

The Harms of Imagining the Ideal

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Volume 7, numéro 1, 2024

Dialogue with Future Bioethicists
Dialogue avec la prochaine génération en bioéthique

URI : <https://id.erudit.org/iderudit/1110331ar>

DOI : <https://doi.org/10.7202/1110331ar>

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Éditeur(s)

Programmes de bioéthique, École de santé publique de l'Université de Montréal

ISSN

2561-4665 (numérique)

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Citer ce document

Chen, S. S. (2024). The Harms of Imagining the Ideal. *Canadian Journal of Bioethics / Revue canadienne de bioéthique*, 7(1), 50–51.
<https://doi.org/10.7202/1110331ar>

Résumé de l'article

Dans cette réponse au commentaire « Disabling Bioethics Futures », je soutiens l'argument de l'auteur selon lequel la théorie et la pédagogie de la bioéthique devraient être recadrées pour mieux intégrer les perspectives des personnes handicapées. Plus précisément, je soutiens qu'il ne s'agit pas seulement d'un défaut pédagogique, mais d'un préjudice actif lorsque la pédagogie de la bioéthique préserve des points de vue irrespectueux ou discriminatoires en utilisant une littérature obsolète.

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RÉPONSE À - TÉMOIGNAGE / RESPONSE TO - PERSPECTIVE

The Harms of Imagining the Ideal

Stacy S. Chen^a

Texte discuté/Text discussed: C Dalrymple-Fraser. [Disabling bioethics futures](#). *Can J Bioeth/Rev Can Bioeth.* 2024;7(1):12-15

Résumé

Dans cette réponse au commentaire « Disabling Bioethics Futures », je soutiens l'argument de l'auteur selon lequel la théorie et la pédagogie de la bioéthique devraient être recadrées pour mieux intégrer les perspectives des personnes handicapées. Plus précisément, je soutiens qu'il ne s'agit pas seulement d'un défaut pédagogique, mais d'un préjudice actif lorsque la pédagogie de la bioéthique préserve des points de vue irrespectueux ou discriminatoires en utilisant une littérature obsolète.

Mots-clés

handicap, bioéthique, pédagogie, inclusion, représentation, théorie de l'idéal

Abstract

In this response to the commentary "Disabling Bioethics Futures", I offer support for the author's argument that bioethics theory and pedagogy ought to be reframed to better incorporate the perspectives of disabled persons. Specifically, I argue that it is not only a pedagogical flaw but an active harm when bioethics pedagogy preserves disrespectful or discriminatory views by using outdated literature.

Keywords

disability, bioethics, pedagogy, inclusivity, representation, ideal theory

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No one should feel that they must argue for their right to exist. As the scope of the spotlighted issues in bioethics expands to illuminate questions and perspectives that have been previously discounted or dismissed, an issue that bioethics as a field must confront is how to teach students about emerging questions and how to facilitate discussions that are respectful and inclusive. Compellingly elucidated in the commentary piece "Disabling Bioethics Futures" (1) is the argument that the complexities and nuances of disability in bioethics deserve more fulsome and representative consideration and respect. In their commentary, the author asks what it would mean to explore disability futures in an academic arena that either a) reduces disability to a factor to be accounted for in determining moral status and personhood, b) uses disability as a metric for calculations of which lives ought to be prioritised, or c) treats disability as a hurdle to be overcome by medical or political means.

A section of the commentary that struck me personally was the discussion around facilitating disability representation in bioethics programs. Specifically, the continued use of outdated literature that has the potential to contain language and arguments ranging from inflammatory to harmful. As the author notes in their commentary, engaging with such literature can exacerbate and compound existing discrimination, disadvantage, and oppression resulting from other intersectional identities. A point of further reflection I want to explore is how pedagogical choices can preserve dominant perspectives in ways that result in harm.

Academic bioethics environments can represent a very specific sociopolitical lens through which theorems and views are filtered. We can learn ways to reflect on this fact from feminist philosophers of science who have demonstrated that the research projects that scientists undertake and the questions they deem worthy of pursuit inherently encode individual and collective biases and perspectives of their researchers (2). Bioethics is no different. Our widely accepted norms, standards, theorems, and principles often appeal to an "ideal theory" that is only accessible to a few: for example, the common presentation of autonomy as focused on the individual, which fails to acknowledge relational facets of autonomy that are more significant in some non-Western cultures and traditions, or how care and vulnerabilities intersect with autonomy in the case of persons who are dependent on others for care (3). When presented with antiquated or outdated literature in a classroom, students who belong to disadvantaged groups (such as disabled students) are implicitly or explicitly asked to view these arguments and sentiments 'objectively'. They are effectively told to leave aside their disadvantages for the moment to consider arguments from the viewpoint of the 'ideal' theorist. But that is or may not be possible for persons who are directly affected by that issue. It is patronising to ask persons to put aside their distress in the face of literature that argues against their existence, by implicitly expecting argumentation from the perspective of such ideal theories to be the default in the bioethics classroom. Furthermore, asking students from marginalised groups to contemplate outdated bioethical arguments that treat their group disrespectfully – or even advocate against them – as part of a so-called intellectual exercise is an active harm on two counts.

The experience is harmful because the affected person must expend emotional and mental energy during and following the incident. When affected in this way, one continues to think about it after it happens – there is an emotional and mental cost of processing the experience; time and energy spent figuring out why it felt wrong and processing one's emotional response (4).

The situation also places the affected person in a difficult position, wherein they must choose between predetermined options, neither of which alleviates their emotional or mental disquiet (5). Either they must act grateful or at least congenial to have been included in the discussion, albeit in this unsatisfying way; or they might speak up, but then must risk being perceived as unreasonable or dramatic and potentially be labelled as a person who makes the learning process “overly complicated” for everyone else (4,5). Thus, for disadvantaged students to be put into this position, owing to a pedagogical choice, is to be forced to sit in discomfort for the sake of other people, and thus accept further oppression in and of itself.

Bioethics is a relatively young and quickly developing field. Looking towards the future requires questioning whether prevailing theoretical and pedagogical norms might be representative of only a few and so harmful to others because, at best, they exclude certain narratives or experiences (such as those of disabled persons) or at worst argue against the rights of certain persons to exist. To be more respectful and inclusive, a concerted effort is required to overcome the inertia of relying on existing theory – just because a theory is established does not guarantee its continuing value or pertinence – and start generating theories that encompass more perspectives and describe more experiences. Building greater inclusivity and representation in academic bioethics, and in our classrooms, will require turning over a new leaf in our literature.

Reçu/Received: 17/07/2023

Conflits d'intérêts

Aucun à déclarer

Publié/Published: 18/03/2024

Conflicts of Interest

None to declare

Édition/Editors: Aliya Affdal

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