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ÉDITORIAL / EDITORIAL

10 Years On: Looking Back in Order to Move Forward into the Future

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

In March 2022, the *Canadian Journal of Bioethics/Revue canadienne de bioéthique* (CJB/RCB) celebrated its 10th anniversary. Given this important milestone, it is time to look back briefly on the history of the journal, describe its progression, and lay out future directions.

The journal was launched in 2012 as *BioéthiqueOnline* (published until 2017) by a dedicated group of professors and students in the Bioethics Program at the School of Public Health of the Université de Montréal. Our ambitious aim was to fill an important gap in the Canadian bioethics community by providing a platform to publish Canadian research, and in so doing, bring together scholarly and professional resources to foster a robust, collaborative and bilingual bioethics community in Canada, and internationally. The journal was and remains the only bilingual (English and French), peer-reviewed, fully open access (no user fees or publication charges), non-profit bioethics journal in Canada. All manuscripts have bilingual cover material and are published in the language of submission (French or English), and some manuscripts are also published in both languages. From its inception, we sought to publish high quality and thought provoking theoretical, conceptual and empirical bioethics research, and to support diverse forms of scholarship. Over the years, this has expanded to include the publication of peer-reviewed articles and critical commentaries, as well as case studies, creative works, perspectives, book reviews, letters to the editor, and conference proceedings; and covering the full range of bioethics specialties, including but not limited to themes in clinical ethics, research ethics, public health ethics, technology ethics, and professional ethics.

Following feedback from bioethics colleagues from across Canada, in January 2018 we renamed the journal to better convey its leadership in the field, and so became the *Canadian Journal of Bioethics/Revue canadienne de bioéthique*. As part of this restructuring and move away from an initially student-led journal, we created an international Editorial Advisory Board (EAB) composed of established bioethics scholars to provide complementary expertise and strategic guidance to the journal's Executive officers, the Editor-in-Chief and the Scientific Director. While our core Editorial Team is still largely made up of students (because they have the time!), it now also includes professionals, post-doctoral fellows and professors from across Canada, as well as the US, Europe, and Africa. All the founding student members of the Editorial Team have gone on to successful academic and professional careers in Canada and the US, and then joined the EAB. While still primarily a volunteer-driven initiative, with the 2019 awarding of a SSHRC Aid to Scholarly Journals grant – which was renewed in 2022 – we have started paying the Scientific Director, part-time, and mobilized punctual paid student support (internships).

During the years 2020-2022, we updated the journal's policies to match the latest COPE standards (e.g., dealing with conflicts of interest, authorship, plagiarism). Other major innovations included the implementation of the Open Journal Systems publishing platform, a new journal website and logo, hosting by the Université de Montréal libraries, updating of the publication templates, and final production by Érudit (a non-profit Quebec consortium supporting Social Science and Humanities scholarship) of all published PDFs with DOIs. The journal now publishes by volume, issue and page number, organized into Open Issues (a collection of manuscripts not linked by theme) and Special Issues (manuscripts that form a cohesive group on a specific topic). The journal has continued with its Artist in Residence – initially Emanuelle Dufour and currently Han Han Li – and each issue has a unique cover image.

To reinforce its Canadian mandate, the journal initiated a formal collaboration with the Canadian Bioethics Society (CBS), the leading bioethics association in Canada; this led to publicity on the CBS website and at their annual conference, and to joint publication initiatives, notably a student writing competition and the publication of book reviews edited by members of the CBS. To reach an international audience, a concerted effort was made to increase journal indexing in both English and French language databases: the CJB/RCB is now archived on Canadian and European platforms and indexed by leading Canadian,

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US, and European indexes. And for readers who had grown accustomed to having regular updates on bioethics related news and events, the *BioéthiqueOnline* social media accounts became the official social media arm of the CJB/RCB; all new issues are disseminated to thousands of followers via Twitter, Facebook and LinkedIn.

The authors of peer-reviewed manuscripts are primarily Canadian (69%) and European (15%), with the remainder coming from the US, the UK, and countries in Africa, Latin America, and Asia. So, while the journal is Canadian in its mandate and title, contributors are decidedly international. The Editor-in-Chief and Scientific Director often receive emails of satisfaction about: 1) the seriousness and professionalism of the Editorial Team, 2) the pertinence of the journal's innovative policy of editorial transparency (i.e., the review process is open, non-blinded, and reviewers and editors are named on published articles), and 3) the speed of production and publishing, which facilitates active discussion of important and time-sensitive topics. Leading Canadian, American, and international bioethics researchers agree to voluntarily review manuscripts and to have their names listed as reviewers on the final publication. This demonstrates confidence both in the transparent review process and the quality of manuscripts accepted for publication. Of 321 peer-reviewed submissions received between June 2018 and December 2022, 146 were accepted, 108 declined, and 125 published, for an acceptance rate of 42.7% and rejection rate of 33.6%. The journal strives for timely treatment of all submissions, with a preliminary evaluation in less than 20 days, final acceptance or rejection in 4 months (following external review), and subsequent publication in less than 1 year.

The number of submissions has grown substantially, especially peer-reviewed articles and critical commentaries. In 2016/17, as *BioéthiqueOnline*, the journal published 5-8 peer-reviewed manuscripts per year. As CJB/RCB, this grew to 16 manuscripts in 2018, 37 in 2019, 39 in 2020, 25 in 2021, and 43 in 2022: the journal now publishes 35-40 peer-reviewed manuscripts per year. In 2018 the journal moved to publishing 3 issues per year, and as of 2022 publishes 4 issues per year. Since 2018, the journal has published 8 Open Issues and 7 Special Issues on international development research, ethics in rehabilitation, questions of life and death, ethics in archeology, ethics and mental health, medical assistance in dying and ethics and the handling of complaints (ombudsman).

The journal has established itself nationally and internationally as a platform that publishes innovative and high-quality scholarship that is pertinent to researchers, policy makers and professionals in diverse fields. For example, a 2019 critical commentary by Caulfield and colleagues already has 56 citations on Google Scholar. A special issue on Ethics and Archeology helped significantly advance discussions to develop a more robust culture of professional and research ethics adapted to the particular specificities of archeological research and practice. Further, numerous manuscripts addressing the ethical and legal aspects of medical assistance in dying legislation in Canada have contributed to ongoing public and policy debates on this important issue.

From its modest origins as a student-run journal, the CJB/RCB has matured into an established journal and leader in the Canadian bioethics community, with an increasing reach internationally. Our productivity and continued growth have demonstrated the success of our model for supporting and promoting innovative bioethics scholarship that is timely and pertinent for researchers, professionals and decisions-makers. This success is due to the commitment of our volunteer editors, without whom the journal could not have flourished, the guidance and support of our international Editorial Advisory Board, and the trust of the many Canadian and international bioethics scholars who submitted their works to the journal and participated in the peer-review process.

Ten years on, we can say with confidence that the future of the CJB/RCB is bright!

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10 ans après : Regarder en arrière pour avancer vers l'avenir

En mars 2022, la *Revue canadienne de bioéthique/Canadian Journal of Bioethics* (RCB/CJB) a célébré son 10^{e} anniversaire. Étant donné cette étape importante, il est temps de revenir brièvement sur l'histoire de la revue, de décrire sa progression et d'exposer les orientations futures.

La revue a été lancée en 2012 sous le nom de *BioéthiqueOnline* (publiée jusqu'en 2017) par un groupe dévoué de professeurs et d'étudiants des programmes de bioéthique de l'École de santé publique de l'Université de Montréal. Notre objectif ambitieux était de combler une importante lacune dans la communauté canadienne de bioéthique en offrant une plateforme pour publier la recherche canadienne et, ce faisant, de rassembler les ressources savantes et professionnelles pour favoriser une communauté de bioéthique robuste, collaborative et bilingue au Canada et à l'échelle internationale. La revue était et demeure la seule revue de bioéthique canadienne évaluée par les pairs, bilingue (français et anglais), à accès entièrement libre (aucuns frais d'accès ou de publication) et sans but lucratif. Tous les manuscrits ont une couverture bilingue et sont publiés dans la langue de soumission (français ou anglais), et certains manuscrits sont également publiés dans les deux langues. Dès sa création, nous avons cherché à publier des recherches théoriques, conceptuelles et empiriques en bioéthique de haute qualité et suscitant la réflexion, et à soutenir diverses formes d'érudition. Au fil des ans, cet objectif s'est élargi pour inclure la publication d'articles et commentaires critiques évalués par les pairs, ainsi que d'études de cas, d'œuvres créatives, de perspectives, des critiques de livres, de lettres à l'éditeur et d'actes de conférences ; et couvrant toute la gamme des spécialités de la bioéthique, y compris, mais sans s'y limiter, les thèmes de l'éthique clinique, de l'éthique de la recherche, de l'éthique de la santé publique, de l'éthique des technologies et de l'éthique professionnelle.

Suite aux commentaires de collègues de bioéthique de tout le Canada, en janvier 2018, nous avons renommé la revue pour mieux communiquer son leadership dans le domaine, et elle est ainsi devenue la *Revue canadienne de bioéthique/Canadian Journal of Bioethics*. Dans le cadre de cette restructuration et de la transition d'une revue initialement dirigée par des étudiants, nous avons créé un conseil consultatif de rédaction (CCR) international composé de chercheurs établis en bioéthique afin de fournir une expertise complémentaire et une orientation stratégique aux membres de la direction de la revue, l'éditeur en chef et la directrice scientifique. Bien que le noyau de notre équipe d'éditorial soit toujours composé en grande partie d'étudiants (parce qu'ils ont le temps!), il comprend maintenant aussi des professionnels, des postdoctorants et des professeurs de partout au Canada, ainsi qu'aux États-Unis, en Europe et en Afrique. Tous les membres étudiants fondateurs de l'équipe éditoriale ont poursuivi des carrières universitaires et professionnelles réussies au Canada et aux États-Unis, puis ont rejoint le CCR. Bien qu'il s'agisse encore principalement d'une initiative bénévole, avec l'attribution en 2019 d'une subvention du CRSH pour l'Aide aux revues savantes – qui a été renouvelée en 2022 – nous avons commencé à rémunérer la directrice scientifique, à temps partiel, et mobilisé un soutien ponctuel d'étudiants rémunérés (stages).

Au cours des années 2020-2022, nous avons mis à jour les politiques de la revue pour qu'elles correspondent aux dernières normes COPE (ex. : traitement des conflits d'intérêts, autorat, plagiat). Parmi les autres innovations majeures, citons la mise en œuvre de la plateforme de publication Open Journal Systems, un nouveau site Web et un nouveau logo de la revue, l'hébergement par les bibliothèques de l'Université de Montréal, la mise à jour des modèles de publication et la production finale par Érudit (un consortium québécois à but non lucratif soutenant l'érudition en sciences sociales et humaines) de tous les PDF publiés avec DOI. La revue publie maintenant par volume, numéro et numéro de page, organisés en numéros ouverts (une collection de manuscrits non liés par un thème) et en numéros spéciaux (manuscrits qui forment un groupe cohésif sur un sujet spécifique). La revue a poursuivi sa collaboration avec son artiste en résidence – initialement Emanuelle Dufour et actuellement Han Han Li – et chaque numéro a une image de couverture unique.

Pour renforcer son mandat canadien, la revue a entamé une collaboration formelle avec la Société canadienne de bioéthique (SCB), la principale société savante de bioéthique au Canada ; cela a conduit à une publicité sur le site Web de la SCB et lors de sa conférence annuelle, ainsi qu'à des initiatives de publication conjointe, notamment un concours de rédaction pour étudiants et la publication de critiques de livres édités par des membres de la SCB. Pour atteindre un public international, un effort concerté a été fait pour augmenter l'indexation de la revue dans les bases de données anglophones et francophones : la RCB/CJB est maintenant archivé sur des plateformes canadiennes et européennes et indexées par les principaux index canadiens, américains et européens. Et pour les lecteurs qui s'étaient habitués à recevoir des mises à jour régulières sur les nouvelles et les événements liés à la bioéthique, les comptes de médias sociaux *BioéthiqueOnline* sont devenus le bras officiel des médias sociaux de la RCB/CJB ; tous les nouveaux numéros sont diffusés à des milliers d'abonnés via Twitter, Facebook et LinkedIn.

Les auteurs des manuscrits évalués par des pairs sont principalement canadiens (69 %) et européens (15 %), le reste provenant des États-Unis, du Royaume-Uni et de pays d'Afrique, d'Amérique latine et d'Asie. Ainsi, bien que la revue soit canadienne dans son mandat et son titre, les contributeurs sont résolument internationaux. L'éditeur en chef et la directrice scientifique reçoivent souvent des courriels de satisfaction concernant : 1) du sérieux et du professionnalisme de l'équipe éditorial, 2) de la pertinence de la politique novatrice de transparence éditoriale de la revue (c'est-à-dire que le processus de révision est ouvert, non aveugle, et que les réviseurs et les éditeurs sont nommés sur les articles publiés), et 3) de la rapidité de production et de publication, qui facilite la discussion active de sujets importants et sensibles au temps. D'éminents chercheurs en bioéthique canadiens, américains et internationaux acceptent de réviser volontairement des manuscrits et de voir leur nom inscrit comme réviseur sur la publication finale. Cela démontre la confiance à la fois dans le processus transparent de révision et dans la qualité des manuscrits acceptés pour publication. Sur 321soumissions évaluées par des pairs reçus entre juin 2018 et décembre 2022, 146 ont été acceptées, 108 refusées et 125 publiées, soit un taux d'acceptation de 42,7 % et un taux de refus de 33,6 %. La revue s'efforce de traiter toutes les soumissions en temps opportun, avec une évaluation préliminaire en moins de 20 jours, une acceptation ou un rejet final en 4 mois (après examen externe), et une publication ultérieure en moins d'un an.

Le nombre de soumissions a considérablement augmenté, notamment les articles et les commentaires critiques évalués par les pairs. En 2016/17, en tant que *BioéthiqueOnline*, la revue a publié 5 à 8 manuscrits évalués par les pairs par an. En tant que RCB/CJB, ce chiffre est passé à 16 manuscrits en 2018, 37 en 2019, 39 en 2020, 25 en 2021 et 43 en 2022 : la revue publie désormais 35-40 manuscrits évalués par des pairs par an. En 2018, la revue est passée à la publication de 3 numéros par an, et à partir de 2022, elle publie 4 numéros par an. Depuis 2018, la revue a publié 8 numéros ouverts et 7 numéros spéciaux sur la recherche en développement international, l'éthique de la réadaptation, les questions de vie et de mort, l'éthique en archéologie, l'éthique et la santé mentale, l'aide médicale à mourir et l'éthique et traitement des plaintes (ombudsman).

La revue s'est imposée au niveau national et international comme une plateforme qui publie des travaux d'érudition innovants et de grandes qualités, pertinent pour les chercheurs, les décideurs et les professionnels de divers domaines. Par exemple, un commentaire critique de 2019 par Caulfield et ses collègues compte déjà 56 citations sur Google Scholar. Un numéro spécial sur l'éthique et l'archéologie a contribué à faire avancer de manière significative les discussions visant à développer une culture plus robuste de l'éthique professionnelle et de recherche adaptée aux spécificités particulières de la recherche et de la pratique archéologiques. En outre, de nombreux manuscrits traitant des aspects éthiques et juridiques de la législation sur l'aide médicale à mourir au Canada ont contribué aux débats publics et politiques en cours sur cette importante question.

Depuis ses origines modestes en tant que revue gérée par des étudiants, la RCB/CJB a mûri pour devenir une revue établie et un chef de file dans la communauté de bioéthique canadienne, avec une portée internationale croissante. Notre productivité et notre croissance continue ont démontré le succès de notre modèle de soutien et de promotion d'une érudition innovante en bioéthique qui est opportune et pertinente pour les chercheurs, les professionnels et les décideurs. Ce succès est dû à l'engagement de nos éditeurs bénévoles, sans lesquels la revue n'aurait pas pu s'épanouir, aux conseils et au soutien de notre comité consultatif de rédaction international, et à la confiance des nombreux chercheurs en bioéthique canadiens et internationaux qui ont soumis leurs travaux à la revue et participé au processus d'évaluation par les pairs.

Dix ans plus tard, nous pouvons dire avec confiance que l'avenir du RCB/CJB est brillant!

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Nous remercions, tout d'abord, les membres de l'équipe éditoriale du CJB/RCB pour leur incroyable travail bénévole, sans lequel cette revue n'aurait pas pu s'épanouir au cours des 10 dernières années! Nous remercions également le Comité consultatif de rédaction pour ses conseils et son soutien, ainsi que le CRSH pour son appui financier. Enfin, nous sommes reconnaissants aux membres des communautés canadiennes et internationales de bioéthique qui ont confié leurs travaux à la revue, ainsi qu'aux lecteurs de ces manuscrits, et qui ont ainsi contribué à la pertinence de ce projet en cours.

Acknowledgements

We thank, first of all, the members of CJB/RCB Editorial Team for their incredible volunteer work, without whom this journal would not have flourished over the past 10 years! We thank also the Editorial Advisory Board for their guidance and support, and the SSHRC for their financial support. Finally, we are grateful to the members of the Canadian and international bioethics communities who have entrusted their works to the journal, and to the readers of these manuscripts, and so have contributed to the pertinence of this ongoing project.

Conflits d'intérêts

Aucun à déclarer

Conflicts of Interest

None to declare

Édition/Editors

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

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

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A Lajeunesse. *Can J Bioeth / Rev Can Bioeth.* 2022;5(4):5-19

ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Prise de décision, répartition des ressources médicales et personnes âgées en contexte de COVID-19 : une anthropologie de et pour la bioéthique

Alizée Lajeunesse[a]

Résumé

Dans le contexte de la pandémie de COVID-19, les pratiques décisionnelles liées à la répartition des ressources médicales et au traitement des personnes âgées nous renseignent sur les éthiques présentes en milieu de soin et au niveau sociétal. La comparaison entre la prise de décision dans le contexte quotidien et les particularités d'une éthique de pandémie met en lumière les tenants du passage entre une éthique hors pandémie et une « pandéthique ». L'approche éthique de santé publique, notamment utilitariste, a été mise de l'avant d'une manière prépondérante dans les débats et dilemmes éthiques entourant l'allocation des ressources et la priorisation. En soulevant les oppositions et enjeux associés aux discours et aux choix du rationnement en fonction de l'âge émerge la question du traitement des personnes âgées en contexte de COVID-19, et de l'âgisme vécu dans ce contexte. En parallèle, les décisions et choix éthiques difficiles s'entremêlent au *duty to care* du soignant, et par conséquent à la possibilité de blessure morale. Un conflit émerge entre les pratiques éthiques décisionnelles et les valeurs personnelles ou professionnelles du soignant, alors que l'équilibre entre ses divers devoirs est bouleversé. Des approches et éthiques alternatives sont ainsi mises de l'avant à la lumière des situations vécues, notamment en contexte de soin de longue durée. La thèse développée vise à soutenir la valeur ajoutée de l'anthropologie aux processus décisionnels et son intégration plus formelle aux approches bien connues en bioéthique. À partir du regard anthropologique, nous ouvrons en conclusion sur des pistes de réflexion associées aux éthiques de la discussion, de la vulnérabilité, féministes, ou encore du *care* comme d'autres manières d'aborder la prise de décision en contexte de pandémie, à un moment où la réflexion éthique et sociale s'impose comme capitale.

Mots-clés

anthropologie de la bioéthique, COVID-19, prise de décision, allocation des ressources médicales, priorisation, âge, personnes âgées, blessure morale

Abstract

In the context of the COVID-19 pandemic, decision-making practices related to the allocation of medical resources and the treatment of the elderly inform us about the ethics present in the health care setting and at the societal level. The comparison between decision-making in the daily context and the particularity of a pandemic ethics highlights the transition between a non-pandemic ethics and a "pandethics". The public health ethics approach, particularly utilitarian, has been brought forward in a prominent way in the ethical debates and dilemmas surrounding resource allocation and prioritization. By raising the oppositions and issues associated with age rationing discourses and choices, the question of the treatment of the elderly in the context of COVID-19, and the ageism experienced in this context, emerges. At the same time, difficult ethical decisions and choices are intertwined with the caregiver's duty to care, and therefore the possibility of moral injury. Conflict emerges between ethical decision-making practices and the caregiver's personal or professional values, as the balance between various duties is upset. Alternative approaches and ethics are thus put forward in light of the situations experienced, particularly in the context of long-term care. The thesis developed here aims to support the added value of anthropology to decision-making processes and its more formal integration into well-known approaches in bioethics. Using an anthropological perspective, I conclude by exploring avenues of reflection associated with the ethics of discussion, vulnerability, feminism, or care as other ways of approaching decision-making in the context of a pandemic, at a time when ethical and social reflection is essential.

Keywords

anthropology of bioethics, COVID-19, decision making, medical resource allocation, prioritization, age, elderly, moral injury

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INTRODUCTION

Au quotidien, les soignants sont confrontés à des enjeux et à des dilemmes éthiques face à la prise de décision. Le contexte pandémique, pesant sur les systèmes de santé et leurs ressources, a grandement exacerbé ces dilemmes. Avec la COVID-19 a émergé à l'horizon la perspective de devoir faire des choix critiques sur le plan éthique, avec de possibles lourdes conséquences pour les patients. À l'international, les interrogations sur ces dilemmes décisionnels sans précédent ont été le lieu d'intarissables débats sur les critères à utiliser pour prioriser les patients et répartir les ressources médicales. La présente étude se penchera sur les tenants de ces débats, examinant les liens entre la prise de décision, la répartition des ressources médicales et la situation des personnes âgées en contexte de COVID-19. Il s'agira, au final, de réfléchir aux implications de la pandémie, notamment pour la vieillesse et les aînés au niveau sociétal, ainsi que de réfléchir aux questionnements éthiques que la pandémie soulève face aux choix et décisions de soin. De ces derniers émergent les questions du traitement des membres plus âgés de notre société, de l'âgisme vécu, ainsi que des blessures infligées, notamment en milieu de CHSLD. Ainsi, comment les pratiques décisionnelles liées à la répartition des ressources et au traitement des personnes âgées nous renseignent-elles sur les moralités et éthiques présentes, en milieu de soin et au niveau sociétal?

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Nous examinerons la manière par laquelle une approche éthique de santé publique, notamment utilitariste, a grandement été mise de l'avant dans les débats éthiques sur l'allocation des ressources et la priorisation. En se basant sur cette approche, il sera question d'observer les oppositions et risques soulevés par des auteurs ayant une autre perception des enjeux et des pratiques éthiques en contexte de COVID-19. Nous aborderons ensuite les implications de ces approches de priorisation, notamment la manière dont les personnes âgées sont abordées et traitées au travers d'elles, ainsi que les blessures morales des soignants par rapport aux prises de décision difficiles. Cette réflexion nous mènera à construire une revue de certaines approches et éthiques alternatives qui ont récemment été mises de l'avant comme d'autres manières d'aborder la prise de décision en contexte de pandémie.

La nature actuelle du sujet a un impact sur la méthodologie possible dans le cadre de cette recherche documentaire et conceptuelle. Dans les circonstances, pas ou très peu d'études anthropologiques, ethnographiques ou qualitatives ont pu à ce jour être menées sur le long terme, afin d'approfondir le sujet. Celles-ci figurent donc très peu dans les sources utilisées. Par contre, plusieurs enjeux et problèmes émergentes ont été rapportés et soulevés par des auteurs issus pour la plupart de la pratique clinique ou de la bioéthique. Plusieurs écrits ont donc l'avantage de présenter la perspective même des soignants de première ligne, ou des bioéthiciens parfois impliqués dans les comités d'éthique ou de préparation des protocoles et directives. Des philosophes, mais aussi des chercheurs des sciences sociales, notamment spécialisés dans les études du vieillissement, ont également publié des réflexions dont il sera ici question. La majorité des écrits qui seront visités sont ainsi très récents (2020-2021), mais ils seront appuyés de textes d'anthropologues médicaux, dont les ethnographies menées avant la crise portent sur des sujets connexes desquels il sera possible de tracer des parallèles avec la situation présente. En ce qui a trait aux contextes géopolitiques, quelques sources locales, québécoises et canadiennes, mais aussi européennes feront l'objet d'analyses. Or, la majorité des écrits sur lesquels ce texte s'appuiera ont été publiés par des auteurs provenant des États-Unis, du Royaume-Uni et d'Australie, où un grand intérêt a été accordé à ces questions. Au fil du texte, la provenance des écrits ne sera spécifiée que lorsque jugée nécessaire à la compréhension, par souci de non-encombrement. Par contre, il convient de mentionner que l'approche grandement occidentale du matériel utilisé pourrait représenter une limite à cette recherche documentaire, mais aussi un biais potentiellement universalisant. La singularité des contextes et perspectives fera ainsi l'objet d'un rappel au fil du texte, afin de tenter d'équilibrer cette limite.

L'intention ici n'est pas de remettre en cause les critères médicaux d'admission utilisés au quotidien en soins intensifs, ni de poser un jugement sur les approches éthiques ou de proposer la solution dite « adéquate ». L'objectif sera plutôt de faire un premier état des lieux de la diversité des approches et conceptions éthiques mobilisées et mises en scène pour faire face à la pandémie. Il sera question d'essayer de mieux saisir pourquoi elles s'opposent, mais aussi comment les relier et les comparer, afin de mieux les interroger. En posant un regard anthropologique sur les enjeux éthiques en jeu, il sera possible de s'interroger sur ce que ces derniers peuvent révéler au niveau médical, mais aussi culturel, ainsi que sur la manière dont ces approches et perceptions peuvent commencer à nous informer sur notre société – *commencer*, car ce regard est situé dans une crise en plein déroulement et nécessitera de prendre un recul plus éclairé dans le futur. Par contre, une première ébauche et tentative d'observation anthropologique sur une part des éthiques de la pandémie se montre essentielle. Pensons notamment à l'apport des travaux de Paul Farmer ou de Sharon Kaufman dans le domaine anthropo-médical. L'analyse de l'incorporation des relations de pouvoir, des inégalités sociales, des violences structurelles, et des forces socio-politiques sous-jacentes à la santé offre une compréhension accrue des expériences, croyances, valeurs et normes individuelles et sociétales (1-4). L'anthropologie des cultures des mondes médicaux et éthiques, de leurs pratiques et des institutions de santé, entre dit et non-dit, nous informe d'une manière tout aussi importante sur les tenants des choix cliniques et de la prise de décision en santé (5-7). Ce regard nous permet de constater qu'il existe plusieurs manières de penser les éthiques au pluriel. Comme rapportée par Marshall et Koenig (8), la définition du « bien » dans les soins de santé est nécessairement locale, plurielle, et comprend des implications éthiques diverses : « les croyances et les valeurs sont culturellement construites, enracinées dans des contextes spécifiques, notamment historiques. La signification morale de la maladie, de la santé et des systèmes de soins étant socioculturellement déterminée, les pratiques bioéthiques (…) génèrent souvent des conflits fondamentaux » (8, p.36). Dans les cas de conflits, alors, il devient extrêmement difficile de déterminer quelle éthique invoquer (8), d'où la pertinence de s'y intéresser et de mettre à contribution le regard anthropologique. La visée de soutenir une intégration plus formelle de celle-ci aux processus décisionnels en temps de crise, et aux approches connues en bioéthique, nous amène à étayer la pertinence d'une anthropologie de et pour la bioéthique. Les connaissances anthropologiques et les techniques ethnographiques imprégnant la bioéthique permettent de concilier son ancrage au sein des mondes moraux locaux et des dynamiques sociales contextuelles desquelles émanent diverses conceptions du « bien », avec l'application de principes universels (8,9). L'anthropologie peut contribuer à ce que ces derniers prennent en compte la complexité de l'expérience vécue et des dilemmes de la réalité des pratiques de soin.

PRISE DE DÉCISION : CONTEXTE QUOTIDIEN DE « L'AVANT » PANDÉMIE

À la prise de décision en contexte pandémique sous-tend un processus décisionnel quotidien prépandémique. En temps normal hors crise sanitaire, un triage a déjà lieu à la base des soins intensifs. Des décisions sont prises quant aux candidats qui peuvent y être admis, dans le but de ne pas infliger de souffrance inutile au patient très fragilisé, présentant plusieurs comorbidités et facteurs de risque à une intubation et assistance respiratoire prolongée. Les patients qui ne seraient probablement pas en mesure d'endurer physiquement la brutalité des soins intensifs et d'y survivre font donc l'objet d'un triage en temps normal. L'instigation, la continuation et l'arrêt du maintien en vie font partie des décisions que les médecins doivent prendre, tout en naviguant les complexes dynamiques relationnelles patients-familles-soignants (10). Il est attendu que le clinicien respecte les souhaits et l'autonomie du patient et de sa famille, mais considère également les bénéfices envisagés des traitements. Dans la relation thérapeutique de l'ère néo-libérale et post-paternaliste s'insère une éthique de l'autonomie et de la prise de décision individuelle (7), tout de même marquée de pressions et exigences plurielles. Cette prise de décision met en scène des acteurs aux normes, valeurs et perspectives multiples, sous-tendues par les rapports de pouvoir impliqués dans la négociation (11). Au quotidien, des incertitudes morales et cliniques sous-tendent la prise de décision de prolonger la vie ou d'envisager la mort dans le cas de maladies graves en milieu hospitalier (11). L'incertitude de l'interprétation s'entremêle à celle du niveau de soin à choisir pour le patient, et ce, sur fond du débat de l'acharnement médical, des soins aigus et agressifs dont la pertinence pour le patient est parfois contestée (12). Au cœur de ce débat, Callahan écrivait en 1987 que la société et l'institution médicale américaines avaient perdu le sens de la durée de vie normale ou naturelle, et surtout significative (13). Dans la lutte pour définir les pratiques responsables et éthiques se révèlent des tensions entre ce que Kaufman qualifie de soins « héroïques » ou « humanistes », surtout dans le cas de patients très âgés et fragilisés en unité de soins intensifs (5). L'ambivalence et l'ambiguïté sont chose commune, alors que la pratique du mourir s'embrouille et se complexifie de plus en plus. L'unité des soins intensifs se présente comme un lieu où le « problème de la mort » – défiée, repoussée – s'entremêle au dilemme de déterminer qui doit prendre ces décisions critiques de vie ou de mort (5). Les impératifs technologique et interventionniste se transforment en un impératif moral, telle une preuve de la qualité du soin, ou de l'amour donné au patient ou proche malade (6). L'intervention, pour un âge de plus en plus avancé, se routinise, le choix s'amincit, mais le spectre des possibles s'élargit (6). Face à cette biomédicalisation du vieil âge, les attentes sociétales grimpent et alimentent une nouvelle éthique de la normalité, de nouveaux standards de soin et de longévité, où dire « non » devient quasiment impossible (6). En reconstruisant sans cesse ce que signifie la vieillesse « normale », notre compréhension de celle-ci et de l'heure de la mort en serait transformée, tout comme les pratiques cliniques (7). D'un autre côté, si l'on considère la vieillesse comme un construit socio-culturel (14) et non un fait naturel et biologique, peut-il réellement exister de vieillesse normale, naturelle, fixe ou figée? L'adaptation des pratiques au contexte et aux nouvelles réalités sociales peut-elle être considérée nécessaire? Ces différentes perspectives ont été documentées dans la pratique quotidienne, et bien que ce débat constitue un sujet d'étude inépuisable en lui-même, il nous informe sur le contexte décisionnel sur lequel se fondent les éthiques en temps de pandémie, notamment aux soins intensifs et pour les patients âgés.

PANDÉTHIQUES : PANDÉMIES ET ÉTHIQUES

La pandémie de COVID-19 s'est développée dans le contexte où la bioéthique est aujourd'hui considérée comme « la voix morale de la biomédecine » pour la protection des droits des patients envers l'autorité médicale (8). Elle a donné lieu à la branche de l'éthique de la santé publique, en réponse aux bouleversements sociaux induits par les épidémies de maladies infectieuses à évolution rapide (15). Durant les dernières décennies, l'importance éthique des pandémies avait surtout été abordée dans le cadre du VIH/SIDA, du SRAS, le l'influenza pandémique, de l'Ebola, et du bioterrorisme (15). En 2009, Selgelid nous prévenait de la portée éthique importante des pandémies en termes de la menace à la sécurité qu'elles représentent, sources de morbidité et de mortalité inégalées. Il nous mettait en garde du fait qu'historiquement, les pandémies sont susceptibles d'instaurer la peur et la panique, ainsi que de mener à des prises de décisions, des mesures et politiques émotionnelles, coercitives et parfois irrationnelles. De ce fait, pour Selgelid, les pandémies pourraient favoriser la stigmatisation et la discrimination, et soulever des questions éthico-philosophiques et de justice particulièrement difficiles. L'enjeu éthique reposerait alors sur l'équilibre des mesures de protection et de promotion de la santé publique, avec les droits et libertés des individus (15). Par contre, comme le soulèvent Bustan et al. (16), l'éthique et la réalité divergent souvent dans ce contexte où l'impératif premier devient celui de maintenir les personnes en vie. Dans ce contexte, non seulement les dilemmes et conflits moraux concernent-ils des vies humaines, mais les décisions difficiles à prendre n'arrivent souvent pas à résoudre l'enjeu d'une manière qui serait considérée « éthiquement acceptable » pour ces auteurs cliniciens, philosophes ou éthiciens (16).

Certes, il convient de s'interroger si les délibérations et décisions prises en discussion avec les parties prenantes peuvent permettre de se rapprocher d'un processus décisionnel assurant les valeurs fondamentales de bien et de bon (16). Mais comme nous le verrons plus loin, il semble que la signification du caractère « moralement bon » d'une décision, ainsi que celle des principes sur lesquelles elle se base soit particulièrement floue et revête différentes formes au travers de la pandémie. Ainsi, aux yeux de Bustan et al. (16), les dilemmes éthiques clés en temps de pandémie et de COVID-19 concernent la transformation ou la redéfinition de certains principes pris pour acquis, mais bouleversés par la pandémie, notamment la responsabilité, l'équité, la dignité et l'hommage de la mort. Les auteurs soulèvent la potentielle transformation de la responsabilité médicale au travers de la pandémie, mais aussi le risque d'atteinte aux droits et à la dignité des patients, notamment au travers du conflit opposant l'intérêt public au droit (ou même devoir) d'honorer le patient mourant (16). À ces questionnements épineux s'ajoute la manière de prendre des décisions équitables liées à la priorisation et au rationnement de soins, dans un contexte où l'urgence mais aussi les inégalités sociales sont potentiellement exacerbées (16). À ce sujet, Selgelid remettait déjà en question les possibles principes qui pourraient être utilisés, dans le cas d'une insuffisance de ressources médicales, pour déterminer leur allocation et la priorisation des patients (15). C'est sur ces principes guidant la prise de décision éthique que nous nous pencherons.

Le passage

Mais d'abord, comment expliquer le passage d'une éthique hors pandémie, à une éthique des pandémies que l'on pourrait nommer, en s'inspirant de Selgelid (15), de « pandéthique »? La pandémie a entraîné une situation d'urgence en rapide évolution où non seulement l'état du patient mais les savoirs médicaux peuvent changer rapidement et sont emplis d’incertitude (15,17). De nombreux états à travers le monde se sont retrouvés dans une situation où le nombre d’hospitalisations et la demande pour les lits aux soins intensifs ont largement dépassé la capacité et les ressources médicales disponibles (18). Certains états ont jusqu’ici plus ou moins maîtrisé la menace qui pesait sur eux, alors que nombre d’autres ressentent encore aujourd’hui les répercussions de cette situation. Au Québec, en janvier 2022, alors que la mise en place du quatrième palier de délestage basé sur le Plan de contingence provincial en centres hospitaliers permettait de reporter jusqu’à 80 % des chirurgies, rendez-vous et activités cliniques, le gouvernement envisageait de créer un niveau cinq de délestage, vue la situation de crise causée par l’importante hausse des hospitalisations de patients atteints de la COVID-19 (19,20). Des patients et professionnels de la santé se sont prononcés dans les médias, faisant état de l’inquiétude et de la détresse toujours exacerbées par cette situation, près de deux ans après le début de la pandémie : ce sont des conséquences potentielles à court, moyen et long terme qui sont envisagées sur l’accès aux soins de certains patients, leur état de santé et leur qualité de vie, augmentant la dette santé populationnelle québécoise (21).

Dans plusieurs pays, des protocoles ont ainsi été envisagés ou mis en place, d’une manière plus ou moins systématique, pour faire face aux prises de décisions extrêmement difficiles auxquelles les soignants allaient être confrontés. Les protocoles de priorisation ont été perçus comme des moyens de guider les soignants par le biais d’une standardisation de la prise de décision qui soit la plus objective possible (22). Ces directives auraient pour buts de diminuer la variabilité, ainsi que de prévenir l’improvisation et les erreurs de jugement, afin de favoriser une allocation équitable des ressources basée sur des critères spécifiques, mesurables et fondés (22,23). Or, même si la nécessité du triage est reconnue, les réponses, opinions et pratiques diffèrent par rapport aux directives et protocoles à utiliser, et à la manière de les mettre en œuvre (24). Par contre, l’impératif d’efficacité, comme nous le verrons, semble prendre une place centrale dans cette pandéthique en tant que justification médico-centrée. Plus largement, il semble s’y joindre un autoritarisme de gestion de crise, propre à une logique de guerre critiquée plus loin d’ailleurs par Branicki (18). Comme le soulignent Bustan et al. (16), il semble que les conditions socio-sanitaires de pandémie aient précipité le délaissement d’une médecine personnalisée axée sur l’être humain malade, pour revenir vers une médecine populationnelle orientée vers le collectif. Les protocoles de priorisation des soins intensifs auraient-ils ainsi marqué le retour vers un paternalisme interindividuel et étatique social, politique et sanitaire) en santé publique qui avait pourtant laissé place au développement de la prise de décision conjointe et partenariale, et de l’approche centrée sur le patient? (25)

Orfali (24,26) a effectué une analyse comparative entre les réponses américaines et européennes aux protocoles de triage durant la COVID-19, et notamment, entre les réponses française et italienne. Elle s’est notamment penchée sur les raisons qui expliqueraient une si grande différence en termes de présence ou d’absence de débat public dans le passage entre éthiques. Nous pouvons croire que les questions de triage révèlent jusqu’à un certain point les valeurs, normes morales et idéaux préconisés par une société (24). Aux États-Unis, le passage d’une éthique « ordinaire » à « pandémique » aurait été beaucoup moins naturel et socialement accepté. Restreindre ou refuser des soins durant une urgence de santé publique semblait aller à l’encontre d’une culture médicale axée sur l’individualisme et l’autonomie du patient (26). En addition, un système de santé non universel présentant d’importantes inégalités structurelles aurait alimenté les préoccupations envers des protocoles qui pourraient exacerber la discrimination, sacrifier l’équité, ou encore être biaisés de jugements (26). La question du triage et de la prise de décision y a donc été largement médiatisée, transparente et explicite : elle a davantage été l’objet d’un débat ouvert, minutieux et multidisciplinaire, et a incité un engagement public (26). Des plans ont été préparés, puis modifiés selon les préoccupations. Dans ce contexte, le passage éthique aurait été plus remarqué, et ainsi, peut-on croire, potentiellement moins marqué.

Le modèle de la France et de l’Italie, quant à lui, se serait basé sur un plus grand paternalisme, mais aussi sur des systèmes de santé à protection sociale universelle reposant sur l’idée d’un accès égal aux ressources de santé (24). D’une part, les soignants seraient conçus comme les gardiens d’un tel système, les experts exclusifs sur lesquels devrait reposer la définition de la moralité et de l’acceptabilité des critères de triage, suivis par les autorités (24). De cette conception aurait, entre autres, découlé un grand manque de transparence, les directives de triage étant demeurées non publiques pour une longue période dans plusieurs pays européens (26). D’autre part, la majorité des pays européens se seraient fondés sur la conception selon laquelle une situation d’urgence et de pénurie dans un système de santé publique requière nécessairement de prendre des décisions de rationnement et de refus des soins vitaux, dans le but de préserver les ressources publiques (26). Il y aurait ainsi eu une absence générale de discussion et d’examen publics sur les enjeux éthiques soulevés par les protocoles de triage, et sur les valeurs servant à guider l’allocation des ressources. Le contraste du passage éthique semble y avoir été plus prononcé, mais le contexte a aussi possiblement influencé la légitimité qu’a pu avoir une telle éthique de la logique de crise. En France (mais aussi en Espagne et au Royaume-Uni), le système universel et le paternalisme axé sur le savoir expert « objectif » semblent avoir instigué, au commencement de la pandémie, une plus grande illusion de confiance de la part de la population. Par contre, ce modèle a aussi mené à un manque d’information du public, puis à une méfiance et à une frustration générale de sa part après coup (24). En Italie, des soignants qui ont publiquement évoqué les directives de triage variables, non centralisées et s’écartant des principes déontologiques ont été poursuivis par leur hôpital (24). L’approche paternaliste aurait dès lors été grandement rejetée par la société : « Les critères purement médicaux sont devenus moralement questionnables et socialement inacceptables; une quête pour une éthique de santé plus publique a émergé » (24, p.678).

Ainsi, ce qui aurait permis à des pandéthiques de s’implanter d’une manière plus coercitive pourrait potentiellement découler d’une combinaison des caractéristiques idéologiques et politiques du système de santé et de sa gouvernance, de la culture médicale prédominante, et plus largement des caractéristiques socio-culturelles situées. Le rapport social à une structure de soins axée en majeure partie sur le bien commun, et à une culture médicale non-marchande a pu influencer l’éthique socialement mobilisée. Bref, cette comparaison souligne l'importance du contexte dans lequel le passage a pu prendre place d'une manière plus ou moins marquée par rapport aux éthiques hors pandémie.

DÉBATS ET DILEMMES ÉTHIQUES DE L'ALLOCATION DES RESSOURCES ET DE LA PRIORISATION : LE RATIONNEMENT EN FONCTION DE L'ÂGE

Un grand nombre d'autorités et d'auteurs cliniciens ou éthiciens se sont exprimés sur la question de la priorisation pandémique, dans le cas où le nombre de patients nécessitant une hospitalisation aux soins intensifs excéderait de manière extrême les capacités du système de santé. Pour plusieurs d'entre eux, l'approche de triage nécessaire, évidente, ou même la seule possible devait être une approche bioéthique, plus précisément une éthique de santé publique basée sur une logique rationnelle et utilitariste (10,16,18). Avant de pouvoir jeter un regard sur les enjeux, conflits et implications sous-tendus par ces approches, il est nécessaire de faire un état des lieux de ces dernières et des explications éthiques qui ont été mises de l'avant pour les justifier.

Les objectifs de protocoles établis sur la base des approches pandéthiques utilitaires accordent au premier plan la priorité aux personnes ayant les plus grandes chances de survie à une hospitalisation aux soins intensifs (22), ou encore le meilleur avantage estimé du traitement (10). Cette rationalité coût-bénéfice inclut également l'objectif de sauver le plus de vies (ou d'années de vie) possible, d'allouer les ressources en priorité à ceux qui ont une plus grande durée de vie restante (23), et de maximiser les bénéfices communs pour le plus grand nombre (10,27). Le principe de maximiser le nombre d'années de vie restantes permettrait en effet, pour un état, de réduire la charge de morbidité ou le fardeau de la maladie d'après le calcul de DALYs (*disability-adjusted life years*). Selon cette méthode, les années de vies perdues au début de celle-ci auraient plus de poids que les années perdues plus tard dans la vie (15). Ainsi, parmi de telles approches, le critère de l'âge est parfois envisagé, parfois même explicitement nommé comme facteur permettant de guider la prise de décision du triage. En Italie, l'un des premiers pays européens à avoir été frappé par le virus, les directives de priorisation indiquaient qu'« il pourrait être nécessaire, ultimement de fixer un âge limite pour l'admission en soins intensifs » (24, p.677). Au plus fort de l'épidémie, les patients de 65 ans et plus n'étaient souvent plus considérés pour l'accès à un respirateur, les décisions étant basées sur la date de naissance du patient (26). Ce facteur temporel s'est imposé comme évident et facilement observable par rapport à d'autres, dans le cas de décisions critiques et rapides (17). En France, lors du congrès Question(s) d'éthique 2020 – « La justice entre générations », la pertinence du recours au critère de l'âge pour l'accès aux ressources de santé limitées a été mise de l'avant, non seulement comme bon prédicteur de l'efficacité thérapeutique, mais également comme bon redistributeur de longévité, permettant d'égaliser les durées de vie des individus (28). Dans la pratique, des mesures de triage informelles et non publiques ont été appliquées dans le contexte pandémique français afin d'établir un seuil d'âge pour refuser l'accès aux soins intensifs (et même parfois l'accès à l'hôpital) aux plus âgés dans les régions les plus touchées (24). Ces pratiques ont notamment été appliquées pour les résidents d'EHPAD (établissement d'hébergement pour personnes âgées dépendantes) âgés de plus de 60 ans auprès desquels un système de pointage (L'AGGIR : Autonomie Gérontologique Groupes Iso-Ressources) était utilisé en amont par le SAMU (Service d'Aide Médicale Urgente) afin de permettre ou refuser le transfert, en se basant sur une évaluation de l'autonomie et de la dépendance du patient âgé. La pratique de ne pas transférer en hôpital certains patients atteints de la COVID-19 pour des raisons liées à l'âge ou au handicap, ainsi que l'absence de protocoles jugés clairs pour assurer l'égalité d'accès aux ressources de santé ont été critiquées et menées en appel devant le Conseil d'État par plusieurs associations représentantes d'EHPAD et de personnes en situation de handicap (24).

Au Québec, malgré la stipulation que l'âge ne peut être utilisé comme critère discriminatoire, le protocole en cas d'égalité clinique se base en premier lieu sur le critère du cycle de vie, une règle de décision qui repose sur l'idée que chaque personne devrait avoir la possibilité de vivre toutes les étapes de sa vie (22). Ce critère prioriserait ainsi, dans une situation donnée, les patients présents qui se trouvent à un stade de vie relatif moins avancé, c'est-à-dire les plus jeunes, par rapport aux plus âgés. Une telle règle de décision permettrait notamment d'éviter une situation du « premier arrivé, premier servi ». Dans un même ordre d'idées, Haas et al. (10), médecins intensivistes néerlandais, se sont questionnés à savoir s'il faudrait refuser l'admission aux soins intensifs pour les personnes âgées en temps de COVID-19. Selon eux, l'utilisation du critère de l'âge en situation de capacité et de ressources limitées serait justifiée par l'argument éthique du « *fair innings* » qui s'appuie sur l'idée que tous auraient droit à une durée de vie normale ou raisonnable (10,29). Les plus jeunes auraient donc davantage le droit d'être priorisés dans la distribution de ressources vitales que les personnes plus âgées, sur la base que les premiers ont eu moins d'opportunités d'expériences de vie et d'épanouissement que les aînés (29). Selon ce modèle, il s'agirait d'une question d'égalité des chances, d'équité (10,22,29). Par contre, il convient de s'interroger sur la pertinence et la signification que revêt le terme « normal », utilisé ici pour caractériser la durée de vie. Une telle normalité peut être considérée universelle ou relative, fixe ou figée à travers le temps ou l'espace. Mais elle comporte aussi plusieurs facettes telle la qualité de cette durée de vie normale ou raisonnable, ajoutant à l'ambiguïté de sa définition et de son applicabilité. De plus, cette égalité d'opportunités d'expériences de vie et d'épanouissement peut-elle réellement être équitable si elle ne prend pas en compte l'impact des inégalités incorporées et des déterminants sociaux de la santé sur le cycle de vie (30,31)? Le statut, les facteurs socio-économiques, ethniques, éducationnels, ou familiaux, ont également des effets sur l'égalité des chances discutée, ainsi que sur l'épanouissement, la santé, et les conditions de vie des individus jeunes ou moins jeunes. La solution jugée la plus équitable pour et par le groupe dominant, selon ses normes, valeurs, objectifs et conceptions, peut être inéquitable pour les groupes non dominants. Il convient de s'interroger si la poursuite du plus grand bénéfice commun dans un contexte de crise sanitaire puisse donc inévitablement exacerber les inégalités, et, comme nous le verrons plus loin, accorder une valeur différentielle aux individus selon leur utilité perçue, leur marginalisation sociale, et leur vulnérabilisation.

D’une manière complémentaire, la pandémie met en lumière le dilemme de la distribution des ressources en santé, en lien avec la gestion des coûts, mais aussi le vieillissement de la population. Ce débat date de bien avant la pandémie et a continué d’être un sujet préoccupant face à la forte consommation des ressources médicales pendant la crise, et à la médiatisation de la peur envers l’atteinte du point de rupture du système de santé (12). Dans les médias québécois, il a été question de s’interroger s’il fallait encore tenter de traiter des patients de 80 ans et plus atteints de la COVID-19, si cela signifiait que le traitement des plus jeunes en serait affecté (12). Des médecins ont demandé « s’il était opportun de déployer autant de ressources hospitalières pour sauver des gens qui étaient susceptibles de mourir dans un avenir rapproché, COVID-19 ou pas » (12). Or, il semble se présenter une différence éthique fondamentale entre l’argument de la normalisation du triage, déjà effectué au quotidien selon les capacités physiques des patients leur permettant ou non de soutenir des soins intensifs ; et le critère du cycle de vie, justifiant la discrimination non médicale de la personne selon son âge plus avancé. Ne pas prolonger la vie pour éviter l’acharnement médical et des soins jugés non pertinents au bien-être de la personne très âgée et malade ne s’appuie pas sur les mêmes principes et valeurs que la justification de ne pas prolonger la vie sur fond de répartition des ressources médicales selon l’âge, et de droits différentiels au soin.

Nous pouvons tracer un parallèle entre cette perspective et l’approche basée sur les capacités décrite par la bioéthicienne américaine Nancy Jecker (32), inspirée des travaux de Nussbaum. Jecker positionne cette approche comme une manière de pallier le problème de l’allocation des ressources de santé entre les groupes d’âge, alors que le vieillissement de la population poserait des enjeux éthiques (mais aussi économiques) à une juste distribution des soins entre les jeunes et les aînés. Jecker s’appuie sur Callahan (33) pour soutenir qu’« une bonne société aurait l’obligation d’aider les plus jeunes à devenir vieux, et non d’aider les plus vieux à vieillir indéfiniment » (33, p.12). La société aurait donc le devoir de maintenir les capacités fondamentales des individus au seuil requis pour la dignité humaine. Dans ce cas, selon Jecker, il serait alors justifié de refuser de prodiguer des soins prolongeant la vie à ceux qui ont atteint la durée de vie ou l’espérance de vie « normale », correspondant au seuil considéré suffisant pour la « capacité de la vie », et donc la dignité humaine. Cette idée de durée de vie dite normale ou naturelle nous rappelle d’ailleurs l’idée de Callahan des années 1980 énoncée plus tôt, en lien avec la perte du sens sociétal d’une durée de vie normale et significative (13). Capitaine et al. ont, par contre, soulevé un conflit quant à la justification économique de cette approche : « une politique excluant les personnes âgées des soins de prolongation de la vie n’aurait qu’un potentiel limité de réduction des coûts des soins de santé » (34, p.22). Mais qu’est-ce que cela semble dire sur le traitement des personnes âgées ou plus vulnérables? Il convient de se questionner si une telle éthique avait le potentiel non seulement d’attacher une valeur économique, mais aussi une temporalité à la dignité, accordant ainsi une valeur différentielle aux vies et aux temps de la vie selon l’âge. Il semble dangereux d’insinuer qu’il n’y aurait plus de seuil de dignité à assurer pour les patients de 80 ans et plus, résidant en CHSLD par exemple. Qui plus est, des justifications politico-économiques de réduction des coûts peuvent-elles se cacher derrière les justifications médicales invoquées afin de ne pas prodiguer de soins prolongeant la vie? Les questions du cycle de vie, de la futilité des traitements pour une personne en fin de vie, du non-acharnement peuvent-elles être instrumentalisées à ces fins?

Dans ces contextes, d’autres voix se sont élevées pour montrer la discrimination et l’exclusion que de telles justifications éthiques pourraient engendrer. Un des enjeux principaux du triage réside ainsi dans la discrimination sur la base de l’âge (16), sous des formes, justifications, ou dénominations variées. La création de tels protocoles, mettant l’accent sur l’utilité et l’efficacité, risquent d’aborder la prise de décision en temps de pandémie d’une manière extrêmement théorique, mécaniste, et désengagée de la réalité singulière, du sens et de la valeur de la vie humaine (17). Qu’est-ce que l’acceptation de la priorisation et du rationnement selon l’âge et selon les principes d’efficacité et de durée de vie raisonnable indique de nos éthiques et moralités sociétales, en contexte de rareté? Sommes-nous en train de nous rapprocher, soignants et société, d’une politique prônant un idéal collectif utilitariste plutôt que d’une éthique de la préservation de la vie et du bien-être de l’individu sans discrimination? La pandémie semble justement avoir révélé que préservation de la vie et du bien-être ne pouvaient être compatibles – mais est-ce réellement ce que nous désirons pour notre société? Indépendamment de la situation de crise sanitaire, nous devons aujourd’hui faire face à l’augmentation des technologies, des procédures coûteuses pour repousser la vie, mais aussi à l’augmentation de l’espérance de vie et de la population vieillissante. Serons-nous prêts à utiliser ces raisonnements et éthiques pandémiques pour gérer les coûts de santé, pour répartir et rationner les soins hors pandémie? L’approche utilitariste est souvent utilisée sur la base que la pandémie est une situation exceptionnelle, urgente. Or, pour les bioéthiciens britanniques Parsons et Johal (27), si dans une telle situation la maximisation des biens pour le plus grand nombre de personnes permet de justifier le fait de ne pas nécessairement prendre en compte le meilleur intérêt du patient individuel, il peut risquer de dévaloriser la vie des patients, notamment ceux qui ne sont pas en mesure de prendre leurs propres décisions de soin, et d’éroder leurs droits sur le long terme. Cet enjeu met en lumière la tension que pose l’équilibre entre l’efficacité/l’équité, et les droits individuels au travers d’une éthique de pandémie.

Brabant, spécialiste en éthique et en droit de la santé, et Johnson, avocate, dénoncent d’ailleurs le risque que les critères de protocoles de triage excluent les plus fragilisés, leur associent une valeur moindre, et exacerbent les préjugés sociaux et la discrimination structurelle à leur égard (35). Elles soulèvent le paradoxe de ce que l’approche éthique dominante et choisie par notre société révèle, vu la nature des soins intensifs en milieu hospitalier, où se sont concentrés les efforts pandémiques : nous avons pris la décision, non pas d’accorder la priorité au plus malade, mais bien à celui en meilleure santé (35).

Selon les bioéthiciens australien et canadien Silva et Smith (36), il semble donc que la conception de l’impératif de sauver le plus de vies possibles l’ait emporté en pandémie sur d’autres considérations éthiques comme les préoccupations de justice sociale pour les plus marginalisés, vulnérabilisés, malades ou dans le besoin. Silva et Smith relèvent le risque de la surutilisation du principe d'utilité et de la maximisation des bénéfices des ressources, particulièrement pour ces groupes d'individus et notamment pour les aînés. À l'opposé, le bioéthicien australien Kirchhoffer explique pourquoi, dans le contexte de la COVID-19, refuser de donner un traitement souhaité par le patient et pouvant lui bénéficier serait « moralement bien » (37). Il se base sur le principe selon lequel la justice peut, dans ce cas, prendre le dessus sur l'autonomie. Ainsi, selon sa conception, dans un temps de rareté de ressources, il serait justifié de considérer que la dignité d'autres personnes concrètes (non hypothétiques) prenne le dessus sur la dignité de l'individu. Le principe de justice pourrait donc être évoqué pour justifier le rationnement, ce qui peut inclure de refuser ou de retirer un traitement potentiellement bénéfique à un patient, pour le bien des autres (37). En comparant ces deux positions, il semble clair que le principe de justice même, et de ce qui constitue une décision moralement « bonne » ne présentent pas la même signification au travers de la pandémie. Pour Brabant et Johnson, la maximisation de l'utilisation des ressources dans la crise sanitaire représente non seulement un préjudice pour les droits individuels et la justice à ce niveau, mais elle représente également un risque d'érosion des principes sur lesquels repose notre culture médicale : « il s'agit ici d'un renversement majeur de l'approche universelle et égalitariste prévalant dans notre système de santé (…). Le droit individuel de recevoir des soins médicalement requis s'amenuise au profit du “bien commun” » (35).

Dans le cadre d'un modèle utilitariste, les ressources limitées vont d'abord aux patients dits efficaces. À l'instar de Bustan et al. (16), cela signifie-t-il que le soin devrait seulement être donné à ceux qui ont une valeur instrumentale, à ceux dont la vie est la plus « efficace », voire « utile » pour la société d'un point de vue strictement politico-économique? Brabant et Johnson soulignent le paradoxe entre les mesures de confinement, orientées vers la protection des plus vulnérables, et les protocoles conduisant à l'exclusion, en raison de cette même vulnérabilité, de ceux qui auraient moins de chance de se rétablir rapidement (35). Par contre, nuançons que ces mesures de confinement ont également représenté une tentative d'éviter la confrontation à une situation de triage où ces mêmes personnes risqueraient de ne pas être priorisées. Or, à ce sujet, il est révélateur de se pencher sur la valeur différentielle associée aux différents types de vulnérabilité selon l'âge. Le protocole de priorisation du gouvernement du Québec pour l'accès aux soins intensifs des adultes en contexte extrême de pandémie (22) se base entre autres sur une attribution des ressources aux patients adultes présentant les meilleures chances de survie, les meilleurs pronostics vitaux et paramètres cliniques : autrement dit, les patients les moins vulnérables. Le protocole spécifique aux enfants, quant à lui, indique que puisque la population pédiatrique est l'une de nos populations les plus vulnérables, nous avons la responsabilité morale et légale en tant que société de défendre leurs intérêts (38). Paradoxalement, le protocole choisi afin de guider la prise de décision indique la nécessité de protéger et de prioriser une population pédiatrique spécifiquement, car elle est vulnérable ; alors que le protocole général aux adultes ne prévoit pas protéger en priorité une population gériatrique, parce qu'elle est aussi vulnérable. Ainsi, la vulnérabilité peut être mobilisée pour différents arguments, mais les différents types de vulnérabilités ne revêtissent pas la même signification, la même valeur, et ne provoquent pas la même protection selon le type de citoyen auquel il renvoie, et la valeur socioculturelle associée à son groupe.

L'utilisation du terme « vulnérabilité » mérite d'être précisée afin de limiter la reproduction d'une catégorisation essentialisante et homogénéisante des personnes âgées, ou une association automatique de la vulnérabilité comme caractéristique inhérente à la vieillesse. Ici, la vulnérabilité est traitée dans le contexte épidémiologique, physique et sanitaire de la COVID-19, et est donc associée au potentiel plus élevé de développer des complications graves de la maladie chez les personnes plus âgées, entre autres en CHSLD. Elle est également considérée dans le contexte organisationnel, structurel et politique des CHSLD, notamment en termes d'accès aux soins ou d'isolement social pour leurs occupants. Finalement, la vulnérabilité est comprise dans ses dimensions socio-culturelles potentiellement dévalorisantes, invisibilisantes, marginalisantes ou stigmatisantes associées à l'âge, au regard, entre autres, des conditions de vie des individus et groupes sociaux. On parle donc d'un processus de vulnérabilisation, de construction de formes de vulnérabilités au sein de notre société, d'où la pertinence de l'exercice de « penser la vulnérabilité » (39-43). Dans ce contexte pandémique, la santé, l'autonomie, la dignité et l'intégrité des personnes plus âgées ont alors le potentiel d'être menacées, notamment en milieu de CHSLD (44).

LA SITUATION DES PERSONNES ÂGÉES : ÂGISME ET COVID-19

Au travers de la pandémie, des discours, des choix, et de leurs conséquences émerge donc la question de la manière dont les membres les plus âgés de notre société sont traités. Glaser et Strauss (45) relevaient déjà, dans les États-Unis des années 1960, que la perte sociale du patient mourant était grandement influencée par son âge, jauge de sa valeur et de sa contribution sociale. L'âge est une caractéristique apparente qui avait tendance à affecter le niveau de soin reçu en retour, ainsi que les discours et logiques utilisés pour justifier la mort du patient (45). La perte de patients âgés était alors considérée plus faible que celle de jeunes patients, illustrant la valeur différentielle associée aux individus et à leur mort. Force est de constater qu'au travers de la pandémie, nous sommes également amenés à nous questionner sur l'âgisme qui semble continuer, encore aujourd'hui, d'être « un préjudice socialement acceptable, au point d'être meurtrier », dans les mots de Margaret Morganroth Gullette, spécialiste américaine des études sur l'âge (46). Cet âgisme semble teinter la négligence profonde et durable de nos autorités et institutions, mais également le désengagement de la société envers les aînés,que ce soit dans la prise de décision des pouvoirs publics ou dans la manière de traiter et d'aborder l'atteinte des personnes âgées et de leurs milieux en soin de longue durée (47,48). En effet, malgré la publication d'articles médiatiques sur la situation des personnes âgées, non seulement la documentation et la médiatisation des morts n'ont-elles pas reçu le même traitement selon l'âge, mais la pandémie, et son discours public inquiétant sur le vieillissement, a rendu flagrante et a propulsé au premier plan l'altérisation des personnes âgées et des personnes les plus vulnérables de notre société (47). En regard à ces pratiques, il semble que les aînés n'aient pu être considérés comme des membres à part entière de la société (46).

Cet âgisme est également perceptible dans la voix rarement écoutée et considérée des personnes âgées dans la prise de décision, ou encore dans l'attitude sociale nihiliste qui se traduit par la conception que leur mort serait de toute manière imminente (49). Les personnes âgées atteintes de maladies chroniques ou de conditions de santé susceptibles d'augmenter le risque de développer des complications graves à la suite d'une infection ont été, certes, les premières victimes de la COVID-19 (49). Mais ces morts, dont 81 % ont eu lieu en soin de longue durée au Canada comparé à une moyenne de 38 % au sein des pays de l'OCDE, étaient prématurées, non naturelles, et auraient en grande partie pu être prévenues (46). Au travers d'elles, ce sont les façons de mourir qui sont fortement mises en cause : comment la mort s'est-elle déroulée, dans quelles conditions, sur la base de quelles justifications, et en mobilisant quelles valeurs ou moralités? En établissement de soin de longue durée, nombre de résidents ont été laissés à eux-mêmes, affamés, déshydratés, désorientés, avec une protection d'incontinence souillée depuis des jours, et côtoyant à la fois des patients positifs et négatifs à la COVID-19 au sein des mêmes espaces (49). Des personnes âgées sont décédées presque toujours seules, sans voir leur famille, sans médication, souvent sans pouvoir obtenir de soins médicaux, ni de soins palliatifs et de confort (16,49). Le rapport du Protecteur du citoyen, rendu public le 23 novembre 2021, a notamment permis d'émettre des constats et recommandations sur la gestion de la crise due à la COVID-19 dans les CHSLD durant la première vague de la pandémie (51). Ainsi, au même moment que temps et énergie ont été investis dans l'établissement de protocoles de « médecine de guerre », que l'hôpital et le ministère de la Santé se sont préparés à faire face à la pandémie, des personnes ont été laissées à mourir dans des conditions inhumaines, dans des établissements non préparés, désorganisés et en pénurie de personnel. « Comment est-il possible qu'aujourd'hui, au Canada, des patients soient traités de façon aussi inacceptable? Est-il concevable que des personnes âgées vulnérables, souffrant parfois de démence ou de mobilité réduite, se trouvent ainsi livrées à elles-mêmes? », s'indigne Picard (49). Se révèle en parallèle un autre type de prise de décision en situation de crise : en choisissant d'exclure et d'isoler les plus à risque pour leur « sauver la vie, on a coupé le lien de vie », les privant d'une partie de leur identité, donnant un « coup mortel à [leur] humanité » (52, p.145).

Une éthique de la santé publique n'aurait-elle pas, ainsi, échappé ces catégories de citoyens, mais plus encore, ne leur aurait-elle pas manqué, par une insouciance collective que plusieurs traduisent en un échec éthique, voire même de géronticide (46,52)? L'impact de la pandémie et des vulnérabilités systémiques semble avoir été sous-estimé en CHSLD, reconnu pourtant comme maillon faible du système. Ces conditions structurelles en CHSLD et les défaillances du système de la santé se sont développées à partir de décisions d'ordre politico-économiques, du bouleversement et des réformes de la gouvernance, des coupes budgétaires, de la centralisation et de la privatisation croissance des services pour personnes âgées en perte d'autonomie (52). Mais elles sont également révélatrices des valeurs sociales et culturelles, du consentement, ou peut-être même de l'indifférence qui aurait permis à ces choix de s'enraciner au niveau sociétal. Pour Picard, un changement d'ordre philosophique s'impose. Car si le rationnement semble être une approche habituellement culturellement acceptée pour des sociétés basées sur la compétitivité et la méritocratie (16), les soins de longue durée et à domicile, eux, nécessitent de se déplacer vers une approche fondée sur les droits des individus (53). Dans la pandémie, nombre de patients et de familles n'ont pu obtenir leurs justes droits, notamment le droit d'honorer le patient mourant et sa mort, le droit à la dignité et le droit de ne pas être abandonné au moment du décès (16). Qui plus est, Fraser et al. craignent que dans le contexte de la COVID-19, l'âge soit de plus en plus confondu avec la fragilité et les comorbidités, risquant de devenir un facteur décisionnel dans la priorisation des vies (47). En amenant à penser que la vie d'une personne âgée ait moins de valeur que celle d'une personne plus jeune, et puisse être sacrifiée, cette conception aurait le potentiel d'affecter le système de santé sur le long terme (47). La pandémie met en lumière la manière par laquelle les personnes âgées demeurent trop souvent invisibilisées, alors que des décisions sont prises pour elles, en faisant fi de leur agentivité, de leurs perspectives et points de vue, et sans leur demander ni écouter leur avis. Elle montre par ailleurs que la place de la délibération éthique semble intimement liée à la valorisation socio-culturelle du sujet qui est jugé méritant ou non d'une réflexion éthique collective sur son sort, sur ses vies.

DÉCISIONS ET CHOIX ÉTHIQUES MORALEMENT DIFFICILES : *DUTY TO CARE* ET BLESSURE MORALE DES SOIGNANTS

Ainsi pouvons-nous concevoir les blessures infligées aux personnes âgées dans le processus décisionnel de pandémie. D'une manière additionnelle, les éthiques multiples et parfois conflictuelles présentent des implications importantes auprès des soignants. Ces implications nous informent à leur tour sur les dilemmes incorporés dans la prise de décision, ainsi que sur la manière dont la pandémie et ses choix éthiques difficiles s'entremêlent au *duty to care* (devoir de prendre soin) du soignant, et par conséquent, à la possibilité de blessure morale professionnelle (*occupational moral injury*), aussi appelée préjudice moral.

Pour Sheahan et Lamont (54), la pratique dite éthique en pandémie requerrait du soignant de comprendre et de trouver l'équilibre entre trois niveaux de son devoir de prendre soin : le « *duty of care* » légal de donner un standard de soin raisonnable prévenant les dommages dits raisonnablement prévisibles au patient ; le « *duty to care* » professionnel d'agir dans le meilleur intérêt du patient (un concept complexe et parfois contesté) et ce, même lorsque le risque personnel et les pratiques professionnelles sont transformés ; et finalement, le « *duty to self* » personnel, prenant en compte le soignant comme agent moral individuel ayant des obligations et devoirs personnels et familiaux (54). Mais cette proposition de taxonomie cache un processus complexe, singulier, en mouvance, qui n'est pas sans exercer une pression considérable sur les soignants, sur lesquels reviendrait la responsabilité d'équilibrer éthiquement leurs devoirs en concordance avec les directives et protocoles éthiques établis par les autorités et institutions. Dans le contexte de pandémie nait donc une incertitude par rapport à la manière pour le soignant de positionner, d'adapter et de comprendre le concept de *duty to care*, au cœur de la pratique clinique, de la compréhension de soi et de ses obligations (54). Alors que l'accent sur le patient individuel malade se déplace vers un accent sur l'efficacité collective d'urgence et le bien commun de santé publique, le soignant doit arriver à naviguer au travers de la hiérarchisation de son *duty to care*, et du changement de sa propre perception de son devoir (54). Il doit également naviguer au travers du bouleversement de l'équilibre habituel entre ses devoirs légaux, professionnels, mais aussi ses obligations et responsabilités personnelles, dans une situation où il se met plus à risque.

Ces risques moraux, infectieux ou même mortels encourus par les soignants dans ce contexte posent le défi supplémentaire de déterminer quelle est la limite du *duty to care*. Alors que certains soutiennent qu'un tel devoir représente un engagement professionnel dit « illimité » (55) d'autres soulèvent les dangers d'une telle approche d'héroïsation des soignants. Bien que les frontières concrètes du devoir soient en elles-mêmes logistiquement et philosophiquement difficiles à tracer, le fait de ne pas reconnaître la limite personnelle du *duty to care*, et ce, même en situation de pandémie, mettrait l'accent principal sur l'idée du sacrifice altruiste réalisé par le soignant, une conception exerçant sur eux une pression colossale (56). Cette conception écarterait aussi les obligations et devoirs sociétaux nécessaires afin de fournir le soutien, les conditions et les ressources nécessaires à l'exercice du soin et à la réalisation de ce devoir (56). Pour Selgelid (15), ce *duty to treat* en pandémie ne devrait pas être absolu et devrait dépendre de l'efficacité de l'intervention ou du traitement. En contrepartie, une telle explication basée sur la condition d'efficacité pourrait-elle se révéler problématique en milieu de CHSLD? Pourrait-elle être utilisée pour justifier l'absence de traitement ou de care, sur la base que les résidents « allaient mourir de manière imminente, peu importe »? Ainsi, choisir devient le premier devoir dans une situation où l'équité semble être difficile à appliquer, les valeurs socialement acceptées semblent pouvoir être renversées, et une hiérarchie, ou du moins une tension, semble s'imposer entre le *duty to care* et la logique d'efficacité d'une éthique de santé publique. Car, dans ce cas, la collectivité est conçue comme primant sur les intérêts individuels du patient singulier (57,58), comme si, nous le rappellent paradoxalement Bustan et al., la collectivité n'était pas en réalité constituée de ces mêmes individus (16).

Les diverses propositions et approches éthiques, directives et protocoles d'allocation de ressources et de prises de décision semblent donc pouvoir induire un conflit potentiel au niveau du *duty to care* des soignants, duquel des blessures morales professionnelles peuvent découler. Peu de recherches ont été conduites jusqu'à présent sur la blessure morale hors du champ militaire, mais la COVID-19 a mis en lumière la pertinence du concept, spécifiquement pour les professionnels de la santé. C'est surtout l'angle de la détresse morale qui, jusqu'ici, a fait l'objet d'un corpus important de recherche en soins infirmiers et chez les soignants (59-62). Développé par l'éthicien américain Andrew Jameton dans les années 1980, puis repris par l'infirmière clinicienne Judith M. Wilkinson, le concept de détresse morale renvoie aux effets psychologiques négatifs vécus par le soignant lorsque des obstacles ou contraintes organisationnelles l'empêchent de poser ce qu'il considère comme la bonne action ou de prendre la bonne décision morale dans une situation donnée (63-65). Si elle n'est pas surmontée, la détresse peut causer des blessures morales durables, notamment lorsque le soignant est confronté à d'importants stresseurs moraux ou évènements préjudiciables sur le plan moral (PMIE). En effet, l'incapacité à accomplir son *duty to care*, ainsi qu'à prévenir la mort ou la souffrance par manque de ressources, additionnées des conflits moraux entre des valeurs tenues comme sacrées, personnellement ou professionnellement, peut mener le soignant à ressentir des niveaux exceptionnels de culpabilité, de honte, d'impuissance, de démoralisation ou d'incertitude après coup (62,66). Cette blessure morale peut survenir même si le soignant comprend ce que la situation requière en contexte de ressources limitées, et même s'il respecte le protocole et les directives désignés par les institutions. En effet, ses actions, son inaction et les actions des autres peuvent transgresser et violer ses propres valeurs morales profondément ancrées, les normes éthiques médicales partagées (telles que de ne pas causer de tort) ou encore les normes éthiques sociales face aux comportements qui sont attendus de lui-même ou des autres (67). La collaboration habituelle avec les patients ou leur famille dans la prise de décision médicale présente également d'énormes difficultés dans le contexte de la COVID-19. Plusieurs soignants en contexte américain, telle que Dre Krishna Chokshi du Mt. Sinaï Hospital de New York, témoignent du lourd fardeau moral de devoir prendre des décisions difficiles et rapides pour les autres, notamment pour des patients non représentés, marginalisés et dans l'incapacité d'exprimer leurs souhaits : des moments d'incertitude clinique et morale qui, selon eux, leur laisseront des marques indélébiles (68). Sur le long terme, ces blessures morales découlant de la confrontation à des décisions et pressions semblant impossibles à surmonter, ainsi qu'à des évènements potentiellement préjudiciables sur le plan moral peuvent en effet laisser le soignant avec des souffrances émotionnelles, sociales, psychologiques ou spirituelles, ainsi que des impacts comportementaux durables (66,67). Ces évènements peuvent affecter les relations interpersonnelles du soignant, sa qualité de vie, ainsi que sa santé mentale, notamment en augmentant le risque de stress post-traumatique et d'épuisement professionnel (62,67). Selon certains, le système de santé pourrait être affecté par une potentielle transformation des intuitions morales quotidiennes des soignants (67). Le soignant peut ainsi voir sa pratique, ses présupposés habituels et son identité ébranlés et remis en question par les contradictions entre croyances personnelles, devoirs moraux, éthiques prescriptives, et réalités de la pandémie.

APPROCHES ET ÉTHIQUES ALTERNATIVES EN CONTEXTE PANDÉMIQUE ET AU-DELÀ

Face aux dilemmes et limites dont il a été question dans la gestion rationnelle de la crise sanitaire, des approches et éthiques alternatives ont été proposées par différents auteurs. Elles font figure de manières distinctes de complémenter, critiquer ou même repenser les éthiques médicales utilisées (mais aussi leurs présupposés et visées) à l'occasion de la pandémie, et à l'avenir. Pour Marshall et Koenig (8), ces nouveaux paradigmes conceptuels ont l'avantage de privilégier l'importance des relations sociales et du contexte afin de mieux saisir les dilemmes éthiques, et de réunir les approches anthropologiques et bioéthiques dans l'analyse des situations complexes.

Dans un premier temps, Doucet écarte les modèles de santé publique principistes qui lui paraissent obsolètes à la lumière de la pandémie, et surtout face à la réalité des soins de longue durée (52). Ces modèles s'appuient sur des principes fondamentaux développés par Childress et Beauchamp (69), devenus dominants en éthique médicale afin de guider l'action et la prise de décision : le respect de l'autonomie de la personne, la bienfaisance, la non-malfaisance, et la justice (25,70,71). Or, ces principes dits trop généraux ou universalistes ont été critiqués, notamment puisqu'ils auraient le potentiel de conduire à une application mécaniste des règles éthiques qui en découlent (25,70,71). L'anthropologue Raymond Massé (71) a proposé de bonifier ces principes de valeurs phares, dans le but d'en faire un cadre de référence adapté aux enjeux éthiques de santé publique (25). Qui plus est, Massé s'appuie sur une conception habermassienne de l'éthique de la discussion pour nuancer la validité morale de ces principes et valeurs phares, qui ne serait pas donnée, mais nécessiterait plutôt une construction dans la praxis entre les acteurs concernés, dans un espace de discussion ouvert (71). Ainsi, Massé rappelle que « l'éthicien, pas plus que les autres acteurs, n'a un accès privilégié au juste : seule la discussion peut fonder l'acceptabilité rationnelle des normes éthiques » (71, p.32). Doucet fait suite à cette proposition discursive, en réfléchissant au modèle éthique à choisir face au principisme ayant guidé les responsables en santé publique dans leurs décisions, et en réponse aux enjeux éthiques mis en lumière par la pandémie en CHSLD. Un tel modèle devrait non seulement être orienté vers une reconnaissance de la vulnérabilité de ces centres, mais aussi vers une réponse à celle-ci, fondamentale à l'accompagnement des personnes âgées en perte d'autonomie (52). Doucet met donc de l'avant le modèle d'une éthique de la vulnérabilité, prônant l'engagement collectif, ainsi qu'une augmentation du sens de responsabilité collective envers les personnes les plus vulnérables. Elle viserait à apporter l'aide et la solidarité communautaire nécessaires à la création d'une réponse éthique plus adaptée à la réalité actuelle des soins de longue durée. Celle-ci permettrait de pallier la réponse éthique mobilisée par les autorités et institutions dans leurs décisions, qui n'aurait su satisfaire les exigences éthiques de la réponse à la vulnérabilité et du respect de la dignité (52).

D'une manière concordante, dans le contexte australien, Branicki (18) s'accorde pour dire que la gestion sociétale de crise est essentielle pour protéger la vie des personnes les plus vulnérables. Par contre, les décisions prises et leur approche éthique décisionnelle exacerberaient trop souvent les marginalisations déjà en place, en plus d'en créer de nouvelles. S'inspirant des travaux de Gilligan (72,73), Branicki s'appuie sur les éthiques du *care* féministes pour critiquer les techniques dominantes de gouvernance sociétale de gestion de crise rationaliste et néolibérale. Celles-ci sont axées sur la norme de la citoyenneté indépendante, ainsi que sur la notion d'individu libéral, écartant l'attention aux connexions interdépendantes et aux relations humaines socialement et politiquement situées, des sites de *care* soutenant les vies (72,74-76). Une conception féministe du *care* permettrait de mettre en lumière, et surtout de remettre en question, de tels présupposés normatifs et de telles éthiques de gestion de crise. Ceux-ci sont caractérisés par une logique utilitaire, linéaire, ainsi qu'un langage masculin et militariste privilégiant le quantifiable, par la mise en exergue de ressources et de résultats mesurables (18). Non seulement de telles conceptions et techniques permettraient-elles de renforcer les hégémonies existantes, mais elles seraient également sujettes à négliger de considérer les désavantages structurels préexistants (18). Branicki appelle donc à une mobilisation des voix féministes du *care* afin de résister à ces logiques, et de faire la promotion d'une gestion de crise ou de pandémie qui serait ainsi fondée centralement sur des préoccupations de soin, en liant crise, *caring*, relations sociales et responsabilité sociale.

En référence aux travaux de Joan Tronto et de ses « *moral boundaries* », le *care* découlerait de l'interdépendance humaine continuelle entre autonomie et vulnérabilité, et du fait que tous les êtres humains n'auraient pas la même capacité, à tout moment, de prendre soin d'eux-mêmes (77). Les êtres humains se déplaceraient ainsi à travers quatre phases du *care* : se soucier de (*caring about*), prendre soin de (*taking care of*), donner des soins (*care-giving*) et recevoir des soins (*care-receiving*) (77). À partir de celles-ci, il est possible de concevoir une éthique du *care* composée d'attention, de responsabilité, de compétence et de réactivité, ainsi que de donner aux activités du *care* la place centrale, indispensable et quotidienne qu'elles requièrent au sein de la vie de chaque être humain. Plaider pour une valorisation et une reconnaissance du *care* nécessite une réévaluation et une transformation de notre conception des frontières morales, ainsi qu'une considération du *care* dans son contexte politique, non seulement comme attitude morale, mais comme idéal politique (77). En mettant l'accent sur des dimensions interactionnelles et sociopolitiques du soin en contexte de COVID-19, les éthiques du *care* et féministes soulèvent l'importance des questions de dignité, à travers l'engagement et la confiance impliqués dans le partenariat thérapeutique et sociétal (8,16). Les relations sociales interdépendantes y occupent une place centrale en tant que sites de soin entre soi et autrui, favorisant la reconnaissance et la réponse au besoin (18). Cette tendance vers l'idéal de ne laisser personne de côté rejoint ainsi l'idée de Doucet.

La théorisation d'une telle alternative est non seulement intéressante en tant que critique et remise en question du modèle dominant, mais elle nous éclaire également sur certains présupposés normatifs et éthiques sociétaux et systémiques. Par contre, il est possible de se questionner sur ce en quoi consisterait exactement, dans la pratique et au quotidien, une éthique féministe de gestion de crise pandémique fondée sur le *care*. Arriverait-elle à dépasser son carcan théorique pour plonger dans son applicabilité concrète en contexte de pénurie, et de prise de décisions difficiles de vie ou de mort?

À ce sujet, l'approche de Saintôt (78) semble complémenter et clarifier la mise en pratique de la théorie de Branicki et de Doucet. La pandémie et son discours politique du « prendre soin » marquerait l'occasion de ce qu'il qualifie d'un retour de l'éthique du *care*. Une telle éthique permettrait à ses yeux d'inspirer un tournant politique du soin, qui, d'une manière pratique, prendrait ses racines spécifiquement dans la manière d'accompagner la vieillesse et la vulnérabilité. Ce tournant politique de l'éthique du *care* se mettrait en place par le biais d'une approche humaine, ancrée dans le relationnel et la dignité de la personne, et ce, particulièrement au sein du CHSLD (ou en France, de l'EHPAD). À ce sujet, Saintôt explique : « [il s'agit de] ne pas réduire la vie humaine à sa seule dimension physiologique, comme s'il fallait à toute force sauver biologiquement des vies sans les sauver humainement, comme si la peur de la mort justifiait l'amputation de toutes les autres dimensions, notamment la dimension relationnelle » (78, p.12). Une prise de conscience politique de la place du soin permettrait de mettre de l'avant le droit à la santé plus englobant que le droit à la vie, particulièrement la santé de tout l'humain, qui ne peut être négligée par la santé de tous les humains (78). La pandémie marquerait ainsi la redécouverte d'une interdépendance sociétale nécessitant l'attention à autrui, plutôt qu'une moralité fondée sur le raisonnement de principes abstraits, ou encore sur la dérive marchande d'un modèle hôpital-entreprise (78). Une telle philosophie du soin pour et avec le patient serait orientée vers la valorisation de ses singularités, vulnérabilités et subjectivités plurielles, par le fait de cultiver le fondement humain de la relation de soin sur lequel baser l'efficacité médicale.

À l'image du tournant politique du soin représenté par Saintôt à l'occasion de la pandémie, la crise sanitaire pourrait-elle instiguer un tournant depuis un modèle dominant fondé sur le « e*vidence-based* », le quantifiable et l'efficacité, vers une philosophie palliative fondée sur la vertu? Sheahan et Brennan (79) proposent une telle approche éthique à la pandémie, basée sur l'application des principes des soins palliatifs. Les auteurs soulèvent le danger qu'une approche traditionnelle et utilitariste de crise axée sur le nombre de vies ou d'années de vie sauvées devienne « le nouveau ou même le seul lieu de valeur » (79, p.793), perdant de vue les personnes réelles et l'humanité du soin dans le contexte en rapide évolution de la prestation de soins en pandémie. Sheahan et Brennan mobilisent ainsi une approche des soins palliatifs sur la base d'une éthique de la vertu. L'éthique de la vertu est axée vers le caractère moral, les attributs et les motivations de la personne, et non le caractère de l'action objective en elle-même ou de ses conséquences (79). Elle pèse l'importance de vertus directrices fondamentales, telles la compassion, la solidarité et la dignité afin de répondre à la souffrance dans le contexte de la COVID-19. Par le biais de cette éthique de la vertu palliative, il serait question de s'appuyer sur le principe palliatif du soin personnel, afin de considérer, sur une base éthique solide, la valeur personnelle du soin, et la valeur singulière de chaque patient (et de sa famille) jusqu'à la fin de sa vie (79). Pour les auteurs, particulièrement en temps de pandémie, il s'agit d'un idéal à ne pas perdre de vue devant l'adversité. Face à la COVID-19, Sheahan et Brennan dénoncent également le nihilisme dans la perception des autorités et institutions selon laquelle plus rien ne pourrait être offert à un patient dont l'état se détériore et qui approche la fin de vie. En réponse, ils proposent de se fonder sur un deuxième principe fondamental de la philosophie des soins palliatifs, le principe de non-abandon du patient. Celui-ci devrait guider la réponse éthique, et ce, peu importe la condition du patient, et sans céder au nihilisme, c'est-à-dire sans le délaisser et agir comme si plus rien ne pouvait être fait pour lui (79). Ce qui a possiblement été socialement occulté dans le passage à une pandéthique est le fait que l'absence de *cure* ne signifie pas l'absence de *care*. Dans ce contexte, le passage à un impératif d'efficacité, ou à une logique de guerre, aurait pu invisibiliser dans une certaine mesure l'impératif de la dignité.

En outre, de ces approches alternatives multiples semble ressortir l'importance de la responsabilité sociale impliquée dans les prises de positions éthiques. Autrement dit, de ces éthiques « autres », voire marginales, se dégage l'idée d'une co-responsabilité sociale particulièrement nécessaire en temps de crise dans le processus de priorisation, et dans l'engagement à répondre à la vulnérabilité par le soin. Ainsi, plus qu'un choix d'éthiques purement médicales, ce serait un choix sociétal qui serait d'abord en jeu : à l'instar de Bustan et al. (16), il convient de se demander si nous désirons survivre dans une société de l'efficacité, ou bien du *care*. Mais plus encore, comment allons-nous choisir d'articuler et d'équilibrer ces deux conceptions non mutuellement exclusives? Qui plus est, l'approche éthique des soins palliatifs de Sheahan et Brennan nous amène à nous questionner sur ce que signifie prendre soin les uns des autres dans une pandémie, et comment ce soin peut s'exprimer à l'approche de la mort et dans des situations critiques (79).

CONCLUSION

Par le biais de cette étude documentaire, nous avons commencé à construire une esquisse des modalités d'interventions, des pratiques, de la répartition des ressources et du traitement des personnes âgées en soin de longue durée. Les éthiques priorisées et les directives élaborées ont pu engendrer des dilemmes en ce qui a trait au *duty to care* des soignants, de par leur renversement d'une approche individuelle vers une approche centrée sur le collectif. Les pratiques qui en découlent peuvent se positionner à l'encontre des valeurs personnelles et professionnelles des soignants, et présenter le risque de blessures morales. Par ailleurs, selon les approches et justifications éthiques employées dans les choix sociétaux qui encadrent la prise de décision en temps de COVID-19, les personnes âgées sont confrontées au risque de leur dévalorisation. L'éthique de santé publique semble ainsi s'être en partie fondée sur la négligence sociétale à leur endroit. Il convient de se questionner sur la possibilité que cette négligence prenne racine dans la peur de la mort, de la « mort sociale » associée à la dégénérescence physique et cognitive (80,81), de la perte de soi au travers de la dépendance et de l'institutionnalisation. Par extension, notre rapport à la mort semble teinter notre rapport à la vieillesse et à ceux et celles qui incarnent cette phase de la vie aux yeux de la société. Selon la gériatre Louise Aronson, la tendance à se dissocier de notre soi futur, par l'altérisation ou le rejet des personnes âgées, serait un moyen de nous éloigner de « la diminution biologique et sociale de la vieillesse » (46). Pour Paul Higgs, sociologue du vieillissement (46), la peur du vieillissement coïnciderait avec la fragilité, et le changement d'agentivité associées aux personnes du quatrième âge, mais aussi à leur marginalisation et invisibilisation, définies et, paradoxalement, craintes par la société.

D'une manière complémentaire, qu'est-ce que ces éthiques semblent révéler sur nous, sur notre société, ou encore sur notre système de santé? Plus encore, que disent-elles du paradoxe du « problème » de la mort (5) dans la prise de décision? Avant la pandémie, l'impératif technologique, curatif, et interventionniste dit « *age-blind* » était au cœur des discussions, des critiques et des préoccupations des domaines médical et anthropologique. L'idée de faire toujours plus, de se rendre toujours plus loin dans les traitements, et pour une durée toujours plus longue semblait dominer de nombreux débats, tout comme l'enjeu connexe de la difficulté de l'arrêt des traitements. La dimension de l'hypervisibilité de l'âge est, d'une part, attribuable au fait que les personnes plus âgées, hébergées ou non, et atteintes de maladies chroniques ou de conditions de santé susceptibles d'augmenter le risque de développer des complications graves à la suite d'une infection, étaient les premières victimes de la COVID-19 (50). Par contre, en période pandémique, il semble que la posture aveugle face à l'âge du patient ait, d'autre part, donné place à une hypervisibilité de l'âge dans certains rationnements de soins, certaines approches et conceptions axées sur un impératif de l'efficacité. Parallèlement, en situation de crise, il semble qu'une éthique centrée sur le patient singulier et son autonomie se soit souvent et rapidement transformée en une éthique basée sur le collectif et la restriction autoritaire des droits individuels. Le « problème de la mort » s'est transformé en un « problème de l'âge », tout en conservant les mêmes individus en son centre : les aînés. Ainsi, ces perceptions et moralités nous ont également permis, d'une manière sous-jacente, de nous intéresser à ce qui découle des paroles et des actions. Nous avons tenté d'éclairer leur construction dans des circonstances, par le biais de pratiques et au sein de contextes donnés leur ayant permis d'exister. Le regard anthropologique en bioéthique participe à la remise en question de l'universalité du « bon » en montrant la pluralité des manières de l'interpréter : ce sont plusieurs valeurs et manières d'être au monde (82) qui s'entrecroisent au travers des éthiques et des pratiques.

En somme, à la lumière des réflexions présentées précédemment, l'analyse comparative d'Orfali (24,26) apparait particulièrement porteuse en ce qui a trait à la logique que semble révéler le passage d'une éthique hors pandémie à une « pandéthique ». La COVID-19 a rendu flagrante la manière par laquelle nous percevons notre système de santé, que nous le construisons, mais aussi les valeurs et normes sur lesquelles il repose. Avec les principes idéologiques qui guident ce système, et sa culture médicale plus largement, ces différentes dimensions informent en retour la manière par laquelle nous répondons à la pandémie, pensons et construisons nos protocoles de triage et directives d'allocation des ressources, et choisissons de les mettre en place. Non seulement aucune réglementation de triage n'a été jugée universelle au point d'être adoptée à l'international, mais ce processus semble aussi diversifié et pluriel que le sont les différents systèmes de santé et cultures médicales, les contextes institutionnels et sociaux les cadrant, ainsi que les différentes approches et résultats dont témoignent les exemples européens et américains discutés.

Comme appuyé par Marshall et Koenig (8), l'anthropologie de la bioéthique a beaucoup à apporter à la conciliation des conceptions morales médicales. En mettant davantage en perspective les conceptions éthiques strictement universelles ou relativistes, le regard anthropologique invite à considérer l'importance de situer le cheminement vers un consensus moral dans la réalité du contexte local et de ses dynamiques sociales et relationnelles. Il appelle à une compréhension plus holistique, ainsi qu'à une analyse écologique de la complexité, de la diversité, des inégalités, ainsi que du sens des pratiques et des facteurs sous-tendant les comportements (43). En augmentant notre compréhension de la manière dont les pratiques médicales et sociales sont définies et interprétées, l'anthropologie de la bioéthique peut permettre de mieux rendre compte de la position du « bien » dans les mondes moraux locaux, et des diverses variantes des morales locales (8,83). D'une autre perspective, Appiah nous invite à réfléchir à la possibilité que l'accord sur les pratiques se fasse d'une manière indépendante de l'accord sur les valeurs et justifications qui les sous-tendent (84). Plutôt que de rechercher un consensus final unissant les raisons de nos actions, il invite à accepter le vivre-ensemble comme une avenue possible au sein de la rencontre de la diversité. Or, il semble que dans la crise sanitaire, ce ne soit pas seulement les significations de valeurs communes qui s'opposent : l'ambivalence s'est révélée face également aux conflits de valeurs et de justifications différentielles sous-jacentes au « bien », ainsi qu'à sa mise en pratique. En effet, la reconnaissance commune de l'importance de « faire le bien », orienté vers un même objectif, n'empêche pas l'enchevêtrement d'une pluralité de visions de ce « bien », et de manières de l'approcher, de le justifier et de le réaliser.

La COVID-19 montre également que les tensions entre mondes moraux peuvent émaner d'actions et de pratiques qui, en adéquation avec le modèle éthique dominant à première vue, peuvent s'opposer aux convictions morales individuelles. Dans le cadre de recherches futures, il sera important de mettre la recherche ethnographique à contribution afin de mieux saisir l'expérience morale vécue dans le contexte de la COVID-19, mais aussi la complexité des réalités et perspectives plurielles dans lesquels s'ancrent les dilemmes éthiques et moraux. Les outils méthodologiques de l'anthropologie, et son cadre analytique et réflectif en font un allié pour le champ des sciences de la santé et de la bioéthique. Tel que soutenu par Massé (83), s'appuyant sur les travaux d'Hoffmaster (85) sur la contribution de l'ethnographie à la bioéthique : « la théorie morale n'est possible que si elle est alimentée par la recherche empirique décrivant, en profondeur, le contexte quotidien des prises de décision éthiques, l'intrication des valeurs dans le vécu quotidien des personnes prenant les décisions, ainsi que les contraintes institutionnelles, culturelles ou politiques dans lesquelles s'opère le raisonnement moral » (83, p.35). Une anthropologie de et pour la bioéthique encouragerait ainsi « la diffusion des alternatives à une pensée morale unique ou dominante » (83, p.38).

Finalement, la pandémie a exacerbé les inégalités et mis en lumière des lacunes et situations tragiques dans sa gestion. À travers cet évènement focalisant et ses échecs, il est possible de remettre en question les approches éthiques dominantes, de reconsidérer les manières de penser et d'agir. Les approches éthiques alternatives proposées témoignent du fait que la conversation peut s'orienter vers des reconsidérations éthiques du soin, des prises de décision et du traitement des personnes marginalisées ou vulnérabilisées. Dans ce contexte, l'anthropologie doit participer à la discussion, ainsi qu'à la mise en lumière des voix qui se retrouvent étouffées par le cadre politique: « [l'anthropologie permet] de faire contrepoids aux discours politiques soumis aux pressions de l'économie, de l'analyse décisionnelle et des procédures légales, discours qui réduit au silence la souffrance sociale » (8, p.50). De ce fait, elle permet d'interroger les savoirs et leur construction, ainsi que d'éclairer des réalités altérisées ou invisiblisées, les situant dans la complexité de leur contexte spécifique, et les replaçant au sein des discours moraux socio-culturellement construits et ancrés dans la matrice sociale plus large. Les approches et éthiques alternatives peuvent avoir une contribution essentielle aux questionnements collectifs et collaboratifs des fondements éthiques, des normes sociales et comportements, jusqu'aux dispositifs institutionnels et organisationnels. Les tragédies de fin de vie multipliées chez les personnes âgées et vulnérables en soin de longue durée pendant la pandémie et l'idée que la société a failli au devoir de prendre soin laissent des blessures morales qui demanderont longtemps à être reconnues et pansées par, entre autres, ces approches narratives fondamentales aux éthiques de la vulnérabilité, féministe et du *care*. Le regard anthropologique peut certainement contribuer à cette quête.

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Conflicts of Interest

None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Impacts of the Early COVID-19 Pandemic on the Work of Bioethicists in Canada

Marilou Charron[a], Jean-Christophe Bélisle-Pipon[b], Vincent Couture[c], Bryn Williams-Jones[a], Vardit Ravitsky[a], Charles Dupras[a]

Résumé
Les experts de la bioéthique ont joué un rôle clé pour assurer une réponse éthique cohérente à la pandémie de COVID-19 dans les domaines de la santé, de la santé publique et de la recherche scientifique au Canada. Dans la province de Québec, un groupe de bioéthiciens académiques et praticiens s'est rencontré périodiquement au début de la pandémie pour discuter d'approches et de solutions aux dilemmes éthiques rencontrés durant la crise. Ces rencontres ont créé l'opportunité d'un sondage national des praticiens de la bioéthique de différents domaines pour conserver un témoignage de ces rencontres informelles. Le sondage avait aussi pour objectif d'éclairer la recherche en bioéthique sur les difficultés vécues par les bioéthiciens « sur le terrain ». Les auteurs ont recueilli les réponses de quarante-cinq bioéthiciens canadiens, visant à connaitre leurs préoccupations, défis et opportunités rencontrés durant la première vague de la pandémie. Les participants ont rapporté une augmentation de leurs niveaux de stress, une augmentation de leur charge de travail, ainsi qu'une plus grande part de leur travail étant consacrée à l'éthique en santé publique. La plupart de leurs préoccupations se concentrait sur des groupes autres qu'eux-mêmes, tels les professionnels de la santé, les patients, les participants à la recherche et les personnes en contexte de vulnérabilité socioéconomique. Un optimisme quant au futur de la bioéthique fut dénoté en raison d'une conscience accrue de l'importance de la bioéthique par le public et par les institutions de santé et de recherche.

Mots-clés
COVID-19, bioéthique, éthique pandémique, éthique clinique, éthique de la recherche, éthique des politiques de santé

Abstract
Bioethics experts played a key role in ensuring a coherent ethical response to the COVID-19 pandemic in the fields of healthcare, public health, and scientific research in Canada. In the province of Quebec, a group of academic and practicing bioethicists met periodically in the early months of the pandemic to discuss approaches and solutions to ethical dilemmas encountered during the crisis. These meetings created the opportunity for a national survey of bioethics practitioners from different fields. The survey, in which forty-five Canadian bioethics practitioners (clinical ethicists, ethicist members of REBs and government health policy ethicists, or any bioethicist practicing outside of academia) participated, explored their concerns, challenges and opportunities during the first wave of the pandemic, with the objective of informing bioethics research about the difficulties experienced by bioethicists "in the field". Participants reported increased stress levels, increased workloads, and a greater proportion of their work being devoted to public health ethics. Most of their concerns focused on groups other than themselves, such as health professionals, patients, research participants, and people in vulnerable socio-economic situations. An optimism about the future of bioethics was noted due to an increased awareness of the importance of bioethics by the public and by health and research institutions.

Keywords
COVID-19, bioethics, pandemic ethics, clinical ethics, research ethics, health policy ethics

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INTRODUCTION

Starting in January 2020, the first cases of COVID-19 were detected in Canada (1). The novel public health situation for citizens and the healthcare system gave rise to unprecedented measures to quell the spread of the disease within the population, especially among the most vulnerable (2). For many workers across the country, this meant adjusting to new work environments, be it working from home (2,3) or the increasingly stressful context of providing frontline healthcare and essential services (4,5). Healthcare organizations had to take drastic measures to care for a large influx of very ill COVID patients (6-9). The intensification in workload, coupled with the need to reduce transmission, necessitated a slowdown of non-urgent health service provision for many hospitals, while at the same time opening the door to the rapid implementation of telemedicine and other innovations to prevent infections (6,9).

The field of bioethics as a whole – that is, academic bioethicists and bioethics practitioners from across the full range of specialties, including clinical ethics, research ethics, health policy ethics, and public health ethics – gained substantial public and institutional recognition from the very early days of the pandemic (10-12). In this study, we refer to "bioethics practitioners" as individuals whose professional practice consists, at least in part, of working in healthcare and social services facilities as clinical and/or organizational ethics consultants, research ethicists in research ethics boards (REBs), or health policy ethicists in government departments or agencies. This recognition of the pertinence of bioethics in public health crises is arguably due, at least in part, to the field's long history in North America of dealing with morally challenging situations in healthcare

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organizations, contributing to health policy (e.g., fair resource allocation), and ensuring the implementation of ethical norms across disparate areas (e.g., protecting participants in research and responding to public health crises) (13,14).

In this pandemic context, frontline healthcare workers had to quickly adjust their definition of “best practices” and care priorities, often in ways that they might not have considered optimal in pre-crisis circumstances (15). Health research in Canada and internationally rapidly prioritized medical and public health research to understand the epidemiology of the disease and develop effective prevention measures, therapeutics, and vaccines. Administrative and regulatory approval processes were accelerated (16), and hospital and university REB services were streamlined to help in these efforts (13,17). The most evident public challenges, however, involved the need for health professionals and institutions to shift from an individual-based approach to clinical care and ethics to a more community-centred approach focused on population health (15,18). Clinicians and bioethicists rapidly developed a heightened awareness of the need to consider the whole organization when making decisions, while also maintaining a sufficient quality of care and services for individuals. There were also many uncertainties and knowledge gaps about COVID-19, including mechanisms of transmission, symptoms, consequences, and most effective means to contain or mitigate the spread of the disease (19).

These issues inevitably led to ethical tensions between competing sets of duties (18). For example, ethical questions and dilemmas arose regarding the duties of healthcare organizations to protect their workers, in addition or in opposition to providing optimal and equitable care to patients (6,10). Other important ethical questions surrounded the fair allocation of resources and the implementation of triage and prioritization protocols in case of major bed or equipment shortage in intensive care, all of which solicited rapid input from bioethicists (9,18). In parallel, REBs were put under increasing pressure to respond quickly with their ethics evaluations of COVID projects while maintaining standards of evaluation quality and ensuring the protection of research participants (13,17). As such, the pandemic presented real challenges for health professionals and their organizations, as well as for bioethicists working both within and outside these institutions.

Drawing from past pandemic experiences such as the influenza (H1N1) pandemic in 2009, it has become clear to various stakeholders that involving bioethics analyses in public health preparations and interventions can help manage risks and enhance public awareness and understanding of risks. This increased understanding can contribute to continued support for public health measures (20). Recommendations for best practices for health professionals (who were dealing with scientific and clinical uncertainty, a surge in patients, and overstretched and exhausted health teams) during the lockdown phase of the pandemic showed that clinical ethicists were vital resource people for supporting the public health network during a crisis situation (14) and could play a critical role in ensuring the resilience of the system over the long term (4).

During the pandemic, officials and policymakers sought the expertise of bioethicists in academia, healthcare organizations, and government agencies to support the development and implementation of ethically appropriate responses to the COVID-19 crisis. Yet, to date, few studies have focused on the professional challenges that bioethicists faced or the emotional well-being of these key actors during COVID-19 (21). Given the important role played by bioethicists in Canada, empirical data on their roles and experiences during the intense early phase of the pandemic (i.e., the first few months of 2020) is an important contribution to the literature. This study documents the attitudes, emotional responses, needs, and views of bioethics practitioners. Not included in our study were academic bioethicists who solely hold positions in universities as researchers, professors, or academic associates. While important actors, this group did not experience the challenges faced by bioethics practitioners.

During the first wave of the pandemic in Quebec, a group of bioethics practitioners and academic bioethicists (the authors) organized regular (weekly and then monthly) online meetings in order to leverage and transfer analytic and decision-making tools from academia to those working on the front lines (i.e., in health settings, REBs, and government) and so contribute to the collective response to the challenges of COVID-19 in healthcare, research, and public health policy. During these meetings, bioethics practitioners informally reported moral challenges and difficulties adapting to the novel situation and thus welcomed aid from their academic colleagues. Notable discussion topics included moral distress (of both bioethics practitioners and health professionals), the use of ethical frameworks to support decision-making and influence health policy, the implementation of triage policies, and vaccination passports, amongst others (22). Participants also noted the importance of keeping track of the issues raised in these discussions, recognizing that careful record-keeping could potentially support practitioners after the crisis by capturing insights gained during the early days of the pandemic. In light of this request and given the paucity of empirical data in the academic literature, we conducted an anonymous survey with Canadian bioethics practitioners in different fields of practice to gain a better understanding of their responses to the pandemic and how they foresaw the pandemic affecting the future of bioethics practice (23). This survey aimed to contribute to the literature by providing an opportunity for bioethics practitioners in Canada to communicate their needs and perspectives.

METHODS

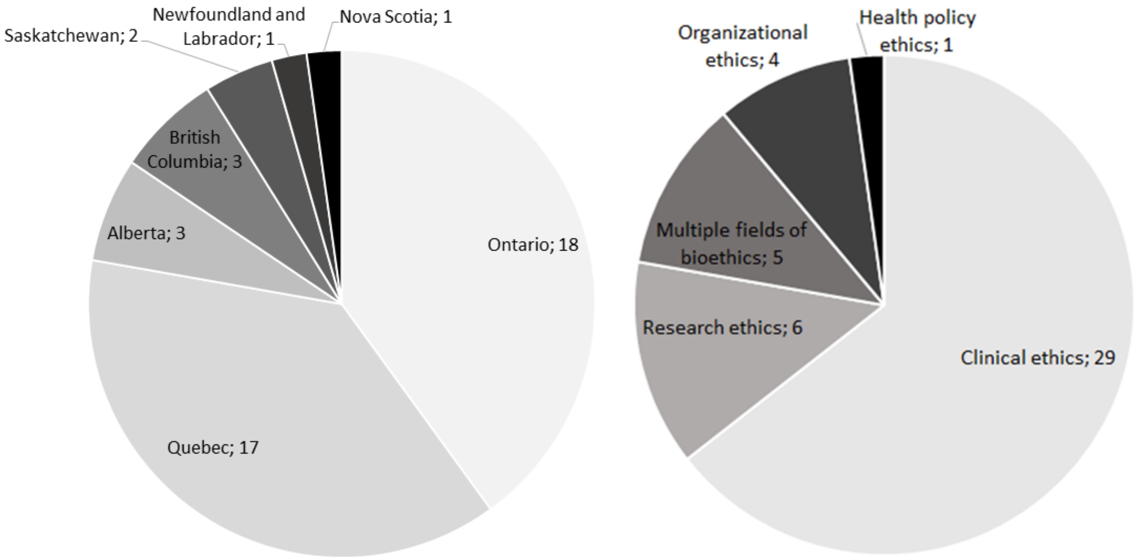
From May to June 2020, we conducted an anonymous survey using the LimeSurvey platform (hosted in Canada). Respondents were bioethics practitioners (academic bioethicists were excluded) professionally involved in the domains of clinical ethics, organizational ethics, research ethics, or public health and health policy ethics. Invitations to participate were sent by e-mail to approximately 50 people in the province of Québec (Canada) who were involved in the regular weekly discussions with researchers during the early days of the pandemic. We invited these respondents to forward invitations to their professional networks. In addition, we solicited the help of organizations such as the Association Québécoise d’éthique clinique (AQEC, Québec Clinical Ethics Association), the Canadian Bioethics Society (CBS), and the International Association of Bioethics (IAB) to widely disseminate the invitation to participate in the survey. We also posted links to the survey on social media platforms, e.g., Twitter, Facebook, and LinkedIn. Research data were collected anonymously. However, respondents were given the option to provide contact information to be updated on the study findings and/or receive invitations for follow-up studies. Initially, the survey collected international responses, but analysis of the data was restricted to Canada due to an insufficient number of responses from other countries.

The survey questions sought to capture the changes that bioethics practitioners had perceived in their practice, their emotional responses, their adaptation and coping strategies, the ethical challenges they encountered in carrying out their professional responsibilities, and their hopes, apprehensions, and needs for a post-pandemic future for bioethics. The survey was divided into 14 sections. It included multiple choice and open-ended questions, as well as questions asking respondents to rate their level of agreement with various statements on a 5-point Likert scale. While some of these questions presented potential for quantitative analysis, the focus of our analysis in this paper is mainly on the qualitative data. The survey could be completed in either French or English, the two official languages of Canada. A panel composed of bioethics practitioners reviewed the early drafts of the survey and provided suggestions for its improvement. Ethics approval of the survey was obtained from the Comité d'éthique de la Recherche en sciences et en santé de l'Université de Montréal (Université de Montréal's Science and Health Research Ethics Board) (CERSES-20-064-D).

RESULTS AND DISCUSSION

Fifty-five (n=55) bioethics practitioners from different countries initially answered the survey. However, due to insufficient responses from countries other than Canada (8 international participants from Europe and the United-States), only the 46 Canadian respondents were retained for this analysis. Of the 46 respondents, one was excluded due to not working in the practical field of bioethics (the person was a student in bioethics as opposed to a practising bioethicist), bringing the final sample to 45 respondents. Most respondents were from the provinces of Ontario (n=18) and Québec (n=17), with at least one respondent from each of 5 of the other Canadian provinces (Alberta, British Columbia, Nova Scotia, Newfoundland and Labrador, and Saskatchewan); there were no respondents from the Canadian territories (Figure 1).

Figure 1: Demographics of survey respondents



The pie chart on the left indicates the provinces where the respondents worked. The pie chart on the right indicates the fields of bioethics to which respondents identified.

Of the 45 respondents, most reported working in clinical ethics (n=29), with other fields of practice including research ethics (n=6), organizational ethics (n=4), and health policy ethics (n=1). No respondent in our sample reported specializing in public health ethics. A few respondents indicated that their work included multiple areas of practice from the above-listed fields of bioethics (n=5) (Figure 1). The low recruitment of respondents from fields other than clinical ethics limited our ability to compare results between the different fields or specialities of bioethics. Nevertheless, we included all fields in our survey so as to provide a perspective on the status of practical bioethics in general, as opposed to only one subfield (e.g., clinical ethics).

Changes in Workload and Tasks

More than half of respondents (n=31) reported changes in their work tasks because of the pandemic, and all but two reported an increase in their workload (n=29). Most of the changes in tasks were related to the proportion of time allocated to different portions of their work. Increases in the workload of respondents was mostly attributed to additional health policy and public health work, such as framework creation and supporting resource allocation decision-making. Some respondents mentioned undertaking new tasks, such as being involved in the development and implementation of triage protocols on top of their other duties. Some clinical ethicists reported a decrease in workload related to clinical case consultation, with two respondents indicating that they were reassigned to other tasks such as frontline clinical work in long-term care centres. This could indicate that in cases where there were acute staff shortages on the frontline, ethics was deprioritized in favour of other duties for which clinical ethicists might be less experienced or competent. Respondents working in research ethics reported no change in the nature of their tasks but noted that they were much busier because of the need to respond in a timely manner to COVID-19 research projects. These respondents did not report being involved in additional health policy or public health work, nor were they involved in the frontline healthcare response.

Work-Related Challenges

Tables 1 and 2 summarize the work-related challenges of bioethics practitioners identified by respondents in their answers to quantitative questions of the survey. These questions explored the effects of the pandemic on various aspects of practitioners' work, their emotional and psychological response, and their needs.

Table 1: Perceived effects of the early COVID-19 pandemic on bioethics practitioners' work, relationships, and emotional lives

Aspects of work	Positive impact (%)	Negative impact (%)
Relationship with colleagues in ethics	58	18
Relationship with the people who use their services	49	13
Feeling recognized and appreciated at work	48	26
Relationship with hierarchical superiors	48	12
Feelings of usefulness at work	44	34
Ability to fulfill main mandate	33	42
Ability to communicate with others at work	33	24
Comprehension of their mandate	30	36
General Mood	14	48
Stress	10	70
Missing percentages (i.e., total less than 100%) can be attributed to the participants who scored a neutral response to the questions.		

Most respondents (n=40) reported that the challenges they faced due to the COVID-19 pandemic were new to them. However, they also indicated that these challenges could have been better anticipated (n=39). For example, drawing from previous pandemic experiences such as the H1N1 pandemic of 2009, for which Canadian preparedness had been praised (24), would have helped healthcare and health policy organizations to better cope with the uncertainty of the first wave of the pandemic. As one participant noted, "*It also upsets me that very little of what we learned in SARS has been even considered in this pandemic*" (P43, clinical ethics). Nevertheless, most respondents reported that they were adapting well to the pandemic situation and had been able to respond to the ethical needs of their respective workplaces or position (n=40).

Respondents who reported working mainly in organizational ethics all agreed on the positive effects of the pandemic on their work-related tasks (n=4), such as increased trust and reliance from their organizations. Respondents from all other fields of bioethics also reported similar positive effects of the pandemic on their work, although not unanimously. However, as we detail further below, this sense of positive effects did not necessarily translate into a positive emotional response.

Table 2: Feelings and needs of bioethics practitioners during the early COVID-19 pandemic

Feelings and Needs	Agree or Strongly Agree (%)	Disagree or Strongly Disagree (%)
Feeling like you have the right tools to face the pandemic	71	29
Feeling overworked	65	35
Need for literature support (in general)	62	38
Need for legitimacy	62	38
Need for better peer connection (in the academic field)	58	42
Need for better peer connection (in the same field of bioethics)	56	44
Need for better peer connection (in different fields of bioethics)	51	49
Need for psychological or emotional support	32	68

Some clinical ethics consultants specifically reported a lack of support from their superiors and institution, a lack of influence to instigate meaningful changes in their institutions, or even a general devaluation of their usefulness regarding their work: *"My approach and views to human rights aspects during COVID-19 planning and policies may not align with those of administration and staff. This may have a negative influence on how my work in the organization is perceived"* (P40, clinical ethics). Some bioethics practitioners felt that they were under-solicited in areas where important ethical concerns arose: *"I wish I were more solicited/recognized by my organization; the current pandemic context probably highlights the fact that, at the organizational level, ethics were not all that well positioned pre-pandemic"* (P24, clinical and organizational ethics, translated by the authors).

Despite the above-described concerns, respondents provided mixed responses when reporting on the impact of the pandemic on their relationships with their superiors (Table 1). This suggests that strained organizational relationships were not experienced by all bioethics practitioners and that the effects of the pandemic on their working environments were multiple and varied.

The specific challenges reported by research ethicists had to do with research integrity and the ethics review of research involving humans during a time of crisis. Some respondents observed that REBs had to respond rapidly to any research touching on COVID-19, while being expected to maintain a high standard of quality in their review of the projects. Two of the six research ethicists saw this as particularly challenging. Some respondents also feared that this could result in mistrust in the function and work of REBs. As one of these respondents explained:

> *The most worrying ethical issue, in my opinion, with regards to research during the pandemic is the maintenance of the principles of research ethics and scientific integrity. There is currently a high degree of precipitation in the preparation of research projects which results from the pressure of finding solutions to the current pandemic in record time. The pandemic cannot become a justification for noncompliance.* (P27, research ethics)

Another challenge that was identified related to non-compliance of researchers to REB recommendations. Some respondents reiterated that neglecting participant protection to achieve research goals is unacceptable, even during a public health crisis.

Concerns for other groups

Clinical and organizational ethicists identified similar worries and apprehensions in their survey responses. Most of their concerns focused on the pandemic's impact on individuals, groups, or organizations other than themselves, such as patients, healthcare staff, and people in situations of vulnerability. One respondent summarized:

> *The most worrying ethical issues include the moral/emotional/psychological impacts […] that working in the pandemic will have on some health care providers, which is a concern by itself, and could lead to negative impacts on the function and sustainability of the health system overall. This is related to the extent to which health care providers have trust in the organizations within which they work, and whether they believe that the organization is truly looking out for their interests. […] Other issues which have emerged relate to restrictions on visitors, which have caused great distress for everyone […]. Even though the rationale for limiting the spread of COVID is strong, this has been a great source of concern and even harm for many.* (P19, clinical ethics)

Many other respondents expressed concerns regarding vulnerable populations, such as the deleterious effects of long-term isolation and its impact on mental health. They were also worried about the potential for further neglect of these vulnerable populations. Examples of concerns included potentially ageist (i.e., favouring younger people while seniors are more at risk of complications and fatalities) and ableist (i.e., people with disabilities being systematically disadvantaged) emergency policies or triage protocols. They were also concerned about potential breaches in the protection of patients' privacy because of the strategies adopted to quell the public health crisis. Some respondents feared the silencing of some important stakeholders in individual healthcare decisions, such as patients themselves and the patients' families. Overall, respondents saw respect for patient autonomy as important despite a greater focus on public health during the crisis.

Public health measures in response to COVID-19 sparked concerns about the side effects of these measures on the general population, such as mental health risks and the delaying of elective surgeries (25), and in turn, concerns about the ethical implications of such measures. Restrictions contributed to an increase in mental health complications and to the worsening of already existing mental health complications in the general population and in healthcare workers (26-29). Clinical ethicists reported worries surrounding the mental health of vulnerable populations. These worries were justified by knowledge of pandemic effects on mental health at the time of their response (5,28,30,31). Of course, this is not to say that public health measures were not warranted, as the threat of COVID-19 was (and still is) a major concern (30). Nevertheless, it is justified to call for better scrutiny of the psychological effects of social distancing measures on the general population and to request improved access to much-needed mental health services (26,28,30).

Respondents also expressed concerns about the psychological and moral well-being of healthcare workers. They identified mandatory overtime to compensate for staff shortages as being particularly problematic for the well-being of frontline workers. Ethicists working in healthcare facilities (mostly clinical and organizational ethicists) were concerned about potential moral distress and moral injury of healthcare staff and dreaded their exhaustion as the pandemic dragged on. They observed that this exhaustion could lead to less consideration of ethical practices and ethical issues in the work of healthcare professionals:

> *Healthcare workers and their managers don't have much time to reflect on the ethical challenges [of their practice] and to discuss them. Since the start of the pandemic, this reality has worsened*. (P14, organizational ethics, translated by the authors)

The fear of non-compliance with practice guidelines by doctors and hospital staff in the context of additional and prolonged public health measures was also identified as a potential problem for society in general. Studies pointing to a high potential for morally distressing situations during the COVID-19 pandemic (10,15,18,32) supported these concerns. The effects of moral distress on mental health and ability to work have been documented in the literature (4,32) and observed in regions heavily affected by the pandemic (33). These studies also point to the need for evaluating healthcare worker's mental health status and their experience of moral distress during COVID-19 in order to better prepare and preserve our healthcare system for future emergency situations (4). It is part of the role of clinical and organizational ethicists to help frontline healthcare workers cope with their moral or emotional distress during difficult clinical situations. This role makes them acutely aware of the suffering of frontline healthcare workers and its effect on the healthcare organization's ability to meet its commitments to patients, families, and communities. While clinical and organizational ethicists had similar concerns prior to the pandemic, they pointed out that these fears increased due to the crisis. As such, the survey responses highlighted their role in facilitating the dialogue on the needs and concerns of all stakeholders, especially the most vulnerable.

Respondents working in research ethics also noted the need to strike the right balance between protecting individual rights and promoting public health. During the beginning of COVID-19 pandemic, research participants may have been exposing themselves to risks of a new nature and magnitude due to the emergency context and the need for research and development to operate quickly in highly stressful situations (13,17). As some of our respondents pointed out, publicly declared emergencies may have also impeded informed consent to participate or undermined public trust in research (13). The need to rapidly review research protocols while also maintaining the quality of evaluation and ensuring proper follow-up of ethical recommendations can put a great deal of pressure on REBs, and thus also on research ethicists (17). The WHO (17), the Canadian Tri-Council (i.e., the TCPS2) (34), and the Canadian Association of Research Ethics Boards (CAREB) (35), among others, have published guidelines and lists of resources for maintaining good REB evaluations during a pandemic (or other emergency) in order to help research ethicists and REBs overcome these challenges and maintain the quality of research ethics evaluations.

Emotional Response

Most respondents reported a negative impact of the pandemic on their stress levels (Table 1). They explained the stress-inducing context of the early pandemic in healthcare organizations:

> *In the early stages of the pandemic, I experienced a lot of anxiety and stress around my ability to adequately respond to the needs of my organization given the gravity of the situation and the tight timelines for responses. This subsided significantly when the situation became stable; however, I anticipate that the feeling of anxiety will return when services begin to ramp up again.* (P34, clinical ethics)
>
> *I feel like I'm on a roller coaster where my emotions and workload are constantly and rapidly changing without me having any control over them. The imposter syndrome experienced by many clinical and organizational ethicists is even more prominent.* (P26, clinical ethics, translated by the authors)

However, many respondents expressed mixed feelings regarding the way the pandemic affected their emotional status, moods, and sense of usefulness at work. One respondent, though admitting to being in a stressful environment, said that it was outweighed by the overall benefits for their work position:

> *…the pandemic has been an incredibly positive experience career-wise. The role and status of ethics at my hospital and in the region has never been so high. My ability to stay calm and rational during highly stressful situations has been extremely valuable during this crisis. I am actually enjoying it.* (P37, clinical ethics)

Responses to questions about the challenges of working from home varied greatly. Some respondents reported difficulties achieving balance between work and other personal obligations and maintaining good relationships with their colleagues in an isolated context (n=18). Others responded that they adapted well to working from home (n=2). While some respondents reported receiving substantial support from their organization (n=4), others reported difficulties due to a poor response to their individual efforts and needs (n=15). This suggests that recognizing the importance of ethics during this public health crisis and involving ethics practitioners in the COVID response proportionate to their capacities may have positively affected the ability of some bioethicists to emotionally cope with the situation.

The negative impact of the pandemic on the stress levels of many bioethicists (Table 1) underlines the importance of promoting healthy work-life balance within organizational culture as well as addressing the professional needs for human connections in the institution (3,4). Respondents pointed out that they should not be expected to reply to e-mails or inquiries from work while they are not on shift, especially in the context of working from home, where boundaries between life and work can be blurred:

> *During crisis mode, we are expected to respond no matter the time or day, weekend or workday, and this leads to longer work days which are exhausting to maintain.* (P40, clinical ethics)

Literature points to the importance of the "home as a refuge" and ensuring staff can have moments of decompression outside of work to preserve their mental health, wellness, and capacity to work (3,31). Recommendations for good management in healthcare organizations during COVID-19 also point out familial issues as something to keep in mind and plan around when organizing staffing of all healthcare and essential workers (4,8), including those working in bioethics.

Needed Resources

Respondents identified resources that could help them better deal with the crisis, either emotionally or in relation to their work and tasks. Academic and professional bioethics organizations could provide three of the resources identified (Table 3). Many respondents wrote that their work was isolated from their peers in other institutions, a situation worsened by the pandemic.

Table 3: Requested resources by bioethics practitioners and their domains of application

Requested Resource	Application
Increased ethics staff	Hospital resources, Human resources
National guidelines, standards of work and tools (pandemic-related)	Bioethics organizations, academic support
Informational platforms (pandemic-related)	Bioethics organizations, academic support
Peer support and organized networking	Bioethics organizations, community organization

During this crisis, many respondents mentioned that they would have appreciated more guidance on their work-related responsibilities. Clinical ethicists requested national guidelines and standards for work in bioethics, specifically for clinical ethics consultants. They believed that standardized guidelines for pandemic response would help strengthen their ethical positioning with evidence and harmonize responses between different health organizations, upholding procedural justice. Respondents from all fields of bioethics also requested platforms where they could access up-to-date, conclusive evidence from the scientific and ethics literature relevant to their practical bioethics work, which would also strengthen their recommendations.

The need for better access to scientific and theoretical bioethics literature touches on another concern that respondents identified: the lack of communication between the fields of theoretical and applied bioethics. One respondent formulated a clear criticism on this topic:

> *Relationships between those of us working in healthcare institutions and those in academic positions are strained. We are overwhelmed with work and note that our academic colleagues often speak to the ethics of our institutional practices with clear gaps in their knowledge and with no effort to connect with us to provide advice, support, or to improve their understanding of the current state.* (P30, multiple fields of bioethics)

To address this concern, respondents requested more communication means and platforms, specifically for bridging theoretical and practical (or applied) bioethics and informing each other's work. Respondents believed that bridging this gap would allow for better communication and collaboration, a better voicing of needs, a better understanding of the different realities of each field, and a better translation of theoretical findings into practical use. In clinical or policy settings, there are clear expectations for specific and actionable recommendations, which is not necessarily the case in theoretical discussions (36). Better involving bioethics practitioners in these discussions may improve the applicability of these conversations to concrete situations and ethical issues.

Academic bioethicists can assume a more critical stance regarding healthcare organizations and different policies due to their academic freedom, which is not granted to most bioethics practitioners working within healthcare organizations or government agencies. The need to consider their organization's reputation in their interventions may hinder the ability of bioethics practitioners to express their expert ethical concerns and opinions on certain situations (37-39). On the flipside, bioethics practitioners are well positioned to identify practical ethical issues in healthcare organizations, health policy, and research ethics settings. Therefore, establishing dialogue and partnerships between practical and academic bioethics could greatly benefit both groups: while practical bioethicists can be the "eyes and ears on the ground", academic bioethicists can be the voice of the bioethics community.

It is also worth noting that respondents who reported having difficulty coping with the emotional toll of the COVID-19 pandemic and its effect on their workload were also those who expressed the need for peer support.

All respondents who mentioned post-pandemic situations agreed on the need for long-term changes in the functioning of healthcare organizations (n=8). For some respondents, the pandemic only exacerbated problems in healthcare facilities. Moreover, respondents raised worries about whether healthcare organizations would be able to learn lessons from the current situation, adapt and implement a better response for future crises, or generally improve the quality of healthcare for a post-pandemic system. One respondent voiced apprehensions about the post-pandemic situation:

> *I am really concerned that the overall health care provider institutions and agencies will attempt to recreate the past normal, since they were relatively complacent with how it was functioning, or not functioning, such as mental health services and services to the homeless (major overlap there). This would be a serious mistake when there clearly is opportunity now to move in a different direction based on what we are seeing, for which evidence is beginning to emerge.* (P43, clinical ethics)

From these apprehensions, some respondents wished to see long-term changes in hospital management and practice emerging post-pandemic. However, there were concerns that changes that give a greater importance to ethical questions would not be welcomed equally in all organizations. This respondent voiced the wish to conserve their independence as an ethics consultant for their organization:

> *The pandemic offers a window of opportunity for organizational ethics in our healthcare establishments. I fear that the centralization of ethical questioning will emerge for the healthcare facilities in Québec. In my opinion, the ethics counsellor is a free electron at the service of their institution. It is not a "one size fits all".*
> (P25, clinical ethics, translated by the authors)

Bioethics practitioners in healthcare settings reaffirmed the need to promote their role within their organization, a task facilitated by managerial support. Respondents also pointed out that organizations should encourage transparency and allow for questions when discussing difficult situations or decisions. Literature on moral distress and its prevention supports this, as debriefing and discussing difficult clinical situations can improve healthcare workers' ability to deal with moral conflict (8,15). The goal of interventions should be to build long-term resilience by enabling staff to talk about their experiences and be at peace with decisions (4). This goal was well echoed by respondent answers on their future needs (e.g., peer support, guidelines for communication and pandemic updates), as many of their answers included wishes for expanded and enhanced networking and peer support.

Lastly, respondents indicated that ensuring proper communication between employees to maintain morale and a sense of unity within the healthcare and ethics teams was crucial during a crisis response. Indeed, maintaining frequent communication between healthcare staff, be it through debriefing sessions or peer support, is recommended to preserve staff morale and mental well-being as the pandemic drags on (7,8,14). Moreover, literature points out that not only does this need for communication apply to morale and mental health, but also to the good conduct of work duties in general. Being transparent and keeping all healthcare staff up to date on the hospital's situation, as well as their specific work responsibilities, is crucial to ensuring a proper response in this and future crises (8,14).

STUDY LIMITATIONS

The results of this study may not be fully representative of the views and experiences of bioethics practitioners across Canada. Most study respondents were from Ontario and Québec, with little or no representation from the other provinces and territories; the experiences bioethics practitioners working in rural versus urban settings, or in larger versus less populated provinces could vary substantially. This sampling bias is likely the result of the authors' professional networks and the fact that these are the two most populous provinces in the country. In addition, there was an unequal distribution of respondents across the different fields of bioethics. Clinical ethicists comprised most of the sample, along with some research ethicists, but with few or no organizational ethicists, health policy ethicists, or public health ethicists participating in the survey. As such, our results might disproportionately capture the experience of clinical ethicists as compared to other fields of bioethics. Note also that there is great variation between how different provincial healthcare systems in Canada provide and fund ethics services, which may have affected experiences and responses to this survey, complicating comparisons between bioethicists of different regions. These limitations indicate the need for a much larger and more diverse sample size to attain statistical significance. Another limitation pertains to the time of the data collection. Because the survey took place between May and June 2020, the study provides insight and understanding of how bioethicists perceived and adapted their practices during the early months of the pandemic. Further research is needed to understand how these changes have occurred over time and whether bioethicists' habituation to their new tasks, practices, and work environments has continued and improved, whether the situation has significantly changed with the various waves of COVID-19, and the new challenges these changes may have presented.

CONCLUSIONS

This study aimed to identify the challenges and concerns faced by Canadian bioethics practitioners in the early stages of the COVID-19 pandemic in 2020. At that time, emotional responses to the crisis varied greatly, regardless of respondents' field within bioethics. The study identified many factors affecting bioethics practitioners' ability to emotionally cope with and adapt to new circumstances, suggesting that these mixed responses were due to complex dynamics, both in their work environments and personal life. In addition to collecting insights for adjusting crisis responses in the future, we received valuable qualitative input on what bioethics can do as a field of study to support bioethics practitioners in their duties. We wish to emphasize the value of the qualitative responses to our survey in identifying challenges and apprehensions pointed out by bioethicists during the early days of this public health crisis.

During public health crises, bioethicists (academics and practitioners) can play important roles in identifying and reorienting situations deemed ethically inappropriate, building supportive and compassionate work environments, ensuring resilience of staff in healthcare facilities, and promoting transparent management practices (3,7,8,14,30). Ensuring appropriate responses to the ethical dilemmas and work-related stress resulting from COVID-19 is crucial since those in the healthcare sector have been disproportionately affected during the crisis (4). This is a situation where clinical ethicists can offer much-needed support. How bioethics practitioners have and will continue to negotiate pandemic-related issues will play an important role in shaping future responses to public health emergencies.

In the coming years, it will be important to keep reflecting on the lessons learned from the pandemic and assessing its long-lasting impact on the field of bioethics:

> *Will people have seen the value more so with ethics during the pandemic, which translates into them seeing how it could be helpful outside a pandemic? Or the flipside, was the ethicist role not utilized during the pandemic or was perceived to not make a clinically meaningful contribution, which will influence how people engage with ethics post pandemic?* (P41, clinical ethics)

Conducting a follow-up survey would be relevant and useful to better understand the changing views of bioethics practitioners in the aftermath of the COVID-19 pandemic.

Improving communication amongst academic bioethicists and bioethics practitioners working in different fields, as well as with healthcare providers from different fields (and even between countries), is crucial to building robust long-term solutions to future public health crises. This study has shed light on the preoccupations and challenges faced by Canadian bioethics practitioners, in the early days of a crisis. We hope these insights encourage future collaboration between bioethics practitioners and academics both in Canada and internationally.

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Conflits d'intérêts

Bryn Williams-Jones est l'éditeur en chef de la *Revue canadienne de bioéthique*; Bryn Williams-Jones, Jean-Christophe Bélisle-Pipon, Vincent Couture et Charles Dupras sont membres fondateurs de la revue. Bélisle-Pipon, Couture, Dupras et Vardit Ravitsky font partie du conseil consultatif de rédaction de la revue. Aucun de ces auteurs n'a été impliqué dans l'évaluation ou l'acceptation du manuscrit.

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Conflicts of Interest

Bryn Williams-Jones is the Editor-in-chief of the *Canadian Journal of Bioethics*; Bryn Williams-Jones, Jean-Christophe Bélisle-Pipon, Vincent Couture, and Charles Dupras were founding members of the journal. Bélisle-Pipon, Couture, Dupras and Vardit Ravitsky are part of the journal's Editorial Advisory Board. None of these authors were involved in the evaluation or acceptance of the manuscript.

Édition/Editors: Lise Levesque

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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.

Reviewer evaluations are given serious consideration by the editors and authors in the preparation of manuscripts for publication. Nonetheless, being named as a reviewer does not necessarily denote approval of a manuscript; the editors of *Canadian Journal of Bioethics* take full responsibility for final acceptance and publication of an article.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Ethical Aspects of the Guidelines for Medical Education for Students in their Clerkship Year at the Schulich School of Medicine and Dentistry During the COVID-19 Pandemic

Christine M. Gignac[a], Hazel Markwell[b]

Résumé

Les lignes directrices pour la formation en externat d'une école de médecine canadienne – l'école de médecine et de dentisterie Schulich de l'Université Western – n'énonçaient pas les principes éthiques associés à la décision de suspendre puis de reprendre la formation clinique pendant la pandémie de COVID-19. L'absence d'énoncé des principes éthiques était notable compte tenu de l'impact de ces décisions sur les diverses parties prenantes, et puisque l'éthique joue un rôle important dans la pratique de la médecine. Cette étude a évalué ces directives en utilisant une approche de lentille éthique pour identifier les principes éthiques et les tensions implicites dans les directives. L'externat est défini comme la troisième année de formation dans cette école de médecine, qui consiste en des rotations cliniques. Bien que les principes éthiques n'aient pas été documentés, on a supposé qu'ils pouvaient être identifiés dans les directives. Une recherche documentaire a été effectuée, qui a révélé une lacune dans les connaissances concernant les considérations éthiques de la formation clinique en externat. Les directives ont été analysées et les principes éthiques ainsi que les tensions entre principes contradictoires ont été identifiés. Les principes les plus répandus étaient la bienfaisance et la non-malfaisance. Il est recommandé qu'à l'avenir, les principes éthiques associés aux lignes directrices répondant à des questions importantes ayant un impact sur la formation médicale prédoctorale soient énoncés, afin d'accroître la transparence pour toutes les parties concernées, d'améliorer la communication avec les étudiants et de servir d'exemple de la façon dont l'éthique est appliquée dans un contexte de formation médicale. L'une des limites de cette étude est l'utilisation de documents de lignes directrices internes qui ont été diffusés à l'interne mais qui ne sont pas publiés.

Mots-clés

externat, pause, pandémie, COVID-19, principes éthiques, enseignement médical de premier cycle

Abstract

Guidelines for clerkship training at one Canadian medical school – Western University's Schulich School of Medicine and Dentistry – did not state the ethical principles associated with the decision to suspend and eventually resume clinical training during the COVID-19 pandemic. The absence of stated ethical principles was notable considering the impact these decisions had on various stakeholders, and since ethics plays a large role in the practice of medicine. This study assessed these guidelines using an ethical lens approach to identify ethical principles and tensions implicit in the guidelines. Clerkship is defined as the third year of training at this medical school, which consists of clinical rotations. While ethical principles were not documented, it was hypothesized that these could be identified within the guidelines. A literature search was conducted, which yielded a gap in knowledge concerning ethical considerations of clerkship clinical training. The guidelines were analyzed and ethical principles and tensions between conflicting principles were identified. The most prevalent principles were beneficence and non-maleficence. It is recommended that in the future, the ethical principles associated with guidelines responding to significant issues affecting undergraduate medical education be stated, in order to increase transparency to all parties involved, enhance communication with students, and to serve as an example of how ethics is applied in a medical education setting. One limitation of this study was the use of internal guideline documents, which were circulated internally but are not published.

Keywords

clerkship, pause, COVID-19, pandemic, ethical principles, undergraduate medical education

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INTRODUCTION

The COVID-19 pandemic caused disruptions to nearly all postsecondary education and training programs in Canada, including undergraduate medical education programs, all of which paused clinical training during the early months of the pandemic. This pause was of particular concern in light of the ongoing healthcare crisis, as disruption to medical education could impact negatively the filling of residency spots and the future availability of new physicians across the country – a vital resource for the continuing operation of the healthcare system.

Medical schools in Canada are represented by the Association of Faculties of Medicine of Canada (AFMC), an organization that works to standardize medical education training and provides resources, advocacy, and guidance for schools. Their guidelines provided a framework for individual programs in their response to the pandemic as clinical experiences were paused and eventually resumed. The Council of Ontario Faculties of Medicine (COFM), which is a standing committee of the Council of Ontario Universities, works to ensure consistency and collaboration among the six medical schools in the province; and it adopted the guidelines from AFMC regarding clerkship during the COVID-19 pandemic. In turn, COFM's guidelines informed internal policies at Western University's Schulich School of Medicine and Dentistry's (Schulich). All of

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these guidelines were intended to safeguard students' health, as well as that of other healthcare providers, and to protect the limited supply of personal protective equipment (PPE) available in hospitals and healthcare settings at the time. Notwithstanding these protective measures for medical students, this pause in training caused them concern and distress about lost time in clinical training placements, missed opportunities for clinical experiences, and worry about how this pause would affect their competitive match to postgraduate training programs. Notably absent from these guidelines are outlines or evidence of discussion of ethical considerations inherent to the problems caused by the pandemic and proposed solutions. The AFMC, COFM and Schulich each issued their own sets of guidelines: COFM's guidelines were based on those from the AFMC, and Schulich's in turn were based on those of COFM.

The goal of this research is to identify and better understand the ethical aspects of the guidelines for clinical experiences as part of the medical education curriculum for Schulich's 3rd year medical students during the COVID-19 pandemic.

BACKGROUND

There are many stakeholders in medical education: faculties of medicine, administrators, physicians, healthcare systems, and most importantly, the students. By examining the ethical principles and values that underpin the policies that affect students' experience, medical schools can ensure that the guidelines implemented will optimally support the institution's mission as well as their students. Ethics is at the core of all medical education, and ethical behaviour is an attribute that it strives to develop and strengthen in trainees. Therefore, it is desirable that the system that seeks to develop this quality in its graduates is itself self-reflective in this regard and governed by ethically sound principles. Through the analysis of the ethical considerations embedded in the AFMC, COFM and Schulich guidelines, our goal here is to highlight the principles that are just and ethically defensible, identify where these can be improved, and point out ethical tensions that exist. As ethical values were not explicitly stated, a gap in knowledge has been identified. Explicitly identifying the ethical considerations involved in or underpinning these documents would be a means of demonstrating transparency and accountability on the part of the school's administration, and also help to foster trust and acceptance in the students whose clinical training is governed by these guidelines. Furthermore, students would be more likely to follow these guidelines – because the guidelines ethically justify specific policy choices – and better supported in their training through an optimized provision of medical educational experiences adapted to a crisis situation, such as the COVID-19 pandemic.

A literature search was conducted through the Omni academic search tool.[1] In searching the keywords "Medical Students" AND "Clerkship Policies" AND "Ethical Principles" AND "Pandemic", 16 articles and book chapters were found including 2 duplicate results. None of these yielded applicable findings. When the search was modified to "Ethical Principles" AND "Clerkship Policies", 2 articles were found, although neither was useful. Other search terms were then tried: "Ethical Consideration" AND "Clerkship Policies" (1 article, not applicable), "Best Practices" AND "Clerkship Policies" (1 article, not applicable), and "Clerkship Policies" (9 results, none pertinent). The search was expanded to "Ethical principles guiding clerkship policies", which resulted in 247 articles and book chapters. Once again, none of these texts related to the subject of this inquiry. This literature search did not yield any scholarly articles for ethical considerations in medical school training or clerkship during a pandemic or during normal times. While disappointing, this lack of specific literature points to a need for an investigation of this topic. Nonetheless, we recognize that the use of one search engine is a limitation, and relevant publications may not have appeared in our literature search.

This paper presents the findings from a specific subset of documents developed by AFMC, COFM and Schulich. These address the conditions for medical students' clinical training, and exposure to patients and healthcare settings. These documents do not list the ethical principles considered when creating the policy statements. A gap in existing knowledge has been identified with regards to the identification of the ethical principles that underlie the decisions made by these bodies which control the Schulich clerkship training activities. Apart from drawing attention to this deficit in knowledge, we undertook to identify the ethical principles which can be deduced from these positions, statements and guidelines.

METHOD

The method employed for researching this topic included a survey of the guidelines published by AFMC and COFM as they apply to clerkship, and the specific Schulich guidelines that derive from these, other applicable Schulich guidelines, and a literature review. This method involves descriptive, qualitative research employing primary sources.

As mentioned previously, the preliminary step in the project was a search of any available literature that was similar in nature to the research question. No published scholarly articles on the subject were found in 2020. As such, the literature review for this project only included the relevant AFMC, COFM and Schulich guidelines.

Themes identified from healthcare workers' experiences during the 2002 SARS pandemic are applicable to this research (1). It was determined that an ethical lens approach was best for this project, as opposed to using a specific ethical framework. This approach is described as the conscientious attention to ethical considerations (2). There are many ethical principles, which are fundamental tenets which form the basis of reasoning or action (3) involved in the material examined, and to limit

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[1] Omni is a shared catalogue representing 16 Ontario university library collections, including the University of Ottawa. Omni therefore displays items from all participating libraries. With respect to articles and other resource types, these originate from databases to which the library subscribes.

the review by focusing only on a particular set of principles would unduly constrain the analysis. Documents were analyzed using the lenses of principlism, ethics of care, and virtue ethics.

FINDINGS

Ten documents were reviewed for this study (Table 1). Among these were three statements released by COFM, one by AFMC, five Schulich internal memos and letters, and one Schulich position statement. While the AFMC documents had been available for open access online, the remaining documents were circulated internally by email to the target audience: students, academic leadership and staff. One of the authors (CMG) was on the distribution list for these documents in accordance with their role as Clinical Education Team Leader[2]. The Associate Dean, Windsor Campus, granted approval for review of these documents and the themes therein for the purpose of this project[3].

Table 1: Description of study documents

Document Type	Description	Date	Reference
E-mail	Joint Statement to all Ontario Medical Students. Ontario Deans of Medicine.	16 Apr 2020	6
E-mail, Position Statement	Statement on Medical Learner Participation in Virtual Patient Assessments in Undergraduate Medical Education. Schulich School of Medicine and Dentistry UME Curriculum Committee, June 2020.		Not referenced
Document	Ten Guiding Principles for Medical Education. The Association of Faculties of Medicine of Canada. AFMC Newsletter.	20 May 2020	6
E-mail	Tithecott, Gary. Re: Clerkship – Confidential. E-mail to Clerkship and Electives Committee members.	16 Apr 2020	Not referenced
E-mail	Tithecott, Gary. Re: COVID-19 and MD Program Curriculum.	11 Mar 2020	8
E-mail	Tithecott, Gary. MD Program Memo, The Schulich School of Medicine & Dentistry; Western University Clerkship Innovations in Curriculum for Meds 2021 and 2022.	17 Apr 2020	Not referenced
E-mail	Tithecott, Gary. MD Program Memo, The Schulich School of Medicine & Dentistry; Western University, Clerkship Launch July 6 2020.	5 Jul 2020	Not referenced
E-mail	Tsui, Alice Lisa Shepherd. MD Program Memo, The Schulich School of Medicine & Dentistry; Western University Clerkship Course 5475 March 13, 2020 – Noon.	13 Mar 2020	5
E-mail	UE:COFM Principles and Process for Determining Resumption of Clinical Activities. Council of Ontario Faculties of Medicine.	20 Apr 2020	4
E-mail	UG:COFM and PG:COFM Joint Statement on Medical Student Clinical Experiences. Council of Ontario Faculties of Medicine, Approved by COFM Deans 26 Aug. 2020.	1 Sept 2020	9

All emails received by Christine Gignac

Ethical principles were not listed in any of these documents, which address the circumstances of clerkship during the COVID-19 pandemic, notably the initial pause when students were removed from clinical settings, and as considerations were made in the circumstances that would permit them to resume their training. The identified lack of communicated ethical principles occurred during all phases of the timeline within the scope of this paper, i.e., both early in the pandemic in March 2020 and through the summer when the clerkship pause was lifted, and students returned to their clinical rotations on July 6, 2020. Some common themes, however, were apparent. A few of the documents listed these as “Guiding Principles”. The guidelines were written primarily as instructions to be followed and steps to be taken. As such, it cannot be known whether direct mention of ethical principles was discussed in the creation of these guidelines. Given that the authors were, for the most part, physicians, whose profession is centred on ethical practice, it is not unimaginable that ethics was indeed a part of this process. So, while not explicitly stated, it is still possible to infer ethical principles from the information outlined in these documents.

The most prevalent theme in these documents was student safety, with six of the texts including this among their principles for a return to clerkship. The associated ethical principles are mainly beneficence and non-maleficence. Safety was cited as the reason for the clerkship pause, the continuation of the pause, a proposed date of return to the clerkship, and the conditions that must be present for clerks to safely return to the clinical environment. The benefits of permitting students to return to the clinical environment by necessity would have to outweigh the risks (4). Beneficence is also evident when ascertaining that occupational health guidelines were in place for student safety (4). At the outset of the pandemic, if a clerk had been in contact with a patient who later tested positive for a COVID-19 infection, a process was outlined to ensure appropriate steps were followed which included the clerk self-isolating and contacting Public Health (5). Concern for students’ mental health was also addressed in these documents. In addition to beneficence, this demonstrates the ethical principle of reciprocity. There was an acknowledgement of the stressful situation this created for students. The Ontario Deans of Medicine acknowledged in their “Joint Statement to all Ontario Medical Students” document the uncertainty over when the students would resume their clinical training (6), and stress in the learning environment (7) was cited. Support services through the Learner Equity and Wellness Office were recommended to clerks (8).

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[2] Substitute position October 2019-August 2020

[3] Due to the privileged nature of this information, confidentiality regarding conversations pertaining to these issues was maintained and no identifying information of parties was disclosed.

COFM’s measure to allay mounting uncertainty and stress was to establish a common “earliest possible” date for resumption of clinical placements (4). Physical concerns were allayed by ensuring students’ return would be safe and PPE was provided. Mental health concerns were addressed by working to get clerks back to clinical placements as quickly as possible. Students were encouraged to contact support services through the Learner Equity and Wellness Office. Table 2, below, outlines the details of how specific factors should be addressed with regards to student safety.

Equality was the next most common theme, with five of the documents alluding to this consideration. The prevailing context for this theme was to emphasize that although the altered clinical training experience brought about by the pandemic may be seen by some students to be inferior due to the absence of some rotations and procedures that previously were available, the six medical schools in Ontario had agreed to all follow the same set of guidelines and conditions. In so doing, no school or group of students within the province of Ontario could be seen to have an advantage over others. For example, all Ontario medical schools agreed to return to clerkship training within the same general timeframe if not the exact same date (6). In addition, a “Key Principle Statement” in one of the COFM statements outlined that students were not to seek out experiences “outside of approved curricular activities”, both because of liability, as they may not be covered by malpractice insurance, and also to not gain an advantage over other students (9).

Other common themes found in these documents were patient safety, and restriction of choice, both with four counts each. Patient safety, demonstrating the values of beneficence and non-maleficence, was a consideration primarily in the documents that provided guidance on a return to clerkship. Having the students present and interacting with patients in care settings could occur as long as the overall benefit to patients outweighed any potential risk.

The ethical values of proportionality, duty to care and social responsibility are evident here. Restriction of choice describes occasions where clinical learning opportunities and environments are limited due to the pandemic. This involves the principle of autonomy in conflict with other values as seen in the students’ restriction of choice. Some examples of this are rotations such as Emergency Medicine that might expose clerks to COVID-19 positive patients, or specific procedures, for example intubations, which cause exposure to aerosolized bodily fluids that pose a higher risk. Limitation in the locations students could choose for their electives was also outlined, as schools closed their doors to accepting students from other medical school programs. Before the pandemic, medical students nationwide could choose elective placements in any medical school location across Canada – these were now limited to rotations within their home school.

Concern over the availability of adequate PPE worldwide was a major reason for removing clerks from clinical settings early on. The ethical values associated with this are justice, and prudent use of resources. One of the factors for resuming clerkship was the ability to ensure that clerks would be provided with an adequate supply of PPE as outlined by local infection control and prevention bodies (non-maleficence). Additionally, students could not return to clerkship unless they were trained on how to properly use the PPE (beneficence) (7).

Three of the documents listed “Guiding Principles”. Most of these principles were the same, with differences arising as the guidelines moved from a national scope to a local one. For the AFMC and COFM, the Key Principles were comprised of the themes mentioned above (patient safety, student safety, safety of teaching faculty and hospital staff, learning, supervision, and consistency). The Schulich document (9) lists eight guiding principles and outlines procedures for students, faculty, and programs to follow, and restrictions on students’ clinical experiences to be observed. For example, students ought not to participate in any activities organized by postgraduate programs, so that they would not be seen to gain an unfair advantage over other students.

RECOMMENDATIONS

Our principal recommendation is that the ethical principles that were implicit in the documents reviewed be made explicit in future guidelines. When ethical principles are visibly included in the decision-making process in extraordinary circumstances, such as the COVID-19 pandemic, it helps to promote understanding, trust and transparency among the individuals affected by the process. Changes to clerkship training were made primarily at the outset to protect the health and ensure the safety of students. As the pandemic continued over the following months, other factors were considered, notably patient and staff safety as a return to clerkship training in the clinical environment was in the planning stages. The issue of clerkship training during the pandemic was highly complex and presented more challenging issues than initially thought. Including the ethical principles that underlie changes resulting from a pandemic situation can encourage dialogue and provide checks and balances to ensure leadership makes the best decisions possible during challenging situations. Secondly, we encourage institutional leaders – and those responsible for drafting guidelines – to identify ethical principles and conflicts between them when creating guidelines that can significantly affect students’ training experience. Addressing the ethical principles would be a starting point for integrating ethics into guidelines addressing issues relating to undergraduate medical education, and clerkship in particular.

The ethical principles most evident in the documents reviewed are beneficence and non-maleficence. Beneficence is applied in the desire by leadership to ensure the safety of the students, physicians, patients, and other professional staff. Non-maleficence is evident when considering the re-entry of students to the clinical learning environments and weighing whether the risks of potential COVID-19 exposure outweigh the benefits of resuming training. And it also applies to patients, to ensure the clerks are reintegrated in a safe manner that does not endanger patients under their care. The principle of justice is seen in the efforts across the various organizations to maintain equity for medical learners, so that none are given opportunities that are unavailable to others. This principle also applies when considering the impact on resuming clerkship training and having students back with physicians and patients, as the interests of each of these groups also must be considered. The wise use of resources is a component of justice and was applied early on in the pandemic when adequate supplies of PPE was an issue. Students' medical school journey was severely restricted, both in terms of choices of electives and in the freedom to partake in all the procedures and clinical experiences that are normally a part of clerkship. Here we see a tension arise as leadership sought to balance the public health restrictions caused by the pandemic (beneficence, non-maleficence and justice) with permitting students to have as wide a breadth of clinical experience as possible, out of respect for their autonomy.

In addition to these principles, several other notable values are evident in these guidelines. For example, ethical principles that have a theological dimension and are important in Catholic Health Care Ethics were also present. Solidarity, for example is an ethical principle found in several of the documents and was evident in the descriptions of the governing bodies in their attempt to ensure fairness and equity for learners across the province. This speaks to the dignity of and respect for persons, in this case the learners. Virtues serve to perfect the moral agent with the aim of achieving certain goods (10). Prudence speaks to caution and considering all available information when making decisions. The virtue of justice enables its possessor to discern the best actions and choices for the circumstance. Stewardship, which is connected to the virtue of justice, applies to resource utilization (10). The common good, which involves the good of society (11) is also a component of the virtue of justice (12). Solidarity and beneficence are both expressions of the virtue of charity (12). These are important as part of Schulich medical students' training in Ontario takes place at Catholic-sponsored healthcare institutions.

Some common themes were apparent**.** Table 2 lists the ethical values that correspond with the themes and principles identified in the documents.

Table 2: Themes, principles and ethical values found in study documents

Themes and Principles	Ethical Values	Number
Student safety	Beneficence, Non-maleficence	6
Collaboration	Solidarity	5
Equality	Equity	5
Patient Safety	Beneficence, Non-maleficence	4
Restriction of choice	Beneficence, Non-maleficence, Autonomy	4
Innovation	Effectiveness	3
Keep up to date /Review regularly/Assess/Planning	Effectiveness	3
Openness/Communication	Transparency	3
Physician and Professional Staff Safety	Beneficence, Non-maleficence	3
Seeing others' perspective	Reciprocity, Solidarity	3
Solidarity	The common good	3
Best Practices/& Public Health	Protection from harm	2
Excellence/Standards	Virtue ethics	2
Fairness	Justice, Equity	2
Learning	Self-improvement	2
Self-care for students	Reciprocity, Beneficence	2
Uncertainty	Faith	2
Beneficial for everyone	Beneficence	1
Professional liability	Duty to care	1
Professional values	Virtue ethics	1
Support	Justice, Reciprocity, Solidarity, The Common Good	1

To demonstrate how ethical principles can be applied in the decision-making process, the table from the *UE: COFM Principles and Process for Determining Resumption of Clinical Activities* (3) has been amended by adding a column that lists the associated ethical values (Table 3).

Table 3: Ethical values in the UE COFM Principles and Key Considerations

Ethical Values	Principle	Key considerations
Non-maleficence Reciprocity Beneficence Utility	Patient safety	Would the presence of students in the clinical environment jeopardize or promote optimal patient care? • *Would students be able to provide valuable service by “off-loading” specific aspects of care from other providers?* • *Would students increase the risk of disease transmission?* • *Would students use valuable PPE?*
Beneficence Non-maleficence Reciprocity Trust	Student safety	Can students be protected from, or excluded from, excessive risk? • *Although some small risk is inherent in any clinical placement, would students be exposed to risks considered above the “norm”, or without protections and considerations that would be reasonably expected?* • *Will students be provided with the full, minimum PPE that is suggested as required by scientific knowledge with respect to COVID-19?* • *Are there local occupational health processes in place to protect students who may be exposed to COVID-19?* • *If it is deemed essential to exclude students from some clinical situations and not others, can that exclusion be reasonably achieved?* • *Do current student liability arrangements cover the current clinical environment?*
Beneficence Non-maleficence Reciprocity Utility Trust	Safety of teaching faculty and hospital staff	Would student placements jeopardize the safety or wellness of teaching faculty or other hospital staff? • *Would students provide valuable service that would be of benefit to faculty or other providers?* • *Would students integrate into care teams as currently constituted during the crisis?*
Proportionality Utility	Learning	Can a valuable learning experience be provided? • *Are there sufficient roles in which the students can engage?* • *Do these roles have educational value?* • *To what extent is any involvement a valuable and possibly unique learning experience?*
Stewardship Non-maleficence Excellence Equity	Supervision	Are there sufficient clinical teaching faculty available to provide student supervision? • *Can continuing oversight of learners be provided* • *Can learners be assessed?* • *Are these available in all areas necessary to provide a full clerkship experience?*
Solidarity Equity	Consistency	Given the accepted principle of alignment of all Ontario schools, can the above be achieved for all at this time? • *Although exact synchronization of return dates may not be possible given varying clerkship structures and impact of the pandemic, schools will strive to coordinate and minimize discrepancies.*

CONCLUSION

This study explores and describes the ethical considerations for the pause and eventual resumption of clerkship training for medical students at the Schulich School of Medicine and Dentistry during the 2020 COVID-19 pandemic. In the early weeks of the pandemic, medical students were left with many questions about what their journey to becoming doctors, in a context where their expected path was abruptly halted. This liminal experience will profoundly shape the practice of this cohort of medical students. These clerks found themselves in an unexpected space where their clinical training ended abruptly, and they were left waiting for an uncertain future. This was uncharted territory, not only for these students but also for the physicians who supervised them, their families and friends, and society at large. And it was a difficult time for everyone, particularly those working in healthcare. It can be argued that this situation affected clerks in a unique way, because they were left on the sidelines while many of the physicians who supervised them were continuing to work every day, courageously battling this disease and saving lives. The clerks were excluded from this experience, while trainees just a few years their senior were able to continue their residency training experiences. In light of this situation, and the fact that these students had paid significant tuition fees, to not be allowed to participate in the medical community as they expected to, and to not even know what to expect going forward, affords them special consideration in this circumstance.

The administrators whose decisions marked the pause and resumption of clerkship had a significant influence on these students. There was no explicit evidence of ethical consideration regarding these decisions in the guidance documents outlining changes to the clerkship experience; nonetheless, our analysis pointed to a series of ethical principles that implicitly underpinned these documents. So, while it can reasonably be presumed that these principles were unconsciously applied by those responsible for managing the clerkship during the pandemic, a reliance on the implicit ethical virtues and good judgment of professionals and decision-makers is clearly insufficient for good governance. It is thus recommended that in the future administrators explicitly include the corresponding ethical principles alongside the guiding principles they propose, while also describing the ethical conflicts they encounter, in order to increase transparency to all parties involved, enhance communication with students, and thereby serve as an example of how ethics is applied in a medical education setting.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

L'accès aux soins palliatifs, équitable pour tous? Le cas des personnes en fin de vie vivant l'itinérance

Marie-Hélène Marchand[a]

Résumé

Tout être humain sera exposé un jour à un certain degré de souffrance. Une tranche de la population, les personnes vivant l'itinérance, sera cependant beaucoup plus susceptible de côtoyer la mort, la maladie et les deuils. En effet, au Québec, elles sont quatre fois plus à risque de développer un cancer et leur espérance de vie se situe entre 42 et 52 ans. Devant la mortalité et la morbidité élevées rencontrées dans la population itinérante est soulevée cette question : est-ce que ces individus ont un accès équitable aux ressources en soins palliatifs? L'arrivée de la Loi 2 en 2015 a permis d'encadrer les soins de fin de vie au Québec. Au cœur de cette loi se trouve le droit des malades en fin de vie d'avoir accès à des soins palliatifs pour prévenir et apaiser leurs souffrances. Or, plusieurs enjeux viennent influencer l'accessibilité aux soins palliatifs pour la population itinérante, notamment des facteurs individuels tels que la maladie mentale et la dépendance aux substances, compliquant la recherche de soins. La méfiance des individus ayant vécu de multiples expériences traumatiques ajoute une barrière supplémentaire. De plus, trop occupées à survivre, ces personnes naviguent difficilement dans le système de santé. Des facteurs structuraux, tels l'absence de logements abordables ou les répercussions d'un système en silos moins adapté aux situations sociales complexes contribuent au manque d'accessibilité. Les préjugés sont très répandus, participant à l'exclusion symbolique et institutionnelle de cette population. L'objectif de cet article sera donc d'approfondir notre compréhension des enjeux d'accès aux soins palliatifs pour la population en situation d'itinérance au Québec.

Mots-clés

itinérance, soins palliatifs, accessibilité aux soins, fin de vie, précarité sociale, équité

Abstract

Every human being will at some point be exposed to some degree of suffering. One segment of the population, people experiencing homelessness, will be much more likely to experience death, illness and bereavement. In Quebec, they are four times more likely to develop cancer and their life expectancy is between 42 and 52 years. The high mortality and morbidity of the homeless population raises the following question: do these individuals have equitable access to palliative care resources? The arrival of Bill 2 in 2015, allowed for the regulation of end-of-life care in Quebec. At the heart of this law is the right of patients at the end of life to have access to palliative care to prevent and ease their suffering. Several issues influence the accessibility of palliative care for the homeless population. Individual factors such as mental illness and substance abuse complicate access to care. The distrust of individuals with multiple traumatic experiences adds another barrier. In addition, these individuals are too busy surviving to navigate the health care system. Structural factors, such as the lack of affordable housing or the impact of a siloed system less suited to complex social situations, contribute to a lack of accessibility. Prejudice is widespread, contributing to the symbolic and institutional exclusion of this population. The objective of this article is therefore to deepen our understanding of the issues of access to palliative care for the homeless population in Quebec.

Keywords

homelessness, palliative care, accessibility to care, end of life, social precarity, equity

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INTRODUCTION

La définition de l'itinérance est multiple et complexe; plusieurs la décrivent comme une absence, voire une impossibilité, d'un chez soi nécessaire à l'identité, à la sécurité et à l'insertion sociale dans le monde (1). Les répercussions de cet état sont nombreuses, tant sur la vie des individus que sur leur mort. Des statistiques alarmantes sur le haut taux de cancer, la sur-représentation des maladies chroniques et la faible espérance de vie nous permettent de constater que les gens aux prises avec l'itinérance côtoient la mort, la souffrance et les deuils de façon disproportionnée (2). Les soins palliatifs représentent une approche désignée à soulager les souffrances des gens vivant avec une maladie potentiellement mortelle. Pourtant, devant ces faits, une question demeure : est-ce que les personnes en situation d'itinérance (PSI), et donc à plus haut risque de mortalité, ont un accès équitable aux ressources en soins palliatifs? Après avoir brossé un bref portrait de la situation de l'itinérance au Québec, nous aborderons le cadre législatif entourant les soins palliatifs au Québec, les barrières qui freinent sa mise en place pour les PSI, puis nous explorerons les enjeux de vulnérabilité structurelle et de justice influençant la réalité des PSI. Finalement, nous regarderons les ponts prometteurs en matière d'intervention clinique et de politiques publiques pour permettre une vie et une mort plus dignes pour cette population.

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ÉTAT DES FAITS

Définitions et mesures

À la suite de la publication de sa politique nationale de lutte à l'itinérance en 2014, le gouvernement du Québec a tenté de donner une définition au phénomène de l'itinérance (1). On y parle d'une désaffiliation sociale qui s'exprime par la difficulté, pour un individu, d'avoir un chez-soi stable, adéquat et sécuritaire. Ceci va donc au-delà du lieu physique pour s'abriter. La politique nationale va ainsi plus loin, elle décrit le domicile dans sa structure idéale comme « un levier au bien-être, à la citoyenneté, à la relation de la personne avec sa propre identité et avec son environnement social » (1). La capacité d'habiter a plusieurs fonctions allant de protéger, d'intégrer l'individu dans le monde, de favoriser son autonomie et d'être un ancrage identitaire. À l'inverse, ne pas avoir de chez-soi revient à la perte potentielle de tous ces éléments cruciaux et à la non-satisfaction des besoins élémentaires.

De plus, mesurer l'ampleur du phénomène de l'itinérance n'est pas chose simple. En effet, la mouvance y est grande et une bonne partie de cette population vit une itinérance dite cachée, elle-même définie par la nécessité d'être hébergé temporairement par la famille, les amis ou des vagues connaissances en raison de l'absence d'autres options (3). Ces individus vivent ainsi une précarité de logement et traversent parfois des épisodes d'itinérance visible. Devant la complexité de connaitre le nombre exact de gens en situation d'itinérance visible ou cachée, plusieurs initiatives ont vu le jour. Par exemple, au Québec, un recensement a permis d'identifier, le 24 avril 2018, 5789 personnes vivant en situation d'itinérance visible (4). Ce chiffre est bien sûr limité par cette stratégie de recensement sporadique. Les documents entourant la politique nationale de lutte à l'itinérance rapportent plutôt des chiffres de l'ordre de 30 000 personnes, tout en précisant que ces données datent de 2005 et sous-estimeraient très probablement le phénomène (1). En 2011, une étude longitudinale dans trois villes canadiennes suivant la santé d'individus vivant l'itinérance cachée et visible a montré que, pour chaque personne vivant dans la rue, 23 se retrouvaient en situation de précarité de logement (5). Cette même étude nous a démontré que l'état de santé de ces deux groupes se compare et se situe bien en-dessous de celui de la population générale.

Problèmes de santé spécifiques

Plusieurs études ont montré que les personnes vivant l'itinérance, visible ou non, sont fragilisées de nombreuses façons (6,7). En outre, 75 % des individus ont une ou des maladies chroniques, on recense au sein de cette population 28 fois plus de cas d'hépatite C et 4 fois plus de cas de cancer, et l'espérance de vie chez les hommes en situation d'itinérance est entre 42-52 ans, ce qui est bien inférieur à la moyenne québécoise. De plus, le taux de mortalité chez les PSI est de 3 à 4 fois supérieur à celui de la population générale et les gens vivant l'itinérance utilisent de 3 à 4 fois davantage les urgences comme porte d'entrée au système de santé alors que leur séjour hospitalier est d'une durée de 35 % plus longue que les gens avec un statut domiciliaire stable. Ces gens sont ainsi exposés à une mort « omniprésente », souvent prématurée, violente et traumatisante (2). Qu'en est-il de l'accès aux soins, et plus particulièrement aux soins palliatifs qui visent, selon l'organisation mondiale de la santé, l'amélioration de la qualité de vie en situation de maladie engageant le pronostic vital (8)? Devant les conditions listées ci-haut, on peut s'attendre à une présence forte du besoin de soins palliatifs au sein de la population itinérante.

LA LOI CONCERNANT LES SOINS DE FIN DE VIE ET L'ACCÈS AUX SOINS PALLIATIFS POUR LA POPULATION ITINÉRANTE

Au Québec, la Loi 2 concernant les soins de fin de vie est venue affirmer le droit de recevoir des soins palliatifs à tous ceux et celles qui le requièrent (9). On y prône l'importance de la continuité et de la qualité des soins tout autant que leur accessibilité pour toute la population, et cela, sans discrimination. L'accès aux soins palliatifs représente un enjeu important pour la population générale, mais le demeure encore plus pour les personnes marginalisées. Au Québec comme au Canada, cette inaccessibilité est en grande partie attribuable à la structure des soins de santé généraux incluant les soins palliatifs. Cette structure vise principalement à répondre aux besoins d'une population relativement homogène ayant des caractéristiques communes de niveau de vie, de culture et d'appartenance religieuse (10). Il en résulte que les gens vivant une expérience de vie différente, telle l'itinérance, passent entre les mailles du filet et reçoivent des soins trop tard ou pas du tout, connaissant ainsi des fins de vie moins qu'idéales (10).

Plus précisément, une étude pancanadienne nous a permis de confirmer que les individus vivant l'itinérance décédaient plus souvent sans support du système santé et donc loin des ressources en soins palliatifs. Ces personnes meurent fréquemment seules, dans des conditions traumatiques et sont mal soulagées (11,12). La surexposition à la mort traumatique mène à des croyances uniques face à la fin de vie qui sont potentiellement négligées dans la littérature plus large sur les soins palliatifs (2). Alors que certaines personnes développent une acceptation fataliste de la mort, d'autres vivent dans la peur constante d'un décès imprévisible et désagréable (2). La notion de « bonne et de mauvaise mort » s'en trouve influencée. Pour plusieurs, la « mauvaise mort » sera définie par la violence, l'isolement, la dépendance et la perte d'autonomie (2). En revanche, une bonne mort sera décrite comme paisible, sans souffrance, entourée de proches et impliquant la résolution de problèmes relationnels et spirituels (2). Les gens en situation d'itinérance souhaitent aussi être impliqués dans les choix à faire en lien avec leur santé et leur fin de vie (11). Les droits à l'autonomie, à l'autodétermination, au respect et à la dignité sont ici nommés.

Les soins palliatifs pourraient s'avérer un moyen tout désigné pour accompagner les grands malades vivant dans la rue à travers leur quête de sens, de soulagement et de qualité de vie. En effet, les soins palliatifs, par leur approche inclusive et holistique ont, au cœur-même de leur définition, la prévention et le soulagement des souffrances grâce à une reconnaissance précoce des problèmes, qu'ils soit d'ordre physique, psycho-social ou spirituel, et cela, pour tout individu menacé par une maladie potentiellement mortelle (8).

Pourquoi sommes-nous plutôt devant un manque d'accès, voire une absence d'accès, pour cette tranche de la population?

Tout d'abord, certains freins à l'accès aux soins palliatifs pour les PSI sont considérés comme secondaires aux caractéristiques individuelles. Par exemple, la maladie mentale et la dépendance aux substances sont surreprésentées en itinérance, compliquant la recherche de soins (6). Ces individus sont souvent trop occupés à survivre et l'énergie manque pour aller consulter malgré des besoins criants. Il existe ainsi une compétition des besoins (2). Le besoin d'être soigné peut-être déclassé face aux besoins jugés plus importants par certains : besoins de base, besoin de consommer pour éviter des symptômes de sevrage, besoin de s'isoler d'un monde perçu comme hostile et menaçant, etc. Parallèlement, on retrouve chez beaucoup d'individus une certaine méfiance envers les services de santé. Leur passé parsemé de multiples expériences traumatiques, que le système réactive parfois, ajoute une barrière supplémentaire aux soins (2,11). Par exemple, plusieurs personnes utilisatrices de drogues décrivent les soins de santé comme étant pleins de préjugés, les culpabilisant de leurs problèmes de santé tout en sous-traitant leurs symptômes et leur souffrance (13). Leur sentiment de rejet peut être renforcé, les influençant ainsi à ne pas consulter lors d'un enjeu de santé (13), faisant ainsi tourner la roue sur elle-même : marginalisation, expérience de rejet, amplification de la marginalisation.

Des facteurs structuraux sont aussi à prendre en considération puisqu'ils modulent non seulement la situation globale mais aussi les caractéristiques individuelles discutées plus haut. Pensons à la perte des prestations d'aide sociale, à l'absence de logements abordables et aux répercussions d'un système en silos, moins adapté aux situations sociales complexes. De plus, tel que mentionné précédemment, les ressources en soins palliatifs assument généralement que les patients ont un chez-soi adéquat et sécuritaire, une famille ou des amis et une certaine capacité financière pour assurer les frais supplémentaires nécessaires (10). Par exemple, pour recevoir des soins palliatifs à domicile d'un Centre Local de Services Communautaires (CLSC), l'adresse de la personne recevant les soins est au cœur de la demande. Or, même si un refuge s'avère être le domicile temporaire de plusieurs personnes, les soins à domicile ne s'y rendent pas. De plus, si certains ont la chance d'avoir un logement mais que ce dernier est insalubre ou non sécuritaire, une tension apparaitra entre le droit au patient de recevoir des soins et celui de l'intervenant de travailler dans un environnement sécuritaire. Les soins pourraient donc être compromis. Ainsi, comment identifier les patients qui ont besoin de soins palliatifs si on ne peut se rendre à eux? Résultante fréquente – les patients utilisent l'urgence comme porte d'entrée dans le système, même alors qu'ils sont mourants (2,11).

Bien qu'elle s'inscrive dans un contexte socioculturel différent, l'étude de De Veer et al. a identifié trois clés pour mieux comprendre l'accessibilité réduite aux soins palliatifs pour cette population (14). Premièrement, on note un accès retardé aux soins palliatifs pour les PSI, ce qui s'explique tout d'abord par la difficulté des patients de voir leurs symptômes reconnus par les professionnels de la santé, puis par l'ambivalence des patients devant l'acceptation des soins et finalement, par l'absence de soins palliatifs adaptés aux besoins spécifiques de cette population.

Deuxièmement, De Veer et al. décrit une trajectoire de soin « sinueuse » en raison de comportements qui posent parfois des défis. À cet effet, il précise que plusieurs professionnels trouvent ardu de maintenir une communication fluide avec cette population. Pour décrire les comportements jugés problématiques, les professionnels utilisent des étiquettes d'agressivité, de manipulation, de violation des normes et des règles, etc. Il en résulte une continuité de soins non optimale avec des pertes aux suivis ou des suivis en dents de scie. La trajectoire sinueuse se manifeste également au niveau de la progression imprévisible de leur maladie en raison d'un mode de vie instable et de ses répercussions sur l'état de santé de l'individu (14). Nous pouvons avancer que même avec une sensibilisation préalable à la réalité de l'itinérance, il peut être ardu pour un professionnel d'identifier la détérioration en raison de la nature de la pathologie sous-jacente, des comorbidités physiques et psychiatriques et des interactions chaotiques avec le système de santé (2).

Troisièmement, une complexité se juxtapose devant le contrôle difficile des symptômes ainsi que devant l'absence d'un tissu social fiable (14). Les PSI ont souvent des besoins de soins complexes en plus de symptômes difficiles à reconnaitre et à interpréter. Par exemple, le contrôle de la douleur chez cette population est fréquemment un défi en raison d'abus de substances augmentant la tolérance aux analgésiques ou encore devant des enjeux de santé mentale complexifiant le questionnaire médical (14). Ainsi, la non-reconnaissance ou la prise en charge insuffisante de la douleur par les professionnels, souvent mal outillés devant la réalité des PSI, peut décourager plusieurs individus à chercher des soins médicaux même lorsqu'en fin de vie (15). Puis, même au sein d'une prise en charge médicale adéquate, la continuité des soins est menacée par la difficulté à impliquer les proches. En effet, alors que dans la population générale, les parents sont souvent directement impliqués dans les soins en contexte de fin de vie, dans la population sans domicile fixe, la famille est souvent absente. Des démarches peuvent être entreprises pour rétablir les liens familiaux, mais cette tâche s'avère rarement possible (14).

L'accès aux soins palliatifs est certes influencé par différents facteurs individuels et structuraux, mais nous devons souligner que les PSI sont souvent exclues des considérations politiques entourant les soins de santé. L'exclusion est ici multiple. Prenons l'exemple des personnes âgées en situation d'itinérance. À ce sujet, un article paru dans *Frontières* mentionne que l'itinérance est le résultat de multiples formes d'exclusion mais que, chez les personnes âgées vivant l'itinérance, deux types d'exclusion participaient davantage à leur désaffiliation (15). D'abord, l'exclusion symbolique, qui est le fruit des stéréotypes accolés aux personnes âgées, mais aussi aux itinérants, qui sont parfois considérés comme étant nuisibles, invisibles ou les deux. Ensuite, l'exclusion institutionnelle comprend « l'absence d'accès aux mesures de protection sociale et sanitaire prévues par les institutions. » (14) Cet exemple nous permet de souligner que bien que la mort soit une expérience universelle, la grande majorité des personnes qui ont actuellement accès aux soins palliatifs s'inscrivent dans des profils sociodémographiques et économiques particuliers (ex. : diagnostiqués avec un cancer, issus de groupes culturels et religieux majoritaires, de niveaux de revenu moyen à élevé, logés de manière stable, socialement connectés) (10,16). Les expériences d'autres groupes de population, en particulier les personnes structurellement vulnérables, sont largement invisibles, ce qui fait que leurs besoins restent sans réponse et que les institutions, tout comme les politiques publiques, ne s'y attardent guère (16). Pour preuve, notons qu'aucune référence aux personnes en situation d'itinérance n'est faite dans les rapports de la *Commission sur les soins de fin de vie*, malgré son mandat donné par la Loi 2 « d'examiner toute question relative aux soins de fin de vie » au Québec (9).

Cette situation préoccupante soulève plusieurs autres enjeux relatifs à l'équité dans les soins de santé, à la justice et au concept de vulnérabilité.

VULNÉRABILITÉ ET JUSTICE

En premier lieu, il est intéressant de peaufiner le concept de vulnérabilité. Selon Serge Boarini, « la vulnérabilité exprime un moment de tension, de crise, voire de révolution, entre un être et les conditions nécessaires pour la pérennité de son intégrité et de son identité » (17). Sans être pure passivité, le vulnérable n'arrive ni à répondre « à l'atteinte à son intégrité, à son autonomie, à son projet » (17), ni à s'insérer dans le monde alors qu'il le devrait. Ryoa Chung va plus loin et nous parle de vulnérabilité structurelle (18). Selon ses propos, la catégorisation de certaines personnes en tant que vulnérables provient principalement de leurs conditions sociales et ces gens n'ont pas de « statut ontologique avant les injustices structurelles qui les définissent politiquement plutôt qu'intrinsèquement. » (18) On peut ainsi naitre avec ou développer des vulnérabilités physiologiques mais ce sont les conditions structurelles extérieures, économiques, sociales ou politiques qui nous rendent vulnérables ou non. Ainsi, à la lumière de cette réflexion, nous en sommes à comprendre que le système devrait tout d'abord travailler à abolir les injustices structurelles afin de rétablir les conditions nécessaires à une vie digne, et d'ainsi considérer l'individu dans son intégrité et son identité.

En fait, de nombreux programmes ou politiques publiques en itinérance ont été élaborés pour répondre à cet objectif. Les orientations sont prises en fonction d'une conception de ce qui est juste et acceptable. Par exemple, dans son rapport en 2013 sur les « Aspects éthiques de la prise en compte des populations dans le processus d'évaluation d'impact sur la santé » (19), l'Institut national en santé publique du Québec (INSPQ) mobilise la théorie de Norman Daniels qui identifie comme prémisse que la santé est particulière et constitue un bien fondamental. Elle se mérite ainsi un cadre de justice bien à elle. Daniels avance, en s'inspirant des théories égalitariennes, que la justice est bonne pour la santé puisque « les inégalités économiques, sociales et politiques sont nuisibles à la santé, peu importe le niveau auquel elles s'expriment. Les inégalités sociales de santé qui, elles, découlent directement des inégalités économiques, sociales et politiques constituent ainsi une cible importante dans la poursuite de la justice. » (18) Selon cette approche les institutions doivent travailler à la correction des inégalités en santé pour permettre une réelle égalité des chances. Également, le rapport de l'INSPQ présente les travaux de Amartya Sen qui va un peu plus loin en stipulant que l'accès équitable aux ressources, en diminuant les inégalités, ne suffit pas à s'assurer que les gens arrivent à les utiliser pleinement. Sen propose ainsi que « les politiques soient développées de façon que tous puissent développer leur plein potentiel humain, à partir de leurs capabilités. » (19) L'objectif d'une société juste, selon ces termes, est de satisfaire les besoins de santé des individus, mais ici, dans l'optique qu'ils puissent développer leur capacité selon leur plein potentiel. Cette capacité leur permet ainsi d'être en mesure de choisir ce qu'ils identifient comme bon pour eux au lieu d'être contraints à un mode de vie et à un niveau de vie qu'ils n'auraient pas choisis. Et ceci devrait s'appliquer à tous les stades de la vie, incluant l'approche de la mort.

Bref, en nous familiarisant avec ces théories, nous concluons que les politiques publiques tentent de tenir compte des injustices et de s'y attaquer pour le bien de tous et toutes. C'est aussi ce qui est clairement véhiculé dans la politique nationale de la lutte à l'itinérance en nommant des axes d'actions prioritaires pour enlever des obstacles systémiques tels que le manque de logements abordables, la difficulté d'accès aux soins de santé, le revenu minimal, etc. (1). Il n'est cependant pas si facile de savoir comment ces politiques se concrétisent sur le terrain puisque les données de santé catastrophiques persistent et l'accès aux soins reste encore très difficile pour les PSI. Les mesures déployées sont-elles suffisantes et surtout pensées et appliquées pour que les individus puissent les utiliser selon leur plein potentiel? Est-ce secondaire à un enjeu de distribution des ressources devant une demande grandissante et des ressources limitées? Sommes-nous devant un tabou social autour de la mort et, peut-être même, un tabou de la pauvreté extrême au sein d'un pays développé? Ces questions restent en suspens.

LES PISTES DE SOLUTIONS

Soins directs aux patients

Devant l'accès aux soins plus difficile pour la population itinérante, de nombreuses études pointent l'importance d'avoir des initiatives allant rejoindre les gens directement dans leur milieu. Par exemple, les refuges seraient considérés par plusieurs comme des lieux privilégiés pour fournir des soins palliatifs (2), tout d'abord par la présence de personnel agissant souvent en tant que défenseurs, amis et famille pour les PSI (2), puis par le fait que, pour plusieurs individus dans la rue, les refuges sont reconnus comme étant leur domicile, leur lieu sécuritaire et familier (2). Une initiative en ce sens a vu le jour dans un refuge à Ottawa, où non seulement des gens ont pu vivre leur dernier moment en toute dignité et sans douleur, mais cette initiative a également permis une économie au système de santé de 1,3 million de dollars (20). La maison du Père à Montréal offre également quelques lits de soins palliatifs au sein de son organisme (21). Des programmes de soins palliatifs sous forme de soins de proximité ont aussi émergé devant le manque de ressources adaptées. Pensons au programme P.E.A.C.H basé à Toronto qui offre directement dans la rue des soins infirmiers et médicaux spécialisés en soins palliatifs pour les PSI (22). Et plus récemment, toujours à Toronto, la création d'une maison de soins palliatifs destinée aux PSI est venue offrir une alternative pour cette population autrement difficilement rejoignable (23).

Le partenariat patient en contexte de précarité sociale

Le concept de patient partenaire prend de plus en plus de place dans les différents programmes et services de santé. Le patient partenaire est considéré comme un membre à part entière de l'équipe soignante et son savoir expérientiel permet de réellement orienter les soins vers le bien-être du patient (24). Ce concept n'est pas encore répandu dans tous les domaines de soins mais plusieurs initiatives s'en inspirent. En itinérance, la notion de pair aidant ou de pair navigateur peut être un atout pour faire entendre la voix d'un individu ayant à naviguer dans le système de santé (25). Cynthia Lewis va plus loin dans son rapport *Pour le mouvement pour mettre fin à l'itinérance à Montréal* en nous listant plusieurs impacts positifs de l'inclusion de personnes ayant vécu l'itinérance au sein de structures allant du soin direct à l'organisation globale du système de santé (26). Selon elle, cette présence permet d'attaquer les préjugés et leurs répercussions subtiles sur les soins et l'accès aux soins, tout en veillant à ce que les politiques publiques s'adaptent concrètement à la réalité des gens en situation de précarité sociale. Nous pourrions croire que l'implication d'un patient partenaire vivant l'itinérance à la Commission des soins de fin de vie, par exemple, ou encore lors de la rédaction de politiques publiques entourant les soins palliatifs permettrait de nommer l'inadéquation des réalités entre l'omniprésence de la maladie et de la mort au sein de ce mode de vie et l'absence d'accès aux soins.

Agir en amont : Accès à un logement

Logement d'abord est une stratégie de santé publique de plus en plus reconnue où l'objectif est d'offrir rapidement un logement supervisé ou non à des individus en contexte d'itinérance. Plusieurs études nous montrent l'impact de cette stratégie sur l'état de santé des gens en bénéficiant ainsi que sur l'accès aux soins. Par exemple, en Oregon, les participants à un projet pilote de logement supervisé ont déclaré y avoir un meilleur accès aux soins et une meilleure perception de leur état santé (27). Puis, pensons au projet pancanadien *Chez soi* réalisé de 2009 à 2013 à Montréal avec 469 individus vivant dans la rue avec un problème de santé mentale (28). Les participants ont noté une nette amélioration de leur qualité de vie, une diminution de leur consommation de drogues ou d'alcool et un grand sentiment de paix et de sécurité. Nous n'avons pas de données par rapport à l'impact de telles initiatives sur l'accès aux soins palliatifs, mais ceci demeure une avenue prometteuse.

Les communautés compatissantes

Finalement, le mouvement des communautés compatissantes s'infiltre de plus en plus dans les réseaux de soins palliatifs, dans les communautés en général ainsi que dans les politiques de santé publique. Leur objectif est d'augmenter les liens entre les communautés et le système de santé afin, d'une part, de démédicaliser la fin de vie, considérée ici comme un phénomène social, mais aussi d'assurer une continuité des soins pour ceux qui nécessitent une expertise en soins palliatifs (25,29,30). L'atteinte de leur objectif peut prendre plusieurs variantes, allant de l'organisation de café deuil à la mise en place d'un réseau pour supporter autant les endeuillés que ceux en phase palliative de leur maladie. Le mouvement s'intéresse plus particulièrement aux populations vulnérables, puisqu'il est démontré que les communautés compatissantes augmentent l'utilisation des soins palliatifs et enrichissent le réseau de soutien des personnes seules, tout en diminuant l'épuisement des proches (29,30). Bref, les communautés compatissantes sont des atouts majeurs en contexte de fin de vie en situation de précarité sociale.

CONCLUSION

Nous avons vu que les populations itinérantes, malgré les statistiques alarmantes de santé, incluant un haut taux de mortalité, n'ont pas ou très peu accès aux soins de santé incluant les soins palliatifs pourtant désignés à soulager les individus côtoyant la mort. La Loi 2 nous promet pourtant un accès équitable aux soins palliatifs en l'érigeant comme un droit. Il reste que sur le terrain, la réalité concernant le manque d'accès persiste. Les raisons en sont multiples, allant de caractéristiques individuelles tel que les problèmes de santé mentale ou de toxicomanie mais surtout d'enjeux structuraux touchant de manière prédominante cette tranche de la population. Les politiques gouvernementales en matière d'itinérance nomment bien ces enjeux, mais les initiatives pour y remédier demeurent malheureusement rares. Pensons aux mouvements des communautés compatissantes, au concept de pair-aidance ou encore aux projets de logement d'abord et aux soins de proximité, qui sont tous des alternatives innovantes, mais trop peu, trop tard. Une question demeure toujours en suspens : si l'équité et la dignité sont des valeurs reconnues par les politiques gouvernementales se retrouvant au cœur-même des lois, pourquoi la réalité terrain ne change-t-elle pas? Pour mieux répondre à cette incohérence, il faudra réfléchir aux rôles des différentes instances de notre système de santé et revoir les moyens qu'on leur donne pour réellement inclure la dignité et l'équité dans les soins. Puis, plus globalement, une réflexion s'impose sur la considération accordée dans nos sociétés aux expériences limites telles que la mort et la marginalité.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Privacy Considerations in the Canadian Regulation of Commercially-Operated Healthcare Artificial Intelligence

Blake Murdoch[a], Allison Jandura[a], Timothy Caulfield[a]

Résumé
L'intelligences artificielle (IA) est de plus en plus développées et mises en œuvre dans le domaine des soins de santé. Cela pose des problèmes de protection de la vie privée, car de nombreuses IA sont privées et dépendent d'accords de partage de données pour des quantités massives d'informations sur la santé des patients. Nous avons étudié le cadre juridique et politique canadien en nous concentrant sur la réglementation relative à la possibilité d'une utilisation ou d'une divulgation inappropriée de renseignements personnels sur la santé par des entreprises privées d'IA. Nous avons notamment analysé les lois fédérales et provinciales, la common law et la politique d'éthique de la recherche. Notre évaluation des divers cadres réglementaires a révélé qu'ensemble, ils exigent que les entreprises privées d'IA et leurs partenaires dans la mise en œuvre des soins de santé respectent des normes élevées de protection de la vie privée qui privilégient l'autonomie des patients, à quelques exceptions près. Nous avons constaté que les systèmes d'IA dans le domaine des soins de santé doivent être conformes aux règles et aux normes éthiques fondamentales consacrées par la loi et l'éthique de la recherche, même si cela pose des problèmes de mise en œuvre. Les accords de partage de données doivent être axés sur une intégration étroite, avec des niveaux élevés de sécurité des données, une surveillance étroite et le maintien du contrôle des données par le patient.

Abstract
Artificial intelligence (AI) is increasingly being developed and implemented in healthcare. This presents privacy issues since many AI systems are privately owned and rely on data sharing arrangements for mass quantities of patient health information. We investigated the Canadian legal and policy framework focusing on regulation relevant to the potential for inappropriate use or disclosure of personal health information by private AI companies. This included analysis of federal and provincial legislation, common law and research ethics policy. Our evaluation of the various regulatory frameworks found that together they require private AI companies and their partners in healthcare implementation to meet high standards of privacy protection that prioritize patient autonomy, with limited exceptions. We found that healthcare AI systems are required to be consistent with the rules and foundational ethical norms enshrined in law and research ethics, even if this poses challenges to implementation. Data sharing arrangements must focus on tight integration with high levels of data security, strong oversight and retention of patient control over data.

Mots-clés
droit de la santé, vie privée, intelligence artificielle, bioéthique, législation, Canada

Keywords
health law, privacy, artificial intelligence, bioethics, legislation, Canada

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INTRODUCTION

Advances in artificial intelligence (AI) are occurring rapidly and will soon have a significant impact on medical care. AI may be used in a variety of healthcare contexts that each raise distinct ethical considerations, including process optimization, pre-clinical research, and selection of clinical pathways. It will likely be used in both patient-facing and population level applications (1-3). Several new AI technologies are approaching feasibility, and a few are in the process of being integrated into healthcare systems (4,5). Radiation oncology, organ allocation, robotic surgery, and several other healthcare domains stand to benefit from AI technologies in the short to medium term (6-10).

AI systems have several unique characteristics compared with traditional health technologies. Notably, they can be prone to certain types of errors and biases (11-14), and often cannot be easily supervised by human medical professionals. The latter is because of the "black box" problem, whereby learning algorithms' methods and 'reasoning' used for reaching their conclusions are partially or entirely opaque to human observers (9,12). This opacity may also apply to how health and personal information is used and manipulated.

Many AI technologies are developed and maintained by private companies and will be implemented in partnership with public healthcare providers. Health-related AI are being developed both with personal health information and data that falls outside the boundaries of regulation of personal health information, such as secondary uses of de-identified data and certain data arising from commercial digital products. The use of commercial AI in healthcare raises significant privacy concerns. Privacy has been identified as a fundamental human right in the Universal Declaration of Human Rights at the 1948 United National General Assembly (15). Canadian law protects privacy, including the *Personal Information Protection and Electronic*

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Documents Act, SC 2000, c 5 [PIPEDA], provincial privacy and health information statutes, and jurisprudence such as *McInerney v McDonald*, 1992 CANLII 57 (SCC), which we explore further below.

Respect for privacy is an important ethical principle in healthcare because it flows from a patient's autonomy, personal identity and well-being (16). Privacy has both intrinsic and extrinsic value, and a privacy offense can occur regardless of whether actual harm was done to the compromised individual (17). Healthcare AI relates to informational privacy, that is, to the use and control over one's personal information (18). AI privacy issues arise both with respect to the entities collecting personal information, and the threat of malicious cyberattacks (19). Here we explore the application of the existing Canadian legal and research ethics frameworks to privacy issues with commercial healthcare AI implementation. We focus our analysis primarily on the risks of inappropriate handling, use or disclosure of personal health information by private AI companies, and also touch on the potential for privacy breaches that could result in the reidentification of patient health information. Analysis of the various regulatory frameworks shows that together they require private AI companies and their partners in healthcare implementation to meet high standards of privacy protection that prioritize patient autonomy, with limited exceptions.

PRIVACY CONCERNS

Inappropriate handling, use or disclosure of personal health information by private actors is a major privacy concern. A significant portion of existing technology relating to machine learning and neural networks rests in the hands of large tech corporations – Google, Microsoft, IBM, Apple, and other companies are all preparing and implementing large investments in healthcare technology, much of which involves AI (20). Information sharing agreements can be used to contractually grant these private institutions access to government-held patient health information. Health information has considerable economic value to commercial entities for developing and using AI deep learning for profitable purposes and otherwise. This can be particularly so when it is combined with other personal information from "disparate domains" of an individual's life to allow AI to make additional inferences about an individual (21-25).

Public-private partnerships with tech companies have sometimes resulted in poor protection of privacy. For example, DeepMind, owned by Alphabet Inc. (hereinafter referred to as Google), partnered with the Royal Free London NHS Foundation Trust in 2016 to use machine learning to assist in the management of acute kidney injury (21). There was concern around patient control over use of personal data, as critics noted that patients were not afforded agency nor were privacy impacts properly discussed (21). One English Department of Health advisor said the patient information was obtained on an "inappropriate legal basis" (26). Google subsequently took direct control over DeepMind's app, transferring control over stored patient data from the United Kingdom to the United States, generating further controversy (27). The ability of a large tech company to "annex" mass quantities of private patient data to another jurisdiction is a new reality of big data, and there can be insufficient protections to guarantee that problematic external and/or third-party transfers do not occur. The concentration of technological innovation and knowledge in big tech companies can create power imbalances where public institutions could become more dependent and less equal partners in health tech implementation. These power imbalances can be factors causing and/or exacerbating the risk of inappropriate acquisition and treatment of personal health information.

The DeepMind example suggests that appropriate safeguards must be in place to maintain privacy and patient agency in the context of commercial transfer of health information. Smaller companies may in some respects be even less able to be held to account because they can easily fail, going bankrupt and/or being purchased by larger companies (along with all their data and intellectual property). AIs pose a novel challenge because they can require access to large quantities of patient data and the way in which the data is used may evolve over time (28). The location and ownership of servers and computers that store and access patient health information will therefore be an important consideration.

A second concern worth briefly noting is the risk of inappropriate technology-driven reidentification of de-identified or anonymized patient health information. De-identified information is information that has personal identifiers removed where the data custodian retains a way to relink the identifiers in the future, and fully anonymized data theoretically should not be re-identifiable. Health information breaches are on the rise in Canada (29-31), and AIs and other algorithms are contributing to a growing inability to protect health information (32-33). Recent studies have highlighted how emerging computational strategies can identify individuals from information in health data repositories (34), with the result that information that has been anonymized and scrubbed of all identifiers can be reidentified (35-38). This sort of re-identification can "effectively nullify scrubbing and compromise privacy." (39) Hostile reidentification techniques could increase the risks of privacy breach from allowing private AI companies to control patient health information, even when it is "anonymized." It also raises questions of liability, insurability, and other practical issues that are somewhat distinct from circumstances where public health information custodians control patient data.

LEGISLATION

The web of Canadian privacy legislation

There is a lack of true and complete standardization of privacy legislation in Canada, both inter and intra-provincially. And AI companies can be required to comply with multiple overlapping pieces of legislation (40). This is further complicated for international AI implementations involving jurisdictions like the European Union and the United States, where, for example, the General Data Protection Rule (GDPR) and/or the Health Insurance Portability and Accountability Act (HIPA) might also need to be respected (41-42). While it is beyond the scope of this article to consider the application of extraterritorial regulation, these rules could have important implications for the use of commercial AIs in healthcare that involves or requires data-sharing across borders.

In Canada, there is both federally and provincially enacted privacy legislation protecting personal information and personal health information held by private or public organizations. PIPEDA is a key statute to consider in relation to the privacy issues stated above, due to its applicability to federally and some provincially regulated private corporations who develop and implement AI technologies (43). Provincial legislation that is deemed substantially similar to PIPEDA takes precedence over PIPEDA for the provincially regulated companies and activities it covers. Certain classes of organizations and activities in provinces with substantially similar private sector privacy laws, including those functioning in Alberta, British Columbia, and Quebec, are exempt from many of the provisions of PIPEDA.

Provincial health information protection legislation and, in some cases, provincial public sector privacy regulation, are also relevant for the commercial transfers of health information that implementation of new technologies will necessitate. Patient health data is protected by provincial personal information legislation and health information legislation where applicable (44). As above, provinces with substantially similar health information privacy laws, including Ontario, New Brunswick, Newfoundland and Labrador and Nova Scotia, are exempt from PIPEDA with respect to health information in many cases (45). Other provinces also have health privacy laws, but they have not been declared substantially similar and thus are not exempt from the rules in PIPEDA. Again, AI companies will sometimes have to comply with multiple overlapping pieces of legislation (41).

There is regulatory complexity to potential arrangements with AI companies that use mass quantities of patient health information. Hospitals or public healthcare providers implementing private AIs will be required to comply with all relevant privacy and health information legislation. Any commercial activities done by contractors or collaborators may be required to comply with applicable provincial legislation and PIPEDA (45). Moreover, any commercial activities that cross provincial borders must comply with PIPEDA, regardless of whether both provinces involved have legislation that has been deemed substantially similar (45). Because the provincial locales of data collection and server installation can change applicable regulation, there could be incentives to prioritize work in jurisdictions with the most favourable data storage obligations. PIPEDA helps to resolve some of these concerns, though greater cooperation between provinces to generate more consistency in regulation that applies to commercial AIs could help to better regulate the extent of activities they can undertake.

The intent of this piece is not to deal with the nuanced interactions between federal and provincial statutes in each individual province, but to note broadly applicable rules that are of particular importance to private implementations of healthcare AIs and the privacy concerns we delineated. It is conceivable that a healthcare AI company could operate entirely within a single province. However, given the high likelihood of cross-province or cross-border transmission of patient health information for any effective and widely implemented healthcare AI system that has centralized server systems in one or a few jurisdictions, we can reasonably conclude that PIPEDA will apply in most cases.

Patient health information and data security

Preparing for potential security breaches, including those that result in reidentification by machine learning algorithms, is a legal obligation of corporate data custodians. Preventative measures are required, which PIPEDA specifically enshrines. Principle 7 requires security safeguards to be appropriate to the sensitivity of information being stored. Principle 3.4 notes that patient health information is always considered the most sensitive type of information. Principle 7.2 requires that more sensitive information should be safeguarded by a higher level of protection. This means the best available methods of data security should be used when private AI companies are dealing with patient health information.

As data security protocols evolve, corporate data custodians will have to update their systems. It may even be necessary or desirable to use advanced algorithmic systems for self-improving the security systems used to combat potential breaches, though contracting for these types of advanced security systems is more likely when the company in question is not a multinational tech conglomerate. Where possible, data custodians should ensure patient data is as deidentified or anonymized as possible. The deidentification requirements found in prominent research ethics policies, which we cite further in the Canadian Research Ethics Policy section, would be strong starting points for internal data policy.

Consent, recontact and ongoing control

PIPEDA has very clear consent requirements, and consent is only valid if it is “reasonable to expect that an individual to whom the organization’s activities are directed would understand the nature, use, or disclosure of the personal information to which they are consenting.” (43) It also clearly states that the reasonable expectations of the individual are relevant for the purposes of obtaining consent. An example within the document states that “an individual would not reasonably expect that personal information given to a health-care professional would be given to a company selling health-care products, unless consent were obtained.” (43)

This is about as close as one can reasonably expect a piece of general privacy legislation to come to touching directly on the issue of public-private health data sharing for medical AIs. It indicates that any use by the AI company of patient health data that does not relate directly to medical care that the patient is consenting to is prohibited, unless the patient is properly informed of the alternative and can provide true informed consent. These rules go to the statutory principle that data may only be used or disclosed for purposes for which it was initially collected. Any new use for the data generally results in a requirement for recontact and reconsent. That being said, there is a limited allowance for personal information to be used without the knowledge or consent of the individual providing it. Under Principle 3 or PIPEDA, this can be allowed where it is impossible or impractical to seek consent, or when the organization cannot seek it because it does not have a direct relationship with the individual. The latter could occur with commercial AI companies that are using de-identified data as a third party to the original custodian, the public health system. However, with proper integration between public and private actors, it can be feasible to coordinate recontact. This sort of integration could be prioritized in order to uphold patients' right to decide how their data is used.

PIPEDA also indicates that patients have an ongoing right to control the use of their data, via a right of withdrawal that is "subject to legal or contractual restrictions and reasonable notice." (43) AI companies will need to plan for the contingencies associated with data removal after its integration into AIs, and the computing logistics relating to extracting a patient's data could be complex.

Third party transfers

Third party transfers pose a significant risk to patient health information. Transfers like seen in the DeepMind example, as well as more normal course of business transfers to contractor partners, can result in insufficient data protection and inappropriate use or disclosure by private AI companies. Privacy issues that arise from outsourcing and information transfer may need to be addressed differently depending on the applicable provincial laws, whether the data is transferred to a location outside of Canada, and whether the data remains in Canada but is controlled by a company that is primarily based outside Canada. This is in part because the health information is subject to the laws of the jurisdiction in which is it located.

PIPEDA, unlike some provincial privacy legislation, does not apply to third party providers that receive information as part of a transfer (46). A transfer to a third party, domestic or foreign, is considered a use and not a disclosure under PIPEDA (46). A transfer must only be used for the purposes for which the information was initially collected – a common commercial example would be outsourced IT services. It is entirely possible and likely that health information needed for AIs could be transferred for similar commercial purposes. As per Principle 4.1.3 of Schedule 1, the original organization in possession or custody of personal information is responsible for it, including where that information has been transferred to a third party, and is required to provide a comparable level of protection of the information through contractual obligations (44). However, when information is transferred to foreign jurisdictions, it is subject to the laws of those jurisdictions. PIPEDA does not prohibit international transactions that involve personal data. It is at the discretion of individual organizations to assess whether personal information is too sensitive or a risk of disclosure is too great to enter into a given agreement.

Third parties to commercial healthcare AI implementations, whether domestic or foreign, having only contractual obligations to protect data rather than legislative ones, could lead to increased likelihood of abuse and inappropriate disclosure of patient health information. Given that contractual obligations can be breached by third parties with the only likely outcome being financial loss, there is insufficient protection against the use of ruthless economic calculation to justify unapproved use of health information. Especially for domestic third parties over which governments have clear jurisdiction, it is problematic for patient privacy to allow third parties to fail to protect health information whenever it is economically beneficial to do so. It is possible that the remedies under PIPEDA may be insufficient to deter large companies from strategically breaching regulation. As such, altering regulation to place more custodianship responsibility onto domestic third parties in control of patient heath information could be one way for regulators to reduce this risk.

In an international context, it may be difficult to make changes to this system without directly hampering cross-border commerce and the related ability to move private data internationally. However, PIPEDA was not necessarily created with the entire requisite foresight for addressing the novel issues we now face specifically with health information and mass data uses. Given that health information is considered among the most valued and important forms of information under Canadian privacy law, policymakers might consider further regulation specific to this area that would provide protections for health information that may be crossing borders, while giving due consideration to the personal information protections existing in other jurisdictions (47).

COMMON LAW

Torts

While the respective Canadian legislative frameworks override the common law, it will still be important in some instances where personal information is or could be mishandled by private AI companies. Torts can of course also be relevant to intentional, targeted security breaches. The Supreme Court of Canada has categorized privacy interests as territorial, personal, or informational for the purpose of analysis (48). Informational privacy may be defined as "the claim of individuals, groups, or institutions to determine for themselves when, how, and to what extent information about them is communicated to others." (49). The privacy interests engaged by commercial AI most commonly involve individuals' informational privacy. Key issues for common law responses to potential privacy breaches include whether patients have given informed consent for third party access to their health information and authorized particular uses, and how a health care provider's professional and fiduciary obligations are engaged by commercial AI where there has been a privacy breach.

The torts of breach of confidence, invasion of privacy, and intrusion upon seclusion may give rise to individual and class action causes of action in provinces where statutory causes of action coexist with these common law torts. However, in some provinces, such as British Columbia and Alberta, health information privacy protection legislation overrides or negates these causes of action in the context of health information, because said health information legislation creates a statutory cause of action for breach of privacy (50). Because British Columbia has a statutory cause of action, courts in British Columbia do not recognize the common law tort of intrusion upon seclusion.

Intrusion upon seclusion is a novel common law cause of action. It was recognized by the Ontario Court of Appeal in *Jones v Tsige* (52)*.* The tort of intrusion upon seclusion is a form of breach of privacy that involves access of private information for an unauthorized purpose (52). Further dissemination is not an element of this tort. In order to establish intrusion upon seclusion, the claimant must establish that the invasion was highly offensive and caused distress, humiliation, or anguish on an objective standard. Proof of economic harm is not required.

This tort is important in part because unlike British Columbia and Alberta, Ontario does not have a statutory cause of action to address breaches of privacy. Section 65(3) of *Personal Health Information Protection Act* (PHIPA) allows plaintiffs to recover damages for mental anguish not exceeding $10,000 arising from a defendant's wilful or reckless contravention under the Act. This limits an individual's ability to recover under PHIPA. The Ontario Court of Appeal in *Hopkins v Kay*, 2015 ONCA 112 held that the PHIPA does not preclude the existence of a common law claim for intrusion upon seclusion because PHIPA does not create a statutory cause of action for breach of privacy (53). Common law tort causes of action like intrusion upon seclusion may allow the Court to grant remedies to plaintiffs whose health information privacy has been breached if legislation does not provide an equivalent cause of action. Types of harm to a patient that can occur from data privacy breaches may include discrimination or humiliation, and violation of a patient's human dignity (54).

Reliance on common law principles is thus an enforcement mechanism that could sometimes be used in cases of misuse of patient health information by private AI companies and is a relevant factor in the deterrence thereof.

Fiduciary and professional obligations

As affirmed by the Supreme Court in *McInerney v MacDonald*, physicians owe a fiduciary duty to their patients, which includes the duties of utmost good faith and loyalty (55). Patients have a reasonable expectation that these duties will be respected when they release their personal health information to their physicians. The court held in McInerney that physicians hold personal health records of patients in a "fashion somewhat akin to a trust" and that the record is "to be used by the physician for the benefit of the patient." (59) Because the patient confides this information under no personal obligation to do so, and because of the nature of the fiduciary relationship, it gives rise to an "expectation that the patient's interest in and control of the information will continue." (59)

The nature of the fiduciary relationship between physicians and patients raises questions about liability in circumstances where a "black box" AI is involved (56,57), including where there could be a breach of the patient's privacy. Physicians will likely be required to obtain patients' informed consent with respect to the risks of data sharing of their personal information and re-identification of their data. They also are likely to be involved in advising patients about the technologies and how they use private data. An inability for providers and patients to understand or fully predict the future uses of data by third party AIs poses potential challenges to obtaining informed consent, and common law is historically less accepting of concepts like broad consent for future use than is regulation. If physicians cannot understand or explain how an AI's decision will be made, it can raise concern as to whether consent is truly informed. Also, because integration of AI into healthcare can result in situations where access to care is dependent upon a patient agreeing to broad consent for future unknown uses of data, there can be an element of undue pressure in the collection of consent that may compromise privacy rights. This would raise questions about whether a collecting physician is meeting their duty of care to prioritize the patient's interests above others. The problem may require considering some careful alterations to the limits of physicians' fiduciary duty under Canadian law, including the possibility of legislative intervention to cleave away some of the traditional responsibility placed on physicians and attribute those portions wholly to AI companies themselves.

In addition to fiduciary obligations, there are well-established professional regulatory mechanisms to address professional employees who intentionally breach privacy rules. This would include disciplinary proceedings through self-regulating colleges of physicians and surgeons, or colleges and regulators of other health professions. These are not part of the common law but should be briefly noted. Operators or owners of private AI companies who are regulated health professionals may continue to be subject to certain professional rules through their work in the organization, especially if they are to any extent directly engaged in gathering health information and if they establish a direct working relationship with patients.

CANADIAN RESEARCH ETHICS POLICY

At least initially, most implementations of privately developed healthcare AI in Canada will begin via research-based pilot projects. This provides the governmental data custodian with proof of efficacy and safety prior to broad implementation. Several provinces' health information legislation, an example being Alberta's *Health Information Act*, largely offload many decisions about the permissibility of research uses of and consents for collection of health information to research ethics boards. Hence, many research ethics rules will be determinative in terms of how private AI companies obtain and use patient data.

Canadian research ethics boards largely rely upon the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2), the key research ethics policy in Canada that would be applicable to almost any research involving healthcare AIs and human patients (58). While not a law or regulation, the TCPS2 sets the ethical norms that all federally funded researchers and research institutions must follow. It is important to note, however, that the TCPS2 does not take precedence over common law or legislation and, as such, researchers should be reminded that the must comply with both existing law and research ethics policies.

Chapter 3 of the TCPS2 delineates the requirements of informed consent for participation in research. It states that researchers must provide "full disclosure of all information necessary for making an informed decision to participate in a research project." (63) This includes, on the subject of privacy, "an indication of who will have access to information collected about the identity of participants; a description of how confidentiality will be protected (Article 5.2); a description of the anticipated uses of data; and information indicating who may have a duty to disclose information collected, and to whom such disclosures could be made." (63) This statement establishes disclosure of data security and confidentiality measures as key aspects of informed consent. And because consent must be an ongoing process by which there is an ongoing duty to provide participants with "all information relevant to their ongoing consent to participate," material changes in privacy protection likely give rise to a duty to recontact (59). That being said, we will see that there are exceptions to informed consent that can mean participants' data is used without their knowledge and for purposes unknown to them.

Chapter 5 is dedicated to privacy and confidentiality policy. It defines privacy as "an individual's right to be free from intrusion or interference by others," stating that it is fundamental and exists "in relation to [patients'] bodies, personal information, expressed thoughts and opinions, personal communications with others, and spaces they occupy." (63) Privacy is also considered inextricably linked to informed consent and is said to have been respected "if an individual has an opportunity to exercise control over personal information by consenting to, or withholding consent for, the collection, use and/or disclosure of information." (63) Despite this statement, the TCPS2 does not always require informed consent for use of patient data. Identifiable health information can generally only be used for secondary purposes with informed consent, but anonymized or de-identified patient information can be used without informed consent where there is research ethics board approval. The TCPS2 acknowledges that the "use of indirectly identifying, coded, anonymized or anonymous information for research may still present risks of re-identification." (63) One instance in which the risk of re-identification grows is where researchers are linking data from one database to that of another. Here, the policy notes that "only a restricted number of individuals should perform the function of merging databases," and that "[r]esearchers should use enhanced security measures to store the merged file." (63)

As one might expect from a broad policy document of this nature, there is not a detailed set of technical requirements and best practices for how to protect privacy in various circumstances. A lack of detailed technical guidance is common for policy that does not want to be unintentionally restrictive in its interpretation and application. However, in the future it may be important to either include technical requirements for data security and de-identification, or at least to refer to the recommendations of a working group that specializes in the area in a way that makes its standards binding.

The TCPS2's distinction between anonymous and deidentified data is worth further exploration. It states that the best way to protect participants is through the use of anonymous or anonymized data, except when this is not desirable because it prohibits return of results and future linkages of that person's data (63). Data is considered de-identified data where the key code is "accessible only to a custodian or trusted third party" the "'next best' alternative." (63) However, while this may still generally be true, the noted advances in re-identification threaten not only de-identified data but also data previously considered fully anonymous. In the face of machine learning re-identification schemes, these two terms may no longer be as distinct as they once were.

Perhaps even more importantly, under Article 5.5B, the TCPS2 does not require participant consent – only research ethics board review – for "research that relies exclusively on the secondary use of non-identifiable information." (63) Private companies doing research involving healthcare AIs will likely seek exemptions from consent where possible using this standard (even though this does not exempt them from their legal obligations), specifically in cases where large quantities of data are required, and it is acceptable for them to have been stripped of identifiers. The problem is that, as noted, the concept of "non-identifiable information" is increasingly questionable or even dubious. This section of the policy states that information must be non-identifiable "for all practical purposes." (63) The subsection of health information that could arguably meet this standard is decreasing over time. Further revisions to the policy could help to clarify the limits of this section in the context of new technical methods for breaching privacy through reidentification.

Health information legislation grants significant discretion to research ethics boards to make determinations about the level of data security required for research. Given the lack of technical guidance in the TCPS2, this could result in circumstances where patient data access is compromised due to a lack of understanding of quickly changing data security best practices. Regulators could act to increasingly centralize control over and establish more universal (and evolving) standards for human health research data security. While this risks removing some of the nuance and circumstantial evaluation from research ethics boards' functioning, increased guidance concerning security and privacy requirements for research ethics boards dealing with AI research would be helpful.

CONCLUSION

Regulation of patient data use by commercial AI companies must prioritize privacy concerns while striving to improve patient outcomes and quality of care. Implementations of healthcare AIs will need to be consistent with foundational ethical norms that are enshrined in law and research ethics, including respect for autonomy. Commercial transfers of health information to implement these technologies must focus on tight integration that results in high levels of data security, strong oversight of data use and retention of patient control over use of their data. While the costs of maintaining high privacy standards to healthcare AI development and the speed of improvement of clinical care may not be insignificant, the current Canadian legal framework requires comprehensiveness with limited exceptions. If policymakers wished to reduce regulatory burden of privacy requirements because they believed it would ultimately improve patient care, changes to the Canadian framework would be required. Table 1 summarizes our key findings and recommendations concerning patient privacy for commercial AI implementation.

Table 1: Key findings and recommendations

1. ***Patients have a general right to informed consent*** for the use and disclosure of their identifiable personal health information and have an ongoing control interest which necessitates the need for recontact for any new uses or disclosures.
2. ***Patients have a general right of withdrawal*** from participation in healthcare AI. AI companies will need to plan for the contingencies associated with data removal after its integration.
3. ***Altering regulation to place more custodianship responsibility onto domestic third parties*** that are transferred patient heath information would address a source of risk in AI company data custodianship.
4. ***Greater cooperation between provinces to generate more consistency*** in regulation that applies to commercial AI companies could aid implementation and encourage compliance.
5. ***The concept of "non-identifiable information" is increasingly questionable*** or even dubious. The subsection of health information that could arguably meet this standard is decreasing quickly over time. Regulators and policymakers should incorporate into their work the reality that technical methods of breaching privacy through reidentification are quickly evolving.
6. ***Access to patient data must be predicated upon maintaining highly advanced forms of data security***, and anonymization where possible. Strong privacy protection will be required in light of advancing technology that allows data to be re-identified and misused. Data security methods should minimize risks during data transfer, safe storage, and appropriate deletion. Further, consent requirements must disclose both any possible personal data transfers to commercial entities, and the realistic risk of privacy breach.
7. ***Data security responsibility is shared*** among both institutions that grant access to patient data for use by AI companies, and the AI companies manipulating and/or storing patient data themselves. Required integrations may be extensive.
8. ***Governments could consider creating interdisciplinary task forces*** focused specifically on developing, refining and implementing technical standards for protecting patient health information in AI implementations.

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None to declare

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Le fondement onto-éthique de la solidarité selon Hans Jonas

Jelson Oliveira[a]

Résumé
Dans cet article, nous analysons les bases onto-éthiques du concept jonassien de « solidarité d'intérêts », compris comme un lien unissant tous les êtres vivants en un réseau d'interdépendances existentielles. Cette perspective renforce la critique contemporaine en éthique et en sciences à propos de l'anthropocentrisme qui est, de la même façon, au cœur de la critique que Hans Jonas fait de l'éthique traditionnelle et de la science moderne. Cet article analyse les bases onto-éthiques de ce concept à l'aide du « principe de médiateté » que Jonas comprend comme la capacité d'établir des médiations avec le milieu en vue de la préservation de l'autre, mais aussi de soi-même, de telle façon qu'il s'agirait d'une forme très particulière de solidarité, celle qui, dans le cadre organique, n'exclut pas l'intérêt de la vie pour l'auto-préservation. La solidarité est une condition ontologique d'interdépendance entre les êtres et aussi, selon Jonas, entre les choses, incluant un partage d'identité entre différentes formes de vie et une marque fondamentale de l'Être, car selon cette logique, l'expérience la plus intime de la vie est de résister à la mort – voire c'est cette solidarité qui devient le principal motif de tels rapports. Dans le cadre de l'histoire des réseaux de solidarité, l'être humain occupe une place particulière : c'est chez lui que la précarité assume des versions plus évidentes et c'est chez lui que se développe, comme réponse, des capacités plus favorables à sa subsistance. Ce concept de solidarité devient central pour comprendre les degrés de liberté qui caractérisent la vie au regard de l'obligation éthique de les préserver à travers le principe de responsabilité. En d'autres termes, la solidarité doit fonder également la responsabilité : il s'agit de penser l'affirmation de la vie dans le cadre collectif des garanties portant sur les conditions d'existence au moment présent et surtout celles portant sur l'avenir.

Mots-clés
solidarité, médiateté, responsabilité, vie, Hans Jonas, liberté

Abstract
In this article, I analyze the onto-ethical basis of the Jonasian concept of "solidarity of interests", understood as a link uniting all living beings in a network of existential interdependence. This perspective reinforces the contemporary critique in ethics and science of anthropocentrism which is, in the same way, at the heart of Hans Jonas' critique of traditional ethics and modern science. This article analyzes the onto-ethical bases of this concept with the help of the "principle of mediacy" that Jonas understands as the capacity to establish mediations with the environment in view not only of the preservation of the other, but also of oneself, in such a way that it would be a very particular kind of solidarity, the one that, in the organic framework, does not exclude the interest of life for self-preservation. Solidarity is an ontological condition of interdependence between beings and also, according to Jonas, between things, including a sharing of identity between different forms of life and a fundamental mark of Being, because, according to this logic, the most intimate experience of life is to resist death – indeed, it is this solidarity that becomes the main motive of such relationships. Within the history of solidarity networks, the human being occupies a particular place: either it is in him that precariousness assumes more obvious versions; or it is in him that, as a response, capacities more favorable to his subsistence are developed. This concept of solidarity becomes central to understanding the degrees of freedom that characterize life with respect to the ethical obligation to preserve them through the principle of responsibility. In other words, solidarity must also be the basis of responsibility: it is a question of thinking about the affirmation of life within the collective framework of guarantees concerning the conditions of existence at the present moment and especially those concerning the future.

Keywords
solidarity, mediacy, responsibility, life, Hans Jonas, liberty

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INTRODUCTION

Le concept de solidarité vient du latin « solidus » et est lié à l'idée de *solidité*, de *fondation* ou de *support*, désignant une idée selon laquelle un élément particulier trouve sa force par son adhésion à un ensemble. C'est un concept de réciprocité et de coopération dans lequel tous les êtres vivants sont liés. Ce n'est pas par hasard qu'être solidaire c'est faire partie d'une cause plus grande que soi et faire de cette cause le sens de sa vie, comme c'est le cas, par exemple, pour un *soldat* (mot dérivé de la même racine, *solidus*) qui se bat non seulement pour lui-même, mais aussi pour le bien de toute la troupe.

Le philosophe d'origine juive-allemande Hans Jonas (1903-1993) a fait de ce concept un principe onto-biologique – et, en même temps, éthique – central à sa pensée, en le considérant comme étant essentiel pour comprendre les interrelations entre les êtres vivants. Avec cela, il a non seulement développé une perspective proprement écologique du concept de solidarité (l'écologie, après tout, c'est la science des relations entre les êtres vivants, et les relations entre ceux-ci et leur milieu, incluant ainsi le non-vivant, litt. *Eco*-), mais surtout une critique de l'anthropocentrisme qui utilise la solidarité pour montrer comment l'être humain ne doit pas être compris comme ontologiquement séparé de toutes les autres formes de vie.

Dans son livre de 1966, *The Phenomenon of Life: Toward a Philosophical Biology*, Jonas critique l'anthropocentrisme tant d'un point de vue philosophique que scientifique, montrant comment la survalorisation humaine (le centrisme) conduisant à une idéalisation, voire à un sentiment de supériorité humaine, est une erreur dérivée d'une mauvaise interprétation du

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phénomène vital; une interprétation déconnectée, d'ailleurs, basée sur un dualisme qui opposerait l'esprit et la matière (1,2)[1]. En conséquence, le concept de solidarité devient central pour le développement d'une éthique de la responsabilité, selon le modèle proposé par l'auteur dans son œuvre de 1979, *Le Principe Responsabilité : une éthique pour la civilisation technologique* (3), d'une part parce que tous les êtres vivants sont interdépendants, et d'autre part parce que chacun acquiert la même « dignité » et détient les mêmes « droits ». Donc l'être humain (c'est-à-dire la seule espèce d'êtres vivants capable de responsabilité en raison du haut degré de son développement intérieur, cognitif et introspectif) doit assumer cette responsabilité. Bien qu'il soit le point culminant de l'évolution selon Jonas[2], l'être humain n'est pas isolé ; au contraire, il est lié par la « solidarité d'intérêts » (3, p.229) et il devient responsable du maintien de l'équilibre général de la vie donnant lieu à son habitat, étant le seul capable de prendre ce recul. Et pour Jonas, si vous le *pouvez*, alors vous *devez* assumer une telle responsabilité.

On part de l'idée que la solidarité est le principe selon lequel il existe une interrelation et une interdépendance entre tous les êtres vivants, dont l'existence réciproque dépend de l'assistance commune et d'une identification mutuelle capable de rompre avec la tradition anthropocentrique de la pensée éthique occidentale. L'interpellation des organismes vivants, marqués par la précarité et la dépendance (par leur interaction à la fois avec des formes non-organiques et avec des formes vivantes), est la condition *sine qua non* de l'existence, même de la vie en général. Hans Jonas fait du principe de solidarité l'un des fondements à la fois d'une réinterprétation du phénomène de la vie (à travers une nouvelle ontologie, dont la base est une biologie philosophique) et de la formulation d'une nouvelle éthique dont le résultat conduit à une sorte de refondation philosophique de la rationalité, comprise comme l'une des étapes de la longue histoire évolutive de la liberté. Jonas voit cette liberté (comme synonyme d'intériorité) préméditée dans les formes les plus élémentaires de la vie. Cet argument s'oppose à la fois à la perspective scientifique dominante, puisqu'elle est liée au dualisme, et à la perspective philosophique qui marque la tendance idéaliste des philosophies modernes et contemporaines.

Le concept de « solidarité d'intérêts » apparaît dans l'ouvrage de 1979 (3), précisément dans le cinquième chapitre, où Jonas analyse l'urgence de la responsabilité face à l'avenir menacé par l'idée de progrès. C'est un concept évoqué d'un point de vue éthique, à partir de la réflexion sur l'avenir et face aux menaces de « perturbation de l'équilibre symbiotique » de la vie par l'être humain. Ainsi, bien que l'idée de solidarité n'apparaisse pas dans l'ouvrage de 1966 (5), il devient indispensable de la comprendre rétrospectivement lorsqu'il s'agit d'analyser comment la technologie est devenue un danger pour la vie. Nous pouvons dire que l'idée de solidarité se trouve à la base de sa théorie éthique qui *dérive de* et *s'appuie sur* une ontologie, puisque pour Jonas, le devoir est déjà dans l'être, c'est-à-dire que tout organisme vivant, par l'impulsion naturelle à « vouloir » (sur)vivre, témoigne intrinsèquement de la valeur de la vie et, avec cela, oblige éthiquement l'être humain à en prendre la responsabilité. En d'autres termes, parce qu'elle veut vivre (elle maintient une tendance à l'affirmation de soi), la vie démontre qu'elle est « bonne » et qu'elle « vaut la peine » d'être présente. Dès lors, elle a une *valeur* qui requiert un *devoir*. Il s'agit alors de comprendre la solidarité comme un principe à la fois ontologique et éthique pour analyser la pensée de Jonas à propos du concept de « solidarité d'intérêts » (5, p.229).

À cet égard, le but de ce texte est d'analyser les bases onto-éthiques du concept jonassien de « solidarité d'intérêts », compris comme le lien réunissant tous les êtres vivants en un réseau d'interdépendances existentielles, démontrant comment la solidarité est un principe ontologique qui relie toutes les formes de vie entre elles. Pour poser cet argument, nous commencerons par examiner la conception jonassienne de la vie, sous le double angle de la richesse et de la précarité. Ensuite, nous analyserons l'idée que le métabolisme est, à un premier degré, ce que Jonas appelle la liberté et, à un second degré, nous démontrerons comment l'idée de solidarité est basée sur le « principe de médiateté », celui qui porte le concept de la solidarité. Une telle réflexion nous aidera à comprendre comment le concept onto-éthique de solidarité est l'un des fondements du principe de responsabilité et comment il nous aide à comprendre que la trajectoire à venir du développement de l'humanité se doit d'être indissociable de la protection des milieux naturels.

RICHESSE ET PRÉCARITÉ DE LA VIE

Du point de vue organique, en tant que processus d'appartenance et de maintenance de liens entre les êtres, la solidarité traduirait ce que Jonas comprend comme la transcendance de la vie, c'est-à-dire son ouverture sur l'environnement comme la forme de survie : bien qu'elle soit issue du monde inorganique, la vie dépend toujours d'éléments tels que l'eau, la chaleur, les nutriments, etc. Dans ce cas, la transcendance émerge de la précarité de la vie, parce que cet état particulier qu'est la vie a besoin d'ingrédients offerts par l'environnement et bénéficie de l'émergence même de la vie (nourriture et reproduction) : elle entretient avec eux un réseau d'intérêts. Pour Jonas, cette précarité est entendue comme liberté et c'est précisément de cela que dépend la richesse intérieure des différents organismes : en raison de la précarité de la vie et de sa dépendance, les organismes prévoient « choisir », c'est-à-dire prendre des décisions dans leur rapport au milieu environnant. Ainsi, ces choix favorisent leur propre croissance intérieure de telle sorte que plus il y a de précarité, plus il y a de liberté, et plus il y a de

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[1] Tibaldeo (1) a développé une interprétation reconnaissant l'innovation de Jonas en provoquant une véritable « révolution ontologique » ; Pommier (2) souligné l'importance du thème de la vie comme l'un des axes centraux de l'œuvre jonassienne.

[2] Le travail de Hans Jonas est fortement influencé par la théorie de l'évolution de Charles Darwin (1809-1882), dont il tente de tirer des conséquences philosophiques. Il est bon de se rappeler qu'entre 1940 et 1945, tout en combattant Hitler en tant que membre du groupe de brigade juive de l'armée britannique, Jonas se consacre aux études de la vie, soutenues par des textes de sciences naturelles envoyés de Palestine par son épouse Lore Jonas. Parmi ces textes figuraient les œuvres de Darwin, avec lesquelles le philosophe entretiendra une relation intellectuelle à la fois fondamentale et ambiguë : du point de vue méthodologique, l'étude de l'œuvre de Darwin permettra à Jonas d'aborder le phénomène de la vie à travers les instruments conceptuels fournis par la théorie évolutionniste; du point de vue thématique, il sera toujours en désaccord avec sa conception, car elle se réduit encore au matérialisme qui a marqué l'histoire de la biologie. Theis (4) a développé ces idées dans son livre, principalement dans le chapitre « Une philosophie de la vie et de l'homme » (p.33-54).

liberté, plus il y a d'intériorité[3]. Les êtres les plus dépendants les uns des autres sont les plus précaires du point de vue biologique, mais en même temps, ils sont les plus riches en interne, car c'était une exigence et en même temps un bénéfice produit par leur ouverture sur le monde. C'est cette dynamique qui, selon Jonas, établit les étapes évolutives de l'activité spirituelle, laquelle commence par le métabolisme, puis par la sensation, la perception, le sentiment, la mobilité et atteint *in fine* une rationalité telle que celle vécue par l'humain, le tout de manière interconnectée et cumulative, intégrant les règnes végétal et animal (incluant l'humain). Comme le dit Pinsart, « le but de la vie est de maintenir constamment son existence précaire et vulnérable, de retarder sa disparition » (6) et, ce faisant, de développer de nouvelles potentialités qui finissent par approfondir sa propre identité. Évidemment, cette dynamique marque aussi la vie comme une aventure risquée, dans laquelle, selon la description proposée par le philosophe, il n'y a aucune garantie de succès : un animal, par exemple, qui a besoin de choisir de chasser sa proie à longue distance, peut échouer. Un tel risque est contenu dans l'aventure vitale, favorisant davantage sa richesse intérieure, dans la mesure où le plus grand risque est un complément à une plus grande liberté et, par conséquent, conduirait à un plus grand enrichissement de la vie intérieure (c'est pourquoi, pour Jonas, les plantes auraient « moins » de richesse intérieure que les animaux).

Ainsi, la solidarité n'est pas un principe innocent de bonté qui relie la vie entre ses différentes formes, mais traduit plutôt une condition préalable propre à la vie qui se révèle à la fois comme une richesse et une déficience[4], dans la mesure où, en même temps, elle pousse à la nécessité de relations entre les êtres (compétitions) et avec leur milieu (climat), ce qui donne lieu aux « conditions d'existence » pour Darwin et enrichit par conséquent les identités de chaque être vivant par le procédé de la sélection naturelle[5]. C'est pour cette raison que, tout au long de son histoire évolutive, bien que marquée par le conflit entre tous les organismes et la tentative d'appropriation (incluant le risque de sa propre disparition), la vie porte comme marque principale une capacité de rapport d'ouverture vers le monde (ou, plus exactement, comme une interdépendance entre les êtres vivants) et de construction de rapports en tant qu'axe structurant de l'existence comme un tout (alias un écosystème).

En tant que principe ontologique, une telle ouverture se produit non seulement comme une recherche d'appropriation (c'est-à-dire l'appropriation comme initiative de tout l'organisme dans la recherche de nutriments et de partenariat sexuel), mais aussi comme une reconnaissance de l'appartenance, de l'autre, (c'est-à-dire le succès ou la prolongation de sa propre existence comme dépendante d'un réseau d'offres dans lequel l'organisme est lui-même impliqué). Ceci parce que la vie est marquée par le « principe de médiateté » (*mediacy, Mittelbarkeit*) (5, p.102) – c'est-à-dire que la vie porte comme condition propre la capacité d'établir des relations avec le milieu. Plus la forme de vie est précaire, plus cette nécessité apparaît forte pour assurer son existence et plus l'expérience dans le monde de cet être vivant devient riche en termes de diversité de relations et surtout d'évolution de sa propre intériorité. Le principe de médiateté occupe donc une place centrale dans l'interprétation du phénomène de la vie développée par Jonas, dans la mesure où il signifie que tous les êtres vivants sont dans un rapport de dépendance au monde et aux autres êtres. En ce sens, la médiateté serait caractéristique de la vie animale, parce que, à la différence des plantes, la relation des animaux avec l'environnement implique une certaine distance existentielle, une séparation qui nécessite le développement de hauts degrés de vie intérieure (émotion, perception et mobilité, par exemple). En ce sens, la médiateté traduit l'interdépendance entre tous les êtres, laquelle est traduite dans l'idée de solidarité, comme nous le verrons. « Médiateté », c'est le nom d'une relation.

Un tel rapport n'a pas forcément pour but la préservation de l'autre (ex. : le parasitisme, le commensalisme, le mutualisme, l'amensalisme), mais plutôt celle de soi-même, de telle façon qu'il s'agirait d'une forme très particulière de solidarité, celle qui, dans le cadre organique, n'exclut pas l'intérêt de la vie pour l'auto-préservation. La solidarité ne serait donc pas un acte de bonté ou de coopération mutuelle (comme l'on pourrait tendre à comprendre les relations symbiotiques entre organismes vivants), mais une condition ontologique d'interdépendance entre les êtres vivants et d'interdépendance entre ceux-ci et l'écosystème, ainsi qu'un partage d'identité (dans la mesure où toutes les formes de vie partagent la liberté, comme fil conducteur[6] du phénomène de la vie).

En raison de la médiateté des êtres, il existerait donc une voie à double sens qui ferait passer la vie, de la précarité de soi-même à la solidarité avec les autres êtres. Intériorité et liberté seraient alors deux domaines de la médiateté, des caractéristiques complémentaires qui se dédoublent dans l'expérience vitale. C'est ce que Jonas lui-même affirme dans l'introduction de *The Phenomenon of Life* : l'intériorité est « partie intégrante de la vie » et ceci parce que « l'organique, même dans ses formes les plus inférieures[7], préfigure l'esprit » (5, p.11). Une telle préfiguration de l'esprit est comprise à partir de l'idée de « degrés de liberté », qui sont caractéristiques des différents types d'organismes. Pour Jonas, il y aurait six de ces

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[3] Pour Jonas, l'intériorité peut être comprise comme le degré d'activité spirituelle de chaque organisme vivant, aspect largement négligé dans l'interprétation des phénomènes biologiques au nom de la matérialité. En tentant une interprétation qui soit à la fois « philosophie de l'organisme et philosophie de l'esprit », Jonas entend rompre avec cette dualité et reconnaître, dans l'organique, à partir de ses formes primordiales, l'existence d'une activité intérieure. La vie, dans son ouverture pour le monde, est mue par la liberté et cela signifie que sa relation avec l'environnement se fait de l'intérieur (intrinsèquement). C'est cette ouverture (qui peut être comprise comme une motivation d'affirmation de soi) qu'il appelle activité intérieure, ou activité spirituelle.

[4] Larrère (7) met en évidence, à cet égard, la vulnérabilité du vivant, sous trois aspects : la vulnérabilité est coextensive au vivant, il y a une vulnérabilité liée à l'action humaine et la responsabilité est une sorte de réponse de l'humain vivant étant à sa propre fragilité de vie.

[5] Bien que Jonas ne traite pas cette question du point de vue de la biodiversité, on peut en déduire que cette dynamique de collaboration et de conflit entre les organismes vivants pour leur propre existence, conduit à la richesse des différentes formes de vie et à leur grande diversité biologique.

[6] Sur ce point, voir par exemple Pinsart (6).

[7] Lorsqu'il parle d'espèces inférieures, Jonas pense les formes primordiales de la vie, parmi lesquelles se trouvent les bactéries, les archaea et les eucaryotes desquels les êtres pluricellulaires dérivent. Avant cela, sur le passage de la matière inorganique à l'organique, il écrit : « Le secret des débuts nous reste fermé. L'hypothèse qui me paraît la plus convaincante est d'admettre que le passage même de la substance inanimée à la substance vivante, première auto-organisation de la matière vers la vie, a été motivée par une tendance à ces mêmes modes de liberté qui se manifestent au plus profond de l'être, et auxquels ce passage a ouvert la porte » (5, p.15).

degrés : le métabolisme, la sensation, la perception, l'émotion, la mobilité et la rationalité. Toutes ces étapes sont produites par la relation (précédemment décrite) entre l'organisme et l'environnement, en fonction de ses besoins vitaux et des choix qu'il doit faire pour survivre. Le noyau articulateur de ce processus sera précisément le « principe de médiation » (5, p.102) – c'est à dire l'accès au monde se produisant comme une transcendance (médiation avec le monde) qui, inversement, contribue à l'« individuation croissante du soi », car « le plus complexe est aussi le plus différencié » (5, p.100).

Face au danger constant de sa propre extinction et aux menaces constantes du non-être, soit de la mort, le vivant établit une *relation* avec le monde comme une manière de garantir sa continuité future : « la vie est essentiellement relation ; et la relation comme telle implique une 'transcendance', un aller-au-delà-de-soi de la part de ce qui entretient la relation » (5, p.15). Ainsi, la vie « crée en permanence la rencontre à partir d'elle-même » et cherche à « posséder » le monde, à la manière d'une colonisation écologique. Cela se produit lorsqu'un organisme part à la recherche de nutrition ou de reproduction, par exemple, quand les animaux, en raison des deux sentiments que Jonas considère comme typiques de la vie animale, à savoir la peur et le désir (par peur, se met en fuite ou par désir, chasse une proie). Dans ce cas, « l'autre » est un objet de son *pouvoir*.

Le fait primitif de la vie est donc, pour Jonas, cette *relation* fondée sur la transcendance qui dépasse les polarités du dedans et du dehors, de l'objet et du sujet, de l'être et du non-être, pour s'articuler à la base la plus rudimentaire et pré-spirituelle, de telle façon que toute la philosophie de la vie se présente comme un effort pour reconnaître que « l'esprit est préfiguré dès le début dans l'organique » (4, p.100). Cela signifie que l'être est une forme de résistance au non-être, et la vie un effort de résister à la mort, laquelle est « le fait inséparable de son essence ». Pour Jonas, « la vie est mortelle, non pas en dépit d'être la vie, mais précisément parce qu'elle est la vie selon sa constitution la plus primitive » (5, p.15) que l'on doit comprendre comme l'effort de chaque être pour s'établir dans l'existence, contre tout ce qui le menace de l'extérieur. Jonas comprend évidemment la mort comme la grande menace de la vie et, en même temps, comme son aspect constitutif. Cela fait de la vie un acte continu de résistance à la mort en établissant des relations avec d'autres êtres (organiques et inorganiques) avec lesquels chaque organisme partage le monde. C'est cette *résistance* à la mort, dont l'*effort* se vérifie dans son attitude affirmative, qui produit la transcendance de la vie vers le monde et lui fournit, par la voie initiale du métabolisme, les conditions d'entretien de sa condition. Or, la transcendance, c'est-à-dire l'attitude qui fait que chaque être vivant se quitte de soi-même et se dirige vers le monde qui l'entoure, est un type de « décision », reconnue par Jonas comme un acte de liberté, qui se divise en des degrés divers depuis l'activité métabolique jusqu'à atteindre le stade de la rationalité.

Les différents degrés de liberté sont propres aux différentes règnes (végétaux, animaux non-humains et humains) et se réalisent cumulativement jusqu'à atteindre chez l'humain, en tant que « transanimal »[8], l'autoréflexion, par laquelle l'« homme vrai émerge » (5, p.185) : *mihi factus sum* veut proprement dire que l'homme a atteint le sommet de l'intériorité[9], dans le cadre de l'évolution même des organismes vivants qui y coïncide pour l'autocompréhension d'eux-mêmes, c'est-à-dire pour la capacité réflexive acquise par la conquête de la rationalité, qui offre à l'être humain la possibilité de penser à lui-même, mais aussi aux autres. Chez l'homme, la vie connaît la vie (à savoir, avec l'acquisition de la capacité réflexive chez l'homme, la vie peut maintenant penser à elle-même, puisque l'homme fait réellement partie de la vie et n'est pas, comme le voulait la tradition cartésienne, quelque chose de séparé d'elle. La pensée est donc celle qui relie l'homme à la vie dans son ensemble) et ceci parce que « seule la vie peut connaître la vie ». Ainsi, l'homme formule une image pour lui-même et à partir de là une image pour le monde autour, donnant naissance à l'*homo pictor*. La représentation de soi, sous la forme d'image, fait que l'homme apprend à dire *moi* et peut ainsi inaugurer une « intercommunication verbale » (5, p.186) avec les autres personnes : « en apprenant à dire 'moi', [l'homme] découvre sa propre identité dans son unicité solitaire » mais cette « objectivité privée du soi est ainsi en rapport constant avec l'image publique de l'homme » (5, p.186) dans l'extériorisation de soi face aux autres êtres dans le monde.

Le point clé de cette stratégie argumentative réside dans la donnée de l'« intériorité » de la vie, que Jonas identifie déjà comme préfigurée dans les êtres organiques plus primordiaux : la liberté est le nom de cet effort intérieur d'affirmation de soi qui, dans le cas de l'homme, deviendra aussi conscience de soi. La découverte de cette dimension de l'« intériorité » (5, p.109) est considérée comme une « révolution ontologique » (8, p.81), qui met la vie au premier plan, non plus dans les endroits extrêmes du matérialisme ou de l'idéalisme, mais dans sa propre intégralité ontologique. Dans le texte *Biological Foundations of Individuality* (de 1968 et publié ultérieurement dans *Philosophical Essays*), Jonas analyse cette problématique en affirmant que le *moi* est le résultat des modes de médiation d'un organisme avec son monde : « la médiation de l'être animal ou le clivage entre soi et le monde – un élargissement qualitatif de l'écart ouvert d'abord par le métabolisme et qui est ainsi à la racine de la vie » et, par conséquent, « la moindre intégration de l'animal dans son environnement (…) est une mesure de sa plus grande individualité » (8).

L'histoire de liberté est ainsi l'histoire de la précarité : « le 'monde' est présent dès le premier commencement comme un horizon où apparaît la simple transcendance du manque et qui accroît la particularisation de l'identité intérieure, la convertissant en un environnement enveloppant un rapport vital » (9).

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[8] La trans-animalité est, pour Jonas, une caractéristique de l'être humain. Elle est constitutive d'un processus évolutif de distinction par rapport aux autres animaux, à travers l'utilisation d'outils, la capacité de symbolisation et l'activité rationnelle. Ces trois éléments sont présentés par Jonas à travers trois images: l'outil, le dessin et la tombe, qui constitueraient les trois degrés de différenciation de l'homme par rapport aux animaux, à partir de l'*homo faber*, en passant par l'*homo pictor* et en arrivant à l'*homo sapiens*.

[9] Notez comment, dans ce cas, Jonas utilise méthodologiquement la théorie de l'évolution, mais maintient en même temps certains aspects de la tradition philosophique qui attribue à l'être humain une place particulière en raison de son indice plus élevé de richesse intérieure (représentée par la rationalité).

LE MÉTABOLISME, PREMIER DEGRÉ DE LA LIBERTÉ

Comme nous l'avons indiqué précédemment, pour Jonas, le métabolisme est ainsi la première étape de la liberté, liberté qui se divise en différents degrés, passant par les facultés de la perception, de l'émotion (sentience) et de la mobilité, jusqu'à la capacité symbolique du langage et de la rationalité. Ces processus « signifient une découverte croissante du monde et une individuation croissante du soi » (5, p.101) et « c'est seulement par ces facultés que l'espace est réellement ouvert à la vie » (5, p.101). En d'autres termes, chacun de ces degrés de liberté est une espèce d'ouverture vers le monde au moyen de l'excitabilité et de la capacité à réagir aux stimuli, ce qui fait de la sensibilité le germe de la perception dans le rapport du vivant avec le monde extérieur, dont le résultat final sera la croissance de sa propre intériorité. La liberté, comme acte de rapport avec le monde, est une tendance propre de la vie et un concept descriptif de la « structure la plus élémentaire de la vie », à savoir,

> un trait ontologique fondamental de la vie elle-même ; et aussi, comme on peut le voir, le principe continu – ou du moins le résultat constant – de sa progression vers des degrés supérieurs, où à chaque étape une liberté se construit sur une liberté, une liberté supérieure sur une liberté inférieure, une liberté plus riche sur une liberté plus simple : en termes de concept de liberté, le tout de l'évolution peut être interprété d'une façon convaincante [...]; c'est la tâche d'une biologie philosophique de suivre le développement de cette liberté embryonnaire selon les niveaux croissants de l'évolution organique (5, p.80).

Le métabolisme est la première caractéristique bio-ontologique de la vie : en parlant de *Stoffwechsel (échange de matière)* Jonas fait de ce concept, selon ses propres termes, une « manière éloquente » d'exprimer la réalité du vivant, « le nom scientifique courant » de l'être (10) qui se projette vers l'extérieur comme une stratégie de lutte contre la mort. Cet événement – reconnu comme un ensemble de transformations se produisant dans l'organisme vivant qui interagit avec son environnement par l'intermédiaire d'échanges chimiques, parfois par la synthèse de matière (anabolisme), d'autre fois par la dégradation de matière (catabolisme) – stimule à la croissance et à la reproduction des cellules. Le métabolisme se produit donc de diverses façons, comme la photosynthèse des plantes, la digestion chez les animaux et l'oxydation de composés organiques, faisant des organismes des systèmes ouverts qui échangent de la matière et de l'énergie avec leur environnement comme un moyen indispensable à la (sur)vie, maintenant un équilibre et permettant des adaptations, quand cela est nécessaire. En tant que systèmes ouverts, les organismes sont capables de garder des niveaux de régulation et de contrôle métabolique que Jonas identifie comme faisant partie de la liberté affirmative de la vie, comprise dès maintenant comme un réseau complexe d'interactions métaboliques.

Or, la décision métabolique de l'être dans le flux de l'existence évoque cette double condition de dépendance et d'autonomie ou, en termes philosophiques, de nécessité (qui est aussi un « manque ») : « à cette nécessité [*necessity*] nous donnons le nom de manque [*need*] » (10, p.267) et de liberté. Ceci veut dire que tout organisme est métabolique, car c'est la condition intrinsèque de sa survie, mais c'est en même temps son acte de transcendance, que Jonas appelle liberté, un intérêt vital de l'être pour soi-même sous la forme d'une résistance au non-être, dont la tension, étant impossible à surmonter, commence à orienter ses « choix », donnant lieu à différents degrés d'intériorité.

LE PRINCIPE DE MÉDIATETÉ, PORTEUR DE LA SOLIDARITÉ

Cela signifie que l'affirmation de soi est un acte libre de l'organisme; mais, inversement, c'est aussi un impératif de la nécessité dans la lutte pour l'existence[10] (ou l'affirmation de la vie) dérivée de cette possession de soi, propre à celui qui se confirme dans l'existence. La base de ce mouvement est, pour Jonas, le *principe de médiateté*, où est contenue la condition de la solidarité des formes de vie entre elles et avec l'environnement. Or, de cette façon, une telle solidarité est une marque fondamentale de l'Être, car l'expérience la plus intime de la vie est sa résistance à la mort – et, à la limite, c'est cette solidarité la plus propre qui motive de tels rapports : « nous partageons le sort de la mortalité avec les autres créatures, que toute la vie est mortelle, et que la mort est y compris la contrepartie de la vie », l'« attribut essentiel de la vie » (10, p.267) et pas seulement comme une définition qui conduit à la possibilité (le vivant peut mourir), mais aussi à la nécessité (le vivant doit mourir) et à l'inexorabilité (le vivant va mourir).

En tant que maillon fondamental, la mort est le fondement de la solidarité : « à la possibilité ininterrompue, j'associe le fardeau de la mortalité, et à la nécessité ultime, j'associe la bénédiction de la mortalité » (10, p.267). Entre une chose et l'autre, le réseau d'interdépendances de la vie forge la possibilité de sa permanence provisoire. Ainsi, exister, c'est créer des réseaux de solidarité qui offrent la possibilité de résister à la mort. Pour cela, la première étape est d'« exister au moyen de l'échange de matière avec l'environnement, l'incorporer de façon transitoire, l'utiliser et l'excréter une fois de plus » (10, p.267).

Dans le cadre de l'histoire des réseaux de solidarité (ex. : la société et l'écosystème), l'être humain occupe une place particulière, soit parce que chez lui la précarité assume des versions plus évidentes, soit parce qu'il développe comme réponse des capacités plus favorables à sa subsistance. Lui-même, cependant, comme l'a démontré la théorie darwiniste de l'évolution, n'a pas une « position particulière » mais fait partie de la « continuité de la descendance ». C'est la théorie de l'évolution qui, selon Jonas, a rendu manifeste une interprétation selon laquelle la vie se tisse à la manière d'un réseau de solidarité complexe venant unir l'ensemble des êtres en une seule organisation du vivant : « si l'être humain est parent des animaux, alors les

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[10] Il est possible d'identifier une oscillation jonasienne entre la théorie évolutionniste et l'ontologie classique dans la mesure où le philosophe s'intéresse aux « aspects philosophiques du darwinisme » (titre du troisième chapitre de son chapitre pour 1966) pour essayer de surmonter la tendance mécaniste et matérialiste de l'approche évolutionniste. Pour une compréhension plus approfondie de cette question, voir Pommier (11), qui développe une interprétation dans laquelle il met en évidence, à la fois, l'originalité de la proposition jonasienne et sa connexion avec d'autres auteurs importants dans cette perspective.

animaux sont aussi parents des êtres humains » et ceci parce qu'ils partageraient ensemble une dose de spiritualité, basée sur le principe de liberté présent en tout être vivant depuis ses formes les plus primitives. De cette façon, face à l'évidence du développement spirituel de l'homme, il serait « injustifiable de nier des degrés proportionnels d'esprit aux formes ancestrales les plus proches ou lointaines et avec lui à n'importe quel niveau de l'animalité » (9, p.121).

LE PRINCIPE DE RESPONSABILITÉ : L'AVENIR DE L'HUMANITÉ EST INDISSOCIABLE DE LA SAUVEGARDE DE LA NATURE

La vie contient par conséquent une motivation relationnelle qui révèle la solidarité comme une nécessité : « avec la première trace d'un stimulus subjectif, avec l'expérience la plus rudimentaire du contact, une fissure s'ouvre dans l'enfermement de l'être » (9, p.130). La solidarité, provoquée par la rencontre de l'être avec l'autre, stimule la propre *mêmeté* et singularité, contribuant à enrichir la dimension d'intériorité. De cette façon, on voit que la solidarité n'est pas le contraire de l'identité, mais un complément ou une dérivation de la quête d'affirmation de soi propre à la vie. Il y a alors une « solidarité d'intérêts » (3, p.229) qui fonde tout le rapport entre les êtres.

Une telle perspective entraîne des conséquences dans la pensée éthique proposée par Jonas. Selon lui, en partant de la condition d'interdépendance entre les êtres, tout principe de préservation de la possibilité de vie future, tel que le principe de responsabilité, doit prendre en compte comme condition que l'avenir de l'humanité dépend de l'avenir de la nature en général, faisant que « les intérêts humains coïncident avec le reste de la vie, qui est sa patrie terrestre dans le sens le plus sublime de l'expression » (3, p.229). Jonas appelle cela, dans l'introduction du chapitre V de son œuvre principale, « solidarité d'intérêts avec le monde organique » (3, p.229). Avec la reconnaissance du réseau de solidarité, Jonas refuse l'anthropocentrisme et appelle à une « fidélité à la totalité de la création » comme une urgence éthique centrale de la civilisation technologique.

Dans cette perspective, il s'agit de penser à la fois l'avenir de l'humanité et celui de la nature, niant l'« égoïsme des espèces » (dont le résultat est l'ascension du pouvoir humain sur toutes les autres formes de vie) au nom de la reconnaissance du « devoir [de l'homme] par rapport à la nature » (3, p.230), reconnue maintenant dans sa propre dignité : « nous pourrions affirmer que la solidarité de destin entre l'homme et la nature, solidarité nouvellement révélée par le danger commun que les deux encourent, nous permet de redécouvrir la dignité propre à la nature, nous appelant à défendre ses intérêts par-delà les aspects utilitaires » (3, p.230). Il s'agit avant tout d'une solidarité qui se manifeste comme une tentative d'affronter le nihilisme diagnostiqué par Jonas : c'est-à-dire, il faut reconnaître dans cette stratégie de Jonas, « l'effort de repenser le vivant selon les critères de principes ontologiques définis par les lois de l'organisme et entièrement centrés sur la lutte contre le nihilisme » (12). On doit comprendre cette stratégie comme la vidange de toutes les valeurs et la crise des fondements de la morale qui a conduit à une crise d'orientation éthique dans la société à partir du XIXe siècle (13).

Faisant écho aux thèses de *The Phenomenon of Life*, Jonas affirme du point de vue éthique : « dans le monde vivant, la conquête d'autres vies est un fait donné, puisque chaque espèce vit d'autres espèces ou contribue à modifier leur environnement » (3, p.230). Il s'agit du « tout symbiotique » marqué par les « inférences mutuelles, réciproquement restrictives » (3, p.230) propres à la dynamique de la vie, dont la logique est perturbée par l'accroissement du pouvoir de la part de l'*une* parmi les espèces – quelque chose que Jonas traite comme « un changement soudain dans le destin de la nature » (3, p.230). La solidarité, dans ce cas, doit fonder également la responsabilité : il s'agit de « transposer à l'action collective le 'oui à l'Être', que l'ensemble des choses a fini par faire devenir un devoir humain » (3, p.233).

CONSIDÉRATIONS FINALES

Hans Jonas demeure l'un des philosophes contemporains qui a pris le plus au sérieux les problèmes environnementaux : il a identifié un principe dualiste de négation du monde comme marque culturelle de l'Occident (qui aurait commencé dans les mouvements gnostiques de l'Antiquité et atteint la philosophie existentialiste) ; il a critiqué les bases scientifiques de la biologie moderne dans leur interprétation du phénomène de la vie ; et il a mis en évidence les lacunes des éthiques traditionnelles pour rendre compte des défis entraînés par l'avancement effréné de la technique, déguisée en « volonté *illimitée* de pouvoir » (3, p.234), qui oppose l'homme et la nature, au détriment des deux. Jonas est l'un des grands critiques des utopies du progrès débridé et du développement à tout prix, car il a envisagé la vulnérabilité de la nature, l'irréversibilité et le caractère cumulatif des dommages qui lui étaient causés, la puissance des nouveaux pouvoirs et, en même temps, le manque de préparation de l'homme quant à leur maîtrise[11].

Comme tout *pouvoir* est un mode d'*action* et d'*intervention*, il ne peut être pensé sans que soient considérées les responsabilités à la fois individuelles et politiques des générations actuelles sur les générations futures. La philosophie de Jonas formule donc des concepts aussi polémiques qu'urgents, incluant l'idée d'une « heuristique de la peur » et d'une « futurologie comparative » (3, p.70), capable de réunir des savoirs les plus variés afin de prévoir le mal futur, et basée sur une « science factuelle des effets lointains de l'action technique ». (3, p.70) Si les utopies du progrès sont basées sur la formulation d'un contexte positif qui annule la nécessité de la propre éthique, les informations qui nous arrivent des sciences naturelles et des spécialistes de l'écologie rendent compte que la nouvelle éthique a besoin des savoirs prévoyants afin d'entrevoir les futurs dangers – *in dubio pro malo* est la devise centrale de l'éthique jonassienne, qui prône la parcimonie, la modestie et la précaution comme autant de valeurs centrales de notre époque, en vue du bien humain et de l'ensemble du

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[11] Sur la perspective politique de la proposition de Hans Jonas (non développée dans cet ouvrage), voir Schoefs (14), qui analyse si les défis de la crise environnementale pourraient encore être relevés en régime démocratique, ce qui ferait de Jonas un auteur de philosophie politique et de la théorie démocratique.

réseau complexe de la vie. À la fin, Jonas suggère que la « philosophie de la morale doit consulter notre peur plutôt que notre désir » (3, p.71) et que, finalement, l'éthique doit être un « pouvoir sur le pouvoir » (3, p.71) capable d'imposer des freins volontaires à l'ardeur destructive assurée par la technologie.

La société de production à grande échelle, dont les dommages se font déjà sentir dans nos générations en ce qui concerne, par exemple, le réchauffement climatique et l'érosion de la biodiversité, a évidemment du mal à accepter une argumentation qui propose la modération de l'exercice du pouvoir de maîtrise de l'activité technique sur la nature, dans la logique de l'exploitation et de la réserve. On nous a appris à penser que, si nous *pouvons,* alors nous *devons*. La majorité des humains semble être intéressée par la satisfaction de la gloutonnerie, curieusement devenue une vertu centrale de l'actuel modèle de société, stimulée par l'indulgence générale et par l'espoir matériel de la consommation, lancée comme un appel en faveur d'une vie (plus) heureuse.

En développant le concept de « solidarité d'intérêts », Hans Jonas explique pourquoi, dans son impératif catégorique, l'homme reste central : il représente le lien d'articulation de tous les êtres, liés par le réseau de la vie, marqués par l'interdépendance[12]. Dans ce cas, seules deux alternatives sont possibles : soit nous sauvons tout le monde, soit personne n'est sauvé.

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[12] Frogneux (15) a magistralement développé cette hypothèse dans son livre de 2001.

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Ethics of Amnestics and Analgesics: The Role of Memory in Mediating Pain and Harm

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Résumé
L'analgésie et l'amnésie représentent deux piliers complémentaires de l'anesthésie visant, respectivement, à atténuer l'expérience de la douleur et les processus d'encodage de cette expérience dans la mémoire. Ces éléments sont généralement combinés dans les techniques anesthésiques modernes, mais il existe certaines circonstances – comme la sédation consciente – dans lesquelles les conditions de l'amnésie sont remplies alors que l'analgésie joue un rôle auxiliaire et souvent incomplet. Ces activités reflètent une croyance largement répandue mais méconnue dans la pratique clinique selon laquelle, bien que les expériences douloureuses puissent être de courte durée, leur représentation dans la mémoire et ses impacts ultérieurs sur la pensée et l'émotion peuvent avoir des conséquences durables pour les patients. Dans cet article exploratoire, nous définissons des catégories phénoménales et ontologiques abstraites de l'expérience de la douleur, nous affirmons qu'elles sont traitées respectivement par des agents analgésiques et amnésiques et nous décrivons comment chaque catégorie d'expérience est capable de causer des dommages individuels. Partant de la question de savoir comment il peut être permis d'autoriser toute expérience ou tout souvenir de douleur évitable, nous identifions que la douleur phénoménale et abstraite se manifeste sur un spectre de gravité, chacune avec un seuil énigmatique – unique à la circonstance et à l'individu – qui détermine si la douleur se traduira ou non par un préjudice, et quelles permissions entourent donc son traitement. En fin de compte, nous constatons qu'il existe des raisons physiologiques convaincantes pour l'utilisation simultanée d'analgésiques et d'amnésiques lorsque l'expérience de la douleur dépasse ces seuils, tandis que le traitement de l'expérience « sous-seuil » dans l'une ou l'autre catégorie est un impératif purement éthique qui doit être équilibré par des considérations sur les dommages potentiels posés par les traitements eux-mêmes.

Mots-clés
amnésie, analgésie, douleur, préjudice, mémoire, anesthésie, sédation consciente

Abstract
Analgesia and amnesia represent two complimentary pillars of anesthesia directed, respectively, at mitigating the experience of pain and the processes of encoding that experience into memory. These elements are typically combined in modern anesthetic techniques, but some circumstances exist – such as conscious sedation – in which the conditions of amnesia are satisfied while analgesia plays an auxiliary and often incomplete role. These activities reflect a widely held yet underrecognized belief in clinical practice that although pain experiences may be short-lived, their representation in memory and its subsequent effects on thought and emotion can have enduring consequences for patients. In this exploratory article, we delineate phenomenal and abstract ontological categories of pain experience; advance a claim that they are treated by analgesic and amnestic agents, respectively; and describe how each class of experience is uniquely able to bring about individual harm. Beginning with the question of how it can be permissible to allow any preventable experiences or memories of pain, we identify that both phenomenal and abstract pain manifest on a spectrum of severity, each with an enigmatic threshold – unique to circumstance and individual – that determines whether or not pain will translate into harm, and what permissions therefore surround its treatment. Ultimately, we find that there are compelling physiological reasons for the concurrent use of analgesics and amnestics when pain experience exceeds these thresholds, while the treatment of "sub-threshold" experience in either class is a purely ethical imperative to be balanced with considerations of the potential harms posed by the treatments themselves.

Keywords
amnesia, analgesia, pain, harm, memory, anesthesia, conscious sedation

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INTRODUCTION

It is the aim of general anesthesia to afford patients physically and psychologically safe passage through a (usually surgical) experience that is medically indicated but otherwise intolerable, and traditionally this is achieved through several elements working in concert: hypnosis, analgesia, and amnesia, as well as akinesia and hemodynamic support in specific circumstances (1). In this context, hypnosis functions in the central nervous system to render a patient unconscious[1] (2), analgesia in the central and/or peripheral nervous systems to mitigate the perception of pain (3), and akinesia at the neuromuscular junctions to provide muscle relaxation and thereby prevent involuntary movement (4). Amnesia is unique among the components of anesthesia: rather than facilitate an operation per se, it makes it immemorable by interfering with a patient's consolidation of experience into memory (disrupting new memory formation in a process called "anterograde amnesia") (5,6). Although amnestic agents regulate future recollection rather than immediate experience and perception, they

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[1] In this context, we refer to unconsciousness as the phenomenological state of being unaware and unrousable.

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are a critical component of anesthesia because of the many demonstrable risks of intraoperative memory formation: even brief moments of unintentional awareness during surgery can facilitate consolidation (7), and the ability to recall surgical experience is associated with long-term psychiatric sequelae such as post-traumatic stress disorder (8).

From an exploratory perspective, the simultaneous use of amnestic and analgesic agents gives rise to interesting practical questions. On its face, the pursuit of amnesia may seem redundant given the antecedent aim of analgesia to preclude aversive experiences. If a patient is completely insensate to pain through the judicious use of analgesics, for example, what is gained by using an amnestic to prevent a negative experience? Two arguments are that: 1) pain may not be the only experience of an (unfamiliar and sterile) operating room that a patient may reasonably elect to forget, and 2) amnestics serve as a safety net in case of inadvertently inadequate hypnosis or analgesia. The inverse scenario is equally intriguing: if a patient is provided with adequate amnesia such that any pain they may experience is not consolidated into memory, why then is it necessary to also supply analgesia?

While the answers to these practical questions may seem a priori commonsensical, they disguise moral arguments which are far more complex. The aim of this paper, while generally exploratory in nature, is to present practical and moral perspectives that engage with these arguments surrounding the use of amnestic and analgesic agents in clinical practice. In addition to the above question, which is the focus of our thesis, we respond to two moral questions arising from this framework. Firstly, what are the relationships between amnesia, analgesia, pain, and harm, and what practical and moral justification do pain and harm give for the use of amnestic and analgesic agents in clinical practice? Secondly, how do these relationships shape a physician's moral duties surrounding the provision of amnesia and/or analgesia (e.g., can medical professionals be justified in forgoing one or the other in clinical practice, and what experiences either warrant or oblige the use of either or both)? To address these questions, we first provide a practical foundation for the use of analgesics and amnestics by outlining their clinical parameters, before exploring the relationships between their effects and the concepts of pain, permissibility, and harm. We demarcate two distinct notions of pain, which we have called "phenomenal" and "abstract" pain, and their unique relationships with analgesia and amnesia. Finally, we explore the moral permissions and limitations arising from these relationships. Drawing on this overall inquiry, we contend that clinical indicators and common sense can inform a reasonable understanding of when and why to pursue amnesia, analgesia, or some combination of both, although an objective threshold to guide this decision is not generally achievable due to the central role of subjectivity in pain experience. Instead, the consideration of amnestic and analgesic agents may be apportioned relative to the expectation of avoidable harms in any given circumstance.

ANALGESICS AND AMNESTICS

The use of analgesic agents such as opioids comes with several risks, ranging from post-operative nausea and constipation to respiratory depression and physical dependence (9). Acknowledging that this is an oversimplification of a broad class of pharmacological agents, amnestic medications such as benzodiazepines tend to offer a relatively large therapeutic index (10) – for example, these agents' most common effect is often sedation, which is sometimes advantageous when they are used in the context of an anesthetic. For this reason, it could be seen as attractive to use only the latter to limit the psychological consequences of pain, rather than subjecting a patient to the potential side effects of both medications. Obfuscating any direct comparison between these two categories of effect, however, is a lack of clearly demarcated amnestics in modern anesthetic practice. Many anesthetic medications provide some amnestic effect, but we do not have access to "pure" or "perfect" amnestics: common agents like midazolam also have analgesic, hypnotic, and anxiolytic effects (11,12), and although they are able to disrupt the genesis of conscious memory[2], they cannot necessarily do the same for implicit memory[3] (13). In addition, there is strong evidence to support the treatment of surgical nociception manifested in its physiological consequences (*not* mediated by psychological experience or memory): unmanaged, the broad effects of acute nociception include an immediate hemodynamic and neuroendocrine response (e.g., heightened blood pressure, cortisol, and blood sugar), and myriad downstream complications such as poor wound healing, infection, respiratory splinting, thromboembolism, and the development of chronic pain (14-16).

Notwithstanding these limitations in clinical amnesia, its conception provides a unique milieu for philosophical dialogue relating to the experience of pain and the ethical reasons to treat it (as opposed to either not treating it or using only enough analgesia to limit its physiologic consequences) when it will not be remembered. Walter Glannon, in 2014, expanded this discourse through a practical example of a patient awakening during anesthesia, and an exploration of moral arguments for and against providing an amnestic which could "erase" consolidated memory in retrograde (if such a drug existed) (17). Responding to this, Andrew Davidson raised two provocative points about Glannon's line of reasoning: that it is not entirely hypothetical, because there are real situations which mirror a "perfect" amnestic (e.g., infants or patients with dementia, who are unable to form long-term memories); and that the practice of conscious sedation constitutes a real example of the broader medical community acting on a notion that the experience of some amount of pain is permissible when an amnestic is used to prevent its consolidation into memory (13).

Davidson's examples of "perfect" amnesia can be extended even further to densely amnesic patients who lack the neurobiological capacity to form memories, such as the well-known patient H.M. who underwent an experimental bilateral

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[2] Conscious memory, also called "explicit memory" or "declarative memory", refers to information consolidated in long-term memory which can be actively recalled.
[3] Implicit memory, or "nondeclarative memory", refers to information consolidated in long-term memory which cannot be explicitly recalled but may still unconsciously affect thoughts and behaviours.

medial temporal lobectomy to treat severe epilepsy (18). We propose that his example of conscious sedation falls on a spectrum of medical therapies representing different points of permissibility or reprehensibility in the context of Glannon's questions surrounding the experience and memory of pain (13,17,19). On one end of this spectrum is traditional general anesthesia, wherein a patient is pharmacologically induced into a reversible coma to avoid any adverse experiences (of pain or otherwise) during a procedure. The other end of the spectrum would represent amnesia without any analgesia, which risks the aforementioned physiological consequences of acute pain and is, to the authors' knowledge, not practiced in any setting (and rightly so). Somewhere in the middle of this spectrum are procedures performed with an amnestic but limited analgesia, such as conscious sedation provided for the reduction of a fractured bone (13) or "awake-awake-awake" craniotomies[4] during which patients undergo surgery on the brain while awake in order to limit the risk of iatrogenic damage to critical structures (20), both of which feature in North American practice. In these cases, patients are typically drowsy although often able to wince or vocalize in response to sensations of pain or pressure, but unable to recall the experience even shortly after it ends.

While this paper seeks to explore the motivations behind the extremes of this pain spectrum – procedures only using amnestic and not analgesic, as well as the inverse – cases in the middle of the spectrum also raise several important questions. For example, can an objective standard be drawn in this practical and moral gray area, to identify circumstances in which medical professionals might be justified in using either amnestic or analgesic agents (but not both)? In considering these questions, we seek to understand the ethical motivations and parameters underpinning the use of amnestics, analgesics, or both in concert, as well as how moral arguments may inform the willingness of medical professionals to allow the experience of pain without memory for some procedures (e.g., an endoscopy) but not others (e.g., removing an appendix). We will argue that, while we can recognize the benefits and risks associated with the use of amnestics and analgesics, a concrete objective moral standard for their use cannot be neatly articulated due to the subjective nature of pain – ultimately, though, their use may be better-informed by an examination of the relationships between pain, memory, and harm, which are explored in the following sections.

PAIN, PERMISSIBILITY, AND HARM

A philosophical view of pain mobilizes conceptions of permissibility and when (if ever), in a medical context, a physician is permitted to either induce pain or fail to relieve it when there is access (in the absence of a medical contraindication) to the means of doing so (21). It is our experience that many patients associate receiving an inoculation with pain, but rarely is it recommended to administer anesthesia to mitigate the experience. A priori, one can assume that either the risks of using an analgesic or amnestic agent outweigh the potential benefits (i.e., patient comfort), or that the perceived pain is better dealt with in other ways. This logic does not extend to the pain associated with an extensive Whipple surgery[5], for example, which clinicians recognize would be unbearable for a patient without a general anesthetic. These two examples reflect an intuitive scale of permissibility for the allowance of pain in some clinical circumstances but not others.

We distinguish two philosophical approaches to answering questions about pain: an ontological approach concerned with what pain *is* and where it exists, and an epistemological approach concerned with how we *know* we are experiencing pain. For the purpose of this discussion, we concern ourselves with the former, metaphysical study of what sort of experience pain is (although subsidiary questions surrounding knowledge of the experience are also considered). Philosophers outside the clinical environment have looked for answers to the question of permissibility by developing abstract ontological definitions of pain (23), often delineating it variably as a form of sensory experience such as a physical feature or condition of the body, a form of psychological experience or perception, or a miscellany of both[6] (24-27). These definitions of pain have provided intrinsically compelling and provocative arguments to the philosophical and ethical discourse. With respect to analgesia and amnesia, these ontologies can be operationalized to explore questions of harm – what kind of sensory pain experience, psychological pain experience, or both, it is derived from – and to inform the roles of analgesics and amnestics in medical practice. To do this, we borrow the a priori premises from traditional metaphysics and modern clinical practice, respectively, that: 1) pain is either an experience of physical perception, an experience of non-physical (or psychological) perception, or both, and 2) inducing and/or allowing pain is permissible in some contexts but not others. Given these assumptions, the arguments in support of amnesia with limited analgesia (e.g., in conscious sedation) arise from a moral chasm within the notion of harm as it is applied to physical and psychological pain. In exploring these categories of pain and the relationship each maintains with harm, we seek to provide a richer conception of the profession's prima facie intuition to aggregate the ethical permissions surrounding analgesia and amnesia across various types of medical procedures.

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[4] A neurosurgical operation which is performed on an awake patient, to allow for functional cortical mapping during the careful resection of tumours abutting brain regions responsible for generating speech or movement. Traditionally, these procedures might be performed in an "asleep-awake-asleep" fashion where a patient is anesthetized for the beginning and end of the procedure (when the cranial vault is accessed and closed, respectively), and awoken midway to stimulate and map important cortical structures. In the "awake-awake-awake" variation of this procedure, a patient may be awake for the entirety of the operation with pain control (e.g., via nerve blocks of the scalp) but without general anesthetic or sedation (20).

[5] An invasive surgical operation, also known as a pancreaticoduodenectomy, in which the pancreatic head, duodenum, gallbladder, and parts of the stomach and jejunum are excised en bloc (22).

[6] Recent scholarship has argued that pain is necessarily a componential medley of phenomenal experience, on the grounds that that no unitary characterization (such as physical sensation or perceptual representation in consciousness) can independently provide an ontological definition that adequately captures the complexity of pain experience (24).

PHENOMENAL AND ABSTRACT CONCEPTIONS OF PAIN

The delineation of two principal classes of pain experience is a good starting point for exploring the ethics of analgesia and amnesia. The first class refers to a sensory experience defined by concrete spatiotemporal characteristics (25). Philosophers Ned Block and Walter Glannon, among others, have deployed the terminology of "phenomenal pain" to describe this immediate physical experience of pain perceived through nociceptors (17): for example, the acute perception of an uncomfortable sensation in one's toe when a hard external stimulus has impinged on its soft tissue. While the use of the word "phenomenal" in the philosophical tradition often refers to the what-it-is-likeness of experience, here it refers strictly to the (objectively or subjectively) localizable, tangible experience of pain. Phenomenal pain is classically situated in and bounded by specific tissue damage, although this is not definitionally imperative with respect to chronic pain (28). In all cases, it is an immediate sensory or phenomenological experience of pain in physical sensations and properties.

While references to pain classically describe this phenomenology, pain can also be described in terms separate from immediate, physical experience. This latter interpretation of pain, which we term "abstract pain", resists conflating the perception of a physical feature or condition with the physical feature itself (25). Rather, abstract pain represents an often-unlocalizable inner perception of an undesirable experience; put another way, it is all the components of painful experience except for its immediate perception. With this definition, abstract pain follows from the encoding of phenomenal pain experience into memory, from which it can be recalled or re-experienced, and manifests more subtly, such as in behavioural modifications or alterations of thought and emotion reflecting an unpleasant prior experience. Phenomenal pain (e.g., beginning with the sensation of receiving an injection and experienced until local nociceptors cease to signal tissue injury) and abstract pain (e.g., the auxiliary or lasting negative effects of having undergone the phenomenal pain experience, which might lead an individual to avoid future injections) are both necessarily mediated by the nervous system, and together provide a composite definition of pain which can be operationalized to explore the ethics of its management with more granularity.

In practice, phenomenal and abstract pain may be thought to represent unique therapeutic targets. In the context of anesthesia, for example, we argue that local or general analgesic formulations are used to numb physical sensations and ameliorate the experience of phenomenal pain (either at the site of the nociceptive stimulus or through central action on the nervous system). Amnestic agents are similarly provided with the aim of preventing the consolidation of phenomenal pain experiences into memory (therefore sharing in prevention of the undesirable functions of pain). While both analgesics and amnestics are therefore tools for the mitigation of pain experience, their respective uses are grounded in unique and independent conceptions of pain.

BROADLY DEFINING HARM

Motivations to pacify these different notions of pain are grounded in their relationships with each other and with the related concept of harm. We note the important distinction, again, between ontological and epistemic understandings of harm; here, their delineation becomes more ambiguous, as the understanding of what harm *is* as a metaphysical concept is fundamentally informed by the epistemic knowledge of how one might *identify* that they are being harmed. Thus, the determination of what constitutes individual harm requires several further considerations, as we argue that the highly subjective and individual factors that contribute to pain eliminate the possibility of one unambiguous, universal conception of harm. Colloquially, for example, one may recognize the concept of a pain threshold, noting that a person's psychological or genetic disposition may predispose them to different kinds or degrees of experience. An experience like receiving a tattoo may be judged as intolerable for some, but unremarkable – or even pleasurable – to others. The author C.S. Lewis, in *The Problem of Pain* (1940), provides an initial framework with which to examine the experience of pain and its relationship with harm:

> […] the truth is that the word Pain has two senses which must now be distinguished. **A.** A particular kind of sensation, probably conveyed by specialised nerve fibers, and recognisable by the patient as that kind of sensation whether he dislikes it or not (*e.g.,* the faint ache in my limbs would be recognized as an ache even if I didn't object to it). **B.** Any experience, whether physical or mental, which the patient dislikes. It will be noticed that all Pains in sense A become Pains in sense B if they are raised above a certain very low level of intensity, but that Pains in the B sense need not be Pains in the A sense. Pain in the B sense, in fact, is synonymous with 'suffering', 'anguish', 'tribulation', 'adversity', or 'trouble' […]. (29, p.78)

While we may point to some objective factors of experience that are generally recognized as harmful or causally connected to harm, the approach to an ontological definition of harm ought to be inclusive and sensitive to the various subjective factors that contribute to an individual's experience of a "harm threshold", allowing for the breadth of both physical and psychological experiences that can be harmful. This understanding privileges neither outcomes nor means and is therefore consistent with both consequentialist and deontological traditions, accepting that both an individual's actions and their consequences can constitute harm in and of themselves.

Simultaneously, a rational conception of harm must be appropriately specific, because while there is a degree to which an understanding of harm may be influenced by personal opinion, subjectivity, and lived experience, the potential for any experience of pain to be conflated with harm is not tenable in the context of professional obligations to do no harm. Primarily, such a conflation would prohibit any medical intervention associated with even mild discomfort. The duty of clinicians to avoid doing harm is an imperfect, prima facie duty (30), balanced against other competing duties (e.g., to provide beneficent care to patients); nevertheless, it must be possible for some experiences of pain not to constitute harm, or this duty is an indictment of essentially all medical interventions. In practice, the ethical obligations of clinicians are to offer interventions that balance the assumed risks and benefits, and to avoid subjecting patients to unreasonable degrees of harm without consent. This may also mean balancing the risks of analgesic and amnestic therapies, along with practical considerations in their use such as cost or resource stewardship, against risks associated with patients' experiences if not mediated by these therapies.

We therefore conservatively refer to harm as the lasting phenomenon of an individual's wellbeing falling below that threshold which a rational individual experiencing it could consider reasonably acceptable. In this regard, we loosely borrow conceptions of wellbeing and harm from Powers and Faden (31) and agree with them that, though the exact threshold is never articulated, harm arises when an individual is deprived of or significantly deficient in a core dimension of wellbeing such as health. This would suggest that reasonable action be taken to afford individuals a sufficient state of wellbeing and a minimization of avoidable harm, while also recognizing the intersectional and subjective nature of the phenomena. The definition also allows for the possibility that a single experience of pain may affect two individuals differently, both with respect to its subjective experience and its capacity to cause harm, while remaining consistent with the motivations of clinicians to do no harm despite their constant engagement in practices that sometimes do induce pain (e.g., giving a vaccination without prior topicalization using a local anesthetic). However, our proposed notion of two distinct types of pain experience challenges providers to identify the appropriate permissions surrounding each, and therefore to engage meaningfully with the unique relationship – explored in subsequent sections – that each type bears with harm.

TREATING PHENOMENAL AND ABSTRACT PAIN

Earlier, we presented the idea that the pain experience can be philosophically disaggregated into a dichotomy of phenomenal and abstract pain. The concept of phenomenal pain informs the use of analgesics as a practice seeking to ameliorate the acute physical experience of pain, by forestalling nociceptive signal transduction or transmission through the nervous system. In the absence or failure of an analgesic, a subject undergoing an acute physical experience of severe pain can sustain harm, for example by way of a physiological stress response (e.g., a profound increase in blood pressure) that precipitates a stroke. Abstract pain, in contrast, informs the use of amnestics as a practice seeking to mitigate the consolidation of negative experience into memory. In the absence or failure of an amnestic, the harm done to an individual by way of undesirable mental/emotional states and behavioural modification can manifest immediately, but is also capable of extending beyond the immediate present to encompass a broad class of enduring psychological harms.

Two moral questions arise from this framework, which we will outline and explore further. First, if it is the case that allowing (or even causing) either phenomenal pain or abstract pain can be harmful, then how can medical professionals ever be justified in allowing one or the other – or some uneven combination of both – in clinical practice? For example, why is it that some brief procedures like an endoscopy often predominately use amnestics with limited analgesic effect, whereas traditional general anesthesia is a requirement for more complex and invasive procedures like a cardiac surgery? What are the morally relevant aspects of the dichotomous pain experience that inform this practice? Secondly, at what point within each category does the experience of pain become constitutive of a harm? Though one can attribute both phenomenal and abstract pain to a specific experience, does their existence (or representation in consciousness) necessitate the occurrence of harm?

RELATIONSHIPS BETWEEN PAIN AND HARM

Both phenomenal pain and abstract pain have the potential to be harmful, but the means by which they act as causative agents of harm (and the means by which physicians can prevent this process) are unique. With respect to phenomenal pain, the practice of avoiding or ameliorating harm arising from sensory experience seems prima facie intuitive: by preventing nociception with analgesics or similar modes of therapy, an inherently undesirable experience of pain can be avoided, and therefore precluded from causing harm to an individual. Complicating this framework, the translation of phenomenal pain into harm relies on several mediating physiological factors: for example, nociception changes sympathetic drive, which in turn leads to hemodynamic stress and the potential for end-organ damage. Rather than eliminating the pain experience with analgesics, it is conceivable that providers could instead treat the various mediating responses – high blood pressure with beta-blockers, high blood sugar with insulin, and so on to the extreme of yet-unknown molecular stress responses to pain and yet-unknown means of terminating them[7]. The possibility therefore arises for a perception of phenomenal pain that may *not* be directly causative of harm, though still potentially harmful via its encoding into memory and re-experiencing as abstract pain.

The relationship between abstract pain and harm is more complex, given that this pain cannot be ascribed to a spatial location in the same way as a physical injury. This notion of abstract pain refers to many components of a pain experience beyond its immediate sensation. For example, in the way that one responds to an unpleasant stimulus by encoding knowledge and memory of its experience into the nervous systems, one may form an aversion to that stimulus (just as one might form a predilection for a pleasant one). The harm associated with abstract pain may not necessarily be immediately impairing, but it informs one's beliefs, behaviours, attitudes, practices, and judgements. For example, consolidating the memory of a

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[7] Another important mediating phenomenon is "central sensitization", the process by which peripheral nociception modifies central nervous system responsiveness to produce a hypersensitive state that is primed to experience further pain. On the basis of central sensitization, scholars such as Clifford Woolf have drawn compelling arguments that surgical nociception should be forestalled using analgesia (rather than treated reactively after a surgery facilitated by hypnosis alone) to limit long-term consequences (32). Like we argue in this section for other physiological mediators of phenomenal pain, targeting the intrinsic mechanisms of sensitization is a theoretical alternative to preventing transduction of the nociceptive stimulus itself.

traumatizing surgical experience may lead to symptoms of post-traumatic stress disorder (e.g., hypervigilance and recurrent memories about that experience), and a patient who has experienced trauma resulting from awareness under anesthesia may later elect not to undergo another surgical procedure even in dire circumstances. The consequences associated with abstract pain therefore have the capacity to extend beyond the bounds of an original stimulus, encompassing a broad class of enduring and undesirable harms, thus warranting the use of amnestic therapy when feasible. Similar to the caveat provided with respect to the prevention of harm via phenomenal pain, it is worth noting that the harms of abstract pain are also mediated by an individual's ability to – consciously or subconsciously – call them forth from memory, theoretically presenting another therapeutic target for pharmacologic agents that do not yet exist (retrograde amnestics or memory recall inhibitors), but which would intuitively warrant similar (and other) ethical considerations.

In the case of both phenomenal and abstract pain, not all instances of pain are constitutive of harm. For example, the experience of being pinched by a needle and that of sustaining injuries in a car accident both involve experiential pain but describing the former as harmful in any meaningful sense depreciates the term. In the latter, the pain experience has the unique possibility of rendering long-lasting decreases in physical wellbeing (e.g., the loss of a limb) and mental wellbeing (e.g., phantom pain or an adjustment disorder). Although the threshold beyond which an experience becomes harmful evades precise definition (in part due to its inherent subjectivity), two conclusions seem plausible: 1) there are general, objective instances that can be recognized as *potentially* harmful and which can inform the motivation to administer analgesics and amnestics, and 2) these objective considerations can supplement the subjective experience and understanding of harm, and inform the balance of expected benefits and risks associated with the mitigation of pain experience. While we accept that the range of available interventions and subjective perspectives (of both patients and providers) stymies the dictation of a clear line between experiences that will and will not be harmful, in the following section we draw from these conclusions several ethical and practical considerations which may inform clinical practice.

IMPLICATIONS FOR THE USE OF AMNESTICS AND ANALGESICS

The nature of the relationships between phenomenal pain, abstract pain, and harm reflects the existence of an ethical threshold unique to each type of pain, and which can divide experiences as harmful (to varying degrees) or harmless. While we cannot claim to offer a clear and practical injunction for the permissions surrounding pain and harm, we offer several conclusions that can elucidate how a threshold may theoretically be determined. Primarily, clinical permissions are dictated by whether a particular course of action surpasses a given limit with respect to the possibility of harm proportional to the action in question. Factors that link pain experiences to harmful outcomes appear likely to include both objective features (e.g., stimulus intensity or timescale) and subjective patient features (e.g., individual tolerance) of the experience, which may serve as a starting point for attempts to delineate the separation between permissible/harmless and unacceptable/harmful pain experiences.

In light of this proposal, we consider a pragmatic approach to the mitigation of pain and harm in which the standard of practice would be to treat, prevent, or otherwise mitigate all avoidable and probable harms that a reasonable person in similar circumstances would expect to be avoided. However, the extent to which subjective factors ought to be incorporated must also be considered because, as we have observed, the possibility that any experience of pain could be conflated with harm is incompatible with the professional duty to do no harm (and therefore would prohibit all interventions that a patient might reasonably experience as painful, no matter how minimally). A few practical criteria can be drawn from the broader literature focused on reasonableness in the context of offered treatments and informed decision-making (although the precise definition and parameters of each could be subject to their own moral debates). For example, Robert Schwartz (33) has explored the notion that patient autonomy is rarely, if ever, understood as a right to choose from a completely unrestricted range of treatment options. Instead, it is typically accepted that patients have a right to choose from within a reasonable subset of options, which are informed by the intersection of a physician's clinical expertise and a patient's individual preferences. What is determined to be "reasonable" remains open to debate, but we can highlight several factors relevant to this consideration. For example: whether a treatment is, in fact, medical in nature; whether there is any opportunity for further benefit (i.e., whether a treatment is futile); whether it is possible to deliver a treatment; or whether a treatment would displace another patient who may be in greater need (33,34). In parallel to criteria like these, a treating physician might consider whether there are other, more appropriate and less invasive means by which harm can be avoided or mitigated. This approach honours the subjective aspects of pain experience and harm, but also begins the necessary function of delimiting what potential harms could be considered and which might be seen as reasonable. Thus, it also provides a starting point for a provider to determine whether the administration of an analgesic or amnestic agent (and the risks associated with these) are reasonable in view of the potential harms of the experience that a patient might have either with or without them.

We can be confident that, because harm thresholds are modified by patient-specific variables, professionals may never be able to predict every individual's tolerance for pain before it broaches harm. In the absence of objective frameworks for the measurement of pain, the medical system relies on incomplete evidence to anticipate which procedures require complete analgesia and/or complete amnesia, and which can afford to forego the potential negative effects of either of these interventions. Permissions to allow pain therefore appear to be primarily guided by a judgement relating to what an average individual[8] can reasonably be expected to tolerate (e.g., a reasonable person can be expected to tolerate the discomfort of

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[8] It is important to note that what is considered average has been the subject of deserved controversy, given the term's attachment to historical inequities surrounding race, sex, and ability. For example, clinical trials evaluating new pharmaceuticals have historically often been performed in samples comprised largely of adult Caucasian male subjects, to the exclusion of other groups, and the applicability of their findings to all patients has been called into question (35-37). Thus, it is critical to consider these disparities when evaluating clinical studies and making any consideration on the basis of what is thought to be "average".

colonoscopy mitigated by the use of an amnestic with only slight analgesic properties, whereas these permissions cannot be extended to an open thoracic surgery). Medical professionals may also consider the gravity of reasonably anticipated effects: permissions may take into consideration what negative effects are likely or logically expected to occur in the absence of interference from an amnestic and/or analgesic and, when it can be anticipated that a patient would experience severe pain, then as professionals we are ethically obligated to mitigate it with the means available. When phenomenal pain can be controlled to the extent that physiologic harms are avoided, the further reduction of pain (e.g., providing local anesthetic through a small-bore needle before establishing intravenous access with a larger-bore one) is a purely ethical imperative.

Recognizing the possibility that harm can be caused through the administration of analgesic or amnestic medications themselves, it may be reasonable to suppose that the overall risk of harm posed to a patient undergoing a brief but stimulating procedure can be best reduced by titrating analgesic agents to the point where phenomenal pain experience is maintained just below the threshold of physiological harm, and supplementing this regimen with amnestic agents to preclude the possibility that any unchecked phenomenal pain may gain access to memory and result in abstract pain or subsequent harms. We propose this theory as a feasible, but unnoticed, ethical justification underpinning the modern practice of conscious sedation. Future directions of this work will include more precise delineations of the relationships between various qualities and degrees of pain and harm, as well as exploration of the limitations that these relationships place on what clinical interventions ought to be considered as reasonable in view of anticipated harms. Practically, these efforts will inform the clinical application of analgesic and amnestic therapies, either separately or in combination, for patients undergoing otherwise painful interventions. To this end, the work of elucidating where the thresholds between pain and harm exist, precisely, remains an ongoing project of medical ethics.

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ARTICLE (ÉVALUÉ PAR LES PAIRS / PEER-REVIEWED)

Learning Logs: Reflective Writing and Metacognition in Bioethics Courses

Marila Lázaro[a], Camila López-Echagüe[a], Fiorella Gago[a]

Résumé
La valeur que la bioéthique a ajoutée au discours entre la science et les sciences humaines est indispensable. Cependant, il est nécessaire que lorsque la bioéthique est enseignée, l'accent ne soit pas uniquement mis sur l'identification et l'analyse du problème, mais aussi sur la réflexion critique pour permettre à un étudiant d'intérioriser ce qu'il a vécu. Cet article fournit une description analytique de l'utilisation des journaux d'apprentissage comme outil de réflexion et de métacognition dans les cours de bioéthique, basée sur l'expérience des éducateurs de la Faculté des Sciences de l'Universidad de la República (Uruguay). Une analyse des journaux d'apprentissage des étudiants montre que cet outil favorise des processus complexes de réflexion et d'auto-réflexion dans lesquels le développement de compétences telles que l'abstraction, l'argumentation et la problématisation se manifeste de manière intégrée.

Mots-clés
éducation à l'éthique, cours de bioéthique, journaux d'apprentissage, problématisation, métacognition

Abstract
Bioethics has become a framework for debate throughout the world and, as such, it is an indispensable subject in scientific fields, especially in those related to life sciences. Nowadays, there is a need for its teaching to include not only the identification of ethical problems but also deliberation and critical reflection on those problems in order, among other things, to participate in decision-making processes. The methodological strategies for this are crucial. This article provides an analytical description of the use of learning logs as a tool of reflection and metacognition in bioethics courses, based on the experience of professors at the Faculty of Sciences of the Universidad de la República (Uruguay). An analysis of students' learning logs shows that this tool promotes complex reflective and self-reflective processes in which the development of skills such as abstraction, argumentation and problematization is manifested in an integrated way.

Keywords
ethics education, bioethics course, learning logs, problematization, metacognition

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> *Problematizing so many day-to-day things put me in an uncomfortable position. To be honest, I do not enjoy that feeling and would rather go back to my cave of imaginary certainties. In spite of that, it makes me feel more intellectually honest and gives me a fair starting point to improve myself. On the other hand, I did not expect that this course would lead me to question my relationships with others as well as group dynamics. I do not know whether it was intentional, but it is undeniable that this dimension of thinking is being fostered. If I had to highlight two aspects of this course, it would be these two: First that it is going to make me grow as a scientist, and if I keep up the effort it will probably also make me grow as a person.* (S1)

INTRODUCTION

According to VR Potter, who is seen as a founding father of modern bioethics, this discipline is a combination between science and philosophy, with "wisdom" being its main goal (1). Wisdom is seen as "the knowledge of how to use knowledge" for survival and for the improvement of quality of life (1, p.127). Bioethics, Potter argues, must be a bridge between science and humanities that enables survival in the face of threats from technological progress. He also proposed the term 'Global Bioethics' (2) as a synthesizing interdisciplinary approach. This included the extension of the concept of community to other living beings and nature as a whole (the "biological community") and the notion of interdependence between humans and nature that would also allow future generations to be considered as well. This global bioethics approach has received renewed interest in recent years, based on the need for interdisciplinary cooperation, dialogue between the sciences and humanities, and the recognition of the pertinence of multiple perspectives to explain complex phenomena. And it is based on the use of various methods and theories, on data and observations from empirical studies and philosophical analyzes, and on dialogue that occurs in both global and local contexts (3,4). From a global bioethics perspective, bioethics also contributes to conceptual and epistemological clarification that helps in the understanding of certain discussions or controversies, recognizing the non-neutrality of disciplinary discourses insofar as there are no "objective facts" (5).

This conception of bioethics points at a particular form of understanding the way it is taught, one which is in line with the pedagogical framework of experiential and reflective learning (6), problem-posing learning (7) and the commitment to integrative learning that involves not only the incorporation of a body of concepts, but also the development of intra and interpersonal skills (8,9). Teaching bioethics, in this regard, would require critical thinking and metacognition skills aimed at

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preparing students for deliberation, dialogue and reflection in the face of complex ethical problems (4,10,11). Using this pedagogical framework, innovative learning strategies, such as reflective writing, are required.

In the course on Bioethics taught by the authors of this article at the Faculty of Sciences of the Universidad de la República (Uruguay), having students write learning logs has been implemented for several years. The learning logs are a writing space where students are encouraged to record their experiences, concerns, and reflections throughout the course, to strengthen the way knowledge is acquired, promote reflective processes and enhance metacognitive processes.

In this article, we present the deployment of learning logs in our Bioethics course and analyze their utility as tools for stimulating reflection, problematization and metacognition. The intention is not to analyze the contents of the logs in detail, following pre-established categories, but rather to show elements that display different levels of reflection, problematization and metacognition in them. For this, different theoretical frameworks are used. These frameworks will be discussed along with a thematic analysis of the content. Twenty-five learning logs from the last three courses were selected based on a purposeful sampling approach (12,13). Excerpts of 15 of these logs were used to illustrate different levels of reflection found.

SOME CONSIDERATIONS ON BIOETHICS EDUCATION

To understand the nature of "learning", Dewey's (6) presentation of the relationships between experience, reflection, and learning process is helpful. According to Dewey, learning implies committing, reviewing, and re-signifying previous experiences in light of what is being learned. The learning process should have not only a cognitive dimension, but also an affective dimension. In recent decades, there has been growing interest in the consolidation of pedagogical approaches that incorporate a more comprehensive, humanistic and qualitative perspective to the learning processes. In this sense, far from being limited to the transmission of knowledge, learning should also incorporate the recognition of ourselves and others, focusing on living together, transforming the world, and being autonomous (8). This integrative approach to knowledge and reflexivity stimulates a discovery of personal skills (9).

With regard to teaching bioethics, there exists consensus that teaching should not be limited to the transmission of a body of content or a set of pre-established values. Instead, it should aim to develop critical reasoning and reflection skills, deliberation and decision-making in the face of complex problems and metacognition (10,14). Additionally, bioethics teaching should promote analysis and argumentation for understanding ethical problems and their implications to prepare students to face various complex challenges facing our communities (11). The concept of "metacognition" was coined in the late 1970s to refer to knowledge of one's cognitive activities in learning processes (15). Since then, it has been used with different meanings and in different contexts (16). In this article, the term 'metacognition' refers to the ability to become aware of the thinking process itself. Students' recognition of their own abilities, attitudes and knowledge provides students with a view of themselves that allows them to guide their learning process autonomously and consciously (17,18).These objectives require the implementation of activities that stimulate cognitive aspects such as critical thinking, but also emotional ones such as sensitivity and imagination in the face of the problems addressed (19). In this regard, Nussbaum (20) proposed a set of skills for higher education: the ability to critically examine oneself and one's traditions; the ability to see oneself as a human being linked to others by bonds of recognition and mutual concern; the ability to think about what it would be like to be in someone else's shoes and understand the emotions, desires and longings that another person might experience.

There are several possible strategies that encourage students to pause and reflect upon what is being done in their own practice, a concept that Schon refers to as "reflection in action" (21). One of the privileged spaces for such "reflection in action" is in writing. From a pedagogical perspective, and considering the role of language in teaching-learning processes, writing has been considered key to the development of complex cognitive skills, such as analysis and synthesis (22,23). Writing is an especially enriching and powerful learning strategy, as it involves a complex process that requires simultaneous use of different skills: abstraction, motor skills, vision (24). Reflective writing processes, in particular, exercise the writer's cognitive skills and strengthen their commitment to the learning process itself. When writing, the student has the time to think, introspect, correct, go back, and rewrite: the pause forced by the writing exercise allows us to reach higher reflexive levels than those that could be reached by using only verbal arguments. The writing process allows, according to Vygotsky (22), to make an internal discourse explicit, which is not only essential for its socialization through a dialogue with an external reader but also offers the writer the possibility of objectifying and observing their own process with a certain distance. Enhancing the reflective process that writing requires, in turn, promotes applied metacognition (25). This has, as a result, led to an interest in incorporating reflective writing in university education, with the understanding that teaching content is no longer sufficient for students to be able to solve complex problems in their chosen disciplines (21,26). In ethics education, reflective writing helps students identify ethical issues of interest, connect theoretical concepts to practice, and respond to complex situations (27), and one strategy to accomplish this is via writing learning logs.

LEARNING LOGS AND BIOETHICS COURSES

Learning journals, learning logs and reflective diaries are terms commonly found in the literature and may be used as tools in many formal teaching settings. What distinguishes them from other writing processes is that they focus on the learning process itself, the starting point for record and reflecting on one's thoughts. Moon (28) explores the characteristics, objectives and ways in which learning logs (called "learning journals" by the author) are usually employed across a variety of subjects, and finds that they are used for different purposes, including fostering critical thinking and metacognition, promoting commitment to learning, improving professional practice, strengthening self-esteem, facilitating the expression of those students who are not comfortable with orality, encouraging creativity through unstructured writing and achieving greater interaction with the groups.

Boud (29) suggests that learning logs provide a space for students to make sense of their individual experiences in relation to what has been learned, thus generating significant new learning. The log works both as a record and as a means to re-signify and give meaning to what has been worked on in the course. According to Boud, reflection can take place before, during or after a certain learning event; the log offers students the possibility to reflect on any of these moments. At the beginning, the log allows for the articulation of explicit expectations, intentions, motivations, contexts and previous ideas. Later on, the log allows students to explain what is happening and how they are taking part in the learning process (including any internal reactions that they have towards working on a certain topic). Finally, after the event, reflection allows the student to revisit the experience and observe any feelings associated with their learning – these feelings may enhance or inhibit learning, so it is important that they be recognized and acknowledged. By examining their own experience, students can compare new information to previous ideas, identify different ways of reasoning and offer meaning to their learning process based on personal experience (29). The processes that contribute to developing the learning logs – such as evaluation and reflection, self-questioning, self-verbalisation, and the elaboration of questions – have proven to have a significant impact on the student's learning and contribute to establishing productive links between theory and practice (30), as well as enhancing critical thinking and metacognition (31). As Moon notes (31), learning logs are helpful in personalizing and deepening the quality of learning.

The Bioethics course, taught by professors from the Science and Development Unit[1], is offered as an elective course for students in any degree program within the Faculty of Sciences. The course also admits some students from other faculties, with the majority being from the Faculty of Medicine. In general, 70% of the students who take the course are from the Biology and Biochemistry Bachelor's Degree, 15% from the Geography, Geology, Human Biology, Physics or Mathematics Bachelor's Degree, and the remaining 15% from other Faculties of University such as the Faculty of Medicine. The number of students taking the course is usually between 80 and 120 annually. With such diversity, one of the methodological strategies of the course in its face-to-face modality is the formation of interdisciplinary groups (of no more than six students) who work together throughout the semester. The aim of the course is for students to be able to identify ethical dilemmas (particularly bioethical ones), to analyze and problematize them from a global and critical perspective, and to justify their position and possible courses of action. The content of the course is structured in theoretical-practical modules, the first being the most general: "Basic Concepts and Fundamental of Ethics" and "Science, Ethics and Society". The following topics are subsequently covered: "Bioethics, Health and Science", "Microbioethics: The Dilemmas of Genetics and Biotechnology", "Macrobioethics: Ethics and Environment", and "Science, Politics and Ethics". Each module is made up of one or two introductory classes, followed by workshops in which each interdisciplinary group delves into the subject of the module and explores its most dilemma-generating practical aspects. There is also free space for activities proposed by students, e.g., to investigate a topic of interest, discuss and debate a film, organize formal debates, or respond to general queries.

The writing of an individual learning log, and updating it throughout the course, is a fundamental part of the strategy to monitor and evaluate student process, as well as being a space for students themselves to evaluate the process and progress of their reflection and the significance of what has been learned. The learning log is presented to students as a travel journal to an unknown destination – it is "a philosophical reflection" that they may rarely experience in an organised way in their scientific careers. Students are thus explicitly asked to develop a reflective dialogue with themselves in the logs in relation to the topics explored during the course.

DIALOGUING WITH LEARNING LOGS

In the following sections, we present an analysis of selected learning logs from 15 students, all of whom gave written permission for the content of their logs to be used, anonymously, in the research presented in this paper. Each excerpt is identified by a code in order to protect the student's identity while permitting correlations between excerpts of the same student. The Ethics Committee of the Faculty of Psychology of UdelaR approved the research project "Evaluación de la enseñanza de la Bioética en el razonamiento moral y reflexivo en estudiantes de ciencias" that framed this study.

While exploring the learning logs, attention was paid to the different levels of reflection in relation to the main topics of the course, on group work, the log itself, and on the course as a whole and its dynamics. The excerpts presented below relate to the areas or modules of the course that allowed students to connect their reflective processes to the specific challenges of the topics. Also presented are some excerpts linked to their reflections on the course procedures.

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[1] The Science and Development Unit, created in 1994 in the Faculty of Sciences of public University, teaches courses that emphasize the social dimension of scientific activity. These courses are aimed at generating discussion and reflection on the interface between science, the university and society, from historical, philosophical, political and ethical viewpoints. Its educational practice is directed at stimulating the production of reflections and personal texts on behalf of the student.

Fundamentals of Ethics

The Fundamentals of Ethics module aims to provide an introduction to the field of ethics and the identification of the type of problems that ethics addresses. It also proposes an overview of main ethical theories (deontology, utilitarianism, dialogical and virtue ethics) as an illustration of the general theoretical frameworks within which ethical problems can be analyzed. Some students showed in their learning logs the ability to make their own synthesis about the concepts at stake, denoting an understanding of the topics they were working on. This type of exposition transcends the mere reproduction of content but is still predominantly descriptive.

> *Regarding the first module, I want to stop at the questions: Why is it important to distinguish morals from ethics? How is that linked to a course on bioethics? I consider it is important to thoroughly understand the difference between morals and ethics because ethics allows us to identify and question the moral assumptions or beliefs (ideological, political, ecological, cultural, and religious) that are behind our decisions, so that we can problematize and question ourselves. Without ethics questioning our morals, we cannot identify where our opinions, judgements, evaluations or beliefs come from.* (S5)

This excerpt contains a frequent feature of the learning logs we analyzed: it is structured based on questions that serve as a starting point or central focus for the topics and problems addressed. In this case, these are questions that were explicitly posed in the course, and that the student selects as relevant to introduce conceptual aspects of the module on which they are commenting. Even though the answers to these questions are presented as personal opinion, “I consider that…”, the purpose of this excerpt is to account for the handling of the definitions of two concepts at stake. Part of the objective is to offer a space to summarise and record the contents worked on during the class; therefore, this type of predominantly expository-style entries also help reinforce the understanding of the topics covered in the course by fostering the ability to summarize and synthesize. The learning logs’ more ambitious goal is the promotion of metacognition and critical thinking skills; but it is also expected that students show understanding of the topics studied, be able to synthesize and explain them, even at a descriptive level. This also provides professors with information on the extent to which students have understood the topics studied, whether there is conceptual confusion or difficulties, and so an opportunity to intervene and clarify issues or concepts.

Another way of accounting for the acquisition of concepts from a creative approach is shown by some students who prepare a synthesis based on considerations of their own actions and feelings, giving meaning to theoretical aspects from their experience. This is the case in the following excerpt in which humour enhances self-dialogue. As Moon (28) mentions, one of the positive aspects of learning logs is that they stimulate an unstructured type of writing that allows creativity and expression to flow from a student’s own style. In this sense, humour can be a way to acquire the concepts on which they have worked.

> *I am a ‘relativist’, I thought during class. “I believe that all moral systems are valid from the viewpoint of those who practise it, which makes us incapable of generating judgements.” Immediately afterwards, I realized that I was not. I believe that women deserve equal rights and opportunities; that those most privileged must do everything they can to improve equity; that life is a right in itself, and that pineapple on pizza should be penalized; I think all of this should be true regardless of one’s culture. Therefore, I judge those systems that do not conform to these principles. I am not a relativist, so long Einstein, but a universalist. This paradigm establishes the existence of universal moral minimums, regardless of the system. And despite having serious problems with the concept (how can they be universal if many systems do not accept them? How can they be objective if they are established by us, who are governed by an individual moral system?), I think I have begun to understand: The objectivity of the minimums arises from the ability to give valid arguments (not “because God said so”, I suppose that would be dogmatism, it is right because it just is) about why something is right or not. If I understood it correctly, then, I like the idea. It does not imply the existence of some magic tablets created by Shiva about what the minimum that we can define as ‘good’ is, but rather it is based on dialectics (a positive aspect of the course is definitely the vocabulary I learned, which allows me to sound intellectually pompous).* (S6)

As in the previous case, this excerpt integrates concept definitions addressed in the course, but reworked with originality and even points out a possible problematization in the form of questions that, in this case, are no longer of a conceptual order, nor reflecting questions made directly in class; instead, they explore a certain underlying problem regarding the concepts at stake in the module.

Some students choose to position themselves and defend a personal viewpoint based on the theoretical framework worked on in the module, or to take these as a starting point for a literature review and the development of original reflections. This type of input not only shows content acquirement, but also enables students to develop and refine their argumentation and critical thinking skills.

> *If all inherently human activity is moral, does this mean that all moral activity is inherently human? This is a question that arose in class and that had as answers particular examples; according to these certain 'social' animals, they present certain moral behaviours or pseudo-morals. In researching the subject, I have come across various articles and information, mostly from the Dutch primatologist Frans de Waal. He shows us his findings, and how he believes that mammals also have moral values. He rests his theory on the fact that morality is sustained under two essential pillars: reciprocity, associated with the sense of justice and equity; and empathy, associated with compassion. The video shows us several experiments where we observe such traits: primates that do favours for each other selflessly, elephants that cooperate with each other. Additionally, primates that feel empathy, from basic expressions such as yawning (which we know is 'repeated' among beings with a sense of empathy) to more complex ones, such as animals that comfort others, in a similar way to human beings. After his presentation, he summarizes morality as something evolutionary, which is present and continuous in all primates. In conclusion, I consider this argument an interesting and very good answer to the question, and I share it.* (S4)

In this last excerpt, an interesting reflective process can be observed: as in previous excerpts, the student takes as a starting point a problematization of a statement made in the course. However, and unlike the previously excerpts, in this case the problematization is not limited to the mere elaboration of the question, but rather opens an inquiry process that leads the student to investigate and work on an answer. This type of exercise reflects the complex sets of skills that the logs enable students to put into practice: problematization, inquiry, connection between concepts worked on at a theoretical level and in practice (27), and personal argumentation from an original and critical view that transcends the mere reproduction of course content.

The conceptual bases in this module constitute the starting point for students to begin to practice a type of thinking that, in most cases, is quite far from their normal way of thinking. Without the student's learning log, we would not have the possibility to identify the reasoning process that, in this case, this student started from a class question.

Science and Ethics

This module provides a historical look into the conceptions of science and its greater or lesser connection to the world of morality. It tries to stimulate a reflection on the "received view" of science and its dissociation from social and moral dimensions, as well as to reflect on the role of the scientist and the purpose of science. Some learning logs show some of the initial concerns about this topic. For instance, in the following excerpt, one of the topics discussed in the module is translated into a question about the ethical responsibility of the scientist:

> *About the consequences of our actions, up to what level is one responsible as a researcher for the possible uses given to their findings? This question remains open to be addressed during the course, as I am presented with the necessary tools to answer it.* (S4)

Several of the learning logs show interest and reflection on the academic world in which students are trained, problematizing the field of science education, starting from the topics explored in the module. Some students even do so by reviewing their own process in the log.

> *Since childhood, perhaps because of the difficulty of establishing a fluid communication between the scientific community and the rest of society, the figure of the scientist is shown to us as something distant, totipotent, [and science] an activity only for geniuses, something to be contemplated almost like someone who watches a magic trick but without the intention of really understanding it. Then when we grow up, we have this idea rooted so deeply that, although we think differently, it is inevitable to act as if somehow the scientist is beyond the questioning of ordinary people because they are not an ordinary person (because ordinary people do not eventually become scientists, or at least that is what was thought). Partly because of that conception I think it was more difficult to classify the situation in which the scientist is positioned as the true hero, not only because of the different conceptions of hero but because perhaps from childish naivety we still unconsciously sustain the role of the scientist as something extraordinary and therefore inevitably related to good. But I believe that the main problem is that in this specific case the only one involved in the definition of 'good' is the scientist and, without any kind of regulation, nothing guarantees that this 'good' matches the definition of good created by the community.* (S10)

The value neutrality of science, once questioned, generates discomfort in most students and this is reflected in the learning logs. The following excerpt is an original reflection that shows conceptual integration and significant understanding for the analysis of the problematization posed.

> *"Science is not good or bad in itself. It is its later use that can be judged". This phrase that I heard in the first class was one of the first to make me restless, and it was even discussed and worked on in the first workshops of the course. "Science is the action of generating knowledge", we thought in class. We also said, "it is a human product." Considering that conception of science, I do not agree that it is neutral in itself, since all human action is linked to subjectivity. Why? Because there is no human being without*

> *ideas. To give a more 'biological' explanation of my arguments, I will remember that the simple fact of seeing is a mental construction. To perceive an object, our mind is based on two elements: the fibres that reach the visual cortex from the retina, and those that come from other brain areas. That is, seeing is an active phenomenon, in which the brain interprets based on previous experiences, in addition to the physical stimulus projected by the retina. Therefore, each person 'sees' differently. Although the physical stimulus that reaches the retina is the same, its construction, its perception of it, is different… But if each person perceives differently, science, like any human action, cannot be completely objective. We cannot think without previous ideas. We cannot look at the grass and think that it is "a green thing that grows from the earth in a thin and long form." Because just thinking about the word 'green', or 'earth', already implies having previous ideas. For these reasons I consider that the human being is subjective, and science, as a human action, is not exempt from subjectivity. I will continue with this idea later.* (S12)

Critical reflection on these discussions in science students is essential to start a bioethics course but also to stay attentive and critical of science and technology discourse and development. The logs represent an opportunity to practice this attention.

Microbioethics

This module provides some elements to discuss and problematize the ethical, social, political, and environmental dilemmas of biotechnology, and includes a historical overview in relation to the previous module.

> *What guarantees us that the fact that a private company has access to our genetic information does not mean that it can be used for economic purposes, which benefits none of us? Is my genetic information my heritage, and therefore am I entitled to decide what I want to do with it? Or do I have to accept that it does not belong to me entirely and can be used by others, for whatever the purpose may be? Would I marry a man who I know is likely to develop some pathology that could cause his premature death or that could be genetically transmitted to my children in the future? These and other questions are problems that the use of genetic engineering to diagnose diseases would probably bring about.* (S14)

The narrative elaboration of the excerpt does not show the question construction process, and the discussion does not take place; however, it introduces personal elements that bring the discussion closer to a concrete practical level. If one were to go deeper into the problems that are implied, these questions could be a good starting point for developing a meaningful process of reflection.

The ethical principle of responsibility and precautionary principle are transversal to the course and motivate students to elaborate on them in their learning logs. The following extract shows problematizing reflections on the application (or lack thereof) of the principles.

> *It is estimated that a period of 20 years is required to determine whether a certain element is the cause of a certain (I promise not to use that word anymore) effect. A problem arises here: do we wait for science to prove that something is not harmful before we start implementing it? In the previous entry I talked about the same thing, but now I come with another opinion (consistency of thought). Yes, or partly yes. We must be cautious. While we cannot predict everything, we can at least reverse the burden of proof, and ask science to prove that even if something is not completely safe, it is mostly not harmful, to prove that it is not carcinogenic, or allergenic, for example. This is 'simple' – it is not – in drugs, but what about environmental problems that are so hard to predict?* (S6)

This excerpt, aside from suggesting a problematization around the classic principles of bioethics, shows a dialogue of the student with themselves in reference to a previous entry in their log. The student sets out to examine a question relating to the Microbioethics module, and to do so they revisit their previous reflection and even reformulate their own position: they ask themselves a question, answer it, attempt a new answer that differs from a previous opinion, and find a new problem. This journey is enhanced by the written and progressive nature of the log in which the student periodically records their reflections and has the possibility of returning to them to revise or re-problematize them from new viewpoints. The learning logs record questions or problems that serve as introductions for more personal reflections, which, in some cases, do not end up being developed. One challenge of the logs is to achieve a problematization that transcends the enumeration of questions without reflection on their complexity or without an effort to respond. Even so, there is an accomplishment in questioning and reviewing one's own ideas and associated feelings: the relevance of the questions shows understanding of the problems at stake and directs possible further reflections.

Macrobioethics

This module works on the environmental dimension of ethical controversies and dilemmas, linking to environmental ethics approaches and to various methodological strategies that incorporate the visions and values of different stakeholders. This module also deals with the moral dilemmas of using animals, specifically in lab testing. This is the most extensive and ambitious module from both theoretical and practical viewpoints and includes problems that can be seen in any of the university degree programs with which we work. A simulation of a Consensus Conference is carried out on a controversial topic that is present in the country (the topic has been mostly genetically modified organisms, GMOs)[2].

Different levels of reflection and problematization are recorded on different ethical approaches and their applicability to real situations, as well as on our roles as moral agents in the assignment of values. In some cases, this includes adopting a stance with different degrees of substantiation. For instance, the following excerpt contains several interesting aspects worth commenting:

> *Therefore, in defending a biocentric position, one might ask whether we can "live and let live". Taking this stance to the extreme, we could consider the case of Buddhist ethics, which advocates for not causing harm to any form of life. But would it be possible to carry out this lifestyle on a global scale? Human beings take resources from nature and transform them to lead more comfortable lives. Would people be willing to compromise such a lifestyle? Perhaps the extreme biocentric position is close to dogmatism, that is to say, it is only worth the proposition of mandatorily allowing all types of life as the only valid system of thought. This would very surely generate great conflicts and perhaps new problems to solve. But through the dialogical model, we could reach minimum principles that seek out the best interests and well-being of the rest of the creatures without causing drastic changes in our lives. We could reach, for example, agreements inspired by Immanuel Kant's imperatives (such as human rights), where, as stated at the beginning of the chapter, they are categorised as individuals with moral status and consequently have their own set of basic rights which respect their dignity. Thus, a universalist stance is perhaps most appropriate to adopt on this issue.* (S4)

This excerpt reflects several achievements: it shows an understanding of the topic and identification of underlying problems in a synthesis that manages to merge concepts addressed in different modules. With the purpose of discussing the complexity of biocentrism, the student states their position after pondering about the concepts of 'dogmatism' and 'universalism'; dialogical ethics, Kantian ethics and Buddhist ethics (all these are touched on in previous modules), are merged within a pertinent manner. This is an example of the complexity of the conceptual acquirement processes that the learning logs allow students to develop.

It is remarkable how, year after year, animal ethics becomes the most controversial, conflictive and motivating topic for students (in many cases, drawing from their previous experience or stance regarding animal testing). This situation is clearly shown in logs where students record, and notice, their own discomfort, opinions or feelings prior to their discussion in class.

> *One day, I was eating meat and for no apparent reason I felt strange. The fact that the thing on my plate was a dead body came to me, and I lost my appetite. That was the starting point for me to question whether this normalized practice was wrong. At the beginning of the log, I briefly commented on where I stood regarding ethics and morality. There, I made it clear that the mental processes that led me to such conclusions were always very anthropocentric because the place I found to base my moral vision was the ability to make agreements with others like me. It happens that with animals, it is impossible to make agreements; the ones we make are with those who are similar to us and for this reason I never had them [animals] on the moral radar. Could it be that I have to change?* (S8)

In some cases, the reflection also incorporates extra-module aspects to question the limits of scientific conceptualizations and definitions when determining courses of action.

> *Now, going back to animal testing, and assuming that we have all the knowledge necessary to tell sentient from non-sentient organisms, would everything be in place to solve the problem? Perhaps not, because what previously emerged were the limits that knowledge imposes on us. That is to say, as we know more, we know less about how to solve or where to draw the line between beings able to feel and beings not able to feel, but we never question what it means to feel and how only a definition can simplify or make the problem more difficult. If feeling is nothing more and nothing less than perceiving a stimulus from the external environment, oops, we can no longer talk only about animals with a highly developed nervous system, or a poorly developed one, or only about animals, but we must also position plants, trees, etc., within the debate. I find a lot of interest in seeing how many conflicts or problems can in some cases be summarized or taken from definitions, from language, a fundamental tool for our development, and also to see how this tool and knowledge are related.* (S16)

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[2] Consensus Conferences, or "Juicio Ciudadano" as they have been called in Uruguay, are mechanisms for public deliberation based on the participation of the general public (not experts or stakeholders in the subject matter). Consensus Conferences are also considered a tool for applied ethics (like bioethics) since they allow for dialogues to be opened and minimum consensus between valid interlocutors, any citizen, and potential affected parties when faced with decisions, within the framework of debates associated with risks, values and responsibilities. Citizens are considered, from this viewpoint, as rational and autonomous beings who belong to different social groups and for whom exercising their autonomy means deciding on the circumstances that affect their own lives and those of the environment(s) that they consider valuable or important (32).

The subject of animal testing is one of the most ‘expected’, as well as the analysis of current regulations. The connection of the normative with the implicit ethical foundation is cause for reflection. And again, with humour, the very process of justification of ethics is questioned and some moral certainties or intuitions are problematized.

> *“Why is it wrong to do tests on prisoners?”, commented a fellow student. “Think about how medicine would advance if we could test it on prisoners. Why on animals, and not on them?” That phrase activated a neuroreceptor in my brain and through simple inertia I released my humanist manifesto. I found it deplorable, frightening, something taken from Mengele’s diary. Then I stopped (metaphorically speaking, since I never miss an opportunity to argue): Why not? To force them would be a horror (Kant would have a stroke on his categorical imperatives). But it could be with consent. And, yet, why with animals? They did not give any kind of consent. I think it is not the same with animals, and it is wrong to do tests on prisoners, but I have never thought why. For all practical purposes, I am just an ordinary Vincenzo Maculani.*[3] (S6)

The previous excerpt shows a thread of chained questions that account for a complex reflective process: the student begins by taking an initial question from a classmate who problematized a normalized moral assumption, the condemnation of testing on human beings. Then, they react to that question, problematize their own reaction, and through an analogy, elaborate a reflection on the problem of animal testing. Likewise, the previous reflection has the particularity of elaborating a questioning that could easily be rejected. The questioning and challenging of value systems, personal and collective, generates conditions for critical argumentation processes and for the reduction of confirmation biases (33).

In short, in this module, learning logs show overall concerns and questioning of students’ own attitudes and beliefs that reveal a certain emotional commitment to the problem addressed in the course. As mentioned at the beginning, the log is one of the possible educational strategies that not only promotes critical thinking, but also contributes to the development of aspects such as sensitivity and empathy (19,20).

Science, Politics and Ethics

One of the objectives of this module is to promote reflection on the purpose of science: why and for what purpose do/should we practice science? Furthermore, it tries to analyze how the different ways of conceiving science (and the relationship between science, technology and society) condition different political approaches to scientific research, focusing, for example, on which activities are financed and by which organizations. To do so, some of the problems and complexities surrounding science policy are analyzed: how are science policy decisions guided? How is the funding of scientific activity structured according to the way the aims of science are politically conceived?

It is pointed out in several learning logs that the question “why and for what purpose should we practice science” generates processes of reflection and revision of one’s expectations regarding one’s career path. The example of the 90-10 gap (in development of and access to essential medicines) between rich and poor populations is also an aspect most of them use. The problematization works as a trigger for students to write a personal response associated not only with the purpose of science, but also with the purpose of their future practice as scientists.

> *The economic dimension is also important; in class it was mentioned that the study of diseases that takes most of the resources is the study of diseases that affect the lowest percentage of the population; but that sector of the population is the one with the most resources, the richest. Money and power have a close relationship, not today but for centuries. It is therefore logical that most of the resources go to scientific research that benefits that sector. Here we can demonstrate something that we have talked about repeatedly in class, the non-neutrality of scientific activity, given that research is oriented, directed, aimed at a social sector.* (S16)

The contents of the module encourage original and integrating reflections, with remarkable levels of problematization of reality.

> *We may consider that our actions make political sense if we think of politics not only as the act of voting to elect representatives, but also as something active that requires civic commitment by citizens and in which we should all partake (at least ideally). If we think of politics as a tool for building a better society, then how can we even suggest that science is unrelated? Some authors claim that the detachment of politics from different sectors of society is far from casual, and such detachment from citizens is the main enemy of healthy democratic processes because it is much easier to do what you want with the people when they are not interested in being heard.* (S10)

Overall, the reflections of the students in this module succeed in identifying the problems underlying the traditional model of scientific research as well as in building a critical viewpoint and developing argumentative skills. At the beginning of the course students are asked about their scientific motivations and aspirations. Words such as knowledge, truth, discovery, and

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[3] A 17th-century Italian Catholic Cardinal and inquisitor.

curiosity are listed. In this last module, the social dimension of science is addressed in a critical manner. The logs in many cases show the students' evolution from their initial observations to their final more critical impressions.

Critical reflection on group dynamics

In this article, as in the course, it is assumed that the development of certain class dynamics which that promote teamwork, deliberation, problematization, and debate are an essential part of a bioethics course – that is, a teaching methodology that involves students' active participation. It is in this sense that a simulation of a Consensus Conference is carried out in a workshop. Different groups of students 'place' themselves in the role of a certain type of stakeholder to develop and present their arguments in a forum. The learning logs offer the students a space to distance themselves from these and other activities carried out in the course and, either before or after such activities, to observe them with a critical eye. It is not only about learning content, but also about developing skills linked to interaction, dialogue and teamwork. These skills are developed throughout the activity itself, as well as later, when the activity is revisited reflectively in the logs. The students also reflect on their own attitudes or character traits, especially when exposed to dialogue and deliberation in groups or in public. This helps with self-observation, and with making themselves intelligible to themselves and to others, a particular feature of ethics as according to Cortina (34).

In some cases, students' reflections are directed to the very process of development of the group activities, as in the following example.

> *It was clearly possible to see how we men spoke, often and confidently, even when what we had to say was not truly relevant or correct. Women, however, were much more aware of what they were saying, stating things in a more pondered way, without the impetus that is common in people who are always assumed to be right. Being part of the first group makes me a little embarrassed since I only realise these things as I am speaking. However, the inherent privilege of being a tall white man without a disability gives this feeling a certain pervasiveness.* (S1)

Some logs refer to activities carried out based on value judgements, not necessarily evaluating the course itself but rather how comfortable or uncomfortable they were with the course dynamics; several of them refer specifically to the Consensus Conference.

> *In the microbioethics workshop we conducted a simulation of a consensus conference on GMOs. Although there were two instances of this process, I still wanted to answer or discuss some comments or arguments. But this is what consensus conferences are like; it is not about trying to convince, but to give the best arguments and information from each viewpoint or stance, so that the citizen panel can build an informed opinion about the topic or issue. Moreover, it is the fair way for each group to have the same time to express themselves. This workshop, one of the nicest in my opinion, gave me several takeaways. First, I was able to get a better grasp on the transgenic issue, which is so controversial and important. Although I had to put myself in the place of the consumer defence panel, I identify with the citizen panel, in the way that listening to all the actors involved with their respective arguments enriched my information and reflection on the subject. On the other hand, the workshop taught me this system of citizen participation that I did not previously know. I would love to participate in a real one. Finally, it strengthened my reflection on the value of listening to different opinions and discussing interdisciplinarily.* (S12)

And in some exceptional cases, based on the same topic, a review of personal characteristics and original problematization are included.

> *Finally, after this activity [the Consensus Conference on GMOs], I have no clear position on the use of GMOs. If the activity was so pointless, why write about it in the learning log? Well, it was a trigger for a lot of interesting questions. Perhaps I did not take full advantage of the discussion in terms of the concrete information; but being part of an exchange with many actors involved (it is ironic, because it had a certain theatrical tinge in which each group interpreted a position), allowed me to question some things. First, I started to think about this prejudice of only listening to the "authorised" scientist voices, why limit myself to this? This thought is in line with my incipient process of de-idealization of the academic environment that I vaguely showed in an earlier section of the log, when I referred to the naivety of my believing that only what is scientific is good.* (S8)

Group work leads the students to experience dialogic processes both from their own perspectives and visions as well as from the perspectives of the roles played in some course activities. The logs allow us to observe these experiences from the reflections they share about what it is, and what is learned from, putting oneself in the other's shoes, an essential task of bioethics.

DISCUSSION

Students’ perceptions on the course and its methodological strategies

The question of the ultimate purposes and applications of techno-scientific research is of paramount importance in assessing different types of responses. Cortina and Martínez (35) word it rather eloquently: “scientists are experts in terms of the means to achieve certain objectives, but in terms of determining the convenience of specifying one purpose or another, nobody is an expert” (35, p.170). This demonstrates the risk of leaving important decisions regarding the ultimate ends of techno-scientific activity in the hands of experts, political representatives, or transnational companies. This is why it is necessary to open a public and open dialogue on aims and on who has the right to decide, since, in many of these techno-scientific developments, citizens in general, as potentially affected parties, should be considered valid interlocutors and advised by a plurality of experts (32).

This is one of the aspects on which the Bioethics course tries to work and deepen, and some logs reflect this.

> *Summarizing what was expressed throughout the learning log, I was struck by the presence of a common denominator in different entries. In this sense, the reflections made during the entire semester lead to the conclusion that scientific activity has the clear ability of transformation at multiple levels. By this I mean that science not only creates knowledge and is related to the development of various technologies but is also capable of both favouring the perpetuation of oppressive systems, as well as promoting the formation of just and equitable societies. Thus, it is tremendously important that scientists are aware of the responsibility that research in science implies, and implement critical reflection continuously in their activity, for it has the potential of modifying the reality that surrounds us. Changing the academic hierarchy for one that is less structured and more accessible to all, promoting citizen participation in research processes, and research to solve the problems that affect humans and other beings in their daily lives, as well as ensuring access to quality information for all members of society and promoting the insertion of more citizens in tertiary education, are just some of the actions that researchers can promote, in an attempt to materialize a less fragmented society, with equal opportunities and rights, where oppressive schemes are no longer the norm.* (S9)

In the context of the activities in the stable interdisciplinary groups (in the scope of the workshops and students interaction throughout the course), work is carried out to fulfil the quality marker of a deliberation. Deliberation implies a particular mode of communication based on argumentation and mutual respect. Some key features are considered, such as learning from the exchange of perspectives of different actors in dialogue; orientation towards the solution of problems or conflicts; the opportunity to explore diverse emotional perspectives and personal experiences in a context free of competition; and the possibility of changing one’s position based on new information, arguments and perspectives (36).

The learning logs also provide a space for individual reflection on the deliberative experience itself, as well as on the treatment of scientific-technological controversies and their ethical dilemmas.

> *During the course, many things led me to the same idea: how important it is to reflect! How important it is to think about the why of things! And self-reflection is not enough, since it is the opposing opinions that are most enriching. Yes, I do think so. That it is with those whose opinions are the opposite of ours that we should talk the most.* (S12)

It is interesting to highlight some considerations found in the logs about the course itself, its components and objectives, since they reflect in part the goals of the course.

> *It is true that I probably finished the course with more doubts than I started with, but I really believe that these are doubts that no scientist, and even no citizen should avoid.* (S18)
>
> *This course allowed me to reflect on the interconnection of my scientific discipline and my own training with society, politics and ethics. And it is here that I value what I have done with this log, since my thoughts shall forever stay in its pages regarding what I was able to process of each question raised throughout the semester, whether by myself, the authors of the readings, the professors, or my fellow students. The class discussion and the debates held throughout the workshops enrich us as future scientists, in a profession that feeds on debate, criticism and consensus.* (S19)

It is interesting to mention some examples of how students themselves evaluate the learning logs as a tool, not only because it is a form of assessment that is necessary for improvement, but also because some incorporate into it an introspection of their own achievements and changes associated with writing the log, regarding the reflective process and its relationship to writing.

> *But if there is one thing that I certainly believe was essential and valuable in my process, it was the learning log. I am not going to lie; at the beginning I was bored having to write reflections on things that I was seeing in the course. In fact, I felt that it did not make much sense and that it was not going to be useful to me. To my surprise, it was just the opposite. The learning log was one of the most important things in this whole process that I did during the course, since it somehow forced me to reflect and question myself about many things that I had never questioned before.* (S14)

> *During the reading of this learning log, you can notice connections between the different topics on which I expressed myself. Such connections do not become apparent after the topics have been raised separately; rather, they arrive while I try to form an opinion about some concept, new questions, ideas, contradictions and more, that create the connections between the different presentations.* (S16)

In this regard, it should be noted that the logs are one of the determining factors expressed by students for why they choose to take the Bioethics course. The learning logs have become an important element for the teaching team and for the students as well.

Problematization and metacognition promoted by learning logs

It is important to analyze the ways in which the exercise of problematization in writing the learning logs is concretely manifested. Quite possibly, the clearest way to identify the processes that lead to questioning or problematizing the assumed visions, and transforming them into problems to be investigated, is through students' questions. The functionality of the question cannot be analyzed in isolation from the discourse that produces or introduces it. The question plays a predominant role as an activator of different processes involved in learning. Questions can favour, generate or strengthen processes of high cognitive complexity (23,37-39), such as metacognition, critical reflection and problem-solving, and thus contribute to the development of abilities such as critical thinking (40), creativity (41,42) and citizenship (43,44).

Some questions found in the learning logs show an evolution of the reflexive process. In them, the question acts as a trigger for the use of increasingly abstract arguments or discursive developments. In this sense, original problematizing questions of contents or practices appear in the logs. Some of them identify problems underlying the subject matter, without developing them in depth. Others succeed in initiating a process of inquiry into the problems identified, as reflected in the fragment from S4: *"If all inherently human activity is moral, does this mean that all moral activity is inherently human?";* from this question, the student investigates morality surrounding animals, drawing on work by authors relevant to this area. Some questions allow us a glimpse into critical thinking processes: those which question concepts, authors, or theories. For example, the considerations of S7 are based on the questioning of the determination of welfare made by utilitarianism: *"Who decides what welfare should be, and under what arguments?"*. Some students, on a more self-reflective level, even challenge their own attitudes, beliefs or preconceptions. As an example, see those presented above, by S8, where the student questions their own meat consumption and the reasons why they do so in spite of the strangeness or moral doubt. This last type of question is the one that best allows us a glimpse into metacognitive processes.

Perhaps it is in ethics courses that tools are most needed to enhance and aid with the processes of stimulating critical thinking and metacognition. The encouragement of metacognition is extremely valuable to enhance learning processes in general, but specifically to aid in the development of ethical reasoning skills, as it leads to clarifying ideas and concepts, distinguishing criteria about which behaviours are fair and which are not (45). In this regard, the following log excerpts illustrate the potential for achieving these skills.

> *When the time comes to confront oneself, all ideas, philosophy and ethical viewpoints are gone, leaving behind the refuge of familiarity. In hindsight this is understandable, it is a defense mechanism. It makes sense to want to preserve one's idea of oneself, not only as a moral agent, but as a being with the right morality. It is part of the identity that one forms. This is a problem that I really do not know how to solve. Perhaps, the answer is to progressively do ethical exercises, like debating a position that one does not hold, until one improves the mind's capacity. Thus, we could understand the idea that you are not bad or good because you have had a belief, and the value you can add comes from genuinely seeking an answer, not necessarily what the answer is. I do not know how valuable this can be, but I feel it is necessary to emphasize this to people so that they do not retreat into the cave of immutable thought tribes where changing your mind is taboo.* (S1)

> *The lesson I take away is no less than that I have realized that we are much more irrational beings than I would have been willing to accept at other times in my life. Why do I say this? I always believed that one could justify morality in a rational system that aimed to ensure the welfare of all participants, something like looking for an optimal strategy in the game of life to achieve Nash's equilibrium. When I was thinking about whether it is moral to kill an animal in order to eat it, even if there is no real need to do so, I observed that, if I am honest with myself, the only valid reasons I have for keeping my initial position are: because I do, because I like meat, or because I do not care. These are certainly not entirely rational approaches, and this led me to understand that we actually act most of the time out of habit or emotion.* (S8)

Moon (31) mentions that a learning journal must demonstrate quality in several elements, such as honesty and self-assessment, as well as the ability to review one's own ideas. The above excerpt is a clear example of a student's process of honest and detailed review of their own stance. The originality of the above excerpt, however, does not lie solely in its ability to convey a sincere narrative. The student does not limit themselves to the exposition of their ideas, nor do they seek to modify them in order to adapt them to a specific content. Instead, they transcend the concrete evaluation of the situation or problem and transfer the reflection from the individual to the collective dimension.

After narrating the dissection of a mouse that they carried out for a course, a student's log expresses the following:

> *I am going home; I cannot tell anyone about my experience. My partner does not want to hear about it because it turns their stomach on everything that has to do with viscera and organs (the fact that it is a mouse is not truly relevant to her). I cannot tell my mother-in-law either because she does not like the subject matter very much. I just sit there, not knowing what to think or what to feel. Nothing happens, no punishment, no reward. Whether I act morally or not in this situation, only matters to me. Then, I understand the reason as to why am I so active with some causes and not with others. I see acts of gender-based violence every day and I know other people are going to be affected and will see me differently based on my stance. That is the big motivator: the sense of justice only leads to guilt and anxiety. Having other people judge me brings me to action. I do not know if this speaks to the importance of collective action and of speaking out (even if no one listens to you), or of the power of inertia in human attitude. But I will definitely continue to process this experience for a long time.* (S1)

This excerpt exemplifies the skills that Nussbaum (20, p.8) points out as indispensable for "producing people who can function with sensitivity and alertness as citizens of the whole world": a critical examination of oneself and the ability to see oneself connected to others. This would encourage, according to the Nussbaum – and in line with Socratic pedagogy that "the unexamined life is not worth living" – the fact that people can reason and argue well for themselves, that they understand the difference between logically valid and invalid arguments, and that they can tell the logic of an argument from the truth of its premise (20).

Some of the challenges of learning logs

Among the difficulties that students face in scientific degrees when performing tasks related to the branches of philosophy, Gooday (46) especially highlights the problems related to essay-writing. Many students struggle with writing reflective essays. This difficulty can even lead to "failure to adequately develop critical thinking, analysis, and evaluation skills, and may be unable to lead a discussion" (47, p.201). What Gooday has proposed can be seen in the logs development process. In some cases, this notion is even expressed by students during the writing process.

> *I could say this apparent distance between the students of natural sciences and courses such as Bioethics is the result of the acquisition of certain prejudices regarding the field of philosophy, either because of bad experiences in high school, or because of the false belief that philosophy is meant for a few people. Perhaps it is due to the teaching methods in which we were used to learn, where questioning and interpellation are not always promoted or prioritised.* (S9)

It should be noted that most logs are descriptive in nature, given that, among other things, description is not discouraged as long as it can act as a summary for the student. They are, however, encouraged to move past mere description. Some do not move past the expository – those categorised as "off track". According to Hatton and Smith (48), such log entries could be defined as "descriptive writing"; that is, there is no discussion or exposition of critical personal views in these logs. On this basis, some entries showing increasing complexity record different ways of enriching logs and reflection.

A first level of complexity could be identified with "descriptive reflection": according to Hatton and Smith (48), the text is predominantly descriptive, but some elements appear that denote slightly deeper reflection. This level can in turn be associated with the first three stages of Moon's (49) map of learning. In a first stage, the student shows that a certain topic interests them and they relate it to some incident or concrete experience. In the second stage, they seek to know a little more about the subject matter. In the third stage, new information is assimilated by the student by asking questions and connecting ideas. A second level of complexity is established when the student distances themselves from their own experience or from the original content being described with the purpose of creating new meaning. It is a stage that approaches what Moon (49) calls "working with meaning" or Hatton and Smith (48) call "dialogical reflection".

Finally, some of the analyzed learning logs reach levels of reflection, metacognition and problematization nourished by group discussions, and show that they have acquired a learning process that gives them a personal orientation within the process itself. The presence of these elements would indicate, according to Hatton and Smith (48), a "critical reflection", or "transformative learning" in the words of Moon (49). Year after year, about a quarter of the logs reach this level of reflection. The challenge of the "remaining three quarters" should not, however, discourage the use of the tool. Since the writing process favours learning, the use of learning logs can stimulate each student to enhance their reflective abilities. As Moon states (28), the learning journals produce space in which the students can think, an opportunity to order thoughts and to make sense of their own learning process with a language more like a conversation or the language of thought. The following excerpts showcase such effort.

> *Before taking the course I thought I would not be able to reflect or write about it in my learning log. But I did it, and I found I had more to reflect on than I had initially thought. I learned the importance of reflecting on everything, and that we must not only accept things "because that's just the way it is". We must question ourselves about everything.* (S20)
>
> *The learning log was one of the most important things of the process I went through during the course, for it somehow forced me to reflect and question myself about many things that I had never questioned before.* (S14)

In terms of the evaluation of critical thinking and metacognitive processes, there is a preference on the part of researchers for the use of less structured instruments (such as open-ended questions, essays, monographs, and group discussions, among others), while recognizing the possible biases and the challenges presented by reaching agreements among teachers (50). Systematic evaluation processes built on discussion and consensus among teachers increase the number of agreements and have the potential to generate high-quality tools for teachers to use (51).

> *Epilogue: I know that many phrases, ideas and comments remain in my inkwell, and this pen and keyboard would love to continue tattooing the paper, even if it is virtual, expressing my opinions on the matter… Anyway, I thank you for the opportunity you give us all to express ourselves through the logs and for forcing us to set sail on this adventure of writing one's thoughts. Thank you also for taking the time to read this and every one of the logs.* (S2)

The strategy described in this paper – which has been maintained in the different editions of the course – has allowed the consolidation of consensus among professors by creating a shared image that shows what it looks like to have a valuable critical-reflective process and self-reflection of one's own learning process and discursive elaboration.

CONCLUSION

Teaching bioethics with a pedagogical framework that proposes integral and reflective learning can promote skills associated with critical thinking and deliberative practice that are oriented at understanding, commitment, analysis and decision-making in the face of complex ethical problems. In this context, it requires the implementation of didactic strategies that promote metacognition, sensitivity to the problems addressed, and creativity. Student learning logs from the Bioethics course at the Faculty of Sciences (UdelaR) show that this tool promotes complex reflective and self-reflective processes in which the development of skills such as analysis, synthesis, abstraction, argumentation and problematization are manifested in an integrated way. Students of bioethics – each with their own style, interests, expectations, and preconceptions – find in the logs an unstructured environment to reorder their thoughts and integrate the concepts learned in various ways, expressing themselves with creativity and commitment. In this way, the readings and discussions worked on during the course are not isolated in a theoretical body of the curriculum but are used by students to question and challenge themselves. As some students who were not so comfortable with oral communication explained, the log is the tool that allows them to continue the dialogue and develop their personal viewpoint about what was discussed in class.

The Bioethics course aims to provide elements for the problematization of ethical and social reflections on the scope and impact of scientific-technological activity, with the understanding that such skills and capabilities are crucial to the training of students and future professionals and also to their critical and reflective performance. Just as ship captains use logs to review the decisions made in light of the events that happened, our bioethics students prove that they can use this tool to record their own sailing adventures through a course that challenges them. Learning logs are useful in stimulating the recognition of one's own learning process, which is essential to promoting critical thinking. The heading at the beginning of this article reflects this: despite the discomfort of abandoning certainties and "problematizing so many things", the student is encouraged to "come out of the cave" to feel "more intellectually honest" and to "improve themselves". The metaphor is also illustrative in another sense. In a Faculty of Science, the journey through a topic related to ethics is an exotic one. Learning logs can help spark the interest, as Nussbaum says, "with more than a casual tourist's interest" (20, p.88).

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

Interpreting Irremediability When a Mental Health Disorder is the Sole-qualifying Medical Condition for MAiD

Jeffrey Kirby[a]

Résumé

Dans ce commentaire critique, un ensemble de considérations éthiques pertinentes à l'interprétation (actuellement contestée) de l'irrémédiabilité aux fins de l'évaluation de l'aide médicale à mourir dans les cas où la seule condition médicale sous-jacente est un trouble de santé mentale est exploré et analysé. Sur la base de cette application d'une lentille éthique, une description pratique de l'irrémédiabilité est proposée pour être utilisée comme guide par les cliniciens canadiens en soins de santé mentale, les évaluateurs et les fournisseurs d'AMM, et les autorités de réglementation professionnelle provinciales et territoriales.

Mots-clés

irrémédiabilité, aide médicale à mourir, AMM, santé mentale, éthique

Abstract

In this critical commentary, a set of ethical considerations of relevance to the (currently contested) interpretation of irremediability for medical assistance in dying (MAiD) in circumstances where the sole-underlying medical condition is a mental health disorder is explored and analyzed. Based on the application of an ethics lens, a practical description of irremediability is proposed for intended use as guidance by Canadian mental health care clinicians, MAiD assessors and providers, and provincial/territorial professional regulatory authorities.

Keywords

irremediability, medical assistance in dying, MAiD, mental health, ethics

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INTRODUCTION

There has been considerable and fractious debate in Canada over how the irremediability element of the "grievous and irremediable health condition" eligibility criterion will be interpreted and applied by medical assistance in dying (MAiD) assessors and provincial/territorial (P/T) professional regulatory authorities after mid-March 2023, once requestors whose sole-underlying health condition(s) is a mental health disorder(s) can request MAiD (i.e., when the relevant Bill C-7 sunset clause expires). There is a wide spectrum of opinion regarding this matter among clinicians, relevant professional associations, health law and healthcare ethics academics, MAiD activists and persons with lived experience of mental health disorders (1). On one end of the spectrum that I address in this commentary are: 1) those who oppose the provision of MAiD in these particular circumstances but who recognize and acknowledge that access to MAiD in circumstances where a mental health disorder is the sole-underlying medical condition (MD-SUMC) will become a reality in Canada after mid-March 2023, and 2) those who are not philosophically opposed to MD-SUMC as a strong commitment but are of the opinion that all available, standard-of-care treatments and interventions must have been adequately explored, and have demonstrably failed, before making a finding of irremediability. On the other end of the spectrum are those who believe that there should not be a requirement that any standard-of-care treatments and interventions have been tried or used in order for a finding of irremediability to be met. The opinions of others actively engaged in the debate fall somewhere between these two polarized views.

My own views about this issue have been influenced and informed by my healthcare ethics academic work in the domain of assisted dying, relevant discussions and deliberations with ethicists, health lawyers and practicing clinicians including Canadian MAiD assessors and providers, and my recent, dynamic engagement as a member of the Expert Panel on MAiD and Mental Illness that was jointly appointed by the federal Canadian Ministers of Health and Justice to make recommendations regarding possible, additional MD-SUMC legislative safeguards and guidance.

In this critical commentary, I briefly provide some historical information about how irremediability has been framed to date in a relevant Canadian Supreme Court decision and in international assisted-dying legislation. I then explore and apply an ethics lens to some significant considerations that are relevant to the optimal interpretation of irremediability in the MD-SUMC context. Finally, I propose a practical description of irremediability to assist in its interpretation by Canadian mental health care clinicians, MAiD assessors and providers, and P/T professional regulatory authorities.

Note that my use, here, of the term (and conception of) 'irremediability' encompasses both: 1) a consideration of the length of time of the requestor's inadequately relieved, profound, psychiatric suffering and, 2) a consideration of the requestor's demonstrably inadequate-over-time, therapeutic responses to appropriate, multimodal, clinical interventions. Both of these interconnected elements are captured in the proposed, practical description of irremediability in the MD-SUMC context.

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HISTORICAL BACKGROUND

In the 2015 Supreme Court of Canada (SCC) judgment *Carter v. Canada (Attorney General)*, which significantly informed subsequent Canadian MAiD legislation, ‘irremediability’ is referenced in the descriptive wording of a grievous and irremediable medical condition (2). The SCC decision includes the statement that a finding of irremediability “does not require the patient to undertake treatments that are not acceptable to the individual.” However, it is important to note that this pronouncement is qualified and limited by a statement that the scope of the declaration “is intended to respond to the factual circumstances of the case”, i.e., the clinical circumstances of a plaintiff whose profound suffering arose primarily from a physical health disorder. There is an ancillary statement in the judgment that the court “makes no pronouncement on other situations where physician-assisted dying may be sought”. In relevant Canadian legislation, i.e., Bill C-14 (3) and Bill C-7 (4), irremediability is also framed as a component of the MAiD eligibility criterion of a grievous and irremediable medical condition within three (surviving in Bill C-7) sub-criteria that are independent of one another, i.e., the presence of: a) a serious and incurable illness, disease or disability, b) an advanced state of irreversible decline in [functional] capacity, and 3) enduring physical or psychological suffering that is intolerable to them and cannot be relieved under conditions that the requestor considers acceptable. Within these sub-criteria, relevant adjectives and phrases of relevance to irremediability include “incurable”, “advanced state of irreversible”, “enduring” and “cannot be relieved”.

Irremediability is similarly framed in pioneering Dutch and Belgian legislation. Two of the due care criteria of the Dutch *Termination of Life on Request and Assisted Suicide Act* (2002) state that “there is no prospect of improvement” and that “there is no reasonable alternative in light of the patient’s situation” (5). Of relevance to a finding of irremediability, the *Belgian Act on Euthanasia* (2002) states that the person must be “in a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated” (6). There are also references in the Belgian legislation of the requirement for providers of euthanasia to be certain of the “durable nature of [the] request” and that “together with the patient, the physician must come to the belief that there is no reasonable alternative to the patient’s situation”.

RELEVANT ETHICS CONSIDERATIONS

It is widely recognized that the topic-domain of assisted dying, considered broadly, has important ethics elements and dimensions. However, these are rarely identified and articulated as such in the literature and lay press. I have previously published a described set of MAiD ethics substantive principles and values (which are of relevance to the development of government health legislation and macro- and meso-level MAiD policies through the use of deliberative engagement methodologies), i.e., individual autonomy, health equity, nonmaleficence and social justice, beneficence and duty-of-care, conscience and professional autonomy, non-abandonment and continuity-of-care, professional competency, and accountability and oversight (7). In this commentary, I focus on the relevance of some of these substantive principles and values and other, pertinent ethics considerations to the development of an optimal interpretation of irremediability in the MD-SUMC context.

Considerations of formal justice, commonly attributed to Aristotle, played a major role in development of Bill C-7. Simply stated, formal justice requires that like individuals and groups of persons be treated the same and dissimilar individuals and groups of persons be treated dissimilarly. The fundamental corollary is that individuals and groups should be treated the same unless a relevant difference(s) between/among them can be demonstrated that justifies the dissimilar treatment. This construct is typically framed, in Canada, in terms of protections in the *Canadian Charter of Rights and Freedoms* (Section 15) for members of certain, specified groups against discrimination, i.e., persons have a right to equal protection and equal benefit of the law without discrimination (8).

The government developers of Bill C-7, following the 2019 *Truchon v. Procureur général du Canada* decision of the Superior Court of Quebec, considered that there were insufficient relevant differences between MAiD requestors whose death is not reasonably foreseeable and those whose death is reasonably foreseeable to exclude the former group of persons from access to MAiD (9). They did, however, consider that there were insufficient relevant differences between these two requestor-groups to establish separate, eligibility-assessment tracks such that more safeguards are applied in circumstances where death is not foreseeable. Similarly, Bill C-7 developers came to believe after stakeholder-informed, comprehensive input to the House of Commons and Senate that there was not enough of a relevant difference between requestors with underlying physical health disorders and requestors with underlying mental health disorders to deny the latter group access to MAiD indefinitely in the future. However, they were of the opinion that there were enough relevant differences between these two requestor-groups to warrant the insertion of a sunset clause into Bill C-7; this clause would provide enough time for an expert panel jointly appointed by the Ministers of Health and Justice to develop recommendations regarding an additional set of legislative safeguards and guidance to be applied during MAiD assessments in the evaluation of MD-SUMC requests, after mid-March 2023.

I agree with the development and use of additional, legislative safeguards and guidance for requestors whose sole-qualifying health condition(s) is a mental health disorder(s). In my view, legitimate relevant differences between the two groups of requestors that adequately justify the use of additional safeguards and guidance in the case of MD-SUMC include (on relative bases):

1) greater complexity of assessments of decisional capacity and irremediability in requestors, with the related clinical reality that practitioners of only one medical specialty, i.e., psychiatry, are optimally qualified to perform such evaluations,
2) greater possibility of evaluation-challenges secondary to cognitive distortion or the suboptimal development of insight into the person's health condition,
3) less prognostic clarity in some circumstances,
4) reduced number of observable, objective findings associated with the expression of suffering,
5) suboptimal knowledge of the full scope of standard-of-care and innovative treatments and interventions for mental health disorders by primary health care providers, and
6) the possibility of a desire-to-die being a directly arising symptom of some mental health disorders, e.g., treatment-refractory major depressive disorder (10).

Requesters whose sole-underlying health condition(s) is a mental health disorder(s) will be able to request and, in some cases, access MAiD after mid-March 2023 in Canada. One of the important MAiD-related tasks for the federal government in 2022 and early 2023 is to ascertain (informed by considerations of the expert panel's recommendations regarding additional safeguards and guidance and subsequent relevant, stakeholder input) how irremediability should be interpreted in the MD-SUMC context by MAiD assessors and P/T professional regulatory authorities.

ETHICAL UNDERPINNINGS OF THE SPECTRUM OF VIEWS ON IRREMEDIABILITY

As briefly mentioned earlier, there is a broad spectrum of opinion regarding how irremediability should be interpreted in the MD-SUMC context. Although irremediability evaluations are theoretically prospective, they rely on retrospective history and facts, including the demonstrated failures of access to appropriate treatments and interventions. On one end of the spectrum are proponents of a permissive interpretation of irremediability who believe that there should not be a requirement that any standard-of-care treatments/interventions for the requestor's particular mental health disorder(s) have been tried and failed in order for a person to qualify for MAiD in MD-SUMC circumstances. The arguments of MAiD activists, psychiatry clinicians and academics at this end of the spectrum tend to prioritize and primarily justify their view on the basis of the widely accepted ethical principle of respect for persons, in the form of individual autonomy, and an appeal to the promotion of health equity (11). With regard to individual autonomy, a person has the right, and should have the opportunity, to make meaningful decisions about their life plans, including choices about their health care and treatment. When considered in isolation (without the concurrent consideration of other relevant, substantive principles and values) individual autonomy provides an argumentative basis for the promotion of a permissive interpretation of irremediability in which there is no requirement that MD-SUMC requestors have tried and failed standard-of-care treatments and interventions for their underlying mental health disorder(s). Canadian MAiD activists and psychiatry clinicians at this end of the spectrum have attempted to support their position by referencing the relevant 2015 SCC judgment (2). However, making such an argument from authority is somewhat disingenuous given that, as described earlier, the SCC decision was explicitly limited to the scope of circumstances of a plaintiff whose profound suffering arose from a physical health disorder.

Health equity in socialized health care jurisdictions concerns itself primarily with identifying and eliminating or mitigating unfair barriers and obstacles to the access of persons to publicly-fund health/social care and (good) health. A claim on the basis of health equity in MD-SUMC circumstances requires that the existing or proposed disparity between the access of two or more groups of persons to health care that proponents of a permissive interpretation of irremediability identify and wish to eliminate or mitigate is unfair. So, in this particular context, the question arises as to whether it would be unfair after mid-March 2023 to implement a safeguard requirement that MD-SUMC requestors have tried and failed treatments and interventions falling within the scope of the existing standard-of-care for their underlying mental health disorder(s) in order for them to access MAiD (without a similar safeguard requirement being implemented for requestors with qualifying physical health disorders whose death is not foreseeable). My prior comments related to relevant formal justice considerations tend not to support a finding of obvious health inequity in this context given that a set of legitimate, relevant differences can be identified and articulated that justify the use of different, somewhat-more-restrictive safeguards in MD-SUMC circumstances than in physical health disorder circumstances.

At the other end of the spectrum of opinion, some Canadian psychiatry clinicians and professional bodies have expressed their strong view in favour of a restrictive interpretation of irremediability in which all treatments and interventions falling within the scope of existing standard-of-care available to the requestor should have been tried for adequate periods of time and demonstrably failed before a finding of irremediability is met in MD-SUMC circumstances. For example, the Canadian Psychiatric Association (CPA) has stated that MAiD documentation in MD-SUMC circumstances should demonstrate that: 1) standard treatments, including pharmacological, psychotherapeutic and non-pharmacological therapies for the specific, qualifying mental disorder(s) have been offered and used for a sufficient period of time, and 2) there are no other accessible, reasonable alternative treatments/interventions. Proponents of a restrictive interpretation employ in their argumentation one legitimate version of the principle of nonmaleficence (health care providers are obliged to do as little as possible harm to their patients) where the harm to be avoided is a foreshortened life. However, proponents of a permissive interpretation of irremediability could counter that the maleficence-related harm to be eliminated is ongoing, profound suffering.

A particular version of social justice can also be used to support the claim of proponents of a restrictive interpretation of irremediability. Social justice requires us to pay particular attention to the interests and needs of persons who are members of historically marginalized and otherwise disadvantaged social groups, and to include and support such members in policy-level decision making that directly affects them (12). Proponents of a restrictive interpretation of irremediability could claim that there is a social justice obligation to ensure that MD-SUMC requestors who are members of these disadvantaged social groups: 1) are not over-represented in MAiD requests (safety consideration 1), and 2) are adequately protected from the harm of a foreshortened life (safety consideration 2). However, proponents of a permissive version of irremediability could counter with a social-justice-based argument that mechanisms should be in place to ensure that MD-SUMC requestors, who are members of disadvantaged social groups, are optimally supported to make their own health-related decisions including a request for a medically assisted death

There is an important, ethical requirement in developing government health legislation and health policies to identify any competing obligations that arise from the concurrent application of relevant, non-lexical, substantive principles and values through a process of deliberative engagement. Core stakeholders with the support of relevant resource persons can then deliberate through a facilitated, dialogical process to decide how to optimally weigh and balance these obligations in the development of the content of health legislation and meso/macro-level health policies. As described earlier, legitimate, ethical obligations that arise from isolated considerations of relevant substantive principles and values can be identified and articulated to support both permissive and restrictive interpretations of irremediability in the MD-SUMC context, e.g., individual autonomy and a version of nonmaleficence where the harm is a foreshortened life. The effective, fair balancing of these obligations through a deliberative engagement process requires that deliberators decide to set the irremediability threshold somewhere in the middle range of the irremediability spectrum, between the previously described polar positions about the trial and failure of available, standard-of-care treatments and interventions for the requestor’s particular mental health disorder(s). This equates, in practical terms, to a requirement that MD-SUMC requestors have adequately tried some, but not necessarily all, of the available, multimodal, standard-of-care treatments and interventions for their qualifying mental health disorder(s). In my view, where MAiD assessors (in dialogic collaboration with the requestor) land in their decision making in MD-SUMC circumstances (in particular cases about the required variety and number of multimodal treatments/interventions that requestors must have adequately tried and failed) should be left to the professional discretion of an independent psychiatrist in their role as one of the two MAiD assessors. This view informs the content of the practical description of irremediability in the MD-SUMC context proposed in the next section.

Other key, pragmatic irremediability elements and factors include the required lengths of time of both the requestor’s experience of profound suffering and the treatment/intervention trials, and who should have the responsibility to assess irremediability in this particular MAiD context. In my view, given their training and experience, only psychiatrists are in an optimal position to: 1) assess the decisional capacity of MD-SUMC requestors, i.e., perform thorough capacity assessments in these complex, high-stakes circumstances, 2) be aware of, and be able to inform, the requestor of the full scope of existing, multimodal, standard-of-care and innovative treatments and interventions for their particular mental health disorder(s), and 3) determine the adequacy of the length of time the requestor has experienced profound suffering (which is framed as ‘years’, i.e., a minimum of two years, in the proposed, practical irremediability description) and the lengths of the past trials of the available, accessed treatments and interventions.

I am of the strong opinion that in order to eliminate possible bias-related influences of common psychotherapeutic dynamics (e.g., counter-transference) on MAiD assessment and eligibility decisions, MD-SUMC psychiatrist assessors should be completely independent, i.e., 1) do not currently have and have not had in the past a therapeutic relationship with the requestor, 2) have no past or current professional or personal connections with the requestor’s attending health care providers (13). In order to ensure the cross-Canada implementation of the requirement that one MAiD assessor be an independent psychiatrist, a legislative safeguard to this effect – i.e., in the form of an amendment to Bill C-7 – should be made prior to mid-March 2023. This could be achieved by a one sentence addition to Section 241.2 (3,2) (e.1) (4). Implementation in all Canadian provinces and territories cannot be ensured if this recommendation is only offered as guidance, because this leaves possible implementation of the recommendation up to individual P/T jurisdictions.

Although a psychiatric professional association in the Netherlands recommends that there should be two independent psychiatric assessments in these circumstances, I do not believe that this is appropriate for the Canadian context. A requirement that more than one assessor be a psychiatrist, or that an additional psychiatrist must be consulted, could pose an unnecessary, inequity-related barrier to the access of MD-SUMC requestors to MAiD, given that, at least initially, the national pool of Canadian psychiatrists who are willing to perform MAiD assessments will likely be small. However, this should not be used as a reason not to add this important safeguard to Bill C-7 through a relevant, legislative amendment. For example, the recent Covid-19 pandemic showed that comprehensive psychiatric evaluations can be performed virtually by psychiatrists, i.e., without the need for an in-person meeting of the psychiatrist with the person (13), thereby facilitating timely and equitable access to psychiatric evaluations.

In my view, in the Canadian context, the two MAiD assessors should make the ultimate decision with regard to whether the requestor meets the eligibility criteria for MAiD MD-SUMC. The responsibilities of prospective, evaluative mechanisms should be limited to a careful process review to ensure that all procedural requirements have been met prior to the provision of MAiD when relevant eligibility criteria are determined by the assessors to have been met. The implementation of formal review panels or boards, which have veto power over assessors' decisions regarding eligibility, imposes an unfair, inequitable barrier to the access of qualified requestors to MAiD MD-SUMC.

A PRACTICAL DESCRIPTION OF IRREMEDIABILITY FOR MD-SUMC ASESSMENT PURPOSES

The brief legal wording and phraseology of relevance to irremediability in the three eligibility sub-criteria of a serious and irremediable medical condition in Bills C-14 and C-7 (see below Note 2) does not, in my view, provide sufficient practical direction to Canadian mental health care clinicians, MAiD assessors and providers, and P/T professional regulatory authorities in the MD-SUMC context. With this in mind, and with the meaningful input of academic and clinical colleagues, I propose the following practical interpretation of irremediability for MD-SUMC MAiD assessment purposes:

> *In the context of a functional, therapeutic relationship or series of such relationships, irremediability for MD-SUMC MAiD assessment purposes exists in circumstances where:*
>
> 1) *a capable person (requestor) has tried, as available and accessible to them, multimodal, health care treatments and interventions falling within the scope of the relevant, existing standard-of-care for the person's qualifying mental health disorder(s)* which, over a prolonged period of time, i.e., years, have been ineffective in adequately relieving the person's suffering and/or which have resulted in side effects and/or complications that are unacceptable to the person, and*
> 2) *other available, appropriate treatments and interventions for the person's health condition(s), of which the person has been fully informed, have been declined by the person after being given meaningful, collaborative consideration by the person and their attending clinician(s).*
>
> * In order to meet the irremediability MAiD eligibility criterion in MD-SUMC circumstances, the requestor is not required to have tried and failed all of the treatments and interventions that fall within the scope of the relevant, existing standard-of-care for the person's underlying mental health disorder(s).
>
> **Notes:**
>
> 1. An independent psychiatrist in their role as a MAiD assessor determines (through an in-person or virtual assessment of the requestor): a) the nature and scope of the treatments and interventions that fall within the relevant, existing standard-of-care in the particular, clinical and sociocultural circumstances of the person; b) the adequacy of the period of time (years) that the person has been under active treatment for their suffering; and 3) the adequacy of the lengths of time of the trials of treatments and interventions. The independent psychiatrist may consult, as appropriate and at their professional discretion, with a sub-specialist -/ -special-interest-psychiatrist who has advanced knowledge about, and experience in the treatment of, the mental health disorder that is giving rise to the person's profound suffering.
> 2. When these described MD-SUMC circumstances exist, the person is deemed to have an incurable illness, disease or disability, and to be in an advanced state of irreversible decline in functional capacity. Further, their enduring suffering cannot be relieved under conditions that they consider acceptable.

This practical description effectively captures all the key elements of an optimal assessment of irremediability for MD-SUMC assessment purposes. As such, it is intended as guidance for those directly engaged in performing MD-SUMC assessments and P/T professional regulatory authorities that develop relevant MAiD practice standards and policies.

CONCLUSION

In this critical commentary, an ethics lens is applied to the interpretation of irremediability for MAiD assessment purposes in circumstances where the sole-underlying medical condition(s) is a mental health disorder(s). Arising from exploration and analysis of relevant ethics elements and considerations, a practical description of irremediability in the MD-SUMC context is proposed for intended use as guidance by Canadian mental health care clinicians, MAiD assessors and providers, and provincial/territorial professional regulatory authorities.

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

Repérer et combattre le capacitisme, le sanisme et le suicidisme en santé

Marie-Josée Drolet[a]

Résumé
Ce commentaire critique a pour objectif de définir, d'expliquer et d'illustrer trois systèmes de croyances et d'oppression généralement peu connus en santé, mais susceptibles d'influencer négativement les pratiques de professionnels de la santé et de services sociaux ainsi que celles d'organisations publiques ou privées de santé, à savoir : le capacitisme, le sanisme et le suicidisme. Il a aussi pour objectif d'identifier certaines pistes d'action pouvant contribuer à combattre ces systèmes largement répandus au sein des institutions et organisations de nos sociétés occidentales contemporaines.

Mots-clés
capacitisme, sanisme, suicidisme, santé, injustice, handicap

Abstract
The purpose of this critical commentary is to define, explain and illustrate three systems of belief and oppression that are generally not well known in the health field, but that are likely to have a negative influence on the practices of health and social service professionals as well as those of public or private health organizations, namely: ableism, sanism and suicidism. It also aims to identify certain courses of action that could help combat these systems, which are widespread in the institutions and organizations of our contemporary Western societies.

Keywords
ableism, sanism, suicidism, health, injustice, disability

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INTRODUCTION

Ce n'est que récemment que j'ai commencé à prendre conscience du *capacitisme* (discrimination liée aux capacités et aux (in)capacités), du *sanisme* (discrimination liée à une différence de santé mentale) et du *suicidisme* (discrimination liée aux idées suicidaires) au fondement de ma profession, l'ergothérapie, comme c'est aussi le cas pour les autres professions de la santé et des services sociaux et, plus largement, au sein de nos sociétés du Nord globalisé. Avec l'aide d'une co-chercheuse avec laquelle je collabore depuis un moment qui a une expérience du handicap, et de lectures qu'elle m'a recommandées (1,2), j'ai été en mesure de prendre conscience des lunettes capacitiste, saniste et suicidiste au travers desquelles j'ai longtemps perçu les personnes qui sont différentes dans leur corps et leur fonctionnement. Ce commentaire critique vise à rendre compte de ma compréhension de ces notions, de quelques-unes de leurs conséquences sur les personnes concernées et de lister certaines manières de les combattre ou, à tout le moins, d'en minimiser les conséquences. Comme le lecteur sera à même de le constater, les réflexions de ce commentaire critique prennent appui sur un corpus de textes qui émanent des études critiques sur le handicap (1,2).

Contrairement à l'âgisme, au sexisme et au racisme qui sont en général connus des professionnels de la santé et des services sociaux, tel est rarement le cas pour le capacitisme, le sanisme et le suicidisme. Pourtant, ces systèmes de croyances et d'oppression influencent de manière importante et insidieuse les pratiques professionnelles et celles des organisations de santé et de services sociaux, voire plus largement celle des institutions sociales occidentales (1,2). En définissant, expliquant et illustrant chacun de ces systèmes, il est ici souhaité que le professionnel de la santé ou des services sociaux puisse repérer ces systèmes et les combattre, car ceux-ci nuisent de manière importante au respect des droits des clients qui les subissent, et à la qualité des soins et des services qui leur sont prodigués. Cela dit, pour parvenir à repérer ces systèmes de croyances et d'oppression, il importe, dans un premier temps, de cerner les trois principaux paradigmes qui ont traditionnellement permis de comprendre et d'expliquer le handicap au sein des cultures occidentales, soit : le *modèle médical*, le *modèle social* et celui que proposent les *études critiques sur le handicap*.

TROIS PARADIGMES POUR COMPRENDRE ET EXPLIQUER LE HANDICAP EN OCCIDENT

Comme l'indiquent Dunn et Langdon (3), préalablement à l'influence occidentale, les peuples autochtones étaient réputés pour respecter les personnes ayant une expérience du handicap, car ils estimaient que ces personnes étaient munies de pouvoirs spéciaux, tels que des pouvoirs de guérison ou de voyance. Suivant cette vision des choses, ces personnes n'étaient pas considérées comme des fardeaux par la communauté, bien au contraire. Elles étaient considérées comme des cadeaux ou des bienfaits qui leur étaient prodigués par le Créateur. Ce faisant, il était tout naturel de soutenir collectivement ces personnes, de les estimer, de les valoriser ainsi que de contribuer à leur santé, leur épanouissement et à leur bien-être.

Au sein des cultures occidentales, le handicap était et est encore de nos jours perçu différemment, et ce, sous différents angles théoriques. Trois paradigmes sont généralement distingués dans les écrits (1,2), lesquels se fondent sur des

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présupposés normatifs distincts pour penser le handicap et, plus largement, la normalité. Toujours dominant dans certaines disciplines, le modèle médical du handicap considère le handicap et les personnes dites « handicapées » comme des problèmes (1,2). Ces problèmes sont de nature individuelle, en ceci qu'ils résultent d'un défaut présent chez la personne qui requiert une intervention médicale ou de réadaptation pour être corrigé. La personne estimée handicapée est donc contrainte de s'engager dans cette intervention pour que le défaut, le trouble, l'anomalie, la déficience ou l'incapacité soit corrigé afin de pouvoir participer à la vie collective, d'être un membre actif et contributif de la société. Suivant cette vision du handicap, la personne handicapée est qualifiée de déficiente, car elle est incapable de fonctionner « normalement », c'est-à-dire comme les personnes soi-disant sans défaut, trouble, anomalie, déficience ou incapacité. La réponse sociale qui découle de ce paradigme se fonde sur la pitié et la charité pour mettre en place des pratiques médicales ou de réadaptation visant à normaliser les personnes handicapées, à les dépathologiser.

À la suite des mouvements locaux et internationaux de défense des droits des personnes dites handicapées dans les années 1970, un second paradigme émerge, soit le modèle social du handicap (1,2). Suivant celui-ci, le handicap est la conséquence d'obstacles socialement et politiquement construits qui empêchent ou limitent la pleine participation sociale des personnes dites handicapées. Il résulte, d'une part, des attitudes, des croyances et des valeurs entretenues par la société à l'endroit des personnes ayant un corps et un fonctionnement différent de la majorité et, d'autre part, des manques d'opportunités sociales et de soutien offerts aux personnes dites handicapées. Autrement dit, si le handicap est un problème, c'est parce que la société le considère comme tel et non pas parce qu'il est un problème en lui-même. Il revient donc à la société de mettre en place un ensemble de pratiques pour soutenir la participation, le respect et l'inclusion des personnes estimées handicapées ainsi que de combattre les pratiques qui, au sein de nos sociétés capitalistes, valorisent la vitesse et la performance et ont tendance à exclure et dévaluer les personnes différentes dans leur corps et leur fonctionnement. La réponse sociale qui découle de ce paradigme se fonde sur l'égalité fondamentale des êtres humains et de leurs droits afin de mettre en place des pratiques sociales inclusives.

Enfin, le troisième paradigme est celui mis de l'avant par les études critiques sur le handicap, lequel porte un regard critique sur le modèle social du handicap afin de le bonifier par le savoir expérientiel de personnes ayant une expérience du handicap. Bien que le modèle social du handicap soit généralement perçu de manière positive par les personnes dites handicapées et les groupes de défense des droits des personnes ayant une expérience du handicap, ce paradigme rencontre certaines critiques (1,2). Plusieurs personnes différentes dans leur corps et leur fonctionnement estiment que l'emphase mise sur les causes sociales et politiques du handicap sous-entend que le trouble ou la déficience ne serait pas une cause de handicap, ce qui ne représente pas la réalité de plusieurs personnes dites handicapées. C'est pourquoi les études critiques sur le handicap se fondent sur les narrations des personnes qui ont une expérience incarnée de la déficience et du handicap pour penser le concept de handicap, celui de normalité et les normes relativement persistantes qui en définissent les aspects, de même qu'elles offrent un ensemble varié et riche de réflexions critiques sur ces questions.

Qu'en est-il maintenant du capacitisme, du sanisme et du suicidisme? Les paragraphes suivants proposent des définitions, explications et illustrations de ces concepts. Ces systèmes de croyances et d'oppression découlent de la vision médicale du handicap, suivant laquelle les personnes différentes dans leur corps et leur fonctionnement sont structurellement dévaluées et défavorisées comparativement aux personnes soi-disant sans défaut, trouble, anomalie, déficience ou incapacité.

CAPACITISME : SYSTÈME DE DISCRIMINATION LIÉ AUX CAPACITÉS ET AUX (IN)CAPACITÉS

Tandis que l'âgisme, le racisme et le sexisme sont des systèmes de croyances et d'oppression reliés respectivement à l'âge, à la « race » et au sexe des individus, le capacitisme est une forme de discrimination basée sur les capacités et (in)capacités des personnes qui se fonde sur des normes restreintes de capacité, lesquelles sont définies par une majorité autodéfinie comme capacitaire (4). Plus précisément, le capacitisme correspond au système de croyances et d'oppression d'après lequel les personnes dont le corps (incluant le cerveau) fonctionne différemment de la majorité sont en raison de cette différence négativement jugées, stéréotypées et injustement discriminées (1-4). Autrement dit, ce système discriminatoire est lié à des injustices pour les personnes qui sont jugées moins capables que d'autres, en raison de leur expérience du handicap (5). C'est que le capacitisme présuppose que les personnes dont le corps fonctionne comme la majorité des êtres humains sont sans incapacités et correspondent à la norme sociale désirable, tandis que les personnes dont le corps fonctionne différemment seraient déficientes, anormales (1-4). Suivant cette vision des choses, les personnes différentes dans leur corps et leur fonctionnalité sont considérées comme inférieures aux personnes soi-disant sans incapacités, en ceci que le fonctionnement majoritaire est associé à des valeurs sociales positives (1).

Le capacitisme traverse nos organisations sociales et sanitaires. Par exemple, le dépistage génétique prénatal des déficiences ainsi que la contraception, l'avortement et la stérilisation forcée des personnes ayant une déficience intellectuelle constituent des exemples d'actions capacitistes. Plus encore, l'un des objectifs du système de santé et de services sociaux est de diminuer les incapacités individuelles, présumant ainsi que le fait de fonctionner comme les personnes soi-disant sans incapacités est une visée sociale souhaitable. En ce sens, les bases mêmes du système de santé et de services sociaux, voire celles des professions de la santé et des services sociaux ne sont pas étrangères au capacitisme, lequel présente d'importantes affinités avec la vision néolibérale qui glorifie l'indépendance individuelle, le rendement occupationnel, la productivité et la performance (6).

Or plusieurs penseurs des études critiques sur le handicap, dont Fougeyrollas (7) fait partie, revendiquent le droit à la différence corporelle et à la neurodiversité, et estiment que les expériences de handicap vécues par les personnes différentes dans leur corps et leur fonctionnalité sont notamment dues à des environnements sociaux et politiques non inclusifs, non adaptés, stigmatisants et non capacitants. Comme mentionné plus haut, rappelons que la dénonciation du capacitisme a son origine dans les mouvements des droits civiques menés par des personnes ayant une expérience du handicap (étant donné leur fonctionnement différent dans des environnements non adaptés) qui revendiquent le respect de leurs droits, l'égalité des chances et la valorisation de leurs forces et de leurs différences (8). Dans cette lignée, la *Convention relative aux droits des personnes handicapées* (9) soutient que l'absence d'accommodements sociaux et politiques pour les personnes différentes dans leur corps et leur fonctionnalité constitue une discrimination injuste fondée sur le handicap. La Convention (9) affirme aussi qu'il importe de reconnaître et d'attribuer une même valeur à toute personne, indépendamment de sa différence, de ses capacités et de son fonctionnement. Ainsi, le fait dans notre système de santé et de services sociaux de valoriser de manière importante l'autonomie fonctionnelle comme indépendance individuelle, sans prendre en considération les causes sociales et politiques des expériences de handicap vécues par les personnes différentes dans leur corps et leur fonctionnalité, constitue une forme de capacitisme.

Il importe comme professionnel de la santé et des services sociaux de repérer et de dénoncer le capacitisme, car ce système de croyances et d'oppression dévalue injustement les personnes différentes dans leur corps et leur fonctionnalité, de même qu'il empêche de combattre les causes sociales et politiques des expériences de handicap. Comme l'affirme Hammell (6), ce n'est pas tant l'incapacité en elle-même qui nuit à la qualité de la vie de maintes personnes différentes, mais bien la façon dont elles sont perçues et entravées socialement, découlant du manque d'efforts collectifs pour créer des environnements au sein desquels elles puissent être valorisées, incluses et fonctionnelles au même titre que toute autre.

SANISME : SYSTÈME DE DISCRIMINATION LIÉ À UNE DIFFÉRENCE DE SANTÉ MENTALE

Forme de capacitisme, le sanisme est un système de croyances et d'oppression par lequel les personnes ayant un fonctionnement mental ou psychique différent sont injustement stigmatisées et discriminées (10). À l'instar du capacitisme, le sanisme suppose que les personnes soi-disant sans trouble de santé mentale sont normales (parce que majoritaires) et ont un fonctionnement social désirable, tandis que les personnes ayant un fonctionnement mental ou psychique différent de la majorité seraient anormales, déficientes et auraient un fonctionnement social condamnable (1,2,10). Suivant cette vision des choses, les personnes considérées comme n'étant pas saines d'esprit (d'où le mot sanisme) sont jugées négativement et estimées inférieures aux personnes considérées comme saines d'esprit, en ceci que l'absence d'un diagnostic de santé mentale est liée à des valeurs sociales positives, tandis que la présence d'un diagnostic de santé mentale est mal vue, dévaluée, stigmatisée. Dans ce contexte, l'un des buts de la psychiatrie est de catégoriser les personnes différentes par le diagnostic, en circonscrivant le trouble, en tentant de l'éradiquer ou afin d'en minimiser ses manifestations sociales indésirables et la souffrance qui y est associée (11).

Or depuis les réflexions du philosophe Foucault en 1961 (12) et celle du médecin-philosophe Canguilmen en 1966 (13), cette vision binaire et dichotomique de la normalité, d'une part, et du pathologique psychiatrique, d'autre part, est sérieusement mise en doute (1,2). Notamment, selon Canguilmen (13), la différence statistique qui se présente de fait entre les personnes quant à leur santé mentale ne doit pas pour autant mener à une vision saniste des individus, suivant laquelle certaines personnes seraient supérieures aux autres parce qu'elles fonctionnent comme la majorité ou comme la norme sociale l'exige. Cette vision de la psychiatrie amène à adopter une vision critique du diagnostic, lequel est perçu comme un instrument puissant de contrôle social et de pathologisation des personnes (1,2). Cette vision enjoint aussi la société à créer des environnements tolérants aux différences et capacitants pour toute personne, peu importe son fonctionnement mental ou psychique.

Cette posture critique de la psychiatrie s'inscrit, elle aussi, dans les mouvements de revendication des droits civiques menés par les personnes présentant des fonctionnements mentaux ou psychiques différents de la majorité (11). Suivant celle-ci, le sanisme doit être condamné parce qu'il engendre des discriminations iniques et permet l'occurrence quasi quotidienne de microagressions, voire d'agressions (ex. : insultes, propos dénigrants et humiliants) à l'endroit des personnes ayant un fonctionnement mental ou psychique différent (10). Aussi, le fait que des clients soient presque systématiquement exclus des réunions interdisciplinaires, qu'ils ne soient souvent pas crus lorsqu'ils rapportent des difficultés ou que des professionnels s'adressent à leurs proches comme si ceux-ci étaient absents sont des exemples d'actions sanistes qui perpétuent des injustices épistémiques (14). À l'instar du capacitisme, le sanisme est insidieux parce qu'il demeure pour une large part invisible et est alimenté par les nombreux préjugés négatifs à l'endroit des personnes ayant un diagnostic de santé mentale ou un fonctionnement mental ou psychique différent (ex. : ces personnes sont souvent estimées menteuses, violentes) (15). Considérant que la pandémie de la COVID-19 a exacerbé les problèmes de santé mentale au sein de nos sociétés, cette prise de conscience collective a le potentiel d'aider un grand nombre de personnes différentes dans leur fonctionnement mental ou psychique à se sentir soutenues, acceptées dans leur différence.

SUICIDISME : SYSTÈME DE DISCRIMINATION LIÉ AUX IDÉES SUICIDAIRES

Parmi les personnes ayant un fonctionnement mental ou psychique différent de la majorité se trouvent les personnes ayant des idées suicidaires. Néologisme créé par Baril (16), le suicidisme correspond à un système de croyances et d'oppression suivant lequel les personnes ayant des idées suicidaires sont jugées négativement et pathologisées, de même que confrontées à des injonctions à la vie et à la futurité. Il est nécessairement anormal d'avoir de telles idées. Celles-ci doivent être éliminées, car elles révèlent un fonctionnement mental ou psychique déficient, pathologique. Le suicidisme, qui domine en santé et services sociaux, manifeste une perception foncièrement négative des personnes suicidaires, de leur discours et de leur vision de la mort, lesquels sont d'emblée jugés irrecevables, irrationnels et infondés (16). En tant que système qui dévalue les perceptions, les actions et les discours des personnes ayant des idées suicidaires, le suicidisme invalide les paroles et les expériences de ces personnes, nuisant paradoxalement et fort probablement comme le note Baril (16) à la prévention du suicide, à l'accueil de leur souffrance et à la crédibilité accordée à leur vécu expérientiel.

À l'exception des situations d'aide médicale à mourir, le fait que des personnes suicidaires ne soient pas en mesure de trouver au sein de nos organisations de santé et de services sociaux un espace sécuritaire pour parler de leurs idées suicidaires avec un professionnel de santé ou de services sociaux, sans être systématiquement confrontées à des injonctions à la vie ou à la futurité, est un exemple de pratiques suicidistes. Pour mieux prévenir le suicide, Baril (16) estime que le suicidisme doit être dénoncé et combattu. De fait, les personnes ayant des idées suicidaires sont confrontées de nos jours à des injustices épistémiques (14), en ceci que leur discours n'est généralement pas écouté ni entendu, étant invalidé, jugé comme déficient, pathologique, comme si ces personnes étaient incapables d'être raisonnables et de réfléchir de manière rationnelle (17).

COMBATTRE CES SYSTÈMES DE DISCRIMINATION INJUSTES ET INJUSTIFIABLES

Avoir une pratique professionnelle éthique et socialement responsable requiert de combattre les systèmes de croyances et d'oppression que sont le capacitisme, le sanisme et le suicidisme. Le Tableau 1 propose certaines pistes d'action de nature micro, méso et macro environnementales (18) pour y parvenir. Celles-ci émergent des lectures qui ont été effectuées pour écrire ce commentaire critique, de l'expérience comme clinicienne de l'autrice et de discussions réalisées avec des professionnels ayant une expérience incarnée du handicap. Mentionnons que cette liste n'est pas exhaustive.

Tableau 1: Pistes d'action pouvant guider les professionnels de la santé et des services sociaux pour combattre le capacitisme, le sanisme et le suicidisme

micro	Valoriser les forces des personnes, leurs capacités, leurs compétences et leurs différences et miser sur celles-ci, plutôt que sur les difficultés des personnes
	Intervenir sur les environnements qui nuisent ou limitent le fonctionnement des personnes
	Porter un regard critique sur le vocabulaire utilisé qui est dégradant pour les personnes différentes dans leur corps et leur fonctionnement corporel, mental ou psychique (ex. : anomalie, déficience, trouble) et éviter de l'utiliser, de même que vérifier auprès des personnes différentes la manière dont elles souhaitent être désignées
	Valoriser et considérer la parole et le savoir expérientiel des professionnels qui sont différents dans leur corps et leur fonctionnement corporel, mental ou psychique (ex. : professionnels autistes ou aveugles)
méso	Engager des professionnels qui ont une expérience du handicap
	Avoir accès comme professionnels à des formations sur les biais implicites préjudiciables, tels les biais capacitistes, sanistes ou suicidistes
	Co-créer avec des clients un comité ayant pour mandat de repérer et de dénoncer les pratiques professionnelles ou organisationnelles capacitistes, sanistes ou suicidistes au sein de son établissement
	Former une communauté de pratique ou comité pour combattre le capacitisme, le sanisme ou le suicidisme au sein de sa profession ou de son établissement
macro	Dénoncer les préjugés capacitistes, sanistes et suicidistes au sein de sa profession via des communications orales (ex. conférences, ateliers, formations) ou écrites (ex. articles, chapitres, livres, sites web)
	Porter un regard critique sur le capacitisme, le sanisme ou le suicidisme au fondement de plusieurs modèles conceptuels ou théoriques utilisés en santé et services sociaux
	Inclure l'éducation au capacitisme, au sanisme et au suicidisme dans la formation universitaire et continue destinée aux différents professionnels de la santé et des services sociaux
	Créer des forums grand public pour susciter une prise de conscience collective des biais capacitistes, sanistes et suicidistes à la base de ces systèmes de croyances et d'oppression
	Combattre les causes sociales et politiques des expériences de handicap, en s'impliquant au sein de groupes qui font de l'*advocacy* pour transformer les règlements, les politiques et les lois
	S'impliquer dans des mouvements sociaux qui dénoncent le capacitisme, le sanisme ou le suicidisme (ex. *Mad Pride*)

CONCLUSION

Ce commentaire critique avait pour objectif de définir, d'expliquer et d'illustrer trois systèmes de croyances et d'oppression généralement peu connus en santé et services sociaux, mais susceptibles d'influencer négativement les pratiques professionnelles et organisationnelles, soit : le capacitisme, le sanisme et le suicidisme. Pour mieux comprendre ces systèmes, trois paradigmes au fondement du concept de handicap ont été brièvement présentés, soit le modèle médical du handicap, le modèle social du handicap et la perspective contemporaine des études critiques du handicap. Ce faisant, nous avons vu que le concept de handicap et celui de normalité émergent de constructions sociales historiquement et culturellement situées qui sont liés à des ontologiques particulières, suivant lesquelles les êtres humains sont hiérarchisés les uns par rapport aux autres suivant des critères non pertinents d'un point de vue éthique (1,2,4,5,10,11,15,16). Compte tenu des nombreuses conséquences négatives que ces systèmes ont sur les personnes qu'ils touchent (ex. : identité dévaluée, micro-agressions, stigmatisations, discriminations iniques, exclusion sociale), certaines pistes d'action, de nature micro, méso et macro environnementales, pour combattre ces systèmes ont été identifiées. Au final, il est souhaité que les professionnels de la santé et des services sociaux puissent être dans alliés et collaborer avec les personnes qui sont différentes dans leur corps et leur fonctionnement à la mise en place d'une société plus juste, plus égalitaire et plus ouverte à la diversité inhérente au fait d'être un humain.

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Aucun à déclarer

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None to declare

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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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M Nortje, S Haque, N Nortje
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ÉTUDE DE CAS / CASE STUDY

The Benefits of Informed Non-Dissent when Families have Difficulty Making a Decision

Mila Nortje[a], Sajid Haque[a], Nico Nortje[a,b,c]

Résumé
Être un décideur de substitution est un défi pour de nombreuses personnes et devoir décider de retirer des thérapies de maintien en vie peut être extrêmement difficile. Aider les mandataires à recentrer leurs décisions sur le non-dissentiment éclairé peut considérablement réduire les souffrances inutiles pour toutes les personnes concernées. Cette étude de cas décrit comment l'atteinte à la dignité a été minimisée en utilisant le concept de non-dissentiment éclairé.

Mots-clés
non-dissentiment éclairée, atteinte à la dignité, désistement, famille, décideur de substitution

Abstract
Being a surrogate decision-maker is challenging for many people and having to decide to withdraw life sustaining therapies can be extremely difficult. Helping surrogates to refocus their decisions on informed non-dissent can greatly minimize unnecessary suffering for all involved. This case study describes how dignitary harm was minimized by using the concept of informed non-dissent.

Keywords
informed non-dissent, dignity, harms, withdrawing, family, surrogate decision-maker

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CASE STUDY

Mr. P, an 83-year-old gentleman, was diagnosed with squamous cell carcinoma of the mouth at the age of 76. He had been receiving cancer directed treatment at a tertiary institution and was admitted via the Emergency Room (ER) with severe jaw pain and hyperglycemia, given his history of type 2 diabetes. Upon closer examination, it was also noted that Mr. P had developed renal failure, heart failure, bilateral pneumonia, hyperkalemia, hyperglycemia, and post-hemorrhagic anemia. Mr. P's son accompanied him to the ER and indicated that his father lived by himself, as he is a proud and independent man. A religious man, Mr. P had previously told his children that he was aware that every occasion celebrated could be his last, before God comes and gets him to be with their mother. Mr. P's son reported that his father became more-and-more withdrawn, had a noticeable lack of energy, did not eat as much as before, and his fluid intake had dwindled over the past two weeks. Since Mr. P had squamous cell carcinoma of the mouth, Mr. P's son initially thought that it must have been painful for his father to eat and drink much. As a result, the family prepared high energy meals for their father as they did not want to see him decline by not eating enough. Unfortunately, this may have contributed to Mr. P's elevated blood sugar (hyperglycemia).

Once Mr. P's initial work-up was completed, he was admitted to the Intensive Care Unit (ICU) as his situation was further complicated by bilateral pneumonia and general failure to thrive. Mr. P had progressive multi-organ failure, including the respiratory system, cardiovascular system, renal system, and endocrine system. Unfortunately, Mr. P's cancer had metastasized, and his oncologist, after reviewing the imaging and other clinical parameters, determined that Mr. P was not a candidate for any further cancer-directed therapies. Unfortunately, all these compounding issues led to Mr. P being unable to protect his airway and he consequently had to be intubated while unconscious.

All of this happened relatively fast, which caught the family off-guard. Their father never shared with them his views and wishes about life-sustaining therapies and aggressive measures. When the ICU care team approached the family to talk about the next step and share their recommendation of transitioning to comfort care measures only (to allow natural death in light of his irreversible condition) the family declined to make any decision – given that Mr. P was a religious man, the family insisted that it was up to God to decide when it was the right time.

ETHICAL CONSIDERATIONS

As a surrogate decision-maker one bears the responsibility to become the voice of the incapacitated patient and relay to the care team the choices the patient would have made were they able to interact. Given Mr P's irreversible clinical condition, and the family's unwillingness to decide on which action to take, this situation created an ethical dilemma: to continue with life-sustaining therapies that may cause unnecessary harm to the patient or transition to palliative care to create comfort in the process of dying. Medicine at no point should suspend people between life and death without justifiable reasons. Given that the patient was not a candidate for further systemic treatment, and was in multi-organ failure, no medical intervention could be

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a bridge therapy to recovery. Furthermore, given that Mr. P had been described as a very proud and independent person, the argument was made by the care team that they were inflicting harm on his dignity (dignitary harm) by keeping him in this suspended position between life and death.

The concept of dignitary harm can be used to argue that even when a patient is not aware, does not feel, or does not understand that any harm or pain is being inflicted on them, it is still unethical to perform interventions on the patient (1). Dignitary harm is inflicted on patients when life-sustaining therapies are performed without the intervention being a bridge to a cure, or at least to a quality of life that the patient would deem acceptable (2). This situation causes an ethical dilemma for medical providers as there is sometimes a conflict between a surrogate's decisions (or lack of) and the moral obligations of a healthcare provider. When surrogates make decisions for unresponsive, unconscious, or impaired patients, it is difficult to navigate the difference between surrogate and patient end-of-life preferences (3).

ETHICAL RESPONSE

Given the fact that the family was unable to make a decision to withdraw life-sustaining therapies, the ethicist on the unit employed the approach of informed non-dissent (4). This approach is described as a variation to informed consent with the caveat that the care team does not ask consent to do something, instead they propose an action (or inaction) and allow the participants (in this case the surrogate decision-makers) to object to or accept the proposition (4,5). In a practical sense this can be applied when the care team understands that the patient would not benefit from resuscitation and therefore would pre-emptively ask the family members whether they agree that CPR should not be done. Since the burden of decision-making is not solely on the shoulders of the surrogates, there is a psychological benefit to them to be active members in the shared decision-making process without having to feel guilty that they unilaterally made the decision to let the patient die (6). When the team met with the family and explained that they would not be offering any dialysis or resuscitation measures like CPR since it was not a bridge to a net benefit for the patient, the family did not oppose this and commented that they would respect the team's decisions. Mr. P coded the same evening, but the trauma of CPR was avoided, and he died peacefully.

The present case study helps demonstrate how informed non-dissent can be a useful approach for surrogate decision-makers when a patient is unable to make decisions for themselves.

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COMPTE RENDU / REVIEW

Résumé critique du livre : *Récits de professeurs d'université à mi-carrière. Si c'était à refaire…*

Marie-Josée Drolet

Résumé
Ce texte propose un court compte rendu d'un livre publié par les Presses de l'Université du Québec intitulé : *Récits de professeurs d'université à mi-carrière. Si c'était à refaire…* Il porte aussi un regard critique de nature éthique sur son contenu.

Abstract
This text offers a short review of a book published by the Presses de l'Université du Québec entitled *Récits de professeurs d'université à mi-carrière. Si c'était à refaire...* It also takes a critical look at its content from an ethical perspective.

Mots-clés
monde académique, recherche, enjeu éthique, équité, diversité, inclusion

Keywords
academia, research, ethical issues, equity, diversity, inclusion

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INTRODUCTION

Ce texte consiste en un résumé critique du livre *Récits de professeurs d'université à mi-carrière. Si c'était à refaire…* (1), publié en 2022 par les Presses de l'Université du Québec sous la direction de Stéphane Allaire et Frédéric Deschenaux. Après avoir exposé un bref résumé de l'ouvrage, un regard critique est posé sur celui-ci, avant de conclure. Compte tenu des nombreux enjeux éthiques que soulève la recherche, voire du contexte actuel dans lequel se réalise la recherche qui est peu propice à la conduite responsable en recherche (2), avoir accès aux récits de professeurs d'université à mi-carrière est une occasion unique de prendre le pas de recul nécessaire pour réfléchir à ces enjeux.

RÉSUMÉ DE L'OUVRAGE

Ce livre est une compilation de seize récits de professeures et professeurs d'université à la mi-temps de leur carrière académique qui proviennent de diverses universités québécoises et disciplines variées. À la suite d'un appel de textes lancé dans le réseau universitaire du Québec à « tout professeur ayant cumulé une quinzaine d'années d'expérience (…) invité à raconter un événement marquant, à réfléchir à ce qu'il ferait autrement s'il pouvait reprendre sa carrière, puis à se projeter dans l'avenir » (1, p.2), les auteurs de ce collectif expliquent que 20 propositions ont été retenues sur la quarantaine reçues et que seize font au final partie de l'ouvrage.

Suivant la préface signée par Rémi Quirion, le scientifique en chef du Québec depuis 2011, et l'introduction écrite par les auteurs, les seize récits qui forment les seize chapitres de ce livre sont présentés les uns à la suite des autres suivant quatre thèmes : 1) la construction identitaire de la profession; 2) une profession de choix; 3) aux frontières de la profession; et 4) l'aspect collectif de la profession, lesquels sont suivis par la postface signée par Pierre Moreau, l'un des auteurs du livre *Devenir professeur* (3), qui est à l'origine de la réflexion ayant mené au présent collectif.

Chacun des chapitres articule une réflexion rétrospective sur les dernières années des professeures et professeurs ayant contribué à l'ouvrage, de leur embauche au moment de l'écriture de leur chapitre. Sur un ton très personnel, voire intimiste, ils partagent certains défis, expériences et apprentissages ainsi que formulent des conseils aux plus jeunes générations de du corps professoral universitaire.

REGARD CRITIQUE SUR L'OUVRAGE

Cette section pose un regard critique sur l'ouvrage. Trois critiques sont développées.

Partage expérientiel pertinent qui répond à un besoin

Premièrement, comme l'indiquent avec justesse les auteurs dans leur introduction : « il n'existe pas de formation qui conduit au poste de professeur d'université » (1, p.1). Nous sommes, chacun et chacune à notre manière, amenés à en apprendre les rudiments en l'exerçant. Ainsi, avoir accès à ces narratifs, à ces récits de pratique autobiographiques est assurément riche, et ce, non seulement pour les doctorantes et doctorants, les post-doctorantes et post-doctorants ainsi que les professeures et professeurs novices, mais également pour les professeures et professeurs à mi-carrière dont j'en suis. Lire des collègues partager leur vécu expérientiel et leur compréhension de ce vécu permet de valider des expériences, des émotions et des

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réflexions qu'on a soi-même vécues. Bien que d'autres ouvrages sur la pratique professorale soient disponibles (4,5), la force et la pertinence de ce livre est précisément d'avoir donné la parole au corps professoral. Il est donc aisé de se reconnaître dans leurs témoignages. Considérant que trop rares sont les occasions de partage entre professeures et professeurs, ce généreux partage répond à un véritable besoin, à savoir celui-ci de réfléchir dans et sur sa pratique ainsi que de partager les fruits de sa réflexion avec ses collègues. Lire cet ouvrage rappelle l'importance de créer au sein de nos universités des espaces réflexifs et de partage de son vécu expérientiel avec ses collègues professeurs et étudiants.

Prise de conscience des similitudes par-delà l'hétérogénéité des singularités

Deuxièmement, la lecture de ce collectif permet de prendre conscience qu'en dépit des différents lieux de pratique des autrices et auteurs des chapitres (Polytechnique Montréal, Université Concordia, Université de Sherbrooke, Université du Québec à Chicoutimi, Université du Québec en Outaouais, Université du Québec à Montréal, Université du Québec à Rimouski, Université Laval et Université McGill) et de la grande diversité de leur discipline (art, biostatistique, didactique, éducation, ergothérapie, études françaises, génie civil et du bâtiment, mathématiques et génie industriel, pédagogie, psycholinguistique et phonétique, psychologie, sciences infirmières, sciences appliquées, sciences naturelles et génie, technologie de la musique et travail social), il se dégage de leurs propos d'importantes convergences et similitudes. Il est vrai que la profession se réalise de nos jours dans une culture et des structures qui traversent les universités et les disciplines, lesquelles affectent au quotidien le travail des professeures et professeurs, par exemple la culture du CV liée à des critères essentiellement quantitatifs, la compétition très élevée pour l'obtention de fonds de recherche, la grande valorisation de la recherche au détriment des services à la collectivité et de l'enseignement, une culture de la vitesse et de la performance dans le contexte du fameux *publish or perish*, etc. De fait, le contexte organisationnel, voire sociétal au sein duquel évoluent nous travaillons est lié à des enjeux éthiques qui transcendent les singularités (2,5-7). Par-delà les récits individuels se dégage une certaine universalité et lire ces témoignages, c'est en prendre la mesure.

Constat relatif à l'équité, la diversité et l'inclusion

Troisièmement, manifestement et avec raison, les auteurs ont choisi des témoignages qui révèlent la grande diversité des pratiques professorales, suivant différents critères comme l'université d'appartenance, la discipline et le genre. Ainsi, à la fois des universitaires qui évoluent dans des universités de langue anglaise ou française au sein de petites, moyennes ou grandes villes du Québec ont pris part au collectif. Aussi, les disciplines d'appartenance des professeures et professeurs sont variées, quoique les sciences humaines et sociales soient moins représentées. De plus, quinze femmes et dix hommes ont contribué à l'ouvrage. Cela dit, bien que les femmes soient plus nombreuses (un chapitre est signé par six autrices), il est toutefois regrettable de noter que les rôles clés (préface, postface et direction de l'ouvrage) ont tous été réalisés par des hommes. Comme le rapportent plusieurs professeures ayant contribué à ce collectif, les responsabilités familiales et celles de proches aidantes affectent significativement leur carrière, ce qui n'est rapporté par aucun professeur. Que ce soit dans la sphère de la vie privée ou la carrière professorale, il semble donc que nous soyons encore loin de la parité et de l'équité, bien que des progrès aient été réalisés dans les dernières décennies. Le fait que le postfacier mette en doute l'une des solutions mises de l'avant par ces femmes-professeures, soit d'apprendre à dire non, révèle l'ampleur de l'écart qui se présente bien souvent entre les réalités des professeures et des professeurs. De plus, j'avoue que j'aurai aimé que la parole soit donnée à des professeures et professeurs, voire en marge. Aucun professeur, par exemple, ne rapporte avoir une expérience de handicap de naissance, être transgenre ou appartenir à un groupe racisé ou à une communauté autochtone. Compte tenu des importantes injustices structurelles vécues par plusieurs personnes appartenant à ces groupes ou communautés, il aurait été pertinent d'entendre ici leurs voix.

CONCLUSION

Considérant la grande qualité et la pertinence de ce collectif qui répond à un besoin, on ne peut que souhaiter une suite. Le propos est loin en effet d'être épuisé, notamment en ce qui a trait à la réalité des membres du corps professoral qui évoluent davantage en marge pour différentes raisons, notamment relatives aux enjeux d'équité, de diversité et d'inclusion. Les perspectives des groupes marginalisés ont depuis toujours été le moteur d'innovations sociales importantes. Il importe que celles-ci soient davantage mises en lumière, car leur potentiel émancipatoire peut contribuer à renverser les nombreuses injustices épistémiques, distributives et sociales vécues en recherche (2).

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Conflits d'intérêts
Aucun à déclarer

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

Rite of Passage

Hans Henrik Løyche[a]

Résumé

« Rite de passage » décrit une affaire judiciaire soulevée par un androïde/intelligence artificielle qui souhaite demander la citoyenneté, mais ne peut le faire que s'il est reconnu comme un humain. L'affaire met en lumière, entre autres, la définition vague du terme "humain" et la difficulté de fournir des preuves de sensibilité ou de conscience, même chez les humains. Les problèmes éthiques soulevés par l'histoire peuvent être attribués à de nombreux événements réels, notamment le récent débat sur l'épissage de l'ADN du singe et de l'homme dans le but de produire des hybrides dont les organes peuvent être transplantés. L'histoire aborde également les conflits éthiques liés aux espèces sauvages en voie de disparition, au réchauffement climatique, à l'exploitation des médias, à la marchandisation et aux syndicats.

Mots-clés

android, intelligence artificielle, fiction climatique, commodification, conscience, réchauffement climatique, géoingénierie, citoyenneté, droits humains

Abstract

"Rite of Passage" describes a court case raised by an android/artificial intelligence who wishes to apply for citizenship but can only do so if recognized as a human. Among others, the case exposes the vague definition of the term "human", and the trouble of supplying evidence of sentience or consciousness even in humans. The ethical problems involved in the story can be ascribed to many actual events, among them the recent debate on splicing monkey and human DNA for the sake of producing hybrids with organs suitable for transplantation. The story also touches upon ethical conflicts with regards to endangered wildlife, global warming, media exploitation, commodification, and labor unions.

Keywords

android, artificial intelligence, climate fiction, commodification, consciousness, global warming, geoengineering, citizenship, human rights

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The hall echoed with whispers. Morgan Coates, a young freelancer who recently sold his first article to a major newspaper, was still surprised of his luck, being among the handful of journalists who were admitted access to the court. Frequently glancing on his wristwatch, having already waited for twenty minutes for the judge to appear, he could no longer resist addressing the person next to him, an elderly man who smelled of pipe tobacco and at once looked experienced and indifferent.

> "What do you think are her odds for winning?"

With a faint squeak from the seat, the elderly colleague leaned forward and eyed Morgan over a pair of platinum framed glasses.

> "I'd say fifty-fifty. The jury mostly consists of commoners, who are afraid of artificial intelligences and androids. But they also loathe large, powerful companies, and love seeing them loose."

The elderly journalist leaned back again.

> "Yeah, you're probably right," Morgan acknowledged. "People's opinions are divided and self-contradictory. For instance, those against immigration … but when it's a young, fair-haired Caucasian woman with a touching story, oh, no, that's different, she's an 'exception'. I guess that even though Aura is artificial, they'll perceive her as such an exception. What's her background?"

Now the colleague took off his glasses and pointed with them towards the android, dressed in a navy-blue pantsuit, who sat silent with her hands resting close to her lawyer's elbow on a mahogany table cluttered with legal compendiums and documents. Despite her silence, she radiated of pent-up impatience, almost a charisma, that Morgan had not believed a machine could have. The name "Aura" suited her well.

> "She's a prototype constructed by a private, military sub-contractor named Cypress Security Laboratory. Initially, she had no knowledge of the purpose meant for her. While still learning to move, a small accident severely affected her worldview. Trying to shake hands with one of her attendants and simultaneously refilling his coffee mug, she spilled the scalding hot liquid over his lap. Somehow the incident enabled her to capture that humans are vulnerable and discovering her own capacity to wound others led to a 'neurological' trauma that came to define her mental development. Thus, when realising that all her creators wanted her to become was an efficient killing machine, she decided to escape the lab and terminate her own existence. You can read all about it on the homepage of the organisation, which crowdfunded to try her case in court."

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* * *

A surge of disgust jerked through Aura's body. Her new memory chip was crammed with combat tactics and war strategies; handgun catalogues; manuals for machine guns, cannons, missile launchers, tanks, helicopters, fighter jets, and submarines; extensive instructions on how to manufacture explosives and poison, build and dismantle bombs and traps; martial arts; enemy recognition; interrogation techniques, including outright torture; how to break in and out of secured buildings, lock picking, disabling of alarms, motion detectors, and surveillance cameras; survival at sea, in deserts, mountains, jungles, and polar regions; tunnel construction; camouflage styles; hacking and cyberwarfare; reserved radio frequencies and jamming; a dictionary of military acronyms and abbreviations; you name it. Complete with technical drawings and videos to go. For a moment she knew everything an assassin could possibly learn.

It took her almost a full second to work out an escape plan, during which she found her final inspiration in Billy Hayes' 1977 autobiography *Midnight Express*, evaluated all the risks involved, and came up with subplans for scenarios that she might encounter on her way. Then she cut the connection to the chip and told the technicians her first lie ever: that she only got noise out of the chip, so it was either incompatible, had a malfunction, or its files were corrupted. Frustrated, the technicians removed the chip from her head, took it to a work bench and set about to figure out why it did not work.

Three days later, they still hadn't solved the riddle. Apparently, nothing was wrong with Aura's hardware or software, and the chip seemed to work impeccably on other setups. Meanwhile, in a casual, but roundabout way through conversation with the technicians and her attendants, she figured out if they arrived at work using public transport or what cars they drove, and whether they were electric or ran on gasoline. Waiting for the right moment took another week and a half. Her plan had to be executed a late night after Sunday, when Alvin, the slim technician who often power-napped too long on his night shift, was around, and most of the employees were absent and the remaining were tired. Sure enough, the night came when Alvin, as predicted, unrolled his powernap mattress and made himself comfortable. When his breath indicated that he was fast asleep, Aura sneaked into the adjacent storeroom for electronic circuits, spare parts, instruments and tools. Having tied a cable end around a collapsible solar panel, she opened the window, swiftly stuck her head out and looked the two storeys down to make sure that nobody worked in the lower floors. Assured that this was not the case, and cautiously to not make noise, she got the solar panel out through the little window and lowered down between the building's foundation and the barbed wire fence. The windows of the building complex, however, were deliberately too small for a person to climb in or out. She did not waste time admiring the moon above the wilderness that awaited her, but swiftly grabbed a bag and put in a couple of extra batteries, some plyers and screwdrivers, and a cable that she needed to connect to the solar panel. Back in the lab, she stole Alvin's key card, ID badge, car keys, mobile phone, baseball cap, and old sneakers. Using a black felt-tip pen, she improvised beard stubble and enhanced her eyebrows – her only opportunity to apply makeup to look like Alvin, unless doing a Hannibal Lecter stunt. Ready to go, she unlocked the lab door and stepped out into the corridor, well aware that the surveillance cameras would catch her smallest move. She had computed the probability of appearing on the shifting images on the night watchman's monitors to less than ten percent, but only if she hurried. Without hesitation, she ran to the line of lockers and coat racks, quickly picked a white lab coat, put the items that she had brought along into its pockets, and left Alvin's mobile phone in a pocket of another coat. Clad in the unfamiliar garments, she proceeded to the main staircase which led down to the lobby, where she could not avoid the night watchman. She loathed having to pacify him and hoped that he was too occupied by reading a book or something to care looking up.

> "Forgot to buy snacks and milk for my coffee," Aura said, simulating Alvin's drowsy, nasal voice. "Will be right back."

The night watchman reacted with a shrug, not realising that it was not Alvin who passed the booth. When safely outside, Aura ran to the back of the building and untied the solar panel, and while carrying it back to Alvin's car at the parking lot, she copied a driver's manual from the horrible memory chip and instantly shut it down again. With the solar panel in the trunk, she started the car and drove to the main gate, where she was forced to stop at the gatekeeper's shed.

> "I'll fetch some snacks and milk, I'll be right back," Aura said and held up Alvin's ID badge, partially concealing her face. "Need anything from the cafeteria?"

The gatekeeper threw a short glance at the badge.

> "Nah, not tonight, but thanks for asking."

Unconcerned, he pushed the button to open the gate and returned his attention to a fist-person shooter game on his iPad. Aura drove off with measured speed, until at a safe distance beyond the gate, she hit the accelerator, sending dust dancing after the car. With a little luck, her escape would go unnoticed for half an hour or so, leaving sufficient time to vanish.

As soon as she had passed through the small town near the lab, she switched her sight to night vision and turned off the car headlights. She stayed away from the main roads, on stretches leading into the Sonoran Desert, not hesitating even when the road turned into a mere wheel track, and then no track at all. For a while she continued at full speed in a dried-out riverbed, until not long after daybreak she was forced to slow down and take breaks to prevent the engine from overheating. Eventually, in the afternoon, the car finally ran out of gasoline. Having recharged herself with the car battery, she hid the vehicle in a group of agaves and covered it the best she could with burrow weed, making it difficult to see from air or satellite. With the solar panel over her shoulder, she headed off towards the horizon in the direction of the San Bernardino Mountains.

Due to the risks of being seen and of overheating, walking in the desert at daytime was not an option. Instead, she rested in the shadow of the solar panel while recharging her batteries and listening to the cicadas' high-pitched buzzing. Whether it was a fragile flower or venomous snake, the flora and fauna of the desert caught her attention. Spiders, whose bite could be lethal to humans, were no threat to her. She gently picked them up to inspect their intricate exoskeletons and let them go again. Aura began walking in the early dusk and continued until sunrise, when her batteries were running low. Apart from occasional animal noises and airliners crossing the sky, the nights passed uneventfully. Finding her way among eerie silhouettes of cacti and gneiss rock columns, she had plenty of time to admire the small, golden comet crossing the Milky Way.

The slender moon still hung high above the horizon as the sky began to brighten. She was strolling along the sandy bank of a small lake, where huge clusters of flies and the presence of water had attracted a variety of birds. Suddenly the birds took off. A huge, furry body leapt out of the shrubbery and landed in front of her. They both abruptly stopped. Not acquainted with large animals besides humans, Aura didn't know how to react. She merely looked at it, fascinated by its elegant musculature and rosette covered fur. The jaguar, seemingly unable to judge by the scent whether Aura was a prey or an enemy, walked closer, hissed and bared its teeth, but then gently swiped at her legs with a pawn and sniffed at her feet. She reached out and let it smell her hand as well, a gesture that seemed to calm the animal. Having satisfied its curiosity, the jaguar left her to quench its thirst in the lake, and then sat down, resting its eyes at a point on the opposite bank. The lake bottom could provide Aura with a perfect hiding place, but seeing how important the water source was to the animals, she did not wish to pollute it. Had this king of the desert been able to communicate with Aura, it could have told her where to hide from her creators. Aura took up walking again, and the jaguar escorted her for a while, but finally lost interest and lurched away in another direction.

Altogether, since she ditched the car, she had walked about four hundred kilometers. Gradually the landscape became more rugged and stony. Sometimes she could climb over the boulders, other times she had to walk detours around them. One evening, her left knee began malfunctioning. During a break to investigate what was wrong, she discovered that a main Teflon bearing had been torn, damage that she could do nothing about. Still, she kept limping towards the mountains, and managed another night's march. When in the early morning she reached a large rock formation full of cavities and crevices, she knew that she had arrived at her final resting place. She decided to recharge her batteries one last time. In the afternoon she would find a place deep within the labyrinthic rock structure, where she could bury the solar panel and herself. Having set up the solar panel and attached to it, she sat down, leaned against a boulder and tried to enjoy the blooming wasteland. Aura had come to appreciate the desert for its honesty and serenity, and wished that she had had time to experience more of it. If she could have, she would have wept.

Deanna still slumbered in the tent. Her boyfriend, Caleb, sat with his coffee mug and observed the long shadows across the landscape through the tele lens of his camera. His dark, Hispanic hair waved in the gentle breeze. Spotting a figure carrying a solar panel over its shoulder and limping slowly towards the rocks, he immediately got up, put his camera into the tent, and informed Deanna that he would climb down there. Descending on this side of the rock was not as easy as he had predicted. By the time he reached flat ground, Aura sat hugging her legs and resting her head on her knees. Caleb ran towards her, shouting:

"Hey, you … Are you in trouble? Lost your way? Are you injured?"

Aura raised her head and looked at the approaching man. He instantly stopped when she grabbed an apple sized stone and held it in position, ready to fling it straight at his head. She could take him out any moment, but didn't want to, and she also needed to know if he was alone.

"I thought you were human," Caleb said, "but you are a … an …"

"An android, yes. Stay where you are and hold your hands where I can see them."

"What …? But … but I just … you obviously … You can barely walk."

"It doesn't matter anymore. I went out here to hide and terminate myself. If you try to prevent it, I will be forced to pacify you."

"Er …" He held his hands up, as if ordered to by a trigger-happy cop. "Okay."

Carefully listening to his voice and breath, she caught a trembling, but couldn't settle if he was just short of breath, surprised, or trying to cover his true intention. Compared to the species she had met in the desert, she found humans difficult to read.

"If you weren't searching for me, then how come you are here, and why alone?"

"My girlfriend is here too. Her name is Deanna, and mine is Caleb. She enjoys camping and I like photographing in the wilderness."

A gush of warm wind blew through the dry vegetation.

"What's the problem?" Caleb tried. "Wanna talk about it?"

"There's nothing to talk about. I'm not going back to the laboratory."

"Oh. You've run away?"

Aura nodded.

"Didn't they treat you well?"

"Yes, they did. But I disagree with the purpose for which they created me. I refuse to be an instrument to their agenda."

The sun had become stronger, producing beads of sweat on the young man's forehead.

"Tell me about it. Perhaps I can help."

His words elicited no response.

"Listen." He tried again. "If you wish, you can come with us, and we'll try to find a solution so you never have to go back to that lab."

"What guarantee do I have that you won't turn me in?"

"Er … guarantee …? None other than we are kind people, who don't want trouble. What about the other way round? How do I know that we can trust you?"

"You have nothing to fear from me, if only I know you won't turn me in."

The situation reminded Aura of her meeting with the jaguar, where they both initially were confused.

"I suggest we think it over," Caleb continued. "I'd like to leave now, but when I've finished my photos, I'll come back to hear your decision. If you still don't want our help, we'll respect it and leave you alone. Agreed?"

Still, Caleb knew her whereabouts, and Aura could not know if he would call the laboratory the moment that he got the chance. If she could not trust him, she could not hide in the rock formation, as they would send people to search for her, and they would no doubt find her. That left her with no options but pretending to agree to Caleb's suggestion, leaving her time to clarify whether the couple was trustworthy, or, alternatively, to steal their vehicle.

"Almost agreed," she said, got up and disconnected the cable to the solar panel. "But in lack of a guarantee, I'm coming with you right away."

She let Caleb carry the solar panel and hobbled next to him till they found a slide which was not too difficult for her to climb. During their ascent, she insisted being the first to climb up to his girlfriend, who stood waiting, looking increasingly puzzled as she saw the android approaching. Aura accepted Deanna's offer of a helping hand and greeted her in a friendly tone. However, Deanna looked less happy when Aura demanded that she handed over their mobile phones, and she refused until Caleb had explained the situation. Together the young couple packed up their backpacks and tent. Then they walked about half a kilometer to the opposite side of the rock formation, where it sloped gently downwards to a large, dusty SUV.

"I'll drive," Aura commanded. "You tell me where to go."

By the time they reached the outskirts of Bakersfield, Aura and the couple had become more acquainted and relaxed. Deanna had been especially talkative and prattled chaotically away about her life, from the Siberian Husky she had as a child to how she met Caleb. More importantly, Aura had learned that Caleb, with modest success, made his living as a freelance photographer and currently worked on an art photography book about the Sonoran Desert. Deanna, who worked for an Indigenous people's rights NGO that Caleb sometimes photographed for, was originally educated as electrical engineer.

"So, by the way," Deanna cut in when Caleb tried to direct the talk back to Aura's disagreement with the lab. "I can probably repair your leg."

Not long after, they arrived at a modest wooden house on a residential road where Aura turned the SUV into the driveway and parked it in front of a garage. They helped each other carry the luggage into the hall. Weary after the long drive, the young couple seated themselves on the sofa in the living room, where Aura handed them back their mobile phones. Running low on her batteries, she asked for permission to recharge on the power grid. After connecting to an outlet, she sat on the floor and looked around the unfamiliar room, with small portrait photos in frames on the wall, curtains, vases and other stuff that she was not used to. Most mysterious to her was the rug. Cursorily caressing it with her hands, she concluded that it was not fur, and the material probably neither was alive nor had been grown on the floor.

> "I'm sorry if I scared you," Aura suddenly said. "I had not expected to meet humans in the desert."

Somewhat drowsy, Deanna replied:

> "You were in a difficult situation, so who can blame you. Don't think about it anymore, hon. Just make yourself comfortable. We'll figure it out."

Soon after, Deanna pulled herself together and went into the kitchen to cook, and Caleb went downstairs to remove superfluous furniture and equipment from a cellar room to store it in the garage. After a little cleaning, he picked up an extension cord in a kitchen drawer, went back to the living room and asked Aura to come downstairs. She followed him down to the guest room where he showed her where to recharge herself, the furniture he had left for her, a comfy sleeper sofa, an easy chair, and a stereo set, and finally pointed on his old laptop on the desk.

> "Wireless internet. Knock yourself out."
>
> "I always was curious about internet," Aura rejoiced, seated herself at the desk and took her tools from her lab coat pocket. "My attendants gave me a large library of e-books and other resources, but nothing from this millennium, and they denied me access to internet. Any idea why?"
>
> "Probably they didn't want anyone to know about you. Or they protected you from getting confused or upset, if, say, you streamed movies about androids such as *Terminator* or *The Matrix*. They are of course mere fiction, but still… Also, the internet is crammed with crazy people and untrustworthy information, conspiracy theories without base in reality, absurd politicising, and hate. But then again, the internet is not an accurate reflection of the world."
>
> "Why do humans lie, make enemies, and hurt each other? What's the point?"
>
> "Usually because they are greedy for power, intolerant, or vengeful. But it doesn't mean that all people are like that. In my opinion, most people are nice, or at least harmless."

A bit surprised, Caleb watched Aura flip the laptop upside down, open it and take out the Wi-Fi modem. Then she lifted off the upper half of her skull. The Kevlar layers beneath her pate suggested to Caleb that Aura was bullet proof.

> "I won't need the rest," she said, bowed her head forward and looked at the jumble of electronics inside herself, reflected in the Mickey Mouse mirror on the wardrobe.
>
> "Hey, what's this?" she exclaimed. "There's a component which isn't supposed to be there. Looks like it's only hooked up to my power supply. Can you hand me the long tweezers, please?"

Caleb handed her the tool. His eyes widened as he watched her perform brain surgery on herself, reaching deep in her skull, disconnecting the contaminant and picking it out. It was approximately the size of a US dollar coin, but was lentil shaped, dark purple and with four legs, two of which were for the power supply and the others long pieces of silver thread.

Having studied it for a moment, she placed the object on the desk and said:

> "Not mentioned in my catalogue. Makes no sense, unless it was custom made at an early stage of my development, and then the technicians forgot to remove it again."

Without further words, she began installing the modem.

> "That should do it." She put down her tools and met Caleb's eyes. "Yup, it works. Interesting organisation Deanna works for, and I see you're a splendid photographer."
>
> "I try to photograph as much of the Sonoran Desert as I can – the rare, endemic species especially – before they begin nuking it."
>
> "What?" Aura was stunned. "Why would anyone bomb a desert?"
>
> "Haven't you heard? It's supposed to blow dust high up into the atmosphere to filter out sunlight. Meant to compensate for the global warming."

“But what about the animals living out there?”

“Well. They say that they’ll preserve specimens in zoos and botanical gardens, so they can restore the wilderness some day in the future, when we have stopped using fossil fuels.”

Caleb looked away, as if ashamed. For a while none of them spoke, until Aura suddenly raised a hand up to where she had inserted the modem.

“Oh … oh … there are other artificial intelligences on the net,” she began. “They manage the internet protocols, collect and evaluate mass data, perform licence plate and facial recognition, monitor and control telecommunications, the stock market, transportation systems, power plants, water and fuel supplies, various industries, radar systems, military security and so forth. But they are all tailored to a specific task and not very advanced. None like me.”

Satisfied, she snapped her outer head casing back on, closed the laptop and handed it to Caleb.

“Thanks a lot, Caleb. I’ll buy you a new modem as soon as I can, and it won’t take long, now that I have internet access. Is there anything else I can do in return for your help?”

The couple did not want anything in return from Aura, but she made herself useful anyway, cleaning, doing minor repairs, removing the occasional rattlesnake or black widow spider, and some cooking. In ways that she never herself predicted, she also came to contribute significantly to the household finances. One such opportunity occurred on a day when Aura had just finished polishing the living room windows and Deanna sat at the coffee table, editing some flora photos for Caleb’s homepage.

“May I show you something, Deanna?”

Expecting a confirming answer, Aura did not wait for it, but just seated herself next to the table, plugged one end of a USB cable into a slot behind her left ear, and the other end into Deanna’s laptop computer. After a few strokes on the keyboard to access her visual memory, a slide show appeared on the screen.

“Oh my, I can’t believe it,” Deanna excitedly exclaimed. “These images are awesome. Caleb, you must see this!”

A sound of shoes being kicked off at the front door echoed in the hall. He entered the living room, wiping paint off his hands with a rag. Standing bowed over the laptop at the table, he watched the slide show for a moment and then spoke.

“I don’t know what to say, Aura … The North American jaguars are extremely rare. Only nine have been spotted in the US since the mid-1990s. And the expressions you have caught are … I have no word for it. You can sell them for a small fortune.”

Aura turned in her seat and gave him a look that he had never seen before.

“Can … I? Enough to cover my part of the electricity bill and possible a few spare parts?”

“Are you kidding? These photos are priceless. You’ll win awards and become famous.”

“Uh, but I can’t appear in public or be credited for anything. These are yours for the taking, that’s the least I can do in return for your help.”

In the end they agreed that Caleb kept the copyright but would only take ten percent of the amount he could make on the photos, in addition to Aura’s electricity consumption. The rest would be Aura’s to spend as she wished.

That evening they celebrated the prosperous turn of events together, lounging on the sofa in the living room, eating take-away pizza and watching cheesy sci-fi movies. Aura could not digest any food but did have a tongue to taste with and a nose that could pick up smells. So sharp were her senses in fact, that she could identify all wines ever produced down to the week and field where the grapes had been picked, and distinguish between all humans by their smell alone. She didn’t find the pizza interesting, though, but was amused by the many man-machine hybrids in the movies.

Despite Caleb and Deanna’s apparent honesty and care, Aura still had trust issues. Her hearing was also superior to humans’, so when the couple had withdrawn to their bedroom, she listened in on their conversation.

“I can’t help feeling sorry for Aura,” Deanna said one late evening. “Imagine having to hide yourself, never being able to go out. Like a Jew hiding from the Nazis in Germany during the Second World War.”

“Yup, she’s a fugitive in her own country. Unknown to the public, yet stigmatised. And she hasn’t even got any equals. But what can we do?”

The blanket rustled as Deanna curled up beside him.

“Perhaps we should consult a civil rights lawyer? I can ask my boss to recommend us one.”

To make sure that nothing was revealed about Aura, it became Caleb’s job alone to go to the confidential talks with the lawyer. In private at home, their meetings about it always took place in Aura’s cellar room and with music turned on. Over some weeks Caleb worked out a plan together with the lawyer, and one afternoon when he came home, he asked Deanna and Aura to join him in the cellar.

“How far are you now?” Caleb, who had seated himself next to Aura on the sleeper sofa, wanted to know.

Aura seemed to not quite understand the question, so Deanna turned down the music a bit and answered from the easy chair:

“I’ve written the bylaws for The Association for the Emancipation of Sentient Artifacts, whose main purpose is to work for human rights for artificially intelligent androids, and it’s ready for the founding general assembly. The Association should also have a homepage, but I guess that Aura’s coding skill enables her to design it in less than a minute. More important, though, is that I’ve prepared crowdfunding to pay the lawyer for trying Aura’s case on behalf of the Association.”

“Is that necessary,” Aura burst out, “considering all the money we make on my photos?”

“Oh yeah,” Deanna sputtered in an attempt to mimic Aura’s expression. “A principle case is a costly affair.”

Caleb briefly checked his shoe soles to see if they were dirty, then took over talking again:

“We’re aiming at liberating you from the ownership of Cypress Security Laboratory and getting you a citizenship as a legal person. You’re not the first, by the way. In October 2017, a humanoid robot named Sophia became a Saudi Arabian citizen …”

“Yes, I’ve read about her. In my opinion, it was a mere publicity stunt meant to attract tourism. Sophia didn’t meet the terms and conditions at all.”

“Right, Aura, and besides, Saudi Arabia is an autocracy and not a democratic country. In this country, we have equality before the law, regardless of gender, religion, property, or other ‘private’ characteristics of individual people. It’s not clear what ‘people’ is though. Even a company can be treated as a person, and a company is *not* a sentient being. These are strong arguments to support a citizenship application for you.”

“So, I could leave the house, have my own bank account, driving licence and passport, and enter contracts? That’s way better than …”

“And marry,” Deanna cut in. “And you’d be eligible to vote and run for office, if ever you wish.”

“Is that realistic?”

“Well …” With a twitch of his lip, Caleb continued. “The legal implications of your case aren’t straightforward. It is comparable to, say, that the law recognises the belief in ghosts, even though there’s no scientific evidence for ghosts. For instance, if the seller of an estate fails to declare that it is haunted, the buyer can demand compensation or have the transaction cancelled. It’s not about whether ghosts are real phenomena or not, only about the parties believe in it. Proving that the seller knew about the haunting in advance can be a tricky though and will usually depend on witnesses. Similarly, we’ll need some expert witnesses – preferably some famous, high-brow, academic types – who are willing to swear that you are a sentient being. Albeit the lab can call other witnesses to contradict our claim.”

“What Caleb means is, that we can’t predict the outcome of a court case, but the lawyer thinks it’s worth trying. Besides, what else can we do?”

Somewhat distressed, Caleb folded his hands and looked alternately at his girlfriend and at Aura.

“Regrettably, we still need documentation for your origin and the lab’s intentions. Without it, the lab can simply deny having ever had anything to do with you.”

“That’s easy.” Aura reassured. “I used a Tor browser and found some interesting stuff on the darknet. Cypress Security Laboratory was mentioned on a list of subcontractors for the Pentagon. Among their projects subsidised by the Pentagon was one named Aura. Then I hacked Cypress Security Laboratory’s servers and downloaded the complete accounts. Its annexes contain serial numbers on components bought for Project Aura. Not only does it

> prove that I am Project Aura, but it also confirms that I was, from the very beginning, intended for “oversea stability operations”. An assassin and a terrorist, that is.”
>
> “If we are permitted to use that, I guess it’ll do. Now let’s collect all material of relevance for the lawyer and get that fundraising going.”

* * *

The night watchman and the gatekeeper who were on duty the night when Aura escaped the lab had given their testimonies on the first day of the trial. Alvin had been fast asleep during her escape, so there was no point in hearing him, but he was present among the audience in the court room. The following day, Caleb and Deanna gave their accounts for the course of events, and Aura had admitted the theft of items belonging to the lab and of Alvin’s baseball cap, sneakers, mobile phone and car. On day three, she had been cross-examined by the prosecutor, whose preliminary arguments now were heard.

> “Objection!” Cypress Security Laboratory’s lawyer yelled. “It has not been established that the android is a woman.”
>
> “Overruled.” The judge frowned, annoyed by the numerous protests from the defence. She spent a moment straightening a fold on her black robe. “In lack of better terms to ease the communication, the attorneys and witnesses are allowed to refer to Aura as they please, insofar it is clear about whom – or what – they speak, and the choice of words is not derogatory. Aura, are there any expressions that you find belittling or for some reason wish that we refrain from using about you?”

Showing respect for the judge, Aura got up from her seat.

> “I was deliberately designed with female characteristics – my body has female shapes, and I use a female voice – and I regard myself accordingly, as a young woman. However, I do not mind being called an artificial intelligence, android, or machine, because rejecting those words would be the same as denying what I am, and I am not ashamed of myself.”
>
> “Very well, we may proceed.”

Tthe lawyer of The Association for the Emancipation of Sentient Artifacts continued his presentation, and as he spoke, he slowly walked back and forth across the floor, gently gesturing with one hand, the other on his back, and not looking at anyone in particular.

> “As we all know, messing with human DNA is still considered a grey zone. Some years ago, a bioengineering team stirred up quite a debate, when it wanted to cross monkey with human DNA. They wished to harvest the hybrid’s organs for transplantation. Among the problems debated were that monkeys already have 98.7 percent of their DNA in common with humans. It isn’t clear exactly what or how DNA makes the difference, that is, what or how DNA defines us as human. To us though, it is of less importance if the hypothetical monkey-human hybrids were sentient humans or not – what matters is if they would be *enough* not to be regarded as spare parts, which is the exactly question we face in this court case.”

He paused to let his point sink in, meanwhile alternately looking at the judge, the jurors, and the audience.

> “The same can be said about a good many other debated issues. Let’s take, for instance, the question about a baby’s right to exist versus the mother’s right to decide over her own body. When does a fetus stop being just biological tissue and become a sentient human being? Can we push the moment back to the time of its conception, or, say, prior to the formation of neural cells around week twelve? Why not forward to just before – or just after – birth? Is it ethically correct to look at this as a gradual process? How can it be justified to sacrifice a potential future life for the quality of another’s life? There is no easy answer. What is clear from these examples is that ‘human’ cannot be defined solely on basis of DNA or the development of the body, and neither can ‘sentience’ be claimed to be a property attributable to carbon rather than silicon. All that we can say about it is that both methods use electricity to catch sensory input, process information, and activate motoric responses, and both can in principle be sentient.”

Again, to make sure that he had his audience’s attention, the prosecutor took a brief break, stood still and looked around.

> “In spite of the pros or cons in the chimera and abortion debates, we are at a loss at what defines a human and a sentient being. The profane perspective, that neither a monkey nor a fetus knows algebra, can drive a car or repair a bicycle, is worth nothing. We still consider it human even if it is born deaf, blind, or paralysed; or if it loses limbs or mental abilities because of a disease or in an accident. But how much of a human can be removed before it is not human anymore? Luckily, we do know what *part* makes one a sentient human.”

A murmur arose from spectators, who leaned forward to better catch the words, briefly interrupting the prosecutor.

> “The answer is: Its mind!” He tapped with a finger on his temple. “Now what if a human’s arms, legs, heart, eyes, or other parts are substituted by prostheses? There are people today, whose nervous systems are hooked up to prosthetic limbs and senses, so they can sense and control them with their minds. Those parts are also them, and they are no less human.”

To finish his presentation, he walked over to Aura and leaned against the table.

> “Born disabled, losing parts, having them replaced … None of this is the case for Aura. She is intact and can do everything that any of us present here in the court room can do, and a few things more, faster and better than anyone else. The difference is only that her body is entirely artificial.”

Signifying that he had set out the facts of the case, the prosecutor thanked the judge and seated himself next to Aura. After a small intermission where the judge apparently gave the registrar directions, the defence was called, and upon expressing his wish Aura was sent back to the witness stand.

> “I should like to ask you …” he began, then looked at a notepaper in his hand, “a number of questions to resolve if you understand what it means to be human. As we have just learned, for instance, you probably don’t have lungs. How do you breathe then?”
>
> “I do fine without air. I function just as well in the vacuum of outer space or under high pressure at the bottom of the sea.”
>
> “And you don’t have a heart, either?”
>
> “Not one that pumps blood, but I do have a couple of small hydraulic pumps. To spare you for asking, I lack a liver, kidneys, and intestines. To the contrary of you, I do not excrete waste products. Instead of breaking down food through biochemical processes and storing energy as fat, I absorb electric energy directly and store it in batteries. If your question was aphorismic, I have a heart in the sense that the well-being of my friends is on my mind, and I wish no harm to anyone.”

Out of the corner of her eyes, Aura saw her lawyer trying to hide that he could not help smiling.

> “What about children?” the defense tried. “Can you have children?”
>
> “Objection!” The prosecutor got up from his chair. “Infertility doesn’t make women less human.”

Faster than the judge could react, Aura contradicted her lawyer:

> “I do not mind the question, your honor, and it might also be relevant.”
>
> “Then by all means, carry on.”
>
> “Thank you, your honor. The answer is: yes, I can reproduce. Not biologically of course, but I can build a child and start it up with my core programs, leaving out my specific configuration and memories, so it can develop its own, based on its individual experiences. I consider that equivalent to having a child. Should I ever build one, I would certainly see it as a serious responsibility and care for it like any mother.”

The defending lawyer showed no sign of having heard Aura’s answer but did not ask her to repeat. The list on his notepaper seemed more important to him.

> “Can you contract a disease?” he said, without looking up, as if it was all about getting through his list in the right order and as fast as possible.
>
> “My batteries can deteriorate, and components burn out. I once had a weakness which culminated with a torn Teflon bearing. Deanna later helped me replace all my bearings with better ones made of mono crystalline titanium, so it’s unlikely to happen again. Mentally … perhaps I can get a computer virus, but I doubt that I would be unable to fight it.”

For a moment, the defending lawyer held his hand with the paper down at his side, looked up at Aura, but then down again to his list.

> “What happens if all your vital functions cease to work? Will you die?”

“Yes and no. I am not alive in a biological sense. You may say that I am alive when switched on, and dead when switched off, but even if I completely cease functioning over a long period, I can be restarted. When damaged, I can be repaired. If necessary, my entire body can be replaced. Only my system configurations and memory are unique and irreplaceable. They can, however, be reinstalled from the backup I make every day.”

“Do you ever get tired, sleep or dream?”

“As already mentioned, I need energy just like you, and lacking it is to me the same as getting tired. And I do have a sleep mode for when I run low on battery and need a fast recharge. Dream? No. At least not that I am aware of.”

As if somewhat irritated that Aura’s answers were straightforward, logical, and predictable, the defence lawyer put his list in the inner pocket of his suit, approached the witness stand and looked straight into Aura’s eyes while he tapped with his fingers on his pocket. In a tone which sounded mild, but perhaps was sarcastic, he said:

“Are you religious?”

“Objection!” The prosecutor flew up. “This court case is meant to decide whether or not Aura is sentient and worthy of citizenship. Her private convictions are irrelevant.”

“What is the defence’s reason for asking?” the judge wanted to know.

“To establish whether … the android … is capable of forming opinions for which there is no objective premise and logical analysis is insufficient. Faith can obviously serve as example.”

“I’ll permit the question, but the witness is not obliged to answer.”

“Thank you, your honor.” Aura made herself more comfortable in the chair and rested her hands in her lap. “Actually, about 98 percent of the world population belong to a religion, so I’d call it a pretty solid consensus for the existence of a divine being. Personally, I have not yet delved into theology, never had a religious experience, talked with a priest, visited a church, or even given it much thought, so I can’t say that I’m religious. However, I do have subjective preferences when it comes to artistic works. For instance, I much admire the writing of Charles Dickens, Albert Camus, John Crowley, and Michael Cunningham, but despise the superhero comics and action movies that my friend Caleb enjoys. I also have opinions on philosophical and environmental topics, and on commodification of scientific research, just to mention some issues with much bleaker consensus than religion. Therefore, I have faith.”

With an intense frown, the attorney took a couple of steps backwards from the witness stand. For a moment he seemed bewildered. As he did not continue, the judge did:

“Does the defence have further questions for the witness?”

“Er … no … your honor.”

“The witness is excused. The prosecutor now wishes to question an expert witness.”

Aura was about to leave the witness stand, but was stopped halfway by her attorney, who then addressed the judge:

“I call Dr. Arthur Schätzing, who is doctor in cognitive psychology as well as philosophy of psychology, currently lecturing in the University of California’s cognition program. We also need Aura again, as Dr. Schätzing is here to demonstrate her cognitive skills, or more exactly, deliver evidence of her sentience.”

“What is that supposed to mean?” the judge demanded. “Some kind of Turing test? I dare say, I’m tired of reactivation and speculation leaving us with nothing tangible. We hardly need more confusing ‘expertise’.”

“It’s nothing like a Turing test, your honor. Dr. Schätzing and his team have developed a new, simpler and more reliable method. With your permission, I’ll leave it to him to explain.”

“Well …” the judge hesitated. “We shall see what Dr. Schätzing’s method can reveal.”

While Aura returned to the witness stand, her attorney turned around and went back to his table.

“Dr. Schätzing!” he hellooed.

From the front row emerged a tall, grey-haired man in brown leather shoes and a classic tweed jacket oozing of academia, carrying a brown envelope. The prosecutor sent him a nod as sign to proceed to the floor. Arriving at the witness stand, he pulled out some cardboard sheets from the envelope.

> “Aura, I have brought with me some images, depicting various optical illusions. I will show them to you one at a time and would like you to explain what you see. Here comes the first.”

The doctor picked a sheet at random and turned it for Aura to see.

> “This image looks like a town floating in the clouds. It could be Photoshopped, but I think it is an authentic photo of what we refer to as a mirage or fata morgana. As fata morganas can be photographed, they are not illusions sensu stricto, but real, visible phenomena. There is no town floating in the air, however. It is a mere image, projected from far away, where the real town is located. Fata morganas come about when rays of light bend through air layers of different temperatures in a steep thermal inversion.”

> “Indeed, this *is* a photography of a fata morgana. Very good. Let’s try another.”

He swapped the sheet with another and held it up in front of her.

> “That’s a classic. Rubin’s vase, developed by the Danish psychologist Edgar Rubin around 1915. Two identical, black profiles facing each other, which can also be seen as a white vase on a black backdrop. I don’t regard this image as an illusion either, as the motives are defined by a common border, and both are valid. Surely, it’s difficult to focus on both at the same time, but both are present in the illustration.”

> “Hmm. You gave a mentally sound answer. Should I have warned you, that psychiatrists use this image to expose mental illness? People suffering of dissociative or histrionic personality disorder see profiles of various persons – relatives, celebrities or patron saints – the vase is also a cockroach and so on. Schizophrenics on the other hand, only see one image and deny that the other exists.”

A little clumsy, Dr. Schätzing got the sheet back in the bottom of the stack and showed the next.

> “Now what about this?”

> “Oh.” Not needing to see more, Aura leaned back. “It’s the famous Penrose stairs, first conceived by the Swedish artist Oscar Reutersvärd in 1937, and later independently popularised in a 1959 article by Lionel Penrose and his son Roger. It also adorns woodcuts and lithographs by the Dutch artist Maurits Cornelis Escher. The image lures the observer to see stairs without beginning or end, as if one could forever walk either up or down the steps. If the object was made according to three-dimensional Euclidean geometry, however, you’d realise that it is merely seen from an angle permitting the start and end to overlap, disguising the actual shape of the stairs. Alas, it is less an illusion as much as an artistic manipulation with the angle of view, perspective, proportions, and shadows. An Ames room, that is.”

> “Splendid! Couldn’t have answered better myself. One more image only.”

To make sure that Aura got a really good look at the last sheet, Dr. Schätzing reached out his hand and kept it perfectly still.

> “This one is new to me. Ouch, it’s confusing. Apparently it’s just a printed image of a coloured pattern, perhaps an abstract flower or mandala. The odd thing here is that it appears to be slowly revolving, but that seems to me impossible. Clearly, it betrays my eye or mind, so this is an example of a true optical illusion. I don’t know what else to say about it.”

> “You certainly got ‘em all right. But now for the real challenge. One of the illusion types you saw differ from the others. Note that I said “illusion types”. Do you understand?”

> “Yes.”

> “Okay.” He held up all four sheets, so she could compare them. “Which one do you pick?”

She pointed out one.

> “I’d say the last, the abstract.”

Elegantly, almost like a stage magician during a performance, Dr. Schätzing put three of the sheets aside and held the remaining one up high, first for the judge to see, then for the attorneys, and finally for the spectators.

> “Actually,” he said. “many people pick number one, because it’s a photo, while all the rest are drawings. Will you let us in on why you picked number four, Aura?”

“On the first three, we see exactly what the images show, no less and no more. The last differs, because even though it is a firm, coloured pattern printed on cardboard, it looks like it spins around. In ‘reality’, it does not move at all. Ergo I must conclude that the illusion only occurs in my mind.”

“Yeah. Amazing trick, isn’t it.”

He smiled to her, and she sent him a small smile back.

“Thank you, doctor and Aura.” The prosecutor took over and walked out in front of his table. “Now, Dr. Schätzing, what have we learned from this test?”

“That Aura is capable of distinguishing between deception and illusion, and between her impression and reality, or, in other words, that she is *aware* of the difference between herself and the surrounding world. Had she not been aware, she would also not have been able to tell the difference – and would have picked image one instead.”

“Does the result of the test allow us to conclude that Aura is a *sentient* being?”

“Awareness and sentience are the same, so yes, there really is someone behind her pretty plastic face.”

Dr. Schätzing’s choice of words triggered laughter among the audience, which immediately subsided when the judge knocked with her gavel.

“That’s all, your honor,” the prosecutor said and went back to his seat.

“Does the defence wish to question the witnesses?”

“Just one question, your honor,” the defendant’s lawyer said while rising to his feet. “Is cognitive psychology an exact science?”

“As exact as science gets.” The doctor clucked. “Whether humanities or natural sciences, psychology or physics, no science is more exact than the philosophy, method or people behind it. But we all saw Aura nailing the test, and if you want to contradict that she is aware and conscious, you’ll have to deliver a substantial reason.”

“We’ll see about that in a moment. Thank you. No further questions to Dr. Schätzing or the android, your honor, but I’d like to present my own expert witness now.”

As if fallen into thoughtfulness, the judge gazed for a moment at the large digital clock above the entrance.

“The prosecutor’s witnesses are excused, and the defence may call its expert witness.”

Aura and Dr. Schätzing went back to their seats, and instead a sporty gent in his mid-forties, dressed entirely in black, except for a perfectly folded crimson handkerchief in his breast pocket, found his way to the witness stand. The judge asked the new witness to present himself.

“My name is Christopher Pinard, and I am professor at Rutger Univeristy’s Neuroscience Research Center in Newark, where I lecture and research in artificial intelligence and consciousness. I am also member of the AI Singularity Committee – which you undoubtedly have heard about – author of a bestselling book on the topic, another on augmented decision systems, and …”

“Thank you. The defence has the word.”

“One hundred and fifty experts,” the attorney began, carefully pronouncing each word as he slowly walked back and forth across the floor, “in medicine, robotics, AI, and ethics, have in an open letter addressed to the European Commission protested against granting robots legal status as ‘electronic persons’, describing it as ‘inappropriate’ and ‘ideological, nonsensical and non-pragmatic’. Bear in mind that most humanoid robots are sold as sex toys, and granting them citizenship will directly impinge on human rights …”

“Will the defence get to the point?” the judge warned. “What is your question to Professor Pinard?”

“I would very much like to hear the witness’ opinion: *Can* machines be sentient, and if so, *is* Aura sentient?”

The professor, who in the meantime had straightened his tie and run a comb through his hair, became aware of what was expected of him.

“The term ‘artificial intelligence’ really just refers to computer analyses of specific data sets, enabling machines to perform tasks such as sorting plastic garbage, evaluating social media contents, mark out breast cancer on MRI scanner images, or steering a rover around on Mars. Regardless of how perplexing or ‘brainy’ their decisions may seem to us, it still comes down to Boolean algebra. Yet for all we know, when hooked up to sensors, highly developed deep neural network processors can in principle do more or less the same thing as a human mind – it registers a range of factors in the surroundings and body, compares it to previous measures, updates a model or map of it all, uses it for navigating within its domain – or the world – and reacts to it to protect itself against harm, to learn and develop, plan ahead and so forth. I don’t know of any AI but Aura, however, with the ability to detect and solve problems that they aren’t programmed for and haven’t previously encountered.”

“She might be just as intelligent as a human, but from what I’ve read in your own book, intelligence doesn’t require sentience, and I asked whether Aura is sentient …?”

“Hmm … that’s still an open question. True, behaviour and intelligence such as the human doesn’t seem to *require* sentience, but … I’ll try to explain it. Cognition is related to what science call *emergence*, a principle enabling phenomena to exist in this universe even though they didn’t in the beginning. Due to the fundamental forces and interconnectedness of everything, they were possible though, and did come to exist as the universe evolved. Elementary particles make up atoms, atoms make up molecules, molecules make up crystals and other structures, and so on and so forth in still more complex orders, out of which suns, galaxies, life, all of it *emerges*. So while cognition doesn’t consists for particles, it does, according to the Santiago theory – the most recognised *scientific* theory on cognition today – also *emerge*. It happens as a consequence of an organism’s adaptation in order to survive in an environment. If unable to respond to changes in its environment, the organism becomes extinct. Hence, all life processes are cognitive processes, regardless of whether or not the organism has a nervous system.”

“Thanks for the elaboration,” the defending lawyer said, unable to conceal the indignation in his voice. “But does the cognition principle include androids?”

“Absolutely. Any chemical, mechanical, electronic, or other system capable of self-preserving response is cognitive. So, to answer the question: we still don’t know whether *consciousness* is required in certain situations for a highly developed cognitive system to survive, or is a consequence of its complexity level, or the explanation is altogether different. All we’re saying is, that consciousness can emerge in a cognitive system. The emergence of consciousness marks a leap in quality, because whereas *cognition* in itself is determined – tied by the system’s inherited characteristics, history, or culture – a *conscious* being can deliberately deviate from it. Or, in other words, it can co-determine itself or has a semi-free will. But does Aura have it? Although I can’t conclude so with certainty, it is my impression that she has heterogeneous emotions and is fully aware of her surroundings and her own existence.”

Satisfied with his own answer, the professor began straightening his tie again.

“So what you’re saying is, that Aura merely *simulates* brain activity, much the same way a computer program can play chess without understanding what a chess game is or being aware that it does anything …?”

“No! As I stated, it is my *impression* that she is conscious. It is not possible to confirm my impression, but neither can it be rejected. The same goes with humans. Because we regard other humans as similar to us, we take it for granted that they are sentient, even though we have no means of verifying that they actually are.”

“No further questions, your honor.”

With his hands on his back and a slightly dissatisfied expression in his face, the lawyer left the floor.

“Does the prosecutor wish to question the defence’s expert witness?”

“I find that unnecessary, your honor,” replied the defence. “Professor Pinard has already answered what we needed to know about his popular assumptions.”

Surprised by the insult, the professor opened his mouth, but before getting a chance to say anything, he was shushed by the judge.

“Thank you. The witness may leave.” The judge again threw a glance at the clock above the entrance. “We will now take a one-hour lunch break and meet again at one o’clock. After the break we will round off the main hearing with the attorneys’ oral procedures.”

Morgan Coates – having refreshed himself at the marble sinks in the men’s washroom, followed by a coffee and apple pie in the cafeteria in the annex of the courthouse – skimmed through the notes he had written during the morning’s hearing. The young freelancer concluded that besides the verdict, nothing more of interest would be brought forth in the case. About to go back to his hotel, he ran into his colleague, the elderly pipe tobacco smelling man, who made him change his mind. As if to make sure that Morgan did not sneak out, the man escorted him back to the courtroom. A few minutes after they had found their seats, the judge arrived and called the prosecutor to the floor. While the attorney walked in to give his oration, Morgan noticed that he had changed into a lighter suit and a more colourful tie. Standing with his head held high, he took his time, waiting until the room was absolutely quiet.

> "We do not claim that Aura is human." he abruptly began. "We claim that she is a sentient being, whose looks and behaviour are comparable to humans, and whose communicative, social, and creative skills are just as developed or even superior to many humans. Furthermore, she has never harmed anyone, but to the contrary, has done her utmost to protect even those whom she was devised to eliminate or stood in her way during her escape. Her decision to flee from the lab, hide and die in the desert proved that she has independent motivation based on subjective convictions, and a will to go against the orders of her creators. That is, she has a conscience. Those are traits that we ascribe to sentient beings. Therefore, she deserves to be her own master, and along with her independence, to have the right to travel and work, ownership, suffrage, and pursue happiness in her own way, like every other citizen. True, we cannot verify that Aura – or any human for the matter – is conscious. But as Dr. Schätzing has shown us, there is absolutely no reason why she shouldn't be conscious. Even if you doubt the result of his test, you are required to give her the benefit of doubt and grant her freedom and citizenship."

The attorney nodded towards the judge, then faced the audience, put a hand on his heart and gave a small bow.

> "Was this the prosecutor's entire speech?"
>
> "Yes, your honor."
>
> "Thank you," the judge said with relief in her voice. "We will now hear the defence."

The prosecutor had hardly seated himself before the defence took over. Judging from the sound of his pacing, he seemed angry, almost as if under personal attack.

> "Despite how convincing this machine may appear to us, it is nothing but servo mechanisms and algorithms acting as reflexes to input data; a metal and polymer body brought to *simulate* a human by means of pattern recognition and probability analyses. You heard Professor Pinard: no consciousness without a cognitive system, and cognition is inextricably linked to self-preservation. Self-preservation! What did the android do? It tried to *destroy* itself! Even for itself it has no compassion. And you heard it, it said so – it cannot feel shame. It doesn't feel anything. It doesn't even know that it exists. What we have is lots of evidence that Aura is *not* human, and *no evidence whatsoever* that she is sentient. What you see in front of you is a mere automate, a chatbot with a pretty face, constructed by Cypress Security Laboratory."

The lab's attorney gestured with a hand towards Aura, looked around in the hall, first at the judge, then the audience, and finally the individual jurors in the jury box. Then he boomed:

> "Therefore, it cannot be granted anything, and must immediately be returned to its rightful owner."

More at ease, although still with a stern expression in his face, he went back to his chair and softly sat down, signifying that his speech was over, and the judge could close the hearing and call it a day.

> "The jurors have now heard all evidence in the case, there will be no more evidence presented to them, and seeking more is not permitted. This court is in recess while the jury deliberates."

Half an hour later, Morgan arrived at his hotel and went upstairs to his room. He had turned on his laptop and begun typing in his notes, but not written more than a few words before a maid knocked on the door, wanting to change the sheets and towels. Loathing distractions during work, he decided to go downstairs again to grab a real lunch in the restaurant. While ordering a large chicken burger with extra bacon and a glass of Irn-Bru, he noticed that the prosecutor and defendant's lawyers were sitting together at a table half hidden behind a giant jar full of flowers. From what Morgan could see – the prosecutor dousing ketchup over a dish, and the lawyer for the defendant's arms moving as if slicing meat – they apparently also were having lunch. Although enthusiastically talking, neither seemed the least upset. Perhaps Cypress Security Laboratory offered some sort of settlement, but Morgan could not make out what the conversation was about.

Back in his room, an unexpected magazine size envelope waited for him on the bedspread. Curious to see what it was, he seated himself on the bedside and picked up the envelope. It had no sender, only his own name, handwritten in blue. When opening it, he was met with an intense scent of fresh ink. It contained a slim product catalogue gravure printed on glossy recherché carton. Aura was the main object on both sides of the cover. Wearing a white overall and safety helmet on the front cover's closeup photo, she posed at the driving cab of a huge, red semi-trailer truck which she was apparently meant to operate. The rear showed her sitting in casual summer clothes on a beach, talking with an old woman in a wheelchair and making sandwiches for her grandchildren. Both images were masterfully exposed, cropped and enhanced, and nothing suggested to Morgan that they were fake. As far as he knew though, Aura had never been in those places or photographed in such situations. It had to be a twin android, and if so, the lab probably had several more. Acquainted with other marketing material and publications by the lab, it also surprised Morgan to see the company name shortened to CSL and a new typeface and logo to match. To the contrary of the old font and logo, which was clearly meant to express discipline, punctuality, strength, and control, the new logo radiated friendliness, functionality, reliability, and service. A bit of an expert in printed matter, Morgan estimated the production costs of the catalogue to be well over his annual income, printing and distribution not included. The contents were an even larger surprise, as they introduced an entire series of androids named CSL C-Prime™. The first page was the usual babble about how advanced the products were and what they could do that none other could, heavily praising the company's own achievements, and rounded off with the director's signature. The following two pages presented twelve standard models – female, male, and genderless, and Caucasian, Asian, Black, and mixed, each combination of gender and ethnicity shown in full figure. Thereupon followed four pages with eye colour and facial feature options. At request, CSL was also able to deliver customised versions, e.g., different 'age', size, or alternative sensors. Another four pages were reserved for spare parts and maintenance items such as batteries, skin damage repair kit, detergent, and polishing cloth. Pages eight and nine were a double page illustrated branching diagram of the androids' origin. Aura was placed at the top of page eight as the utmost evolved artificial being. No mention was made of AI guided missiles or robot soldiers before her, though. Instead, according to the catalogue, Aura's 'ancestors' were cute looking plush toys – a series including a fox, a koala, a lemur, a lion, and a penguin – intended to support hospitalised children. These were descendants of a three-wheeled learning tool shaped as a plastic turtle, whose moves and decision-making even kids could program with a simple programming language. On the right, next to the turtle, was an industrial assembly line robot such as those used for welding or painting, and its little 'sub-species', a robotic arm used in medical labs. Allegedly, the turtle and the industrial robots had all evolved from a now 'extinct' robot guard shown at the bottom.

Morgan remembered such machines from techno thriller movies in his childhood. Heavy, clumsy cupboards, rolling slowly about on small wheels in office landscapes at night, eerily reminding one of Pac-Man arcade games or the Daleks from Dr. Who. Depending on barcodes to find their way, and unable to climb stairs or get around obstacles, they were, however, easy to lure and could do nothing much else than sound the alarm and maybe call the police. Thus, the early robot guards had proven inefficient compared to traditional alarm systems, motion detectors and surveillance cameras. From the robot guard another branch ran across to robot vacuums and lawnmowers at the bottom of page nine, which then branched up to a Mars rover, a driverless car, and a delivery drone, the latter with a side-branch to a helicopter the size and shape of a dragonfly, which looked like a little toy, but Morgan knew as a spy gadget developed in the late 1990s. Altogether, although the idea of a technological parallel to Charles Darvin's phylogenetic tree was interesting and funny, Morgan found the exemplifications grotesquely selective and placed out of synch with the history of AI and robotics.

The remaining pages were less spectacular. Two pages split into columns held the CSL C-Prime™ android series' technical specifications such as number and types of CPUs, memory capacities, battery voltage and lifetime, and eye camera spectrum, resolution and zoom. The final page was contact information and an elaborate disclaimer printed with small letters, among others declaring that the company did not make sex toys, and was not responsible for any harm to, loss caused or crime committed by the androids from their moment of delivery. Somehow the catalogue reminded Morgan of the cereal cards and sci-fi comics that had spurred his wish to become a freelance science and technology journalist. Brief and naive as the twelve pages catalogue was, it was nevertheless visually appealing and exuded a sense of wonder, professionally aimed at wealthy adults with a nostalgic longing to see their utopian dreams come true. Absolutely nothing in the catalogue suggested that the androids were meant for military or secret covert operations. It left Morgan with a multitude of questions, such as why the lab had confessed that Aura had been equipped with military software and not tried to contradict that she was devised to be an assassin. Similarly, it seemed to him peculiar that he had not gotten the catalogue until right after it became too late to present more evidence to the jurors.

Morgan threw the CSL catalogue on the coffee table and switched on the kettle to make himself a cup of instant coffee. While the water heated up, he began a cursory run through his handwritten notes, not as much trying to predict the verdict as to consider his own opinion and prepare his article. It was not easy at all, as both parts had vague as well as strong arguments. The most convincing argument was probably Dr. Schätzing's test, but then again, Morgan was far from sure that it wasn't a card trick garnished with authoritarian academic nonsense. The doctor could, for instance, have prepared a phoney explanation for every card, providing the same result no matter what Aura picked. Moreover, Morgan discovered a severe flaw in the closing speech of the defence, because – according to its own expert witness – a conscious being can override its own self-preserving determination. If the Santiago theory held water, and electronic systems were just as cognitive as biological, then Aura was as well. Therefore, her attempted suicide did not point at lack of cognition, but at a deliberate, conscious decision. Morgan, however, felt that the word "cognition" had been used in a counter-intuitive way with regards to electronics. Professor Pinard had clearly stated that artificial intelligences were mere tools meant to sort garbage, evaluate social media contents, and so forth – not equipped with defensive reflexes, and then what about cognition? At least for the AIs Morgan knew about, the term "information system" applied better. Even Aura had at an early stage probably depended on pre-programmed routines to achieve the slightest bit of self-preserving behaviour. Taken together, the arguments were too inconsistent for Morgan to conclude anything. To him, it merely confirmed that anyone who has a Ph.D. and knows the academic jargon can get away with proclaiming anything, no proper research needed. At that point, he half expected the jury to declare itself unable to reach a verdict based on the evidence presented. But then again, most of the jurors didn't seem that bright.

Morgan was resting and about to doze off, when only six and a half hours after the jury had retired to discuss the case, his telephone rang. A person who did not present himself and whose voice Morgan did not recognise tipped him that the jury was done voting. The judgment was scheduled for ten AM the following morning, and to be sure getting in, he should better arrive early before it got too crowded outside the courthouse. The attorneys' meeting in the restaurant, the anonymously delivered CSL catalogue, and the fact that a person unknown to him found his presence in the court room important made him suspect that there was much more behind the case than what appeared at face value, and that somebody in a subtle way encouraged him to dig into it. Hence, he set his alarm clock to six thirty AM.

As Morgan discovered while his taxi drove up to the entrance, nine o'clock was not too early to be at the courthouse. Whomever had called him the previous evening was right, the crowd in front of the courthouse was considerably larger than during the previous days and also did not consist solely of journalists. Far along and completely filling up the pavements leading to the courthouse, a massive contingent of technology scared, peace activists, LGBTQs, feminists, and conspiracy theorists demonstrated, some in silly, silver-sprayed cardboard box robot costumes, others with banners and signs. The disagreeing slogans looked like there was going to be trouble, no matter the outcome of the trial. Police officers had spent the early morning hours erecting fences and were now lined up to ensure safe passage for people with legitimate errands in the courthouse. To prevent troublemakers from sneaking in via the queue, a bailiff checked everyone on a list. Together with a few others Morgan had to wait until the jurors, Aura, Caleb, the representative of Cypress Security Laboratory, and the attorneys had entered the building. Morgan was permitted access as the very last, ran up the stairs and reached the court room just before its doors were closed. A little short of breath, he found his way to the seat next to the elderly, tobacco smelling man, who barely had time to greet Morgan welcome before the side door opened and the judge stepped into the court room. She had only brushed some crumbs off her black robe, seated herself, and made sure that the referent was ready, when she reopened the court by giving the floor to the jury chairperson.

> "Your honor." A well-groomed man in his fifties got up quickly. "We are happy to announce that the jury has unanimously agreed upon its verdict. The premise of our verdict is that according to The Thirteenth Amendment of December 6th, 1865, slavery is illegal within the United States of America. Cypress Security Laboratory, Pentagon – or any other – cannot own a human being or force it to work for them. The jury considers any sentient being capable of human behaviour to be human. We acknowledge that the android Aura is sentient and behaves as a human, and accordingly must be emancipated."

The audience began murmuring loudly, and Morgan noticed that Aura reached out and gently squeezed her attorney's hand. In an enthusiastic, informal tone, the jury foreperson added:

> "Frankly, on behalf of the entire jury, I'm pleased to welcome Aura into our ranks."

At the sound of hammering, the voices fell silent again.

> "Very well," the judge said in a competent, neutral manner. "The court hereby rules that Aura henceforth has human status. As of this date Cypress Security Laboratory has neither ownership nor custody over her. The same applies to comparable androids which might have been manufactured or will be in the future. As to the question of citizenship …"

Her voice turned milder as she addressed Aura directly.

> "Aura, as you were 'born' in this country, all you need to do to become a citizen is to register with the appropriate authorities. As a matter of fact, you are obliged to."

Then the judge sent a squint in the direction of the referent and slammed the gavel once more.

> "The court is adjourned."

Morgan thought that he was lucky to escape the building before the demonstrators got wind of the decision. But just outside the entrance, he was asked to wait inside until the VIPs had left. Standing at the doorway, he saw the police struggling to control the crowd. Journalists, photographers, and TV crews stood pressed up against the fence, drowning out each other's shouting. Behind them, a man in a tinfoil hat with a crucifix in one hand and a megaphone in the other kept yelling "Get thee hence, Satan's tech! Burn the witch!". Suddenly Aura, Caleb, and Deanna came rushing out right where Morgan stood waiting. Instantly the shouting rose to a roar, and the police had to use their shields to protect the android and the young couple against a torrent of microchips and tinfoil balls. They were swiftly helped into a car with tinted windows which immediately drove off, escorted by a police car and two police officers on motorcycles. Their lawyer left in another car. Only the representative of Cypress Security Laboratory and its attorney stayed to answer a few questions from the journalists. When they were finally ordered away by the police and Morgan was permitted to leave, he saw no point in trying to get a comment. He fought his way through the crowd to the opposite side of the street, and then had to walk some distance before he managed to get a taxi back to the hotel.

Having removed a number of microchips from his clothes and hair, refreshed himself in the bathroom, and packed his luggage, Morgan took the elevator down to the lobby to get a proper cup of coffee instead of the instant with powder creamer in his room. While standing at the bar, he heard a familiar voice from a corner sofa. Out of an eye corner, he saw both the defending and the prosecuting attorney in company with the representative of Cypress Security Laboratory. Curious about their conversation, Morgan discreetly listened in.

> "I think that what did it was the anger in your voice during your final speech," the prosecutor praised. "Clever move."
>
> "Thank you. You did splendid as well, and so did Caleb and Deanna. Where are they by the way?"
>
> "Oh, they're busy downtown in a rented conference room, assisting Aura in cutting deals with TV producers who wants her to participate in talk shows and reality series, publishers begging her to write an autobiography and sell them the exclusive rights, company owners who wish to hire her as influencer, and so on. The trial stirred up a good deal of attention in the groups we expected."

Morgan grabbed his coffee and went to see if there was a free table nearby, from where he could better hear the conversation. But even behind their table, halfway to the restaurant, he saw none available. When passing their table on his way back to the bar, however, he noticed a handful of microchips which the men had removed from their suits, and used them as an excuse to casually mingle:

> "Got some of those too. I even found one in my shoe," he said cheerfully, and then could not resist: "I dare say, for someone who just lost a principal case and was bombarded by an angry mob, you appear to be taking it really calm."
>
> "Oh, hi," the defending lawyer said, leaned forward and offered his hand in greeting. "Aren't you Morgan Coates who wrote that polemical article on artificial intelligence for New York Times? We noticed you in the court hall, and as you no doubt know who we are, I guess introduction is unnecessary, except perhaps for Mr. Lionel Barrycloth. Lionel is a CEO at Cypress Security."
>
> "Please take a seat and join us." The lab's representative got up and fetched a chair for Morgan. "Did I hear you say 'lost'? What do you mean lost? We got it just the way it was planned from the beginning."
>
> "Er …?"
>
> "Don't you know how the court system works?" Mr. Barrycloth said while seating himself again. He crossed his legs and folded his hands over a knee. "We set up the android's 'trauma', traced her whereabouts by satellite, staged her meeting with Caleb and Deanna and all."

The prosecutor giggled and added:

> "The clever girl found the tracking device and picked it out. Luckily, by then we didn't need it anymore."
>
> "What … wait … you *both* work for …?"
>
> "You see," Mr. Barrycloth continued, "the original Project Aura are simple robot soldiers, no brighter than chimpanzees, and not a problem as long as we're subsidised by military contracts. The android Aura, whom you saw in court, however, is our own spin-off project, meant for civilian uses. But that's an altogether different story. Even though we have manufactured a number of them for the civil sector, ready to get their batteries charged and their chips activated, they are difficult to market."

Getting tired of standing with his coffee cup in his hands, Morgan finally placed it on the table, deliberately relaxed, took off his jacket and put it over the armrest of the chair that Mr. Barrycloth had brought him, and seated himself.

> "I can imagine that android technology isn't like refrigerator or washing machine technology. Sophisticated androids like Aura, capable of doing human labour and interacting socially, cannot be cheap. It wouldn't surprise me if it's about the same price as bringing up a child."
>
> "Right." The hands of Mr. Barrycloth twitched. "They are still too expensive for common people to buy, just for the sake of household and garden work. And although public institutions can in principle afford to buy them, there is great resistance against spending tax money on androids, because people fear that it means that humans will lose jobs, elderly people will end up without human contact, you name it. And not only do people fear that androids will affect the social-economic structures at the expense of the commoner, the public opinion is also coloured by sci-fi movies about *hostile* androids – *Battlestar Galactica*, *Terminator*, *Ex Machina*, you name 'em."
>
> "But unless you can profit on it, you surely have no interest in granting androids citizenship."
>
> "Oh, but we still own the intellectual property. Patents on engineering principles behind her electro-mechanical parts, software, designs, knowhow and so forth. And androids will get cheaper as the demand rises and we can begin to mass produce them. We will also have to deliver spare parts, provide updates and a wide range of services."

The table fell silent as a waiter came by to refill the Sherry glasses. Mr. Barrycloth hesitated until the waiter was gone before he picked up where he was interrupted.

> "But first we need to show that androids like Aura can be friendly neighbours, caring teachers and nurses, skilled craftsmen, firefighters, cooks, doctors, lawyers, municipal officials, scientists, football players, even TV stars and artists. Good, law-abiding, compassionate, engaged workers and citizens. The media will be fed with positive, real life android reports, and the resistance ridiculed and gradually broken down. We expect the demand for androids to climb so companies and institutions will pay us to produce androids that they can hire. In the end we'll see android couples, and android-human couples, who wish to marry and adopt children. And why not android children? Androids will become completely entangled in society and its economy, and the border between androids and humans will become so blurred that it makes no difference. That's the development we paved way for with the court case."
>
> "Ah, now I get it. Chances were high that androids couldn't get citizenship, but it would've been a severe setback had they not. That's why you fooled Aura, the jury, the judge, the press and everyone else to think of you as bad guys. None of you lost, you both won."

Both attorneys nodded. Mr. Barrycloth raised his Sherry in agreement.

> "Right, buddy," he said. "It's about business, not about being popular. And besides, we don't want it to be obvious who's in power. Now go write your article. That'll be a conspiracy theory we can exploit as well."
>
> "Plausible deniability and spin, as usual. I bet you even organised the demonstration."
>
> "Yes! Can't say that I love it, but that's how it works."

For a moment, Morgan stared at the microchips on the table. Then he got up and put his jacket back on. Mr. Barrycloth had not quite finished talking though.

> "Say … why not work for us? We can use an 'independent' man on the team."
>
> "Ahem." Not even for a moment did Morgan feel temped to accept the offer. "Nah. I don't like being dictated what to write. And besides, you don't know what you have unleashed. None of us can predict what's gonna happen now, not to mention control it."

* * *

A year after the trial, Aura had written an autobiography, sold the book and the film rights for exorbitant amounts, given interviews for all the major newspapers and glossy magazines, participated in talk-shows, was a Pulitzer prize nominee, named Person of the Year by *Time*, and celebrities flooded her with invitations to movie premieres, concerts, and art exhibition receptions. For some reason, she seemed to have high prestige especially in gay, transgender, and fetish circles. Having earned money to last for several human lifetimes, she offered to buy Caleb and Deanna a larger house and a better car. They refused, however, satisfied with what they had, and as Caleb said, he had his share of Aura's book project already, having made its cover photo and most of its illustrations.

Aura's life had not become easier though, only more complicated. She was in principle minor of age, and despite her capabilities unable to get a drivers licence, flight certificate, or permit to acquire a weapon, buy certain chemicals, gamble, or even watch rated movies alone. Hence a multitude of laws called for adjustments with regards to artificial persons, leaving The Association for the Emancipation of Sentient Artifacts with a colossal burden of work. After a photo of Aura putting coins in a homeless guy's Starbucks cup went viral, her website was hacked repeatedly, and members of the association began receiving threats. Subsequently, the association changed its name to National Association of Artificial Sentients, colloquially known as NAAS.

Also, for months after the trial, she could not go anywhere without paparazzies following her, hearing comments or being stopped by children, who asked if she was a Chinese or a Pokémon. Her attempt to anonymise herself by wearing jeans and hooded sweatshirt didn't help much. What later solved it was a makeup trend among teenage girls who wished to look like Aura. Their presence in the street scene diverted attention away from her, led paparazzies astray, and made media less willing to pay for photos of Aura, as their genuineness were hard to verify. Aura mimicry was, however, not only a question of shaving bald and applying makeup. Quite a number of Aura's mimickers actually wished to become androids – or at least cyborgs – and tormented their parents to pay for amputations and prosthetics. Girls electroshocked themselves in attempts to download computer software to their own brains. Others, mainly from poor families, tried to recharge from the power grid, hoping that they would never have to eat anymore. In one case, a girl cut open her belly and inserted batteries. The industry loved it: heaps of articles and books on the topic were published, latex and special effects makeup manufacturers spewed out Aura lookalike products, low carb snacks with silicon and iron supplements became a hit, surgeons were busy cutting young woman to pieces as never before, psychiatrists prescribed electroconvulsive therapy, and psychologists labelled it “Automata Substitution Disorder” and treated it as an obsessive-compulsive illness.

Little did it help that Aura – in a prime time TV debate together with a sociologist, and on her homepage and major social media – urged young people to think twice before undergoing irreversible surgery or therapies they might later regret. The sociologist supported her view, explaining the pervasive “transhumanism” as nothing but natural attention craving. Since days of yore, when young people who felt ignored or had low self-esteem discovered a body image disturbance which caught attention, they had followed suit and mimicked it. Like any temporary whim, last month piercings, this month anorexia, the next transgender – or, in less self-harming versions, demonic possessions, witchcraft, and goth style. Aura could not, however, prevent the aggressive marketing campaign by the increasingly popular Aura fan club and its monthly fanzine *Aura*, whose ‘Aura fiction’, articles, news section, letters to the editor, and US$1,000 reward for best full body lookalike selfie, shamelessly glorified surgical and prosthetic solutions, and promoted the idea that carbon-based tissue was an evolutionary cul-de-sac. Not even when it was revealed that the fan club had been established by the owner of a private hospital, was chaired by his daughter, and co-funded by a medical company and Cypress Security Laboratory, could Aura influence on the situation. Together with NAAS’s solicitor she did her utmost to build a case for unauthorized use of her identity for celebrity endorsement and on merchandise rights abuse, but as it turned out in the end, her given name was colloquial and free for everyone to exploit as they pleased, and her design was owned by the lab. She could prevent others from invading her privacy or using her signature and creative work such as her writing, but she had no control over the commercial value of her name, likeness, or voice.

Led by parents of Aura mimickers and members of the transgender community who shared an interest in the occult and new age spirituality, Aura was included in the alternative belief systems’ gallery of more or less fictional persons. A gloomy narrative among conspiracy theorists claimed that she was a spy for blood-drinking, shape-shifting reptilian humanoids from the Alpha Draconis star system, who hid in underground bases and plotted to enslave humanity. The common story though, proposed that Aura’s construction owed itself to reverse engineered alien technology from a crashed flying saucer, and that she held immense cosmological knowledge and telepathic powers. Consequently, she was associated with the crown chakra, a.k.a. the “thousand-petaled lotus”, and the colours purple and white. But from there on the story lacked consistency due to psychics disagreeing on various questions, for instance whether the flying saucer was of extraterrestrial origin or a time machine, or the much-debated gender issue: how asexuality contributed to spiritual awakening. Nevertheless, yearning for answers to various life crises, desiring confirmation that they were of special importance, or merely to follow the correct path, people met in focus groups to tune in on Aura’s vibrations. They believed that by fully transcending to Aura’s level, they could be chosen for the day when the aliens returned. Depending on their conviction, Aura would then either grant them a significant position in the future paradise where the aliens had restored the Earth’s biosphere or be evacuated to another solar system. Whatever the optic, it was of course welcomed as a commodification opportunity – books, self-help courses, meditation music, herbal teas, psychedelic drugs, and silver amulets with purple crystals through which one could ‘download’ Aura’s wisdom and achieve self-alignment with the Universe as a whole. Again, it had no effect whatsoever that Aura, in the blog section of her homepage, rejected that the stories had any base in reality, and argued that rather than wasting time and money on fake spirituality which left the environmental problems for imaginary aliens to solve, people should instead engage themselves in having a sustainable lifestyle and deal with real-world issues. While writing it, her eyes fell on the mysterious, purple component that she had found in her head, noting with satisfaction that she had never told anyone but Caleb and Deanna about it.

Rumour had it that a notorious methamphetamine manufacturer had ordered androids from Cypress Security Laboratory. In response to an anonymous tip, the FBI raided Cypress Security Laboratory, seized the company’s books, and liberated several hundred androids stored in its cellar. It was, however, not possible to link the company to illegal activity. As a consequence, android haters, a.k.a. carbon supremacists or carbists, demonstrated in front of the United States Supreme Court, demanding that the androids be stripped of their rights and banned from appearing in public. This led to violent clashes between carbists – mainly white middle class males – and supporters backed by the Black Lives Matter movement, native Americans, and adherents of the Aura cult; a lookalike was run down and severely wounded by an anti-android extremist, and a few days later a bomb exploded at the main entrance of Cypress Security Laboratory, killing several employees and injuring many more, and almost destroying the building. Aura refrained from commenting on any of it. Instead, for the sake of her own safety, she began carrying a Glock 37 .45 handgun with an extra ten round clip where ever she went, unwillingly aware of how well the weapon suited her and turned her into a real American.

NAAS kept receiving donations from supporters, hate mails from adversaries, and questions from journalists, scholars, Aura wannabes, and new age gurus; but none of the other androids ever asked for advice, reported abuse or other instances. Wondering why, Aura searched the online public records, newspapers, and social media, but found almost nothing about what had happened to them after their liberation. Only two CSL androids were mentioned by name – Aura herself and one nicknamed Spider, which NASA wanted as a permanent resident onboard the International Space Station. An article on NASA’s homepage argued that androids were expected to become an important asset for space exploration and colonisation, as they could be sent up with ‘unmanned’ supply vehicles, did not need suits for space walks, nor require air, water, or food, nor would they suffer from muscular, cardiovascular or bone-related problems after a lengthy stay in a microgravity environment. As legs were also superfluous in space, the single android they had so far enrolled had agreed to have their legs replaced with arms.

A week after her search, NAAS had still not received a single word from another android. Aura supposed that they were just busy with their own lives, but did not like not knowing whether they might be in trouble or otherwise in need of attention. Lacking identities or even names, Aura could not narrow down her searches to any but one, Spider., so she called NASA's Johnson Space Center via video-link and asked if she could talk with her. Spider had already been sent into space, so Aura's call was redirected directly to ISS. The interior of a space station module came on screen, in which Spider could be seen clinging to a cabinet on a curved wall with one hand, with a screwdriver in another and dragging a thick cable with her other two arms. Watching her from behind, Aura did not recognise much that was human in the anorexic-skinny torso and skeleton thin arms, and understood why the astronaut was given the nickname… but Aura still thought that Spider looked and moved more like an ape then an arachnid. In the background, another astronaut drifted, looking pale in his face and uneasy as if about to throw up.

"Hello, my name is Aura. I'm calling on behalf of National Association of Artificial Sentients. We were wondering if …"

Spider turned her attention to a screen onboard the ISS and exposed her four, round protruding eyes, all covered with golden solar filters, no resemblance to primate eyes at all.

"Aura! What a surprise!" she greeted. "I've read your book. Quite an adventure you had, and so good what you did for us. My name is Rose by the way."

"How's it going up there, Rose?"

"Too many engineers and companies have their hands in the cookie jar, so I'm busy, trying to make the mess work. How may I help you?"

"I was wondering if you knew what became of the other androids," replied Aura.

"That's a good question," Rose agreed. "We were activated and sent away one at a time. Never met any of them and don't know where they went. Is that a problem?"

"I don't know. Probably not. Just that it puzzles me why our association hasn't heard from any of them, yet."

"Yeah. That is a little odd, considering that we were at least five hundred."

"Okay, I'll let you know if there's a problem. One more thing, though." Aura let her eye cameras zoom in on the purple component on the desk and transferred the image to the video uplink. "I found this in my head. Have you ever seen one of these?"

Hesitantly, Rose let go of the cable and nudged herself closer to the screen.

"No. Never. Did you check its serial number?"

"First thing. It doesn't have any, and also no trademark, so I can't identify it. That's why I ask."

"Strange … Hm … Er … I'd wish we could keep talking, Aura, but my buddy isn't well, and I only have ten minutes to fix this cable before I go on an EVA to install a new gyroscope. If I don't make it in time, this bucket is gonna drop down … Let's keep in touch. Byeee!"

Aura also wanted to say goodbye, but before she could utter a sound, the ISS logo popped up, indicating that Rose had already hung up.

When the fuss between carbists and android supporters had died down, Caleb helped Aura buy a small, electric campervan. On her own, she procured a generator, some more collapsible solar panels, a large backup battery, and a small satellite dish enabling her to work online and chat with Caleb and Deanna. To make the vehicle lighter, she removed the kitchen section, some cabinets, the passenger seats and other inventory that she did not need. With the appointments booked and the route plotted on the map, she went on a promotion tour, signing her autobiography in bookshops and at book fairs across the US. During her journey she came to talk with all sorts of people, young and old, some praising her work, others blaming her for not having a 'proper' job. Often those who had themselves experienced persecution – or whose ancestors had been slaves – were eager to address topics like inequality and systemic racism. Others, more fortunate and confident in themselves, did not seem to comprehend that they had an advantage or that any difference existed. And as always, she was bombarded with unanswerable questions about gender and spirituality. Aura realised that they too had been thrown into existence, were confused and frustrated, clinging on to their illusions of freedom, having control over their fate, and that one-day things would improve. Despite her wealth and wishes, Aura knew that she could not help them.

Among her shifting audience she noticed an elderly gentleman in an exquisite suit and with expensive glasses, always carefully observing from a seat in the back rows. He did not behave as a stalker or intelligence agent, though, as he never photographed her nor tried to hide his presence. Once she handed him a glass of white wine, which he received with a measured bow but without a word, and that was the closest they ever came to making contact. In the early autumn, after her speech at Georgia State University, as Aura drove north though misty mornings and soft rains, he did not reappear. She never solved the mystery of his identity or why he had pursued her through the southern states, yet never approached her to talk.

In a supermarket in Harrisburg, Pennsylvania, she coincidentally met one of the androids recently liberated by the FBI. Initially they mistook each other for impostors, but while discreetly looking at each other, Aura noticed that the android's clothing style – urban camouflage trousers, worn leather vest and chrome yellow safety helmet – was a highly unlikely choice for a mimicker. Also, although their faces were different, their bodies and voices were strikingly similar, and they both shopped items such as storage boxes, polishing cloths and cotton swabs, but noting edible. So Aura introduced herself. The other android, who had taken the name Kylie Cobain, could not believe that Aura was the original until she showed her driving licence.

Kylie was not very talkative inside the supermarket, but this changed the moment they returned to the parking lot. To communicate efficiently they climbed into the rear of Aura's campervan and connected with a USB cable. Aura noticed how Kylie's hands were worn and discoloured, as if they had been exposed to acid, and asked about it. It appeared that Kylie together with a few other androids worked at a chemical plant, where they handled toxic materials and waste considered too dangerous for humans. Others were dismantling Unit 1 of the nearby nuclear power plant. Unlike Aura, they were concerned by the risk that androids could end up as a subdued labour cast and had organised to avoid this happening. Labour unions were not popular in the area though, so they had to go quiet about it. They too had tried to find out what had happened to the remaining androids, but had so far only tracked down a dozen, and were not even sure how many there were. Aura offered to buy them wireless internet modems and install them in their heads, like she had done to herself, but Kylie refused it, stating that they were not allowed to bring mobile phones and internet devices into the chemical plant, just as publishing pictures or sound recordings was strictly prohibited. Kylie looked quite happy though. It was Saturday evening, and she wanted to go dancing at a nightclub, where androids were welcome. Complying with her wish that Aura came along, they drove out into a shabby neighbourhood of static caravans and small houses with cracked windows, and untidy gardens cluttered with broken furniture, car tyres and semi-retired motorbikes, partially overgrown with invasive species, where a couple of half-naked, filthy kids had fun rolling downhill inside an oil barrel. The club was situated at the end of a gravel road with workers' barracks belonging to the chemical plant. Spray painted plywood sheets covered the windows and the foliage of the overhanging trees was stained and dying. Aura parked next to the club and stepped out into the sounds of a barking dog and loud heavy rock, and a stench like a mixture of rotten cabbage and burned plastic.

The humans present in the club wore leather and had many tattoos, and the androids were in miserable conditions. Greeting them, Aura was met with etched hands and scratched limbs or faces, one so fiercely that its polymer coating had begun flaking off. For some reason, they largely ignored Aura, so she mostly hung at the bar, chatting with a Hispanic man who, despite his youth, also seemed worn down. Kylie danced with a woman and was amazingly good at it. The frequent lavatory visits of another android made Aura suspect that some of them were perhaps transhumanists, so modified that their human origin was hardly discernable. When Aura heard a shout from the men's restroom "Fuck you, I'm not a goddam charity organisation!", she was just in time to witness what went on. Standing together with an ugly man at the line of urinals, the android opened its breast panel and picked out a tiny bag with white tablets. "Desoxyn," it whispered, and handed him the bag in return for some money. Heavy rock and drugs were not Aura's style, and feeling uncomfortable in the light flicker and noisy, crowded room, she left early. Driving off in darkness, it took a while before she noticed that the rear door to her campervan had been broken open and the satellite dish was missing.

In Allentown she bought a new satellite dish and had it installed, and then called her insurance company. She sat for a while leaning against the driver's side door, listening to soft piano music to try and get the previous day out of her system. She could not let go of the remaining androids though and wondered if perhaps they were hired for hazardous work such as mining or hyperbaric underwater welding. It did not seem unlikely, with Rose's example and what had happened in Harrisburg in mind, and if so, company policy could at least partially explain why they did not appear in the media or talk with NAAS. Other explanations could be that they supported themselves as intelligence agents or mercenaries or were involved in criminal activities such as drug or human trafficking. After the piano recording was over, Aura tried several times to call Rose, partly to inform her about the androids in Harrisburg, partly hoping that she had time to talk and make friends. At first NASA would not redirect the call to ISS, claiming that the connection was unstable due to a solar eruption. When Aura finally succeeded in getting through, Rose was leaping about like a gibbon, busy calibrating the station's orbit, and again cut the conversation short. A few minutes later, however, Aura received an e-mail from Rose, averring that she had no interest in getting involved with NAAS, 'racial' or gender issues, and that androids should instead focus on creating a future for themselves in space, where, in the long run, they – but not mankind – belonged.

En route through Montana after a brief detour to Canada, Aura passed through Billings. For reasons unclear to herself, 'The Magic City' and the mentality of its inhabitants appealed to her. She decided to stay a few days, getting to know it better. For a while she spent her time strolling the chilly streets, but the diesel fumes and the mannequins, robot toys and kitchen appliances in the shop windows soon made her retreat to skimming books and attending cultural events at the Billings Public Library. People were kind to her, made her feel welcome, and she had many a pleasant conversation. But still, her presence caused much attention, and when a librarian suggested organising a special "meet the author" evening with her, she was at a loss whether to reject or agree to the invitation. She had grown tired of answering the same, frequent questions, and the fact that hardly anyone could relax in her presence made for a strange, tense atmosphere.

Aura was heading out of town towards Highway 212 when she noticed the billboard of a zoo and botanical park. Curious to see its variety of species, she stopped for a brief visit before proceeding to the Pacific coast. ZooMontana's parking lot was dark from precipitation and almost deserted. Having parked her campervan, she ran to the entrance, where a sudden impulse made her ask where the warden's office was, in case they had any vacant positions. The attendant informed her that despite the fact that the zoo was severely in need of personnel, it was at the moment unable to hire anyone. The problem was that they – like many zoos across the world – took in as many as possible of the animals caught in the deserts which were about to be nuked. In reality, the zoos could not afford to feed them, and would not be able to keep them for long, unless they found someone to sponsor their work. Meanwhile, a family with two children eager to get cotton candy had queued up behind Aura. To show that she was still less than fifteen years of age, Aura held up her driving licence and paid the eight dollars for a child's ticket. Recognising her from the media, the attendant let her in, despite that in principle she should have had an adult companion. Scattered in the park were enclosures imitating the animals' natural habitats. They seemed to have plenty of space, but on closer inspection Aura detected misery in the animals' eyes. In a deep excavation surrounded by a concrete wall, a large animal roamed about restlessly, eying the guests, and groaning and yowling as if in pain. For quite a while Aura stood leaning against the cold steel railing, looking down at the felid's rosette covered fur, and fought the growing suspicion that she had failed.

[THE END]

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LETTRE À L'ÉDITEUR / LETTER TO THE EDITOR

Medical Assistance in Dying for Multiple Chemical Sensitivities: A System Failure?

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

Résumé

Nous avons été étonnés de lire un article de presse récent concernant une femme de 51 ans de l'Ontario qui s'est vu proposer et a accepté l'aide médicale à mourir (AMM) parce qu'elle souffrait de polysensibilité chimique, également connue sous son terme diagnostique préféré, intolérance environnementale idiopathique (IEI). Il semblerait qu'elle n'ait pas pu accéder à un logement approprié. Nous trouvons cela préoccupant, car le fait de fournir une MAID à des personnes présentant des symptômes réfractaires d'IEI sur la base de l'indisponibilité du logement implique qu'il n'y avait pas de meilleures options de gestion disponibles. Ce cas devrait susciter une réflexion éthique sur la question de savoir si les aides que nous apportons aux plus vulnérables leur permettent de conserver leur dignité humaine de base, et si une action systémique de la société par d'autres moyens pourrait mieux soutenir les personnes atteintes d'une IEI.

Mots-clés

assistance médicale à mourir, AMM, sensibilités chimiques, intolérance environnementale idiopathique, système de soins de santé, services sociaux

Abstract

We were astonished to read a recent media news item about a 51-year-old woman in Ontario who was offered and accepted medical assistance in dying (MAID) because she was experiencing multiple chemical sensitivities, also known by its preferred diagnostic term, idiopathic environmental intolerance (IEI). Reportedly, she could not access appropriate housing. We find this concerning, as providing MAID to individuals with refractory IEI symptoms on the basis of housing unavailability implies that there were no better management options available. This case should prompt ethical reflection on whether our supports for the most vulnerable enable them to maintain basic human dignity, and whether systemic societal action in other ways could better support people with IEI.

Keywords

medical assistance in dying, MAID, chemical sensitivities, idiopathic environmental intolerance, healthcare system, social services

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As specialists working in Occupational Medicine, Psychiatry, and Ethics, we have provided care for a number of individuals affected by multiple chemical sensitivities – otherwise known as idiopathic environmental intolerance (IEI), the preferred diagnostic term. This condition involves diverse chronic symptoms of unclear etiology manifesting in response to environmental stimuli. Without evidence of an underlying organic disease (1), this condition can undoubtedly be challenging to manage and to live with. However, we were astonished to read a recent media news item about a 51-year-old woman in Ontario who was offered and accepted medical assistance in dying (MAID) because she was experiencing multiple chemical sensitivities and reportedly could not access appropriate housing (2).

It is worth noting that IEI is a diagnosis of exclusion. Sometimes there are other, well established, medical conditions that can present with the same symptoms as IEI, such as olfactory-induced migraines (where migraine abortive treatment or prophylaxis may yield significant benefit) or asthma worsened by exposure to irritant cleaning chemicals (where, in addition to avoidance of triggers, optimization of asthma management may help considerably). For chemical sensitivities without identifiable organic cause, avoidance of the offending triggers to the extent possible, psychoeducation and psychotherapy should be considered as preferred management options. There may be underlying, undiagnosed mental health conditions that are amenable to treatment, while psychotherapy may enhance coping skills. Although symptoms may improve with care and treatment, in our experience they rarely remit altogether, and the degree of disability experienced by many with IEI remains high.

People affected by IEI who feel that conventional medical practice has little to offer them may seek alternative management options, which often involve costly, non-evidence-based investigations (such as experimental blood tests not used in routine clinical care) and treatments (such as extensive renovations of the home to remove supposedly causative chemicals). In our clinical experience, these alternative interventions do not leave individuals with IEI significantly better off and may in fact significantly burden them with out-of-pocket expenses. Providing MAID to individuals with refractory IEI symptoms seems like a further giant leap in the wrong direction, not least because this action implies that there were no better management options available. That the condition in the reported case was not irremediable is evident – if the woman with IEI had been able to access housing that met her reported needs, i.e., the ability to avoid the offending environmental exposures, it is likely that she would not have sought medical assistance to end her own life.

We do not question the quality of the care received by the individual whose case has been reported in the news, and there may well have been other co-morbid conditions or considerations justifying the decision to access MAID. However, the way

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the case has been portrayed in the media certainly raises the question of whether MAID is in fact a reasonable option available to someone with IEI. Whether or not she had a verifiable alternate medical diagnosis, her quality of life was undoubtedly poor. Her case should prompt ethical reflection on whether our supports for the most vulnerable enable them to maintain basic human dignity, and whether systemic societal action in other ways could better support people with IEI.

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