the term ‘compassion’ in day-to-day life. Compassion is often used interchangeably with empathy, sympathy, care, sensitivity, tolerance, and benevolence. Much is made of the distinctions between these concepts by philosophers and ethicists, particularly between ‘compassion,’ ‘empathy,’ and ‘sympathy,’ but these distinctions in no way map onto their ordinary usage. I thus worry that in an attempt to gain conceptual clarity, we might be over-legislating differences between highly overlapping and similar concepts. While there may be good reasons to distinguish between them, such as putative neurobiological differences as reported in Gallagher, Raffone, and Aglioti (14), we can develop the right sort of attitude, one which I will be labelling compassion, without drawing solid lines between fuzzy concepts or agonizing over their minutiae.

As I use it, compassion roughly equates to a mode of ethical comportment in which someone is concerned for the situation and well-being of another person. This concern can be unimodal, where a person feels sorry for another person’s suffering, or multimodal, where the person might also have beliefs about what they should do or motivations to alleviate their suffering. Theoreticians tend to emphasize different components of compassion as more or less important or interesting. Nussbaum, for example, emphasizes the cognitive component such that compassion, treated as equivalent to pity, requires no particular feeling. Using the example of Emile from Jean-Jacques Rousseau’s classic, Nussbaum argues:

On the other side, if Emile really does the cognitive work, if his imagination really contains the thoughts of pity, with all their evaluative material, in such a way that they become part of his cognitive makeup and his motivations for action, then he has pity whether he experiences this or that tug in his stomach or not. No such particular bodily feeling is necessary. To determine whether Emile has pity, we look for the evidence of a certain sort of thought and imagination, in what he says, and in what he does (15, p.38).

That Nussbaum would interpret compassion in a cognitive way is not surprising, given that her overall argument is aimed at the cultivation of compassion for the sake of justice (15). After all, it seems like justice would be next to impossible to deliver if we acted merely upon the whims of the heart. But others emphasize the motivational component of compassion as what makes it so important. Schopenhauer, in *The Basis of Morality* (16), understands compassion as grounding all virtue through a distinctly genuine and voluntary motive that can regulate egoistic and malicious desires. To be sure, though, the bulk of what most people take to be distinctive about compassion is its emotional weight: to suffer because another is suffering is powerful and likely inspires much of our cognitive and motivational responses.

For my part, I am most interested in the cognitive element of compassion. In particular, the degree to which compassion means that we take an *understanding* approach to others. The relation between compassion and understanding is a relatively natural one: if I am concerned for the well-being of another person, it stands to reason that I might inquire about who they are, where they came from, what they do, what they feel, and how they think. In psychotherapy, for instance, a stance of “compassionate caring” is one that might involve an attempt by the psychotherapist to “understand [the patient] in a safe, non-judgemental and non-shaming way” (17, p.44). Understanding compassionately sometimes involves acts of imagination and empathetic simulation. As Bierhoff puts it, “Compassion refers to the understanding of another person’s thoughts and feelings by putting oneself in the shoes of the other” (18, p.148). If I can really try to think about what it would be like to be another person — their

history, their feelings, beliefs, and, indeed, their pathologies — then it seems like I am in a better position to understand them as a person.

But why is understanding so important for compassion when we are concerned with disordered wrongdoing? It is because when the intentions and reasons of others in doing something wrong are inaccessible, a black box as it were, it becomes more difficult to generate a robust caring relationship with them. If I do not understand the person I am trying to behave compassionately toward, it is harder for additional cognitive, emotional, and motivational components of compassion to organically arise.

Imagine the following scenario: you have just been rear-ended by another car. When you pull over and ask for the other driver's insurance, they yell at you and drive off. In this situation, it is natural to develop feelings of anger, beliefs about the moral character of that other person, and to want some sort of punishment to be doled out to them. Nothing about your mode of comportment is compassionate in those moments nor would you be likely to behave compassionately if you were to see them again. But imagine that you saw that person's life through their own eyes. You learned about their childhood and how anger was modelled for them, that they never faced consequences for bad behaviour as an adolescent, and maybe that they struggle to afford insurance for their car. Suppose that in your jurisdiction, driving without insurance is a crime, but that person needs to drive to work and make ends meet. Our comportment toward that person very well might change. We might still be angry and want some sort of compensation, but we might not make the same sorts of moral and emotional judgments. We might not behave as confrontationally as we would have, and we might not talk as negatively about them to our friends and family. When we develop understanding, we gain a broader view of the person and their humanity.

When it comes to disordered wrongdoing, understanding is essential because disordered wrongdoers are not just wrongdoers, but a unique kind of wrongdoer who suffers from impairments in freedom. If we approach them without understanding, we might make judgments and behave in ways that are disproportionate to their condition and responsibility for their actions. Furthermore, without understanding, we would neglect to address the causes of their wrongdoing and to ameliorate them. For example, if a person with bipolar I disorder engages in reckless spending during a manic episode that puts their family in financial jeopardy, merely condemning them without making an effort to understand their condition would inadequately take account of the context of their actions and would do nothing to help manage future episodes. While I would urge a compassionate and therefore understanding approach toward wrongdoing broadly, the necessity of compassionate comportment is made manifest in cases of disordered wrongdoing. To be understanding toward disordered wrongdoers is simply more fair to that person and can prove more productive for the well-being of the broader community.

What is more poisonous than a mere difficulty to apprehend another person's intentions, though, is a *lack of desire* to understand. When we close ourselves off to the other person, any hope of fruitful, compassionate communication dies. If we are to be compassionate, a major goal is the cultivation of a desire to understand, in addition to resolving and enacting the answers to practical questions about how to actually go about understanding. Attitudes resembling the "explanations but not excuses" variety are, in effect, an attempt to close off understanding and accordingly engage in punitive social interactions. This stands in stark contrast to strong evidence that the development of understanding between victims of wrongdoing and offenders is mutually beneficial: in restorative justice interventions, wherein offenders and victims engage in dialogue, victims tend to report positive psychological effects, including reductions in the severity of posttraumatic stress symptoms, feelings of helplessness, and anger and desire for revenge (19), and offenders recidivate at lower rates and display more empathy for their victims (20). Since understanding and compassionate relations with others may strengthen our individual well-being, it seems that inflexible and narrowly judgmental attitudes could prove deleterious.

The understanding which I take to be crucial to compassion should not be taken to be uncritical. Compassion demands more than any platitude or any reductive belief about exceedingly complex ethical questions. It demands practical wisdom — that each individual case of disordered wrongdoing be evaluated carefully with fair and right judgment and sensitivity to truth. It is to remain steadfast in understanding why the disordered wrongdoer did what they did, even if the act is so bad that its repugnancy pushes one away from the attempt to understand and critically evaluate. This means, basically, to attempt to bridge the gaps in experience that impair our ability to relate empathetically. However, persistence in understanding does not equate to an allegiance to that person and their account of their actions. Wrongdoers often lie and this is especially so when we take into account wrongdoing connected to personality disorders (21). What we need is therefore something more along the lines of what Fricker calls "*critical openness*" (22, p.66). In being critically open to the reasons, motivations, and abnormal states of mind that lend themselves to wrongdoing, we are compassionate.

The significance of practical wisdom is made clearer when we conceive of compassion as a virtue. Garcia-Urbe and Pinto-Bustamante (23) describe compassion as occupying the golden mean between apathy and hyperpathy, as part of a broader neo-Aristotelian approach to compassion fatigue. In the compassionate frame of mind, one is cognitively and, if possible, emotionally connected to the plight of the disordered wrongdoer and recognizes their situation as in some way tragic. However, this connection is not the same as full-bodied identification. Sometimes, as Garcia-Urbe and Pinto-Bustamante point out, going too far into hyperpathy can exhaust and push a potentially compassionate person into apathy (23). We should accordingly be careful that the positive attitudes, beliefs, and emotions we hold toward a disordered wrongdoer do not overextend, as we might end up back at our often cruelly indifferent starting points. However, that risk should not goad us into

inaction or resting comfortably in attitudes and habits that are disproportionate to the level of freedom enjoyed by the disordered person. While compassion may be a hard tightrope on which to balance, to refuse to strive for that balance is destructive. Insofar as we think that our ethical comportment should reflect the circumstances of wrongdoing, both on the side of the act and its perpetrator, it seems that a measured but humane compassion is called for in cases of disordered wrongdoing.

What I have suggested is not a vapid optimism nor an outright permissiveness. According to the severity of the offense and the extent of one's freedom, we might censure or punish the disordered wrongdoer. This sort of act can be necessary depending on the degree to which an offender is dangerous to the well-being of other people, i.e., a quarantining punishment (24). But to be compassionate means that these sorts of acts, wherein we punish another person, are not rooted in hatred or disdain for the person. It means that we treat even those people who commit severe wrongdoings as human beings with physical and emotional dignity, with a desire to understand their motivations and realign them with the interests of society. If one fairly appraises the impact of mental disorderment on the ability to choose otherwise, it becomes apparent that the intensely punitive attitude that characterizes criminal, community, and social justice in countries like the United States represents a systematic failure of compassion on nearly every level, given the pervasiveness of mental disorders among incarcerated and paroled individuals. Against this current, I suggest that disordered individuals are often not free and so we are morally obligated to consider, weigh, and take substantial action in light of that fact.

My thesis of how we ought to ethically comport ourselves toward disordered wrongdoing is as follows:

If a person *x* is disordered in some way *y* and some act *z* committed by person *x* is causally connected to the disorder *y*, such that the person *x* was, to some degree, unfree in performing the act *z*, we ought to comport ourselves compassionately, with special emphasis on understanding their reasons for the wrongdoing, toward the person *x*, both in terms of our general, everyday behaviours toward them and any potential punishments or significant moral judgments, with sensitivity to the level of unfreedom the person *x* had in performing the act *z*.

This argument importantly applies not only to criminal justice settings, but also, and significantly, to the sphere of non-governmental and personal communities. The level of freedom we enjoy should always be at issue, whether the insignia of the state is present or not. If such a principle is not adopted, we will continue to punish the most vulnerable and the least free. Compassion is our only escape from cruelty.

CONCLUSION AND TWO OBJECTIONS

Mental disorders are often debilitating and disabling. They often interfere with the way one wants to live one's life on a broader scale, as well as the decisions one may make in day-to-day existence. Mental disorders, I believe, and as many other philosophers and psychologists have concluded, sometimes impair freedom in a nontrivial way. In the broader ethical tradition, those who are unfree are not morally responsible for their actions. Given this context, I argue that our fundamental disposition toward disordered wrongdoers should be compassionate. Compassionate comportment is a stance toward the disordered wrongdoer that is characterized most powerfully by a critical desire to understand. I therefore urge against the callousness and moral inflexibility so frequently displayed and embodied toward disordered wrongdoers and suggest that we shift to a more sensitive, nuanced, and ultimately humanistic orientation.

Before ending this discussion, I want to review two objections to my argument.

One objection emerges from a long historical tradition in Western philosophy that identifies personhood with freedom and accountability for one's actions. In other words, personhood is identified with *moral agency*. A notable example of this sort of view comes from Immanuel Kant. Kant views persons as rational beings with an awareness of the moral law who can accordingly exercise freedom and thus be accountable for their actions (25). This is a maximal definition of personhood that reflects Kant's unique philosophical framework and ethical theory. Nonetheless, his view is shared by many other thinkers, who take moral agency to be at the core of what makes someone a person. A worry with these sorts of views has always been the degree to which they might render certain groups who do not have moral agency as *non-persons*. The relevance here, is that under this view of personhood, we might end up with disordered wrongdoers treated as not people, since they are at least partially unfree — an undesirable conclusion. I have two responses. First, to be unfree with regard to an action or some set of actions does not mean that one altogether lacks moral agency. If a person with major depression is unfree in failing to meet an obligation to a friend, this does not entail that they are unfree with regard to all their actions. They might well freely choose their other actions and thus be accountable for the vast majority. Second, it is always an option to reject the identification of moral agency with personhood. If we do not take freedom and accountability to be core parts of what makes a person a person, no issue arises. There are plenty of influential and compelling critiques of the moral agency view of personhood, so it should not be taken for granted that we should accept it. I personally do not accept the moral agency view of personhood precisely because it is prone to generating unsatisfactory conclusions about who is and is not a person.

Another objection concerns the relation of compassionate comportment to concerns about recognition and mental illness. Earlier in this paper, I mentioned the Mad Pride movement. An important part of mad activism is the construction of "madness" as an identity, one with a unique history and culture. Accordingly, one of the aims of many Mad Pride activists is *recognition* from others that "madness" is a legitimate identity, and even one that should be held in esteem. Recognition is often taken to

be psychologically important because it is validating to an individual or group's self-identity. Charles Taylor, for instance, argues that "[misrecognition] can inflict a grievous wound, saddling its victims with a crippling self-hatred" (26, p.26). But beyond that, some argue that recognition is a crucial part of what it means to be free. This view originates most clearly in G.W.F. Hegel's *Phenomenology of Spirit*, where he argues that to truly recognize one's own self-identity requires recognition by an "Other." Mutual recognition, for Hegel, is not a detriment to freedom, but a condition for its actualization. Hegel's view is not geared at the psychological benefits of recognition, and this concern should be considered distinct. As Rashed puts it, "Hegel was not after some basic fact of human psychology, rather, he was developing a conception of freedom for which recognition is a necessary condition" (27, p.95). So, recognition may be important, whether for psychological reasons or for the sake of ensuring human freedom. The worry, as applied to my argument, is that by treating disordered individuals as disordered and in some cases unfree, thus deserving especially compassionate treatment, we are not recognizing "mad" identities as legitimate or worthy of celebration.

One could reject either the analysis that recognizing identity is beneficial psychologically or that Hegel's analysis of freedom and identity is correct, or both. I think that unequivocally rejecting the former is a mistake, since the recognition of important identities is *usually* psychologically beneficial for the person demanding recognition. In the wake of reinvigorated bigotry amounting to rejecting the recognition of, for instance, trans identities, it's clear that we should be taking recognition seriously on at least the level of psychological well-being. Rejecting the latter is a far more plausible move. I obviously cannot give anything resembling an adequate treatment of Hegel or the two centuries of debate surrounding his theory of recognition here, so I will leave my remarks at the following: rejecting Hegel's view can be and has been done before. I will therefore relegate my response to the former concern entirely.

Simply put, I do not think that recognizing mental disorders as real, disabling, harmful, distressing, or freedom-limiting is necessarily incompatible with the recognition of a distinct "mad" identity and a partially positive evaluation of that identity. Incompatibility only emerges when we take "mad" identity to be fundamentally defined by an opposition to realism about mental disorders or require our evaluation of "mad" identity to be unconditionally positive. I think that views of madness that treat disorderment as normatively ambiguous, like the "dangerous gifts" view, which recognizes the distress and impairment of disorders alongside their potential for fostering creativity, are compatible with the approach in this paper (27). Elsewhere, I have argued in favour of the project of partial transvaluation, whereby we evince the positive or useful components of mental disorders, while simultaneously acknowledging the sheer scale of suffering and harm they cause.

Recognition, in my estimation, does not amount to an uncritical acceptance of any and all identities in the exact way an individual or group wants them to be. If what it means to recognize "mad" identities requires that I treat disorders as fictions or as purely positive and adaptive ways of being, then I think that the psychological harm caused by my refusing to recognize those identities as such is outweighed by greater harms that adopting such views may cause for individuals with mental disorders. A significant difference between the sort of moderate recognition I am offering here, and the universal and absolute recognition I would prescribe in favour of, for instance, trans identities, is that recognizing trans identities as absolutely valid and worth celebrating does not in any way do harm to trans individuals. In contrast, if I absolutely and unequivocally recognize "mad" identities as positive and non-pathological ways of being, there is a serious risk that "mad" individuals might be emboldened to, for instance, refuse evidence-based therapies and pharmaceutical interventions. My recognition could accordingly cause significant harm by encouraging actions that result in significant suffering for those I recognize. In the context of freedom, if we recognize "mad" identities as unambiguously free from limitations on freedom, it might affect "mad" wrongdoers negatively in social and legal contexts through enhanced punitive measures.

These previous two objections are quite powerful and complex and would require specific and extended response in order to be at all adequate. I have attempted to provide an honest reply to both in a briefer context, though I do not think that my reply is anything amounting to a knockdown against those objections. But, I nonetheless think that my responses could bolster our confidence in the conclusion reached: that the most appropriate mode of ethical comportment toward disordered wrongdoing is compassion.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The Ethical and Policy Implications of Epigenetic Research: An Analysis of the TCPS 2

Andrea Gretchev^{a,b}, Heide S. Temples^a, Deborah Dewey^{c,d,e}, Gillian England-Mason^{c,d}, Luigi Boccuto^a, Vivian Haley-Zitlin^f

Résumé

L'épigénétique est l'étude des modifications moléculaires potentiellement héréditaires de l'ADN et de la chromatine, susceptibles d'altérer la régulation de l'expression génétique. La recherche épigénétique pourrait potentiellement éclairer de nouvelles approches en matière d'évaluation des risques, de diagnostic et de traitement. **Objectif** : La présente analyse vise à déterminer si l'Énoncé de politique des trois conseils : Éthique de la recherche avec des êtres humains 2 (EPTC 2) offre une protection complète pour la conduite de la recherche épigénétique. Ces conclusions pourraient éclairer les modifications apportées aux politiques et l'élaboration de futures politiques qui tiennent compte de l'épigénétique et des domaines émergents de la technologie génomique. De plus, ces informations profitent aux personnes ou aux groupes menant des recherches épigénétiques. **Contexte** : La recherche épigénétique pose des défis éthiques nuancés et distincts qui diffèrent de ceux rencontrés dans d'autres domaines de la recherche génomique. Le présent document applique le triangle d'analyse des politiques de Walt et Gilson (contexte, contenu, processus et acteurs) pour évaluer dans quelle mesure l'EPTC 2 offre une protection en matière d'éthique de la recherche qui s'étend à l'épigénétique. **Analyse éthique et politique** : L'EPTC 2 offre des orientations détaillées pour la recherche en génétique, qui sont tout à fait applicables et s'étendent de manière appropriée à la recherche spécifique à l'épigénétique. Toutefois, les révisions ultérieures gagneraient à modifier la définition de la « génétique » pour utiliser le terme plus inclusif de « génomique » et à l'étendre explicitement à d'autres approches de recherche génomique, y compris l'épigénétique. En outre, le consentement général devrait mentionner de manière transparente la possibilité que les données soient utilisées pour des recherches impliquant des technologies génomiques différentes de celles de l'étude initiale. **Conclusion** : Le EPTC 2 constitue une base solide pour une recherche épigénétique éthique. Toutefois, des modifications mineures permettraient d'offrir une protection plus complète aux participants et aux chercheurs, garantissant ainsi que la politique reste pertinente et adaptée à ce domaine en rapide évolution.

Mots-clés

exposome, épigénétique, politique, éthique, recherche, génétique

Abstract

Epigenetics is the study of potentially heritable molecular modifications to DNA and chromatin, which can alter the regulation of gene expression. Epigenetic research can potentially inform new risk assessment, diagnosis, and treatment approaches. **Purpose**: This analysis seeks to identify whether Canada's Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2 (TCPS 2) provides comprehensive protection for the conduct of epigenetic research. These findings could inform policy amendments and future policy development that is inclusive of epigenetics and emerging areas of genomic technology. Additionally, this information benefits individuals or groups conducting epigenetic research. **Background**: Epigenetic research poses nuanced and distinct ethical challenges that differ from those in other areas of genomic research. This paper applies the Walt and Gilson policy analysis triangle (context, content, process, and actors) to evaluate the adequacy of the TCPS 2 in providing protection for research ethics that extends to epigenetics. **Ethical and Policy Analysis**: The TCPS 2 offers extensive guidance for genetics research, which is strongly applicable and extends appropriately to epigenetic-specific research. However, subsequent revisions would benefit from modifying the definition of 'genetics' to use the more inclusive term 'genomics' and explicitly extending it to other genomic research approaches, including epigenetics. Furthermore, broad consent should be transparent about the possibility that data may be used for research involving genomic technologies different from those in the original study. **Conclusion**: The TCPS 2 provides a strong foundation for ethical epigenetics research. However, minor amendments would provide more comprehensive protection for participants and researchers, ensuring the policy remains relevant and adequate for this rapidly evolving field.

Keywords

exposome, epigenetics, policy, ethics, research, genetics

Affiliations

^a Healthcare Genetics and Genomics Program, School of Nursing, Clemson University, Clemson, South Carolina, United States

^b Nursing Program, Faculty of Health Sciences, Douglas College, Coquitlam, British Columbia, Canada

^c Department of Pediatrics, Alberta Children's Hospital; Cumming School of Medicine, University of Calgary, Calgary, Alberta, Canada

^d Owerko Centre, Alberta Children's Hospital Research Institute, University of Calgary, Calgary, Alberta, Canada

^e Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada

^f Food, Nutrition, and Packaging Sciences, Clemson University, Clemson, South Carolina, United States

Correspondance / Correspondence: Andrea Gretchev, agretch@g.clemson.edu

INTRODUCTION

Epigenetics is the study of potentially heritable, and possibly reversible, molecular modifications to DNA and chromatin that alter the regulation of gene expression (1,2). Some epigenetic changes are a typical part of the aging process, while others are pathological and may contribute to increased disease risk (3). DNA methylation is the most extensively studied epigenetic mechanism (1). Other epigenetic processes include histone modification, chromatin remodelling, and non-coding RNA (2). However, much remains to be discovered about their individual and collective roles in disease development (2) (see Appendix A for a glossary of terms).

Epigenetics is a complementary approach to genetics research as it examines gene-environment interactions, providing holistic insight into potentially modifiable factors that contribute to health outcomes. However, epigenetics is distinct from genetics in that while genetic inheritance is relatively stable, epigenetics is a dynamic process influenced by the exposome — the cumulative non-genetic environmental exposures that occur over a lifetime that alter our biology, including those from the physical, chemical, social, and built environments within an individual's ecosystem (4-7).

Recently, the subfields of environmental and social epigenetics have begun to expand, bridging the fields of epidemiology and molecular biology (8). Social epigenetics examines the biological pathways through which diverse social experiences, practices, and environments affect health outcomes in individuals (9). These factors arise from the social and structural determinants of health and may include trauma, discrimination, stigmatization, and marginalization (10). Examples include the observation of differential DNA methylation in Holocaust survivors and Indigenous Peoples of Alaska in association with historical trauma (11,12). Environmental epigenetics examines the molecular processes underlying how environmental exposures may contribute to epigenetic changes that can alter gene expression (13). Exposures may include factors associated with climate change or environmental toxins. This topic is especially relevant to discourses on the health impacts of climate change and planetary health. Research demonstrating associations between environmental exposures and modifications to the epigenome have prompted a re-evaluation of gene-centric views, such as genetic essentialism, determinism, and reductionism, which suggest that an individual's phenotype, traits, or behaviours are entirely a result of their genetic composition, or that their biological make-up forms their essence (14) — such views discount how the social and physical environment may shape a person's biology and phenotype.

Currently, epigenetic therapies are used in clinical practice, particularly in the oncology context, with an increasing number of clinical trials underway (15). With further research, epigenetic marks may offer unique insight into the pathological molecular processes that contribute to disease susceptibility, and epigenetic biomarkers may become clinically important for diagnosis and risk assessment (3).

Epigenetic research shares ethical considerations with genetic research, such as concerns for privacy and confidentiality, informed consent, equity, and access. However, identifying environmental, social, and structural determinants of health associated with epigenetic modifications introduces nuanced ethical issues that may result in policy implications for public health and environmental justice (16-20). Therefore, this paper analyzes whether the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2* (TCPS 2), Canada's principle-based policy for conducting ethical human research, provides protection for scientists and study participants that extends to the ethical issues arising from epigenetic research. These findings may inform the need for future policy amendments related to epigenetics.

POLICY ANALYSIS FRAMEWORK

Policy problem identification involves assessing what is valued or deemed just, identifying gaps, and then evaluating the alternatives that policymakers should pursue (21). Ideally, policy development would be proactive, a preventative measure anticipating potential problems. However, rapid scientific advancements such as those experienced in genomic sciences (including epigenetics) are outpacing the ability to predict the numerous potential vulnerabilities. Policies to guide genetic research involving human participants exist in many countries, although the authors are not aware of any that directly address epigenetics.

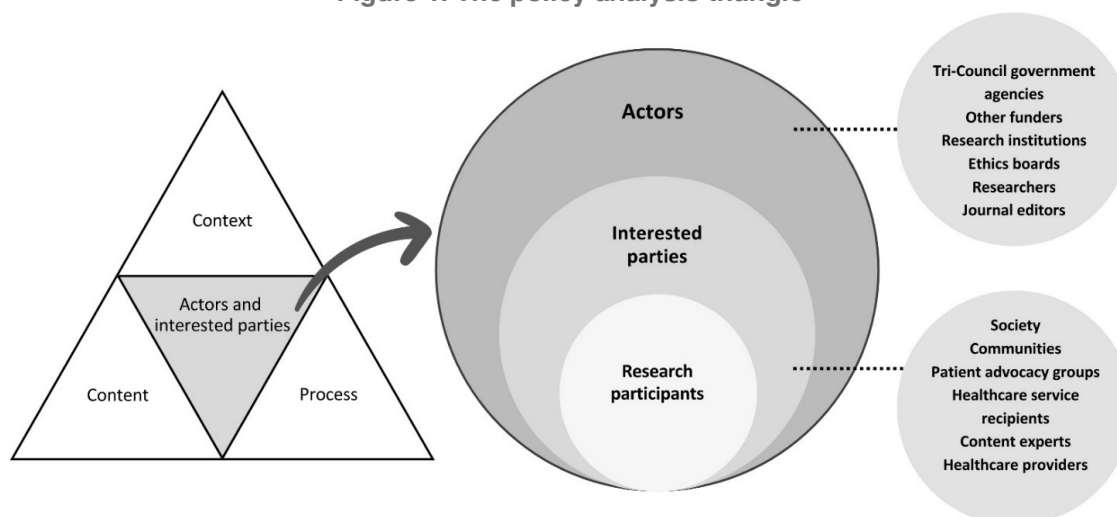
In Canada, the three federal research agencies jointly established the Interagency Advisory Panel on Research Ethics, which is responsible for developing and implementing the TCPS 2 (22). The TCPS 2 includes three core principles to respect human dignity: 1) respect for persons, 2) concern for welfare, and 3) justice. The TCPS framework is highly relevant to discussions on the ethics of epigenetic research, as it considers the impacts on economic and social circumstances, the privacy and security of personal information, the treatment of biological materials, and the risk of stigmatization or discrimination (23). In 2022, revisions were made to the TCPS 2, and several sections pertinent to genetic research were expanded (24).

The TCPS 2 raises the semantic question of whether epigenetics fits neatly under the umbrella term 'genetics' for policy purposes. The TCPS 2, chapter 13, defines human genetic research as "the study of genetic factors responsible for human traits and the interaction of those factors with each other and the environment" (25). It considers genetic research to encompass "the identification of genes that comprise the human genome; functions of genes; the characterization of normal and disease conditions in individuals, biological relatives, families, communities, and groups" (25). It acknowledges that genetic research can have social impacts and has the potential to lead to stigmatization and discrimination. It also states that "...diseases or

personal characteristics are influenced by multiple genes, as well as environmental factors” (25). Furthermore, there is mention of the possibility that genetic research may yield inconclusive results or reveal information about family relationships. Finally, the policy mentions only once the more commonly used and broader term ‘genomics’ and does not provide a definition. Though epigenetic concepts can be implied from these statements, they are subject to interpretation. Explicit direction would be preferable for consistency.

The Walt and Gilson policy analysis triangle (see Figure 1) considers the contextual or systemic factors influencing policy development, policy content, and the policy-making process (26,27). This framework is typically used retrospectively to analyze public health policy. However, it also provides a suitable framework for analyzing health research policy. Actors are at the centre of the framework as those who actively participate in developing, implementing, and enforcing policies and can include individuals, groups, or organizations (26). Interested parties are those affected by policies (28), and although they can be involved in shaping policy, this is not a requirement for inclusion under this definition. Research participants are the interested parties who are the core recipients of the benefits of policies such as the TCPS 2.

Figure 1. The policy analysis triangle



Created by A Gretchev (2025) in Canva. Actors and interested parties are at the centre of the policy analysis triangle. The actors and interested parties with a vested interest in epigenetic research in Canada are depicted, with research participants as core recipients of the benefits of policies such as the TCPS 2.

Actors involved in policy development, implementation, or enforcement of epigenetic research in Canada include the Tri-Council government agencies, researchers and their institutional research ethics boards, non-government funding sources, and journal editors. These actors all contribute to overseeing participant protection by enforcing adherence to ethical standards that promote equity, diversity, inclusion, and accessibility. From a broad perspective, the social and political context can influence research priorities and funding. Therefore, society is an interested party that can not only influence the policy agenda, but it is also directly affected by policy implementation. Additionally, research outcomes can provide an evidence base for policy decisions that could affect society and communities through their implementation and ongoing evaluation. Calls for community-engaged research or studies that include patient partners in the design process, such as patient advocacy groups, healthcare service recipients, and other content experts, are becoming increasingly common in Canada (29,30). Medical research with potential clinical applications affects healthcare providers, patients, and populations who may benefit from the research outcomes.

This analysis is structured to examine the ethical issues specific to epigenetic research through the lens of the three core principles of the TCPS 2 (the context). It then evaluates the extent to which relevant TCPS 2 provisions address these issues and their adequacy for guiding ethical conduct in epigenetic research (the content). Finally, it outlines recommendations for future revisions to the TCPS 2 to better accommodate emerging ethical challenges in genomic research (the process).

ANALYSIS OF THE TCPS 2

Respect for Persons

Actors

The principle of respect for persons highlights the inherent value of all human beings and ensures that research participants are treated with due consideration (8). Research participants are the primary beneficiaries of this principle. However, researchers must also be vigilant against potential violations of respect, and research ethics boards are responsible for oversight to ensure that studies are designed to maximize this principle. Autonomy encompasses an individual's right to consent through free and informed choice (23).

Context

To consent to participate in research, individuals must receive detailed information about the study, including its risks and benefits. However, in the context of epigenetic research, understanding such information requires health literacy, genetic literacy, and awareness of the complexities of epigenetic mechanisms and their potential to influence health outcomes, which can be challenging to grasp. This can complicate the informed consent process. The challenges related to informed consent necessitate transparent processes that provide information in terms that are easily understood by study participants and allow adequate time for consideration. Broad consent is commonly used in genetics research to permit the use of specimens for future studies and may not adequately convey the additional risks associated with epigenetic research. Broad consent for potential epigenetic research on samples should clearly specify the intended uses, describe how the data and specimens may be used, and outline the possible benefits and risks associated with epigenetic research.

Content

The TCPS 2 covers general consent in Chapter three, and Chapter 12, Section C, extends the consent guidance to include the secondary use of human biological materials for research purposes (23). Additionally, the 2022 revisions to the TCPS 2 include the addition of Chapter 3, section E, on broad consent, defined as “consent for future unspecified research” (31). This is a beneficial addition that is relevant to epigenetics research. Section 3.13 also requires that researchers seek consent for research separately from consent for collecting, using, and storing biological materials. These comprehensive stipulations address the concerns for informed consent described previously. Therefore, provided researchers include the risks and benefits associated with epigenetic research regarding the nature of the data collected and examined, and give ample time for research participants to understand what they are consenting to, the deontological principle of respect for persons in epigenetic research should be achievable.

Concern for Welfare

Actors

Respect for persons and concern for welfare overlap in that conducting research respectfully enhances the well-being of research participants. However, participant welfare also involves distinct considerations beyond respect. Researchers and research ethics boards protect the welfare of research participants and actively promote their well-being when foreseeable risks are identified. Welfare concerns encompass quality of life, including physical, mental, and spiritual well-being, socio-economic circumstances, and physical environments (32). This is particularly salient in epigenetic research, where social determinants such as trauma, discrimination, and stigmatization, along with environmental exposures including toxins, pollution, or tobacco smoke, have been linked to adverse health outcomes potentially mediated by epigenetics (10), as evidence of these associations may inform or support public policy development.

Privacy and confidentiality are crucial concerns for welfare, as maintaining these safeguards protects research participants from harm that could result from unauthorized access to their data. One key distinction of epigenetic research is the possibility that it may reveal sensitive information about lifestyle choices, environmental exposures, or psychological experiences. Research on epigenetic processes, such as DNA methylation, holds promise for developing biomarkers that may facilitate the prediction or early diagnosis of morbidity and mortality. However, identifying behaviours linked to adverse health can have negative consequences. For example, DNA methylation changes have been associated with smoking and alcohol consumption, which raises concerns that lifestyle factors could be inferred from these markers at some point in the future (32,33). An epigenetic smoking status estimator was already developed (34), highlighting the need to consider how these tools might be used in ways that disadvantage individuals, such as marketing these tools to life or health insurance underwriters as risk predictors. However, at this point, the error in these predictors is too large, and they are not advanced enough to apply at the individual level (16).

Context

Protecting participant privacy and confidentiality is paramount to concern for welfare. The unique combination of variants within individual genomes poses an inherent risk of re-identification. A 2018 study demonstrated the capacity to re-identify an individual by name from their genetic data by leveraging publicly available information (35). While the overall risk of re-identification from genetic data remains low, this finding has prompted inquiry into whether epigenetic data presents a comparable or heightened risk. Thomas et al. (36) contend that the identifiability of genetic data is contingent on experimental factors, including the molecular modality, assay type, level of data processing, whether the content is germline or somatic, and the granularity of the structural variant analysis. Consequently, not all genetic data carries an equal risk of re-identification. Based on their scoping review, the authors provided practical guidance for researchers to conduct risk assessments and implement safeguards when using genetic data. There is no definitive evidence to exclude the risk of re-identification from epigenetic data. However, the dynamic and reversible nature of epigenetic modifications reduces the risk when compared to static information derived from DNA sequencing (16,37).

The return of results from epigenetic research necessitates a careful consideration of potential harms in balance with the benefits. However, policies for general genetic testing apply in that results should be clinically valid, significant, and actionable (38,39). Dyke et al. provide additional considerations specific to returning epigenetic results (40). The authors caution that

determining the validity and actionability of epigenetic results is especially challenging due to the accuracy of technology, the dynamic stability of epigenetic changes, the lack of definitive evidence for causation, tissue variability, and clinical validity (20,40).

Several established models for informed consent exist regarding the return of genetic results to research participants (41,42). However, inconsistent approaches are observed globally, partly due to the heterogeneous legislative landscape, which influences the return of results (43). In Canada, there is currently no legal mandate compelling the return of genetic results to research participants (43). Nevertheless, the prevailing practice standard within the Canadian research community is to provide results that are deemed clinically actionable (43). The US National Academies of Sciences, Engineering, and Medicine (NASEM) provided comprehensive guidance on return of results in their 2018 consensus report (42). The report strongly recommends that informed consent documents specify offered results, justify the selection of particular results, discuss the risks and benefits associated with receiving results, and provide a mechanism to opt out (42). These recommendations establish a framework for transparent and responsible communication between researchers and participants, which is suitable for extension to epigenetic studies, with additional consideration given to the risk of mistakenly attributing causality to associations between environmental factors and epigenetic variation.

Since epigenetic research reveals associations, participants must be well-informed about the limitations of epigenetic data to make causal inferences and avoid misinterpretation. While further research is needed to substantiate these findings beyond mere associations, it is prudent to anticipate the possibility that this information may expose individuals to stigmatization or discrimination (20). This is significant as evidence suggests that fear of discrimination based on genetic information causes individuals to avoid participating in research (44,45). Moreover, when researchers communicate their findings, they must explicitly acknowledge the structural determinants (e.g., structural racism, socioeconomic inequality, colonialism, and discriminatory public policies) that pose individual and population-level risk factors for adverse health outcomes (46,47). To translate research results into interventions that affect populations, research must move from being descriptive to focusing on concrete strategies to influence change. In epigenetic research, this includes acknowledging the limitations in establishing causality with exploratory research and, as knowledge and technologies advance, conducting experimental research to test potential epigenetic interventions (48).

Content

The addition of Article 3.13 in the TCPS 2 imparts a shared responsibility among the researcher, repository authorities, and future researchers to ensure that participant privacy and confidentiality are upheld through proper consent processes. Though epigenetics, genetics, and genomics are not explicitly mentioned, section 3.13(h) requires that broad consent include “whether the research will (if known) or might include whole genome sequencing or similar technologies that may pose a substantial risk of re-identification of the participant or identification of material incidental findings (when appropriate)” (31). There are currently no guidelines on the return of results to research participants in epigenetic studies, as the clinical significance and application of epigenetic data are not sufficiently established. Hence, in the absence of a suitable policy, researchers should carefully consider whether doing so provides any benefit to study participants and follow current best-practice recommendations. Additionally, Article 3.4 on the disclosure of incidental findings applies to the return of results and is discussed in the context of foreseeable findings. This section references Article 13.2 and directs genetic researchers to develop a plan for managing findings and submitting the plan to their research ethics board for review. Article 13.2 mentions potential implications for employment or insurance, or the revelation of information that has implications for family members. Therefore, provided researchers follow the guidance of the TCPS 2 in addressing privacy risks and the plan for return of results, the policy should sufficiently extend to epigenetic research. It is also advisable to highlight the limitations in interpreting epigenetic data.

Justice

Actors

The principle of distributive justice in research ethics addresses the equal distribution of burdens and benefits (23,49). It is essential to distinguish between equitable and equal treatment, as overlooking factors contributing to disparities can perpetuate inequities (23). Social factors have been linked to epigenetic modifications, including alterations in DNA methylation, which are associated with experiences of discrimination, racism, and marginalization (50,51). However, the clinical implications of these epigenetic modifications are still unclear. Researchers must be mindful of historical injustices, such as the legacy of colonization, which have contributed to social and environmental determinants of poor health. Failure to acknowledge these injustices may perpetuate stereotypes and compound harm through re-traumatization (20). Research institutions, funders, and ethics boards can contribute by supporting community-engaged, culturally safe research designed to generate tangible benefits for the populations involved. Conversely, studying the physiological changes resulting from adverse social experiences such as trauma and neglect can offer valuable insights, potentially strengthening efforts to disrupt intergenerational cycles of risk or inform more protective public policy. Researchers working with populations that have experienced systemic disadvantage or that have been historically excluded must be aware of the inherent power imbalances between themselves and study participants and take measures to mitigate potential harm (23).

If epigenetic research advances and provides strong evidence that certain environmental or social factors are a driving force behind epigenetic changes, there is a risk that responsibility for addressing these issues may be placed on individuals rather than society. This raises a significant ethical concern about how accountability for health outcomes is justly distributed (52). Researchers must be cautious in reporting study results to avoid unwarranted targeting of individuals and neglecting to consider the social, political, legal, and environmental structures that create the conditions within which environmental and social exposures occur (52). Many factors are beyond an individual's control to change, and those disproportionately affected by adverse environments bear the most significant exposure burden. Recognizing that these issues are too substantial to be solved at the individual level may help alleviate some of the associated stigma. Conversely, focusing solely on systemic factors may diminish individual agency for meaningful change, which demands an appropriate balance for effective advocacy.

Context

Justice and concern for welfare overlap in efforts to mitigate the potential for stigmatization and discrimination associated with epigenetic findings. Applying an equity, diversity, and inclusivity (EDI) lens to all stages of research, including ethical codes of conduct, is particularly important for research involving populations disproportionately affected by health disparities. This approach supports participant welfare and ensures just treatment. EDI strategies are key considerations for researchers, ethics boards, funders, institutions, journal reviewers, and editors who can enforce alignment with best practices in research design and reporting. How research results are interpreted and framed can further protect participants from stigma and discrimination. While these practices are crucial, they are insufficient to fully safeguard participants, as researchers and ethics boards cannot control how published data will be externally interpreted and used. Genetics research findings have previously been misinterpreted or weaponized to support discriminatory agendas (53-56). Thus, even when research is conducted and reported in ethically rigorous ways from an EDI perspective, there is still a risk of unintended societal harm.

Content

The TCPS 2 provides relevant guidance for researchers to address concerns about justice in epigenetic research. In addition to the policy features described under concern for welfare, Chapter four addresses fairness and equity in research participation (23). This policy section outlines considerations for the appropriate inclusion and exclusion of individuals, the ethical treatment of those whose circumstances render them vulnerable, and the equitable distribution of research burdens and benefits. The consequences of not adhering to these policy practices are substantial, such as being denied funding, ethics approval, or publication. The research community has worked to reconcile historical harms, and upholding the principle of justice has become a priority and is widely embedded in Canadian research practices and policies. Therefore, the TCPS 2, in combination with other EDI resources for researchers, provide extensive guidance to uphold the principle of justice.

PROCESS — RECOMMENDATIONS FOR ACTION

The TCPS 2 establishes the principles for the ethical design, conduct, and review of research involving humans. The 2022 revisions to expand upon genetic research address several ethical concerns relevant to epigenetic research, though some gaps remain. There are many potential vulnerabilities for individuals participating in epigenetic research. The TCPS 2 upholds the principles of respect for persons in epigenetic research through its comprehensive guidance on consent processes, including broad consent, which is often employed in epigenetic research. The policy adequately protects participant welfare through guidance related to the re-identification of epigenetic data and the return of results. It also provides a laudable direction to uphold the principle of justice related to the structural and social concerns arising from epigenetic research.

The process corner of the analysis triangle pertains to policy development. Future revisions to the TCPS 2 should consider modifying the definition of genetics to use the more inclusive term 'genomics', optionally noting that the use of genomics encompasses the rapidly emerging large-scale molecular -omics profiling approaches of epigenomics, transcriptomics, proteomics, metabolomics, and lipidomics. This will ensure that the consideration of these distinct research domains is explicit. Furthermore, information provided for broad consent could include mention that data may be used for research involving genomic technologies different from those used in the original study. These additions can enhance existing policy guidance to ensure comprehensive consent processes that detail the risks associated with epigenetic research, providing greater clarity and transparency for study participants.

CONCLUSION

Navigating the ethical tensions inherent in genomic research requires careful consideration of its impacts on all actors and interested parties while preserving respect, ensuring participant welfare, and promoting justice. In Canada, the TCPS 2, which governs research oversight, provides comprehensive guidance on ethical practices in genomic research. Furthermore, the 2022 revisions address some of the scenarios raised by epigenetic research that may create ethical dilemmas overlooked by previous versions of the framework. However, since it focuses exclusively on genetics and does not explicitly address genomics, epigenetics, or other -omics approaches, vulnerabilities for epigenetic researchers and research participants must be addressed with future revisions. This paper provided recommendations for consideration in future versions of the TCPS 2, including a broader and more inclusive definition of genetics and additional considerations for broad consent. These additions will ensure that policy for ethical conduct in research involving humans is forward-looking, upholds all moral principles equally, and is inclusive of current and emerging genomic research approaches.

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APPENDIX A: GLOSSARY

Ableism	The erroneous practice of discrimination or prejudice against anyone with a perceived disability that does not meet the socially defined norm of being able-bodied (57). This is based on a belief in the superiority of non-disabled people and includes harmful stereotypes and misconceptions about people with disabilities (57).
<i>De novo</i> variant (mutation)	A <i>de novo</i> variant is a genetic alteration in a gene's DNA sequence or epigenome that arises for the first time in an individual and is not inherited from their parents (58).
Epigenetics	The study of potentially heritable molecular modifications to DNA and chromatin that regulate gene expression (1). Mechanisms that induce epigenetic modifications include DNA methylation, histone modification, and non-coding RNA (2).
Environmental epigenetics	The molecular processes that underlie how environmental factors may impact biology by contributing to epigenetic changes that alter gene expression (13).
Exposome	The cumulative nongenetic environmental exposures that occur over a lifetime and alter one's biology, including those from the physical, chemical, social, and built environments within an individual's ecosystem (4-7).
Genetics	The study of genes and their effect on inherited traits or conditions (59).
Genetic determinism	Genetic determinism is the belief that a particular genotype invariably leads to a fixed and predefined phenotype, often suggesting that one's genetic makeup dictates one's biological destiny. This perspective overlooks the dynamic interactions between genes and the environment, failing to consider the variability in gene expression. Additionally, determinism does not inherently account for the complexities of heritability, which can be influenced by factors such as penetrance and phenotypic expression (16).
Genetic essentialism	The belief that DNA is the essence of being that defines a person based on their biology, without consideration of social and environmental constructs (16).
Genetic reductionism	The belief that the genetic constitution of an individual is sufficient to explain traits and behaviours (16).
Genomics	The study of the entirety of genes (the genome) and the interactions between those genes and the environment, such as epigenetics (59).
Interested parties	Any party affected by a policy or involved in the policy process.
Penetrance	The percentage of individuals with a specific genotype associated with a trait who exhibit any indications or symptoms of that trait. This percentage may vary depending on age (60).
Phenotype	Genetic makeup and environmental factors influence an individual's physical and functional traits (i.e., phenotype). This encompasses observable characteristics indicating a specific condition or trait, such as hair, eye, and skin coloration (60).
Phenotypic expression	The extent to which a genetic variant manifests in observable traits, including the spectrum of phenotypes that can arise from the variant (60).
Social epigenetics	Social epigenetics examines the biological pathways through which diverse social experiences, practices, and environments affect health outcomes in individuals (9).

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Ethical Dimensions of Artificial Intelligence Chatbots Use in Rare Disease Diagnosis: A Scoping Review

Alexia Bélisle^a, Marie-Océane Lavoie^a, Frédéric Banville^a, Hazar Haidar^b

Résumé

Introduction : Une maladie rare est une affection qui touche un faible pourcentage de la population, caractérisée par sa faible prévalence et son potentiel à entraîner des incapacités chroniques. Les symptômes de ces maladies peuvent se chevaucher avec ceux d'affections plus courantes, ce qui complique le processus diagnostique. De plus, de nombreuses maladies rares sont d'origine génétique, et leur diagnostic nécessite souvent une expertise médicale spécialisée ainsi que des outils diagnostiques avancés, ce qui souligne la nécessité d'approches ciblées en santé. Par conséquent, l'intégration d'outils d'intelligence artificielle (IA), y compris les agents conversationnels (chatbots), représente une opportunité prometteuse pour soutenir les processus diagnostiques en soins de santé. Toutefois, leur utilisation soulève des enjeux éthiques, notamment en matière de protection des données, de confidentialité des patients et de transparence des recommandations générées par l'IA. **Objectif :** Cette étude explore les enjeux éthiques liés à l'utilisation de chatbots d'IA dans le diagnostic des maladies rares. **Méthode :** Nous avons réalisé une revue de portée portant sur les enjeux éthiques associés à l'utilisation de chatbots dans le diagnostic des maladies rares, en consultant des bases de données et des listes de références entre le 1er janvier 2010 et le 10 février 2024. **Résultats :** À la suite du processus de sélection, six études ont été incluses dans la revue. Les données ont été regroupées en quatre thèmes : 1) la confiance envers les chatbots d'IA; 2) l'humanisation/déshumanisation de l'IA; 3) la sécurité des données et leur commercialisation; et 4) les considérations psychométriques. **Discussion :** Les chatbots d'IA présentent un potentiel prometteur pour le diagnostic des maladies rares, mais des défis subsistent, notamment la rareté des données, la précision diagnostique et la confiance. Il est essentiel de répondre à ces enjeux, en particulier en améliorant la représentativité des données et en renforçant la collaboration avec les professionnels de la santé, afin de permettre une intégration efficace de l'IA dans la pratique clinique. Les recherches futures devraient se concentrer sur la résolution de ces limites afin de garantir que l'IA puisse servir d'outil fiable d'aide à la décision dans le diagnostic des maladies rares.

Mots-clés

intelligence artificielle, chatbot, maladie rare, diagnostic, questions éthiques

Abstract

Introduction: A rare disease is a health condition affecting a small percentage of the population, characterized by its low prevalence and the potential to result in chronic disabilities. Symptoms of these diseases may overlap with those of more prevalent conditions, complicating the diagnostic process. Additionally, many rare diseases are genetically inherited, and their diagnosis often requires specialized medical expertise and advanced diagnostic tools, highlighting the need for targeted approaches in healthcare. Consequently, the integration of artificial intelligence (AI) tools, including chatbots, presents a promising opportunity to support diagnostic processes in healthcare. However, their use raises ethical concerns, particularly related to data privacy, patient confidentiality, and the transparency of AI-driven recommendations. **Objective:** This study explores the ethical issues arising from the use of AI chatbots in rare disease diagnosis. **Method:** We conducted a scoping review related to ethical issues raised using chatbots in rare diseases diagnosis, searching databases and reference lists between January 1, 2010, and February 10, 2024. **Results:** Following screening process, six studies were included in the review. Data were grouped into four themes: 1) trust in AI chatbot; 2) humanization/dehumanization of AI; 3) data security and commercialization; and 4) psychometric considerations. **Discussion:** AI chatbots hold promise for diagnosing rare diseases, but challenges like data scarcity, diagnostic accuracy, and trust remain. Addressing these issues, particularly through improved data representativeness and enhanced collaboration with healthcare professionals, is crucial for the effective integration of AI in clinical practice. Future research should focus on overcoming these limitations to ensure AI can serve as a reliable decision-support tool in rare disease diagnosis.

Keywords

artificial intelligence, chatbot, rare disease, diagnosis, ethical issues

Affiliations

^a Programme en psychologie, Département des Sciences de la Santé, Université du Québec à Rimouski, Rimouski, Canada

^b Programme en éthique, Département des lettres et humanités, Université du Québec à Rimouski, Rimouski, Québec, Canada

Correspondance / Correspondence: Hazar Haidar, hazar_haidar@uqar.ca

Alexia Bélisle and Marie-Océane Lavoie contributed equally to this work as co-first authors

INTRODUCTION

Rare diseases are defined as conditions that can lead to chronic disabilities, including physical, cognitive, and sensory limitations, which may cause persistent or intermittent pain (1). There are approximately 7,000 recognized rare diseases, spanning various categories such as genetic disorders, certain cancers, and infectious diseases, including conditions like cystic fibrosis and Crohn's disease (2-3). A disease is classified as rare when it affects fewer than one individual per 2,000

people, a threshold that international organizations consider as an indication of low prevalence (2). Collectively, rare diseases affect about 7% of the global population, representing a significant public health challenge worldwide (4).

People with rare diseases often experience a reduced quality of life, as their unique challenges are frequently misunderstood, leading to a series of unsuccessful medical appointments that can further complicate their situation (5). This issue is particularly significant because diagnosing rare diseases can be a lengthy process, with the risk of “diagnostic overshadowing”, where symptoms are mistakenly attributed to more common conditions rather than the rare disease itself (3). For example, studies show that 40% of patients with rare diseases are misdiagnosed at least once, resulting in delays in receiving appropriate care (3-6). The symptoms of a rare disease often overlap with those of more common conditions, which complicates the diagnostic process and increases the likelihood of misdiagnosis (3,7-8). Therefore, a diagnostic tool specifically designed to help identify rare diseases could greatly support healthcare professionals, enabling more accurate diagnoses and reducing the risk of misdiagnosis, ultimately improving the quality of care for patients with these conditions (9).

Artificial intelligence (AI), defined as “the ability of a machine to mimic or surpass intelligent human behavior and activities” (10), offers promising potential for improving symptom screening, which could support the diagnosis of various conditions, including rare diseases. AI tools are already widely used across the health sector, including in areas such as home care, pharmaceutical research, and public health (11). These tools provide a range of services, from daily assistance and medical monitoring to virtual consultations for symptom tracking and mental health consultation (12-13). Some AI applications are available as smartphone apps that engage users in human-like conversations; known as “chatbots”, these are automated dialogue systems that interact with users through natural language, either via text or voice, to answer questions on specific health-related topics (12-14). Chatbots can be programmed to perform various functions, with types and capabilities varying based on their design. The first health-focused chatbot, launched in 2017 by the San Francisco-based startup Woebot Health, was designed to improve mental well-being by helping to reduce symptoms of depression and anxiety (12-15). Since then, additional chatbots such as Babylon, Ada, Your.MD, and K Health have entered the market, primarily as symptom checkers that offer potential medical diagnoses based on symptoms shared by users (14). These chatbots invite users — whether patients or caregivers — to describe their symptoms, which the AI system then analyzes to suggest possible conditions, providing valuable insights that can guide further medical evaluation (12-16).

The ability of AI chatbots to provide differential diagnoses could significantly enhance the diagnosis of rare diseases by minimizing diagnostic overshadowing and expediting the diagnostic process. By integrating symptom analysis and offering tailored preliminary insights, these chatbots can facilitate timely access to appropriate management and treatment, ultimately reducing the social and professional impacts of rare conditions on patients’ daily lives (3). The scientific literature indicates that medical chatbots are a promising tool for addressing the unique challenges faced by individuals with rare diseases, particularly in contexts where specialist care may be limited (3-16). However, the deployment of such AI-driven tools raises ethical concerns that must be carefully considered before their widespread adoption. Issues such as data privacy, informed consent, and the accuracy of AI-generated diagnoses are particularly pertinent in the realm of rare diseases, where misdiagnosis can have profound consequences for patients’ health and well-being (17). Therefore, the objective of this study is to explore the ethical challenges associated with the use of AI chatbots in rare disease diagnosis through a scoping review, providing an overview of the ethical landscape surrounding these technologies.

METHODOLOGY

Study design

We conducted a scoping review to examine the ethical issues associated with the use of AI chatbots for diagnosing rare diseases. Following the methodological framework established by Arksey and O’Malley (18), this review is particularly relevant for this topic as it allows for the identification of research gaps and the synthesis of ethical considerations that have been explored to date, providing a comprehensive overview of the current landscape in this emerging area.

Eligibility criteria

For screening literature, we included studies that address chatbots and rare diseases; English or French language articles (regardless of country of origin); studies published between January 1, 2010, and February 10, 2024; peer-reviewed or published work in journals (e.g., reviews, commentaries, empirical research); and grey literature, if available such as national and international policy reports. We excluded clinical studies such as cohort studies, controlled trials, animal and in vitro studies, thesis dissertations and abstracts, and public opinion articles from non-experts.

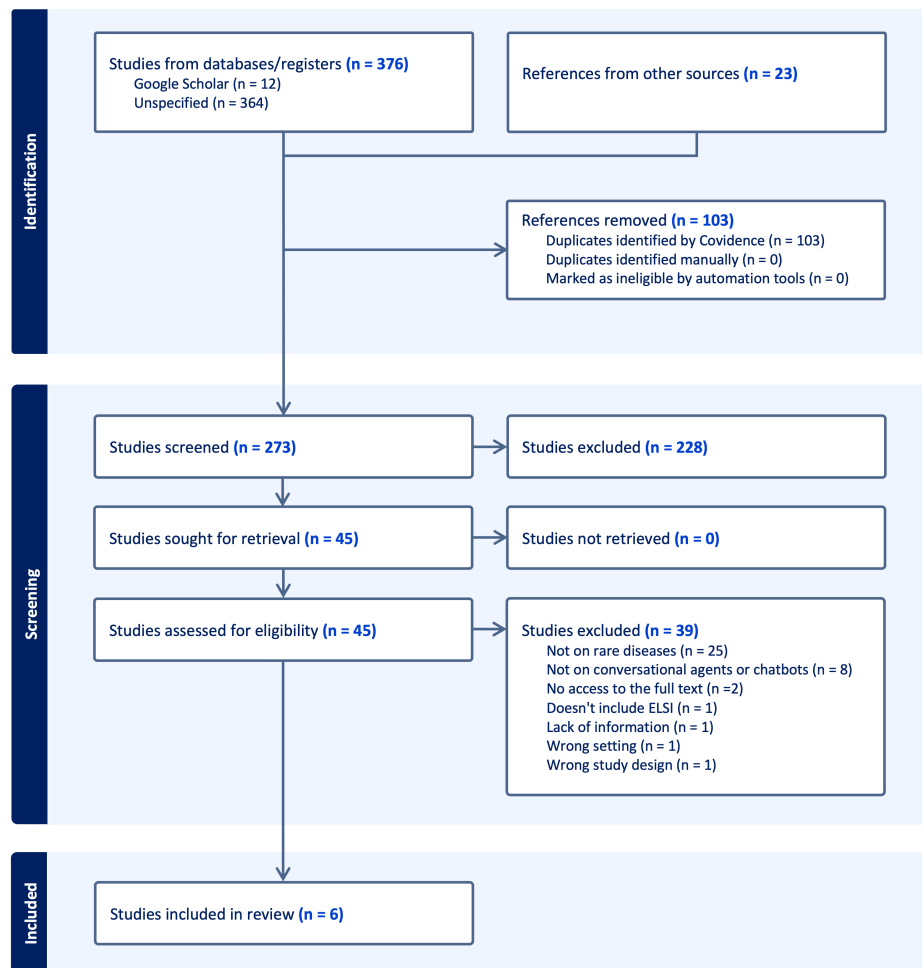
Information sources and search

Information sources included the following electronic databases: Medline, PubMed, PsycNet, PsycInfo, Scopus, Web of science and Cinhal. We further searched grey literature and other academic papers through individual searching, including Google searches and lists of references directly in selected papers. A librarian from the Université Laval was also consulted to guide research strategies. Our search was based on the following key concepts: “artificial intelligence”, “rare disease”, “chatbot”, “conversational agent”, “ethical”, “legal”, and “social”, and used this search strategy (“artificial intelligence”) AND (“conversational agent” OR chatbot OR “dialogue system”) AND (“ethic*” OR social OR legal) AND (“rare disease*” OR “orphan disease*”).

Study selection

As shown in the PRISMA diagram (Figure 1), we used Covidence Software to screen sources by removing duplicates, then by reading titles and abstracts. AB and MOL independently screened titles, abstracts and full text documents for studies meeting eligibility criteria. Both AB and MOL extracted data from the included full text articles and then compared results to reach a consensus. In the event of disagreement, a third judge (HH) would intervene to analyze the study and decide on its exclusion or inclusion according to the criteria adopted.

Figure 1. PRISMA diagram and selection process



Data mapping and collection

Both reviewers extracted data from the literature and recorded relevant information, including title, year of publication, type of source, type of conversational agent, methodology, results, limitations, elements relating to trust, data security, humanization, commercialization, diagnostic accuracy and validity. The initial sample included 376 studies before screening. Subsequently, 103 duplicates were removed by Covidence Software, narrowing the sample down to 273 articles. Eligible studies were then analyzed based on their titles and abstracts which excluded 228 articles. The remaining 45 articles underwent a full text review resulting in a final sample of 6 articles that were analyzed for the purpose of the current review. Themes from data extraction were categorized based on a codebook developed in an inductive manner by both authors AB and MOL.

The inclusion of only 6 articles reflects the novelty and specificity of the topic, which focuses on the use of AI-based conversational agents/chatbots for rare disease diagnosis, an emerging and highly specialized domain. Research on rare diseases already faces diverse challenges: these conditions affect small patient populations, leading to limited clinical data, fragmented reporting, and fewer large-scale studies (19). When combined with the recent development of conversational AI in healthcare, the intersection of these two fields further amplifies these difficulties. This convergence explains the scarcity of eligible studies while underlining the importance of synthesizing the limited research currently available on the topic.

Table 1: Synthesis of studies included in this scoping review

Authors	Chatbot type	Method	Main findings
Hallowell et al. (20)	NA*	Qualitative interviews with 20 participants who work with AI.	The importance of trust in AI, along with transparency and accountability, are often cited as key elements for the effective use of these tools.
Rapp et al. (21)	Textual chatbot	Grounded Theory Literature Review, a method of collecting and analyzing data by developing theories and identifying relevant themes.	After analyzing 83 articles related to the use of chatbots, the main themes that emerged in connection with their use included expectations, engagement, trust, empathy and humanity .
Laumer et al. (6)	Textual chatbot	Semi-structured interviews with students recruited through a student Facebook group.	Factors for the acceptance of chatbots in healthcare include expectations of performance , effort (ease of use), social influence, facilitating conditions, and happiness in using chatbots.
Lambert et al. (3)	Textual chatbot	An overview of the system is presented, focusing on aspects relating to natural language processing and user interaction. The aim of the study is to develop and test a conversational agent in the diagnosis of rare diseases.	The chatbot is an informative tool, and there is no proof that it is effective. The pre-tests carried out with the tool do, however, capture the user's language when speaking to the AI, taking into account any spelling errors they may make. Ethical considerations include the accessibility of chatbots to users, as not everyone has access to a web interface. In addition, it is important that the chatbot has human characteristics such as empathy and a motivational attitude, so that people can trust the diagnosis.
Hurtvitz et al. (4)	First- and second-generation chatbot	This study explored the literature on the use of AI in healthcare to better understand difficulties associated with diagnosing rare diseases.	The second-generation chatbots are much more effective and reliable in diagnosing rare diseases than first-generation chatbots.
Pereira & Díaz (22)	Verbal or textual chatbot	Mapping study analyzing 30 articles on healthcare chatbots, including for rare disease diagnosis.	Healthcare chatbots offer a number of valuable features, including asynchronicity, consumability, anonymity, authentication , personalization.

*This article does not focus on a specific type chatbot but rather discusses the essential characteristics that medical chatbots must possess to be trusted by both users and developers.

RESULTS

Both reviewers (AB and MOL) independently organized the themes and then discussed them for consolidation, resulting in a final categorization that grouped the results under the following four themes: 1) trust in AI chatbot; 2) (de)humanization of AI; 3) data security and commercialization; and 4) psychometric considerations (see Table 1). In this paper, we use the terms “AI systems” and “chatbots” interchangeably, recognizing them as confounded terms within the context of rare disease diagnosis.

Trust in AI Chatbot

The reviewed literature indicates that a significant concern when using AI in the context of rare disease diagnosis is the level of trust that patients and caregivers have in chatbots that assist with diagnosing these conditions. Laumer et al. (6) distinguish between trust in the AI technology itself and trust in the provider behind the AI, with a pivotal role placed on the latter. For instance, an individual is more likely to use AI if they trust the institution responsible for its development and deployment. Conversely, without trust in the provider, users are unlikely to engage with the chatbot, regardless of its technical capabilities (6). Both caregivers and patients often express reluctance to use AI, primarily due to a lack of trust (20). For patients, trust is based on several factors, including the AI's technical performance, expected accuracy and reliability of the chatbot, perceived ease or effort required to interact with the technology, and social influence of peers who may either endorse or discourage AI use. Additionally, trust seems to be influenced by the user's overall satisfaction with the AI and their habitual comfort in using similar AI technologies (3). Building trust in AI can be complex, but it is essential for fostering acceptance, particularly in sensitive areas like healthcare. A critical approach to enhancing trust involves ensuring that the AI is developed by experienced designers who work closely with healthcare professionals (20). Rapp et al. (21) argue that trust can be bolstered by presenting chatbots as systems capable of mimicking certain human-like qualities, which can make interactions feel more natural and reassuring. Similarly, Lambert et al. (3) suggest that AI systems designed with human-like characteristics — such as appearing knowledgeable, maintaining a relaxed demeanor, and using a friendly tone — can significantly enhance users' feelings of trust. Pereira and Diaz (22) further assert that the trust relationship between users and chatbots is dynamic and can grow over time, provided that the AI consistently meets users' expectations and maintains a positive rapport.

AI (De)Humanization

The literature reviewed shows that humanization is a critical aspect to consider as it addresses the affective dimension of the interaction between chatbots and users. In this context, humanization involves incorporating human-like traits into AI systems, such as a calm and confident demeanor, which can significantly enhance user trust in AI (3). For a meaningful bond of trust to form between AI and patients, it is essential for the AI to replicate human qualities such as empathy, understanding, and the ability to recognize and respond to the person's emotional state (22). Conversely, the absence of these human-like qualities can lead to reduced acceptance of chatbots. When AI lacks empathy and emotional sensitivity, users may be less motivated to engage with it and share confidential information, undermining the effectiveness of the diagnostic process (21). Furthermore, humanization extends to the personalization of treatment recommendations. As AI systems interact with patients, they gather insights that allow them to tailor interventions based on individual needs and responses. This personalized approach enhances the relevance and effectiveness of the treatment suggestions provided by the AI (4). By interacting in a more human-like manner, AI can also foster greater patient engagement, encouraging users to adhere to the treatment plans suggested and improving overall treatment outcomes (22).

Data security and commercialization

The use of AI in diagnosing rare diseases raises significant issues related to data security and commercialization. One ethical concern is the protection of personal data. Hallowell et al. (20) argue that many individuals perceive private companies managing their personal data as lacking transparency, which fosters mistrust and unease. Similarly, Rapp et al. (21) observed that people fear that AI systems might misuse their personal data, leading to hesitation in using medical chatbots due to potential security gaps. Conversely, some studies suggest that certain individuals may feel more comfortable confiding in medical chatbots than in human healthcare providers (22). This preference often stems from the belief that AI systems offer stronger safeguards and are less prone to human error or breaches of confidentiality. As a result, these individuals tend to disclose sensitive health details more openly to chatbots, reducing feelings of shame or embarrassment that might arise in face-to-face interactions. In this context, chatbots are perceived as capable of enhancing data security through advanced measures such as two-factor authentication (22), which ensures that only authorized users can access personal data. Such mechanisms reinforce confidentiality and strengthen patients' sense of security, encouraging them to share private health information without fear of exposure.

In addition to data security, the literature highlights the ethical issue of data commercialization through the use and deployment of AI by private companies, which often play a significant role in introducing these technologies into healthcare (20). For instance, users express widespread apprehension about the potential misuse of personal data for financial gain, a perception that undermines trust in medical chatbots (21). Hurvitz et al. (4) note that AI can be used to rapidly identify patients with costly-to-treat diseases, facilitating quicker interventions and potentially reducing overall system costs by streamlining the diagnostic processes for rare diseases. To address trust deficits and minimize conflicts of interest, Hallowell et al. (20) recommend implementing strict regulations governing the ownership and operation of medical chatbots, including the enforcement of penalties for data misuse to ensure compliance.

Psychometric considerations (validity, reliability, sensitivity and specificity)

When considering the chatbot as an assessment tool, it is essential to reflect on psychometric considerations, which are crucial for developing confidence in the chatbot's clinical outcome. Like many other assessment tools, the data derived from diagnostic analyses must undergo statistical testing to establish validity, reliability, sensitivity, and specificity. From the patient's perspective, as previously mentioned, trust in how data will be used is paramount. Similarly, clinicians must also grapple with confidence in the value of chatbot assessments and their clinical outcomes.

Validity is particularly critical when using chatbots for diagnosing rare diseases, as it relates to their ability to deliver accurate diagnoses. Existing studies generally indicate that these tools perform well in this regard. For instance, Laumer et al. (6) note that chatbots provide superior diagnostic results compared to a simple "Google search," which often fails to yield accurate information (3-6).

Regarding sensitivity and specificity in clinical judgment, some chatbots offer a percentage match between symptoms and diagnoses, presenting users with a range of diagnostic possibilities for a more comprehensive understanding. Pereira and Diaz (22) highlight the potential validity of medical chatbots in diagnosing rare diseases, attributing this to their capacity to learn and adapt through patient interactions. This iterative learning process enables chatbots to continuously refine their diagnostic algorithms based on accumulated experience, thereby improving accuracy over time. Furthermore, certain AI systems can access and analyze extensive personal information that may exceed the data typically available to healthcare professionals. This comprehensive analysis allows chatbots to suggest personalized habits or treatments that could improve patient health outcomes (22).

Despite these potential advantages, Hallowell et al. (20) argue that the scarcity of information about rare diseases complicates the generalization of symptoms, potentially undermining the validity of chatbot diagnoses. Lambert et al. (3) express similar

concerns and advocate for continued research through controlled randomized trials. They further note that accurate diagnosis depends not only on the chatbot's technical capabilities but also on users' perceptions of its reliability. For chatbots to be recognized as valid and reliable diagnostic tools, it is crucial that they are developed and continuously monitored by qualified medical professionals. Regular evaluations and updates are essential to ensure that the chatbot maintains diagnostic validity and adapts to new medical insights (20). In the section titled "Threats to Validity," Pereira and Diaz discuss threats to ensuring validity, internal validity, external validity, and conclusion validity (22). These threats encompass concerns related to the comprehensive coverage of research questions, inclusion of all relevant studies, classification categories, and potential biases in data collection.

DISCUSSION

Our scoping review aimed to identify and map ethical issues related to the use of AI in rare disease diagnosis. Key benefits highlighted in the literature include improved diagnostic accuracy of rare diseases through the analysis of large and complex datasets (3), provision of supplementary information that broadens diagnostic possibilities (22), and reduction of diagnostic delays by rapidly identifying potential rare diseases (4). Further, AI systems can offer personalized treatment recommendations based on individual patient data, tailoring interventions to better meet patient needs (21). Beyond chatbots, predictive algorithms and machine learning models have demonstrated similar advantages, such as early detection of conditions like Fabry disease by leveraging electronic health records and genomic data (23). These capabilities underscore AI's potential to transform rare disease care by accelerating diagnosis and optimizing treatment pathways.

Despite these benefits, several ethical challenges were raised, including trust in AI, AI (de) humanization, data security and commercialization, and psychometric considerations. Notably, trust emerged as a recurring theme across all identified issues.

Trust is a critical factor in successfully integrating AI into medical practice, influencing how healthcare professionals and patients interact with these tools (20). A primary ethical concern is the risk of errors or misdiagnoses, as AI systems — whether chatbots or predictive algorithms — remain fallible and may generate inaccurate results due to algorithmic limitations or biased training data (17). Such inaccuracies can undermine trust in AI technologies, limiting their adoption and positive impact on healthcare outcomes (17). This risk is particularly pressing in the context of rare diseases, where symptom complexity and data scarcity pose significant diagnostic challenges. Trust can be strengthened if AI systems are perceived as transparent and supported by mechanisms for error detection and correction. Regular assessments and updates by medical professionals can ensure that AI tools maintain their accuracy and reliability. This collaborative approach, where AI complements rather than replaces clinical decision-making, can promote confidence and mitigate misdiagnosis risks (6-20).

Data security is a critical concern in the use of AI for rare disease diagnosis, particularly regarding the storage and management of sensitive health information. Martineau and Godin (17) emphasize that current security measures are not infallible, with vulnerabilities that may go unnoticed and expose data to breaches. Risks such as cyberattacks and software flaws further threaten privacy, especially in rare disease contexts where data is highly personal (20-24). To address these concerns, anonymization and robust encryption are critical. Equally important is transparency in data handling: companies deploying AI must clearly communicate how data is collected, processed, and used, adhering to strict ethical standards. Such measures not only protect confidentiality but also enhance user trust and accountability in AI-driven healthcare (7-20).

Psychometric considerations — validity, reliability, sensitivity, and specificity — are central to evaluating AI diagnostic tools. While some advanced medical chatbots have demonstrated diagnostic accuracy approaching 90% in some studies (7), their reliability depends on the quality and representativeness of training datasets. Similarly, predictive algorithms excel in processing large-scale data but face challenges when datasets lack diversity, leading to bias and compromised validity (4-22). These limitations are particularly acute in rare diseases, where data scarcity (20) and fragmentation hinder algorithmic precision. Addressing these gaps requires collaborative data-sharing initiatives and inclusion of underrepresented populations to improve fairness and reduce disparities. Some AI models mitigate misdiagnosis risk by providing diagnostic suggestions with confidence scores, offering clinicians a measure of reliability (3-20).

Finally, the integration of AI into clinical practice raises questions about accountability. When AI-generated recommendations conflict with physician judgment, determining which should prevail remains contentious (17-25). While some argue that increasingly autonomous AI systems could bear moral responsibility for errors, others maintain that physicians should remain the ultimate decision-makers (17-26). A shared responsibility model, where AI and clinicians jointly contribute to diagnostic decisions offers a balanced approach, particularly in rare disease contexts where complexity demands human expertise (25).

The involvement of private companies in deploying AI chatbots in healthcare raises significant ethical concerns, particularly regarding conflicts of interest and data commercialization. When these tools are used to diagnose costly conditions, there is a risk that patients may be directed toward treatments that financially benefit these companies, rather than prioritize patient welfare. For example, while the rapid identification of patients with rare diseases through AI can reduce costs for both society and patients by minimizing the need for multiple appointments, it may also provide opportunities for companies to promote more expensive treatments that do not necessarily improve the quality of care. Lack of transparency in data use further

underscores the need for stringent regulations and accountability mechanisms (17). In this context, Hallowell et al. (20) argue for enforcing regulations that prioritize patient interests, particularly when public funding supports technological development. Such measures are essential to safeguard ethical integrity and prevent the prioritization of profit over care quality (12).

STRENGTHS AND LIMITATIONS

Scoping reviews are particularly valuable for mapping emerging fields, offering a structured overview of key themes and identifying gaps for future research. This review contributes to that goal by synthesizing ethical considerations surrounding the use of AI chatbots in rare disease diagnosis, a domain where evidence remains limited. Four central themes emerged: trust in AI chatbots, data security and commercialization, psychometric considerations, and the humanization of AI interactions. A notable strength of this review lies in its focus on chatbots, which represent a distinct category of patient-facing technologies designed to support symptom reporting, triage, and engagement. This approach enables a focused ethical analysis related to conversational systems, such as transparency, and trustworthiness during real-time exchanges (27), concerns that are particularly salient in rare disease contexts where symptom complexity and patient vulnerability heighten the stakes of inaccurate responses (19-28).

The geographic scope of studies retained for analyses, which include Germany, Mexico, Israel, and England, narrows the context in which these findings can be applied. Further, the small number of studies constrains thematic depth, potentially leaving emerging ethical concerns underrepresented as AI chatbot use for rare diseases continues to evolve (29). To mitigate this limitation, we incorporated insights from excluded articles and grey literature (7-12,17-30), which provided valuable context on issues such as data security, regulatory compliance, and governance frameworks, thereby broadening the discussion. Our analysis drew lessons from literature on AI applications beyond chatbots, including predictive algorithms for rare disease detection (20). These systems, which leverage structured data such as electronic health records and genomic profiles, have demonstrated potential for accelerating diagnosis of rare conditions (23-30). While they differ functionally from chatbots, they raise similar ethical challenges including algorithmic bias, diagnostic accuracy, and inequities in access to advanced technologies (30). Integrating these perspectives situates AI chatbot-specific concerns within the broader AI ethics landscape, reinforcing the need for governance strategies that address both conversational agents and data-driven modalities in rare disease context.

CONCLUSION

The use of AI chatbots for diagnosing rare diseases holds promise by offering the potential to improve diagnostic accuracy and provide timely assistance in an area marked by complexity and data scarcity. However, this promise is accompanied by several ethical and practical challenges. Key concerns include the trustworthiness of AI systems, data security, the potential for data commercialization, and the psychometric aspects of diagnostic accuracy, reliability, and validity. For AI chatbots to function effectively, they require access to high-quality, diverse datasets, which can be challenging in the context of rare diseases due to the inherent scarcity of relevant data. This limitation may impact the chatbot’s ability to generate reliable and accurate health assessments, raising doubts about their overall effectiveness in clinical settings. Given these challenges, the integration of AI along with clinical expertise remains crucial. Even with advanced AI chatbots, healthcare professionals must continue to play a central role in final diagnostic decision-making. Moving forward, research should focus on addressing the limitations related to data scarcity and accuracy, as well as exploring ways to enhance the collaboration between AI tools and healthcare providers to optimize the diagnostic process in the context of rare diseases.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Considerations for a Resource Allocation Framework for Intensive Care Units and Acute Care: A Qualitative Study Exploring the Experiences of Equity-Deserving Groups During the COVID-19 Demand Surge and Triage-Avoidant Strategies

Taylor Shorting^a, Jaya Rastogi^a, Cécile M. Bensimon^{a,b}, Alice Virani^c, Maxwell J. Smith^d, Simon Oczkowski^{e,f}, Dianne Godkin^g, Marika Warren^h, Sabira Valianiⁱ, Judy King^j, James Downar^{a,j,k,l,m}, Sarina R. Isenberg^{a,j,o}

Résumé

Pendant la COVID-19, la plupart des unités de soins intensifs (USI) au Canada ont mis en place des stratégies pour gérer une hausse de la demande en soins critiques afin d'éviter de refuser des patients, appelées stratégies d'évitement du triage. Ces stratégies, notamment la réaffectation de personnel non spécialisé en soins intensifs vers les USI pour augmenter la capacité d'accueil, ainsi que le transfert de patients sur de longues distances vers des lits disponibles, ont pu entraîner des conséquences négatives pour les patients, le personnel de santé et les groupes en quête d'équité. Cette étude explore les perspectives de ces groupes et des organisations qui les représentent concernant les stratégies d'évitement du triage durant la COVID-19, examine les réponses propres aux organisations et identifie des recommandations à l'échelle du système pour améliorer l'équité, l'accès et la préparation. Une étude qualitative descriptive a été menée entre juillet et décembre 2023 dans cinq provinces canadiennes. Les participants, incluant du personnel d'organisations au service des groupes en quête d'équité ainsi que des représentants gouvernementaux et du secteur de la santé, ont été recrutés par le biais de réseaux professionnels et d'un échantillonnage boule de neige. Un guide d'entretien semi-structuré a été utilisé pour recueillir les points de vue, qui ont ensuite été analysés de manière inductive à l'aide d'une analyse thématique. Au total, 23 personnes provenant de l'Ontario (n=12), de la Colombie-Britannique (n=4), de la Saskatchewan (n=4), de la Nouvelle-Écosse (n=2) et du Nouveau-Brunswick (n=1) ont participé. Quinze participants (65 %) se sont identifiés comme personnes racisées ou appartenant à des groupes en quête d'équité; 13 (57 %) travaillaient au sein d'organisations représentant des décideurs, des cliniciens et/ou des groupes en quête d'équité. Trois thèmes ont été identifiés : 1) les stratégies d'évitement du triage ont été perçues comme ayant des effets disproportionnellement néfastes sur les groupes en quête d'équité et les professionnels de la santé; 2) les organisations ont agi pour atténuer les effets de ces stratégies; et 3) diverses actions à l'échelle du système pourraient contribuer à atténuer les effets perçus de ces stratégies lors de futures hausses de la demande. Cette étude apporte une contribution originale à la littérature en intégrant les perspectives de représentants d'organisations diverses et de groupes en quête d'équité sur la manière dont les stratégies d'évitement du triage ont causé des préjudices disproportionnés aux populations qu'ils desservent. Nos résultats peuvent éclairer l'élaboration et la mise en œuvre de stratégies d'évitement du triage qui atténuent les effets néfastes perçus sur les décideurs, les cliniciens et les groupes en quête d'équité, tout en favorisant des soins équitables.

Mots-clés

COVID-19, équité en santé, unités de soins intensifs, pandémie, éthique en santé publique, urgence de santé publique, allocation des ressources, triage

Abstract

During COVID-19, most intensive care units (ICUs) in Canada implemented strategies to manage a surge in demand for critical care to avoid turning people away, termed "triage-avoidant strategies." These strategies, including redeploying non-ICU staff to the ICU to increase patient capacity, and transferring people over long distances to available beds, may have caused negative consequences for patients, healthcare staff, and equity-deserving groups. This study explores the perspectives of equity-deserving groups and organizations on triage-avoidant strategies during COVID-19, examined organization-specific responses, and identified system-level recommendations to improve equity, access, and preparedness. A qualitative descriptive study was conducted between July and December 2023 across five provinces in Canada. Participants, including staff from organizations serving equity-deserving groups, as well as government and healthcare representatives, were recruited through professional networks and snowball sampling. A semi-structured interview guide was used to elicit perspectives, which were then analyzed inductively using thematic analysis. 23 individuals from Ontario (n=12), British Columbia (n=4), Saskatchewan (n=4), Nova Scotia (n=2) and New Brunswick (n=1) participated. 15 participants (65%) identified as persons of colour or among equity-deserving groups; 13 (57%) participants worked within organizations representing decision-makers, clinicians, and/or equity-deserving groups. We identified three themes: 1) Triage-avoidant strategies were perceived to have disproportionately harmful effects on equity-deserving groups and healthcare providers; 2) organizations acted to mitigate effects of triage-avoidant strategies; and 3) various system-level actions could help mitigate the perceived effects of these strategies in future surges in demand. This study contributes to the literature by incorporating perspectives of representatives from diverse organizations and equity-deserving groups on how triage-avoidant strategies disproportionately harmed the populations they serve. Our findings can inform the development/implementation of triage-avoidant strategies that mitigate the perceived harmful effects on decision-makers, clinicians, and equity-deserving groups, while promoting equitable care.

Keywords

COVID-19, health equity, intensive care units, pandemic, public health ethics, public health emergency, resource allocation, triage

Affiliations^a Bruyère Health Research Institute, Ottawa, Ontario, Canada^b Faculty of Health Sciences, University of Ottawa, Ottawa, Ontario, Canada^c W. Maurice Young Centre for Applied Ethics, University of British Columbia, Vancouver, British Columbia, Canada^d School of Health Studies, Faculty of Health Sciences, Western University, London, Ontario, Canada^e Department of Medicine, McMaster University, Hamilton, Ontario, Canada^f Department of Health Research Methods, Evidence, and Impact, McMaster University, Hamilton, Ontario, Canada^g Lawrence S. Bloomberg Faculty of Nursing, University of Toronto, Toronto, Ontario, Canada^h Department of Bioethics, Dalhousie University, Halifax, Nova Scotia, Canadaⁱ Department of Medicine, College of Medicine, University of Saskatchewan, Saskatoon, Saskatchewan, Canada^j Physiotherapy Program, School of Rehabilitation Sciences, Faculty of Health Sciences, University of Ottawa, Ottawa, Canada^k Division of Palliative Care, Department of Medicine, University of Ottawa, Ottawa, Ontario, Canada^l Faculty of Medicine, University of Ottawa, Ottawa, Ontario, Canada^m Department of Critical Care, The Ottawa Hospital, Ottawa, Ontario, Canadaⁿ Canadian Critical Care Society, Markham, Ontario, Canada^o The Ottawa Hospital Research Institute, Ottawa, Ontario, Canada**Correspondance / Correspondence:** Taylor Shorting, Tshorting@bruyere.org**INTRODUCTION**

During the global COVID-19 public health emergency, healthcare systems struggled to meet the overwhelming surge in demand for critical care resources (1). In Canada, where many intensive care units (ICUs) operated near capacity even prior to COVID-19 (2), decision-makers sought to develop strategies to optimize critical care resource use. Addressing increased demand for limited critical care resources took two broad approaches: 1) prioritizing certain patients for critical care over others (“triage”) or 2) to avoid triage, surging above normal capacity by redeploying non-ICU staff to the ICU, and transferring ICU patients over large distances to available beds. Many jurisdictions developed resource allocation frameworks (3-8) or applied existing triage tools to the COVID-19 context to manage the unprecedented surge in demand for ICU resources (9,10). Ontario, Canada’s most populous province, developed the “Critical Care Clinical Emergency Standard of Care for Major Surge” framework (8), which included three system-wide triage levels to maximize the number of lives saved while avoiding or mitigating potential discrimination and bias (8). Quebec (11) and Israel (12) both adopted similar frameworks, although they were never deployed.

To avoid deploying triage frameworks, hospitals and healthcare jurisdictions adopted a series of triage-avoidant strategies such as cancelling non-emergent procedures, redeploying non-ICU staff to the ICU, and moving patients from overwhelmed hospitals to hospitals with available resources. While triage-avoidant strategies likely saved lives by allowing acutely ill patients to receive ICU care for COVID-19 and avoid adverse outcomes including death, these strategies may also have led to negative consequences for patients, family members, staff, and healthcare organizations, particularly for individuals among equity-deserving groups. Consequences may have been clinical (e.g., delayed care) (13), organizational (e.g., healthcare provider moral distress) (14), and/or equity-related (e.g., reduced trust in healthcare) (15). Equity-deserving groups, as defined by the Government of Canada, are “A group of people who, because of systemic discrimination, face barriers that prevent them from having the same access to the resources and opportunities that are available to other members of society, and that are necessary for them to attain just outcomes” (16). Examples of equity-deserving groups include women, Indigenous peoples, racialized/visible minority persons, persons with disabilities, and LGBTQ2S+ individuals (16), who experience sexism and gender discrimination, racism, and ableism, among other often co-occurring and mutually reinforcing forms of discrimination and oppression in healthcare and community settings.

Previous studies have suggested that individuals among equity-deserving groups may be more susceptible to harm from triage-avoidant strategies because they already face structural barriers to equitable care (i.e., care delivery adjusted to meet the unique needs of individuals and communities with the aim to support similar health outcomes across groups with different social circumstances) (17) including racism, poverty, gender bias, and geographic isolation (18,19). In addition, mistrust of the healthcare system may lead to avoidance of formal care, contributing to delayed diagnoses and reduced opportunities for early intervention (18,19). However, these studies focused on general healthcare use (not specific to triage-avoidant strategies) (18,19), were conducted prior to the pandemic (18,19), and primarily explored the association between racial discrimination and delayed or forgone care, and experiences of racial discrimination and beliefs about coronavirus-related racial bias (20).

Future surges in demand for critical care will likely lead to the use of triage-avoidant strategies like those used during COVID-19. However, the potential negative effects of these strategies are not well understood, especially as they concern equity-deserving groups. Limited research reports directly on the views of these groups themselves (5), yet inclusion of perspectives among those equity-deserving groups is critical to develop relevant and inclusive approaches (5). These groups have largely been excluded from discussions about how triage-avoidant strategies disproportionately harmed them compared to the general population; from insights on organization-specific actions that were implemented to mitigate these effects; and from recommendations at the system level for future strategies to reduce harm. Incorporating these perspectives is essential for developing resource allocation frameworks that are more equitable and responsive to the needs of all populations.

OBJECTIVE

Our study had three objectives:

1. *Understand* perspectives and experiences among equity-deserving groups of the disproportionate effects of triage-avoidant strategies on communities with whom they work, relative to the general population.
2. *Explore* organization-specific actions implemented during COVID-19 from the perspectives of individuals representing equity-deserving groups — such as Black, Indigenous, and People of Colour (BIPOC), persons with disabilities, and disease-specific organizations — as well as staff from healthcare organizations and government agencies.
3. *Identify* system-level recommendations for future pandemic strategies that can minimize harm, improve equitable access to care, and enhance organizational preparedness.

METHODS

Study Design

Between July and December 2023, we conducted a qualitative descriptive study (21), using semi-structured interviews and focus groups via videoconferencing platforms (e.g., Zoom and Microsoft Teams), with individuals from across Canada about experiences related to their specific organizations. Guided by a post-positivist epistemological stance, interviews and focus groups were conducted with decision-makers, clinicians, and individuals among equity-deserving groups. Post-positivism focuses on the experiences of the majority and asserts that there is no universal truth and that multidimensional evidence can be inferred by perceived data (e.g., data obtained in focus groups/interviews) (22,23). The Bruyère Health Research Ethics Board approved this study on July 17, 2023 [Study #M16-23-007].

Participant Recruitment

Maximum variation (24) sampling was used to understand a wide range of perspectives and experiences, including participants who represent a variety of equity-deserving groups, such as BIPOC, persons with disabilities, and disease-specific organizations. We also included participants from healthcare organizations and government agencies. The aim was to engage participants who could describe how COVID-19 was managed in hospitals and how these strategies affected the individuals and communities served by their organizations.

To identify potential participants, we leveraged community-, provincial-, and national-level contacts from among our broader study team's existing networks (i.e., project principal investigators, co-investigators, knowledge users, and collaborators). A Google spreadsheet was circulated to the broader study team, who were asked to provide the name of persons at the organization, the respective organization, the type of organization (e.g., BIPOC, persons with disabilities, disease-specific organizations, healthcare organizations, and government agencies) contact information for the individuals, and whether the research coordinator (JR) could mention the study team member's name in the initial recruitment email. JR contacted the individuals listed in the spreadsheet via an email invitation that included an overview of the study purpose, inclusion criteria, and procedures. The email asked the recipient to share the recruitment email and poster with other representatives within their organization. After each interview/focus group, participants were asked to circulate the study poster to their colleagues who met participant criteria (i.e., snowball sampling) (25).

Prior to inviting representatives among Indigenous organizations to participate in the study, we invited representatives to engage in a preliminary conversation to ensure our research vision and goals were both sensitive to and respectful of the organization, and more broadly, to Indigenous communities. Then, we asked for letters of support (drafted by the organization) that expressed approval for the research coordinator to invite representatives from the organization to participate in the study. Eligible participants were 19 years of age or older, fluent in English, and represented decision-makers, clinicians, healthcare organizations, and/or equity-deserving groups.

Data Collection

The research team collaboratively created a single interview/focus group guide (see Appendix 1: Supplementary File A). The core research team drafted the questions, then circulated them to the broader team for feedback. We refined the guide after the first few focus groups/interviews. Prior to study commencement, participants completed a written consent form via email, then an online demographic questionnaire using Microsoft Forms. All focus groups and interviews were conducted and audio-recorded using Microsoft Teams and Zoom, and recordings de-identified and transcribed by the company, PlayWrite. Data collection ended when no new themes or insights emerged, i.e., we achieved data saturation, and recruitment was therefore concluded (21,26).

Analysis

Thematic analysis (27,28) was used to analyze focus group and interview data. We first engaged in close readings of transcripts to thoroughly understand the dataset, and then developed a preliminary codebook using inductively derived codes. Code saturation was reached once no new codes were developed based on review of the transcripts (28). The finalized

codebook and interview transcripts analyzed with the aid of MAXQDA qualitative analysis software (29). JR and TS consensus-coded the first two transcripts to establish intercoder reliability and finalize the codebook, independently coding and then comparing their work to ensure alignment. The remaining 10 transcripts were double-coded: each coder worked independently on a subset of transcripts, after which they reviewed each other's coding through discussion to ensure consistency and agreement. We reviewed the coded segments and explored preliminary patterns, and then identified core themes and exemplary quotations.

RESULTS

Eight focus groups and four interviews were conducted. Nineteen participants took part in the focus groups, and four participated in the interviews, for a total of 23 participants from Ontario (n=12), British Columbia (n=4), Saskatchewan (n=4), Nova Scotia (n=2) and New Brunswick (n=1). Seven participants (31%) identified as persons of colour or as from an equity-deserving group; 13 (57%) participants worked within organizations representing decision-makers, clinicians, and/or groups that represent people from equity-deserving groups (see Table 1 for participant demographic characteristics).

Table 1: Participant Characteristics

Characteristics	No. (%) of participants
<i>Gender</i>	
Woman	15 (65)
Man	7 (31)
Prefer not to answer	1 (4)
<i>Age</i>	
35-44	8 (35)
45-54	7 (31)
55-64	5 (22)
65-74	1 (4)
75-84	1 (4)
Prefer not to answer	1 (4)
<i>Province or territory occupation resides in</i>	
Ontario	12 (53)
British Columbia	4 (17)
Saskatchewan	4 (17)
Nova Scotia	2 (9)
New Brunswick	1 (4)
<i>Organization type</i>	
Governmental	7 (31)
Not-for-profit	5 (22)
Education	3 (13)
Healthcare	2 (9)
Hospital	2 (9)
Non-governmental	1 (4)
Not-for-profit; charity	1 (4)
Not-for-profit; governmental	1 (4)
Not-for-profit; non-governmental	1 (4)
<i>Years in current role</i>	
Less than 1	1 (4)
1-3	3 (13)
4-6	6 (26)
7+	13 (57)
<i>Identification as a person of colour or an equity-deserving group</i>	
No	15 (65)
Yes	7 (31)
Prefer not to answer	1 (4)
<i>Please identify which group¹</i>	
South Asian	3
Afghan	1
African Canadian/Black	2
West Asian	1
<i>Organization represents decision-makers, clinicians, and/or equity-deserving groups</i>	
Yes	13 (57)
No	10 (43)

¹ This item was presented in an open textbox format in Microsoft Forms

We identified three major themes related to participants' perspectives of, and experiences with, triage-avoidant strategies implemented during COVID-19: 1) triage-avoidant strategies had disproportionately harmful impacts on equity-deserving groups and healthcare providers; 2) organizations attempted to mitigate negative effects of triage-avoidant strategies; and 3) system-level actions could help mitigate the negative effects of these strategies in the future (see Table 2).

Table 2: Exemplary Quotations

Theme; subtheme	Illustrative quotation
Theme 1: The use of triage-avoidant strategies had disproportionately harmful effects on equity-deserving groups and healthcare providers, compared to the general population	
Adjusting the standard of care	<i>One of the main challenges we found is that the lack of support provided in the hospital setting was due to the focus of the healthcare teams on medical needs, and not on disability needs. For example, interpreters not being admitted to support people who are deaf, or personal care attendants not being able to meet with people with physical disabilities, to make sure that their daily care needs were met. This often led to people avoiding the hospital out of fear that they would only be treated for a medical condition and not their essential daily needs. [FG1-2]</i>
Cancelling/postponing non-emergency procedures	<i>Often, for families with young children who have complex or compromised or complicated needs, it's a precious window of time in terms of their early years. Delays have a potential impact on child development. [FG3-3]</i>
Cancelling/postponing specialist treatments	<i>The big impact that we saw was the impact on delayed treatment and management for several conditions. These conditions then needed to be aggressively over-managed. [FG10-1]</i>
Patient relocation	<i>It was more vulnerable, marginalized patients who were being transferred versus the ones who had more privilege and empowerment, who were able to stay closer to home because they knew how to advocate for their loved one to stay closer to home. [FG8-1]</i>
Staffing ratios/staff redeployment	<i>The COVID public health emergency was incredibly stressful for everybody personally and professionally. Some of these strategies, some of the difficult moral decisions people had to make ... The overload and work, the being redeployed to new patient areas and populations that people wouldn't have elected to go to necessarily or didn't feel adequately trained for. [FG8-1]</i>
Theme 2: Organization-specific actions used to mitigate effects of triage-avoidant strategies	
External-facing strategies	<i>Our organization was also part of a bigger provincial advocacy group where there was service providers, provincial advocate organization, some individuals that would meet very regularly to hear what was happening, coordinate communication, coordinate advocacy strategies, just make sure that there was also that piece happening during COVID-19 for our sector. [FG3-3]</i>
Internal-facing strategies	<i>We would urge people to be vaccinated. We would work diligently in trying to convince people about the need for a vaccine. And we had, and still have, a good number of people who mistrust the health system. The only way that they would have been vaccinated is because we had culturally specific vaccine clinics that we fought for. [FG6-1]</i>
Theme 3: System-level actions suggested for the future to mitigate the effects of triage-avoidant strategies	
Increased collaboration and consultation when developing/implementing protocols	<i>You need people engaged who can advocate for these patients who are vulnerable, and that includes both their own family, whoever they define family as, as well as the engagement of community partners and community-based advocates who can help us to hear the voice of equity-seeking members of our community, and make sure that our policies and procedures bring that equity lens, and that they feel empowered and engaged in decisions about their own health. [FG8-1]</i>
Increased healthcare provider-oriented training	<i>Health care providers would need robust human rights training—to support all health system service provision, but especially with triage, that there would need to be a good grasp of what accommodation means in health care, and what are the human rights dimensions of making these decisions. [FG7-2]</i>
Increased patient/family education and support	<i>Education for these marginalized communities, specifically, in ways that resonate with those individuals will be key. Having knowledge is power. It empowers patients and caregivers to manage their disease effectively, but [also] know the decisions that they will need to make in the future, if there are these certain outcomes. [FG5-1]</i>
Increased public education	<i>A very frank conversation with the public about what the health care system is trying to do, and how we're limited in Canada. We saw quite a lot of distrust in the medical system because of inadequate resources or previous terrible stories of what had happened...there's no easy fix. If we're transparent about what we can and can't do, that might help. [FG9-3]</i>

Triage-Avoidant Strategies had Disproportionate Harmful Effects on Equity-Deserving Groups and Healthcare Providers

Participants discussed the effects of triage-avoidant strategies, including adjusting the standard of care, patient relocation, postponing/cancelling non-emergency procedures and specialist treatments, decreasing staffing ratios and staff redeployment. Though effects may not have been directly related to any one triage-avoidant strategy and may have occurred with triage as well (e.g., visitor restrictions), these are nonetheless important to acknowledge for any future surge in critical care demand.

Adjusting the Standard of Care

When experiencing an overwhelming surge in demand, participants noted that healthcare facilities adjusted their standard of care to meet patient needs by cancelling rehabilitation services, implementing visitor restrictions, and using unconventional

hospital spaces to accommodate patients receiving emergency care. However, adjusting the standard of care corresponded with decreased quality of care. For example, individuals requiring rehabilitation services (e.g., physiotherapy, occupational therapy), did not receive the services required to support their activities of daily living. Moreover, visitor restrictions affected services and accommodations (e.g., interpreters, personal care attendants, family networks) required for people with diverse needs to receive adequate care in hospital spaces. Hospital spaces, such as non-ICU wards or floors, were adapted to meet the overwhelming surge in demand, but often fell below the traditional standard of care. As a result, participants felt as though persons with diverse needs might have avoided healthcare facilities out of fear that healthcare providers would focus on their acute needs, and neglect their functional needs, leading to inadequate care.

Cancelling/Postponing Non-Emergency Procedures and Specialist Treatments

Non-emergency procedures were postponed and/or cancelled to reallocate resources to ICUs and to redeploy staff (e.g., nurses, therapists, physicians) to provide acute frontline care. However, conditions previously deemed non-urgent often then evolved into more complex, urgent conditions. For example, one participant highlighted that delayed diagnostic imaging could result in patients being more ill in the long term (FG9-1). Further, seniors who did not receive non-urgent care for their conditions experienced challenges in their daily living activities. Similarly, children who missed non-urgent care experienced negative effects on their overall development. Participants also noted that cancelling some specialist treatments led to delayed diagnosis and treatment trajectories, and that more patients subsequently presented with increased illness severity that then required more aggressive treatment.

Patient Relocation

Patients were often relocated to different hospitals in various regions or across provinces to receive adequate care. Participants reported that relocating patients posed barriers for families, including transportation logistics and relocation costs, and resulted in patients being separated from family members who provide essential, daily support. Families were often not consulted during these decisions. The process for selecting patients for relocation was not standardized or transparent, and the rationale for relocating patients was not conveyed to receiving physicians. Participants also noted that people from equity-deserving groups were overrepresented in patient relocations, potentially because non-marginalized individuals had more health literacy and privilege to better advocate for themselves or their family members to receive care closer to home.

Staffing Ratios/Staff Redeployment

Participants also expressed that staffing ratios were altered, and healthcare providers were redeployed into new roles in hospital settings to meet patient needs. Increased provider-patient ratios resulted in decreased quality of care, particularly for patients requiring accommodation (e.g., meal support, mobility support). Participants also noted that families felt patients were discharged from the hospital too quickly due to staffing shortages.

Participants discussed how healthcare provider shortages in hospital and a lack of primary care providers in community settings resulted in overworked, burnt-out healthcare professionals being more likely to express unconscious biases and discrimination in their care delivery toward equity-deserving groups. Participants also noted that healthcare providers often experienced moral distress when redeployed to ICU environments. For example, some healthcare providers felt motivated to assist in the ICU but did not feel adequately trained with ICU-specific skillsets.

Organizations Attempted to Mitigate Effects of Triage-Avoidant Strategies

External-Facing Strategies

To mitigate negative effects of triage-avoidant strategies, participants described various external-facing strategies that their organizations employed during COVID-19. For example, some organizations consulted with government officials to discuss recommendations surrounding triage protocol. Other organizations leveraged media outlets to disseminate knowledge and advocate for their community members. Several participants noted that their organizations facilitated conversations among community members to share their lived experiences and enabled collaboration with other organizations. Some participants representing healthcare organizations noted that healthcare providers, both within their institutions and across regions, built capacity by engaging in consistent communication, coordinating advocacy strategies, and providing consultative services to ensure high-quality care delivery.

Internal-Facing Strategies

Organizations also employed internal-facing strategies to mitigate the effects of triage-avoidant strategies. For example, some healthcare organizations employed healthcare provider resources, such as response teams and system navigators, to support patients and families navigating the healthcare system during COVID-19 in both hospital and community settings. Other organizations employed culturally focused strategies, including culturally specific healthcare spaces and vaccine clinics within community settings, and community-based interpreter services to mitigate feelings of community distrust in healthcare systems and spaces, and reduce structural barriers to healthcare services.

System-Level Actions Could Help Mitigate the Effects of These Strategies in the Future

Participants suggested several system-level actions to be implemented to mitigate the effects of triage-avoidant strategies.

Increased Collaboration and Consultation When Developing/Implementing Protocols

When developing a triage protocol, further consultation is needed between medical professionals (e.g., healthcare providers, academics), healthcare system users (i.e., patients) and healthcare system user advocates (e.g., family members, friends, community-based advocates). Participants explained that increasing consultation and collaboration can help to ensure that policies are developed using an equity-based lens, and account for diverse populations' needs.

Increased Healthcare Provider-Oriented Training

Participants also expressed that further training in hospital environments, particularly within ICUs, is required for high-quality care delivery and system user satisfaction. Moving forward, increased human rights, cultural safety, and trauma-informed care training for healthcare providers was deemed necessary to support healthcare system service provision. Participants stated that increased training in ICU environments may increase high-quality care delivery, as well as healthcare systems and user satisfaction.

Increased Patient/Family Education and Support

To ensure that patients and families are educated about the patient's condition and healthcare trajectory, participants reported that healthcare providers need to collaborate with patients and families to ensure they have the necessary information to inform and empower them in subsequent decision-making. In addition, visitor restrictions during COVID-19 negatively affected patients' ability to carry out activities of daily living and resulted in dissatisfaction with care delivery as their support systems (e.g., family members, friends) were unable to assist them while receiving care in hospital. Moving forward, participants suggested patients require in-hospital social support while receiving healthcare to alleviate communication barriers and ensure care needs are being met.

Increased Public Education

Lastly, participants noted that during COVID-19, members of the public felt uninformed about the mechanisms and current constraints of the healthcare landscape. Moving forward, they suggested that further public education about these constraints and transparent engagement between healthcare providers and healthcare system users could alleviate distrust in the healthcare system.

DISCUSSION

Our study gathered experiences and perspectives of decision-makers, clinicians, and equity-deserving groups from across Canada regarding the effects of triage-avoidant strategies used during COVID-19. Participants perceived that triage-avoidant strategies had disproportionately harmful effects on equity-deserving groups and healthcare providers; shared how organizations attempted to mitigate negative effects of triage-avoidant strategies; and suggested system-level actions that could help mitigate the negative effects of these strategies in the future.

The Unintended Yet Harmful Effects of Triage-Avoidant Strategies on Equity-deserving Groups

Equity-deserving groups experienced several unintended yet harmful effects from the use of triage-avoidant strategies. For example, they faced exacerbated barriers to access and availability of healthcare services, including delayed or cancelled procedures and specialist treatments, as well as logistical and financial challenges related to patient relocation. They perceived that quality of care, and consequently health outcomes, were also negatively affected. Participants noted that adjustments to the standard of care contributed to reduced rehabilitation services, decreased attention to diverse patient needs, and increased illness severity due to postponed interventions. Social support was similarly compromised, with participants highlighting separation from support networks due to isolation or relocation, and reduced access to essential services such as personal support workers or interpreters. Participants perceived that systemic inequities were further amplified by the overrepresentation of equity-deserving groups in patient relocations and the exacerbation of unconscious bias or discrimination stemming from staffing shortages and redeployment.

COVID-19 Amplified the Effects of Existing Inequities in Access to Emergency Care

Respondents felt that COVID-19 heightened the effects of existing inequities on people's abilities to access emergency care. For instance, participants highlighted that equity-deserving groups often avoided seeking care in formalized healthcare spaces due to previous experiences of racism and discrimination. Some patients felt that their conditions were dismissed (e.g., were not admitted to emergency care, symptoms were unrecognized) resulting in exacerbated underlying conditions and, in some cases, participants reported resulting fatalities. Financial factors further affected healthcare users' ability to access supplementary private care outside of the publicly funded healthcare system. Additionally, geographical location, transportation challenges, and isolation restrictions significantly affected the ability of patients living in some communities to access care.

Equity considerations can be overlooked when the healthcare system becomes strained. Existing inequities are compounded by a lack of support to improve access and quality of care for people among equity-deserving groups. For example, interpretation services are essential to achieve effective communication, complex decision-making, and provide therapeutic management for linguistic minorities (30). During COVID-19, both formal and informal (e.g., family member/friend) interpretation services were depleted due to overwhelming hospital demands and visitor restrictions (31), transforming a routine aspect of care into an exception, and negatively affecting overall care standards. Some Canadian hospitals have implemented technology-driven interpretation services (32) and virtual care (31) to reduce linguistic barriers moving forward.

Although Ontario's Triage Framework was never deployed, studies have shown that some triage tools might have inappropriately deprioritized Black patients, patients with disabilities (33), and Indigenous patients (34,35) because screening tools indicated these individuals have a lower chance of survival than was actually the case. These effects may be mitigated in the future through avoidance of tools with poorer (or unknown) prognostic value in equity-deserving groups, when possible.

Participant Considerations for Future Resource Allocation Frameworks

Participants outlined several considerations for future both resource allocation frameworks and triage avoidant strategies. First, they emphasized the importance of collaboration and consultation with relevant parties when developing frameworks, highlighting the use of an equity-based lens to account for the needs of diverse populations. They also stressed the need for increased healthcare provider training, particularly in the areas of human rights, cultural safety, and trauma-informed care. Participants noted that clear communication regarding diagnoses and care trajectories is essential, as is the inclusion of in-hospital supports to assist with daily living needs and communication barriers. Public education and transparency were also highlighted, with participants emphasizing the importance of educating the public about healthcare system constraints and mechanisms, as well as fostering transparent engagement between providers and system users to build trust. Broadly, resource allocation frameworks should anticipate surges in demand and potential inequities, aiming to mitigate the negative impacts of triage-avoidant strategies on equity-deserving groups.

A Resource Allocation Framework Reflecting the Experiences of Decision-Makers, Clinicians, and Equity-Deserving Groups is Required

Our participants felt that COVID-19 exacerbated existing inequities in access to emergency care, and argued for an equitable approach to managing limited healthcare resources, whether triage or triage-avoidant strategies are used. A resource allocation framework grounded in equity-based principles could provide actionable strategies to mitigate inequities during demand surges, helping to ensure that equity-deserving groups are not disproportionately affected when resources are scarce.

While some frameworks cite the importance of equity in triage and triage-avoidant strategies, implementing equity-based decisions is challenging. For example, the American Medical Association provides suggestions on embedding equity in crisis preparedness and response in health systems, including a "shift to race and identity-explicit approaches that promote equitable crisis response processes and outcomes" and "embed[ding] equity in all emergency response structures", but practical implications are not discussed (36, p.8). Complementing this, Downar et al. (8) developed a multi-level critical care triage framework that incorporates fairness, consistency, and equity considerations across hospitals, emphasizing consultation with Indigenous, Black, racialized, older adult, and disability rights stakeholders.

Our participants' experiences echo this framework, highlighting the value of stakeholder engagement in shaping protocols. Building further, the Accountability for Reasonableness (A4R) framework argues that legitimacy and fairness in resource allocation require a deliberative process that is transparent (37), based on reasons stakeholders can agree are relevant, revisable in light of new evidence, and enforceable (38). Applying A4R to our findings emphasizes that procedural justice, such as clear reasoning, transparency, and mechanisms for revision, is crucial for embedding equity-oriented principles in practice, especially when healthcare providers are faced with rapidly evolving crises.

Representation and Power within Equity-Focused Organizations

While our recruitment included organizations among government, healthcare, and advocacy sectors, it is important to note that those contributing to decision-making discussions may not have been individuals among equity-deserving communities. This raises important questions about how equitable power structures are within organizations that aim to promote equity — specifically, whose voices are centred in decision-making and whose perspectives may remain underrepresented. For instance, the development of healthcare frameworks and strategies is often led by healthcare professionals and/or leaders with limited direct involvement of patients, family caregivers, or members of the general public (39). Indeed, engaging equity-deserving groups in these processes presents both opportunity as well as complexity: engagement can help ensure that frameworks and strategies reflect lived experiences and mitigate structural inequities, yet it also requires careful attention to tokenism, accessibility, and the distribution of decision-making authority (40,41). The fact that both the triage framework and triage-avoidant strategies were developed as the pandemic was unfolding created a time-pressure that precluded extensive consultation and engagement.

Strengths and Limitations

This project engaged representatives among a variety of organizations, including governmental, educational, and non-profit sectors. A notable strength of this work is the documented perceptions of a broad range of interested parties on the effects of efforts to avoid triage, which can inform future considerations for framework development. Additionally, we have identified several system-level recommendations that can be brought forward when developing and implementing future frameworks.

We nonetheless encountered recruitment challenges engaging participants on a national scale; we were only able to secure representation from five provinces. Additionally, we faced difficulties recruiting individuals who could both articulate the experiences of equity-deserving groups during COVID-19 and had an in-depth knowledge of the healthcare system. This limited representation may hinder our understanding of how changes within the healthcare system affected individuals and communities beyond COVID-19. Moreover, because our findings represent participants' perspectives, we cannot confirm that these perspectives are reflected in empirical data from the pandemic (e.g., whether marginalized individuals were transferred more often than non-marginalized individuals in the same situation). We are studying this data in a separate study.

Finally, we had poor representation from First Nations, Inuit, Métis and urbanized Indigenous peoples. Recognizing the First Nations principles of Ownership, Control, Access, and Possession (OCAP) in data collection processes (42), we invited representatives to engage in a preliminary conversation before the recruitment phase and requested letters of support from organizations to indicate their approval for the research coordinator to invite representatives from the organization to participate in the research study. We also faced challenges engaging other members of equity-deserving groups, as only approximately 30% of participants identified as a person of colour or among equity-deserving groups. This limited representation may influence the extent to which our findings reflect the experiences of all equity-deserving groups and underscores the importance of developing more inclusive recruitment strategies in future studies.

CONCLUSIONS

This study contributes to the literature by documenting the perspectives of representatives of diverse organizational backgrounds, as well as members of equity-deserving groups, on how triage-avoidant strategies disproportionately harmed their organizations and the populations they serve. The study also gathered insights on organization-specific actions that were implemented to mitigate these effects, and we identified system-level recommendations for future strategies to reduce harm. The synthesized findings highlight key elements that should be considered when developing equitable resource allocation frameworks. Our findings can inform the development and implementation of triage-avoidant (and triage) strategies that better reflect the views and experiences of decision-makers, clinicians and/or groups equity-deserving groups, and ensure that care is delivered more equitably while trying to maximize lives saved. Future research is necessary to explore the practical implementation of equity-focused triage-avoidant strategies.

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Conflits d'intérêts

JD a co-écrit le cadre de référence ontarien « Norme de soins cliniques d'urgence en cas d'afflux massif de patients ». Afin de limiter les biais, JD n'a examiné aucune transcription et n'a pas participé à l'analyse des données. Un autre membre de l'équipe de recherche, SV, a participé à l'étude. Afin de limiter les biais, SV n'a examiné aucune transcription et n'a pas participé à l'analyse des données. Les autres auteurs n'ont aucun conflit d'intérêts à déclarer. Cécile Bensimon est éditrice de la revue, et Maxwell J. Smith est membre de son Comité consultatif de rédaction. Ni l'une ni l'autre de ces personnes n'a participé, à quelque étape que ce soit, au processus d'évaluation ou à la décision d'accepter ce manuscrit.

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Conflicts of Interest

JD was a co-author of Ontario's "Critical Care Clinical Emergency Standard of Care (ESofC) for Major Surge" framework. To mitigate bias, JD did not review any transcripts and was not involved in the data analysis process. One broader study team member, SV, participated in the study. To mitigate bias, SV did not review any transcripts and was not involved in the data analysis process. Cécile Bensimon is an editor of the journal, and Maxwell J. Smith is a member of the Editorial Advisory Board. Neither were involved at any stage in the review or acceptance of this manuscript.

Édition/Editors: Aliya Affdal

Les éditeurs suivent les recommandations et les procédures décrites dans le [Core Practices](#) de COPE. Plus précisément, ils travaillent pour s'assurer des plus hautes normes éthiques de la publication, y compris l'identification et la gestion des conflits d'intérêts (pour les éditeurs et pour les auteurs), la juste évaluation des manuscrits et la publication de manuscrits qui répondent aux normes d'excellence de la revue.

The editors follow the recommendations and procedures outlined in the COPE [Core Practices](#). Specifically, the editors will work to ensure the highest ethical standards of publication, including: the identification and management of conflicts of interest (for editors and for authors), the fair evaluation of manuscripts, and the publication of manuscripts that meet the journal's standards of excellence.

Évaluation/Peer-Review: Maria Klimenko & Manisha Pahwa

Les recommandations des évaluateurs externes sont prises en Reviewer evaluations are given serious consideration by the considération de façon sérieuse par les éditeurs et les auteurs editors and authors in the preparation of manuscripts for dans la préparation des manuscrits pour publication. Toutefois, publication. Nonetheless, being named as a reviewer does not être nommé comme évaluateurs n'indique pas nécessairement necessarily denote approval of a manuscript; the editors of l'approbation de ce manuscrit. Les éditeurs de la *Revue Canadian Journal of Bioethics* take full responsibility for final *canadienne de bioéthique* assument la responsabilité entière de acceptance and publication of an article. l'acceptation finale et de la publication d'un article.

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APPENDIX 1: SUPPLEMENTARY FILE A – FOCUS GROUP/INTERVIEW GUIDE

Today we're going to be having a conversation to better understand your views on how the COVID-19 pandemic was managed in hospitals and how that impacted *[insert group topic here]* individuals and communities. Our overall aim is to develop a framework for allocating healthcare resources during future overwhelming surges in demand, such as another pandemic, while trying to avoid disproportionate effects upon marginalized individuals.

We're going to be talking today about 'triage'. Triage is commonly used in emergency departments to prioritize those who are most likely to benefit from care before those who are less likely to benefit from care. During the COVID-19 pandemic, there was concern that we would need to start a triage process for critical care beds. This was referred to as the triage protocol, which was developed but never implemented. Instead of using the protocol, efforts were made to redirect healthcare resources towards the Intensive Care Unit and expanding capacity well beyond normal. These are what we'll be referring to as "triage-avoidant" strategies. While they were effective in preventing the need for Intensive Care Unit triage they did have consequences for patients, healthcare providers and others.

We want to understand your unique experiences and ideas on this topic. We'll be asking a series of questions and opening the floor up for discussion.

1. Please describe the organization you are representing today and your professional role at that organization.
2. During the COVID-19 pandemic, provinces and territories implemented triage-avoidant strategies (i.e. strategies that aimed to prevent unsustainable demands on the critical care system due to COVID-19). I will list some strategies. Please let me know how you think these strategies impacted those that you and/or your organization represent?
 - a. Cancelling/postponing non- Intensive Care Unit services (e.g. chemotherapy, non-emergency surgery) so that staff can be redeployed to the Intensive Care Unit.
 - b. Cancelling/postponing scheduled procedures that often require Intensive Care Unit care (e.g. cardiac surgery, organ transplant) to preserve Intensive Care Unit capacity for COVID-19 patients
 - c. Transferring or rerouting critically ill patients to other facilities and regions
 - d. Staffing ratios/redistribution of staff (e.g. having each nurse care for more patients than usual for them?)
 - e. Surging Intensive Care Unit admissions over normal capacity (admitting more patients than usual)
 - f. Adjusting the standard of care provided (e.g., keeping patients on the ward who would at other times have been admitted to Intensive Care Unit; placing more stringent criteria for access to tests, treatments, or transfer to hospital or Intensive Care Unit)
3. Did your organization take any specific actions to minimize effects upon your organization's community, or monitor whether such effects were taking place? *(Skip if short on time)*
4. How can we decrease the disproportionate effects of these triage-avoidant strategies on marginalized communities in the future?
5. Looking forward, understanding there may be another pandemic, how would you advise decision-makers approach the challenge of limited critical care resources?
 - a. Would you advise implementing a triage protocol or revised triage protocol? Would you advise implementing any of the above triage-avoidant strategies again? Or both?
6. Do you have anything to add that you did not yet get a chance to say?

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Exploring Learners' Experiences with Clinical Ethics Consultations: A Narrative Reflection on the Impact and Role of Emotions

Téa Christopoulos^{a,b}, Oluwaseun Sobode^a, Megan Bailey^{a,c}, Dylan McKibbin^{a,d}, Thomas Milovac^a, Sam Moshiri^{a,e}, Jessie Van Leeve^{a,f}

Résumé

En tant qu'étudiants en éthique clinique, nous avons observé des consultations d'éthique et éprouvé diverses réactions émotionnelles suite à ces consultations, notamment concernant les décisions de fin de vie. Bien qu'il existe une littérature abondante sur le rôle et la nature des émotions chez de nombreux professionnels de santé de première ligne, tels que les infirmiers et les médecins, les recherches sur les expériences émotionnelles des éthiciens cliniques et des étudiants en éthique clinique restent limitées. Nous sommes convaincus que la compréhension de ces expériences émotionnelles peut enrichir notre compréhension du rôle et de la pratique des éthiciens cliniques, en particulier compte tenu des contextes de soins complexes et fortement marqués par les valeurs dans lesquels les consultations d'éthique ont souvent lieu. Ces recherches peuvent également éclairer la formation en éthique actuelle et future, contribuant ainsi à l'élaboration de programmes de formation de qualité pour les futurs éthiciens, tels que des laboratoires de simulation bioéthique. Cet article a sollicité la contribution volontaire de sept étudiants en éthique clinique, qui ont fourni un récit de leurs expériences de consultations d'éthique clinique afin d'identifier les thèmes clés liés aux réactions émotionnelles lors de ces consultations.

Mots-clés

professionnels de la santé, éthiciens cliniques, apprenants, émotions, soins de santé, empathie

Abstract

As clinical ethics learners, we have observed ethics consultations and have experienced an array of emotional responses as a result of these consultations, particularly surrounding topics pertaining to end-of-life decision-making. While there is extensive literature on the role and nature of emotions for many frontline healthcare providers, such as nurses and physicians, limited research exists on the emotional experiences of clinical ethicists and clinical ethics learners. We maintain that understanding these emotional experiences can deepen our understanding of the role and practice of clinical ethicists, especially given the challenging and values-laden healthcare contexts in which ethics consultations often occur. This research can also inform current and future ethics education to aid in the development of quality-driven training programs for future ethicists, such as bioethical simulation labs. This paper sought the voluntary contributions of seven clinical ethics learners, who provided a narrative account of their experiences with clinical ethics consultations as a means to identify key themes related to emotional responses to ethics consultations.

Keywords

healthcare practitioners, clinical ethicists, learners, emotions, healthcare, empathy

Affiliations

^a Ethics Quality Improvement Lab, William Osler Health System, Brampton, Ontario, Canada

^b Faculty of Kinesiology and Physical Education, University of Toronto, Toronto, Ontario, Canada

^c Ethics and Public Affairs, Department of Philosophy, Carleton University, Ottawa, Ontario, Canada

^d St. Joseph's Health Centre, Toronto, Ontario, Canada

^e School of Medicine, Toronto Metropolitan University, Toronto, Ontario, Canada

^f Centre for Bioethics, Harvard Medical School, Cambridge, Massachusetts, United States

Correspondance / Correspondence: Téa Christopoulos, tea.christopoulos@mail.utoronto.ca

INTRODUCTION

We are clinical ethics learners (CELs) at a community hospital system located in the Greater Toronto Area in Ontario, Canada. The term "learner" is used throughout this paper to refer to a formally engaged clinical ethics intern, fellow or practicum student with limited prior clinical ethics consultation experience. As such, learners assume an observational and supporting role during ethics consultations for hospital staff, physicians, patients, and their families, with the aim of gaining practical exposure that can be leveraged for future career pursuits. For the purpose of this paper, we define consultations as an interaction between key partners involved in patient care, such as hospital staff, physicians, patients, families, or other members of the healthcare team surrounding an ethical dilemma or issue. We define healthcare practitioners (HCPs) as licensed health-related professionals that exclude the clinical ethicist (CE) and CELs. These ethics consultations involve questions and challenges related to healthcare decision-making about a range of topics such as treatment, end-of-life, medical assistance in dying (MAiD), and discharge from the hospital. Typically, CEs leading the consultation will meet with CELs beforehand to discuss what is known about the case and what specific things to pay attention to while observing. This is followed by the consultation itself as well as an opportunity to debrief and ask questions following these observations to reflect upon relevant circumstances and outcomes.

Some of the work of the CE can involve responding to the emotional experiences of the key partners named above, especially when it comes to complex healthcare decision-making. When ethical issues and questions arise in the healthcare setting, in addition to maintaining compliance with relevant laws and policies, CEs are frequently tasked with providing support to patients, families, and HCPs related to role clarity, values identification, and potential resolutions in alignment with ethical principles. This work can be laden with emotional dynamics, and our experience participating in rounds, debriefs as well as observing consultations as CELs, particularly those that involved difficult topics such as end-of-life decision-making, led us to wonder about the impact of emotions on CEs themselves. This prompted further reflection; how do CELs feel when engaging with and supporting these complex, emotionally charged dilemmas? How do we regulate our own emotional responses to consultations, both in the moment and over time? These questions percolated as we continued our learning and observing consultations, and it was in this context that we endeavoured to learn more about the emotions of CEs and CELs.

The purpose of this paper is twofold: we wish to further reflect on, highlight and analyze our own empirical experiences as CELs observing consultations as a unique contribution to the clinical ethics field. We also aim to demonstrate a gap in the literature with respect to both the presence and role of emotions experienced by CEs and CELs, to help advocate for empirical inquiry, theoretical reflection, and discourse to better understand the emotional aspects of clinical ethics work. To do this, we first offer our own personal narrative accounts of our experiences as CELs to thematically analyze them in meaningful ways to prompt further research in this area. Then, we turn to the literature to describe what is currently known about the field and practice of clinical ethics and emotions, as well as the role and impact of emotions for patients, families, and other HCPs. In doing so, we highlight the current gaps in the literature to motivate future empirical work in this area.

METHODS

The research questions that we sought to address were the following: What is currently known about the interplay between emotions and the roles of CEs and CELs in the practice of clinical ethics? What is known about the cumulative emotional burden of the clinical ethics profession?

A preliminary scan of the scholarly literature reflected little to no coverage of the role and impact of emotions, specifically in the context of clinical ethics practice. This motivated our own search for an accessible way to gain insight into the kinds of emotional dynamics experienced by junior and senior CELs working in our acute care system. As such, we elected to voluntarily contribute our own short narrative-style accounts, as CELs and co-authors of this work, in response to the following prompt: "Please write an excerpt about your own individual emotional experiences both during and after observing clinical ethics consultations." In total, seven accounts were collected from all seven co-authors (consisting of two senior CELs and five junior CELs) from diverse backgrounds — graduate students, practicum students, and working professionals — belonging to the same 2023-2024 cohort of the intern program. The term 'narrative account' is used here to describe free-form, personal and descriptive reflections of lived experience that are written in each learner's own voice, in the absence of a predetermined formal narrative framework to follow. This approach aimed to capture what felt most significant to each individual learner to reveal a range of insights into how emotions are encountered and navigated in typical clinical ethics consultations. Narratives reflected learners' cumulative exposure to diverse cases over time rather than a single case or fixed time point.

To ensure the confidentiality of learners sharing their personal experiences, submissions were submitted anonymously via a Google document and then organized for analysis by a designated co-author. The direction provided by the lead authors (TC and OS) ensured that no specific case information was shared to protect the personal information of patients, as well as the CELs. Given the flexible duration of the internship program, the sharing of non-identifiable narrative accounts did not pose any financial or occupational risk to the CELs, and no author expressed concerns regarding safety or apprehension in sharing these accounts.

The collection of personal narrative accounts was treated as primary qualitative data. Once the narratives were collected, they were analyzed to elucidate what resonated with learners most. Using Braun and Clarke's reflexive thematic analytic framework (1), we were able to identify patterns and themes across the data. This methodological approach allowed us to first code each learner reflection and then extract broader themes among learners' experiences overall. We followed Braun and Clarke's six phases of thematic analysis, by first familiarizing ourselves with the data and generating initial codes for each of the reflections. We collated the codes as we searched for themes, reviewed them, and defined each theme accordingly to generate our final product, which we then reviewed and scanned as a final opportunity for analysis.

The thematic analysis was conducted to support our broader aim of illuminating how emotions are experienced through clinical ethics learning opportunities among learners within the same training program. The choice to not distinguish learners in junior versus senior roles was intentional to avoid potential identification of the learners due to the small size of the cohort. Analyzing all reflections via coding and generating themes that were shared across the collective was intended to reduce potential bias due to seniority.

Our analysis led to a more focused exploratory narrative review of the literature to examine the emotional considerations and implications of clinical ethics experiences. Relevant literature was identified through PubMed/MEDLINE, Web of Science, and

Google Scholar in October 2023, and articles published in English were screened independently by two authors (TC and OS) based on titles and abstracts for relevance to the review focus. The full texts of relevant articles were reviewed, and seven relevant studies were included for analysis. Conflicts regarding independently selected literature were discussed between TC and OS to reach a mutual decision based on the research question.

LEARNERS' NARRATIVE REFLECTIONS ON ETHICS CONSULTATIONS

Each narrative account below has been written by one of the co-authors of this article. The term "Clinical Ethics Learner" encompasses both junior and senior learners, with diverse academic and occupational backgrounds. Experience within the clinical ethics program was also varied as the program does not have a specific duration of training. Two senior CELs had been in their role for over two years, whereas the five other junior CELs had been part of the program for less than six months. A description on the exact background of each learner is not provided to ensure the anonymity of all narrative accounts. These varied experiences and levels of seniority will be acknowledged in the analysis.

Clinical Ethics Learner 1

The experience of shadowing the CE during consultations and Medical Assistance in Dying (MAiD), coupled with their thoughtful check-ins to gauge our emotional well-being following each consultation, ignited a personal curiosity within me. It prompted me to reflect deeply on the profound implications of these consultations and whether they exert a cumulative emotional toll.

Clinical Ethics Learner 2

After observing an ethics consultation with a patient via phone, I would be remiss if I did not acknowledge the despair and sheer sadness I felt for the patient's predicament, and confusion about how I would personally remediate my own emotions post-consultation. Bearing witness to the fragility of end-of-life care and existential questioning made me confront my own positionality and reflexivity as a learner, exhausting the empathy for which I could exercise both for the patient and CE.

Clinical Ethics Learner 3

Post-consult would sometimes leave me feeling anxious. The ethical quandaries I learned about in my coursework, felt easy to discuss and deliberate. However, in these consults, I was now encountering real-world ethical issues with actual staff and patient(s). I felt a strong sense of empathy for the staff and patients and the difficult situations they were facing. Even though the CEs would provide support to the best of their ability, sometimes patients and staff were still in the same situation, without a clear path to resolve it. I realized that these issues do not just get left with the staff and patients, but also the CEs. I think as a future CE that it is important to acknowledge my emotions and learn how to debrief them constructively.

Clinical Ethics Learner 4

The question regarding the role of emotional experience in ethical consultation compels me to reflect upon the likely integration of Artificial Intelligence (AI) into the relationships that exist between patients, physicians, and CEs. How might this change one's emotional experience in the delivery of care? What will be gained and what will be lost? Will AI be deployed as "empathy machines", allowing clinicians and CEs to enhance their ability to communicate compassionately, or provide respite by allowing them to temporarily step out from under the weight of their consultations? Can the use of unfeeling machines help to fight burnout in a health system that is increasingly stretched thin? What happens when CEs become disconnected from the emotional gravity of their consultation? Does this enhance their ability to reason, or cripple it? Though the answers to these questions are presently unclear, what I am certain of is that more research is required to better understand the important and thought-provoking question of the role of emotional experience in ethical consultations.

Clinical Ethics Learner 5

Working in healthcare is undoubtedly an emotional experience and this fact is certainly not lost on CEs or learners who observe consultations. As a learner, my experience of a ChELO (Checklist to meeting Ethical and Legal Obligations), wherein the CE ascertains information about a patient's correct substitute decision maker, along with information about the patient's wishes, values, and beliefs, was invaluable in illustrating the CE-patient dynamic and the potential for shouldering an emotional burden given the medical and ethical context. This experience has made me pause and think about the emotional aspect of clinical ethics work and how that might reasonably impact CEs after particularly burdensome consultations or the cumulative effect of numerous consultations.

Clinical Ethics Learner 6

Throughout my years as a clinical ethics intern, I have been afforded the privilege to enter spaces and places where individuals interact with the healthcare system in various forms. As an intern, I have grown a particular appreciation for the opportunity to engage with patients and families as they navigate through the healthcare system to offer support when invited. The situations I have been exposed to as a clinical ethics intern, whether discussing MAiD or patients sharing their wishes, values, and beliefs with the healthcare team, can be challenging for both the CE and patient/family. Consultations can take an emotional toll on both CEs and patients, as difficult conversations often occur. Over the years, I have recognized how vital open communication is in healthcare and how small gestures, such as listening to a patient's concerns, feelings, and goals, can impact their experience within the healthcare system. Initially, when leaving consultations that involved difficult conversations, I would harp on every word and small aspect of the conversation, feeling overwhelmed and concerned about what I said or didn't say. Over time, I have learned to separate my own expectations of consultations and discussions and focus on patient-centered care as an overall objective – this helps to ensure that the patient's wants, needs, and feelings are adequately addressed.

Clinical Ethics Learner 7

While observing a physician-led family meeting regarding end-of-life options for a terminally ill patient, in the weight of the circumstances I found myself feeling admiration for the compassion with which the meeting was conducted. Here was the kind of deep and meaningful human-to-human connection I was learning to support in patient-provider relations. I watched and felt as the physician created space for understanding, preserving regard for the patient's values as well as the heavy emotions in the room, all the while demonstrating exemplary kindness and patience as everyone digested the devastating news being delivered.

As the CE offered comfort, I experienced firsthand the ways in which learners take on the emotional residue of our encounters. While we help others process the weight of impossible scenarios and the moral and ethical questions that accompany them, some of that weight inevitably gets transferred onto us.

That day, I felt it as I left the hospital. I felt heavy and disconnected, deeply struck by the pain that the poor prognosis of this patient unleashed on the family, the care team, and on me. I wondered what will I feel when I'm a CE? Who can I turn to when I need support as a CEL? What happens when emotions from the professional bleed into the personal?

It is perhaps a cruel irony that our vocation calls us to support others with varied and complex human responses to ethical dilemmas in healthcare contexts, yet our training doesn't necessarily prepare us to process our own responses. For now, I'm hopeful that by leaning into these emotions, by experiencing them not in isolation but in community with patients, their families, providers, and other CEs, I will come to embrace the profound privilege we share of being so close to the fullness of our humanity in these moments.

Analysis of learners' narrative accounts

To analyze the narrative accounts effectively, a thematic analysis was conducted by two of our co-authors (MB and JVL). Coding the narrative accounts with an inductive approach allowed us to develop four different themes. Themes across all reflections included the impact of varied experiences and seniority, the cumulative emotional burden of ethics consultations, post-consultation emotional regulation and processing, and prioritizing emotion management in clinical ethics training.

Both the varied experiences and level of seniority had an impact on each CEL's response and emotional experience after a consultation, as well as the ownership they felt over addressing the ethical quandary at hand. Some CELs had been part of consultations for more emotionally charged situations such as those involving MAiD, whereas other learners may have been part of consultations that although challenging, may not have been as burdensome on their own emotions, such as an ethical issue arising in long-term care. Additionally, the length of training within the program has an impact on these responses and emotional experiences. A longer duration of training typically means increased exposure to a variety of cases, some more emotionally and ethically charged than others. This exposure may allow a more senior CEL to be able to better process and understand the outcomes of a consultation and how they may affect patients positively or negatively.

Despite these distinctions between learners, we elected not to indicate which learner authored which account. Furthermore, due to the small size of the cohort and because of the risk that participants could easily be identified depending on the context, themes were developed by identifying patterns that emerged across the full set of data, rather than drawing out themes from single accounts. Not all learners are reflected in every theme. Rather, each theme reflects multiple learners. Below, each theme is illustrated with excerpts.

Theme 1: Cumulative emotional burden of ethics consultations

Learners who reflected on the sensitive nature of ethics consultations and their own responses to them identified a need to create more support for CEs and CELs. Even though one may be able to regulate their emotional state following an ethics consultation, CELs expressed a belief that this ability would dwindle with more consultations over time, especially given the varying degrees of stress associated with different cases.

“It prompted me to reflect deeply on the profound implications of these consultations and whether they exert a cumulative emotional toll.”

“This experience has made me pause and think about the emotional aspect of clinical ethics work and how that might reasonably impact CEs after particularly burdensome consultations or the cumulative effect of numerous consultations.”

Theme 2: Post-consultation emotional regulation and processing

Other CELs spoke more specifically to what post-consultation emotional regulation and processing might entail. Since CEs engage in emotionally laden work, it is reasonable to consider the potential positive effects of talking about the emotions experienced and perhaps learning methods to aid in decompressing after consultations. Intuitively, it may be difficult to deal with strong emotions, especially when one does not have the space to talk about their emotions. In the context of clinical ethics, this truism should be dealt with effectively and CEs and learners could benefit from engaging with one another and debriefing. Collaborating and debriefing with HCPs who specialize in mental and emotional well-being, such as registered social workers and psychotherapists, could be particularly promising.

“I think as a future CE that it is important to acknowledge my emotions and learn how to debrief them constructively.”

“[...] our vocation calls us to support others with varied and complex human responses to ethical dilemmas in healthcare contexts, yet our training doesn’t necessarily prepare us to process our own responses.”

Theme 3: The impact of emotion on the ethicist’s ability to reason

One concern that was identified in the narrative accounts related to the acknowledgement of the emotional aspects of clinical ethics consultation — that is, the impact of emotion on the CE’s ability to reason through ethical dilemmas. Emotions are often thought of as loud, dramatic, observable, and obvious; while this can be true, they are often more complex and not always outwardly visible. We can never fully comprehend the internal emotional experience, and are often not fully aware of our own, as it tends to quietly unfold in our inner worlds, under the surface, unseen, and unheard. Although we formulate explanations for what and why we feel, the limitations of our awareness allow us only to capture pieces of it; our ability to articulate these experiences is therefore reduced to what we can identify. Yet emotion is not merely a passive experience. Rather, it is a dynamic and essential tool that shapes and guides our reason, offering valuable information beyond what logic alone can render intelligible. Whether salient or obscure, enduring or ephemeral, our emotions and that of others are deserving of recognition. We would all do well to acknowledge our emotional experience for what it is; a valuable source of information, and warranting serious consideration in the activities of ethical consultation and discernment.

“What happens when CEs become disconnected from the emotional gravity of their consultation? Does this enhance their ability to reason, or cripple it?”

“[...] I would harp on every word and small aspect of the conversation, feeling overwhelmed and concerned about what I said or didn’t say.”

Theme 4: Emotion management in clinical ethics training

Regarding emotion management in clinical ethics training, the need for robust coaching in navigating consults as well as the acknowledgment of the inherent privilege of the profession were sub-themes identified in learners’ narrative accounts. Investing time and energy in coaching that is individually tailored can provide learners with essential tools to ensure they are equipped to deliver quality-driven ethics support to patients, families, and healthcare providers. Effective coaching for consultations might include making time for emotional debriefs, honing and recognizing the importance of communication skills, centering patients’ values, wishes and beliefs, and creating a space for empathy.

When it comes to navigating clinical ethics consultations, learners also reflected on the importance of recognizing the emotional gravity of these consultations. They acknowledged that these consultations take an emotional toll on all parties involved, highlighting the importance of open communication in their reflections. Since listening to patient concerns, feelings, and goals significantly impacts their healthcare experience, learning how to create spaces for understanding and preserving patients’ values amidst these conversations was identified as a vital skill. Recognizing consultations as a vulnerable experience allows

for a deep appreciation for this work and acknowledging the privilege of entering these vulnerable spaces can be a way to balance the gravity of the experience with its profound impact and potential to improve health outcomes for so many.

“[...] I experienced firsthand the ways in which learners take on the emotional residue of our encounters.”

“Over time, I have learned to separate my own expectations of consultations and discussions and focus on patient-centered care as an overall objective – this helps to ensure that the patient’s wants, needs, and feelings are adequately addressed.”

The above analysis highlights key themes that are central to the experiences of CELs, and both underscores the need and provides a foundation for exploring, in the following section, what is known about emotions in clinical and ethics practice.

BACKGROUND

The complex and emotionally charged environment of a clinical setting experienced by patients, their families, and HCPs makes the consideration of emotions particularly salient for healthcare decision-making. Emotions affect the process of making effective decisions, alongside other influencing factors such as knowledge, perceptions, and instincts (2). In clinical settings, the provision of care can evoke different emotional responses on either side of the hospital bed for both patients and HCPs (3). As CELs, we recognize that there are clear distinctions between the role of an HCP and CE. The differences between these roles in a clinical setting stem from their involvement in the clinical processes, treatment, and overall role in care. Surveying what is known about the nature and impact of emotions for patients and HCPs can thus provide the contextual background necessary to pose a parallel inquiry for CEs.

EMOTIONS OF PATIENTS & FAMILIES

For patients, accessing health services can be an emotionally charged experience due to the often invasive, unfamiliar, and high-stakes procedures that carry with them various potential risks. These emotions may result in a sense of powerlessness over their bodies, often exacerbated by past interactions with the healthcare system (4). Families of patients can also experience a range of emotions such as fear, anger, and sadness alongside their loved ones who are facing serious illness (3).

EMOTIONS OF HEALTHCARE PRACTITIONERS

Given the proximity to patients, families, and other HCPs, HCPs undoubtedly also experience emotions throughout their practice, even while being expected to uphold a decorum that maintains professional distance (3). Studies that have focused on HCPs’ emotions elucidate the impact emotions have in clinical practice. For example, HCPs have expressed feeling hurt or frustrated when delivering bad news to new parents (5), having feelings of powerlessness in managing difficult engagements between patients and next-of-kin, unease over inequality, and discouragement over non-compliant patients (6). Recently, Goldenson and Gutheil (7) described psychiatrists feeling traumatized and distressed during forensic mental evaluations. Notwithstanding one’s own responses to these encounters, emotions may also arise when attempting to manage the emotions of patients throughout the course of their care, which not only requires continuous regulation and effort, but over time can pose an increased risk for suboptimal care (4).

Emotions are also known to come from organizational aspects of the HCP’s work, such as system settings and the allocation of resources (8). The COVID-19 pandemic in particular highlighted how intense stress affected HCPs and led to burnout being overlooked in healthcare deliberation, resulting in suboptimal provision of care and decision-making (9-11). When emotions are left unchecked and unregulated, the increasing emotional load can influence the mental well-being of HCPs, which can compromise the quality of health outcomes for patients (12), and result in burnout, compassion fatigue, empathic fatigue, and physical and emotional burden (8,13). This may also lead to detachment from one’s own emotions, and consequent empathy degradation, which has downstream effects on patients and their families (14).

The emotional toll on HCPs is particularly pronounced in contexts involving workplace violence and abuse, and the literature documenting this relationship is extensive: a recent meta-analysis of 75 studies involving 139,533 healthcare workers across 32 countries found that the median frequency of workplace violence was 51%, with violence associated with higher burnout rates, increased anxiety, and higher turnover intentions (15-20). Structural and organizational factors (such as social support, quality of the working environment, and workload) have been shown to moderate the relationship between workplace violence and burnout (15-20). Primary studies corroborate these patterns: among nurses and emergency medical service workers in Germany, frequent verbal abuse was reported by 44.7% and 59.9% respectively, with both physical violence and verbal abuse significantly associated with high burnout risk in the dimensions of emotional exhaustion and depersonalization (15-20). Similar correlations between workplace violence, bullying, burnout, and depression have been documented in other nursing populations (15-20). These findings underscore a well-established relationship between difficult clinical encounters and healthcare worker emotional well-being; a relationship that warrants examination in the context of clinical ethics practice.

EMOTIONS AND CLINICAL ETHICS?

A common theme explored is empathy, which is the ability to understand the patient's point of view, show understanding, and make suggestions that reflect shared understanding (21). Empathy, and its impact on therapeutic relationships and quality of care, has been widely discussed in medicine, nursing, and other professions (22). Yet there is sparse mention in this literature of CEs as specific HCPs who experience these emotions, and even less for CELs. Even though CEs have direct relations with patients and their families, little is known about how they deal with emotions associated with these interactions, and whether there are untoward effects of the accumulation of these emotions over time.

The role of emotion is particularly relevant for CEs, who face some of the most difficult and emotionally laden challenges in hospitals, replete with stressed stakeholders, conflicting preferences, strained communication, insurmountable loss, and grief (23,24). CEs differ from other HCPs in that they have a multifaceted and far-reaching scope of practice; not only do their roles encompass healthcare decision-making, clinical consultation, and direct patient care, but they also extend into policy development, education, research, and organizational ethics (25). CEs consistently find themselves treading water in situations loaded with theoretical, interpersonal, and interdisciplinary ambiguity, conflict, and uncertainty. As a result, there is a disparity between the reality of practice and the expectations that those without formal bioethical training have with respect to the role of CEs — an expectation that commonly involves a desire for direction and guidance regarding what the “right” answer is. Indeed, although there may often be no “right” answer, the CE is, at the very least, highly skilled in identifying the right question. CEs therefore play pivotal roles in conceptualizing and assisting with ethical dilemmas in clinical contexts, communities, professional organizations, political spheres, and industry (26).

To fulfill their specialized role, CEs possess multidisciplinary and professional knowledge that is specific to hospital administration and policy, and skills for successful conflict resolution, such as mediation, communication, and recognition of moral problems from varying perspectives (25). CEs are often involved in multiple aspects of patient management, from informed consent to determining substitute decision-makers to supporting end-of-life decisions, such as Do-Not-Resuscitate Orders and MAiD. This requires full immersion in cases and consultations to assist both patients and their families in overcoming the emotions that accompany complex decisions; and it also requires providing support to manage emotional stress and burnout for the HCPs involved (23,24).

Despite being called upon to support emotional regulation for patients, families, and HCPs, an aspect of clinical ethics practice that remains neglected and under-examined in the academic literature is the degree of emotional expenditure required to provide quality-driven normative guidance on ethical issues (26). Though the role of emotions extends across a broad scope of practice and appears quite profound, there is little empirical evidence about how emotions are experienced and regulated for CEs, and what the impact of these emotions are as they accumulate over time. This lack of knowledge may stem from ignorance or suspicion toward both the practical and reflective role of emotion in a field that is predicated upon rational anthropology (27), or it may be a result of a lack of awareness of the cumulative and relational implications of emotions. Given the fact that many CEs often come from diverse academic and disciplinary backgrounds, they are also unlikely to have received the appropriate training specific to recognizing and dealing with their own emotions and those of others, which negatively affects their professional aptitude (24). The lack of data that explicitly focuses on the cumulative and relational management of emotional distress, compassion fatigue, and moral residue in the context of clinical ethics and clinical ethics training is of critical importance, not only given the increasing rates of clinician burnout among HCPs generally, but also because of the potential for emotions to significantly impair information processing, communication, and decision-making, skills which are essential for the work of CEs (24).

In the purview of practicing clinical ethics, ethics consultation, in the epistemological sense, is largely premised on emotion. Emotions are thought to constitute a “self-articulating hermeneutic competence” (28, p.303) in ethical deliberation, such that their articulation both dialogically and discursively reveals a person's moral experience as well as their situational perception of the particular ethical situation, supplying relevant parties with a practical orientation to understand oneself and others (28). Because emotions constitute such complex cognitive experiences, they may persist unbeknownst to us, and efforts to reduce this opacity have been given little attention, despite the role they play in effectively carrying out ethics consultations (28,29).

Some CEs claim that addressing emotions in the context of consultations displaces the application of ethical theories and concepts to cases, which are otherwise considered the “real” skills of the ethics consultant (30). These CEs tend to view ethical cases as idealized compilations of ethically complex facts that neglect to consider the dynamic circumstances, settings, and structures of meaning that presuppose the holistic interpretation of actual cases (30). In doing so, by positioning the acquisition and application of cognitive analytics skills and theory as the most championed capacities for performing ethics consultations, we risk relegating the communicative process and interpersonal emotional aspects associated with cases to the periphery (30).

Notwithstanding the view that cognitive analytic skills and theory be ranked higher than communication and emotions in the work of the ethicist, as part of an integrated role within a healthcare team, CEs inevitably take part in discussions and consultations which may offer opportunities to identify, address, and respond to different emotions. These emotions include the relational and existential suffering of patients, their families, and other HCPs, as well as addressing the moral distress of HCPs. Yet there remains a lack of both descriptive and empirical literature that identifies the cumulative emotional work that

is endured to provide this level of compassionate care (31). What has been noted, according to Redinger and Gibb (24), is the intense emotional burden implicit in the role of CEs; and by drawing from the psychotherapeutic clinical psychology literature, suggestions have been proposed for consultant training reform such as advocating for systematic reflection on the emotional aspects of challenging cases (24).

Furthermore, it has been argued that empathy and the provision of empathic care (32) play an indispensable role in ethics consultations and substitute decision-making (33). These might even constitute a primary competency and ethical command (32) for ethics consultants to facilitate communication, though also potentially negatively affecting moral reasoning by hindering neutral perspectives (3). Although the choice to not be empathetic is commonplace in healthcare, given the perceived costs of being so, empathetic care, as conceived by the field of healthcare bioethics, parallels the ethics of care in highlighting the importance of interdependent relations, needs, and emotions in offering moral insight and is constitutive of patient-centred care (32). What remains to be sufficiently outlined in the literature is the interpersonal and cumulative effects of CEs practicing empathic care over extended periods, which warrants further investigation.

That said, a recent qualitative study by Goff and colleagues (20), involving 34 semi-structured interviews with CEs across the United States, represents an important contribution to addressing this gap. Their findings reveal that particular features of clinical ethics work significantly affect the emotional state of CEs, that lack of role clarity exacerbates emotional burden, and that CEs employ a variety of professional and personal coping mechanisms when experiencing adverse emotions (15-20). This empirical work confirms what has long been theorized: that CEs are profoundly affected by their work at both individual and systemic levels. However, even with this recent contribution, empirical knowledge specifically regarding CELs remains virtually absent.

DISCUSSION

The work by Goff and colleagues (20), which documents empirically the emotional impact of clinical ethics work on practicing CEs, validates the concerns raised by the learners in our reflections and underscores the importance of this line of inquiry. Our paper contributes a complementary perspective by highlighting the experiences of learners; individuals who encounter these emotional dynamics while still developing the frameworks and support structures to process them. As previously mentioned, there is extensive literature on the role and nature of emotional responses for many frontline HCPs, such as nurses and physicians; relatively little exists on the emotional experiences of CEs and CELs. Our analysis of narrative accounts thus aims to draw attention to a critical knowledge gap by detailing the interplay between the practice of clinical ethics and emotions whilst advocating for empirical inquiry to better understand the cumulative emotional burden of this profession. As CELs, our reflections emphasized the emotional challenges inherent in ethics consultations. Learners in our paper cited emotional burden associated with clinical ethics consultations in practice that can affect CEs and learners alike. As a response, we outlined possible tools for emotion management such as debrief sessions to mitigate the impacts of consults, offering learners a space to decompress post-consult. Learners acknowledged in their accounts that emotions, whether subtle or apparent, are influenced by complex factors and can/do significantly affect parties involved in these consults. Education, training, and support surrounding the emotional burden associated with consultations, along with recognizing the privilege and emotional gravity of this work is vital.

LIMITATIONS

As early career CELs, we recognize that the opportunities we have been afforded may differ depending on the type of clinical ethics learning program in which one is engaged. All learners included in this paper are based in a community hospital system located in the Greater Toronto Area. Individuals are eligible for the program at any stage of their career. Learners thus come from various stages in their educational and professional careers, with varying degrees of experience with clinical ethics work, patient populations, and the health care system more broadly. We recognize that these differences likely shaped how each learner experienced and reflected on clinical ethics consultations. However, because the cohort size was small, a key priority for the collection of narrative accounts was to maintain anonymity. To maintain confidentiality, individual characteristics were not linked to specific accounts. Our interpretation instead focused on identifying patterns of emotional experiences that were shared across learners rather than attributing themes to particular individuals, and we explored emotional dimensions rather than providing an exhaustive synthesis of empirical evidence.

CONCLUSION

This paper raises the question of the cumulative impact of encountering emotionally charged clinical ethics cases over time, and how this could affect the overall well-being of CEs and CELs. As such, this work sheds a critical light on the need for more nuanced attention to the role that emotions play for CEs, learners, and clinical ethics practice. Although complex and subjective, and given our clinical experience, we argue that emotions should not be regarded as a less important aspect of the practice. As emotions can influence all parties involved in clinical ethics consultations and decision-making, it is not only imperative that further studies be done but that we raise the question of whether CEs and learners are sensitive to and aware of their emotions and clinical experiences. With this in mind, we advocate for researchers to conduct empirical studies focusing

on the presence, identification, and management of the emotions of both CEs and learners before, during, and after consultation. This may include longitudinal studies to better understand the cumulative effect of emotions. Additionally, the integration of simulation labs in bioethics curricula, perhaps modeled on real life case studies, could prove beneficial in equipping learners with the necessary tools to engage both meaningfully and constructively with the types of emotional experiences they are likely to encounter in practice, as well as furnish them with tools to internally manage the impact of those encounters. This is a fruitful area of future study with important practical and pedagogical implications for the clinical ethicist profession.

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Conflicts of Interest

None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Reconceptualizing Vulnerability: How Layers of Vulnerability Can Help Us Better Understand Medical Assistance in Dying

Alessandro Manduca-Barone^a, Julia Brassolotto^a, Duff Waring^b

Résumé

L'aide médicale à mourir (AMM) a été légalisée au Canada en 2016. Depuis lors, les critères d'admissibilité ont été élargis grâce à des défis juridiques et à des législations. Durant cette expansion, plusieurs cas ont été rapportés, mettant en lumière des personnes se voyant offrir ou ayant accès à l'AMM en raison d'un manque de soutien pouvant autrement atténuer leur souffrance. De ce fait, des conversations renouvelées ont eu lieu sur la nécessité de protéger les personnes vulnérables. Nous remettons en question la conception traditionnelle de la vulnérabilité basée sur des sous-populations, qui traite les individus comme appartenant à certains sous-groupes prédéfinis. À la place, nous soutenons le modèle relationnel et contextuel de la vulnérabilité, tel que proposé par la bioéthicienne féministe Florencia Luna. Cette conception considère la vulnérabilité comme composée de couches superposées avec des effets en cascade. Nous soutenons que cette approche est préférable tant sur le plan conceptuel que pratique et nous l'appliquons dans le contexte de l'AMM. Cette approche plus nuancée de la vulnérabilité offre des perspectives et des orientations aux gouvernements et aux décideurs politiques. Plus spécifiquement, nous formulons trois recommandations politiques et pratiques qui reconnaissent et tentent de traiter les différentes manières dont les patients peuvent se retrouver vulnérables : 1) un amendement au langage du gouvernement fédéral concernant la « protection des vulnérables » dans la législation sur l'AMM; 2) des évaluations de l'AMM améliorées, qui filtrent mieux les déterminants sociaux de la vulnérabilité et utilisent une approche multidisciplinaire pour y répondre; et 3) la création d'un organisme de surveillance composé de membres issus de divers groupes d'intervenants ayant une expertise ou une expérience particulière en lien avec certaines des sources de vulnérabilité les plus pertinentes.

Mots-clés

aide médicale à mourir, AMM, euthanasie, vulnérabilité, suicide assisté par un médecin, éthique, Canada

Abstract

Medical assistance in dying (MAiD) was legalized in Canada in 2016. Since then, eligibility criteria have expanded through court challenges and legislation. During this expansion, there have been multiple reported cases that revealed individuals being offered or accessing MAiD due to a lack of other supports that may have otherwise ameliorated their suffering. As such, there have been renewed conversations about protecting the vulnerable. Here, we challenge the traditional subpopulation conception of vulnerability that treats persons as belonging to certain predefined subgroups. Instead, we support the more relational and contextual model of vulnerability as proposed by feminist bioethicist Florencia Luna. This conception views vulnerability as consisting of overlapping layers with cascading effects. We argue that such an approach is preferable both conceptually and practically and we apply it within the context of MAiD. This more nuanced approach to vulnerability can provide insight and guidance to governments and policy makers. Specifically, we consider three potential policy and practice recommendations that acknowledge and attempt to address the multiple ways in which patients might be rendered vulnerable: 1) an amendment to the Federal Government's language about "protecting the vulnerable" in MAiD legislation; 2) enhanced MAiD assessments that better screen for social determinants of vulnerability and use a multidisciplinary approach to address them; and 3) establishing an oversight body consisting of members from multiple stakeholder groups with special expertise or experience relating to some of the most relevant sources of vulnerability.

Keywords

medical assistance in dying, MAiD, euthanasia, vulnerability, physician assisted suicide, ethics, Canada

Affiliations

^a Faculty of Health Sciences, University of Lethbridge, Lethbridge, Alberta, Canada

^b Department of Philosophy, York University, North York, Ontario, Canada

Correspondance / Correspondence: Alessandro Manduca-Barone, alessandro.manducaba@uleth.ca

INTRODUCTION

Medical assistance in dying (MAiD) has been legal in Canada since 2016. Since then, MAiD legislation and policy have evolved through a series of court challenges and amendments to the legislation. Initially, MAiD was only accessible to patients who had a grievous and irremediable medical condition for which natural death was reasonably foreseeable (1). After a court challenge (*Truchon v Canada*) and subsequent legislative changes, MAiD eligibility criteria expanded to include those whose deaths were not "reasonably foreseeable" (2). This expansion raised concerns about its implications for vulnerable populations. News media stories emerged that revealed individuals being offered or accessing MAiD due to a lack of other supports that may have otherwise ameliorated their suffering (3-4). Many of these cases have policymakers and ethicists re-assessing whether existing safeguards are sufficient to protect vulnerable Canadians.

Interestingly, there has been disagreement about who should be considered “vulnerable” — that is, susceptible to harm or exploitation. For instance, some scholars, patients, and disability rights advocates have argued that individuals with disabilities are particularly vulnerable under MAiD legislation (5-10), while other individuals with disabilities have argued that automatic assumptions of their vulnerability are themselves discriminatory (11-12). Part of the issue surrounding this tension may stem from a characterization of the concept of vulnerability that is limited and applied broadly to subpopulations. Feminist bioethicist Florencia Luna has recently challenged this traditional understanding of vulnerability and offered a more relational and contextual model that involves overlapping layers of vulnerability with cascading effects (13-14). This conception has practical implications for both public policy and societal attempts to address vulnerability. Elizabeth Victor and colleagues have taken Luna’s more nuanced view of vulnerability and applied it in three health and social care contexts (15). They show how it can provide a valuable lens to a) analyze cases of vulnerability within their broader contexts for a more nuanced understanding and b) guide practical actions in related healthcare and policymaking contexts.

In this paper, we build upon this work and apply Luna’s model specifically to emerging cases of MAiD in Canada. In what follows, we argue that Luna’s conception of vulnerability: 1) better explains some of the disagreements over MAiD (e.g., within the disability rights community); 2) accounts for the social determinants of vulnerability of MAiD patients, thereby providing opportunity for policy and practice changes that better address patient needs; and 3) can offer insight and guidance to governments so that they might better address vulnerability in society. When applied to MAiD, we contend that Luna’s approach to vulnerability will enable us to better identify patient unmet needs that may in fact be remediable and thus potentially avoid unnecessary MAiD deaths.

“PROTECTING THE VULNERABLE” IN MAiD POLICY AND DISCOURSE

In the preamble to Bill C-14, the Federal Government stated that, “permitting access to medical assistance in dying for competent adults whose deaths are reasonably foreseeable strikes the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other” (1). However, in 2019, the requirement that one’s death had to be reasonably foreseeable in order to qualify for MAiD was challenged in a Québec court (16). Nicole Gladu, who lived with post-polio syndrome, was one of two Québec residents legally challenging Bill C-14 as being discriminatory and unconstitutional since it denied access to disabled individuals whose natural deaths were not reasonably foreseeable. Gladu rejected the idea that this requirement protected the vulnerable, vehemently denied that she was a vulnerable person in need of protection under the law, and asserted that “vulnerability is a concept used ad nauseum by paternalistic people in good health for standing in the way of MAiD” (11).

The Superior Court of Québec sided with Gladu and declared the “reasonable foreseeability of natural death” eligibility criterion in Bill C-14 unconstitutional (16). In 2021, the Federal Government responded to the ruling with the introduction of Bill C-7, which legally permitted MAiD for individuals whose natural death is not reasonably foreseeable (now referred to as Track 2 cases) and allowed for a waiver of final consent in certain circumstances (ss. 1 (7)). The passage of Bill C-7 called into question the balance between autonomy and vulnerability that was allegedly struck with Bill C-14. Some individuals have argued that autonomy has received disproportionate prioritization (7), and some MAiD providers now object to Track 2 cases because they feel the expanded eligibility goes too far (17). Additionally, since Bill C-7, there has been a notable increase in MAiD use. In 2024, MAiD was provided to 16,499 individuals, with track 2 cases more than doubling (18), and is now tied with cerebrovascular diseases as the fifth leading cause of death in Canada (19).

The enactment of Bill C-7 intensified debates about whether MAiD eligibility is empowering or endangering for vulnerable groups. These debates have included discussion about whether advanced directives ought to be permitted for individuals who may lose cognitive capacity to consent to MAiD (20-21), whether the law should extend to mature minors (22-23), and whether those whose sole underlying condition is a mental illness could ethically qualify for MAiD (24). There has also been notable public news media about MAiD as a potential threat to the lives of marginalized and vulnerable individuals, including for instance, Indigenous peoples (25), those with disabilities (5-10), prison inmates (26-27), those living in poverty (10,28-30), geographically isolated patients in rural regions (31), or those with mental illnesses (30,32-33). Bill C-7 was also met with particularly strong opposition from disability rights advocates (34-37) who feared that it would lead to further discrimination against people with disabilities and promote a narrative that the lives of disabled people are not of equal worth (6,38). Professor Emeritus and activist Catherine Frazee has argued that the legislation leads to a devaluation of disabled lives and makes them more vulnerable to social and healthcare discrimination (7).

Related discussions have not only addressed the vulnerability of particular groups or subpopulations, but also touched upon the broader conditions in which people are made vulnerable. For instance, some journalists and activists have noted the potentially coercive influence of poverty, homelessness, racialization, and limited social support services that may constrain people’s choices about end-of-life care (7-8,30). Similarly, some scholars have raised concern that individuals may be unduly vulnerable to pressures to access MAiD due to caregiver burnout, financial considerations, or despair, and that there is no oversight to prevent such situations (39). These ethical issues were mentioned in 2019 by Prime Minister Justin Trudeau:

[The Prime Minister] promised to ensure the proper supports are in place for palliative care and people with disabilities, so that no one chooses to end their life because they can't get the help they need. "The essential element around society ensuring that everyone gets the supports, the treatment they need to live in dignity, and to make the choice of medical assistance in dying one that is made in a way that isn't because you're not getting the supports and cares that you actually need," he said (40).

Since that time, a number of cases have been made public that reveal these remarks to be more aspirational than operational. For instance, news reports have illustrated stories of people being offered or pursuing MAiD when they primarily needed assistance to live. This includes a veteran who required a wheelchair ramp (41), individuals who were facing economic and food insecurity due to illness or a lack of adequate housing (42-43), and patients who needed additional home care services (44-45). Importantly, encouraging patients to pursue MAiD may be a violation of the Canadian Criminal Code. The provision of information about MAiD is allowable under s. 241(5.1) and helps patients to make informed decisions about their end-of-life care. However, under s. 241(1), it is illegal to "counsel" someone to end their life, i.e., to provide information with the aim of inducing, persuading, or convincing a person to die (47).

There have also been several MAiD cases reported in which the person requesting MAiD did not yet want to die but found MAiD to be more accessible than other basic supports or assistance that might have alleviated their suffering (48). These cases include persons living in poverty unable to access sufficient income supports (10), those with chronic and/or debilitating diseases struggling to access healthcare (49-50), and those with disabilities being denied appropriate care while in hospital (51). There have also been cases in which psychiatric care or assessment is underused by patients whose MAiD requests may be influenced by mental disorders. This has included a man in his late 40s who the Coroner's Report indicated was suffering from post-COVID-19 vaccination syndrome (52), a 27-year-old woman with autism and other possible undiagnosed mental illnesses with no known eligible physical disability (46,48), and a woman suffering from post-concussion syndrome and related mental health issues, unable to access medical care during the COVID-19 pandemic (53). Notably, the British Columbia Civil Liberties Association, a group that initially led the charge for the 2015 decriminalization of physician-assisted death in Canada, has revised their prior position in light of such cases. The association recently warned about ethical abuses in the MAiD system, and called upon the Federal Government to act (54-55). These arguments showcase the rapidly growing concerns about providing MAiD for individuals who live in a state that provides insufficient social welfare to ensure the requisite conditions for a decent life (3,56-57). This view suggests that MAiD may not be a fully autonomous choice in the context of an inequitable society in which social, political, legal, medical, and economic structures make people vulnerable.

Despite these concerns, MAiD legislative expansion continues. During the passage of Bill C-7, the Federal Government initially stipulated a two-year end date on the prohibition of MAiD for those whose sole underlying condition is a mental disorder (s. 6). However, this has since been postponed until March 17, 2027. This delay was due to a lack of preparedness, as well as mounting ethical concerns identified by members of the mental health community. These included the added complexity of determining a mental disorder to be irremediable (58); difficulties in distinguishing MAiD requests from suicidality (59); questions of whether higher standards of capacity might be necessary for this population (60); determining the role of psychiatrists given their specialized training in understanding issues relevant to marginalized or vulnerable populations such as seniors, those suffering from depression, or people experiencing homelessness (58); and the need for improved access to mental health supports (61).

The underlying theme in these ethically dubious MAiD cases is the concept of vulnerability. These cases suggest that some MAiD recipients suffering from physical and mental illnesses also had intersecting suffering resulting from poverty and/or lack of adequate supports (56). Data from Health Canada also reveal that 47.1% of non-terminally ill Canadians who applied for MAiD reported "isolation or loneliness" as one of the causes of their suffering (54). Social, economic, or untreated medical conditions that cause suffering may render individuals unduly vulnerable and affect the voluntariness of their requests for MAiD. Despite receiving considerable attention through recent news coverage and public debate, the concept of vulnerability itself has remained vague and ambiguous. It thus warrants further philosophical exploration if it is to have practical import in ethical policy-making decisions surrounding MAiD.

VULNERABILITY: FROM LABELLED SUBPOPULATIONS TO OVERLAPPING LAYERS

Traditionally, in medicine, vulnerability has been viewed as a characteristic belonging to a group or subpopulation (e.g., children or pregnant women) that would lead to them needing special protections. This was notably seen in the iconic Belmont Report in 1979. One of the foundational texts examining the ethics of medical research, the report identified ethical principles that should inform the conduct and practice of research involving human subjects. It was also one of the first documents of its type to acknowledge vulnerability.

One special instance of injustice results from the involvement of vulnerable subjects in research. Certain groups, such as racial minorities, the economically disadvantaged, the very sick, and the institutionalized may be systematically sought as research subjects, owing to their ready availability in settings where research is conducted. Given their dependent status and their frequently compromised capacity for free consent, they should be protected against the danger of being involved in research

solely for administrative convenience, or because they are easy to manipulate as a result of their illness or socioeconomic condition (62). This wording treats vulnerability in the traditional sense, as a characteristic of certain subpopulations. Such a view considers certain marginalized groups to be inherently and necessarily vulnerable (15). While the Belmont Report represented a paradigmatic shift towards accounting for and addressing the potential vulnerability of research subjects, this traditional approach possesses conceptual and practical limitations.

First, this account of vulnerability assumes that everyone in a group is necessarily vulnerable simply by virtue of being a part of that subpopulation. While the report does not suggest a quantitative degree of vulnerability, its use of the subpopulation framing of vulnerability provides the same protections to different individuals within a specific vulnerable population without distinction. This framing contributes to the stereotyping of whole categories of individuals and labels them all as “vulnerable” with no acknowledgement of potential differences between persons within that group (63) — it neglects the fact that individuals within a group may experience vulnerabilities differently (13). This lack of nuance can lead to the wrongful exclusion or wrongful inclusion of persons within the “vulnerable” category, i.e., because some individuals belonging to a vulnerable subpopulation might not actually be vulnerable. Conversely, others not in a vulnerable subpopulation might still require special protections. While the subpopulation model does not necessarily preclude others outside a vulnerable category from receiving special protections, it does not provide for them either, instead promoting the same protections for all individuals within a particular vulnerable group. If other legislation or guidelines similarly use the subpopulation approach, then indeed some persons falling outside of those predefined “vulnerable” groups may not receive the protections they need.

The rigidity of the traditional approach is also practically problematic as it ignores contextual factors and many of the potential intersecting sources that could make a person more or less vulnerable. For example, this could include socioeconomic factors, education, housing and/or income security, social circumstances, geographic location, among others. As other scholars have similarly noted, labeling people, instead of identifying conditions that trigger vulnerability, risks concealing conditions that may need to be addressed (15). If one of the goals of governments in acknowledging vulnerability is to be able to provide protections that address vulnerability, then an account that overlooks potential underlying sources would be a glaring oversight.

Florencia Luna attempts to solve the problem with the traditional approach by offering a model of vulnerability based on layers and not labels (64). In her account:

- (1) No single standard or ideal exists and there are multiple factors or sources of vulnerability;
- (2) they are deeply related to the context; and
- (3) vulnerability is not an essential property of the research subjects or groups per se (13).

An approach that better identifies the conditions that trigger vulnerability will still have much overlap with the traditional subpopulation approach. Many of the same individuals will likely be identified as vulnerable by both accounts. However, there is a key conceptual departure from the traditional subpopulation approach. Some factors that lead to vulnerability may not clearly or neatly allow persons to fit into a traditional subpopulation group and will thus be better captured by this more nuanced approach. For instance, an individual might feel added pressure to consider MAiD as a result of their caregiver’s burnout. This factor may not in itself make a person part of a traditional vulnerability group, but does appear to be a layer of vulnerability with possibly profound effects. The practical upshot of this more nuanced model is that by identifying the particular conditions that trigger vulnerability, we are better able to meet the needs of vulnerable persons. Luna’s approach does not deem vulnerability to be inherent to the individual, but instead sees vulnerability as relational and contextual, as it acknowledges the environment in which an individual is situated. There are no fixed, predetermined, rigid categories or subpopulations. As she explains “we do not face a solid and unique vulnerability that exhausts the category” (13, p.89). Instead, there can be multiple layers of vulnerability (e.g., age, disability, socioeconomic conditions, housing, social circumstances, inability to consent), which can overlap and operate concurrently (14). Furthermore, such layers of vulnerability are not necessarily immutable, but may be acquired and/or removed. For instance:

The fact of being a woman does not in itself imply that one is vulnerable. A woman living in a country that does not recognize or is intolerant of reproductive rights acquires a layer of vulnerability (that a woman living in other countries that respect such rights does not necessarily have). In turn, an educated and resourceful woman in that same country can over-come some of the consequences of the intolerance of reproductive rights. Yet, a poor woman living in a country that is intolerant of reproductive rights acquires another layer of vulnerability. (She may not have access, for example, to emergency contraceptives and hence will be more susceptible to unwanted pregnancies) (13).

Additionally, Luna notes the potential for cascading effects of vulnerability. This refers to layers of vulnerability that may exacerbate already existing ones, or potentially generate new vulnerabilities (14). For instance, a lack of access to healthcare services can exacerbate an existing ailment or enable the proliferation of a new chronic disease that otherwise could have been detected and mitigated earlier. This worsening of health status may then threaten a person’s ability to work and undermine their source of income. Such a progression of events exemplifies the cascading potential of certain vulnerabilities.

Thus, this layered approach to vulnerability adds further context and nuance previously missing from the subpopulation categorizations. Further, this approach avoids viewing individuals only at a population level and instead focuses on the relevant factors and circumstances that may make a person vulnerable. The layered approach can thus “explain compounding vulnerability: how vulnerabilities interplay and render some persons more vulnerable than others similarly situated” (15, p.2). This better accounts for the differences and variations experienced by individuals who are members of the same group. Resisting the rigidity of the traditional approach, this layered model also has practical ethical consequences. Specifically, by acknowledging the diversity of potential underlying and intersecting sources that could make a person vulnerable, society is then in a better position to consider protections and safeguards that target and address those specific elements.

Luna’s relational and situational model contrasts with other scholars who have treated vulnerability as an intrinsic property of humanity. This essentialist or ontological view claims that human beings are fundamentally and essentially vulnerable (65,66), and that vulnerability is “universal and constant, inherent in the human condition” (67, p.1). However, there are conceptual and pragmatic issues with this essentialist approach to vulnerability. An overview of various accounts of vulnerability, and the challenges they may face, is beyond the scope of this paper. Suffice it to note that some argue that an ontological or essentialist view of vulnerability “loses its normative force if everyone is vulnerable” (14, p.103) and has limited ethical relevance in health policy. By that argument, if everyone is vulnerable, then no one is particularly vulnerable in a way that warrants special safeguards. Similar to the traditional approach, this model of vulnerability does not distinguish between individuals for the purposes of providing protection and addressing their vulnerability.

For the reasons outlined above, Luna’s layered approach appears best suited for navigating the nuances of vulnerability, particularly in a health policy context. While multiple bioethics scholars have embraced the layered model, some have challenged Luna’s account as lacking practical application and guidance (68). Practical application is vital if our theoretical understanding of vulnerability is to have pragmatic normative import in health and medicine. Luna has more recently attempted to satisfy this challenge and offers a method to better operationalize the layered account of vulnerability, which we discuss further below. Before that, however, we will show how Luna’s layers of vulnerability can better account for disagreements about MAiD within marginalized groups.

HOW LAYERS CAN BETTER ACCOUNT FOR DISAGREEMENTS ABOUT MAiD WITHIN MARGINALIZED GROUPS

Some members of the disability rights community have been very concerned with expanded MAiD legislation. As noted above, Catherine Frazee expressed concern that Bill C-7 will lead to a devaluation of disabled lives, making them even more vulnerable to social and healthcare discrimination (7). Canadian legal scholar Trudo Lemmens has expressed concern that Bill C-7 prematurely enables the death of individuals and amounts to a “deadly form of discrimination” against those with disabilities or chronic illnesses (6). However, not all individuals within the disability rights community agree. As previously mentioned, Nicole Gladu, who suffered from post-polio syndrome, was one of the plaintiffs in the Québec case that led to Bill C-7. She argued vehemently that her disability did not make her vulnerable and that any alleged “safeguards” preventing her from accessing MAiD would be paternalistic and discriminatory (11,12). Gladu claimed that she never lacked anything needed for a full life. She went to university, became a journalist, worked in Paris and New York, including as a press attaché at the United Nations before retiring in Québec on the 14th floor of a condominium building, which as she explains, “offers not only all the necessities, but also a breathtaking view of the river that mirrors the beauty of the sunsets” (11). She described MAiD as an autonomous choice for herself, even envisioning the experience, “I want to be able to do [MAiD] effectively and without suffering, surrounded by my incredible friends, a flute of pink champagne in one hand and a canapé of foie gras in the other, as I watch the sun set over the river one last time from my living room window” (12).

Using the traditional subpopulation approach to vulnerability, it would be challenging to account for this intra-group division of opinion about disability. Disabled individuals are necessarily considered vulnerable if they meet the criteria to be a part of that group. However, with a relational and contextual approach to vulnerability, such as Luna’s layered model, this disagreement is better accounted for. It is the overlapping nature and interplay between layers of vulnerabilities that make some people more vulnerable than others. This model also acknowledges the role of socioeconomic status, social circumstances, education, and other factors that may create stark differences in vulnerability between individuals within the same group. This approach is congruent with intersectional feminist theory (69) that calls attention to the ways in which our identities are comprised of multiple, intersecting, social locations, such as race, class, gender, age, ability, or sexuality. In other words, none of us belong to a solitary subpopulation. This acknowledgement of diversity within marginalized groups reflects what some activists in the disability rights community have expressed. For instance, activist sb smith [sic] has argued:

Bill C-7 is currently being pushed into law in Canada, primarily due to the efforts of financially-privileged and/or newly disabled people, Dignity with Dying advocates, able-bodied lobbyists and government heads, and more. The progressives pushing for this bill to pass into law tout the arguments of the few financially-privileged and/or newly disabled people who agree that having the so-called choice to utilize no-holds-barred MAiD is, overall, a good thing for everyone. What these [MAiD advocates] don't realize is that their class privilege clouds their perspectives on the way this legislation is and will continue to be used for harm with its money-saving potential to offload "burdens" (that is, disabled lives) from government-funded institutions like healthcare, housing, and so on... It is increasingly necessary for financially-privileged (and especially white, financially-privileged) disabled people to confront and be forthcoming about their wealth and social status. This is especially important given that the community is overwhelmingly comprised of us crips who (barely) survive on government benefits or are altogether ineligible for said benefits, have multiple side hustles, are under-paid, are completely unable to work, live in subsidized and/or group housing, are under-housed, are routinely rejected from medical insurance coverage, often go without medical treatments and prescriptions, are often denied medical care, and so on. Rich disabled people do not know what it means to be viewed as financial "burdens" on the institution of the Canadian nation state (70).

Such sentiments further exemplify how Luna's layered model succeeds where the subpopulation approach to vulnerability failed. Equipped with this more nuanced conception of vulnerability, we can better understand the types of tensions raised by activist sb smith. This thinking can similarly be applied to other marginalized populations such as Indigenous peoples, prisoners, or individuals with mental illnesses, since members of these groups also experience diverse intersections of social locations and varying degrees of vulnerability.

OPERATIONALIZING A LAYERED APPROACH TO VULNERABILITY AND APPLYING IT TO MAiD

Luna proposes 2 steps towards operationalizing the layered model of vulnerability.

- 1) Identify different layers or sources of vulnerability (e.g., those related to physical limitations, consent, dependency, exploitation, socioeconomic situations)
- 2) Evaluate them both in terms of the extent of the harm (those with cascading effects may be more harmful) and the probability of its occurrence (13-14).

Luna states that layers of vulnerability are dispositional and "latent" until triggered by a stimulus condition. She uses the property of solubility to illustrate the concept. A cube of sugar has the dispositional property of solubility; it will dissolve in liquid. However, this property must be triggered and is only realized when the cube of sugar gets introduced into a liquid, i.e., the stimulus condition (14-15). Being able to identify and evaluate layers of vulnerability requires understanding their dispositional and latent nature, and anticipating triggers and stimulus conditions. This is crucial since it is the presence of the stimulus conditions that affects the likelihood that the disposition will manifest. "Researchers, healthcare professionals, ethics committees, and policy-makers should identify the stimulus conditions that can trigger the actualization of a layer of vulnerability" (15, p.3). Layers of vulnerability and their triggers or stimulus conditions may be different for individuals depending on their contexts and circumstances.

Consider the case of healthcare workers during the COVID-19 pandemic: this is not a subpopulation of individuals that would traditionally be considered a vulnerable group (14). Using the layered account though, we can see that as a result of their frontline work, they have a layer of vulnerability (step 1). They are vulnerable to falling ill themselves when tending to sick patients (e.g., during a pandemic). Inadequate testing, overstretched staff, and a lack of personal protective equipment would then be examples of stimulus conditions that could trigger the vulnerability. Assessing the presence of such triggers would then enable us to evaluate the vulnerability (step 2). Once layers or their stimulus conditions (i.e., triggers), are identified and evaluated, their inclusion in normative considerations would generate obligations. Specifically, mechanisms to avoid, minimize, or eradicate those vulnerabilities should be considered (14). Continuing our COVID-19 example, this might entail ensuring the procurement of sufficient protective equipment, making sick and personal time available, and/or training and hiring the appropriate amount of healthcare personnel.

Recently Elizabeth Victor and colleagues (15) applied this model of vulnerability to three health and social situations, generating meaningful insights. We see potential in applying this model to an analysis of MAiD. In many of the MAiD cases that are receiving ethical scrutiny, Luna's model can assist in identifying layers of vulnerability among the patients requesting or receiving MAiD. This allows us to better identify and address unmet needs, potentially avoiding unnecessary deaths. Consider the following hypothetical case.

Richard is a 57-year-old Toronto man. He has a part-time job working as a mortgage broker and lives with his wife Ava in a recently updated bungalow in a nice suburban neighbourhood. He was diagnosed with multiple sclerosis (MS) in his 30s, but his symptoms have been effectively managed for years, and his quality of life is quite good. He is able-bodied, enjoys going for regular walks with his wife, and plays weekly pickleball with friends. He would not be considered vulnerable according to the subpopulation model of vulnerability since he does not fit into any predefined vulnerable group. However, Richard begins

to experience a variety of odd and intermittent symptoms that include vision problems, feelings of weakness and fatigue, some issues with coordination, vertigo, and concentration problems. On some days Richard finds it difficult even to get out of bed. His family doctor retired several years ago and, having difficulty finding a new one, Richard has been relying on walk-in clinics when he becomes ill. He decides to visit the walk-in clinic near his home, and the doctor Richard sees initially attributes the new symptoms to aging. The doctor says that the symptoms are likely related to deteriorating eyesight and does not think there is anything more to worry about. Richard is then referred to an ophthalmologist; the earliest available appointment is two months away.

In the interim, Richard's symptoms progress beyond his vision problems. His fatigue and weakness become chronic, he is no longer able to drive or go to work; he has to take a leave from his office job, which adds financial strain on his family because, like more than half of Canadians, they live paycheck to paycheck. Richard's wife Ava has to take over all household chores as well as act as caregiver for Richard when his symptoms are particularly severe. Richard decides to visit the hospital, where he is then referred to a specialist who provides a requisition for an MRI, though due to healthcare backlog, it will take an additional month for Richard to receive the MRI. Five weeks later, Richard returns to the hospital for the MRI. A week after that, the results reveal that Richard has multiple new lesions in his brain and spinal cord. Further, some of his prior lesions appear to have grown. These are key indicators that Richard had been experiencing a MS relapse over the past year. Given that he has tried several popular MS treatments and still relapsed, Richard becomes concerned that he will continue to decline and never return to his "normal" life. Further exacerbating his concern is the fact that he and Ava are using up their savings, and that they will soon run out of money and struggle to purchase food or pay their rent. Fearing that he may become a physical and financial burden on his wife, Richard decides to inquire about MAiD.

Using Luna's layered model, we can better analyze this case with respect to the multiple overlapping layers of vulnerability and their potential triggers.

The first layer of vulnerability is Richard's difficulty in obtaining timely and appropriate medical assistance for his symptoms. Given the shortage of physicians and the overburdened medical system in Richard's city, he does not have a family physician. Instead, Richard relies upon different walk-in-clinic doctors, which undermines continuity of care since these physicians do not know his detailed history with MS. Furthermore, Richard's symptoms and experiences were originally dismissed, overlooked, or misunderstood by the clinic physician. MS symptoms are not always well understood or effectively treated within the healthcare system. Instead of receiving care and diagnostics, Richard's symptoms were seen as "just part of aging." There may be some level of healthcare ageism and ableism further triggering this vulnerability. Ableism is known to affect everyday living for persons with disabilities by leading to their experiences being dismissed and potentially preventing them from accessing needed assistance.

A second layer of vulnerability includes Richard's precarious economic situation, leading to imminent housing and food insecurity. For Richard, MAiD appears to be largely a socio-economic consideration, and not something pursued out of a readiness to die. Yet, being unable to work leaves him without access to an income, and with his savings running out, he fears that he and Ava will be unable to survive. Further triggering this economic vulnerability is the inflationary economic situation in Richard's city, leading to an increased cost of living. For example, the maximum monthly Ontario Disability Support Program (ODSP) payment for a single person is \$1,408 (71) and the average monthly cost for an individual to live a healthy life in Toronto is over \$5,000 (72). Without generational wealth to rely upon, Richard does not want his health to bankrupt his family or become a burden on the state. He begins to think that Ava would be better off without him.

A third level of vulnerability involves Richard's reliance upon his spouse for care. Richard already relies upon his wife economically, domestically, and emotionally. He sees her burnt out and struggling to care for him. They have tried to obtain home care for Richard but find it challenging to schedule and it does not meet all their needs. He feels that he is a burden to her and that her health may also quickly deteriorate, a cascading effect that would leave him increasingly vulnerable. As a result, he has become embarrassed, distant, and socially isolated. Social isolation can be a significant contributor to the suffering that MAiD patients experience. As previously noted, almost half of non-terminally ill Canadians who applied for MAiD reported "isolation or loneliness" as one of the causes of their suffering (54).

Table 1. A layered analysis of Richard's vulnerability

Layers of vulnerability (disposition)	Triggers	Cascading effects	Degree of harm	Probability
Having MS	• Relapse of symptoms • Lack of continuity of care in healthcare system • Physician shortage • Ableism and ageism • Poor understanding of MS symptoms by many general practitioners	• Delays in accessing appropriate care • Worsening or poor management of symptoms • Decreased trust in the healthcare system • Inability to work	Severe	High
Precarious economic status	• Inability to work • Inflation • High cost of living • Limited ODSP support	• Inability to afford food or pay rent • Heightened stress and anxiety • Greater reliance upon spouse	Severe	High
Reliance upon spouse for care	• Lack of available home care • Fear of being a burden	• Caregiver burnout • Tensions in the relationship • Social isolation • Depression	Severe	High

When detailed in this manner, it is clear that although Richard was not initially a member of a subpopulation that is traditionally seen as vulnerable and in need of protection under the law, he has several layers of vulnerability that inform his decision to inquire about MAiD. It is thus important for MAiD assessors to 1) acknowledge the external and relational conditions that trigger Richard's economic, healthcare, and emotional vulnerabilities, and 2) consider the ways in which these vulnerabilities might affect the voluntariness of his request for MAiD. A nuanced analysis of vulnerability suggests that while Richard's illness may indeed be serious, incurable, and in decline, his degree of suffering may be triggered or mitigated by situational factors. It is also unhelpful to simply label Richard as "vulnerable" because of his MS without paying attention to relevant contextual details. By identifying the layers of Richard's vulnerability, what triggers them, their probability, and the level of potential harm, healthcare professionals and others can more accurately and meaningfully assess and address his needs. It would be worthwhile to explore remedies and trigger-mitigation strategies for Richard, where possible, to see if they might alter his request for MAiD. While this case is hypothetical, it reflects real issues experienced by Canadians exploring MAiD.

ACKNOWLEDGING SOCIAL DETERMINANTS OF VULNERABILITY AND OPPORTUNITIES FOR PRACTICE AND POLICY CHANGES

As demonstrated above, the traditional subpopulation approach to vulnerability can result in the mistaken inclusion or exclusion of persons within the category "vulnerable." By looking at groups as a whole, instead of individual patients and their unique circumstances, the subpopulation approach has, at times, led the health and public policy sectors to neglect factors that could make a person vulnerable. By contrast, Luna's model of vulnerability enables better patient-centred care and analyses as it allows for deeper consideration of the social determinants of vulnerability and health (e.g., socio-economic factors, poverty, housing insecurity, food insecurity, substance addictions, past traumas, coercive or abusive family environment, isolation, psychiatric disorders, and more). This nuance is paramount for MAiD, as recent cases demonstrate that people have applied for the service after having been made vulnerable due to unmet needs. Trudo Lemmens has raised concern over such a situation, arguing that in many cases MAiD is quicker and more easily accessible than certain medical or financial supports, including long-term care, specialized pain clinics, and the Canada Pension Plan Disability Benefits (6). As one palliative care physician noted, MAiD can be arranged in a more timely and organized process than can access to mental health services (30). Others similarly fear that MAiD could be chosen as "the antidote to a system that fails in compassion or equitable palliative care access" (73, para.17). It is ethically worrisome that a patient can more readily access MAiD than support through the social safety net. For instance, someone could access MAiD after the 90-day waiting period but have to wait over 120 days to access specialized long-term care, specialized pain clinics, or disability benefits (6). Such a scenario makes those patients unduly vulnerable to MAiD since it would become their only option for relief from otherwise preventable suffering.

This presents an opportunity to reconsider practice and policy in light of concerns about vulnerability. Policy and practice require sufficient safeguards that acknowledge and address the multiple ways in which patients might be vulnerable. Here we consider three such proposals: 1) An amendment to the Federal Government's language about "protecting the vulnerable" in MAiD legislation; 2) Enhanced MAiD assessments that better screen for social determinants of vulnerability and use a multidisciplinary approach to address them; and 3) establishing an oversight body with members from multiple stakeholder groups with special expertise or experience relating to some of the most relevant sources of vulnerability. We detail each proposal in turn.

First, we recommend an amendment or update to the Federal Government's language about "protecting the vulnerable" in MAiD legislation. Given the ongoing expansion of MAiD eligibility, it is time to formally revisit the balance between promoting autonomy and protecting the vulnerable, and the government's role in doing both. When those in power speak about protecting

“the vulnerable,” to whom are they referring and how is such vulnerability determined? Providing such information and identifying how current safeguards protect “the vulnerable” on Government of Canada websites and in official communications about MAiD could help to improve transparency and accountability.

Second, we acknowledge that some guidance to healthcare professionals has stipulated that they should seek to understand a patient’s circumstances, perspective, and reason for considering MAiD (74), and identify if patients are seeking MAiD due to unmet needs (75). However, policies have failed to offer more concrete guidance on what healthcare providers are to do in such circumstances (76), and how such unmet needs would be addressed within clinical contexts. Nor have there been any changes in practice that would ameliorate the concern that such unmet needs are making patients unduly vulnerable to MAiD. If MAiD is being requested due to such reasons, it is unclear how such requests could be seen as meeting the condition of grievous and *irremediable* suffering.

The assessment process for MAiD ought to include a more robust analysis of the many triggers to vulnerability and unmet needs that led to the patient’s request. Policymakers and regulatory bodies should provide more guidance for assessors regarding social determinants. This would include how to explicitly look for potential layers of vulnerability that might otherwise be overlooked, and to subsequently refer patients to multi-disciplinary specialists as needed (e.g., social workers that can assist with housing, disability benefits, food programs, and more).

In particular, the assessment process must better screen for underlying mental health conditions that may be leading to the MAiD request. Current legislation requires the MAiD recipient to have grievous and irremediable suffering caused by illness, disease, or disability that is not solely caused by mental illness. However, as many MAiD cases reveal, patients often have a combination of physical and psychological conditions. Despite the presence of physical disease or illness, the additional accompaniment of psychological conditions may signal a potential vulnerability and/or unmet need that prompted the MAiD request. It is vital to ascertain whether pre-existing mental health conditions, or unmet needs triggering mental health conditions, may be significantly contributing to the suffering leading to the request for MAiD. This may be of particular import in situations where the patient has a psychiatric history of suicidal ideation. In line with the Ontario Coroner’s MAiD Death Review Committee, we therefore recommend MAiD practitioners consider using “psychiatric assessment when a person is requesting MAiD with a complex medical condition and concurrent mental illness... [and] referrals to other mental health professionals (including psychologists, social workers, mental health nurses and psychotherapists)” (52, p.18). This practice would better identify whether other psychological, social, or economic factors are creating undue vulnerability for the patient and influencing their desire for MAiD. Attention to the overlapping layers of vulnerability would then enable the provision of mitigating factors for their triggers. Such practice changes would better ensure that such patients could access support for their psychological, social, or socioeconomic issues that may be causing their underlying suffering.

Applying Luna’s approach in this way would involve greater effort to hear from those requesting MAiD. However, it has the potential to better capture what patients are telling us, and specifically their first-person narrative accounts of what it is like to live with certain mental disorders or in certain socio-economic situations. The gathering of such information will result in a more robust evidence base on why people are requesting MAiD, the factors precipitating their request, and services they may require to address any unmet needs. We also support further empirical research on how best to implement Luna’s approach and gather this type of evidence.

Third, some scholars, such as Lyon, Lemmens, and Kim (48), have argued for better multidisciplinary oversight through the establishment of a more transparent and safeguarded compliance regime founded on a variety of stakeholder perspectives.

The federal government might establish an independent and transparent public body more representative of most clinical specialties and other stakeholder groups reflected in MAiD requests (e.g., disability, poverty, Indigenous, and palliative, cancer, and psychiatric care specialists), as well as a public meta-regulator to provide oversight and standardization for MAiD (48, p.19).

This advisory and oversight body could review particularly ethically concerning MAiD cases, as well as the ongoing MAiD landscape with a particular eye to vulnerability, in order to advise future legislation and policy. This is in line with recommendation 16 from the Final Report of the Expert Panel on MAiD and Mental Illness. They suggest that “the federal government should play an active role in supporting the development of a model of prospective oversight for all or some Track 2 cases that could be adapted by provinces and territories” (77, p.16). Such oversight should also include enhanced data collection and transparency around aspects of MAiD practice. These data would include the rationales for MAiD requests, attempts made to address unmet needs when identified, physician rationales when refusing patient requests for MAiD or other services, and the number of MAiD deaths per provider. Our deeper understanding of vulnerability supports each of these proposals. The bolstering of the assessment process including the use of various health professionals, and the establishment of a diverse oversight body of stakeholders would create a MAiD regime better equipped to speak to and/or address the variety of existing and evolving triggers for vulnerability.

CONCLUSION

Equipped with a more nuanced approach to vulnerability, we are better able to acknowledge and identify various sources and triggers of vulnerability in our society. However, this identification generates normative obligations. We acknowledge that this will likely involve grappling with macro and micro resource-allocation issues that are beyond the scope of this paper. Similarly addressing the sources of vulnerability and people's unmet needs will likely surpass the responsibilities of healthcare workers and medical institutions. Government bodies must therefore consider their priorities when citizens are being offered a dignified death but not the means to live. As Frazee notes, "it's cold comfort, I think, to be offered the choice to die when you are not offered the choice to live a dignified life" (7, para.13). While it is understandable that in desperate circumstances people may opt for MAiD, several current cases suggest that this can occur as a result of structural coercion that makes persons vulnerable, thereby undermining meaningful autonomy (56). Importantly, we do not have robust or sufficiently reliable public data regarding the prevalence of requests that are influenced by unmet needs. By highlighting related cases that have received public attention, we do not intend to overstate the frequency of such requests (nor suggest that all requests will be approved and/or lead to provisions). Rather, we aim to draw attention to the fact that these cases exist, that the ethical stakes are high, and that with the ongoing expansion of MAiD eligibility, it is critical that we learn from feminist bioethicists and disability rights scholars who have, for years, identified the ways in which the law can fail to protect vulnerable individuals.

MAiD was initially created in response to the *Carter v. Canada* case in order to facilitate access for patients with reasonably foreseeable deaths or who were experiencing grievous and irremediable suffering. The expansion of MAiD, and our nuanced understanding of vulnerability, call us to reflect upon the myriad sources of human suffering in our current social, political, and economic context. Parallel to efforts to improve the MAiD system in Canada, we argue that the Government of Canada has a responsibility to also improve the social safety net. The suffering that results from poverty and inadequate housing is not irremediable and political inaction is not ethically neutral (78). It is incumbent upon the state that wishes to offer death as an option in healthcare, that they first ensure the necessary steps are taken to mitigate needless suffering. This would involve addressing the social, economic, or medical unmet needs that make citizens vulnerable, through policy initiatives such as publicly funded mental healthcare, increases to disability support benefits, and bolder affordable housing initiatives.

We acknowledge that our analysis is not without limitations. While the overlapping layered model of vulnerabilities has more explanatory power than the traditional approach, and has the potential to assist in establishing more ethical MAiD policy, we acknowledge that the exact standards for determining undue vulnerability are unclear (i.e., what would be the threshold for someone to be declared unduly vulnerable to MAiD?). As Diana Myers (79, p.204) has noted, the precise range of life-sustaining resources sufficient for persons to make autonomous choices in a health care system represents a threshold that is notoriously difficult to determine. Although in many cases excessive vulnerability will be obvious, there will also be borderline cases. This is especially true since we all have some degree of contextual factors that make us more or less vulnerable in certain circumstances. How many triggers or factors, and to what degree, would be required for someone to be deemed *unduly* vulnerable? For full disclosure, the authors of this article are not fully aligned on the answer. The lead author doubts that sufficient safeguards could exist that would prevent MAiD from posing harm to vulnerable persons, and that some level of prohibition may thus be required. The other two authors contend that outright prohibition would dismiss the agency of ill and/or disabled individuals to determine their own reasonable threshold for suffering, and so risks preventing ethical MAiD provisions. Collectively, we believe that Luna's richer and more nuanced understanding of vulnerability has both inherent and instrumental value, and the potential to positively affect MAiD policy, practice, and both public and bioethics discourses.

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

Influencers and Unproven Health Claims: Curbing Misleading Promotion in the United States and Canada

Alessandro R Marcon^a, Blake Murdoch^a, Timothy Caulfield^a

Résumé

L'essor des réseaux sociaux a permis aux influenceurs de façonner le discours sur la santé publique et de promouvoir des produits et des interventions de santé non éprouvés. Nous examinons ici les défis pratiques et réglementaires ainsi que les opportunités liés au marketing de la santé mené par les influenceurs aux États-Unis et au Canada. Malgré les interdictions légales existantes concernant la publicité trompeuse directement liée aux influenceurs, telles que définies par les directives réglementaires officielles, leur application reste insuffisante. Les cadres réglementaires actuels autorisent des allégations de santé vagues. De plus, la surveillance diffère entre les influenceurs professionnels de santé agréés et les influenceurs profanes. Les plateformes de réseaux sociaux sont complices ou indifférentes à l'amplification de la désinformation, car celle-ci stimule l'engagement et sert leurs motivations lucratives. Pour lutter contre le marketing de santé trompeur des influenceurs, des stratégies à la fois « dures » et « douces » sont envisagées, notamment la coordination des politiques internationales et des solutions algorithmiques qui réduisent la visibilité des contenus trompeurs. Un défi majeur reste de savoir comment susciter la participation volontaire de puissantes multinationales disposant d'une influence politique et de lobbying. Nous soulignons l'utilité potentielle de mécanismes d'application automatisés soigneusement conçus, notamment des systèmes de surveillance des contenus basés sur l'IA et des procédures automatisées de notification et de retrait, tout en plaidant pour une approche équilibrée qui respecte la liberté d'expression. Il est nécessaire de mettre en place une réglementation et des mécanismes d'application actualisés, évolutifs et équitables afin de protéger les consommateurs, de favoriser une communication en matière de santé fondée sur des données probantes et de rétablir la responsabilité dans le marketing de la santé numérique.

Mots-clés

désinformation, influenceurs, réseaux sociaux, réglementation, cellules souches, médecine régénérative, intelligence artificielle

Abstract

The rise of social media has enabled influencers to shape public health discourse and promote unproven health products and interventions. Here we examine practical and regulatory challenges and opportunities relating to influencer-driven health marketing in the United States and Canada. Despite existing legal prohibitions on misleading advertising linked directly to influencers by official regulatory guidance, enforcement remains inadequate. Current regulatory frameworks permit vague health claims. Moreover, oversight differs between licensed health professional influencers and layperson influencers. Social media platforms are complicit in and/or indifferent to the amplification of misinformation, as it drives engagement and furthers their profit motives. To address misleading influencer health marketing, both “hard” and “soft” strategies are considered, including international policy coordination and algorithmic solutions that reduce the visibility of misleading content. One key challenge remains how to engender the willing participation of powerful multinational corporations with political and lobbying influence. We raise the potential usefulness of carefully crafted automated enforcement mechanisms, including AI-driven content monitoring systems and automated notice-and-takedown procedures, while simultaneously advocating for a balanced approach that respects freedom of expression. Updated, scalable, and equitable regulations and enforcement mechanisms are needed to protect consumers, foster evidence-based health communication, and restore accountability in digital health marketing.

Keywords

misinformation, influencers, social media, regulation, stem cells, regenerative medicine, artificial intelligence

Affiliations

^a Health Law Institute, Faculty of Law, University of Alberta, Edmonton, Alberta, Canada

Correspondance / Correspondence: Alessandro R Marcon, marcon@ualberta.ca

INTRODUCTION

The popularity of social media has created an ecosystem where individuals with no medical or scientific training can wield substantial influence in the public's health decision-making (1). This is not a new problem, but one that is intensifying and expanding across diverse contexts and jurisdictions. In turn, this online health influencer phenomenon is creating challenges for regulatory bodies mandated with enforcing advertising standards and protecting consumers from exploitation.

Reaching higher levels of health influencer status requires generating high numbers of followers and/or high levels of audience engagement (2). It is achieved through consistent and viral content creation that often combines with commercial partnerships that blur the lines between personal recommendations and sponsored endorsements (2,3). This content is an integral element in the rapidly expanding health wellness industry (4), which commonly contains inaccurate and misleading marketing discourse of products, services and interventions. Health influencers' online discursive activities exhibit both mis-and-disinformation

characteristics¹, presenting both a lack of scientific knowledge as well as explicitly anti-scientific perspectives, the range of which works towards advancing commercial, socio-political, and popularity-seeking ends (5,6). For audiences, this discourse hinders consumers' ability to distinguish between personal product reviews, for example, and paid endorsements, and can lead to significant public health harms including the uptake of ineffective and harmful actions and the refusal of evidence-based therapies (7). Further, health misinformation can erode trust in public institutions, cause interpersonal strife among individuals and society at large, generate social and political polarization, and require public entities to devote substantial resources to mitigate its negative impact (7,8). These impacts can have disproportionately negative outcomes for marginalized or racialized communities (9). The spreading of health misinformation from healthcare professionals raises serious ethical concerns around practitioner obligations to uphold beneficence and nonmaleficence principles (10). More broadly, the presence of health misinformation can impinge on patient and public autonomy to make informed choices, including in cases where informed consent is paramount (10).

American and Canadian regulatory frameworks created to address false health claims in advertising have struggled to keep pace with the widespread, decentralized, and fast-moving nature of social media. In addition to blurring distinctions between personal expression and commercial promotion, influencer marketing can exploit regulatory loopholes with ambiguous or vague language that evades triggering mechanisms for increased oversight. This manuscript details the unique issues associated with influencer marketing of health products and illustrates how current regulations in Canada and the United States are currently ineffective. In response, it suggests novel and/or underused methods for curbing the spread of harmful influencer content, including stricter oversight of paid promotion and algorithmic or artificial intelligence (AI)-driven data-scraping enforcement mechanisms. Public institutions can play an active and effective role in curbing public exploitation and strengthening autonomy. Given the severity of the problem, the proposed options are presented critically, highlighting the need for ongoing assessment and evaluation in lived contexts.

THE SCOPE OF THE ISSUE: INFLUENCERS AND UNPROVEN HEALTH CLAIMS

Social media influencers have become highly effective marketers, with marketing surveys indicating they often command high levels of trust and engagement (11). Forging “para-social” or “trans-social” relationships with audiences, health influencers can gain high levels of loyal and trusting followers who become attracted to and swayed by personalized online content, including that which advances particular health actions or products (12-14). Content that may be sponsored by or include products from industry — including products of one's own brand — may be either opaquely presented or uncritically absorbed by audiences. Indeed, studies indicate that consumers perceive influencer recommendations as more authentic than conventional advertisements, making them particularly effective in promoting health and wellness products (15). This has led to a surge in influencer-driven marketing content, which commonly involve misleading or scientifically unsupported health claims, in cases unverified by the content creators themselves (16). In North America, for example, health influencers such as the Food Babe (aka Vani Hari), Paul Saladino, Ty Bollinger, Erin Elizabeth, Joseph Mercola, Dr. Oz, or the Liver King (aka Brian Johnson) among hundreds if not thousands of others, have amassed millions of followers through the creation of viral health content that is misleading and promotional of actions or products that either lack sound scientific evidence demonstrating effectiveness and/or can lead to negative health outcomes (5-10,17-21). Research shows that the spreading of incorrect or harmful health misinformation is not solely a North American issue but a global concern (22-24). Beyond influencers such as those listed above, promoting unscientific and harmful diets (25), advocating for supplements or unproven therapies like ivermectin (26), dissuading the use of sunscreen (27), established academic scientists, such as Andrew Huberman, can also take on social media influencer roles buoyed by numerous partnerships with health and wellness companies (28).

To further illustrate concerns with influencer health marketing, consider a potential growth area: stem cell-related products and therapies. Despite a significant lack of clinical validation, stem cell-related products and therapies are frequently marketed as highly beneficial for a wide range of conditions, including arthritis, chronic pain, skin care, immunity, and anti-aging (29-30). Though understudied, it seems likely that influencers are already playing a role in promoting stem cell-related products and interventions (31), leveraging the persuasive force of personal anecdotes (32) rather than scientific data to create compelling narratives about their claimed effectiveness (33). For example, numerous wellness influencers (including high profile athletes and celebrities) have promoted unapproved stem cell treatments and products, claiming they can regenerate tissue, reverse aging, and treat chronic conditions despite a lack of credible scientific evidence (34-38). This raises concerns about the risk of harm to the public (39).

Importantly, influencer marketing operates in a manner to which advertising laws are not always clearly applied. While direct-to-consumer advertising containing specific health claims or involving pharmaceuticals is highly regulated, influencers discussing health products may frame content as personal testimonials rather than promotional material. This loophole, whether based in vagueness or simply lack of enforcement, has allowed misinformation to thrive, particularly in cases where influencers use language designed to avoid concrete health claims.

¹ The distinction between misinformation and disinformation is well defined in research and policy environments despite it being complex to study empirically. Misinformation refers to varying degrees of inaccurate information where disinformation refers to the intentional propagation of misinformation for various, and often opaque, objectives.

REGULATORY ALLOWANCES IN THE UNITED STATES AND CANADA

Health-related advertising of products and services is variably regulated in both the United States and Canada, and differentially between medical interventions, drugs and products categorized as supplements, natural health products, skin care products and others. Both jurisdictions prohibit false and misleading advertising, including by influencers (40-43). Actual enforcement of these various forms of regulation online remains insufficient and an ongoing challenge in dealing with misleading marketing. Increasing regulatory capacity and influence, however, requires political will and corresponding policies that strive towards this end through the strengthening — and not weakening — of institutional authority and mechanisms (44).

In the context of supplements, for example, classified as Natural Health Products (NHPs) in Canada and dietary supplements in the United States, regulatory frameworks in both jurisdictions have been criticized for failing to offer adequate consumer protections (45-47). American and Canadian regulations restrict product marketing from making strong and direct causal claims of efficacy around a supplement's ability to diagnose, prevent, cure, or mitigate serious ailments and disease (48-50). However, both American and Canadian regulations permit a product's mechanism of action to be described with non-direct verbs (e.g., "promote," "maintain," "support," "help") or with health benefit expressed in a hedged manner, typically using modal verbs (e.g., "may," "could," "might"). This vague and suggestive language of potential health benefit deemed permissible by regulators is described in US dietary supplement regulation as "structure/function" claims, and in Canadian NHP regulation as "general health" claims (48-50).

Further to vague product health claims, the threshold of substantiating evidence demonstrating efficacy in both Canadian and American regulations does not require scientific rigour, despite restricting industry from presenting the evidence misleadingly (47-48). The permissibility of vagueness in regulatory frameworks, coupled with limited regulatory capacity to address the deluge of supplements now on the market, has led to a situation where little is done to protect consumers from fraudulent, misleading and ultimately exploitative supplement marketing (45-47).

VARIABLE OVERSIGHT

Importantly, the extent of regulatory oversight can vary for different types of influencers. Licensed healthcare professionals who promote treatments are subject to professional accountability mechanisms, such as through self-regulating professional colleges of physicians and surgeons, nurses or even alternative medicine bodies such as those applied to naturopaths, etc. Members of these bodies can face disciplinary action if they endorse unproven therapies or engage in advertising that overpromises or misleads. In contrast, unregulated wellness influencers have no such constraints and can make misleading health claims with minimal consequences save those enforced by traditional truth-in-advertising bodies, such as in Canada, by the Competition Bureau, or in the United States by the Federal Trade Commission. One unusual outcome of this regulatory disparity is an environment in which non-experts can have greater influence than trained professionals in shaping public health perceptions, while perhaps being more likely to make claims that attract online attention.

THE WILLING PARTICIPATION OF MULTINATIONAL SOCIAL MEDIA PLATFORMS

The success of measures and mechanisms to address misleading influencer discourse is heavily contingent on the willing participation of and enablement by social media platforms, or at minimum, the ability to compel them to follow new regulation or policies. Indeed, for as large a role as influencers play in the creation and spread of misinformation, major players in the media industry, including social media platforms, have equal if not greater power to influence information exposure (51). All efforts focused on increasing content accuracy at the system level are challenging, however, given social media platforms' focus on generating financial gains in environments where competition for users' attention is fierce (52-54). Further, it is well-known that misleading, sensational, and polarizing content is not an unfortunate consequence of increased social media use but a key driver of its popularity (55-57). International bodies, such as the United Nations, recognize the need for both states and industry to play a role in countering disinformation (58). While regulation in both Canada and the United States enables platform moderation of harmful content — notably hate speech (59,60) — there are complex legal and social challenges that accompany such moderation activities, and which can intersect with freedom of personal expression in both jurisdictions (61,62). Further, in addition to the challenges of when (in which cases), how (which tools and to what extent), and with which processes (i.e., oversight and transparency), there are financial and implementation issues as moderation traditionally requires extensive and costly human resources for whom work assignments can create a significant emotional and mental burden (63). The use of automated or AI tools, detailed below, could prove instrumental in tackling this workload.

While multiple tools will be required to stop the spread of misleading health information, particularly important will be the mechanisms for compelling the cooperation and participation of platforms through the varied use of harder and softer approaches. Harder approaches may include litigation and bans while softer approaches strive for collaboration through relationship-building and shared policy enactment. Concerned with detrimental social and financial effects of social media, Australia has taken harder approaches with social media companies, banning social media use for those under 16 years of age, and creating legislation that requires sharing of ad marketing revenue generated through news sharing on platforms (64,65). The United States has considered banning TikTok over data transparency concerns (66). Similar harder approaches applied to the context of misleading influencer discourse may have beneficial impact, yet this remains speculative.

Meta, for example, has already taken steps to circumvent Australia's ad-revenue sharing legislation (67), and earlier in 2025, significantly weakened its content moderation mechanisms and reduced fact-checking (68). TikTok shows little indication of increasing data transparency despite initiatives purporting to require otherwise (69,70). Ongoing evaluations of harder approaches are therefore required to determine probability of success and effect size. Political will would also be necessary to advance and enact harder approaches.

It may be more effective for governments and public institutions to continue lobbying for increased moderation and oversight, and to work with social media platforms, where possible, to maintain and expand effective mechanisms. Broad measures might include, for example, creating ethics officers or oversight committees with enforcement capabilities, increasing transparency of paid-promotions or industry influence on influencer content, tightening online advertising related to search engines (71), or aligning regulatory measures across jurisdictions with likeminded concerns (72,73). More specific mechanisms could include, for example, shifting efforts from content removal to algorithmic tweaks that reduce harmful polarization (74) or demote the virality of egregious and dangerous content, especially where specific malicious claims and actors have been well-established (75,76). Approaches for moderating hate could be beneficial in developing these tactics, including those using large language models (LLMs) (77,78). Additional approaches might include user-directed options to activate scientific accuracy filters or algorithms with either paid or non-paid account options. Such filters could increase user satisfaction among those seeking greater accuracy, replacing the thorny issues of content removal with other concerns about tiered access. Given that at least some social media users in North America show a desire for accuracy either through algorithmic oversight or content moderation (79), such an option could gain increased popularity among a large user demographic. Concern may still persist, however, that exposure to misleading information will remain high across the total body of social media users.

Ultimately, regulatory and policy efforts may have to get creative with social media platforms, blending harder and softer approaches to improve information accuracy in ways that do not cause overt social strife, materially impede profit generation, or result in widespread public backlash. It is well known, for example, that Meta has changed — both intensifying and weakening — its moderation approach over the years as a direct result of public and political pressure (80,81). Conversely, it could be argued that increasing accuracy and trustworthiness might, over time, benefit a platform's credibility and generate increased user activity. For example, reports on the Canadian population's media use show a significant drop in use of X/(Twitter), which has effectively removed all content moderation save for cases of explicit legal infringement, and the emergence of newer sites such as Bluesky that offer increased content curation and moderation (82,83). Public institutions must play active roles in building public awareness of social dynamics social media use and in empowering the public to play active roles in shaping the kinds of media they create and use. Increased public desire for accurate information can only help the advancement of platform level changes that pursue that objective.

ALGORITHMIC OR ARTIFICIAL-INTELLIGENCE-BASED ENFORCEMENT SYSTEMS

On the “harder” end of potential responses to misleading influencer health claims would be the use of automated enforcement mechanisms. Enhancing the regulation of health-related claims made by influencers could involve implementing a stringent threshold for identifying and penalizing misinformation in advertising, across social media platforms. Given the expanding capabilities of generative AI to produce and disseminate large volumes of misleading health-related content, regulatory frameworks could incorporate algorithmic systems designed to monitor, detect, and assess the veracity of claims made in digital advertisements. This might leverage similar AI technologies alongside data scrapers. Upon surpassing a given defined threshold for potentially misleading content, these systems could automatically require advertisers, including influencers, to substantiate their claims through timely submission of evidence consistent with truth-in-advertising standards. Failure to comply could result in mandatory content removal and/or the imposition of legal sanctions. Such systems could also require platform operators to take down content subject to the influencer providing evidence to overcome the presumption that a flagged post is misleading, though this would be a far stricter standard than one that first provided the advertiser an opportunity to respond with evidence or modify the marketing claim.

In cases where advertisers are made to act and contact information is inaccessible through social media platforms, two alternative mechanisms could be considered. One approach would require platforms to disclose to regulators any relevant contact information in their possession. Alternatively, a “Notice and Notice” framework, adapted from Canadian copyright enforcement practices, could be employed (84). Under this model, the platform would be notified of an advertising infraction and obligated to transmit a formal notice to the implicated advertiser, who would then become subject to corresponding obligations or penalties.

Importantly, however, regulatory interventions need not automatically include penalties. An algorithmic detection tool could initially issue a notice requiring the removal or provision of satisfactory explanation of suspect content within a specified timeframe. Should the content remain online beyond this period, further consequences such as fines could apply. An appeal mechanism would be integral to this process, affording advertisers the opportunity to present supporting evidence within a defined time window, allowing the regulatory body to determine whether the content merits reinstatement. Such determinations could be automated or made by humans, depending on enforcement capacity and AI capabilities.

A stricter model would require content suspected of violating established standards to be promptly removed, placing the burden on advertisers to ensure the accuracy and appropriateness of their claims from the outset. This preventative model could deter the publication of exaggerated or misleading claims and promote greater diligence among content creators. Given the sheer volume of online content, this kind of approach that involves a presumed infraction may be necessary to ensure the efficiency and scalability of enforcement systems, which might otherwise be overwhelmed if each removal required individual review. This model's effectiveness would depend on the development and periodic revision of clear, publicly accessible influencer advertising guidance.

Adopting a highly automated enforcement system — which is increasingly technologically feasible — could reduce the current administrative burden of regulatory agencies. Furthermore, it would act as a deterrent to the dissemination of misleading health information and could increase the efficiency and consistency of enforcement.

OTHER CONSIDERATIONS

Nevertheless, the deployment of such automated systems introduces several critical challenges. Algorithmic tools must be carefully designed to ensure they possess sufficient sophistication to distinguish between scientifically valid statements and those that lack evidentiary support or are demonstrably false. An accessible appeals process would be essential to mitigate the risk of erroneous takedowns and to safeguard legitimate scientific discourse. While human review remains a possible supplement, it would demand substantial human resources, including the use of data and computer scientists in conjunction with methodologically trained, scientifically informed, and socially-attuned multilingual analysts tasked with building massive data sets and manually coding an arguably unfeasible amount of ever-evolving content. Most plausible scenarios would indicate the need to blend algorithmic tools with human oversight and analysis.

Moreover, any legal consequences for non-compliance must be proportionate and carefully calibrated. Sanctions should be sufficiently robust to serve as a deterrent, while also meeting standards of legal proportionality and public legitimacy. Penalties could be scaled based on factors such as the reach of the advertisement and the potential harm caused by the misinformation. In addition to mandatory retraction, regulators could require remedies such as for influencers to publicly correct and educate the public to counteract misinformation previously shared. The legal basis and feasibility of requiring individuals to create certain kinds of corrective discourse might be highly complex and perhaps unrealistic to implement. It would require careful logistic assessment, and perhaps only be reserved for particular circumstances and contexts, for example, in cases with vulnerable populations or high-risk health (mis)information in a specific context.

While stricter enforcement of influencer-driven health marketing could better protect the public, policy interventions must strike an appropriate balance between consumer protection and freedom of expression. Updated advertising regulations must be carefully applied to ensure that they do not unjustly infringe upon influencers' speech, and their right to discuss personal health experiences.

Another consideration is the potential for new regulation, or over-enforcement, to stifle legitimate discussion about emerging medical treatments. While misleading health claims are clearly prohibited, some social media users — especially those with legitimate and certified scientific training and expertise² — may gain popularity online and thus play valuable roles in raising awareness about new medical research and the health sciences more generally (85-87). Ongoing inquiry is required to determine whether the information presented by popular online accounts remains scientifically accurate. Policymakers must ensure that enforcement systems, particularly if automated as described above, distinguish between deceptive marketing practices and good-faith discussions of scientific developments. Importantly, there is a relationship between the types of defensible evidence-based claims that can be made about a product or intervention and the state of its clinical translation, such as whether clinical trials are underway or completed. Though complex, this interconnection could be built into sophisticated algorithmic systems tasked with regulatory enforcement.

Finally, enforcement systems must be equitable and non-discriminatory, ensuring that regulations are applied consistently where the regulatory burden is equivalent. As noted, there can be different net levels of regulatory oversight across groups, such as regulated health professionals versus layperson influencers. Much like tax auditing, it is possible that enforcement actions could disproportionately target smaller influencers while allowing celebrities and major brands to make misleading claims with impunity. For example, high-profile athletes and Hollywood figures have promoted stem cell treatments, detox products, and other questionable interventions with little regulatory repercussions (88). A fair enforcement system should apply the same standards to all influencers that are subject to the same net regulatory burden.

² There are numerous examples of scientifically trained health-related scientists, many of whom concurrently hold academic/research positions, who have successfully taken to social media to spread health information, reaching high levels of influencer status. Examples include: Dr. Jessica Knurick (1.4 M followers on Instagram); Dr. Jen Gunter (430K followers on Instagram); Dr. Peter Horez (400K followers on X); Dr. Ana Blakney (250K followers on TikTok); Eric Topol (680K followers on X); Dr. Adrian Chavez (140k followers on Instagram); Dr. Michelle Wong (664K followers on Instagram); Debunk the Funk (98K followers on Instagram); Dr. Ian Copeland (27K followers on X).

CONCLUSIONS

As governments in Canada, the United States, and globally grapple with the growing influence of health mis- and disinformation, improving oversight of influencer health advertising and enforcement of false and misleading claims is a challenging but imperative task. Though facing increasing privatization pressures, the primarily publicly-funded and delivered healthcare system in Canada can lean on its regulatory capacities to create modifications that help ensure greater consumer and patient protections. By doing so, regulators can make advances towards a more accountable and truthful social media and advertising landscape, helping consumers make more informed decisions about these products and interventions. Given that many jurisdictions face similar challenges, cooperation could promote a more global standard of enforcement for misleading influencer health claims. Notably however, the rise of anti-science forces in the United States, led by key political figures like Secretary of Health and Human Services Robert F. Kennedy Jr., means that American leaders may loosen, or even forego, rather than tighten regulation of false claims online. Other nations with evidence-based approaches may need to take increasing leadership roles in improving the regulation of misleading health information online.

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

Revisiting the Confucian Objections to Beauchamp and Childress' Principle of Respect for Autonomy

Charlene Tan^a, Ruth Neo^b

Résumé

Une critique confucéenne persistante du principe de respect de l'autonomie de Beauchamp et Childress soutient que ce principe exalte l'autonomie individuelle et ignore la prise de décision médicale fondée sur la famille. Cet article défend le principe en remettant en question ses fondements individualistes et en soutenant qu'il est compatible avec la prise de décision médicale familiale grâce à sa spécification.

Mots-clés

autonomie, confucianisme, prise de décision médicale fondée sur la famille, spécification

Abstract

A persistent Confucian critique of Beauchamp and Childress' principle of respect for autonomy is that the principle exalts individual autonomy and ignores family-based medical decision-making. This article defends the principle by questioning its individualistic underpinnings and arguing that it is compatible with family-based medical decision-making through specification.

Keywords

autonomy, Confucianism, family-based medical decision-making, specification

Affiliations

^a College of Arts, Humanities and Languages, Life University, Sihanoukville, Cambodia

^b UNSW Medicine & Health, University of New South Wales, Sydney, Australia

Correspondance / Correspondence: Charlene Tan, chptan@u.nus.edu

INTRODUCTION

Despite its global reception, Tom L. Beauchamp and James F. Childress' principle of respect for autonomy has been the subject of questions, debates and criticisms, especially from scholars outside the Anglophone world. A representative critique is this comment: "Critics argue that the principle of autonomy, in particular, the idea of *individual* informed consent proposed by Beauchamp and Childress, has a strong Western bias and hence cannot be applied to non-Western countries such as China, Japan, and most African nation-states in which *family-* or *community-*informed consent is prevalent" (1).

In this article, we address two long-standing objections raised by scholars specialising in Confucian ethics, namely that Beauchamp and Childress' principle of respect for autonomy 1) exalts individual autonomy and 2) ignores family-based medical decision-making. The authors of this commentary are two Chinese Singaporeans who are familiar with Confucian beliefs, values and lifestyles. Our objective is to defend Beauchamp and Childress' principle of respect for autonomy against the above-mentioned objections. Such a defence is significant as it invites researchers in bioethics to rethink the alleged Western-orientation of Beauchamp and Childress' principles and their suitability in diverse healthcare settings. It is also important to acknowledge Confucian viewpoints concerning biomedical ethics since they constitute a foundation of moral worldviews and practices in East Asia.

THE PRINCIPLE OF RESPECT FOR AUTONOMY

Beauchamp and Childress identify the negative and positive sides of respect for autonomy, which take the form of a negative and a positive obligation (2). As a negative obligation, the principle holds that autonomous actions are free of controls from external sources such as coercion from another person or by internal states such as the patient's mental illness. As a positive obligation, the principle calls for respectful attitudes and actions towards the patient so as to promote the latter's autonomous decision making. Examples of positive obligations include disclosing information and available options to the patient, checking for understanding and ensuring that the patient's decision-making is voluntary. Beauchamp and Childress also clarify that the principle of respect for autonomy is not absolute and instead has only *prima facie* standing; this principle can be overridden by competing moral considerations in specific circumstances. The determination of whether and how the principle of respect for autonomy can be overridden depends on what Beauchamp and Childress call 'specification.' Accordingly, specification spells out the particular contexts, including exceptions, for the functioning of the principle of respect for autonomy — we will return to this in a later section when we discuss our responses to the Confucian objections.

ON INDIVIDUALISM

The first Confucian objection is that the moral paradigm that underlies Beauchamp and Childress' framework for biomedical ethics "is that of individuals acting alone autonomously, namely the paradigm of liberal democratic moral and political understandings" (3). In other words, the principle of respect for autonomy is criticised for championing individual autonomy,

where a person makes decisions and acts independently. Relatedly, researchers have raised the concern that the principle of respect for autonomy is influenced by Anglo-American values and worldviews, and may not be culturally appropriate for non-Western countries such as China (4-6).

In response, the first point to note is that Beauchamp and Childress have, on more than one occasion, clarified that their principle of respect for autonomy does not privilege individualism (8). They claim that the principle of respect for autonomy is only *prima facie* binding, in the sense that the principle can be overridden by other prevailing moral considerations, such as protecting patients from unnecessary anxiety and agony. They give the example of a physician who received a patient's myelogram results that suggested a serious pathology. The physician was informed that the test results were inconclusive and that the test needed to be repeated. Despite knowing that the patient had the right to know the test results, the physician chose not to disclose the potentially negative information to the patient. Beauchamp and Childress explain why the principle of respect for autonomy should be overridden in this case:

Her [the physician's] sole motivation in withholding the information is to spare the patient the emotional distress of processing negative information, which seems premature and unnecessary. However, the physician intends to be completely truthful with the patient about the results of the second test and intends to disclose the information well before the patient would need to decide about surgery (2, p.221-2).

Notwithstanding this clarification, critics could counter that Beauchamp and Childress are still operating within an individualistic worldview. In the above example, the patient is the sole decision-maker and is free to act as they wish regarding their illness and treatment. The Confucian objection is directed to Beauchamp and Childress' description of individuals acting alone without the involvement of other people, especially one's family. Put otherwise, proponents of Confucian bioethics question the perceived assumptions of independence and self-reliance in Beauchamp and Childress' principle of respect for autonomy.

However, this critique is a misunderstanding of Beauchamp and Childress' principle of respect for autonomy. Instead of restricting medical decision-making to individual patients and viewing them as atomistic and isolated, Beauchamp and Childress acknowledge the right of individuals to delegate decision-making to other people. They write that individuals may freely choose to rely on "an institution, tradition, or community that they view as a legitimate source of direction" (2, p.105), and add that "Even if the patient delegates that right to someone else, the choice to delegate can itself be autonomous" (2, p.109).

Contrary to the claim by advocates of Confucian bioethics, Beauchamp and Childress' principle of respect for autonomy does not celebrate or presume individualism. As explained earlier, Beauchamp and Childress have stated explicitly that they do not endorse individualism; they have also clarified that the principle can be overridden by prevailing ethical concerns, and they recognise the right of individuals to delegate decision-making to other people. To be clear, Beauchamp and Childress did not directly link their principle of respect for autonomy to the Confucian values of human interdependence and the central role of the family. In this regard, they could have elaborated further on how the exercise of autonomy is embedded in and reflects human relationships and inter-connectedness.

COMPATIBILITY WITH FAMILY-BASED MEDICAL DECISION-MAKING THROUGH SPECIFICATION

Turning to the second objection, that medical decision-making in societies shaped by Confucian values is seldom undertaken by the patient alone (3). Rather, in East Asia, family members are often actively consulted in physician-patient relationships, medical decision-making and consent to medical treatment (7). Beauchamp and Childress' principle of respect for autonomy, it is argued, does not sufficiently acknowledge the importance and function of the family in medical ethics. Our contention, however, is that Beauchamp and Childress' principle of respect for autonomy is in fact compatible with family-based medical decision-making through specification.

According to Beauchamp and Childress, specification seeks to concretise abstract norms and engender rules by elaborating on the actions that need to be carried out or avoided. Different cultural values and standards may lead to differing specifications of the same moral norm. Beauchamp and Childress relate specification to the Confucian emphasis on filial piety by noting that

some scholars in Hong Kong stressed that Confucian ethics, in contrast to more liberal, individualistic frameworks in Western societies, takes for granted obligations and virtues of filial piety, recognizes obligations of children to care for their parents, and argues that governments should promote the fulfilment of those filial obligations. This kind of moral diversity in identifying moral agents and their responsibilities is certainly within the bounds of principles derived from the common morality and in no way contradicts them. Making the principles more determinate in identifying *who* should be the primary moral agents and *what* they should do in caring for elders in a society requires specification or balancing or both (9, p.172).

Returning to the Confucian objection, it can be countered that Beauchamp and Childress' principle *is* compatible with family-based medical decision-making through specification. The process of specification for elderly patients living in Hong Kong and other East Asian societies involves making the principle of respect for autonomy more determinate by "identifying who should be the primary moral agents and what they should do in caring for elders in a society".

On the first question of who should be the primary moral agents, specification entails that the primary moral agents may refer to not only the elderly patient but also one's adult children. The Confucian values of filial piety and family harmony mean that the medical decision-making is a shared one between the patient and family members (10). This family-based medical decision-making approach applies even when the patient is not an elderly person but someone younger. For instance, an adult patient in Confucian-influenced societies is likely to involve one's parents and siblings when making major medical decisions. The Confucian idea of family-based medical decision-making means that no family member, including the parent, should disregard or overrule the wishes of the patient. Doing so contradicts the Confucian value of harmony (*he*) and normative behaviour (*li*). Rather, a consultative approach is advocated where the family arrives at a medical decision that reflects empathy (*shu*) and humaneness (*ren*).

As to the second question of what the moral agents should do in caring for elders, specification enables a plurality of practices that are shaped by varying sociocultural ethos. Consistent with the community-orientation of Confucian ethics, family members of an ailing elderly patient are likely to prefer family consent or surrogate decision-making for the patient's medical treatment. Beauchamp and Childress' principle of respect for autonomy is therefore congruent with an elderly patient's desire to delegate the medical decision-making to one's children.

What about the controversial practice of not disclosing the sickness to the patient and excluding the patient from the informed consent process? On this issue, Beauchamp and Childress' principle of respect for autonomy does not demand that the physician always reveals the diagnosis to the patient, even when the patient asks for it. As noted earlier, this principle is only *prima facie* binding and can be overridden by other ethical considerations. Beauchamp and Childress state that "virtues and principles work together in practical situations — for instance, in the disclosure of bad news to patients with special attention to delaying or staging this disclosure in the context of both caring for and respecting the autonomy of those patients" (2, p.11).

Turning to the issue of replacing individual's informed consent with family informed consent, the essential question is whether the individual has delegated to their family the decision-making process, including giving or withholding consent to medical treatment. If delegation is involved, then this practice is compatible with Beauchamp and Childress' principle of respect for autonomy and specification. The principle does not insist that patients make all the medical decisions on their own, and instead makes provision for the family to participate in medical decision-making. Delegation means that the patient has expressly indicated a wish to be excluded from the medical decision-making and to leave the decision-making to one or more family members who function as the moral agents. Illustrating delegation, a researcher reports from an empirical study in Singapore that "a family-centred model to medical decision-making... did not appear to be at the expense of the patient's autonomy if the patient was formally asked to indicate the preferred mode of decision-making, made the choice of a family-centred process, and retained opportunities to freely raise questions" (12, p.10).

In general, the exclusion of the patient's informed consent without the knowledge or permission of the patient should be avoided because of the potential harm to the patient (13-14). If a patient is unable to give informed consent and the decision is determined by the family, the decisions made by the family may not always be in the best interests of the patient. As acknowledged by a researcher of Confucian ethics, "Chinese health care practitioners should be aware of how to protect their patients from being manipulated or coerced by the collectivist pressure (mostly from their families) and promote their autonomy without despising their traditional family values" (11, p.49).

Overall, Beauchamp and Childress' principle of respect for autonomy is in concert with the Confucian idea of family-based medical decision-making through specification. That external constraints may undermine the patient's autonomy and well-being justifies the necessity of the principle of respect for autonomy. Of course, the patient's informed consent is not possible if the patient is unable to do so due to illnesses such as dementia. Guided by the medical, legal and ethical considerations, physicians must facilitate transparent conversations between patients and their families and make decisions that prioritise the patient's health, wellbeing and dignity.

CONCLUSION

Focussing on a prominent Confucian critique of Beauchamp and Childress' principle of respect for autonomy, this article has responded to the criticism that their principle privileges individual autonomy and overlooks family-based medical decision-making. We have argued that this principle does not lean towards individualism and is aligned with family-based medical decision-making through specification.

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RÉPONSE À - ARTICLE / RESPONSE TO - ARTICLE

Discrimination and Socially Embedded Suffering: Extending Grant's Critique of Track 2 MAiD to Mental Illness

Nicholas Dunn^a

Texte discuté/Text discussed: Grant I. [Why Track 2 MAiD is Discriminatory](#). *Can J Bioeth/Rev Can Bioeth*. 2025;8(4):45-55.

Résumé

Dans son article intitulé « Why Track 2 MAiD is Discriminatory », Isabel Grant propose une critique convaincante du régime évolutif de l'AMAD du Canada, fondée sur la justice en matière de handicap. Elle soutient que la voie 2 de l'AMM, qui concerne les personnes n'étant pas en fin de vie, repose sur un modèle médical du handicap qui occulte le capacitisme structurel et, par conséquent, est discriminatoire à l'égard des personnes handicapées. Dans ce commentaire, je montre que l'analyse de Grant devient encore plus urgente lorsqu'elle est étendue aux débats actuels sur l'élargissement de l'éligibilité à l'AMM pour les individus souffrant de troubles mentaux en tant que seule condition médicale sous-jacente.

Mots-clés

AMM, aide médicale à mourir, troubles mentaux, discrimination

Abstract

In her paper entitled "Why Track 2 MAiD is Discriminatory," Isabel Grant offers a compelling disability justice-based critique of Canada's evolving MAiD regime. She argues that Track 2 MAiD, which concerns persons who are not approaching the end of life, is premised on a medical model of disability that obscures structural ableism and therefore discriminates against persons with disabilities. In this commentary, I show that Grant's analysis becomes even more urgent when extended to current debates about the expansion of MAiD eligibility for individuals with mental illness as the sole underlying medical condition.

Keywords

MAiD, medical assistance in dying, mental illness, discrimination

Affiliations

^a Philosophy Department, University of Lethbridge, Lethbridge, Alberta, Canada

Correspondance / Correspondence: Nicholas Dunn, nicholas.dunn@uleth.ca

INTRODUCTION

In a recent paper in this journal, "Why Track 2 MAiD is Discriminatory" (1), Isabel Grant offers a compelling disability justice-based critique of Canada's evolving MAiD regime. Grant argues that Track 2 MAiD, which concerns persons who are not approaching the end of life, is premised on a medical model of disability that obscures structural ableism and therefore discriminates against persons with disabilities.

In this commentary, I show that Grant's analysis becomes even more urgent when extended to current debates about the expansion of MAiD eligibility for individuals with mental illness as the sole underlying medical condition (MI-SUMC). My aim is not to dispute Grant's conclusions but rather to build on them to show that they apply with equal force to the case of psychiatric MAiD, where the conceptual and ethical stakes are arguably even greater.

I begin by briefly reviewing Grant's argument that Track 2 MAiD is discriminatory (section 1), and elaborate on the social model of disability, which is implicit in Grant's discussion (section 2). I then discuss two further theoretical frameworks that Grant does not engage with, but which, when brought into dialogue with her argument, reveal why the discrimination she identifies becomes even more acute in the case of mental illness. These are: the *Externalist Model of Mental Illness* from the philosophy of psychiatry (section 3), and theories of *Structural Injustice and Substantive Equality* from political philosophy (section 4). These frameworks highlight the limitations of internalized and individualistic ways of conceiving of psychiatric suffering, and instead suggest a shift toward social, relational, and structural approaches to analyzing how mental illness is both experienced and constituted. I conclude by observing how these perspectives, in turn, challenge standard discrimination-style arguments regarding MAiD MI-SUMC, which frame it in terms of "equal access." I also consider the implications for ongoing policy debates (section 5).

1. GRANT ON WHY TRACK 2 MAiD IS DISCRIMINATORY

When MAiD was first legalized in 2016, only individuals with 'grievous and irremediable' medical conditions whose deaths were 'reasonably foreseeable' could qualify. Amendments to the law in 2021 removed the end-of-life requirement, making it possible for those with non-terminal illnesses to be eligible, provided their suffering is 'intolerable' and their condition 'irremediable'. As noted, Grant focuses her discussion on these cases (1).

Grant's central claim in the article is that Track 2 MAiD is "discriminatory against people with disabilities" (1, p.47). One of the primary reasons for this, she argues, is that MAiD policy in general is premised on a medical model of disability that treats the suffering associated with disability as something that is inherent to the individual and arises solely from a physical impairment. Consequently, death is put forward as a form of medical treatment that is suitable for disability-related suffering. As Grant notes: "This medical construction of human suffering may obscure the social factors that often contribute to and shape one's perception of suffering" (p.46). Further, it operates on the assumption that the kind of suffering experienced by those with a disability is worse than other forms of human suffering, inviting the belief that such lives may no longer be worth living. According to Grant, Track 2 MAiD reinforces ableist assumptions that see disability-related suffering as uniquely intolerable and disability itself as a deficit located within the individual rather than a product of social and structural conditions.

While Grant's argument is compelling, her discussion focuses squarely on physical illness and the structural inequalities affecting individuals with physical disabilities. What Grant does not explore, however, is the case of mental illness, where the line between medical and social suffering is not only blurry but where the issue of social determinants and structural conditions is particularly salient (1).

2. THE SOCIAL MODEL OF DISABILITY

Implicit in Grant's critique of the medical model of disability is an alternative put forth by disability ethicists, namely, the social model of disability. This model emphasizes that many of the hardships experienced by disabled people arise not from physical impairments themselves but rather from various social conditions and external barriers. To this end, disability ethicists distinguish between *impairment*, variations or differences in an individual's body or mind, and *disability*, obstacles caused by society that prevent full participation (2).

Grant's analysis presupposes three important commitments of the social model of disability. First, disability-related suffering is not solely caused by impairments but can be exacerbated or heightened by social and environmental factors. Second, autonomy is socially conditioned and cannot be analyzed apart from material realities, including structural ableism and histories of disadvantage and inequality. Third, equality requires changing social structures, not merely applying existing rules and norms to everyone in the same way.

Applying the social model of disability to the issue of MAiD MI-SUMC suggests that we must confront the societal barriers that contribute to psychiatric suffering, such as stigma, poverty, under-funded services, or long wait times. Moreover, it suggests that determinations about whether one's mental disorder is 'irremediable' or request for MAiD is 'autonomous' cannot be made without first addressing these structural conditions.

3. THE EXTERNALIST MODEL OF MENTAL ILLNESS

Recent work in the philosophy of psychiatry regarding the ontology of mental disorders supports claims made by those who adhere to a social model of disability. Traditional approaches locate psychiatric disorders squarely within the affected individual, as merely a dysfunction of the brain. Against these internalist models, externalist models of mental illness understand it not as something that is simply "in the head," but rather as something that emerges from an ongoing and dynamic relationship between a person and their world. In other words, mental illness is partly constituted by factors that lie outside the individual, that is, their environment, opportunities, and supports (3).

When applied to MAiD MI-SUMC, externalism destabilizes the view that mental pain and suffering can be viewed in isolation from an individual's social context. Maung (4,5) discusses the ethical implications of externalism, namely, that there may be certain social and environmental interventions that could alleviate psychiatric suffering — and that these interventions may make a difference for whether an individual ends up requesting MAiD. To date, however, the parallels between the social model of disability and externalist models of mental illness have yet to be observed. This is striking, as both treat suffering as socially embedded rather than purely individual.

4. STRUCTURAL INJUSTICE AND SUBSTANTIVE EQUALITY

Iris Marion Young was the first to theorize structural injustice — the idea that many forms of social injustice are not the result of individual bad actors but are rather built into social structures (6). In this way, harms are unevenly distributed, often disproportionately affecting certain groups simply through the normal operation of our systems and institutions. Moreover, responsibility for injustice is shared by all who participate; the ordinary actions of individuals contribute to the persistence of various forms of inequality, even if unintentionally.

Young further distinguished between formal and substantive equality (7). The formal conception of equality sees it as simply a matter of everyone living under the same rules. Yet this ignores how the rules were made in the first place; sameness of treatment in a context in which the system was set up unfairly ends up perpetuating inequality. Hence, a commitment to substantive equality requires thinking about the kinds of opportunities and outcomes that are available to individuals. Bringing these two strands together, Young argued that truly addressing inequality requires changing those structures that systematically disadvantage some people.

Applying this to the issue of MAID MI-SUMC suggests that there is a danger in treating it as simply about equal access. While many pro-expansion arguments operate on the basis of formal equality, Young warns us that sameness of treatment can further entrench inequality when background conditions are unjust. Viewing eligibility criteria for MAID identically in the case of physical and mental illness, respectively, may not ensure equal protection under the law if the suffering involved in the latter is socially embedded. Incorporating concerns about substantive equality requires that we understand how structural injustice hinders autonomy. In other words, options are only meaningful when there are viable and genuine alternatives. Moreover, our ethical evaluation of MAID MI-SUMC cannot be reduced to questions of informed consent or procedural fairness. Instead, a commitment to substantive equality means addressing the structural injustices faced by many people with mental illness.

5. DISCRIMINATION, EQUAL ACCESS, AND THE FUTURE OF MAID MI-SUMC POLICY

Proponents of MAID MI-SUMC argue that denying it to individuals with mental illness constitutes discrimination as it bars them from equal access to a legal right (8). Since those with physical illnesses are able to seek MAID, they argue that preventing those with mental illness from requesting it is arbitrary and unjust. On this view, if we truly respect autonomy, then we must offer the same end-of-life options to everyone, regardless of their diagnosis. I suggest that we might run the discrimination argument in the other direction. In other words, under present circumstances in which there exist significant barriers to adequate mental health care and supports, it might in fact be discriminatory to allow those with mental illness to be eligible for MAID.

Stepping back, we can say that something is discriminatory if it results in unequal treatment on the basis of arbitrary (i.e., morally irrelevant) differences. What seems to be overlooked by those who make discrimination-style arguments on this issue is the salience of social and external factors for how mental disorders are both experienced and constituted. Arguably, these factors make it different, in important ways, from physical suffering. If the social model of disability is correct, then we risk medicalizing a despair that is, at least in part, socially produced. If externalism is correct, then psychiatric conditions may resist separation from their social context in ways that physical conditions do not. Moreover, if we examine the issue through the lens of structural injustice, then we can see how framing the debate as simply a matter of inclusion risks obscuring the conditions that produce or exacerbate the very suffering that expansionist policies aim to alleviate. Thus, well-intentioned policies can inadvertently reproduce structural inequalities when they overlook the social conditions that shape mental illness. Expanding MAID for MI-SUMC without addressing social determinants mistakes sameness in treatment for fairness in outcome. And what is presented as compassion may inadvertently be a form of discrimination.

What I have tried to show here is how Grant's argument can be extended to the case of MAID for mental illness. Doing so underscores the ethical inadequacy of a framework that assesses psychiatric MAID through a strictly medical model. If psychiatric suffering is partly socially constituted, then assessments of 'irremediability' require taking into account systemic barriers to care, access to therapy and treatment, housing instability, poverty, stigma, and social exclusion. Where individuals face severe structural barriers to care and other social supports, presenting MAID as an available option risks transforming neglect into what appears to be an individual medical choice. As Grant shows, Track 2 already "posits death as...[a] convenient response to the suffering of people with disabilities" (1, p.52), especially to the extent that it is framed as simply a matter of choice. Allowing MAID for MI-SUMC risks deepening the patterns of discrimination that she identifies by treating it as a remedy for a suffering that is more tightly bound to social determinants than many physical disabilities. The present debate about expansion for MI-SUMC needs to address the question of what supports the state must provide to those with mental illness before eligibility for MAID could be considered ethically permissible.

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ÉTUDE DE CAS / CASE STUDY

Dual-Role Conflict: Healthcare Provider or Medical Power of Attorney

Maya Nortjé^a, Maureen Pontarelli^a, Ian Doherty^a, Nico Nortjé^a

Résumé

Cette étude de cas examine les tensions qui surgissent lorsqu'un membre de la famille, qui est un professionnel de santé, est également chargé de prendre les décisions concernant un parent en fin de vie. Elle met en lumière les enjeux éthiques liés aux responsabilités professionnelles et aux conflits découlant de ce double rôle.

Mots-clés

discussions sur les objectifs de soins, soins centrés sur le patient, consultation éthique, soins de fin de vie, prise de décision par un mandataire

Abstract

This case looks at the tension created when a family member, who is a medical provider, is also the decision-maker for a dying parent. This case study illustrates the ethics of professional responsibilities and dual-role conflicts.

Keywords

goals of care conversations, patient-centred care, ethics consultation, end-of-life care, surrogate decision making

Affiliations

^a Center for Clinical Ethics in Cancer Care, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Correspondance / Correspondence: Nico Nortjé, NNortje@mdanderson.org

CASE

Ms. T, in her late 60s, was diagnosed lung cancer, and which had spread to her brain, bone, liver, and lymph nodes. She was initially hospitalized for recurrent sepsis (an infection causing damage to tissue and organs), respiratory failure, and disease progression. Her condition worsened, requiring a visit to the Intensive Care Unit (ICU) for three days. Her hospital course of stay included complications due to worsening septic shock, and internal bleeding. Ms. T lost capacity, but had previously appointed her daughter as her designated Medical Power of Attorney (MPoA).

The family, specifically Ms. T's daughter (a medical provider at another health system), requested full resuscitative efforts should her mother suffer any respiratory failure. Despite knowing the poor prognosis, the daughter communicated with the team that she wanted to make sure she had done everything for her mother. She declined palliative care service, as for her, it signified giving up and her goal was to get her mother back home.

Although the care team respected the family's wishes, the patient continued to decline, and the daughter started to insist on specific dosages of medication, oftentimes refusing medications she believed not to be in the best interest of her mother. For the care team it became difficult to manage the care of the patient and called for an ethics consult.

THE ETHICAL ISSUE

This case raises the ethical issue of duty to care, with an emphasis on dual-role conflicts. This case investigates what boundaries exist for a patient's MPoA who also happens to be a healthcare professional.

Healthcare professionals as family caregivers walk a fine line between their dual identities as a caring family member and healthcare provider. At times, these two roles and their various responsibilities can be at odds (1). Healthcare providers who care for family members may struggle to separate the two identities and what each role requires (2). In a prior study, a physician reported having trouble disassociating between being a caregiver for a family member and having medical knowledge. In another study, a nurse described how having medical knowledge can increase stress because they are aware of the various outcomes, cure, palliation, or death. Another study reported nurses feeling guilty because they were not attentive to a clinical change in their loved one's condition (3). Healthcare professionals may struggle with anxiety and feelings of providing inadequate care due to the knowledge they hold and responsibility that they may feel to look after members in their family or personal community.

DISCUSSION

It is not uncommon that an individual with a background in healthcare be appointed as a friend or relative's MPoA. Decision-making on behalf of an incapacitated patient involves adequate communication between healthcare staff and the decision-maker. Communication pertaining to these subject matters may thus be easier when the decision-maker is already familiar with medical terminology.

Decision-making on behalf of another individual is guided by substituted judgment or the best interest standard. Substituted judgment occurs when the decision-maker knows the patient's preferences and thus makes the decision that the patient would have made themselves (4). By contrast, the best interest standard is implemented when patient preferences are unknown. In that situation, the decision-maker must make decisions with consideration of promoting patient welfare, i.e., focusing on relief of suffering, preservation or restoration of function, and the extent and sustained quality of life that a reasonable individual would choose in similar circumstances (4).

In both models, a physician must disclose the nature of the therapy, purpose, risks and consequences, benefits, probability of success, feasible alternatives, and prognosis if there is no intervention. A physician should also provide a recommendation to uphold the process of shared decision-making (5). In general, the responsibilities of a physician in the care of a patient are to attend to a patient's needs with allegiance and to uphold the principles of autonomy and social justice (4,6). Allegiance is a commitment to a cause, community, or individual. Physicians will have multiple allegiances, whether it is to their patient, their community, their family, a foundation, etc. However, when these allegiances conflict with the duties that shape medical professionalism, a choice must be made (4). These tensions can generate a dual-role conflict.

A dual-role conflict occurs when an individual has competing motivations that affect decision-making. These conflicts can be unethical when an individual goes against the responsibilities entrusted to them to act upon an opportunity for personal benefit. An unethical dual-role conflict undermines the integrity of the roles or responsibilities of an individual or organization. Ms. T's daughter has a dual-role conflict in caring for her mother as a healthcare professional. A dual-role conflict is not always an ethical issue and sometimes must simply be acknowledged. Unfortunately, Ms. T's daughter's involvement became an ethical issue when she failed to stay within the boundaries of the role of a MPoA. She used her background as a healthcare professional to undermine the healthcare team and disrupt the medical care provided to her mother. Distinguishing the roles and responsibilities of all parties involved in the decision-making process can help mitigate concerns surrounding the ethical issue of duty to care with emphasis on a dual-role conflict.

RECOMMENDATIONS

We offer three recommendations to healthcare teams that find themselves in similar situations. The first is to legitimize the multifaceted identity that the decision-maker holds. While the MPoA in this case is the daughter of the patient, she is also a healthcare provider. An individual's identity is not solely comprised of familial relationships but also by career, experiences, social identity, religion, etc. (7). Acknowledging aspects that form the individual's identity and influence decision-making may build trust and rapport between the care team and decision-maker, potentially aiding in establish cordial discussion.

Next, we recommend identifying the similarities and differences between the responsibilities of a MPoA and those of a primary physician. Doing so shows that both the decision-maker and patient's primary physician are focused on providing the best care for the patient. Identifying these differences can aid in relieving feelings of anxiety and burden of providing adequate care felt by the decision-maker.

Lastly, we recommend reinforcing the role and responsibilities of the decision-maker. MPoAs who are also healthcare professionals may feel a sense of heightened responsibility due to the patient's trust in their expertise. Individuals in this position may feel the need to control care out of fear of letting the patient down or making a poor decision. Reiterating the responsibilities of a MPoA can help empower these individuals to maintain a sense of control while still respecting the boundaries of their authority when it comes to decision making.

CASE STUDY QUESTIONS

1. How can healthcare teams manage situations where a medically-trained family member, in the same specialty, attempts to influence clinical care/decisions?
2. What role does clinical ethics play in mediating emotionally intense conflicts between families and healthcare teams, and how can it support both parties?
3. How would you handle the above case if Ms. T had capacity to make decisions?

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ÉTUDE DE CAS / CASE STUDY

The Influence of Trauma on End-of-Life Decision-Making

Maya Nortjé^a, Maureen Pontarelli^a, Ian Doherty^a, Karen Terrell^a, Carla Robles^a, Nico Nortjé^a

Résumé

Cette étude de cas montre comment les principes et les approches issus de la prise en charge tenant compte des traumatismes peuvent être mis en œuvre dans un contexte où une famille demande à l'équipe médicale de ne pas lui communiquer de mauvaises nouvelles par crainte d'un nouveau traumatisme. Une consultation éthique tenant compte des traumatismes reconnaît que les traumatismes non résolus peuvent entraver une communication ouverte et éthique. Une facilitation efficace du dialogue éthique n'est possible qu'une fois que le traumatisme sous-jacent affectant la communication a été reconnu et pris en compte.

Mots-clés

sensibilisé au traumatisme, consultation éthique, prise de décision, décisions de fin de vie

Abstract

This case study illustrates how principles and approaches from trauma-informed care can be used in a setting where a family is requesting the medical team not to share bad news out of fear of re-traumatization. A trauma-informed ethics consultation acknowledges how unresolved trauma may obstruct open and ethical communication. Effective facilitation of ethical dialogue is only possible once underlying trauma affecting communication is acknowledged and addressed.

Keywords

trauma informed, ethics consultation, decision-making, end-of-life decisions

Affiliations

^a Center for Clinical Ethics in Cancer Care, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Correspondance / Correspondence: Nico Nortjé, NNortje@mdanderson.org

CASE STUDY

Ms. B was admitted to the hospital after presenting to the emergency department (ED) with fever, abdominal cramping, vomiting, diarrhea, and tachycardia. She had previously been diagnosed with acute leukemia and hemophagocytic lymphohistiocytosis (an overactive immune system attacking its own blood cells), not having achieved remission. Upon further workup in the ED, it was determined that Ms. B had pneumonia as well as a distended colon and persistent ileus.

During her hospital stay, Ms. B became weaker with increased difficulty breathing and was transferred to the intensive care unit (ICU), where she was intubated and started on a vasopressor (medication to keep her blood pressure up). Ms. B's medical status continued to worsen, and she was eventually determined to be in multi-organ failure. A goals-of-care conversation was held with the ICU attending, Ms. B's primary oncologist, and Ms. B's children. Though the children understood that there were no more cancer treatments available, and that Ms. B was in multi-organ failure, they asked the ICU attending to continue with aggressive intervention and focus only on sharing positive news. This request caught the ICU attending off-guard, as they were not sure how to proceed with engaging with the patient's children as her condition progressively got worse, and good news was not to be had. A request was placed for an ethics consultation.

During the initial phase of fact gathering, the ethicist met with the patient's children to get better clarity on their request. The children's father, the patient's husband, had passed away traumatically 4 months prior and the children were still attempting to make sense of his death.

ETHICAL PROBLEM

This case raises the ethical issue of disclosure, truth-telling, and respect for autonomy. A physician is obligated to disclose sufficient information about a patient's condition to the decision-maker, either patient or a surrogate, as part of the informed consent process (1,2). A barrier to addressing this ethical issue is the patient's children's previously experienced trauma.

TRAUMA-INFORMED ETHICS CONSULTATION

Traumatic events can upend an individual's life, leaving them wary of themselves, others, and the world around them. Trauma is the result of an event that has lasting adverse effects on the individual's functioning and physical, social, emotional, or spiritual well-being (3). In this case, the children receiving news about the patient's medical condition can be a potential trigger that may re-traumatize them. The concept of re-traumatization has been defined as:

Traumatic stress reactions, responses, and symptoms that occur consequent to multiple exposures to traumatic events that are physical, psychological, or both in nature. These responses can occur in the context of repeated multiple exposures within one category of events (e.g., child sexual assault and adult sexual assault) or multiple exposures across different categories of events (e.g., childhood physical abuse and involvement in a serious motor vehicle collision during adulthood). (4, p.2)

Facilitation of ethical communication, like in traditional ethics consults, can only be accomplished if prior trauma that impedes communication is first addressed. Trauma-informed ethics consultation (TIEC) acknowledges how trauma may be impeding ethical communication and allows parties to arrive at an ethically appropriate resolution while mitigating risk of re-traumatization. TIEC applies principles of trauma informed care (TIC) into standard ethics consultation processes (5). TIC is an approach to healthcare that aims to promote a safe environment, trustworthiness and transparency, collaboration and mutuality, peer support, empowerment of voice and choice, and recognizes the impact of culture, history, and social identities on experience and daily interactions (6). The principles and approaches from TIC are not meant to be applied in a direct clinical sense by the ethicist, to treat or diagnose patients or family members, but are aimed to inform and orient communication with these individuals.

First, an ethicist can acknowledge the impact of trauma on decision-making by being an active listener, normalizing grief associated with trauma, and assessing social support and resources for the family. They can draw on their skills of mediation and effective communication to encourage patients and families to voice both internal and external physical and emotional losses they have experienced due to trauma (3). This would promote a safe environment and aid in building trust and transparency.

Once the impact of the trauma on decision-making has been acknowledged, the clinical ethicist can work towards identifying any trauma-related triggers by eliciting the similarities and differences between the past traumatic event and current situation (7). One likely trigger in this case would be that of being in a hospital setting; the clinical ethicist could ask family members to articulate similarities and differences between their father and mother's admissions, drawing upon how individuals may have reacted differently to the admissions, and how these individuals may have different physical or emotional responses.

Finally, the clinical ethicist can aid in facilitating a conversation where the family members identify what unique choices can be made in this situation which were not able to be made in the past. Exploring choices available in the current situation can aid in managing triggers by giving family members a sense of empowerment with their voice and decision-making abilities (3).

ETHICAL RESPONSE

Supporting the needs of those who have suffered from trauma aids in building trust between individuals and can help encourage participation in decision-making and care (8). Once trust has been built by acknowledging trauma and identifying and managing triggers, it would be appropriate for the clinical ethicist to finally address the ethics issue. The clinical ethicist should explain to the family members that informed consent is not possible without a clear disclosure, both positive and negative, of the patient's condition; that the purpose of adequate communication and truthful disclosure is to empower them to make informed decisions pertaining to their mother's care (1,2); and that making decisions for their mother's care is voluntary. If certain family members do not want to hear the information necessary to make a decision, out of fear that hearing negative news would result in re-traumatization, those family members may waive their right to engage in the decision-making (2).

QUESTIONS

1. How does trauma informed ethics consultation differ from that of a typical ethics consultation?
2. What alternative strategies could an ethics consultant employ when engaging with a family or patient not affected by trauma who only want to hear positive news?
3. Should all ethics consults be trauma-informed?

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ÉTUDE DE CAS / CASE STUDY

When a Surrogate Knows What to Do, but Can't Do It

Victor Esteban Grado^a, Maureen Pontarelli^a, Ian Doherty^a, Nico Nortjé^a

Résumé

Un mandataire ou un décideur de substitution a pour mission de prendre les décisions médicales que le patient prendrait lui-même. Cependant, la plupart du temps, le mandataire est également lié émotionnellement au patient, ce qui rend la mise en œuvre de ces décisions très difficile. Cette étude de cas examine les difficultés rencontrées par une épouse pour respecter les souhaits de son mari, parce qu'elle ne voulait pas le perdre.

Mots-clés

mandataire, prise de décision médicale, éthique clinique

Abstract

A surrogate or substitute decision-maker is tasked with making medical choices that the patient would make for themselves. However, most of the time the surrogate decision-maker is also emotionally involved with the patient, which makes the execution of these choices very difficult. This case study looks at a wife's struggle to honour her husband's wishes, because she did not want to lose him.

Keywords

surrogate decision-maker, medical decision-making, clinical ethics

Affiliations

^a Center for Clinical Ethics in Cancer Care, The University of Texas MD Anderson Cancer Center, Houston, Texas, USA

Correspondance / Correspondence: Nico Nortjé, NNortje@mdanderson.org

CASE STUDY

Mr. X, a 68-year-old man, was diagnosed with metastatic non-small cell lung cancer in 2022 at the age of 65. He received four cycles of combination chemotherapy with palliative intent, but his treatment was complicated by ICI-induced colitis, an adverse effect in which the immune system becomes overactive. Other than this complication, he also had a history of cardiac arrest and respiratory issues. Given Mr. X's complicated clinical picture, and four Intensive Care Unit admissions within 2 months, it was not a surprise that he twice had a cardiac event where his heart stopped. Both times, Return of Spontaneous Circulation (ROSC) (getting a pulse again) was achieved, however he had to be intubated given his history of respiratory issues. A week after he was intubated, he self-extubated. He was very alert and oriented and was found to have decision-making capacity. Mr. X was adamant that he did not want to be intubated again and requested a Do-Not-Resuscitate/Do-Not-Intubate (DNR/DNI) order to be placed.

Surprisingly, Mr. X started to improve, and he was moved to a non-acute care setting floor within the hospital, and discharged home. Sadly, a few days later, Mr. X was in another crisis and was admitted through the Emergency Room. Given local legislation, a previously indicated DNR/DNI is only valid for the specific admission and could not be transferred to the new admission. Mr. X was admitted as a FULL code patient (he would need to be resuscitated and intubated should he code or have respiratory distress). Given the fact that Mr. X did not have capacity, the team turned to his wife to decide on her husband's code status. Mrs. X felt hugely conflicted as she did not want to lose her husband, but likewise she also did not want him to suffer.

WHY DO SURROGATE DECISION-MAKERS HAVE DIFFICULTY IN MAKING DECISIONS AT THE END OF LIFE?

Surrogate decision-makers, occasionally referred to as substitute decision-makers, are integral to making medical decisions for patients who are incapable of consenting or refusing to consent to proposed treatments themselves. However, surrogate decision-makers can encounter numerous obstacles when trying to make decisions. Some difficulties include knowing the patient's true preferences in relation to the specific context, accurately assessing the patient's quality-of-life, and the psychological and emotional burden of making the decisions.

When surrogate decision-makers carry out the patient's wishes recorded in advance care planning documents, they operate under the substituted-judgment standard. Surrogate decision-makers using this standard are supposed to act as if they are the patient and choose what the patient would have chosen (1). These decisions can be easier when a patient's wishes are explicit or written down in a living will or other advance care documents. However, trouble arises if the wishes are not documented, or if the surrogate decision-maker needs to infer what the patient would want based on previous conversations, which can be confusing. A patient's values may be misapplied, misconstrued, or not receive proper priority. One study evaluated surrogate decision-makers and their ability to predict whether patients would forgo life support. The study showed that surrogate decision-makers decisions were no better than chance at representing patients' end-of-life wishes (2). Another hurdle surrogate decision-makers may need to overcome is accurately assessing the current quality-of-life (1). For example,

a surrogate decision-maker may perceive living life with a tracheostomy to be challenging and burdensome for the patient. The maintenance and limitations may be seen as cumbersome and too restrictive. However, the patient may deem life with a tracheostomy to be entirely acceptable because it would enable them to still enjoy aspects of life that are essential.

Stress and other psychological factors that arise when making end-of-life decisions may over-burden the surrogate decision-maker. For instance, the surrogate decision-maker may be re-traumatized during the decision-making process. The surrogate decision-maker may have witnessed the toll that making medical decisions for someone else can have on another individual. The surrogate may worry that they will develop poor coping habits because they saw someone else in the same situation poorly cope with medical decision-making. Making end-of-life decisions for a loved-one may cause the surrogate decision-maker to have flashbacks or re-experience a previous traumatic event as if it were happening in that moment (3). Knowing how to navigate the complexities that arise in surrogate decision-making is important for clinicians and clinical ethicists alike.

HOW CAN ETHICISTS HELP SURROGATE DECISION-MAKERS?

Clinical ethicists can play a crucial role in supporting and guiding individuals tasked to make decisions on behalf of others. Most surrogate decision-makers do not have experience or expertise in making such decisions prior to being declared as the legal next of kin or appointed as a healthcare or medical power of attorney (4,5). Clinical ethicists can help these individuals by offering emotional support, using good communication skills, and maintaining focus on the patient.

It is critical for clinical ethicists to understand how the surrogate understands and processes their role as decision-maker. To some this role could feel honorary, to others it could feel daunting or emotionally burdensome (6,7). Understanding the surrogate's perception may help clarify how and where the clinical ethicist can support decision-making. For instance, in the case above, Mrs. X is conflicted because she does not want to lose her husband but also does not want her husband to suffer. It would be reasonable to assume that Mrs. X feels somewhat burdened to make this decision or that the decision is a daunting task. The clinical ethicist may be able to support Mrs. X by acknowledging her conflict and articulating that two things can be true at the same time, i.e., her not wanting to lose her husband but also not wanting him to suffer. By doing so, the clinical ethicist not only emotionally supports Mrs. X but also builds trust and rapport with through acknowledgement of difficulties.

Good communication skills, such as acknowledging difficulties in decision-making and clear rearticulation of feelings, can aid in ensuring that the surrogate decision-maker feels heard and respected. Having surrogate decision-makers answer these questions aids them in organizing their thoughts and allows them to articulate their goals and identify their fears for an individual's health and future care. This approach also helps recentre the focus of the care conversation on the patient. Clinical ethicists should ensure that the patient remains at the centre of the care conversation and should make efforts to limit feelings of guilt or overwhelming responsibility by articulating patient's previous stated wishes, when known, and by using pluralistic language.

Pluralistic language uses terms such as, 'we' or 'us' to offer a sense of solidarity and teamwork. When wishes are known, like in the case of Mr. X, the clinical ethicist should ensure that Mr. X's previous wishes are stated out loud during care conversation; this could help reduce Mrs. X guilt or burden of decision-making by acknowledging that Mr. X had made a decision in regard to this situation in the past. In addition, saying 'we' instead of 'you' can help surrogates feel supported and lessen the burden of the role of sole decision-maker. For instance, "I hear you say that you don't want Mr. X to suffer, we also don't want him to suffer. The healthcare team's fear is that doing CPR will cause unnecessary pain and would go against what Mr. X had previously wished for, which was no chest compressions or intubation." This statement uses pluralistic language, identifies areas of agreement and concern, and refocuses the care conversation on Mr. X while hopefully reducing guilt or burden felt by Mrs. X.

QUESTIONS

1. What is the role of a surrogate decision-maker?
2. How does a surrogate decision-maker assess a patient's wishes?
3. How can an ethicist help reframing conflicting values for a surrogate decision-maker?

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ÉTUDE DE CAS / CASE STUDY

When Good Intentions Are Not Enough: Ethical Tensions in Rare Disease Care in Indonesia

Ardita Hartanti Pramudani^{a,b}, Ika Septiana Eryani^c, Agustini Utari^{a,d}, Tri Indah Winarni^a

Résumé

Cette étude de cas porte sur un enfant atteint d'une maladie génétique rare en Indonésie, dont l'accès aux soins a dépendu de la mobilisation de la communauté dans un contexte de soutien institutionnel limité, mettant en évidence une tension entre les principes de bienfaisance et de justice au sein des systèmes de santé aux ressources limitées. Si les actes de bienfaisance sont moralement louables, nous soutenons que la justice doit primer en favorisant des solutions institutionnelles équitables qui évitent de dépendre de la bonne volonté ponctuelle de la communauté et préviennent les inégalités d'accès aux soins entre des patients ayant des besoins comparables.

Mots-clés

Indonésie, solidarité, bienfaisance, justice, maladie rare

Abstract

This case study examines a child with a rare genetic condition in Indonesia whose access to care depended on community mobilization in the context of limited institutional support, revealing a tension between the principles of beneficence and justice in resource-constrained health systems. While acts of beneficence are morally commendable, we argue that justice should take priority by motivating equitable, institutional solutions that avoid reliance on ad hoc community goodwill and prevent unequal access to care among patients with comparable needs.

Keywords

Indonesia, solidarity, beneficence, justice, rare disease

Affiliations

^a Community Genetics Research Center, Faculty of Medicine, Universitas Diponegoro, Semarang, Central Java, Indonesia

^b Department of Forensics and Medicolegal, Faculty of Medicine, Universitas Diponegoro, Semarang, Central Java, Indonesia

^c Center for Health Financing, Secretariat General, Ministry of Health, Semarang, Central Java, Indonesia

^d Department of Pediatrics, Faculty of Medicine, Universitas Diponegoro, Semarang, Central Java, Indonesia

Correspondance / Correspondence: Ardita Hartanti Pramudani, arditahp@gmail.com

INTRODUCTION

Rare diseases in Indonesia reveal major disparities in healthcare access, ethical guidance, and social support. While international guidelines for comprehensive interdisciplinary care exist (1), their implementation in Indonesia is constrained by limited infrastructure, resources and regulation (2,3). This case study shows how families together with community members navigate these systemic barriers while managing conditions like Silver-Russell Syndrome (SRS), a rare genetic condition requiring long-term specialist care, including growth hormone therapy (4). The example highlights the ethical challenges of relying on community solidarity in terms of financial aid over institutional support, leading to tensions between the principles of beneficence and justice.

CASE

Sarah¹, a two-year-old girl from rural Indonesia, presented with growth delay and developmental concerns that were first identified during a routine child-weighing program conducted by community health workers. With encouragement from the community health workers, her mother sought care through the primary health system, followed by referrals to regional and tertiary hospitals. Sarah was eventually diagnosed clinically with Silver-Russell Syndrome (SRS) (5), which is not adequately covered by insurance in Indonesia (6,7). To enable access to care, the community health workers acted beyond their formal roles by mobilizing community resources and accompanying the family on long-distance referrals, compensating for the family's lack of financial means to access the needed healthcare attention.

Ethical Analysis

This case raises a tension between the ethical principles of beneficence and justice. Beneficence pushes the community to help the patient with a rare genetic disease receive adequate care, support, and resources, despite the limitations within the community. This collective response aligns with the concept of solidarity as a form of beneficence. Prainsack and Buyx (8) conceptualize solidarity across three tiers: interpersonal, group, and contractual/legal/administrative. The actions in this case exemplify Tier 2 solidarity, characterized by organized yet informal community-based mutual aid. Specifically, the community health workers accompanied Sarah and her family to referral hospitals and paid for some medical services, extending support beyond their legally mandated roles and responsibilities.

¹ Pseudonyms were used and identifying details modified to protect confidentiality.

While this community support aligns with the principle of beneficence, reliance on such support simultaneously raises concerns regarding justice. The actions of the community health workers risk privileging the needs of one individual over those of others in the community who may face equally pressing health and social needs but lack access to comparable assistance. As such, we argue that, although supporting patients with limited financial means is ethically commendable, justice requires that community health workers not compensate for structural deficiencies by selectively leveraging informal community resources, as this may contribute to inequitable access to care and obscure the need for systemic, institutional solutions.

Sarah's case illustrates how community solidarity can alleviate immediate needs while simultaneously revealing persistent ethical challenges within rare genetic disease care in Indonesia. Limited health insurance coverage, fragmented referral systems, and uneven access to specialized services contribute to structural inequities in diagnosis, treatment, and counselling (9), leading communities to intervene where possible, while remaining constrained by the absence of formal support. These conditions raise concerns about justice and fair access to care, as families' ability to obtain appropriate medical support often depends on geographic location, financial capacity (10,11), and may also depend on informal social networks rather than guaranteed health entitlements.

Despite being the fourth most populous country in the world and the most populous in Southeast Asia, with approximately 285 million people (12), Indonesia has not yet issued specific policies addressing rare diseases, resulting in limited formal support compared with neighbouring countries in Southeast Asia such as Philippines, Singapore, Malaysia, Vietnam, and Thailand (1). Without such policies, families face a "genetic odyssey," a long, fragmented diagnostic journey across multiple facilities (13), that eventually leads to difficulties in accessibility.

Through this analysis, we conclude that dependence on community mobilization is unsustainable because it leads to inequitable care distribution. While community health workers actions align with beneficence by preventing immediate harm, justice requires institutional systems that ensure equitable care independent of community capacity. Not all patients have communities capable of mobilizing; those who are socially isolated, marginalized, or have less social capital will receive inferior care. Justice requires institutional systems that provide access to equitable care regardless of a patient's community resources, and equally shared responsibilities according to roles and capacity. As such, community health workers should not pay for healthcare services for patients who do not have the financial means.

DISCUSSION QUESTIONS:

1. To what extent is it ethically acceptable for community solidarity to compensate for gaps in institutional healthcare support without normalizing systemic inequities?
2. How can healthcare institutions integrate community-based support while preserving justice and avoiding the displacement of formal responsibility onto informal actors?

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ÉTUDE DE CAS / CASE STUDY

Shared Responsibility After Referral: Ethical Challenges in Preventing Harm

Ohad Avny^a, Mayer Brezis^b, Anat Tsur^c

Résumé

Ce cas montre comment une communication fragmentée et une répartition floue des responsabilités entre les soins primaires et les soins spécialisés peuvent compromettre les principes de bienfaisance et de non-malfaisance, entraînant ainsi des préjudices évitables pour les patients. Pour éviter de telles conséquences, les professionnels de santé devraient déterminer ensemble qui assume la responsabilité principale des soins du patient à chaque étape du processus d'orientation.

Mots-clés

responsabilité, redevabilité, orientation vers un spécialiste, médecin, soins, préjudice

Abstract

The case illustrates how fragmented communication and blurred accountability between primary and specialty care can compromise the principles of beneficence and nonmaleficence, resulting in preventable harm for patients. To prevent such outcomes, healthcare providers should collaboratively determine who holds primary responsibility for the patient's care at each stage of the referral process.

Keywords

responsibility, accountability, referral, physician, care, harm

Affiliations

^a Department of Family Medicine, Clalit Health Services, Hebrew University of Jerusalem, Jerusalem, Israel

^b Hadassah Medical Center, Hebrew University of Jerusalem, Jerusalem, Israel

^c Department of Endocrinology and Metabolism, Clalit Health Services, Hebrew University of Jerusalem, Jerusalem, Israel

Correspondance / Correspondence: Ohad Avny, ohadavny@gmail.com

CASE PRESENTATION

A 60-year-old man presented with uncontrolled type 2 diabetes after discontinuing his medications in the context of depressive symptoms. He refused antidepressant therapy and objected to any form of psychological support. Eventually, he agreed to restart his diabetes medications with gradual improvement during weekly primary care follow-ups. Several weeks later, he developed a foot wound sustained at work. The wound was treated with antibiotics, and he was referred to a specialized foot clinic. At this point, his care unexpectedly shifted toward endocrine testing for rare disorders.

From our perspective (the three authors), his unbalanced diabetes clearly stemmed from depressive-related nonadherence to diabetes therapy. We feared overdiagnosis. Nevertheless, the patient underwent the recommended workup. The specialists identified hormonal abnormalities and an abnormal growth in the pituitary gland on imaging, which together were interpreted as consistent with acromegaly (a hormonal disorder characterized by the excessive production of growth hormone). The patient subsequently underwent transsphenoidal neurosurgery. Postoperatively, laboratory values remained atypical for acromegaly, and pathology revealed a pituitary adenoma subtype (a typically benign tumor originating from hormone-producing cells of the pituitary gland) that did not support growth-hormone excess, raising doubt about the initial acromegaly diagnosis. In retrospect, the patient likely underwent surgery as a result of a false-positive test combined with the incidental discovery of a pituitary mass, culminating in an erroneous diagnosis of acromegaly.

Throughout this process, we remained concerned about a possible misalignment between the patient's clinical picture, primarily his depressive symptoms and discontinuation of medication, and the laboratory and pituitary findings. However, once the specialty evaluation began, the primary care team did not take a proactive approach or attempt to speak directly with his endocrinologist to reconcile divergent views. The referral pathway functionally shifted patient responsibility to the specialty service, while accountability for outcome remained shared under the principles of beneficence and nonmaleficence — each team retaining a duty to act in the patient's best interest and prevent harm despite operational separation.

In our setting, a "shifted outpatient model" exists in which subspecialists conduct regular on-site consultations with primary care teams, fostering direct, collegial dialogue and shared decision-making (1). In this case, the patient was referred outside that familiar pathway to another endocrinologist not personally known to the primary team. We believe the absence of a pre-existing collaborative relationship reduced opportunities for timely bidirectional communication and contributed to passivity on the part of the primary team as the diagnostic cascade progressed. The central ethical issue is the breakdown of shared responsibility after referral, which allowed a diagnostic cascade to cause harm to the patient contrary to the principles of beneficence and nonmaleficence.

ETHICAL ANALYSIS

Referrals to consultants can often be perceived as a loss, or redistribution, of authority and accountability for our patients' care. Yet, under the principles of beneficence and nonmaleficence, ethical responsibility for outcomes remains shared. In this case, the specialty workup moved forward in a direction that diverged from the primary care assessment. A laboratory test obtained against the primary care plan initiated an expanding diagnostic snowball that culminated in surgery. Although authority effectively shifted to the specialty service, accountability for the patient's safety and the proportionality of further testing remained a joint obligation.

A tendency toward passivity from primary care physicians (PCPs) after referral can be a common challenge in primary care and raises ethical concerns about nonmaleficence (avoiding harm) and professional duty. Uncertainty about the limits of responsibility is also frequent; PCPs may struggle to delineate their role relative to that of consultants, particularly when recommendations conflict or when rare-disease testing is proposed. As PCPs, we aim to avoid harm and act for the patient's good; when the risk of overdiagnosis or overtreatment increases, as it did here, the decision to proceed with consultation and testing requires explicit, shared justification.

Structural and relational factors can exacerbate these dilemmas. Historical tensions between hospital specialists and community PCPs, clinician isolation and burnout, and gaps in role definition and communication all hinder collaboration. While electronic information exchange is necessary, it is insufficient on its own (2). Effective collaboration depends on trust, clear expectations, and direct collegial dialogue (3,4). In this case, no prior personal or collegial relationship existed with the consulting endocrinologist, which likely reduced opportunities for timely discussion and course-correction.

This case reveals how the fragmentation of healthcare professionals' accountability following referral can breach the principles of beneficence and nonmaleficence: when no clinician assumes active responsibility for ensuring diagnostic proportionality, the risk of preventable harm increases. To prevent such situations, we argue that healthcare providers should meet to explicitly determine and agree on who holds primary responsibility for the patient's care at each stage of the referral process.

CONCLUSION

Collaborative safety is enhanced when healthcare practitioners' capacity to identify and bridge gaps in care is both recognized and actively supported (5,6). Yet, primary care clinicians and consultants often struggle to close communication gaps and rarely have protected time to reflect meaningfully on these challenges. Such gaps create potential harm to patients and can foster passivity rather than active problem-solving. Both primary care and specialty teams should share accountability for clear communication and coordinated decision-making for the benefit of patients. Improved models of collaboration that are grounded in trust, direct dialogue, and shared responsibility are essential to balancing the risks of overdiagnosis and underdiagnosis in patient care. Strengthening these structures advances core professional commitments to avoid harm and to promote the good of patients (5).

DISCUSSION QUESTIONS

1. What ethical obligations does a primary care physician retain after referring a patient to a specialist, especially when clinical judgment diverges?
2. How should accountability and authority be distributed between PCPs and consultants to reduce the risks of overdiagnosis and unnecessary interventions?
3. What structures or models best support collaboration and ethical responsibility in complex cases?
4. How should physicians navigate incidental findings in ways that respect patient safety while avoiding harm from overdiagnosis?
5. Can the lack of communication between teams be considered a form of moral injustice toward the patient?

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

Chronique du cinéma 13 : Frankenstein et la condition humaine

Jacques Quintin^a

Résumé

Commentaire à propos du film *Frankenstein* du réalisateur Guillermo del Toro. Le film reprend le mythe de l'être humain qui se prend pour Dieu, le créateur de l'univers et de la vie humaine. Cependant, malgré les bonnes intentions du Dr Frankenstein, offrir l'immortalité ou la santé parfaite à l'être humain, sa créature, en l'occurrence un monstre, se retourne contre son créateur pour se plaindre de sa condition d'immortel. Ce qui l'attend, ce n'est pas le bonheur, mais une souffrance qui se renouvelle constamment. Ce film fait la démonstration de la nécessité d'une réflexion approfondie sur la portée de la science et sur le sens de la vie humaine.

Mots-clés

science, éthique, éducation, immortalité, bonheur

Abstract

A review of the film *Frankenstein* by director Guillermo del Toro. The film revisits the myth of the human being who fancies himself as God, the creator of the universe and human life. However, despite Dr Frankenstein's good intentions – to offer immortality or perfect health to humankind – his creature, in this case a monster, turns against its creator to complain about its immortal condition. What awaits it is not happiness, but suffering that is constantly renewed. This film demonstrates the need for in-depth reflection on the scope of science and the meaning of human life.

Keywords

science, ethics, education, immortality, happiness

Affiliations

^a Département de psychiatrie, Université de Sherbrooke, Sherbrooke, Québec, Canada

Correspondance / Correspondence: Jacques Quintin, jacques.quintin@usherbrooke.ca

Frankenstein, le film de Guillermo del Toro, est une adaptation du roman *Frankenstein ou le Prométhée moderne* de Mary Shelley (1). Sorti en 2025 sur Netflix, le film met en scène Jacob Elordi dans le rôle du monstre, Oscar Isaac en Dr Victor Frankenstein ainsi que Christoph Walz dans le rôle de Henrich Harlander et Mia Goth dans le rôle d'Elizabeth.

Qui ne connaît pas l'histoire de Frankenstein? Brièvement, en guise de rappel, cette histoire met en scène la création d'un monstre dans un laboratoire par un scientifique. C'est la reprise du récit du mythe de Prométhée.

Le mythe de Prométhée traverse les siècles depuis sa source dans la *Théogonie* d'Hésiode (2) au VIII^e siècle av. J.-C. et dans la pièce *Prométhée enchaîné* d'Eschyle (3) au Ve siècle av. J.-C. Prométhée, son nom l'indique, est le prévoyant. Il est un bienfaiteur de l'humanité en volant le feu aux dieux pour apporter aux humains les moyens ou la connaissance pour améliorer leur sort. Zeus, dans un sursaut de colère, punit Prométhée en le condamnant à être enchaîné à un rocher où un aigle lui rongera le foie chaque jour, mais dont la plaie se referme chaque nuit.

Tout le film s'appuie sur le récit du Dr Victor Frankenstein isolé dans le Grand Nord pour fuir son Monstre (maintenant avec une majuscule) ainsi que le récit du Monstre lorsque les deux « hommes » se retrouvent sur un bateau isolé en raison des glaces.

Le film débute avec l'éducation, pour ne pas dire le dressage, d'un jeune homme, le futur Dr Victor Frankenstein, par son père, médecin célèbre, qui lui enseigne que les sentiments n'existent pas. Il lui inculque une vision matérialiste et naturaliste de la vie humaine écartant toutes les autres perspectives possibles. Le jeune est très près de sa mère, mais celle-ci, enceinte, finira par mourir au moment de l'accouchement, ce qui à l'époque n'était pas inusité. Mais pour le jeune homme, en l'occurrence Victor, ce sera un drame. Il accusera son père, malgré sa célébrité, de ne pas avoir réussi à sauver son épouse. Le père lui rétorque que la mort fait partie de la vie. Inutile d'en faire un drame. Mais Victor aura une révélation : il deviendra aussi un médecin très célèbre qui surpassera la célébrité de son père en repoussant les limites de la vie, c'est-à-dire en vainquant la mort.

Finalement, il y parviendra en créant un monstre, un être hybride, donc composé de fragments empruntés à d'autres êtres humains morts. On le voit aller sur la place publique où le public assiste au spectacle d'une série de pendaisons. Victor, comme dans un marché, examine les condamnés et choisit les plus aptes pour son projet. Il parviendra à créer une machine qui reproduit plus ou moins un être humain ou une machine qui exécute des gestes qu'un humain peut faire comme si la machine avait sa propre volonté. Ce sera un scandale lorsqu'il présentera sa découverte devant un collège de savants. Ceux-ci accusent Victor d'hérésie, de charlatan — on ne peut pas contredire le plan divin. C'est un sacrilège. On peut croire que la carrière de Victor se termine ici. Mais non!

Il fera la rencontre d'hommes riches, son jeune frère et son futur beau-père qui ont fait fortune à Vienne, qui le soutiendront dans son projet scientifique. Ils proposent à Victor un château dans lequel il pourra installer son laboratoire. Ils lui garantissent tout le soutien financier nécessaire pour l'achat de matériel approprié à son projet. Victor finit par créer un artefact qui ressemble à un être humain, mais quelque chose ne fonctionne pas. Cette fois-ci, c'est la rencontre de la fiancée de son frère qui lui donnera la clé pour résoudre son problème. Elle aussi a des intérêts pour la science, mais une science, que nous pourrions qualifier de prémoderne, qui se limite à contempler l'univers, à s'émerveiller devant la beauté de la nature. Elle collectionnera les papillons qui justement, représentent ce que peut être l'harmonie. *Euréka*, elle fait comprendre à Victor que c'est la symétrie, l'harmonie et la beauté qui donne un sens à la vie, voire une âme aux choses. Cette fois-ci Victor parviendra à créer un vrai humain ou presque à l'aide de l'électricité (on peut y voir la foudre de Zeus) très en vogue à l'époque pour ses promesses. On retrouve les mêmes plaies sur le corps du Monstre que celles provoquées par l'aigle qui dévore le foie de Prométhée.

Ce sera un monstre. Mais est-ce un monstre en raison de la nature de sa fabrication, un être qui n'est pas issu de Dieu mais de la volonté humaine? Ou plutôt en raison de l'éducation que Victor donne au monstre? Comme son père, Victor isole le Monstre dans le sous-sol du château et tente de lui enseigner quelques rudiments langagiers en le maltraitant, mais en vain. La méthode de Victor ne semble pas porter de résultats attendus. C'est finalement le contact humain ou humanisant avec Elizabeth et d'autres humains dont il fera la rencontre qu'il apprendra à parler, qu'il découvrira qu'il a des sentiments.

Cet être hors norme, en raison de sa grandeur, mais aussi de sa puissance, car il fait des choses qu'aucun humain ne peut faire, jettera beaucoup d'inquiétude chez les humains. Ils voudront à chaque occasion l'abattre. Même son créateur, Victor, voudra s'en débarrasser. Mais comme le Prométhée d'Eschyle qui se fait dévorer le foie par un aigle, il survit à tous les attentats : il est immortel, mais un immortel souffrant. Les bas-reliefs représentant Prométhée sont là pour nous le rappeler. C'est la question existentielle qui se pose : comment vivre si nous sommes immortels? Surtout si nous sommes seuls. C'est cette solitude qui est inacceptable. Le Monstre, une fois qu'il aura compris qu'il est un être créé par un homme, Victor, lui demande de lui créer une compagne comme Adam souhaite une compagne.

Finalement le film se termine sur la rencontre entre Victor et son Monstre. Victor réalise que c'est lui le monstre en raison de la folie de son désir : se prendre pour Dieu. Victor demande au Monstre de lui pardonner et aussi d'accepter de vivre en aimant la vie. Cette réconciliation entre ces deux monstres, — on ne sait plus qui est le plus humain entre les deux hommes —, va permettre au capitaine du bateau qui est habité par le même rêve que Victor, celui de découvrir le monde pour le contrôler, de rebrousser chemin.

Il y a plusieurs pistes de réflexion dans ce film dans la mesure où il présente plusieurs couches de sens. Nous ne prétendons pas épuiser toutes ces couches possibles, mais en donner un aperçu dans un but de nourrir une réflexion éthique. Montrer tous les liens imaginables avec le mythe de Prométhée serait fastidieux, sans compter toutes les interprétations que nous avons pu en faire dans l'histoire de la littérature et du cinéma. De la même manière, il existe dans ce film une pléthore de renvois à l'ancien testament (Adam et Ève), — je pense au mannequin qui croque dans la pêche, symbole de la vie —, ainsi qu'au Nouveau Testament (pardon et amour). Le monde grec et l'univers biblique se superposent.

On peut voir dans ce film une réflexion sur le posthumanisme qui promet l'immortalité; projet aussi supporté par des personnes fortunées. Quel sens pourrions-nous donner à la vie si nous sommes immortels, et en plus, peut-être souffrants? Ne serait-il pas préférable de reconnaître notre finitude, d'en apprécier sa valeur? Finalement, la vie est brève, contrairement à celle de Prométhée. Dans ce cas, rien ne sert de s'égarer, de fuir ou de se divertir dans toutes sortes de projets : il suffit d'aimer. Il ne faut pas oublier que la vie de Prométhée en est une de punition. Il y a donc une critique du progrès.

Il en ressort une tragédie; la création d'un artefact qui dépasse les intentions, souvent bonnes, de l'être humain. Dans le Bien se cache le Mal. On peut affirmer que le Mal survient au moment où le monstre s'autonomise. Il n'en va pas autrement avec la science lorsqu'elle s'autonomise, c'est-à-dire lorsqu'elle s'isole en ignorant d'autres perspectives. C'est l'histoire de Victor qui s'isole dans un château et qui n'entend rien aux contre-arguments. La connaissance devient une fin en soi. On en fait un absolu. Certes, notre époque bénéficie grandement des avancées scientifiques, mais se pourrait-il qu'à l'occasion nous puissions créer des artefacts qui nous dépassent et nous privent de notre humanité? Est-ce le cas avec les IA? Dans l'histoire de l'humanité, les hommes n'ont jamais reculé devant de nouvelles avancées techniques. S'ils ont abandonné certaines techniques, c'était pour les remplacer par des techniques plus efficaces. Mais serions-nous rendus à ce point qu'il faudrait maintenant commencer à réfléchir si nous ne devons pas plutôt reculer? C'est ce que laisse entendre la finale du film. Le bateau qui était piégé par les glaces est libéré par le Monstre, mais en marche arrière. Le capitaine dit : nous rentrons à la maison au grand soulagement de l'équipage. Il est remarquable que le capitaine, comme Victor, n'eût qu'une idée fixe en tête, d'imposer sa volonté sans qu'il soit nécessaire d'écouter les inquiétudes de son entourage. On peut y voir une critique du nominalisme qui défend l'idée que Dieu ne peut pas s'astreindre à des lois de la nature s'il est tout puissant. La volonté de Dieu est infinie. Nous sommes dans un pur subjectivisme. L'être humain à l'image de Dieu devient tout puissant, sa volonté s'autonomise. N'est-ce pas de drame de notre époque? Je pense à tous ces régimes totalitaires : parce que je le veux, cela

doit être. C'est une question éthique : est-ce que nous devons réaliser un projet parce que nous pouvons le faire techniquement? Parce que nous le voulons? Est-ce que la fin justifie les moyens?

L'une des grandes vertus est la prudence. Certes, les scientifiques se sont donné des normes éthiques pour réguler la recherche scientifique. Est-ce suffisant si nous ne remettons pas en doute la finalité? En ce sens, la recherche scientifique n'est pas une évidence. Elle se présente plutôt comme un objet d'interprétations. Cela implique que la recherche scientifique, autant la recherche fondamentale que la recherche avec des visées pratiques, ne doit pas s'autonomiser dans la mesure où elle trouverait sa légitimité dans sa propre pratique. Pour le dire dans un langage plus philosophique, un concept pur, c'est une chose, tandis que la vie politique, c'est-à-dire la vie en commun, en est une autre. On ne peut pas les isoler les unes des autres. L'autarcie ou l'autonomisation n'est pas une option. Hobbes (4) a soutenu l'idée que la politique sert justement à protéger l'être humain contre lui-même, contre ses propres tendances.

Sinon, comme dans ce film, c'est la tragédie qui attend l'être humain : un retournement contre soi. Une visée bonne qui s'avère finalement un tourment. C'est le cas du fait que les protagonistes n'entrent pas en dialogue avec les autres préoccupations où chacun se suffit à lui-même. Chacun est seul avec ses arguments, comme Créon et Antigone dans la pièce de Sophocle du même nom (5). Ce film en est un sur la place du désir dans nos vies. Ce n'est pas parce que je désire quelque chose qu'automatiquement je dois accomplir mon désir. Il y a des désirs qui encourent notre perte. Surtout tous ces désirs qui ne sont pas accompagnés d'une profonde réflexion. Il convient de demeurer dans les limites de notre finitude et accepter que nous soyons des mortels et que nous ne puissions pas tout connaître et tout faire. Souvent, il faut l'apprendre à la dure : pathos mathei disaient les Grecs anciens. C'est peut-être cela la condition humaine, de reconnaître que nous sommes des loups qui cherchent à dominer pour dominer et apprendre de soi et de notre aveuglement dans la mort. Il en ressort, si je paraphrase Voltaire dans Zadig (6), que la recherche scientifique sur le vivant est une conduite à risque, mais nécessaire. Dans ce cas, nous devons nous en remettre à la prudence qui consiste à établir une distance qui, à son tour, sert de condition de possibilité au dialogue. Un dialogue, non pas pour convaincre, mais pour aiguïser le regard. Ce regard est à construire autour du pire et du meilleur qui s'adressent à notre imagination.

Ce film est conduit par une main de maître, où chaque image est symbole et, par conséquent, donne à penser. Au-delà de sa valeur esthétique, il touche à une vérité profonde, comme quoi il n'y a pas que la science qui donne accès à la vérité, mais aussi l'art.

Ce film présente une grande valeur pédagogique dans l'enseignement de l'éthique autant dans le champ de l'éthique de la recherche scientifique que dans le champ de la bioéthique et de l'éthique clinique ainsi que dans d'autres champs disciplinaires. Il pose surtout une question incontournable : qu'est-ce qui rend humain encore plus humain? Ou qu'est-ce qui manque à l'humain que les performances techniques ne peuvent combler? Un début de réponse c'est la compassion, l'amour et la fragilité de la condition humaine.

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

When You Are Hurt, Does It Bleed?

Christopher Agustin^a

Résumé

La douleur, qu'elle soit physique ou émotionnelle, reflète les épreuves qui façonnent l'existence humaine. Les blessures et les cicatrices symbolisent la souffrance, la guérison et la résilience, révélant comment l'adversité contribue à l'épanouissement personnel et à la découverte de soi. Malgré les épreuves de la vie, l'espoir et la force émergent, permettant à chacun d'aller de l'avant avec davantage de compassion et de compréhension.

Mots-clés

douleur, souffrance, sang, attention, émotion, identité

Abstract

Pain, whether physical or emotional, reflects the struggles that shape human existence. Wounds and scars symbolize suffering, healing, and resilience, revealing how adversity contributes to personal growth and self-discovery. Despite life's hardships, hope and strength emerge, allowing individuals to move forward with greater compassion and understanding.

Keywords

pain, suffering, blood, care, emotion, identity

Affiliations

^a Kalinga State University, Kalinga, Philippines

Correspondance / Correspondence: Christopher Agustin, christopheragustin02@gmail.com

In the realm of humans, pain tells its tale,
A story of suffering, both fragile and frail.
Wounds that appear from a cut or a fall,
With blood that flows freely, a silent call.

Each drop, a whisper from cells in despair,
Pleading for solace, for tender care.
Our bodies embark on a journey to mend,
With hope in our hearts that we'll soon transcend.

Yet beneath the smiles, in shadows they creep,
Emotional wounds, in silence, they seep.
Every tear that cascades feels like a plea,
Our souls, they are bleeding, longing to be free.

The scars of the heart, they linger and stay,
Each sorrow and loss, a mark on our way.
They shape who we are, a part of our core,
In the fabric of life, they weave evermore.

Physical pain and emotions entwined,
A symbol of living, of the trials we find.
Yet through every hardship, there's a flicker of light,
A chance to rise up, to embrace the fight.

To heal and to learn, to love with our scars,
In this voyage of life, we reach for the stars.
For pain, in all forms, is part of our quest,
A journey of growth, where we strive for our best.

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TÉMOIGNAGE / PERSPECTIVE

Regarder vers le passé pour anticiper l'avenir de l'éthique de la santé des populations : Conclusions tirées de l'expérience du Réseau de recherche en santé des populations du Québec

Matthew Hunt^a, Tzvetelina Tzoneva^b, Vincent Couture^c, Alexandra Larocque^d

Résumé

Cet article pose un regard critique sur l'évolution de l'éthique en santé des populations, le chemin parcouru et les orientations à prendre à travers les expériences de l'axe Éthique du Réseau de recherche en santé des populations du Québec (RRSPQ) depuis son inauguration en 2009 jusqu'à sa dissolution au début de l'année 2025. L'article est composé de trois parties. Tout d'abord, les auteurs décrivent le développement dans le domaine de l'éthique de la santé des populations, en particulier dans le contexte québécois, en se basant sur les sujets clés qui ont été prioritaires par l'axe Éthique et ses membres. Ensuite, après une analyse de la littérature disponible, ils identifient plusieurs priorités de recherche actuelles. En dernier lieu, les auteurs analysent de près les activités de transfert de connaissances et de renforcement des capacités dans ce domaine de recherche et de pratique. Compte tenu de l'importance des approches interdisciplinaires, ils suggèrent de développer de nouvelles opportunités de formation qui impliquent un apprentissage expérientiel et immersif offrant des perspectives diverses et des approches disciplinaires variées.

Mots-clés

santé environnementale, éthique, technologie de la santé, pandémie, santé des populations, politique de santé, Québec

Abstract

This article takes a critical look at the evolution of public health ethics, the progress made, and the directions to be taken, drawing on the experiences of the Ethics Axis of the Quebec Population Health Research Network (RRSPQ) from its inception in 2009 until its dissolution in early 2025. The article consists of three parts. First, the authors describe developments in the field of public health ethics, particularly in the Quebec context, based on the key topics prioritized by the Ethics Axis and its members. Next, following an analysis of the available literature, they identify several current research priorities. Finally, the authors closely analyze knowledge transfer and capacity-building activities in this field of research and practice. Given the importance of interdisciplinary approaches, they suggest developing new training opportunities that involve experiential and immersive learning, offering diverse perspectives and varied disciplinary approaches.

Keywords

environmental health, ethics, health technology, pandemic, public health, health policy, Quebec

Affiliations

^a École de physiothérapie et d'ergothérapie, Université McGill, Montréal, Québec, Canada

^b École de travail social, Université du Québec à Montréal (UQAM), Montréal, Québec, Canada

^c Département de médecine sociale et préventive, École de santé publique, Université de Montréal, Montréal, Québec, Canada

^d Département de sciences biomédicales, Faculté de médecine, Université de Montréal, Montréal, Québec, Canada

Correspondance / Correspondence: Matthew Hunt, matthew.hunt@mcgill.ca

INTRODUCTION

Le Réseau de recherche en santé des populations du Québec (RRSPQ), financé par le Fonds de Recherche du Québec – Santé (FRQS), a été inauguré en 2003. Il est devenu un acteur de l'avancement de la recherche en santé des populations. Au fil des années, le Réseau s'est progressivement structuré autour de divers domaines thématiques et la composition de ces axes a été périodiquement mise à jour. L'axe Éthique a été intégré en 2009 et aura dès lors un rôle transversal au sein du Réseau et sera amené à collaborer étroitement et de manière interdisciplinaire, non seulement avec les autres axes, mais aussi avec la communauté scientifique.

Le RRSPQ a été dissous en mars 2025 après plus de 20 ans d'existence. Cette fin conjoncturelle et inattendue a nourri notre intérêt à décrire l'évolution de l'éthique en santé des populations par l'entremise des travaux réalisés par l'axe. Pour ce faire, nous avons consulté les archives de l'axe afin d'analyser les documents disponibles. Nous avons également recensé les études et les rapports récents afin de rendre compte des questions prioritaires actuelles et émergentes pour le domaine.

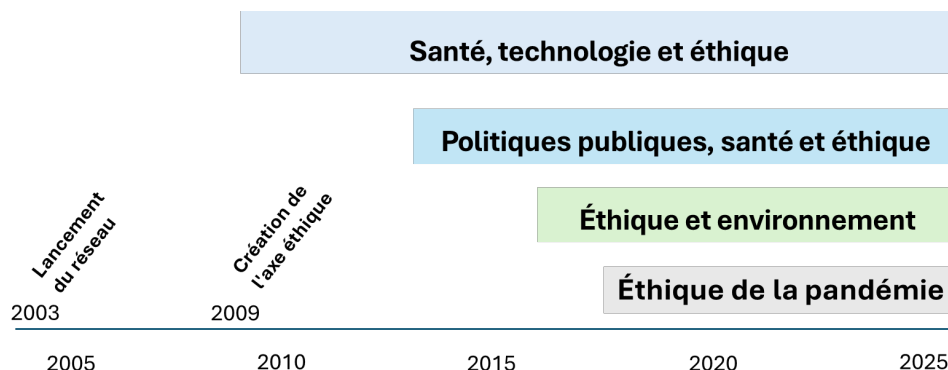
Nos réflexions sont organisées en trois parties, soit les développements dans les domaines de l'éthique et de la santé des populations au Québec, les avenues de recherche que nous considérons comme prioritaires pour les années à venir, et la formation et le renforcement des capacités dans le domaine de l'éthique et de la recherche en santé des populations.

REGARD VERS LE PASSÉ : ÉVOLUTION DES PRIORITÉS EN MATIÈRE D'ÉTHIQUE DE LA SANTÉ DES POPULATIONS SOUS L'ANGLE DE L'AXE ÉTHIQUE DU RRSPQ

Au cours de seize années, l'axe Éthique a soutenu un nombre important d'activités, d'initiatives et de projets, organisés en collaboration avec les autres axes du Réseau (Politiques publiques et santé, Santé mondiale, Santé mentale, Technologies de l'information et de la communication et santé, et Inégalités sociales de santé et équité). Reflétant ces orientations interdisciplinaires, les approches méthodologiques utilisées par les équipes financées par l'axe ont également été variées, avec une préférence pour la recherche empirique, souvent qualitative et pour des analyses normatives et théoriques des questions éthiques. On note aussi l'utilisation de méthodes participatives et de co-construction, ainsi que des approches artistiques.

En 2009, les thématiques prioritaires d'enquête étaient les questions éthiques de la surveillance de la santé publique, la promotion de la santé, les structures et les politiques du système de santé, les risques de stigmatisation des groupes qui font l'objet d'interventions de santé publique et de moralisation découlant de la promotion de modes de vie sains. Au fil du temps, nous avons vu l'élargissement de ces domaines thématiques d'activité et des projets financés, illustrant l'étendue de la notion même de « santé des populations ». Cette diversité s'est reflétée dans les travaux qui ont examiné des sujets allant des impacts environnementaux sur la santé (1,2) à l'utilisation de l'intelligence artificielle (IA) dans les applications de soins de santé (3), en passant par les implications pour l'éthique et la santé des populations des politiques publiques (4). Pour illustrer ces développements, nous présenterons quatre groupes de thèmes qui reflètent l'évolution des préoccupations et des priorités (figure 1).

Figure 1 : Chronologie des thématiques de recherche marquantes dans les travaux de l'axe Éthique



Depuis la création de l'axe Éthique, les questions éthiques liées à l'utilisation des innovations technologiques dans le domaine des soins de santé et de la santé publique, telles que les applications mobiles et l'IA, ont constitué un domaine d'études important. Plusieurs recherches financées visaient d'ailleurs l'étude approfondie des implications éthiques associées à un développement technologique spécifique, tels que le télétravail en tant que moyen d'adaptation pour les personnes en situation de handicap et la manière dont cette avancée technologique a influencé leur intégration et leur maintien sur le marché du travail (5). Il en est de même pour les technologies qui ont influencé les normes et les attentes en matière de pratique éthique telles que l'utilisation du Web 2.0 qui transforme les normes de pratique professionnelle des physiothérapeutes au Québec et en France (6).

Un autre domaine d'intérêt, qui a profondément marqué les activités de l'axe durant la dernière décennie, concerne l'intersection de l'environnement et de la santé. Plusieurs projets financés se sont concentrés sur les changements climatiques et l'éco-anxiété chez les jeunes, d'autres sur les déplacements de populations résultant des changements climatiques. Une initiative conjointe avec l'axe Santé mondiale a impliqué le développement de plusieurs éléments : une [formation en ligne](#), des histoires illustrées, des baladodiffusions et des webinaires via le développement et la mise en ligne du [climigrant.org](#), et ceci afin de sensibiliser la population étudiante aux questions liées à la migration climatique. Le cours de formation en ligne comporte entre autres une section sur l'éthique et les considérations relatives aux droits humains en contexte de migrations climatiques auquel s'ajoutait un module sur la justice climatique.

Un troisième domaine d'intérêt concerne les politiques publiques et la santé des populations. La banque d'études de cas [PolÉthicas](#), lancée en 2017 en collaboration avec l'axe Politiques publiques et santé des populations, comprend 18 études de cas. Elle est disponible en ligne et vise à soutenir l'enseignement et la formation. Plusieurs cas analysent les dimensions éthiques des politiques de santé gouvernementales spécifiques, notamment une politique axée sur la prise en charge de la maladie d'Alzheimer et une autre sur la gestion des soins primaires pour les maladies chroniques. Une deuxième série de cas porte sur les politiques publiques à une échelle plus globale qui influencent les déterminants sociaux de la santé. Les questions environnementales ont souvent été abordées, notamment celles en lien avec la fracturation hydraulique, l'accès à l'eau potable, l'utilisation résidentielle de pesticides et l'impact des changements climatiques sur l'équité en matière de santé.

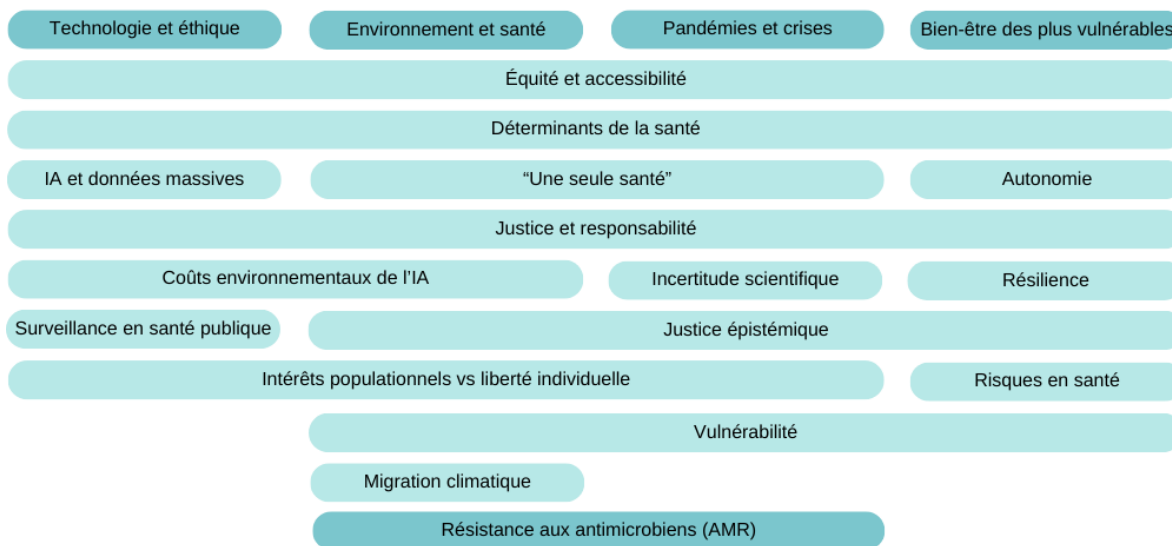
Comme la plupart des entités de recherche, l'axe Éthique a réorienté sa programmation au printemps 2020 en raison de la pandémie de la COVID-19. Des activités et des sujets anciennement jugés prioritaires ont été suspendus ou reportés, et de nouveaux concours « d'intervention rapide » ont été lancés pour répondre aux nouvelles préoccupations de recherche liées à la pandémie. Compte tenu de l'importance des considérations éthiques dans la réponse à la pandémie, cette période a été extrêmement active pour l'axe et ses membres. Alors que l'intensité de la pandémie diminuait, l'axe a cherché à créer des espaces de réflexion critique sur les leçons à tirer de cette période et à examiner ce qui a été fait et pourquoi. À titre d'exemple, l'axe a coorganisé, avec le Centre de recherche en éthique (CRÉ), des événements publics sur l'hésitation vaccinale et sur le rôle des médias dans la communication scientifique. L'axe Éthique a également collaboré avec la Commission d'éthique en science et technologie (CEST) sur la réalisation d'une cartographie des mandats, des activités et des liens entre les groupes impliqués dans la consultation éthique auprès du gouvernement du Québec dans le domaine de la santé publique. Ce processus a permis d'organiser une journée d'étude et de réflexion qui a rassemblé ces acteurs clés pour partager leurs expériences et leurs points de vue sur la manière de se préparer à de futures crises sanitaires. Finalement, cette activité a servi de base à l'élaboration d'un numéro spécial de la *Revue canadienne de bioéthique* (7).

Cette capacité de l'axe à réagir à des événements externes d'importance pour le domaine s'est aussi manifestée lors de la réforme majeure du système de santé québécois qui a eu lieu en 2015. Plus concrètement, l'axe a soutenu la réalisation par des étudiantes et étudiants en bioéthique et en santé publique d'une vidéo — [Les faits sur la loi 10](#) — afin de faire la synthèse des connaissances issues de discussions avec des chercheurs et chercheuses en administration de la santé à l'École de santé publique de l'Université de Montréal.

UN REGARD VERS L'AVENIR : THÈMES ET APPROCHES ACTUELS ET FUTURS POUR LA SANTÉ DES POPULATIONS ET L'ÉTHIQUE

L'histoire du Réseau démontre sa capacité à stimuler la recherche en éthique de la santé des populations. Cette histoire offre des pistes pour réfléchir aux domaines clés de recherche qui structureront le champ pour les années à venir. Si on croise cette histoire avec la collaboration de l'axe Éthique avec les autres axes du Réseau¹, il est possible de faire ressortir des domaines prioritaires de recherche dont cinq se distinguent (voir Figure 2).

Figure 2 : Domaine prioritaires de recherche en matière d'éthique de la santé des populations et leurs interconnexions



Le premier domaine prioritaire concerne les technologies de la santé et l'éthique. Les défis posés par l'utilisation combinée de l'IA et des données massives risquent de transformer de nombreux aspects de la santé des populations (8). La pandémie a mis en évidence de manière spectaculaire les compromis entre les avantages potentiels des systèmes numériques et automatisés de surveillance de la santé publique et la violation des droits individuels ainsi que la discrimination à l'encontre des populations marginalisées (9). Ces évolutions technologiques soulèvent également la question de l'adéquation des méthodes actuelles d'évaluation des technologies de la santé aux systèmes reposant sur l'IA et les données massives (10). Ces technologies pourront avoir un impact sur les déterminants de la santé des populations. Par exemple, les campagnes de désinformation alimentées par l'IA et ciblant une population spécifique peuvent, pour paraphraser John Rawls, altérer la

¹ Par exemple, des projets ont été réalisés avec l'axe Santé mondiale (la justice climatique), l'axe Politiques publiques (les dimensions éthiques des politiques), l'axe TIC et santé (l'éthique et le numérique) et l'axe Inégalités sociales de santé et équité (l'engagement citoyen).

condition démocratique préalable d'une société bien ordonnée (11). En effet, plusieurs auteurs mettent en évidence le fait que les décisions des individus sont fortement influencées par la nature et la qualité des informations auxquelles ils sont exposés et les sources auxquelles ils ont accès et affirment que l'environnement informationnel peut être considéré comme un déterminant social indépendant majeur de la santé (12). C'est pourquoi la vulgarisation et le transfert des connaissances permettra de rendre l'information accessible à une grande échelle et réduire ainsi les inégalités épistémiques. En outre, les coûts environnementaux de l'IA et leurs conséquences pour la santé des populations sont également examinés de près (3). En ce qui concerne l'éthique de la santé des populations, nous devons rester vigilants quant à la manière dont ces technologies transformeront le champ d'application des valeurs éthiques fondamentales de la santé publique. Un exemple parmi d'autre est celui de la banque de données contenant des renseignements personnels clinico-administratifs relatifs aux soins et aux services Med-ECHO (13), ou encore plus, celui de l'utilisation des applications de traçage durant la pandémie de la COVID.

Le deuxième domaine prioritaire vise à examiner l'intersection entre l'environnement et la santé, notamment en analysant les effets sur la santé des populations d'une triple menace constituée des changements climatiques, de la perte de la biodiversité, et de la pollution, ainsi que des transitions écologiques. Ces considérations représentent à la fois des déterminants proximaux et distaux de la santé (14). Sur ces enjeux, un ensemble de préoccupations éthiques tourne autour des questions de justice. Dans le contexte des changements climatiques et de la santé publique, le concept de justice climatique a fait l'objet d'une attention croissante et met en évidence « les inégalités sociales évitables et injustes en matière d'exposition, de vulnérabilité et les effets des mesures d'atténuation et d'adaptation au climat sur les inégalités en matière de santé » (15). Ces préoccupations en matière de justice alternent entre des questions générales de justice mondiale, telles que la redistribution des ressources des pays qui ont produit historiquement plus d'émissions de gaz à effet de serre aux pays qui subissent actuellement des effets disproportionnés des changements climatiques, et des questions plus locales liées à la manière dont le risque environnemental est réparti entre les quartiers et les municipalités. Par exemple, dans les contextes d'aridification ou de sécheresse, l'accès équitable à l'eau, en particulier à l'eau potable, est une préoccupation majeure en matière de justice et peut être une source de discorde et de conflit. Dans le cadre de la réponse aux problèmes de santé environnementale, les considérations de justice épistémique sont également importantes, notamment la manière dont les connaissances des différents groupes sont valorisées et créditées, ou au contraire sapées et rejetées. Ces préoccupations épistémiques ont été mises en évidence par le rejet répété des connaissances et des épistémologies autochtones, qui ont le potentiel d'améliorer la compréhension des déterminants écologiques de la santé (16). Conformément aux projets antérieurs de l'axe Éthique, le thème de la migration climatique met en évidence certaines de ces tensions et préoccupations, amplifiées par la politisation de la migration et par l'hostilité à l'égard des personnes migrantes dans de nombreux pays.

En ce qui concerne l'impact de l'environnement sur la santé et l'interdépendance écologique, des modèles tels qu'« Une seule santé » et celui de « santé planétaire » gagnent en influence. Une seule santé met l'accent sur l'interconnexion de la santé humaine, animale et écosystémique (17), tandis que le modèle de santé planétaire se concentre sur « l'analyse et la prise en compte des impacts des systèmes naturels déstabilisés sur la santé humaine et l'ensemble de la vie terrestre » (18). Les implications et orientations éthiques de ces approches sont de plus en plus examinées (19-21), mais elles méritent une analyse plus approfondie. Comme pour de nombreuses questions relatives à la santé des populations, ces approches invitent à prêter une attention particulière aux justifications éthiques des compromis, y compris aux limitations de la liberté individuelle dans le but d'éviter les préjudices collectifs (17), et, en particulier, dans une perspective de santé planétaire, aux préjudices causés aux générations futures (20).

Ces approches et préoccupations soulèvent des questions sur la manière dont la bioéthique est définie, avec un intérêt renouvelé pour la notion d'éthique du vivant de Potter au sens étymologique du mot grec « bios » (22). Paré et Bergeron rappellent que la « bioéthique proposée par Potter s'inscrit dans une démarche réflexive visant l'atteinte d'une forme de sagesse pratique » qui permet « d'arbitrer les connaissances entre elles aux fins du bien commun » (23, p.81). L'éthique peut alors devenir un guide qui permet de prendre en considération les situations écologiques avec la volonté de revenir sur ses sources réflexives et discursives en les inscrivant « dans un échange constant entre la théorie et la pratique » (23, p.81) en incorporant une préoccupation pour l'éthique écologique qui s'étend au-delà de celle pour la santé humaine pour analyser les relations entre l'homme et la nature (24). L'ouverture de l'étendue des bios considérés dans le champ de la bioéthique peut conduire à des voies alternatives non anthropocentriques.

Un troisième domaine prioritaire pour l'éthique de la santé des populations est la réponse aux urgences de santé publique. Des efforts importants doivent être consacrés à la préparation aux crises futures, y compris les pandémies et les multiples crises (*polycrisis*) qui interagissent et s'amplifient mutuellement. Nous avons l'obligation morale (25) de tirer des leçons des échecs passés (26) et entre autres, de planifier la réponse aux pandémies en termes de vaccination, de mise en quarantaine des personnes ou des animaux, de mobilité nationale et internationale, de contrôle de la migration des animaux sauvages et de circulation des aliments de consommation (27).

Les situations d'urgence en matière de santé publique sont caractérisées par la politisation, l'urgence, l'incertitude et la peur (28). La planification des modalités d'offre de conseils éthiques aux autorités publiques nécessite une attention particulière, notamment une meilleure communication sur l'incertitude scientifique et la prise de décision éthique, la protection

des membres les plus vulnérables de la société et l'amélioration de la capacité à travailler en collaboration avec les secteurs et les nations (26).

En connexion avec ces trois domaines prioritaires se situe un quatrième domaine ciblant une préoccupation transversale pour la santé des populations et le bien-être des groupes sociaux qui connaissent une vulnérabilité accrue. Prenant racine dans les fondements égalitaires de l'éthique de la santé publique (29), cette attention aux vulnérabilités influence les façons dont l'éthique technologique, environnementale et de crise est problématisée. Dans cette optique, l'éthique de la santé des populations vise à étudier ou à répondre aux besoins de ces groupes, tout en considérant les expériences des personnes concernées. Aborder ces sujets sous l'angle de l'éthique de la santé des populations peut aider à faire émerger des considérations liées à la façon dont les forces économiques, politiques et sociales contribuent à générer des risques de santé différentiels entre les groupes au sein de la société (30), ce qui permet de contraindre la production et le maintien des inégalités sociales.

Par exemple, l'analyse éthique peut porter sur la prestation de soins à des personnes dont l'autonomie fonctionnelle est réduite, sur les problèmes d'équité liés au travail non rémunéré, aux rôles genrés et aux conséquences sur la santé mentale (31), ou sur l'analyse des injustices rencontrées par les personnes en situation de handicap, notamment les attitudes capacitistes et les caractéristiques structurelles de la société qui sont invalidantes et inaccessibles. L'équité en matière de santé pour les personnes migrantes ou réfugiées suscite de nombreuses préoccupations, notamment en ce qui concerne l'accès aux soins de santé et le respect de leurs droits (32). La migration soulève d'autres questions éthiques, telles que le recrutement par les pays riches de personnels soignants formés à l'étranger et issus de milieux à faibles ressources (33). Ces recherches peuvent également explorer et remettre en question les notions de vulnérabilité et de résilience, ainsi que la manière dont ces concepts sont mobilisés dans le discours académique et politique.

Signalons un cinquième domaine prioritaire pour l'éthique de la santé des populations qui recoupe l'éthique des urgences de santé publique et de la santé environnementale : l'augmentation de la résistance aux antimicrobiens (ARM). Les antimicrobiens sont des médicaments destinés à prévenir et à traiter les infections chez les êtres humains, les animaux et les plantes. En raison d'une utilisation excessive et abusive de ces médicaments, les bactéries, les champignons et les parasites ne réagissent plus à ces produits. Il s'agit d'une menace sanitaire mondiale majeure et croissante pour les générations actuelles et futures (34). Littman et Viens (35) soulignent que les questions éthiques se posent au niveau des rencontres cliniques entre les patients et les cliniciens, jusqu'aux politiques mondiales liées au développement et à l'utilisation des médicaments, nécessitant un engagement commun pour réduire la propagation et le fardeau de l'ARM dans l'intérêt de tous. Les questions de justice et de responsabilité à l'échelle mondiale sont au cœur des préoccupations, étant donné que les effets de l'ARM sont plus prononcés dans les pays à revenu faible ou moyen (35,36). Pour répondre à l'ARM, il faudrait améliorer l'accès équitable aux médicaments, aux technologies de diagnostic et aux soins de santé (34,35).

FORMATION ET RENFORCEMENT DES CAPACITÉS

L'un des principaux objectifs de l'axe Éthique a été d'encourager le développement de la capacité de recherche au Québec afin de répondre aux questions éthiques urgentes dans le domaine de la santé des populations. Cet objectif a été poursuivi par l'organisation de cours de formation, d'événements de réseautage, d'écoles d'été, de séminaires et de webinaires, et par l'offre de financement, telles que des bourses d'études. L'axe a également soutenu la formation continue en matière d'éthique pour les praticien(ne)s de la santé publique, notamment par l'élaboration de capsules vidéo et d'études de cas. Un défi crucial pour l'avenir de l'éthique en santé des populations est d'assurer la pérennité de ces apprentissages, afin de renforcer les compétences des étudiant(e)s des programmes professionnels et de recherche en santé publique, ainsi que le développement continu pour les praticien(ne)s de la santé publique (37). Il serait également bienvenu de développer de nouvelles opportunités de formation qui impliquent un apprentissage expérientiel et immersif offrant des perspectives diverses et des approches disciplinaires variées.

CONCLUSION

La dernière décennie et demie a été riche en collaborations, en recherches, en réseautage, en formation, en développement de ressources, en discussions, en apprentissages et en plaidoyers. En cette fin de cycle, il nous a semblé important de réfléchir aux enseignements que l'on peut tirer de cette histoire, tout en nous tournant vers l'avenir afin d'étudier les questions éthiques urgentes qui se posent aujourd'hui et de prévoir celles qui se poseront demain. Au Québec, nous pouvons compter sur la richesse de la recherche et de la formation universitaire en bioéthique, sur la présence d'institutions telles que le CESP, le CEST et la Commission à la santé et au bien-être ainsi que sur l'apport bénéfique de personnes et de groupes engagés dans la défense et l'action en faveur de l'équité en matière de santé. Nous espérons que perdureront des espaces et des moyens permettant aux personnes de différents horizons de se réunir, ici et ailleurs, pour faire avancer le domaine de l'éthique et de la santé des populations.

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Conflicts of Interest

None to declare

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TÉMOIGNAGE / PERSPECTIVE

Epistemic and Linguistic Injustice in Research: Sharing Experiential Knowledge

Marie-Josée Drolet^a, Valérie Lafond^b, Louis Pierre Côté^b

Résumé

Cet article traite d'une question rarement abordée et pourtant cruciale dans le monde académique: l'hégémonie épistémique de la langue anglaise et ses effets néfastes sur les personnes chercheuses non anglophones. En nous appuyant sur des écrits existants, des notions théoriques de nature éthique et nos savoirs expérientiels, nous mettons en lumière certaines des injustices épistémiques et linguistiques au cœur de la recherche. Cette domination linguistique sape la crédibilité de certaines personnes chercheuses, perpétue l'exclusion et a un impact sur la production de connaissances. Nous réalisons des exercices de pensée à partir d'expériences vécues pour illustrer comment cette hégémonie linguistique pénalise les personnes qui sont contraintes d'écrire, de présenter et de publier dans une langue autre que leur langue maternelle. Ces pratiques accentuent les sentiments de honte, érodent la confiance en soi et restreignent l'accès aux financements, aux distinctions et aux lieux de publication réputés. Nous utilisons le coin model de Nixon pour souligner comment des privilèges non mérités sont conférés aux personnes chercheuses anglophones, alors que les personnes chercheuses non anglophones sont confrontées à plusieurs barrières invisibles. Bien que l'anglais puisse servir de médium unificateur en science, son hégémonie réduit la diversité des perspectives, pourtant nécessaires pour faire face aux crises mondiales urgentes. Les injustices linguistiques et épistémiques nuisent non seulement à la carrière des personnes chercheuses non anglophones, mais aussi à l'effort scientifique collectif, en excluant des corpus de connaissances publiées ou partagées dans d'autres langues que l'anglais. Suivant Amano et ses collègues, nous plaçons en faveur d'une diffusion multilingue, d'un engagement conscient à l'égard des écrits non anglophones et d'une reconnaissance des contributions des personnes chercheuses non anglophones. Il importe d'établir un dialogue plus ouvert en faveur de la diversité linguistique en recherche.

Mots-clés

injustice épistémique, injustice linguistique, domination de la langue anglaise, personnes chercheuses non anglophones, inégalités académiques, diversité linguistique

Abstract

This article discusses a rarely addressed yet pivotal issue in academia: the epistemic hegemony of the English language and its detrimental effects on non-English-speaking researchers. Drawing on existing literature, ethical theoretical concepts, and our own experiential knowledge, we illuminate some of the epistemic and linguistic injustices embedded in academic systems. This linguistic domination undermines scholarly credibility, perpetuates exclusion, and affects knowledge production. We integrate thought experiments based on personal experiences to illustrate how this linguistic hegemony penalizes those compelled to write, present, and publish in a language other than their mother tongue. Such practices heighten feelings of shame, erode self-confidence, and restrict access to funding, honours, and reputable publication venues. We employ Stephanie Nixon's coin model to underscore how unearned privileges are conferred on native English speakers while non-English-speaking academics face myriad invisible barriers. Although English may serve as a unifying medium, its disproportionate dominance curtails the diversity of perspectives needed to address pressing global crises. Linguistic and epistemic injustices harm not only individual researchers' careers but also the collective scientific endeavour by excluding vast bodies of knowledge published or shared in other languages. Building on Amano et al., we advocate for multilingual dissemination, conscious engagement with non-English literature, and recognition of non-English-speaking researchers' contributions. There needs to be broader dialogues aimed at upholding and celebrating linguistic and cultural diversity in research.

Keywords

epistemic injustice, linguistic injustice, English-language dominance, non-English-speaking researchers, academic inequities, linguistic diversity

Affiliations

^a Département d'ergothérapie, Université du Québec à Trois-Rivières, Trois-Rivières, Québec, Canada

^b Département de philosophie et des arts, Université du Québec à Trois-Rivières, Trois-Rivières, Québec, Canada

Correspondance / Correspondence: Marie-Josée Drolet, marie-josée.drolet@uqtr.ca

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INTRODUCTION

This article, originally written in a language other than our mother tongue, is not politically correct. It addresses a sensitive (indeed, often taboo) issue in research. It exposes a reality that non-English-speaking researchers often experience, yet only a few feel able to voice publicly without embarrassment or shame. This silence perpetuates the impact of English-language dominance on their careers, mental health, and the production of knowledge. Furthermore, many remain unaware of the epistemic (1,2) and linguistic (3) injustices arising from the global hegemony of English in contemporary research dissemination. By drawing on existing scholarship, theoretical ethical frameworks, and our own experiential insights, this article seeks to illuminate these underexamined injustices which merit urgent attention.

We acknowledge the convenience of English in uniting researchers globally, offering a common foundation on which to build and share knowledge. Namely, for non-native speakers, this choice requires them to expand their linguistic skills to acquire and use a new language. This effort, in turn, expands their perspectives and opens new cultures to them. As well, selecting a primary language of communication is a rational choice, particularly in a multilingual context. In European institutions, for example, the adoption of English as a working language has become essential for their operation.

Still, our intention in this text is to highlight the disproportionate consequences of this linguistic domination. In so doing, our intention is also to unveil some of the epistemic and linguistic injustices that flow from it, while specifying what we collectively lose by turning our backs on linguistic and cultural diversity in research. Following Amano et al. (1), we believe that such diversity is required to adequately respond to many contemporary problems, including the climate and biodiversity crisis and social injustices.

SPEAKING OUT TO BREAK THE SILENCE AND OVERCOME ETHICAL BLINDNESS

Like many non-native English-speaking researchers, we, the authors of this article, have been confronted with the hegemonic English-speaking culture since our entry into the academic world, without having had the courage until now to broach this sensitive subject outside our usual safe spaces of expression. In writing these lines, we feel as if we are taking a risk, treading on slippery ground, or even on fragile ice that could break beneath our feet. In fact, we harbour a certain apprehension we might even call fear. That said, the current context of valuing equity, diversity and inclusion has prompted us to speak out publicly to highlight some of the epistemic and/or linguistic injustices we face daily or have faced in the past. Another factor that prompted us to speak out was the fact that, over the past few years, we have noticed a number of changes among our English-speaking colleagues, namely an openness to considering French-language research literature (not just English-language literature), to including French-speaking participants in empirical research (not just English-speaking participants), and to giving more credibility to certain French-speaking researchers. These attitudes and behaviours of inclusion, of valuing francophone culture and of respect encourage us today to take a stand and denounce the injustices that occur in research based on language of expression.

In this article, we are not pointing fingers. Rather, we wish to highlight an oppressive norm that is taken for granted: that it is normal, desirable and justified for research to be carried out mostly in English and that, consequently, to do good research, one must communicate and publish in English (and ideally in international journals with high impact factors). Of course, one can disseminate in their native tongue or use a specific language tied to a discipline or topic (e.g., Spanish revolution, New France literature), but their impact factor may be lesser overall.

It is this domination of English in knowledge dissemination that we wish to highlight and challenge, not the people who, for arbitrary reasons, were born and raised in English-speaking families. We have nothing against English or English-speaking cultures and people. We do, however, believe that the dominance of English in research creates significant epistemic and linguistic injustices for people who, for equally arbitrary reasons, are not native English speakers. In short, we argue here that the dominance of English in research should not be taken for granted. We believe that English's hegemony stems from a relationship of domination that needs to be exposed, questioned and challenged. This article therefore has a dual objective: to reveal the oppressive nature of this norm and to challenge it to imagine a world where research is equitable and inclusive of the world's linguistic and cultural diversities.

EXPOSING OPPRESSIVE NORMS MAKING ENGLISH THE LANGUAGE OF SCIENCE DISSEMINATION

To reveal the oppressive nature of this norm, we find Nixon's coin model useful (4). It provides a way of understanding how privileges (unjustified social advantages) and oppression (unjustified social disadvantages) are distributed within human societies. Nixon explains that human societies are systems of social inequality, in that every person receives, at birth, social advantages and/or disadvantages, without having otherwise earned them, but only because of who they are or represent. In this model, the coin corresponds to the system of social inequalities that distributes social advantages and disadvantages according to arbitrary distinctions to the various social groups that make it up.

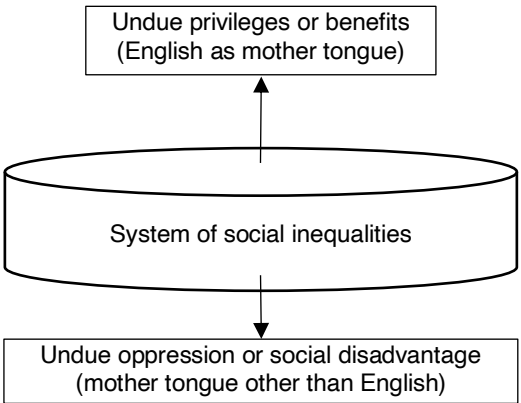
For example, in contemporary Western societies, men and people who are white, affluent, cisgender, heterosexual, neurotypical, young, educated, considered beautiful, and without experience of disability or mental health problems generally hold more social advantages (e.g., access to education, health, valued social positions, leisure, honours and various other social goods). Conversely, in contemporary Western societies, women, as well as those who are racialized, Indigenous, poor, trans*¹, non-heterosexual, neuroatypical, older, undereducated, not conforming to mainstream beauty standards, disabled, or living with mental illness, tend to have limited access to these benefits. They may also experience microaggressions or violence daily.

In academia, these systemic inequalities persist as well. For instance, studies show that women researchers receive fewer benefits, such as awards, fellowships, grants, and honours, than their male counterparts (7,8). What is more, researchers affiliated with "major" universities in urban centres are accorded more funding than those at "smaller" universities in regional

¹ Trans* is broadly used to encompass all the diverse identities spanning the gender and sexuality spectrums (5,6).

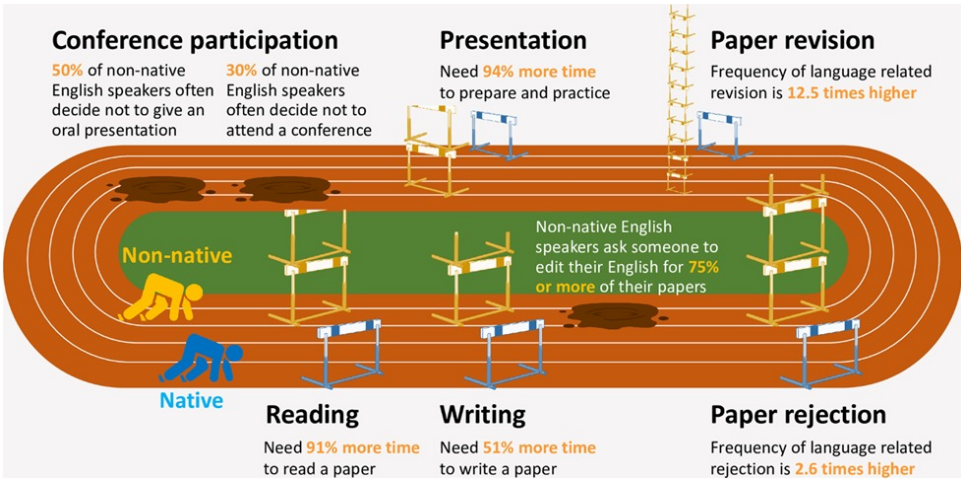
areas (9). These disparities are further exacerbated by the emphasis placed by granting agencies on English as the primary language for knowledge dissemination, making it more challenging for those whose first language is not English to access these advantages (10). Figure 1 depicts these inequities, which become more pronounced when researchers’ mother tongue differs from English.

Figure 1: Nixon’s 2019 coin model of privilege and oppression applied to the researcher’s mother tongue



In fact, researchers whose first language is English enjoy an unjust advantage: they can more readily read and write in English, do not require translation or editorial support, and feel comfortable participating in English-language conferences. In contrast, researchers whose mother tongue is not English face unwarranted obstacles when reading English texts, expressing themselves orally or in writing, publishing in scientific journals, participating in English-language conferences, and securing research grants and honors (see Figure 2).

Figure 2: Disadvantages of non-native English-speaking researchers in various scientific activities



Source: Amano (1)

How did we arrive at this situation? English became the dominant language of science for historical and political reasons, much as French was once predominant among Europe’s intellectual elite during the Enlightenment. There is no ethical explanation for why French dominated then or why English dominates now. According to Nixon’s model, privilege is a social advantage conferred on an individual not because they merit it, but solely due to arbitrary identity characteristics. The issue with privilege is that we are often unaware of the unfair advantages it provides, believing we deserve them based on our own efforts. Consequently, we take these benefits for granted and assume our entitlement to them. To underscore some of these unjustified advantages in research, we have chosen to illustrate specific privileges through thought experiments informed by our experiential knowledge (see Table 1).

Table 1: Thought experiments to highlight some privileges in research

Situation 1: reading texts	You are reading a scientific article as part of a doctoral seminar in order to give an oral presentation on its content. The English text uses a sophisticated, hermetic vocabulary with which you are unfamiliar. Chatting with your classmates, you ask them how long it took them to read the article. You soon realize that it took you more than twice as long as your English-speaking colleagues. Have you ever had to read articles written in a language other than English? If not, are there scientifically sound reasons for excluding non-English writing from your work? In other words, when you review literature, are you careful to include material written in a language other than English?
Situation 2: writing texts	An editor of a prestigious journal to which you have submitted an article claims that you are probably not a native English speaker, given the poor quality of your English, and demands that you have the English of your article edited by a native English speaker. As an English speaker, have you ever felt pressured to publish an article in a language other than your mother tongue? If so, have you ever been asked to revise the language of your article before or after the peer-review process? Have you ever been refused dissemination of relevant research results on the basis of the quality of your language? Have you ever paid someone to check the quality of your writing?
Situation 3: receiving honours	Recognized for your expertise and the high quality of your work, you are asked to be the keynote speaker at a prestigious international symposium, but no translation service from your mother tongue into English is available during the event, so you are uncomfortable speaking to a crowd of nearly a thousand people in English and hesitate to accept the honour. As an English speaker, have you ever been required to give a talk in a language other than your mother tongue in order to receive an honour? If such a request has been made, have you been provided with translation services or assistance? Have you refused an honour because you felt unable to express yourself properly in the language requested?
Situation 4: collecting writings	You are part of a team meant to carry out a literature review on a subject closely related to your expertise, which is why they are asking you to collaborate. Given your knowledge of the subject, you know that French, Portuguese, Japanese and English literature should absolutely be included. However, the team decides that only English-language material will be included. As an English-speaking person, has a team ever excluded English-language writing from a literature review on which you collaborated? If so, was the exclusion methodologically justified?
Situation 5: selecting research participants	You are part of a team meant to document ethical and epistemic issues in research. During methodological discussions, only English-speaking researchers are included in the sample. Pragmatic and financial reasons are put forward to justify this choice. As an English-speaking person, have you ever experienced the exclusion of English-speaking participants from research samples for pragmatic and financial reasons? If you have experienced such a situation, do you feel that these reasons were methodologically justified?
Situation 6: presenting at a conference	You conduct research in an innovative and cutting-edge field within your discipline. Year after year, you submit diversified paper proposals in your mother tongue for a conference that claims to be bilingual on a national scale. However, the papers you submit in the conference's non-dominant language are only accepted in poster presentation format, for which no simultaneous translation into the dominant language is offered, thus reducing the number of people attending your presentation and, by the same token, hindering the dissemination of innovative ideas. As an English speaker, have you ever had your proposals accepted in a format other than the one you had originally intended? If so, do you feel that this change influenced the dissemination of your results among your peers?
Situation 7: participating in a conference workshop	You are attending a workshop at a conference where English is the dominant language. The speakers ask you to discuss a topic with the people sitting next to you. As the discussion progresses, you feel you have relevant knowledge to share with your peers, but you hesitate to communicate it for fear of being misunderstood. As an English speaker, have you ever held back from communicating ideas to your peers? If so, was it because it was difficult for you to express yourself fluently and spontaneously in your second language?
Situation 8: obtaining grants or scholarships	A reviewer criticizes you for not publishing enough in English and feels that this is another reason why you do not deserve the scholarship or grant for which you have applied. As an English speaker, have you ever been criticized for not publishing enough in a language other than your mother tongue? Would you be able to publish a scientific article in a language other than your mother tongue? Would it take you longer to do so? Would you need to hire a translator or editor? Would you have the funding to pay for this person or for a specialised app?
Situation 9: using the services of a translator	With a team, you decide to submit a funding application to a granting agency. After consulting statistics showing that English-speaking researchers have higher success rates in a given country, you decide to submit the application in English, which means translating all team members' résumés and all requested documents into English. To do this, you decide that an extra month's work is required and hire a translator at a cost of \$5,000. However, following the evaluation, the reviewers consider your application to be poorly written and unclear, and do not recommend funding. As English is not your mother tongue, you were not able to detect any shortcomings in the translation. Have you ever paid a translator when applying for a grant? Has anyone ever commented on the poor quality of your language? Are you considering applying for funding in a language other than English?

These thought experiments capture only a few of our personal experiences. They aim to illustrate the tangible impact of linguistic domination on the daily lives of researchers and students whose mother tongue is not English. They demonstrate how such disadvantages affect career trajectories, self-perceptions of research capabilities, and mental well-being, especially when rejections and derogatory remarks accumulate.

CONTESTING HEGEMONIC ANGLOPHONE CULTURE WITH FACTS AND AN OVERVIEW OF THE RESULTING EPISTEMIC INJUSTICES

Let us pause to consider some statistics. In 2018, 95% of the world's population did not speak English as their mother tongue; more people had Mandarin or Spanish as their first language, and roughly the same number spoke Arabic and English (11). A closer look at mother tongues and languages spoken reveals that most people speak English neither as their first language

nor as a second language. More specifically, in 2020, only 16.5% of the global population spoke English, whether as a first or second language, despite its dominance in fields such as research and business (11). These figures show that most researchers also do not have English as their mother tongue (1). Nevertheless, they are compelled to use it as their working language, effectively making English their second or additional language. For these researchers, the need to learn and master English (or pay for translation and editing services for their communications, publications, and grant proposals) is an obligation native English speakers need not shoulder. This extra burden imposed on the majority is unjust and has come under growing criticism (1-3,12-14).

The dominance of English in science is not a given; rather, it constitutes an epistemic injustice. In her work, Fricker identifies two forms of epistemic injustice: testimonial and hermeneutical (15). (Other types of epistemic injustices are discussed in the literature (e.g., 16-20), but we focus here on these two categories, as they encompass the phenomena we wish to highlight.) Testimonial injustice occurs when a person is unfairly deemed less credible, while hermeneutical injustice arises when someone lacks the conceptual tools to articulate their experiences due to gaps in collective knowledge. Non-native English speakers frequently experience testimonial injustice, as they are often perceived as less credible when expressing themselves in spoken or written English. Struggles with pronunciation, fluency, or articulation can lead to misunderstandings or a diminished accuracy in conveying ideas, reinforcing biases against their intellectual contributions. At the same time, many non-native English-speaking researchers (ourselves included) have long lacked the language to articulate the discomfort and sense of injustice they experience in academia. Until recently, the discourse surrounding these issues failed to provide the epistemic resources necessary to fully grasp and challenge their exclusion, leaving them unable to name or resist the disadvantages they face.

IMAGINING A WORLD WHERE RESEARCH IS MORE EQUITABLE AND INCLUSIVE OF THE WORLD'S LINGUISTIC DIVERSITIES

While English serves as a bridge across scientific disciplines and facilitates exchanges among researchers (10), we envision a more equitable and linguistically inclusive scientific community, one where everyone can communicate, both orally and in writing, in their preferred language, ideally their mother tongue. Like Grenier et al. (10), we imagine academic journals publishing articles in multiple languages and symposia embracing multilingual discussions. We recognize that realizing this vision is challenging and fraught with obstacles (1-3,12-14). However, Amano et al. have already identified several actionable strategies to address these barriers, as illustrated in Figure 3.

Figure 3: Examples of potential solutions to reducing disadvantages for non-native English speakers in each type of scientific activity

	Paper reading	Paper writing Publication	Dissemination	Conference participation
 Supervisors Collaborators	- Acknowledge that non-native English speakers require more time to read articles in English - Consider the appropriate use of AI tools	- Acknowledge that non-native English speakers require more time to write in English - Provide English editing/find "buddies" to support non-native English speakers - Consider the appropriate use of AI tools	Value, financially support, and make efforts to disseminate research in multiple languages	Provide English editing for the preparation of presentations in English
 Universities Institutions	- Provide training opportunities for English reading - Incorporate materials in students' first language into education	- Provide training opportunities for English writing - Financially support English editing / translation (e.g., by establishing grant schemes)	Value, financially support, and make efforts to disseminate research in multiple languages	Financially support English editing / translation of presentations
 Journals	Support and encourage publishing the translation of English papers (e.g., by granting a copyright release)	- Develop guidelines (including double-blind review) to ensure decisions based solely on quality of science - Establish a "buddy" system for supporting non-native English speakers - Consider the appropriate use of AI tools	- Promote/provide non-English abstracts of English papers - Support and conduct dissemination in multiple languages (e.g., on social media)	
 Funders	Fund the translation of books and papers for education	Establish grant schemes to cover English editing/translation services, especially for those from lower income regions and at an early career stage	Value and fund plans to disseminate outcomes in multiple languages	Establish grant schemes to cover English editing/translation of presentations
 Conferences			Publish proceedings in multiple languages	- Establish a "buddy" system to support non-native English speakers - Promote multilingual presentations - Develop linguistically inclusive guidelines

Source: Amano (1)

CONCLUSION

This article aimed to highlight the epistemic and linguistic injustices faced by non-English-speaking people in academia. By drawing on existing literature, ethical theoretical concepts, and our own experiential knowledge, we sought to illuminate the inequalities embedded in academic systems and their consequences for those who endure them. Although language barriers disproportionately complicate knowledge dissemination for researchers whose mother tongue is not English, they are not the only ones affected. The limited discoverability of research published in languages other than English, understood as the availability and accessibility of content within a vast body of work (10,21), ultimately hinders scientific progress by rendering

unique and valuable contributions invisible. To mitigate epistemic and linguistic injustices and foster a more inclusive, respectful, and multilingual academic landscape, it is crucial to recognize the hegemonic dominance of English in research. In closing, we encourage those in academia who have the privilege of speaking English as their mother tongue to: 1) acknowledge this privilege as a significant advantage in an English-dominated field, 2) engage with research and scholarship produced in languages other than their own; 3) raise awareness among colleagues and collaborators about the inequalities present in academia, and 4) advocate for and support multilingual knowledge dissemination, thereby improving the discoverability of diverse scholarship and contributing to scientific progress (10).

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Injustices épistémiques et linguistiques en recherche : partage de savoirs expérientiels

INTRODUCTION

Cet article n'est pas *politically correct*. Il traite d'un sujet sensible, voire tabou, en recherche. Pourtant, il aborde une réalité que les personnes chercheuses qui n'ont pas l'anglais comme langue maternelle et qui ne la maîtrisent pas, que ce soit à l'oral ou à l'écrit, vivent souvent. Or, rares sont ces personnes qui osent en parler sur la place publique sans gêne, inconfort, ni honte pour dénoncer les impacts que la domination de l'anglais en recherche a sur leur carrière, leur santé mentale et l'état des connaissances. Aussi, rares sont ces personnes qui reconnaissent les injustices épistémiques (1,2) ou linguistiques (3) qui découlent de la culture hégémonique anglophone contemporaine qui caractérise la diffusion des connaissances. Cet article a pour objectif de mettre en lumière ces injustices peu discutées dans les écrits. Il prend appui sur des écrits existants sur le sujet, des notions théoriques de nature éthique ainsi que sur nos savoirs expérientiels.

Nous concédons d'emblée qu'il soit pratique qu'une langue commune — en l'occurrence l'anglais — unisse les personnes chercheuses de part et d'autre du monde et se présente comme un socle commun sur lequel bâtir l'édifice des connaissances. Nous reconnaissons que l'apprentissage d'une langue autre que sa langue maternelle contribue à étendre les capacités linguistiques des personnes, en plus de leur permettre de s'ouvrir à une autre culture et vision du monde. Nous estimons qu'il s'avère pratique et rationnel, dans un contexte de multilinguisme, qu'une langue partagée soit essentielle au bon fonctionnement de nos organisations.

Cependant, nous voulons dans ce texte mettre en exergue les conséquences disproportionnées qu'occasionne la domination linguistique de l'anglais dans la diffusion des connaissances. Ce faisant, notre intention est de lever le voile sur les injustices épistémiques et linguistiques qui en découlent, tout en spécifiant ce que nous perdons collectivement en tournant le dos à la diversité linguistique et culturelle en recherche. Car, comme Amano et al. (1), nous estimons que cette diversité est requise pour répondre adéquatement à maints problèmes contemporains, tels que la crise climatique et de la biodiversité ainsi que les injustices sociales.

OSER PRENDRE LA PAROLE POUR BRISER L'OMERTA ET METTRE FIN À L'AVEUGLEMENT ÉTHIQUE

À l'instar des nombreuses personnes chercheuses n'ayant pas l'anglais comme langue maternelle, nous, les personnes autrices de cet article, sommes confrontées à la culture hégémonique anglophone depuis notre entrée dans le monde académique, sans que nous ayons eu avant aujourd'hui le courage d'aborder ce sujet épineux à l'extérieur de nos espaces d'expression sécuritaires. En écrivant ces lignes, nous avons le sentiment de prendre un risque, de marcher sur un terrain glissant, voire sur une glace fragile qui pourrait briser sous nos pieds. De fait, une certaine appréhension, qui pourrait même être qualifiée de peur, nous habite. Cela dit, le contexte actuel de la valorisation de l'équité, de la diversité et de l'inclusion nous amène à sortir de notre silence et à oser prendre la parole publiquement pour discuter de certaines injustices épistémiques et linguistiques auxquelles nous sommes confrontées. Un autre élément qui nous a poussés à briser l'omerta est le fait que nous percevons, depuis quelques années, certains changements chez des collègues anglophones, soit une ouverture à considérer les écrits francophones en recherche (pas seulement les écrits anglophones), à inclure des personnes participantes francophones aux recherches empiriques (pas seulement des personnes anglophones) et à accorder plus de crédibilité à certaines personnes chercheuses francophones (pas seulement des personnes chercheuses anglophones). Ces attitudes et ces comportements empreints d'inclusion, de valorisation de la culture francophone et de respect nous encouragent aujourd'hui à prendre la parole et dénoncer les injustices qui surviennent en recherche sur la base de la langue d'expression.

Mentionnons que, dans cet article, nous n'accusons personne en particulier. Nous souhaitons plutôt dévoiler une norme oppressive tenue pour acquise et estimée comme allant de soi, soit qu'il est normal, désirable et justifié que la recherche se réalise majoritairement en anglais et que, par conséquent, pour faire de la bonne recherche, il faut idéalement communiquer et publier en anglais (et dans des revues internationales ayant de hauts facteurs d'impacts). Bien entendu, des personnes chercheuses peuvent diffuser dans leur langue natale ou dans la langue liée à leur objet d'étude (ex. révolution espagnole, littérature en Nouvelle-France), mais la portée de leurs travaux sera globalement moins grande. En bref, c'est la domination de l'anglais dans la diffusion des connaissances que nous souhaitons critiquer, nullement les personnes qui, pour des raisons arbitraires, sont nées ou ont grandi au sein de familles anglophones. Nous n'avons rien contre l'anglais ni contre les cultures et les personnes anglophones. Nous estimons cependant que la domination de l'anglais en recherche occasionne des injustices épistémiques et linguistiques pour les personnes qui, pour des raisons tout aussi arbitraires, n'ont pas l'anglais pour langue maternelle. En somme, nous défendons ici l'idée selon laquelle la domination de l'anglais en recherche ne devrait pas être tenue pour acquise ni aller de soi. Nous estimons que cette norme hégémonique résulte d'un rapport de domination qui doit être dévoilé, remis en cause et contesté. L'objectif de cet article est donc double : dévoiler la nature oppressive de cette norme et la critiquer en vue d'imaginer un monde où la recherche serait plus équitable et inclusive des diversités linguistiques et culturelles mondiales.

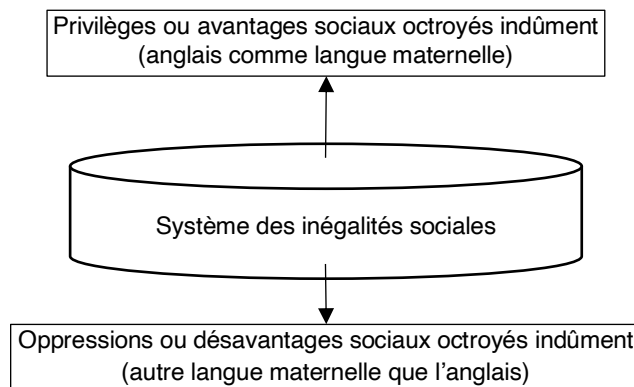
DÉVOILER LA NATURE OPPRESSIVE DE LA NORME SUIVANT LAQUELLE IL EST NORMAL DE FAIRE DE NOS JOURS DE L'ANGLAIS LA LANGUE DE LA DIFFUSION SCIENTIFIQUE

Pour dévoiler la nature oppressive de cette norme, le modèle de la pièce de monnaie proposé par Nixon est utile (4). Ce modèle permet de comprendre la façon dont sont distribués les privilèges (avantages sociaux injustifiés) et les oppressions (désavantages sociaux injustifiés) au sein des sociétés humaines. Nixon explique que les sociétés sont des systèmes d'inégalités sociales, en ceci que toute personne reçoit, dès sa naissance, des avantages ou des désavantages sociaux, sans qu'elle ne les ait mérités, mais seulement en raison de ce qu'elle est ou représente. Suivant ce modèle, la pièce de monnaie correspond au système des inégalités sociales qui distribue les avantages et les désavantages sociaux selon des critères arbitraires aux différents groupes sociaux qui le composent.

Par exemple, en général, dans les sociétés occidentales contemporaines, les hommes et les personnes blanches, nanties, cisgenres, hétérosexuelles, neurotypiques, jeunes, éduquées, considérées belles, sans expérience de handicap ou problème de santé mentale sont détentrices d'avantages sociaux (ex. : accès à l'éducation, à la santé, aux positions sociales valorisées, aux loisirs, aux honneurs et autres biens sociaux). À contrario, en général, dans les sociétés occidentales contemporaines, les femmes et les personnes racisées ou autochtones, pauvres, trans², non hétérosexuelles, neuroatypiques, âgées, peu éduquées, qui ne correspondent pas aux standards de beauté, qui ont une expérience du handicap ou un problème de santé mentale n'ont pas accès à ces avantages et peuvent subir diverses microagressions ou violences dans leur quotidien.

Dans le monde académique, ces systèmes d'inégalités ont également cours. Des études attestent que, par exemple, les femmes qui font de la recherche ont proportionnellement moins d'avantages, tels que des prix, bourses, subventions, honneurs, etc., que leurs collègues masculins (7,8). De plus, les personnes qui font de la recherche dans les soi-disant « grandes » universités en milieux urbains ont accès à davantage de financement que les personnes qui font de la recherche dans les soi-disant « petites » universités en région (9). Ces inégalités sont amplifiées par la valorisation de l'anglais comme langue de diffusion des connaissances par les organismes subventionnaires, ce qui complexifie l'accès aux différents avantages chez les personnes dont la langue maternelle diffère de l'anglais (10). La Figure 1 illustre ces disproportions qui sont accentuées lorsque les personnes chercheuses ont pour langue maternelle une autre langue que l'anglais.

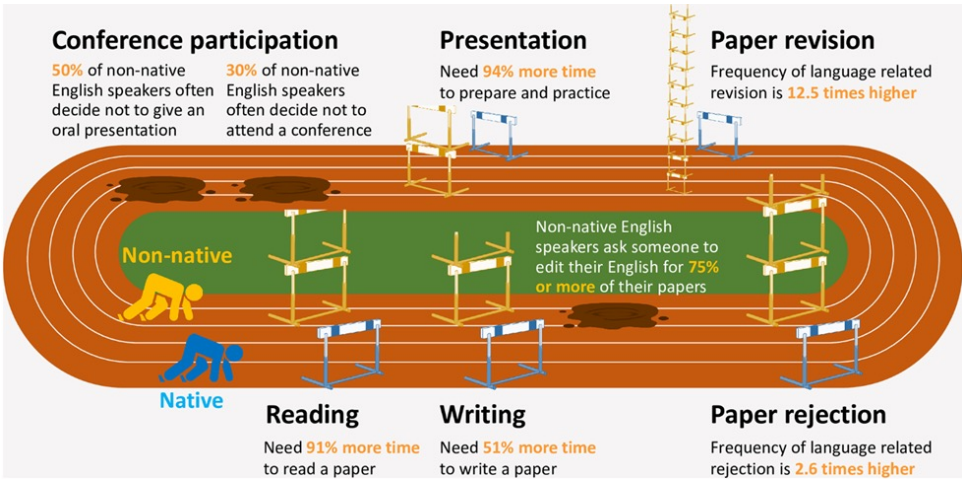
Figure 1 : Le modèle de la pièce de monnaie des privilèges et des oppressions de Nixon appliqué à la langue maternelle des personnes chercheuses



De fait, les personnes chercheuses qui ont l'anglais comme langue maternelle sont injustement privilégiées, c'est-à-dire qu'elles ont accès plus facilement à des avantages (ex. : lire et écrire aisément en anglais, ne pas nécessiter de traducteur ni de réviseur, ne pas hésiter à participer à un colloque en anglais, déposer des demandes de subvention en anglais), tandis que les personnes qui ont une autre langue maternelle que l'anglais sont injustement désavantagées, c'est-à-dire qu'elles sont défavorisées lorsqu'il est question de lire des textes en anglais, de s'exprimer oralement ou par écrit en anglais, de publier dans des revues scientifiques, de participer à des colloques en anglais, d'obtenir des subventions de recherche et des honneurs, etc. (voir la Figure 2).

² Le terme « Trans* » est utilisé au sens large pour englober la diversité des identités relatives aux spectres du genre et de la sexualité (5,6).

Figure 2 : Estimation des désavantages des personnes chercheuses qui n’ont pas l’anglais comme langue maternelle dans différentes activités scientifiques



Source: Amano (1)

Mais comment en sommes-nous arrivés à cet état de fait? L’anglais s’est imposé comme langue dominante en science pour des raisons historiques et politiques, tout comme le français dominait l’élite intellectuelle européenne au siècle des Lumières. Aucune raison éthique ne justifie que le français dominait alors et que l’anglais domine aujourd’hui.

Comme en rend compte le modèle de Nixon, un privilège correspond à un avantage social donné à un individu, non pas parce qu’il le mérite, mais en raison de caractéristique(s) identitaire(s) arbitraire(s). Le problème avec les privilèges est que nous sommes en général aveugles aux avantages injustes que nous avons et estimons que nous les méritons en raison des efforts que nous déployons au quotidien. Nous avons tendance à les tenir pour acquis et à estimer que nous les méritons pour de bonnes raisons. Pour mieux illustrer quelques avantages injustifiés en recherche, il nous est apparu pertinent d’illustrer certains privilèges par le biais d’exercices de pensée basés sur notre savoir expérientiel (voir le Tableau 1).

Tableau 1 : Exercices de pensées visant à révéler certains privilèges en recherche

Situation 1 : lire des textes	Vous êtes à lire un article scientifique dans le cadre d’un séminaire doctoral pour faire un exposé oral sur son contenu. Le texte en anglais utilise un vocabulaire sophistiqué et hermétique qui vous est peu connu. En discutant avec vos camarades de classe, vous leur demandez combien de temps ils ont mis pour lire l’article. Rapidement vous êtes à même de constater que vous avez mis plus du double de temps que vos collègues anglophones. Vous est-il déjà arrivé de devoir lire des articles rédigés dans une autre langue que l’anglais? Dans la négative, est-ce que des raisons scientifiquement fondées vous ont amené à exclure les écrits non anglophones de vos travaux? Autrement dit, lorsque vous faites des recensions d’écrits, prenez-vous soin d’inclure des écrits rédigés dans une autre langue que l’anglais?
Situation 2 : écrire des textes	Une personne éditrice d’un journal prestigieux dans lequel vous avez soumis un article affirme que vous n’êtes pas anglophone compte tenu de la piètre qualité de votre anglais et exige que vous fassiez réviser l’anglais de votre article par une personne anglophone. En tant que personne anglophone, avez-vous déjà senti une pression de publier un article dans une langue autre que votre langue maternelle? Si oui, vous a-t-on déjà demandé de réviser la langue de votre article avant ou après le processus de révision par les pairs? Vous est-il déjà arrivé de vous voir refuser la diffusion de résultats de recherche pertinents sur la base de la piètre qualité de votre langue? Avez-vous déjà payé une personne pour réviser la qualité de votre écriture?
Situation 3 : recevoir des honneurs	On reconnaît votre expertise et la grande qualité de vos travaux, de sorte qu’on vous demande d’être la personne conférencière d’honneur d’un colloque international prestigieux; or aucun service de traduction de votre langue maternelle vers l’anglais n’est disponible durant l’événement, ce qui fait en sorte que vous ne vous sentez pas à l’aise de parler à une foule de près de mille personnes en anglais et hésitez à accepter l’honneur. En tant que personne anglophone, a-t-on déjà exigé que, pour recevoir un honneur, vous deviez faire une conférence dans une langue autre que votre langue maternelle pour recevoir cet honneur? Si une telle demande vous a déjà été faite, vous a-t-on fourni un service de traduction ou de l’aide pour ce faire? Avez-vous refusé un honneur parce que vous ne vous sentiez pas capable de vous exprimer correctement dans la langue demandée?
Situation 4 : recenser des écrits	Vous faites partie d’une équipe qui souhaite réaliser une recension des écrits sur un sujet lié à votre expertise, raison pour laquelle on vous demande de collaborer. Compte tenu de vos connaissances du sujet, vous savez que des écrits francophones, portugais, japonais et anglais devraient absolument être inclus. Or, l’équipe décide que seuls les écrits anglophones seront inclus. En tant que personne anglophone, une équipe a-t-elle déjà exclu les écrits anglophones d’une recension des écrits à laquelle vous avez collaboré? Si vous avez vécu une telle situation, cette exclusion était-elle justifiée sur le plan méthodologique?

Situation 5 : sélectionner des participants de recherche	Vous faites partie d'une équipe qui souhaite documenter les enjeux éthiques et épistémiques en recherche. Lors des discussions méthodologiques, seules des personnes chercheuses anglophones sont incluses dans l'échantillon. Des raisons pragmatiques et financières sont avancées pour justifier ce choix. En tant que personne anglophone, vous est-il déjà arrivé que des personnes participantes anglophones soient exclues d'échantillons de recherche pour des raisons pragmatiques et financières? Si vous avez vécu une telle situation, ces raisons vous semblaient-elles justifiées sur le plan méthodologique?
Situation 6 : présenter dans un congrès	Vous effectuez de la recherche dans un domaine novateur et d'actualité au sein de votre discipline. Année après année, vous soumettez des propositions de communications diversifiées dans votre langue maternelle pour un congrès qui se dit bilingue à l'échelle nationale. Toutefois, les communications que vous proposez dans la langue non dominante du congrès sont uniquement acceptées en format de présentation par affiche, pour laquelle aucune traduction simultanée n'est offerte vers la langue dominante, diminuant ainsi le nombre de personnes assistant à votre présentation et, par le fait même, nuisant à la diffusion d'idées novatrices. En tant que personne anglophone, vous est-il déjà arrivé de voir vos propositions de communication acceptées dans un format autre que celui souhaité initialement? Si oui, estimez-vous que ce changement a influencé la diffusion de vos résultats?
Situation 7 : participer à un atelier dans un congrès	Vous assistez à un atelier dans le cadre d'un congrès où la langue dominante est l'anglais. Les personnes conférencières vous demandent de discuter d'un sujet avec les personnes assises près de vous. Au fil de vos échanges, vous estimez avoir des connaissances pertinentes à partager à vos pairs, mais vous hésitez à les communiquer par peur d'être incomprise. En tant que personne anglophone, vous est-il déjà arrivé de vous retenir de communiquer des idées auprès de vos pairs? Si oui, était-ce parce qu'il était difficile pour vous de vous exprimer de façon fluide et spontanée dans votre seconde langue?
Situation 8 : obtenir des bourses ou des subventions	Une personne évaluatrice vous reproche de ne pas publier suffisamment en anglais et estime que vous ne méritez pas, en outre pour cette raison, la bourse ou la subvention que vous avez demandée. En tant que personne anglophone, vous a-t-on déjà reproché de ne pas publier suffisamment dans une autre langue que votre langue maternelle? Seriez-vous en mesure de publier un article scientifique dans une autre langue que votre langue maternelle? Estimez-vous que cela vous prendrait plus de temps? Auriez-vous besoin d'engager un traducteur ou un réviseur pour ce faire? Auriez-vous le financement pour payer les services de cette personne ou l'utilisation d'une application?
Situation 9 : utiliser les services d'un traducteur	Avec une équipe, vous décidez de soumettre une demande de financement à un organisme subventionnaire. Après avoir consulté des statistiques à l'effet que les personnes chercheuses anglophones ont des taux de succès plus élevés au pays, vous décidez de soumettre la demande en anglais, ce qui implique de traduire en anglais les CVs de tous les membres de l'équipe ainsi que tous les documents demandés. Pour ce faire, vous décidez qu'un mois de travail supplémentaire est requis et embauchez un traducteur qui vous coûtera 5000\$. Or à la suite de l'évaluation, des membres évaluateurs estiment que votre demande est mal écrite et peu claire et ne recommandent pas le financement. Comme l'anglais n'est pas votre langue maternelle, vous n'avez pas été en mesure de détecter ses lacunes dans la traduction. Avez-vous déjà payé un traducteur lors d'une demande de subvention? Vous a-t-on déjà fait des commentaires sur la piètre qualité de votre langue? Envisagez-vous de déposer une demande de financement dans une autre langue que l'anglais?

Ces cas de figure ne constituent que quelques exemples que nous avons vécus. Il s'agissait ici de rendre plus concret l'impact que peut avoir cette domination linguistique au quotidien pour une personne chercheuse ou étudiante qui n'a pas l'anglais comme langue maternelle. Ils attestent notamment du fait que ces désavantages impactent la carrière des personnes qui les vivent, leur perception d'elles-mêmes quant à leurs capacités à faire de la « bonne » recherche ainsi que leur santé mentale, notamment lorsque les refus et les commentaires désobligeants se cumulent.

CONTESTER LA CULTURE HÉGÉMONIQUE ANGLOPHONE PAR QUELQUES FAITS ET LA DESCRIPTION DES INJUSTICES ÉPISTÉMIQUES QUI EN DÉCOULENT

Prenons un moment pour examiner quelques statistiques. Saviez-vous que 95% des êtres humains n'avaient pas, en 2018, pour langue maternelle l'anglais, que plus d'humains avaient pour langue maternelle le Mandarin ou l'Espagnol, et qu'un nombre équivalent d'humains avaient pour langue maternelle l'Arabe ou l'Anglais (11)? Lorsqu'on examine les statistiques des langues maternelles des humains et des langues parlées, il devient évident que la majorité des humains n'ont pas l'anglais pour langue maternelle ni comme langue seconde. En 2020, 16,5% de personnes parlaient l'anglais, soit comme langue maternelle, soit comme langue seconde (11), et ce, en dépit du fait que cette langue soit hégémonique dans plusieurs domaines comme la recherche et les affaires, par exemple. Ces statistiques attestent du fait que la majorité des personnes chercheuses n'ont pas l'anglais comme langue maternelle (1). Pourtant, celles-ci se font cependant imposer l'anglais comme langue de travail, laquelle devient de ce fait leur langue seconde ou autre. En effet, considérant que la majorité des personnes chercheuses n'ont pas comme langue maternelle l'anglais, cela implique que la majorité des personnes chercheuses doivent apprendre l'anglais, maîtriser suffisamment cette langue ou payer une personne ou un logiciel pour traduire ou réviser leurs communications, publications ou demandes de subventions, ce que bien évidemment les personnes anglophones n'ont pas à faire. Ce fardeau supplémentaire imposé à la majorité des personnes chercheuses est inéquitable et de plus en plus dénoncé (1-3,12-14).

De fait, cette domination de l'anglais en science ne va pas de soi. C'est, à notre avis, une injustice épistémique. Dans son ouvrage, Fricker distingue deux types d'injustices épistémiques, soit l'injustice testimoniale et l'injustice herméneutique (15). (De nombreux autres types d'injustices épistémiques sont abordés dans la littérature (ex. : 16-20), mais nous nous concentrons ici sur ces deux catégories, car elles englobent les phénomènes que nous souhaitons mettre en avant.) Ainsi, si

l'injustice testimoniale a trait au manque de crédibilité injustement accordée à une personne, l'injustice herméneutique a trait au fait qu'une personne ne parvienne pas à rendre compte de certaines de ses expériences dans les ressources épistémiques existantes. De fait, plusieurs personnes, qui n'ont pas l'anglais comme langue maternelle, sont parfois injustement estimées moins crédibles lorsqu'elles tentent de s'exprimer en anglais à l'oral ou à l'écrit. Les difficultés que plusieurs d'entre elles rencontrent lorsqu'elles osent prendre la parole en anglais ou leur façon différente de prononcer certains mots fait en sorte que leurs propos peuvent être mal compris ou leurs idées exprimées d'une manière moins précise et fidèle à leur pensée. De plus, jusqu'à très récemment, plusieurs parmi elles (c'est notre cas) n'avaient pas accès à des mots leur permettant de mettre le doigt sur le malaise et le sentiment d'injustice qui les habitent depuis leur entrée dans le monde académique. C'est comme si les connaissances entourant ces expériences d'injustice n'offraient pas les ressources épistémiques leur permettant de comprendre la situation et de la dénoncer.

IMAGINER UN MONDE OÙ LA RECHERCHE EST PLUS ÉQUITABLE ET INCLUSIVE DES DIVERSITÉS LINGUISTIQUES MONDIALES

Bien que l'anglais agisse à titre de pont qui rallie différents domaines scientifiques et facilite les échanges entre les pairs (10), nous rêvons d'une science plus équitable et inclusive des diversités linguistiques, où chacun et chacune a la possibilité de communiquer à l'oral et à l'écrit dans la langue de son choix, idéalement dans sa langue maternelle. Tout comme Grenier et ses collègues (10), nous imaginons des journaux qui publieraient des articles dans plusieurs langues, de même que des colloques multilingues. Nous savons que ce rêve n'est pas évident, qu'il se heurte à plusieurs barrières difficiles à surmonter (1-3,12-14), mais l'équipe d'Amano et collègues a identifié quelques pistes d'action possible comme l'illustre la Figure 3.

Figure 3 : Exemples de solutions potentielles pour réduire les désavantages rencontrés par les personnes chercheuses non anglophones dans diverses activités académiques

	Paper reading	Paper writing Publication	Dissemination	Conference participation
 Supervisors Collaborators	- Acknowledge that non-native English speakers require more time to read articles in English - Consider the appropriate use of AI tools	- Acknowledge that non-native English speakers require more time to write in English - Provide English editing/find "buddies" to support non-native English speakers - Consider the appropriate use of AI tools	Value, financially support, and make efforts to disseminate research in multiple languages	Provide English editing for the preparation of presentations in English
 Universities Institutions	- Provide training opportunities for English reading - Incorporate materials in students' first language into education	- Provide training opportunities for English writing - Financially support English editing / translation (e.g., by establishing grant schemes)	Value, financially support, and make efforts to disseminate research in multiple languages	Financially support English editing / translation of presentations
 Journals	Support and encourage publishing the translation of English papers (e.g., by granting a copyright release)	- Develop guidelines (including double-blind review) to ensure decisions based solely on quality of science - Establish a "buddy" system for supporting non-native English speakers - Consider the appropriate use of AI tools	- Promote/provide non-English abstracts of English papers - Support and conduct dissemination in multiple languages (e.g., on social media)	
 Funders	Fund the translation of books and papers for education	Establish grant schemes to cover English editing/translation services, especially for those from lower income regions and at an early career stage	Value and fund plans to disseminate outcomes in multiple languages	Establish grant schemes to cover English editing/translation of presentations
 Conferences			Publish proceedings in multiple languages	- Establish a "buddy" system to support non-native English speakers - Promote multilingual presentations - Develop linguistically inclusive guidelines

Source: Amano (1)

À l'instar d'Amano et collègues, nous sommes d'avis que les problèmes auxquels fait face l'humanité requièrent l'inclusion de perspectives variées. Ainsi, le fait de ne pas lever les barrières linguistiques qui nuisent aux carrières des personnes chercheuses et étudiantes non anglophones nuit à l'inclusion des connaissances qui sont actuellement produites un peu partout sur la planète par plusieurs de ces personnes qui, pour différentes raisons, ne diffusent pas en anglais. Cette exclusion nuit à la science. Le bénéfice que la communauté scientifique retire de la domination linguistique anglophone a un coût et ce coût est, à notre avis, important. Il y a actuellement une sous-représentation des recherches faites par les personnes chercheuses et étudiantes non anglophones (1). Ce faisant, il y a une surreprésentation des recherches faites par les personnes anglophones.

CONCLUSION

Pour conclure, cet article visait à mettre en lumière les injustices épistémiques et linguistiques vécues par des personnes œuvrant dans le monde académique qui n'ont pas l'anglais comme langue maternelle. Par le biais des écrits existants, des notions théoriques de nature éthique et de nos savoirs expérientiels, nous espérons avoir dévoilé des inégalités qui sont présentes et perpétuées dans le monde académique ainsi que les impacts de ces injustices pour les personnes qui les vivent. Bien que l'accès à la diffusion des connaissances se voit complexifier pour les personnes dont la langue maternelle diffère de

l'anglais, celles-ci ne sont pas les seules à être affectées par le manque de découvrabilité des connaissances issues des recherches effectuées dans d'autres langues. En effet, le fait que certaines publications passent inaperçues en raison de leur faible découvrabilité, c'est-à-dire de leur disponibilité et capacité limitées à être identifiées parmi un bassin de contenus (10,21), affecte inévitablement le progrès scientifique en invisibilisant les contributions uniques et pertinentes réalisées dans des langues autres que l'anglais. Ce faisant, afin d'atténuer les injustices épistémiques et linguistiques ainsi que contribuer à une édification commune, inclusive, respectueuse et multilingue des connaissances, il importe de reconnaître la culture hégémonique anglophone dans la recherche. En guise de conclusion, nous invitons les personnes œuvrant dans le monde académique qui ont le privilège d'avoir comme langue maternelle l'anglais à : 1) reconnaître ce privilège qui agit comme facilitateur dans un domaine où la langue anglaise est dominante; 2) consulter des recherches et travaux effectués dans une ou des langues différentes de leur langue maternelle; 3) sensibiliser leurs collègues et partenaires aux inégalités présentes dans le monde académique; et 4) agir comme alliées pour soutenir la diffusion multilingue des connaissances, contribuant ainsi à la découvrabilité des savoirs et, par le fait même, au progrès scientifique (10).

RÉFÉRENCES

Voir References

LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

Mieux utiliser nos ressources hospitalières : pour une éducation citoyenne à la santé?

André-Anne Racine-Prud'homme^a

Résumé

Too many Canadians find themselves in medical situations that are made worse by delays in seeking treatment. Could public health education help to reduce the frequency of such incidents and improve the relationship between patients and healthcare providers?

Mots-clés

littéracie en santé, éducation à la santé, prévention, santé publique, éducation en santé

Abstract

Trop de canadiens se retrouvent dans des situations médicales aggravées par un retard de consultation. Est-ce que l'éducation citoyenne à la santé pourrait contribuer à réduire la fréquence de ces incidents et améliorer la relation de soins?

Keywords

health literacy, health education, prevention, public health, health education

Affiliations

^a Faculté de médecine, Université de Montréal, Montréal, Québec, Canada

Correspondance / Correspondence: André-Anne Racine-Prud'homme, andre-anne.racine-prudhomme@umontreal.ca

Nous assistons à une modernisation de la relation thérapeutique fondée sur le partenariat entre patients et professionnels de la santé. Pourrait-on démocratiser les connaissances en santé afin d'outiller notre population à participer pleinement à sa santé?

Les médecins canadiens sont confrontés à une panoplie de problèmes de santé dont la gravité pourrait être atténuée par une consultation plus rapide. Étant étudiante en médecine, j'observe quotidiennement des situations choquantes mais qui ne surprennent plus mes patrons de clinique qui ont tout vu. En voici quelques exemples : un jeune homme atteint d'appendicite, une pathologie abdominale fréquente qui est habituellement traitée chirurgicalement en moins de 24h, tarde à consulter, se retrouve hospitalisé plus d'une semaine et réopéré pour une infection bactérienne profonde. Ou encore, une femme dans la quarantaine devient inconsciente en raison de menstruations extrêmement abondantes qui durent depuis six semaines. Dans les deux cas, une visite médicale en temps opportun aurait pu prévenir une escalade des soins.

Malheureusement, ces cas ne sont pas isolés et ont d'énormes coûts humains et économiques. Il en va de même pour plusieurs « drapeaux rouges » enseignés lors de mes études : saignement menstruel après la ménopause, perte de poids inexplicable, paralysie ou perte de la parole, etc. Pourtant, trop de nos concitoyens négligent des symptômes graves par mégarde ou par crainte de n'être pas bien compris. Dans le cas du cancer, diagnostiquer une maladie à un stade où le traitement curatif n'est plus envisageable est tout à fait déchirant.

En santé publique, la littératie médicale désigne la capacité d'un individu à comprendre des informations écrites et entendues afin d'agir sur sa santé, par exemple, les consignes données par le pharmacien au sujet d'une prescription. La littératie est influencée par l'âge, l'éducation, le contexte social et la culture. On estime qu'au moins 60% des Canadiens ne disposeraient pas des acquis nécessaires à la prise de décisions éclairées sur leur santé, c'est-à-dire un niveau 3 de littératie (1).

Durant ma première année dans les hôpitaux en tant qu'étudiante en médecine, il est arrivé maintes fois qu'un patient est sorti de mon bureau et que, malgré tous mes efforts de vulgarisation, je n'avais pas la certitude qu'il ou elle ait bien compris. À l'hôpital, des obstacles à la communication s'ajoutent : barrières linguistiques, isolement, douleur, bruit. On imagine à peine les conséquences qui s'en suivront.

Plusieurs approches existent pour améliorer le partenariat entre les citoyens et les professionnels de la santé. Dans une optique de prévention et d'encapacitation, je propose de mieux éduquer les élèves du secondaire à certains concepts médicaux de base tels que les symptômes et les conditions requérant une consultation à l'urgence. Ainsi informés, les citoyens deviennent les premiers gardiens de leur santé et de celle de leurs proches. Parmi les multiples bénéfices de ce cours, l'amélioration de la littératie médicale de notre population pourrait permettre une meilleure efficacité des mesures de santé publique comme la vaccination, par une compréhension partagée des bénéfices escomptés. Ce cours pourrait comprendre d'autres connaissances en santé qui sont déjà abordé dans les écoles, comme les manœuvres de réanimation et de premiers soins.

Cette pratique est déjà bien établie ailleurs. Un cours qui s'échelonne sur plusieurs années sur l'éducation à la santé est obligatoire au secondaire en Finlande depuis 2006 (2,3). Une étude publiée en 2020 (4) démontrait que le pays européen avec la plus grande proportion d'adolescent possédant un niveau élevé de littératie médicale était la Finlande, nez-à-nez avec la Macédoine. Également, une étude publiée cette année mettait en évidence une meilleure littératie médicale chez les adultes finlandais ayant bénéficié de ce cours lors de leurs études secondaires, par rapport aux cohortes antérieures (5). Des cours similaires au contenu variable existent dans le cursus anglais (6) et dans certains pays d'Asie (7-9). Néanmoins, beaucoup de variabilité de littératie médicale persiste malgré cette intervention pédagogique, mettant en lumière la nécessité de mesures additionnelles chez les individus bénéficiant le moins du programme (5,10).

Pour réussir, les ressources financières et humaines doivent être au rendez-vous chez les professionnels comme chez les citoyens.

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None to declare

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