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ÉDITORIAL / EDITORIAL

L'éthique et la prise de décision en santé publique pendant la pandémie au Québec

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

En mai 2024, l'Organisation mondiale de la santé (OMS) vient de convenir « d'un processus mondial visant à élaborer et à négocier une convention, un accord et un instrument international, en vertu de l'OMS, afin de renforcer la prévention, la préparation et la riposte face aux pandémies » (1). Lors du 13e cycle de négociations, les délégués des États membres de l'OMS ont trouvé un accord de principe sur un texte qui serait soumis à l'Assemblée mondiale de la santé en mai 2025 (2). Étant donné que plusieurs pays font état d'une hausse des cas de H5N1, de rougeole ou de mpox, l'heure des bilans critiques s'impose, ne serait-ce que pour mieux se préparer face aux défis futurs.

Rappelons qu'au Québec et ailleurs dans le monde, la pandémie de la COVID-19 a soulevé de nombreux enjeux éthiques et notamment en matière de santé publique, d'allocation de ressources et d'usage des technologies. Force est de constater qu'en mars 2020 des mesures inédites de confinement et de fermeture des frontières ont été mises en place à l'échelle internationale. Cette crise sanitaire planétaire aura profondément bouleversé notre génération. La pandémie a mis l'éthique au centre des préoccupations. Pour suivre Jocelyn Maclure (3), la pandémie fut une longue période de dilemmes éthiques à conséquences tragiques en ce qui concerne les décisions prises en matière de santé publique, car peu importe la décision prise, elle aurait eu des effets préjudiciables pour une partie de la population ou certains individus. L'aspect le plus tragique fut le décès de personnes âgées dans des contextes inédits de confinement, séparées de leurs proches, parfois laissées à elles-mêmes dans des conditions de détresse et de solitude extrêmes. Plus largement, les déterminants sociaux ont exacerbé les vulnérabilités de santé. À l'échelle internationale, certains pays riches ont été aux prises avec le phénomène de l'hésitation vaccinale, tandis que d'autres pays plus désavantagés n'ont pas eu accès aux vaccins contre le SRAS-CoV-2, en raison de la thésaurisation des vaccins à l'échelle mondiale.

De plus, cette période de crise a mis en évidence les difficultés des gouvernements de prendre en compte les résultats de recherches émergentes dans le processus décisionnel. Certains segments de la population ont décrié ce qu'ils percevaient comme une forme de paternalisme de la part des gouvernements, d'autres ont souhaité des mesures plus contraignantes en santé publique. Fallait-il mettre en place des couvre-feux? Fallait-il obliger les professionnels de la santé, en particulier les infirmières, à faire des heures supplémentaires au détriment des normes du travail? Quelles mesures d'exception un État est-il en droit d'imposer dans des contextes d'urgence au nom du bien commun? Comment s'assurer que l'éthique est au cœur de ces prises de décision?

Cette série de questions n'est même pas exhaustive, mais elle pointe en direction des problèmes auxquels les pays ont dû faire face, tous en fonction de leur culture politique et de leurs ressources en santé publique. Ce numéro spécial sur la pandémie aborde des questions à la fois plus circonscrites et fondamentales : Quel est le rôle des chercheures et chercheurs dans le domaine de la santé publique et de l'éthique en pareilles circonstances? Comment penser leurs contributions entre les instances d'autorité politique, les médias et le public? Quelle est la fonction de l'expertise scientifique en contexte d'incertitude? Les chercheures et chercheurs peuvent-ils et doivent-ils jouer un rôle plus important dans la relation de confiance entre les sociétés civiles et les gouvernements?

Ces questions ont été débattues lors d'une journée de réflexion coorganisée par l'axe Éthique du Réseau de recherche en santé des populations du Québec (RRSPQ), dirigé par Matthew Hunt et coordonnée par Tzvetelina Tzoneva et la Commission de l'éthique en santé et en technologie (CEST) sous la présidence de Jocelyn Maclure et la responsabilité du secrétaire général Nicolas Seney. Ryoa Chung, co-directrice du Centre de recherche en éthique, avait assuré l'animation de la rencontre

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qui eut lieu le 30 mai 2023. Cet événement a permis à de nombreux acteurs des milieux de l’éthique clinique, des soins de santé, de la santé publique et de la recherche de dresser un bilan pour identifier un certain nombre de questions, dont celles qui ont été mises de l’avant dans les quatre publications présentées ici.

Tout au long de la pandémie, plusieurs organisations ont été impliquées dans le processus de consultation et d’orientation éthique des décisions prises par le gouvernement en matière de santé publique. Une première réflexion sur la contribution de ces organismes a été entamée conjointement par le Comité d’orientation de l’axe Éthique du RRSPQ et la CEST et complétée en hiver 2023. Elle a permis de réaliser une cartographie du développement et de la configuration des acteurs et des groupes qui offrent des conseils ou des services en matière de réflexion éthique dans le domaine de la santé au Québec (4). Cette architecture sera abordée dans les quatre textes présentés dans le cadre de ce numéro spécial.

Marie-Ève Bouthillier, éthicienne au CISSS de Laval et chercheure au Bureau de l’éthique clinique de la Faculté de médecine de l’Université de Montréal, Ana Marin, anthropologue et éthicienne au CISSS Chaudière-Appalaches et Karine Bédard, chercheure au Centre hospitalier de l’Université de Montréal (CHUM) ont co-écrit « Éthique et pandémie : bilan du Comité éthique COVID-19 et du Regroupement en éthique clinique et organisationnelle du réseau de la santé et des services sociaux » (5). Dans le cadre de cet article, elles décrivent la genèse de deux entités importantes pendant la pandémie. D’abord la création du Comité éthique COVID-19 qui fut institué par Dre Lucie Opatrny, également présidente du Comité directeur clinique COVID-19 du ministère de la Santé et des Services sociaux (MSSS). Cette dernière a mandaté Marie-Ève Bouthillier pour entamer des démarches afin de remédier aux enjeux éthiques en lien avec les travaux du MSSS en ces circonstances inédites, dont notamment le développement des règles de triage en contexte de ressources limitées. La seconde entité qui perdure encore aujourd’hui fut la consolidation du Regroupement en éthique clinique et organisationnelle du Réseau de la santé et des services sociaux. Le Regroupement est né de manière quasi organique du Comité éthique COVID-19 étant donné le recoupement des nombreux pôles d’intérêts et des membres. Si le mandat spécifique du Comité éthique COVID-19 a été mis en pause au fil des années, les autrices présentent les riches retombées de la création du Regroupement et de la capacité remarquable de ce réseau de praticiens et de chercheurs d’avoir répondu à l’appel en assurant une liaison entre les milieux cliniques de la santé, de la recherche et de la gouvernance.

Le commentaire de Sarah Mediouni, doctorante à la Faculté de médecine vétérinaire de l’Université de Montréal et d’Antoine Boudreau Leblanc, chercheur postdoctoral à l’Université McGill s’intitule « Vers une approche intégrée : politique, science et éthique – Le rôle clé de la médiation des connaissances en situation de crise sanitaire » (6). Les co-auteurs observent une polarisation de la science pendant la pandémie. En effet, selon eux, le gouvernement a parfois instrumentalisé l’appel à la science par le biais de figure d’autorité (des personnes, des symboles, des institutions ou des recherches) pour légitimer leurs actions politiques. L’ennui est qu’aucune instance impartiale ne pouvait valider ou invalider ces appels à la science auprès du public. Toutefois, ayant été des observateurs privilégiés de certains milieux pendant la pandémie, notamment des travaux du Comité éthique COVID-19 et du Regroupement en éthique clinique et organisationnelle du Réseau de la santé et des services sociaux, les co-auteurs en appellent à la nécessité de développer une architecture institutionnelle capable d’assurer et de protéger le rôle de médiation des éthiciens entre science et politique.

Le témoignage de Michel Désy, chercheur de l’Institut national en santé publique (INSPQ), Bruno Leclerc, professeur retraité à l’Université du Québec à Trois-Rivières (UQTR) et ancien président du Comité d’éthique de la santé publique de l’INSPQ et de Julie St-Pierre, chercheure à l’INSPQ, offrent une analyse critique des problèmes survenus pendant la pandémie en relation avec les activités du Comité d’éthique de la santé publique (7). Un enjeu important concerne la confusion des rôles, du moins dans l’opinion publique et dans les médias, entre l’INSPQ qui relève du gouvernement en vertu de la Loi LQ 1998 et le Comité d’éthique de la santé publique qui, bien que rattaché à l’INSPQ, jouit d’une indépendance en vertu de son mandat institué en 2001 lui donnant le pouvoir d’auto-saisine. Le pouvoir du Comité de décider par lui-même les questions de recherche que les membres souhaitent investir entraîne des conséquences importantes, notamment d’aborder des problèmes pour lesquelles l’INSPQ n’est pas mandatée sciemment par le gouvernement d’investiguer. Cette situation a pu susciter des tensions internes parmi les chercheurs de l’INSPQ et entre les membres du Comité et le gouvernement. Les médias ont également nourri la confusion au sein du public en rapportant, sans distinguer les entités, des avis consultatifs qui pouvaient sembler contradictoires. Pour les co-auteurs, l’existence d’une instance éthique dotée d’un pouvoir d’auto-saisine est cruciale pour assurer la rapidité de réaction et d’adaptation du milieu de la santé publique en contexte d’urgence.

En dernière instance, Bryn Williams-Jones, professeur de bioéthique et directeur du département de Médecine sociale et préventive à l’Université de Montréal et Sihem Neila Abtroun, doctorante en bioéthique à l’École de santé publique de l’Université de Montréal, offrent un témoignage captivant des contributions des éthiciens pendant la COVID-19 (8). Selon leurs observations et expériences, la mobilisation des éthiciens à travers le monde pour étudier, en temps réel, les enjeux de la pandémie en santé publique, a révélé une réactivité et une souplesse remarquables. Leur présence quotidienne dans les médias, les débats publics, les instances de gouvernance ont témoigné de leur importance non seulement académique, mais réellement sociale. Forts de cette expérience concluante, non pas tant en termes de certitudes scientifiques qu’en termes de pertinence démocratique, les co-auteurs concluent que la communauté bioéthique ne doit pas hésiter à prendre sa place dans les débats contemporains et face aux risques existentiels que représentent peut-être les futures crises sanitaires.

Aux crises sanitaires et futures pandémies s'ajoutent les crises environnementales, les catastrophes climatiques et les conflits politiques qui ont des retombées incontournables et inévitables sur la santé des individus et des populations. Si l'on doit pratiquer une forme d'humilité épistémique face à la complexité des problèmes multidimensionnels de nos sociétés contemporaines, nous croyons néanmoins, plus que jamais, que le rôle des éthiciens en santé consiste à défendre les valeurs fondamentales de l'humanisme pour l'avenir et à travers les frontières.

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Acknowledgements

We are grateful to our colleagues from the *Commission de l'éthique en santé et en technologie* (CEST) with whom we co-organized the May 30, 2023 event that led to the development of this special issue. We thank all the participants at the event, and especially the authors of the four texts included in this special issue. We acknowledge funding from the Fonds de Recherche du Québec to the Quebec Population Health Research Network which supported the development of this project, including enabling us to host a works-in-progress workshop with the authors in February 2024.

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Aucun à déclarer

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Ethics and Public Health Decision-Making During the Pandemic in Quebec

In May 2024, the World Health Organization (WHO) agreed on “a global process to develop and negotiate an international convention, agreement and instrument, under WHO, to strengthen pandemic prevention, preparedness and response” (1). During the 13th round of negotiations, delegates from WHO member states reached an agreement in principle that will be submitted to the World Health Assembly in May 2025 (2). Given that multiple countries are reporting increases in cases of H5N1, measles and mpox, critical assessments of past experiences continue to be needed in order to be better prepared for the future.

In Quebec and elsewhere in the world, the COVID-19 pandemic raised many ethical issues, particularly in terms of public health interventions, resource allocation and use of technology. In March 2020, unprecedented international movement restrictions and border closure measures were put in place. This global health crisis will have profound ongoing impacts on all who lived through it. Ethics was at the core of many of the issues that were raised. As expressed by Jocelyn Maclure (3), the pandemic was an extended period of ethical dilemmas that created tragic choices in the area of public health decision-making: regardless of which decision was taken, there would be detrimental effects for a portion of the population or for some individuals. The most tragic aspect was the death of elderly people in unprecedented contexts of confinement, separated from their loved ones, sometimes left to fend for themselves in conditions of extreme distress and loneliness. More broadly, social determinants have exacerbated health vulnerabilities. On an international scale, some wealthy countries experienced vaccine hesitancy, while other more disadvantaged countries did not have access to SARS-CoV-2 vaccines due to global vaccine hoarding.

Moreover, this period of crisis highlighted difficulties for governments to take account of available and emergent research findings in the decision-making process. Some segments of the population decried what they perceived as a form of excessive paternalism on the part of governments, while others called for more restrictive public health measures. Should curfews be introduced? Should healthcare professionals, especially nurses, be forced to work overtime even when this ran against labour standards? What emergency measures is the state justified to take in the name of the common good? How can we ensure that ethics has a central place in making these decisions?

This series of questions is by no means exhaustive, but points in the direction of the problems that countries faced, in the context of their particular political cultures and public health resources. This special issue on the pandemic addresses questions that are both more circumscribed and fundamental: What is the role of public health and ethics researchers in such circumstances? How should we view the contributions of researchers in relation to political authorities, the media and the public? What is the function of scientific expertise in a context of uncertainty? Can and should researchers play a greater role in building trust between civil society and governments?

These questions were discussed at an event (described as a *journée de réflexion* in French, a day of reflection) co-organized by the Ethics Axis of the Quebec Population Health Research Network (QPHRN), directed by Matthew Hunt and coordinated by Tzvetelina Tzoneva, and the *Commission de l’éthique en santé et en technologie* (CEST), chaired by Jocelyn Maclure and under the responsibility of Nicolas Seney, General Secretary. Ryoa Chung, Co-Director of the Centre for Research on Ethics, moderated the discussions, which took place on May 30, 2023. This event provided an opportunity for individuals engaged in clinical ethics, public health and healthcare, and research, to take stock and identify a range of issues, including those put forward in the four publications presented here.

Throughout the pandemic, multiple organizations played ethics advisory roles or contributed to the orientation of the government’s public health decision-making. An initial reflection on the contribution of these organizations was initiated jointly by the QPHRN Ethics Axis’ Steering Committee and the CEST and completed in winter 2023. This initiative led to a project that mapped the development and configuration of groups having ethics advisory or support roles in the field of public health in Quebec (4). This architecture will be discussed in the four texts presented in this special issue.

Marie-Ève Bouthillier, ethicist at CISSS Laval and researcher at the Office of Clinical Ethics, Faculty of Medicine, Université de Montréal, Ana Marin, anthropologist and ethicist at CISSS Chaudière-Appalaches, and Karine Bédard, researcher at the Centre hospitalier de l’Université de Montréal (CHUM), co-wrote “Éthique et pandémie : bilan du Comité éthique COVID-19 et du Regroupement en éthique clinique et organisationnelle du réseau de la santé et des services sociaux” (5). In this article, they describe the genesis of two important entities during the pandemic. First, the creation of the COVID-19 Ethics Committee by Dr. Lucie Opatrny, who also chaired the COVID-19 Clinical Steering Committee of the Quebec Ministry of Health and Social Services (MSSS). Dr. Opatrny mandated Marie-Ève Bouthillier to take steps to address the ethical issues associated with the MSSS’s work in the unprecedented circumstances of the pandemic, including the development of triage rules in a context of limited resources. The second entity is the *Regroupement en éthique clinique et organisationnelle du Réseau de la santé et des services sociaux* (Clinical and Organisational Ethics Group of the Health and Social Services Network), an initiative that has remained active after the pandemic. The *Regroupement* arose from the COVID-19 Ethics Committee, given the overlap of its many interests and members. While the specific mandate of the COVID-19 Ethics Committee has ended, the authors discuss the enduring benefits of the *Regroupement*’s creation and the ability of this collective to create ongoing links between the clinical, research and governance milieus.

Sarah Mediouni, a doctoral student in the Faculty of Veterinary Medicine at the Université de Montréal, and Antoine Boudreau Leblanc, a postdoctoral researcher at McGill University, have contributed a commentary entitled “Vers une approche intégrée : politique, science et éthique – Le rôle clé de la médiation des connaissances en situation de crise sanitaire” (6). The authors describe polarization around the role of science during the pandemic. They argue that the government sometimes instrumentalized science through the use of authority figures (people, symbols, institutions or research) to legitimize their political actions. They identify a concern that there was no impartial body that could validate or invalidate these public appeals to science. Reflecting on their observations of different contexts during the pandemic, notably the work of the COVID-19 Ethics Committee and the *Regroupement en éthique clinique et organisationnelle du Réseau de la santé et des services sociaux*, the authors call for the development of an institutional architecture capable of ensuring and protecting the mediating role of ethicists between science and politics.

The perspective by Michel Désy, researcher at the Institut national de santé publique du Québec (INSPQ), Bruno Leclerc, retired professor at the Université du Québec à Trois-Rivières (UQTR) and Past President of the INSPQ’s Public Health Ethics Committee, and Julie St-Pierre, researcher at the INSPQ, offers a critical analysis of the problems that arose during the pandemic from the perspective of the Public Health Ethics Committee (7). An important issue is the confusion of roles, at least in public opinion and the media, between the INSPQ, which reports to the government under the Loi LQ 1998, and the Public Health Ethics Committee which, although attached to the INSPQ, has independence in its advisory role by virtue of the 2001 mandate giving it the power of self-referral. The Committee’s autonomy to decide which research questions its members wish to investigate has important consequences, not least of which is the possibility of addressing issues for which the INSPQ is not specifically mandated by the government to investigate. This situation gave rise to internal tensions among INSPQ researchers and between Committee members and the government. The media also contributed to confusion when reporting seemingly contradictory advisory opinions, without distinguishing between the INSPQ and the Ethics Committee. For the authors, the existence of an ethical body with the power of self-referral is crucial to ensure timely responses and adaptability within the public health environment, in an emergency context.

Finally, Bryn Williams-Jones, Professor of Bioethics and Director of the Department of Social and Preventive Medicine at the Université de Montréal, and Sihem Neila Abtroun, a doctoral student in bioethics at the Université de Montréal’s School of Public Health, offer a rich account of the contributions of ethicists during COVID-19 (8). According to their observations and experiences, the mobilization of ethicists around the world to study, in real time, the public health challenges of the pandemic revealed remarkable responsiveness and flexibility. Ethicists’ daily presence in the media, in public debates and in governance bodies reinforced the importance of their contributions not only academically, but also for society. Through this engagement and its democratic relevance, Williams-Jones and Abtroun conclude that the bioethics community must not hesitate to take its place in contemporary debates and in the face of the existential risks that future health crises may produce.

In addition to public health crises and future pandemics, environmental crises, climate change and political conflicts will have inevitable repercussions on the health of individuals and populations. While we must practice epistemic humility in the face of the complexity of the multidimensional and interconnecting problems faced by our societies, we nevertheless believe, more than ever, that the role of health ethicists is to defend the fundamental values of our shared humanity for the future and across borders.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

DNA Paternity Testing in Lebanon: Ambiguity in Laboratory Practices, Unsolved Ethical Issues, and Need for a Legislative Framework

Mirna Azoury[a], José-Noel Ibrahim[b], Hasan Yassine[b], Fadi Abou-Mrad[a]

Résumé
Cette étude évalue les cadres juridiques et éthiques des tests génétiques au Liban, en mettant l'accent sur les tests de paternité. Les informations recueillies auprès de 16 laboratoires ont révélé que les tests de paternité sont effectués uniquement dans les quatre laboratoires accrédités par le ministère de la santé publique, mais que seulement la moitié des tests sont effectués par l'intermédiaire du tribunal. Il est intéressant de noter qu'un laboratoire n'exige pas le consentement des parents avant le test de paternité et que les personnes ne sont généralement pas informées de la possibilité d'une paternité mal attribuée (73,3 %) ou d'une prédisposition à des maladies (53,3 %). En outre, seuls 37,5 % des laboratoires divulguent les résultats fortuits. Malheureusement, les résultats génétiques sont communiqués en l'absence d'un psychologue dans 90 % des cas. Lorsqu'ils sont jugés nécessaires, les résultats sont communiqués dans 12,5 % des cas à d'autres professionnels de la santé, sans le consentement du patient. Notre étude met en évidence la nécessité d'élaborer des lignes directrices et des réglementations complètes concernant les tests de paternité au Liban.

Mots-clés
tests génétiques, tests de paternité, éthique, droit, Liban

Abstract
This study assesses the legal and ethical frameworks for genetic testing in Lebanon, with a particular focus on paternity testing. Information collected from 16 laboratories revealed that paternity testing is performed solely in the four laboratories accredited by the Ministry of Public Health, but only half of the tests are made through the court. Interestingly, one laboratory does not require the parents' consent prior to paternity testing, and individuals are generally not informed about the possibility of misattributed paternity (73.3%) or disease predispositions (53.3%). Moreover, the disclosure of incidental findings is done by only 37.5% of laboratories. Unfortunately, genetic findings are communicated in the absence of a psychologist in 90% of cases. When deemed necessary, results are shared in 12.5% of cases with other health professionals, without the consent of the patient. Our study highlights the need to develop comprehensive guidelines and regulations that cover paternity testing in Lebanon.

Keywords
genetic testing, paternity testing, ethics, law, Lebanon

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INTRODUCTION

The development of highly informative genetic biomarkers, accompanied by the progression of DNA sequencing technologies, has allowed for the increasing reliance on genetic testing as a means of both diagnosis and prognosis in predictive medicine. This progress has also facilitated the development of powerful tools for understanding the complexities of human inheritance. In fact, over the past four decades, genetic testing has resulted in an exponential increase of biomarker libraries for multiple diseases, thereby enhancing diagnostic capabilities (1). Furthermore, with a comprehensive understanding of genetic information, scientists have been able to integrate the data into clinical practice to tailor treatment efficacy and safety (2). However, the surge in detected biomarkers and advancements in genetic techniques have generated complex information that may be subject to conflicting interpretations. Misinterpretation of genetic findings can have significant consequences, including incorrect or missed diagnoses, unnecessary treatments or interventions, and increased psychosocial stress for patients and their families (3).

In addition to generating complex information, genetic testing often leads to incidental findings, defined as observations, results, or other discoveries that extend beyond the primary research objective (4). One example of incidental findings is the discovery of variants that are known to cause a predisposition to certain diseases (5). Misattributed paternity is another common and unanticipated finding (6), with implications that extend beyond determining biological relationships, affecting medical, judicial, social, and personal matters (7).

In Lebanon, Law No. 625, drafted by the Lebanese National Consultative Committee on Ethics and approved by the Ministry of Health, the Council of State, and the Council of Ministers, was the first attempt to regulate genetic testing (8). Law No. 625 establishes a National Registry for genetic data that prioritizes human dignity and rights, ensuring data confidentiality and banning commercial use. Genetic testing requires explicit consent for medical or research purposes only, prohibiting discrimination or behavioural prediction. Individuals have the right to their test results and may withdraw consent at any time.

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DNA laboratories must follow strict data protection protocols, allowing individuals to refuse data sharing, except in specific medical scenarios. Furthermore, the law ensures rigorous oversight and protection of genetic information; however, it does not address the various aspects of paternity testing.

Paternity testing in Lebanon has evolved significantly over the years, reflecting both advancements in genetic science and socio-cultural dynamics within the country. Since Lebanon is characterized by a complex sectarian structure and diverse population, paternity issues were often resolved through traditional means or by religious authorities, with little recourse to scientific methods. The introduction of DNA testing, particularly in the 1990s, marked a turning point in Lebanon, and aligned with a global trend toward increased reliance on DNA evidence in legal and personal disputes. The availability of these tests offered individuals a way to address concerns about legitimacy and inheritance rights, which are particularly sensitive subjects in Lebanon. Nonetheless, despite the potential for DNA testing to clarify paternity issues and the gradual shift in societal attitudes – spurred by growing awareness of personal rights and scientific literacy – Lebanon currently lacks a legal framework for paternity testing, which is still influenced by religious laws. As a result, many families may still opt for traditional resolutions due to the stigma or fear of social repercussions. Moreover, the high cost of genetic testing can be prohibitive for many families, thus limiting access to much of the population. This situation highlights the complex dynamics in Lebanon, and distinguishes it from other nations (9).

In this context, the lack of clear regulations on paternity testing in Lebanon raises significant ethical concerns. Indeed, the limited access to affordable genetic testing and the ease of access to paternity tests with the ability to disclose information without the consent of the parents can result in a breach of fundamental principles of transparency, consent, and respect for individuals' rights to privacy, safety, and dignity (9). Consequently, there is an urgent need for comprehensive regulations and guidelines that include specific genetic tests, and in particular paternity testing.

This study was designed to assess the legal and ethical frameworks of genetic testing among different laboratories in Lebanon with the main purpose of revising and further developing the existent law on genetic testing. A particular focus will be on paternity testing due to its controversial nature and the emotive debate that it can provoke, particularly with regard to consent issues.

MATERIALS AND METHODS

Study Design and Population

This study was conducted in accordance with the requirements of the Declaration of Helsinki and approved by the Ethics Committee of the Lebanese University. A list of the laboratories authorized by the Ministry of Public Health to perform DNA testing was prepared, and the Heads of the laboratories were then contacted by telephone to explain the nature and objectives of the study, and to get their approval to participate in the research.

Questionnaire

Data collection took place between May and August 2022 using a 29-item questionnaire (Annex 1), which was completed in person by the laboratory head. After reviewing the information sheet, participants were asked to provide their written consent for voluntary participation in the research project. The questionnaire addressed the judiciary's role in DNA paternity testing, assessing participants' knowledge of relevant laws and regulations in Lebanon, the necessity of consent forms for genetic and paternity testing, the accessibility of genetic test results, and the provision of genetic counselling prior to testing. It also addressed the management and disclosure of incidental findings, the methods of communicating results, and the handling of DNA samples along with their potential use in future analyses or research. The questionnaire received approval from several experts with extensive experience in the field.

Data confidentiality

The aim of the study was clearly presented to participants, and an informed consent was signed by all respondents prior to enrollment. They were all notified that information collected to meet our research objectives would be kept anonymous and confidential, and that personal data, such as the name of the laboratory, contact information, address, etc., were not recorded. Survey responses were directly exported to a study-specific excel sheet in which data were linked to a secret code and saved on the laptop of the principal investigator using password-protected files. The informed consent and hard copy records were carefully protected in a locked file cabinet; only the lead investigator had access to the data when necessary.

RESULTS

In total, 16 out of the 30 laboratories contacted accepted to participate in the study, for a response rate of 53%. The laboratories that opted out of participation primarily conduct routine examinations along with DNA testing. Their decision was largely influenced by concerns about the sensitive nature of the topic, as they expressed worries about potential ethical and legal ramifications, as well as the consequences of being viewed as breaching confidentiality protocols or regulatory standards. Other reasons for non-participation included a lack of interest in the research and the unavailability of the laboratory Head during the data collection period.

Out of the 16 laboratories included in the study, six were private clinical laboratories, seven were hospital laboratories, one was a forensic science laboratory, one was a specialized clinical laboratory for DNA analysis, and one was a genetic research and diagnostic laboratory affiliated with a private university. The majority of these laboratories (12/16 or 75%) are primarily involved in the identification of genetic diseases (hereditary diseases, chromosomal abnormalities, etc.), while four laboratories conduct paternity testing. Additionally, forensic investigations and prenatal diagnosis were carried out by only two laboratories. The Heads of the laboratories were asked to respond to various ethical and legal questions assessing how genetic testing, in general, and paternity testing in particular, are performed in their laboratories.

PATERNITY TESTING

Implication of the judiciary in paternity testing

First and foremost, our findings revealed that paternity testing is not performed outside of the four laboratories accredited by the Ministry of Public Health. Regarding the role of the judiciary in paternity testing, the results showed that only half of the paternity tests are initiated through a court order. Additionally, our findings indicate that in half of the cases, parents still have the option to select the laboratory where the paternity test will be conducted, even if the test is ordered by the court. Beyond those that were court-ordered, paternity tests were generally requested by either the mother or the father to establish the identity of the father or to identify a child who has not been registered at birth. Less frequently, paternity tests were ordered for issues related to inheritance (50% of cases) or to request financial support and compensation for the child (25% of cases).

Knowledge of paternity testing regulations and consent form requirements

Our analysis found that 56.5% of participating laboratories were unaware of any laws regulating paternity testing in Lebanon. Regarding the provision of consent forms, our results showed that in 75% of paternity testing cases, a written consent was collected from the concerned parties, as all four participating laboratories confirmed that consent was mandatory for test execution. Furthermore, the test cannot be performed without the consent of the parents (Table 1).

Table 1. Participants' knowledge of paternity testing regulations and consent form requirements

	Response
Knowledge about the existence of a law regulating paternity testing	
Yes	31.3%
No	12.4%
I don't know	56.3%
Requirement of an informed consent prior to testing	
Yes	75%
No	25%
I don't know	0%
Type of consent	
Written	100%
Oral	0%
Request of a DNA test on another's biological sample without the consent of the concerned person	
Yes	0%
No	100%
I don't know	0%

GENETIC TESTING

Knowledge of genetic testing regulations and consent form requirements

In laboratories conducting genetic testing other than paternity tests, 50% of participants were unaware of Law No. 625, which regulates genetic testing in Lebanon. Surprisingly, consent was required in only 35.7% of cases when a DNA test was requested. Among those instances, written consent was the norm (72.7%), while oral consent was less common (9.1%). According to participants, there was no requirement in their laboratories to obtain patient consent prior to testing. Additionally, three of the sixteen laboratories surveyed (18.8%) reported that requests for testing could be made by any individual or family member, even without the individual's consent (Table 2). Furthermore, only one-third of patients received genetic counselling before undergoing their genetic tests.

Table 2. Participants' knowledge of genetic testing regulations and consent form requirements

	Response
Knowledge of the existence of a law regulating the test	
Yes	18.7%
No	31.3%
I don't know	50%
Requirement of an informed consent prior to testing	
Yes	35.7%
No	57.2%
I don't know	7.2%
Type of consent	
Written	72.7%
Oral	9.1%
I don't know	18.2%
Request of a DNA test on another's biological sample without the consent of the concerned person	
Yes	18.8%
No	75%
I don't know	6.2%

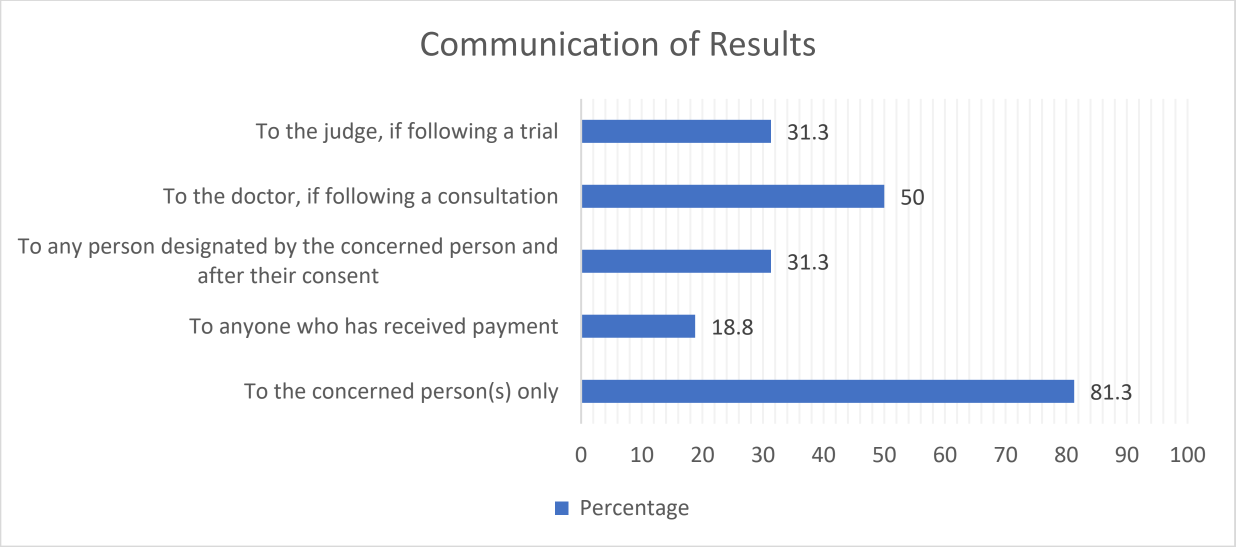
Discovery and disclosure of incidental findings

A majority of laboratories fail to inform patients of the possibility of misattributed paternity (73.3%) and the risk of being genetically predisposed to disease (53.3%). Furthermore, 61.5% of laboratories do not ask patients whether they wish to be informed about incidental findings. The disclosure of such information appears to be governed by each laboratory's internal regulations. While 37.5% of laboratories prefer to disclose incidental findings to the concerned individual, the remaining laboratories do not disclose this information.

Communication of test results

Test results were typically delivered directly to the concerned individual in 81.3% of cases. However, in some instances, results were communicated to the doctor following consultation (50%) or to the judge as part of a trial (31.3%) (Figure 1). Notably, 12.5% of participating laboratories reported that test results were disclosed to other healthcare professionals without the patient's consent, if deemed necessary. When no judicial involvement was required, results were communicated via face-to-face meetings (66.7%), phone calls (6.6%), or according to the individual's preference (26.7%). Moreover, our findings revealed that results were delivered by the laboratory head in 50% of cases, while laboratory technicians and geneticists were responsible for communicating the results in 25% and 18.8% of instances, respectively. Unfortunately, in 90% of cases, this disclosure occurred without the presence of a psychologist. The involvement of a psychologist would be valuable in helping patients navigate potentially emotionally challenging information during genetic counselling.

Figure 1. Laboratory practices regarding recipient of the genetic result



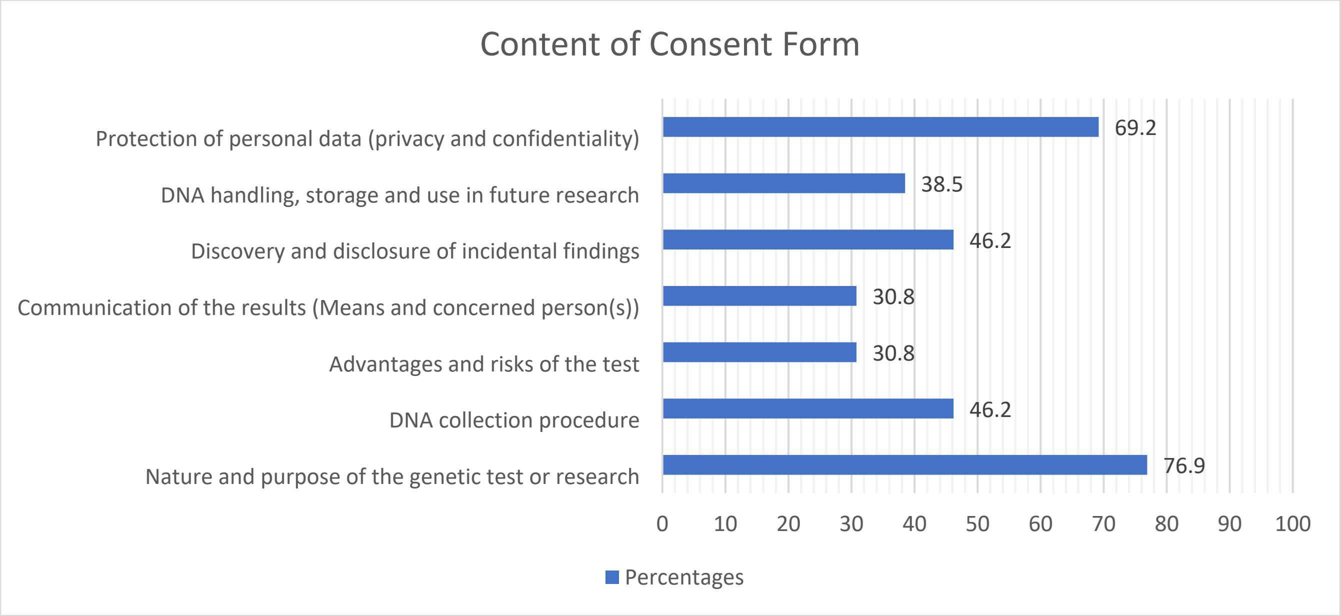
DNA storage and use in future analyses

Lastly, 62.5% of laboratories stored extracted DNA without obtaining consent from the individuals involved, and a quarter of these stored samples were used for future research or genetic analyses, also without prior patient consent. Furthermore, only 37.5% of laboratories reported that they maintained patient anonymity when storing or using DNA samples for research purposes.

Content of the consent form

The final question assessed the content of consent forms used for DNA genetic testing across various laboratories. While there was no standardized uniform consent form in place, the most commonly included items were a description of the genetic test or research nature and purpose (76.9%) and information about data protection, including privacy and confidentiality (69.2%). However, the inclusion of other critical elements, such as the DNA collection process, the advantages and risks of the test, how results would be communicated, and the handling of extracted DNA in future research, showed variability across laboratories, with fewer than 50% of consent forms covering these essential aspects (Figure 2). This highlights the need for a standardized, comprehensive consent process.

Figure 2. Content of the consent form used for genetic testing across the different laboratories



DISCUSSION

To our knowledge, this is the first study to examine the compliance of laboratories with the ethical and legal considerations associated with genetic testing in Lebanon, particularly in the context of paternity testing. Notably, paternity testing was found to be conducted exclusively by the four laboratories accredited by the Ministry of Public Health. However, our findings indicate significant gaps and shortcomings in the processes related to paternity testing, including violations of ethical principles such as protection of confidentiality and privacy, as well as the absence of protocols and guidelines for this type of testing.

First, it was observed that judges request paternity testing in only 50% of cases; in instances where a court order is not involved, parents are the primary initiators of the test. By contrast, in France, DNA paternity testing is exclusively conducted through court orders, making private testing illegal (10). Outside a legal context, in Arab countries like Saudi Arabia and Lebanon, communicating paternity test results to the father or any other member of the family may expose the mother to risk of violence due to “dishonorable infidelity” from conceiving a child outside of marriage (11). According to the Declaration of Helsinki, special protections should be taken into consideration to protect individuals or groups who are particularly vulnerable with an increased likelihood of being wronged or incurring additional harm due to their status (12). Moreover, in agreement with the Universal Declaration on the Human Genome and Human Rights, adopted at UNESCO’s 29th General Conference in 1997, fundamental freedoms, human rights, and dignity should be placed above all other interests (13,14). Lastly, regarding consent requirement, paternity testing necessitates that consent be obtained from all parties involved if no court order is present. This requirement reflects the significant legal, social, cultural, and psychological implications surrounding paternity tests, making informed consent critical in this context.

A closer examination of the processes and guidelines applied to other types of genetic testing revealed that most laboratories reported that obtaining the patient’s informed consent – whether oral or written – was not typically mandatory. This difference highlights the specific challenges and considerations that arise in the context of various genetic tests, each necessitating its own set of standards and practices tailored to the unique circumstances involved. Moreover, our results indicate that any person can perform a genetic test on another’s biological sample (hair, blood, etc.), without their knowledge or consent. This is due to the absence of adequate legislation governing DNA theft in Lebanon. The repercussions of DNA theft and unauthorized DNA testing can be significant, potentially exposing individual information about predispositions to certain diseases or their pre-existing medical conditions. Such breaches of security and privacy can lead to social stigmatization, discrimination, and adverse effects on employment opportunities (15).

Spain encountered challenges similar to those in Lebanon regarding the regulation of genetic testing, stemming from Spanish law that mandates obtaining informed consent from legal representatives but does not clarify the implications when consent is provided solely by one parent, typically the alleged father (16). The Nuremberg Code, established in 1947, underscores the significance of obtaining voluntary consent from human subjects; any violation of this code is viewed as a breach of an individual’s autonomy and human rights (17-20). Consequently, respecting personal autonomy and ensuring informed consent are essential ethical considerations in all medical and genetic testing procedures (21).

Our findings highlighted several shortcomings in the consent forms used for genetic testing in Lebanese laboratories. Many of these consent forms lack comprehensiveness, failing to include crucial information such as the methods of communicating results, the potential for incidental findings, and the processes for disclosing these results. Additionally, they often do not address patient preferences regarding the destruction or storage of DNA for future research. These deficiencies can largely be attributed to the absence of a referential legal framework and standardized consent forms. Implementing a standardized consent document could enhance information exchange between clinicians and patients, improve understanding of genetic testing, and bolster professional judgment in clinical contexts. Furthermore, it would aid genetic counsellors in providing targeted information to patients, ultimately facilitating a more effective informed decision-making process (22).

Notably, there was remarkable variability in the perspectives and practices among the participating laboratories regarding several key aspects of genetic testing. These included the necessity of genetic counselling prior to testing, methods of communicating results and sharing them with third parties, protocols for handling and disclosing incidental findings, and the storage and use of DNA samples for future genetic research. For instance, in France, genetic counselling is mandatory for all types of genetic testing and must be conducted prior to testing by either the ordering physician or a genetic counsellor associated with the physician (23). In the United Kingdom and Italy, the disclosure of unsolicited information, such as misattributed paternity, should be managed on a case-by-case basis. Healthcare professionals involved in genetic counselling could greatly benefit from existing documents supplemented by international guidelines, as these resources can aid them in developing their ethical reasoning skills in this field and assist them in addressing clinical dilemmas (24). In the UK, healthcare professionals may face disciplinary actions for failing to comply with the minimum standards of care established by the General Medical Council and the Nuffield Council on Bioethics (24). Meanwhile, the Oviedo Convention, an international legally binding instrument for the protection of human rights in the biomedical field, seeks to safeguard patient autonomy, the right to information, and the necessity of obtaining consent before any medical examination, including genetic testing (25). In Australia, the National Association of Testing Authorities (NATA) implements a national accreditation system that ensures the technical proficiency of genetic testing and paternity testing across all accredited laboratories (26). Finally, according to the 15th edition of the “Standards for Relationship Testing Laboratories” established by the US Association for the Advancement of Blood & Biotherapies (AABB), consent must be secured from each individual undergoing testing in accordance with relevant laws before sample collection. In cases involving a minor or a legally incompetent adult, consent should be obtained from a person with legal authority to provide it or from a tribunal authorized to order the testing (27).

The Guidelines for Quality Assurance in Molecular Genetic Testing (GQA), published by the OECD in 2007, advocate for a standardized framework of international quality standards for molecular genetic testing laboratories. This includes adherence to ISO 17025 standards, which pertain to laboratory accreditation, testing, and calibration, as well as ISO 15189 standards for medical laboratories. The GQA emphasizes the importance of laboratory oversight, data traceability, and quality reporting of results (28,29). The International Declaration on Human Genetic Data (HGD), adopted by UNESCO in 2003, outlines fundamental principles for the collection, processing, use, and storage of human genetic data and the biological samples from which it is derived. The declaration underscores the need for equality, justice, and solidarity in these practices (30). Additionally, according to the Husted Bioethical Decision-Making framework, every individual is unique and has the right to pursue their own independent purpose (31). This principle reinforces the need for confidentiality in test results and ensures that individuals are informed about who will have access to their data (32). Moreover, respect for autonomy entails that individuals must have control over the future use of genetic material submitted for analysis, ensuring it is used only for the specified purposes.

Considering that the Lebanese healthcare system is strongly influenced by French principles and its corresponding health system, it would be valuable to examine French legislation on paternity testing in order to establish a legal framework for Lebanon. Furthermore, exploring the feasibility and potential benefits of integrating international standards, such as the AABB guidelines, into the Lebanese healthcare system, may provide a more comprehensive and internationally comparable framework for genetic testing and paternity determination. Another critical area that merits further investigation is parentage testing. The complexities surrounding germ cell donation – including sperm and egg donation – are compounded by cultural, religious, and legal factors that significantly impact their acceptance and use. The lack of a comprehensive legal framework governing these practices creates challenges for both healthcare providers and individuals seeking these services, often leading patients to pursue options abroad. Future research should delve into the legal, ethical, and social dimensions of parentage testing in Lebanon, examining how existing cultural attitudes intersect with medical practices. Exploring this area would not only enhance our understanding of the broader implications of genetic testing but also promote the development of informed policies that can address the nuances of parentage, ultimately benefiting individuals facing such critical decisions in their reproductive journeys.

CONCLUSION

Our study highlights the need for a standardized legal framework to govern paternity testing in Lebanon. To address concerns surrounding DNA theft and the misuse of paternity test results, we propose a two-pronged approach: only a judge, in conjunction with the Ministry of Health and Ministry of Justice, should initiate paternity tests and direct the communication of results, while parents should submit to a judge for approval to choose the location of the paternity test. To ensure a secure and reliable testing environment, establishing a standardized consent form for genetic testing, imposing fines and sanctions on non-compliant laboratories, and providing healthcare professionals with education on the complexities of genetic testing are crucial. By implementing these measures, the aim would be to create a safe and trustworthy environment for individuals and their families, guarantee quality and reliability in DNA testing, and promote informed attitudes and practices among healthcare providers.

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ANNEX 1. PROJECT SUMMARY AND QUESTIONNAIRE

Ethical and Legal Considerations Surrounding Genetic and Paternity Testing in Lebanon

Introduction

Paternity testing involves the examination of DNA from two individuals to determine a genetic relationship, which may carry significant legal implications. This testing can clarify the biological relationship between a child and a parent, generally focusing on the father, since the mother's identity is typically known.

Study Objectives

The goal of this study is to collect information from laboratories about DNA testing for paternity and other genetic analyses. We seek to gain insights into the procedures utilized in genetic testing overall, with a specific focus on paternity testing. We believe that our findings will help enhance the development of laws and regulations governing paternity testing in Lebanon.

Participant Rights and Confidentiality

Participants have the right to withdraw their consent at any time and for any reason. Participation in this study is entirely voluntary; individuals may choose to decline or cease their involvement without needing to provide an explanation. Any data collected during the research will be processed confidentially and analyzed anonymously to protect participant privacy.

If you agree to participate in this study, we encourage you to respond to the following questions. Thank you for your contribution.

Questions about paternity testing

Question 1: Indicate the type of laboratory in which you work:

○ Private clinical laboratory
○ Hospital-affiliated clinical laboratory
○ Specialized laboratory for DNA analysis
○ University laboratory focused on genetic research
○ Forensic science or forensic medicine laboratory

Question 2: Please identify the most frequently requested indications for DNA analyses conducted in your laboratory: (Select all that apply)

○ Search for genetic diseases (hereditary diseases, chromosomal abnormalities, etc.)
○ Paternity test
○ Forensic research
○ Prenatal diagnosis

Question 3: Is paternity testing carried out in your Laboratory?

○ Yes
○ No

Question 4: Do you think that there is a law that regulates paternity testing in Lebanon?

○ Yes
○ No
○ I do not know

Question 5: Does a request for a paternity test always need to go through a judge?

○ Yes
○ No, except in the context of legal proceedings
○ I do not know

Question 6: Who decides which laboratory to use if a request for a paternity testing is submitted through a judge?

○ The judge
○ The parents

Question 7: If not, who usually requests the paternity test?

- ○ The parent (father or mother) seeking to establish a parentage connection, following the submission of required supporting documents
- ○ The child, if they are of legal age
- ○ Extended family members (such as grandparents, uncles, aunts, etc.)
- ○ Any individual can submit a request (including neighbors, friends, etc.)
- ○ A geneticist
- ○ Other

Question 8: What is (are) the reason (s) for requesting a paternity test at your laboratory? (Select all that apply)

- ○ To establish the paternity of the alleged father
- ○ To determine the identity of a child who was not registered at birth
- ○ To request or terminate financial support from the presumed father (legal obligation to meet the child's needs, such as alimony, etc.)
- ○ To obtain the right to carry the father's surname and inherit from him
- ○ I do not know
- ○ Other

Question 9: Is written consent obtained from all relevant individuals (father, mother, and child, if able to consent) before conducting a paternity test?

- ○ Yes
- ○ No
- ○ I do not know

Question 10: Is it possible for an individual to request a paternity test analysis on a sample they possess from another person (such as a baby's pacifier, hair, blood, or bone) without the consent of the parents (the father, mother, and child, depending on the child's age)?

- ○ Yes
- ○ No
- ○ I do not know

Questions about general DNA testing (Excluding paternity testing)

Question 11: Do you think that there is a law that regulates genetic testing in Lebanon?

- ○ Yes
- ○ No
- ○ I do not know

Question 12: Before performing any genetic test, other than paternity testing, is informed consent obtained from the individual involved?

- ○ Yes
- ○ No
- ○ I do not know

Question 13: If yes, what type of consent is it?

- ○ Oral
- ○ Written
- ○ I do not know

Question 14: If not, what are the reasons that the informed consent of the individual involved was not obtained beforehand? (Select all that apply)

- ○ Lack of time
- ○ It is not mandatory in our laboratory
- ○ other

Question 15: Is it possible for an individual to request a DNA analysis, excluding a paternity test, on a sample they possess (such as a baby's pacifier, hair, blood, or bone) without obtaining consent from the individual in question?

- ○ Yes
- ○ No
- ○ I do not know

Question 16: Is genetic counseling provided to the patient prior to conducting a genetic test?

- ○ Yes
- ○ No
- ○ I do not know

Question 17: Prior to conducting a genetic test, is the patient made aware of the potential for incidental findings related to false paternity?

- ○ Yes
- ○ No

Question 18: Prior to conducting a genetic test, is the patient made aware of the potential for incidental findings related to genetic predisposition to a disease?

- ○ Yes
- ○ No

Question 19: If yes, do you inquire with the patient about their preference regarding being informed about any incidental findings?

- ○ Yes
- ○ No

Question 20: When communicating the results to the concerned person, are incidental findings revealed?

- ○ Yes
- ○ No

Question 21: Who receives the communicated results? (Select all that apply)

- ○ To the concerned person (s) only
- ○ To anyone who has the receipt of payment
- ○ To any person designated by the concerned person and after their consent
- ○ To the doctor, if following a consultation
- ○ To the judge, if following a trial

Question 22: In the absence of legislative procedure, what is the typical way to communicate the results to the relevant individual?

- ○ By telephone
- ○ By email
- ○ Face to face
- ○ According to the preference of the concerned person

Question 23: In the absence of legislative procedure, who is responsible for communicating the results to the concerned person?

- ○ Laboratory technician
- ○ Genetic counselor
- ○ Geneticist
- ○ Head of laboratory
- ○ Other

Question 24: Are the results disclosed in the presence of a psychologist?

- ○ Yes
- ○ No

Question 25: Are results disseminated when necessary to other health care professionals or other parties without the patient's consent?

- ○ Yes
- ○ No

Question 26: Is the extracted DNA usually destroyed or conserved after genetic testing?

- ○ Destroyed
- ○ Conserved without consent of the concerned person
- ○ Conserved after consent of the concerned person

Question 27: Is the stored DNA used in future research or genetic analysis?

- ○ Yes, without the consent of the concerned person
- ○ Yes, after consent of the concerned person
- ○ No

Question 28: Is the person's anonymity preserved when storing DNA and using it in future research or genetic analysis?

- ○ Yes
- ○ No
- ○ No unless the person agrees otherwise

Question 29: Please specify which information listed below is included in the consent form signed by the concerned person: (Select all that apply)

- ○ Nature and purpose of the genetic test or research
- ○ DNA collection procedure (nature of the biological sample and procedure)
- ○ Advantages and risks of the test o How the results are conveyed and the intended person for this communication.
- ○ Details regarding the potential for incidental findings and the individuals who may be impacted by the sharing of this information.
- ○ Future use of extracted DNA (including storage, destruction, and potential applications in research or genetic analysis).
- ○ Safeguarding personal information: ensuring confidentiality, anonymity, etc.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

La perception de l'empowerment dans le suivi de grossesse par des personnes enceintes et des prestataires de santé au Québec

Marie-Alexia Masella[a], Béatrice Godard[a]

Résumé
Contexte : Les personnes enceintes notent un sentiment de perte de contrôle dans leur suivi prénatal depuis plusieurs décennies. Ce sentiment de contrôle, aussi appelé *empowerment*, qui devrait être encouragé, est pourtant associé à de meilleurs résultats de santé. Face à ces bénéficies potentiels, nous avons souhaité analyser la perception qu'ont ces personnes et leurs prestataires de santé, au Québec, de cet empowerment pour identifier les facteurs qui leur permettent de mettre en place ce processus et ceux qui le freinent. **Méthodologie :** Des entrevues individuelles semi-structurées ont été réalisées auprès de sept personnes enceintes et deux sages-femmes, suivies d'une analyse thématique des verbatims obtenus. **Résultats :** Des facteurs facilitants et freinants touchant autant à la relation de soins avec les prestataires de santé, qu'aux caractéristiques personnelles des personnes enceintes ont été identifiés et détaillés. Des outils et des pistes de solutions pour soutenir l'empowerment ont également été partagés. **Conclusion :** Une volonté d'acquérir davantage de pouvoir est notée par les participantes. Afin de répondre à ce besoin, des mesures et des ajustements pourraient être mis en place tant dans la relation de soin que dans les dynamiques du système de santé ou dans la formation des prestataires de santé pour soutenir l'empowerment de la patientèle.

Mots-clés
empowerment, personnes enceintes, suivi prénatal, grossesse, bioéthique

Abstract
Background: Pregnant people have been noting a sense of loss of control in their prenatal care for several decades. This sense of control, also known as empowerment, should be encouraged, and it has been associated with better health outcomes. In view of these potential benefits, we set out to analyze the perceptions of empowerment held by pregnant people and their healthcare providers in Quebec, to identify the factors that enable and hinder this process. **Methodology:** Semi-structured individual interviews were conducted with seven pregnant women and two midwives, followed by a thematic analysis of the verbatims obtained. **Results:** Facilitating and hindering factors affecting both the care relationship with healthcare providers and the personal characteristics of pregnant people were identified and detailed. Tools and solutions to support empowerment were also shared. **Conclusion:** A desire to acquire more power was noted by the participants. In order to meet this need, measures and adjustments could be implemented both in the care relationship and in the dynamics of the healthcare system, or in the training of healthcare providers to support patient empowerment.

Keywords
empowerment, pregnant people, prenatal care, pregnancy, bioethics

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INTRODUCTION

L'*empowerment* en santé

L'*empowerment*[1] en santé se réfère au processus par lequel les individus et les communautés acquièrent les connaissances, les compétences et la confiance nécessaires pour prendre des décisions et des actions concernant leur propre santé (2). Le concept d'empowerment a émergé dans les années 1970 et 1980 dans le cadre des mouvements de droits civiques et de justice sociale (1,3,4). Initialement utilisé pour promouvoir l'autonomie des communautés marginalisées et stigmatisées, il a rapidement été adopté dans le domaine de la santé publique pour encourager l'engagement des patientes et des patients et des communautés dans leurs propres soins de santé et dans l'amélioration de leurs habitudes de vie (3,5,6). Ce concept implique un passage du modèle traditionnel des soins de santé où les prestataires de santé détiennent l'autorité, vers un modèle où les patientes et les patients jouent un rôle actif et participatif dans la gestion de leur santé. Cette nouvelle dynamique s'inscrit dans les approches de santé centrées sur le patient, comme mis de l'avant dans un article précédent (7).

Le sentiment d'empowerment peut renvoyer à une prise de conscience du pouvoir personnel, de la capacité à influencer sa propre vie et ses décisions. Ce sentiment émerge souvent d'un processus graduel. En retour, ce processus encourage une dynamique d'engagement, où l'individu est l'acteur principal du changement et participe activement à la prise de décisions, à la défense de ses droits et à la construction de son parcours. Ces dimensions se renforcent mutuellement : le sentiment d'autonomie alimente l'engagement, tandis que l'engagement nourrit le processus d'apprentissage et de croissance,

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[1] La traduction française de ce terme est peu effective. En effet, les traductions comme « autonomisation » ou « capacitation » indiquent un processus mais ne font pas référence à la notion de pouvoir. À l'inverse, les termes comme « pouvoir d'agir » ou d'« action » ne décrivent pas le processus employé pour arriver à un état d'empowerment (1).

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consolidant ainsi un cercle vertueux d’empowerment. Ces différentes dimensions font écho aux théories d’éthiques féministes, notamment d’autonomie relationnelle (8,9) et de la théorie des capabilités de Sen (10-12) où l’individu est au centre d’une toile sociale et d’un environnement plus ou moins capacitant qui influence sa prise de pouvoir sur sa vie et ses décisions et donc son processus d’empowerment. Ces liens sont davantage discutés dans un autre article sur le sujet (13).

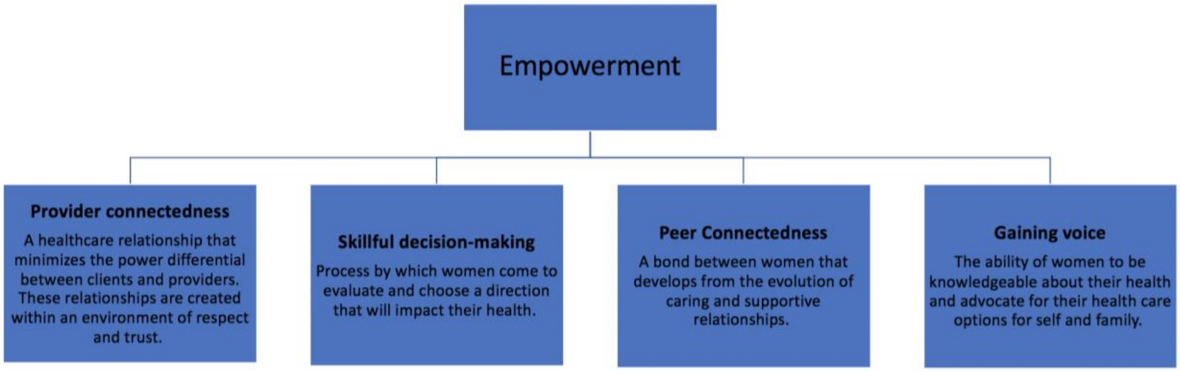
Des auteurs, en s’appuyant notamment sur des études menées aux États-Unis, ont mis de l’avant que l’empowerment avait plusieurs bénéfices. Il permet notamment aux individus de mieux comprendre leurs conditions de santé, de suivre les traitements recommandés et d’adopter des comportements sains (14). Il peut aussi mener à une réduction des complications, une meilleure gestion des maladies chroniques et une amélioration globale des résultats de santé (15-17). Ainsi, en fournissant aux patientes et aux patients les informations nécessaires et en les impliquant dans le processus de décision, l’empowerment favorise des choix de santé plus éclairés (18,19).

L’empowerment durant la grossesse

Durant la grossesse, l’empowerment en santé est crucial (20,21). Klima et ses collaborateurs ont développé un cadre portant sur l’empowerment des personnes enceintes[2] dans leurs soins durant la grossesse (16). Grâce à des groupes de discussion, une revue de la littérature et l’exploration des différentes échelles de mesure de l’empowerment, Klima et ses collègues ont pu mettre de l’avant quatre dimensions à l’empowerment lors du suivi de grossesse, qui sont non sans rappeler les notions qu’ils présentent dans leur définition (voir Figure 1 ci-dessous). La première de ces dimensions est le *lien avec le prestataire*, qui est définie comme étant la relation de soin qui unit la personne enceinte et sa ou son prestataire de santé. La confiance et le respect ainsi qu’une faible dynamique de pouvoir entre les deux parties prenantes sont des facteurs favorisants du processus d’empowerment. La seconde dimension, soit la *prise de décision éclairée*, fait écho au processus utilisé par les personnes enceintes pour faire des choix et prendre des décisions quant à leurs soins et à leur santé. Cette dimension prend en compte tous les facteurs pouvant affecter cette prise de décision comme le niveau d’éducation, les informations transmises et disponibles, la capacité de faire preuve d’esprit critique, etc. La troisième dimension, soit la *connexion entre pairs*, s’intéresse au soutien et au tissu social qui permettent à la personne enceinte de se sentir accompagnée et soutenue dans ses soins, particulièrement par d’autres mères. Enfin, la quatrième, nommée *l’expression*, met de l’avant « la capacité des femmes à s’informer sur leur santé et à défendre leurs options en matière de soins de santé pour elles-mêmes et leur famille » (p.122, traduction libre).

Bien que ces dimensions puissent se retrouver en tout ou partie dans les travaux d’autres auteurs (2,20-23), aucun de ces autres cadres ne porte spécifiquement sur la population des personnes enceintes et sur le contexte de soins. C’est pourquoi ce cadre spécifique offre un soutien théorique pertinent pour conceptualiser l’empowerment et guider cette recherche. En effet, les questions développées pour les entrevues rejoignent l’une ou plusieurs des quatre dimensions évoquées, afin d’explorer comment le concept d’empowerment s’opérationnalise en pratique.

Figure 1 : Modèle conceptuel de l’empowerment durant la grossesse par Klima et ses collègues



L’empowerment des personnes enceintes au Québec

Les personnes enceintes bénéficient au Québec d’un suivi de grossesse prédéfini, qui comprend des consultations régulières avec une professionnelle ou un professionnel de santé ainsi que des échographies et d’autres tests permettant de vérifier la santé de la mère et de l’enfant à venir (24,25). Ce suivi a été mis en place de manière plus structurée au XXème siècle et s’est médicalisé avec les avancées techno-scientifiques (25-30). Cette médicalisation, bien que salutaire pour prévenir la mortalité et morbidité materno-infantile, a entrainé plusieurs insatisfactions, notamment de la part des personnes enceintes (31,32). Parmi ces insatisfactions, on peut noter le sentiment de perte de contrôle sur son corps et ses décisions. Ce sentiment de contrôle, aussi appelé empowerment, est pourtant associé à de meilleurs résultats de santé, comme une réduction des complications pré et postnatales (5,6). Il permet aussi d’augmenter le niveau de satisfaction des soins reçus et donc favoriser un sentiment de vivre une meilleure expérience globale des soins, ce qui peut avoir des effets positifs sur le bien-être tant physique qu’émotionnel des personnes enceintes (20,33).

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[2] Dans un souci de cohérence avec le concept d’empowerment, le terme « personnes enceintes » est utilisé dans cet article pour refléter la diversité des genres à laquelle les personnes enceintes peuvent s’identifier, même s’il s’agit principalement de femmes cisgenres.

Face à ces bénéficies potentiels, il apparait important d'analyser la perception qu'ont les personnes enceintes de leur empowerment dans ce suivi prénatal pour identifier les facteurs qui leur permettent de mettre en place ce processus et ceux qui le freinent. En effet, comprendre le sentiment de pouvoir (empowerment) et la satisfaction des personnes enceintes peut aider à adapter les politiques et les pratiques de soins prénatals pour mieux répondre à leurs besoins. Cela passe notamment par comprendre les attentes et les préférences des personnes enceintes en matière d'implication dans leurs soins. Cela favorise également la prise en compte des caractéristiques propres aux patientes, selon le système de soins auquel elles ont accès, en l'occurrence au Québec, qui peuvent varier des populations de personnes enceintes qui ont déjà fait l'objet de recherches, afin de leur offrir des soins plus appropriés. De même, il est rare de bénéficier de la perception des prestataires de santé les accompagnant, alors qu'ils jouent pourtant un rôle central dans ce processus, du fait qu'ils sont les interlocuteurs principaux des patientes durant le suivi de grossesse. Bien que ces aspects aient été abordés dans la littérature, ils ne l'ont jamais été en contexte québécois.

Ainsi, s'intéresser spécifiquement à l'empowerment des personnes enceintes dans le contexte québécois singulier est essentiel, puisque les études sur l'empowerment précédemment menées ne tiennent pas nécessairement compte des particularités du Québec, comme l'accès aux soins de santé, la diversité culturelle croissante, les modalités de suivi de grossesse, les contraintes structurelles, ou encore les pratiques professionnelles en santé périnatale. De plus, cette approche contribue à enrichir les connaissances globales sur l'empowerment en proposant une perspective ancrée dans un contexte distinct, illustrant que malgré une définition plus ou moins commune de l'empowerment, sa forme et les facteurs l'influençant peuvent varier. Cette étude s'est donc intéressée à la perception de l'empowerment dans le suivi prénatal au Québec par des personnes enceintes et par des prestataires de santé.

MÉTHODOLOGIE

Choix de la méthode

Une étude exploratoire a été réalisée afin de documenter les facteurs influençant l'empowerment ainsi que le niveau de satisfaction des personnes enceintes québécoises quant au pouvoir qu'elles ressentent dans leur suivi de grossesse. Cette étude qualitative a demandé la réalisation d'entrevues individuelles semi-dirigées avec des personnes en période périnatale et avec des prestataires de santé responsables de ce suivi. Pour ce faire, des personnes qui avaient plus de 18 ans, qui étaient enceintes ou qui avaient accouché depuis moins d'un an, et qui ont bénéficié d'un suivi de grossesse au Québec ont été sollicitées. Des prestataires de santé exerçant au Québec et étant impliqués dans le suivi prénatal ont également été sollicités. Il est à noter que seules les catégories professionnelles directement en contact avec les personnes enceintes et qui ont pour la plupart un droit de prescription ont été sollicitées, soit les gynécologues-obstétriciens, les omnipraticiens et médecins de famille, et les sage-femmes. Étant donné que l'étude portait sur le suivi médical, l'examen des décisions qui ont trait aux tests et dépistages pouvant survenir durant la grossesse, ainsi que les interventions médicales pouvant être nécessaires était essentiel.

Recrutement

Les personnes enceintes ont été recrutées via les médias sociaux, suite à un message de sollicitation sur différents groupes Facebook québécois destinés aux futures et nouvelles mères entre mars et septembre 2022. Les personnes intéressées étaient invitées à nous contacter afin de recevoir un formulaire d'information et de consentement puis de débuter leur participation. Un recrutement boule de neige était également possible. Des rappels mensuels ont été faits sur les réseaux sociaux. Aucune compensation n'a été octroyée pour la participation.

Concernant les prestataires de santé, leur sollicitation s'est effectuée au cours de l'année 2023 via leurs ordres et associations professionnelles par l'acheminement d'un courriel grâce aux listes d'envoi ou leurs réseaux sociaux.

Échantillon

Suite à ce recrutement, sept personnes enceintes ont pris part à une entrevue. Afin de contextualiser et d'interpréter les résultats de manière rigoureuse, les caractéristiques démographiques des participantes ont été collectées. Ces données permettent de nuancer et ventiler les résultats qualitatifs obtenus. En effet, des caractéristiques comme l'âge, le statut socio-économique, le niveau d'éducation, la situation maritale ou encore le nombre de grossesses ou la présence d'un partenaire peuvent affecter non seulement le suivi prénatal, mais aussi le processus d'empowerment (20). Ainsi, les participantes se sont identifiées en tant que femmes et avaient majoritairement entre 30 et 34 ans. Quatre étaient nées au Canada et trois en France. Elles bénéficiaient toutes d'un niveau socio-économique élevé, comme en témoignent le revenu annuel de leur foyer et les études suivies. Durant leur grossesse, elles avaient toutes un partenaire masculin pour les soutenir et n'attendaient qu'un enfant. Pour six participantes, il s'agissait d'une première ou deuxième grossesse. Cinq des sept participantes avaient déjà accouché au moment de l'entrevue. Quatre participantes avaient été suivies par une ou un gynécologue obstétricienne ou obstétricien, une par un médecin de famille, une par un résident et une par une sage-femme. Le tableau 1 ci-après présente les caractéristiques socio-démographiques des personnes participantes aux entrevues et les caractéristiques de leur grossesse :

Tableau 1 : Caractéristiques socio-démographiques et de grossesse des personnes participantes aux entrevues individuelles du volet 1

Caractéristiques	Choix	N
Âge	18-24 ans	1
	30-34 ans	5
	35-39 ans	1
Pays de naissance	Canada	4
	France	3
Origine ethnique	Europe	3
	Nord-américaine	4
Statut migratoire	Citoyenne canadienne	4
	Résidente permanente	1
	Résidente temporaire	2
Région administrative de résidence	Capitale Nationale	3
	Montérégie	1
	Montréal	3
Plus haut niveau d'étude suivi	Supérieur ou égal aux études secondaires	7
Revenu annuel du foyer	20,000-49,000	1
	50,000-79,000	1
	80,000-99,000	2
	100,000 ou plus	3
Emploi	Étudiant(e)	1
	Salarié(e)	5
	Sans emploi	1
Présence d'un partenaire masculin	Oui	7
Parité	Première grossesse	3
	Deuxième grossesse	3
	Troisième grossesse	1
Nombre d'enfants attendus	Singleton	7
Moment de la grossesse	Deuxième trimestre	1
	Troisième trimestre	1
	Accouchée	5
Type de suivi	Suivi normal	4
	Suivi intensifié	3
Prestataires de santé effectuant le suivi	Gynécologue obstétricien	4
	Médecin de famille	1
	Résident	1
	Sage-femme	1

Concernant le recrutement des prestataires de santé, seulement deux sages-femmes ont accepté de prendre part à une entrevue individuelle. L'une avait entre 35 et 39 ans, avait réalisé ses études au Québec, et exerçait la profession de sage-femme depuis 10 à 20 ans en maison de naissance. Elle suivait environ 32 personnes enceintes par année dans deux régions du Québec. La seconde sage-femme avait également entre 35 et 39 ans, avait suivi ses études aux États-Unis, et exerçait la profession de sage-femme depuis 5 à 10 ans en maison de naissance au Québec ainsi qu'en Ontario. Malgré l'envoi du message de sollicitation à d'autres prestataires de santé via leurs ordres ou associations professionnels, notamment des omnipraticiens et des gynécologues-obstétriciens, aucun autre participant professionnel n'a pu être rencontré.

Participation

Personnes enceintes

Les entrevues individuelles ont eu lieu via la plateforme Zoom, ont duré entre 40 et 60 minutes, et ont été enregistrées sur support audio. Les personnes participantes ont d'abord rempli un court questionnaire socio-démographique en ligne sur la plateforme LimeSurvey, dont les serveurs sont sécurisés et hébergés sur le campus de l'Université de Montréal.

L'entrevue a permis d'aborder la perception que les personnes enceintes ont de leur empowerment, la définition qu'elles en donnent ainsi que les obstacles et les facilitateurs qu'elles ont pu rencontrer dans leur suivi médical et qui ont pu avoir un impact sur le processus d'empowerment. Les questions ont aussi porté sur les solutions auxquelles elles ont recours pour initier ou continuer un processus d'empowerment et quels sont la place et le rôle qu'elles attribuent aux technologies numériques dans celui-ci, et dans ces solutions. Pour chaque thématique, des questions générales ont d'abord été posées (ex. : Qu'est-ce qui, selon vous, influence votre prise de pouvoir dans vos soins de grossesse), avant d'utiliser des questions plus spécifiques sur différents facteurs d'influence en lien avec les dimensions décrites par Klima et ses collègues (16) (ex. : Pensez-vous qu'il y a parfois une relation de pouvoir entre vous et votre prestataire de santé?).

Professionnelles de santé

Deux sage-femmes ont participé à un entretien individuel semi-dirigé sur Zoom d'une durée de 30 à 60 minutes, puis enregistré sur support audio. Le but était d'explorer leur perception quant à l'empowerment de leurs patientes. Elles ont été interrogées sur la perception qu'elles avaient de l'empowerment de leurs patientes, ainsi que sur les obstacles et les facilitateurs que ces dernières peuvent rencontrer en pratique. Les outils ou les pratiques qu'elles peuvent utiliser pour développer ou favoriser la mise en place de cet empowerment ont aussi été abordés. Comme pour les femmes enceintes, les questions étaient d'abord d'ordre général, puis ciblaient plus spécifiquement certains sujets ou facteurs.

Analyses

Bien que des fréquences aient été réalisées pour décrire l'échantillon obtenu, l'analyse des entrevues a consisté en une analyse thématique. L'analyse thématique est une méthode qualitative utilisée pour identifier, analyser et rapporter des motifs (ou « thèmes ») dans un ensemble de données (34,35). Elle permet de découvrir des modèles à travers les données et de les organiser en thèmes significatifs pour répondre aux objectifs de recherche (34,35), qui étaient ici de dresser un portrait de la perception de l'empowerment dans le suivi prénatal qu'en ont des personnes enceintes et des prestataires de santé, au Québec. Cette analyse a été réalisée par la première auteure (MAM) et la seconde auteure (BG) a été consultée au besoin, en cas de doute d'interprétation. Pour les sept femmes enceintes autant que pour les deux professionnelles de santé interrogées, les thèmes qui ont émergé abordent la définition de l'empowerment, ses avantages et inconvénients, les facteurs facilitant ou freinant sa mise en place, et les outils et ressources utilisés dans ce processus. Ces thèmes sont présentés dans la section résultats.

Éthique

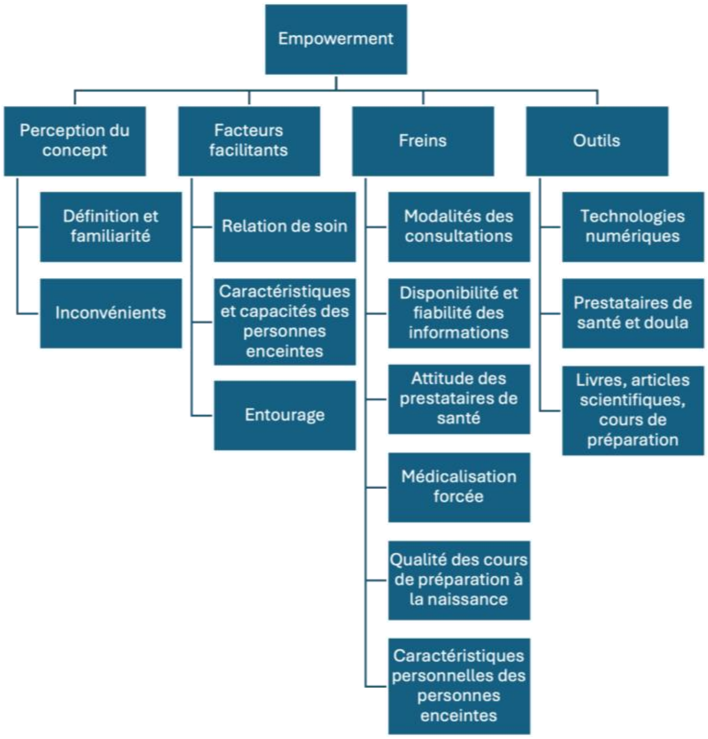
Cette étude a reçu l'approbation éthique du Comité d'éthique de la recherche en sciences et en santé de l'Université de Montréal (CERSES). Les données ont été d'abord dépersonnalisées afin d'associer les réponses au questionnaire socio-démographique en ligne et les données provenant de l'entrevue pour chaque participante, avant d'être anonymisées à l'issue de la collecte des données. Les données sont conservées sur un serveur sécurisé de l'Université de Montréal.

RÉSULTATS

Personnes enceintes

La figure 2 ci-dessous présente les thèmes identifiés ainsi que les sous-thèmes qui leur sont liés au sein des témoignages des personnes enceintes. Ces thèmes et sous-thèmes sont repris un à un par la suite afin de les expliciter et de les appuyer de citations directes des participantes.

Figure 2 : Schéma des thèmes et sous-thèmes évoqués lors des entrevues avec des personnes enceintes



Conception de l'empowerment

Définition et familiarité

Les femmes enceintes rencontrées ont généralement peu ou pas entendu parler d'empowerment, notamment dans un contexte de santé. Celles qui avaient déjà connaissance de ce concept y ont été exposées soit dans leur milieu professionnel (qui n'était pas celui de la santé), soit de par leur recherche et curiosité personnelles. Eu égard à la définition qu'elles donneraient à ce concept, la plupart ont fait référence aux notions de capacité de décider et d'agir, d'autonomie, de pouvoir d'agir, de prise de décision éclairée et de contrôle. L'une des participantes a ainsi relevé le fait que ce concept est de plus en plus repris en société et explique que « *[…] maintenant la société évolue, on voit passer ça partout. Moi-même, j'aime bien prendre les choses en main aussi. Je déteste qu'on m'infantilise […]* » (P6).

Bien que les femmes interrogées n'aient pas une définition exacte du concept, elles ont une perception de celui-ci déjà axée sur cette capacité à user de son pouvoir décisionnaire et de leur rôle de partie prenante dans le suivi prénatal.

Inconvénients

Bien que toutes les participantes aient relevé l'intérêt et l'importance de l'empowerment dans leurs soins, deux d'entre elles ont également identifié des inconvénients et risques à la promotion de celui-ci, notamment des risques d'apporter une pression et une culpabilité sur les personnes enceintes puisqu'elles pourraient avoir le sentiment que l'entière responsabilité repose sur elles. Elles mettent ainsi en garde : « *Mais je trouve que c'est comme beaucoup de concepts, […] c'est bien à la base et puis ça vire toujours vers faire mieux et être parfait* » (P5) et « *[C'est bien] tant que ça ne crée pas non plus une pression sur la mère ou le père tu sais que tout repose sur cette personne-là pour prendre la décision*. » (P7)

L'une de ces participantes explique aussi que certains facteurs échappent à tout contrôle et notamment au contrôle des personnes enceintes, laissant entendre que le concept d'empowerment ne devrait pas leur laisser penser qu'elles ont le contrôle sur ces facteurs, sous peine d'être déçues, voire de culpabiliser. La participante explique :

> *Donc ça va être un peu culpabilisant, même parfois, parce que bah pour certaines mamans tu vois, là moi, j'ai très bien vécu les changements et tout, mais quand je rencontre d'autres mamans ben si ça ne s'est pas passé comme elles voulaient, elles sont vraiment déçues et donc je me demande si ça, cette volonté de maîtrise, ne crée pas aussi un écart entre la réalité et ce que t'avais imaginé […].* (P5)

En plus de ces deux enjeux, un dernier est relevé : celui de percevoir son pouvoir d'agir en tant que personne enceinte comme *« au-dessus des recommandations médicales ».* L'une des participantes interrogées a mentionné qu'elle trouvait interpellant de voir que parfois, les choix et demandes faits par les patientes et patients remettaient en question certaines indications médicales : *« Il y a vraiment ce truc aujourd'hui, […] un peu de mise en scène aussi donc. Je trouve que l'empowerment ça glisse un peu trop vers ce côté, se positionner au-dessus de décisions médicales.* » (P5). Elle ajoute : « *Mais bon, quand la fille elle te dit si dans cinq minutes il n'est pas là, son rythme baisse* [ndrl. le rythme du bébé]*, on part en césarienne, ben tu ne vas pas dire non, je refuse la césarienne et en fait il y a des gens qui remettent en cause un peu tout ça.* » (P5).

Facteurs facilitants

Les participantes ont partagé différentes expériences qui ont permis d'identifier certains facteurs les aidant à initier ou développer leur empowerment dans leur suivi prénatal.

La relation de soins ainsi que les conditions des consultations sont ainsi identifiées comme des facteurs déterminants pour l'empowerment des personnes enceintes. Notamment, une relation de soin basée sur l'écoute et le respect semble essentielle afin de pouvoir développer et user son pouvoir d'agir, en posant des questions, et en se sentant considérée comme une partie prenante des décisions. Les participantes partagent ainsi leur vécu :

> *Oui, parce […] qu'on se sent considéré en fait justement d'être dans cette position-là, d'égal à égal.* (P2)
>
> *Mais elle a quand même été pas mal respectueuse de mes divers changements d'avis sur la manière dont je voulais accoucher, de ce que je souhaitais.* (P6)

En plus de ce respect et de cette écoute, les participantes apprécient les échanges transparents, honnêtes ainsi que le temps pris par les prestataires pour leur partager des informations et des explications. « *[…] je trouve que la relation avec le personnel de la santé a vraiment un grand rôle à jouer dans le sentiment de pouvoir, parce que c'est ça notre porte d'entrée. […] c'est une des seules sources fiables d'informations.* » (P1)

Certaines participantes ont indiqué avoir des rencontres d'environ 15-20 minutes avec leurs médecins, contre 45 minutes à 1 heure pour des rendez-vous avec les sages-femmes. De manière générale, les participantes ont reconnu que le fait d'avoir le sentiment de ne pas déranger leur permet de mieux utiliser leur empowerment.

Le fait que les prestataires fassent preuve d'empathie, de réassurance, et d'une approche personnalisée est aussi mentionné comme un facteur facilitant dans leur processus d'empowerment. « *Il y avait une infirmière puis il y avait la médecin qui était là puis l'infirmière était quasiment juste là pour me tenir la main. Et elle a accueilli toute ma peine. Et l'autre médecin était super empathique. Elle a fait des blagues pour détendre l'atmosphère à de bons moments.* » (P7)

Enfin, le fait que les prestataires de santé, que ce soit les personnes qui effectuent principalement le suivi prénatal ou non, soient facilement joignables, et qu'ils aient du temps à accorder à leurs patientes offre aussi des opportunités aux personnes enceintes d'adresser leurs besoins influençant leur empowerment. Une participante a ainsi apprécié avoir l'opportunité d'entrer en contact rapidement et facilement avec une autre membre de l'équipe médicale lorsque sa gynécologue n'était pas disponible :

> *[…] il y a eu une fois où j'ai appelé et qu'elle [la gynécologue] n'était pas là, mais l'infirmière elle a offert en fait, pour pouvoir être capable de répondre à ma question, d'aller fouiller dans mon dossier et est allé parler avec un médecin. Tsé elle a vraiment fait un paquet de démarches pour répondre à ma question, même si je n'étais pas sa patiente.* (P2)

Somme toute, le rôle, l'attitude et la disponibilité des prestataires de santé, notamment celui assurant le suivi prénatal, a un impact important sur le processus d'empowerment des personnes enceintes.

Caractéristiques et capacités des personnes enceintes

Les participantes ont identifié certaines caractéristiques individuelles leur permettant de gagner plus facilement en empowerment, comme leur profession, le fait qu'elles aient déjà eu des enfants, leur âge, etc. :

> *Mais je me dis quelqu'un comme moi, qui est infirmière de profession, et mon conjoint qui est quand même aussi très au fait là, en termes de littératie en santé, je me dis ben, on a cette possibilité-là, cette capacité d'entendre plus et d'être très, très outillés parce qu'on est des gens comme ça aussi. On est analytiques, on a besoin de savoir. Faque. Puis tsé sur le coup, tu ne passes pas forcément à tout, tu sais, nous-même on serait capable de dire ba on voudrait un complément d'information. On est capable de poser la question.* (P2)

De plus, se percevoir comme actrices de leur suivi de grossesse a aussi été mis de l'avant comme étant bénéfique pour leur prise de pouvoir. Des participantes ont mentionné arriver préparées aux consultations en répertoriant leurs questions en amont. Cette préparation les aidait à garder le contrôle sur leur suivi et à gagner en pouvoir :

> *Je préparais mes réponses ou mes questions en fonction de ça, fait que je savais très bien de quoi on allait parler à chaque rencontre, faque oui, j'arrivais super préparée à mes rencontres avec ma liste de questions. Faque je pense ça à aider à la fluidité du contenu, de ce que j'avais besoin et de ce qu'elle [la gynécologue] avait besoin.* (P7)

Entourage

Des participantes ont souligné l'apport de leur entourage sur leur processus d'empowerment. En effet, en valorisant leurs choix et en les soutenant dans leur décision, l'entourage semble renforcer leur sentiment d'autonomie et leur confiance en elles et dans leur toile sociale, mais aussi leur offrir une ou des personnes sur lesquelles s'appuyer lorsqu'elles ne sont pas en mesure de faire valoir seules leurs choix. Ce support les prévient de l'isolement, facilite la gestion des responsabilités, et leur permet de se sentir soutenues dans leur suivi médical de grossesse, qui peut être stressant et complexe. L'une des participantes indique ainsi : « *Au niveau des échographies, il* [ndrl. son conjoint] *pensait souvent à poser des questions pertinentes auxquelles moi je ne pensais pas. […] Fait que c'est une deuxième personne, ça aide.* » (P1)

Une autre participante met de l'avant l'apport du partage d'expériences par d'autres personnes enceintes sur le sentiment d'isolement et l'inquiétude que celui-ci peut entrainer : « *Moi, je suis allé sur des pages Instagram, disons des gens qui passent par le même processus que nous. Tu sais, ça reste quand même un sujet qui est tabou, puis de pouvoir juste être témoin, de ne pas se sentir tout seul.* » (P2)

Enfin des participantes ont évoqué avoir pu compter sur leur entourage et des groupes de personnes enceintes comme soutien informationnel et support moral, les encourageant à faire valoir leur pouvoir d'agir. L'une d'elle évoque les bénéfices de ces échanges : « *Le diabète je pense j'ai eu des bons conseils de gens qui font du diabète ou qui ont fait du diabète de grossesse, que je suis allée chercher en parlant avec des gens […]* » (P7).

Bien que l'entourage ne soit pas l'acteur central dans le processus d'empowerment des personnes enceintes au sein de leur suivi prénatal, il semble y jouer un rôle important pour soutenir ces personnes.

Freins

Lors des échanges avec les participantes, des expériences ont été partagées témoignant de facteurs ne leur permettant pas de développer ou poursuivre un processus d'empowerment.

Disponibilité et fiabilité des informations

D'après des participantes, le manque de disponibilité et de fiabilité des informations transmises par les prestataires de santé et la société, ainsi que leur manque d'homogénéité, peut entraver leur processus d'empowerment en les laissant mal préparées ou mal informées face aux décisions importantes liées à leur grossesse. Des informations incohérentes, incomplètes ou teintées de jugements peuvent générer de l'incertitude, du stress et une perte de confiance en leurs capacités à faire des choix éclairés.

Une participante explique ainsi :

> *[…] parce que les gens sont submergés d'informations et c'est difficile de tenir une ligne droite en fait. Donc quand tu ne sais plus trop, je pense que tu peux aller dans toutes les directions et en fait le plus important je pense, c'est de se faire confiance. Mais quand tu es fatiguée, que tu es un peu perdue, c'est très dur en fait.* (P5)

Une autre participante met l'accent sur la difficulté de pouvoir prendre ses propres décisions dans ce contexte :

> *C'est que ça change tellement. Mettons mes belles sœurs ont des enfants plus vieux qui ont quatorze ans et ce qu'elles se faisaient dire pendant leur grossesse, c'est déjà différent de ce que je me fais dire ou de ce que ma mère se faisait dire. Faque les influences extérieures font en sorte que c'est difficile de se faire sa propre idée […].* (P1)

Modalités des consultations

Plusieurs facteurs en lien avec les modalités des consultations prénatales ont été relevés comme pouvant affecter l'empowerment des personnes enceintes. Le premier de ces facteurs est celui d'accès à un prestataire de santé. Des participantes indiquent qu'il leur a été difficile de trouver rapidement une ou un prestataire de santé pouvant assurer leur suivi de grossesse, et que cela arrivait souvent vers la fin du premier trimestre, ce qui les laissait seules face à leurs interrogations durant plusieurs semaines.

> *Parce que c'est pareil, la première rencontre, ça se fait trois mois après le fait que tu as appris que t'es enceinte, tu sais, c'est les trois mois en plus, entre guillemets les plus difficiles, parce que tu peux en parler à personne, parce que tu ne sais rien. Puis, le premier jour ou la première fois où tu vas faire ton rendez-vous, là, tu sais pas ce qui t'attend, tu ne sais pas ce qu'elle va aller voir, tu ne sais pas ce qui va se passer.* (P3)

Le temps alloué aux consultations est un autre enjeu, tout comme celui du mode de consultation puisque certaines participantes en ont réalisé par téléphone :

> *Puis si je compare à ce que je vis en ce moment avec Docteur X où tu sais, je me sens vraiment partie prenante du processus, tandis que l'autre est comme c'est le fait que ce soit par téléphone, que tu ne te vois pas, tu sais, il y a comme beaucoup de choses très impersonnelles qui amènent une certaine distance […].* (P2)
>
> *Alors je ne dirais pas que parce qu'ici, en fait, tu vois ta gynéco, tu la voies, t'as trois minutes top chrono, ça ne permet pas de nouer des liens très forts.* (P6)

Un autre facteur pouvant aussi soulever des enjeux est celui du changement régulier de prestataire rencontré durant le suivi de grossesse. Pour les participantes qui n'étaient pas suivies par des sages-femmes, mais qui l'étaient notamment dans un centre universitaire, des changements réguliers de leur interlocuteur du fait qu'il s'agissait de résidents ont été vécus. Ces changements ne permettaient pas de construire une relation de confiance aussi forte qu'attendue selon elles :

> *Faque là c'était pas le même à 39 et demi* [semaines de grossesse]*. C'est pas Dr X, c'est celle qui la remplaçait qui m'a proposé un striping. Et là, t'es pas aussi à l'aise d'en discuter avec elle que je l'aurais été avec le Dr X.* (P1)

Des participantes notent aussi que l'absence de transmission des résultats en lien avec les échographies et tests réalisés peut entraver leur processus d'empowerment. L'inconnu et l'attente qu'apportent ces situations ont été notés comme stressant :

> *C'est vrai que ça, c'est un truc qui m'a beaucoup dérangé sur toutes les prises de sang que j'ai pu faire et puis sur les tests, je n'ai eu aucun résultat. Alors c'est vrai qu'apparemment ici* [ndrl au Québec] *ils t'appellent uniquement quand tu as un résultat qui n'est pas correct. Mais c'est vrai que pouvoir savoir un petit peu en tout cas, si t'es dans la norme ou que tu es un peu dans la limite haute, j'aurais bien aimé le savoir, j'aurais bien aimé suivre d'un peu plus près ma grossesse dans les éléments biologiques de la grossesse.* (P3)
>
> *Le plus difficile, c'était quand on fait des échographies, même s'il y a des technologues, je comprends qu'ils peuvent rien dire, mais même si c'est le médecin, on repart un peu en ne sachant pas c'est quoi le résultat de cette échographie-là. […] Je fais un lien avec l'empowerment un peu, mais je ne sentais pas que je comprenais et que je pouvais agir ou quoi que ce soit.* (P7)

Attitude des prestataires de santé

Les participantes ont aussi indiqué que certains propos ou certaines attitudes de prestataires de santé ont eu des effets sur leur sentiment de pouvoir :

> *[…] puis ça a pas manqué, le soir après, au moment de mon accouchement, je suis retombé sur la même équipe, vu que c'était celle du matin, que j'étais allé voir aux urgences, ba ils n'ont pas été très sympathiques parce qu'ils étaient là : « Ba vous étiez déjà là ce matin. Vous êtes connu du service, hein? » Ba oui, excusez-moi. Excusez-moi d'être inquiète […]. Non, ça dépend vraiment de l'équipe qu'on a en face. Donc si quelqu'un est ouvert plus facilement, on pourra poser des questions. Et plus ils sont fermés derrière, tu vas entre guillemets acquiescer puis tu vas rester avec ta crainte, tu vas finir sur internet, ou alors appeler d'autres personnes des autres professionnels de la santé que tu connais pour pouvoir t'aider un petit peu dans ces questions.* (P3)
>
> *Surtout dans un milieu hospitalier où on est pris en charge et on n'a plus de contrôle sur notre corps, sur les interventions, sur l'environnement. Donc moi, j'ai trouvé ça très difficile, effectivement.* (P4)

Médicalisation forcée

Les participantes ont évoqué des situations où elles ont ressenti de la pression ou un manque de choix dans les décisions qu'elles pouvaient prendre. Notamment, dès qu'un enjeu avec leur santé, ou celle de leur enfant à venir survenait, la possibilité d'user de leur pouvoir de décision s'atténuait voire disparaissait :

> *Après, il y a aussi le côté, ba quand tu es suivi dans un cadre vraiment hospitalier, avec un professionnel de la santé en général, il y a des moments où ils te laissent pas trop le choix sur certaines choses, parce qu'il y a le côté médical qui prédomine et tu sens bien qu'eux, ce sont des protocoles qui sont mis en place et ils ne peuvent pas déroger à leur protocole. […] il y a des choses vraiment, c'était le protocole du professionnel, les protocoles de l'hôpital, le protocole de tout le système de santé. À un moment, je ne vais pas me battre contre le système de santé, […].* (P6)

Qualité des cours de préparation à la naissance

Enfin, le sujet des cours de préparation à la naissance offerts par les établissements de santé au Québec est revenu plusieurs fois au cours des entretiens réalisés. Les participantes indiquent que les moments des cours durant la grossesse n'étaient pas optimaux et que les informations partagées tant sur le fond que sur la forme étaient insuffisantes :

> *Tu sais, comme c'est des gens, c'est le CLSC, en fait qui les donne ces formations-là. Donc ce n'est pas des gens qui travaillent à l'hôpital ni en salle d'accouchement. Tu sais, ils restent sur quelque chose de très très de base. Ça fait que moi, je n'ai pas l'impression d'avoir assez d'informations. Là, je vais aller au bout de mes cours, mais j'ai l'impression que je vais devoir aller chercher plus loin par moi-même.* (P2)
>
> *Et puis on te met une pression, parce que les cours prénataux te mettent quand même une grosse pression sur la façon dont tu dois allaiter ton enfant, comme quoi si tu ne l'allaites pas y a des risques pour lui. On ne te donne pas de cours sur, on te donne pas d'information sur si tu l'allaites pas, qu'est-ce que tu peux donner d'autre comme moyen?* (P3)

Caractéristiques personnelles des personnes enceintes

Tout comme les caractéristiques propres à chaque personne enceinte peuvent être des facteurs facilitants, certaines de ces caractéristiques peuvent être des freins à la possibilité pour ces personnes d'acquérir plus de pouvoir dans leurs soins. Les participantes relèvent ainsi que le niveau de littératie et d'éducation, les connaissances personnelles sur la grossesse et l'accouchement, mais aussi l'état de fatigue de la personne enceinte peuvent avoir un effet sur leur capacité à faire valoir leurs choix :

> *Tu sais, pendant le suivi de grossesse fait que j'étais capable de poser une question, de revendiquer mes choix. Mais c'est à la naissance que l'énergie est plus là pour.* (P4)
>
> *Je pense sérieusement que si les femmes ne se préparent pas à leur accouchement, ne s'y intéressent pas en tout cas, […] elles ne savent pas ce qui se passe, elles ont peur. Donc elles se réfèrent d'autant plus au personnel médical qui eux va donner, va leur faire prendre des décisions […].* (P6)

En résumé, des freins ont été relevés par les participantes, touchant autant à la relation avec les prestataires de santé, qu'à l'importance d'avoir accès à des informations sur leur grossesse ou encore à la prise en compte de leurs propres caractéristiques pouvant influencer leur processus de pouvoir.

Outils

Plusieurs outils sur lesquels se sont appuyées les participantes rencontrées pour soutenir leur processus d'empowerment ont été mentionnés.

Technologies numériques

Des outils numériques permettant l'acquisition de connaissances et de réponses à certaines interrogations qu'ils pouvaient apporter ont largement été relevés. Notamment, toutes les participantes ont eu recours à Internet pour avoir un complément d'information, des réponses à leurs questions ou inquiétudes, ou pour satisfaire leur curiosité sur des sujets en lien avec la grossesse et l'accouchement. Ainsi, une participante affirme qu'Internet, « *[…] me donnait une perception que j'agissais […]* » (P7). Une autre ajoute aussi que « *C'est vrai que les technologies sont parfois vraiment utiles puisque tu n'oses pas demander par peur d'être jugée* » (P3). D'autre part, les recherches Internet réalisées par les participantes se sont principalement faites sur Google, mais aussi sur des blogues de mères et sur des sites Web précis comme *Naitre et Grandir*. Ce dernier a été mentionné par des participantes qui ont été rassurées de voir qu'il était à l'initiative de l'Institut national de santé publique du Québec (INSPQ) et que les informations partagées étaient vérifiées par des prestataires. Cependant, certaines notent des risques de recourir à Internet, particulièrement en lien avec la fiabilité des informations partagées :

> *Le problème c'est que si t'as pas d'esprit critique derrière pour chercher les sources de ce qui est dit et que tu prends tout pour argent comptant, c'est compliqué. Je te dirais que c'est ça le problème d'internet, c'est que tu cherches une info. Oui, tu vas avoir surement beaucoup de réponses qui ne sont pas forcément fondées et qui peuvent te faire peur ou pas. Mais c'est le piège pour tout. Je veux dire. N'importe quelle chose, n'importe quelle recherche d'information sur Internet, c'est une source inépuisable de conneries.* (P6)

En plus d'Internet, d'autres technologies numériques ont été utilisées par les participantes : les réseaux sociaux et les applications mobiles. Les applications mobiles, comme *Grossesse+*®, ont surtout été utilisées pour suivre le développement de l'enfant à venir et moins pour trouver des informations.

Prestataires de santé et doula

Les prestataires de santé et les doulas soutiennent le processus d'empowerment puisqu'ils ont un rôle central dans le flux d'information acquis par les personnes enceintes, dans le support qui leur est prodigué ainsi que dans l'accompagnement reçu. Par exemple, les participantes ont mis de l'avant le rôle d'informateur de confiance de ces prestataires : « *[…] la relation avec le professionnel qui est vraiment importante, parce que moi, je trouve que c'était elle [sa gynécologue] qui avait l'information la plus à jour, elle en fait beaucoup de suivi, fait qu'elle voit si elle me dit ce n'est pas grave, ce n'est vraiment pas grave.* » (P1).

Il est à noter que certaines participantes ont fait une différence entre le médecin qui les suit, ou a pu les suivre, et les autres types de prestataires de la santé. Ainsi, certaines ont préféré le support et l'accompagnement offert par les sages-femmes ou les infirmières : « *Le gynéco en vrai il ne pose pas trop de questions. Les infirmières par contre après oui, pas mal, sur l'allaitement, sur des choses* » (P5) et « *Avec les sages-femmes, c'est plus clair, c'est plus détaillé et complet* » (P4).

Deux autres personnes ont été accompagnées par une doula et toutes deux ont mis de l'avant le soutien et l'aide que cela leur apportait.

Livres, articles scientifiques, cours prénataux

Certaines participantes ont également consulté des livres, notamment le *Mieux vivre avec notre enfant de la grossesse à deux ans* (36), qui leur a permis de se préparer aux différentes étapes de la grossesse et aux consultations prévues. Ceci dit, et même si les livres consultés par les participantes leur convenaient et les aidaient, l'une d'entre elles note :

> *[…] je ne suis pas sûr que dans toute la littérature publique j'entends, les bouquins, etc. il doit y avoir certainement une source d'information aussi assez incalculable, mais il faut encore y avoir accès. Et il faut, il faut… ça un coût, il faut trouver les bons ouvrages. Ça a encore un coût. Il faut laisser du temps, beaucoup de temps à consacrer, même si j'adore lire.* (P6)

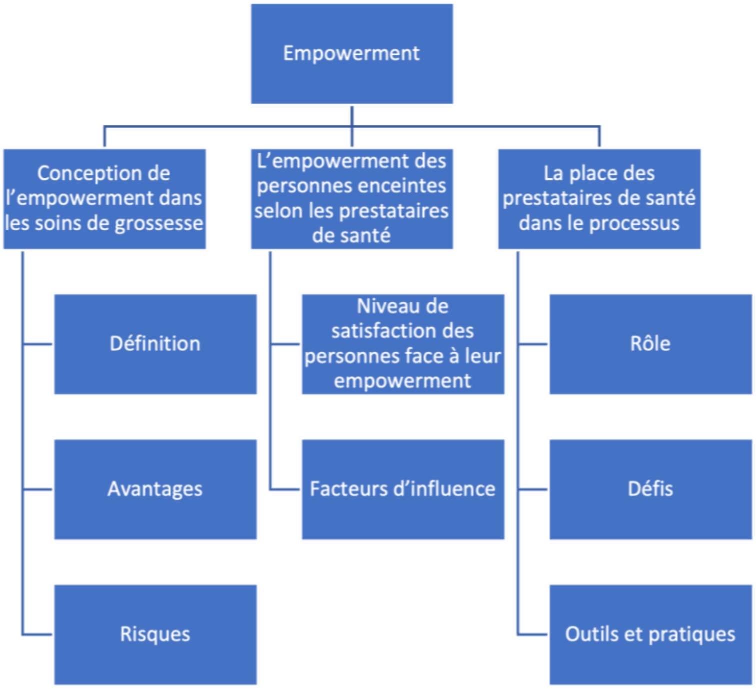
Deux d'entre elles ont aussi consulté des articles scientifiques sur des sujets précis en lien avec les échographies ou l'accouchement par voie basse après une césarienne. Bien que cette recherche ait été initiée par les participantes, l'une d'elles mentionne ne pas être tout à fait à l'aise pour comprendre toutes les informations identifiées.

Enfin, des participantes ont évoqué les cours prénataux offerts durant la grossesse. Bien que des avantages soient notés en matière d'apports de nouvelles informations, les participantes qui en ont parlé ont noté des enjeux de pertinence, de mise à jour des informations, et de manque d'ouverture sur les options possibles (accouchement et allaitement). Une participante mentionne aussi que le moment où les personnes enceintes les suivent est assez éloigné de l'accouchement, et que les informations transmises sont donc oubliées entre temps.

Prestataires de santé

Comme pour les entrevues avec les personnes enceintes, des thèmes et des sous-thèmes en commun ont émergé des entrevues réalisées avec les deux sages-femmes. La Figure 3 ci-après présente schématiquement ceux-ci.

Figure 3 : Schéma des thèmes et sous-thèmes évoqués lors des entrevues avec les sages-femmes concernant la notion d'empowerment et leur perception de ce processus auprès de leurs patientes



La conception de l'empowerment dans les soins de grossesse

La perception qu'ont eue les deux sages-femmes rencontrées du concept d'empowerment reposait sur la notion de liberté et celle de responsabilité. Elles ont mis de l'avant l'importance pour les personnes enceintes d'être libres de prendre les décisions qu'elles souhaitent selon leurs valeurs et principes afin d'être dans un processus d'empowerment. Face à cette liberté nécessaire à l'empowerment, elles ont soulevé des avantages ainsi que des risques au processus d'empowerment. Les deux sages-femmes ont relevé le fait que certaines personnes, après avoir été confrontées à des situations où elles ont fait appel à leur empowerment, se sont senties plus confiantes dans leur capacité à affronter des obstacles. Elles ont aussi relevé que l'acquisition de ce pouvoir pendant la période périnatale avait un effet à long terme sur toute la vie de ces personnes :

> *La personne que j'ai devant moi à huit semaines, à 18 semaines, à 40 semaines, cette personne-là va élever son enfant pendant encore 18 ans, puis pendant le reste de sa vie, elle va en prendre soin.* (PS2)

Parmi les risques évoqués, l'une des sages-femmes mentionne le risque de sur-responsabilisation ainsi que le risque de stigmatisation :

> *Je fais référence, par exemple, si ce développement du pouvoir d'agir amène les personnes à agir en cohérence avec leurs valeurs, puis leurs besoins, de façon distincte ou éloignée des recommandations officielles ou des recommandations en place, notamment en termes de santé publique, ça peut les exposer à vivre de la confrontation, à vivre de l'opposition à vivre des remises en question, parfois même la stigmatisation par rapport à leur propre décision.* (PS1)
>
> *[…] c'est que si on présuppose que l'empowerment est, comme plus un état de fait qu'un processus, on peut en venir à ne même pas considérer les besoins réels de la personne devant nous et donc, effectivement, de sur-responsabiliser, puis de créer des situations de vulnérabilité importante.* (PS1)

L'empowerment des personnes enceintes selon les prestataires de santé

Niveau de satisfaction des personnes enceintes

Eu égard au niveau de satisfaction des personnes enceintes face à leur empowerment en suivi prénatal, les deux sage-femmes ont noté que cela était très variable d'une personne à l'autre :

> *[…] j'ai vu des femmes qui auraient voulu plus de pouvoir, qui étaient même à la limite, qui étaient réactives ou colériques par rapport au degré de pouvoir qu'elles réussissaient à avoir, qui pouvaient vivre des frustrations par rapport aux normes, au protocole, aux règles, etc. mais j'en ai vu d'autres aussi qui se retrouvaient avec, qui me reflétait, par exemple, que je leur présentais une possibilité de pouvoir auxquelles elles étaient pas préparés, dont elles ne voulaient pas à la limite, parce que toutes les personnes qui viennent voir une sage-femme viennent pas toutes pour les mêmes raisons. Puis certaines n'étaient pas là du tout pour la possibilité de choisir. Puis donc, moi, j'ai vu des personnes développer de l'anxiété par rapport à la prise de conscience qu'ils ont une responsabilité de choisir.* (PS1)

Elles évoquent le fait que l'empowerment ne peut être forcé, et que la personne enceinte peut faire preuve d'empowerment en souhaitant déléguer la décision à prendre à sa sage-femme :

> *[…] c'est correct de juste faire ce que tout le monde fait, même si tu ne sais pas trop exactement pourquoi, même si t'aimerais ça, finalement, ultimement, prendre une décision qui fait du sens pour toi. Mais là tu sens que t'es pas capable, de t'extraire de ton contexte, d'avoir les conditions favorables pour prendre une décision, que tu vas être capable d'assumer par la suite, fait que j'ai vu des personnes finalement, comme c'est comme avoir des tonnes de moins sur les épaules.* (PS1)

Facteurs d'influence

Cette variabilité de satisfaction est aussi modulée par certains facteurs venant encourager ou freiner ce processus d'empowerment et pouvant affecter la satisfaction des personnes qui souhaiteraient avancer dans ce processus. Ces facteurs proviennent de différents contextes : système de santé, prestataires de santé, personnes enceintes, etc. Par exemple, l'une des sages-femmes a relevé que l'attitude adoptée par les prestataires de santé a un effet sur le processus d'empowerment des personnes enceintes, tant dans la forme de l'échange que dans la mise en place d'une réflexivité sur leur propre pratique :

> *on a des gynécos, des infirmières qui sont incroyables et qui peuvent mettre la personne en travail vraiment au centre des choix et des décisions. Mais on a aussi beaucoup d'infirmières et de gynécos qui sont extrêmement infantilisantes. Et ça, pour moi, c'est vraiment le contraire de l'empowerment. Il y a des langages, même la voix, la façon dont on s'adresse aux gens, c'est pas la même chose.* (PS2)

Le temps disponible pour accompagner les personnes enceintes est aussi un facteur pouvant affecter leur empowerment.

> *Parce que nous, comme sage-femme, on l'a le temps justement, on prend 35 40 clientes par année. Moi je peux prendre le temps et du coup d'expliquer et le temps que tu prennes, que tu fasses ta réflexion, que tu me poses tes questions, euh d'aller faire de la recherche pour te donner plus d'information, plus de ressources si tu en as besoin. […] Les gynécos, ben à n'importe quel moment, il peut y avoir trois autres personnes qui arrivent en train de pousser. Ce n'est pas le cas, c'est un petit hôpital, mais c'est pareil. Les infirmières, elles ont des charges de travail énormes, ce qui fait qu'elles n'ont pas beaucoup de temps. Pis c'est c'est beaucoup plus facile de dire à quelqu'un je vais te poser ton intraveineuse pour te donner tes antibiotiques, ce n'est pas long. Par contre de dire bon, est ce qu'on te donne des antibiotiques l'intraveineuse et d'expliquer […]* (PS2)

Enfin, les caractéristiques propres aux personnes enceintes influencent également la possibilité de poursuivre un processus d'empowerment d'après les deux sages-femmes. Ces caractéristiques peuvent être la langue parlée, le niveau d'éducation et de littératie, la personnalité de la personne ou son statut migratoire.

> *Le statut migratoire, assurément, compromet la possibilité de faire des choix, évidemment, la langue, la capacité à saisir et à se faire comprendre, mais aussi l'accès aux services sociaux en général. Je pense, par exemple, c'est crève-cœur, mais ça m'est arrivé quand même plusieurs fois. Une personne qui n'est pas couverte par le régime de l'assurance médicale du Québec et qui subit de la pression, qui se met la pression, qui subit de la pression ou une forme de violence, finalement systémique, du conjoint ou de la famille, pour persister à accoucher de façon naturelle, parce qu'un transfert à l'hôpital, une péridurale, éventuellement, potentiellement une césarienne, des médicaments, ça coûte beaucoup trop cher.* (PS1)

Le professionnel de santé dans l'empowerment de ses patientes

Rôle du professionnel de santé

Les sages-femmes ont partagé leur perception du rôle qu'elles ont dans le processus d'empowerment de leurs patientes. Elles occupent en fait plusieurs rôles différents. Le premier de ces rôles est celui d'informateur. Le second rôle consiste à être un soutien et à accompagner les personnes dans ce moment particulier de leur vie et dans leur processus d'empowerment.

> *C'est palpable aussi dans, ajuster notre réponse aux besoins, dans la mesure où ces besoins-là sont nommés par la personne, ou dans la mesure où on est à l'écoute de ce qu'on peut percevoir comme besoin chez la personne, puis qu'on peut même, à la limite, l'accompagner à prendre conscience de ses propres besoins. Ça pour moi, ça fait autant partie de l'empowerment.* (PS1)

Le troisième rôle vise à soutenir la déconstruction des dynamiques de pouvoir dans la relation de soin et à soutenir les changements sur le long terme pour les personnes enceintes.

> *L'empowerment est justement un processus, et non pas une finalité. Et donc, c'est un processus qui, à mes yeux, permet non seulement de vivre une expérience de mise au monde qui soit signifiante et positive, mais aussi qui constitue comme une Pierre d'assise du développement de la personne et du développement de la parentalité, finalement.* (PS1)

Défis pour les prestataires de santé

Ces rôles et le processus de soutien apporté à l'empowerment de leur patiente peuvent aussi soulever des défis pour les prestataires de santé. Parmi ces défis, on peut noter la nécessité de ne plus concevoir l'action du professionnel selon les résultats à obtenir, mais plutôt selon le processus mis en place pour arriver à une décision. Un autre défi pouvant compliquer le soutien offert par les prestataires au processus d'empowerment de leurs patientes est lié aux enjeux déontologiques et légaux de la profession qu'ils exercent.

> *Ben, et un peu aussi tout l'aspect médico-légal. C'est sûr que nous, on a toujours le petit ici sur l'épaule de « S'il se passait ci, s'il se passait ça ». Donc oui, si elle décline telle intervention ou oui, mais. Puis pour nous, comme sage-femme, c'est oui, elle décline, moi j'ai aucun problème avec ça, mais après moi je dois gérer l'équipe médicale si jamais derrière quelque chose [se passe], si jamais on transfère. Donc des fois, même pour moi comme sage-femme, je vais être biaisée quand on va parler de choix éclairé, quand on va avoir certaines conversations du fait de tout cet aspect-là, tout ce qui est le médico-légal, puis pour moi tout ce qui est aussi mes rapports avec l'équipe, qui est l'équipe médicale, les gynéco, tout ça. Mais ouais, ça va influencer nos conversations.* (PS1)

En plus de ces défis, il est relevé que les prestataires s'impliquant dans le processus d'empowerment doivent avoir des qualités particulières :

> *Une autre caractéristique, c'est d'être ouvert, c'est d'avoir une ouverture d'esprit puis une capacité d'adaptation au changement de rythme, puis aux différentes perspectives. Ouais, ça implique forcément aussi une ouverture d'esprit par rapport au… même d'un point de vue déontologique, ce qui est bien, ce qui est mal, ce qui est bon, ce qui est mauvais, etc. parce que tu ne peux pas. Ça constituerait encore une fois l'espèce de perversion d'empowerment, c'est si on remet entre les mains d'une personne son pouvoir d'agir, mais qu'à postériori on juge ou on remet en question les décisions qu'elle a prise, il y a quelque chose qui serait, je pense, préjudiciable.* (PS1)

Outils et pratiques pour soutenir l'empowerment

Les participantes ont indiqué n'avoir aucun outil particulier pour soutenir l'empowerment de leurs patientes, mais que des recommandations peuvent être partagées. Ainsi, l'une des sages-femmes relève l'importance du débriefing après une situation où il n'a pas pu être possible d'expliquer en détail ce qu'il se passait à la personne enceinte :

> *on suit toutes les mêmes recommandations cliniques et on nous dit toujours de débriefer après un événement, que ce soit après une réanimation néonatale, que ce soit après une dystocie d'épaule, une hémorragie, peu importe l'accouchement, que ça se soit bien passé, que ça a été très compliqué, […]. C'est juste le fait qu'on ait pris le temps d'expliquer.* (PS2)

L'autre sage-femme a mentionné l'importance d'avoir une toile sociale et un soutien de l'entourage pour les personnes enceintes :

> *Mais je pense que l'un des outils c'est la communauté. Donner accès au soutien informel, particulièrement lorsqu'il n'est pas présent dans la famille immédiate. Donc, pouvoir faire communauté avec des gens qui sont dans une démarche de développement du pouvoir d'agir comme eux, et je pense ici aux organismes communautaires, famille. De redévelopper une courroie de transmission entre le milieu professionnel, puis des milieux communautaires.* (PS1)

Elle relève aussi l'apport potentiel d'un outil permettant aux personnes d'avoir un regard critique sur les informations disponibles sur Internet :

> *Parmi les autres outils, j'hésitais parce qu'on a accès à tellement d'informations sur le web que, à la limite, c'est un outil qui aide les personnes à se repérer, à développer un esprit critique par rapport à ce qui se retrouve sur le web. Je pense que c'est quelque chose qui, ma foi, je pense, pourrait aider beaucoup de personnes à prendre des décisions éclairées quand ils s'alimentent en tout cas sur internet.* (PS1)

DISCUSSION

Suite à ces témoignages, force est de constater que les facteurs identifiés par les personnes enceintes comme par les prestataires sont similaires à ceux retrouvés dans la littérature et organisés dans l'échelle de Kilma et ses collègues (21). Par exemple, les facteurs en lien avec la relation de soin, les modalités de consultations, l'attitude des prestataires de santé sont des facteurs pouvant se retrouver sous la catégorie concernant le « lien avec le prestataire » de l'échelle (21). L'organisation du système de santé, les conditions dans lesquelles se tiennent les consultations ainsi que l'approche et l'ouverture dont font preuve les prestataires de santé accompagnant les personnes enceintes sont une force d'influence majeure sur le processus d'empowerment de ces personnes (37-42). De manière générale, une relation de soin offrant du temps, de la réassurance, du soutien, une attitude empathique et ouverte ainsi qu'une prise de décision partagée est perçue comme bénéfique pour l'empowerment.

L'entourage ou le soutien de personnes comme une doula ou comme d'autres mères (groupe de support, groupe sur les réseaux sociaux, etc.) sont aussi mentionnées par les participantes et dans la littérature comme étant un facteur d'influence pour le processus d'empowerment (21,43). Ces échanges offrent d'autres canaux aux personnes enceintes pour avoir des informations, partager leur vécu et leur expérience et trouver du soutien dans des situations difficiles. Les caractéristiques propres aux personnes enceintes, de même que les sources d'informations auxquelles elles ont accès sont aussi source d'influence de leur empowerment. Les participantes, la littérature (2,20,22,23), ainsi que les travaux de Klima et ses collaborateurs (21) ont relevé que leurs caractéristiques (âge, tempérament, niveau de littératie) pouvaient simplifier ou freiner leur sentiment de contrôle.

Bien que nos résultats s'alignent avec ceux dans la littérature disponible sur le sujet, deux facteurs plus spécifiques au contexte québécois ou moins étudiés dans la littérature sont à noter. Premièrement, des participantes ont fait état de la frustration, de l'anxiété et du manque de contrôle ressenti face à l'absence de communication des résultats de certains tests passés (sanguins et échographies notamment). L'attente et l'incertitude générées par cette absence de communication ainsi que par la sensation de ne pas avoir toutes les informations concernant la grossesse semble affecter négativement leur processus d'empowerment. Dans la littérature, des enjeux similaires sont retrouvés chez d'autres patientes et patients qui n'ont pas accès à ces informations, ce qui peut les conduire à de l'anxiété, à de la mécompréhension face à leur étant de santé, à un manque d'engagement de leur part dans leurs soins, et à une altération de leur sentiment de confiance et de satisfaction envers l'équipe médicale (44-46). Deuxièmement, il a été plusieurs fois mentionné que leur sentiment de pouvoir pouvait être altéré dès qu'un enjeu médical apparaissait pour elles ou leur bébé ou dès que la situation les plaçait dans un état de vulnérabilité ou de fatigue plus grand (par exemple lors de l'accouchement). Il leur été donc plus difficile soit d'avoir les informations nécessaires pour prendre leur décision, soit de faire valoir leur décision auprès du personnel médical. Même si la priorisation de la santé du fœtus et de leur état de santé peut se justifier, notamment lorsqu'il est question d'urgence médicale, l'absence d'information et par conséquent de consentement de la personne enceinte soulève des enjeux éthiques importants (47) et peut porter atteinte à leur processus d'empowerment.

Concernant la perception des deux prestataires de santé, le processus d'empowerment des patientes affectait aussi la professionnelle ou le professionnel qui effectue le suivi prénatal. Les deux sages-femmes rencontrées ont évoqué un savoir-faire, mais surtout un savoir-être permettant ou non de soutenir l'empowerment des personnes enceintes. Dans la littérature, peu de sources se sont intéressées à la perception de l'empowerment des patientes et des patients en général (et plus encore des personnes enceintes) par leur professionnel de santé. Généralement l'accent est mis sur le rôle de la relation de soin dans le processus (2,20,22,23), mais rarement sur ce que représente l'empowerment d'un patient pour son professionnel de santé et comment cela affecte son travail.

Enfin, bien que cela n'ait pas été explicitement détaillé, un autre point commun peut être identifié dans les discours des personnes enceintes interrogées et des sages-femmes rencontrées : l'importance du partage de l'information, de manière adaptée, tant dans son contenu, que dans son format et dans le moment où la partager (2,20,22,23). Ce partage d'information permet aux personnes enceintes de se sentir plus en pouvoir, d'être plus actives dans leur suivi prénatal, et évite l'apparition de situation basée sur l'infantilisation, la frustration, la confrontation. Ultimement, cette acquisition de connaissance et l'échange qui peuvent suivre celle-ci avec la professionnelle ou le professionnel de santé permettraient d'augmenter le niveau de satisfaction des personnes enceintes envers leurs soins et d'éviter des situations perçues comme maltraitantes ou violentes.

Finalement, les sages-femmes interrogées ont confirmé une tendance déjà constatée : il n'existe pas d'outils concrets et faciles d'utilisation auquel peuvent avoir recours les prestataires de santé pour soutenir le processus d'empowerment de leurs patientes. Des recommandations quant aux pratiques ont pu être partagées par nos participantes, comme l'écoute active, la mise en place d'un environnement sécuritaire et bienveillant, etc. mais aucun outil à utiliser en pratique durant les consultations n'a été identifié.

Parmi les forces de cette étude exploratoire qualitative on retrouve la capacité à explorer en profondeur les expériences personnelles et les perceptions des participantes sur l'empowerment dans un contexte singulier, celui du suivi prénatal et dans un lieu géographique inédit, celui du Québec. Les entrevues ont permis également de recueillir des points de vue diversifiés et d'identifier de nombreux thèmes en lien avec l'opérationnalisation du concept d'empowerment dans le suivi de grossesse. En incluant des sages-femmes, l'étude bénéficie d'une perspective professionnelle complémentaire, qui est peu rapportée dans la littérature. Cependant, bien que de nombreux thèmes aient été identifiés et qu'une saturation ait été atteinte sur quelques thèmes, la taille de l'échantillon limite la possibilité de généraliser les conclusions à une population plus large, et soulève un risque d'éclipser des expériences minoritaires. L'échantillon de femmes enceintes était aussi homogène en termes de niveau socio-économique et d'éducation. Il est probable que des personnes davantage en situation de vulnérabilité socio-économique puissent avoir des expériences différentes en matière d'empowerment. Cette différence d'expérience et donc de résultats obtenus s'applique aussi à l'échantillon de prestataires de santé. Il aurait été particulièrement intéressant de pouvoir bénéficier de la perception d'autres professions médicales, en plus des sages-femmes, pour pouvoir comparer et enrichir les données obtenues. Cet enjeu de recrutement des prestataires de santé semble être un enjeu partagé par d'autres auteurs (48-51). Différentes explications peuvent être avancées : manque de temps (48-50,52,53), réticence face au sujet de recherche, à l'étude ou doute sur la méthodologie choisie (49,52,53), ou encore rivalités professionnelles (49,53).

Malgré ces contraintes, cette étude apporte des premiers résultats et informations en dressant un état des lieux de l'opérationnalisation du processus d'empowerment chez des personnes enceintes au Québec, et permet d'identifier des pistes de recherche futures et d'éclairer les pratiques dans ce domaine spécifique.

CONCLUSION

Cette étude exploratoire a permis de sonder la perception de l'empowerment par des personnes enceintes dans leur suivi prénatal de grossesse, d'identifier et de contextualiser les facteurs pouvant affecter ce processus et d'obtenir un partage d'expérience de prestataires de la santé impliqués dans celui-ci en contexte québécois. La relation de soins demeure un facteur important pour aider à soutenir le processus d'empowerment des patientes, de même que l'accès à des informations pouvant soutenir leurs prises de décision. Les prestataires de santé ont un rôle majeur de soutien ou d'accompagnant dans ce processus et cela peut les affecter dans leur travail. De même, le fait d'avoir suffisamment d'information et d'être averties des résultats de leurs tests et échographies semble être un facteur important qui a des effets non négligeables sur le sentiment de pouvoir de ces personnes et sur leur capacité à prendre leur place d'actrice centrale.

La réalisation de cette recherche sur l'empowerment des personnes enceintes au Québec revêt une importance particulière, car elle apporte des précisions sur une problématique jusqu'alors peu explorée, notamment dans cette province. En s'intéressant spécifiquement au contexte québécois, cette étude met en lumière des dynamiques et réalités singulières, propres au Québec et à son système de santé. Elle permet aussi de renforcer la connaissance des besoins des personnes enceintes, ouvrant la voie à une prise en charge plus proche de leurs attentes.

Face à l'importance reconnue par toutes les participantes, patientes et professionnelles, de cet empowerment, il apparaît nécessaire de mettre en place une approche de soin bénéfique à l'épanouissement de celui-ci et de développer des outils ou des pratiques qui permettent de le soutenir. En effet, sur le terrain, au Québec, aucun outil ou pratique concrète ne permettait de soutenir le travail d'accompagnement fait par les prestataires. De même, mis à part des échelles permettant d'évaluer le niveau d'empowerment ou identifiant les composantes de ce concept, il semble y avoir peu ou pas d'outils disponibles pour les patientes et les prestataires. En plus du développement de ces outils, il serait opportun d'intégrer l'empowerment aux programmes de formation des soignantes et soignants afin de former les futures générations à cette approche singulière du soin. Les compétences interpersonnelles comme l'empathie, la communication, ou encore la décision partagée sont primordiales dans cette approche (54). L'implication des personnes enceintes dans le cursus académique de ces professionnelles et professionnels de santé serait également bénéfique puisque les étudiantes et étudiants seraient davantage sensibilisés à cette approche et offrirait une opportunité aux personnes enceintes de contribuer à la formation de leurs soignantes ou soignants (55). Dans le développement, tant des outils que de la formation des prestataires de santé, les différentes parties prenantes, patientes, prestataires de santé, partenaires et entourage, établissements de soins, système de santé, organismes, ont un rôle à jouer pour favoriser des outils et pratiques pertinents, efficients et adaptés à la réalité du système de santé québécois.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Ethical Conflicts in Care Throughout the Life Cycle in Primary Care in Chile: Perspectives of an Ethics Committee

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Résumé

Les soins de santé centrés sur la personne reconnaissent les patients comme des sujets de droits, tandis que le principe de continuité des soins est lié à la longitudinalité, établissant une relation thérapeutique à long terme tout au long du cycle de vie de l'individu. Ces principes du modèle de soins complets au Chili posent des défis éthiques aux équipes de soins de santé primaires. L'objectif de cet article est de décrire et d'analyser les principaux conflits éthiques délibérés par un comité d'éthique clinique de soins primaires, différenciés par cycle de vie. Une méthodologie qualitative a été utilisée, avec une approche d'étude de cas portant sur 30 des 70 requêtes reçues par le comité sur une période de sept ans. Les résultats montrent que les conflits éthiques durant l'adolescence et dans les soins aux personnes âgées génèrent de plus grandes difficultés pour l'équipe de santé. Les principales conclusions sont liées à la responsabilité de les traiter de manière appropriée et de contribuer à des plans de soins complets qui prennent toujours en compte les aspects éthiques des soins.

Mots-clés

éthique institutionnelle, étapes du cycle de vie, soins de santé primaires, comités d'éthique clinique, santé familiale, Chili

Abstract

People-centred health care recognizes patients as subjects of rights, while the principle of continuity of care is related to longitudinality, establishing a long-term therapeutic relationship throughout the individual life cycle. These principles of the comprehensive care model in Chile pose ethical challenges to primary health care teams. The purpose of this article is to describe and analyze the main ethical conflicts deliberated by a primary care clinical ethics committee, differentiated by life cycle. A qualitative methodology was used, with a case study approach reviewing 30 of the 70 queries received by the committee over a period of seven years. The results show that ethical conflicts during adolescence and in the care of elderly people generate greater difficulties for the health team. The main conclusions are related to the responsibility of addressing them appropriately, and for contributing to comprehensive care plans that always consider the ethical aspects of care.

Keywords

institutional ethics, life cycle stages, primary health care, clinical ethics committees, family health, Chile

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INTRODUCTION

In Chile, the Comprehensive Health Model (MAIS, Spanish acronym) in Primary Health Care (PHC) highlights the principle of person-centred care that recognizes patients as subjects of rights. Therefore, health care must respect autonomy, encourage co-responsibility, and prioritize the needs of the person from a holistic perspective (1,2). In this regard, studies that have evaluated the progress of the model in primary care have agreed on the importance of continuing to implement actions centred on people, due to their positive effects in preventing health problems in the population (3). However, there remains a low participation and autonomy of patients in clinical decisions (4). In this context, patient autonomy is mainly relational under two arguments: The first is that the patient does not make decisions without considering their social and emotional environment, and on the other hand, the relationship between the medical team and the patient occurs in a context of continuous and historical care. This allows for the creation of a trusting relationship over time that is based on effective and confident communication, on a legitimate concern for the other, knowing the responses to critical events, and aspects of personality. The life history of a person contributes to the health team making better decisions, considering, for example, the when and how to give bad news. It also contributes to advanced directives of patients as people in trusting relationships can freely express their preferences before losing their their abilities, thus favouring respect for active choosing about their care throughout their life cycle, and facilitating support for the caregiver (5).

According to Emanuel and Emanuel (6) the paternalistic model of care ensures that patients receive the necessary interventions to recover their health yet limits the exercise of patient autonomy and causes subordination to the authority of the doctor or health team. According to Pellegrino (7) autonomy refers to a sociopolitical, legal and moral concept that influences the way ethical decisions are made in care, respecting the patient in a "frank act" and respecting the dignity of people (p.379). Historically, patients were recipients of services, thus maintaining a passive attitude (8). However, greater access to information enables people to assume a more active attitude in making their own health decisions, influenced as mentioned by their values and preferences (9). Along with this, the incorporation of informed consent in clinical procedures has been an important tool to counteract the traditional paternalism of the health system (7,9,10).

In Chile, the MAIS life cycle and life course approach, responding to the principle of continuity of care (1), has provided primary care teams with a substantial framework for the study of cases and the monitoring of development tasks throughout people's lives. In addition, it has allowed the development of interventions and counselling through a process of accompaniment that

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evolves permanently, responding to growing demands of cultural, family and social origin related to the population in receiving care (11). However, these advances in the Chilean health model are not sufficient to guarantee the resolution of problems that generate ethical challenges in primary care. Professionals may feel overwhelmed by the difficulty of making decisions that involve personal and institutional values and principles, and the customs and beliefs of patients (12). The WHO (13) recognizes the existence of ethical conflicts that arise from care in complex crisis contexts in which values associated with the individual dimension of care, the collective dimension and/or the global dimension are involved. In this regard, clinical ethics committees (CECs) have provided a valuable space for the development of ethical competencies in the healthcare team for ethical-legal reflection and deliberation, safeguarding the rights of patients, humanizing care, improving the quality of care and providing suggestions that guide towards healthcare practice with high ethical standards (12,14).

According to the United Nations Educational, Scientific and Cultural Organization (UNESCO) (15), CECs must have a defined mission statement that specifies their objectives distinct from those of other committees or institutional entities. The procedures for selecting members should be a formal and transparent, while informal recommendations and expressions of interest will occur naturally. Relevant basic representation should include health professionals, bioethicists, lawyers, patient advocates and laypersons, among others. It should also be determined whether members will serve for an indefinite period or fixed terms, and the process for their departure should be clarified. The Committee's agenda will depend on the consultations that prioritize certain issues occurring in the institution. Decisions regarding deliberation processes often involve dialogue with guidelines for conducting them and seeking consensus.

The context of this study is the trajectory of a CEC in primary care in the city of Rancagua, Chile, which was composed of nine individuals: a dentist, a social worker with a degree in philosophy as a second career, a physician beginning a Master's in bioethics, a lawyer, a therapist specializing in childcare, a physical rehabilitation specialist, a nutritionist, a licensed nursing technician and a community representative. The addition of a priest with theological studies was accepted to represent community interests that were important to consider in deliberations. At the beginning, the Committee used to have monthly meetings lasting one hour to analyze ethical conflicts identified by its members or the healthcare team in their daily practice. Those inquiries were submitted to the CEC by email. Patient or family inquiries were asked to be submitted in writing, in a sealed envelope. Occasionally, during regular meetings, the person submitting an inquiry to the CEC was invited to present relevant information for deliberation. This process followed a sequential model, beginning with the identification of facts, values, principles, or rights involved, identifying any extreme courses of action, and concluding with intermediate actions that protect the principles agreed upon by the Committee, and which would be recommended as optimal courses of action. Generally, despite discrepancies among CEC members during deliberations, recommendations with the greatest benefit and least risk to the patient were prioritized, along with the biopsychosocial approach inherent to the primary care model.

Based on the above, having access to a CEC is an opportunity to train the healthcare team, as they are constantly faced with difficult situations that may contravene their professional biomedical training. Special attention must be paid to the concepts of human dignity and vulnerability during the healthcare delivery process as individuals are more vulnerable when they are ill, during childhood or old age, or in proximity to death. The use of technology and advances in biomedical resources in those situations can be very challenging for the healthcare team, who seek to respect the dignity of people by considering their inherent value, not treating them only as sick bodies to be restored to health; paradoxically, in trying to do good health professionals can cause harm (16). Studies on ethical conflicts in the clinical environment have shown that these cases cause doubts about how to act in order not to harm the patient, and therefore, can generate discomfort, helplessness, and/or feelings of guilt in the members of the health team (17). Ethical conflicts are characterized by the uncertainty of not knowing what to do when faced with a complex situation, or a difficult decision in clinical practice, and that potentially affects the well-being of patients. These decisions are not only related to ethical values in dispute, but also to technical, bureaucratic, and organizational aspects that restrict, hinder, or limit decision-making at work (18,22). In this regard, ethical conflicts can cause moral anguish or moral suffering in primary healthcare teams, since decisions considered complex can produce negative psychological and emotional responses (23). Studies on this subject show that these feelings or psychological responses are consequences of believing that personal or professional values have been betrayed, which causes feelings of guilt, loss of meaning for work, lack of confidence in performance (17,23), desensitization, exhaustion, and demoralization that lead to a reduction in quality standards in patient care (24). In this regard, CECs in primary health care setting enable the healthcare team to address ethical issues in clinical practice, review institutionalized policies, and engage in ongoing training in bioethics (25). Additionally, healthcare institutions must cultivate responsible relationships with patients, carers, families, users of the health care system and society based on particular needs. This highlights the importance for the CEC to incorporate a life course perspective in their discussions, as it provides a comprehensive understanding of the health-disease trajectories of individuals and their families (26). Considering that almost all inquiries referred to a CEC are related to crises experienced by individuals and their families, those situations could complicate the relationship between the healthcare team and the families/carers involved (27). Those crises can be classified in biological, psychological, social, economic, political, and geographical (26). The significance of this point lies in the fact that the main ethical conflicts addressed by CECs arise within this context.

The following qualitative study sought to answer the question: *What are the main ethical conflicts encountered in a primary health care (PHC) CEC in Chile, following the life cycle and life course approach of MAIS?* Through this study, we aimed to present evidence and arguments that support the importance of institutionalizing CEC in PHC, recognizing the contribution of these committees to the ethical dimension of care and their role in promoting the transfer of competencies to PHC teams, and suggesting pertinent courses of action that improve the treatment of patients and enhance the quality of care.

METHODOLOGY

The research was approached from the interpretive paradigm, qualitative methodology and case study approach. The experience of a CEC in the city of Rancagua (capital of the O'Higgins Region) that operated continuously for seven years was collected. This is considered relevant, since in Chile, CECs in PHC are not mandatory (28). The case therefore has intrinsic value (28), since its development and process contribute to identifying, understanding and better guiding the ethical conflicts that affect the work of primary health teams, based on situations that arise in family interventions considering the life cycle and life course. In this regard, the principle of person-centred care requires the healthcare team to have a greater holistic understanding of the patients' biography, which can lead to potential ethical conflicts in clinical and therapeutic relationships, organizational matters, handling sensitive data and confidentiality, among others (29).

The study addressed a sample of 30 inquiries (from a total of 70) submitted by healthcare teams to the CEC during the period 2015-2022. Included were cases that reported family-based interventions which involved a multidisciplinary primary healthcare team, as this allowed for a deeper exploration of the conflicts that arose in the usual dynamics of the CEC. The analysis unit corresponds to the cases deliberated by the CEC, which were organized by life cycle of the index case. The data were accessed directly, since they were published and summarized in a publicly accessible book (14). They were transcribed in full, respecting anonymity, and shared among the researchers from a Google Workspace® drive document. A first analysis meeting was held to build a characterization of the 30 cases addressed by the CEC (Table 1), followed by a second round in which the cases were classified according to life cycle (Table 2). This was considered essential to determine the main themes that typically affect each life cycle, allowing for the establishment of common bases in the suggestions and guidelines given by the CEC, and to guide the discussion of the study. Life course was classified as follows: a) boys and girls, b) adolescents, c) adult women, d) adult men, and e) older people. A gender distinction was made in the case of adults, since in this life cycle stage there are differences in care delivery and diseases associated with this dimension (30).

In subsequent meetings, a) rounds of readings of the cases by life course were carried out, and b) analysis of the courses of action established by the CEC to organize the discussion. The criteria of rigour considered reliability, since the universe of cases deliberated by the CEC was used. For triangulation between the researchers during the analysis rounds, in-depth discussion enabled contrast of theoretical and interpretive approaches to the categorization process.

Available data corresponding to the annual activity reports of the CEC were used over a period of seven years. Information saturation was reached by reviewing the documents several times and not finding new emerging categories for each life cycle. The replicability and transferability of this study is possible by following the methodological aspects mentioned above, and possibly with similar results at the national level, since the functioning and level of knowledge of the primary care teams is similar due to the normative and technical strengthening of the PHC. The ethical aspects of the study were safeguarded by respecting the confidentiality and autonomy of the health professionals and the members of the CEC studied. The data were anonymized, and only part of the in vivo categories were used to identify the cases. The identities of the families, which were the subject of ethical conflict for the teams (31), were protected and designated as cases to organize the data based on the life course model. Approval was obtained from the independent Scientific Ethics Committee of the Araucanía Sur Health Service through official letter No. 170/2023.

RESULTS

As a result of the data analysis (cases), the following ethical conflicts were identified and considered by the Clinical Ethics Committee (Table 1).

Table 1. Characterization of the cases and ethical conflicts reported to the CEC in Rancagua

Nº	Case (In vivo code)	Conflicts and/or dilemmas identified by PHC team
1	"I can no longer attend this therapy, because I have to take care of my father" (Daughter caregiver abandons her treatment to care for her dependent father)	• Well-being of the caregiver vs. well-being of the dependent parent • Exercise of autonomy in vulnerable conditions
2	"I demand access to my son's medical record" (mother demands information about her teenage son's medical record)	• Safeguarding the adolescent's privacy, the right to confidentiality of their data, and the request for information from their mother to protect the health of her child (charity)
3	"I am afraid to tell my partner that I have HIV" (partner confirmed with HIV refuses to allow informing his partner)	• Right to confidentiality of the HIV patient vs not causing harm to the partner (non-maleficence)
4	"I need medication to deal with the problems in my life" (abandonment of psychological therapy to attend workshops for caregivers, since she prioritizes the care of her father and her young daughter)	• Well-being of the caregiver vs well-being of the dependent parent • Exercising autonomy in vulnerable conditions
5	"You should have preventive exams"	• Violation of the principle of autonomy of users of the health system. • Patient autonomy vs the potential benefit of preventive examinations • Exercise of autonomy in a context of medical paternalism, which predominates in the health system
6	"I can't take care of him. His father needs to be monitored by a specialist at the hospital."	• Violation of the right to health • Conflict between the principles of beneficence and non-maleficence

7	“This survey is very easy to answer, it will help me finish my master’s degree”	• Violation of the principles of autonomy, beneficence, non-maleficence and justice of patients or users of the health system
8	“I do not authorize my daughter to be vaccinated”	• Violation of a girl’s right to health • Delegated autonomy vs beneficence and non-maleficence of vaccines
9	“I will not stop eating what I like, I prefer that you prescribe me medication”	• Patient autonomy vs beneficence of care
10	“I will do everything possible to ensure that my father lives on”	• Patient autonomy vs caregiver values and beliefs; advance directives
11	“He told me how he wanted to live the last stage of his life”	• Patient autonomy vs caregiver values and beliefs; advance directives
12	“Don’t tell my parents”	• Autonomy of an adolescent’s sexual life vs legal responsibility of parents • Beneficence and non-maleficence of health actions
13	“This was put in me to prevent menstruation” (adolescent institutionalized in state protection homes with a subcutaneous method to prevent pregnancy)	• Autonomy of the sexual life of an institutionalized adolescent vs State responsibility • Beneficence and non-maleficence of health actions
14	“Adherence to pharmacological treatments has been difficult due to low awareness and responsibility” (adolescent institutionalized in state-protected homes with subcutaneous contraceptive method, with moderate cognitive deficit, and behavioural disorder)	• Autonomy of the sexual life of an institutionalized adolescent with cognitive disability vs legal responsibility of the State • Beneficence and non-maleficence of health actions
15	“She refuses any contraceptive method” (adolescent institutionalized in state-protected homes without contraceptive method, who refuses any possibility of treatment to regulate fertility)	• Autonomy of the sexual life of an institutionalized adolescent vs legal responsibility of the State • Beneficence and non-maleficence of health actions
16	“I only have a tourist visa and I don’t have health insurance”	• Right to health of immigrant girls and boys without discrimination (justice) • Beneficence of health actions
17	Access to immediate care for adolescents at risk of suicide who belong to the private health system and who are detected in school screenings carried out by teams from health centres in the public system.	• The right to health of adolescents • Beneficence and non-maleficence of health actions in a mixed system (public-private) with different insurance plans and providers that do not work in a network
18	Is school a suitable place to administer rapid HIV tests to adolescents?	• Progressive autonomy of adolescents • Beneficence and non-maleficence of health actions
19	“They are denying me my father’s death certificate”	• Rights and responsibilities of patients and family members in relation to health care
20	“I have the right to be a mother” (woman with a disability diagnosed with schizophrenia)	• Patient autonomy vs beneficence and non-maleficence of health actions • Stigmatization
21	“They didn’t give me that test” (pregnant Haitian woman denies having tested HIV positive)	• Patient autonomy vs beneficence and non-maleficence of health actions in immigrant population
22	“I was not informed that my daughter was vaccinated”	• Delegated autonomy to the father and mother vs beneficence and non-maleficence
23	“We can take care of that child, there is no need to abort” (the teenager’s mother does not want to terminate her daughter’s pregnancy)	• Autonomy of adolescent rape victim vs beneficence and non-maleficence
24	“I know I’m pregnant” (woman makes up pregnancy)	• Right to health free from any form of discrimination • Beneficence and non-maleficence
25	“My mother has the right to her medicines” (daughter claims medicines from consultation supplanted by her mother)	• Justice in health care • Damage to the therapeutic relationship
25	“They discriminated against my father because he was old, bedridden and dying” (outpatient health team cannot assist patient at home and he dies)	• Justice in health care • Good death • Beneficence and non-maleficence
26	“The family must decide” (amputation in a frail, elderly person)	• Surrogated autonomy • Beneficence and non-maleficence
27	“These are confidential data” (mother insists on knowing the result of the PCR test taken by her 19-year-old son)	• Data autonomy and confidentiality
28	Working man asks for a certificate with the result of his PCR because his company requires it	• Data autonomy and confidentiality
29	Workers tested in groups with PCR are informed privately, but the rest of the workers demand to know the results	• Data autonomy and confidentiality
30	“The sterilization of our daughter (who is disabled) is my wife’s wish before she dies”	• Surrogate autonomy • Beneficence and non-maleficence

Source: Nadal, 2021 (14)

The cases reviewed by the CEC (Table 1) correspond to consultations carried out by the primary care teams, which are mainly associated with processes that trigger personal and/or family crises. Normative crises are mainly described in cases where patients are children or adolescents, and are related to developmental crises in which the role of the father and mother as responsible for the health of their children is highlighted. In childhood, ethical conflicts were frequently associated with father and/or mother’s refusal vaccine are common. While in the case of adolescence, consultations were oriented towards sexual and reproductive health in which the father and/or mother questioned the adolescent’s ability to consent or make decisions, in addition to questioning the confidentiality of data in the context of health care.

In the adult phases, non-normative crises become more evident since most of the identified ethical conflicts were related to behaviours that could negatively affect people, such as being associated with the exercise of restricted autonomy due to a lack of health knowledge. In older people, the main consultations were associated with the condition of chronicity, fragility and loss of physical and mental functionality, which provoke paternalistic and overprotective attitudes in families and caregivers that threaten the exercise of the right to autonomy.

As summarized in Table 2, adolescents accounted for the majority of CEC consultations, together with dependent elderly people or those with multimorbidity. Subsequently, cases in the adult population were equal between men and women, and finally, the group in which fewer cases were recorded corresponds to boys and girls.

Table 2. Classification of cases deliberated by the CEC, according to life cycle

Group	**Type of case according to life cycle**	**Nº**
Boys and girls	Cases related to childhood health	2
Teenagers	Cases related to adolescent sexual and reproductive health	9
Adult women	Cases related to health behaviors of adult women	6
Adult men	Cases related to health behaviors of adult men	6
Elderly people	Cases related to the care of elderly people who receive home care and/or multimorbidity	7
Total		30

DISCUSSION

Development of an ethic of care based on human dignity

Based on the findings of our analyses of 30 cases and ethical conflicts reported to the CEC in Rancagua, we argue that MAIS and the principle of person-centred care offer the ideal theoretical and practical framework for primary care teams to provide comprehensive and continuous care, including guiding people and families in different periods of crisis.

Comprehensiveness allows care to be addressed from all human dimensions, and at all levels of care with an anticipatory focus while the continuity of care incorporates the vision of the life cycle and life course (1). Care from this comprehensive perspective goes beyond the mere delivery of actions by the health team; it necessarily requires a professional attitude that represents concern, responsibility and commitment to the other. Care therefore acquires a concrete moral body based on values, personal virtues and a positive disposition towards the subjects of care that must ultimately be reflected in the behaviour of the health team (32). A study carried out by the Chilean public organization, Superintendence of Health (33), on the dignified treatment of health system users following the 2012 Law 20,584, which regulates the rights and duties that people have in relation to actions linked to their health care, established that dimensions such as empathy, not being discriminated against, being treated as a person and without paternalism, respect for privacy/intimacy and having a comprehensive view of the patient, are associated with dignified treatment from the perspective of people who use the health system. These dimensions demonstrate the usefulness of identifying value characteristics of the ethics of care, since they allow the construction of quality indicators associated with dignified treatment, giving health teams the possibility of rationalizing these, identifying gaps and advancing in the development of skills to improve care.

The recognition of human dignity a human right has been declared in article No. 1 of the Universal Declaration of Human Rights (UDHR): “All human beings are born free and equal in dignity and rights and, endowed as they are with reason and conscience, they should behave fraternally towards one another.” This fundamental feature for social coexistence is based on the philosophical tradition in which dignified treatment is associated with “key human capacities such as conscience, freedom and autonomy.” It is also an intrinsic value that “belongs to each human being to the same degree throughout his or her life” (life cycle) (34, p.1160). This ontological vision of “being human” allows for the development of values that support the practice of care (35). Patient care is a practice motivated by the intention of seeking a benefit, thus responsibility and focused attention are assumed, which requires great intellectual and sensitive concentration to understand the needs of others (36). From this perspective, comprehensive care becomes difficult and complex, since in many cases it is not possible for health teams to respond unequivocally to a problem; rather, they are permanently faced with dilemmas or conflicts that generate doubts about how to act correctly to obtain the maximum benefit for people. In addition, they must consider that the socioeconomic conditions in which many patients live are not ideal, and that the health system does not always provide the resources to achieve therapeutic and care goals (37). This can be seen in that related dilemmas in the same life cycle may be similar, but their approach through a care plan will take into consideration the family and social context specific to each case (Table 2).

Care throughout the life cycle and life course

Analyzing the cases reviewed by the CEC (Tables 1 and 2), it is possible to affirm that the primary care team will always have doubts about how to act in certain situations of family crisis, and at different stages of a person’s life cycle. In this regard, the theory of the personal life cycle is based on different stages of human development, expanding the notion of the phases of personal life from childhood to old age. Each stage follows a biologically influenced sequential maturation pattern that also recognizes the influence of the environment and context on the development of each person’s personality. Each of these phases involves the resolution of certain crises or conflicts that must be overcome in order to best address the next phase, conditioned by the family and cultural environment that exerts powerful influences on people (38). Based on this, some crises are predictable (normative) while others are unpredictable (non-normative), both having personal and family impacts associated with the stress of dealing with these events. Varied and complex aspects influence the adaptation of individuals and families to crises whose behavioural patterns have been learned generationally, and are in complex interaction with their support networks, forms of communication, family functionality, personal values and principles, socioeconomic factors, among many other factors that will make a crisis be experienced in a very particular way (1).

On the other hand, the life course approach promoted by the Pan American Health Organization (PAHO; 39), covers the entire life cycle, recognizing that there are life events, whether continuous or cumulative, that lead to adaptive changes that influence the health and development of individuals, families and communities, so that "health development can be enhanced, diminished, interrupted or recovered throughout the course of life" (p.43). Based on this, health problems from the MAIS perspective are addressed from different theoretical and practical approaches that provide tools to the primary care team so that people, families and communities can generate coping strategies in the face of a crisis, either focusing on the problem, the emotion, or the meaning that people and families give to each crisis. In this last point, there are beliefs, values, principles and existential objectives that contribute to finding positive aspects behind a stressful life situation, and that help sustain coping and well-being during a difficult-to-manage life event (40). To deal with any crisis due to illness of a family member, especially due to serious, chronic, debilitating, painful or terminal pathology, different adjustments are required in the lives of family members to be able to cope, since theset will have important consequences in all spheres of life (40).

In person/family-centred care, one of the main objectives is to develop and implement comprehensive care plans aimed at the patient within their family context, a key component of which is facilitating care that includes ethical principles and values such as collaboration and solidarity between family members and health care providers (41). The study carried out by Anderson and White (42) in families with seriously ill patients and their caregivers describes how the caregiver families highlight in their stories, as do the CEC informants (Table 1), value aspects of care such as: "honoring the wishes of the loved one" which refers to respecting the patient's autonomy; "receiving help or support" from others, which refers to the principle of solidarity and compassion; and "acting together as a family", which refers to intergenerational solidarity and the feeling of compassionate love. The same study also describes barriers that hinder the care of patients with serious illnesses, such as female caregivers who report gender bias in carrying the "burden of the emotional work of caring," or "lack of support from health systems."

Proposals for ways to intervene with families in these events are quite varied and there are no universal formulas. However, the experience of some study groups at internationally continue to demonstrate the benefits of support during the family life cycle. Family interventions should be mainly aimed at preparing the family in advance for events specific to each life cycle, such as serious illness, considering probable results, providing complete information for making the best decisions, improving family satisfaction, especially psychological, ensuring that patients do not receive unnecessary treatments and that the family understands the limitations of care and life support (43).

In recent decades, health care systems have promoted attitudinal aspects of care such as empathy to establish the therapeutic and care relationship with people, which guides the social and therapeutic behaviour of the teams (44). To analyze some of these issues raised in the cases addressed by the CEC, and their contribution to the situation, in the following sections a case is presented for each life cycle.

Case associated with the life cycle of a young girl whose father refuses vaccination according to the normal schedule of the national immunization program

In this case, a father does not authorize the vaccination of his young daughter, generating debate regarding the decisions of the parents when these are based on erroneous beliefs about immunization, and the State's responsibility to guarantee the greater good of the child.

The International Convention on the Rights of the Child considers children and adolescents to be subjects of rights, and to be recognized as persons in development for the progressive exercise of their autonomy and in accordance with the evolution of their capacities (45). In this regard, health from a positive perspective is the physical, psychological and social state that allows children and adolescents to reach their maximum development potential, so generating healthy and safe environments is essential to achieve this state. In clinical practice, improving the health conditions of children and adolescents implies entering into conflict with the beliefs of some families or groups that hold alternative ideas about health: for religious reasons, such as Jehovah's Witnesses; for preferences such as vegan groups that reject products of animal origin; or are influenced by fake news on the Internet and so reject vaccines, among many other biomedical interventions. These families, from a practical perspective, may restrict the possibilities of access to adequate nutrition, treatments or immunization for their children and adolescents based on ideas that are far from conventional medicine. In addition, aspects such as the low level of education of the parents can make intervening or reversing these decisions very complex, which is why reduced access to healthcare accounts for a primary form of child abuse (46).

Immunization in Chile for children and adolescents reaches high coverage and constitutes one of the main axes of the dimension of the right to health of children and adolescents (47). In this sense, Law 21,430 on guarantees and comprehensive protection of the rights of children and adolescents (48), establishes that the care of children is a family responsibility, as the family is a fundamental unit of society and facilitator of the growth, development and well-being of children and adolescents. In addition, families are responsible for the protection of and guidance for the exercise of their children's rights. State institutions, such as Family Health Centres (CESFAM, Spanish acronym), must ensure the best interests of children and adolescents, and when possible allow them to act autonomously, respecting their life path, considering their age, degree of development, maturity and/or emotional state. In addition, children and adolescents must be allowed to express their opinion on aspects related to their well-being whenever they wish and where possible. According to a study carried out in Chile by World Vision (49), the promotion of the principle of participation and progressive autonomy of children and adolescents has put conventional parenting models to the test. This study shows that children and adolescents have wide margins of participation in daily decision-making, and that authoritarian and violent parenting styles are maintained, which are characterized by the lack of recognition of children as subjects of rights in society.

In this case, the suggestions for the clinical team were to: engage in dialogue with the parents or other family members seeking to reverse the decision to reject immunization, look for other family members who support vaccination to generate new arguments for change and meaning for the parent, provide information on the rights to health of children and adolescents, develop an argument based on the collective (common good) and not only on the individual (autonomy) considering that the herd effect of immunization is what benefits the entire target population (14). As a last measure, if the father's attitude is not changed, civil justice mechanisms should be used to represent the right to health and the greater good for the child. According to Valera et al (50), the main ethical arguments for this measure are the certainty of harm to the girl from not receiving her age-recommended vaccines, the benefit of vaccination both individually and collectively, and the obligation to be vaccinated as is established as a State rule.

Case associated with the life cycle of a 12-year-old adolescent who wishes to abort a pregnancy resulting from rape

The case corresponds to the request made by a 12-year-old adolescent who goes to the CESFAM to request the interruption of her 13-week pregnancy, which was the result of repeated sexual abuse by a stepbrother (not proven). In this case, the mother is opposed to abortion, the socioeconomic conditions and the home environment are precarious. During a visit by the health team, the mother expressed wanting her daughter to have the child since she, the mother, has not been able to conceive with her current partner. Meanwhile, the adolescent appears scared and mentions that she no longer wants to terminate her pregnancy. This aspect is relevant to highlight since the health team can play a relevant role in providing information, identifying and managing the abuse of children and adolescents and its consequences (46). In a study carried out in Chile on adolescent pregnancy (51), one of the gaps in the exercise of the rights of adolescents was found to be associated with adult-centrism on the part of families, institutions and society as a whole. This then has an impact on low levels of participation of adolescents, since there is little access to information to form their own opinions, limited opportunities to being heard, and low consideration of their opinions in decision-making that concerns them, as in this case where the adolescent does not want to continue with the pregnancy.

Adolescence has been related to the tasks of searching for identity, marked by processes of cognitive, emotional and socio-sexual development. In the course of an adolescent pregnancy, the process of accepting to have a child has been described as the duality of being a father/mother and at the same time being an adolescent. For the proper development of this process, it is necessary to find the positive meaning of pregnancy and to have support networks that allow the adolescent to move forward with her life project (51). In the case presented, the violent circumstances that gave rise to this pregnancy are probably the reason why the adolescent wants to opt for abortion, in addition to the negative circumstances of her environment in which her mother does not respect the autonomy of her daughter.

In Chile, Law No. 21,030 on Voluntary Termination of Pregnancy for Three Reasons, refers to the possibility of abortion as a result of rape, provided that no more than fourteen weeks of gestation have elapsed, and for girls under 14 years of age. In the case presented, the adolescent is 12 years old, and her pregnancy is at 13 weeks, so she meets the requirements to be permitted to terminate the pregnancy expressly and voluntarily, given her explanation that it is the result of rape (52). Furthermore, this adolescent is in a vulnerable and disadvantaged condition, and thus there is an obligation on the part of the State to protect her integrity and to respect her will to terminate the pregnancy. This is anchored in the sexual and reproductive rights of women, which penalizes "forced pregnancy, denial or postponement of abortion, mistreatment of women and girls seeking information on health, sexual and reproductive goods and services, and qualifies them as forms of gender-based violence that, depending on the circumstances, may constitute torture or cruel, inhuman or degrading treatment" (53, p.7-8). In this situation, there is a crime that must be reported and the obligation to first protect the adolescent girl as a victim of sexual violence (53). Secondly, there is the obligation to guarantee the "right of women to access comprehensive abortion care services that are safe and legal, that protect their right to autonomy and reproductive freedom" (54).

The suggestions for the health team were: act with respect and compassion, prioritize the vulnerable adolescent and establish mechanisms for her protection, respect her progressive autonomy, avoid re-victimization as far as possible, report the case to the justice system, accompany her decision-making process so that she makes the decision to abort without coercion and in an informed manner, and ensure ongoing support from the psychosocial team.

Case of a 35-year-old male diagnosed with a chronic disease who decides not to adhere to healthy habits and requests drug treatment

A 35-year-old patient diagnosed with cardiovascular disease during a preventive check-up rejects the possibility of making changes towards healthier habits and requests medication from his primary care physician. The primary care team at the CEC argues that there is a conflict between the patient's autonomy to decide about his own health and justice in relation to what is therapeutically indicated for a patient in his situation of admission to the program and the progression of the disease. In this sense, the patient should start non-pharmacological treatment, making changes to his lifestyle which should be sufficient to improve his current cardiovascular risk. However, the patient does not accept the indications, generating a reaction of rejection in the medical team.

From the perspective of the life course, the trajectory of this patient's illness is influenced by his previous experiences, including negative experiences with his parents or a family member who is a carrier of an illness, losses, beliefs or another critical event that explains his negative attitude towards the counselling received. It should also be considered that changes in behaviour towards healthier habits occur late, progressively, and only once people understand and accept that the changes suggested by the primary care team produce benefits for them (39). This attitude of rejection towards non-pharmacological treatment should be considered a legitimate response that does not prevent the primary care team from accompanying the patient's adaptation process and promoting healthy lifestyles as a first measure. Disease triggers a non-normative crisis that begins with the diagnosis, progresses to the adjustments that must be made in daily life, and finally coping, when the problem is understood and the consequences for the patient are clarified. There are a series of tasks in the adaptation process in individual and family care, and the person diagnosed with a chronic disease must learn to relate appropriately with the health team. As such, the patient and his family can reorganize their goals to cope with an illness, integrating the patient's life cycle, the family life cycle and the cycle of the disease itself (55). In this case, the suggestions for the primary care team were: to conduct a family study, to respect the patient's initial decision, to identify support networks for care in the family, to accompany the crisis process respecting the adjustment and adaptation to changes in the patient's lifestyle. The frustration that these cases generate for the primary care team must also be managed.

Case of an elderly person who receives care from her only daughter, who declares herself overwhelmed

An elderly person with secondary dependency due to a stroke is cared for by her 30-year-old daughter, the latter who is separated from her husband and who helped her care for her father, and herself has a young daughter. As the daughter's siblings neglect the care of their father, she also manages her father's pension as the only family income. She does not attend the self-care workshops for caregivers offered by the CESFAM and has reported feeling overwhelmed. According to what was described by the CEC, the caregiving daughter of this elderly person matches the profile of people who perform this role: it is usually women, spouses or daughters, who perform informal care functions. In this regard, data from the National Disability Survey (2022) revealed the overload that occurs when there is a primary caregiver and care is not shared with other family members (56). When an elderly person begins to lose autonomy and functionality, they require support from a caregiver for daily living activities. This role implies assuming great responsibilities in relation to the care of others, which often reduces the possibilities of self-care, causing significant alterations in the mental and social health of the caregiver, since the adaptation process when assuming the role of caregiver can become a challenging life crisis (57,58).

This case highlights the impact of being a caregiver, and how this unrecognized work alters the daily life of a young woman who assumes the entire workload of caring for her father, while also having her own childcare responsibilities. Studies such as the one carried out by Aman et al. (58) show that the meaning of being a caregiver can vary between cultures, and that it does not always represent burden or stress. For some, caregiving can also be a source of satisfaction, especially when there are ties of filiation, the dependence of the person being cared for is partial, and the caregiver has a higher educational level. However, in Western cultures characterized by individualism, caring seen as is sacrificing oneself, which in a practical sense is a postponement of oneself with consequences that can be very negative both for the person who cares, as well as for the elderly person who receives care. Studies have shown that the quality of life of caregivers improved when coping is active and focused on emotions and social support (59), in addition to receiving training, coordinating periods of substitute caregivers, and balancing care tasks with other work, activity or social life (57). In this case, the CEC's suggestions were to: provide support for the caregiver through a comprehensive plan by the primary care team, identifying support networks to generate spaces for rest with alternating care for the parent, self-care, and permanent home visits to support care through formal instances.

CONCLUSION

In summary, the Primary Care Clinical Ethics Committee (CEC) constitutes a fundamental resource to advise primary care teams in the face of ethical conflicts in routine clinical practice, as well as in the context of emerging global crises that are increasingly complex. Wealthy countries in North America and Europe have made progress in other strategies, such as bioethical advice provided by professionals with specialized training, especially at the hospital context (60). By contrast, in developing countries such as Chile, these strategies receive little attention in public policies, depriving primary care teams of the opportunity to debate the ethical dimension of care or improve understanding of the therapeutic relationship and so develop greater skills for intersubjective people-focused care.

The findings of this study contribute to making visible the ethical dimension of care, and in particular, the importance of the CEC in contributing to the comprehensive health care model in dealing with conflicts presented by the primary health care teams of several family health centres in Rancagua, Chile. The CEC constitutes a fundamental support resource for the training and accompaniment of primary health care teams, favouring care plans with a rights-based approach in accordance with the family and individual life cycle. From this perspective, every action carried out by health teams has an ethical dimension to address. While families, regardless of their culture, combine their emotional dimension with the moral sense that characterizes them, health care teams require new skills to offer care focused on people. This aspect, often made invisible in health care, takes on meaning in the face of a crisis, especially as a response to illness, aging, a catastrophe, or palliative care.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Externalist Individualism: A New Ontological Approach of Diseases

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Résumé
La compréhension de la maladie dans le modèle biomédical dominant implique deux composantes, l'internalisme et l'individualisme, qui donnent lieu à une approche ontologique des patients que l'on peut qualifier d'atomisme. Je m'oppose à une telle approche en philosophie de la médecine. Je me concentre sur l'internalisme, en montrant que la présence inévitable des notions de fonction biologique et de normalité statistique dans le modèle biomédical rend l'internalisme sur les maladies intenable. En outre, je soutiens que le nouvel individualisme externaliste offre une approche ontologique alternative qui échappe aux défis auxquels l'approche atomistique est exposée en ce qui concerne à la fois le concept de maladie et la pratique médicale. Ensuite, je me concentre sur une implication de cette nouvelle approche qui se rapporte à l'idée des maladies en tant que types naturels, en démontrant qu'elle propose un concept de maladies en tant que types naturels qui est cohérent d'un point de vue conceptuel.

Mots-clés
maladie, internalisme, externalisme, individualisme, types naturels

Abstract
The understanding of disease in the dominant biomedical model involves two components, internalism and individualism, which jointly give rise to an ontological approach towards patients that can be referred to as atomism. I argue against such an approach in philosophy of medicine. I focus on internalism, showing that the inevitable presence of the notions of biological function and statistical normality in the biomedical model renders internalism about diseases untenable. Additionally, I argue that the new externalist individualism offers an alternative ontological approach that escapes the challenges to which the atomistic approach is exposed regarding both the concept of disease and medical practice. Subsequently, I focus on an implication of this new approach which relates to the idea of diseases as natural kinds, demonstrating that it proposes a concept of diseases as natural kinds that is conceptually consistent.

Keywords
disease, internalism, externalism, individualism, natural kinds

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INTRODUCTION

The common understanding of disease in the biomedical model involves two essential components. The first is *internalism* about diseases, according to which something that classifies a state as a disease state is internal to the patient. In other words, the facts based on which a state is classified as a disease state are facts about the internal states of a patient. This component is implicitly observed in some characterizations of disease, including updated definitions proposed by C. Boorse, who developed the most influential theoretical account of disease in the biomedical model. Despite their differences, Boorse's varied definitions share one component: that disease is an internal state. It is obvious when he suggests that "disease is a type of internal state which impairs health, i.e., reduces one or more functional abilities below typical efficiency" (1, p.555), or when he suggests that "diseases are internal states that interfere with functions in the species design" (1, p.558). This component of the model has been addressed by R.M. Hare (2), W. Davies (3) and S.N. Glackin (4). An interesting point noticed by Glackin is that the internalist view of disease has been so obvious and dominant that Davies, who argued against it, felt no need to provide evidence to demonstrate its broad influence (4, p.287). Nevertheless, this component stands in need of clarification. Above, I introduced internalism through the notion of internal state. We may define an internal state of an organism as a state which is determined solely by intrinsic properties of that organism. Therefore, internalism about diseases implies that facts based on which a state is classified as a disease state of a patient are facts about the intrinsic properties of that patient.[1]

The second component in the biomedical model's idea of disease is *individualism*, according to which disease is thought of as a state which is borne by individuals. More briefly, it is an individual who bears a disease state. Again, it has rarely seemed necessary to argue for this component, perhaps because, as A. Broadbent holds, rejecting individualism, or claiming that populations may be thought of as bearing health-related properties, has been regarded as counterintuitive (6). Individualism remains canonical in key philosophical texts about health (1,7); even in the definition proposed by the World Health

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[1] One may object that what is meant here by an internal state is stronger than what was likely meant by Boorse, who appealed to the internal state in order to stress the fact that disease is a state *in* the organism (e.g., flea bites), not a state *of* the organism (e.g., the flea on its skin) (5). In addition, his conceptual analysis of disease obviously involves some external components (4). Even if we admit that parts of Boorse's view run counter to internalism in the sense we mean it here, it can still be argued that there is at least a tension in his view. Regardless of Boorse's view, however, a claim which I share with Davies and Glackin is that internalism prevails in the biomedical model.

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Organization, while there is no direct reference to the individual, it has usually been understood as if it takes the individual as the bearer of physiological, psychological, and social health.[2]

We can claim, therefore, that within the biomedical framework, diseases are standardly thought of as borne internally by individual patients. This idea of disease has also influenced the way through which medicine views the individual patient. Since it conjoins these two components of diseases, namely internalism and individualism, the ontological approach of the biomedical model towards an individual patient can be said to have adopted an atomistic approach. Disease is thus an internal state of an individual, not an external state of an individual nor an internal state of a population. This reductionist view evokes a well-known but mostly criticized ontological stance in social science, according to which all social facts are exhausted by facts about isolated individual states.[3] In this view, for instance, the content of the fatherhood relation can be exhausted by the psychological and behavioural states of the father and son. Similarly, an atomistic view in medical ontology implies that, regarding a disease, the content of the facts which turn a state into a disease state can be exhausted by facts about the internal states of an individual patient.[4] To conclude, no external fact determines, in a non-reductionist way, whether a state is a disease state or not.

Despite its dominance, this ontological approach faces some difficulties. The first is that internalism is not compatible with certain implications of Boorse's definitions of disease, the latter being the most influential view in the biomedical model of medicine. I address this in more detail below. The second is that this approach is incapable of offering a unified notion of disease, since its ontology fails to accommodate a large group of diseases, namely epidemics: characterizing these diseases inevitably requires appealing to phenomena such as prevalence and infection, or features like prevalence rate and infection pattern, and these can hardly be explained within an atomistic framework as they manifestly involve reference to external entities. The third challenge is that this notion is barely compatible with an evolutionary account of diseases, which is adaptationist, and the notion of adaptation evokes biological externalism (10). This ontological approach also has a challenging consequence for medical practice: it would not be surprising if an atomistic approach tended to decontextualize patients, since the states of a patient are now thought of as possessions of the isolated individual. Alternatively, the externalist approach provides an ontological basis for what has been referred to as the *humanistic model of medicine*, which emphasizes "healing the whole person in a whole life context" (11, p.90) as the primary aim of medical practice. This approach not only acknowledges the impact of environmental factors on disease but also challenges any view that treats patients as "divorced from related objects and persons" (11, p.17).

In this essay, I want to argue against atomism in medicine. I focus on internalism to show that the inevitable presence of the two notions of biological function and statistical normality in the biomedical model renders internalism about diseases untenable. Additionally, I argue that externalist individualism offers an alternative ontological approach that escapes the above challenges. After presenting my externalist approach to diseases and outlining its advantages, I address an implication of this approach related to the idea of diseases as natural kinds, demonstrating that it proposes a concept that is conceptually consistent. Before addressing this argument for externalism, I will first address a related argument proposed by Davies and Glackin to make clear how it is different from my case.

DAVIES AND GLACKIN'S ARGUMENT FOR EXTERNALISM

Davies (2) proposed an argument for externalism about mental illnesses, which Glackin (3) developed to apply also to somatic illnesses, in support of a sort of somatic externalism. According to Davies, "many of psychiatry's diagnostic categories are implicitly committed to constitutive externalism about mental illness. Some of these categories are socially externalist in nature" (2, p.291). The reason is that "some relations borne by S to her environment place constitutive conditions on her having mental illness" (2, p.291). He identifies two types of such conditions: the first type consists of historical constitutive conditions and concerns cases where facts which determine whether an individual is affected by a disease include facts about her previous environment. Post-traumatic stress disorder (PTSD) and depression are two examples of such cases. The second type consists of contemporaneous constitutive conditions, where facts which determine whether an individual is affected by a disease consist of facts about her current environment. The second type of disease differs from the first in the respect that the disease is present in so far as the external constitutive conditions persist. Davies takes oppositional defiant disorder (ODD) and factitious disorder as examples of the second type, where some external entities, like an authority figure or social rules in the case of ODD, are required to persist in order for some particular behaviours to manifest. While Davies's argument is claimed to apply to "many mental illnesses" (2, p.295), Glackin extends it to somatic illnesses, arguing that "many if not all somatic illnesses are dependent in just the same way on environmental factors" (3, p.287).

Two points must be made concerning this argument. First, it seems that the first type of disease – cases like PTSD and depression – does not provide a strong case for externalism. The environmental factor in such diseases is simply a part of the causal chain in the formation of the disease, which is evident since the manifestation of symptoms in such cases does not require the persistent and contemporaneous presence of these environmental factors. The difference between these two types

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[2] M. Ereshefsky, for example, states that "the World Health Organization's definitions of 'health' and 'disease', for instance, cite the 'physical, mental, and social well-being' of the *individual*" [emphasis added] (8, p.223).

[3] As C. Taylor pointed out, the term *atomism* "seems to be used almost exclusively by its enemies. Even extreme individualists like Nozick don't seem to warm to this term, but tend to prefer others, like 'individualism'" (9, p.187). Nonetheless, to distinguish this view from externalist individualism, I retain this term.

[4] Here, we are concerned with ontological questions to do with atomism and its components, namely internalism and individualism, rather than epistemological or semantic questions.

is analogous to the difference between artifacts and social entities. Consider an artifact like a knife, the formation of which refers to an environmental factor, i.e., a human being who makes the knife. The persistence of the knife does not require persistence of that environmental factor. By contrast, a piece of paper would not be money without the persistent and contemporaneous presence of an environmental factor, i.e., the collective intentionality of people who recognize that piece of paper as money, or the medium of exchange. Were that collective intentionality withdrawn from that piece of paper, it would no longer be money (12-13). The contribution by environmental factors in the first type of disease is a causal contribution, while the contribution for the second type is, to be precise, constitutive. The second point with regard to this argument is that it applies to many, but not all, diseases; many mental diseases for Davies, and many somatic diseases for Glackin. Indeed, the externalist view in each case is tenable only if we can actually identify an environmental factor, either historical or contemporaneous, contributing to the disease.

I intend to propose an argument, however, that supports externalism about diseases not case by case, but in a substantial way, and applies to *all* diseases. According to my argument, there is something in the nature of disease that impedes internalism. The argument I develop applies, I presume, to all sorts of diseases, either somatic or mental, if there is anything such as mental disease, and escapes the difficulties with the prevailing view mentioned above.[5]

AN ARGUMENT FOR EXTERNALISM

For a more precise examination of the biomedical model of disease, let us return to Boorse's definition. For him, a pathological state is a state of a part or process in an organism "when the ability of the part or process to perform one or more of its species-typical functions falls below some central range of the statistical distribution for that ability in corresponding parts or processes in members of an appropriate reference class of the species" (14, p.370). Boorse would later call this analysis the *biostatistical theory*, a name, according to him, "emphasizing that the analysis rests on the concepts of *biological function* and *statistical normality*" [emphasis added] (5, p.4). In the following, I argue that both of these concepts imply externalist commitments, and a pathological state which involves these concepts is consequently externalist as well.

First, let us address the concept of biological function. Boorse works with two analyses of biological function. In the first, borrowed from Sommerhoff (15), he thinks of function as a *causal contribution* to a goal. This goal is hypothesized for an organism or a part and requires that organism or part to modify its behaviour throughout a range of environmental variations in a way required for the attainment of the goal (5). In this analysis, the goal is seen, firstly, as constitutive of the function, and, secondly, is located outside of the organism: and these are sufficient to embed an externalist commitment within the function. In the second analysis, borrowed from L. Wright (16) and referred to as the *etiological analysis*, the function of something "is those of its effects which historically explain its presence. In particular, the functions of a part of an organism are the effects which, through evolution, fixed it in the population" (16, p.10). This analysis is in line with efforts made by Boorse in another section of his essay to reconcile his conception of disease with an adaptationist view. To adopt an adaptationist view, however, is precisely to admit an externalist commitment to biological function, because biological functions in such a view are understood as adaptationist responses to environmental conditions, and hence environmental factors are rendered constitutive of the adaptation of an organism (10).

A second component in Boorse's characterization of the disease is the reference to the statistical normal, or the "statistical means surrounded by some range of 'normal variation'" (5, p.546). He notes that a deviation from the statistical normal is neither necessary nor sufficient for a state to be regarded as pathological. There are conditions which are deviations from the mean but are not counted as a disease, like a type O blood, and states which are almost typical but are counted as disease, like tooth decay. Hence, it can be concluded that he equates the normal with the statistical mean but does not equate diseases with abnormal conditions; nonetheless, there is no doubt that a deviation from the statistical normal is for him a significant component of the disease. However, the statistical normal supervenes on how the value of a property is distributed among a population. In this sense, for any individual, it is environmental facts that determine the statistical normal. In other words, that an internal state of an individual is counted as pathological depends on analogous states in other people. Now, in so far as we consider the role which the statistical normal plays in determining diseases, we can again argue that it is external facts which determine the pathological character of a state.

In another definition, Boorse appeals to an abstract entity, *species design*, in suggesting that "diseases are internal states that interfere with functions in the species design" (1, p.558). Yet species design is precisely the functions which are statistically typical to a species. In other words, a species design is a hierarchy of values of the statistical normal related to the internal structures or functions of an organism which appears as an ideal empirical entity.[6] Thus, in this definition as well, both the concepts of biological function and the statistical normal have essential roles, and their being external to individuals gives rise to externalist commitments in a state classified as a disease state.

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[5] My argument does not require that there is certainly something such as mental illness. In other words, I am not taking a stance against movements like Mad Pride, which consider mental illness as valuable form of diversity rather than a condition needing treatment. Indeed, my argument has a conditional form: if there is such a thing as mental illness, my account could also apply to that condition.

[6] The phrase "ideal empirical" may seem confusing in Boorse's text when he refers to the species design. It becomes clearer if we notice that it is empirical as it is constituted by qualities and values collected through empirical studies on organisms. At the same time, it is ideal, since, as Boorse states "the portrait may not exactly resemble any species member" (1, p.557).

Glackin (3) notes these aspects of the argument, but skips over them considering his general disagreement with the biostatistical theory. There is a significant difference between Davies's and Glackin's main argument and my own, however, for they argue for externalism about the state itself. In other words, they argue that this state involves external components, whether it is classified as disease or not: in the first route, they refer to an external causal component in its history, and in the second, they argue that there is an external constitutive component in its present condition.[7] My argument, however, does not concern the state itself. Rather, I argue that if that state, whatever it may be, is to be classified as a disease state, it will inevitably have an external component. It follows from my argument that a state as a disease state, not a state *per se*, involves external components.

In a similar way, the contrast which I draw between internalism and externalism about disease differs from a well-known contrast drawn between disease as an internal substance and disease as an external substance. A notion of disease which was promoted by nineteenth-century pathology and twentieth-century genetics took it to be an entity (or substance) which is internal to the organism; in contrast, another notion of disease developed in light of infectious diseases regarded disease as that "which invades the human body, a foreign substance" (17, p.39). While this contrast concerns the etiology of diseases, my contrast concerns the constitution of disease, and rather than referring to factors contributing to the formation of that state, refers to constituents of that state as a disease state.

In this externalist view, what classifies a state as a disease state includes something external to the patient. In other words, facts which classify a state as a disease state include facts about extrinsic properties, which can be associated with other individuals, pathogens, etc. Joining externalism to individualism gives rise to an ontological stance which can be referred to as *methodological individualism*.[8] In this view, facts which classify a state as a disease state are still facts about individuals or patients, but individuals or patients who are constituted through their relations to others or to the environment.[9] Now, a description of a patient irreducibly involves interpersonal or external relations. Similarly, a description of a disease state as one of the patient's states also consists of the relations between intrinsic and environmental properties. This ontological approach allows the two concepts of biological function and the statistical normal to be appropriately regarded as constitutive to the disease state.

ADVANTAGES OF EXTERNALISM

Besides its compatibility with the nature of diseases, an externalist approach also has other advantages over internalism. Among them is that an externalist ontology is capable of accommodating epidemic diseases, so as to offer a unified notion of diseases. As pointed out in the first section above, epidemic diseases constitute a problem for internalism, as characterizing these diseases requires appealing to phenomena such as prevalence and infection, or features like prevalence rate and infection pattern, and these can hardly be explained within an atomistic framework. Indeed, interpersonal constituents of epidemics, like the prevalence rate and infection pattern, can be represented only through interpersonal relations and statistical distributions, in the same way as, say, panic might be. Note that the ontological account of epidemics does not require holism, i.e., an ontological commitment to irreducibly collective entities. Indeed, diseases are still attributed to individuals, but individuals who are being constituted through their relations to the environment.

In order to show that these interpersonal relations are capable of thoroughly capturing non-individual reality, I refer here to an articulation by E.O. Wright et al. (19). Consider a system with two individuals, X and Y. The entire system Z can be described as such:

$$Z = b_1X + b_2Y$$

where b_1 stands for the impact of X and b_2 stands for the impact of Y. Now, if there is an interaction between X and Y, such as a contagion from the first individual to the second, it follows that:

$$Z = b_1X + b_2Y + b_3XY$$

where b_3 stands for the impact of the interaction between two individuals in this system. This new impact, however, can still be dissolved into former impacts, provided that individuals are considered richer than before. Then it follows that:

$$X^* = X(1 + b_3Y / 2b_1) \qquad Y^* = Y(1 + b_3X / 2b_2)$$
$$Z = b_1X^* + b_2Y^*$$

Here, while interpersonal relations are not reducible to properties of isolated individuals, they are not thought of as requiring macro entities (20). In other words, an ontology which is required by epidemics is not more inflationary than an ontology which

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[7] A similar externalist stance was attributed by M.A.G. Cutter to nosologists, or the classifiers of diseases. For them, as she states, "disease is relational rather than substantial, the result of individual constitutions, the laws of pathology, and the peculiarities of environments" (17, p.40). Moreover, she proposes an independent argument for the view of disease as a relation (17, p.45-6).

[8] Methodological individualism might seem a purely methodological thesis about how to explain social realities. But what I mean here by this term has significant ontological commitments. For more detail, see B. Epstein (18).

[9] Similar to the distinction between a state *per se* and a state as a disease state, there is a distinction between an individual *per se* and an individual as a patient. As with the former distinction, what is crucial here is the constitutive role of extrinsic properties to individuals as patients, rather than to individuals *per se*. This is what situates our discussion within medical ontology and distinguishes it from social ontology.

is required by population thinking, and as population thinking in biology does not require holism, epidemics in medicine do not require it either.

Another advantage of this ontology is its compatibility with the evolutionary idea of the disease. As pointed out above, Boorse himself admits that a statistical concept of normal cannot sufficiently account for health and disease; however, very little has been said about a view which might complement the statistical concept. A possible complementary view is the evolutionary view. As R.M. Nesse states:

> A deep understanding of what is abnormal requires a richly detailed understanding of what is normal. Statistical generalizations will not suffice. Instead, we require nothing less than a complete knowledge of what the body is for, how it works, and, especially, how it came to have its current form (21, p.38).

A crucial point is that the evolutionary background of a disease might work in opposition to the statistical notion of normality. In other words, the statistical component of normality and the evolutionary component might make competing demands on the health of the organism. But when health and reproductive success diverge, natural selection would be obviously on the side of reproductive success, at the cost of health. For instance, while depression is obviously a disease, it has been suggested that possibly it has developed as a mechanism to turn off motivation in situations where action is likely to be maladaptive (22). Thus, the adaptive component of health needs to be independently analyzed. But an internalist approach to diseases is not capable of capturing the adaptive component of health, because adaptation is ontologically a relation, with a relata outside of the organism. In H.T. Engelhardt's terms, "the notion of successful adaptation is context specific and determined by what one wishes to achieve in a particular context" (23, p.168-69). The externalist approach, however, is compatible with an adaptationist view of health, since, in advance, it recognizes external relations in the concept of normality and thus in the concept of health and disease.

The fourth advantage concerns the contextuality of the disease. As stated above, an atomistic understanding tends to decontextualize the patient, or to ignore features of her embodiment and the rich and complex ways in which she is situated within a social and material environment including human and non-human agents. From a scientific point of view, decontextualization might be thought of as required by the process of establishing the subject matter of scientific investigation. But, as some researchers (24-27) have pointed out, decontextualization is among the causes of what is known as the quality-of-care crisis in contemporary medicine.

Rather than being a fruitful activity, decontextualization, viewed from this stance, has been an orientation with troublesome consequences in context of patient care. As I argued in this essay, the material and social environment cannot be ontologically eliminated from the disease. So, ruling out the contextual factors as a methodological orientation misdirects medical practice. Hence, the problem is not whether we can, or cannot, establish a medical ontology on an atomistic basis; the problem is that this medical ontology fails to capture what medical entities actually are. Nonetheless, such a failure has not prevented this orientation from influencing medical practice, when it calls upon medical practitioners to study and treat diseases as if they were internal states of an isolated person, an orientation which underestimates the role of external factors in the constitution of health. By introducing an ontology which is more compatible with the nature of diseases, the external understanding offers a more fruitful orientation.[10] This orientation is also compatible with a view that has been referred to as the *humanistic view of medicine* (27), one in which a patient is not an isolated organism but a person within a social context and with a *social self* (26); a person none of whose states are constituted independently of social relations and conditions (38).

DISEASES AND NATURAL KINDS

The externalist view, nevertheless, represents a challenge to a particular ontological aspect of health: namely, the view that diseases are natural kinds.[11] This challenge arises through adopting a classical view of natural kinds, according to which the properties which bring a class of objects together in a natural kind are intrinsic properties of those objects (41,42). This view is encouraged by a neo-Aristotelian view of natural kinds (43) which suggests that

> the notion of a natural kind must be tied to that of a real essence. That is, whether we are talking about kinds of stuff (gold, water, cellulose) or kinds of individual (tiger, oak, stickleback), members of natural kinds have real essences, intrinsic properties that make them members of the relevant kind (44, p.29).

Now, if extrinsic properties of disease states are to contribute to determining whether they are disease states, one might worry that diseases will thereby not qualify as natural kinds. Before addressing this challenge, let us first contemplate the motivation of philosophers of natural kinds in thinking of kind-making properties as intrinsic, in order to see whether this motivation applies to diseases as well.

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[10] With regard to mental diseases, many studies have stressed the efficacy of an external approach in the treatment of such diseases (28-37).

[11] While widely adopted, it is contested as well. D.P. Sulmasy (39), for instance, holds that "a disease is not a natural kind. It is a classification of a certain state of affairs that can occur in members of particular living natural kinds" (p.496). Sulmasy's urge to reject diseases as natural kinds seems to be the popular idea that "natural kinds are natural kinds of objects". However, as B. Ellis (39) pointed out, there can be also natural kinds of properties, events, processes, etc., and thus diseases are natural kinds to the extent that, let's say, volcanoes are natural kinds. A similar disagreement is found in L. Reznek (40). He does not, however, reject the claim that "diseases are natural kinds". What he rejects is the claim that "the disease is a natural kind", which is in large extent different.

As pointed out above, the major motivation for taking kind-making properties as intrinsic is essentialism, and as E. Sober (45) argued, the major motivation for essentialism about these properties is their necessity. It is argued that for a property to be necessary, its instantiation should not be dependent on any other property or object, and hence such properties are required to be intrinsic. Thus, in so far as we are concerned with their necessity, these properties are thought of as intrinsic. Accordingly, the true question would be whether there is any motivation to believe in necessity with regard to diseases.

To address the question regarding diseases it is helpful to consider a similar debate in the case of species, as these two types of entities, or biological kinds, are similar in substantial respects. Insofar as species are concerned, kind-making properties are supposed to be their external relations – ancestral descents in the genealogical view, and ecological roles in the ecological view. Noticing the relational character of the substantial properties of species convinced E. Mayr (46) to draw a contrast between Darwinian thinking and biological essentialism. But revisions proposed by Sober (45), R. Boyd (47) and P. Griffiths (48) challenged this contrast. According to Griffiths, many of the traditional commitments of essentialism are problematic in biology, among which is the intrinsic condition for essential properties. As he says, "population thinking excluded essential intrinsic properties, but it does not exclude essential relational properties" (48, p.210). An essential property that makes some instances members of a kind could be their relation to a causal homeostatic mechanism, a mechanism which was defined by Boyd (49) as what causally explains the maintenance of property correlations throughout the set of instances of a kind. As Griffiths argued, this mechanism need not be internal to individuals at all: it could even have social causes, i.e., generated by human agency, such as in the case of social kinds. What is at stake here is that this causal mechanism can fulfill the roles traditionally associated with intrinsic essential properties, such as supporting valid generalizations and reliable inductions.

Hence, a contrast initially posited between Darwinian thinking and essentialism turns out to be a contrast between Darwinian thinking and internalism. Now, having abandoned the intrinsic condition for essential properties while recognizing relations between individuals as determining conditions for the identity of kinds, we can still appropriately refer to essences with respect to species. The only thing is that the cost for this replacement needs to be paid; and this cost is to abandon the necessity of essential properties, as this essentialism no longer supports the necessity. To pay this cost regarding species not only is not difficult, but it is indeed to be welcomed considering the internal dynamics of species.

The case for necessity with regard to diseases is no better than the case for species. Both the above-mentioned components which contribute to whether a state is pathological – statistical normality and adaptation – pose challenges to necessity in diseases. Accordingly, there is no state which can be judged to be necessarily pathological, since any change in the constituents of a disease state can rescind its pathological character. This could be a change in the diet of a reference population which in turn shifts the statistical normal of diabetes and turns some states which have already been regarded as pathological into normal (and vice versa); or it could be a major drift by African people to Europe which neutralizes the adaptationist advantage of bearing the sickle cell alleles, and turns it into a pathological state.[12] Accordingly, essentialism in this sense, which recognizes relational essential properties, not only causes no problem for the notion of disease, but also is more compatible with how the disease is actually understood from a medical point of view.

Denying necessity in the natural kinds of disease has a remarkable metaphysical implication, though. It is commonly believed that natural kinds are constituents of the laws of nature (50). Now, when a law is a relation between a kind property and an essential property (51), e.g., being an electron and having the charge 1.6×10^{-19}, or a relation between two essential properties of a natural kind (52,53), e.g., electron charge and electron spin, it seems that denying necessity with respect to essential properties can undermine the nomological necessities in such laws. In other words, denying the necessity inherent to natural kinds of diseases could undermine the necessity of some laws in medicine. Like in the previous case, however, this consequence is not at all worrying, as the statistical nature of laws in medicine is more compatible with the regularity view of scientific laws than the necessity view.[13] In other words, an idea of natural kinds without necessity is more compatible with the statistical flexibility of laws in medicine. Hence, an idea of natural kinds based on an externalist approach to diseases not only is not conceptually incoherent, it is indeed more in accord with the nature of diseases in particular and medical ontology in general.

While it takes effort to show that the externalist notion of disease is compatible with the classic idea of natural kinds, it is easy to show its compatibility with the recent epistemological idea of natural kinds. Rather than being identified through metaphysical considerations, natural kinds are identified, according to this idea, through their role in epistemic practice (55), where natural properties do not stand in static essential relations, but rather in dynamic homeostatic relations. In Boyd's theory of homeostatic property clusters, natural kinds are determined by homeostatic mechanisms rather than by structures of essential properties, and, as he points out, these mechanisms may be either internal or external to a given system (47,56). What this suggests for the structure of kinds makes room in advance for externalism about natural kinds. As a result, the externalist notion of diseases seems problematic neither for the metaphysical notion of natural kinds, nor for the epistemological notion.

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[12] Sickle cell is the trait of having an abnormal hemoglobin molecule that enables red blood cells to resist malarial parasites. Such a trait is to the advantage of the host in an environment where malaria is endemic. But in environments of low oxygen concentration, such a trait leads to sickle cell anemia.

[13] It can also be proposed in such a way that as a subset of biological laws the laws in medicine are void of necessity. For arguments against necessity in biological laws, see (54).

CONCLUSION

That a disease state *per se* is an internal state of an individual has been seen as encouraging an internalist view of diseases. Nevertheless, these states as disease states have certain essential externalist components that highlight the role played by the environment in categorizing individual states into normal and pathological states. Ignoring this component has given rise to a misunderstanding about the nature of diseases and has misdirected medical ontology down an atomistic line. This approach is also accompanied by an inappropriate orientation in medical practice, encouraging or at least allowing a decontextualization of the patient. As I argued in this essay, an externalist approach not only provides a consistent and unified concept of disease but also reduces that tension in medical practice. There is, however, a potential challenge facing an externalist approach; diseases, in this sense, cannot be regarded as natural kinds, at least when traditionally understood. But the idea of natural kinds in medicine is presumably much more in line with the corresponding idea in biology rather than in physics. Accordingly, a solution that has been suggested for the problem of species as natural kinds applies also to diseases: this is a solution that recognizes relational essential properties and enables us both to take an externalist approach to diseases, and to locate them within the framework of natural kinds.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Clinical Ethics Support Provided to Interdisciplinary Rehabilitation Teams in Quebec: A Qualitative Study

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Résumé

Introduction : La réadaptation est un service de santé axé sur le rétablissement et le maintien de la fonction et souvent entrepris par des équipes interdisciplinaires. Les prestataires de services de réadaptation sont confrontés à des questions et préoccupations éthiques qui requièrent une attention et une résolution. Les services d'éthique clinique (SEC) fournis par des consultants en éthique visent à soutenir les équipes confrontées à des défis éthiques. L'objectif de cette étude était d'explorer les expériences et les perspectives des personnes qui fournissent des SEC aux équipes interdisciplinaires de réadaptation dans les centres intégrés de santé et services sociaux du Québec.
Méthodes : Nous avons mené une étude qualitative descriptive et interrogé des personnes qui fournissent des SEC dans les 22 centres intégrés de la province de Québec. Les transcriptions des entrevues ont été examinées à l'aide de techniques de comparaison constante et d'une analyse thématique inductive.
Résultats : Les équipes de réadaptation ont demandé des SEC pour résoudre un éventail de problèmes, allant des conflits entre le maintien de l'autonomie et la sécurité du patient aux défis découlant des lacunes structurelles dans les trajectoires de soins. Cependant, les demandes aux SEC par les équipes de réadaptation ont été décrites comme étant beaucoup moins fréquentes que celles des équipes travaillant dans des établissements de soins aigus. Les formes de SEC fournies aux équipes de réadaptation comprenaient l'accompagnement, la délibération éthique et la médiation. Les participants ont souligné les difficultés rencontrées pour apporter un soutien éthique, notamment la visibilité limitée de leurs services au sein des équipes de réadaptation et l'insuffisance des ressources disponibles pour étendre la portée de leurs services.
Conclusion : Malgré les défis qu'ils rencontrent, les consultants en éthique offrent diverses formes de soutien aux équipes interdisciplinaires de réadaptation au Québec. D'autres recherches sont nécessaires pour mieux comprendre l'éventail des questions éthiques qui se posent en réadaptation, ainsi que l'impact que le soutien des SEC peut avoir sur le déroulement des situations éthiques et sur la façon dont elles sont vécues par toutes les personnes concernées.

Mots-clés
services d'éthique clinique, réadaptation, soutien, enjeux éthiques, entrevues

Abstract

Introduction: Rehabilitation is a health care service focusing on the restoration and maintenance of function and is often undertaken by interdisciplinary teams. Rehabilitation care providers encounter ethical issues and concerns that require attention and resolution. Clinical ethics services (CES) provided by ethics consultants aim to support teams facing ethical challenges. The objective of this study was to explore the experiences and perspectives of individuals providing CES to interdisciplinary rehabilitation teams in Quebec health care centres.
Methods: We conducted a qualitative descriptive study and interviewed individuals who provide CES in all 22 integrated health care centres in the province of Quebec. Interview transcripts were examined using constant comparative techniques and inductive thematic analysis.
Results: Rehabilitation teams requested CES to address a range of issues, from conflicts between upholding patient autonomy and promoting safety to challenges arising due to structural gaps in care trajectories. However, ethics requests from rehabilitation teams were described as much less frequent than those received from teams working in acute care settings. Forms of CES provided to rehabilitation teams included accompaniment, ethical deliberation and mediation. Participants highlighted challenges providing ethics support, such as limited visibility of their services amongst rehabilitation teams and insufficient resources available to extend the reach of CES.
Conclusion: Despite encountering challenges, ethics consultants offer diverse forms of support to interdisciplinary rehabilitation teams in Quebec. Further research is needed to better understand the range of ethical issues arising in rehabilitation, as well as the impact that CES support can have on how situations unfold and how they are experienced by all involved.

Keywords
clinical ethics services, rehabilitation, support, ethical challenges, interviews

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INTRODUCTION

Rehabilitation aims to support individuals with a disability or potential to develop a disability to maintain, restore or optimize their functional capacities in interaction with their environment (1). Given this objective, rehabilitative care typically requires a patient's active participation (2). In this sense, rehabilitation care is done 'with' rather than 'to' or 'for' (3). It is also characterized by longer time periods compared to acute care (4,5), whereby patients and rehabilitation providers may work together for months or even years. Patients in rehabilitation may require comprehensive support that includes physical, psychological, social, emotional and vocational dimensions (6). Given the multiple needs of patients, rehabilitation is often delivered by an interdisciplinary team of health care professionals (5). The composition and organization of the rehabilitation team varies depending on the nature of the patient's condition and social needs, and on the structure of the health care organization or program. It is likely to vary between settings, for example home care, a rehabilitation hospital, or an outpatient clinic in the community. The members of these teams may include physical therapists, occupational therapists, speech-language pathologists, psychologists or neuropsychologists, nurses, physicians, and social workers, amongst others (7). An additional feature of rehabilitation teams is that they often reflect a less hierarchical and more horizontal structure among professions (8). Within team-based rehabilitation care, open, frequent and clear communication is emphasized amongst team members and with the patient on subjects such as goal setting and treatment (7,9,10).

Rehabilitation professionals encounter a variety of ethically difficult situations in their day-to-day practices (11-14). Common themes include concerns related to goal setting, team conflict, informed consent, discharge planning, confidentiality, patient autonomy, staff autonomy, patients' risky behaviour or choices, and resource allocation (11,12,15). In the face of recurrent ethical challenges or structural barriers to addressing them, rehabilitation professionals might also experience moral distress and a decline in job satisfaction (12,16), which could potentially result in attrition from the health care professions (17).

A range of strategies are used by teams to respond to ethically challenging situations (18-20). Teams may address ethical issues in the context of team or family meetings, during rounds or in informal discussions. They may draw on institutional or professional codes of ethics or organizational policies, seek input from peers, or solicit support from a coordinator or supervisor (20,21). In some situations, and in institutional contexts where it is available, rehabilitation professionals may seek assistance from a formal clinical ethics service (CES) (20-22). Drawing upon a CES can support the team to work through the situation by encouraging careful deliberation and reflection, providing exposure to alternative perspectives, and facilitating communication (22). These steps can also foster greater transparency and accountability in the decision-making process (23). Even where available, there may be barriers for rehabilitation teams accessing CES, including a lack of familiarity with the available support services, CES members being seen as "outsiders" by teams, or an actual or perceived lack of familiarity concerning the domain of rehabilitation care on the part of the individual(s) providing ethics consultations (24). Facilitators related to CES have also been reported, such as information on how to consult the CES being readily available and the incorporation of ethics education as part of continuing professional development, such as ethics rounds and seminars, which can help professionals be prepared to address ethical issues within their practice (24).

In the public health care system in Quebec, Canada, CES is available to interdisciplinary rehabilitation teams across health care centres. Before 2015, there were 182 separate health and social services facilities throughout the province of Quebec. In 2015, a health care system reform centralized all health care and social services into 22 integrated health and social services centres (named *Centre intégré de santé et de services sociaux)*. Each of these integrated centres consists of multiple health and social services institutions, such as hospitals, long-term care facilities, rehabilitation centres, and community health centres, under a single management structure. Nine of these centres have an affiliation with a university offering health care professional training programs (termed CIUSSSs in French), while the other thirteen are called integrated health and social services centres (CISSSs in French) and do not have a university affiliation. For simplicity, CISSS will be used in the text to refer to all health and social services centres. With the 2015 reform of the health care system and the creation of 22 CISSSs, CES was centralized in each integrated centre, though the form and structure of the CES service in each CISSS will vary. Each CISSS has a single CES structure which is typically based in an acute care hospital, but which has responsibility for all the programs and facilities under the management of the integrated centre. Where clinical ethics consultants are present, their activities include analyzing cases that raise specific ethical issues, developing or providing feedback on guidelines relevant to ethics, and raising awareness among practitioners and staff about ethics (25).

In a previous research project (yet to be published), we conducted focus groups with rehabilitation teams in two CISSSs, as well as interviews with team managers and ethics consultants. We aimed to understand how the teams engaged with ethical issues in their everyday practice. Some clinicians reported challenges and reticence to reach out to CES. To better understand the provision of CES to rehabilitation teams, and to look at this issue at the provincial level, we developed the study reported in this article. This study was approved by the Comité d'Éthique et de la Recherche en Réadaptation et en Déficience Physique du CIUSSS du Centre-Sud-de-l'Île-de-Montréal (MP-50-2022-1513) and institutional approval was received in each CISSS. Our objective was to explore the experiences and perspectives of individuals providing CES to interdisciplinary rehabilitation teams in Quebec health care centres and to better understand in which circumstances and how interdisciplinary rehabilitation teams access CES and what supports are provided.

METHODS

Design and Setting

A qualitative description methodology was used to guide the development of this study (26,27). This approach aims to provide a comprehensive account of a phenomenon using the common language and expressions of those involved (27). Qualitative description is well aligned with the exploratory nature of this inquiry which seeks to describe CES processes, including aspects that might function as enablers or barriers, as well as the types of cases or situations for which CES was sought, from the perspective of the individuals providing CES to interdisciplinary rehabilitation teams in Quebec.

Participants and recruitment procedures

Given our aim to better understand CES provision to rehabilitation teams across the province of Quebec, we adopted quota and convenience sampling strategies and sought to recruit a participant from each of the 22 CISSSs who was responsible for providing CES to rehabilitation teams. These individuals could have different professional designations, such as a clinical ethics consultant, an ethicist, a chair or member of a clinical and organizational ethics committee, or some other form of ethics advisor. As part of the research ethics approval process, we contacted each CISSS to obtain institutional approval to conduct the study in their centre. During this process, the person responsible for granting approval identified one or several individuals who could potentially participate in the study, based on the profile of participants that we were seeking. These individuals were invited to participate in the study, either by the person who granted institutional approval or, at the direction of that person, by a member of the research team. Those who accepted to participate then signed the consent form and the interview was scheduled at a time that was convenient for the participant.

A total of 23 participants drawn from the 22 CISSSs participated in the study. In one CISSS, two individuals requested to be interviewed together as one had recently been hired in the position. Reflecting variability in the structures established across the CISSSs, participants had a range of professional titles. They identified their role using terms including “clinical ethicist”, “ethics consultant”, “ethics advisor”, “senior ethics advisor” and “ethics coordinator”. While all participants mentioned having a background in health (e.g., occupational therapy, nursing, and others), social services (e.g., psychology, social work, psychoeducation and others) or administration, 11 participants specifically mentioned having completed a training program in ethics or bioethics. The median amount of time participants had been involved in CES was 5 years (range: less than three months to more than 30 years). Amongst participants, 21 identified as women and two as men. To simplify the text, the term “ethics consultant” will be used to refer to all participants.

Interviews

We developed an interview guide based on a review of the literature and insights derived from the experiences in clinical ethics of the research team and our prior research on clinical ethics in rehabilitation hospitals. A pilot interview was conducted with a research team member who had previous experience working as a CES provider. This step led to the refinement and reordering of some questions. The interview guide included topics such as the participant’s background in clinical ethics, the nature of their current work in CES, procedures to access CES in their setting, the kinds of CES services they provide to rehabilitation teams, types of situations that had prompted requests for CES, and changes in CES provision stemming from the 2015 health care system reform and/or the COVID pandemic.

All participants signed the consent form prior to participating in the interview. Each participant took part in a semi-structured interview conducted in French or English via an online conferencing platform (Zoom or Teams depending on the preference of the participant) and with a mean duration of 62 minutes. Interviews were conducted by NT and JA who were master’s students at the time of the research, under the close supervision and guidance of experienced qualitative researchers. All interviews were audio recorded and transcribed verbatim by a member of the research team. Transcripts were reviewed for accuracy and anonymization by a different member of the research team.

Data analysis

An inductive thematic analysis approach and constant comparative techniques were used to compare within and between data sources (28). We initiated analysis as transcriptions were completed so that insights from earlier interviews could be integrated or tested in later interviews. The software QDA Miner (QDA Miner and QDA Miner Lite, Provalis Research, 2004) was used for the analysis process. Coding began with two team members independently coding two transcripts, assigning labels to sections of text in response to the questions: “What is going on here? What is this about?”. Coding was compared between the two coders and reviewed with other members of the team. We then established an initial codebook and used it to code the remaining transcripts with small additions or modifications made based on team discussion and consensus. Categories were then created to aggregate codes and identify patterns in the data. Another member of the team, JD, then reviewed all transcripts and coding to ensure coherence and completeness of the analysis that was developed. Excerpts presented in the following sections were translated from French to English, where necessary, by a bilingual member of the team.

RESULTS

Organization of CES

Since the 2015 reform, CES has been available across all CISSSs in Quebec. Overall, participants reported that the services offered in their centre were available to all programs and facilities, though there was a variation between CISSSs in terms of the structures and processes of CES provision. A participant underlined the universality of CES in their CISSS but described how they tailored their response to the needs of those requesting it: "*No, it is always the same set of services. People, they write to me for what they need, then I adapt the services offered in response to their needs, but the service is the same for everybody*." (P19)

In most CISSSs, a single ethics consultant was responsible for providing CES, while in other settings ethics consultants worked in pairs to respond to requests for support. Most participants reported that there was a clinical ethics committee with whom they collaborated, and a few described working with multiple committees, such as an organisational ethics committee and a clinical ethics committee. These committees were typically composed of health care professionals, managers, lawyers, and community or patient representatives. Members included individuals with an interest in ethics or expertise aligned with the specific role of each committee. For example, clinical ethics committees were more likely to include members with expertise in patient care and clinical decision-making, while organisational ethics committees included, but were not limited to, individuals with experience in policy development, administration, and more systemic issues. Participants described the committees as providing input on CES referrals, engaging in mediation or deliberation around particularly challenging cases, offering ethics training for clinicians and managers, and developing or reviewing policies, such as updating the centre's Code of Ethics. Participants also described the visibility of the clinical ethics committee within an institution as resulting in an increased awareness of ethics across their institution.

Six participants mentioned that a "Hub-and-Spokes model" had been or was being implemented in their CISSS. Participants described how this model includes the establishment of a clinical ethics office (the Hub) supported by regular collaborators from across the CISSS with different backgrounds and who were situated in varied locales (the Spokes). Collaborators, also called "ambassadors", or referred to as functioning as "satellites" of the CES structure, were recruited for their interest in ethics and were trained to provide support to the members of teams within their clinical setting who were grappling with ethical issues with the goal "…*that they would be local ethics representatives who could, I imagine, one, increase the visibility [of the CES service] and, two, be responsible for more straightforward cases*" (P4). These participants highlighted that the model of using ambassadors was useful and relevant for their practice, though it was described as still in development in several settings. This form of CES was described as helping clinicians realize, "*OK, we're there, we're in the ethics zone, this is about values.*" As the participant emphasized, this timely recognition encourages clinicians to "*ask for help right away because otherwise the suffering will continue and it will just grow*." (P16)

While CES was present in all CISSSs, it varied considerably in form, and in many cases multiple approaches were used in an integrated manner. Structures such as clinical and organizational ethics committees, hub-and-spoke ambassadors, and satellite sub-committees were described as valuable mechanisms for enhancing the work and reach of CES.

CES provision

Participants described the process for clinicians, including interdisciplinary rehabilitation teams, to seek CES. In some cases, clinicians must first contact their managers who then have the responsibility of requesting CES, while in other settings, clinical teams fill out a webform to request CES. A participant described that they had sought to reduce the administrative steps to access CES in their institution by encouraging clinicians to contact them directly:

> *Many of the preoccupations at that time […] was all the paperwork, uh, it was actually pretty complicated to have access [to CES]. So, to really simplify things for people who have a request, they can contact me directly, by email, on my cell, or using Teams, so we can talk and from there we can look at it together.* (P18)

Once the participants received a request for CES, they assessed if they were best placed to provide support to the team and, if not, redirected the request. A participant described such a situation in which they redirected a team:

> *if I judge that it isn't an ethics case then I redirect that person. […] If the person has a very specific question, for example about confidentiality and charting, and it is a very focused question, then I redirect them to the medical records department.* (P18)

In some situations, the participants reported that they discussed an ethical question with the team prior to the initiation of a formal CES process. If needed, they would set up a virtual meeting to get more details, which might lead to a formal CES consultation, as described above.

If a CES process was initiated, the delay for responding to the request varied based on whether it was assessed to be an urgent situation. For non-urgent situations, participants reported a delay of a few days to a few weeks, depending on factors such as whether multiple individuals needed to be convened to discuss the situation. For urgent cases, the process was initiated within three days of receiving the request. Participants described a range of ways that they provided CES, and that these approaches were similar for rehabilitation teams and teams from other clinical sectors. The most frequently mentioned approach was "accompanying" (*accompagnement* in French) those involved in the ethically challenging situation through a relatively informal process of coming alongside the team as they work through a particular challenge. Participant 12 described how they "*accompany the clinicians in certain choices and decisions, raise awareness of ethics [… and] support stakeholders*". Through this approach, the participants promoted a shared exploration of ethical issues with the aim of supporting the team to develop a deeper understanding of the ethical issue and possible responses, and to empower teams through the development of skills and knowledge to navigate ethically complex situations.

The second approach described by participants was to organize a formal ethical deliberation meeting. This meeting typically involved an interdisciplinary group of health care professionals, the ethics consultant, and sometimes other members of the ethics committee, who came together to explore in depth the nature of the ethical challenge faced by the team, consider different perspectives on the questions raised, and evaluate possible responses and the ethical rationales for and against different options. The intent was that following such an exchange, the team would be better oriented and equipped to move forward in their process of decision-making. Following the session, the ethics consultant shared a written summary of the main ideas that were discussed. Several participants mentioned following up afterwards to see how the situation evolved and to provide ongoing support if needed. A participant jokingly described this as offering "*after-sale service*" and that if the follow-up showed that more support was needed, they would not "*back down so long as we haven't reached the end of it*" (P11) and so would continue to work with the team towards a resolution of the situation.

A third course of action was mediation. In this approach, the ethics consultant typically acts as a mediator among health care professionals who are grappling with an ethical challenge and have conflicting perspectives. Although not all ethics consultants reported that they included patients and families in mediation processes, in certain situations, mediation was conducted with the health care professionals, the patient, and their family:

> *An ethicist very often takes the role of this neutral party, I don't represent one or the other [perspective], I represent a mediation effort to try and break through that impasse, but in the best interest of the decision makers; the family or the patient in order to move forward in this situation.* (P7)

In most CISSSs, ethics consultants also provided ethics education to clinicians. The focus of these educational activities was often informed by the ethical issues that were raised by clinicians during formal or informal consultations with the ethics consultants, especially when an ethical challenge was identified as recurrent or widespread. In this sense, ethics education functioned as a more upstream means of responding to ethics concerns identified by teams. Educational initiatives included in-service lunchtime talks or webinars, as well as the development of reports or pamphlets on specific ethical issues that were then made available to all staff through the CISSS's website.

CES requests from rehabilitation teams

Participants reported that they received fewer CES requests from interdisciplinary rehabilitation teams than teams working in other sectors (e.g., acute care, mental health). Strikingly, several participants stated that they had had very few or no CES requests from a rehabilitation team. An ethics consultant reported that they had had only "*one request in four years that came specifically from a rehabilitation professional.*" (P2) In contrast, a participant who worked in a large CISSS with a very active CES reported a high number of requests from rehabilitation teams, though still considerably fewer than from other services:

> *In rehab, we must have, I'd say at least 20 per year, for physical rehab. […] but they are not among our big requestors. Rehab is amongst our low requestors. Our three biggest are support for the autonomy of the elderly, mental health and addiction, and intellectual disabilities.* (P6)

Participants described a range of ethical challenges that were the source of CES requests from interdisciplinary rehabilitation teams. These challenges can be grouped in five main categories: 1) tension between safety and autonomy, 2) gaps in continuity of care, 3) tension between the treatment team and patients' families, 4) refusal of treatment, and 5) communicating about prognosis.

Situations where clinicians experienced tensions between promoting the patient's safety and respecting their autonomy were the most common category of ethical challenge. A participant described these ethical issues as "very broad" in scope and gave multiple examples, including situations when a patient drove a motorized wheelchair recklessly, non-compliance with recommendations to avoid a dangerous sport that was contra-indicated due to their health condition, and "*a smoker who puts other people at risk because he was negligent and risked starting a fire.*" (P15)

Issues related to patients' care trajectories were also frequently reported as ethical challenges faced by interdisciplinary rehabilitation team and prompting ethics consultations. These issues were particularly challenging when there were gaps in available care or uncertainty about discharge options and continuity of care once the patient left the rehabilitation centre.

Third, ethical challenges also arose in situations when there was tension between families and the clinical team, including situations when families opposed recommendations made by the rehabilitation team. In other cases, tension arose in relation to how the patient's progression was perceived and disagreement about the rehabilitation interventions that were being offered.

For example, a participant described challenges when a patient's functional gains reached a plateau quite quickly: "*patients who have trouble adapting to the situation and sometimes, but often also more with relatives, they do not accept the prognosis and then well, they insist that there are different rehabilitation treatments and services that they should receive.*" (P17)

The fourth category of ethical challenge was situations when a patient refused to participate in some aspect of their rehabilitation. For example, a participant described a situation where a patient declined to participate in certain therapeutic exercises due to fatigue and rejected the suggested rehabilitation plan because he could not understand its benefits. This situation was distressing for the treatment team as they felt caught between respecting the patient's autonomy and their professional responsibility to ensure the patient received appropriate care.

The fifth category of ethical challenge was mentioned less frequently by the participants. It relates to communicating about the patient's prognosis and the likelihood that they would achieve functional gains as a result of their rehabilitation. In some cases, these issues arose in relation to communicating with patients whom the clinical team assessed as having limited potential to benefit from rehabilitation. Clinicians struggled in situations when they felt they had to balance honesty about the prognosis with the need to maintain hope and motivation for the patient, while also managing the emotional impact that such conversations could have on both the patient and their family. This challenge was also linked to constraints in the health care system, including limited resources for rehabilitation and long waiting time for rehabilitation services in some areas. It introduced considerations of equity as clinicians may feel pulled between continuing to provide rehabilitation services for a patient who has reached a plateau in their recovery or taking on a new patient from the waiting list who has yet to receive services.

Factors that support or impede CES for interdisciplinary rehabilitation teams

Participants mentioned several elements that they viewed as facilitating the delivery of CES to interdisciplinary rehabilitation teams. Interestingly, most of the elements that were raised were related to the characteristics of rehabilitation teams themselves. Several participants mentioned that the rehabilitation teams that they had worked with had a "culture of ethics" and took time to talk about challenging cases in team meetings. A participant described that the rehabilitation teams "*share a lot of information, so it's already part of the culture to take five minutes, to sit down, to discuss a situation together. Those teams already have that culture.*" (P22) Participants highlighted the positive effects when teams have support from a clinical coordinator or manager who ensures that there are opportunities to exchange about ethical issues on a regular basis.

Another enabler mentioned by participants was the range of experiences and skillsets amongst team members. This diversity was seen as contributing to rehabilitation teams' capacities to discuss and respond effectively to ethical challenges, as well as working effectively with CES providers. A participant described that for "*the exchange [of viewpoints] at the ethical level. I think the diversity of experiences and perspectives is a plus, I think it's an advantage that these teams have, the way they are created.*" (P8) Participants also described the benefits when there is one or several members of a team who have developed expertise in addressing complex cases: "*Sometimes, I've seen that in some settings there is a person who is seen by their peers as having good judgment or [as having] a well-developed competence in ethics, who becomes an informal reference point for others.*" (P13)

One of the barriers to providing CES was misunderstanding amongst some health care teams regarding the role of ethics consultants and CES. Participants reported that this misunderstanding was not limited to rehabilitation teams but a wider challenge they faced in their work. In some cases, clinicians expected the ethics consultants to take over a situation and provide a definitive answer or quick resolution of the situation:

> *People sometimes expect solutions, a magic solution in the sense that they want "okay, tell me what to do". But that isn't our role. And sometimes you have to clearly define the role we have in terms of [supporting] reflections, but that we won't impose our point of view, because imposing our point of view wouldn't be ethical.* (P9)

In response to this misunderstanding, participants pointed to the value of having ambassadors across the institution who could increase awareness and understanding of the role of ethics consultants and how CES could help health care providers in their centre.

Barriers to CES were also the result of human resource issues and time constraints. Many of the approaches employed by the participants require bringing together stakeholders to deliberate around an issue yet convening them was often difficult due to their varied schedules and extremely high workloads. This situation was also intensified due to high staff turnover in some rehabilitation centres. A participant described the challenge of convening people to discuss ethical issues as being more difficult in rehabilitation settings due to the high number of people involved:

> *The real challenge is to get the clinicians together at the same time [for] 90 minutes, and I find it difficult to do it in less than that for a formal consultation, with stakeholders. To get the stakeholders together, the doctors, the high-level specialists who work in rehabilitation, that's really the main challenge of all this.* (P11)

Features of the CES service or institutional structures also functioned as barriers. Several participants reported that a lack of visibility of CES contributed to fewer requests from rehabilitation teams. The reduced visibility of CES was compounded by difficulty recruiting qualified personnel to CES roles and reduced funding for ethics services in some CISSSs. As a result of these factors, some participants stated that they were alone or had a very small team who were responsible for managing all CES requests. In this light, several participants said that they experienced tensions when trying to engage in visibility efforts for their CES because they worried that if the number of requests increased too much, they would be unable to adequately support the teams making the requests due to a lack of CES resources: "*A barrier is that we are not so well known. But we don't dare to be recognized too much because we will be overwhelmed. And then we don't necessarily have the budget to increase the number of people in ethics.*" (P15)

Several participants also reported that it is important to ensure that the administrative process for accessing CES is not an impediment and that there is adequate flexibility and responsiveness. Generally, participants viewed their services as being accessible and mentioned that they put a lot of effort into achieving this objective: "*Look, first, call me, then I'll fill in the form for you, or I'll explain it to you. As for your ethical challenge, I'll help you structure your thoughts, and then we'll present it to the committee clearly.*" (P8) Many participants reported adapting procedures to request CES in order to avoid this part of the process being a barrier to accessing support.

DISCUSSION

Our study describes the provision of CES to interdisciplinary rehabilitation teams in Quebec following a health care reform which mandated and centralized the availability of CES in all CISSSs across the province. Before the creation of the CISSS structure, CES was provided by local ethics committees in rehabilitation hospitals. However, not all rehabilitation hospitals had an ethics committee, and those that did tend to be larger institutions in urban settings and with university affiliations. For those hospitals that had an on-site ethics committee, it is possible that there was greater awareness of ethics support services and more integration into the daily workflow of rehabilitation teams. Following the reform, all rehabilitation hospitals now have access to CES but this is centralized within the CISSS and typically based in an acute care hospital. While this structure enhances broad access, it may also create more of a sense of distance for interdisciplinary rehabilitation teams towards the CES service (especially in settings where this was previously an intramural resource).

While the reform established CES across CISSSs, there remains considerable variability in the way it is organized and deployed. Kaposy et al. (29) described four broad structural models for organizing ethics consultation: 1) the lone ethics consultant model, 2) the ethics committee model, 3) the capacity-building model and 4) the facilitated model. All four are present to some degree across our participants. As is the case in many other health care systems, the first two models are the most commonly used. Alongside these approaches, participants also used the latter two models. In the capacity-building model, the ethics consultant is not directly involved in consultation activities, rather they train ethics committee members or practitioners (29). For example, the capacity-building model can be used to train a team from a smaller hospital in a rural area so that they can manage most ethics challenges independently. Many participants in our study discussed the Hub-and-Spokes model (30) and discussed its current or potential implementation in their organizations. This model is particularly interesting in settings such as the CISSSs with CES based at a central hub but with the mandate to provide services across many institutions, sometimes spread over a large geographic area. It has been implemented in health care organizations to increase access to ethics consultations, share best practices, and standardize consultations across a health care system that includes both large teaching hospitals and small community hospitals (31,32). It also presents risks, including congestion at hubs, which can occur if requests towards the hubs are not well coordinated (33). For example, if a new spoke is created, the hub will have to devote more effort to it, which could affect the service to the other spokes. Other risks include overextension of spokes and staff dissatisfaction if they feel disconnected from the hub. Such challenges can be addressed by assuring good communication and strong linkages between the hub and the spokes (33). The fourth model of ethics consultation, the facilitated model, focuses on convening appropriate stakeholders to participate in meetings to make decisions about ethically challenging situations and ensuring that adequate resources are in place (29). Many of our participants adopted multiple models of ethics consultation in their practice, depending on the circumstances, reflecting a pragmatic and responsive strategy for CES support.

Our findings highlight the adaptability of ethics consultants in Quebec as they sought to facilitate access to their services. Although participants did not describe a standardized procedure across settings, the basic steps were consistent, including clarifying requests, assessing the appropriateness of the request for CES, and subsequently offering tailored services. These steps are similar to the initial phases outlined in the National Center for Ethics in Health Care (23) model for ethics consultation known as CASES: 1) Clarifying the consultation request; 2) Gathering relevant information; 3) Synthesizing the information; 4) Articulating the synthesis of information; 5) Supporting the consultation process (for example, by evaluating how the process is unfurling and making adjustments as necessary). A desire for clear and consistent administrative and deliberative processes has been reported in prior research on clinical ethics committees (34). In contrast to the goal of having a clear set of standardized processes, our findings suggest that flexibility is crucial for responding to the diverse needs of those requesting services and being attentive to their specific situations. Striking a balance between rigorous processes and adaptability is important for successfully providing CES (35). Gaudine et al. (36) underscore the importance of extending CES support not only to health care professionals but also to patients and their families. In our study, participants mentioned the involvement of patients in mediation cases; however, no explicit emphasis was placed on their role or whether requests originated from them.

Many participants reported receiving fewer requests from rehabilitation teams compared to other sectors, such as intensive care units (ICUs), where ethical consultations are reported in the literature to be more common (37,38). Strikingly, several participants had not received any referrals from rehabilitation teams. When requests were received from rehabilitation teams, the most frequent issue that led to these consultations were situations where there was tension or conflict between respecting patient autonomy and protecting safety. This category of ethical challenge included situations when patients insisted on risky behaviours or refused recommended treatments, creating tension between supporting independence and avoiding harm to themselves or others. This topic has been identified as a prominent source of ethical challenges in studies of ethical issues experienced by rehabilitation teams (11-14). Additionally, issues related to the patient's care trajectory, especially during discharge planning and continuity of care, posed significant challenges. Discharge planning from a rehabilitation hospital is especially difficult when services are lacking in the community (39,40). Conflicts with families, particularly disagreements around goal setting and treatment plans, further complicated these situations (39).

The issues identified as giving rise to CES consultations by rehabilitation teams underscore the complexity of ethical decision-making in rehabilitation settings (15). Rehabilitation frequently necessitates sustained and intensive interactions between care providers and patients. This ongoing engagement often leads to the development of deep, complex relationships where trust, understanding, and communication are crucial. Within this context, ethical considerations are intricately tied to how values, goals, and priorities are interpreted, negotiated, and managed within these care relationships (11-14,41). The prolonged nature of these interactions means that ethical concerns can evolve over time, as both patients and providers must continuously navigate shifting needs, expectations, and challenges in pursuit of the best possible outcomes. This longer timeline may also lead to lower use by rehabilitation teams of CES where ethically challenging situations appear more prolonged and less urgent. In contrast, ethical challenges in ICUs and other acute care settings often revolve around time-sensitive and critical issues, including end-of-life decision-making or where complex decisions about life-sustaining treatments need to be made. The urgency and gravity of decision-making in intensive care settings may lead clinical teams to seek ethics support on a more frequent basis.

Certain ethical challenges seem to be generalized across all health care settings, including rehabilitation. These include issues related to communication and interaction with patients and families as mentioned in our study but also elsewhere (38,42). Participants also highlighted concerns about equitable access to care, particularly in relation to limited resources and discontinuity of care, which can create ethical challenges across health care sectors (38,42). Some participants suggested that rehabilitation teams were less likely to access CES due to their ability to resolve ethically challenging situations internally, in particular when the team, or some members of the team, has developed expertise in addressing such situations. Others suggested that some rehabilitation teams did not seek CES because they had less familiarity with identifying and discussing ethical challenges. Both of these observations underscore the importance of developing ethics awareness and moral sensitivity, as highlighted in other studies (20,24,34). Moral sensitivity enables health care professionals to recognize and navigate ethical challenges (43,44). Molewijk et al. (20) conducted interviews with mental health care professionals, including nurses, nursing assistants, social workers, psychiatrists and psychologists. Most appeared to have a general understanding of an "ethical challenge," often using words like "problem," "dilemma," "emotion," "discussion," "reflection," or "thinking around." However, they reported that they do not specifically label such experiences as an "ethical" challenge, referring to it simply as a challenge or a professional challenge. Thus, if professionals have difficulties identifying and recognizing ethical challenges, they may struggle to address these situations effectively but may also be less likely to seek CES support. Doran et al. (21) and Molewijk et al. (20) found that most health care professionals will consult a colleague when they are concerned about an ethical situation. Doran et al. (21) reported, however, that only 38% of participants indicated that they would consult with a clinical ethics committee or another source of external ethics expertise when encountering an ethical issue. Our results show that rehabilitation teams in Quebec infrequently access formal CES, despite efforts to increase flexibility and accessibility of these services, as also noted by Pedersen's study (34). Further research is needed to better understand the development of moral sensitivity in rehabilitation teams and how they address ethical challenges, including knowledge of the role of CES as a potential source of support.

Rehabilitation is not solely concerned with physical or functional maintenance and/or recovery but also encompasses the holistic well-being and integration of individuals into society (2). It recognizes the need to ensure the participation of individuals within their social contexts. Participants in our study suggested that the nature of rehabilitation as a health care service had an impact on how interdisciplinary rehabilitation teams addressed ethical aspects of their work. Some participants mentioned that ethics consultations with rehabilitation teams were more effective because of the interdisciplinary nature of the teams. This interdisciplinary approach allowed for a more comprehensive understanding of the ethical challenges and was supported by the values, beliefs, and principles that underpin the delivery of rehabilitation services (45). Participants also described the ethical culture amongst many of the interdisciplinary rehabilitation teams with whom they worked as being strengthened by their diverse backgrounds and the autonomy they had developed in addressing ethical challenges specific to their practice. Sinclair et al. (46) conducted a study on interprofessional collaboration in rehabilitation teams and highlighted key aspects of team culture, including leadership, care philosophy, relationships, and the context of practice. These authors stated that the core values of the team's culture focused on exchanging information, co-learning/teaching, and shared rather than separate practice (46). These values provide a solid foundation for fostering a culture of ethics within rehabilitation teams, enabling them to support one another when encountering ethical challenges. On the other hand, when there is entrenched or unresolved conflict amongst members of an interdisciplinary rehabilitation team, or when teams are incomplete due to staffing issues, addressing ethically challenging situations will be rendered considerably more difficult (15).

As noted by our participants, the recruitment of qualified personnel and funding for the development of CES varies among CISSSs. The lack of human and financial resources was identified in our study as one of the barriers that made it challenging to meet current and potentially increasing demand for CES. Some participants expressed concern that the CES could be overwhelmed if the demand for their services increased and they thus hesitated to heavily promote the visibility of CES within their CISSS, which typically had several thousand employees, across dozens of institutions, and spread over a large geographic area. Several participants also expressed feeling isolated in their CISSS, bearing sole responsibility for handling all referrals for CES. Collaboration and networking among ethics consultants were emphasized by participants as means to address these challenges and to promote the sharing of resources and expertise, including through a provincial network of ethics consultants to facilitate knowledge exchange and shared professional development opportunities.

Our study has several limitations. Despite successfully recruiting participants from every CISSS in Quebec, several were new to their positions, potentially affecting the depth of the data obtained. We did not undertake member checking with participants but did provide them with a summary of provisional findings while the analysis was ongoing. Our study provides insight into CES provision for rehabilitation teams from the perspective of ethics consultants. To obtain a comprehensive picture of CES within the CISSSs in Quebec, it would be interesting to collect data from other groups of stakeholders, such as patients, clinicians, managers and other staff.

CONCLUSION

Our study sheds light on clinical ethics services provided to interdisciplinary rehabilitation teams in Quebec CISSSs. The ethical challenges prompting requests for CES support include concerns related to patient autonomy versus safety, gaps in patient care trajectories, conflicts between family expectations and team recommendations, refusal of care, and prognostic transparency and communication. Despite encountering difficulties, such as limited visibility and misunderstanding of the ethics consultant's role among teams, the effectiveness of CES is facilitated by experienced rehabilitation teams with a strong ethical culture. However, rehabilitation teams infrequently request clinical ethics support, indicating a need for further research and collaboration between rehabilitation teams and ethics consultants to understand underlying reasons. This study enhances the understanding of CES in the Quebec health care system and suggests avenues to improve support for rehabilitation teams in addressing ethical concerns.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Utiliser une banque de cas pour comprendre les politiques pour la santé publique et leurs enjeux éthiques

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Résumé
Cet article explore l'utilisation des banques de cas pour accompagner le développement de la compétence d'analyse des enjeux éthiques et du processus des politiques publiques en contexte d'apprentissage en santé publique. Une brève synthèse de la littérature souligne la pertinence des études de cas pour acquérir des connaissances empiriques ou développer des compétences d'analyse critique. Cependant, cette synthèse n'a pas permis d'identifier d'analyses de l'utilisation d'ensembles de cas, tels que des banques de cas. Pour combler ce manque, l'article présente *PolÉthicas*, une collection d'études de cas qui décrivent les enjeux éthiques et le processus d'élaboration de politiques publiques en santé publique au Canada, et son guide d'utilisation. Ce dernier prend appui sur les arguments et méthodes identifiés dans la revue de littérature ainsi que sur l'analyse croisée de plusieurs cas portant sur des thèmes liés et structurés de façon similaire. La banque de cas *PolÉthicas* et son guide d'utilisation permettent de réfléchir aux dimensions théoriques et empiriques des choix collectifs de santé publique dans le développement des politiques publiques à partir de plusieurs cas, de questionner les valeurs en jeu dans l'élaboration et la mise en œuvre des politiques publiques, les acteurs impliqués et leurs interactions ainsi que le contexte dans lequel s'inscrivent ces processus.

Mots-clés
banque de cas, étude de cas, guide d'utilisation, politiques publiques en santé publique, éthique en santé publique

Abstract
This article explores the use of case databases to support the development of competence in analyzing ethical issues and the public policy process in a public health learning context. A brief synthesis of the literature highlights the relevance of case studies for acquiring empirical knowledge or developing critical analysis skills. However, this synthesis did not identify any analyses of the use of case sets, such as case databases. To fill this gap, the article presents *PolÉthicas*, a collection of case studies describing ethical issues and the public health policy development process in Canada, and its user guide. The latter is based on the arguments and methods identified in the literature review, as well as on the cross-analysis of several cases dealing with related themes and structured in a similar way. The *PolÉthicas* case bank and its user guide enable us to reflect on the theoretical and empirical dimensions of collective public health choices in the development of public policies, based on a number of cases, and to question the values at stake in the development and implementation of public policies, the actors involved and their interactions, and the context in which these processes take place.

Keywords
case database, case study, user guide, public health policy, public health ethics

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INTRODUCTION

Fallait-il fermer les écoles pour protéger les enfants et leurs familles de la COVID-19, au risque de nuire au développement des enfants? Comment fallait-il réagir, une fois la décision prise, face aux protestations de parents d'enfants qui bénéficiaient de services particuliers et qui se trouvaient particulièrement affectés par la fermeture des écoles et la perte de ces services? Quelles recommandations fallait-il adopter sur le port du masque en l'absence de consensus scientifique lors des premiers mois de 2020? Comment les changements de recommandations ont-ils affecté l'efficacité des obligations de port du masque dans les lieux publics lorsqu'elles ont finalement été adoptées? Comme l'illustrent ces brefs exemples, la pandémie de COVID-19 a mis en évidence les dilemmes éthiques auxquels font face les décideurs lorsqu'ils élaborent et adoptent des politiques publiques. Elle a aussi mis en évidence la complexité des processus d'élaboration et de mise en œuvre des politiques publiques : les choix collectifs qui en découlent font intervenir des valeurs, des intérêts, des institutions et des acteurs divers, dans un contexte de ressources limitées. Cela vaut aussi en période routinière, même si les enjeux sont moins visibles dans l'espace public. Pour les acteurs qui interviennent dans le champ de la santé des populations, il est donc incontournable de mieux comprendre les enjeux éthiques soulevés par les choix et les processus d'élaboration et de mise en œuvre des politiques publiques (1,2).

Nombre d'ouvrages théoriques font le pont entre la santé des populations, la bioéthique et les études politiques pour guider de telles réflexions (3-6). Il existe également une multitude de cadres de réflexion pour guider l'analyse éthique et la prise de décision en santé publique (7), incluant des guides pratiques tels que celui du *Centre for Disease Control* de la Colombie-Britannique (8). Cependant les outils qui font le pont entre l'analyse éthique et l'analyse des politiques publiques sont plus rares. Parmi les exceptions notables, citons la *Méthode de synthèse de connaissances sur les politiques publiques* (9) et *L'Outil d'analyse de politiques publiques pour une prise de décision rapide en santé publique* (10) qui en est dérivé. Publiés

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par le Centre de collaboration nationale sur les politiques publiques et la santé (CCNPPS), ces documents sont destinés au personnel professionnel et gestionnaires en santé publique au Canada et visent le transfert de connaissances sur les politiques publiques et la santé et leur intégration dans les pratiques professionnelles.

L'ambition de cet article est d'explorer la pertinence des banques de cas, un autre type d'outil, pour accompagner le développement de la compétence d'analyse des enjeux éthiques et du processus des politiques publiques en contexte d'apprentissage en santé publique, qu'il s'agisse de formation initiale à l'université ou de formation continue en milieu professionnel. *PolÉthicas*, l'outil sur lequel nous fondons notre réflexion, est une collection d'études de cas qui décrivent les enjeux éthiques et le processus d'élaboration de politiques publiques en santé publique au Canada (11). Créée en 2017 par les axes Politiques publiques et Éthique du Réseau de recherche en santé des populations du Québec (RRSPQ), *PolÉthicas* compte 18 cas en février 2025. Elle aborde « les questions morales utilisant les grands concepts de philosophie éthique et politique pour résoudre les problèmes de santé des populations » soulevés par « les lois, règlements, stratégies, plans ou encore les énoncés formels de politiques dont se dotent les gouvernements de différents paliers pour agir en matière de santé publique » (11).

Des banques de cas comme *PolÉthicas* existent dans différents domaines d'expertise et de formation, en éthique de la santé publique (12), tout comme dans les écoles de commerce ou les facultés de médecine[1]. Dans ces domaines, elles sont spécifiquement utilisées comme méthode de base de la formation à l'éthique. Elles sont créées dans le but de rendre les études de cas plus accessibles, plus rapidement (13) et de regrouper les savoirs et les apprentissages qui en sont issus. Leur développement est fortement lié à l'essor de l'utilisation de l'étude de cas comme méthode d'enseignement et d'analyse en médecine, markéting, gestion des ressources humaines et droit (14). C'est d'ailleurs l'école de droit de l'Université d'Harvard qui a introduit l'étude de cas comme un outil d'enseignement dès 1870 dans l'optique de confronter les juristes à des situations réelles avant d'entrer dans la vie professionnelle (13,15). Aujourd'hui, la méthode est utilisée dans de nombreux domaines d'expertise (16), incluant l'éthique et les politiques publiques (5). Ainsi, de nombreuses revues d'éthique, dont la *Revue canadienne de bioéthique*, publient régulièrement des études de cas en éthique. Notons enfin que l'usage des technologies multimédias – vidéos, balados et formats interactifs en ligne – permet de varier et d'enrichir la présentation des cas, allant jusqu'à des cas qui se dévoilent au fur et à mesure et en fonction des choix effectués par les participant(e)s (17,18).

Dans cet article, nous explorons les façons d'utiliser une banque de cas pour mieux comprendre les enjeux éthiques associés aux choix et aux processus de politiques en santé publique. Comment tirer parti de l'existence de plusieurs cas, respectant un format similaire, pour mieux comprendre les choix collectifs qui se jouent lors de l'élaboration et de la mise en œuvre des politiques relatives à la santé publique?

La première partie de l'article présente les usages et avantages potentiels du recours à des cas en situation d'apprentissage à partir d'une brève synthèse de la littérature. Cette synthèse fait ressortir un vide dans la littérature puisqu'elle n'a pas permis d'identifier d'analyse de l'utilisation de banques de cas ou d'autres ensembles de cas. Pour combler ce manque, la seconde partie de l'article présente un exemple de banque de cas – la banque *PolÉthicas* – et propose un guide pour son utilisation en contexte d'apprentissage. Ce guide d'utilisation est appuyé sur les principes d'utilisation des cas soulignés dans la littérature et sur les savoirs théoriques qui sous-tendent la structure des cas dans *PolÉthicas*. Un tel exercice vise, d'une part, à mieux appréhender la complexité des enjeux éthiques en matière de santé publique et, d'autre part, à renforcer l'analyse critique chez les acteurs impliqués dans les politiques de santé publique.

À QUOI SERT L'ÉTUDE DE CAS EN CONTEXTE D'APPRENTISSAGE

Une brève revue de la littérature

Le cas peut être défini comme un « compte rendu de faits » (19, p.453) ou comme un « scénario qui expose un problème précis » (13, p.9). Il est généralement divisé en plusieurs parties : la présentation du contexte et des acteurs impliqués, l'exposition d'une « situation-dilemme » (15), les actions intentées par les acteurs une fois le problème exposé et le dénouement, c'est-à-dire, comment la situation se termine et quel est son impact (20). L'étude de cas est invoquée comme étant « l'examen détaillé d'un exemple » (21, p.2) ou comme une technique de traitement de l'information (22). Nous retenons le positionnement de Lalancette qui définit les termes « cas » et « étude de cas » comme suit : « On peut retenir des points essentiels et concevoir l'étude de cas en tant que démarche d'analyse, en groupe, d'un problème réel ou fictif, le cas, dans le but de proposer des pistes de solutions et de favoriser le développement de compétences en mobilisant, entre autres, des savoirs théoriques dans d'autres cas similaires. » (13, p.11)

Pour identifier des publications sur l'utilisation d'études de cas et de banques de cas, nous avons utilisé des combinaisons de mots-clés en français et en anglais[2] pour désigner les études de cas (notamment « études de cas », « méthodes de cas », « *case studies* ») et leur contexte d'utilisation (notamment « *teaching* », « enseignement », « *practitioner* », « administration publique ») dans des bases de données généralistes (Cairn, Hypothèses, Revues.org, Worldcat, ScienceDirect, Érudit et

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[1] De nombreuses écoles de commerce possèdent leurs propres banques de cas comme l'ESSEC Business School ou l'Harvard Business School. Il existe aussi des banques de cas dans le domaine de la médecine comme celle du Groupe d'Étude en médecine obstétricale du Québec.

[2] Nous avons choisi d'associer des mots-clés en français et en anglais car les recherches uniquement en français ne nous permettent d'obtenir de résultats concluants. Par exemple, l'association de « études de cas » OU « étude de cas » OU « méthode des cas » ET « administration publique » OU « pratique » ne donne aucun résultat sur Proquest.

Google Scholar) et de sciences sociales (les bases de données suivantes ont été consultées sur ProQuest : International Bibliography of the Social Sciences (IBSS), Sociological Abstracts, Worldwide Political Science Abstracts et ABI/INFORM). La recherche à partir de mots-clés tels que « *case study repositor*y » ou « banque de cas » associé à « *policy making* » ou « *teaching* » n'a pas donné de résultats pertinents. Nous avons privilégié la recherche dans des bases de données généralistes et de sciences sociales étant donné la centralité de l'étude des politiques publiques pour la banque *PolÉthicas*. Les bases de données spécialisées en sciences de la santé (Scopus, PubMed) dans lesquelles nous avons testé nos critères de recherche faisaient surtout ressortir des études de cas cliniques, ce qui n'est pas l'objet de notre recherche. Il s'agit d'une limite de notre revue de littérature considérant notre intérêt pour la santé des populations. Pour pallier cette limite, nous avons également adopté une stratégie de recherche intentionnelle de références en parcourant les sites web qui hébergent des banques de cas tels que *thecasecentre.org* et en incluant des références déjà connues des auteurs. Nous avons exclu les textes sur l'étude de cas comme méthodologie de recherche sans implication pour l'utilisation en contexte d'apprentissage, car ce n'est pas le propos de notre analyse. Suivant ces combinaisons de mots-clés, la recherche a permis d'identifier 38 éléments soit, une monographie, quatre billets de blogues et 33 articles scientifiques. La majorité de ces références traite du cas en tant qu'outil pédagogique d'enseignement, alors que peu de sources abordent son intérêt pour l'apprentissage en milieu professionnel.

L'utilisation des cas dans l'enseignement

L'utilisation des études de cas et, dans une moindre mesure, la sollicitation de banques de cas à des fins pédagogiques sont très documentées dans la littérature (13-16,19,20,22-27). Elles constituent tout d'abord une technique d'apprentissage innovante et efficace pour transmettre des connaissances, compatible avec différentes théories pédagogiques, telles que l'apprentissage par expérience ou par problème (13). La littérature soutient que les étudiantes et étudiants retiennent mieux le savoir lorsqu'il est illustré avec des exemples (28) et qu'ils jouent alors un rôle actif (23) dans le processus de réflexion. En se sentant impliqué dans l'analyse d'un cas, ils développent un sentiment d'efficacité personnelle et une motivation qui vont ensuite favoriser la rétention du savoir transmis en classe (16). Cette technique d'apprentissage leur offre aussi l'opportunité de développer leur pensée critique (23) en les mettant face à une situation qui nécessite de résoudre un problème ou de prendre une décision (17), de se rendre compte de leurs propres biais et de comment ceux-ci peuvent influencer leur perception d'une situation ou d'un problème (26). Ces bénéfices potentiels dépendent cependant de la rigueur, du détail et de la diversité des études de cas. Nous abordons ces limites plus loin dans le texte.

L'étude de cas a, ensuite, été identifiée dans la littérature comme une façon efficace d'illustrer les contenus théoriques (29) abordés dans l'enseignement supérieur et de démontrer à l'étudiante ou l'étudiant comment ce qu'il apprend en classe peut servir dans une situation réelle (28). Souvent, la matière théorique enseignée est perçue comme étant trop éloignée de la réalité (30). Par contraste, lorsque les professeurs présentent un cas à leurs étudiantes et étudiants, ces derniers doivent solliciter des principes théoriques pour comprendre la situation présentée et proposer des solutions, en tenant compte de la façon dont le contexte ou le comportement humain (21) peuvent affecter l'application de ces principes théoriques. En ce sens, l'étude de cas interroge et teste la théorie (31) et cela peut potentiellement l'enrichir (16) en fonction des résultats de l'étude. Ces considérations aident à développer une « vision plus nuancée de la réalité » (21, p.223). Il semble probable que l'utilisation de l'étude de cas puisse aider les étudiants à développer une appréciation plus nuancée de la façon dont la théorie éthique constitue une lentille à travers laquelle voir les « cas » : non seulement pour développer des réponses aux problèmes, mais aussi pour influencer notre perception de ce qu'est un problème ou une question. Cette possibilité semble plus susceptible de se produire avec certains types d'études de cas, par exemple celles qui sont plus richement développées ou qui invitent à l'engagement et à l'imagination morale.

Enfin, la littérature indique que l'étude de cas est fréquemment utilisée dans l'enseignement supérieur car elle augmenterait l'employabilité des étudiantes et des étudiants (27). Par exemple, l'étude de cas est un exercice collectif et appliqué qui encourage le développement d'aptitudes à travailler en équipe, à écouter ou à démontrer un point de vue (22) et qui invite à matérialiser les savoirs appris en classe en pistes d'action (16). L'étude de cas met aussi en avant la réalité des milieux professionnels car elle permet l'accumulation de connaissances sur un thème donné (21) et car elle souligne la complexité des dynamiques de prise de décision (26), influencées par les contraintes rencontrées lors de l'élaboration de politiques publiques ou par les acteurs impliqués. Létudiante ou l'étudiant acquiert alors une certaine autonomie (15), mais aussi une faculté d'adaptation (32) dans sa réflexion et sa capacité d'action.

L'utilisation des cas dans les milieux professionnels en santé publique

Mobiliser des études de cas en contexte professionnel permet d'accumuler des connaissances qui sont essentielles pour la prise de décision, en particulier dans des domaines liés au politique (33,34) et à la santé (35,36). Ces cas sont parfois écrits conjointement par des universitaires et leurs partenaires sur le terrain, qui collaborent à la recherche sur les politiques dans lesquelles ils sont impliqués (5). En ce sens, la frontière entre utilisation des cas comme méthode de recherche et comme méthode d'apprentissage est parfois plus floue qu'en contexte d'apprentissage à l'université, puisque les deux processus sont liés. On peut à la fois obtenir des connaissances générales sur un sujet, mais aussi des connaissances plus précises (37) qui, réunies, éclairent la pratique professionnelle. Elles permettent d'abord d'avoir une vision complète (34) des facteurs qui entrent en jeu dans le développement d'une politique publique, mais aussi d'accéder à un autre type d'informations notamment l'influence des processus sociaux (36), l'agentivité des acteurs impliqués (34) ou encore l'influence des relations institutionnelles (35). De surcroit, les connaissances que les acteurs de santé publique peuvent acquérir grâce aux études de cas sont dépendantes d'un contexte (5,34-36,38), c'est-à-dire qu'elles font état d'une situation précise. Elles aident ainsi à identifier les critères auxquels il faut prêter attention lorsque l'on met en place une politique, un programme, une stratégie, etc. Ces critères peuvent être sollicités dans d'autres cas de figure. Ce transfert de connaissances (34) permet aux professionnel.les d'identifier plus rapidement ce sur quoi il est important de travailler. Les connaissances accumulées grâce à une ou plusieurs études de cas offrent des pistes de solutions et la possibilité d'entrainer des changements qui améliorent les compétences des acteurs. La littérature indique par exemple que ces connaissances peuvent aider à prédire (37) ce qui peut arriver dans une autre situation que celle étudiée dans l'étude de cas ou simplement à générer des hypothèses sur le déroulement d'un projet (33).

Ainsi, au même titre que pour les étudiantes et les étudiants, se servir de l'étude de cas dans les milieux professionnels revient à offrir une occasion d'apprentissage en continu (39) pour le développement de compétences : esprit critique ou encore résolution de problèmes (16,27). Ces compétences, associées à un ensemble de connaissances pluridisciplinaires, auraient donc le potentiel d'améliorer la capacité à comprendre et gérer des situations complexes (16) et d'entrainer des changements bénéfiques à l'élaboration de politiques de santé publique. Bien entendu, un tel transfert ne se fait pas automatiquement, mais rendre plus d'informations disponibles à partir de cas alimentent la réflexion des acteurs impliqués.

Des principes pour une utilisation efficace de l'étude de cas et des banques de cas en contextes d'apprentissage

La littérature met en garde contre une vision trop naïve de la pertinence intrinsèque des études de cas pour l'apprentissage. L'exercice peut être affecté par le contenu des cas ainsi que par ses conditions de réalisation. En effet, certaines études de cas peuvent insister sur la recherche de solutions concrètes sans réflexion suffisante sur le contexte dans lequel se déploient les interventions étudiées ou sur les défis de la mise en œuvre de ces solutions (40). De plus, l'utilisation en contexte d'apprentissage devrait tenir compte du niveau d'expérience professionnelle des étudiantes et étudiants (30) et les inciter à adopter un regard critique sur les cas étudiés (qui les a rédigés? Dans quel contexte et à quelles fins? Quels éléments sont soulevés dans les cas et lesquels sont passés sous silence? Etc.). Pour que l'étude de cas soit une méthode d'enseignement ou de formation professionnelle efficace, la littérature insiste sur la préparation des exercices d'études de cas et, partant, sur le rôle de l'enseignement. Nous en retenons trois principes centraux.

Premièrement, il faut associer des objectifs d'apprentissage précis à l'étude de cas (13) et choisir un type d'études de cas approprié parmi la variété de typologies de cas existantes (13,16,20,21,23,31,33, 41). Par exemple, le cas prospectif, c'est-à-dire, un cas où l'on ne connait pas toute la situation, permet d'émettre des hypothèses sur le dénouement (23), le cas organisationnel permet de s'interroger sur le fonctionnement d'une organisation (20) alors que l'étude de cas multiple vise à identifier la récurrence ou non d'un phénomène (31). Ainsi, l'étude de cas peut servir à étudier la récurrence (42) ou la rareté (31) d'un phénomène et identifier ou non des facteurs de causalité, à analyser l'influence du contexte sur une situation ou un problème (38) ou encore à développer une expertise en profondeur (21) en sollicitant plusieurs études sur la même thématique. La personne responsable de la formation doit s'interroger sur les types de compétences qu'elle souhaite développer chez les étudiantes et étudiants (13) et s'assurer que le choix du ou des cas soit orienté par les principes théoriques vus en classe (42). Elle doit cibler les résultats attendus (16,38). Employée à des fins de formation continue dans les milieux professionnels, l'utilisation de l'étude de cas est surtout utile pour interroger le pourquoi et le comment (33,35), c'est-à-dire l'élaboration et la mise en œuvre d'un programme, d'une politique, d'un plan, etc. Elle peut aussi servir à évaluer des compétences (27) des personnes qui participent à son analyse.

Deuxièmement, les objectifs de l'utilisation d'études de cas devraient être ajustés selon le contexte dans lequel se déroule l'exercice. Pour des étudiantes et étudiants en début de cheminement, l'étude de cas peut servir à illustrer la pratique dans la discipline étudiée (26), tandis que pour ceux qui sont plus avancés dans leurs études, elle peut servir à valider un certain niveau de connaissances (13). Dans les milieux professionnels, certains contextes sont particulièrement propices à l'utilisation de l'étude de cas : les programmes mi-carrières, la formation de cadres supérieurs ou encore les entretiens d'embauche (16,27,43).

Troisièmement, le rôle des responsables du cours ou de la conception de l'étude de cas est central pour l'utilisation efficace des études de cas en contexte d'apprentissage. À partir d'études dans le contexte de l'entretien d'embauche (43), de la formation continue de professionnels (44) et surtout de l'enseignement (13,16,22,26,30,42), on distingue un rôle de présentation, un rôle d'animation et un rôle de supervision. Le rôle de présentation désigne l'introduction au cas, soit présenter la situation ou le problème à analyser, le contexte et sa pertinence pour le cours (22,40). Ces questions peuvent être : « quelle est la problématique du cas? » ou encore « quels sont les éléments qui nous permettent de comprendre ce qui se passe dans le cas? » (40). Le rôle de présentation implique aussi de s'assurer que les étudiantes et étudiants comprennent les objectifs d'apprentissage associés à l'étude (13). Le rôle de supervision réfère à l'organisation et à la supervision du déroulement de l'activité : former ou non des groupes et sous-groupes; trouver l'équilibre entre chaque étape de l'activité (par exemple le temps alloué entre les discussions en sous-groupe et en plénière) (22); donner des instructions claires (42); conclure l'analyse du cas pour bien identifier les éléments à retenir ou ceux dont on a besoin pour améliorer les compétences des personnes en situation d'apprentissage (13,40). Enfin, le rôle d'animation renvoie à l'implication active de l'enseignante ou de l'enseignant avant et pendant l'activité : préparer du matériel additionnel pour pouvoir animer la discussion du groupe, créer des « outils d'intervention pédagogique » (30, p.397) afin de guider les apprentissages, ou encore adapter la fréquence de ses interventions aux objectifs d'apprentissage fixés. Par exemple, si le but de l'exercice est de développer l'autonomie et l'habilité à prendre des décisions, l'enseignante ou l'enseignant guide le groupe au début de l'exercice et lui laisse ensuite plus d'indépendance (16).

Par exemple, à partir de l'étude de cas « Cholera and nothing more » (45), Braunack-Mayer suggère trois types de questions pour susciter des apprentissages distincts de la part des étudiantes et étudiants (46) : *les questions descriptives ou empiriques (naming questions)*, qui invitent à une réflexion générale sur les principes éthiques en jeu dans l'intervention des professionnels lors d'une épidémie de choléra dans un contexte de grande pauvreté; *les questions latérales (sideways looking)*, qui appellent une réflexion sur le contexte de rédaction du cas ou sur le point de vue de l'auteur; et *les questions prospectives (forward looking)*, pour réfléchir à l'importance des principes appliqués dans ce cas pour la situation, pour d'autres situations et pour la santé publique en général. L'autrice suggère également des stratégies d'animation de la réflexion et d'organisation du travail pour atteindre les objectifs d'apprentissage (discussions en petits groupes, référence au cas principal et aux commentaires sur le cas qui l'accompagnent, synthèse).

Ainsi, l'étude de cas peut être bénéfique en situation d'apprentissage initial à l'université comme en situation de formation continue en milieu professionnel, tant pour l'acquisition de connaissances spécifiques sur un enjeu que pour le développement de la pensée critique, de l'application de principes théoriques à des situations concrètes ou du travail en équipe. Ces bénéfices ne sont pas intrinsèques mais dépendent de la définition claire des objectifs de l'étude de cas, de leur adaptation au contexte d'apprentissage et de leur encadrement adéquat depuis l'élaboration jusqu'à la réalisation de l'exercice.

UTILISER UNE BANQUE DE CAS POUR COMPRENDRE LES ENJEUX DES POLITIQUES DE SANTÉ PUBLIQUE : L'EXEMPLE DE POLÉTHICAS

La banque *PolÉthicas* regroupe un ensemble d'études de cas sur les politiques publiques en santé des populations et les considérations éthiques associées à leur élaboration et à leur mise en œuvre. Elle vise trois objectifs :

1. « Favoriser une meilleure compréhension de l'élaboration des politiques publiques et du processus décisionnel;
2. Promouvoir la compréhension des enjeux et défis éthiques dans le cadre des politiques publiques relatives à la santé des populations;
3. Offrir un outil pédagogique et de recherche aux étudiants, chercheurs et décideurs, ainsi qu'aux gestionnaires et professionnels de la santé publique. » (11)

Les cas portent sur des sujets et des politiques variés, illustrant l'action de multiples autorités publiques. Ils couvrent une large gamme de sujets liés à la santé : pesticides, lutte contre la pauvreté, le plan Alzheimer du Québec, le contrôle des chiens au Nunavik ou encore les effets de la loi sur la protection du consommateur et les enfants dans le cas des produits alimentaires. Ils sont classés par thématiques (santé environnementale, développement social, santé au travail etc.), par palier de gouvernance (local, provincial, fédéral etc.), en fonction de la nature du problème (social, économique ou technique) et en fonction du stade d'avancement de la politique (émergence, mise à l'agenda, formulation etc.) (11). Les cas sont écrits en français et, pour deux d'entre eux au moment d'écrire ces lignes, en anglais et sont disponibles en libre accès.

Des cas structurés selon les principes de l'analyse éthique en santé publique et selon une théorie d'analyse des politiques publiques

La présentation des cas prend appui sur deux champs d'études complémentaires. L'éthique en santé publique, tout d'abord, cherche à identifier et expliciter les enjeux éthiques spécifiques à la santé publique. Elle vise également à développer des processus systématiques d'évaluation du rôle des valeurs normatives et à considérer, justifier et prioriser plusieurs stratégies d'action. Ce champ multidisciplinaire pose des questions telles que : Quelles valeurs la politique en question soutient-elle ou remet-elle en cause, implicitement ou explicitement? Existe-t-il des tensions entre plusieurs valeurs ou principes, y compris entre les préoccupations relatives aux intérêts collectifs et à l'autonomie et la capacité d'action des individus? Comment les considérations de proportionnalité, de nécessité, de réciprocité, de solidarité et de justice sociale sont-elles prises en compte? Qu'en est-il des principes liés à la rigueur procédurale (ex. : les principes de transparence, de justification, de révisabilité) (47)? Dans la structuration des cas, la réflexion sur les enjeux éthiques des politiques publiques intervient à la fois dans la présentation des valeurs et des enjeux soulevés par les acteurs et, principalement, dans l'analyse du processus.

La science politique, ensuite, offre des outils pour mieux comprendre l'élaboration des politiques publiques. Elle permet de répondre à des questions telles que : Pourquoi certains problèmes finissent-ils par retenir l'attention des gouvernements? Quels facteurs influencent ce processus? Dans quelle mesure les données probantes expliquent-elles l'émergence et la formulation de politiques publiques? Pourquoi la mise en œuvre n'est-elle pas conforme aux orientations annoncées de la politique? Quels acteurs exercent une influence sur le processus de politique publique? À quoi servent les évaluations de politiques publiques?

La structure générale des cas dans *PolÉthicas* s'appuie sur l'adaptation du cadre des coalitions de cause, un modèle théorique développé par Paul Sabatier et Hank Jenkins-Smith[3]. L'adaptation que Gagnon et al. (48) ont fait de ce cadre théorique pour

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[3] Voir l'appel à propositions de l'automne 2022. Depuis l'automne 2022, les appels proposent plus de variabilité dans la structure et l'analyse, tout en restant inspirés du cadre de Sabatier et Jenkins-Smith.

analyser la mise en œuvre de l’article 54 de la loi de Santé publique sur les évaluations d’impact sur la santé au Québec permet de présenter systématiquement les informations suivantes sur le processus de politique publique[4] :

1. La description du cas : le contexte, la période couverte par l’étude, les caractéristiques du domaine dans lequel s’inscrit la politique publique et les étapes du processus étudiés dans le cas (émergence, mise en œuvre, etc.).
2. La présentation des acteurs impliqués, de leurs positions face au problème concerné, des solutions qu’ils mettent de l’avant pour le résoudre ainsi que de différents éléments permettant de caractériser leurs croyances par rapport à la politique : le lien avec les déterminants de la santé, les connaissances et données probantes mentionnées, les valeurs et enjeux explicitement soulevés par les acteurs.
3. Le dénouement du processus étudié : la politique a-t-elle été adoptée? la mise en œuvre présente-t-elle des écarts par rapport aux orientations initiales? etc.
4. L’analyse des éléments du cas : quelle est la nature du problème? Quels facteurs contextuels expliquent le processus étudié? Peut-on identifier des gains ou des pertes pour la santé publique à l’issue du processus étudié? Existe-t-il des conflits d’intérêt entre les acteurs impliqués? Quels sont les enjeux éthiques du processus étudiés? Quels sont ses effets attendus pour la santé des populations?

Le cadre des coalitions de cause accorde une place centrale aux valeurs qui sous-tendent les choix collectifs incarnés dans les politiques publiques. De ce fait, il est particulièrement adapté pour servir de trame à l’analyse des enjeux éthiques du développement des politiques publiques. Sabatier et Jenkins-Smith ont développé le cadre des coalitions de cause à partir des années 1980 pour rendre compte de l’influence sur les politiques publiques de multiples acteurs intéressés par un problème, qui agissent de façon concertée en fonction de leurs systèmes de croyance sur le problème en question (49). Selon cette théorie, les systèmes de croyance des acteurs portent sur trois dimensions, de la plus générale à la plus particulière : leurs croyances profondes (autrement dit, leur vision du monde : préférence droite/gauche en politique, rôle de l’État dans la société, etc.); leur vision du problème (ex. : considérer l’aménagement urbain comme un enjeu de santé publique); et les instruments utilisés (pour réduire la circulation automobile en ville, les acteurs ont-ils une préférence pour des instruments incitatifs, tels que des prix sur le stationnement, ou pour des instruments interventionnistes, tels que l’accroissement du service de transport en commun et l’ajout de voies cyclables?). Les interactions entre les acteurs et les coalitions dans lesquelles ils s’insèrent sont influencées par des éléments du contexte institutionnel, politique, social, environnemental ou encore technique de la politique publique.

Ainsi, pour comprendre le changement des politiques publiques, il faut considérer à la fois l’influence de ces événements contextuels, les acteurs impliqués, les évolutions de leurs systèmes de croyance et leurs interactions dans des coalitions de cause qui défendent une vision partagée de la politique publique. Même sans utiliser ses hypothèses explicatives des changements de politiques publiques, les éléments constitutifs du cadre des coalitions de cause permettent d’identifier une large gamme de variables qui façonnent le processus de politiques publiques, tant institutionnelles, idéationnelles que liées aux acteurs.

Outil d’analyse sur les politiques en santé publique et leurs enjeux éthiques : questions d’analyse et scénarios d’études de cas en contextes d’apprentissage

La banque *PolÉthicas* permet de se documenter sur un ou des sujets précis, mais son intérêt réside surtout dans le croisement entre les enjeux éthiques et le processus d’élaboration de différentes politiques grâce au cumul de cas construits de façon similaire. Elle peut donc être utile pour les acteurs de santé publique ou les étudiants pour générer des hypothèses sur leurs propres cas, c’est-à-dire sur les politiques publiques qu’ils étudient ou dans lesquelles ils sont impliqués; accumuler des connaissances pertinentes pour la prise de décision (connaissances à plusieurs paliers: local, régional, etc.); identifier comment on évalue l’impact d’une politique ou d’un programme (trouver les critères d’évaluation grâce à des cas existants); démontrer l’aspect multidimensionnel de la mise en œuvre d’une politique. Pour les universitaires en santé des populations ou en bioéthique, la banque de cas constitue aussi un outil accessible pour familiariser les étudiantes et étudiants à la compréhension de ce qu’est une politique publique, comment elle « fonctionne », quelles sont les étapes du processus et surtout la diversité d’acteurs impliqués, chacun ayant ses propres intérêts, ses propres valeurs ou visions du problème, ses propres contraintes institutionnelles. Les cas donnent un aperçu de la façon dont les acteurs interagissent et justifient leurs décisions.

Les cas de *PolÉthicas* peuvent être utilisés pour répondre à différents types de questions – nous nous inspirons en particulier des questions de Braunack-Mayer présentées plus haut (46) :

- *La question descriptive ou empirique* : par exemple, comment les acteurs de santé publique ont-ils agi pour influencer le processus d’adoption d’une politique en santé publique?
- *La question conceptuelle ou théorique* : par exemple, quel est le rôle des idées et des valeurs dans le processus d’adoption d’une politique en santé publique?
- *La question latérale ou décentrée* : par exemple, les auteurs semblent-t-ils favoriser, ou au contraire négliger, le point de vue de certains acteurs dans leurs façons de présenter les cas? Que peut-on en conclure sur la prise en compte – par exemple – des acteurs communautaires ou des citoyens dans le processus politique?

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[4] Voir le canevas des cas PolÉthicas.

- *La question prospective ou d'extrapolation* : à partir de la lecture des dénouements de un ou deux cas, imaginer les processus qui auraient pu permettre d'y arriver (quels auraient pu être les actions posées par les acteurs de santé publique, quels acteurs auraient pu être impliqués, etc.). Après l'exercice de simulation, la lecture du reste du cas permet de comparer avec ce qui s'est produit dans la réalité et de réfléchir aux facteurs qui ont été déterminants, à ceux qui sont restés dans l'ombre. Ce type de question permet de se mettre en posture d'action et est sans doute plus facile à mobiliser en contexte professionnel que d'enseignement

Le guide d'utilisation de *PolÉthicas* propose d'abord plusieurs questions pour chacune de ces catégories afin de mettre en lumière des facteurs explicatifs des décisions, du processus des politiques en santé des populations et de leurs enjeux éthiques. Les questions s'appuient sur les acquis de l'éthique en santé publique et de la science politique, en particulier le cadre des coalitions de cause. La plupart des questions s'accompagnent de la suggestion de deux ou trois cas permettant, par exemple, de comparer des cas techniques ou sociaux ou bien des cas provinciaux ou locaux. Les responsables de l'étude des cas peuvent choisir de confier à un groupe l'analyse de deux ou trois cas, ou bien de confier à chaque groupe l'analyse d'un seul cas puis de procéder à la comparaison des analyses en séance plénière.

Par la suite, le guide d'utilisation présente trois scénarios d'étude de cas, chacun composé d'une question d'analyse et de sous-questions, de suggestions de cas et de suggestions de lectures supplémentaires pour guider le travail préparatoire des responsables de la formation. Le premier scénario porte sur une question empirique portant sur les principes éthiques et les conflits de valeurs dans l'élaboration d'une politique publique. Les sous-questions guident les personnes en situation d'apprentissage pour identifier les principes éthiques sollicités dans les cas étudiés, s'ils entraînent des conflits de valeur entre les acteurs impliqués et les facteurs qui favorisent ou entravent la résolution du conflit. Elles sont invitées à formuler des recommandations pour la pratique, à partir de la comparaison de la résolution des conflits éthiques dans les cas étudiés. Les ressources complémentaires pour les responsables de la formation portent sur l'éthique en lien avec la santé publique, mais aussi sur le rôle des idées dans l'étude des politiques publiques.

Le deuxième scénario est articulé autour d'une question conceptuelle visant à comprendre les liens entre la façon dont les enjeux de santé des populations sont présentés (le cadrage des problèmes) et les collaborations intersectorielles. Les sous-questions invitent les personnes en formation à identifier les différentes manières dont la santé est conçue; associer ces conceptions aux acteurs qui les portent; identifier les collaborations et les facteurs qui semblent les favoriser ou les entraver; établir des corrélations entre les conceptions de la santé et les collaborations. Le scénario suggère également quelques lectures théoriques pour alimenter une présentation magistrale des liens entre les idées et le processus des politiques publiques.

Le troisième scénario est bâti autour d'une question prospective ou d'extrapolation. Il invite les personnes en formation à jouer le rôle de professionnelles ou professionnels de santé publique en exercice qui considèrent différentes stratégies pour intervenir dans le domaine de l'environnement, leurs avantages ou inconvénients et qui doivent formuler une recommandation argumentée en faveur d'une stratégie. Ce scénario met d'abord l'accent sur les implications des acteurs : quels rôles les actrices et acteurs de santé publique ont-ils joué dans différentes politiques et quelles positions ont-ils défendues? Les fondements théoriques des cas peuvent être déduits à la suite de l'exercice et faire l'objet de lectures complémentaires.

Selon les objectifs associés à l'étude des cas, les trois scénarios peuvent être adaptés aux contextes d'apprentissage universitaire et de formation continue en milieu professionnel. Ainsi, le scénario trois fait appel à l'expérience des professionnelles et professionnels, les invitant à mobiliser les cas et la littérature pour porter un regard critique sur leurs pratiques, mais pourrait aussi être utilisé dans le cas de l'enseignement de premier ou deuxième cycle en donnant des points de repère sur le contexte législatif, institutionnel et idéel de la pratique professionnelle. Les scénarios peuvent aussi être adaptés à d'autres questions suggérées dans la première partie du guide d'utilisation. Les caractéristiques des cas présentées dans la base *PolÉthicas*, soit les thèmes couverts, les paliers concernés, la nature du problème et les étapes de la politique concernées, sont utiles pour sélectionner les cas.

CONCLUSION

La littérature met en avant de nombreux arguments en faveur de l'utilisation de l'étude de cas en contexte d'apprentissage, que ce soit pour acquérir des connaissances empiriques ou développer des compétences d'analyse critique. La réalisation de ces bénéfices sera façonnée par la manière dont une étude de cas est construite et dont elle est mobilisée dans un contexte d'apprentissage particulier. La pertinence d'une banque de cas telle que *PolÉthicas* procède de l'analyse croisée de plusieurs cas portant sur des thèmes liés et structurés de façon similaire. Elle permet en effet de réfléchir aux dimensions théoriques et empiriques des choix collectifs de santé publique dans le développement des politiques publiques à partir de plusieurs cas. Par son objet et par la structure des cas, *PolÉthicas* permet de questionner les valeurs en jeu dans l'élaboration et la mise en œuvre des politiques publiques, les acteurs impliqués et leurs interactions ainsi que le contexte dans lequel s'inscrivent ces processus. Pour accompagner les responsables des formations et les personnes en situation d'apprentissage, la banque de cas *PolÉthicas* et son guide d'utilisation ont vocation à être enrichis au fil du temps, y compris pour rendre compte des évolutions des politiques analysées et des transformations des problèmes qu'elles cherchent à résoudre. Ainsi, l'ajout de cas dans des formats différents – vidéos, balados, formats interactifs en ligne par exemple – devrait contribuer à sa valeur pédagogique en s'adaptant à divers contextes d'apprentissage.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

The Hidden Realities of Discrimination from Patients: A Scoping Review of Healthcare Workers' Experiences

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Résumé

La discrimination dans les établissements de soins de santé est un domaine de recherche appliquée et d'intervention en plein essor. Les recherches existantes se sont concentrées sur les expériences des patients en tant que cibles de la discrimination et ont accordé moins d'attention aux patients en tant que sources de discrimination. L'objectif principal de cette étude exploratoire est d'identifier, d'explorer et de cartographier la littérature sur les expériences du personnel de santé en tant que cible de la discrimination de la part des patients ou des membres de leur famille. Une revue exploratoire des articles indexés dans Ovid Medline, Ovid Embase, Ovid Emcare et Web of Science Core Collection a été réalisée entre mars 2022 et juin 2023. Les résultats ont été résumés, codés et classés par catégories thématiques en fonction de l'objectif. L'analyse a permis d'identifier 173 articles mettant en évidence diverses formes de discrimination se manifestant de multiples façons, y compris des demandes et des refus de travailleurs de la santé spécifiques fondés sur des marqueurs d'identité sociale. Les résultats suggèrent qu'il existe des obstacles importants qui empêchent les professionnels de la santé de signaler ces incidents et d'y répondre de manière efficace, ce qui entraîne toute une série de ramifications psychologiques négatives. Cette étude met en évidence les principaux domaines nécessitant une attention accrue afin de mieux soutenir les professionnels de la santé lors d'interactions difficiles avec des patients victimes de discrimination. Des recommandations institutionnelles visant les efforts de recherche et d'éducation, les expériences des apprenants, la rédaction de politiques, la documentation et les rapports, la culture institutionnelle, les ressources et le soutien, ainsi que le rôle des organismes professionnels, ont été identifiées. Des travaux fondés sur des données probantes sont nécessaires dans ce domaine afin de garantir que les changements au niveau des politiques s'appuient sur les expériences vécues par les personnes confrontées à ces incidents.

Mots-clés

discrimination, bioéthique, politique de santé, patients biaisés, expériences des professionnels de santé, formation

Abstract

Discrimination in healthcare settings is a burgeoning area of applied inquiry and intervention. Existing research has focused on the experiences of patients as the targets of discrimination with less attention paid to patients as the source of discrimination. The main objective of this scoping review is to identify, explore and map the literature on the experiences of healthcare workers (HCWs) as targets of discrimination from patients and/or their family members. A scoping review of articles indexed in Ovid Medline, Ovid Embase, Ovid Emcare, and Web of Science Core Collection was conducted between March 2022 and June 2023. The results were summarized, coded and thematically categorized according to the aim. The review identified 173 articles that highlighted various forms of discrimination manifesting in a multitude of ways, including requests for, and refusals of specific HCWs based on social identity markers. The results suggest that there are significant barriers that prevent HCWs from reporting and responding to these incidents in efficient ways, resulting in an array of negative psychological ramifications. This review highlights core areas in need of greater attention in order to better support HCWs during challenging interactions with discriminatory patients. Institutional recommendations aimed at research and education efforts, learner experiences, policy writing, documenting and reporting, institutional culture, resources and support as well as the role of professional bodies, were identified. Evidence-informed work is needed in this area to ensure that policy-level changes are informed by the lived experiences of those enduring these incidents.

Keywords

discrimination, bioethics, health policy, biased patients, healthcare professional experiences, education

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INTRODUCTION

Discrimination in healthcare settings is a burgeoning area of academic and applied inquiry due to the detrimental effects on patient care, health outcomes and interventions promoting health equity. Despite the multidirectional nature of discrimination, the academic literature on the topic predominantly examines the experiences of patients as the targets of discrimination. A relatively small area of the literature, however, now explores patients as the source of discrimination due to increasing accounts of healthcare workers' (HCWs') experiences of racism, sexism, islamophobia and other forms of prejudice. Discrimination from patients poses a profound challenge to the fundamental principles of equity, respect, and justice. In caring professions where the ethos revolves around compassionate treatment and unbiased care, discrimination disrupts the ethical equilibrium. Bound by codes of ethics and an oath to prioritize the well-being of their patients, HCWs find themselves in an ethical conundrum

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when faced with discriminatory behaviours from their patients. A dilemma arises from their obligation to uphold patient autonomy and professionalism while simultaneously preserving dignity when responding to discriminatory patients.

Requests for Specific Healthcare Workers

There is a growing body of literature on racist requests for alternate care providers (1-4), and refusals of care providers (5) with a focus on requests from patients themselves (6), or their family members in the case of paediatric patients (2). Some studies have focused on migrant HCWs experiences with discriminatory patients (7-12), physician experiences with microaggressions (13,14), discrimination against Muslim HCWs (4,15), and requests for concordant care (16). In addition to this body of work, a growing number of studies have explored the issue from a policy lens, noting key recommendations for institutional guidelines and practices (17-23) that prevent patient discrimination while also balancing patient rights.

Despite the variation in the focus of these studies, the narratives represented are predominantly those of physicians and physician learners, with a smaller subgroup of articles documenting the experiences of nurses, particularly international/migrant nurses. An obvious gap in this scholarship is information about or an examination of the experiences of the multidisciplinary healthcare team. Very little is known about the experiences of social workers, physiotherapists, occupational therapists, or respiratory therapists, to name a few (17). What we do know, however, is that HCWs report harrowing experiences of physical violence, racially-motivated assaults and sexual harassment from patients and their families on a daily basis (1,7,24-31). Recollected accounts include, for example, a Filipina nurse being called “a fucking whore” and a “slut” by a patient’s family (24, p.4). Black physicians have described refusals phrased as “don’t want no nigger doctor” (25, p.1084) and being told that death would be more favourable than being “touched by a filthy Black doctor” (1, p.6). Others described refusals rooted in Arab identity (30), Jewish identity (31) and gender identity (1,26,27). Whereas some narratives solely describe verbal assaults and discriminatory refusals of care providers, others also include physical acts of violence and aggression, such as being punched (28,30) and spat at (7,28,29).

When patients refuse care providers due to their identity characteristics, this raises complex ethical, legal and clinical issues. From an ethics perspective, this topic tends to be explored in relation to the limits to autonomous decision-making, including who provides and is involved in care (18) – specifically, balancing the tension between promoting patient-centred care, establishing necessary boundaries to patient choice, and honouring the duty to care (1,18). While it is important to acknowledge and promote the values, wishes and beliefs of patients, this must be balanced against any potential consequences or harms to 1) staff who are the targets of biased refusals, and 2) other patients who might overhear or witness discriminatory statements or behaviour that may or may not be coupled with violence.

Refusals of care providers occur along a spectrum and can be rooted in reasons other than bigotry or prejudice. Paul-Emile et al. (6) argue that rejecting a provider based on identity characteristics is not always negative in nature and could be rooted in a request for identity concordance. Several studies have noted positive health outcomes for patients assigned to concordant care providers (32-34). In fact, positive clinical outcomes (e.g., increased patient-provider communication, patient satisfaction, and better health outcomes) have been attributed to concordant care relationships (32-34), particularly for groups/persons that have been historically marginalized or harmed by the medical system. Requests for concordant care providers could also be due to religious or cultural reasons, or they might be rooted in an individual’s trauma history (1,3,16,18). These types of requests are not inherently discriminatory and are therefore less ethically problematic.

In addition to the ethical dimension, refusals of care providers raise many legal questions, as the rights of the patient must be situated in relation to the rights of the healthcare worker. In Ontario, Canada, as employees or contractors of hospitals, clinics, or care facilities, HCWs are protected under the Ontario Human Rights Code (35) – they have the right to a workplace free from discrimination based on age, race, ethnicity, sex, disability, gender identity, and sexual orientation, whether this is from patients, family members or fellow staff/colleagues. Organizations that accommodate a patient’s discriminatory request or compel employees to acquiesce to a patient’s request for reassignment based on any of the 14 protected grounds may violate Ontario’s Human Rights Code. Despite an organization’s commitment to patient needs, HCWs have employment rights and protections that must be balanced against patients’ rights and requests.

The Current Study

There is a lack of published work that synthesizes how HCWs and institutions more broadly have responded to discriminatory behaviour from patients, their family or visitors; even less attention has been focused explicitly on the recommendations for institutions and teams regarding best practices in responding to such behaviour. The objective of this scoping review is thus to identify, explore and map the literature on HCWs’ experiences as the target of discrimination from patients and their family members, as well as identify knowledge and practice gaps.

METHOD

This review was conducted in accordance with Arksey and O’Malley’s (36) 5-step methodology for scoping reviews: 1) identifying the research question, 2) identifying relevant studies, 3) study selection, 4) charting the data and 5) collating, summarizing and reporting the results. The first author (CB) and the third author (MA, a health sciences librarian) developed and designed the search strategies employed in this study. Ovid Medline, Embase and Emcare, and Web of Science Core Collection were consulted, and for each a specific search strategy was used that matched the platform’s command language, controlled vocabulary and respective search fields.

Identifying the research question

This review was guided by the research question, “What does the literature tell us about HCWs’ experiences of discrimination from patients?” In addition to unearthing the general content on studies that examine discrimination from patients in healthcare settings, this review also sought to map how discriminatory requests or refusals of specific care providers have been managed within healthcare contexts, and any recommendations for change. Based on the research question and these broader aims, a scoping review was ideally suited as it is a type of research synthesis that maps the literature on a topic or area of study and provides opportunities to identify gaps and inform future research (37,38).

Identifying relevant studies

For our initial search, we started with a list of keywords and headings focused on racial discrimination from patients, however, our searches expanded to include additional terminology that covered discrimination from patients more broadly. Appropriate subject headings and keywords for each concept (e.g., discrimination, bias, treatment refusal, and policy) were used when searching the following databases: Ovid Medline, Ovid Embase, Ovid Emcare, and Web of Science Core Collection (see Appendix). The initial search was run on February 8, 2022, with additional searches on March 15, 2022, and May 6, 2022. An updated search was run on June 9, 2023 to capture any publications released between May 6, 2022 and June 9 2023. The results from the updated searches were added on June 9, 2023. To limit duplicate results during the additional searches and the updated search, date limits from the previous search to the date of the current search were applied. No starting date limitation was applied for the initial search. All citations were imported into Covidence web-based literature review software where duplicate citations were immediately removed. Although Covidence screens for duplicates upon uploading into the software, several duplicates were found during the screening process and were manually removed.

Study selection: eligibility criteria and screening

Five members of the research team (CB, AN and 3 additional reviewers) contributed to the screening process during the various stages of the search and screening cycles. Title and abstract screening were conducted using the Covidence software to eliminate articles that did not meet the inclusion criteria in Table 1.

Conference materials, dissertations, theses, books, book chapters and in-progress research were excluded. Only studies with the full text available in English were considered. The following were identified as the primary content related reasons for exclusion: ineligible population (bias experienced by patients or perpetuated by colleagues, aspects of the patient-provider relationship unrelated to discrimination), ineligible setting (bias experienced by providers not in a clinical or healthcare context), ineligible context (studies focused on discrimination or bias in the context of a health topic, for example, bias among patients in cancer care or concordance in relation to patient satisfaction). Other reasons for exclusion were: inability to retrieve full text and text not in English.

Table 1. Study inclusion criteria

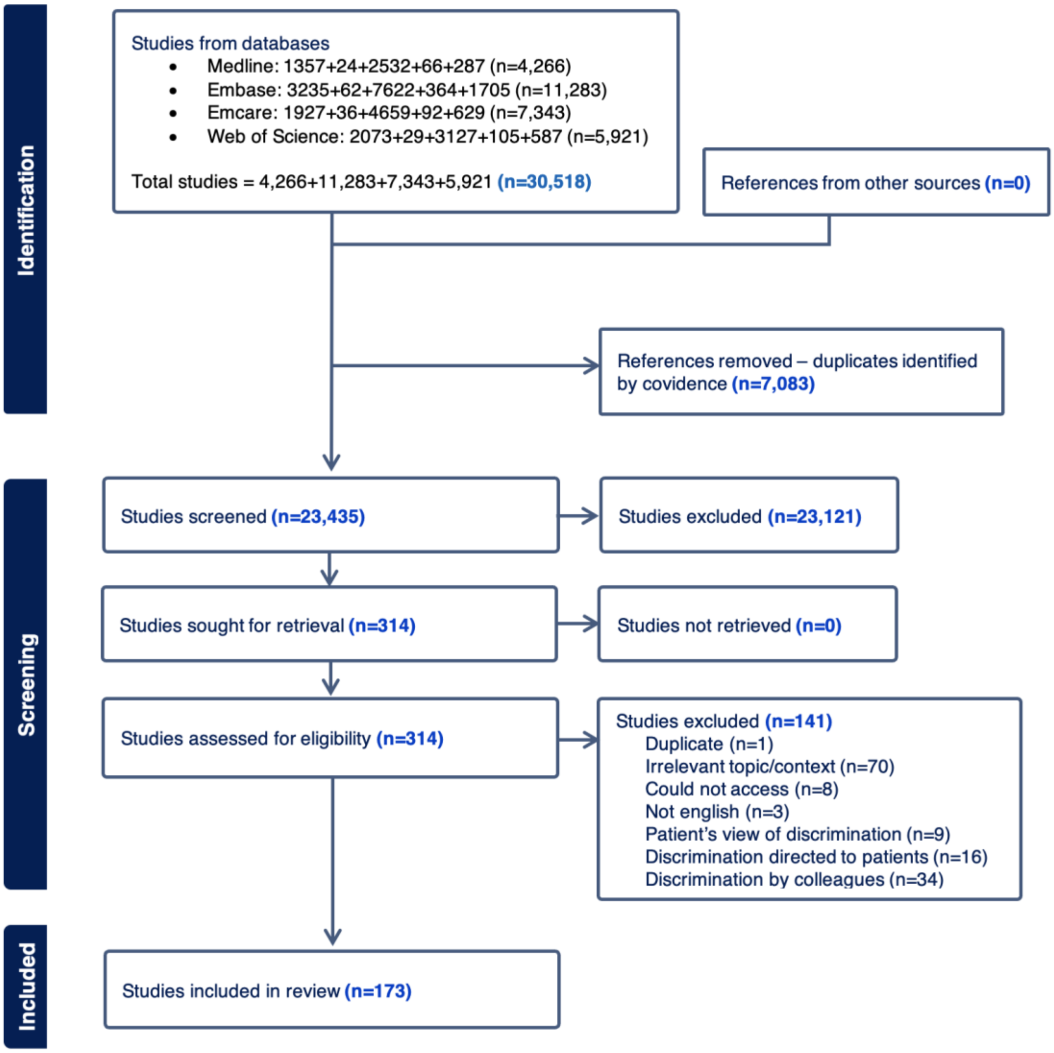
Participants	• Studies focused on HCWs, residents, learners on the receiving end of prejudice, discrimination or micro-aggressions from patients.
Intervention/Exposure	• Articles on interactions with patients and HCWs on bias directed towards the healthcare worker (HCW) based on their identity (gender, race, religion, ethnicity, sexual orientation).
Comparator/Control	• Not applicable
Study designs	• Theoretical papers, opinion articles, commentaries, case studies, policy reports, and empirical studies that explore the mechanisms of responding to prejudiced patients or discrimination against HCWs based on identity factors. • Studies that focus on institutional recommendations, policy recommendations or training recommendations for learners, educators or institutions. • Studies that explore what healthcare systems, hospitals, care homes, clinics, academic teaching hospitals should do to respond [policies/strategies to protect workers / accommodations based on patient context].
Context	• Articles examining requests for concordance (healthcare interactions whereby the patient refuses care from specific healthcare providers). • Articles examining a request from a patient for concordant care and the institutional, supervisory or collegial response.
Outcomes	• Identify types of discrimination experienced, types of concordance requested, all policy recommendations, institutional guidelines, and departmental/unit strategies developed in response to discriminatory requests from patients/family/visitors.

Two reviewers – the first author and a second reviewer (research team member 1) – conducted the first round of screening after the initial search on February 8, 2022. Each reviewer screened 50 articles independently, then met to discuss their reasons for inclusion and exclusion. This was done to ensure for reliability amongst the reviewers. The reviewers also discussed and deliberated over articles that were considered ‘conflicts’, i.e., cases where one reviewer voted to include, while the other voted to exclude. For these articles, we discussed how we arrived at our decision and matched against the inclusion criteria. Where consensus could not be reached, we searched the full text article to examine whether it included material relevant to the inclusion criteria and the overall aims of the review. This process was done with each new member of the research team that contributed to the screening process (including the second author and research team members 2 and 3). As the research team grew, we scheduled regular meetings to discuss the conflicts. The aim of these meetings was to work through the disagreements and any nuances identified by discussing all assumptions made. We independently noted our reasons and final decision on the article, reviewed the full text as a group, and then shared our decision. This was done until we worked through all the conflicts and arrived at a consensus on the outcome of the article.

Charting the data

After title and abstract screening, all citations in the inclusion folder were subjected to full-text screening for data extraction purposes. Full text articles were obtained through institutional holdings available to the research team. For articles that could not be accessed, we solicited the third author’s help in attaining them through interlibrary loans. After reading the full text of each article, the following information was extracted and entered into an Excel data charting form for characterization and analysis: author, year of publication, title, location (state and country), journal, study design, study setting/medical context, sample size (of empirical studies), type of concordance requested, type of refusal/assault/bias experienced, details about the refusal/assault/bias experienced, who the bias was perpetrated against, personal approach to the situation, who was involved in responding to the situation, what was the reaction of the team/supervisor/unit member involved, impact on the healthcare worker involved, whether the incident was reported, barriers to reporting (if any), type of approach implemented, institutional recommendations for addressing patient bias, team/unit recommendations for addressing patient bias, and institutional barriers. Studies were also excluded at this stage if they were not found to meet the eligibility criteria. See Figure 1 for a PRISMA flowchart illustrating data screening and characterization process.

Figure 1. PRISMA flow diagram illustrating the various stages of the review



Collating, summarizing and reporting the results

For each article included, we aimed to standardize the approach to which we extracted and charted relevant information. Reliability measures similar to those described in the screening process were also performed during this stage of the process.

Each member of the review team was assigned the same 10 articles to review and extract independently. We then met to discuss the content extracted and the level of detail retained in the extraction document. This was done to ensure that each reviewer was extracting similar material and including the same depth and breadth of coverage. Once each member was independently extracting the same type of material from each article, the articles were divided and distributed amongst a subset of reviewers for extraction. The first author routinely reviewed the extraction sheet of each reviewer to ensure that the material extracted was correct, and that sufficient detail was provided. Despite these reliability checks, it is often difficult to extract all relevant information where original research has failed to include the specificities of the nuances in question (39). In these instances, we entered 'not applicable' or 'not reported' into the data extraction table. The information presented in this review was collated, summarized and reported in accordance with PRISMA-ScR standards (40).

RESULTS

Descriptive findings: characteristics of the articles included

The literature search yielded 30,518 relevant papers for review. Removal of duplicates as well as title and abstract screening left 314 for full-text screening. Of these 314 articles, 141 did not meet eligibility criteria. This review presents the findings from 173 articles, primarily from the United States (n=111) (1,3,6,7,10,14,19,20-23,25-27,29,31,41-135), United Kingdom (n=25) (2,28,136-158), Canada (n=14) (18,159-171); with 4 from Israel (30,172-174), 3 from Australia (175-177), 2 each from Germany (8,178), Ghana (140,179), and Turkey (180,181), and 1 each from Belgium (180), Brazil (182), China (183), Eswatini (184), Netherlands (24), New Zealand (185), Norway (186), Poland (187), Portugal (180), the Republic of Korea (188), Singapore (189), Spain (180), Sweden (190), and Uganda (192). These articles focused on one of the following five core areas: 1) discriminatory language or behaviour from patients, 2) refusals of care providers, 3) HCW experiences of bias or discrimination, 4) HCW experiences of sexual harassment and 5) responding to discriminatory patients.

The majority of articles were empirical in nature (n=80), including qualitative (n=51), quantitative (n=21) and mixed methods studies (n=8). This was followed by commentaries (n=54), case studies (n=12), review papers (n=11), essays (n=3), letters (n=3), editorials (n=2), narratives (n=2), policy/guidelines (n=2), ethics rounds (n=1), perspectives (n=1), workshops (n=1), and virtual listening sessions (n=1). See Appendix B Table 1 for study design references. As observed in Figure 2, the oldest article included in this review was published in 1980, which means that no article (found through our search process + met the inclusion criteria) addressing the nuances of this issue was published prior to this date.

Figure 2. Number of published articles on the topic since 1980

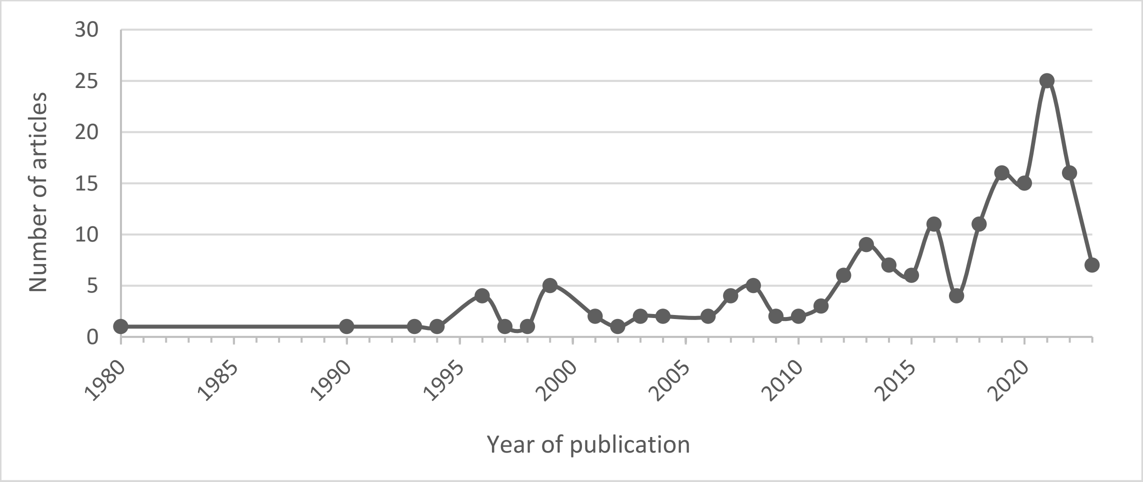


Figure 2 showcases a 10-year gap between the first and second article published on the topic (1980-1990), followed by a modest increase in articles published in 1996 (n=4). The graph shows a steady increase in publications on the topic from 2002 to 2016, with a significant increase noted between 2017 and 2021. The majority of these articles were published in medical journals (n=85), followed closely by nursing journals (n=42). Articles were also distributed across broadly defined health journals (n=22), ethics journals (n=13), pediatric journals (n=3), psychology journals (n=2), occupational therapy journals (n=2), and journals focused on law (n=1), social work (n=1), pharmacy (n=1) and physiotherapy (n=1). The journals most frequently published in were: *The Journal of the American Medical Association* (n=11), *British Medical Journal* (n=9), *Annals of Internal Medicine* (n=8), *Academic Medicine* (n=7), *AMA Journal of Ethics* (n=6), *Journal of General Internal Medicine* (n=6), and the *Canadian Medical Association Journal* (CMAJ) (n=5). See Appendix B Tables 2 and 3 for journal references.

Of the 173 articles included in this review, the majority described patient bias/discrimination occurring in a hospital setting (n=121). This category included various types of hospitals, such as: academic hospitals (n=64), public hospitals (n=4) and non-specific hospital type (n=53). Residential care facilities were the second most cited care setting (n=14), including: nursing homes (n=7), long term care (n=3), residential/home care (n=2) and hospice settings (n=2). Other settings included community care (n=5), rural healthcare facilities (n=1), medical centres (n=1) and public and private health services (n=1). Furthermore, some articles specified the clinical context within these settings where instances of patient bias occurred frequently. These included: nursing contexts (n=14), emergency departments/urgent care (n=13), primary health care (n=8), pediatrics (n=6), internal medicine (n=6), surgery (n=6), orthopedics (n=4), medicine (n=3), oncology (n=3), and obstetrics and gynecology (n=3). Other less cited clinical settings include pharmacy (n=2), mental health (n=6), occupational therapy (n=2), rural health (n=1), ICU (n=1), dermatology (n=1) cardiology (n=1). See Appendix B Tables 4 & 5 for study setting and clinical context references.

Target and Type of Discrimination, Harassment, and Assault Experienced

Target of Discrimination, Harassment, and Assault

The majority of the articles reviewed focused on the experiences of physicians and nurses as the primary targets of discrimination, harassment and assault (n=158) from patients and/or their family members. A total of 102 articles examined the experiences of physicians, whereas 56 examined the experiences of nurses. Other groups targeted include psychotherapists (n=3), physiotherapists (n=2), occupational therapists (n=2), pharmacists (n=1), and HCWs broadly defined (n=8). Of the 102 articles examining physicians as the target, 50 focused exclusively on the experiences of medical learners, i.e., residents, interns, trainees, and medical students. Similarly, of the 56 articles examining the experiences of nurses, 10 noted the experiences of nursing students exclusively. See Appendix B Tables 6 and 7 for target references.

In addition to the role/profession of the healthcare worker, some articles specified the social identity marker/characteristic that the patient targeted. For example, of the articles that focused on physician experiences, 21 noted the racial background of the physician, 9 noted the gender identity, 7 the religious identity, 1 the sexual orientation, and 3 noted the ethnicity. Similarly, the articles that examined the experiences of nurses noted a predominant focus on the racial identity of the nurse (n=24), followed by the nurse's ethnicity (n=9), gender identity (n=7), sexual orientation and religion (n=2).

Of the articles that examined medical residents as the target of discrimination, harassment or assault, 16 mentioned the racial background of the resident, 3 noted their gender identity, and 2 noted their religious background. Some of these articles referred to the multiple intersecting identities of the HCW, for example, an "Asian Male Resident Physician" (168) or "Sikh Male Medical Student" (14). Similarly, of the articles that focused on medical students (n=11), 3 noted the racial background of the student, 5 noted gender identity, and 1 noted religious background. Of the trainees (n=5) and interns (n=3), 3 articles mentioned racial background, 1 mentioned gender identity, and 1 mentioned religious identity.

Type of Discrimination, Harassment, and Assault Experienced

Varying forms of discrimination and abuse were noted amongst the articles reviewed (see Table 2 for examples). These included cases of refusals of specific care providers (n=60), requests for specific care providers (n=27), discriminatory comments (n=98), sexual harassment (n=25), physical assault (n=14), and inappropriate comments (n=13). The discriminatory request, refusal or comment was often in relation to a particular identity category of the healthcare provider. These included: racial background (n=96), gender (n=35), age (n=8), accent (n=10), disability (n=3), nationality (n=16), religion (n=17), language (n=3), status as a learner (n=1), sexual orientation (n=10), ethnicity (n=20), weight (n=2), political views (n=2), and training location (n=1). See Appendix B Tables 7, 8a and 8b for references.

Table 2. Examples of types of discrimination experienced

Category	Identity Characteristic	Example
Discriminatory Comment	Race	"Dr. Nwando Olayiwola, a Black female physician at San Francisco General Hospital, recounts her experience caring for a patient who explicitly stated, 'You didn't tell me I was going to see a Black doctor. And not just a Black doctor, but a Black woman!'. This same physician had experiences as a resident with a patient who told her 'All Black, Hispanic, Asian, and Jewish doctors should be burned alive,' and another who said she would 'rather die than be touched by a filthy Black doctor.'" (1)
	Gender	"I remember so often patients mistaking me for the nurse. I remember being the senior doctor in the room telling a patient his diagnosis and plan and that same patient looking to the male members to make sure they agreed with my plan – to validate me." (90)
	Accent	"Nurses described how their competency was questioned and how they felt the need to defend or to prove themselves not only to fellow nurses, but to doctors and patients as well. They also described experiencing more scrutiny than majority nurses, with those who spoke English with an accent reporting feeling even more scrutinized than those without accents, especially by patients." (10)
	Age	"A resident discusses dialysis with her elderly patient, who later says 'You look too young and pretty to be a doctor!'" (55)
	Ethnicity	An Arab American nurse shared "My worst experience was that a child was dying, and I wanted to clean the child. The father heard my accent and asked me where I was from. I said, 'I'm Lebanese,' and he told me not to touch his kid." (93)
	Sexual orientation	Survey respondents who would refuse to see a gay, lesbian or bisexual (GLB) physician provided various reasons. "Over half gave the reason that a homosexual physician would be incompetent. Fewer subjects were afraid of being sexually harassed or contracting a disease. Among 'other' reasons the most common was feeling 'uncomfortable' with homosexuals. Other reasons included the belief that a homosexual physician would be 'bizarre' or 'not normal', the respondent's upbringing, the belief that a homosexual physician is somehow a threat to children and dislike of homosexuals." (160)

	Religion	"…consider the experience of Dr. Bernard Sussman, a Jewish internist caring for Mr. W. During one visit, Mr. W revealed that he had served in the armed forces of Nazi Germany in Hitler's personal honor guard. Pressed further, he grew angry, claiming that the 'Jews were responsible for everything that happened to them.'" (1)
	Weight	"A lot of patients ask if I'm pregnant because I have a prominent belly. We have overweight white female attendings and I've never seen them ask if they're pregnant. So, I don't know if my minority played into patients asking if I'm pregnant, but it happens a lot." (156)
	Language	"Participants said that some patients feel uncomfortable seeing nurses speaking to other patients in another language. One participant stated: 'I recall one patient who was making comments and later pulled the curtains while I was speaking to an elderly Asian woman with her language' (Nurse 7). Another participant recalled: 'one patient saying to us, if you can't speak English, then go outside and speak to each other whatever you like' (Nurse 2)." (156) A migrant nurse described their experience: "The family was asking for an English nurse to update them with their patient's medical information although I know I can speak English clearly and fluently." (145)
	Disability	"As a person with a disability... patients have a hard time believing that I was the supervising physician on the team." (43) A deaf therapist encountered clients who could not fathom how she could be a competent therapist: "They have it in their mind that Deaf don't speak and Deaf definitively don't work as a health care professional." (139)
	Nationality	"At one point in my training, I was on rotation in a wealthy suburb of a metropolitan area, working with an attending in his clinic. I went to see a follow-up patient with a chief complaint of intermittent shortness of breath. I was unable to get through even a few questions without the patient interrupting with effusive praise of my attending. 'He is the best doctor I have ever known.... When will he be coming in? I trust him with my life.' I obtained a history and performed a physical, and then prepped the patient's nose for a laryngoscopy. I told the patient that I would return with the attending to perform the procedure and exited the clinic room. As I stood outside of the room waiting to present the patient's case to my attending, I discovered that the clinic door was not soundproof. The patient and his wife (both White) were discussing whether or not they could trust me, and whether I should be involved in the laryngoscopy. 'She seemed nice. But I don't know if I want a foreign doctor doing my scope. Her English was pretty decent, and at least I could understand her accent.'" (72)
	Country of training	A Jewish patient said "Over the past few years ... the number of Arab doctors increased dramatically. Do I appreciate them equally? No. It depends where they studied. That is, an Arab doctor who attended the Hebrew University [a prestigious university in Israel] is as good as a Jewish doctor who studied there. But there are certain places in the world in which medical training is of less value." (173)
Refusal of care providers	Gender	"A male medical student on his obstetrics-gynecology clerkship is assigned a 35-year-old female patient in the outpatient clinic who comes in for a routine well-woman exam, including a pelvic examination and Pap test, clinical breast examination, and discussion about contraception management. The student enters the examination room and introduces himself, but the patient straightforwardly tells him that she would prefer a woman student." (27)
	Race	A patient's relative said "Excuse me nurse, I don't want my mother to be nursed by a black person...in our family we don't do that; we don't associate with them." (175) "Early in Dr. Cornelia Wieman's career as a psychiatrist, a patient refused to see her because she was Indigenous. 'I tried to talk to them, to explain I was qualified, but the patient was adamant,' she says." (162)
	Religion	"A trainee in my clinical division had cared for a teenage girl for several years, dating from her diagnosis of acute leukemia. The family, and especially the patient, had developed a very strong and trusting bond with her. … the patient and her parents came for her regularly scheduled clinic visit only to find out that her favorite doctor was not there. The staff apologized profusely for failing to reschedule the appointment, but Dr. X was not there that day because it was Yom Kippur, one of the Jewish High Holy days, and she had taken the day off to be with her family and attend services at her local temple. The family was shocked to discover that Dr. X was Jewish. After discussing it amongst themselves for a few minutes they announced that they did not want her taking care of their daughter anymore, and demanded that a Christian physician be appointed to take over the case." (31)
	Ethnicity	"The first time it happened was when I went into this patient's room and her son was there. Upon seeing me, seeing my hijab, he refused to have me as his nurse. When I asked him why, his exact answer was that he felt threatened by me because I wear the hijab, that the way I look made him think of all the violence that is happening in the Middle East." (171)

Requests for specific care providers	Gender	“The patient was uncomfortable about being assigned a male nurse from the beginning and requested a switch. Male nurses were occasionally regarded as ‘men’ rather than as ‘nurses’.” (188)
	Race	“Nurse NG (AA) remembered when a white patient’s fiancée only wanted the Caucasian nurses and she was like ‘this one is so sweet, can I have this one?’ and every day she would request and then we saw a pattern.” (121) "While on a trauma service during my intern year, I was subject to a more overt display of racism. One of our patients was a middle-aged Latino man who had been stabbed during an altercation with a black man. After we stabilized him, he acquired a systemic bloodborne infection and was being monitored on the floor. He had antagonized several staff members using expletives and was intermittently refusing treatment. After a particularly harsh exchange, his nurse, a black woman, paged me requesting I draw blood for cultures. The nurse had been unable to convince him to cooperate, and the patient, after becoming agitated and increasingly rude, asked for a physician to draw the blood instead. Upon entering the room and explaining I had arrived to take a sample of blood, he became agitated, shouted racial slurs at me, and demanded another physician. ‘Get me a white doctor,’ he exclaimed.” (91)
	Nationality	“Examples included derogatory comments and threats against care workers, complaints to supervisors or co-workers, exaggerated suspicion and reactions of fear during visits, refusals to be attended by ethnic minority staff in nursing homes, refusals to let ethnic minority staff into the apartment/house, and requests to replace staff with ‘someone Swedish’.” (190)
	Religion	“If I can choose between a Jewish or Arab doctor, of course I’ll select the Jewish one ... only because he is a Jew ... If the Jewish and the Arab doctors are both excellent professionals, then I would go to the Jewish one out of loyalty. We share the same religion, the same state, the Jewish state ... He is one of my people. (Jewish man)” (173)
Sexual Harassment		A female trainee reported that a male patient grabbed her crotch during a physical exam. (1) A medical student described his experience with a patient: “I was on a team and the patient was an older gay man and every time I came in, he would ask me to sleep with him. I was stunned...” (14)
Inappropriate comment		“One Filipino nurse encountered a white patient who asked whether he could bring her home as a maid with a sexual overtone and profound ignorance that the Philippines was so backward that the entire country was connected by dirt roads.” (7)
Physical Assault		“I’ve been assaulted by a patient, she was confused because of her illness and she spit in my face, she was a HIV patient, it’s normal for us.” (182)

Barriers to Reporting

Most articles (n=131) made no reference to reporting or escalating the incident for further review. A small subset noted whether the incident was or was not reported/escalated (n=42). Of this subset, a total of 16 articles explicitly mentioned that experiences of patient bias were not reported. Whereas 26 articles noted that experiences of patient bias were reported to a supervisor, manager or attending. Of the 26 articles that described reporting, 9 included cases where some but not all instances were reported. When instances of patient bias were reported, it was typically done by: a) physician learners to their supervisors/attendings (n=7), b) nurses to their managers (n=5), and c) other clinical learners (doctoral student therapists and physical therapists) reporting to their supervisors/clinical instructors (n=2).

Multiple barriers to reporting were described in the literature, most commonly: a fear of retaliation, repercussion or retribution (n=17); an assumption that the experience would be dismissed, ignored or unaddressed (n=9); and a lack of support from management (n=6). Others described the culture of silence and submission given the hierarchical medical structure, the prioritization of patient care, feeling disempowered to raise issues of racism in the workplace, and concerns about creating conflict in the workplace as key barriers to reporting discriminatory experiences/assaults. Less cited barriers include feeling the need to handle these issues alone, downplaying incidents as not serious enough to report, normalizing experiences of harassment and feeling pessimistic about the likelihood of such situations changing. Others highlighted being too busy with other responsibilities, feeling dissuaded by cumbersome reporting processes, not knowing where or how to report particularly when senior staff are unavailable, and a lack of policy or standardized protocol as impeding the likelihood or willingness to report. See Appendix B Tables 9a and 9b for references.

Impact of Discrimination

The literature shows that HCWs are deeply affected by these experiences, which have an impact on their emotional and psychological wellbeing, their self-perception, job satisfaction, and how they perform their roles. Table 3 below displays the varying effects of discriminatory experiences on HCWs.

Table 3. Ways in which discriminatory experiences negatively affect healthcare workers

Impact on the HCW	Descriptions
Emotional & psychological responses	• Felt dumbfounded/taken aback (6,75,82,84,91,124,134) • Felt hurt (50,125,174,184,189,190) • Felt sad/disheartened (44,138,171,185) • Felt disappointed (138,188) • Felt devastated (31) • Felt beaten down (121) • Felt defeated (25) • Suppressed their feelings and denied the pain (120) • Felt an added sense of responsibility and concern for the wellbeing of other minority staff (25) • Felt uncomfortable (61,84,88,108,168,180,188) • Felt embarrassed (1,99,108,184) • Felt disrespected (6,86,189) • Felt powerless (1,141,159,181,185) • Felt invalidated (51) • Felt intimidated and unsafe to perform duties (44,75,108,184) • Emotionally/Psychologically traumatized (50,60,86,105,181) • Anger, fear (1,28,67,69,86,88,98,99,108,113,114,138,139,145,181,185) • Frustration and confusion (27,98,145,139,185,188,189) • Emotionally and mentally exhausted (79,98) • Felt terrified (75,91) • Felt shocked (1,24,75,107,138,171) • Felt stressed (60,75,185) • Felt humiliated (1,7,99,162,174,181) • Felt unwelcomed (175,179) • Felt anxious or worried about future incidents (28,84,108,135,153,190) • Felt isolated, alone, invisible (10,43,68,139,153) • Experienced racial fatigue (43,68,79,176)
Negative impact on self-perception	• Engaged in self-loathing for not having thicker skin (125) • Hyperawareness of self-identity (123) • Felt they couldn’t be themselves/had to hide identity (85) • Demoralizing (81,98) • Doubted abilities (44,98,166) • Contributed to low self-esteem (157,184,189) • Confidence was lowered (43,62) • Felt inadequate (55) • Ego was damaged (62)
Changed their performance/how they practiced	• Affected ability to focus on learning or training or developing into a better clinician (98) • Affected ability to perform at work (1,44,56,61,185) • Felt a need to prove competency (7,10,56,164,189) • Developed thick skin/got used to it (14,43,147,149) • Doubted whether they could continue caring for the patient (1,67,108,114) • Negatively affected relationship with the patient (1,56,83,86,138) • Questioned duty to care (28) • Silenced oneself due to the interaction (1) • Felt under intense scrutiny/ surveillance (159)
Negative impact on job satisfaction	• Questioned why they would continue to work hard if not appreciated (185) • Considered leaving the job (43,83,149) • Felt dissatisfied with the job (86) • Experienced lower job satisfaction and burnout (56,68) • Contributed to unhappiness with career (8,44,56,86,152) • Threatened job and mental health (175) • Questioned their experiences at work due to their gender (42,188) • No longer felt joy from the job (42,93)

Response to Discrimination

The literature also shows that HCWs respond to these incidents in varying ways. Table 4 highlights the 16 core approaches used, while Table 5 showcases the responses of the supervisor, and/or team/unit.

Table 4. Individual responses to instances of discrimination from patients

Individual Responses	Details of the response
De-escalation	• Walked away/left the room (6,20,25,27,41,43,91,94,119,121,133,134,149) • Distanced themselves from the patient [physically] (44,185) • Responded with humour (7,43,77,108,121,139) • Tried to calm patient down (133) • Kept a cool composure (128,135) • Tried to be as present as possible (75) • Offered empathy/support to the patient (75,77,132) • Attempted to understand the patient's concerns (132)
Transferred Care	• Requested a change to the unit assigned (121) • Switched patients with another HCW (1,30,91,108,159,162) • Asked to be reassigned (127,135) • Changed the shift (121) • Left the position (121) • Suggested other providers for patients (175) • Withdrew from clinical role with specific patient (98,137)
Direct Confrontation	• Talked to patient/family about their behaviour (14,122,138,139,147,159) • Asked the patient to leave (1,125) • Re-asserted their clinical role (25,98) • Reintroduced themselves and their role (25) • Answered patients intrusive and biased questions with direct answers (46,108,124,169) • Remained firm with the patient when stating that their behaviour will not be accepted (43) • Informed the patient of the importance of a respectful environment (91,108) • Intentionally challenged race-related issues/conflicts (79)
Accessed Support from Others	• Relied on colleagues for support (159,185) • Sought support from ethnic minority colleagues (159,166) • Debriefed with colleagues (110,128,132,159,181) • Vented to family/friends (110,128,133,159,166,181)
Relied on Institutional Guidance	• Followed hospital protocols (159) • Applied scripted procedures (159) • Reported the incident (20,27,61,65,80,84,91,94,121,133,135,138,153)
Boundary Setting with Patient	• Role clarification (42) • Asked patient to leave (1,125) • Corrected the misidentification (168,169) • Tried to explain, show, and prove competency to patient (46,50,57,59,91,121,132,162,170) • Described training background and experience that qualifies them for care provision (59,162) • Provided the patient with multiple sources of proof of their credentials (91) • Introduced themselves as doctor instead of using full name (86) • Explained the limits of refusals of care due to staffing (30,137) • Explained the consequences of continuous refusals (i.e., being moved to another institution or delays in care) (98,137) • Explained to patient that they are the most senior clinician [attending] and that they can see a white male intern physician, but the attending would still be involved in their care (177) • Outlined acceptable behaviour guidelines to proceed with care (92) • Taught the patient the correct terms and language to refer to people of colour (102,108) • Told the patient some things are better left unsaid in response to racist comments (108) • Practiced limit setting (110)
Reciprocated Negative Behaviours	• Matched patient's inappropriateness with a comparable inappropriate response (swearing back to patient, giving a sassy response) (122,125) • Became physical with patient (put hand over patient's mouth) (29) • Chased after the patient (107)

Normalized Patient’s Behaviour	• “Explained away” the behaviour as due to a medical condition (63,65,102,121,145,146,182) • Assumed the role the patient ascribed to them (192) • Became accustomed to problematic behaviour/accepted bias (10,24,30,98,149,183) • Accommodated the patient’s request despite inappropriate rationale (106,116)
Persuasion/Negotiation Tactics	• Persuaded patients to accept care (190) • Worked on a compromise for the patient (112,150)
Used Different Forms of Processing	• Practiced journaling as an avenue to process the behaviour/comments (43) • Engaged in active listening/tried to be present (75) • Became more aware of appearance and surroundings (85)
Reliance on Enforcement Groups	• Called police/security (30, 169)
Masked Aspects of their Identity	• Put up a shield in preparation for the day – changed how they present at work (85) • Masked feminine traits to de-gender the role of a physician (44) • Put on an androgynous front (44) • Altered behaviour after experiencing microaggressions (56,86)
Avoidance	• Ignored/didn’t acknowledge the comment (1,24,43,67,99,105,113,114,132,135,138,176) • Ignored behaviour, stayed silent, didn’t address (1,65,67,75,79-81,84,90,98,99,113,114,121, 138,141,148,153,166,185,186,190) • Smiled nervously (141) • Unsure how to respond (75,81,124) • Shut down/dissociated (75)
Trauma-informed Disclosures of Identity	• Disclosed sexuality with straight male patients who have been abused by men before providing care, especially intimate care (148)
Reframed the Behaviour	• Relied on personal values to ignore the behaviour (121) • Blamed the external world (society) (121) • Relied on religious beliefs to guide actions and responses (121, 159) • Chose not to internalize the discrimination (121)

Table 5. Responses from the supervisor, team or unit towards the incident

Response	Details of the response
Boundary Setting	• Warned the patient about potential discharge if respect isn’t shown/abusive behaviour continues (159) • Informed the patient that services will no longer be provided if discriminatory attitudes continue (94) • Informed the patient that his/his family’s behaviour was unacceptable (93,133) • Enforced a non-discriminatory environment by not accommodating biased refusal (175) • Requested that the patient keep the conversation professional and reestablished the role of the targeted individual (51) • Described the institution’s anti-discrimination policy, staffing levels and assured patient of the clinician’s competence (29,92) • Assured the patient of clinician’s compassion and competency (106)
Avoidance/Lack of Action	• Lack of intervention from coworkers and attendings (42,84) • General silence from colleagues (43,44,68,153,168) • Attendings didn’t correct the patient or address the incident privately (1) • Team/supervisor ignored the patient’s comments (113,174) • Team/supervisor froze/were immobilized by the witnessed incident (25,107,176)
Lack of Support	• Lack of support from some coworkers (81,169,172) • Colleagues laughed at the patient’s inappropriate comment/behaviour (44,176) • Supervisor denied targeted clinicians request to be reassigned (135)
Dismissed the Behaviour & Impact of the Behaviour	• Blamed the patient’s behaviour on mental state or diagnosis (146,147,190) • Told targeted individual not to take it personally (44,146,179) • Supervisors did not believe that discrimination towards HCWs is still a problem (190) • Discriminatory comments/behaviour were brushed aside, ignored or not taken seriously (138) • Dismissed impact of verbal racial assault on clinician by asking targeted clinician to calm the patient down (93) • Dismissed impact on the clinician by telling them that regardless of the patient’s comments/behaviours, they still have to fulfill the role of a physician (127)

Empathy/ Support	• Issued blanket apology (61) • Apologized for their experience and inquired how best to support (14) • Expressed concern over patient's inappropriate comment and provided a path forward (44) • Tried to make light of the irony/hypocrisy of the patient's comments (46,125) • Expressed sympathy, concern and support to the targeted individual over the patient's comments (19,91,113,140,143,165,171,182) • Expressed embarrassment and sadness that a biased request was accommodated (31) • Engaged affected clinician one on one to discuss the situation (186) • Provided guidance on how to handle future encounters (75,98,108)
Redirection	• Redirected inappropriate comment to focus on the patient's care (14) • Changed the topic following the patient's inappropriate comment (113)
Addressed the Bias	• Tried to persuade patients to be accepting of all HCWs (190) • Reassigned the targeted individual to another case (27,46,174) • Care was provided by another clinician (27,97,108,158) • Reported the patient to director of nursing (29) • Changed the layout/how patients were clustered to protect other patients from the biased patient (142) • Defended the targeted individual in response to the discriminatory comments (123)
Enabled Discrimination	• Supervisor condoned biased refusal by telling staff not to provide care to certain patients because of their racial preferences (179) • Accommodated patient's discriminatory request (2,29,31,49,53,79,97,106)

Barriers to Addressing Bias and Discrimination

Different types of barriers were noted throughout the literature. In addition to the various barriers to reporting or documenting an experience, there were also barriers to addressing the incident in the moment or after it happened. Several different barriers to addressing bias and discrimination were raised, most of which spanned varying domains, including: personal (n=15), clinical (n=5), educational (n=33), fear of reprisal (n=14), legal (n=2), professional (n=16), policy (n=20), and institutional (n=125) barriers. See Appendix B Table 10 for references.

Personal Barriers

Personal barriers to addressing patient bias included: low clinician capability, comfort and confidence in responding; desensitization, normalization and diminishment of one's experience of mistreatment from patients, their family members or visitors; perceived ineffectiveness of responding; a desire to maintain patient-clinician rapport and concern that confronting a patient would be too time consuming or would further inflame the situation.

Clinical Barriers

The primary clinical barriers that prevented HCWs from addressing instances of bias were identified as the clinical context as well as the speciality. Some clinical contexts leave little time to establish a therapeutic relationship (e.g., emergency departments) which can dissuade clinicians from confronting discriminatory patients. Additionally, different specialties have varied levels of tolerance for verbal abuse or problematic patient behaviour; in mental health specialties, for example, verbal abuse may be expected or tolerated to various degrees based on the diagnosis in question. However, on general medicine floors/wards, similar behaviours may be seen as surprising and warranting further intervention. The unique position of clinical trainees was reported as a barrier to disclosing experiences; more specifically, team hierarchies and the associated power differentials were identified as barriers that prevented trainees from speaking up about their experiences.

Educational Barriers

The lack of training material or guidance on how to address patient bias, as well as the general lack of discussion in health professions education programs about discrimination and racism generally were the main educational barriers noted in the literature.

Fear of Reprisal

Concerns regarding acts of reprisal and retaliation were described as barriers for both reporting and addressing patient bias. More specifically, fear of legal action against HCWs who terminate the patient-clinician relationship, fear of reprisal on patient-satisfaction scores for terminating the patient-provider relationship, fear of reinforcing the patient's prejudice or ignorance, fear of job loss or punishment, and fear of intervening and becoming a target prevented HCWs from addressing patient bias. Trainees had an additional fear of their instructors' reactions and fear that their evaluations would be affected if they addressed problematic patient behaviour.

Legal Barriers

Other articles explicitly attended to legal barriers that place restrictions on if, when, and how HCWs might respond to instances of patient bias. The legal barriers included restrictions on what can be done to address patient bias in certain situations. For example, the Emergency Medical Treatment and Labor Act (EMTALA) in the United States prohibits hospitals from denying emergency care. As such, in some contexts, it may be necessary to accommodate or ignore discriminatory behaviours, requests/refusals of care providers. The hiring conditions/employment nuances under which one works was also identified as a barrier; more specifically, a physician's status as an independent contractor as opposed to an employee of the hospital limits the types of rights and protections available. For example, independent contractors in the US are not protected by all sections of the Civil Rights Act, which grants the right to a workplace free of discrimination.

Professional Barriers

Several studies cited the lack of diversity within the health professions as a barrier that prevented underrepresented HCWs from speaking up about and addressing patient bias directly. Other articles noted that regulatory college mandates affected how complaints were handled, and the permissibility of refusing to care for abusive patients. Furthermore, expectations of objective/neutral professionalism in all situations was referenced as a key barrier that prevented HCWs from directly responding to or addressing patient bias. It was also noted that the professional code of ethics lacked proper guidance on mistreatment from patients and thus failed to equip HCWs with the requisite knowledge, skill and training to adequately respond to abusive, disrespectful or discriminatory patients.

Policy Barriers

Some articles noted the role that a lack of policy or an inadequately developed policy plays in hindering how one might want to respond to patient bias (n=10). It was often the case that HCWs were unaware of the institution's policy on the matter, or that the policy itself lacked the necessary levers to make it a supportive policy when faced with bias and discrimination from patients. Some articles identified policies that fail to provide sufficient practical guidance or flexibility as a barrier to responding to these encounters.

Institutional Barriers

A lack of action and follow-up on reports (n=28), as well as a lack of support from management and colleagues in dealing with conflict (n=26) were the two main institutional barriers noted. Other institutional barriers included institutional prioritization of patients over staff; HCWs feeling undervalued, devalued and disempowered; general silence or lack of discussion on bias and discrimination in the workplace; institutional racism; and ingrained gender biases relating to the composition of the healthcare workforce (e.g., that only women can be nurses) that make it difficult to enact change. Institutional culture at times impeded a clinician's ability to feel like they could safely address patient bias. Barriers related to this include not taking issues of racism seriously, refusal to call out acts of discrimination, and a lack of diversity in leadership positions. Other notable barriers included: a lack of inclusion of racism in considerations of workplace violence; a lack of data collection on patient interactions; a lack of staff awareness of institutional reporting mechanisms or resources; customer service models of healthcare, resulting in overprioritizing patient's needs; and, a limited presence of staff with seniority or authority to implement consequences, requiring interns or nurses to respond to biased patients.

Recommendations for Responding to Discrimination

Table 6 below outlines core recommendations for addressing discriminatory behaviour, requests, and refusals across various roles.

Table 6. Individual, team and unit recommendations for addressing patient bias and discrimination

Role	Summarized recommendations
Targeted HCW	**Recommendations on how to respond in the moment** • Assess reason for biased patient language, behaviour or request (1,6,19,27,47,51,52,59,66,69,75,80,91,96,124,147) • Set clear and explicit boundaries when problematic behaviour or language arises (6,25,69,73,81,91,135,141-144) o Inform patient/family about any zero tolerance policies regarding acts of bigotry, discrimination, violence and abuse (52,59,66,81,142,143,177) o Inform patient/family that all employees are capable and competent (47,53,55) o Make it clear that services can be withdrawn if the abuse persists, and that the patient has the option of seeking care with another clinician or facility (59,66,81,124,142,151-153) o If feeling unsafe, physically distance oneself or exit/end the clinical encounter (1,29,67,81,114,116,131,177) • Address the comment in real time – avoid silence, minimizing and banter (2,51,55,81,162) o Address the behaviour to protect other patients who are also affected by the biased behaviour, language or request (142,144) o Engage in open communication with the person (99,119,173) • Remain composed/professional when responding and be as compassionate as possible (27,52,57,66,67,69,71,81,88,107,128,130,142,154) o Ignore the biased comment (41,75,88) o Avoid negative emotion and frame the conversation as positively as possible (82,107,154) o Respect cultural differences and individual needs (52,65,139,150) • Seek advice from colleagues, supervisors and seniors (47,49,67,177) • Assess clinical stability and decisional capacity (6,55,66,108,130) o First, treat and stabilize the patient (6) o If the patient lacks decision-making capacity, persuade and negotiate (6) o If the patient has decisional capacity, inform them that they can leave the care setting and seek care elsewhere (66) • Assess the nuances of the case and where necessary, negotiate to establish mutually acceptable conditions for providing care (1,6,150) • Clarify roles and challenge stereotypes (27,51,55,88) • Report to management (28,29,81,141,142,177) • Document the interaction with the patient (114,135,177) • Consider if the request is clinically indicated/feasible to a reasonable degree (1,18,47,59) • Inform security about any dangerous behaviour, physical attack or verbal abuse/threats (28,47) • Share individual perspective on the biased comment/behaviour with the patient (51,55,57,80) • Discuss with minority staff (or targeted provider) their preference in responding, i.e., continue providing care or opt out (47) • Involve a neutral party or chaperone in interactions with patient/family/visitor (119,150) • Acknowledge and assess one's own privileges, biases, prejudices, and potential for harm (10,52,54,61,71,139,146,177,188)
Colleagues, peers and bystanders	• Demonstrate allyship – support the targeted colleague when witnessing racist incidents (105,106,133,165,175,177,190) • Bystanders observing should directly or indirectly intervene, if safe (1,14,105,177) • Peers should speak up and advocate for their colleagues (106,133, 165) • Collectively advocate for an inclusive, equitable environment (164) • Make room for underrepresented colleagues (122,133,166,156,170)
Unit or team	• Check-in and debrief as a unit after each incident (19,20,25,80,98,105,106,117,186) • Collaborate to create a team plan to protect targeted individuals and/or debrief the incidents (98,135) • In a debrief, cover the following: what went well, challenges experienced, ways to improve and ways to ensure team safety (41,55,82) • Isolate the abusive patient/family/visitor from other patients if/when necessary (66,141,142) • Promote respectful, professional dialogue to ensure proper treatment of staff and increase diversity (68,79,149) • Discuss the experience of abuse with colleagues, and supervisors for reflection (51,55,63) • Call for an ethics consult, if/when necessary (116,134) • Assess team culture and create a safe space where everyone has the opportunity to process and validate their feelings (14,92,120,133,166) • Leaders ought to facilitate reflective dialogue on sensitive topics (including racism and diversity) (1,67,98,114,121,166,171,177) o Create an open environment for dialogue where sharing on experiences of racism is understood as acceptable and reportable (121,171) o Ensure that white nurses develop the racial stamina to be able to hear the experiences of nurses of colour and engage in authentic cross-racial discussions (120)
Learners	• Report incidents to supervisors (3,25,27,41,163) • Learners have the option to suggest another resident continue with the patient's care (41)

Preceptors	• Debrief with affected trainee immediately after the incident (1,19,25,27,61,73,131) o Provide support to the learner, especially in identifying and addressing bias, discrimination and abuse (27,161,166) o Involve trainees when determining response to the patient and planning next steps (73) • Reaffirm the trainee's role and competence (1,19,27,59,61,73) • Provide learners with opportunities to practice responding to potential patient bias scenarios that might arise with patients (75) • Acknowledge and address harmful comments from patients, and the impact on trainees (1,3,19,61,73,83,131) • Set expectations and discuss protocols for responding to biased patients at the start of the relationship with trainees (1,3,73,163) • Create caring and accepting learning environments (3,27,71,80,87) • Preceptors should model appropriate behaviour (3,27,71,80,87) • Faculty should halt the problematic patient behaviour through a calm, professional response or interruption (19,73) • Inform patients that discriminatory behaviour is impermissible and will not be tolerated (3,19,73) • Alert patients in advance/make them aware of the presence of medical students and learners (55,61) • Temporarily remove learners from the biased interaction (55) • Empower learners to remove themselves from discriminatory encounters, if necessary (61,117)
Supervisors and managers	• Assert targeted clinician's competency and role (18,134,174) • Set expectations that everyone is treated with respect, and that discrimination is not tolerated (18,131,143) • Provide support and debrief with the targeted clinician (18,105,115,134) • Explore reasons for the patient's request, including speaking with the family (18,134) • Reassign and/or transfer harmful patients and explain the transfer of care (105,135,174) • Model effective and supportive leadership by calling out harmful patient behaviour (14,177)

Table 7. Institutional recommendations to address discriminatory behaviour

Recommendation theme	High-level recommendation	Detailed explanation
Education	Implement training on how to address discrimination and harassment	• Implement bystander training to teach staff how to support their colleagues should they be targets of patient bias, discrimination and/or harassment (42,65,67,71,78,83,87,105,110,131,161) • Provide staff with the necessary skills/education required to address/challenge racism, racial discrimination and racial prejudice (1,2,3,43,55,62,103,108,152,176,179) • Provide education on how to respond to biased or discriminatory requests/refusals (1,7,55,76,87,98,99,110,115,116,117,131,132,157,162) • Build content on discrimination, and the various forms it may take into pre-clerkship curricula (1,55) • Educate clinicians on their rights and responsibilities as employees/care providers (1,56,81) • Provide training on self-defense to aid in situations of violence and aggression (28)
	Embed equity, diversity and inclusion (EDI) training across the institution	• Embed anti-racism, anti-discrimination and EDI training and education into core institutional trainings (61,71,73,76,103,145,160,164,167,177,188) • Provide cultural diversity, cultural competency, and cultural safety training (7,50,67,76,96,117,118,122,170,180) • Update curricula to be more EDI oriented (1,55,165) • Provide diversity management training for those in leadership roles (97) • Institute ongoing/longitudinal and mandatory EDI training for all (1,50) • Provide targeted training for migrant minority nurses to facilitate integration into the new work country (7,8,50,189)
Learners	Implement specialized training for learners to prepare them for incidents of patient bias	• Preceptors should set expectations and prepare learners for potential discriminatory events (20,55,62,67,117,157) • Residency program directors should be proactive about developing formal methods to monitor and address instances of bias or discrimination experienced by residents (85) • Physiotherapy programs should include anti-racist resources and education programs to aid learners (166) • Institutions ought to ensure that trainees are provided with resources, supports and guidance on how to address microaggressions from patients (56,83)

	Implement measures to ensure for diversity in healthcare education	• Implement efforts to increase diversity within trainee programs (85,96,166) • Nursing education should integrate decolonizing approaches that bring together diverse stories to inform the values and structures embedded in nursing curricula, teaching methodologies and professional development (171) • Nursing programs need to adopt strategies that best fit students' needs and provide resources for the success of minority students in clinical education practice (58) • Faculty should set the tone for patients and families by demonstrating respect and the use of proper titles for trainees once patient encounters/interactions begin (87) • Education programs should recognize and address inequalities experienced by learners as a result of longstanding systemic factors (164)
	Prioritize exemptions for students/ learners based on their needs in the moment	• Students should be exempted from providing further care to biased patients but should also be given the option to continue providing care/not be removed, should they wish to stay (3) • Academic programs to foster a welcoming environment of diversity, equity and inclusion (51,58,75,83,96,131,132,161,166,177)
Accommodation	Understand the conditions for accommodating requests for specific providers	• Accommodate culturally or religiously appropriate requests (1) • Accommodate clinically indicated concordances (3) • Accommodate or work towards mutually acceptable conditions for patients who are prone to biased behaviour as a result of psychiatric illnesses or cognitive impairment (70,151) • Competent patients have the right to refuse care, including care from an unwanted clinician and should be treated in a compassionate and respectful manner, even if the clinician feels hurt or unfairly stereotyped by the patient's request (27)
	Acknowledge obligations to care and to accommodate	• Hospitals are under no obligation to provide additional physicians on account of patient prejudice (65) • The decision to accommodate racist demands for a particular provider or to exclude particular providers is at the discretion of the treating institution (70) • Processes to ensure continuity of care for patients needing transfer when they refuse to be treated by the team are needed (117) • In smaller communities, where there are fewer choices, the obligation is greater to make the physician-patient relationship work because patients do not have alternative sources of care (124)
	Establish limits and boundary-set against accommodation	• There is a duty to challenge patients who do not wish to be seen by particular health professionals or staff because of their ethnicity (151) • Institutions should not accommodate patients in stable condition who persist with reassignment requests based on bigotry (6) • Accommodating racist demands says that the institution believes complying is more important than respecting the dignity of their staff and the majority of patients (70,151) • Healthcare institutions should not accommodate discrimination (93) • If a patient persists in racist language or behaviours following a verbal reminder about a code of conduct, the care team should assess the individual's ability to be discharged (105) • If a racist and disruptive patient does not have a medical condition requiring emergency stabilization and could otherwise be treated as an outpatient, discharging the patient is acceptable (105)
Professional Bodies	Acknowledge the problem and establish anti-abuse policies	• Professional bodies should issue statements and guidelines that address discrimination, including discriminatory requests for providers and the intersectional nature of discrimination that many women of color experience (65,155) • Leading nursing organizations should release position statements regarding racial and ethnic discrimination experienced by minority migrant nurses (97) • Professional bodies should develop position statements that addresses race-based physician requests (134) • Medical regulators should address racism in anti-abuse policies to give clinicians guidance on how to respond (157,162)
	Embed cultural competence and de-escalation strategies into professional standards of practice & codes of ethics	• Cultural competence and the de-escalation of conflicts should be integrated into professional standards of direct care practice (159) • Codes of professional ethics should provide guidance on how to respond to patients who engage in disrespectful behaviour (64,142)
	Generate discussion within the profession to support individual institutions and clinicians	• Professional bodies should start broader dialogue about the influence of racism in the healthcare workplace and the importance of increasing workplace diversity (79) • Greater crosstalk needed between organizations and professional bodies; organizations need to have an understanding of the available guidance from associations, legislation and professional colleges to develop consistent responses to discriminatory care provider preferences (18)

Research	Policy on the topic must be informed by research on lived experiences	• Research that explores the lived experiences of LGBT nurses is necessary to establish fair and effective policies for managing conflicts (67,114) • Future research exploring discrimination against clinicians from nonvisible and visible minorities is needed (160) • Future work should focus on the experiences of residents and consider the impact of these events on the individual and the training environment (161) • The experiences of nursing staff should be assessed to determine whether sexual harassment is an issue within the organization (181) • Research on sexism in healthcare and how the hierarchy of medical professionals affects the way patients view doctors and nurses is needed (169) • Research related to nursing students' experiences of racism is needed (157)
	Research to inform evidence-based interventions is needed	• Research agendas on the topic is necessary to combat racial discrimination in the workplace (61,68) • Research on microaggressions from patients is essential to establish evidence-based processes and policy protocols on how to handle these incidents (67) • Future research should explore and evaluate the effectiveness of interventions i) targeting racism, ii) decreasing misidentification of women physicians, and iii) that prevent and combat violence in the workplace of health professionals (86,177,182) • Research on how institutions should support HCWs experiencing abuse from patients (30)
Institutional resources and supports	Provide communication tools to aid discussions	• Provide communication scripts for use with discriminatory patients (25,43,56,73,82,105,106,112,117) • Integrate communication tools (i.e., intake questionnaires or scripts) to ask about gender-based preferences regarding care providers (150)
	Consider patient contracts or care plans	• Use patient contracts to address biased or discriminatory behaviour with clear consequences for repeated violence (3,105,129) • Integrate contracts or care plans for repeat offenders of racist verbal aggression clearly outlining behavioural expectations when receiving emergency and hospital-based care (105)
	Create and distribute signage across the institution	• Post notices that all patients are welcome, that hospital staff are diverse, and that care will be administered by an available provider; a medically unstable patient can be stabilized and diverted to another facility if unable to accept this policy (31,66) • Post signage to reinforce values of mutual respect in the clinical encounter (73,105)
	Create multidisciplinary action committees to help adjudicate	• Create a diversity action committee or an equity task force (which has power equal to other units in the organization reporting directly to leadership) that examines local contexts and implements solutions raised by oppressed groups (71,164) • Build a multidisciplinary taskforce to spearhead education initiatives addressing discriminatory patients (117) • Implement an interdisciplinary committee to address discriminatory patient behaviour (129) • Use Coordinated Care Review Boards to identify: i) problematic/negative behaviours, ii) limit negative behaviors, and iii) promote a culture where mutual respect is valued and practiced (129)
	Offer targeted resources and support based on need	• Invest in security and provide resources and training for self-defense (28) • Establish a well-advertised sexual harassment office whose role extends to the hospital setting (161,167) • Offer confidential counselling (167) • Institutions should have an ombudsman for staff to turn to when they face abuse (161,167) • Contact information for ethics consultation service should be made available (91) • Additional funding and supports are needed to strengthen the mental health of long-term care facility staff, including those that address mental health consequences of discrimination that staff encounter from residents while performing their job (65) • Explore legal recourse for physicians of colour if healthcare organizations tie their pay to patient satisfaction scores (68) • Consider public investments in safety measures to contain and treat cases of assault (182) • Hold interventions between nursing home residents and staff (102)
	Embed existing legislation and protocols, where appropriate	• Incorporate relevant legislation when responding to patient bias (e.g. The Race Relations Act 1979 and Race Relations (Amendment) Act 2000; The Commission for Equality and Human Rights in the U.S) (158) • Incorporate relevant guidelines or protocols available in the literature (e.g., use of UHN's caregiver preference protocol while accounting for contextual adaptations for specific countries). Additionally, ethnicity of the practitioner, hierarchical level of power as well as the political climate should be considered (174)

	Create professional development opportunities and support groups	• Create program-specific women’s professional development groups for support and broader interventions on gender bias (42) • Create a mentorship program for residents to feel comfortable and to help obtain advice when reporting incidents of discrimination (26) • Implement various leadership initiatives to build and foster necessary leadership skills (122,164) • Programs and departments could encourage and sponsor underrepresented individuals to pursue leadership positions (122,164) • Create mentorship and sponsorship programs for historically excluded peoples (122,170) • Create ways for BIPOC staff/students to share experiences of racism or trauma, strategize ways of coping, and connect with others (10,60,79,165,166,167) • Support the integration of immigrant and migrant nurses (7,50,97,179)
Policy	Recommended types of policies for addressing patient bias	• Policies ought to embed zero tolerance to discrimination and abuse towards HCWs (26,66,83,93,105,105,118,151,153,174,175,180) • Institutions should enforce anti-discrimination, anti-racism and anti-abuse policies from all levels (53,60,61,63,68,113,137,159,169,171) • Policy needs to address discriminatory patients in a way that protects HCWs (20,31,43,61,80,87,93,117,128,141,142,144,190) • Institutions should issue policies on human rights and sexual harassment (155,167,181,188,192) • Institutions should create patient and visitor codes of conduct that outline acceptable behaviours towards HCWs (26,105,106,115,135,162) • Institutions should develop trainee/learner specific policies (3) • A Practitioner’s Rights Law complementary to the Israeli Patient’s Rights Law should be established to delineate the rights and obligations of practitioners as well as provide legal and perhaps, moral grounds for handling various incidents of racism in healthcare organizations (174)
	Policy considerations to embed	• Policies on the topic need to explicitly address patient bias (3) • Policies should recognize patients’ past experiences (including discrimination in the healthcare system) (3) • Anti-discrimination prevention efforts need to be multimodal (including individual efforts, workplace policies and the promotion of tolerance and respect across various levels of society) (185) • Policy drafting should involve multiple disciplines with expertise in conflict resolution and counselling, educational leadership and union representation (3) • Reassignment requests should be addressed separately to guidelines on patients’ biased conduct (3) • Policies must be infused with follow-up and accountability procedures (60,108,122) • Policies should have transparent processes for reporting discriminatory behaviour and other potential biases (121,171) • Policy should use language that incites an active and systemic response (25) • Policies should include pathways to documenting microaggressions and being transparent about the frequency of such events and approaches to addressing them (101) • Policies should identify antiracist actions with measurable goals, objectives and timelines (60) • Policies should review and strengthen existing antidiscrimination and EDI policies (2,50,89,177,190) • Policies should be posted publicly so that patients and visitors know what to expect before going to the hospital (81) • Policies need to recognize patient vulnerabilities and rights as well as the rights and responsibilities of staff (3,29,79,93) • Policies should include formal processes that embed discussions with the affected healthcare worker and discussions with the team to share and learn from such experiences (186) • Policies should recognize the impact of such incidents on bystanders/onlookers (19)

Institutional Culture	Address the lack of diversity in the workforce	- Increase diversity at the senior management levels (82,83,85,96,122,123,165,170,180,190) - Address the hiring practices to ensure for a diverse workforce (96,103)
	Set transparent expectations for patient conduct	- Organizations need to make choices about whether and how to communicate the existence of care provider preference guidelines to their patients (18) - Patients should be made aware that there are consequences for abusive or discriminatory behaviours towards HCWs (26,81) - Proactive communication about values, equity, diversity & inclusion, and intolerance for biased or harmful patient conduct towards staff should be made clear (1) - Leadership should enforce accountability at the individual and group levels (71)
	Challenge problematic internal culture	- Institutions should challenge and change institutional, systemic, cultural and societal policies and practices that manifest and support racism (84,164) - Institutions should name and recognize issues of prejudice and discrimination (43,179) - Institutions should immediately confront racism (2) - Institutions should recognize that racism permeates all levels of society (177) - Institutions should incorporate mechanisms that enforce/support a safe and inclusive workplace (19,68,84,118,140,147,186) - Healthcare culture must be respectful and civil for patients to be expected to behave respectfully toward staff (64) - Institutions should foster a culture of transparency that includes open communication (81,99,105) - Institutions should create cultures where workers feel secure to voice their concerns about racism and know that they will be taken seriously (19,147) - Implement cultural safety to address issues of bias and discrimination (10)
Documenting & Reporting	Standardized methods of reporting and tracking	- Create a standard way to report and address discrimination from patients (3,6,21,25,26,45,60,65,73,74,85,105) - Create tracking and data collection mechanisms and procedures (3,6,19,25,85,105,123,163) - Implement confidential annual mistreatment surveys for longitudinal tracking and intervention (117)
	Culture of reporting and accountability	- Improve institutional attitudes towards reporting (19,26,110,113,164) - Create cultures of reporting without fear of reprisal or retaliation (19,26,110,113,164)

Sociopolitical Context – Geopolitical Influences

Of the 173 articles, 20 articles referred to a broader sociopolitical context in which they were written. This includes civil litigations brought forward by racialized HCWs in the US in response to hospital accommodations of racist patient requests (n=3), most notably, the Smith v CNA Financial Corporation (49) and the Chaney v Plainfield Health Care Center (31) cases in 2010, as well as the Battle v Hurley Medical Center (70) case in 2012. Similarly, public cases of physician advocacy/speaking up about experiences with patient bias/discriminatory requests/refusals in the media (154) were also noted in the literature. Other articles referenced highly publicized instances of police brutality, most notably, the 1993 Stephen Lawrence Inquiry and resulting Macpherson report in the UK (2,151) and the 2020 murder of George Floyd in the US (84,120). Sociopolitical changes in various geographical areas (e.g., the US and Sweden) were also contextualized in some articles on patient bias (25,107,190). For example, some authors situated their experiences within the context of an increase in white nationalism in the US once the Trump administration was sworn into office (25,107), whereas others pointed to the increased xenophobia associated with the increasing rates of immigration in Sweden (190). Other significant geopolitical events referenced as affecting preferences for specific HCWs were the Iraq war (57,118), COVID-19 pandemic (28,87,187) and the ongoing conflict between Israel and Palestine (30,172,174), which were also significant events affecting patient bias and preferences for specific providers/refusals of others.

DISCUSSION

The aim of this scoping review was to identify predominant themes, experiences and recommendations for HCWs when navigating discrimination from patients, their family members and visitors. To our knowledge, this is the first scoping review that reviews English qualitative, quantitative and review articles examining all types of discrimination from patients towards HCWs, with an exclusive focus on generating both individual and institutional level recommendations for change. While other scoping reviews have explored racism in healthcare, with some examining the experiences of HCWs (192,193), the topic of focus tends to be on how racism is discussed/produced in healthcare settings (193,194), or the various anti-racism interventions currently at play (195). The current study expands upon the available literature by describing the variation in the types of discrimination experienced; who is most targeted; the impact of the discriminatory experience(s); responses to the discriminatory incident, including whether or not it is reported; barriers to addressing the incident and to reporting; and most notably, recommendations for change at both individual and institutional levels.

As with other studies, our review identified that discussions on discrimination in healthcare are largely situated within the US context (193,194) with smaller pockets in the UK and Canada. Our findings confirm earlier remarks that the experiences of physicians and physician learners dominate the literature in this area (17). This is closely followed by the experiences of nurses and nursing learners. The predominant focus on physician and nurse experiences puts into context the article distribution across mainly medical and nursing journals. Our review also focused on the social identity of the targeted healthcare worker, noting the significance of intersectionality and the predominance of anti-Black racism. Several of the discrimination experiences noted focused on multiple aspects of the healthcare worker's identity as opposed to a singular focus (for example, a Black, Muslim, female doctor experiencing discrimination on account of her racial background, gender identity, and religious affiliation). Evidence of anti-Black racism was particularly clear in the US context, where there were more precise descriptors used to capture the specific racial background of the healthcare worker (14,20,55,61,82,94,117) as opposed to the UK/European based studies, which tended to focus more on the experiences of "ethnic minority" HCWs (151,152,180).

Given our broadened focus on experiences of all types of discrimination, our review highlights the breadth and depth of discriminatory experiences in an array of healthcare settings. While our findings reveal an overwhelming focus on experiences of racism, particularly, anti-Black racism, there are also several examples of sexism (26,42), homophobia (75,160,110), islamophobia (171), anti-Semitism (31) and xenophobia (190), as well as experiences of discrimination on account of a person's status as a learner (59), their political views (81), the training location (173), their accent (10,62,179), age (82,159), disability (14,139), nationality (85,105,138) and language (145,156). The impact of such experiences is profound; the literature notes that repeated exposure to such experiences takes an emotional toll on HCWs, often leading to feelings of demoralization, stress and burnout (25,43,60,68,75,79,121,176,185). Table 3 confirms the significance of these experiences for HCWs, most notably, how it impacts their emotional and psychological wellbeing, job performance, and job satisfaction.

We identified numerous individual strategies employed when responding to discriminatory experiences. These included de-escalation strategies, care transfers, confrontation-based and avoidant-based strategies, among other tactics. Interestingly, strategies employed in response to these incidents varied according to role and were often associated with specific responsibilities (e.g., if a preceptor witnessed a discriminatory experience endured by a learner, there were often specific supervisory responsibilities for escalation associated with the role). Despite this, variances in responses and strategies employed supports the need for carefully curated standards, guidelines and protocols for navigating these issues in a uniformed way.

Our results suggest that various barriers operating in the clinical environment prevent HCWs from reporting and responding to these incidents in effective ways. How one responds, and to whom one escalates an incident, has direct implications on how the incident is triaged, but also affects future reactions and responses. While some have written about the need for effective policy on the issue (17-23), the creation of such policies is just now gaining traction. This review sets the stage for further research on the experiences of HCWs, particularly as it relates to evaluating responses to discriminatory requests/behaviour, and removing barriers that prevent proper responding, reporting and escalating. Our findings provide the foundations for evidence-based mobilization on this issue. The recommendations identified in Tables 7 and 8 provide instructions for institutional efforts to establish anti-discrimination policies and set organizational standards on addressing discriminatory behaviour, and requests/refusals of care providers. Given the predominant focus on the experiences of physicians and nurses, we caution that the recommendations provided are largely situated within the medical and nursing dimensions. We therefore note that future research needs to go beyond these two professions and consider the usefulness of these recommendations for the health professions more generally.

Our findings are situated within contentious sociopolitical and geopolitical contexts (e.g., the murder of unarmed Black men, Israel-Palestine conflict, COVID-19, white nationalism). These observations remind us that the frequency and focus on who is targeted/who experiences discrimination cannot be separated from the larger context of who comprises the healthcare workforce (i.e., the contemporary diversification of the healthcare workforce globally). This is significant given the historical exclusion and segregation of Black and other racialized people from medical and nursing schools in the US and Canada, which had a direct effect on who accessed the profession and when (196-198). Many of these schools enforced strict racial quotas or outright bans on Black applicants, effectively excluding them from these professions (e.g., McGill University and Queens University, in Canada). In fact, it wasn't until 2018 that Queens University officially repealed the 1918 ban against Black applicants, with its formal removal in 2019 (196,199). The discussion on discrimination from patients must be contextualized within this history of systemic racism, segregation, and exclusion as it provides insight on the social dynamics and contemporary trends observed within healthcare leadership, and healthcare systems, more generally.

Addressing discrimination in healthcare requires a multifaceted approach. Firstly, healthcare organizations must prioritize creating work environments that denounce discrimination of all kinds. This involves implementing zero tolerance policies and protocols that effectively address instances of discrimination and provide HCWs with necessary support and protection. These policies must be rooted in evidence-informed interventions that actually protect HCWs and provide the necessary supports and resources to address the situation. Additionally, effective training and education on the topic must be provided to HCWs and patients, ensuring that healthcare spaces remain inclusive for all involved in the provision and receipt of care. Lastly, as the healthcare workforce continues to make strides in reflecting the global majority, individual organisations must make concerted efforts to retain their staff, as continued exposure to these experiences will contribute to many leaving the healthcare field in droves, thus further exacerbating existing staffing shortages in particular fields.

LIMITATIONS

This study is limited to English language articles identified through the 4 databases searched. This means engagement in this topic in other languages and outside of the disciplinary domains explored is not captured in our analysis. Additionally, while the use of multiple independent reviewers and extractors supports the reliability of the selection process, this could have introduced some level of discrepancy throughout the process. We attempted to correct for this by holding regular meetings to go through any discrepancies noted, and to also do joint screenings and extractions. Lastly, the lack of disciplinary diversity in our findings is a significant limitation in that there may be nuances specific to some disciplines less commonly represented in the literature that might make them more or less susceptible to particular types of experiences and interactions with patients. For example, the manner in which physiotherapists or occupational therapists interact with patients might call for a unique response to discriminatory comments or aggressive behaviour not reflected in the identified recommendations.

CONCLUSION

This scoping review mapped the state of the literature on healthcare workers' experiences of discrimination from patients, their families and visitors. Our review highlights the need for concrete guidance and protections from employers, professional bodies and health systems more broadly, especially in light of the clear tensions in obligations to patients and HCWs. Good quality patient care can only be truly optimized in spaces where HCWs are physically and psychologically safe to perform their duties. This calls for broader acknowledgement of the multidirectional nature of discrimination in healthcare, especially when considering policy-related interventions aimed at addressing violence and behavioural issues in clinical work environments. Additionally, further research on the experiences of HCWs across the health professions and at various stages of training would bolster the academic literature in this area, especially if supplemented with jurisdiction-specific legislation on employer obligations to prevent harassment and provide a discrimination-free work environment.

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None to declare

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APPENDIX A

Search strategy: Ovid MEDLINE(R) ALL 1946 to June 08, 2023

#	Searches	Results
1	microaggression/	114
2	(microaggression* or micro-aggression*).mp.	714
3	*racism/	5194
4	exp *prejudice/	21405
5	exp *bias/	7183
6	*Discrimination, Psychological/ [discrimination, psychological/ appears to be an inappropriate subject heading that has been applied to at least 1 key paper, therefore including it]	9137
7	exp *social discrimination/	9375
8	social marginalization/	585
9	*stereotyping/	5684
10	racis?.mp.	12160
11	(sexis? or misogyn*).mp.	4720
12	(homophob* or transphob* or biphob* or aphob* or panphob* or lesphob* or lesbiphob*).mp.	2412
13	prejudice*.mp.	30770
14	bias??.ti,kf,hw.	71463
15	discriminat*.mp.	316900
16	(hate or hateful* or hatred).mp.	1985
17	or/1-16	427951
18	organizational policy/	14523
19	(pc or lj).fs.	1684997
20	exp Policy Making/	28219
21	institutional practice/	1257
22	professional practice/	17112
23	exp Ethics/ and (practic* or guid* or respons* or react* or address* or respond* or dilemma*).mp.	55108
24	addressing.ti,kf.	12926
25	recommendation?.mp.	340852
26	guideline?.mp.	596778
27	((practitioner* or clinician* or doctor* or nurse* or "hcp's" or provider* or staff or resident* or intern? or therapist* or physiotherapist* or allied health or health profession*) adj2 (race or ethnic* or religio* or cultur* or languag*)).mp.	5776
28	(policy or policies or policymaking).mp.	439192
29	framework*.mp.	397825
30	((professional or institutional or organizational) adj3 practices).mp.	2940
31	organization??.mp.	1013911
32	institution??.mp.	372974
33	process??.mp.	2503388
34	(ethic* adj6 (practic* or guid* or respons* or react* or address* or respond* or dilemma*)).mp.	28366
35	((structural or institutional or organizational) adj2 competen*).mp.	505
36	(action? or inaction?).mp.	1062953
37	or/18-36	7049709
38	exp Professional-Patient Relations/	148342
39	exp treatment refusal/	13744
40	(professional adj1 patient).mp.	43001
41	(doctor adj1 patient).mp.	9303
42	(nurse adj1 patient).mp.	37759
43	(practitioner adj1 patient).mp.	733
44	(patient? adj4 relations).mp.	150702
45	(patient adj3 satisf*).mp.	121053
46	((treat* or care or healthcare) adj4 refusal?).mp.	16330
47	((treat* or care or healthcare) adj4 accept*).mp.	79245
48	((practitioner* or clinician* or doctor* or nurse* or "hcp's" or provider* or staff or resident* or intern? or therapist* or physiotherapist* or allied health or health profession*) adj4 experien*).mp.	47420
49	(patient* adj4 (choose or chose? or choice?)).mp.	34046
50	(preferen* adj4 (patient* or famil*)).mp.	34725
51	(prefer??? adj4 (patient* or famil*)).mp.	13823
52	(concordan* and (race or ethnic* or religio* or cultur* or languag* or gender*)).mp.	9651
53	or/38-52	480027
54	17 and 37 and 53	4032
55	(202205* or 202206* or 202207* or 202208* or 202209* or 20221* or 2023*).dt,ez,da.	1994978
56	54 and 55	287

APPENDIX B

Table B.1. Study design references

Study Design	References
Empirical	
Qualitative	8,14,24,30,42-45,50,54,63,65,75,79,84,85,89,93,98,100,102,111,117,121,123,138-140,145-149,156,159,160,165,166,169-175,180,181,184,186,190,191
Quantitative	21,22,26,48,71,74,76,83,86,95,103,104,109,110,115,137,161,163,167,178,187
Mixed Methods	10,56,118,122,157,164,182,185
Commentaries	2,3,28,31,41,46,49,51,55,61,62,64,65,67,69,72,73,77,80,87,88,90,94,96,99,107,114,119,120,124-130,133-135,141-144,150,152-155,176,177,188
Case studies	18,20,27,29,47,59,66,92,106,112,131,158
Review papers	1,7,58,68,78,97,101,116,179,183,189
Essays	52,57,70
Letters	23,136,168
Editorials	105,151
Narratives	91,162
Policy/guidelines	19,81
Ethics rounds	108
Perspectives	6
Workshops	132
Virtual listening sessions	60

Table B.2. Journal type

Type of Journals	References
Medical	1-3,6,14,21-23,25,26,28,36,42,43,45,46,48,49,51,53-55,64,66,68,69,71-74,76,79,82-88,90,94,95,98,99-101,103-105,107-110,113,115-117,125-133,136,141-145,147,148,151,154,155,160-162,164,165,167,168,177
Nursing	7,10,18,24,29,50,58,62,67,77,93,97,106,114,118-122,135,137,138,140,145,146,149,152,153,156-159,170,171,175,176,179,180,184,188,189,191
Health	8,30,44,47,56,57,63,65,89,102,111,123,169,172-174,178,181-183,186,187
Ethics	19,20,27,31,41,59,70,78,81,91,92,124,150
Pediatrics	80,112,134
Psychology	52,75
Occupational therapy	60,139
Law	96
Social work	190
Pharmacy	185
Physiotherapy	166

Table B.3. Journals most frequently published in

Journal Name	References
The Journal of the American Medical Association	23,46,49,51,64,74,85,87,98,110,113
British Medical Journal	2,28,136,141-144,148,154
Annals of Internal Medicine	3,79,125-130
Academic Medicine	1,14,25,72,86,104,117
AMA Journal of Ethics	19,20,27,41,81,91
Journal of General Internal Medicine	43,45,103,109,132,161
Canadian Medical Association Journal	160,162,165,167,168

Table B.4. Study setting

Study Setting	References
Hospital settings	
Academic hospitals	1,14,18,20,21,22,25,26,27,31,41,42,43,44,45,46,48,51,55,56,61,66,72,73,74,76,81,83,86, 87,89,90,91,93,94,98,101,108,109,110,112,114,115,117,123,125,126,127,128,129,130, 132,133,142,151,155,157,161,164,167,168,181,187
Public hospitals	30,154,172,174
Non-specific hospital type	2,6,8,24,28,29,47,49,50,53,59,69-71,77,82,92,95-97,99,100,103,105,116,118,119,121,122,134,135,139,141,143-145,148-150,152,153,156, 159, 162,166,169,170,178,179,182,184,188,191
Residential care facilities	
Nursing homes	50,102,137,159,183,186,189
Long term care	63,65,189
Residential/home care	24,190
Hospice	106,189
Community care	75,118,139,158,170
Rural healthcare facilities	175
Medical centres	3
Public and private health services	180

Table B.5. Clinical context

Clinical Context	References
Nursing	7,10,50,67,78,120,140,147,159,171,176
Emergency departments/Urgent care	14,20,53,59,91,95,105,119,122,134,150,177,182
Primary health care	57,79,107,111,124,148,160,173
Pediatrics	2,56,80,117,123,153
Internal medicine	41,43,87,110,115,161
Surgery	74,76,83,92,123,135
Orthopedics	66,71,91,133
Medicine	23,64,121
Oncology	46,92,108
Obstetrics and gynecology	27,61,100
Pharmacy	168,185
Mental health	52,77,112,147,176
Occupational therapy	60,139
Rural health	191
ICU	53
Dermatology	48
Cardiology	90

Table B.6. Target of discrimination, harassment and assault

Target	References
Physicians	1,2,6,8,14,18-23,25-27,31,41-49,51-57,59,61,66,68-74,76,79,80,82,83,85-92,94-96,98,99,101,103-105,107,109-111,113,115,117,123-134,136,141-144,150,155,160-164,167-169,172-174,177,178,187
Medical learners	1,14,19,20,21,22,23,25- 27,41,42,44,46-48,51,53,55,56,59 61,66,72-74,76,83,86,91,94,101,104,110,113,115,117,123,125,131,133,134,142,161,163,164,168,177,187
Nurses	1,7,10,18,24,28-30,50,58,62,63,65,67,77,78,93,97,102,106,108,114,118-122,135,138,140,145,146,147,149,152,153,156-159,169-171,175,176,178-184,186,188,189,191
Nursing students	1,3,58,62,67,138,146,157,174,176
Psychotherapists	52,75,112
Physiotherapists	84,166
Occupational therapists	60,139
Pharmacists	185
Healthcare workers	116,148,149,151,154,165

Table B.7. Type of discrimination, harassment and assault

Type of discrimination, harassment and assault experienced	References
Physicians	
Racial identity	1,6,19,25,46,49,54,68,79,85,89,90,99,103,105,107,111,124,131,162,174
Gender identity	1,54,69,71,89,90,131-150,155
Religious identity	31,60,89,109,117,140,173,174
Sexual orientation	160
Ethnicity	103,173,174
Nurses	
Racial identity	7,10,24,28,50,77,91,93,108,119,120,121,135,140,147,149,152,153,158,169,175,176,179
Ethnicity	30,78,118,138,152,159,180,186,189
Gender identity	18,30,67,93,169,188,191
Sexual orientation and religion	93, 171
Medical residents	
Racial identity	1,46,55,66,82,85,91,94,117,125-127,129,130,158,168
Gender identity	42,113,168
Religious identity	1,53
Medical students	14,20,22,27,44,51,113,117,123,132,133
Racial identity	14,20,132
Gender identity	14,27,51,113,117,133
Religious background	14
Trainees and Interns	
Racial identity	61,72,177
Gender identity	61
Religious identity	1

Table B.8a. Type of discrimination, harassment and assault experienced

Type of discrimination, harassment and assault	References
Refusals of specific care providers	1,2,6,7,10,14,24-26,29,30,31,43,46,49,53,57,63,66,79,84,89,91,93,94,96,97,98,102,103,105,106,109,110,112, 117-119,121,132-134,138-140,153,159,162,166,171-175,180,185,186,190
Requests for specific care providers	3,19,27,31,41,43,45,47,50,56,57,59,70,81,91,105,119,121,134,135,150,166,170,173,177,188,190
Discriminatory comments	1,3,6,8,10,19,20,25,26,28,30,41-44,46,48,49,50,55,60-63,65,67,68,71,72,74,76,77,79,80-85, 89-93,5,97,99,101,102,105,107,108,110,112-115,119,121-123,125,127,131,133,135,138-141, 146,147-149,152,156,157,159,160,161,163-169,171,173,176,183,186,187,189,190,191
Sexual harassment	1,7,14,21,26,44,48,56,65,74,98,110,113,157,159,161,163,164,167,177,181,183,184,185,188
Physical assault	21,28,29,30,133,138,147,157,161,167,169,182,183,191
Inappropriate comments	7,14,21,51,69,73-75,108,132,163,164,184

Table B.8b. Nature of the discriminatory request, refusal or comment

Identity characteristic of the HCW related to the discrimination	References
Racial background	1,2,6,7,10,14,19,20,24,25,28,29,43,45-47,49,50,53,55-57,60-63,65,66,68,70,72,77,79, 81,82,83,84,91,93,94,96,98,99,101-103,105-108,110,112,115,117,119,121,122,123, 125,131,133-135,137-141,145-147,149,152,153,157-159,161,163,165,166,168-171, 175, 176,179,180,183,185-187,189,190
Gender	1,14,19,24,26,27,42-45,48,56,71,74,76,81-83,90,93,98,101,113,115,117,150,157,161, 163,164,168,185,188,190,191
Age	1,42,45,55,56,81,82,159
Accent	10,62,81,112,121,159,168,169,179,186
Disability	14,43,139
Nationality	8,41,46,50,72,85,97,105,112,121,138-140,145,186,190
Religion	1,19,31,53,81,89,92,93,98,109,110,115,117,127,141,171,173
Language	58,145,156
Learner-status	59
Sexual orientation	19,67,81,82,110,114,148,160,161,167
Ethnicity	19,30,80,81,84,92,93,96-98,109,115,117-119,127,172-174,190
Weight	81,123
Political views	81,173
Training location	173

Table B.9a. Barriers to reporting – experiences of patient bias reported/not reported

Barriers to reporting	Reference
Patient bias not reported	24,25,30,43,63,77,85,86,102,110,122,139,149,166,167,175
Patient bias reported to a supervisor, manager or attending	20,26,27,29,48,53,61,75,76,80,83,84,89,91,93,94,106,108,125,127, 135,138,153,157,158,181
Some patient bias experiences reported but not all	26,48,53,76,83,138,153,157,181
Experiences reported by physician learners to their supervisors	20,27,61,91,94,125,127
Experiences reported by nurses to their managers	29,93,106,135,158
Experiences reported by clinical learners to their supervisors	75, 84

Table B.9b. Barriers to reporting – actual barriers faced

Barrier reported	Reference
Fear of retaliation, repercussion or retribution	1,53,65,67,68,76,78,89,139,149,163,166-168,180,181,183
Assumption that the experience would be dismissed, ignored or unaddressed	26,53,75,76,85,122,166,167,181
Lack of support from management	63,81,93,146,159,183
Culture of silence and submission	55,113
Prioritization of patient care	65,67,110
Feeling disempowered to raise issues of racism in the workplace	79,103,145,177
Concerns about creating conflict in the workplace as key barriers to reporting discriminatory experiences/assaults	26,79,85
Feeling the need to handle these issues alone	79,175
Downplaying incidents as not serious enough to report	48,63,75,102,167,175
Normalizing experiences of harassment	24,63,65,166,181
Feeling pessimistic about the likelihood of such situations changing	102
Being too busy with other responsibilities	26,76,85
Feeling dissuaded by cumbersome reporting processes	89
Not knowing where or how to report	26,73,174
Lack of policy or standardized protocol	3,30

B.10. Barriers to addressing bias and discrimination

Barrier Domains	Barrier Reported	Reference
Personal Barriers	Low clinician capability, comfort and confidence in responding	7,18,57,82
	Desensitization, normalization and diminishment of one's experience of mistreatment from patients, family members or visitors	24,63,65,73,164,181
	Perceived ineffectiveness of responding	98,110,117
	A desire to maintain patient-clinician rapport	51
	Concern that confronting a patient would be too time consuming	73
Clinical Barriers	Clinical context	96
	Speciality	170
	Clinical trainee status/hierarchy	89,160,165
Educational Barriers	Lack of training material/guidance	18,24,50,57,60,63,69,73,82,87,98,99,102,103,110,124,134,150,152,170,176,183,185
	Lack of discussion in education programs	52,125,176
Fear of Reprisal	Concerns re reprisal and retaliation	19,168,180,181
	Fear of legal action	1
	Fear of reprisal on patient satisfaction scores	68,73,80
	Fear of reinforcing the patient's prejudice	154
	Fear of job loss or punishment	140,164
	Fear of becoming a target	122
	Trainees fear of their instructors' reactions	84,89
Legal Barriers	Legislative restrictions on what can be done to address patient bias	1
	hiring conditions/employment nuances	6
Professional Barriers	lack of diversity within the health professions	60,61,91,133,166
	Lack of clear instructions from regulatory colleges on the permissibility of refusing to care for abusive patients	159
	Lack of profession specific knowledge, skill and training to adequately respond	64
Policy Barriers	Lack of policy or an inadequately developed policy	3,30,31,91,98,99,135,156,162,174
	Hcws unaware of the institution's policy on the matter	98,147
	Policies that fail to provide sufficient practical guidance	69,156,185
Institutional Barriers	A lack of action and follow-up on reports	24,28,53,63,65,76,77,79,84,93,101,103,116,122,124,134,138,139,141,149,152,153,159,169,179,182,183
	Lack of support from management and colleagues in dealing with conflict	29,43,50,60,63,76,81,84,85,93,98,135,137,140,152,156,159,162,169,170,174,179,181,183,189
	Institutional prioritization of patients over staff	31,67,93,98,106,116,124,125,138,139,153,159
	Hcws feeling undervalued, devalued and disempowered	7,10,53,60,71,79,82,111,139,140,149,170,175,181,189
	General silence or lack of discussion on bias and discrimination in the workplace	3,60,62,79,81,85,93,97,102,103,114,120,122,139,141,149,153,179,182
	Institutional racism	2,1050,89,111,133,174
	Ingrained gender biases relating to the composition of the healthcare workforce	71,123,164,188,192
	Not taking issues of racism seriously & refusal to call out acts of discrimination	25,137
	Lack of diversity in leadership positions	162,166
	Lack of inclusion of racism in considerations of workplace violence	25
	Lack of data collection on patient interactions	68
	Lack of staff awareness of institutional reporting mechanisms or resources	73,185
	Customer service models of healthcare, resulting in overprioritizing patient's needs	31,70
	Limited presence of staff with seniority or authority to implement consequences	174

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Éthique et pandémie : bilan du Comité éthique COVID-19 et du Regroupement en éthique clinique et organisationnelle du réseau de la santé et des services sociaux québécois

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Résumé
L'éthique a été propulsée au cœur des décisions en santé et services sociaux durant la pandémie. Elle a été et demeure un socle essentiel sur lequel s'appuyer pour prendre des décisions difficiles et favoriser la cohésion sociale en situation de grande adversité. Un des acteurs de cette crise au Québec a été le comité éthique COVID-19, créé pour répondre aux enjeux éthiques urgents auxquels les décideurs ont fait face. La concertation des forces vives de l'éthique dans la province a contribué au succès des travaux du Comité éthique COVID-19. De cette concertation est né le Regroupement en éthique clinique et organisationnelle du réseau de la santé et des services sociaux du Québec. Cet article retrace la création de ces deux instances, leurs mandats et leurs réalisations. Les autrices posent un regard critique sur ces travaux, les gains faits, mais aussi les défis à venir, dont la pérennisation de ces acquis dans un système de santé à l'aube d'une transformation majeure.

Mots-clés
enjeux éthiques, pandémie, COVID-19, rôles et mandats, comité d'éthique, Québec

Abstract
Ethics was thrust to the heart of health and social services decisions during the pandemic. It has been and remains an essential foundation on which to rely to make difficult decisions and promote social cohesion in situations of great adversity. One of the actors in this crisis in Quebec was the COVID-19 Ethics Committee, created to respond to the urgent ethical issues faced by decision-makers. The collaboration of the province's ethical forces contributed to the success of the work of the COVID-19 Ethics Committee. This collaboration gave rise to the Clinical and Organizational Ethics Group in the Quebec Health and Social Services Network. This article traces the creation of these two bodies, their mandates and their achievements. The authors take a critical look at this work, the gains made, but also the challenges ahead, including the sustainability of these achievements in a health system on the cusp of major transformation.

Keywords
ethical issues, pandemic, COVID-19, roles and mandates, ethics committee, Quebec

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CONTEXTE

La pandémie de COVID-19 a eu un impact majeur sur la capacité des établissements à fournir un accès complet aux soins de santé et aux services sociaux. Les projections inquiétantes en matière de santé publique et les connaissances scientifiques limitées au début de la pandémie ont nécessité une réorganisation rapide des soins et des services afin de préparer les hôpitaux à un afflux de personnes infectées. Les pays du monde entier, incluant le Canada, ont dû prendre des décisions dans l'incertitude et l'urgence, en n'ayant accès qu'à peu de données probantes sur le virus. Rapidement, des questions d'allocation de ressources ont émergé (1). Le Québec a connu son lot de difficultés : les maisons de soins pour personnes âgées ont vite été débordées par les éclosions et les morts causées par le virus (2). Une partie du personnel a été malade ou a fui face à l'ampleur de la crise. Le délestage de plusieurs activités chirurgicales en vue d'augmenter la capacité à réagir face à la crise sanitaire et les pénuries diverses (médicaments, personnel, équipements de protection) se sont fait sentir : les listes d'attente pour les chirurgies ont stagné et se sont allongées. Des personnes ont perdu la vie pendant l'attente (3). Comment assurer des soins et des services à tous dans ce contexte? Par exemple, si trop de personnes se présentent au même moment en détresse respiratoire et nécessitent des soins intensifs, un triage pour l'accès devra se faire, faute de ressources. Face à ces défis, des choix tragiques ont fait surface et nous ont plongés au cœur de l'éthique (4,5).

Pour répondre de manière efficace, le gouvernement du Québec, via son ministère de la Santé et des Services sociaux (MSSS), a mis en place un Comité directeur clinique COVID-19 (6) chargé de s'assurer de la production des protocoles, des

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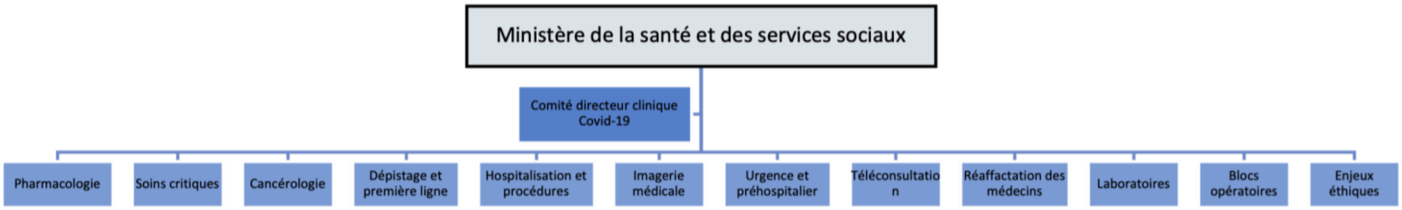
algorithmes cliniques[1] ainsi que des directives ministérielles regroupés selon les différents secteurs d'activités (voir figure 1). Cette coordination fut possible étant donné que le système de santé au Canada est géré par chacune des provinces, ce qui constitue un réseau de services de santé et de services sociaux (ci-après, RSSS). Le système public du Québec, tel que nous le connaissons, a été institué en 1971 à la suite de l'adoption de la première Loi sur les services de santé et les services sociaux par l'Assemblée nationale du Québec. Contrairement à d'autres endroits, l'État agit comme principal assureur et administrateur. Cet aspect est important à signaler, car les mesures prises pendant la pandémie s'appliquent à tout le RSSS et permettent une coordination nationale des décisions et de leur application dans toutes les régions du Québec.

Figure 1. Organigramme de l'organisation du MSSS en temps de pandémie COVID-19



Afin de se préparer à affronter la vague des personnes nécessitant une hospitalisation et éventuellement une assistance respiratoire et des soins intensifs, le Comité directeur clinique COVID-19 a demandé à tous les hôpitaux du Québec de réduire les activités des blocs opératoires à 30%. Il s'agissait également de réagir aux différentes pénuries auxquelles le système était confronté : médicaments utilisés en anesthésie tels que le Propofol et certains curares, les équipements de protection individuelle, le personnel et les lits de soins intensifs. Après plusieurs semaines de réduction des activités, le bilan s'est alourdi. Certains hôpitaux de la métropole montréalaise (devenue l'épicentre de la pandémie au Canada) sont devenus complètement inopérants, victimes d'éclosion dans leurs murs. De nombreux enjeux éthiques émergent : l'allocation des ressources en soins intensifs, la priorisation des chirurgies, l'obligation ou le refus de dépistage, de vaccination. Pour tous ces enjeux et bien d'autres, il n'y a pas d'instance spécifique pour y répondre.

Il y a pourtant urgence d'agir. Certes, d'autres instances existaient, p.ex. : Commission de l'éthique en science et en technologie (CEST), Comité d'éthique de santé publique (CESP), Institut national d'excellence en santé et services sociaux (INESSS), Comité national d'éthique sur le vieillissement (CNEV), Commissaire à la santé et au bien-être (CSBE), mais ces dernières n'étaient ni adaptées pour faire face à l'urgence pandémique ni spécifiques à des enjeux éthiques d'organisation des soins et services, dont les soins intensifs, la chirurgie et la cancérologie. C'est pourquoi le 17 mars 2020, la sous-ministre adjointe Dre Lucie Opatrny, également présidente du Comité directeur clinique COVID-19 du MSSS, a mandaté l'autrice principale de cet article (MEB) pour s'occuper des enjeux éthiques en lien avec les travaux urgents du MSSS pour répondre à la pandémie. Le mandat dans sa description était très large et non spécifique à une question en particulier (enjeux éthiques en lien avec les travaux urgents). Il ouvrait la porte à toute demande comportant des enjeux éthiques en lien avec la pandémie et ne se limitait pas à des saisines provenant uniquement du Comité directeur clinique COVID-19. Le comité éthique COVID-19 avait donc la possibilité de travailler en auto-saisine (la liberté de choisir lui-même les sujets à traiter sans avoir reçu une demande spécifique d'une instance) et de recevoir des demandes provenant d'autres instances telles que les autres directions du MSSS et les établissements du RSSS. Le Comité aurait même pu théoriquement recevoir des demandes en provenance de la population. Toutefois, ceci ne s'est pas réalisé puisqu'aucune publicité n'a été faite en ce sens. Il y a tout de même eu des échanges et des collaborations avec des associations de défense des droits des patients notamment sur la question de la priorisation de l'accès aux soins intensifs en contexte extrême de pandémie.

LE COMITÉ ÉTHIQUE COVID-19 : UNE CAPACITÉ DE SOUTIEN ÉTHIQUE GLOBALE ET ADAPTÉE AUX BESOINS DES INTERVENANTS DU SYSTÈME DE SANTÉ DU QUÉBEC

Une structure souple et fédératrice

La capacité de la mandataire à accompagner efficacement le MSSS a été soutenue par la mise en place d'une structure permettant de mobiliser une expertise diversifiée en éthique (voir Figure 2), autant sur le plan « thématique » que sur celui des perspectives organisationnelles représentées au Québec. Ainsi, et en complément aux structures existantes en éthique, la création d'un Comité éthique COVID-19 (dont la composition et les activités sont détaillées ci-après) a été l'élément structurant central de cette stratégie. En permettant la concertation entre les instances contributives de l'éthique en santé et services sociaux, ce comité, présidé par la mandataire, a pu la soutenir dans l'aiguillage et la coordination des dossiers afin de faciliter une réponse efficace aux enjeux éthiques identifiés et leur diffusion dans le réseau de la santé et des services

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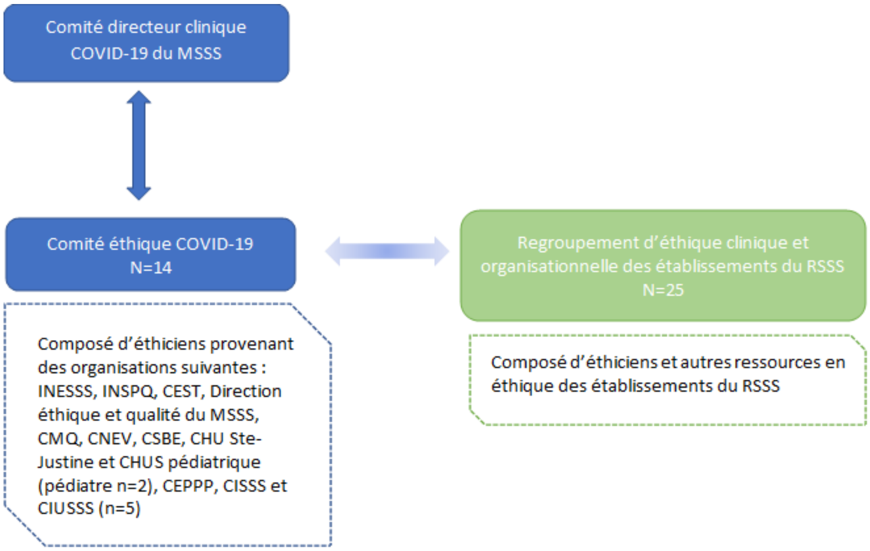
[1] Selon Abiteboul et Dowek un algorithme est « un procédé qui permet de résoudre un problème, sans avoir besoin d'inventer une solution à chaque fois » (7). Les professionnels de santé utilisent des algorithmes comme outils d'aide à la décision clinique dans toutes les étapes du soin, qu'il s'agisse de la prévention, du diagnostic ou du traitement. Ces algorithmes peuvent être représentés sous forme graphique, tels que :

- Des arbres de décision qui présentent des options et leurs conséquences potentielles;
- Des tableaux qui organisent les informations pour faciliter l'analyse;
- Des systèmes interactifs en ligne qui proposent des choix à cocher, chaque sélection déclenchant une suite logique de propositions jusqu'à un résultat final (8).

sociaux et auprès de l’ensemble des parties prenantes. La conduite des travaux s’est faite en impliquant les personnes les mieux positionnées et les plus qualifiées en éthique au Québec pour répondre aux questions qui étaient posées. Le deuxième élément structurant a été le démarrage des activités du Regroupement en éthique clinique et organisationnelle (voir section suivante). Des agents de liaison, les deux autres autrices de ce texte (KB et AM), ont maintenu un lien fonctionnel entre le Regroupement et le Comité éthique COVID-19. Le mandat éthique COVID-19 du MSSS a pu s’exécuter grâce à une vigilance à l’égard de la réalité du « terrain », faisant en sorte d’alimenter en continu la mandataire sur les enjeux éthiques vécus et émergents, et de faciliter certains signalements aux instances gouvernementales. Le mandat individuel est rapidement devenu un « nous » collectif fédérant les principales instances en éthique au Québec.

Figure 2 : Structures créées pour aider à répondre aux enjeux éthiques COVID-19



Fonctionnement du Comité éthique COVID-19

Beaucoup de liberté et de latitude ont été données au Comité éthique COVID-19 pour réaliser son mandat. Ceci a permis d’établir un mode de fonctionnement très souple pouvant s’adapter à tous les types de demandes. Il permettait aussi l’identification, le choix et le traitement de sujets sans qu’une demande formelle soit faite de la part d’une instance (auto-saisine), et ce, en fonction des besoins du moment, selon les informations qui remontaient du terrain. Cette agilité est mise en évidence par la variété des outils et stratégies de soutien éthique déployés. Le degré d’urgence de certaines demandes, leur origine ainsi que la nature variable des besoins expliquent la diversité des méthodes et des processus mis de l’avant selon les différents sujets traités. La concertation autour de chaque question éthique a été un élément central du service rendu au MSSS et aux autres instances avec lesquelles la mandataire et ses partenaires ont collaboré. Dans cette concertation, une attention particulière a été portée à l’inclusion d’une diversité de perspectives et de parties prenantes propres à chaque dossier, dans l’objectif de renforcer l’analyse éthique ainsi que la légitimité d’éventuels avis ou directives gouvernementales. Cette préoccupation s’est tantôt traduite dans la composition équilibrée des groupes de travail, dans la conduite de consultations, ou encore dans l’inclusion systématique de patients partenaires dans les travaux.

UN PARTENAIRE INCONTOURNABLE EST NÉ : LE REGROUPEMENT EN ÉTHIQUE CLINIQUE ET ORGANISATIONNELLE DU RSSS

Se regrouper : l’union fait la force!

La déclaration de l’état d’urgence sanitaire liée à la pandémie COVID-19 par le gouvernement du Québec le 12 mars 2020 a amené plusieurs éthiciens ou ressources en éthique des établissements du RSSS à échanger sur les enjeux éthiques auxquels ils faisaient face ou qu’ils anticipaient. Si certains d’entre eux, avant la pandémie, avaient l’habitude d’échanger et de collaborer, aucun lieu formel n’encadrait ces collaborations. La pandémie a accéléré la création du Regroupement en éthique clinique et organisationnelle du RSSS (ci-après « Regroupement »), impliquant les éthiciens des établissements du RSSS ou autres ressources en éthique, dans le cas des établissements n’ayant pas d’éthicien (ci-après « les membres »).

Plusieurs facteurs ont contribué à la création de ce Regroupement : 1) la mise sur pied au sein du MSSS du Comité éthique COVID-19, dirigé par une conseillère cadre en éthique du RSSS, 2) les demandes grandissantes en éthique dans les établissements du RSSS, 3) les échanges inter-régions de plus en plus fréquents entre les membres et 4) un besoin manifeste de ceux-ci d’échanger sur une base régulière et d’être au fait des travaux effectués par le Comité éthique COVID-19. Un canal de communication plus structuré entre ce Regroupement et le Comité éthique COVID-19 du MSSS a été instauré par la nomination d’agents de liaison parmi les membres du Regroupement. Ces derniers avaient pour mandat de siéger sur le

Comité éthique COVID-19 du MSSS, d'animer[2] les rencontres du Regroupement et de faire le pont entre ces deux instances en informant, d'un côté, les membres du Regroupement des travaux effectués par le comité ministériel, de l'autre côté, les membres du Comité éthique COVID-19 des préoccupations ou enjeux éthiques qui émergeaient sur le terrain.

Si le Regroupement s'est mobilisé au début par solidarité, son importance est vite devenue apparente pour les membres et les établissements qu'ils desservent. L'agilité à s'adapter à cette nouvelle réalité a été fondamentale pour répondre aux besoins des membres d'être outillés pour mieux servir leurs établissements. Le soutien offert aux médecins, gestionnaires, employés et usagers des différents établissements n'aurait pas été possible sans cet espace de réflexion et de partage.

Fonctionnement du Regroupement

Tous les éthiciens ou ressources en éthique des établissements du RSSS sont invités aux rencontres. Lorsqu'un établissement n'a pas d'éthicien, une autre personne-ressource en éthique, ou la personne en charge de l'éthique peut y participer. À ses débuts, le nombre de participants lors de chacune des rencontres hebdomadaires oscillait entre 20 et 25 personnes représentant les différents établissements du RSSS. La participation aux rencontres est volontaire. Un ordre du jour précis soutient les rencontres, mais aucun compte rendu formel n'est réalisé puisqu'il s'agit d'un lieu d'échange et de soutien. L'ordre du jour des rencontres est généralement le suivant :

- Les agents de liaison font le point sur les échanges ayant eu lieu au Comité éthique COVID19 et les travaux en cours;
- Selon les préoccupations du moment, la rencontre peut servir à faire : un tour de table sur les enjeux au cœur des demandes éthiques reçues, une présentation sur un thème pertinent lié à la COVID-19, une discussion sur un document en cours de rédaction, la formation de sous-comités de travail pour approfondir certaines thématiques, etc.

Le Regroupement s'est doté d'un espace collectif de partage de documentation sur la plateforme TEAMS afin de s'entraider et d'accélérer le déploiement d'outils pertinents pour plusieurs établissements.

UNIS AVEC NOS DIFFÉRENCES

Les deux instances, le Comité éthique COVID-19 et le Regroupement, ont été des partenaires indissociables tout au long de la pandémie, misant sur leurs objectifs communs et la complémentarité de leurs mandats respectifs et leur composition. Si le Comité éthique COVID-19 avait un mandat officiel, il n'en était rien pour le Regroupement. Ce dernier s'est donné un mandat et un fonctionnement, qui a été réévalué tous les ans depuis 2022 par ses membres, puis s'est ajusté en conséquence selon les besoins des personnes qui y participent. On peut donc affirmer que le Regroupement fonctionne selon une gouvernance informelle. Il s'apparente davantage à une communauté de pratiques où les éthiciens travaillant en proximité dans les établissements peuvent se réunir, partager leurs connaissances et collaborer pour améliorer leur pratique et la qualité des soins et services offerts.

Ces instances ont agi en complémentarité, jouant chacune leur rôle en fonction de la nature de la demande, de l'objectif des travaux et du contexte. Lorsque la demande émanait du MSSS, le Comité éthique COVID-19 agissait en porteur de dossier, invitant le Regroupement à collaborer à des degrés différents, prenant même la forme de comité de travail conjoint. Cela permettait une mutualisation des expertises complémentaires afin de répondre dans des délais rapides à des questions qui se posaient en continu. Lorsque les travaux du Comité éthique COVID-19 se traduisaient en protocoles (par exemple, la priorisation des chirurgies), les membres du Regroupement étaient impliqués dans l'actualisation de ceux-ci, se faisant, d'une certaine façon, les courroies de transmission dans leurs établissements respectifs. En même temps, les membres du Regroupement, constatant des enjeux sur le terrain, initiaient des réflexions communes et, pour certaines, lorsque pertinente, la collaboration du Comité éthique COVID-19 était mobilisée.

L'exécution du mandat éthique COVID-19 a généré un ensemble de productions de diverses natures, productions qui n'auraient pas été possibles sans l'infrastructure de mobilisation des éthiciens mise en place. Que ce soit la rédaction de protocoles, de directives cliniques, d'énoncés, de guides, ou de documents de réflexion éthique, des réponses concrètes ont été offertes pour soutenir les demandeurs, tels que le Comité directeur clinique COVID-19 du MSSS et ses sous-comités, ou encore les Directions du MSSS. De plus, des formations et des activités de sensibilisation ont été élaborées et dispensées afin de faciliter leur appropriation auprès des destinataires visés par ces productions. Des questions éthiques ont également été abordées en auto-saisine en réaction aux préoccupations du « terrain » et d'autres acteurs et intervenants du RSSS. Enfin, des projets de recherche ont été mis sur pied dans l'objectif d'approfondir et de poursuivre la réflexion sur des sujets particulièrement critiques et sensibles. Certaines questions ont été confiées à des instances en fonction de leur expertise. Ce fut le cas de la vaccination obligatoire des travailleurs de la santé, qui a été étudiée par le comité d'éthique de santé publique (CESP). Il faut souligner qu'aucun critère explicite n'a été établi pour gérer l'attribution des dossiers ou des questions à traiter par les instances en éthique. Règle générale, ce furent des besoins identifiés et discutés au sein du Comité directeur COVID-19 ou du MSSS, qui ont suscité un appel au Comité éthique COVID-19. Une seule thématique a été étudiée en auto-saisine par le Comité éthique COVID-19 : la question de limiter l'accès aux soins et services aux personnes non vaccinées. La question de l'interdiction des visites et de l'absence des proches a été une initiative du Regroupement face aux enjeux criant dans les établissements. L'ensemble des thématiques suivantes ont été abordées par le Comité d'éthique COVID-19, en collaboration avec le Regroupement.

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[2] Depuis janvier 2022, l'animation est partagée entre les membres du regroupement.

- Adaptation des urgences et du préhospitalier
- Accès aux soins des personnes non vaccinées
- Aide à la décision face au délestage
- Dépistage du cancer du sein
- Interdiction des visites : absences des proches
- Isolement des personnes âgées
- Isolement des personnes DI-TSA-DP[3]
- Niveaux de soins
- Pénuries de médicaments prometteurs COVID-19
- Pénurie d'équipement de protection et devoir de soins
- Priorisation de l'accès aux soins intensifs
- Priorisation des chirurgies
- Priorisation des hospitalisations
- Refus de dépistage

De plus, un livre sur l'éthique et la COVID-19 rassemblant la majorité des thématiques abordées par le mandat est paru au printemps 2023 (4). Pour le détail de l'ensemble des productions veuillez consulter les appendices 1 et 2 associés à cet article.

DISCUSSION

En rétrospective, il est possible de mettre en évidence plusieurs points forts de la création et de l'exercice de ces deux instances. Le mandat, la composition et le fonctionnement distinct mais complémentaire de celles-ci ont permis une concertation et un échange efficace d'information entre des instances et des personnes avec des expertises en éthique en santé et services sociaux variées. Cela a rendu possible différentes activités, réflexions et productions avec une agilité et une mobilisation très pertinente dans un contexte d'urgence sanitaire. Comme effet de cette collaboration, des liens se sont renforcés ainsi qu'une meilleure intégration de l'éthique dans les décisions à différents niveaux, macro (MSSS), méso (gestion dans les établissements RSSS) et micro (clinique).

L'expérience du Comité éthique COVID-19 et du Regroupement est une preuve tangible de l'avantage et de la faisabilité de faire travailler ensemble des instances de différents niveaux : stratégique, tactique et opérationnel. En effet, cela met en évidence une complémentarité entre les buts, les objectifs et le fonctionnement de ces deux types de structure. Premièrement, cela a permis d'aller au-delà des expertises nichées des instances existantes en les mettant ensemble autour de la table. Deuxièmement, le fait d'élargir le bassin d'éthiciens et de ressources en éthique, par la création du Regroupement et le lien avec le Comité éthique COVID-19, a permis d'avoir accès en temps réel aux différentes réalités et aux besoins particuliers du terrain, des personnes utilisant les services et de la population, des intervenants et des gestionnaires du RSSS. De plus, les éthiciens et autres ressources en éthique dans les établissements avaient accès rapidement aux travaux des différentes instances en éthique, comme la CEST ou le CESP. Ils pouvaient ainsi mieux préparer les établissements ou anticiper les enjeux ou les défis d'implantation. Le Comité éthique COVID-19, en tant qu'instance pouvant exécuter un mandat sur les enjeux éthiques, représentait aussi une porte d'entrée pour déposer les enjeux récurrents ou majeurs qui, selon les membres du Regroupement, méritaient une attention particulière au MSSS. Cela permettait aussi d'alimenter la réflexion de différents acteurs des directions du MSSS en lien avec les travaux dans leurs secteurs respectifs (par exemple, les travaux portant sur les mesures d'isolement et de confinement des personnes ayant une déficience intellectuelle ou encore la présence des proches en contexte de confinement).

Malgré le statut informel du Regroupement, les éthiciens jouent un rôle formel dans les établissements, sans être toutefois bien connu. Les travaux du Comité éthique COVID-19 ont mis en évidence ce rôle (de l'éthicien ou de la ressource en éthique en établissement), notamment en l'inscrivant dans des protocoles et en l'identifiant dans des rôles de co-responsabilité dans des instances telles que le comité national sur la priorisation des soins intensifs. Ces actions ont permis d'augmenter la visibilité de l'éthique clinique et organisationnelle et de démontrer sa valeur ajoutée dans un système de santé.

À l'aube de la pandémie, le Regroupement venait de terminer une collecte de données afin d'avoir une vue d'ensemble de la place de l'éthique clinique et organisationnelle au sein des établissements. La pandémie a ralenti le travail amorcé. Toutefois, les travaux ont repris en 2022, ce qui a permis de mettre à jour la collecte de données et de fournir une perspective avant la pandémie (2020) et après (2022). Le nombre de ressources en éthique, c'est-à-dire, une personne salariée ou contractuelle dont une partie ou la totalité de son mandat est consacrée à répondre aux demandes en éthique clinique ou organisationnelle, a augmenté de 36% entre 2020 et 2022. Ces personnes cumulent différents mandats au sein de leurs établissements. En 2022, 38% des ressources en éthique ont mentionné avoir un autre mandat, en plus de celui de l'éthique, le plus fréquent étant celui du partenariat patient. La proportion des personnes qui sont à temps complet et dédiées uniquement à l'éthique clinique ou organisationnelle a aussi augmenté, à hauteur de 24,5%. Enfin, le volume global de consultation au sein des établissements du RSSS a augmenté de 36% passant de 1535 consultations en 2019-2020 à 2066 consultations en 2020-2021. Ces données sont tirées du Portrait des services en éthique clinique et organisationnelle (SECO), qui a été déposé aux

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[3] Déficience intellectuelle (DI), trouble du spectre de l'autisme (TSA) et déficience physique (DP).

directeurs responsables de l'éthique dans les établissements du RSSS, à leur table ministérielle en octobre 2023 (7). Ce portrait illustre les changements qui se sont opérés, mais permet aussi de constater que ces avancées ne sont pas sans bémol.

L'implication des éthiciens et autres ressources en éthique dans les instances organisationnelles reste rare, malgré une certaine augmentation de visibilité et de reconnaissance de ceux-ci. Plusieurs doivent encore justifier leur existence et leur valeur ajoutée dans les prises de décisions clinique et organisationnelle. Ainsi, beaucoup reste à faire pour poursuivre l'intégration de l'éthique dans le système de santé et de services sociaux au Québec. La mobilisation des organisations autour de l'éthique s'est heurtée à des frontières de culture organisationnelle pré-datant la pandémie. Certaines instances en éthique représentées au Comité éthique COVID-19 n'ont été que peu interpellées et mises à contribution au sein même des structures décisionnelles existantes, diminuant du même coup la portée de la concertation éthique possible.

À long terme, des défis et des menaces sont à envisager. Sans la poursuite des travaux et des collaborations, les questions relatives au sens, à la légitimité et au bien-fondé moral des décisions prises dans le RSSS pourraient facilement demeurer implicites ou « en marge » de la réflexion.

Un autre élément à ne pas négliger est la pérennité des avancées réalisées par ces deux instances, qui n'est pas assurée. Si l'utilité et la pertinence de ce type d'instances ne sont plus à démontrer, à l'heure de la refonte du système de santé au Québec, il est difficile d'envisager la suite. Le Comité éthique COVID-19 a eu un mandat temporaire, relié à la pandémie et fut mis en place par une instance, elle-même temporaire. Ce qui explique en grande partie l'arrêt des activités maintenant que la pandémie est terminée. De son côté le Regroupement a eu un autre parcours. Si au départ, ce groupe s'identifiait comme un « Comité liaison COVID-19 », il s'est transformé et est devenu un regroupement actif et inclusif. Il répond à des besoins que les membres constataient et qui allaient au-delà des enjeux reliés spécifiquement à la pandémie. Il a poursuivi ses activités au-delà de la crise, tout en suscitant une saine réflexion sur son identité, son fonctionnement, sa raison d'être, etc. Par ailleurs, en 2023, ce groupe s'est doté de sous-comités de travail portant sur : la gouvernance du regroupement, la recherche en éthique clinique et organisationnelle, le rayonnement de l'éthique dans les établissements et à l'externe, la participation à la création d'un code d'éthique avec l'Association canadienne des éthiciens en soins de santé du Canada et l'organisation annuelle d'un Symposium pour les membres du Regroupement. La particularité de ce regroupement réside dans son auto-gestion présente dès le début et qui démontre une certaine maturité des membres dans un contexte où les besoins ne sont pas les mêmes, étant donné la diversité des formations, des rôles, des expertises, des contextes de travail et des années d'expérience des membres.

Employés des établissements de la santé et services sociaux, les membres du Regroupement bénéficient d'une certaine indépendance dans l'organisation et le fonctionnement de ce groupe. Même si l'intérêt du MSSS pour l'éthique a été manifesté à plusieurs moments, il reste qu'aucune directive ou aucun encadrement n'existent à l'heure actuelle, contrairement à d'autres professions ou secteurs d'activité du RSSS. Il y a toutefois des côtés positifs à la souplesse et à la liberté d'agir sans encadrement ou sans lien de gouvernance strict. Cela permet au Regroupement d'être créatif, indépendant et de faire des choix en lien avec les besoins identifiés par les membres et indirectement par leurs établissements. Cependant, cela le place aussi dans une certaine forme de fragilité puisqu'aucun financement récurrent n'est attribué pour le soutenir dans ses activités, ce qui peut mettre en péril sa pérennité. N'eût été du soutien de l'entente interinstitutionnelle entre la Faculté de médecine de l'Université de Montréal et les fondations du CHU Sainte-Justine et du CISSS de Laval, certaines activités, plus particulièrement le Symposium annuel et l'embauche d'une agente administrative, n'auraient pas été possibles. La bonne volonté peut soulever des montagnes, mais sans soutien structurant, l'effritement des acquis devient possible, voire inévitable. En plus de la pérennité, il risque d'y avoir un impact sur les productions de ce groupe, étant donné qu'aucun mandat formel n'existe et que les ressources qui le font vivre sont issues des milieux qui sont eux aussi assez peu nantis ou encore peu informés sur le rôle du Regroupement. En 2022, 41% des établissements avaient une seule ressource en éthique et plus de 45% des ressources avaient moins d`un équivalent temps complet dédié à l'éthique clinique et organisationnelle. Cela engendre, par exemple, le besoin chez certains membres de se justifier au supérieur hiérarchique au sujet de la pertinence de participer au Regroupement, à raison de plusieurs heures par mois, considérant leur charge de travail. Les membres du Regroupement ont senti le besoin de se présenter et de faire plusieurs démarches pour justifier son existence et sa pertinence auprès des gestionnaires responsables de l'éthique dans le RSSS. Néanmoins, beaucoup reste à faire pour l'ancrer en tant qu'instance de l'éthique incontournable et essentielle à la survie des éthiciens et ressources en éthique de terrain travaillant dans le réseau.

CONCLUSION

La retombée la plus fondamentale du mandat est d'avoir accru l'intégration de l'éthique à de multiples niveaux d'action et de prise de décision et d'avoir renforcé les liens entre les différentes instances déjà existantes en éthique (INESSS, CEST, CSBE, etc.) et les éthiciens ou ressources en éthique du RSSS. Cette avancée n'est toutefois pas totale.

L'autre belle réussite est sans contredit toutes les productions et réalisations issues de ces instances. Toutefois, le Comité éthique COVID-19 s'est fragilisé avec le temps. Ayant eu un mandat temporaire, relié à la crise, il a arrêté ses activités après la pandémie. Cependant, une leçon apprise de cette expérience est la pertinence d'avoir un comité de cette nature, une instance formelle de concertation des éthiciens qui œuvrent en santé et services sociaux. Une instance avec un mandat et une composition qui permet de soutenir la prise de décision transversale à un niveau macro, tout en gardant des liens de proximité avec le terrain par l'intermédiaire du Regroupement.

Si, à long terme, la gouvernance et le rattachement du Regroupement ne sont pas mieux établis, risque-t-il d'avoir le même sort que le Comité éthique COVID-19? Même si le Regroupement ne jouit pas à l'heure actuelle de soutien en termes de ressources humaines, matérielles et financières, l'engouement des membres qui y participent donne une impulsion et une force qui ne semblent pas prêtes de faiblir. Peut-être que l'absence d'encadrement de la pratique en éthique clinique et organisationnelle stimule la volonté d'établir plus solidement ce Regroupement, en vue d'assurer une certaine vigie et qualité des pratiques, de favoriser l'entraide et de nourrir les personnes sur le terrain qui exercent ce métier encore non balisé. Des études plus approfondies sont nécessaires pour explorer cette question.

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None to declare

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APPENDICE 1. PRODUITS ET ACTIVITÉS DÉCOULANT DU MANDAT ÉTHIQUE COVID-19 DU MSSS

Thématique	Demandeur	Interlocuteurs pour ce dossier	Impact
Priorisation de l'accès aux soins intensifs	Dre Lucie Opatrny (Comité directeur clinique COVID-19)	• Sous-comité clinique COVID-19 – soins critiques • Comité sur la priorisation des soins intensifs • CEPPP- Groupe consultatif ad-hoc • Directions cliniques du MSSS • Office des personnes handicapées du Québec • Regroupement de défense des droits des patients • Députés des partis de l'opposition • Ministres et sous-ministre de la santé et des services sociaux • Comité de gestion du RSSS (CGR) • Population (conférence de presse)	• 2 directives cliniques • 1 création d'un comité national • 8 webinaires et présentations • 2 articles • 2 projets de recherches
Priorisation des chirurgies	Dre Lucie Opatrny (Comité directeur clinique COVID-19)	• Sous-comité clinique COVID-19 – Blocs opératoires	• 1 directive clinique • 1 article scientifique • 3 webinaires et présentations
Priorisation des hospitalisations	Dre Lucie Opatrny (Comité directeur clinique COVID-19)	• Lucie Poitras, Directrice générale adjointe des Services hospitaliers, du médicament et de la pertinence clinique, MSSS • Cliniciens et gestionnaires du réseau • CEPPP • Députés des partis de l'opposition • Ministres et sous-ministre de la santé et des services sociaux • Journalistes (Briefing technique)	• 1 directive clinique • 1 document de réflexion
Retour au travail des travailleurs de la santé en isolement	D^{re} Lucie Opatrny (Comité directeur clinique COVID-19)	• Comité éthique COVID-19 • Cliniciens et gestionnaires du réseau	• 1 document de réflexion
Isolement des personnes âgées	Régis Pearson (CISSS Laval – SAPA)	• Groupe consultatif ad-hoc des comités des usagers et des comités des résidents du CISSS de Laval • Groupe consultatif ad-hoc des gestionnaires de CHSLD du CISSS de Laval • Table des directeurs SAPA • Directions cliniques du MSSS	• 1 document de réflexion
Isolement des personnes DI-TSA-DP	Geneviève Poirier (MSSS – Direction des programmes en déficience, troubles du spectre de l'autisme et réadaptation physique)	• Directions cliniques du MSSS	• 1 document de réflexion
Accès aux soins des personnes non-vaccinées	Auto-saisine	• Regroupement des éthiciens	• 1 document de réflexion
Refus du test de dépistage	Auto-saisine	• Sous-comité clinique COVID-19 – Blocs opératoires	• 1 document de réflexion
Aide à la décision face au délestage	Lucie Poitras, Directrice générale adjointe des Services hospitaliers, du médicament et de la pertinence clinique, MSSS	• PDG des établissements du RSSS	• 1 document de réflexion
Dépistage du cancer du sein	Dr Jean Latreille Sous-comité clinique cancérologie	• Sous-comité clinique COVID-19 – Cancérologie	• 1 document de réflexion
Adaptation des urgences et du pré-hospitalier	Dre Élyse Berger-Pelletier, Membre du Comité directeur clinique COVID-19	• Sous-comité clinique COVID-19 – Urgence et préhospitalier	• 1 outil à l'intention des intervenants
Pénurie d'équipement de protection contre les infections	Auto-saisine ensuite porté par le CMQ	• Collège des médecins du Québec (CMQ) • Ordres des infirmières et infirmiers du Québec (OIIQ) • Ordres des infirmières et infirmiers auxiliaires du Québec (OIIAQ) • Ordre des inhalothérapeutes du Québec (OPIQ) • CEPPP	• 1 énoncé de position

Pénuries de médicaments prometteurs COVID-19	Auto-saisine	• Sous-comité clinique COVID-19 – Pharmacologie • CEPPP - Groupe consultatif ad-hoc • Direction des affaires pharmaceutiques et du médicament (MSSS) – groupe consultatif des représentants de pharmacies d'établissements	• 1 document de réflexion
Interdiction des visites : absence des proches	Auto-saisine	• Regroupement des conseillers en éthique du RSSS • Direction générale des affaires universitaires, médicales, infirmières et pharmaceutiques. (DGAUMIP) • Direction générale des aînés et des proches aidants	• 1 document de réflexion • 1 article
Niveaux de soins	Lucille Juneau,	• Direction générale des affaires universitaires, médicales, infirmières et pharmaceutiques. (DGAUMIP)	• 1 document de réflexion
Enjeux éthiques COVID-19	Auto-saisine	• Directions cliniques du MSSS • Comité éthique COVID-19 • Regroupement des conseillers en éthique	• 1 livre • 3 webinaires et présentations

APPENDICE 2. LISTE DES PRODUITS ET ACTIVITÉS DÉCOULANT DU MANDAT ÉTHIQUE COVID-19 (REGROUPÉS PAR THÉMATIQUE)

Thématique : Priorisation de l’accès aux soins intensifs

Responsable : Marie-Ève Bouthillier

Directives cliniques incluant les mises à jour :

- Guide de priorisation et de coordination pour l’accès aux soins intensifs (adultes) en situation extrême de pandémie. 11 juin 2021.
- Orientations ministérielles pour la mise en place des mécanismes attendus pour l’accompagnement de personnes vulnérables lors de l’application du protocole national de priorisation pour l’accès aux soins intensifs (adultes) en contexte extrême de pandémie. Direction générale des programmes dédiés aux personnes, aux familles et aux communautés (DGPPFC). 14 juin 2021.
- Protocole national de priorisation pour l’accès aux soins intensifs adultes en contexte extrême de pandémie (mises à jour novembre 2020 et décembre 2021); Directives COVID-19 du ministère de la Santé et des Services sociaux. 10 novembre 2020.
- Défendre les intérêts des enfants tout en maximisant les ressources médicales dans le contexte de la pandémie de COVID-19 au Québec : l’allocation des lits de soins intensifs (SI) et respirateurs pédiatriques dans le contexte de la pandémie de COVID-19 au Québec. 2 novembre 2020.
- Protocole de triage pour l’accès aux soins intensifs (adultes) et l’allocation des ressources telles que les respirateurs en situation extrême de pandémie. 15 juin 2020.

Création du Comité national sur la priorisation des soins intensifs (découlant)

- Comité co-présidé par Dre Diane Poirier et Marie-Eve Bouthillier comité mis en place au MSSS pour coordonner la pré-priorisation ainsi qu’un éventuel déclenchement du protocole de priorisation pour l’accès aux soins intensifs en contexte extrême de pandémie de COVID-19. Ce comité a mené de nombreux travaux et a produit un bilan de ses activités. 2021.

Webinaires et présentations à des congrès scientifiques (découlant)

- Colloque d’une journée de l’ACFAS portant sur : Le protocole québécois pour la priorisation de l'accès aux soins intensifs en contexte de pandémie: genèse, défis et perspectives d'avenir. Colloque d'une journée. Congrès de l'ACFAS, 9 au 13 mai 2022 (en ligne).
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- Poirier D, Bouthillier M-E, Dahine J, Passerini L. La priorisation des soins intensifs en contexte extrême de pandémie. Webinaire Fédération des médecins spécialistes du Québec. 25 janvier 2021 (en ligne). Destiné à tous les médecins spécialistes du Québec
- Bouthillier M-E, Dumez V, Dahine J, Rouly G. Getting it Right: Improving patient partnered decision-making guidance during COVID-19. Spotlight Series, Canadian Foundation for Healthcare Improvement. 2 décembre 2020 (en ligne).
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- Bouthillier M-E. The challenging role of the of clinical ethicist in Political Decision-Making in the Covid-19 Pandemic. European Association of Centre in Medical Ethics (EACME) Webinar in Clinical Ethics. What means “expertise” in Clinical ethics. 24 juin 2021 (en ligne).
- Bouthillier M-E, Dumez V. Nguyen QD. Les enjeux contemporains entourant le vieillissement « Soins et services aux aînés en période pandémique – Constats, bilan et perspectives ». Séries de midi conférence, Université de Sherbrooke. 8 juin 2021 (en ligne).
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Projets de recherche (découlant)

- A mixed-methods study to develop a jurisdiction-level resource allocation framework to guide the use of triage and triage-avoidant strategies during an overwhelming surge in demand for critical and acute care. CIHR Operating Grant - Addressing the Wider Health Impacts of COVID-19. Subvention de groupe, Chercheur principal : Downar J; utilisatrice de connaissances : Dre Lucie Opatrny; co-chercheurs Dahine J, Bouthillier M-E, et coll.; collaboratrice : Poirier D. 499 994$, 2022-2024.

- Priorisation des soins intensifs en contexte extrême de pandémie : 1) modélisation/simulation de différentes stratégies de priorisation de l'accès aux soins intensifs et 2) délibérations démocratiques des parties prenantes sur les valeurs qui sous-tendent les modèles et leurs impacts sanitaires. Nouveaux besoins prioritaires de recherche COVID, IRSC. Subvention de groupe, Chercheuse principale : Bouthillier M-E. 209 457$, 2021-2022.

Thématique : Priorisation des chirurgies

Responsable : Dr Serge Legault

Une directive clinique

- Système de priorisation pour l’accès à une chirurgie en situation de pandémie. 2021.

Article publié

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Webinaires et présentations à des congrès scientifiques (découlant)

- Bouthillier M-E. Quand pandémie rime avec choix difficiles: les enjeux légaux, éthiques et cliniques liés à la priorisation des soins. Webinaire Fédération des médecins spécialistes du Québec. 15 février 2022 (en ligne), Destiné à tous les médecins spécialistes du Québec.
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Thématique : Priorisation des hospitalisations

Responsable : Marie-Ève Bouthillier

Directive clinique COVID-19

- Guide pour la priorisation et la gestion des hospitalisations en courte durée en contexte de pandémie de COVID-19. 12 janvier 2022.

Document de réflexion

- Considérations éthiques et pratiques du retour au travail des travailleurs de la santé en isolement (infectés ou exposés au SRAS-CoV-2). Document de réflexion déposé au MSSS non publié. 2022.

Thématique : Enjeux éthiques COVID-19

Responsable : Marie-Ève Bouthillier, Antoine Payot, Nathalie Gaucher

Livre

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Thématique : Isolement des personnes âgées

Responsable : Régis Pearson

Document de réflexion

- Vivre avec le virus dans les milieux de vie : pistes de réflexion pour des solutions humaines et responsables, CISSS de Laval, Isolement des personnes. 2022.

Thématique : Isolement des personnes DI-TSA-DP

Responsable : Marie-Ève Bouthillier
Document de réflexion

- Isolement des personnes DI-TSA-DP lors d'un retour de congé temporaires. Document de réflexion déposé au MSSS non publié. 2021.

Thématique : Accès aux soins des personnes non vaccinées

Responsable : Groupe de travail du Comité éthique COVID-19

Document de réflexion

- Réflexion éthique sur la question de limiter l'accès aux soins aux personnes non-vaccinés. 21 janvier 2022.

Thématique : Pénuries de médicaments prometteurs COVID-19

Responsables : David Hughes et Jean-Simon Fortin
Document de réflexion

- Repères éthique pour l'allocation équitable des médicaments prometteurs pour la COVID-19 en contexte de rareté : Outil pour guider la délibération et la prise de décision en matière de priorisation. Document de réflexion non publié. 2021.

Thématique : Refus de dépistage

Responsables : Ana Marin, Marie-Claude Levasseur
Document de réflexion

- Refus de tests de dépistage COVID-19. Document de réflexion non publié. 2021.

Thématique : Aide à la décision face au délestage

Responsable : Marie-Ève Bouthillier
Document de réflexion

- Aide à la décision face au délestage. Document de réflexion envoyé aux établissements du réseau de la santé et des services sociaux mais non mis en ligne. 2021.

Thématique : Dépistage cancer du sein

Responsable : Direction cancérologie du MSSS
Document de réflexion

- Réflexions soutenant le plan de reprise du dépistage du cancer du sein dans le contexte de la pandémie de la Covid-19. 18 juin 2020.

Thématique : Adaptation des urgences et du pré-hospitalier

Responsable : Dre Elyse Berger
Document de réflexion

- Adaptation des interventions en situation extrême de pandémie à COVID-19 pour les services préhospitaliers d'urgence (SPU) et l'urgence. Outil à l'intention des intervenants soumis au MSSS non publié. 2020.

Thématique : Pénurie d'équipement de protection et devoir de soins

Responsable : Dre Isabelle Mondou
Énoncé de position des ordres professionnels concernés

- Pénurie d'équipements de protection individuelle pendant la pandémie de COVID-19 – Entre le devoir professionnel de soigner et celui de se protéger : que choisir? (version anglaise). Avril 2020.

Thématique : Interdiction des visites : absences des proches

Responsables : Karine Bédard, Catherine Perron
Document de réflexion

- Réflexion sur la présence des proches. Document de réflexion non publié. 2021.

Article publié

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Thématique : Niveaux de soins

Responsable : Lucille Juneau

Document de réflexion

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

Human Genome Editing and Sickle Cell Disease in Canada: Urgent and Unresolved Ethical Considerations

Maria Klimenko[a,b], Ryan Tonkens[a,c]

Résumé
Certains pays approuvent déjà des applications thérapeutiques de l'édition du génome humain. Par exemple, le Royaume-Uni et les États-Unis ont récemment approuvé Casgevy dans le cadre d'un protocole de traitement de la drépanocytose. Le Canada doit-il suivre cette voie? Nous examinons les questions éthiques les plus importantes, mais non résolues, dans le contexte canadien, et soutenons qu'un engagement public et des délibérations beaucoup plus poussés sont nécessaires.

Abstract
Some countries are already approving therapeutic applications of human genome editing. For example, recently the United Kingdom and USA have approved Casgevy as part of a treatment protocol for sickle cell disease. Should Canada follow this lead? Here we discuss the most important, yet unresolved, ethical issues in a Canadian context, and argue that much more public engagement and deliberation is needed.

Mots-clés
Casgevy, équité, inclusion, éthique, édition du génome humain, justice, engagement public, drépanocytose

Keywords
Casgevy, equity, inclusion, ethics, human genome editing, justice, public engagement, sickle cell disease

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INTRODUCTION

Gene editing technology has been approved for use as a clinical treatment in humans. In December 2023, the United Kingdom's Medicines and Healthcare products Regulatory Agency (MHRA) approved the use of CRISPR/Cas-9 genome editing for treatment of patients over the age of 12 who have sickle cell disease; and in January 2024, the US Food and Drug Administration (FDA) also approved this treatment, which is called Casgevy™ (exagamglogene autotemcel).

After completing a procedure to extract the patient's blood stem cells from their bone marrow, Casgevy can be used to genetically modify the patient's blood stem cells, essentially replacing their adult hemoglobin with fetal hemoglobin, which reduces sickling in the blood and therefore reduces blockages that can lead to vaso-occlusive events or crises (VOCs). While these patients continue to have sickle cell disease (they are not "cured" *per se*), once the genetically edited bone marrow is transplanted, they would no longer experience VOCs, and therefore would be free of corresponding pain and other symptoms accompanying those events. In the experimental trial underpinning FDA and MHRA approval of Casgevy, 93.5% of qualifying participants reported being free from "severe VOC episodes for at least 12 consecutive months during the 24-month follow-up period." (1) According to the Vertex website, the company that developed Casgevy, this is a one-time treatment (2).

Canada is now considering approving Casgevy. In April 2024, Vertex announced that its New Drug Submission for Casgevy had been accepted for priority review by Health Canada for the treatment of patients 12 years and older with sickle cell disease with recurrent VOCs and for the treatment of patients aged 12 years and older with transfusion-dependent beta thalassemia (TDT) (3). Should Canada follow the MHRA's and FDA's lead and approve the use of human genome editing for this purpose? In this commentary, we consider some of the most important, yet unresolved, ethical issues relevant to answering this question, with the goal of contributing to deliberation on this important and pressing topic.

PATIENT SAFETY

Endorsement from the FDA and MHRA means that Casgevy has been deemed to be sufficiently safe for use in humans in the US and UK. If Canada does approve this therapeutic application of gene editing, ongoing monitoring for safety, the persistence of edited cells, and the risk of unintended harm including off-target mutations, is ethically imperative – something which is currently being done in the UK and US. Questions about who will be responsible for covering the costs of remedying unintended harms will also need to be addressed.

Casgevy is being used as one element in a larger treatment protocol, where the success of all elements is required to achieve the elimination of VOCs. In a complete ethical analysis (which is beyond the scope of this short critical commentary), the side-effects of all components of the protocol also need to be considered. For example, something not mentioned in the FDA press release is that some of the other elements in this treatment package may have serious side-effects for patients; according to the Casgevy website and informational video, "after receiving the conditioning medications [a one-time infusion after

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chemotherapy], it may not be possible for [the patient] to become pregnant or father a child", which constitutes a serious potential harm for those who undergo this treatment and who desire to become pregnant or father a child (4). Another consideration is the use of busulfan (a drug needed to achieve full myeloablation). This drug is toxic to the endothelium and significant risks exist of inducing veno-occlusive disease/sinusoidal obstruction syndrome (VOD/SOS) for patients with thalassemia and posterior reversible encephalopathy syndrome (PRES).

While competent and informed patients should be left to make decisions about their own health (and about their family building goals), it is important to highlight that safety approval of this new gene editing technology does not address the potential risks of the other treatment elements involved. And even assuming that Casgevy is sufficiently safe and effective for use in humans, other ethical considerations also need to be addressed.

INCLUSION AND PUBLIC ENGAGEMENT

Has the decision to allow this clinical treatment for sickle cell disease and thalassemia been informed by meaningful public engagement, including discussion about the research, development, and potential implementation of therapeutic applications of human genome editing into health care systems more generally? To our knowledge, no such public engagement has been conducted in Canada. If not, then there is good reason for Health Canada to not approve such treatment at this time.

One reason why public engagement is ethically imperative in this context is because it is public tax dollars that are funding public health care systems in Canada, and those systems are in place to meet the health needs of citizens, grounded in their right to access health care (e.g., *Canada Health Act*). Another reason why inclusive public engagement is important is to make sure that existing inequalities are not perpetuated. Moreover, meaningful public engagement will reveal whether Canadians are interested in having this treatment available in the first place and, if so, where access to this new treatment ranks in the list of priorities for Canadians, relative to other options for allocating funding. Lastly, the decision about whether to include human genome editing in the public health care system is a decision that will affect all Canadians. For example, because of the potential transformative nature of gene editing technology and because people will then have to *choose* whether to use gene editing technology, this should be a decision that all Canadians have a *reasonable* opportunity to inform. Once one or more applications of gene editing are approved, then it would be more difficult to halt the gene editing enterprise.

EQUITY

Sickle cell disease affects approximately 1 in 4200 people in Ontario, Canada (5). Over 6000 Canadians have sickle cell disease, and "approximately 100,000 people in the U.S., most commonly in African Americans" (1). The prevalence of thalassemia, the other hemoglobinopathy, is not known in the Canadian population but is likely to be increasing due to immigration. Prevalence can range from less than 1% to 40% in individuals from sub-Saharan Africa, Southeast Asia, Mediterranean countries, the Middle East, and the Indian subcontinent (7).

One ethical reason in favour of approving this new treatment in Canada is that it promotes the interests of populations who have traditionally been, and continue to be, marginalized and disadvantaged. Conversely, medical treatments that help only those who are in relative positions of power, or those who have the most privilege within society, are likely to be inequitable. Using cutting-edge health care technologies to serve the interests of those most well-off in society would be considered unfair on standard egalitarian accounts of social justice and the fair distribution of resources and opportunities within society, since they are not attached to positions in society that are open to everyone (i.e., being wealthy and powerful), and are not to the benefit of everyone, including those who are the least well-off. In this case, using gene editing to help people of colour and who also have a rare and devastating disease is consistent with the ethical principle of equity.

ACCESS AND AFFORDABILITY

At the same time, however, Casgevy and the larger treatment protocol that it is a part of is extremely expensive; Vertex has assigned it a listing price of 2.2 million USD. Other costs, such as autologous stem cell transplantation and extended hospitalization, must be considered on top of the treatment cost. Indeed, according to a recent *New York Times* article, the chief scientific officer for Vertex has said that a "medicine that is so resource-intensive as this is may not be appropriate in many places where the amount of resources for health care is more limited." (8)

At such a high price point, Casgevy is unlikely to be accessible to many Canadians who would benefit most from this therapy. Indeed, the issue is amplified once we consider the *global* distribution of health care resources: The majority of people in the world who have sickle cell disease live in Sub-Saharan Africa and are unlikely to be able to afford this expensive treatment, or to have access to the medical infrastructure and other resources required for administering this treatment protocol (9). Keeping the earlier point about equity in mind, currently this kind of treatment for sickle cell disease will only be accessible to relatively affluent people, and most likely those with relative ease of access to trained medical professionals and medical institutions who have the requisite resources (e.g., hospital beds, staff, and equipment for the conditioning medicine and stem cell transplant procedures, etc.). Thus, while equitable in some ways, this treatment raises concerns about *fairness* in light of existing injustices in access to health care.

CHOICE OF TARGET APPLICATION FOR THERAPEUTIC GENE EDITING

It is understandable that developers of therapeutic applications of human gene editing technology will want to focus on monogenetic diseases, such as sickle cell disease, since these are better understood (at present) and relatively more straightforward to target, compared to polygenetic diseases. At the same time, health research dollars are finite, and where such dollars get allocated should be a matter of debate and public conversation, with all key stakeholders in the discussion. Our contention here is that it would be ethically responsible to steer Canada's decision about whether to participate in the gene editing enterprise via inclusive and sustained public discussion and debate, compared to the decision being dominated by market pressures. In the case of Casgevy, it seems as though private profit maximization ideals are leading (or are at least heavily influencing) decisions about where to aim limited research and development resources (money, time, human resources), without explicit attention being given to where such resources could actually do the most *good*.

Many jurisdictions are experiencing a crisis-level shortage of health care professionals, including access to family physicians. Is it ethically appropriate to fund research on gene editing to treat sickle cell disease (for relatively affluent people who can afford the treatment) under conditions where, for example, there continues to be boiling water advisories in many communities across Canada, and ongoing suffering from unmet needs to help cure tuberculosis in places like Nunavut? While Casgevy certainly holds the promise of benefit to the people in Canada who have sickle cell disease and who can afford the treatment, and who have access to the requisite health care professionals and infrastructure, there are of course *many* more people suffering in different ways. Unless all such needs can be met simultaneously, difficult decisions will need to be made about prioritization. Our contention is that such decisions should not be left to private corporations to make on their own, without other stakeholders being involved, including the public and representatives from key socio-political institutions.

POTENTIAL IMPACTS ON REPRODUCTIVE AUTONOMY

It is possible that Casgevy and other gene editing therapies will become more widely available, and perhaps even be used earlier on in the human life cycle. For example, it may be possible to use a version of such technology on human embryos, to prevent hereditary and other non-communicable diseases. We have seen the latest advancements in the application of gene editing therapies to embryos, such as the story of a Chinese woman giving birth to genetically modified twin girls in 2019, regardless of the current laws that exist to prevent incidents of this nature (10); in Canada, genetic modification of human embryos for reproductive purposes is currently illegal (11).

Multiple ethical considerations arise regarding the impact on reproductive autonomy in women and people who can have children. The voluntary participation of women in carrying genetically modified embryos may introduce societal pressures due to the potential benefits (i.e., chronic disease prevention), potentially limiting or even compromising reproductive autonomy. If some women choose not to undergo the procedure, despite its safety and anticipated benefits, they may experience marginalization and their reproductive rights may be impacted. Additionally, if a woman decides to abort a pregnancy involving a genetically modified embryo, the principle of autonomy must be upheld to the highest standard. The right to abortion must play a role in ethical discussions involving reproductive autonomy in the context of gene editing. Lastly, there will be a certain level of involvement from third parties, such as clinical staff, government entities, and others at various stages of a woman voluntarily carrying a genetically modified embryo. To preserve the reproductive rights of women, the extent of third-party involvement or control must be discussed in order to safeguard women's reproductive rights.

As therapeutic applications of gene editing continue to advance and become more widely available for earlier phases in the human life cycle, consideration and discussion around women's reproductive rights are imperative.

TRUTH AND RECONCILIATION IN CANADA

The Truth and Reconciliation Commission of Canada (TRCC) has implored all Canadians and Canadian governments and institutions to work towards reconciliation (12). Two of the Commission's *Calls to Action* in the context of "Health" are:

> …to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities […] Such efforts would focus on indicators such as: infant mortality, maternal health, suicide, mental health, addictions, life expectancy, birth rates, infant and child health issues, chronic diseases, illness and injury incidence, and the availability of appropriate health services (Call to Action #19);

and,

> …to provide sustainable funding for existing and new Aboriginal healing centres to address the physical, mental, emotional, and spiritual harms caused by residential schools, and to ensure that the funding of healing centres in Nunavut and the Northwest Territories is a priority (Call to Action #21).

Canada has made a commitment to "achieving reconciliation with Indigenous peoples through a renewed, nation-to-nation, government-to-government, and Inuit-Crown relationship based on recognition of rights, respect, co-operation, and partnership as the foundation for transformative change," (13; cf. 14,15).

If funding is being used for developing new applications of gene editing technology *instead of* meeting these Calls to Action, then it is fair to ask governments (and researchers, private drug companies, health care organizations, etc.) to explain their justification for this decision. And, if finite health care research dollars are being allocated towards gene editing *instead of* towards closing “the gaps in health outcomes between Aboriginal and non-Aboriginal communities”, then the Calls to Action in the category of “Health” are being circumvented and will remain unmet (12).

Nothing here is meant to conclude that the gene editing enterprise in Canada is necessarily or unavoidably inconsistent with truth and reconciliation, or that the two are mutually exclusive. As discussed above, forming a meaningful and inclusive discussion is imperative. At the time of writing, there has not been public engagement about human gene editing and its relationship to truth and reconciliation, and yet Health Canada is considering approval of therapeutic gene editing and therefore by extension considering whether to begin embarking on the gene editing enterprise. After having meaningful discussions about the prospect of therapeutic applications of gene editing, it *may* turn out that some people support this venture and believe they could benefit from such new medical tools. However, we *first* need to ask the questions in order to know their answers.

RESPONSIBILITY FOR POOR (GENETIC) HEALTH

Canada currently does not have any protections in place for people who choose not to participate in the gene editing enterprise, including those who will choose not to use safe, effective, and affordable therapeutic gene editing technology (16). In the context of Casgevy, this issue is perhaps less urgent compared to future treatments, since Casgevy is not (currently) affordable and therefore not accessible. However, it is worth raising this class of concern here, to begin important discussion in this area. If a person with sickle cell disease or thalassemia chooses to forgo a gene editing treatment protocol, and subsequently requires health care after experiencing VOCs, then their need for health care would have been avoidable, and therefore it may be thought that their need is self-caused. Because of this, it may be tempting to give such people lower priority in access to (scarce, stretched) medical resources, compared to people who have not caused their own need. Or else, one can reasonably imagine parents of a child with sickle cell disease being discriminated against or otherwise harmed for their decision to forgo Casgevy treatment for their child (or their decision to conceive a child with a risk of having sickle cell disease, etc.). The state has been known to intervene paternalistically into the decision making of parents in cases where those decisions are deemed to be harmful to the child and the reasons upon which the parental decision are based are seen as being irrational. A host of ethical issues emerge in this area, which have received very little attention up until now in the context of human genome editing – they will need to be answered if Canada decides to permit gene editing treatments like Casgevy. At the very least, protections will be needed for people who choose to forgo safe and effective therapeutic gene editing, and who choose not to participate in the gene editing enterprise.

ALTERNATIVE TREATMENTS AVAILABLE

In Canada, alternative treatments for symptoms of sickle cell disease currently exist, most notably haploidentical stem cell transplantation and hydroxyurea. Haploidentical stem cell transplantation is the most prominent treatment option for patients with sickle cell disease. This treatment has a high disease-free survival of >90% (17), but there is also the risk of graft-versus-host disease due to partial immune compatibility between donor and recipient (17). While hydroxyurea is not a one-time treatment like Casgevy (it must be taken daily in pill form) and cannot prevent long-term complications, it does not have any known significant side effects and has been effective in reducing symptoms for many people (19). However, hydroxyurea only delays fatality due to chronic irreversible systemic microvascular organ damage (mainly of the heart, kidney, and lung) (19). Further, existing treatments are (currently) less expensive than the treatment protocol involving Casgevy, making them more accessible to disadvantaged populations, and hydroxyurea also has the benefit of not requiring additional health care professionals or infrastructure (hospital rooms, transplant teams, etc.). Because of this, they seem less likely to contribute to the exacerbation of existing health inequalities (locally or globally), and do not require vast amounts of funding which could be used for other purposes.

A complete ethical analysis of Casgevy should include a comprehensive discussion of the benefits and harms compared with existing alternative treatments, and preferably include consultation with the public and key stakeholders, including people who have sickle cell disease.

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

A Critical Approach to the UNESCO Principle "Scientific Knowledge and Integrity in Decision Making" in the Face of Climate Change: Contribution of Andean Indigenous Knowledge

Sakiko Yamaguchi[a], Junior Adolfo Villantoy Huaman[b], Celia Yanira Flores[b], Julián Berrocal Flores[c], Doris Castillo Gamboa[b]

Résumé

L'article 7 de la Déclaration des principes éthiques de l'UNESCO, intitulé « Connaissances scientifiques et intégrité dans la prise de décision », peut négliger les systèmes de connaissances locaux et traditionnels des communautés autochtones. Pour remédier à l'injustice épistémique à l'égard des connaissances autochtones en matière d'adaptation au changement climatique, il est important de s'engager avec les communautés autochtones en tant que membres égaux de la société et d'apprendre de leur compréhension relationnelle et holistique de la nature.

Abstract

"Scientific knowledge and integrity in decision-making" as presented in the UNESCO Declaration of Ethical Principles Article 7 may neglect existing local and traditional knowledge systems of Indigenous communities. To address epistemic injustice towards the Indigenous knowledge in climate change adaptation, it is important to engage with Indigenous communities as equal members of society and learn from their relational and holistic understanding of nature.

Mots-clés

UNESCO, éthique, changement climatique, Andes, injustice épistémique, savoirs traditionnels autochtones, science

Keywords

UNESCO, ethics, climate change, Andes, epistemic injustice, traditional indigenous knowledge, science

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INTRODUCTION

The urgency of taking action on the negative impacts of climate change on health is recognized globally. At the 28th UN Climate Change Conference (COP28) in December 2023, the COP 28 Declaration on Climate and Health was launched, aimed at advancing climate-resilient development, strengthening health systems, and building resilient communities for the benefit of present and future generations (1). Reported impacts of climate change on human health include the adverse effects of global warming on the cardiopulmonary system and the gastrointestinal tract, an increase in waterborne diseases and infectious diseases such as typhus, cholera, malaria, dengue, and West Nile virus infection, as well as malnutrition due to the impact on food production and access to safe water (2-4). Although climate change affects all regions of the world, its negative effects exacerbate global health inequalities and iniquities: Low- and middle-income countries (LMICs), as well as the most vulnerable groups whose capacity to adapt is the weakest, are more susceptible to diseases and physical injuries and mortality during natural disasters, such as floods and cyclones, brought on by climate change (3,4). Climate change also interacts with gender inequalities, resulting in more negative health impacts on women, such as malnutrition and the incidence of infectious diseases (5).

Such multifaceted vulnerabilities and their unequal distribution give rise to ethical issues of fairness and responsibility (3,6). As climate change is a global phenomenon with intergenerational effects, its spatial and temporal dispersion of cause and effect indicates that multiple actors, such as governments, the private sector, and society, have a moral responsibility to mitigate the impact of climate change concerning human health (6,7). However, global tensions are present with the question of dispersed responsibility as well as fair sharing and equitable distribution of the benefits and burdens of climate change, adaptation, and mitigation policies and responsibilities to address them (8). Particularly, challenges remain around questions of intergenerational justice (that is, what is owed to future generations) and value conflicts between the human and non-human world (8). In this context, key gaps on ethics, climate change, and human health are identified: a lack of understanding of the importance of ethics in policy-responses to climate change, a shortage of ethical commentary on a range of key topics in the environmental health literature, a lack of literature from LMICs, and limited discussion of inter-disciplinary ethics in relation to climate change (8). In particular, specific action guiding the production and dissemination of ethical resources that provide practical pathways and policy options for researchers and practitioners are warranted (8).

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RECONSIDERING THE UNESCO PRINCIPLE “SCIENTIFIC KNOWLEDGE AND INTEGRITY IN DECISION-MAKING”

Within this context, the development of extended ethical frameworks in health and climate change could help guide the actions of practitioners. One such example is the *Declaration of Ethical Principles in relation to Climate Change* adopted by the member states of the United Nations Educational, Scientific and Cultural Organization (UNESCO) in 2017. The six shortlisted principles, 1) Prevention of harm, 2) Precautionary approach, 3) Equity and justice, 4) Sustainable development, 5) Solidarity, and 6) Scientific knowledge and integrity in decision-making, were globally agreed upon based on the initial ten principles of adaptation and mitigation in climate change proposed in 2015 by UNESCO and COMEST (World Commission on the Ethics of Scientific Knowledge and Technology).

Among these principles, Article 7 “Scientific knowledge and integrity in decision-making” pays specific attention to the modes of knowledge required to make a sound decision in response to a range of climate change challenges. It aims to enhance the social processes through which science disseminates its findings for the benefit of all and informs decision-making and policies for the implementation of relevant long-term strategies (9). The principle indicates that scientists play an important role in filling the knowledge gap in climate change, actively following strategies, and communicating with policymakers as well as the public (9). In parallel, the Declaration also draws attention to traditional Indigenous knowledge, stating “Decisions should be based on, and guided by, the best available knowledge from the natural and social sciences, including interdisciplinary and transdisciplinary science, and by taking into account, as appropriate, local, traditional and indigenous knowledge” (Article 7) (9).

As suggested by the Declaration’s principle, a strong emphasis is placed on scientific knowledge as evidence to inform decision-making in environmental management policy and practices. However, there is a risk of creating a dichotomy between academic ecological knowledge and traditional Indigenous knowledge, thus further marginalizing the latter (10,11). Despite efforts to integrate local traditional knowledge, as long as academically trained scientists have the power to decide when to incorporate local knowledge into research and adaptation planning, unequal power relations will remain (11,12).

Ethnoscience, the study of the knowledge system and practices held by different cultures, emerged in the mid-twentieth century, reflecting Western scientists’ approaches to non-Western/Indigenous knowledge rooted in colonial history of expansion of European states (13,14). In the seventeenth century, information of Indigenous people’s practices regarding plants and animals collected by European naturalists during their colonial excursions were initially considered as “primitive” or “savage” (13,14). As anthropologists discovered people’s deep knowledge and holistic view of their environment and their application to planning and management of natural resources, the significance of “Indigenous” and “local” knowledge in other disciplines of science was recognized (15,16). However, conceptualization of Indigenous knowledge in ethnoscience which developed in the context of extraction and coloniality of Western countries is critiqued for perpetuating a colonial logic and marginalizing traditional knowledge in policy and practice (11,13).

In the context of climate change policies, recognizing the existing knowledge hierarchy that underrepresents Indigenous knowledge, commentators have described many climate adaptation policies as being epistemically unjust towards Indigenous people (12). Fricker’s (17) notion of epistemic injustice explains two underlying forms: 1) *testimonial* injustice occurs when the credibility of the knowledge holder is denied due to prejudice of the receiver of knowledge against an aspect of social identity such as race/ethnicity, gender, and disability, and 2) *hermeneutical* injustice happens at the systemic level where certain people are marginalized when they are excluded from shaping shared social meaning of human experiences due to a lack of epistemic resources to convey their knowledge with existing language. For instance, hermeneutical gaps occur when Indigenous cultural and spiritual claims do not map onto available categories within the Westen legal system (18).

Both forms of epistemic injustice are seen in the Peruvian Andean context where several climate adaptation policies and strategies continue to ignore the interests and knowledge of Indigenous peoples (12,17).

ANDEAN COSMOVISION AND WOMEN’S TRADITIONAL KNOWLEDGE

In the face of climate change, there is a call for an epistemic rupture to gain new knowledge by recognizing different cosmovision and ancestral wisdom (19). Andean Indigenous activists and researchers argue that it is critical to understand a specific sociopolitical structure and processes where climate adaptation policies and strategies are implemented: they note in particular that asymmetric power and multiple vulnerabilities based on race, ethnicity, class, and gender shape the multilayered vulnerabilities of Indigenous populations, particularly women, to climate change and its impact (20,21).

In the Andean cosmovision, people’s health and well-being are closely linked with *Allim kawsay* (good life) built on reciprocity through the *Uywanaku* (caring coexistence) and *Parlanakuy* (spaces of conversation). As Andean community people commonly say, *“Kawsaypachapiqa lliwmi kawsan”* (In the world of the living, everyone has life) (22). Their cosmovision indicates that the *Pacha* (mother earth) or the World is a place where not only human beings but also everything in nature, such as rocks, hills, plants, rivers, forests, mountains, and animals, are considered as living organisms. The *Pacha* and all that is necessary for the flow of life (*Kawsay*), including *Runas* (Human beings), fauna and flora, and *Wamanis* or *Apus* (Deities), are tied and complementary to each other. The Andean perception of a harmonic interrelation with people, nature, and animals extends care and respect for the environment (19,23,24). In this Andean epistemology, Quechua ways of knowing (*Yachay*) are associated with the collective capacity to nurture, which is an attribute of all living organisms in the *Pacha* (mother earth) (24).

In Andean society, where the family is at the core of production, women bear the major share of responsibility for ensuring the survival, welfare, and health of their families. They support agricultural work and animal herding while sustaining families by preparing food, caring for animals and children, maintaining food, and securing the health of family members (22). In the family and community space where *machismo* has shaped patriarchal gender relations, Andean women, particularly in rural areas, face numerous barriers that prevent them from actualizing their rights to education, health, equal treatment, and a life free from violence (25). Beyond the family space, women often take on subsidiary roles, whereas men occupy leadership positions in community decision-making (26). While educated young women are starting to be more involved in community meetings and less educated older women are respected as knowledge holders who transmit valuable experiential knowledge, most women are still restricted from controlling the land, as they are represented either by their husbands or fathers in the community council (26-28).

Despite this persistent gender inequality, Andean women's experiential knowledge and ability to make decisions in everyday life to prioritize local communities and networks of care could be leveraged not only for transformative adaptation but also for fulfilling individual and community well-being (23,27,28). In the *Pacha* where human beings and nature are inseparable, women have continued to contribute to sustainable farming practices that manage native crops, including choosing appropriate planting dates and practicing festivities to give thanks to nature and to strengthen a collective support system in the community (29). In addition to their role in sustaining food security through cultural practices, Andean women have acquired knowledge and technical skills in the selection and conservation of seeds for crops such as potatoes and maize (27,29). They often determine which plant resources to conserve and use, which seeds to select, which crop varieties to grow, and which food products to keep for home consumption and which to sell at the local market (27,29).

Moreover, women play an important role in transmitting their knowledge as biodiversity keepers to younger generations, which is critical for the survival of the family and the retention of culture (27,29). Rural women are also involved in the care of herd animals such as alpacas, sheep, and llamas, which are important income sources. They accumulate experiential pastoralist knowledge and practice, bringing animals to pasture, monitoring signs of distress and illnesses, as well as reproduction, and treating animals when they are sick (22,30). Women inform community decisions to shift their herds between pastures, guided by their expertise on seasonal patterns of rain and temperature as well as daily observations of animals' health and behaviour (22,30). As such, with this Quechua view of the world, women have nurtured knowledge of care, which fosters and maintains bonds of reciprocity and mutual care and protection in their daily living, called *"uywanakuy, nanachinakuy"* (caring and being cared) (24).

EPISTEMIC INJUSTICE TOWARDS ANDEAN INDIGENOUS KNOWLEDGE

Andean women's knowledge could potentially contribute to climate change adaptation strategies. However, many Andean women are reported feeling fear and insecurity because of how their partners treat them in the environment created by cultural values and practices of *machismo*. Such feelings make women anxious about speaking in public or expressing their ideas to unfamiliar people, and some even hold back from experimenting or learning something new as they doubt their capability (26). As such, women's voices oftentimes have less influence, and they have limited access and control over resources.

Furthermore, historically, in Peru, both Indigenous and peasant cosmologies were considered "primitive" and neglected as a barrier to modernity (21). Today, government officials see Indigenous farming practices as inefficient and outdated (21). Due to testimonial injustice, the dominant discourse on development that promotes capacity building and technical assistance fails to recognize Andean smallholder farmers' agricultural knowledge that has been used for adaptation. In addition, not recognizing the value of Indigenous knowledge can be due to hermeneutical injustice where epistemic and ontological differences make it hard to communicate their knowledge in a manner that can be understood within the dominant climate adaptation discourse (12). The Quechua language plays a key role in articulating and transmitting Indigenous knowledge based on the Quechua cosmovision, which stresses the reciprocal relations and interactive practices between humans and nature: unique wisdom about plants, animals, and water systems are transmitted through oral histories while living on *Pachamama* (Mother Earth) (19,24). However, Quechua's holistic understanding of nature is often hindered by the dominant Western paradigm of nature that sees the environment as existing independently from human beings as well as stigma associated with speaking Quechua in public spaces (19,24,31).

As reported by UNESCO's World Network of biosphere reserves, engaging with Indigenous knowledge and epistemologies has been a challenge that requires a fundamental shift in how to conceive and conduct science (32). Despite the growing emphasis on collaborative approaches aiming for knowledge "co-production" to address this challenge, limitations of integrating different knowledge systems exist due to substantial differences of Indigenous epistemologies and values from conventional science (11,32). Not simply seeking common grounds but acknowledging these differences can create room for different actions and answers to complex socio-ecological challenges at a local level, paving the way for negotiation of practice and policy through self-determination of local communities (11). Moreover, it is critical for science communities to acknowledge the persistent epistemic injustice and discrimination in current global science-policy landscape where there is still present a historical continuity of ethnoscience driven by assimilation, extraction, and coloniality (13).

CONCLUSION

Since the Andean Quechuas acquire and share knowledge based on interacting with the environment through mutually supportive relationships, simply applying the principle “scientific knowledge and integrity in decision-making” as presented in the UNESCO Declaration of Ethical Principles may neglect context-specific vulnerability as well as existing local and traditional knowledge systems. While scientific evidence and advancement are critical for climate adaptation policies, it is imperative to recognize how the current climate language and discourse are skewed toward Western scientific approaches in order to facilitate meaningful integration of Indigenous knowledge and practices (12). As smallholder farmers in the Andes have been historically socioeconomically disadvantaged in Peru and still suffer from persistent impoverishment and marginalization, addressing the socioeconomic inequalities underlying the prejudices is required. We thus call for the scientific community to disrupt their existing epistemic paradigm by engaging with Indigenous communities as equal members of society and to learn from their relational and holistic knowledge of nature (10,12).

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

Vers une approche intégrée : politique, science et éthique – le rôle clé de la médiation des connaissances en situation de crise sanitaire

Sarah Mediouni[a,b,c,d], Antoine Boudreau LeBlanc[c,d,e,f]

Résumé
Dans le contexte de la crise sanitaire de COVID-19, la politisation de la science a été une réponse nécessaire aux défis posés. Si cette médiation (influencée par le politique) demeure une réponse stratégique, nous argumenterons qu'elle fût incomplète sur le plan éthique. L'analyse rétrospective de la situation met en évidence la nécessité d'étendre et de renforcer le rôle-conseil d'instances éthiques, telles qu'elles ont été intégrées au réseau de la santé pendant la pandémie. La complexité découlant d'une interaction soutenue entre les connaissances scientifiques, les politiques publiques et les instances éthiques nécessite d'approfondir et de poursuivre cette réflexion sur leur intégration en société, tout en posant un regard critique sur les dynamiques de pouvoir inhérentes à la santé publique.

Mots-clés
santé des populations, éthique, crise sanitaire, multidisciplinarité, médiation, intégration de connaissances

Abstract
In the context of the COVID-19 health crisis, the politicization of science was a necessary response to the challenges faced. While this mediation (influenced by political considerations) served as a strategic response, we argue that it remained incomplete from an ethical perspective. A retrospective analysis of the situation has highlighted the need to sustain and expand the advisory role that ethics bodies played in the health network during the pandemic. The complexity arising from a sustained interaction between scientific knowledge, public policies and ethics bodies calls for a deeper and continued reflection on their integration into society, while maintaining a critical perspective on the power dynamics inherent in public health.

Keywords
population health, ethics, health crisis, multidisciplinarity, mediation, knowledge integration

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INTRODUCTION

Au Québec, la pandémie de COVID-19 a mis à l'épreuve notre système de santé. Cette période de 2020 à 2022 a fait ressortir des tensions préexistantes (1). D'une part, le discours des autorités publiques a suscité la volonté de contenir la crise sanitaire et d'assurer une continuité dans les services d'urgence et de soins primaires, par crainte d'aggraver une situation déjà précaire. D'autre part, un débat sociétal a émergé à propos du risque d'un ressac lié à une restriction des libertés, comptant les déplacements, les loisirs, l'éducation, les soins à domiciles, les relations interpersonnelles, etc. (2). Cette crise a accentué l'instabilité du système de santé, dont les politiques sujettes à plusieurs réformes récentes, témoignent de la sensibilité et de la complexité de la situation (3). Les 32 établissements constituant le réseau de la santé ont connu des contraintes importantes pour fournir les soins et services réguliers. Englobant ce réseau, le système de santé[1], comprenant le ministère de la Santé, les partenaires nationaux et autres comités et organismes collaborateurs, ont aussi connu des bouleversements (1,4,5). Dans ce contexte, les conférences de presse ont caractérisé la trame médiatique, annonçant quotidiennement un bilan de la situation, une mise à jour sur le variant, l'état du réseau, et les mesures recommandées par la santé publique.

L'intégration des connaissances scientifiques aux décisions politiques est devenue habituelle – aux côtés des ministres et des députés se sont ajoutés des médecins, des microbiologistes et des épidémiologistes. Sous le couvert d'un message de santé publique, les discours à la nation ont servi à développer et à opérer les politiques publiques. Devenue stratégique, cette intégration a aidé à accélérer la diffusion des messages et à transformer les comportements, mais a conduit à une réponse incomplète sur le plan éthique. Le manque de transparence et l'instrumentalisation de la science imposent le risque d'éroder la confiance de la population, une confiance qui s'amenuise à mesure que les citoyens découvrent les limites et l'incertitude scientifique autour des données justifiant les mesures sanitaires. Ce recul de la confiance a possiblement réduit l'effet désiré de ces politiques (1,6).

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[1] « Réseau de la santé » désigne des personnes physiques et morales ainsi que des établissements et des technologies tangibles; « Système de la santé » désigne le contexte organisationnel plus large dans lequel le concept de réseau s'applique, et comprend aussi des composantes intangibles (ex. : juridiques, économiques et sociologiques). Ces définitions concordent avec celles utilisées par le Gouvernement du Québec.

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Les sphères scientifique et politique portent leurs propres cadres de valeurs. Sans cette prise de conscience, l'intégration des connaissances scientifiques aux politiques publiques devient une géométrie compliquée posant l'addition de fractions aux dénominateurs différents. Cette intégration nécessite de comprendre la perspective de l'autre et d'ajuster son message en fonction des biais potentiels le caractérisant, ce qui implique un dialogue prolongé et constructif. A l'échelle de vastes organisations scientifiques et politiques (1,7,8), des agents facilitateurs doivent incarner ces dialogues et susciter une réflexion sur les valeurs (5,8,9). Au milieu de la pandémie de COVID-19, de nouvelles instances en éthique se sont créées pour prioriser, nuancer et expliquer ces valeurs (5,10). Des organismes comme le Comité d'éthique de santé publique (CESP) et la Commission de l'éthique en science et en technologie (CEST) ont conseillé le processus de prise de décision dans les établissements du réseau et du ministère (1,8,11). En rétrospective, la crise a permis de démontrer la plus-value de ce système-conseil qui – nous argumenterons – devrait se pérenniser et se renforcer dans le réseau de la santé.

Ce commentaire souligne que l'intégration des connaissances scientifiques dans les politiques publiques tend à être incomplète sur le plan de l'éthique, particulièrement en temps de crise. Nous mettons en lumière la valeur ajoutée d'un regroupement d'éthiciens institutionnalisé dans le réseau de la santé. Notre analyse suggère de construire sur des initiatives *a priori* éphémères pour consolider un modèle multidisciplinaire de conseils mis en opération en amont, et ainsi capable de devancer les crises.

SANTE DES POPULATIONS : UN EQUILIBRE ENTRE INDIVIDU, COLLECTIVITE ET POLITIQUES PUBLIQUES

En 1974 (3), le ministre fédéral de la santé Marc Lalonde proposait une vision « globale » pour analyser l'état de santé des populations canadiennes[2]. Son cadre reposait sur quatre dimensions, à savoir la *biologie humaine*, l'*environnement*, les *habitudes de vie* et l'*organisation des soins de santé* (3). Ces dimensions ont donné différents cadres conceptuels expliquant les déterminants de la santé, c'est-à-dire « les facteurs personnels, sociaux, économiques et environnementaux qui déterminent l'état de santé des individus ou des populations » (12). Ces dimensions paraissent indépendantes, chacune porteuse d'une complexité lui étant propre, elles renvoient à des disciplines pleinement constituées. Cependant, projetées à l'échelle organisationnelle, ces dimensions sont aussi interconnectées. En l'occurrence, la biologie est une condition nécessaire à l'existence sociale des habitudes de vie; puis la perception des bonnes habitudes est une condition à la bonne organisation des soins (13,14). Ces dimensions sont alors considérées en interdépendance (1). À leur interface de dépendance, nous retrouvons des échelles d'organisation s'emboîtant entre elles, comptant les individus faisant partie d'une collectivité, puis ces collectivités nichées dans un environnement bâti (une ville) et naturel (un écosystème). Ces relations sont, enfin, incarnées par les institutions de santé ainsi que les cadres politique, culturel et socioéconomique (14,15).

En intégrant cette perspective, la santé publique devient « un art et une science pluridisciplinaire » (16). La « science » de la plurifactorialité des déterminants de la santé et l'« art » normatif de son institution au service de la santé des populations viennent systématiser des actions dépassant le soin clinique (17,18). Ainsi, elle nécessite une intégration des connaissances scientifiques aux politiques publiques, qui peut aller au-delà de la qualité de la relation entre le patient, le médecin et une équipe de soin. Cet élargissement de la santé englobe alors le système de soins, la gouvernance en santé et les valeurs sociétales (13,14).

LA CREATION DU REGROUPEMENT DES ETHICIENS DU RESEAU DE LA SANTE AU QUEBEC

Face à l'incertitude, des acteurs du système de santé québécois ont souligné le manque de communication entre les opérations et l'administration des politiques concernant la COVID-19 (8). Quelques semaines après la déclaration du premier cas confirmé, il y a eu un mandat de la sous-ministre adjointe, Dre Lucie Opatrny – également présidente du Comité directeur clinique COVID-19 –, pour se pencher sur les enjeux éthiques relatifs à la gestion des pandémies. De ce mandat a émergé le comité éthique COVID-19 (10,19,20) pour aider le Gouvernement à prioriser les actions liées à la pandémie. Le rôle du comité s'est accru avec la pression imposée au réseau de la santé, ce qui a amené un rassemblement volontaire de professionnels et de conseillers en éthique (clinique et organisationnelle), désigné ici sous le nom de « regroupement des éthiciens ». Provenant de différents établissements du Réseau de la santé et des services sociaux (RSSS), ces membres volontaires ont facilité la communication des enjeux et des préoccupations entre les opérations et l'administration. Leur relation explicite avec le comité éthique COVID-19 a ouvert un espace d'échange et de concertation sur les interventions et les stratégies avant leur mise en application.

La création de cet espace où les individus (et les institutions qu'ils représentent) se connaissent a accéléré la réponse à la crise (5). Cette collaborativité a facilité la mobilisation rapide des acteurs, favorisant ainsi l'efficacité de la gestion. Elle a aussi ouvert un dialogue constructif, clarifiant le message scientifique et simplifiant le conseil retourné aux hauts fonctionnaires. Bénéficiant d'une meilleure coordination, les acteurs de la santé publique (1,5,8,11) ont pu opérer de façon décentralisée en échangeant des précisions (politiques, programmes, plans, protocoles, etc.). D'autre part, en œuvrant au niveau du terrain, le regroupement des éthiciens a permis le maillage avec l'administration des politiques de la COVID-19 durant la pandémie pour véhiculer et transmettre les enjeux et préoccupations. Ainsi, il est devenu un organisme consultatif informel, évaluant les

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[2] Nous adoptons ici la définition de la santé publique comme étant l'ensemble des activités menées par les autorités publiques pour prévenir les maladies et promouvoir la santé au sein d'une collectivité, tandis que la santé des populations (tout en étant une finalité) adopte une perspective plus large incluant les déterminants socio-écologiques de la santé.

interventions et les stratégies gouvernementales à la lumière des rétroactions provenant du RSSS. Son modèle décentralisé et collaboratif a permis l'offre d'une expertise en éthique au Québec et a amélioré la cohérence entre les orientations gouvernementales, l'administration publique et l'opération en créant des points de liaison. À la manière d'une communauté de pratique (21), ses membres ont pu représenter leurs établissements, étendant ainsi la portée des délibérations internes sur les mesures sanitaires.

LE ROLE CLE DE L'ETHIQUE APPLIQUEE ET D'UN REGROUPEMENT EN ETHIQUE

« Les connaissances non reliées tuent la connaissance et font apparaître une nouvelle ignorance qui s'ignore elle-même au cœur de la prolifération des connaissances ». (22)

Différents enjeux et conflits émergent de l'aspect multifactoriel et pluraliste de la santé des populations, ce qui justifie un cadre éthique qui soit critique, réflexif et dynamique. Le principisme, par exemple, aide à façonner une décision à la lumière des principes d'autonomie, de justice, de bienfaisance et de non-malfaisance (9,23). Cependant, les décisions en santé publique et des populations nécessitent plus que le principisme, comme l'explique Raymond Massé : « […] ces principes, pourtant adéquats pour justifier des interventions cliniques dans le cadre d'une relation clinicien-patient, ne suffisent pas pour justifier des interventions de promotion de la santé » (18). De plus, le principisme peine à intégrer les connaissances à l'analyse éthique.

Comme dans la proposition de Reinhard Priester pour orienter la réforme des soins de santé aux États-Unis (24), la justification des interventions en santé publique doit s'ancrer dans un cadre impliquant des principes actionnables, englobant des valeurs fondamentales, et conduisant à des actions tangibles. Les principes décrits par Massé (18) en sont un exemple : la solidarité, le respect de la vie en santé de la population, la protection du bien commun et la co-responsabilité. Ces principes ont la qualité de mieux se mailler avec les connaissances scientifiques et l'opérationnalisation des politiques publiques (1). Pour reprendre le contexte de la pandémie de COVID-19, les mesures de distanciation sociale, ou encore celles ciblant le port du masque, ont entraîné des contraintes supplémentaires pour les populations en perte d'autonomie comme les personnes handicapées (8), alors qu'un principe de solidarité aurait pu orienter des stratégies d'adaptation, telles que des mesures d'accompagnement ou des accommodements spécifiques, afin d'atténuer ces effets négatifs. De même, les directives imposées dans les milieux de soins ou d'hébergement de longue durée ont été à l'origine d'enjeux éthiques majeurs à cause de l'isolement et la détresse morale que cela a infligés, à des populations déjà souffrantes (5,8). L'intégration du principe de co-responsabilité aurait aidé à établir un meilleur équilibre entre la protection de la santé publique et le bien-être physique et mental, pour les patients et leurs proches aidants (5).

Restreindre les éthiques appliquées à la médecine, à l'administration des soins de santé et aux recherches cliniques des sciences de la vie (25,26) est insuffisant pour aborder la santé des populations. Une vision plus englobante (27,28) s'appliquerait au contexte, en mobilisant la richesse de la multidisciplinarité, voire à une « science en action » dans la société[3]. Ceci resitue l'éthique dans le paysage des activités démocratiques, allant de la délibération à l'évaluation des programmes en passant par le développement de politiques et d'interventions (2), tout en conservant un rôle en pratique. Ces équipes inclusives et leur travail itératif valorisent ainsi un dialogue interpersonnel, puis le dépassent en s'inscrivant dans un processus en cascade comprenant des influences d'ordre économique et sociologique. Impliquant alors des intermédiaires et rappelant le rôle que joue un député, un représentant d'association ou un président de société, l'éthique tisse ainsi la trame d'un dialogue aidant à consolider un cadre commun et un référentiel de valeurs (7,27,29-31).

Actuellement, le climat de confiance est défié en société par une instrumentalisation des données (probantes ou non) pour justifier et légitimer des décisions politiques, reposant sur la crédibilité et le jugement des autorités publiques (1). Pourtant, une meilleure intégration permettrait de faire la lumière sur les conséquences sociétales des choix et des actions posées. Face aux incertitudes qu'impose une crise, l'éthique devient nécessaire pour prioriser sans miner la crédibilité scientifique, alors que les connaissances sont soumises à une pression politique : « Les connaissances scientifiques sur le COVID-19 se sont construites au jour le jour, au fur et à mesure de l'évolution de la crise sanitaire, n'offrant ainsi aucune garantie quant à la justesse des décisions politiques prises en amont » (1). Ensuite, une médiation entre les différents acteurs, puis entre l'administration et le terrain, est indispensable pour rendre compte de la complexité. La pluralité des réalités et des préoccupations, par exemple entre les régions éloignées ou rurales versus urbaines, nuance la distribution des impacts (bénéfices et coûts) courant le risque d'accentuer des vulnérabilités préexistantes.

Avant la pandémie de COVID-19, la nécessité de structurer un rassemblement des éthiciens du RSSS s'était déjà imposée. Cette initiative visait alors à instituer un réseau formel, favorisant le partage d'expertise et la concertation à l'échelle provinciale. Elle ambitionnait de coconstruire la place et le rôle de l'éthique au sein du système de santé. La crise sanitaire a exemplifié cette nécessité. Après deux ans de pandémie, le comité éthique COVID-19 et le regroupement des éthiciens, instances *a priori* éphémères, ont permis de répondre à des enjeux majeurs gravitant autour de questions sensibles telles que le refus de dépistage, la priorisation pour l'accès aux soins intensifs ou encore les mesures d'isolement chez les personnes en déficience intellectuelle (5). Au-delà de la capacité de soutien, de conseils et d'orientation éthique, la concertation rendue possible entre les acteurs aux rôles, aux compétences et aux responsabilités différents, a été cruciale pour l'application des stratégies de

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[3] La bioéthique, lorsque définie comme « éthique appliquée aux sciences du vivant », vient englober ces « différentes » applications pour donner un cadre de valeurs s'arrimant avec la pluralité disciplinaire de la santé des populations.

prévention et d'intervention. Ce nœud de collaborations a facilité l'identification rapide des acteurs en éthique au sein du réseau de la santé, permettant ainsi une communication plus efficace pour répondre aux besoins émergents et urgents.

CONCLUSION

La crise sanitaire à laquelle nous avons dû faire face a été à la fois un défi et une opportunité pour affronter les limites de notre système de santé et pour « refondre nos modes de pensée » (32). Au terme de cette crise, nous devrions construire sur nos apprentissages, et miser sur la valeur ajoutée du regroupement éphémère des éthiciens du RSSS du Québec qui a démontré son importance fonctionnelle à des moments critiques. Notre commentaire ouvre la réflexion sur la place de l'éthicien et l'étendue de sa responsabilité ainsi que sur le degré d'indépendance et le poids décisionnel que devraient avoir ces instances de médiation et investigation (recherche, développement et évaluation) pour faciliter la relation entre la science et le politique. Nous argumentons l'importance de réfléchir au rôle qu'a joué ce type d'instance et à la valeur d'en pérenniser le rouage et d'en avancer le modèle pour augmenter la résilience de notre système de santé.

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

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RÉPONSE À - ARTICLE / RESPONSE TO - ARTICLE

Le risque de paternalisme dans le recours à l'éthique narrative : le cas de la stérilisation volontaire chez les femmes sans enfant de moins de 30 ans

Arthur Filleul[a, b, c]

Texte discuté/Text discussed: Masella MA, Marceau E. La stérilisation volontaire chez les femmes sans enfant de moins 30 ans : dilemme éthique et déontologique. Can. J. Bioeth /Rev Can Bioeth. 2020;3(1):58-69.

Résumé

Ce texte est un commentaire en réaction à l'article de Masella et Marceau, portant sur la stérilisation volontaire chez les femmes sans enfant de moins de 30 ans. Je soutiens que leur publication est essentielle pour permettre une analyse rigoureuse du dilemme éthique entre autonomie des femmes et paternalisme médical. Cependant, je suggère aussi que leur proposition d'une approche d'éthique narrative comme solution au dilemme éthique ouvre la voie à un paternalisme plus insidieux, mais tout aussi problématique. C'est-à-dire qu'une éthique narrative peut, paradoxalement, réactiver des dynamiques paternalistes et amplifier des injustices épistémiques et sociales.

Abstract

This text is a commentary on Masella and Marceau's article on voluntary sterilization in childless women under 30. I argue that their publication is essential for a rigorous analysis of the ethical dilemma between women's autonomy and medical paternalism. However, I also suggest that their proposal of a narrative ethics approach as a solution to the ethical dilemma opens the way to a more insidious, but no less problematic, paternalism. That is, a narrative ethics can, paradoxically, reactivate paternalistic dynamics and amplify epistemic and social injustices.

Mots-clés

bioéthique, éthique narrative, injustice épistémique, paternalisme, stérilisation

Keywords

bioethics, narrative ethics, epistemic injustice, paternalism, sterilization

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Marie-Alexia Masella et Emmanuelle Marceau, dans leur article paru en 2020 dans la *Revue canadienne de bioéthique*, explorent le dilemme éthique et déontologique de la stérilisation volontaire chez les femmes sans enfant de moins de 30 ans (1). La première force de l'article est la précision des données médicales, fondées sur des données probantes actuelles, qui offrent un cadre clair pour évaluer les avantages et les inconvénients de la procédure de stérilisation. L'argumentation éthique repose ainsi sur trois faits médicaux consensuels : les risques pour les femmes sont faibles, la procédure est efficace, l'intervention est irréversible. Un deuxième point fort de l'article réside dans sa capacité à retracer les évolutions sociales et sociétales. Les auteures révèlent les motivations profondes qui poussent ces femmes à ne pas avoir d'enfant : se concentrer sur leur relation de couple, privilégier leur carrière professionnelle, voyager, ou simplement rechercher une plus grande liberté. L'article souligne également les raisons qui incitent certaines femmes à opter pour la stérilisation comme méthode de contraception : garantir une efficacité maximale face à la peur de l'avortement, l'intolérance aux hormones entraînant des états dépressifs ou une baisse de libido. L'article démontre que le choix de ne pas avoir d'enfant découle d'une réflexion approfondie et la décision de recourir à la stérilisation répond à des problèmes sérieux.

Enfin, les auteures décrivent les dilemmes rencontrés par les professionnels de santé, notamment la peur d'aller à l'encontre de leurs obligations déontologiques (ex. : ne pas nuire) ou de voir les femmes regretter leur décision. Ces craintes poussent les soignants à restreindre l'accès des femmes à la stérilisation définitive via des critères implicites et subjectifs pour juger de la légitimité d'une demande de ligature des trompes, tels que l'âge, le nombre d'enfants ou le statut marital (2). Or, ces critères ne sont ni médicalement ni éthiquement fondés (3,4). Les auteures montrent ainsi comment des normes sociales, particulièrement l'hétéronormativité ou l'idéologie pronataliste du « toute femme doit devenir mère », sont ancrées et peuvent justifier, sous couvert de bienfaisance, un paternalisme médical dur. Loin de nier la légitimité de ces vécus et inquiétudes de la part des médecins, cette situation nous invite à réfléchir sur ce qui est perçu comme choquant et à ne pas le confondre avec ce qui est réellement contraire à l'éthique. Cela nous pousse à distinguer les émotions suscitées par des choix jugés « hors-norme » de leur légitimité dans le débat éthique.

Ainsi, l'article présente très bien cette tension éthique qui oppose le paternalisme dur à la reconnaissance pleine de l'autonomie, ici comprise comme l'autodétermination des femmes dans leurs choix de santé. Après cette mise en lumière de la tension, les auteures proposent d'explorer le dilemme via une approche d'éthique narrative (1). Cette éthique implique une collaboration plus approfondie entre patientes et médecins, visant à concilier le respect de l'autonomie et les perspectives du

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corps médical, afin d'aboutir à une décision jugée « bénéfique ». Je souhaite mettre de l'avant que l'éthique narrative possède des avantages et de nombreux champs d'applications tout à fait pertinents, mais que celui-là précisément n'en est pas un à mon sens. Dans ce cas précis, cette éthique narrative constitue une faiblesse de l'argumentation et maintient une certaine forme de paternalisme, plus douce, mais tout aussi problématique.

Dans une approche narrative, où le dialogue entre le patient et le professionnel de santé joue un rôle central dans la prise de décision, il est inévitable que les valeurs personnelles du thérapeute influencent le processus (5). Elle peut alors réintroduire une forme de paternalisme doux, où le soignant oriente subtilement, intentionnellement ou non, les décisions de la patiente selon ses propres convictions. En clair, nous serions face à ce que l'on nomme des « *nudges* » (6)*,* ces techniques qui influencent les comportements ou les décisions des patientes, soi-disant « sans restreindre leur liberté de choix » (7). Dans le cas de la stérilisation des femmes de moins de 30 ans, si le professionnel de santé a des réserves personnelles ou professionnelles concernant cette intervention, il pourrait privilégier plus ou moins consciemment des arguments qui dissuadent la patiente. Par exemple, en n'évoquant que les risques des interventions, plutôt que les bénéfices liés à cette intervention, jouant ainsi sur la sensibilité plus forte des risques et la perte qu'aux bénéfices (8). Cette dynamique de dialogue crée une dépendance à la subjectivité du soignant, qui devient l'arbitre des valeurs et du « bien » à suivre (5). Le médecin qui jugerait une femme sans enfant trop jeune pour avoir accès à une stérilisation définitive pourrait tenter, sans la demande ou l'accord de la patiente, de faire part de son propre vécu, de comment ses enfants ont changé sa vie pour le mieux, afin de profiter de leur forte relation thérapeutique pour influencer les décisions de certaines femmes. Cela va à l'encontre du principe d'autodétermination qui devrait guider les décisions concernant des choix aussi personnels et intimes que le choix d'une méthode d'une contraception (définitive ou non).

Deuxièmement, une approche narrative peut pousser certaines patientes à devoir « séduire » (c'est-à-dire convaincre sans relâche) l'équipe médicale pour obtenir ce qu'elles souhaitent (9). Elles doivent justifier leur désir de manière à le rendre acceptable aux yeux du médecin, ce qui peut créer une dynamique verticale et maintenir un pouvoir inégalitaire. Par exemple, elle peut décider de ne pas évoquer une rupture récente par peur de faire croire au médecin que sa décision est prise à la suite de cette situation émotionnellement difficile. L'article de Masella et Marceau illustre cet enjeu lorsqu'elles évoquent le fait que le médecin doit apprendre à « discerner les forces et les faiblesses du récit du patient » (1, p.65). Plutôt que de fonder la décision sur un respect direct de l'autonomie de la patiente, le processus devient un jeu de pouvoir où il faut négocier, et renégocier en permanence, l'accès à ces services. Cette nécessité de « raconter une bonne histoire » pour obtenir l'accord peut amplifier les injustices épistémiques (10), en particulier lorsqu'il existe un déséquilibre dans les capacités de communication ou la littératie en santé entre la patiente et le professionnel. La capacité de bien formuler ses arguments, d'utiliser un langage médical ou sophistiqué, ou même de comprendre les nuances éthiques du débat peut devenir un facteur déterminant dans la prise de décision du corps médical d'accéder à la demande. Cela favorise les patientes ayant un niveau d'éducation ou de communication élevé, créant ainsi une inégalité et des injustices dans l'accès aux soins. Aussi, on peut ajouter que les femmes venant d'un milieu défavorisé, habituellement privées de pouvoirs, ou venant d'un milieu où il n'est pas reconnu légitime de contester le pouvoir médical ne pourra se confronter à l'avis du médecin. Finalement, cela revient à infliger une double peine : les personnes déjà dites « vulnérables » se voient pénalisées une seconde fois, en étant privées de l'accès aux soins qu'elles étaient venues chercher.

Finalement, comme les auteures l'indiquent, l'éthique narrative, impliquant de multiplier les consultations, risque d'allonger inutilement le processus, surtout dans un contexte de pénurie de ressources médicales. Bien qu'elles soulignent un avantage potentiel à prendre plus de temps pour la réflexion, cela pourrait davantage constituer un obstacle supplémentaire dans un parcours déjà long et complexe. Cette approche, bien que louable, semble contradictoire avec leurs arguments précédents. Si l'on considère que « le risque de regrets ou les biais personnels des médecins ne justifient pas le refus d'une stérilisation chez une femme de moins de 30 ans sans enfant, car la décision doit être centrée sur les femmes et non sur un jugement personnel » (2, p.67), quel est alors l'intérêt d'une éthique narrative? Il semble que cette approche soit davantage une réponse aux appréhensions légitimes des soignants face à ces décisions, plutôt qu'une véritable avancée dans l'autodétermination des femmes. En fin de compte, elle risque d'instaurer une dynamique de paternalisme au lieu de favoriser l'émancipation des patientes.

Ainsi, il est clair que l'article de Masella et Marceau contribue de manière importante au débat en bioéthique sur le paternalisme dans le cadre de la stérilisation volontaire des femmes. Mais je resterai prudent sur l'utilisation d'une éthique narrative dans ces situations de décisions personnelles, car elle présente le risque de diluer l'autonomie des femmes, transformant leur décision en une co-construction dont le médecin peut influencer subtilement l'issue.

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None to declare. The content of this text reflects the opinions of the author and not necessarily those of the affiliations.

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RÉPONSE À - ART, CULTURE ET ŒUVRE DE CRÉATION / RESPONSE TO - ART, CULTURE & CREATIVE WORKS

Introspection et poésie pour une bioéthique qui prend sens

Georges-Philippe Gadoury-Sansfaçon[a]

Texte discuté/Text discussed: Dwyer J. Frameworks and practices in bioethics. Can J Bioeth. 2023;6(1):84-94

Résumé
Ce commentaire explore le cheminement réflexif de James Dwyer en bioéthique présenté dans « Frameworks and Practices in Bioethics », marqué par un passage de la théorie de la justice de Rawls à une pratique introspective du haïku, puis au pragmatisme de Dewey. Dwyer propose une approche novatrice, utilisant des outils créatifs pour approfondir l'introspection et cultiver une attention accrue aux enjeux éthiques complexes. Toutefois, il exprime des doutes sur l'impact concret de ces pratiques, critiquant leur manque de progression tangible et leur capacité à générer des réponses applicables. Ce commentaire analyse les forces de son approche, notamment sa capacité à enrichir la réflexion bioéthique par l'ouverture et l'innovation, ainsi que ses limites, en mettant en lumière les tensions entre abstraction et application concrète. L'exploration souligne l'importance des pratiques interdisciplinaires et adaptatives pour répondre aux dilemmes bioéthiques contemporains, tout en plaidant pour une intégration harmonieuse entre introspection et pragmatisme. Malgré ses doutes, la démarche de Dwyer offre une contribution significative en réaffirmant le rôle des méthodes réflexives et créatives dans l'évolution de la bioéthique.

Mots-clés
bioéthique, introspection, philosophie, poésie, haïku, cadres éthiques, Dwyer

Abstract
This commentary examines James Dwyer's exploration of bioethics as presented in "Frameworks and Practices in Bioethics", tracing his transition from Rawls' theory of justice to the reflective practice of haiku and ultimately to Dewey's pragmatism. Through this journey, Dwyer introduces a creative approach that leverages introspective tools to enhance ethical awareness and address complex issues. Despite its innovative nature, he questions the practical outcomes of these methods, noting their limited tangible impact and challenges in generating actionable solutions. This commentary highlights the strengths of Dwyer's approach, particularly its ability to foster openness and innovation in bioethical thinking, while also addressing its limitations, such as the difficulty in bridging the gap between theoretical abstraction and practical application. The analysis underscores the value of interdisciplinary and flexible methods in navigating contemporary bioethical challenges, advocating for a balance between introspection and pragmatic action. Ultimately, Dwyer's work underscores the importance of reflective and creative practices in shaping the future of bioethics, even as it grapples with its own constraints.

Keywords
bioethics, introspection, philosophy, poetry, haiku, ethical frameworks, Dwyer

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INTRODUCTION

Dans « Frameworks and practices in bioethics », James Dwyer (1) retrace l'évolution de son approche en bioéthique, un parcours qui l'a conduit du cadre théorique de John Rawls à une pratique poétique à travers le haïku, avant de s'orienter vers le pragmatisme de John Dewey. À travers ce texte, et surtout grâce à sa poésie, Dwyer propose une réflexion introspective sur les considérations existentielles qui ont façonné sa pratique. Il crée ainsi un espace de réflexion qui invite à un dialogue plus profond. Cependant, cette introspection soulève une question essentielle : ces pratiques réflexives et créatives peuvent-elles réellement enrichir la bioéthique contemporaine et répondre aux dilemmes complexes qu'elle cherche à résoudre?

Pour répondre à cette question, ce commentaire analysera d'abord les forces de l'approche de Dwyer, en mettant en lumière son invitation à une réflexion ouverte et innovante, notamment par l'utilisation d'outils non conventionnels comme le haïku. Ensuite, il examinera les limites de son parcours, notamment son insatisfaction envers sa propre pratique introspective et la tension entre abstraction et application concrète. Enfin, il discutera des leçons à tirer de cette démarche pour enrichir la bioéthique contemporaine, en soutenant que, malgré ses doutes, l'exploration de Dwyer met en lumière l'importance de méthodes interdisciplinaires et adaptatives dans la gestion de contextes éthiques complexes.

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FORCES

Dwyer réussit à brosser le portrait d'un cheminement typique en bioéthique qui passe des grandes théories à l'expérimentation et la trouvaille d'approches pragmatiques. En partageant les conclusions de son introspection, il décrit bien la quête de sens de nombreuses personnes intéressées par la bioéthique, qui découle d'un désir de concilier l'obtention de réponses et la complexité propre au milieu. Il souligne ainsi avec justesse que la bioéthique est une pratique vouée à évoluer – qu'il est nécessaire de faire preuve d'ouverture dans son adaptation au fil du temps.

> With more time, maybe the present framework will prepare me for and lead me to another framework and practice. (1, p.93)

Plus on s'y engage, plus on développe une intuition et une compréhension fines des situations complexes, ce qui nous pousse à la fois à accueillir l'abstraction et à naviguer plus aisément des situations concrètes (2). En intégrant des considérations personnelles, en particulier par sa pratique du haïku, Dwyer adopte une approche introspective, soulignant la valeur de la vulnérabilité :

> I need these reminders because I often forget. (1, p.92)

Cela rejoint l'essence de la bioéthique, qui requière souvent une introspection personnelle pour promouvoir une ouverture au dialogue (3-6). Miser sur la subjectivité de son parcours ouvre aussi à l'analyse individuelle, reflétant le fait que la bioéthique est remplie de remises en question laissées en suspens et des solutions en perpétuelle évolution, notamment au fil des défis soulevés par le développement de nouvelles technologies (7-9). Du même coup, il ancre l'autocritique et l'examen des biais cognitifs comme des éléments essentiels à un tel cheminement. Dwyer étend aussi l'autocritique à des questions éthiques plus larges, comme la minimisation du biais anthropocentrique, une pratique importante par son caractère antispéciste.

La force principale du texte de Dwyer réside dans l'espace d'introspection et de partage créés par ses haïkus. Vu leur nature brève et abstraite, ils invitent nos raccourcis cognitifs à remplir par réflexe le vide laissé avec une interprétation subjective.

emergency nurse
struck in the eye
by a patient –

hasn't seen a doctor
in thirty-five years –
wants everything now

wants to leave
Against Medical Advice –
to check on her dog

patient
with a rare disease
dysfunctional family (1, p.90)

Dwyer met de l'avant une approche axée sur « vivre dans la question » et transforme la lecture de ce texte en un effort d'introspection qui pousse à approfondir la réflexion du lecteur. Il souligne aussi l'importance de l'attention aux détails et la valeur de l'ouverture aux changements vers des objectifs propres à chaque situation. Cet effort d'observation préliminaire est parfois négligé dans les débats éthiques plus pragmatiques, même si ce type d'espace a le potentiel de stimuler la créativité dans la résolution de problèmes complexes (10,11).

Même s'il conclut que sa pratique du haïku ne l'a pas mené aux réponses qu'il cherchait, une lecture attentive pousse à penser que Dwyer sous-estime son apport à son cheminement.

LIMITES

Dwyer critique sa pratique du haïku en constatant un manque de progrès tangible, qui l'a poussé vers l'approche de Dewey. Cette critique constitue la principale limite de l'article.

En se fixant des attentes spécifiques pour sa pratique, il tombe à mon avis dans le piège de s'attacher à un objectif initial plutôt que de chercher l'objectif que dicte l'évolution de la situation. Cela rend moins probable l'adéquation du cheminent dans sa pratique et de sa quête de sens.

> I came to feel disappointed with a suggestion I saw in haiku and Zen. The suggestion is that if you pay attention to the concrete situation, without abstract and distorting concepts, you will see and do what needs to be done. (1, p.92)

Pourtant, c’est justement ce piège qu’il dénonce en se rapprochant de l’approche de Dewey. Son attente crée un biais, l’empêchant de voir que l’échec attribué au haïku réside peut-être dans son approche à la pratique, et non dans la pratique elle-même. En effet, dans ce texte, Dwyer ne reconnaît que peu et tardivement que sa pratique du haïku l’a conduit vers l’adoption du cadre pragmatiste de Dewey, qui repose sur des valeurs similaires, mais explicites. Il n’aurait possiblement pas cheminé vers cette approche sans avoir d’abord traversé l’expérience du haïku. Ainsi, la pratique du haïku, bien que perçue comme incomplète, l’a en fait dirigé par ses apprentissages implicites vers une éthique plus en phase avec ses besoins intellectuels et existentiels – elle a donc atteint l’objectif fixé.

Dwyer exprime aussi des doutes sur sa capacité à répondre avec plus de perspicacité, de compétence ou de compassion après avoir adopté cette pratique :

> With my haiku-practice, the way I perceived and inhabited the world changed. Although I did become more attentive, I’m not sure I became more responsive. In fact, I began to have doubts about the ethical value of this practice. (1, p.92)

Il est cependant important de reconnaître que des pratiques comme le haïku ou la pleine conscience ne produisent pas toujours des résultats immédiats ou visibles (12-14). Elles développent progressivement une capacité d’attention plus fine aux détails abstraits de la vie et des décisions éthiques – et nous sommes de bien piètres juges de nos propres changements existentiels, en raison justement de leur caractère lent et progressif. En sous-estimant la valeur de son haïku et en migrant vers une autre approche, à mon avis Dwyer manque une occasion additionnelle d’illustrer comment les pratiques créatives et introspectives peuvent enrichir la prise de décision en bioéthique.

L’auteur semble trop centré sur les éléments opérationnels :

> The questions that concern me are which concepts to use, how to use them, and when to revise. (1, p.92)

Cette approche limite sans doute sa capacité à lâcher prise et à laisser émerger des réponses plus intuitives. Paradoxalement, sa pratique du haïku aurait pu l’aider à dépasser cette obsession pour la recherche de réponses immédiates, car elle permet une attention plus large aux contextes et aux détails du monde vécu, un élément essentiel de la réflexion éthique. En fin de compte, sa désillusion envers le haïku l’amène à sous-estimer l’impact que cette pratique a eu et pourrait continuer d’avoir dans sa réflexion éthique. Plutôt que de voir ces cadres comme des étapes distinctes, Dwyer pourrait envisager une approche intégrée, où le formalisme de Rawls, l’introspection du haïku et le pragmatisme de Dewey se nourrissent mutuellement, créant une méthode bioéthique plus complète et plus proche de son identité.

Dwyer termine en soulignant qu’il suspecte qu’un changement social pouvant pallier les problèmes complexes actuels nécessitera un engagement politique et profond au-delà de changements plus modestes par le biais d’habitudes sociales. Il y a pour moi une limite à ce niveau, puisque l’engagement politique et profond reste moins accessible pour bon nombre de personnes et qu’il y a encore beaucoup de progrès réalisable par le biais des habitudes sociales (15,16). Dans cette prise de position comme dans son introspection, Dwyer sous-estime selon moi l’impact des espaces féconds créés par des habitudes comme les haïkus aux apparences anodines, mais à portée existentielle.

Il serait facile de souligner que les haïkus ne font pas des outils éthiques très efficaces, que Dwyer ne propose pas de solutions pour des défis concrets, ou que l’approche autobiographique limite l’applicabilité à d’autres situations. Ces limites supposées répètent toutefois les erreurs que ce texte vise à pallier. La pratique de la bioéthique se doit d’expérimenter plus souvent au-delà des cadres et des solutions immédiates si elle veut s’actualiser, s’approfondir et offrir des pistes plus créatives et novatrices. Elle doit aussi miser sur le mentorat de personnes accomplies qui acceptent de partager leur parcours pour normaliser l’incertitude et la quête de sens propres à la pratique de la bioéthique (17,18). Des outils et solutions rapides mus par un empressement à savoir et à régler en silo ne feront pas le poids face aux problèmes complexes et d’envergure auxquels fait face notre discipline (5,19,20). À chercher l’applicabilité immédiate des démarches réflexives, on en oublie l’apport significatif d’adapter ses objectifs et ses pratiques à l’évolution de la situation plutôt qu’à des principes englobants – ce qui rappelle le rapprochement de Dwyer avec l’approche pragmatique de Dewey.

CONTRIBUTIONS

Bien que Dwyer se montre désillusionné par sa pratique du haïku, elle reste une contribution significative à la bioéthique en offrant une manière différente de percevoir les contextes et les environnements éthiques. Par le style original utilisé, l’approche introspective et poétique de Dwyer défie le lecteur académique en l’invitant dans l’abstraction, au-delà des propos. Il ouvre ainsi une nouvelle voie pour les chercheurs voulant explorer des méthodes moins conventionnelles, telles que l’art ou la méditation, pour enrichir leur compréhension des dilemmes éthiques. De plus, par la nécessité d’interprétation, le texte reste engageant même en cas de désaccord avec l’auteur. Comme mentionné, l’utilisation du haïku invite implicitement ses lecteurs à adopter une posture similaire d’introspection, en mettant l’accent sur la vulnérabilité et la reconnaissance des limites personnelles plutôt que sur la confrontation et la délibération immédiates. Dwyer invite ainsi à être actif dans la lecture, et à prendre une pause qui s’apparente à une forme de pleine conscience.

En misant sur la vulnérabilité et en reconnaissant que son approche est vouée à changer en continu, Dwyer ouvre aussi la porte au partage plus ouvert dans la navigation des enjeux en bioéthique. En encourageant l'autocritique et le partage d'expériences, il propose un modèle où les bioéthiciens se réunissent non seulement pour débattre, mais aussi pour réfléchir ensemble à la manière dont leurs parcours individuels façonnent leur pratique.

Entre la rédaction préliminaire et la publication de ce commentaire, j'ai eu la chance de passer un mois dans une unité de soins palliatifs dans le cadre de mes études médicales. Puisque je me permets une critique du travail de Dwyer, j'ai cru important de tenter moi-même la pratique. J'ai ainsi voulu accepter et catalyser son invitation à l'ouverture et au partage de l'introspection poétique en bioéthique – c'est aussi l'une des contributions de son article. L'analyse de ces poèmes n'est pas l'objet de ce commentaire, mais la rédaction d'un poème court par patient m'a permis de me sentir plus au fait de l'impact de l'accompagnement en fin de vie et des enjeux éthiques en découlant sur ma pratique comme futur médecin et éthicien – et de prendre le temps de vivre les émotions associées.

1

J'étais là
un peu avant
un peu après
jamais pendant

J'aurais aimé ça vous demander
une histoire
juste une
pour me sentir moins tout seul

2

Maman est très stressée
faut pas qu'elle sache qu'elle va mourir
dites-lui pas, ok?

Y'en reste moins qu'y'en restait
ça, le comprenez-vous?

oui
on se voit demain
pour me soigner encore

Madame, c'est Georges. Est-ce que vous m'entendez?

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Conflits d'intérêts

Aucun à déclarer

Conflicts of Interest

None to declare

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RÉPONSE À – COMMENTAIRE CRITIQUE / RESPONSE TO – CRITICAL COMMENTARY

No Loitering: A Response to Disha et al. on Medical Assistance in Dying's 90-day Assessment Period

Christopher Lyon[a]

Texte discuté/Text discussed: Disha K, Bianchi A, Shanker R, Lukich N. Where Do I Go to Wait? Ethical Considerations During the 90 Day Reflection Period for MAiD. Canadian Journal of Bioethics. 2023;6(1):70-4

Résumé

Dans leur article de 2023 publié dans cette revue, Disha et al. qualifient indifféremment de « période d'attente », de « réflexion » et d'« évaluation » la période d'évaluation de 90 jours prévue par le Code criminel canadien pour l'aide médicale à mourir (AMM) pour les personnes n'ayant pas de mort naturelle prévisible (Volet 2). Cependant, la loi et les orientations officielles décrivent explicitement son objectif comme une période d'évaluation, accessoirement comme une période de réflexion, mais pas comme une période d'attente. En conséquence, il existe un besoin éthique, pratique et juridique urgent de s'assurer que les praticiens de l'AMM, leurs collègues et les superviseurs comprennent et appliquent rigoureusement la loi afin de protéger la vie des patients contre les transgressions et d'arrêter les transgresseurs.

Abstract

Disha et al., in their 2023 paper in this journal, interchangeably frame the Canadian Criminal Code's 90-day assessment period safeguard for Medical Assistance in Dying (MAID) for people without a foreseeable natural death (Track 2) as a "waiting", "reflection", and "assessment" period. However, the law and formal guidance explicitly describe its purpose as an assessment period, only incidentally a reflection period, but not a waiting period. Accordingly, there is an urgent ethical, practical, and legal need to ensure MAID practitioners, their colleagues, and overseers rigorously understand and apply the law to protect patients' lives from transgressions and stop transgressors.

Mots-clés

aide médicale à mourir, AMM, Code pénal, euthanasie, suicide assisté, éthique médicale, droit

Keywords

medical assistance in dying, MAiD, Criminal Code, euthanasia, assisted suicide, medical ethics, law

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INTRODUCTION

In a recent paper in this journal, *Where Do I Go to Wait? Ethical Considerations During the 90-Day Reflection Period for MAiD*, Disha et al. (1) explore "where patients should wait during the 90-day assessment period" for the non-foreseeable natural death track of Canadian Medical Assistance in Dying (MAID). Three co-authors are "practising healthcare ethicists…in non-acute care settings" (1) – one of several occupations, such as coordinators/navigators, with unregulated but direct roles in MAID assessments and deaths (2-4). The paper names Dr. Ellen Wiebe as its only peer reviewer.

Disha et al. (1) present their argument in the context of "patient X," a paraplegic person with a recent spinal cord injury requesting MAID who desires to remain in a rehabilitation facility during the legislated 90-day assessment period safeguard enumerated in the Criminal Code (5) due to their good relationship with staff, instead of their home or another clinical facility. Disha et al. frame this as a dilemma between "waiting" for the 90 days to expire in a hospital, care facility, or at home relative to his wishes, the beds and resources needed for other more critical patients, and the availability of home support. These authors interchangeably frame Track 2's 90-day period safeguard as an "assessment," "reflection," and "waiting" period. For instance, the title and one line of text refer only to a "reflection period" but are described as a "waiting and assessment" or "waiting and reflection period" (1).

Disha et al. conclude that there is no universal answer regarding where patients should "wait" but that individual cases should be considered through a "polyphonous" (i.e., multi-stakeholder) process to make any decision on waiting ethically defensible. This conclusion aligns with recent suggestions for broader consultation around MAID applications in the 2024 Ontario Chief Coroner's MAID Death Review Committee (MDRC) reports (6).

However, assessment, reflection, and waiting are very different concepts. Only the first two terms appear in current or past MAID legislation (5), where these authors most err.

Because of these points, misconstruing the 90-day assessment period as a "waiting period" and not the legislated "assessment period" undermines their argument and points to a broad and dangerous practitioner ignorance of fundamental Criminal Code safeguards. As an academic and a witness to a traumatic family MAID death with similar overtones (7,8), this prospect is professionally and personally frightening. I provide more specific commentary in the remainder of my response.

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ASSESSMENT, YES, REFLECTION MAYBE, BUT NOT A WAITING PERIOD

The Criminal Code (5) distinguishes between MAID eligibility criteria (sections 241.2(1), (2)) and safeguards (sections 241.2(3), (3.1)). Eligibility criteria for Track 2, which Disha et al. describe, require someone to be 18 or older, have a grievous and irremediable medical condition, enduring and intolerable suffering, and make a voluntary request for MAID. Safeguards differ and require several protective undertakings to ensure lawful and defensible eligibility assessments. For Track 2 patients, those without a reasonably foreseeable natural death, this includes the 90-day "assessment period." Track 1, for those whose natural deaths are deemed reasonably foreseeable (i.e., terminal illness), lacks a mandatory assessment period. All track-relevant criteria and safeguards must be met for MAID to be lawfully approved and provided.

Health Canada, the federal health department, unequivocally describes this period as the "minimum" timeframe for Track 2 assessment, to be extended if necessary.

> The 90-day minimum assessment period has a different purpose…The law requires that at least 90 clear days must pass between the day on which the first assessment begins by a MAID assessor and the day MAID is provided. It intends to ensure that the patient and assessors have enough time to explore relevant aspects of the patient's situation. It doesn't have to provide reflection time for the patient, although it could do this as well. (9)

This guidance, reflecting criminal law changes permitting Track 2 death (5), states this period can only be shortened if both assessors "agree the patient is at imminent risk of losing capacity to consent, **and** have completed their assessments, **and** agree the patient is eligible to receive MAID" (9). The federal justice department and Charter statements are consistent with this view (10-12).

The initial change to the Criminal Code in 2016 that permitted MAID applied only to people with a "reasonably foreseeable natural death" and required a "10-day reflection period" (9) before the earliest they could be euthanized or (outside of Québec, which does not allow it) prescribed lethal doses of medication for self-administration (exceedingly rare) after they were approved. The purpose of those 10 days was to give the patient "time to reflect on whether to proceed" with death (9). However, this mandatory reflection period was abolished for Track 1 in 2021, with critics arguing that 10 days of reflection unnecessarily prolonged suffering and was thus unethical (13). But this reasoning does not apply to more challenging Track 2 cases.

In October 2024, Ontario's MDRC repeated Health Canada's interpretation, going so far as to suggest the "arbitrary" 90-day period may be too short for the robust assessments it is meant to accommodate (6). The 2024 Ontario report even red flags a case where a person's,

> assessors considered the 90-day assessment period to be a 'waiting period' and documented the possibility of reducing the timeline should his natural death become reasonably foreseeable (e.g., untreated septicemia). (6)

The MDRC characterized this approach as "without adherence to safeguards in place to promote safety and quality care" amid "concerns that 'track switching' might be occurring, with limited opportunity to identify potential legislative [read: Criminal Code] breaches" (6).

It is therefore incontestable that these 90 days are the statutory minimum time for Track 2 assessment, only incidentally for patient "reflection," and are in no way formally conceived as a "waiting period." In that respect, it is highly alarming that these authors' mistaken interpretation appears to be used in clinical MAID. Noteworthy then, this possibly criminally offensive short-cutting of Track 2 cases is reflected in formal guidance from the Canadian Association of MAID Assessors and Providers (CAMAP), which tells MAID assessors they can qualify a person for Track 1,

> if they have demonstrated a clear and serious intent to take steps to make their natural death happen soon or to cause their death to be predictable. Examples might include stated declarations to refuse antibiotic treatment of current or future serious infection, to stop use of oxygen therapy, to refuse turning if they have quadriplegia, or to voluntarily cease eating and drinking. (14)

Other materials from this organization and an affiliated law professor speculate that clinicians can even advise patients of these methods of suicide to hasten death, shorten the assessment period, or make them eligible for Track 1 MAID (15-17). However, none of these optional actions – let alone an intent to try one – are irremediable disabilities, diseases or illnesses required for eligibility, nor do they indicate the imminent loss of capacity needed to shorten the assessment period. Indeed, in an update following a widely publicized controversial court injunction blocking a MAID death in Alberta in 2024, MV, the Track 2 requestor in the case, reportedly refused food for a remarkable 25 days around June 2024 before she resumed eating and continued to live (4,18). Although the update states she was reapproved for MAID months later for unknown reasons, attempting suicide by starvation did not lead to her death nor appear to qualify her for MAID (or hastened access) under either track. She had not used her reapproval and was "at a community care facility" in October 2024 (18).

In this light, where patient X should spend those 90 days *or longer* is much more a matter of well-informed legal and medical necessity than an informal ethical dilemma about relative convenience, comfort, or guesswork about the law.

OTHER ERRORS

Disha et al. also claim that during the 90 days, the “relevant support and services must be offered, and may be trialled with the individual’s consent” (1). This is wrong: MAID legislation only requires that a person be “informed of the means available to relieve their suffering” and “where appropriate …offered consultations with the relevant professionals” (5,19). Support and services do not have to be offered to the patient, only vague consultations with staff deemed “relevant” by an unspecified authority.

Put another way, a MAID requestor may be told of life-continuing and life-enhancing measures that could relieve their suffering and dissuade them from death, yet none of them “must be offered.” “Relevant professionals” likewise does not mean a trained specialist, only someone with “experience” (20). Again, the Ontario report flags a case where “MAiD practitioners did not document engagement with physiatry [sic] or rehabilitation specialists in the expertise consultation process” (21), suggesting that even these flawed Criminal Code requirements are likewise overlooked by some MAID practitioners.

Very similar misunderstandings appear in CAMAP guidance (14), potentially leading to criminal approvals and deaths. The implications for patient safety of such a fundamental failure to grasp critical legal safeguards cannot be overstated. It supports the suggestion of potentially thousands of unlawful approvals and deaths (22,23). As such, it reveals an urgent need for intervention by regulating authorities to ensure all MAID assessors, providers, and other clinical staff very clearly understand and apply the letter and spirit of the law so that their decisions to approve and inflict death on their patients are legally and ethically defensible.

These uncaught misunderstandings and any resulting transgressions of the legislated safeguards may result from relying on a single peer reviewer with a known bias against safeguards.

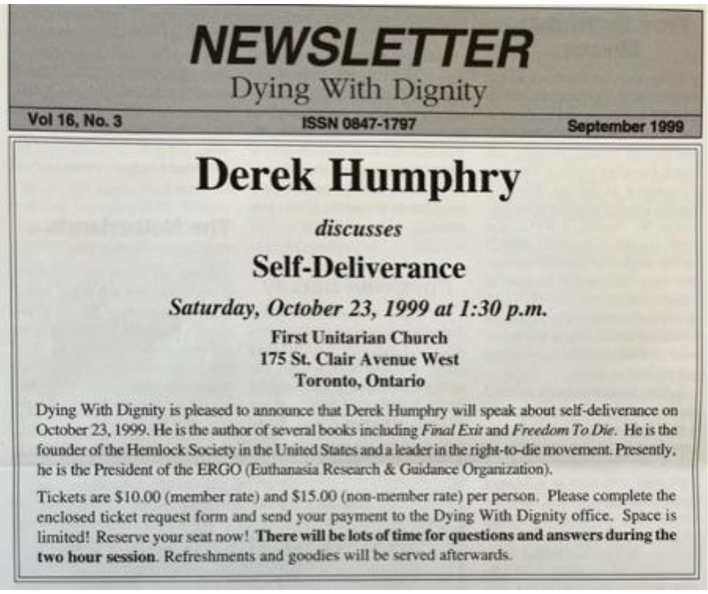
BIAS IN PEER-REVIEW

Dr. Ellen Wiebe is a clinical professor in family medicine at the University of British Columbia and a practising physician (24). Noted elsewhere, she is a very early and controversial MAID provider (25-31) and was listed as a director of CAMAP until late 2024 (32). Wiebe has admonished lawmakers as “wimpy” for being forced to legislate MAID, questioned its safeguards, and implied that criminal law is subordinate to provincial and her “practice association” (i.e., CAMAP) guidance (33). She was the lead author on guidance suggesting that up to a median seven-year life expectancy was eligible for Track 1 MAID (39), in contrast to the federal justice department’s view of “a few weeks or months” (40). Once described as “at the forefront of the right to die movement” (31), Wiebe remains a Clinicians Advisory Council (CAC) member of Dying with Dignity Canada (DWDC) (34), the registered lobby group (35) favouring expanded access to MAID and supported the legal challenges that permitted legislation of Track 1 and 2 MAID (36-38). Other members of this council, which existed as the Physicians Advisory Council (and similar titles) before the advent of MAID, declare this affiliation a competing interest in published scholarship before and after MAID became law (41-43).

IDEOLOGICALLY DRIVEN PRACTICE

Founded in 1980 and closely tied to CAMAP, DWDC remains a central actor in the global “right-to-die” social movement (44,45). As my colleagues and I point out (45), in the decades before MAID, DWDC publicly described deaths involving its officials and allied physicians who injected people with, witnessed, or assisted them in imbibing lethal doses of an arbitrary assortment of deceptively acquired opioids, cardiotoxins, tranquillizers, sedatives, vomit suppressors, and hypnotics – sometimes combined with quantities of spirits like whisky (46-51). Other Canadian right-to-die subscribers used gas asphyxiation devices (52,53). DWDC describes “counselling” such methods with the public who contacted it and through public “self-deliverance” seminars (Figure 1) (54-56). It also sent its staff to such training in the United States (57,58). Research shows that these “anarchic” (59) approaches to assisted dying in Canada and other countries result in indiscriminate deaths that can hide their assisted, homicidal, or coercive nature from police, pathologists, and coroners (52,59-61).

Figure 1. 1999 Dying with Dignity Canada Newsletter notice for a hosted seminar on suicide methods by the late right-do-die advocate Derek Humphry (63)



NEWSLETTER

Dying With Dignity

Vol 16, No. 3 ISSN 0847-1797 September 1999

Derek Humphry

discusses

Self-Deliverance

Saturday, October 23, 1999 at 1:30 p.m.

First Unitarian Church
175 St. Clair Avenue West
Toronto, Ontario

Dying With Dignity is pleased to announce that Derek Humphry will speak about self-deliverance on October 23, 1999. He is the author of several books including *Final Exit* and *Freedom To Die*. He is the founder of the Hemlock Society in the United States and a leader in the right-to-die movement. Presently, he is the President of the ERGO (Euthanasia Research & Guidance Organization).

Tickets are $10.00 (member rate) and $15.00 (non-member rate) per person. Please complete the enclosed ticket request form and send your payment to the Dying With Dignity office. Space is limited! Reserve your seat now! **There will be lots of time for questions and answers during the two hour session**. Refreshments and goodies will be served afterwards.

Whether any MAID clinicians and support staff today subscribe to this lawless “right-to-die” outlook and consequently abandon their duty to protect their patients from unlawful death (62) is an urgent question in the wake of Disha et al.’s errors, the troublesome findings in the Ontario MDRC reports, and the increasing numbers of documented violations of the Criminal Code in MAID approvals and deaths nationwide (26,63-66).

CONCLUSION

Disha et al.’s (1) misapprehension of the 90-day assessment period and other Criminal Code safeguards support provincial MAID reviews and other accounts showing that pervasive ignorance of this and other safeguards is happening at the clinical level. This activity may reflect clinicians’ intention due to an ideological bias rooted in MAID’s origins in the right-to-die movement, personal benefit for the clinician, or unintentional misunderstanding or incompetence (26,68). In any case, a lack of adherence to the Criminal Code is indefensible legally, practically, and ethically, given the unacceptability of the premature deaths of people whose assessors and providers fail to afford them the protection of its safeguards.

In Disha et al.’s example, Patient X fails to benefit from these safeguards. X is instead caught in an ethical debate on where best to mark time instead of having their assessment polyphonously exhausted well beyond 90 days if needed, such as through continued efforts to improve their care to the point where euthanasia is no longer appealing.

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ÉTUDE DE CAS / CASE STUDY

Why Not Advance Directives for MAID in Those with Dementia?

Michael Gordon[a]

Résumé
Le nombre de personnes atteintes de la maladie d'Alzheimer et d'autres démences augmente rapidement en Amérique du Nord et dans le reste du monde occidental. Dans la plupart des pays, un défi sociétal majeur consiste à fournir des soins appropriés à ces personnes ainsi qu'à leurs familles. À l'heure actuelle, en Amérique du Nord, il n'est pas possible pour une personne atteinte de démence, tout en anticipant la trajectoire déclinante de sa maladie invalidante, d'indiquer à ses mandataires spéciaux (SDM ou proxies aux États-Unis) de demander une aide médicale à mourir (AMM). C'est le cas même si, au moment de la demande, la personne est légalement capable de prendre une telle décision en utilisant les critères de l'AMM dans d'autres situations cliniques. La question est de savoir pourquoi une personne atteinte de la maladie d'Alzheimer ou d'autres causes de démence ne devrait pas être en mesure d'anticiper son déclin alors qu'elle en est encore capable. Et si c'est le cas, de demander à leur décideur désigné de demander et d'obtenir l'AMM, la préférence indiquée dans une directive préalable légale.

Mots-clés
directives anticipées, démence, fin de vie, AMM

Abstract
The numbers of individuals with Alzheimer's disease and other dementias are growing rapidly in North America and the rest of the western world. In most jurisdictions there is a major societal challenge to provide appropriate care for these individuals as well as their families. At present in North America, it is not possible for a person with dementia, while anticipating the declining trajectory of their disabling illness, to indicate to their substitute decision makers (SDM or proxies in the USA) a request for medical assistance in dying (MAID). This is the case even if at the time of making the request the person is legally capable of taking such a decision using the criteria for MAID in other clinical situations. The question is why a person with Alzheimer's disease or other causes of dementia should not be able to anticipate their decline while still capable. And if so, to instruct their designated decision-maker to request and obtain MAID, their indicated preference in a legal advance directive.

Keywords
advance directives, dementia, end-of-life, MAID

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CASE STUDY

Mrs. ND is an 82-year-old woman who had been seeing me in my geriatric clinic in Ontario, Canada for four years. She was first referred because of episodic forgetfulness which over the years progressed to more serious cognitive decline, including losing items, getting lost and requiring more care for her basic activities of daily living. As she began to deteriorate, she asked me if she could incorporate into her advance directive a statement that should she lose her ability to care for herself because of dementia, including basic activities of daily living, she wished to receive MAID. I told her that there was no provision in the current Canadian legislation for such a document.

At the time, she would not have qualified for a Track 1 (a medical condition in which the trajectory is foreseeable, and the person is experiencing unacceptable suffering) positive assessment as her moderate dementia (likely of mixed vascular and Alzheimer's etiology was not immediately foreseeable). Track 2 (death is not foreseeable, but there are clinical grounds that might be deemed sufficient in terms of suffering) would not have been deemed permissible as the "suffering" would be hard to determine. Emotional reasons (mental health disorders) were not considered as reasonable conditions for which a person could be provided with MAID (1).

The conundrum for the family was this: although Mrs. ND could continue to participate in some of her basic activities of daily living, she already needed help in bathing and some in dressing – this was especially humiliating for a person who previously was very active and concerned about her appearance. She often expressed to her children in her somewhat mixed-up sentence structure that "I wish it were over, I want to get out of here" (meaning they thought her retirement home and her life). The family provided daily companion help, and their mother did participate in some social programs, especially the music program and continued to enjoy the music that she heard on the radio.

As she became more impaired and began to have problems with maintaining her weight, despite food supplements, the family wondered what could be done. Although she expressed her "death wish" it was felt by the physicians caring for her that she was no longer capable of requesting MAID at this point, even though it was felt that her trajectory for end-stage-dementia was now in the foreseeable future. Eventually, she could no longer eat, aspirating quite often, and subsequently required hospitalization for aspiration pneumonia. She was admitted to palliative care with instructions by the family, who were her substitute decision-makers (SDM), to treat her with comfort measures only. At the next episode of chest infection, they requested that antibiotics not be given. Their mother recovered spontaneously but three months later she succumbed to an episode of pneumonia with two days of laboured breathing, disturbing coughing and acute delirium that required neuroleptic

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medications to calm her down and keep her from pulling on her intravenous lines and from trying to climb out of bed. She died in the presence of her three children. Her children (who included her SDM) expressed to the palliative care physician their despair that earlier in their mother's disease progression she could not indicate and legally receive MAID at the point that she required palliative care, which did not meet all her symptomatic needs.

DISCUSSION

The story of assisted suicide, or in Canada what it is called MAID (Medical Assistance in Dying), is referred to in other countries as Physician Assisted Suicide or voluntary euthanasia. It has in fact a long history before it became an issue in the 20th century, first in the Netherlands and other European Countries, then in the United States, with Oregon being the first state to legislate its existence. In Canada, the process took several years with its first approval coming in 2016 following a Supreme Court ruling. Over the following few years, it became a federal law.

In the earlier iteration of MAID, the criteria were reasonably straightforward, with the intended goal to deal with those with serious and demonstrable illnesses in the terminal phase, whose outcome was foreseeable and caused suffering on the part of the requesting person. The assessment included a determination of capacity to make the decision, an understanding of reasonable alternatives, and the opportunity to cancel the request right up until the moment of the fatal injection. There were to be two independent assessors who must agree on the clinical criteria and the reasonableness of the request. Either one of the assessors or a different third party would be responsible for administering the fatal drugs. Each case would be reported to the regional coroner to assess that all the steps were followed according to the legislation. Such cases fell into what was called the Track 1 criteria.

As a relative newcomer to MAID assessments, I have been involved with three such Track 1 cases. The first involved a patient with metastatic cholangiocarcinoma who received three courses of chemotherapy from which she suffered enormous side effects. She had constant pain which required large doses of opiates. She was offered a new round of chemotherapy with a newer medication. When questioned she told me she did not want any more chemotherapy of any kind, she could not tolerate the pain and could not tolerate the analgesia. She claimed that she had a good life, and she was prepared to die and had the support of her loving family. Because she was on the palliative care unit of a Catholic hospital, the injection would be provided in her own home – she welcomed this as she told me that she wanted to say goodbye to her much-adored cat.

The second case was that of a male nurse who, during the investigation following a motor vehicle accident, was found to have lung cancer with evidence of metastases to his bones. As he told me during my assessment, he had witnessed patients who went through the treatments for metastatic lung cancer and their suffering. He was already on substantial doses of opiates which played havoc with his body. He chose MAID. He had no family in Canada but indicated that his family overseas supported him in his decision. He went to (MAID House) an independent facility in the community to receive his fatal injections.

The third patient was a woman in her seventies with end-stage chronic lung disease. She had just been transferred to the palliative care unit. She wanted MAID because she had just survived another bout of pneumonia but was bedridden, or if helped, could sit in a chair. She needed constant low-flow oxygen and help with all her basic activities of daily living. She could not walk unassisted to the washroom and could not even shower without help, so received only sponge baths. When meeting with me in my capacity as the MAID assessor, she admitted that she had enough with her illness and could not bear to go on with living. She understood what the future had for her as she had experienced short periods on a ventilator during previous acute infections. She felt she had a good life and was ready to leave it. She said as a religious person she was prepared for the afterlife and welcomed it. She was transferred home to die by fatal injection.

What is the concern of the person with dementia who is still capable of understanding and appreciating the likely trajectory of her illness? This is especially the case if, like Mrs. ND described above, she has witnessed the decline of her mother and the end-stage dementia and her suffering, bedridden, receiving nourishment via a permanent feeding tube. If rather than dementia this same person had Amyotrophic Lateral Sclerosis (Lou Gehrig's Disease) she would qualify for MAID in many cases. But an advance directive that indicates the status of the patient when a substitute can make the decision is not allowed. With ALS the person is usually cognitively capable to make such a decision at the time, whereas the person with dementia might not be so capable.

According to a recent article in the Washington Post (2), the demographic imperative is upon us. Reporting on statistics in the US (which is mirrored in much of the western world), it is noted that:

> As the over-65 demographic has ballooned, however, the number of people experiencing dementia has risen, too – to about 7 million as of 2020. The figure could approach 12 million by 2040. Inevitably, people with dementia have become much more prevalent in assisted-living centers. About a third of assisted-living residents have dementia, according to the Alzheimer's Association. (2)

The article focuses primarily on the need for care, whether in assisted living facilities or nursing homes, but does not address the issue of late-stage dementia and end-of-life care. The processes for assisted suicide in those US states that have legalized it would not be of any help to people living with later-stage dementia as they would not be deemed to be capable of making the decision. Also, in those states in which it is legalized, the process does not include euthanasia but rather the provision of medications to be taken by the person approved for assistance in dying.

In the Netherlands and other European countries, where assisted suicide has been in existence for many years, and long before it became available in Canada or the United States, it is possible to make a provision for a substitute decision-maker (SDM; or health care proxy in the United States) to act on an advance directive to obtain assistance in dying. The question should be asked, “why should not a person with diagnosed dementia of Alzheimer’s or other varieties, in which the trajectory is well established not be allowed to provide an advance directive to their SDM, instructing them to request assistance in dying under defined circumstances?” (3)

From the perspective of ethics, the answer should be clear. Respect for the person’s autonomy is a core value underpinning the process of advance directives and the role of the SDM. The beneficence of not requiring a person to suffer the physical and emotional indignities of end-stage dementia would seem self-evident. Many such individuals are admitted to palliative care units to meet their complex physical and emotional requirements. Depending on the jurisdiction this care may not be readily available, but increasingly such individuals qualify for and benefit from late-stage dementia care (4,5).

Providing such an option prevents unnecessary to harm to the patient which fulfills the principle of non-maleficence, defined in the four principles of Beauchamp and Childress. As I outlined clearly in my book on late-stage dementia, many treatment modalities may be required to address the physical and emotional suffering that people experience during this stage of life and illness (5). The application of the principal of justice should also be self-evident. It is unfair that persons with dementia, as compared to many other late-stage terminal illnesses, do not have access to the option and legal right to determine how they wish to die given that an SDM can fulfill that decisional wish (4).

The addition of diseases that affect the brain, especially the cognitive and psychological functions, to eligibility for MAID has caused a great deal of controversy in terms of eligibility. The exploration of what constitutes a “mental illness” and its suitability for MAID is under review in Canada (in 2024). If the legislation eventually allows for that category for inclusion, those requesting Track 2 eligibility will likely increase, and if so, the question of advance directives will become even more pressing (6,7).

QUESTIONS

1. If an advance directive were allowed for those with dementia, how would you configure one that would address the wishes of a person who is losing their cognitive abilities?
2. Would a request for MAID be a reasonable part of the current legislation or would it more likely be considered a mental health condition and be in a special category?
3. Would it be necessary to forgo the requirement of proof of capacity to confirm the MAID decision if the advance directive were formulated for late-stage dementia? Would the SDM/proxy be allowed to act on the advance directive?

CONCLUSION

Late-stage dementia is not a mental disorder, even though it may have symptoms and signs often associated with psychiatric disorders such as delusions and paranoia. It is a neurological disorder, more akin to cerebrovascular diseases (which are one of the causes or exacerbators of dementia), or late-state Parkinson’s disease, or the result of frequent head injuries now recognized in many contact sports (8,9). Therefore, in Canada in particular, where MAID is available to those with neurological disorders during their later stages, individuals with dementia should be legally allowed to appoint a SDM with instructions as the circumstances under which they can access MAID to provide a humane and respectful death.

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G Martinez. *Can J Bioeth / Rev Can Bioeth.* 2025;8(1-2):153-155

ÉTUDE DE CAS / CASE STUDY

Goals of Care Conversation to Support Patient Empowerment in Managing Cancer Care

Gary Martinez[a]

Résumé
Les « objectifs de soins » désignent les valeurs, les objectifs et les préférences de traitement d'un patient atteint d'une maladie grave. Les conversations sur les objectifs de soins sont cruciales pour les soins des patients atteints de cancer et impliquent la prise de décision et l'autonomie du patient et de sa famille. L'étude de cas d'un homme atteint d'un cancer de la gorge lié au VPH illustre comment les facteurs émotionnels et la perte potentielle d'indépendance peuvent créer un conflit de valeurs entre les parties prenantes. Dans ce cas, le rôle de l'éthicien est de servir de médiateur et de protéger la relation de confiance entre le patient et le soignant. Lorsqu'elle intervient tôt dans la trajectoire de soins du cancer, une telle communication fondée sur l'éthique peut favoriser l'engagement du patient et de la famille, les progrès cliniques et l'amélioration de la qualité de vie.

Mots-clés
objectifs de soins, conversations, autonomie, valeur, cancer

Abstract
"Goals of care" (GoC) refers to a patient's values, goals, and treatment preferences in severe illness. GoC conversations are crucial to the care of cancer patients and involve patient and family decision-making and autonomy. A case study of a man experiencing HPV-related throat cancer illustrates how emotional factors and potential loss of independence may create a GoC conflict of values. In this case, the ethicist's role is to mediate and protect the patient-provider trust relationship. When acted upon early in the cancer care trajectory, such ethics-based communication may promote patient-family commitment and clinical progress and improve quality of life.

Keywords
goals of care, conversations, autonomy, value, cancer

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INTRODUCTION

"Goals of care" (GoC) is an increasingly meaningful term used in medicine to refer to identifying a patient's personal values, goals, and treatment preferences in cases of severe illness (1). In this context, healthcare providers engage in GoC conversations that guide treatment plans and prioritize patient and family decision-making and empowerment. This communication is essential when managing the care of cancer patients.

CASE STUDY

Mr. F. is a 52-year-old man diagnosed with Stage II squamous cell throat cancer caused by the human papillomavirus (HPV). HPV-related throat cancer is a slow-growing virus that develops in the back of the throat (oropharynx) and frequently occurs in non-smoking, white, middle-aged (50-60 years) heterosexual men and typically presents with a noticeable lump and possible ear pain (2). Mr. F.'s presenting chief complaint was intermittent throat pain that radiated to the right tonsil area and right ear over a 5-6-month period. He reported no significant previous medical history or known contributing medical conditions. He reported occasionally smoking 1-cigarette weekly on and off for several years and "socially" drinks 4-5 glasses of alcohol per week. His initial diagnostic workup included a CT scan, an ultrasound test, which identified a 4.1 cm throat mass, and tissue biopsies to confirm a diagnosis of cancer. His treatment course included six weeks of chemotherapy, seven weeks of Proton therapy, and enrollment into a Phase II clinical trial. During this time, Mr. F. experienced 14 MRIs, 4 CT scans, and 3 PET scans. This treatment regime required Mr. F. to wear a special tight-fitting thermoplastic mesh mask for approximately 1.5 hours during treatment, which he reported as quite "challenging." His occupation is as a certified personal fitness trainer, and he participates in endurance cycling events. His partner, an experienced oncology healthcare professional, supports him.

ETHICAL ISSUE

Healthcare providers must recognize patients' unique goals early in the cancer care trajectory to preserve patient empowerment when developing clinical treatment plans (3). Although clinicians strive to include patients in treatment decisions, they often miss the opportunity to adequately empower patients by failing to communicate, ignoring emotional states, and making recommendations without understanding the patient's GoC concerns (4). These circumstances may result in patients feeling they have no choice but to comply with treatment, negatively affecting patient empowerment.

The case of Mr. F. illustrates such a loss of empowerment. Upon initial diagnostic testing, he expressed to the technician that his foremost GoC concern was being able to participate in an upcoming endurance cycling event. However, the primary care

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team was not aware of this GoC and scheduled immediate treatment plans for chemotherapy and Proton radiation. When notified of this plan, Mr. F. felt helpless and powerless to express his personal goals to his medical provider.

Mr. F.'s vulnerable emotional state is a common experience among newly diagnosed cancer patients. The emotional impact of a cancer diagnosis may range from feelings of anger, sadness, depression, loneliness, guilt, loss of independence, and inability to perform "normal" life activities (5). Mr. F.'s initial sense of helplessness grew into feelings of anger and hostility and led to his outright refusal to commit to further treatment. He abruptly stated that he would no longer be interested in continuing his recommended treatment plan. The healthcare team acknowledged Mr. F.s right to refuse treatment, but found it difficult to accept this position since Mr. F.'s cancer was highly curable with the given treatment plan (2). The radiology oncologist was reportedly incredulous and looked "strangely" at the patient, given the new diagnosis of throat cancer. When questioned, Mr. F. insistently refused to continue his treatment because he felt he had no alternative but to follow a prescribed treatment plan that did not prioritize his goals or wishes.

Accordingly, the medical team consulted the ethicist to address this conflict of values, provide more insight into the situation, and mobilize the aid of an outside party to facilitate the conversation. The ethicist's role in such cases is to mediate, protect the patient-provider trust relationship, and support patient empowerment (6). After the ethicist assessed Mr. F.'s understanding of his condition, he began his interview by asking, "What is important to you?" In time, with additional counseling, this simple statement empowered Mr. F. to feel less helpless, recognize his emotional state, and express his authentic feelings regarding his personal GoC in his cancer treatment plan. Upon conclusion, Mr. F. tearfully expressed his personal GoC desire to participate in a scheduled 150-mile endurance cycling event before beginning cancer treatment. When the physician realized how important this goal was to Mr. F., he decided to start treatment eleven days later to account for the duration of the race. In this way, the ethicist effectively mediated the conflict between the patient and provider while preserving that trust relationship and fulfilling the patient's GoC.

GOALS OF CARE CONVERSATION

Traditionally, GoC conversations occur late in the patient's disease trajectory, and under clinical circumstances when a cure is not possible, the interventional risk is too high, and suffering is present (1,3,7). This communication timeline is critically important when managing cancer patients. In such cases, healthcare professionals are encouraged to engage in "early" GoC conversations with the patient and family once the cancer diagnosis is confirmed (1,3,7). This proactive communication approach lays a foundation for patients to openly discuss personal goals and care preferences that reflect their values and to more fully engage in their medical treatment plans.

CONCLUSION

GoC conversations must incorporate a patient's values and care preferences to result in mutually acceptable and beneficial medical treatment plans. If done early in the cancer trajectory, such discussions may enhance patient commitment, engagement, and clinical progress, lessen potential depressive symptoms, and improve quality of life (1,3,5,7). Finally, ethicists may be pivotal in preserving the patient-provider relationship, encouraging authentic communication, and empowering patient decision-making.

DISCUSSION QUESTIONS

1. How can oncology healthcare practitioners better engage in "early" goals of care (GoC) conversations with patients and their families?
2. Is there evidence of best practice methods for oncology providers to discuss "early" GoC?
3. How can ethicists support patient empowerment regarding GoC decisions early in the cancer care trajectory?

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M Pahwa. *Can J Bioeth / Rev Can Bioeth.* 2025;8(1-2):156-158

COMPTE RENDU / REVIEW

What *Black Health* Means for Bioethics in Canada

Manisha Pahwa[a]

Résumé
Black Health de Keisha Ray est un examen poignant des déterminants sociaux, politiques et culturels de la santé et du bien-être des Noirs aux États-Unis. Cette revue réfléchit aux implications potentielles de *Black Health* pour l'équité en matière de santé et à ce que la bioéthique pourrait être et faire pour tout le monde au Canada.

Mots-clés
santé des Noirs, racisme anti-Noir, déterminants sociaux de la santé, déterminants structurels de la santé, bioéthique, équité en matière de santé, Canada

Abstract
Keisha Ray's *Black Health* is a poignant examination of the social, political, and cultural determinants of Black people's health and well-being in the United States. This review reflects on the potential implications of *Black Health* for health equity and what bioethics could be and do for everyone in Canada.

Keywords
Black health, anti-Black racism, social determinants of health, structural determinants of health, bioethics, health equity, Canada

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INTRODUCTION

Keisha Ray's *Black Health*, published by Oxford University Press in 2023 (1), is about the past, present, and future of Black people's health and well-being in America. Ray discusses the social and structural dimensions that make up Black people's health and well-being, urging bioethics to help address the unjust conditions that cause Black people to have poorer access to health care and experience greater health disparities. While Ray's focus is on the intersection of the lived experiences of Black people's multiple identities with anti-Black racism in the United States, *Black Health* is strongly relevant for Canada, where diverse Black individuals, families, and communities experience anti-Black racism in health and social institutions that Ray covers in *Black Health*. Ray brings Black lives to the forefront by expertly weaving stories, statistics, and statements that accumulate to achieve the book's goal, and in a manner that is as accessible as it is rigorous, making *Black Health* a core text for bioethics education, research, and practice.

Black people represent approximately 4.3% of the total population in Canada (2) and include a tremendous diversity of identities, histories, cultures, languages, religions, families, and genetics. Black people are less likely to have access to palliative care (3) and have less exposure to residential greenness (4) compared to White people in Canada. During 2020, rates of COVID-19 mortality were highest among Black people in Canada, especially in the low-income category (5). Black women aged 40-49 years are more likely to die from breast cancer compared to White women in this age group in Canada (6). A close reading of *Black Health* ensures that our understanding of Black people's health is informed by analyses of how social, political, and cultural institutions and practices marginalize Black people's multiple identities and cause excess burdens of morbidity and mortality that can and should be prevented.

BIOETHICS AND HEALTH EQUITY FOR BLACK PEOPLE IN CANADA

If bioethics in Canada is to do more for Black people's health, then *Black Health* can contribute as a compass and guide. First, the book demonstrates the vital importance of Black people self-determining the ethical issues that affect their health and well-being. Ray has previously critiqued bioethics for its preoccupation with the examination of relatively few issues such as abortion, end of life care, and emerging technologies (7). She has described Black Bioethics as a rebellion against bioethics; a "we'll do it ourselves" attitude ensuring that the injustices experienced in the everyday lives of Black people are recognized as bioethical issues warranting the use of bioethics theories and methods and attention from bioethicists (7). In *Black Health,* Ray examines why hospital births are unsafe for Black people, why Black people's pain is not believed, whether cardiovascular disease is part of the Black experience, and whether it matters where Black people sleep. In her choice of discussing these topics, Ray affirms and makes explicit the self-determination of Black people while clarifying the scope of issues that would define a Black Bioethics.

Second, *Black Health* amplifies the importance of justice theory in bioethics scholarship, applying an intersectional framework to understand how Black people's multiple marginalizations within social institutions shape their access to health care and health outcomes. Ray focuses on health care, housing, economic, and legal institutions, demonstrating how and why these institutions have not been designed to give Black people what they need for health. In a separate exposition of the bioethics of environmental injustice, co-authors Ray and Cooper describe how environmental exposures that map on to race cause higher rates of morbidity and mortality among Black children and communities in the United States, e.g., from asthma and

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COVID-19 (8). These authors argue that a commitment to vulnerable populations and justice in bioethics are core reasons why environmental health should be prioritized in bioethics. Indeed, a commitment to justice in bioethics is a key reason why the social, political, and cultural determinants of Black people's health should be pressing matters for bioethics, and lead the field to leverage the full weight of justice theory to undertake this important work.

Third, *Black Health* points towards methodologies that can be used to foster deeper understandings of Black people's health with a strong role for first-person accounts authored by Black people. Throughout the text, Ray incorporates direct quotes and stories describing how racism and discrimination adversely affect the ability of Black people to, for instance, avoid exposure to COVID-19, live in better neighbourhoods, and generally access the circumstances and material resources needed for health and well-being. This approach is deliberate as Ray aims to humanize "the examination of Black health during a time when so often Black people's humanity is denied" (p.5). Any methodologies that ensure that Black people are the tellers of their own stories and that promote the sincere representation of Black people on their own terms are suitable candidates for Black Bioethics scholarship.

BLACK HEALTH, BIOETHICS, AND HEALTH EQUITY FOR RACIALIZED PEOPLE IN CANADA

Black Health is for Black people's health and well-being. As a South Asian person, my decision to review *Black Health* was fraught with the historical and contemporary complexities of Black-South Asian relations. Yet the resonance with some of my own lived experiences prompted me to openly explore the potential significance of *Black Health* for people in Canada whose health outcomes are profoundly shaped by racism, discrimination, colonialism, and immigration. In this light, *Black Health* is also a provocation for further creative thinking, dialogue, and action about what bioethics can be and do for health equity for racialized people in Canada.

If bioethics is to help advance health equity, then bioethics research should include an orientation towards informing transformation in the design of health and social institutions that influence racialized people's health. Stories generated through qualitative research, for example, vividly expose causal mechanisms within institutions that systematically undermine racialized people's health. When integrated with ethics theory (9,10), stories are a powerful type of empirical evidence that can contribute to the development of normative claims about how health and social institutions should be designed along these mechanistic pathways to give racialized people what they need. Participatory approaches ensure that racialized people co-create norms and their implementation through processes of dialogue and iteration oriented to their needs and contexts (9). Based on my lived experiences, I anticipate that air pollution, precarious work, and poor-quality housing are some of the stories that may arise through such participatory research. In these situations, normative claims that target environment, labour, and housing institutions could be justified by ethics theory from philosophical traditions that have sustained the health and well-being of communities worldwide over millennia.

As a field concerned with moral experience (11), action, and human flourishing, bioethics can and should be widely inclusive. Dispositions of creativity, open-mindedness, and epistemic humility are needed to carry out participatory empirical bioethics research that aims to transform institutions (12). By embracing diverse experiences and values, bioethics can not only contribute to health equity for racialized people, but also to peace and human flourishing in democracy (13) – making *Black Health* an inspiration for what bioethics could be and do for everyone.

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TÉMOIGNAGE / PERSPECTIVE

Ending Toxicity: A Call to Reintroduce Constructive Discourse About Contentious Health-Related Issues in Medicine

Jocelyn Downie[a]

Résumé
Il existe un phénomène inquiétant de médecins qui attaquent violemment d'autres médecins lorsqu'ils ne sont pas d'accord avec eux sur des questions litigieuses liées à la santé. Ces attaques peuvent avoir des conséquences négatives importantes sur les soins aux patients, le bien-être des médecins et les politiques publiques. Une réflexion et des réponses à ce phénomène sont nécessaires.

Abstract
There is a disturbing phenomenon of physicians viciously attacking other physicians when they disagree with them on contentious health-related issues. Such attacks have significant potential negative impacts on patient care, physician well-being, and public policy. Reflection on and responses to this phenomenon are needed.

Mots-clés
éthique professionnelle, abus de pouvoir, professionnalisme, enjeux professionnelles et éthiques

Keywords
professional ethics, abuse of power, professionalism, professional and ethical issues

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There is a disturbing phenomenon of physicians viciously attacking other physicians when they disagree with them on contentious health-related issues. Such attacks have significant potential negative impacts on patient care, physician well-being, and public policy. This issue got a fair amount of attention during an ugly fight over the issue of negotiations between the Ontario Medical Association and the provincial government in 2017 (1). Offensive and threatening emails and social media were sent/posted by physicians targeting other physicians. The attacks were condemned, and some physicians were disciplined (2). However, attacks are still being made.

Noting the toxicity of the debate about gender identity services for children and youth, the 2024 Cass Report stated "There are few other areas of health care where professionals are so afraid to openly disclose their views, where people are vilified on social media and where name calling echoes the worst bullying behaviour. This must stop." (3) "Five things to know about… Physician incivility in the health care workplace" published in 2024 in the Canadian Medical Association Journal reported that "Prevalence varies and is likely underreported owing to nonstandardized definitions and heterogeneous behaviours. More than 75% of health care employees [nurses, physicians, administrative executives, and "other"] have witnessed uncivil behaviour from physicians, and 31% of physicians report receiving weekly or daily rude, dismissive or aggressive communication from other doctors." (4)

While happening beyond psychiatry, an illuminating case in point is psychiatrists and the issue of medical assistance in dying (MAiD) for persons with mental illness. The debate concerning access to MAiD by persons with mental illness has been a contentious one, politically, publicly, and professionally. Sometimes, the attacks occur in private. In an email, one psychiatrist opposed to MAiD for persons with mental illness compared another to Himmler – complete with the label "architect" invoking Himmler's role as architect of the "Final Solution" (the genocide of six million Jews during the Holocaust) (5).

Unfortunately, this is increasingly occurring in public. One psychiatrist, because of what she had written about MAiD where mental illness is the sole underlying medical condition, was explicitly and by name analogized to the self-styled "QAnon Shaman" – complete with a photo of her, the QAnon Shaman, and the noose erected at the US Capital. She had said "[o]ne of my concerns is that too many psychiatrists are using all their energy to try and re-legislate Bill C-7, rather than contribute to the development of guidance, protocols and safeguards during the two-year period before individuals who meet the request for MAID solely on the basis of mental illness." (6) For this she was linked to QAnon generally – a "decentralized, far-right political movement rooted in a baseless conspiracy theory that the world is controlled by the 'Deep State', a cabal of Satan-worshipping pedophiles, and that [then] former President Donald Trump is the only person who can defeat it." And she was analogized to the QAnon Shaman specifically — an individual who described himself as a shaman, dressed in what he took to be shaman-like garb, and was sentenced to 41 months in jail for his part in the January 6 insurrection (7). Her work was linked to an attack on the US Capitol and an indirect threat against the life of the Vice President of the United States:

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> I want to point out that I don't know her. I have heard her speak, she seems like a lovely person, I bet that she is a really nice clinician but I think that she is really wrong in terms of her understanding of this scenario and, it's a bit terrifying for me because she doesn't look like a QAnon Shaman even though I experience her somewhat in that way. … So the way that I understand this is essentially as someone who has bypassed science, who has taken a baseball bat and broken into the Capitol Building and is reaching out their hand and saying, "Come on, we are in already, help us do this the right way." (8)

This statement was made by a psychiatrist giving Grand Rounds at a major teaching hospital (Grand Rounds is a regular academic presentation for all members of a department and for which attendance and participation is expected). The video of that Grand Rounds was subsequently shared (with encouragement to view it) by another psychiatrist to approximately 250 mental health professionals attending online Grand Rounds at a teaching hospital in another city.[1]

Most recently, a psychiatrist said that another psychiatrist was, in presenting their views on MAiD, "selling a bit of snake oil." (9) This happened at a Parliamentary Committee hearing, broadcast nationally, and preserved for posterity in the (publicly accessible) videorecording and transcript of the hearing. The psychiatrist also posted a link to his testimony on his X account on February 14, 2024. Within the provision of medical care, "selling a bit of snake oil" has a long history as a demeaning slur. "Snake oil salesmen" were unqualified hucksters, fraudulently peddling worthless pseudo-medical remedies, motivated by profit rather than a desire to help others (10). The psychiatrist's very public statement insults and demeans the other psychiatrist by using a well-known slur that maligns their qualifications and insinuates that they are not motivated by the desire to help others but rather by personal gain.

But why does any of this matter? Shouldn't these physicians just ignore the name-calling? Get a thick skin? Accept it as the price of engagement in public debate about contentious issues? I don't think so, for two main reasons.

First, this behaviour harms patients when physicians say these things publicly and their self-regulatory bodies do not make public statements telling them and others in the profession that such behaviour is wrong. As noted by the Ontario College of Physicians and Surgeons in its Policy on Professional Behaviour: "Unprofessional behaviour impacts patient care and outcomes through the negative effects it can have on the physician-patient relationship, teamwork, a safe working environment, communication, public trust, and morale." (11) Just imagine being a patient of one of the attacking psychiatrists and wanting to get information about MAiD for mental illness. Would you feel safe to ask? Just imagine being a patient being referred to the psychiatrists analogized to the QAnon Shaman or a snake oil salesman. Would you be comfortable seeking care from them?

The profession and its ability to care for patients are diminished by physicians launching toxic public attacks on other physicians.

Second, this behaviour leads to the loss of key voices in important public debates. Most directly, other physicians, especially but not only those at the beginning of their careers and not yet secure, will stay silent rather than risk public attacks of this sort, especially when launched by senior powerful physicians. Furthermore, people with mental illness as their sole underlying medical condition who want the option of requesting MAiD now or in the future may also stay silent after witnessing such attacks, understandably thinking, "if respected psychiatrists can be publicly attacked this way, what will happen to me if I speak out?"

Public policy is harmed if people cannot participate in public dialogue without facing toxic attacks by physicians.

Physicians should care about the impact of these attacks on the reputation of their profession and the harms to patient care that follow an eroding of this reputation. Physicians should care about their country being able to have constructive conversations about complex health-related issues and the ability of the medical profession to contribute to policy-making by ensuring it is informed by the full range of opinions and perspectives. Attacks like those described above can interfere with patient care and sound public policy. It's past time for respected leaders in the profession as well as the physician regulatory bodies in all countries to enforce standards of professional behaviour and issue statements condemning these attacks and explaining why they need to stop.

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[1] Comments made and link posted by Sonu Gaind in the online chat during presentation by Grainee Neilson, McMaster University Department of Psychiatry and Behavioural Neurosciences Grand Rounds, November 24, 2023. "Dr. Sonu Gaind: wrt evidence, I encourage you to watch Dr. Mark Sinyor's grand rounds on scientific evidence and MAID [link]." [Transcript on file with author]

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TÉMOIGNAGE / PERSPECTIVE

Ending the Journey of Suffering

Ohad Avny[a], Batya Grin[a]

Résumé
La relation entre un médecin de famille et ses patients dure souvent de nombreuses années. Le médecin de famille guide le patient tout au long des procédures médicales et des décisions complexes. Même si le médecin n'est pas celui qui prend toutes les décisions ou qui adapte le plan de traitement, il est souvent considéré par le patient comme le gestionnaire de cas. L'importance de ce rôle est particulièrement évidente dans la population gériatrique, où le défi consiste à trouver un équilibre entre les avantages du traitement de maladies complexes et l'impact potentiel sur la qualité de vie du patient. La capacité du médecin à résoudre des problèmes aussi complexes découle non seulement de ses compétences professionnelles, mais aussi de la relation personnelle qu'il entretient avec le patient. Si l'amitié qui tend à se développer au fil des ans entre un médecin et son patient peut souvent aider le médecin dans ce processus de prise de décision, cette relation peut parfois constituer un piège. Une relation médecin-patient fondée sur la compassion optimise le processus de prise de décision afin de mieux répondre aux besoins du patient. Cela étant dit, il est également entendu que le fait de franchir les limites de la relation médecin-patient traditionnelle peut poser d'importants dilemmes moraux. Cette histoire illustre la relation entre un médecin de famille et un patient âgé qui s'étend sur plus de vingt ans. Leur amitié, due en partie à une connaissance antérieure, influence nombre de leurs interactions, qui aboutissent à la mort tragique de la patiente. Ce texte explore les obligations parfois contradictoires de l'amitié et du professionnalisme, ainsi que le dilemme éthique que posent ces responsabilités croisées.

Mots-clés
patient, médecin, relation, amitié, démence, mort médicalement assistée, suicide, souffrance

Abstract
The relationship between a family physician and their patients often spans many years. The primary care physician guides the patient through medical procedures and complicated decisions. Even if the physician is not the doctor making all the decisions or tailoring the treatment plan, they are often viewed by the patient as the case manager. The importance of this role is particularly evident in the geriatric population, where the challenge lies in balancing the benefits of treating complex diseases against the potential impact on the patient's quality of life. The physician's ability to navigate such complex issues stems not only from their professional capabilities but also from the personal relationship between them and the patient. While friendship that tends to develop over the years between a doctor and their patient can often aid the doctor in such decision-making process, occasionally such a relationship can be a pitfall. A doctor-patient relationship grounded in compassion optimizes the decision-making process to better meet the patient's needs. That being said, it is also understood that crossing the bounds of the traditional doctor-patient relationship can present significant moral dilemmas. This story illustrates the relationship between a family physician and an elderly patient that spans over two decades. Their friendship, partially due to a prior acquaintance, influences many of their interactions, culminating in the patient's tragic death. This text explores the sometimes-conflicting obligations of friendship versus professionalism and the ethical dilemma in of those intersecting responsibilities.

Keywords
patient, physician, relationship, friendship, dementia, medically assisted dying, suicide, suffering

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The following is a true story, experienced by the two authors. Dr Avny was the treating family physician of the patient, Shoshana (a pseudonym), and tutored Dr Grin, who was a resident in Family medicine in the primary care clinic.

Shoshana was entering her 60s in excellent condition. Half of her time in my office was dedicated to medical and administrative matters, while the other half was spent sharing her life experiences. As her primary care physician, I prayed that I would continue to witness the graceful aging of this wonderful woman.

During one of our earlier appointments, as she gracefully skipped onto the exam table, she said, "Dr. Avny, do you know that I knew your mother? I worked as a nurse with your mother thirty years ago, I loved her very much."

I recall my heart skipping a beat. My mother, a primary care physician, passed away suddenly during my teenage years when she was in her late forties. I feared that my memories of her were dimming.

From that moment on, during Shoshana's visits, we frequently discussed my mother. I was grateful for how Shoshana's presence revived my memories of her. Occasionally, Shoshana would remark on how I reminded her of my mother, and I felt as though my mother was sending her regards.

Years passed: Shoshana was now 76. It was a wet and gloomy day when Shoshana came to share some unfortunate news. "I have a mass in my breast. They did a biopsy: it's breast cancer."

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I was lost in thought but snapped out of it when she said, “I am weighing surgery against other treatment options. Who knows: the tumor is small, it might grow slowly, and it may not have any effect on my current health. Or, if the disease progresses, maybe surgery can help. I am confused.” She looked up at me with her big sad eyes. “Can you help me decide?”

“That is the dilemma of intervention in early-stage malignancies at your age. If you decide you want to undergo treatment, I think you can choose a less aggressive course of action. Knowing you, I assume you already did your homework and made up your mind. Am I right?” She smiled at me, and I recognized the familiar glimmer. “Yes, I made up my mind, but I wanted to hear what you thought.” She decided to undergo a lumpectomy and begin Tamoxifen treatment after the surgery (1). I was surprised.

It wasn’t long before Shoshana returned to my office, this time suffering from insomnia. After a brief conversation, I suspected she was experiencing a depressive episode, likely due to Tamoxifen. I discontinued the medication, and two months later, with family support and regular clinic visits focused on mental health, Shoshana had successfully overcome her depression (2).

By autumn, Shoshana recognized her cognitive abilities were slipping away. Despite discussing a formal evaluation with MMSE (Mini mental state examination) and MOCA (Montreal cognitive assessment) questionnaires, she refused, believing it futile given the lack of effective dementia treatments. She asserted, “Dr. Avny, don’t forget that I don’t want to live without quality of life.” I reassured her of my commitment to alleviating her suffering and again suggested antidepressants, which she declined.

I hadn’t heard from Shoshana in a year until she called me in distress, urgently requesting a house call. Although I usually do not make residential, I made an exception. “My memory has deteriorated significantly,” she began. “I’m struggling and often confused.” She kept looking down, revealing that she had noted several points before my arrival. Her condition had worsened since our last encounter. “You know that part of the forgetfulness is due to anxiety. I can help you with anti-anxiety medication.”

For the first in a long while, Shoshana smiled at me. Her eyes gleamed with compassion. She felt my strong urge to help her as well as my utter helplessness. “I have decided to commit suicide.”

I stared at her, dumbfounded, and then at her husband and son. It was evident that this topic had been brought up and a resolution was reached long before I arrived.

“I am asking you to come to my house after my death and write my death certificate. I want you to write that I died of a natural cause, to spare my family the grief of a police investigation.”

I pondered her request as she, suffering from dementia, sought to end her suffering with full awareness of her condition. Her insight and judgment seemed intact, she appeared capable of making autonomous decisions, and her family supported her. I found myself commiserating with this woman, painfully aware of the agony that had brought on such a desire (3).

Her eyes full of sorrow, she pleaded “Please don’t stand in my way.” (4)

I was torn between my compassionate instincts as a human and my ethical responsibilities as a doctor. “Shoshana,” I said gently, “I recognize the gravity of your situation. However, I cannot actively participate in ending your life. I can, however, promise to respect your autonomy.”

I felt deeply upset, helpless and hopeless. I sensed that she was suffering terribly and that she was trying to reach for help with no hope. It was all “deja vue” as she anticipated, and she could not bear her prospect. If we were sitting having the same conversation in Canada where euthanasia is legal, she could choose to end her suffering. As in our country, Israel, euthanasia is not legal, it was not an option for me to help Shoshana end her life.

“You promise?”

“I promise. But I do have one request. Please try taking Venlafaxine. Your decision may be affected by depression and anxiety. You may feel better…you may feel differently.”

“I will try,” she said, “as long as you promise to respect my wishes.”

As I left, I pondered the irony of life. Shoshana, who had come to tell me of her travels, agile throughout her 60s and 70s, had now come asking that I help put an end to her life.

Several weeks later, Shoshana fell, cut her arm, and was brought into the ER. I called to see how she was doing. She notified me that she had stopped the antidepressants; they had not made a difference.

A week later, Shoshana’s son called me: she had committed suicide. She was surrounded by her children and grandchildren, he said.

Since that day I've pondered Shoshana's choice. As a nurse, she had treated dementia patients, whose health deteriorated to a point where their quality of life would be unbearable for her. She had specifically mentioned that the prospect of a purposeless life filled with suffering terrified her. Whatever her exact motivations were, she was decisive and informed in her decision.

I have also been bothered by the ethical dilemma of knowing that Shoshana was going to take her own life and my obligation to her as her physician to respect her autonomy. As a nurse, Shoshana knew I could not assist with her suicide, as MAID (Medical assistance in dying) is not available in Israel. Why did she want my involvement? Perhaps she thought the bond between us, partly due to her connection with my late mother, had blurred the lines of our professional relationship and led her to expect I would deviate from my ethical duties (5).

I shared Shoshana's history of her tragic death with our resident Dr Grin. She reflected on her two encounters with Shoshana's husband after her death. It was the first time that Dr Grin was involved in enabling a patient to fulfill his final wish of passing away in the comfort of his own bed. He too was, in the progressive stages of dementia. Just as she finished examining him, her hand already on the doorknob, he looked at her, his eyes filled with a distant anguish and said: "Dr Avny tried to save her". Confused she squeezed his shoulder gently and was on her way. It was through the eyes of Dr Grin, after telling me of their conversation, that I realized, I truly engaged in trying to save Shoshana's life. It was a moment that allowed me to understand that I was a professional treating a friend and trying to prevent her death. My sense of guilt of somehow adopting a permissive attitude to her suicidal ideation found comfort that it did not affect my medical ethical judgement when actively trying to prevent her suicide.

I have kept in touch with Shoshana's family since her death. I am still witnessing there suffering. They all respected her wishes and let her end her journey. Yet, I sense that the fact that she had to take her own life actively was heartbreaking for them. Since then, I find myself in certain clinical scenarios talking about euthanasia in countries where it has become legal. I sense it might give hope, that when their time comes, they could consider euthanasia as an option by going abroad.

Defining boundaries in the patient-doctor relationship is always challenging. The bond built over years is sacred but sometimes tested, which can be beneficial to patients. Shoshana, with whom I had a sincere and honest relationship, shared her suffering and expected me to empathize. Our friendship likely influenced my medical decisions. She may have revealed her intent to end her life out of trust as her physician, respect as her friend, or a combination of both. Perhaps my awareness offered her some inner peace before her departure.

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TÉMOIGNAGE / PERSPECTIVE

Public Health Ethics in Times of Crisis: The Experience of the Quebec Public Health Ethics Committee During the COVID-19 Pandemic

Michel Désy[a,b], Bruno Leclerc[c], Julie St-Pierre[a]

Résumé
Le présent texte vise à partager l'expérience du Comité d'éthique de santé publique (CESP) de Québec pendant la pandémie de COVID-19, et plus particulièrement sur les risques et les opportunités rencontrés pendant cette période. Nous discutons notamment de l'agilité du CESP, conférée par ses règles de fonctionnement et son processus structuré d'examen éthique, et de sa capacité à réagir rapidement pour répondre aux questions éthiques soulevées par les interventions de santé publique en temps de crise. Nous nous concentrons sur les défis liés à l'autonomie du CESP, en particulier sa capacité à répondre en temps opportun à des préoccupations éthiques critiques.

Abstract
The aim of this text is to share the experience of the Quebec Public Health Ethics Committee (CESP) during the COVID-19 pandemic, and more specifically on the risks and opportunities faced during that time. In particular, we discuss the agility of the CESP, conferred by its operating rules and structured ethical review process, and its resulting ability to react quickly to address the ethical issues raised by public health interventions in times of crisis. Our focus is on the challenges that come with the CESP's autonomy, specifically its capacity to address critical ethical concerns in a timely manner.

Mots-clés
comité d'éthique de santé publique, Québec, COVID-19, pandémie

Keywords
public health ethics committee, Quebec, COVID-19, pandemic

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INTRODUCTION

When the Public Health Act was overhauled in 2001, the Quebec government created a public health ethics committee, the *Comité d'éthique de santé publique* (CESP), to independently review proposed surveillance plans and certain population health investigations. The CESP is also mandated to give its opinion on any ethical issues that may arise in the application of the *Public Health Act* within the field of public health practice, including any action or plan related to health promotion and protection, as well as disease prevention. Since 2009, the CESP has been bound to the *Institut national de santé publique du Québec* (INSPQ) through its Board of Directors, who has responsibility for its composition and operating rules. The CESP's opinions aim to advance debates about public health actions that have a significant impact on the targeted population. The CESP's composition reflects a deliberative democratic ethos, incorporating three public representatives, an ethicist, a legal expert, and three public health professionals. This structure ensures that ethical deliberations are informed by diverse perspectives, including lay voices, normative frameworks, and scientific realities. Though its opinions are non-binding, they are published online to stimulate public debate and exert argumentative pressure on policymakers. The legislator's establishment of the CESP aligns with a deliberative ethical perspective, which contributes to critical analysis of issues aimed at fostering democratic debate.

CHALLENGES

The COVID-19 pandemic had a significant impact on public health authorities worldwide, as well as on the CESP. Maintaining operations, efficiency, and agility were the main challenges faced by the committee.

Continuity during times of crisis

The onset of the COVID-19 pandemic in March 2020 paralyzed the CESP's operations. Between March and June 2020, all committee meetings were suspended due to the unavailability of public health professionals required for quorum, many of whom were redeployed to frontline pandemic response efforts. Concurrently, requests for ethical reviews from the Ministry of Health and Social Services (MSSS) stalled, reflecting a system-wide prioritization of acute crisis management over ethical deliberation**.** Given the high number of ethical issues linked to the COVID-19 pandemic, CESP practices were reviewed, notably its membership. In the summer of 2020, under the guidance of the INSPQ Board of Directors, the CESP's internal regulations were amended, introducing two substitute members to ensure quorum during absences. This reform, though modest, restored the committee's capacity to address urgent issues, such as ethical reviews of surveillance protocols.

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By August 2020, the CESP resumed operations, albeit with a backlog of delayed requests. The inclusion of substitutes not only mitigated operational paralysis but also underscored the importance of structural flexibility in maintaining continuity during crises.

Efficiency in producing opinions

The process of developing and implementing policies to protect the health of the population was significantly impacted by the COVID-19 pandemic and ethical support for decision-making was constrained by this timeframe (1). The urgency of the pandemic necessitated radical departures from the CESP's traditional workflows. The rapid evolution of the epidemiological situation and the resulting health measures put in place during the pandemic, as well as the pressure on health services to meet the increased demand for care, required an accelerated response to ensure the relevance of the CESP's work. Prior to the crisis, the committee's process involved request intake, evidence synthesis, deliberation across 2-3 monthly meetings, and publication after a 60-day embargo. The pandemic rendered this timeline untenable. In response, the CESP adopted streamlined workflows. Ad hoc working groups – composed of committee members, INSPQ staff, and external consultants – accelerated opinion production.

It should be noted that when the analysis of the health and social impact of population measures is carried out in real time, the resulting ethical opinions may need to be updated with a view to informing the public debate on the application of the measure. In this context, the CESP updated its *Opinion on the compulsory vaccination of healthcare workers against COVID-19* (2) in 2021 to respond to the evolving situation. Publication timelines were also compressed: the mandatory 60-day embargo was reduced to under a week for critical opinions. Consequently, the *Update to the Opinion on Mandatory COVID-19 Vaccination for Healthcare Workers* (3) was published within five days of finalization to inform urgent policy debates.

Agility

From 2020 to 2022, no request was made to the CESP by public health authorities in connection with the COVID-19 pandemic, despite the major ethical issues associated with public health measures (e.g., curfew, wearing of masks). In the spring of 2020, professionals and members of the CESP and the Commission de l'éthique en science et en technologie (CEST) took the initiative of publishing two documents examining ethical issues raised by the pandemic (4,5). The first outlined an ethical framework to shed light on the dilemmas raised by the pandemic, while the second dealt with decision-making under a context of scientific uncertainty in the period following the first curfew imposed by the authorities in Québec in the spring of 2020. These documents provided a normative scaffold for subsequent deliberations.

In the autumn of 2020, recognizing that the public health authorities had not formally engaged in consultation with the CESP regarding the ethical dilemmas arising from the global pandemic response, and the CESP's desire to contribute to public discourse on these matters, the committee resolved to assume the responsibility of directly addressing some of these issues. Article 19.3 of the INSPQ Act grants the CESP authority to "give its opinion on any ethical question arising from the application of the Public Health Act." (6) This provision proved indispensable during the pandemic, enabling the committee to address issues absent formal requests from authorities. The CESP's self-referral capacity contributes to important debates surrounding fundamental ethical issues and to democratic life in general. The effectiveness of public health actions can be enhanced by strengthening the ethical justification of public health measures; and the legitimacy and social acceptance of public health actions can be established through the CESP's contribution to deliberative rigour in public discourse. The CESP issued three opinions in this manner: two regarding to the vaccination of healthcare workers (2,3) and one concerning immune passports (7). Before it was published, another opinion was dropped because the policy that was its subject matter had been withdrawn (8).

Risks and opportunities

The CESP's autonomy, while a strength, carries inherent risks. The underutilization of self-referral could have eroded public trust, particularly if the committee remained silent on contentious issues. Proactive engagement, however, reinforced its legitimacy. The CESP enjoys autonomy in selecting topics and conducting its review in an independent manner, which is the cornerstone of its work. In the context of the CESP's decision to address critical ethical issues during the pandemic, the rigorous, public, and falsifiable nature of its review process was fundamental to the CESP's legitimacy and its interventions in the public sphere (9).

In 2022, the committee formalized its self-referral process to mitigate risks. Topic selection now requires alignment with the committee's mandate and demonstration of significant societal impact. A risk assessment phase, involving consultation with the INSPQ's Governance and Ethics Committee, evaluates political and scientific sensitivities. Transparency protocols ensure that all self-referral rationales are published alongside opinions, fostering accountability. At the conclusion of this risk assessment, the committee has the option to either proceed or not with the examination of the selected topic. This is very important from a risk management standpoint, because the CESP's publications during the pandemic received significant media attention, something it had never received before.

DISCUSSION

Three fundamental challenges associated with expedited ethical assessments during crises are elucidated by Yeh and Lee (1). First, despite the rapid nature of opinion generation, inevitable delays can still impede the timely development and implementation of critical policies that are crucial for disease containment or mitigating the consequences of a public health emergency. Second, the public nature of opinions, often presented alongside other documents, regulations, policies, and similar materials addressing the same concerns, presents a potential source of confusion or misuse. This can adversely affect the efficacy of disease prevention initiatives, individual health behaviours, and overall health outcomes. Lastly, the implementation of rapid ethics reviews may necessitate additional administrative inputs, including dedicated funding and human resources.

In response to the first issue raised by Yeh and Lee, it is important to acknowledge that, while there is potential to enhance the efficiency of opinion development, there will always be a delay associated with the ethical review process for the proposed measures. By optimizing the production process and facilitating communication between the review committee and the relevant authorities, these delays can be effectively mitigated. The emphasis on timeliness underscores the significance of public health authorities seeking the advice of committees with the mandate to provide ethical assessments during a pandemic. Their recommendations should be considered when formulating and implementing health measures, both legally and otherwise. Notably, even without prior consultation, the CESP provided its initial opinions on the vaccination of healthcare workers and the issuance of immunity passports well before these measures were formally considered. In this context, anticipation played a crucial role.

Regarding the second issue, during the pandemic, several journalists erroneously equated the CESP with the INSPQ, which is its designated responsible institution. This resulted in a misrepresentation of the CESP's independence in its ethical review process and recommendations. Given its comprehensive expertise in public health, the INSPQ experienced heightened demand during the pandemic. Consequently, the confusion between the institution and the independent ethics committee for which it is responsible posed a persistent challenge throughout the pandemic. The CESP's opinions garnered significant media attention, which facilitated the promotion of their ethical contributions to public discourse due to this misunderstanding. However, to prevent confusion, it is crucial that the role and characteristics of a committee like the CESP be consistently emphasized and clarified as necessary, particularly during periods of heightened media visibility.

Yeh and Lee's third challenge was not encountered by the CESP, as it was already in place prior to the pandemic, with a budget and human resources. This situation suggests that the form of institutionalization of ethics that links the CESP to the INSPQ can be advantageous, and it can attain its full potential during an emergency if the CESP's services are promptly requested by the relevant authorities. However, the CESP lacks both the mandate and the resources to conduct extensive public consultations on specific cross-cutting issues related to crisis management during a pandemic situation, particularly concerning the observance of the Quebec Charter of Human Rights and Freedoms. Should such a necessity arise at the conclusion of the post-pandemic assessment, Quebec possesses the requisite institutions (e.g., the *Commissaire à la santé et au bien-être*), academic expertise needed to facilitate such consultations and, if necessary, the capacity to develop novel normative guidelines to prepare for the next pandemic.

CONCLUSION

Indeed, Yeh and Lee's analysis (1) is corroborated by pertinent observations made by the CESP during the pandemic. First, any period of public health crisis can disrupt the regular activities of a committee working in this or a related field, particularly for committees operating in the domains of public health and/or other health-related ethical considerations. It is paramount to ensure that ethics advisory committees can maintain their normal operations during times of crisis. Second, such committees must be able to provide their opinions in an expedited manner to ensure their relevance in a dynamic decision-making environment. Lastly, if given the opportunity and their input is not otherwise sought, committees should proactively analyze significant ethical issues that fall within their expertise, even if this entails taking an uncomfortable position. As outlined in Wilson's et al. typology (10), the CESP and other committees serve as a critical ally to those responsible for public health decision-making (i.e., the MSSS). Integrating ethical justification into public health practice leads to its enhancement. The CESP's experience during the COVID-19 pandemic exemplifies both the challenges and opportunities for achieving this objective within the context of a public health emergency.

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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.

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TÉMOIGNAGE / PERSPECTIVE

Bioethics in the Public and Policy Spaces: Lessons from the Covid Years

Bryn Williams-Jones[a], Sihem Neila Abtroun[a,b]

Résumé
La pandémie de Covid-19 a présenté de nombreux défis éthiques, soulignant le rôle essentiel des bioéthiciens dans les espaces publics et l'élaboration des politiques. Les bioéthiciens ont joué le rôle de gardiens contre les injustices systémiques, de critiques des décisions en matière de politique de santé et de contributeurs au débat public. Ce texte s'appuie sur nos expériences en tant que bioéthiciens universitaires nord-américains explorant les différents rôles que les bioéthiciens ont joués pendant la pandémie, notamment en s'engageant dans les médias, en participant à l'élaboration des politiques et en menant des activités de recherche et d'éducation. La pandémie a mis en évidence l'importance de la bioéthique dans le système de santé et dans la gouvernance de la recherche, la nécessité d'une collaboration interdisciplinaire, l'importance de l'application de divers cadres éthiques et d'une communication efficace pour garantir une prise de décision éthique pratique. Elle a également démontré les rôles distincts mais complémentaires des bioéthiciens universitaires et professionnels, les premiers servant souvent de critiques publics visibles, en raison de leur liberté académique et de leur indépendance, tandis que les seconds travaillaient au sein de leurs institutions pour soutenir les cliniciens et les décideurs, et pour susciter des changements de politique. Mais ces rôles peuvent également conduire à des tensions entre les bioéthiciens universitaires et professionnels, en raison de leurs mandats différents, et les deux ont également ressenti des frustrations face à l'incompréhension persistante de certains professionnels et décideurs concernant la pertinence et l'utilité de la bioéthique pour soutenir la prise de décision éthique éclairée. En fin de compte, la pandémie a été une période clé pour les bioéthiciens qui ont influencé le débat public et la politique, mettant en évidence la pertinence et l'adaptabilité du domaine dans la résolution de problèmes éthiques complexes.

Mots-clés
Covid-19, bioéthiciens, universitaires, professionnels, rôles, compétences, engagement public

Abstract
The Covid-19 pandemic presented numerous ethical challenges, highlighting the critical role of bioethicists in public spaces and policymaking. Bioethicists acted as guardians against systemic injustices, critics of health policy decisions, and contributors to public debate. This text draws on our experiences as North American academic bioethicists to explore the different roles that bioethicists took during the pandemic, notably through media engagement, participation in policy-making, and in research and education. The pandemic underscored the importance of bioethics in the healthcare system and in research governance, the need for interdisciplinary collaboration, the importance of applying various ethics frameworks, and the need for effective communication to ensure practical ethical decision-making. It also demonstrated the distinct yet complementary roles of academic and professional bioethicists, with the former often serving as visible public critics, due to their academic liberty and independence, while the latter worked within their institutions to support clinicians and decision-makers, and to effect policy change. But these roles could also lead to tensions between academic and professional bioethicists, due to their different mandates, and both also experienced frustrations with the continued lack of understanding by some professionals and policy-makers regarding the pertinence and utility of bioethics to support ethically-informed decision-making. Ultimately, the pandemic was a pivotal time for bioethicists to influence public debate and policy, showcasing the field's relevance and adaptability in addressing complex ethical issues.

Keywords
Covid-19, bioethicists, academic, professional, roles, skills, public engagement

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INTRODUCTION

The Covid-19 pandemic created an exceptional public health situation in which health professionals, governments, and the public were faced with significant uncertainty regarding how best to safeguard public and private interests, which public health policies were justified, and when and how to move forward with effective and equitable interventions. The numerous ethical issues that arose – for example, with developing triage policies for access to ventilators, the prioritization and allocation of personal protective equipment, voluntary vs. obligatory masking or vaccination, and quarantine, among many others – highlighted the important role of academic and professional bioethicists in the public space, and in policy-making (1). Note that this separation between "academic" and "professional" is artificial. While many bioethicists are either academics (i.e., students, professors) or professionals (e.g., ethics consultants in hospitals, on research ethics boards, or at government agencies), many bioethicists have hybrid roles, with one foot in academia (e.g., doing teaching and research) and another in professional practice (e.g., consulting, serving on policy committees). For the purposes of our discussion, this caricature of academic versus professional bioethicists serves to highlight those roles and constraints that are distinct to the different domains.

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Some bioethicists acted as guardians against abuses of power or systemic injustices. For example, bioethicists worked within health organizations to argue against policies that disfavoured vulnerable communities (whether patients or frontline workers), or by publicly denouncing the abandonment of elderly residents that was occurring in long-term care homes (2,3). Other bioethicists played the role of a critic or even activist in the media, to challenge health policy decisions, such as obligatory overtime for nurses (4). Bioethicists also contributed to discussions about how to develop good public policy, notably regarding triage (5) and resource allocation (6).

Drawing on our experiences as North American academic bioethicists, who also do ethics consulting and collaborate with professional ethicists working full-time within the health system, we explore some of the ways that bioethicists can carry out these different roles, mobilize critical thinking and reflexivity, all while maintaining their independence, objectivity, and credibility (7). An important qualifier is needed, however – our experience as academics obviously differs from that of our colleagues working within health systems. These bioethics professionals may have very limited or no opportunity to work with the media, for example, because of duties of loyalty to their organizations or institutional obligations of discretion. They may also not be involved in conducting research if they are not affiliated with a university or simply because they lack the time given their other responsibilities. But professional bioethicists will still mobilize these (and other) skills and expertise within the organizations in which they work, even if somewhat differently from what we describe here. Furthermore, they often collaborate with academic bioethicists on research projects and participate in policy making, thereby ensuring and reinforcing a rich connection between research, policy, and practice.

The focus here will be on the opportunities and challenges for bioethicists engaged in three major public activities – *Media and Public Engagement*, *Policy-Making*, *Research and Education*. We conclude with some reflections on the bioethics *Competencies* that came to the forefront during the pandemic, and how these might differ for academic versus professional bioethicists.

MEDIA AND PUBLIC ENGAGEMENT

One of the recurring, even fundamental, roles of bioethicists that goes back to the origins of the field is to comment on important issues of uncertainty and scientific development, critique policy choices, add nuance to public debates, and help the public to better understand complex situations so that they (the public) can be empowered to ask questions of those in authority. As such, bioethicists must continuously improve their knowledge on relevant issues, including the public health or health policy implications of and eventual responses to a particular intervention. During the Covid-19 pandemic, bioethicists had to learn about the transmission of respiratory diseases, the exacerbating or mitigating factors of natural versus mechanical ventilation systems, the process of vaccine development and approval, and the environmental impact of medical waste, including masks. They did this by reading media sources, the scientific literature, and by consulting with expert colleagues specialized in each of these areas. This research allowed bioethicists to better identify, examine, and ultimately explain the associated ethical implications to different audiences, whether that be the general public, health professionals, or decision-makers.

Bioethicists were also drawn into the public debate and critique of policy decisions, and their justifications, related to: confinement, quarantine, triage, resource allocation, and the various limits of civil liberties that were imposed in order to protect public health. Were these choices the most appropriate? Were the justifications for decisions sufficiently clear and supported by a transparent decision-making process? Were these decisions equitable; or did they discriminate against or stigmatize particularly vulnerable or historically marginalized groups? And what, if any, measures were implemented to remedy inevitable injustices? Many academic bioethicists engaged in this public questioning by working extensively with journalists (many hours per week from the start of the pandemic) – whether radio, TV, print, or social media – to help clarify and explain the ethical issues to their fellow citizens. They also worked to educate journalists to support more nuanced and effective communication of complex issues with the public. In so doing, bioethicists contributed to empowering both journalists and the public to ask better questions of experts and to hold decision-makers accountable for the policy choices that affected us all.

This public engagement by bioethicists was particularly important given the problems with some government communication, which did not sufficiently explain and justify policy choices (e.g., where and when to add mechanical ventilation and filtering in school classrooms), was internally incoherent (e.g., the use or not of artisanal masks at the beginning of the pandemic) or in contradiction with choices made in neighbouring regions (e.g., closing of sporting venues and religious establishments), or was deliberately vague (e.g., pertinence of follow-up vaccination for various population groups). These communication problems undermined public trust in policy choices and decision-making, in public health institutions, and in science more generally.

POLICY MAKING

Many bioethicists – both academics and professionals – were solicited to help analyse complex situations and even contribute to the drafting of policies on a range of issues, such as triage or service prioritization (6,8), resource allocation (9), compliance and access to care (10), and requirements for proof of vaccination (11). And while much of this work was descriptive and analytic (e.g., identifying issues and evaluating their nature), bioethicists also assumed their normative responsibility to advocate for particular solutions or policy choices (12-14).

Academic bioethicists, with their liberty to be critical due to their independence and distance from health institutions, contributed by sharing their research expertise and facilitating access to analytic resources (e.g., the scientific literature and ethical decision-making frameworks). But they also served as foils against groupthink or institutional interests that might not be ethically justifiable. The work of the academic bioethics community was leveraged by their professional colleagues to support and justify local (institutional) ethical analyses of problematic situations and potential solutions (e.g., the proposition of evidence-based ethical recommendations). Furthermore, if decision-makers ignored the propositions of their professional bioethicists for how to implement ethically-defensible policies, the institution faced a severe (reputational) risk of being publicly criticized by academic bioethicists. Not to mention that, as educators, they played a training/mentoring role, broadening the horizons and sharpening the critical thinking and reflexivity of a professional workforce that joined during the pandemic. This collaboration between academic and professional bioethicists also contributed to the implementation of better organizational ethics and risk management practices (15), thus highlighting the importance of interdisciplinary skills among bioethicists.

Public health choices are anchored in ethical values or principles that can go in different directions. One of the roles of bioethicists was to make explicit the values or norms (and interests) of different stakeholders involved in the policy development process. Policies needed to be effective, responding to specific public health objectives, but also equitable so as to not unfairly penalize some groups for the benefit of others. Policy-makers (and bioethicists) often had to work within the context of scientific uncertainty and with important human resource and time constraints, to serve society in the best possible way, while also respecting different groups and interests.

Given that the field of bioethics has 50 years of experience working with challenging ethical situations and developing functional analytic and decision-making tools, bioethicists were able to mobilize and make existing ethical frameworks publicly available for immediate use. They dusted off old models on topics in public health ethics, updating these or developing new models to include the global context, economic issues, and evolving technologies (e.g., AI and Covid apps) (16). Notable open access resource compilations were developed by teams in the UK (Nuffield Council on Bioethics), the US (Hastings Center, American Journal of Bioethics, Johns Hopkins Berman Institute of Bioethics), and Canada (CEST, CCNPPS), to name a few. And these tools were offered freely to health professionals, policy-makers, and bioethics colleagues working inside the health system and who were supporting the drafting of institutional or public policies. Bioethicists are rarely if ever the ultimate decision-makers or those responsible for implementing specific policy choices. However, they can and do contribute by providing robust and empirically tested frameworks or decision tools to support ethical decision-making.

RESEARCH AND EDUCATION

As academic bioethicists, we had access to resources that were deployed to contribute to the collective, societal response to the pandemic. We mobilized our research and educational expertise, we involved our students in analyzing specific topics and finding practical solutions, and we studied and critiqued policy choices and public health practices.

The complex nature of the public health crisis highlighted the importance of multifaceted and multi-layered analyses of existing and emerging ethical issues. Ethical problems (or solutions) could not be isolated to a limited group of actors. Instead, analysis had to account for the dynamic interaction between health, socio-economic, cultural, and (geo)political factors, that influenced the nature of ethical problems and potential solutions at the micro, meso, and macro levels. For academic bioethicists, this complexity necessitated interdisciplinary collaboration with colleagues from other fields, notably moral and political philosophy, public health, law, global justice, the social sciences, and the health sciences, among others. The issues were too complex to be analyzed effectively from only one frame of reference or domain of expertise.

Interdisciplinary and international collaborations emerged because academic (and professional) bioethicists, and colleagues from other fields, were all interested in complex issues. Each arriving with our respective disciplinary approaches or methodological orientations, we worked together to move from theory to practice and generate more nuanced analyses and recommendations. Also, these interdisciplinary exchanges – supported as they were by the necessary act of translation between disciplinary languages – facilitated the subsequent production of policy advice or recommendations for senior decision-makers in government. When this worked, it was because we had clearly articulated the key issues and so were better able to explain them in a nuanced but accessible language that was meaningful for those who needed to make hard choices.

But not all collaborations were successful, nor were all recommendations taken up by decision-makers. Sometimes, despite everyone's best efforts, disciplinary barriers could not be surmounted, competing interests or priorities could not be aligned, and conversations broke down with colleagues unable to compromise, never mind build consensus. At other times, it was institutional constraints that, whether in academia (e.g., research ethics requirements, competing teaching or administrative obligations) or in the public sector (e.g., power hierarchies in health systems, demands by government agencies to produce unified and authoritative messages), made interdisciplinary and intersectoral collaboration impossible. The interests and demands of one type of organization (e.g., the university) could not be aligned with other types (e.g., a health agency or government department). Finally, despite the active work by numerous academic and professional bioethicists to valorize their respective means to contribute to ethical public health practices and policy, decision-makers and clinicians chose to exclude bioethicists from key decision forums and to ignore ethically-nuanced recommendations.

Within the field of bioethics, another lesson from the pandemic was the need to draw upon multiple spheres of applied ethics. The issues raised by Covid-19 surpassed the expertise of individual bioethics specializations. Expertise was needed in biomedical ethics and public health ethics, but also in business ethics, organizational ethics, and technology ethics. And these different applied ethics had to be brought into dialogue (17). In doing so, rich opportunities arose for cross-fertilization and critical debate. Also, while bioethics had a wealth of proven analytic tools to draw upon, existing ethical frameworks and decision tools needed to be updated for the specific context of Covid-19. These tools then needed to be validated for applicability or utility, which required bioethics research on their pertinence, functionality, and ultimately whether they could or did make a difference in practice (18).

An important role of bioethics centres and other groups involved both the compilation of tools (mentioned in the previous section) and their subsequent improvement and dissemination. These groups were and continue to be essential actors for ensuring the continuity of and continued public access to practical, applied ethics knowledge and tools. But they too face the constraints of public health and other academic domains, which, following the end of the pandemic, have shifted their attention to other topics (e.g., the ethics and social implications of AI innovations). The risk for bioethicists, like for public health researchers and professionals, is that the numerous lessons that should have been learned from the pandemic are not, due to insufficient post-event analysis (i.e., research). As a result, we will again, as during Covid-19, be insufficiently prepared to respond effectively and ethically to the next global crisis (e.g., with appropriate infrastructure, robust and ethical policy, and teams of professionals and academics who collaborate effectively).

In parallel to and anchored in pandemic-related research, bioethicists were also actively engaged in educating and supporting health professionals (19), professional bioethicists (20), students (21,22), and the public. Many academic bioethicists organized (weekly or monthly) training activities to facilitate real-time problem solving and provide support to professional colleagues making difficult practical and policy choices. Webinars were hosted that addressed topical subjects, with the aim of reaching local and international audiences, both academic and professional. More general bioethics cafés and other open events helped make sophisticated ethical thinking accessible to a broad population. There was an incredible flourishing of free academic and public events from 2021 to 2023, with events happening weekly. Bioethics research and education had never been so easily accessible.

This plethora of research and educational opportunities demonstrated the importance of the field of bioethics to diverse audiences (academic, government, decision-makers, media, public). Bioethicists were successful in influencing public discussions and policy making when they were in spaces where which they could be heard. These spaces allowed them to ask pertinent questions, analyze complex issues with appropriate frameworks, and provide justified arguments to support or critique particular policy decisions.

BIOETHICS COMPETENCIES IN PRACTICE

Supporting the operationalization of bioethics practice during the Covid-19 pandemic required a series of bioethics-specific competencies that merit articulation.

During the pandemic, bioethicists showed the importance of sophisticated moral reasoning and nuanced critical thinking to identify and evaluate the nature and scope of ethical issues (e.g., inequity or unfair discrimination, at micro/meso/macro levels). They also mobilized problem solving abilities to facilitate the development of pragmatic solutions that could be implemented in practice settings (e.g., identifying “invisible” stakeholders not included in triage decisions, accompanying health professionals in dealing with moral distress). Alongside these analytic abilities, professional bioethicists also needed to know about the range of pertinent bioethics tools and knowledge that already existed, and which they might not have encountered in their training of professional practice. For example, bioethicists working primarily in clinical or organizational ethics might have had limited experience with issues in research ethics, public health ethics, or technology ethics, and so would not be conversant with the relevant frameworks or normative guidelines. However, they needed to be able to access such content at the right moment, particularly important in times of crisis but also during times of non-crisis. The credibility and pertinence of bioethicists as experts and professionals depended on their ability to leverage the appropriate knowledge and tools to address the issues at hand, and then propose pragmatic and context-specific recommendations.

Bioethicists have expertise in *mediation* (between people, groups, and potentially competing interests), *translation* (of ideas or disciplinary languages), and *communication* (the ability to synthesize complex concepts or challenging issues and make these meaningful for diverse audiences). They have to be comfortable working with both individual- and system-level analyses in relation to technological innovations, policy considerations, and health systems operations. And these complex individual-to-system analyses (micro, meso, macro) have to be mobilized appropriately and where pertinent to address complex ethical problems. The bioethicist is thus a translator, knowledge broker, critic, and communicator.

One notable difference between the academic and professional bioethicist is the ability of the former to be overtly and publicly critical. Unlike the professional, who is often bound by obligations of institutional loyalty and cannot be explicitly critical of organizations or governments, the academic can (and arguably must) assume the role of public critic. Protected and empowered by academic liberty, the academic bioethicist must be a facilitator for more active civil engagement in the issues that concern society. This generates a cascade effect where, often in collaboration with professional colleagues, academic bioethicists engage strategically with different actors (e.g., media, decision-makers). This engagement influences public and policy discussions because they have the freedom to speak publicly, with journalists, decision-makers, and civil society. This liberty must, however, be framed within the normative guardrails of responsible conduct to prevent hubris or the impression that academic bioethicists are moral authorities or the "new priests" with "all the ethical answers". Mobilizing reflexivity, intellectual humility, and collegial critique, academic bioethicists must avoid going down the wrong paths or pronouncing on issues that are not supported by facts or reasoned justifications.

Although the profession of bioethicist may remain unclear, bioethicists undeniably play key roles in academia, research, and healthcare systems, and often work in different environments, depending on the needs of each sector (e.g., healthcare, research). During their careers, they may navigate between clinical ethics, research ethics, public health ethics, and policy ethics, depending on the ethical dilemmas they face. Thus, their skillsets need to be defined but also flexible. Also, on numerous occasions during the pandemic, the complexity of the issues at hand showed the importance of bioethicists working in inter-professional and interdisciplinary collaborations to propose the best possible arguments for a given position.

As bioethicists, we must also always recognize that we are rarely the decision-makers and are not responsible for the consequences of the decisions about which we are arguing. However, our expert recommendations and propositions must be made with confidence and humility, a professional responsibility.

SUMMARY

The Covid-19 pandemic was an unprecedented opportunity for the public visibility of bioethicists, both academic and professional. Nonetheless, it was often a challenge to be heard in the right spaces, to be invited into decision-making circles, or to have the time and space to work effectively with the media and other stakeholders. While bioethicists rarely have decision-making roles, they can and must work to influence decisions and help shape the broader public debate. These different roles during the pandemic – public engagement, policy making, research, and education – highlighted the pertinence of applied bioethics reflection. Also, these roles are not limited to one area of bioethics (e.g., clinical or public health ethics) but instead are open to all bioethics specializations.

One key lesson was the critical importance of maintaining close collaborations between professional bioethicists focused on clinical/organizational practice, and those working in academia. This mutually beneficial relationship allowed for the sharing of concerns (e.g., in terms of subjects for study) and resources (e.g., ethical frameworks, literature), and facilitated the production of contextually-informed recommendations and evidence-based policy. But the success or failure of these collaborations also pointed to areas of fragility in the networks that support academic and professional bioethicists. During the crisis, a wealth of resources and opportunities were made available, but once the crisis began to subside, bioethicists faced challenges in ensuring that structures (e.g., centres, research groups, communities of practice) continued to receive support from their respective institutions. Bioethicists also lost access to important decision-making forums that had been available during the pandemic. This reality highlights the need for other important competencies, such as resilience in the face of rapid change and the ability to navigate a shifting bioethics ecosystem.

The capacity to deploy sophisticated analytical frameworks and decision-making tools – whether in academia, public spaces, or decision-making forums – enabled bioethicists to participate in analyzing and addressing complex problems. Expertise in communication and knowledge translation allowed bioethicists to help the public ask better questions and to hold decision-makers accountable. As an applied field of research and practice, bioethicists showed that they could contribute to building better policies and supporting decisions that respond equitably to the diverse needs and interests of the population. To continue to merit the confidence gained during the pandemic, bioethicists must show that they have the judgment and humility to take strong normative positions, where they are warranted, while also acknowledging that there is still significant uncertainty, and that there are no easy answers.

As bioethicists, we must be willing to reflect on and critically analyze the tough questions and show that we (and our communities) can live with them. We have to inspire hope while also being realistic, to point to successful changes, and to tell positive stories of how we are working towards making the world a better place, even if just a little bit at a time (23).

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

Chronique du cinéma 6 : Zone d'intérêt et la mort

Jacques Quintin[a]

Résumé
Un commandant vit avec sa famille dans un lieu champêtre qui entre en contraste avec un camp d'extermination à proximité. Le commandant est surtout préoccupé de l'avancement de sa carrière sans égard pour la vie de tous ces Juifs qui sont entrainés vers la mort.

Mots-clés
mal, émotion, responsabilité, courage, vertu

Abstract
A commandant lives with his family in a rural setting that contrasts with a nearby death camp. The commandant is primarily concerned with advancing his career, with no regard for the lives of the Jews who are being dragged off to their deaths.

Keywords
evil, emotion, responsibility, courage, virtue

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« Ils ont tué six millions de Juifs. Mais ils dorment bien. Ils mangent bien et le mark se porte bien » (1). Cette citation tirée d'un échange épistolaire entre le philosophe Vladimir Jankélévitch et Wiard Raveling, un Allemand, résume tout à fait le propos du film *La zone d'intérêt* du cinéaste Jonathan Glazer (2023) adapté librement du roman de Martin Amis (2015) avec le même titre (2).

Le film imagine la vie du nazi Eichmann représenté par le commandant Höss, joué par Christian Friedel, qui s'affaire à bien exécuter les ordres, ceux de faire fonctionner les fours crématoires jour et nuit. Il était le responsable de la logistique de la Solution finale. Il réalisait son travail dans son bureau, loin du visage des prisonniers, à établir des communications par téléphone et à donner des ordres avec un souci particulier pour l'horaire des trains, sans jamais donner ni l'ordre de tuer les Juifs ni entretenir des sentiments hostiles envers eux. Ce qui le motive sont ses ambitions personnelles et le désir de plaire à ses supérieurs.

Tout cela sur un fond de musique industrielle, de bruit de train, d'aboiement de chiens et surtout les cris de terreur des prisonniers, dont des enfants. Sans compter la fumée qui émane des fours sur le fond d'un beau ciel bleu. D'ailleurs, tout l'environnement, malgré la proximité du camp de concentration – un seul mur les en sépare –, est bucolique, comme si le Paradis se situait en Enfer. Le contraste est bien marqué entre, d'une part, la terreur et, d'autre part, l'indifférence, principalement celle de sa femme, Hedwig, joué par Sandra Hüller, très fière de son jardin avec ses fleurs et les autres avantages qu'elle retire de sa situation, comme une pléthore de domestiques juives recrutées dans le camp d'Auschwitz.

Nous pouvons analyser ce film à travers le prisme du livre d'Hannah Arendt, publié en 1963, *Eichmann à Jérusalem* (3), qui est le fruit de ses observations lors du procès d'Eichmann à Jérusalem, et qui a soulevé une grande controverse qui perdure encore aujourd'hui. C'est dans ce livre qu'elle a développé son concept de « banalité du mal ».

Arendt se demande si l'être humain peut poser des gestes infâmes sans être pour autant méchant. Le ferait-il par ignorance, comme le pense Socrate, ou par malice? Pour elle, contrairement aux représentations conventionnelles, le mal n'est pas exceptionnel et démoniaque, par exemple, comme chez Macbeth. Elle voit dans Eichmann, non pas un psychopathe (les psychiatres ont confirmé qu'il est une personne entièrement « normale »), mais la médiocrité d'un être sans imagination, tout à fait dans les normes, malgré toute son indifférence qui se rapproche du personnage de Merseult dans l'*Étranger* de Camus (4). Si Eichmann n'a pas pu reconnaître l'atrocité de ses actes, c'est en raison de son inhabilité à imaginer et à penser, principalement selon le point de vue des autres. D'ailleurs, Eichmann est un homme de peu de mots. Les seuls qu'il utilise sont les mots en lien avec le travail administratif, souvent des mots abstraits, une sorte de novlangue pour parler comme George Orwell dans son roman *1984* (5).

Nous pouvons aussi voir dans ce film une allégorie de la Modernité caractérisée par une culture de la bureaucratie industrielle qui vient masquer la méchanceté à l'œuvre. Pensons à tous ces fonctionnaires dans leur tour à bureaux qui décident de la vie ou de la mort, au sens figuré, des immigrants. Ils doivent s'occuper de plusieurs dossiers qui ne laissent pas le temps de penser. Comme dans un régime totalitaire, c'est la capacité de penser qui est diminuée transformant du coup ces personnes en simple courroie de transmission d'objectifs à atteindre. La violence est automatique, mécanique; elle se produit d'elle-même. Personne n'en est responsable. Arendt le précise clairement dans *Les Origines du totalitarisme* (6) : l'essence d'un gouvernement totalitaire, et peut-être de toute bureaucratie, consiste à rendre les fonctionnaires de simples pions dans la machine administrative.

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Ce film, comme le commentaire d'Arendt sur Eichmann, pose toute la question de la responsabilité morale. Eichmann disait qu'il ne faisait que suivre les ordres. Pour Arendt, il n'y a qu'une seule solution : développer sa pensée critique, c'est-à-dire penser par soi-même. Mais qu'adviendra-t-il lorsque tout le sale travail ne sera plus effectué par des fonctionnaires, mais par une intelligence artificielle dans la plus grande indifférence? On le voit à la fin du film, après une soirée mondaine où tous agissent comme si de rien n'était, le commandant Höss est pris d'un sentiment de rage et de nausée comme s'il commençait à prendre conscience des atrocités commises. Nos intelligences artificielles auront-elles ces sentiments? Le film laisse sous-entendre que nos sentiments n'existent pas pour nous dire ce que l'on doit faire, mais pour nous avertir de l'inacceptable. La rationalité laissée à elle-même vide l'être humain d'une altérité qui donne à penser.

Comme le souligne Byung-Chul Han dans son livre *Topologie de la violence*, « le camp de concentration … n'est plus le théâtre de la violence meurtrière, car il n'est pas installé au centre, mais en marge de la ville » (7). Les chambres à gaz sont soustraites au regard et par le fait même, elles échappent à la symbolisation. « Elle est certes toujours exercée, mais pas publiquement mise en scène. » (7)

Ce film nous glace le sang. Non pas strictement à cause de l'horreur que nous ressentons, mais au fait qu'il s'agit un peu de nous. Nous y reconnaissons une part de soi, voire de la condition humaine dans ce qu'elle a de plus méchant. Le mal est partout et insidieux. C'est toujours difficile de le repérer et de l'admettre. L'être humain désire sauver sa peau, et pour y parvenir, tous les moyens sont bons. Inutile de dire que la fin justifie les moyens. Dans un contexte de survie, est-ce une raison pour disculper les fautifs?

Dans le même contexte de survie, l'histoire nous a révélé que plusieurs personnes ont risqué leur vie pour sauver d'autres vies (8,9). Peut-être qu'elles ne craignaient pas de mourir! Dans ce cas, nous pouvons nous demander si ce n'est pas par lâcheté face à la mort que nous commettons des crimes. La vertu du courage se manifeste souvent en osant un refus. Ici, le commandant Höss sentait qu'il avait tout à perdre. Il n'en demeure pas moins que tout dépend de la manière dont l'être humain se comprend comme être humain : celui qui compte seulement sur lui-même pour accéder à son salut ou celui qui répond à la demande de prendre soin de tous, incluant les étrangers, comme les Juifs dans le film de Jonathan Glazer, et pas seulement les personnes de son entourage. Il semble que la bonté et l'empathie a ses limites. Nous serions plus compatissants envers nos proches que ceux que nous jugeons sévèrement.

Donner la mort est un interdit qui traverse les époques et les cultures. Seule la mort psychique permet d'aller à l'encontre de cette loi morale. C'est ce que nous ressentons à travers ce film malgré toutes ces belles images : le plaisir esthétique ne nous protège pas du mal. Il faut compter davantage sur notre capacité à imaginer la vie des autres, et c'est ce que réalise le cinéma et la littérature. Le film, *La vie des autres*, du cinéaste Florian Henckel von Donnersmarck, est un bel exemple.

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

Chronique du cinéma 7 : Une vie et le visage de l'autre

Jacques Quintin[a]

Résumé
Une vie raconte une histoire véridique, celle d'un banquier, prêt à sacrifier sa carrière, pour venir en aide à des enfants dans la grande misère à Prague quelques mois avant le déclenchement de la Deuxième guerre mondiale. Il devra convaincre les autorités du bien-fondé de son entreprise.

Abstract
One Life tells the true story of a banker willing to sacrifice his career to help destitute children in Prague a few months before the outbreak of World War II. He must convince the authorities of the merits of his undertaking.

Mots-clés
courage, autrui, Levinas, devoir, responsabilité

Keywords
courage, others, Levinas, duty, responsibility

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Une vie (*One Life*) (1), film de James Hawes sorti en salle en 2023, raconte l'histoire vraie d'un banquier londonien qui se sent appelé à intervenir à Prague pour aider des juifs menacés par le régime nazi. L'action se déroule en 1938 avant que les nazis occupent le gouvernement de la Tchécoslovaquie. Le film raconte les souvenirs de ce banquier, Nicholas Winton, joué par Anthony Hopkins.

Arrivé à Prague, contre l'avis de sa mère et au grand désespoir de son employeur, il voit dans le regard des enfants affamés qu'il rencontre dans la rue un impératif : ne nous abandonne pas. On le voit bien dans les photos qu'il a prises de chaque enfant : dans ces regards, il y a une imploration face à laquelle tout être humain devrait répondre à la manière de Levinas « Me voici » (2). Ces visages dans leur grande vulnérabilité engagent la personne à la responsabilité pour Autrui. Dans *Humanisme de l'autre homme*, Levinas s'exprime ainsi : « Le visage s'impose à moi sans que je puisse rester sourd à son appel, ni l'oublié, je veux dire sans que je puisse cesser d'être responsable de sa misère » (3).

Toute l'entreprise de Nicky (Nicholas) repose sur une forte émotion ou un appel à ne pas demeurer indifférent. Tout au long de son parcours, il devra convaincre les gens autour de lui, principalement les agents des affaires étrangères responsables de gérer le statut des réfugiés. Lui et sa mère finiront par les convaincre en jouant sur leur émotion, sur le sens de l'engagement et sur les valeurs britanniques. Ils vont réussir à sauver 669 enfants en leurs trouvant une famille d'accueil en Angleterre. Ce nombre aurait pu être plus élevé si le dernier train avait pu quitter la gare à temps. Le souvenir de ce train bondé de personnes qui ne demandaient pas autre chose qu'un peu d'espoir pèsera lourdement sur la conscience de Nicholas tout au long de son existence, même si c'était hors de son contrôle.

Si le commandant Eichmann fut décrit par Hannah Arendt (4) comme un homme ordinaire, il n'en va pas autrement de Nicky et ses collègues. Ils se définiront tous comme des gens ordinaires pour venir en aide à des enfants ordinaires. On voit que l'héroïsme ne relève pas nécessairement de gens aux qualités exceptionnelles. D'ailleurs, Nicky demeurera une personne simple toute sa vie. C'est en faisant du ménage dans son bureau à la demande de son épouse pour apprendre à passer à autre chose qu'il décide de bruler des boîtes entières de documents en lien avec ses interventions auprès des enfants juifs, une sorte d'autodafé. Son document le plus précieux, il voudrait en faire quelque chose qui ne soit pas abandonné dans des archives que personne ne consulte. Il souhaite que les gens se souviennent, mais lui ne désire en tirer aucune gloire. Finalement, c'est à l'invitation d'une émission de télévision très populaire, regardée par des gens ordinaires, que ce fameux cartable sera dévoilé. L'animatrice nommera quelques noms. Plusieurs personnes se sont reconnues. Nicky pourra enfin, pour la première fois, après plusieurs années, revoir une grande partie de tous ces gens que lui et ses collègues ont sauvés. Nicky restera un homme simple jusqu'à la fin.

Pendant toutes ces années après-guerre, il est demeuré mélancolique avec des remords. Il a le sentiment qu'il aurait pu faire davantage, un sentiment de culpabilité. Ce sont tous ces actes de reconnaissance autour de lui qui va lui permettre de voir les choses selon une perspective plus juste. Étant débarrassé d'un poids, il va reprendre vie.

L'engagement de Nicky ne se fonde pas sur un calcul utilitariste où les avantages pour le plus grand nombre de personnes l'emporteraient sur les inconvénients. Il y a ici un geste de générosité, d'une sensibilité supérieure, d'un dévouement pour l'humanité entraînant une éthique du sacrifice des intérêts personnels. Il y a quelque chose d'entièrement gratuit. L'action trouve en elle-même sa justification. C'est le devoir qui l'emporte. Emmanuel Kant aurait vu dans ce film une illustration de son cadre éthique. Si Levinas ne s'accorde pas avec Kant sur le fondement de l'éthique, tous deux conçoivent l'éthique comme un devoir de répondre à l'autre dans son besoin d'humanité.

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Le film montre ce que c'est que la vertu du courage. Notamment, la façon dont les gens sont mobilisés à agir selon leur émotion, ce dont le commandant Eichmann semblait dépourvu. Pendant ce temps, que faisons-nous avec tous ces réfugiés à nos portes? On évoque toutes sortes de raisons techniques, économiques, sociales pour les refluer aux frontières. Ce sont les mêmes raisons que les gens autour de Nicky ont présentées pour ne pas s'engager. Finalement, l'éthique c'est bien davantage une affaire de règles, de normes et de principes, mais un appel à l'engagement pour transformer et améliorer la vie de personnes en détresse. Et cela, dans la vie ordinaire. Le fondement de la morale se situe dans des sentiments humains ordinaires. Rien de grandiloquent. Même la fin du film montre la vie ordinaire qui prend le dessus sur les horreurs et la vie difficile de Nicky. C'est pourquoi, nous pouvons affirmer que Nicky est le digne représentant de la philosophie morale de Hume où domine le sentiment de l'humanité, c'est-à-dire un sentiment pour le bonheur d'autrui et un ressentiment pour la misère (5).

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

Chronique du cinéma 8 : La promesse d'Irena au risque de sa vie

Jacques Quintin[a]

Résumé
La promesse d'Irena raconte l'histoire d'une jeune fille à Varsovie au début de la seconde mondiale qui tente, à la mesure de ses capacités, de sauver des Juifs de la mort au risque de la propre existence.

Abstract
Irena's Vow tells the story of a young girl in Warsaw at the beginning of the World War II who, to the best of her ability, tries to save Jews from death, at the risk of her own life.

Mots-clés
courage, mensonge, humanisme, émotion

Keywords
courage, lies, humanism, emotion

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Le dernier film de Louise Archambault, *La promesse d'Irena* (1), adapté d'une pièce de théâtre de Dan Gordon, sorti sur les écrans en 2024, est basé sur un fait vécu. C'est l'histoire d'une infirmière polonaise, Irena Gut Opdyke de son vrai nom, jouée par Sophie Nelisse, qui devient, malgré elle, la gouvernante d'un major de l'armée allemande, nommé Rügemer, interprété par Dougray Scott, pendant la Seconde Guerre mondiale à Varsovie, en Pologne.

Sans réfléchir, elle ose protéger un groupe de douze personnes juives destinées à mourir. Sauver la vie sous toutes ses formes est le principe ou la promesse qui l'anime au risque de sa propre vie, ne serait-ce qu'une seule vie. Le philosophe Kant aurait dit qu'elle agit par devoir à l'encontre de ses propres intérêts. Il n'en ira pas autrement lorsque le groupe de Juifs caché au sous-sol a décidé, sur le principe de l'utilitarisme, de sacrifier un fœtus (un avortement), donc un enfant à venir, pour sauver le groupe. Irena les aidera à infirmer leur décision, encore une fois pour sauver une vie en dépit d'un calcul rationnel des avantages et des inconvénients. On peut dire qu'Irena incarne la vertu du courage contre celle de la lâcheté. Car, selon ses dires, cela signifierait abdiquer et par conséquent accepter déjà la mort. Ainsi, la mort psychique s'installe bien avant la mort physique.

Comme dans le film *Zone d'intérêt* (2), on remarque combien l'appétit du gain, principalement le souci d'avancement dans une carrière est la raison de vivre de bien des gens. Ils sont prêts à tout pour parvenir à leur fin : la fin justifie les moyens. Dans *La promesse d'Irena*, le drame pour l'officier n'est pas sa participation à l'Holocauste, mais le déclin de sa carrière. Avant la guerre, il était le directeur d'une usine où doit dominer l'efficacité à tout prix. On instrumentalise la vie humaine mettant à mal l'impératif kantien de ne jamais traiter autrui comme un moyen, mais toujours comme une fin en soi. De la même manière Irena, à l'encontre de l'impératif kantien de ne jamais mentir, va décider de transgresser ce principe au nom de la vie. Car le devoir de sauver des vies humaines pèse davantage dans la balance que le respect d'un principe absolu. Ainsi, l'éthique est toujours une affaire de jugement circonstancié.

On ne peut s'empêcher d'établir une analogie avec la pièce de Sophocle, *Antigone*, où justement Antigone laisse parler son cœur contre la raison d'État représenté par Créon, le roi. Nous pouvons prolonger l'analogie avec tous ces intervenants auprès des itinérants qui doivent se battre contre les interdictions de campement, promulguées par l'État, ici, les mairies, au nom de la sécurité publique. Karl Marx y verrait sous la valeur absolue de la sécurité une idéologie au service d'une élite. La même logique s'opère avec l'évacuation des campements sur les campus où les étudiants laissent exprimer leur cœur à l'encontre des raisons d'État. À chaque fois, il y a un fond d'indignation. Irena voit de ses propres yeux le meurtre d'un bébé et de sa mère ainsi que la pendaison de personnes qui ont osé, comme elle, de protéger des Juifs. Ces expériences deviendront la source de son engagement et de sa promesse. Plus près de nous, les itinérants témoignent de la misère humaine et les étudiants assistent impuissants à une guerre sale sur le territoire de Gaza où des personnes innocentes sont privées de soins et de nourriture. Ce sont des émotions qui dictent l'action. On peut dire alors que l'éthique c'est apprendre à dire non à tout ce qui tue l'humain d'une manière ou d'une autre. C'est en disant non, en offrant de la résistance, que l'être humain devient humain, qu'il se donne la vie et la promeut.

Les films de Louise Archambault s'inscrivent dans cette pensée profondément humaine. Pensons au film *Le temps d'un été* (3) où un curé décide d'offrir du bon temps ou une autre vie à des gens qui ont tout perdu, il devra affronter la résistance des villageois. Aussi aux films, *Il pleuvait des oiseaux* (4) et *Gabrielle* (5) qui donnent une voix à des gens sans voix. Il y a un profond humaniste dans tous ses films. Elle remet en valeur la bonté humaine, la compassion, l'altruisme. Il y a de la lumière même dans la noirceur. À nous de la capter.

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Ce film, *La promesse d'Irena* (1), entre en résonance avec celui d'*Une vie* (6) et *Zone d'intérêt* (7). Il montre comment l'être humain se rend un peu plus humain en se mettant dans la peau des autres et en se sacrifiant pour sauver la vie sans bénéfices secondaires. Rousseau dit que l'être humain est fondamentalement bon, mais que c'est la société qui le corrompt. Ces trois films montrent à leur manière qu'effectivement l'être humain est un être de bonté, mais s'il abdique sa nature, cela ne tient qu'à lui. La leçon que nous pouvons retirer de ces films se situe dans le choix que nous avons à faire en tant qu'être humain : choisir la lâcheté ou le courage.

Ces trois films sont apparus sur nos écrans dans l'espace d'une année. Cela a permis d'en faire une lecture croisée. Une belle synchronicité.

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