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Advocates, Activists, Architects of Moral Space?

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ÉDITORIAL / EDITORIAL

Reclaiming Moral Space in Contemporary Bioethics

Ann Munro Heesters^{a,b}, Jason T. Eberl^c

Mots-clés

bioéthique, bioéthiciens, plaidoyer, activiste, menaces, espace moral bioethics, bioethicists, advocacy, activist, threats, moral space

Keywords

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Several months ago, in response to an unprecedented breakdown in relations between the governments of the United States and Canada, we distributed a call for papers designed to rally members of the bioethics community to help us make sense of the role of bioethicists in these challenging geopolitical times. Little did we know that, many months later, there would be an imposition of further tariffs, unimaginable cuts to biomedical research and public health initiatives as well as research and clinical ethics programs, increasingly bellicose expressions of American and Canadian nationalism, or that interactions between friends, families, and colleagues would continue to be strained despite the profound need and desire that most of us have for comity with our cross-border (literal and metaphorical) cousins.¹

The title of this special issue, “Advocates, Activists, Architects of Moral Space?” was framed as a question because we recognized that our understanding of the nature of our work as bioethicists, and efforts to answer questions about our purpose — whether in the clinical, educational, or wider societal context — would be enriched by encouraging contributions representing a broad range of perspectives. Although we had a sense that almost no one among our confreres would deny that bioethicists have an important role to play in elucidating the justice-related and other ethical concerns arising in the context of our professional practices, we appreciated the contributors’ various calls to think more expansively about bioethicists’ professional mandate and methodologies.

We also had an instinct that our strength would lie in resisting the forces that threaten to divide and weaken our discipline — and we were not disappointed by the vigour of the responses that made this point clearly. The sorts of advocacy or activism that our contributors recommend offer hope for a renewed bioethics that appreciates the prophetic power of the educator, the wisdom that can come from a more porous conception of the client/ethicist/advocate boundary, and the strength that can be found in a willingness to reflect humbly and generously on the identities and values that have so often been derided in shrill partisan debates. These papers have drawn us into conversations that bolster our conviction that there are fragile moral spaces that we share — regardless of our national, political, or professional identities — and must fight to protect.

This issue contains papers that challenge and inspire us. The authors are recent graduates of bioethics programs, those in the early and mid-points of their careers, and well-established leaders of the field. Salem (2) and Stevens & Bartolotto (3) question the authenticity and accuracy of the stories with which we comfort ourselves. Ray & Olmos Perez (4) defiantly announce that they will not “shut up and dribble”. Boerstler et al. (5), Carter et al. (6) and Swana & Shah (7) contend that we must continue to diversify bioethics itself by embracing positionality and centring marginalized voices within a culture of epistemic humility. Wightman (8) calls for a “revolutionary” conceptualization of our field, while de Bie et al. (9) emphasize cultivating methods of “peer support” and Hanson (10) advocates fostering “solidarity” with our members who represent marginalized identities. Kuczewski (11) offers a vision of the educational aspect of our work that manages to be both familiar and liberatory.

Finally, in a paper entitled “Fair Trade,” Joseph Fins (12) provides us with ample reason to celebrate the disciplinary diversity of our field. By drawing on the lengthy and intimate history of US-Canada exchanges and relationships, Fins casts an historical eye on the benefits of cross-border collaboration and thereby makes us question what we think we know about the origins and identities of our forebearers. Our hope is that each of these papers will make readers think about what we get right, collectively speaking, where we have ample room for improvement, and how we might fulfill the promise of the social movements that spurred the creation of our field (13). By listening to one another and taking heed of those who challenge us to show leadership and courage, we have a unique opportunity to restore or rebuild our dwelling place. This feels like a project worth doing (together), even as we struggle to hear and be heard above the din of those who threaten to burn down the house of bioethics.

¹ A recent poll showed that nearly 18% of Canadians cited US-Canada relations as their greatest concern presently (1).

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TÉMOIGNAGE / PERSPECTIVE

The Silent Message We Send to Future Bioethicists

Nada Salem^a

Résumé

De nombreux bioéthiciens ne considèrent pas que l'engagement fasse partie de leur rôle, malgré les effets considérables du climat sociopolitique actuel sur les soins de santé et la recherche en santé. En tant qu'étudiante canadienne graduée aux États-Unis, je réfléchis à l'expérience unique que représente l'étude de la bioéthique à une époque où le financement de la recherche en santé est en déclin et où la culture de la répression académique domine. Je discute des leçons passives que les étudiants tirent des actions (ou de l'absence d'actions) des bioéthiciens, et explique pourquoi le fait d'exprimer notre solidarité avec d'autres groupes touchés peut renforcer notre communauté universitaire, en donnant des exemples de ce à quoi peuvent ressembler ces efforts de défense des droits.

Mots-clés

éducation, mentorat, engagement en bioéthique

Abstract

Many bioethicists do not consider advocacy to be part of their role despite the longstanding relationship between health research and the sociopolitical forces that shape it. As a Canadian graduate student in the United States, I reflect on the unique experience of studying bioethics at a time of declining funding in health research and a dominating culture of academic suppression. I discuss the passive lessons that students are learning from the actions (or lack thereof) of bioethicists, and why expressing solidarity with other affected groups can strengthen our academic community, pointing to examples of what these advocacy efforts can look like.

Keywords

education, mentorship, bioethics advocacy

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INTRODUCTION

I am a Canadian graduate student who studied bioethics at Harvard, an institution that is renowned for the worldwide talent it attracts and, at the time of writing, is at risk of losing the ability to host an entire population of international students like me. I am a person of colour. I am a woman. I am an academic. All of these are layers of identities that are affected in various ways by the policies of the current administration. As *Harvard v. USA* battles it out in the courtroom, international students are caught in limbo, living in fear that they will have to pack up and leave tomorrow.

Many have spoken about the state of science and research funding and its ripple effects on local and global health. Instead, what I want to share here is my perspective as an early-career bioethicist figuring out my limits in a field that is still negotiating its role in the world. I hope this perspective can illuminate a few reasons why the advocacy efforts, or lack thereof, that bioethicists undertake today will influence who chooses to join this field in the years to come.

My observation, just a few months into the declining support for science, medicine, and academia at large, is that advocacy is not field-specific. The loudest voices have come from individuals, from political scientists to health practitioners, who dared to publicly question policy decisions. Others have taken a different route — scrubbing research grants of specific words, changing the names of whole departments, and switching gears to focus on 'safe' research as they ride out the current climate of uncertainty. When academies do, on occasion, take a public stance, it sometimes feels performative rather than substantive. Take, for instance, public statements defending university ideals, in contrast with actions taken to shut down or rebrand programs and research agendas (1).

Both approaches to dealing with the political challenges of today have their risks and benefits. Applied ethics is a practice that blends moral philosophy with risk analysis. We are taught to weigh the risks and benefits and look for the unintended consequences. If putting one's research at risk hurts more people than it helps, then advocacy may seem a liability. It is certainly easier to be an advocate when one does not have a department to run and grants to secure. That is why the youth, with less to lose, have historically been the loudest voices in movements for change. A study by Pacia et al. shows that the trend continues today, with early-career ethicists across Canada and the US being more likely than their senior colleagues to support social justice work in bioethics (2).

Bringing advocacy into higher stake scenarios, however, makes it all the more meaningful and effective. It signals to students and staff that each of us matter, regardless of the identities we cannot hide and the thoughts and ideas that we are now encouraged to bury inside. Yet in spite of bioethicists' perceived commitment to justice, they have not been the most active group speaking truth to power. An earlier CJB perspective tackled a similar conundrum by attempting to explain "why philosophers aren't better people" (3). Dwyer describes his experience in bioethics in the following reflection:

I was surprised to find that they were not better people. It's not that these philosophers were bad people; it's just that they were not any better (or worse) than the biologists and sociologists that I met. [...] We all need to respond to misfortunes and difficulties: illness, death, insults, criticisms, splashes of water, and whatever happens in daily and political life. Philosophy should train us to respond in better ways (p.175-76).

PROTECTING BIOETHICS AND THE BIOETHICIST

It is my personal conviction that bioethics, in an applied or practical sense, is uniquely positioned for advocacy — its practitioners are experts on how to navigate the moral challenges affecting the healthcare community. Other bioethicists may choose not to partake in social justice movements in order to maintain a certain perception of objectivity, neutrality, and non-partisanship. However, some have rejected this choice between advocacy and objectivity as a false dichotomy, arguing that knowledge cannot be separated from the sociopolitical context in which it is produced and that it inevitably reflects the values and interests of its makers (4). Embracing "strong objectivity," as coined by feminist epistemologist Sandra Harding, allows us to bring the many influences behind knowledge production to the surface, and acknowledges the power structures that elevate some viewpoints above others (5).

There are many ways that the current climate of academic suppression weakens discourse in bioethics. Bioethics, as a field, prides itself on pluralistic problem-solving. When we stand by and make it okay to exclude different ideas from our spaces, we normalize an environment that undermines the field's capacity for moral pluralism. We send a message that only specific viewpoints and specific people are welcome; and so naturally, some people will stay away from these spaces. For those who see bioethics as a purely academic endeavour, advocacy and civic engagement in these times is still necessary to protect the academic freedom needed for strong objectivity and to protect the voices and viewpoints at risk of being silenced by intensifying power structures.

Without the capacity to explore different ideas and ask difficult questions, we may begin to undermine the core mission of bioethics and its ability to be a convening space for conflicting ideas. By disengaging from advocacy, bioethicists send the message that we will not stand up for each other, in our bioethics community, with the same resolve we bring to our ethical commitments towards those we serve in clinical care, public health, and beyond. Further still, the lesson young bioethicists are learning is loud and clear: When it comes to injustice, our role is to observe it, occasionally call it out, but almost never to act on righting the wrongs.

And yet, who else is better positioned than bioethicists and moral philosophers to speak up about a moral crisis?

The COVID-19 pandemic called on health professionals to work on the frontlines at the risk of their own health and well-being. This was the job and the mission they signed up for. Maybe today's fight against injustice should be our version of this calling. When human dignity is under attack, and the ethical principles we hold near and dear are violated, it is our turn to rise up to address the challenges that we signed up for.

WHERE TO BEGIN AGAIN AS HISTORY REPEATS ITSELF

Canadians should remember that these are not issues constrained to the US. Canada faced its own anti-science era over a decade ago under a federal government that was systematically sidelining science, slashing grants, and suppressing researchers. The moment called upon Canadian researchers to adopt a spirit of activism and work together to protect public science from political interference, leading to tangible outcomes that formalized scientific integrity in federal policies and mandates (6). As we watch some of this history repeat itself south of the border, we can learn from the lessons of Canadian scientist-activists who came before us on how to react in the face of an anti-science agenda and safeguard our ability to pursue scientific objectives free of undue influence.

Protecting the field of bioethics requires that we embrace the moral courage to translate abstract inquiry about moral conduct into action. This work can start small, by supporting and amplifying the efforts of advocacy groups, like the ongoing campaigns by the Union of Concerned Scientists (7) and Stand Up for Science (8), and by lending our voices and expertise to the many scientists and physicians pushing to safeguard our collective academic freedom. It can also start in the classroom, by affirming to students from all walks of life that they still belong in these spaces even when the news and the leadership tell them otherwise.

What I remember most from graduation was not the thousands of grinning faces under a sea of black caps, nor the moment that I finally received my degree. It was the few professors who joined the ceremonial procession wearing circular badges that read, "Without our international students, Harvard is not Harvard". Years later, when I look back on my graduate education, the mentors who stood up for me are the ones I will always remember.

Bioethicists, look around you — at patients whose health is on the line, at students who you lecture on virtues of moral courage, at the integrity of a field that is inseparable from a history rooted in social justice. Students like me are looking at mentors like you for guidance on how to act in these trying times in order to uphold the principles that we have learned are so integral to the work of bioethics. Many of us are still waiting for you to lead by example.

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TÉMOIGNAGE / PERSPECTIVE

A Broader “Call to Action”: Returning to Advocacy as a Core Mission of Bioethics

Ian Stevens^{a,b}, Claire Bortolotto^{c,d}

Résumé

Les événements politiques récents, tels que l'appel lancé par l'administration Trump en faveur de la suppression des initiatives en matière de diversité, d'équité et d'inclusion, continuent de saper les progrès marginaux que le domaine de la bioéthique a cherché à réaliser au cours des dernières décennies. Dans un contexte mondial marqué par la montée du nationalisme et de la rhétorique d'extrême droite, de nombreux bioéthiciens basés aux États-Unis sont contraints de trouver leurs marques dans un environnement politique qui évolue largement à l'opposé de leurs valeurs personnelles et professionnelles. Cependant, certains bioéthiciens sont confrontés depuis longtemps à cette situation, restant exclus des discours bioéthiques dominants, et dont l'expertise doit être plus que jamais mise à profit. Dans cet article, nous soulignons le rôle central que le plaidoyer a joué et devrait jouer en bioéthique, comme le démontrent les travaux actuels des bioéthiciens marginalisés. Pour revenir efficacement à la défense des droits comme mission fondamentale de la bioéthique et pour mobiliser les actions de défense contre les injustices causées par les courants politiques actuels, nous soutenons que les efforts de collaboration nécessitent l'engagement sans réserve de toutes les parties plutôt que de permettre leur fonctionnement cloisonné en dehors des paradigmes dominants, privilégiés, occidentaux et exclusifs qui ont historiquement dominé le domaine. Si cela peut être réalisé, nous pensons que la bioéthique s'assurera un avenir durable, indépendamment des adversaires gouvernementaux ou des structures de pouvoir auxquels elle pourrait être confrontée.

Mots-clés

plaidoyer, bioéthiciens, marginalisés, injustice, EDI

Abstract

Recent political events, such as the Trump administration's call for the removal of Diversity, Equity, and Inclusion initiatives, continue to undermine the marginal gains that the field of bioethics has sought to make in recent decades. Amidst growing nationalistic, far-right rhetoric worldwide, many bioethicists based in the United States are being pressed to find their footing in a political environment evolving largely in opposition to their personal and professional values. However, there are pockets of bioethicists who have long faced these circumstances, remaining excluded from mainstream bioethical discourse, and whose expertise must be embraced now more than ever. In this commentary, we highlight the central role advocacy has had and should play in bioethics, as demonstrated by the ongoing work of marginalized bioethicists. To effectively return to advocacy as a core mission of bioethics, and to mobilize acts of advocacy against injustices brought about by political tides, we argue that collaborative efforts require whole-heartedly engaging *all* parties rather than allowing their siloed operation outside the mainstream, privileged, Western, and exclusionary paradigms that have historically dominated the field. If this can be achieved, we believe that bioethics will secure an enduring future irrespective of any governmental adversaries or power structures that it may face.

Keywords

advocacy, bioethicists, marginalized, injustice, DEI

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INTRODUCTION

We are two early-career bioethicists who are worried about the future of the field. While we are certainly appalled by the political climate of misplaced power, control, and influence that is evolving in the United States (1) and how this may affect the practice of bioethics, our motivation to write this perspective is also driven by the sudden “call to action” (2) for interprofessional collaboration in response to bioethics’ most privileged members — most often identifying with white, cisgender, and/or heteronormative groups — now feeling the sting of political alienation.

As relatively new members of the community, we have become disheartened by how the evolution of bioethics has effectively carved out the act of advocacy from its mainstream practice. Instead, most advocacy takes place within groups of marginalized bioethicists, including those from the Global South, who continue to fight for inclusion and justice through their practice. Despite the outstanding quality of work generated by these groups¹, they are less likely to enjoy the same “bioethical legitimacy” — that is, widespread recognition and/or institutional adoption — as some of the field’s more privileged members, who have instead upheld and contributed to long-standing Western philosophical traditions that often parallel neocolonial paradigms. One can imagine how bioethicists who don’t embrace these traditions can implicitly become “outsiders” to the discussion, given how knowledge generated in Western practices continue to dominate mainstream ways of knowing.

¹ We wish to note that we too are members of these privileged groups. We do so to highlight the inherent limits to our perspective, to convey our intention to use this privilege to foster a more inclusive community of practice and to encourage those in similar positions to do the same.

Moving forward, we feel that to become effective advocates, mainstream bioethicists must learn from these groups and place their expertise at the forefront of the field's work. While there are indeed calls to do so across institutions, these efforts often fall short of meaningful change in the long run, instead becoming exercises of tokenism and diversity washing. However, we believe that current political tides, albeit alarming, provide an impetus for such a shift insofar as they remind the community that "bioethics has an inescapable activist element because ethics itself is partisan, in the sense that it always entails a move toward the normative" (3).² If this can be achieved through actionable initiatives, then ironically, in its attempts to quash ideological opposition, actions on behalf of emerging far-right political powers could end up facilitating the reworking of bioethics to render it stronger than it was before.

THE ADVOCATIONAL IMPERATIVE

While we propose that advocacy sits at the heart of bioethics, we must first acknowledge the waves of debate regarding its role that have occurred over the past 50 years (5). To begin, we must highlight positions on advocacy that we reject. For instance, some have argued for a style of advocacy that is inherently separate from the "legitimate" institutional roles in which bioethicists find themselves. They call for a "clear boundary between academic analysis and political engagement" so that bioethics as an academic field does not risk "losing its authority, primarily with governments and regulators, but also with other members of the academy and wider society" (6). They have described it as a "non-political and dispassionate stance in bioethics" (6).

We also resist the tendency to associate advocacy with lesser forms of, or the suspension of, reason. Those who are inspired to participate with communities or activist groups reportedly must then avoid said groups, to avoid limiting their views on the situation. A bioethicist's strong interest in seeking out justice for vulnerable populations purportedly makes it "difficult then to subject 'the underdogs' truth' to the same rigorous examination that would be applied in other contexts" (7). Such a bioethicist may also "just lack the courage to challenge what they privately consider to be their collaborators' wrong-headedness" (7).

These lines of reasoning, seeking the demarcation of professional practice from advocacy, are of particular concern, especially in consideration of the "epistemic ignorance" that bioethics has historically endorsed (8). Indeed, despite efforts to make "itself useful to medicine and science, bioethics has failed to maintain sufficient independence and distance [from academic institutions of the Global North] to consistently fulfil its critical, corrective role" (9). Because while formally embedding bioethics in these faculties can be beneficial for enacting change, the field's fundamental failure to address disagreements about bioethicists' role as advocates — and the ignorance surrounding the duties of this role — has inadvertently led to the perpetuation, rather than alleviation of injustices.

Given the engagement that bioethics has with normative concepts like justice, owing to its conceptual roots in the post-World War II and civil rights movements, there is a clear imperative for bioethicists to act in an advocationnal manner (10). Understandably, some of those familiar with the field feel they "don't know how we justify the claim that bioethics is not political or politically engaged" (5). Similarly, others have highlighted that when medical professionals engage in normative discussions, as opposed to empirical ones, "they are engaged in advocacy in a manner that is not ethically distinct from what a disability or patient advocacy group might do on behalf of its constituency" (11). Exactly where, and how, bioethicists should engage in advocacy is open to debate, as some recommend it for "achieving and reinforcing concrete change at the institutional level" (12), while others caution that some of "the norms and venues of rational discourse, as it has traditionally been practiced, may disproportionately serve the interests of the powerful" (9). As such, bioethicists must be acutely aware of the contexts within which they operate.

As Lisa Parker highlighted back in 2007, "most bioethicists are quite comfortable — materially and socially — within the admittedly nonideal political structures of the United States", revealing the privilege of many bioethicists who, in acknowledging the imperfect nature of the political structures with which they interact, also recognize they may not be directly affected by them (9). Of course, a lot has changed since 2007; the nonideal political structures of the United States, among many others across the globe, have become much worse. Now, even the "quite comfortable" lifestyles of bioethicists are under threat, as it seems that despite the field's habit of collaborating "less with the truly vulnerable than with those in power" (9), it's still feeling the sting of ostracization amidst today's sociopolitical climate. And with this sting, we hope, comes a wakeup call. We posit that instead of trying to find a way back into these settings by "compromising our ideals" (13), as bioethicists, we should acknowledge that we never fully belonged there in the first place. More specifically, we believe that bioethicists must recentre advocacy in their roles, so as to enhance their ability to address injustices stemming from ever-changing political structures, rather than conforming to the structures themselves.

RECENTRING ADVOCACY

Our argument for recentring a mission of advocacy in bioethics was inspired in part by the call for contributions made by the Canadian Journal of Bioethics ("CJB") which sought to promote discussion on the role that scholars from Canada and the United States embody as "Advocates, Activists, [and/or] Architects of Moral Space" (2). Although the CJB's call for cross-

² Although we will use them synonymously here, we fully recognize that there are nuances between 'advocacy' and 'activism' that are beyond the scope of this text (4).

border collaboration between Canadian and American bioethicists in response to the Trump administration's recent mandates is well-intentioned, we worry that it fails to recognize all groups who should be included, if they wish to participate, in the discussion (14). However, this subtle tone of exclusivity is nothing new to the field of bioethics, suggesting that, beyond banding together to mobilize the practice against oppressive political structures, we must rebel "against the status quo in bioethics" and to seek a reworking of the practice as it stands (9,15).

We might first consider the redistribution of the previously mentioned "epistemic power" by giving weight to the perspectives of those with the most experience in the pursuit of justice; that is, those who, arguably, will bear the greatest impact of the ideological momentum being gained by far-right political structures (8,16). In doing so, we must discontinue the prioritization of Western values in bioethical discourse in ignorance of the plethora of alternative frameworks available (15). For example, the widely used "Four principles" remain a core pillar of the practice, and while the principles are marketed as a one-size-fits-all approach, their design is inherently grounded in Western belief systems (17). Traditional notions of autonomy, namely, remain a cornerstone of Western bioethics, marked by the presumptive priority of individual rights above competing interests built upon the "individual endeavor historically native to, and the vanguard of, European men" (18,19).

More recently, mainstream bioethical paradigms have been challenged, as many have come to recognize their incompatibility with communities across the globe (20). We might understand the inherent limitations baked into the individualistic notions of autonomy, for instance, with Feminist or Indigenous perspectives that consider autonomy as a relational construct based on one's connection to factors such as their community, sociopolitical structures and the natural environment (17,21-23). And indeed, these challenges are warranted, as when narrow ideological imperatives are imposed on groups with differing values, we observe what has been described by some as a sort of "moral imperialism" (17,18). Such a stance comes from an "epistemological arrogance, supported by economic and political power and animated by the idea that the dominant systems of knowledge...are superior to those of other cultures and, therefore, have universal validity" (24). Moreover, this sort of moral imperialism is not unique to the field of bioethics but is reflected in numerous ideologies monopolized by privileged groups, which have historically led to problematic social movements and consequential injustices.³ Redistributing epistemic power in bioethics, then, means reducing the influence of mainstream ideologies and instead incorporating the variety of bioethical frameworks being drafted by communities across the globe, and for this work to be integrated into a much more intentional course correction of the field's priorities.

We must also confront the exclusivity of the field of bioethics, as simply becoming a bioethicist can require enrolling in or engaging with some of the most elite academic establishments in the world, essentially to be trained — ironically — in how to be more inclusive. Consider how "Global Health" programs are distributed internationally (25). For instance, a recent survey revealed that many American bioethicists come from backgrounds of families with higher education, which are generally whiter, more liberal, and less religious than the overall population, further revealing how and why dominant perspectives in the field are associated with specific demographics (26). And so, instead of just "getting our house in order" as Jecker et al. (10) suggest, in order to incorporate "greater diversity within our own ranks", we call for a more comprehensive remodeling of the estate to support effectively those facing greater structural barriers in the pursuit of a career, or simply voice, in bioethics.

Despite the uphill battles they face, bioethicists belonging to marginalized communities have continued to generate scholarship, hold conferences, and publish work on reconstructing the problematic pillars on which the field is built (27). We question, in the name of becoming a stronger collective, why it is that we tend to bring in the perspectives of Queer (28), Indigenous (29), Decolonial (30), Latin (31), African (15,32,33), or Black (34) bioethicists, to name but a few, when discussing gaps in our practice or issues specifically pertaining to these communities? By imposing these viewpoints as equal — at best — and as other, we reinforce the notion of Westernized, colonial frameworks having a central role if not taking a precedence, when really, these alternative frameworks are likely much better suited to address the ongoing injustices of contemporary society (29). While these recommendations may make some uncomfortable:

[a]s we rationalize (to ourselves and others) why we are personally not responsible for bringing about needed change, we contribute to acts of displacement, and displacing blame, power, responsibility, labor, and compensation are themselves acts of injustice...even how institutional commitments to diversity can fail to provide adequate support and space for nonwhite scholars...Is our fear of giving up our power and privilege preventing us from realizing how we are displacing others from the power (and voice) that they deserve?...we must embrace an ethic of discomfort — being comfortable with the uncomfortable — in order to facilitate the necessary learning and growth in these areas (35).

From personal experience, it has been challenging for us as early-career scholars to engage in a field in which the voices of many of our colleagues continue to be suppressed by the same community of practice that claims to support them. We have seen too many good ideas discarded by the field of bioethics, which continues to fail in reckoning with its own class, gender, and racial ignorance. And while recognizing and celebrating the plethora of bioethical frameworks developed by communities across the globe is a positive step forward, instances like President Trump's attacks on Diversity, Equity, and Inclusion (DEI) helps remind us that pluralism built on a foundation of colonial tradition achieves very little. It is unrealistic to believe that ideologically narrow frameworks operating alongside overfunded, unstructured attempts at inclusivity achieve a level of advocacy needed to bridge the opportunity gap between privileged and marginalized communities (36). However, we are also

³ Consider "White-Man's Burden", Civilizational Feminism, and Liberal Imperialism to name a few.

aware that bioethicists may not always be best suited to accomplish the goals of social change in isolation, because of both their primary skillset of speaking out against injustice as well as their embeddedness within the governmental and academic systems they strive to change. As scholars have pointed out, “it would behoove the field to celebrate, center, and learn from, but not co-opt the work of, individuals, organizations, advocacy, and activist groups like BLM [Black Lives Matter] who exist outside academia and are already working to combat injustice and inequality in health and society” (16,37). As such, we suggest that the interprofessional community of bioethics follow suit, not to enhance but to rebuild in a manner that diversifies and consequently strengthens its ability to achieve meaningful advocacy.

BROADER NUANCES

Before concluding this commentary, it is important to note that our recommendations for recentring advocacy within bioethics are provided with contextual nuance. Firstly, despite bioethics being “a young product of the Western culture” (20), we are far from the first to highlight the importance of perspectives from outside the Global North; there have been decades of dialogue regarding the feasibility of a global form of bioethics, in contrast to universalist theoretical standards in Western cultures (20,23,24,38). These discussions have brought “glocal” or “transcultural” forms of bioethics to the forefront, which we commend as foundational normative work (24,38). Our goal has been narrowly focused to highlight the role these discussions have served as a form of intellectual advocacy, and that those in the Global North who tend to under prioritize them ought to instead learn from them to better understand the role that bioethics ought to play in society.

Secondly, as briefly touched on in the previous section, we hope that recentring the role of advocacy within bioethics does not fall into the same trap that “decolonizing” or “DEI” language has encountered in Western academia. With the former, simply using the language of decolonization and the colloquial motivations it implies can miss how “this term was invented by the imperialist to serve the purpose of what might be described in a loose sense as a red-herring, targeting those in the struggle against neocolonialism” (33). With the latter, striving to fight for the protection of DEI programs misses how they have largely been a “corporate pacification project dressed as progress” (39). With advocacy, the goal is to actively call out the misuses of power, even if in the form of intellectually rigorous materials that make some uncomfortable. It is important to understand that simply being bioethicists or using progressive language is ultimately insufficient, given how historically, even significant philosophers like John Locke, and the field’s management of their scholarly legacy, tend to glaze over their negative impacts on the eighteenth-century debate about slavery (40).

CONCLUSION

Through our daily work as colleagues, we recognize that professional solidarity is paramount but understand the inherent limitations that our views raise for the much broader bioethics community. As such, our call for collaboration goes beyond immediate tensions in the Global North. While we don’t support the defunding of certain initiatives akin to efforts towards DEI, we respect how largely fruitless an endeavour they have been to meaningfully engage in critical discussion or meaningful change of the status quo of dominant Western traditions. If the importance of advocacy and solidarity with myriad communities can be seen within the field of bioethics, we feel that its future as both a field of study and a positive force for social change will be cemented regardless of the societal or political hurdles that it may face.

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TÉMOIGNAGE / PERSPECTIVE

Bioethics Cannot Afford to “Shut up and Dribble”

Keisha S. Ray^a, Alexandra Olmos Perez^b

Résumé

Le sens de la justice de la bioéthique se manifeste souvent sous la forme de ce que l'on appelle désormais les valeurs d'équité, de diversité et d'inclusion (DEI). À mesure que les programmes et initiatives EDI se multiplient, de nombreux bioéthiciens se voient conseiller, sous diverses formes, de « ne pas parler de EDI et de se contenter de faire leur travail ». Lorsque les bioéthiciens sont invités à abandonner ou à « modérer » leur position sur l'EDI, plusieurs conséquences s'ensuivent : 1) notre travail consistant à remettre en question et à interroger la moralité de nos actions collectives et individuelles et à encourager les autres à faire de même est ignoré; 2) notre identité professionnelle et nos valeurs sont réécrites et utilisées contre nous; et 3) nos identités sociales en dehors de notre pratique de bioéthiciens sont ignorées; cependant, il n'y a pas de bioéthique sans du travail EDI.

Mots-clés

équité, diversité, inclusion, EDI, bioéthiciens, identité professionnelle

Abstract

Bioethics' sense of justice often manifests itself as what has become known as diversity, equity, and inclusion (DEI) values. As more DEI programs and initiatives are targeted, many bioethicists are being told some variation of "keep quiet about DEI and just do your job." When bioethicists are told to abandon or "tone down" DEI a few things follow: 1) our job of challenging and questioning the morality of our collective and individual actions and encouraging others to do the same is ignored; 2) our professional identity and values are rewritten and weaponized against us; and 3) our socially situated identities outside our practice as bioethicists are disregarded; however, there is no bioethics without DEI work.

Keywords

diversity, equity, inclusion, DEI, bioethicists, professional identity

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INTRODUCTION

Although it may seem new and unprecedented, changes in public opinion on diversity, equity, and inclusion (DEI) values, and laws and policies eliminating DEI programs are not new. Instead, they can be understood as a different manifestation of a problem familiar to bioethicists. Bioethics has always required a resolve to do what is moral in the face of bigotry, disregard for some humans' lives, and legislation that challenges the foundation of our field. Bioethics is thought to have come about in response to unethical treatment of patients, women, disabled people, Indigenous Peoples, Black men in the US Public Health Syphilis Study, Jewish people subjected to Nazism, and soldiers, among other marginalized people (1,2). To speak against these abuses, in honour of the abused, bioethicists have always had to value justice, particularly for the least well off.

Bioethics' sense of justice often manifests itself as what has become known as DEI values. In fact, given that justice is one of its foundational principles, bioethics can be thought of as a tool to promote DEI. For instance, the abuses and affronts to humanity that prompted the genesis of bioethics can be characterized as the antithesis of the very principles of DEI, namely not valuing and respecting diversity of thought, belief, and identity, not promoting and advancing equitable treatment of all humans, and denying equitable access to resources people need to participate and thrive in society. As bioethicists called out these injustices, we were calling out a lack of respect for DEI. We were saying that these abuses go against how we think about bioethics and its role in people's lives, namely as a tool to ensure their entitlement to fairness and right not to be harmed, regardless of their race, nationality, abilities, gender, and other identities. This means that the very foundation of bioethics is intimately intertwined with, and arguably is inseparable from, DEI values. As a tool of justice, one that can facilitate DEI values, it is important to get the relationship between DEI and bioethics right so that bioethics is used to help rather than harm people.

As more DEI programs and initiatives are targeted, and purposefully dismantled or challenged — particularly in the US, but also in other jurisdictions too — and public backlash against DEI has grown, in an effort to uphold federal and state laws and organizational policies, and maintain funding, many bioethicists are being told some variation of "keep quiet about DEI and just do your job." Some bioethicists are being asked to separate DEI efforts and initiatives from their academic or clinical work so as not to "ruffle feathers" or jeopardize funding for their organizations. Some bioethicists may even impose these behavioural changes on themselves in an attempt to secure their employment.

Bioethicists are not the only ones who have been told to be quiet about social issues and do the job they are paid to do. Beginning in 2018, political conservatives began directing the saying "shut up and dribble" at professional athletes, like the current most famous player in the National Basketball Association (NBA), Lebron James, who advocated for social justice or made comments about social issues such as gun policies, mass shooting events, and Black people's experiences with existing

in the United States (3). The idea was that these athletes were not qualified to make comments on social issues, the general public was not interested in what they had to say because of their status as *just* professional athletes, and that their value to the public was limited to the skills they performed on the court or field. In reality, these remarks were meant to silence demands for equitable treatment for all and keep power with those who were already the most socially and politically powerful.

Similarly, when bioethicists are told to “shut up about DEI and do your jobs,” the equivalent of “shut up and dribble,” the intent is to silence our calls for socially just and ethical behaviour and keep power where it lies — with institutions and governments — rather than with individuals who are demanding better treatment. When bioethicists are told to abandon or “tone down” DEI a few things follow: 1) our job of challenging and questioning the morality of our collective and individual actions and encouraging others to do the same is ignored; 2) our professional identity and values are rewritten and weaponized against us; and 3) our socially situated identities outside of our practice as bioethicists are disregarded.

BIOETHICS AND DEI VALUES

Bioethics has always been a tool to advance DEI efforts and values. As the scope of our work indicates, whether we are concerning ourselves with ethics in clinical settings, or drawing attention to social and political factors outside of clinical settings that influence our health and wellbeing, we are engaging in work that honours and advances DEI, namely work that is predicated on the principle that all humans, regardless of social and political status, deserve equitable access to health. This value, along with some of the other humanistic values we put forth, may be controversial to some, politicized by others, or viewed as progressive lunacy. But arguably, for most bioethicists, this is a basic idea that drives much of our work.

A practical example of how bioethicists working in clinical settings necessarily find themselves centring DEI values is when a medically complex pediatric patient, living in a remote community, is offered a surgery that is considered standard of care for their condition. The intervention is deemed to be the best clinical option but, while it typically would be recommended, the healthcare team is reconsidering due to concerns about limited local follow-up services, access to rehabilitation, and lack of respite care for the family, which may limit the foreseen benefits of the intervention and potentially magnify the risks. These concerns, albeit not standard concerns, typically stem from the socioeconomic status of the patient.

The patient's family, likewise, is hesitant to consent to surgery. They worry about logistical barriers, and their past adverse experiences with the healthcare system have undermined their trust in the medical team. They fear that if they agree to treatment and are unable to meet follow-up expectations, they could be accused of neglect, or that the patient will face significantly worse outcomes than those projected by the medical team.

Clinical ethicists are consulted by diverse teams that often serve diverse communities. Having a process that allows for dialogue that will include those who are most affected by the decision and having the knowledge and skills to explore different views and values in a way that feels safe and inclusive, is crucial to identifying ethical tensions and exploring options for an appropriate resolution. A clinical ethicist can proactively identify barriers to appropriate outcomes and provide sound ethical advice to the health care team, thereby ensuring equitable care. Clinical ethicists should be able to ask questions and make recommendations that explicitly highlight the need to uphold equity while acknowledging how historical and systemic factors, including experiences of racism, colonialism, ableism, and structural inequity have undermined the trustworthiness of healthcare systems and institutions. Therefore, as a part of bioethics, DEI is integral to the clinical consultation process itself. The work of clinical ethicists demonstrates the fact that we cannot separate DEI from bioethics work and still do the work properly. Bioethics stripped of DEI would fall short in addressing the challenges it is tasked to undertake, be forced to slim its toolkit and ability to ask the right questions and hamper its ability to find the right answers. Bioethics can be a tool for social justice for everyone, regardless of status, race, gender, and other aspects of our identity; but every tool can be used as a weapon that causes harm. And if bioethics is not a tool for DEI, then it risks becoming a weapon, advancing the opposite — inequity, violence, and exclusion. And there is no future in which these values can be reconciled with bioethics and bioethics still be a means to promote ethical behaviour.

WE ARE MORE THAN “JUST” BIOETHICISTS

Bioethicists do not cease to be individuals once we start practicing bioethics. Our social, cultural, and political identities exist alongside the professional work we do. Our lived experience also provides us with a broader lens and perspective to address challenging ethical issues that may be harder for those without first-hand experience to understand.

Additionally, many of us intertwine our social and our professional lives by doing work with communities with whom we have shared identities, such as when Black bioethicists research racial disparities in health outcomes, or when Indigenous scholars study the health effects of environmental injustice. Often, we are drawn to these areas of research because they reflect our experiences, values, and desire to help the least well off. As such, asking people to separate themselves from their DEI-focused work is not realistic, as people may seek to realize their personal values through their professional practice. And for many bioethicists, DEI represents deeply held personal and professional values.

Being asked to distance our social identities from our work in the name of respecting anti-DEI policies is also disheartening. Bioethical work can call on us to study, research, and teach some of the most violent parts of our past and present society. In the clinics, we can often confront some of the saddest, most vile parts of humanity, and yet we are asked every day to press on.

We are continually confronted with actions that violate the most basic parts of our own morality, and yet we keep moving forward with our obligations to organizations, students, and patients. We engage in mentally and spiritually taxing work, so when we can personally connect with the bioethical work we do, it can keep us moving forward. Removing ourselves from our work is impossible, but it would also take the heart out of the often times heartbreaking endeavour. For many who hold marginalized identities or serve marginalized communities, it is a direct harm to remove DEI efforts, as it would result in them experiencing and witnessing discrimination and other forms of oppression.

GOING FORWARD

While jurisdictions outside of the United States may not be facing the same threats to DEI policies and values or be explicitly under attack (in terms of funding, or dismantling programs, or preventing people from engaging in DEI efforts or research), this does not mean that there will not be threats in the future. And if bioethicists in the US, or anywhere else, are prevented from embedding and advancing DEI as a foundation for their practice, this is not to be taken lightly. One of the most important principles of anti-oppression practice is solidarity and allyship, and this is the time for bioethicists to support each other and defend (what should be understood as) the very foundation and *raison d'être* of our field, which is social justice and equity.

When outside forces silence our DEI work (or we impose silence upon ourselves) we cannot do bioethics work. Instead, we are asked to be less human, and to uphold systems and structures that harm us, our loved ones, our communities, and those we serve. DEI is the work; it is not optional. Those institutions and individuals wishing to hide behind politically-washed research, or who choose to sit out the moment by removing or decentring DEI values from their mission, are doing work antithetical to bioethics and in turn advancing anti-DEI sentiments.

As a matter of professional ethics, bioethicists must also do the work to examine our own contributions to anti-DEI sentiments. It cannot be the case that bioethicists who hold identities that have been pushed to the margins feel welcomed in the profession so long as they do not question the status quo or dare to take on the most pressing challenges of our time. Bioethicists from marginalized communities cannot be paraded in front of audiences as a sign of progress and diversity in the field and then be expected to assimilate and keep quiet. Bioethics as a profession cannot appear progressive to the world yet remain silent on these issues behind closed doors.

In times like these, bioethicists should not fold their hands when it comes to DEI efforts. This is the time to embed DEI into our work more explicitly and unapologetically. Bioethicists should continue to be supported and encouraged to do DEI work as a foundational aspect of our practice, regardless of the nature of our work. DEI work for many is not a side quest or passion project. DEI is precisely the kind of work that needs to be at the core of ethical practice. There is no bioethics without DEI. And any requirement that removes DEI from bioethics is an attempt to strip us of our power, personhood, and professional identity and, on a broader scale, is an attempt to remove democratic values like justice and equality from our society, making us less able to connect with one another at the basic human level.

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TÉMOIGNAGE / PERSPECTIVE

Intersectional Lenses of DEI: Bioethicists' Duty to Advocate

Jillian Boerstler^a, Nanette Elster^b, Kayhan Parsi^b, Bryan Pilkington^c

Résumé

En nous appuyant sur les fondements historiques de la bioéthique, nous soutenons que les bioéthiciens, avec leurs approches et leurs parcours intrinsèquement interdisciplinaires, sont bien placés pour promouvoir l'équité, la diversité et l'inclusion (DEI) dans le milieu des soins de santé grâce à la pratique de l'éthique clinique. Dans le climat culturel et politique actuel, les bioéthiciens ne peuvent rester silencieux tout en restant fidèles aux principes de leur domaine. Les dispositions du code de déontologie de l'American Society for Bioethics and Humanities (ASBH) et l'expérience vécue par les bioéthiciens canadiens offrent des orientations pertinentes. Nous soutenons que la compétence en éthique clinique oblige les bioéthiciens à identifier et à chercher à éliminer les obstacles systémiques auxquels sont confrontés ceux que les éthiciens cliniques ont le privilège de servir. En adoptant une approche intersectionnelle de la bioéthique clinique, les bioéthiciens peuvent devenir les défenseurs de la promotion de soins de santé équitables.

Mots-clés

équité, justice, bioéthiciens cliniques, EDI, code de déontologie, intersectionnalité, devoir

Abstract

Building on the historical foundation of bioethics, we argue that bioethicists, with inherently interdisciplinary approaches and backgrounds, are well positioned to promote Diversity Equity and Inclusion (DEI) in the healthcare setting through the practice of clinical ethics. In the current cultural and political climate, bioethicists cannot remain silent while staying true to the tenets of the field. Provisions in the American Society for Bioethics and Humanities (ASBH) Code of Ethics and the lived experience of Canadian bioethicists offer relevant guidance. We argue that competence in clinical ethics obliges bioethicists to identify and seek to remove systemic barriers facing those whom clinical ethicists are privileged to serve. By adopting an intersectional approach to clinical bioethics, bioethicists can become advocates for the promotion of just healthcare.

Keywords

equity, justice, clinical bioethicists, DEI, code of ethics, intersectionality, duty

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In the span of a few months, the current US administration has waged an intense onslaught against diversity, equity, and inclusion (DEI), a set of principles meant to bolster fairness and promote participation of equity-deserving groups (1). This agenda has prompted several regressive responses. Private corporations that were previously publicly committed to DEI principles have abandoned their commitments. US government agencies have purged any mention of DEI in their public-facing materials. Even US universities that are presumably committed to the ideals of academic freedom and free speech have turned away from DEI.

Purging DEI has a direct impact on bioethics and clinical bioethicists. Bioethicists have a long history of advocating for social change. As documented by historians such as Robert Baker, some historical roots of bioethics are tied to the civil rights movements of the 1960s and 1970s. In *Making Modern Medical Ethics*, Baker states the following:

A Patient's Bill of Rights was negotiated to assert the rights of welfare recipients and later those of all clinic and hospital patients in the context of a nonviolent populist insurrection against ableist, ageist, classist, racist, and sexist practices perpetrated by American hospitals that viewed "charity" through the lens of a white middle-class scientific medical paternalist gaze (2).

Baker argues that traditional histories of bioethics focus on the role of formal commissions, think tanks, and reports. In his historical account, however, bioethics, like other social movements, was shaped by many unrecognized individuals who challenged and confronted prevailing norms and institutions. Building on this historical foundation, we argue that bioethicists, with inherently interdisciplinary approaches and backgrounds, are well positioned to promote DEI in the healthcare setting through the practice of clinical ethics. In the current cultural and political climate, bioethicists cannot remain silent while remaining true to the tenets of the field. Provisions in the American Society for Bioethics and Humanities (ASBH) Code of Ethics (3) and the lived experience of Canadian bioethicists offer relevant guidance. We argue that competence in clinical ethics obliges bioethicists to identify and seek to remove systemic barriers facing those whom clinical ethicists are privileged to serve. By adopting an intersectional approach to clinical bioethics, bioethicists become advocates for the promotion of just healthcare. This is when bioethicists are needed the most.

Clinical ethics facilitation may involve decisions affecting patients identifying as First Nations, Indigenous and/or other equity-deserving groups. Colonialization has harmed First Nations and Indigenous communities who lived in North America for

millennia (4). In Canada, generations suffered in Residential Schools and understaffed and overcrowded “Indian hospitals.” (5) This may explain why those identifying as First Nations or Indigenous and their families are fearful and perhaps distrustful in their encounters with the Canadian healthcare system and Western medicine’s often paternalistic approach.

Despite this history, clinical bioethicists are witness to some of the most complex cases facing patients and their loved ones. Through their interdisciplinary training in mediation, facilitation, and ethical analysis, clinical bioethicists have a unique opportunity as members of the care team to ask probing questions in a case: how might systemic inequities affect this patient’s circumstances? What conscious or unconscious biases may be influencing the team’s perspectives? How should cultural or religious worldviews be considered? How might scarce healthcare resources be allocated so that those most in need are prioritized? The role of the clinical bioethicist is to ask these questions. This inquiry allows patients’ goals and values to be prioritized, and their voices amplified. In the process of asking these questions and by facilitating ethical dialogue, clinical bioethicists also serve as architects of moral space, opening opportunities for reflection by all stakeholders on the needs and values of patients.

To place patients’ wellbeing at the centre of clinical ethics consultation, bioethicists have a duty to identify, challenge, and promote DEI considerations. Members of the care team may be unaccustomed to consideration of DEI matters; some may not be able to see beyond the clinical facts or inherent biases in a case. In those situations, clinical bioethicists must highlight DEI, illuminating patterns facing equity-deserving groups experiencing systemic bias in provincial/state and/or federal systems.

ASBH offers guidance to bioethicists in its Code of Ethics (3). Highlighting tenets such as competence and a responsibility to promote justice, the Code offers scaffolding to clinical bioethicists in their practice. Competency in clinical ethics consultation means that uncertainties or conflicts regarding value-laden concerns are illuminated and addressed. Advocating for DEI is a way of promoting justice. Doing so requires an intersectional approach.

In an interview with the “Antiracism in Medicine” series of *The Clinical Problem Solvers* podcast, legal and sociology scholar Dorothy Roberts discussed the topic of intersectionality. She said:

we also have to recognize that race intersects with other statuses as well. It intersects with socioeconomic status, with education, with geography, with sexual orientation, with religion. We could go on and on. And all of those statuses I just mentioned, in our racial capitalist, anti-immigrant society, also affect gender. All of that. These are all hierarchies that intersect in our lives and they intersect in society (6).

In integrating DEI into clinical ethics, bioethicists should adopt an intersectional approach within their ethical analysis and throughout the facilitation process. Kimberlé Crenshaw defined “intersectionality” as the connection between two constructs such as race and gender (7), and exposed the limitations of “single-axis” thinking. Intersectionality examines the dynamics of difference and sameness, playing a major role in facilitating consideration of gender, race, and other axes of power (8). A commitment to intersectionality in clinical bioethics implies that care teams must consider different lenses; for instance, a white cis male will have a different lived experience than an Indigenous person who identifies as Two Spirit.¹

Scholars such as Brunig and Salloch (10) have also called for the use of intersectionality in bioethics. Because of the interdisciplinary and multidisciplinary nature of the field, an intersectional bioethics approach is apropos. They state that “intersectional perspectives should complement the work of bioethicists to make structural discrimination visible, to make marginalized voices heard, and to advance work toward more self-reflection, as well as a diversification of bioethics itself.” (10) Bioethicists are equipped with multiple lenses, each sharpening and adding dimension to the DEI issues that often underlie and underpin clinical ethics cases. For example, end-of-life treatment options may favour individual autonomy, ignoring some cultures’ priority of family and community in decision making. Bioethicists’ training and positionality can prepare them to be attuned to issues that “single-axis thinking” misses.

Consider the term “framework” as it pertains to bioethics; clinical bioethicists rely on frameworks, at times, which can be understood as colonial ways of organizing concepts. Intersectional bioethics acknowledges worldviews beyond those of white colonizers; some cultures embrace ways of thinking and knowing that are not linear, that may occur in steps, akin to braiding, or weaving a tapestry.²

While clinical bioethicists are trained in and rely on Western biomedical ways of thinking about ethics, ethical exploration must not stop there. In other words, the four principles of autonomy, beneficence, non-maleficence, and justice may serve as a starting point but ought not end there. Western bioethics tends to prioritize personal autonomy, but patients’ cultures may conceive of autonomy differently, focusing instead on family or community wholeness (11). Other approaches provide additional lenses for intentional inquiry related to areas of DEI. For instance, principlism acknowledges the importance of justice and self-determination in the clinical encounter. A narrative approach enriches the understanding of justice as not just a theoretical concept but one that is embedded in a larger historical narrative that is unique and personal to the patient. A narrative approach recognizes both subjective and objective aspects. Feminist and care ethics include historically excluded

¹ For additional information on intersectionality in clinical ethics practice, see (9).

² The term “framework” is not an inherently colonial term but use of it can perpetuate systems of power, white supremacy and/or elitism. The authors offer an attempt to decolonize clinical bioethics thinking and they are unable to cite this section, as citations themselves could be considered a colonial imposition.

groups and individuals. Used together, these various approaches can provide a richer, more nuanced, and holistic understanding of the intersectionality inherent in clinical ethics work.

An intersectional approach also offers opportunities to avoid or remedy challenges and pitfalls particular to the use of any single approach. For example, a consequentialist framework — which is often employed in public health bioethics — might ignore the aforementioned richness of the lives of particular persons. A virtue theoretical approach, while taking seriously particular persons, might lack the robust action-orientation that is often called for in clinical bioethics. A deontological framework may lend itself to bioethics-related policies but may leave out the humanity of the clinician and their own history and values, even if it attends to the explicit duties of clinicians toward patients. In considering and bringing together various ways of thinking and knowing, bioethicists can do their work best and, in so doing, make implicit arguments for DEI, which they ought to (also) make explicitly.

Current events suggest another rights movement lies ahead, furthering those of the 1960s and 1970s. In their clinical work, scope, and *raison d'être*, clinical bioethicists are well-suited to address DEI using both the practical and theoretical tools that are part of the bioethicists' specific training. The conceptual approaches of casuistry, feminist bioethics, virtue ethics, and care ethics, for example, combined with the practical tools of narrative ethics and principlism, can and must "intersect" to ensure that DEI remains a central priority of clinical ethics. This approach highlights the ongoing need for diversity, equity, and inclusion, which is currently facing perilous pressure in the US.

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TÉMOIGNAGE / PERSPECTIVE

The Morning: Constructing Moral Space from the African American Experience in Bioethics

Donald E. Carter, III^a, Kara Simpson^b, Alvin L. Reaves, III^c

Résumé

Les bioéthiciens du monde entier ont toujours entretenu des relations et des échanges collaboratifs. Cependant, compte tenu des tensions politiques actuelles, la réflexion morale est menacée et affaiblie. La recréation d'espaces moralement sûrs et la recherche de la vérité exigent l'incarnation du courage moral et de l'intentionnalité. Pour répondre à cette situation, la bioéthique doit dépasser la neutralité en s'inspirant de l'expérience afro-américaine, qui met l'accent sur la clarté morale et la responsabilité communautaire, en adoptant une positionnalité et en mettant au centre les voix marginalisées afin de faire face aux tensions sociopolitiques au sein et au-delà du monde universitaire. Les concepts des 3M (*moaning*, *mourning* et *morning*) fournissent un cadre pour créer un espace moral plus inclusif. Basé sur la praxis théorique du travail social, « *Moaning* » fait référence à la douleur et à la souffrance des Afro-Américains, « *Mourning* » à l'effort collectif pour surmonter le chagrin, et « *Morning* » à la représentation de la percée et de la transformation à partir des épreuves. Bien que ces trois concepts constituent une exploration puissante de la tradition afro-américaine, ils peuvent être utiles à d'autres personnes en dehors de cette communauté. Cet essai se concentre toutefois uniquement sur le concept de « *Morning* » — une métaphore qui sert de modèle à la profession de bioéthique pour aborder le climat politique actuel. Il est impératif que la bioéthique fasse entendre la voix des personnes marginalisées et opprimées et écoute leurs expériences passées. Ces expériences peuvent fournir un modèle pour transcender les barrières des inégalités sociales et politiques, tant au niveau national qu'international. Nous suggérons de réévaluer le recours à la neutralité et d'opter plutôt pour des engagements clairs sur les dilemmes éthiques.

Mots-clés

Afro-Américains, courage, interdépendance, morale, neutralité, marginalisation sociale, soutien social

Abstract

Bioethicists, globally, have historically enjoyed collaborative exchange and relationships. However, given the current political strain, moral deliberation is threatened and diminished. The redevelopment of morally safe spaces and the pursuit of truth require the embodiment of moral courage and intentionality. To meet the moment, bioethics must move beyond neutrality by drawing on the African American experience's emphasis on moral clarity and community accountability — embracing positionality and centring marginalized voices to confront socio-political tensions within and beyond academia. The concepts of the 3Ms (*moaning*, *mourning*, and *morning*) provide a framework for creating a more inclusive moral space. Based in social work theoretical praxis, *Moaning* refers to African American pain and suffering, *Mourning*, the collective effort to overcome grief, and *Morning*, the representation of breakthrough and transformation from hardships. Despite the three concepts being a powerful exploration of the African American tradition, it can be helpful to others outside this community. This essay focuses, however, only on the concept of "Morning" — a metaphor that serves as a blueprint for the bioethics profession to address the current political climate. It is imperative that bioethics elevate the voices and listen to the past experiences of the marginalized and oppressed. These experiences can provide a blueprint for transcending barriers of social and political inequities, both domestically and abroad. We suggest reevaluating the use of neutrality, opting instead for clear commitments to positions on ethical dilemmas.

Keywords

African Americans, courage, interconnectedness, morals, neutrality, social marginalization, social support

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INTRODUCTION

In the wake of the current global sociopolitical unrest, marginalized voices are increasingly being suppressed, positions of neutrality are becoming more prevalent, and the existing bioethical framework continues to face challenges in transitioning from an individual-centred perspective to one that embraces relationality and collective identity. Ashby and Morrell describe neutrality in bioethics as "a non-political and dispassionate stance" that "gives the field a certain detached authority" (1, p.479). Neutrality has enabled bioethics to establish moral credibility across academic, research, and governmental domains, fostering trust in its expertise. However, the practice of bioethics' neutrality conflicts with its aim of interconnectedness and commitment to social justice (2). Neutrality in bioethics can imply complicity in perpetuating moral conflict and societal division. Bioethics would benefit from borrowing from the African American experience by rejecting neutrality, embracing positionality, and centring marginalized voices by moving beyond academia to engage directly with oppressed communities. Only then can it address and affect sociopolitical tensions globally and locally.

TENSIONS BETWEEN INTERCONNECTEDNESS AND NEUTRALITY

Interconnectedness is foundational not only to the human experience but our very existence, for the joining of resources and the union of voices often equates to survival. The greatest milestones in American history underscore what is possible through collective action and shared sacrifice. Simply put, our victories have not been won alone but in the company of hope and strength lent by others — neighbours, outsiders, and distant friends. Once in pursuit of a more perfect union that valued and nurtured these cooperative relationships, the United States now appears to be ushering in a return to a policy favouring isolationism. Decisions that unapologetically strain our foreign alliances abound, signaling a fundamental shift in national ethos and an increasing detachment from the principles by which our unity was forged. Historically, bioethics has often remained neutral in domestic governance and international affairs, particularly related to war and climate change. Bioethics, rather, has predominantly lent its voice to the clinical space, biomedical research, and public/global health. Neutrality, an apolitical stance, comes into tension with the implicit charge of bioethics to foster connection and relationships, similar to the notion of kinship or interconnectedness within the African American community. These alliances are essential to the work of bioethics. Thus, our relational bonds necessitate that bioethics move away from neutrality.

In an era of ethical complacency and professional detachment, Canadian bioethicist Benjamin Freedman asks a question that is no less pressing nearly 30 years later — “Where are the heroes of bioethics?” Historical and current events such as police brutality, or more recently the deportation of immigrants in the US, questions whether the silence of bioethicists, those considered truth-tellers of moral actions, in the face of systemic injustice, constitutes ethical neutrality or moral failure. Can neutrality be moral when the silence of the bioethics community is causing harm? Freedman argues that bioethics lacks moral heroes — people who demonstrate courage and self-sacrifice when placed against institutional and societal pressures (3). The African American experience illustrates that heroism is possible even in the face of exploitation and oppression. It doesn’t require perfection. Instead, it demands a consistent moral orientation and the courage to speak, especially under pressure.

Traditions in African American culture assist with emotional healing, assimilation resistance, and communal solidarity. A class of people with a well-documented legacy of tragedy, African Americans also have an equal, if not arguably stronger, heritage of survival and flourishing. Elmer P. Martin and Joanne Mitchell Martin capture this philosophical essence of the African American experience using three fundamental concepts: *Moaning*, *Mourning*, and *Morning* (4). Milestones within an emotional and cultural cycle, these concepts depict the progression of grief toward remembrance and then renewal. Despite these three concepts being a powerful exploration of the African American tradition, it can be helpful to others outside this community. However, this essay focuses only on the concept of *Morning* — a metaphor that will be used to map how the bioethics profession can address the current political climate.

THE AFRICAN AMERICAN EXPERIENCE AS ETHICAL BLUEPRINT

The African American experience in the US has been marred by suffering and brutality since 1619, when the first Africans were brought to the shores of this continent. Their contributions take up significant space in America’s historical landscape. However, over the ensuing centuries, their beings and voices have been hushed; their narratives, particularly their triumphs and overcoming, have been overtly discounted by the dominant voices, such as Western, elite, and male perspectives. Yet, what has pierced through the iron walls and curtains of systemic injustice and reverberated through the journeys of African Americans has been their moaning, their guttural release of pain.

History should be considered a significant and fundamental building block of a moral space, as “historical ethics can bring more voices to question, focus more on the process of moral deliberation rather than just the ‘right’ answer” (5, p.17). Consider narratives of the Tuskegee Syphilis Study (6) and The Mothers of Modern Gynecology (7), both of which involved injustices towards African Americans. The Tuskegee Syphilis Study, a catalyst for modern bioethics, was a US Public Health Service experiment in which Black men with syphilis were deceived and denied treatment so researchers could observe the disease’s natural course. Its racism, exploitation, and disregard for informed consent made it one of the most egregious ethical violations in US medical history, prompting significant reforms in research ethics. The Mothers of Modern Gynecology (Anarcha, Betsey, and Lucy), were enslaved Black women on whom J. Marion Sims performed repeated, non-consensual surgeries to develop gynecological techniques. Their suffering, including infections from unsterilized instruments and the denial of anesthesia, reveals how key medical advances were built on profound racial injustice and the violation of Black bodies. In both examples, historical ethics asks: “Whose voices shaped the event, whose voices were left out, and how did we get here?” There must be an understanding of how ethical decisions were made. Equally important, why were ethical and moral leaders — that is, heroes — absent? Vital is the storytelling and the public collective deliberation of the lack of ethical leadership. Without it, history will repeat itself (e.g., the COVID-19 vaccine rollout and the overturning of *Roe v. Wade*), leaving society to moan and mourn in ways that mimic the grieving process, ultimately, transforming into political acts.

MORNING AS PRAXIS

A critical practice to consider in shaping our future trajectory is the reassessment of ostensible neutral positioning in relation to contemporary political and social issues. Within bioethics, educational institutions, workplaces, and professional organizations often reinforce a stance of neutrality in political discourse. While there is an argument for political neutrality to minimize or eliminate prejudice, marginalized communities such as women and people of colour in the workplace are vulnerable to backlash if they take a stance. Neutrality is often enacted due to concerns about professional repercussions,

including loss of employment or advancement opportunities. Many bioethicists have navigated significant hardships to attain professional standing, often necessitating strategic neutrality or even silence (8). Yet, refusing to take a position is not merely an absence of action; it can inadvertently signal complicity or tacit agreement with prevailing structures that perpetuate inequity. Some argue for political neutrality in clinical and academic spaces as a way to serve patients without prejudice and teach students to reason without bias (8). While neutrality is often seen as a shared value across clinical, academic, and research settings, its place becomes contested when injustice is present. In such moments, bioethicists must prioritize justice to avoid harm and prevent complicity. Re-examining the role of neutrality is essential for fostering a more just and ethically engaged bioethics discourse.

The morning metaphor serves as a powerful reminder of the ancestral tenacity that has historically driven systemic change in the US, exemplified by the Abolitionist Movement (9) and the passage of the Civil Rights Act of 1964 (10). It is important to note that the abolitionist movement wasn't relegated to just the Western territory of the world. It was a global social and political movement aimed at the liberation of enslaved people. International efforts led to treaties and declarations. The abolitionist movement paved the way for the civil rights movement, establishing the framework for activism. These movements were founded upon the fundamental conviction that all individuals are entitled to freedom, liberty, and dignity — principles that inherently reject the notion of neutrality. The morning compels us to act with moral courage, particularly in times of political discord, oppression, and societal upheaval, reinforcing the urgency of advocacy and ethical engagement in the pursuit of justice.

Reevaluating established bioethical practices is imperative in this historical moment. While traditional academic methods — such as publications, teaching, and scholarly discourse — are valuable, their influence remains largely confined to institutional settings rather than reaching the broader population. For African American bioethicists, prioritizing and advancing community-based bioethical education and action initiatives is crucial to serving those most affected by systemic inequities: marginalized communities. Historically, grassroots movements — including religious organizations, social clubs, labour unions, and service agencies — have been central to political change, often emerging in direct response to oppression. Given this legacy, bioethicists must foster strategic alliances and actively participate in grassroots efforts to ensure bioethics is both accessible and meaningful beyond academic circles.

CALL TO ACTION

Ethicists in the US and Canada are navigating a rapidly evolving landscape concerning things such as globalization, immigration, democratic governance, social justice, and the rule of law. More broadly, international issues such as global health, climate change, and crimes against humanity transcend our borders and should concern both American and Canadian ethicists alike. These motifs should continuously challenge our shared values, such as human rights, confronting our responsibilities as ethicists to provide oversight to powerful nations if there is to exist any form of public accountability.

Overcoming neutrality will require extraordinary courage and, more importantly, sacrifice. Addressing our sociopolitical climate and international affairs will necessitate an expansion of traditional topics in the field, challenging us to make space for the views and differing opinions and empowering one to act on them. Historically, the act of deterrence in the form of gatekeeping in public spaces — such as publications and conferences — by negativistic senior professionals of authority has caused those desiring to challenge the system to seek alternative venues such as podcasts and blogs. What is missing in bioethics is a community-centred approach that values individuals outside of medicine and academia, that is, those who provide a practical and lived experience to shape moral ideas and influence ethics, policy, and advocacy.

Freedman argues that without moral courage and visible action, the field of bioethics risks irrelevance. To avert this, there is a historical and contemporary silence that must be addressed to prevent it from becoming bureaucratized and institutionalized. Morality, the action of doing right over wrong, should never concede. Our moral space should never shrink; rather, our shared commitments to the well-being and flourishing of humanity ought to ever expand the boundaries of our moral imaginations. We have experienced a widening societal chasm stoked by differences in political ideologies, ethnicity, and religious differences in healthcare, social sciences, and academia. It is imperative at this time in our fractured world that bioethicists lead the charge to be advocates or activists, and "architects of moral space." There is a need for a bioethics that appeals to our broad, shared moral commitments to one another, to humanity, and to an ethical stance that allows us to live up to our highest ideals.

CONCLUSION

Globally shared moral and ethical interest — pluralism — should not be constrained by borders, race, or ethnicity. We must work to maintain and build moral space for partnerships and continued collaboration across borders with our neighbours. We must remain united in our pursuit of moral truths. Such efforts, especially now when fighting against strongman leadership in our individual countries, threaten to keep our communities numb, fatigued, and reticent to be the voices of resistance. However, we must embody the moral courage to intentionally develop spaces of moral safety and truth. Bioethics must be at the forefront, serving as a voice to speak out against hypocrisy and advocate for justice. We must become heroes.

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TÉMOIGNAGE / PERSPECTIVE

What We Ask of Others: Ethics on the Record, Institutional Power, and Moral Practice in a Fractured World

Matimba Swana^a, Niyoshi Shah^b

Résumé

À une époque marquée par l'hostilité politique, l'aggravation des inégalités et la méfiance croissante à l'égard des systèmes de santé publique, les bioéthiciens doivent s'interroger sur ce que signifie être des acteurs moraux au-delà des frontières. Cette réflexion s'inspire de *Ethics in Practice*, une série de balados qui relate des histoires personnelles de convictions morales et d'actions dans le domaine de la recherche en santé mondiale. Au cours de cinq épisodes, nos invités ont réfléchi à ce que signifie défendre des valeurs éthiques telles que la justice, la solidarité et la responsabilité individuelle face aux barrières institutionnelles, aux asymétries de pouvoir et aux préjugés moraux. Ce commentaire se concentre sur l'objectif plus large du balado : rendre visibles les luttes quotidiennes et la résistance subtile de ceux qui tentent d'agir pour le bien au sein de systèmes complexes. En tant que tel, le balado se positionne comme une réflexion sur l'action éthique et une expression de celle-ci, car il utilise non seulement la narration pour explorer la complexité morale, mais aussi pour créer un espace moral. Nous avons utilisé des extraits des épisodes du balado pour mettre en évidence les défis éthiques et les solutions collaboratives en matière de bioéthique. Nous explorons l'« aspect sous-développé » du rôle d'un bioéthicien et plaitions en faveur d'une pratique de l'éthique qui soit relationnelle, imparfaite et guidée par l'imagination morale. Il s'agit à la fois d'un défi et d'une invitation pour les bioéthiciens des États-Unis, du Canada et d'autres pays à faire preuve de solidarité morale au-delà des frontières. Au milieu du deuil collectif et des dommages systémiques, nous sommes appelés à nous soutenir les uns les autres, non seulement en principe, mais aussi dans la pratique.

Mots-clés

éthique au quotidien, éthique dans la pratique, balado, recherche en santé mondiale

Abstract

In a time of political hostility, deepening inequality, and growing distrust in public health systems, bioethicists must ask what it means to be moral actors across borders. This reflection draws on *Ethics in Practice*, a podcast series that captures personal stories of moral conviction and action in the field of global health research. Across five episodes, our guests reflected on what it means to uphold ethical values, such as justice, solidarity, and self-accountability in the face of institutional barriers, power asymmetries, and moral injury. This commentary focuses on the broader effort of the podcast: to make visible the everyday struggles and subtle resistance of those trying to be good within complex systems. As such, the podcast is positioned as a deliberation on and an expression of ethical action, for it not only uses storytelling to explore moral complexity but also to create moral space. We have used excerpts from the podcast episodes to highlight ethical challenges and collaborative solutions in bioethics. We explore the “underdeveloped aspect” of a bioethicist’s role and argue for a practice of ethics that is relational, imperfect, and guided by moral imagination. It is both a challenge and an invitation for bioethicists in the US, Canada, and other countries to stand in moral solidarity across borders. Amid collective grief and systemic harm, we are called to show up for one another, not just in principle, but in practice.

Keywords

everyday ethics, ethics in practice, podcast, global health research

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INTRODUCTION

Bioethicists have increasingly had to tackle issues that involve advocacy or activism. As ethical frameworks evolve, especially amid political hostility and institutional instability, we are asked to consider: what does it mean to act ethically across borders? What is the role of the bioethicist in contexts characterised by systemic and structural injustice? The strained Canada-US relationship, marked by trade disputes and polemic rhetoric, adversely affects access to cross-border healthcare, resource allocation, and partnerships. Current political tensions and the loss of US funding present issues beyond these borders and are an opportunity to explore the role of the bioethicist. This commentary takes its inspiration from *Ethics in Practice*, a podcast series exploring how researchers follow their moral compass in day-to-day work (1). The podcast is an open-access platform showcasing diverse narratives from health and research professionals, including critiques of biases and institutional constraints. It acts as an archive of moral conviction and action; we use here excerpts from various episodes to explore the bioethicist’s role in social justice.

This podcast grew from the understanding that most people develop their notions of goodness long before encountering bioethics (2). Their family, location, and personal experiences play formative roles in shaping the core values by which they navigate the complexity of medicine and health research later on (2). With this premise, *Ethics in Practice* shifts away from the canonical principles of autonomy, beneficence, non-maleficence, and justice to focus on ethical behaviour in everyday life,

particularly when it poses an internal conflict or dissonance. The content plan was shaped by our experiences as early career researchers and insights from a survey shared across our networks. Each episode's topic guide was co-developed with the guests to ensure relevance, and community value. Over five episodes, ten health and research professionals shared personal stories and insights on themes of epistemic pluralism, fieldwork, teaching bioethics, systems change in health, and reckoning with wrongdoing and injustice.

BROKEN SYSTEMS, ORGANIZATIONAL SILENCE, AND SILENCING INDIVIDUALS

Bioethicists work within a complex environment that can involve conducting research on ethical issues, teaching and educating others about bioethics, developing institutional policies and guidelines, serving on ethics committees, and providing consultation and advice on ethical dilemmas. It is necessary to critically examine this environment in light of the current political climate. Our discussions with the podcast guests revealed that they are less troubled by moral dilemmas in their research than by the challenges of being ethical in "violent systems," as described by Anna Dowrick, a Senior Researcher from the University of Oxford:

A lot of people get burnt out through research, through this type of research, which is also true when people are out doing activism, and any job like this. Yes, it's all part of the oppression, all part of the violence of these systems. But then, we're part of it too. And that's why I always think of these as political issues, because I'm not just a passive observer (3).

Health and research professionals may need to independently explore how power and injustice affect health because their ethics education does not cover these topics. Mario Vaz, a retired Professor from St John's Medical College, highlighted that institutional dynamics affect both ethics instruction and the willingness to address these issues:

Some of the ethical issues that people face are actually related to systemic issues within the institution that they work for, and it is difficult for them to speak out openly because, of course, they're worried about their jobs and how they will be perceived (4).

The field of bioethics faces challenges due to a collective silence among practitioners regarding how its own systems perpetuate the injustices they aim to address. We heard stories of how those who presented an alternative view were questioned or dismissed, even by fellow bioethicists, often limiting the field's ability to respond to real-world complexities. This silence has ethical implications (5). As Michael Certo recently observed, we must ask whether the risks of speaking out against unjust policies outweigh the dangers of allowing them to continue unchallenged (5). Amar Jesani, an independent consultant, researcher, and teacher from India, stressed the dual importance of both structure and agency in addressing these issues:

Institutionalisation is required, but at the same time you require checks and balances on the institutionalisation. If they are not there, the standard of ethics does not go up. So, that is how I said that inside as well as outside, you will have to keep working both ways if you are concerned about the larger goal of bioethics (6).

Bioethics often operates within institutional boundaries, while meaningful change is often brought about by those working at the margins of or outside formal structures altogether. It is this tension, between internal critique and external pressure, that ethical progress occurs. This dynamic highlights the importance of maintaining a generative balance between procedural ethics, bioethics as a discipline, and 'everyday' ethics as it is practiced by individuals within the system and outside it.

RECOGNIZING THE ARCHITECTURE OF EXCLUSION

The withdrawal of US funding has sent shock waves through the global health research and humanitarian communities, but arbitrary displays of power are not new. There are several communities across the world for whom this is a persistent reality. They have navigated shifting geopolitical power and could offer valuable lessons on how to mitigate these effects. However, bioethics often overlooks these diverse perspectives due to its alignment with institutional authority, disciplinary limitations, and reluctance to engage in political critique. While some bioethicists critique systemic injustices, fewer acknowledge their own complicity or that of their institutions. This moment requires a reawakening, urging bioethicists to say plainly when "the king is naked" and to openly challenge injustices, even if it disrupts comfort or consensus. The current political climate poses threats to diversity, equity, inclusion, and accessibility (DEIA), but bioethics must also reflect on its internal issues. Despite advocating for justice and care, the field's institutions often remain exclusive, hierarchical, and slow to embrace epistemic and methodological diversity (7). On our podcast, Christina Lee, a Research Associate at the University of Sheffield, shared her experiences as a disabled woman of colour in academic spaces:

As a disabled person, I've always been afraid of roads and I wanted to use that metaphor to express the sense of vulnerability that disabled people in academia often experience, particularly if you are a disabled woman or a disabled woman of colour (8).

The backlash against DEIA initiatives has also been driven by fears of "reverse discrimination". This frames these efforts as unfair to certain groups, especially white individuals, while questioning their effectiveness and legality (9). Bioethicists might

view this as a problematic situation; however, this could also compel the field to confront the deep institutional racism that persists within it (10). Bioethics has fallen short in confronting the unequal distribution of power within academic institutions (11). As a result, institutions seem to be responsive while failing to adequately tackle the underlying causes of discrimination in bioethics and, more broadly, in academia as a whole (11). Moreover, there is a need to recognise the interconnectedness of human, animal, and planetary health, as discussed by Nicole Redvers, Associate Professor and Director of Indigenous Planetary Health at Western University, who reminded us of the need to integrate diverse knowledge systems, including decolonial, Indigenous, and environmental bioethics:

I witnessed very clearly not only the lack of accessible services, but also the lack of trustworthiness between Indigenous peoples and what was seen to be colonial governments because, of course, Canada was a colonised country. But layered on that was the great environmental changes that have been happening and are still happening in the sub-Arctic and Arctic with strong climate-change impacts. The environmental provisions that many indigenous communities rely on — the hunting, the fishing, the gathering — are becoming more difficult with the changing climate (8).

WE'RE ALL IN THIS TOGETHER

Social justice centres fairness, equity, and human rights, closely aligning with bioethics. However, as our podcast conversations revealed, movements for social justice require collective effort, and often originate outside of bioethics, a field which tends to prioritise individualism and neutrality over direct political critique. As has been noted by our guests, calls for attention to significant social issues like racism in healthcare did not originate from bioethics but from external advocates (6). Bioethicists, such as Fletcher and colleagues, have called for a shift towards social justice, and have highlighted the need for the field to address its limitations and engage more with external movements to promote equity and accountability (12). Instead of framing ethics as individual virtue, or institutional compliance, our podcast guests point toward a broader, more relational role for the bioethicist: one rooted in solidarity and attentive to the ethical labour of researchers and practitioners who may not identify as bioethicists yet engage deeply with moral complexity in their everyday work.

Solidarity involves acting in response to specific events or concerns and providing support amidst differing views (13). Effective solidarity acknowledges epistemic humility and diverse perspectives within the bioethics community and emphasizes mutual obligations (9). The challenges we face are local, national, and global. To tackle them requires collaboration and a greater allowance for reasoning and disagreement in bioethics. This “space for reasoning and disagreement” should allow individuals to express views and engage in constructive debate, thereby encouraging respect, active listening, and openness to alternative perspectives. Scholars have explored solidarity in multiple dimensions: as lived experience, as political, as collective action against injustice, and as transformative and emancipatory (14). The podcast is an invitation for bioethicists in the US, Canada, and elsewhere to engage in cross-border solidarity even, or especially, when that means challenging our own knowledge and value systems.

Addressing challenges within health and research systems, where competition often overshadows collaboration, can be quite difficult. There are limited opportunities for practitioners to engage in more personal discussions on the burden and desire to be ethical in an increasingly unethical world. This is why we have come to recognise our podcast as a moral space for reflection and dialogue between guests that hail from very different backgrounds, country, community, experience, and seniority. We hope the podcast encourages creative projects in bioethics because there is no prescribed way of standing up to power. We need to explore new vehicles for storytelling that capture the mess and imperfection of practicing ethics, such as the podcast. With a healthy disregard for convention, these media can also offer an alternative way of framing bioethics as a collective effort to ensure that our institutions are not only designed to prevent harm but to strive towards the higher ideals of equity and justice.

CONCLUSION

Bioethics cannot expect to advocate for moral space if it remains unwilling to interrogate the power structures and exclusions within its own field. Calls for justice and equity in bioethics ring hollow if the discipline itself reproduces the very forms of structural racism, elitism, and epistemic exclusion it claims to challenge. Bioethicists must model the kind of institutional introspection and structural change it often calls for in others. As political divisions grow and institutional failures mount, the need for courageous, relational ethics is more urgent than ever. This reflection does not offer answers, but a further provocation: How might we centre spaces in bioethics for social justice, disagreement and dialogue, solidarity, diverse knowledge systems, and diverse project-engagements that offer alternative narratives on what it means to be ethical? How might we reimagine bioethics not only as a set of ideals, but as a plural and lived practice? Bioethics must adopt a bolder stance if it intends to create significant and enduring change. In the face of intense political debates and systemic injustices, we are urged to support one another not only in theory but also through our practice.

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TÉMOIGNAGE / PERSPECTIVE

Meeting the Moment: Bioethics in a Revolution

Aaron Wightman^{a,b}

Résumé

Les États-Unis d'Amérique connaissent actuellement une révolution politique et une révolution morale sous-jacente. Le rôle de la bioéthique pendant une révolution n'est pas clair. Cet article propose quatre suggestions pour que la bioéthique et les bioéthiciens puissent répondre aux besoins actuels : abandonner le sectarisme et l'absolutisme, considérer l'honneur d'un œil critique, accepter le statut d'outsider et agir.

Mots-clés

révolution, partisannerie, absolutisme, honneur

Abstract

The United States of America is undergoing a political revolution and an underlying moral revolution. The role of bioethics during a revolution is unclear. This paper offers four suggestions for bioethics and bioethicists to meet our current moment: abandoning partisanship and absolutism, critically considering honour, embracing outsider status, and doing things.

Keywords

revolution, partisanship, absolutism, honour

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INTRODUCTION

The United States of America is undergoing a political revolution. Revolutionaries, popularly elected, confirmed, or appointed now hold positions of power in American government. Revolutionaries seek to replace existing systems, structures, or paradigms rather than improve or operate within them. In a revolution, truths once considered almost self-evident come to be viewed as not evident at all (1).

Importantly, the current political revolution should not be viewed as solely political. Writing about the French Revolution, Mill noted that "All political revolutions not effected by foreign conquest originate in moral revolutions." (2) Mill recognized the French political revolution as originating from a moral revolution that rejected an inegalitarian conception of morality, where aristocracy and church determine rightness of action, and replaced it with an egalitarian conception. Public outrage over scandals like Thalidomide, Willowbrook, and Tuskegee provided the opportunity for the bioethics moral revolution in the 1970s and 1980s and its resulting influence on research, medical education, clinical practice, policy development, and societal influence (1,3). In our present moment, the nature of the concurrent or preceding moral revolution is less clear, but it seems to include rejection of concepts of egalitarianism, communitarianism, equity, and perhaps the common morality.

In its current form, bioethics may struggle to meet this moment. Much of the foundation of bioethics begins with an appeal to the common morality (4-6). Does the current revolution suggest that the common morality is much narrower than previously perceived? If bioethicists do not appeal to a common morality, what provides its legitimacy or standing? Bioethics occupies a space between government and biomedicine. It is beholden to both. For example, the American Society of Bioethics and Humanities ASBH Core Competencies for Healthcare Ethics Consultation note that ethics consultants should make sure decisions stay within the bounds of "prevailing ethical and legal standards." (5, p.9) Bioethics is reactive to medicine and medical research, and technocratic with its focus on reform within the existing governmental and biomedical systems. In addition, bioethics and medicine and medical research operate under shared paradigms — paradigms that assume that healthcare, research, and technology are positive; research participants deserve protections; and that patient autonomy and informed consent are paramount. In this American revolution, the space for bioethics is narrowing and may be disappearing to be replaced by advocates, special interest groups, or corporate interests (7). The paradigms within bioethics have become unstable and may not survive these serious challenges. The traditional role of reform within the previous paradigms will not meet the demands of the current moment.

In considering this moment, it is critical to recognize that this political revolution, and its underlying moral revolution, will have limitations. Its new morality will fail to resolve existing challenges and create new ones. There will be important gaps in public policy, health policy, research, and patient care. Eventually, such gaps will result in scandal. The public will rebel. Such moments Baker argues "enable opinion leaders and others to peer beyond accepted paradigms and glimpse the world through the lens of an alternative new paradigm." (1, p.20) Bioethics will need to change to meet these needs. I offer four suggestions to meet this revolutionary moment.

MOVE PAST PARTISANSHIP AND ANY PRETENSE OF MORAL ABSOLUTISM

Bioethics was initially embraced, at least partly, because it promised to provide a space for morally neutral, apolitical, discourse and was thought to have its foundation in the common morality (8). At present, bioethics suffers from an increasing real or perceived partisanship. In a critique of the field, Evans argues that bioethics has failed to reflect the views of a substantial portion of the US population (7). Certain segments of society, such as much of the religious right and libertarians, have not participated in bioethics discourse, scholarship or public policy efforts. These groups do not accept that the bioethics profession advocates for the public's values in public policy or ground their appeals in a common morality; instead, they maintain that bioethics advocates for particular liberal political values not shared by much of the public. Evans gives the example of the schism that arose among bioethicists during Leon Kass's tenure as chair of George W. Bush's President's Council on Bioethics. Kass argued that the methods of bioethics and previous President's councils excluded other perspectives, particularly from Conservative Christians and Evangelicals, and debated upon predetermined ends in biosciences rather than ends for humanity (9). Such views were met with derision and disdain from other bioethicists. Subsequently, each side became aligned with their own political parties and affiliated social movement organizations such as Planned Parenthood, the National Right to Life Committee, Paragon Health, Whitman-Walker Institute, or Evangelical groups. As a result of this partisanship, the influence of bioethics and bioethicists upon government regulation and public policy about health and biosciences has waned and been replaced by activists or political groups who make no appeals to, or claims to represent, a common morality (7).

Similarly, bioethics and bioethicists should abandon moral absolutism and absolutist rhetoric. Moral absolutism elevates ethical ideals to the status of universal truths surrounded with an aura of false objectivity that are unlikely to reflect the common morality (1). This seeming objectivity can undermine pluralism, exclude others, and overlooks that bioethicists are not infallible and that morality drifts, is reformed, and can undergo revolution.

Partisanship or absolutism, real or perceived, serves little purpose in our field other than to further diminish its legitimacy. The work of bioethics and bioethicists should not exactly match the policies or beliefs of any political movement. Instead, bioethics and bioethicists need to ally themselves with the shared moral values of the public and those who hold them. To meet this moment, we need to revive the virtue of humility and our ability to discuss with, interact positively with, be curious about, and care about those with whom we disagree. We need to seek out those who hold marginalized and differing views and promote an open environment for discourse. Imperfect examples include George W. Bush's President's Council on Bioethics, The Seattle Growth Attenuation and Ethics Working Group, and conferences such as Decision Making and the Defective Newborn, After Barney Clark, and Cognitive Disability: A Challenge to Moral Philosophy (10-13), which sought to bring those with wide-ranging views together to engage in what Jonsen called "dialogue... not merely the willingness to converse, but a conviction that truth could be uncovered by that conversation." (10, p.41) We must recommit to promoting respectful multidisciplinary, multi-view, and multi-community discourse as was present at the founding of the field, and we must do more. We should seek to bring together disparate groups focused on human flourishing, and amplify the voices of those who are marginalized, oppressed, or excluded from current discourse. Inclusion of disparate groups also requires seeking to include those who may currently be, or have previously been, censured for expressing viewpoints — whether intentional or inadvertent — that are perceived by some as harmful. Such viewpoints may include, but are not limited to, those considered ableist, racist, or transphobic. While ableism, racism, and transphobia should not be amplified, respectful attempts to probe, clarify, and understand the views of those with whom we disagree is critical to broad inclusion and identification of shared values rather than exclusion. While challenging, such a course offers the best chance to rebuild a foundation of common morality that provides our field with legitimacy and bioethicists have the skillset to do it.

CRITICALLY CONSIDER THE ROLE OF HONOUR IN UNDERSTANDING AND RESPONDING TO OUR CURRENT MOMENT

Having honour means being entitled to respect. Though honour is morally neutral, Appiah has argued that concern for honour may sustain harmful beliefs and practices. Yet this concern can also galvanize individual moral convictions, collective associations, public campaigns, and social change (11). An honour code says how people with certain identities can earn the right to respect from others. As Appiah notes "we live not after honor but with new forms of honor" (11, p.193). Recent sociological analyses note the role of honour within shared deep narratives that contribute to failures of reasoned appeal and seemingly counterintuitive choices among constituents. Examples of such narratives include, "I deserve respect and to be recognized as better or more deserving than someone else" and "it's unfair that others are getting ahead of or apace with me." (12-14) Until these deep narratives are recognized, engaged with, and shift, moral arguments may remain ineffective at persuasion or promoting change (1,11-14).

Honour has also become tied to political values, and perhaps bioethical positions, about topics such as abortion, stem cell research, or definitions of death. Consider the responses of prominent bioethicists to the case of Jahi McMath. Statements such as "Their thinking must be disordered, from a medical point of view. ... There is a word for this: crazy", "you can't really feed a corpse," and "her body will start to break down and decay. It's a matter of when, not whether" are closer aligned to maintaining honour than an ethical position (15,16). Bioethics has had relatively little direct engagement with honour, perhaps considering its influence on modern life as outdated (11). Yet further exploration may offer a pathway to deeper dialogue with communities that hold seemingly opposed views or maintain incongruous or self-defeating beliefs (1,11). Cultivating curiosity about identity, sources of pride and shame, and reframing opportunities for respect may be critical in creating spaces for civil discourse, deliberation, and positive changes in health and the biosciences.

EMBRACE OUR NEW (OLD) ROLE AS OUTSIDERS AND MORALISTS

One role of bioethicists has been to serve as moralists. Moralists perceive as morally questionable or immoral what those around them do not find morally suspect or immoral (3). Insider moralists — that is, those operating within traditional systems of power such as government, law, academia, and biomedicine — do not have a clear role in a revolution if the wider community and its authorities do not share the moralists' perception of immorality. As in previous revolutions, when moralists speak out in opposition, they risk ostracism and censure by their immediate community and invite the wrath of its authorities (3). In the current environment, that could mean public censure, the withholding of federal funds or cancellation of grants, or being targeted through legal mechanisms. This places bioethicists and their institutions in an unenviable situation: speak out and risk the wrath of the revolution, remain silent, or engage in anticipatory compliance?

In this revolution, it may be necessary to return to our status as outsiders. As Baker describes, the field of bioethics was created and shaped by outsiders (3). Examples include Francis Kelsey's efforts to call for drug safety and the informed consent of research participants; reports of scandalous research abuses by Maurice Papworth, Peter Buxton, William Hyman, and others; and George Wiley's activism in support of the patient's rights movement (3,10). Early bioethicists were also outsiders. Warren Reich and Robert Baker described those entering bioethics at the beginning of the field as possessing a shared a commitment to focus on the care of the whole person, pluralism, a contextual appreciation of the complexities of moral decision-making, and "the conviction that ethics must be prepared to be countercultural, ready to challenge the moral priorities of powerful institutions." (17, p.167). Outsider status allowed for perception of moral wrongs not clearly visible to insiders. We should embrace a return to this role.

Outsider status may allow for a reconsideration and potential broadening of the scope of bioethics. Bioethics has focused largely on individual decision-making rather than broader social concerns. This focus, Bosk argued, led bioethicists to exclude other political issues that could be defined as ethical questions: "the presence of so many millions of Americans without health insurance, the multiple ways the production pressures of managed care undercut the possibilities of the doctor-patient relationship that bioethics celebrates, the inequalities in health status between rich and poor, or the replacement of professional values with corporate ones." (18, p.64) In our current moment, outsider status may allow our focus to expand to encompass the ends of humanity or flourishing — thereby bringing to the centre universal issues such as global warming, poverty, pollution, education, racism, classism, and war. The field could also widen from being centred on individual human beings to one that centres relationships or communities alongside individuals or shifts to broader consideration of the welfare of all living things.

LIKE THE CURRENT US ADMINISTRATION, BIOETHICS NEEDS TO DO THINGS

A feature of the current political revolution in the US has been the remarkable ability of revolutionaries to "do things" and enact widespread change in a very short period (19). As a field, and as individuals, we must seek to do the same. In the context of unjust law and policies, protest and civil disobedience are necessary, but alone they are insufficient and fail to contribute positively to the current discourse or offer solutions to problems. Baker argues that no insurrection has successfully disestablished a dominant moral paradigm without offering an incompatible alternative paradigm (1). When this revolution fails, bioethicists can be invaluable guides whose expertise may offer a new appreciation of significant anomalies and open pathways to alternative paradigms (1). We must partner and ally with communities and be active within institutions, professional societies, and as individual scholars striving to develop solutions to the problems presented by the current revolution. While it is difficult to predict from within the current revolution, such efforts may necessitate changes in the purview and focus of bioethics from a preoccupation with autonomy, self-determination, and the rights of individual patients or research participants in isolation, in order to devote greater attention to the communities and environments in which they live and engage with one another. There may also need to be a shift away methodologies which rely on foundations of rationality and impartiality to those which prioritize connection, kindness, humility, and love.

The sum of these suggestions may be no less than a new paradigm for bioethics with a new understanding of the field and its purpose. The underlying goal, as Appiah puts it, is that in the future most of the community will look at our present moment and ask "What were we thinking? How did we do that?" (11, p.12). As Baker notes, "As in any other conflict between incompatible paradigms no empirical data or clever argument can resolve the issue or persuade someone to change his or her view — only a paradigm shift can culminate in a change of views." (1, p.17). This means the time is ripe for a call for a second bioethics revolution.

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TÉMOIGNAGE / PERSPECTIVE

Protecting Peer Support Values and Ethics Through Community-Engaged Bioethics

Lee de Bie^{a,b,c}, Julia Knopes^d, Allison Dunning^e, Allyson Theodorou^f, Brookelyn Fortier^e

Résumé

Il existe une longue histoire d'échanges fructueux entre le soutien par les pairs (SP) aux États-Unis et au Canada, mais la collaboration a diminué au cours des deux dernières décennies, le SP s'étant de plus en plus professionnalisé. Grâce à la reconnaissance et au financement du gouvernement, le SP est passé d'amitiés informelles au sein de la communauté entre personnes ayant vécu des expériences similaires à un emploi rémunéré dans les services cliniques. Dans ce commentaire, nous soutenons que le SP au Canada et aux États-Unis devrait recommencer à travailler ensemble. Nous partageons les défis éthiques liés à la professionnalisation — et à la cooptation et à la dérive qui y sont associées — du SP, qui s'éloigne de ses fondements uniques que sont les relations humaines authentiques, l'organisation de mouvements sociaux et les valeurs fondamentales d'autodétermination, de partage du pouvoir, d'espérance et de mutualité. La perte de pouvoir transformateur du SP qui en résulte est particulièrement importante à l'heure actuelle, alors qu'il a tant à offrir. Nous décrivons comment notre équipe de bioéthiciens engagés dans la communauté au Canada et aux États-Unis et les leaders de la discipline SP au Canada collaborent pour élaborer, légitimer et protéger les valeurs et l'éthique uniques de cette modalité de soins en pleine expansion et en constante évolution.

Mots-clés

bioéthique communautaire, cooptation, dérive du soutien par les pairs, professionnalisation, mouvement des survivants de la psychiatrie

Abstract

There has been a long history of cross-pollination between peer support (PS) in the United States and Canada, but collaboration has declined over the past two decades as PS has become increasingly professionalized. With government recognition and funding, PS has moved from informal friendships in the community towards paid PS employment in clinical services. In this commentary we argue that PS in Canada and the US should return to working together. We share ethical challenges related to the professionalization — and associated co-optation and drift — of PS, where PS deviates from its unique grounding in authentic human connection, social movement organizing, and core values of self-determination, shared power, hope, and mutuality. The resulting loss of the transformative power of PS is particularly potent in our current moment when it has so much to offer. We describe how our team of community-engaged bioethicists from Canada and the US and leaders of the PS discipline in Canada are collaborating to elaborate, legitimize, and protect the unique values and ethics of this expanding and evolving modality of care.

Keywords

community-engaged bioethics, co-optation, peer support drift, professionalization, psychiatric survivor movement

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INTRODUCTION

Peer support (PS) is, in its most expansive sense, “a naturally occurring, mutually beneficial support process, where people who share a common experience meet as equals, sharing skills, strengths and hope; learning from each other how to cope, thrive and flourish.” (1) Formal PS “begins when persons with lived experience who have received specialized training, assume unique, designated roles...to support an individual’s expressed wishes.” (1) Although formal PS is a growing approach to relational support that can improve mental health outcomes, address health disparities, and reduce healthcare costs (2), it has been under-supported by bioethicists.

There has been a long history of cross-pollination between PS in the United States and Canada, but collaboration has declined over the past two decades as PS has become increasingly professionalized. With government recognition and funding, PS has moved from informal friendships in the community towards paid PS employment in clinical services (3). In this commentary, we argue that we should return to working together through shared ethical challenges related to the professionalization — and associated co-optation and drift — of PS. We describe how community-engaged bioethicists can support the PS discipline in elaborating, legitimizing, and protecting the unique values and ethics of this expanding and evolving modality of care.

HISTORICAL INTERCONNECTEDNESS OF PEER SUPPORT IN CANADA AND THE US

PS in Canada and the US has a long and shared history. One tradition of PS commonly practiced today in health systems in Canada was inspired by the advocacy, community organizing, and self-help initiatives of the 1960s-1970s psychiatric

consumer/survivor/ex-patient (C/S/X) movement in the US, which was informed by — and interconnected with — other liberation movements of the era (4).¹ For example, the critiques of scholars writing from the US, such as Goffman (7-8) and dissident mental health professionals like Chesler (9) and Szasz (10-12), fueled the movement in both countries, at a time when there were few such leaders in Canada (13-15). These authors' critical analyses of the psychiatric system helped PS emerge as a less harmful alternative.

The 1980-1990 production of *Phoenix Rising*, a Toronto-based national psychiatric survivor newsletter, was inspired by the American *Madness Network News* (15), and the online publication *Mad in Canada* arose as an affiliate website of the widely-read *Mad in America*, founded in 2012. These publications played a significant role in spreading PS knowledge and practice. The 1990s development of "recovery philosophy" in the US, which emphasizes how individuals can live purposeful, hopeful, and meaningful lives even in the midst of mental health challenges (16-17), became a key principle of PS in Canada in the early 2000s (18). *Making the Case for Peer Support*, the foundational document promoting the expansion of PS in Canada, heavily references research evidence and best practices from the US (3).

This influence is bidirectional. For example, Judi Chamberlin, a key leader in the American psychiatric survivor movement, dedicates a full chapter of her 1978 seminal book to describing her visit to the Mental Patients Association in Vancouver (19). The expansion of Mad Pride in the US and internationally as a community-building initiative and alternative to biomedical paradigms was informed by early 1990s Psychiatric Survivor Pride Day activities in Toronto (20-21). The Canadian development of Mad Studies in the 2000s, an academic discipline emerging from the C/S/X social movement, has also spread to inform PS in the US and beyond (22-23).

This flow of ideas between the US and Canada has informed the design of PS programs, and the consolidation of PS values and ethics (24). Without US "evidence" of peer support's legitimacy and effectiveness, our uptake of this approach in Canada would have been significantly delayed.

SHARED PRESENT-DAY CONCERNs ABOUT PROFESSIONALIZATION AND PEER SUPPORT DRIFT

Over the past two decades, PS has become increasingly professionalized. There is a growing expectation that peer supporters complete training and certification before they go on to work within clinical environments. While both countries have tracked a similar trend, the speed and scale of professionalization in the US have greatly surpassed that in Canada. For example, in 1993, New York was the first US state to establish a formal "peer specialist" role title, conveying recognition of unique expertise (25). In 1999, Georgia became the first state to allow government-funded Medicaid billing for peer support services, which was expanded nation-wide in 2007 (25-28). As of 2014, 38 US states had peer specialist certification programs that required completion of a state-approved training course and/or multiple-choice exam (25,29). In contrast, Canada has a national, voluntary, PS certification program that is peer-run with no government influence.

While training and certification requirements can ensure that peer supporters have the necessary skills to journey with people in their recovery, PS practitioners and scholars have critiqued these mechanisms in the US as a loss of self-governance and control over PS education that poses a risk of great harm to the integrity of the practice. For instance, Penney and Prescott raise alarm that some state-based programs do not include training on the core values and history of grassroots PS (25). When clinical training (e.g., in diagnoses, therapies) is valued more than lived experience, or overrides or replaces experiential skills and knowledge, PS experiences epistemic injustice, drifts from its roots in authentic human connection and civil rights struggles, and fails to offer a distinct alternative to traditional health services (24,29). Activists in the C/S/X and PS movement have worried about this threat — most often called "co-optation" in US scholarship, and "peer (support) drift" in Canada — for many years, but we're seeing increased concern among US and Canadian practitioners, as well as those writing from the UK, Australia, Germany, and internationally (42-47).²

PS drift is an ethical problem caused by a deviation from the unique PS values of self-determination, shared power, hope, voluntariness, mutuality, and social justice (25,39,48). Dynamics pushing peer supporters to drift from their values are complex. As an example, many peer supporters in Canada hold precarious and isolated roles in workplace cultures that are often incongruent with PS values (e.g., hierarchical provider-client relationships; medical diagnoses that take away a person's power of self-definition; use of non-voluntary, paternalistic, and coercive practices of social control) and do not respect their lived experience. It is difficult to continue the emancipatory impulse of the C/S/X social movement and challenge the status quo when they lack power and support to do so (3,48).

Additionally, in a clinical environment where non-peer supervisors and colleagues misunderstand the unique role of PS, peer supporters are often directed to set more rigid, emotionally detached, "professional" boundaries akin to those of clinical professionals (38). These expectations prevent them from performing the core responsibility of the PS role, which is to draw

¹ While beyond the scope of this commentary, it is important to note that both Canadian and US psychiatric survivor and peer support movements have been influenced by international efforts, especially those in the United Kingdom and global efforts to protect human rights (5-6).

² For example, a search of the blog *Mad in America* returned 1010 hits for the keyword "co-optation" and only two for "peer drift". Other American texts also tend to adopt the term "co-optation," (19,25,26,30-37) while "peer (support) drift" is the more common term in Canada (38,39). Our best guess is that this phrase was popularized in the Canadian PS community by Theresa Claxton-Wali (40), a North Toronto-based PS leader, inspired by the work of US Veterans Affairs (41).

on and meaningfully disclose their lived experience to build mutual and trusting relationships with peers and facilitate the sharing of power and learning (42).

PS drift causes significant harm and loss to health systems, society, and peer supporters. Crucially, when values-based PS is practiced with integrity, it has a unique ability to bridge gaps in the healthcare system, address the unmet needs of marginalized groups, and reduce stigma and isolation through the rebuilding of relationships and community. When PS drifts from its special role and essential features and duplicates conventional health services, we are deprived of these health equity-enhancing possibilities, and peer supporters themselves can be harmed through moral injury, exploitation, and a waste of their capabilities (48-50).

This loss of the transformative power of PS is particularly potent in our current historical moment. PS emerged as a successful response to the 1960s-1970s upheaval of oppressive societal structures, authority, laws, traditions, and norms through the creation of radical self-help alternatives (4,27). PS can do so again now, preventing the pathologization and medicalization of human distress and supporting individuals and communities in weathering our current times (51,52), if its core values and outcomes are preserved.

THE DECLINE OF PS INTERCONNECTEDNESS IN THE WAKE OF PROFESSIONALIZATION

The increasing turn to the professionalization of PS over the past two decades has focused inward, locally, provincially, and nationally, and taken us away from cross-national collaboration. In the US, many PS initiatives are now tied to state-based certification and Medicaid funding. In Canada, PS became increasingly valued as a component of the publicly-funded Canadian health system when the Mental Health Commission of Canada was established and published the first national mental health strategy in 2012 (53).

While government funding has supported internal capacity building of PS initiatives in Canada, the PS discipline has not been afforded adequate resources to facilitate sustainable provincial or national PS conversations, much less international ones. Additionally, the majority of Canadian advocacy to address PS drift and protect PS values is necessarily directed locally — at government policy, funding models, health system restructuring, and community partnerships (48). This loss of Canadian-US collaboration arguably weakens our national and international PS movement.

To address co-optation, peer supporters are encouraged to connect to the psychiatric survivor movement and its values and struggle for human rights and self-determination (30). In Canada, we've started returning to stories about the "roots" of PS in the psychiatric survivor movement, histories often interwoven with activism from the US (48,54). We need to collectivize beyond state-based borders.

FUTURE DIRECTIONS: COMMUNITY-ENGAGED BIOETHICS TO ADVANCE PEER SUPPORT ETHICS

One recommendation for preventing and addressing PS drift that emerged through consultations with peer supporters across the province of Ontario is to further consolidate ethical guidelines specific to the PS role (48). We therefore came together as a team of two bioethicists with backgrounds in PS (one from Canada, and one from the US), the Executive Directors of the national Canadian and provincial Ontario PS associations, and several supporting peer supporters and academic colleagues, to explore how to best support PS ethics.

Funded by research planning and knowledge translation grants from the Canadian federal government, we are pursuing several activities. First, we have observed that the esoteric academic theory and concepts of "ethics" are rarely discussed in PS communities (or when they are, have been noted to be inaccessible) (55). Yet we wondered how an effective translation of academic ethics tools into PS language and practice might help the PS discipline address its serious concerns about co-optation and drift from PS values. We thus developed a 4-session Community of Practice on PS ethics that we have facilitated with three cohorts of peer supporters from across Canada, using several ethical reflection tools we have adapted for a PS audience.

Second, PS ethics have been cultivated orally within PS communities for decades but have not been well defined and documented in the ways that tend to garner broader recognition and respect (3). Accordingly, we are engaged in national consultation about potentially developing a PS Code of Ethics. We are deepening our understanding of the shared challenges we face as peer supporters across Canada and national borders, and areas of potential consensus and difference regarding PS ethics, as influenced by the diverse organizational contexts in which peer supporters practice, as well as individual variation in peer supporters' values and beliefs. We hope that this consensus-building project can help us collectivize across Canada, as well as help us communicate with PS associations internationally.

Third, our collaborative work aims to re-ignite the flow of ideas and collective momentum between the Canadian-US-international PS movements through development of the (currently very limited) international academic literature on PS ethics (56). Further scholarship on PS ethics can help describe and validate the skill and intentionality that peer supporters bring to their work, the values and social movement traditions that ground their approach, and how their ethical practices are

no less valid and robust than those of other health professions (56,57). Contributing to the evidence base for PS can help practitioners defend the legitimacy of their practices and resist PS drift. We are therefore working to strengthen relationships with interdisciplinary researchers, ethicists, and peer supporters to begin conceptualizing a future research project.

Bioethicists have a role to play in supporting the PS discipline (56). The risk for co-optation and drift of PS is highest in the conventional healthcare settings in which bioethicists predominantly work, but we are unaware of examples of bioethicists beyond our team who are collaborating with peer supporters to address these concerns.³ Furthermore, we must address the critique that bioethics is largely focused on the dramatic clinical ethics issues in in-patient healthcare settings and poorly engaged in organizational ethics and supporting our communities, including predominantly community-based peer supporters, with their everyday ethical questions and needs (60). PS values and ethics are a promising antidote to our current crisis. They deserve our full support.

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TÉMOIGNAGE / PERSPECTIVE

Moral Space Through Professional Solidarity

Stephen S. Hanson^a

Résumé

Créer un espace moral implique des actions et des omissions. Une omission importante en matière de solidarité consiste à refuser d'organiser ou d'assister à des congrès professionnelles dans des pays et des États américains où les lois et l'approbation sociale rendent la participation inconfortable, imprudente ou dangereuse pour certains membres de la communauté professionnelle. Le principe du sacrifice inadmissible de Markowitz, qu'elle a utilisé pour critiquer les politiques en matière d'avortement, est utilisé pour montrer pourquoi il est erroné d'organiser une conférence professionnelle dans un tel État et pourquoi la solidarité nécessite le soutien de toutes les personnes morales. Si cet article décrit l'importance de ce principe aujourd'hui en ce qui concerne les personnes LGBTQ+, il pourrait également s'appliquer bientôt, voire dès maintenant, aux personnes de couleur, aux femmes ou aux citoyens non américains en visite. Il montre également pourquoi la solidarité contre les sacrifices inadmissibles est un meilleur moyen de fonder les décisions concernant le lieu ou la participation à des congrès qu'un argument téléologique sur les boycotts visant à changer les politiques.

Mots-clés

LGBTQ+, espace moral, professionnalisme, sacrifice, solidarité, lois étatiques, transgenre, États-Unis

Abstract

Creating moral space involves actions and omissions. An important omission of solidarity is to refuse to hold or attend professional conferences in countries and American states where laws and social approbation make it uncomfortable, unwise, or dangerous for certain members of the professional community to attend. Markowitz's Impermissible Sacrifice Principle, which she used to critique abortion policies, is employed to show why it is wrong to hold a professional conference in such a state and why solidarity requires the support of all moral persons. While this article describes the importance of this principle now in terms of LGBTQ+ persons, it may also apply soon or even now with regard to persons of colour, women, and/or visiting non-American citizens. It is also shown why solidarity against impermissible sacrifices is a better way to ground decisions about locating or attending conferences than a teleological argument about boycotts to change policy.

Keywords

LGBTQ+, moral space, professionalism, sacrifice, solidarity, state laws, transgender, United States

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One of the most important things that can be done to create moral space in these troubled times is to maintain solidarity with oppressed groups. One specific way this should be done is by avoiding holding and attending professional conferences in areas of the US which are hostile to some potential attendees.

I have previously argued that it was inappropriate to hold the 17th World Congress of Bioethics in Qatar because this placed an "Impermissible Sacrifice", as defined by Sally Markowitz, on LGBTQ+ persons, especially those who do not pass easily in heteronormative spaces (1). The same general form of argument applies to holding any conferences in multiple US states with restrictive laws against transgender persons. The conclusion of this must be that not only bioethics groups, but indeed any group interested in behaving ethically, must not hold conferences in these US states.

This follows from an important argument made by Markowitz in the context of abortion (2), arguing that it is particularly unjust to force an oppressed group to sacrifice in order to help maintain their own oppression. Markowitz argues that legally prohibiting abortion in a society where "[w]omen are, as a group, sexually oppressed by men; and this oppression can neither be completely understood in terms of, nor otherwise reduced to, oppressions of other sorts" violates the "Impermissible Sacrifice Principle," which is "*When one social group in a society is systematically oppressed by another, it is impermissible [unjust] to require the oppressed group to make sacrifices that will exacerbate or perpetuate this oppression.*" (2, p.7) In Markowitz's argument, she is objecting to women having to sacrifice by carrying unwanted pregnancies to term when that sacrifice will help to perpetuate this oppression of women; this principle can apply with as much validity to other sorts of sacrifice in other contexts.

Based on this, I argued that it is impermissible to hold a conference in Qatar, a country which explicitly makes being LGBT illegal, which has no legal protections for LGBTQ+ persons, where it is not clear that the state would respond to stop a group beating someone up because they were perceived to be gay, lesbian, or transgender (3), and where the state may try to target visiting LGBTQ+ persons through use of social media (4,5). It is impermissible not only because these are morally unacceptable laws and behaviours, but because the sacrifices that this requires of LGBTQ+ persons — either closeting themselves if they can pass heteronormatively, not attending the conference (at least not in person) or risking their health and freedom — actually help to maintain their oppression. Societies are most able to discriminate against persons perceived as different when they can control the public perception of those persons, and requiring persons to pass heteronormatively or

face risk of state-sanctioned violence allows persons in that society to see very few LGBTQ+ persons outside of caricatures approved by the state. Consequently, I argued, any conference, meeting, or group association — but especially one focused on ethics — ought to employ a basic test for locations and rule out those where some attendees would be likely to feel significantly less safe and comfortable attending the conference and exploring the local city outside the conference than they would in their home country/city.

Participation in a conference virtually is still possible without risk to health and safety; however, it retains much of the sacrifice that inability to attend would provide. Virtual attendance asks that LGBTQ+ persons sacrifice some of their professional development in order to help maintain their own oppression. Since so much of the function of a conference is not just papers and colloquia, but also collaboration, networking, and professional reinvigoration through informal conversations and interactions, virtual attendance is a poor substitute when others are able to attend in person. It remains a sacrifice to be forced to attend only virtually for fear of one's safety. Further, virtual attendance does not prevent the maintenance of one's own oppression, since it allows the discriminatory society to maintain its discrimination by keeping LGBTQ+ persons from having normal representation in society.

By this argument, Qatar is not the only place where an ethics-related conference ought not be held. The same should apply to the multiple US states who have or will soon have, if expected legal changes are made in the next few years, significant restrictions on transgender persons. Multiple states currently have or are seeking to pass such restrictive laws. The specific laws that are most problematic are “bathroom laws” which seek to restrict persons who are transgender from using the bathrooms, changing rooms, and other “single-gender” spaces that match their outward presentation and internal self-understanding of their gender. Other laws and behaviours contribute to a hostile environment that can make conferences in those states also unacceptable. Notable examples include restricting the use of preferred names and pronouns in school settings, language restrictions to attempt to erase acknowledgement of LGBTQ+ persons in schools, grants, universities, and government documents, and the glee with which Governor Abbott of Texas enjoyed the firing of a person for including their pronouns in their email signature (6) or the (repeated) painting over of a rainbow crosswalk memorializing “the deadliest act of violence against LGBTQ+ people in U.S. history” at the Pulse nightclub in Orlando (7).

An identical form of the Qatar-directed argument will not work directly. A significant portion of that argument was that Qatar's population sees very few openly LGBTQ+ persons; the ability of the state of Qatar to discriminate against LGBTQ+ persons is enabled by this lack of awareness. Most persons in the US are not as unaware of LGBTQ+ persons. Still, a very similar argument can show that there is an Impermissible Sacrifice being demanded of LGBTQ+ persons, specifically but not exclusively transgender persons, in these states.¹

Social approbation of LGBTQ+ persons can be maintained by a state like Qatar when very few LGBTQ+ persons are even known by the general public. But it can also be maintained by a US state if the majority of LGBTQ+ persons are seen only through a political lens rather than as just everyday participants in society. If the only LGBTQ+ persons widely known are politically active, even if only politically active against laws that harm them, then the entire group can be minimized and demonized as an “Other.” If most non-LGBTQ+ persons only know of LGBTQ+ persons as members of an active group promoting a political agenda that can be posited by politicians, media, religious groups, etc., as evil, anti-family, anti-science, or otherwise wrong, then they can be positioned by those persons as being an outside group to be placed in opposition to a group that can think of themselves as the “Us” in an “Us vs. Them” dynamic. This further enables the non-LGBTQ+ residents of a state to perceive themselves as an oppressed group, even though they are in a significant numerical majority. Being able to categorize LGBTQ+ persons as an impersonal juggernaut rolling over “Our” common everyday lives allows for unlikely, even absurd positions to be held (e.g., “the gay agenda”, “Rapid onset gender dysphoria”, “groomers”, and other implausible conspiracy theories). This contributes to the harm and risk of harm of visiting such an area. Conversely, if LGBTQ+ persons are seen as doctors, nurses, professors, theologians, or other persons who might be conference attendees, this sort of paranoia becomes much harder to maintain.

If part of the point of a state enabling conferences to take place there is to benefit the state through taxation, entertainment, and increased visibility and tourism, then the state benefits from having a conference. If visitors to a state are made to feel uncomfortable being openly LGBTQ+ to the point where they must sacrifice their safety or their selves in order to attend the conference, or their careers by avoiding it, they must sacrifice because of that conference being in that state. They must risk harm, hide their real selves (if possible) or avoid the professional benefits that come from attending the conference. For the state to benefit while LGBTQ+ persons are required to sacrifice in a way that benefits a state that is actively hostile to their lives, means they are required to sacrifice to help maintain their own oppression.

The argument derives its moral value from solidarity. It undermines solidarity to make persons choose between different modes of reinforcing their own oppression, and this solidarity is not just with LGBTQ+ persons but with all persons. First, there are individuals who are in the threatened community (in the US this is currently mainly trans persons but may include any within the umbrella of LGBTQ+) but are able to pass as heteronormative. They may choose to obtain all the benefits of attending a conference in person, including the business contacts, invitations to present or write for other people's projects, learning, teaching, camaraderie, and so on that influence careers in many small ways. Doing so means, of course, suppressing and

¹ Arguably this applies to the whole of the United States regardless of state, because of federal positions taken by the current administration. This possibility will not be directly addressed here.

hiding a part of oneself, but it also means benefiting while at the same time maintaining the oppression of others who cannot or choose not to attend. Persons in this group have a decision to sacrifice benefit to their own development and careers, in solidarity with those who cannot pass heteronormatively, or to attend and benefit their own careers.

The second group is LGTBQ+ people who do not pass easily as heteronormative. They do not have the above option to attend with little risk to themselves. If they attend, they may gain the benefits of attendance, but only at significant risk of verbal, physical, or legal abuse from residents or law enforcement of the locality where the conference is held, and likely without being able to fully experience the social aspects of a gathering. Conversely, these persons may choose not to attend to avoid these risks.

The third group is persons who are not LGBTQ+ and appear as society expects persons of their sex and gender to appear, and the fourth is persons who are not LGBTQ+ but who do not always appear as society expects of them. This latter group is often forgotten but is becoming more widely recognized as cis/straight persons find themselves emboldened to challenge other people who don't match their expected views of (usually) femininity.² This currently is seeing the most impact in policing women's bodies in sports and public bathrooms, but as bills proposed in multiple states suggest, it may soon be applied anywhere in public. This policy allows all four groups to be in solidarity with each other as the only way that they can all be supported. It is not merely a matter of being in solidarity with LGBTQ+ persons, but rather with all persons.

It is important to note several points about this argument. This is not an argument for a boycott in an effort to force, through financial or social pressure, change in the objectionable laws of these states. Whether such an argument is good would be at least partially dependent upon the likelihood of such a boycott having the desired effect of policy change. Instead, this argument is valid whether any change in the laws is likely. If such a boycott were to be effective that would be a bonus, but the force of this argument is as strong even if, as is possible, it results in no change at all in the laws of the states or even reactionary backlash. Unlike these sorts of teleologically grounded arguments, the grounding for this objection lies in the moral offensiveness of forcing oppressed individuals to sacrifice in order to participate in the oppression of themselves, others in their oppressed group, or both.

In addition, it does not matter whether a state puts forth a “biology-based” argument for their laws. Although these arguments are not generally valid, this critique does not depend upon them being wrong. Even if something is true, enforcing a policy based on it that causes an oppressed minority to sacrifice to help maintain that oppression is still morally unacceptable.

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² But not always. The person fired in Texas for referring to his pronouns in his email signature was a man assigned male at birth using he, him pronouns.

TÉMOIGNAGE / PERSPECTIVE

This Year's Bioethicist: From Influencer to Prophetic Educator

Mark Kuczewski^a

Résumé

Au cours des 50 dernières années, les bioéthiciens professionnels ont été de plus en plus acceptés dans les milieux médicaux et universitaires aux États-Unis. Cependant, depuis l'arrivée au pouvoir de l'administration actuelle en janvier 2025, les questions concernant le rôle approprié des bioéthiciens dans la préservation des valeurs et de l'éthique des établissements médicaux et universitaires se sont multipliées. Je soutiens que la caractérisation tripartite habituelle du service, de la recherche et de l'éducation reste valable, mais que notre interprétation de ces rôles et de leur importance relative a changé. Si notre rôle établi d'influenceurs des politiques institutionnelles reste important, le climat de silence induit par la peur nous oblige à mettre l'accent sur notre voix prophétique pour appeler les professions et les institutions de santé à rester fidèles à leurs valeurs fondamentales. En outre, je recommande de mettre à nouveau l'accent sur l'éducation de base des professionnels afin de consolider leur formation.

Mots-clés

liberté académique, EDI, peur, influenceur, immigration, professionnalisme, représailles

Abstract

Professional bioethicists have gained increasing acceptance in the healthcare and academic communities of the United States over the last 50 years. However, since the current administration took office in January 2025, questions concerning the appropriate role of bioethicists in preserving the values and ethics of healthcare and academic institutions have abounded. I argue that the usual tripartite characterization of service, scholarship and education still apply but how we interpret those roles and their relative importance has changed. While our established role of influencers of institutional policies remains important, the climate of fear-induced silence challenges us to emphasize our prophetic voice in calling the healthcare professions and institutions to remain faithful to their fundamental values. Furthermore, I recommend a renewed emphasis on basic education of professionals to solidify their formation.

Keywords

academic freedom, DEI, fear, influencer, immigration, professionalism, retaliation

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INTRODUCTION

The climate in which US healthcare institutions and universities operate has changed so dramatically since January 2025 that nothing seems the same. These institutions are now under a plethora of pressures that had previously seemed unimaginable. For instance, efforts to promote diversity, equity, and inclusion (DEI) are suddenly feared to place these institutions at risk of investigations and withholding of federal funding. And exercises of the basic freedom of institutional representatives and employees, including professors and students, to express opinions regarding matters such as the human rights of Palestinians can lead to similar consequences in addition to revocations of student and faculty visas, detention, and deportation.

When fear is so pervasive, clear, consistent reasoning concerning moral obligations can be difficult to attain. And rational internal dialogue about policy and ways of proceeding can be eschewed in favour of a risk management strategy of whispering among a very small number of administrative leaders. While this environment is very different from the world in which US bioethicists have thrived for the last 50 years, I believe that bioethicists have the skills and a calling to play important roles within it. I have elsewhere articulated the bioethicist's main role as one of a behind-the-scenes influencer (1,2). However, in a climate where truth is oftentimes suppressed, we must summon the courage to use our voices prophetically and our educational platforms to call healthcare professionals and institutions to truth-based advocacy for patient populations who are unjustly demonized. In other words, bioethicists must build upon our role as institutional influencers and do our work in a more public and educationally engaging manner. I will refer to this role as that of the bioethicist as prophetic educator.

WHAT HAS THE BIOETHICIST'S WORK TYPICALLY LOOKED LIKE?

Bioethics has ancient roots, but its professionalization is relatively new. Questions related to medicine and life and death decisions have been discussed by philosophers at least since the time of Plato's Republic and has a storied history among physicians (3). But the existence of professionals who work in multidisciplinary centres, consult with clinicians and patients at the bedside, engage in fostering ethically compliant biomedical research, and provide recommendations on organizational policies is a phenomenon that began in the second half of the 20th century. Such professionals are still sufficiently few in number in the US that we might better be thought of as an epiphenomenon relative to the massive healthcare establishment. Nevertheless, bioethics has been successful in establishing an awareness of the ethical dimensions of much of clinical practice and biomedical research. This awareness has influenced institutional practices.

Bioethics has provided ordinary, everyday responses to the dramatic. The field has sometimes received impetus from high-profile cases that capture national attention, such as the famous end-of-life cases of Karen Ann Quinlan and Nancy Beth Cruzan, and from scandals that cry out for new safeguards such as the coming to light of US Public Health Service (USPHS) Untreated Syphilis Study at Tuskegee. But when the dust settles, these issues — as they manifest in hospitals, clinics, and laboratories across the country — are ameliorated by things such as improved communication and shared decision-making procedures or increased oversight by multidisciplinary committees. Such approaches do not deny the profundity of the life issues and mysteries involved. But bioethics often makes the issues manageable through routinization of processes. The successful bioethicist sometimes keeps their institution out of the media spotlight through this management of difficult decisions.

I have suggested elsewhere that this method of operation has often allowed bioethicists to gain significant influence in their healthcare and academic institutions (1). Initial suspicions that bioethicists might be “loose cannons” who embarrass their institution through public crusades about the institution’s behaviour or insistence on unrealistically idealistic goals have been overcome. We are often seen as trusted colleagues who have the dual value of managing problems while also reinforcing the integrity of healthcare providers and institutions. Who wouldn’t want a little bit more of that?

This kind of institutional political capital enables a bioethicist to sometimes raise new issues and influence an appropriate response to developments that might otherwise escape the notice of clinical leadership. For instance, in 2024 the state of Florida mandated that hospitals ask patients their immigration status during the admission process. This kind of requirement might not seem terribly important to high-level hospital administrators, and they could unthinkingly delegate its implementation to hospital compliance officers. However, bioethicists called attention to the potentially “chilling effect” on seeking care that this requirement would likely have on patients who are immigrants to the US (4). They were supported by a statement from the Association of Bioethics Program Directors (ABPD) that highlighted the threat to the identity of caregivers and caregiving institutions from carrying out this mandate (5). This statement provided documentation that individual bioethicists could use to demonstrate to their institutional leaders that they were not raising idiosyncratic concerns. While each institution must comply with the law, the work of bioethicists within their institutions often led to creative approaches to mitigating the harmful effects of asking the question, including creating welcoming and explanatory signage and engaging in widespread patient and community education. Bioethicists acted as influencers of institutional awareness and policy to bring about a more ethical and just outcome. While this may seem a mundane example, how to respond to a requirement that ran counter to the values of healthcare professions and institutions was a high-stakes discussion, because seeming to resist the requirement could potentially jeopardize an institution’s Medicaid reimbursement from the state. This issue presaged the current national political environment (6).

HOW HAS THE WORK CHANGED IN THIS EXTRAORDINARY ENVIRONMENT?

As the example of the Florida anti-immigrant law indicates, there are ways in which the skills of bioethicists are suited for the kind of work that is currently needed. For instance, bioethicists are well-suited to highlight the professional identity and ethical issues that are at stake from federal pressures such as those being exerted to undermine DEI efforts, to forgo various types of research, and to cooperate with immigration enforcement officers. Using our accumulated internal political capital, we’re usually able to help institutional leaders to understand the necessity of crafting paths forward that continue to honour their core values to the fullest extent possible.

What is new to the environment is the widespread fear among institutional leaders that their institution may be perceived by government authorities as resistant to the imposition of their desired policies. As I previously noted, I first saw this at the state level in the case of the Florida required-ask policy. Administrators sometimes expressed fears of retaliation from the state government, such as delays in Medicaid reimbursement, if they came to be seen as hostile to the policy. Such retaliation could even be an existential threat to facilities that do not have a large number of days of cash on hand. In this kind of fear-filled climate, bioethicists have good reason to consider whether their usual method of operation is sufficient.

The bioethicist’s usual mode of operation assumes a social context in which free speech is generally taken for granted. A threat to long-held professional and institutional values must be addressed on the reflective level of the self-understanding of professionals and institutions in addition to the clinical level. Professional values and identity can easily erode if threats are not recognized and highlighted. As the name “profession” indicates, values must be professed in an ongoing way. This is a basic aspect of collective and individual professional identity formation. In the US, we have traditionally expected that institutions and professional organizations will vociferously represent their concerns in the public square. But this assumption has been surprisingly easily undermined by fears of retaliation.

In the Florida case, the values at stake as well as the practical implications for public health from asking patients their immigration status were articulated by the ABPD, the American College of Physicians, and some specialty news organizations (5,7,8). The lack of statements by Florida’s medical societies and major health systems was conspicuous. It fell to organizations outside of Florida to articulate the threat as professional organizations and institutions within the state felt at risk. If it were not for these national organizations illuminating the threat to the professional identity of Florida’s healing professions, it would have been possible to “to unwittingly sleep through subtle changes that erode the mission of our health care institutions.” (4)

When the threat comes from the federal government, there are no US professional organizations and institutions outside the reach of retaliation. When fear of retribution is nationwide, a kind of values somnambulism could easily become the order of the day. In this new era of potential retaliation from state and federal governments, bioethicists have an enhanced duty to identify challenges to the identity and values of healthcare professionals and institutions and to publicly articulate them. We must aim to foster reflection rather than accept moral sleepwalking. This duty may be in some tension with our behind-the-scenes influencer roles in our respective institutions.

BIOETHICISTS AS PROPHETIC VOICES AND EDUCATORS

In the current sociopolitical context, key values and ethical tenets of the healing professions and institutions could be easily eroded without widespread notice if bioethicists restrict themselves to their institutional role as influencers. We may accomplish some positive benefits within our institutions but even those would be more difficult without being able to publicly anchor the issues in terms of established norms of professional ethics. While steering protocols in an ethical direction is important, without a widespread understanding of the rationale, mistaken, even harmful conclusions may be drawn by key stakeholders.

For instance, some of our institutions may take some symbolic steps such as to roll back the language of DEI ("rebrand") as a way to avoid governmental scrutiny and retaliation while retaining the moral substance of DEI programs, e.g., correcting for structural bias and seeking to provide fair opportunity to previously excluded persons. Unfortunately, in a climate of fear-induced silence, observers, including staff and patrons of our institutions, may conclude from the linguistic change that a fundamental value shift has been embraced. This might facilitate professional identity malformation because it would be reasonable to conclude that the institution now sees its former position as mistaken or perhaps simply not important.

In an environment where healthcare institutions, colleges and universities, and professional societies have been muted regarding the negative implications for their missions and identities, moral truth itself can become a casualty. As a result, the bioethicist has a duty to articulate the truth regarding the values at stake, the duties of the professions, and the missions of healthcare and academic institutions that are threatened by new governmental policies. The bioethicist must become a prophetic voice, or less dramatically a moral educator.

Catholic writer Michael Sean Winters tells us that a "prophet does not simply point to some future of his or her own imagining. A prophet calls a people to return to their truest selves in order that they may return to a righteous path." (9) In other words, the prophetic voice in healthcare and academia is one that calls out on behalf of the fundamental values of professional identity. The moral truths being obscured by politics and intimidation are again illuminated.

A simple and inspiring example of this can be seen in an editorial in the American Journal of Bioethics entitled "Bioethicists Must Push Back against Assaults on Diversity, Equity and Inclusion." (10) This essay does exactly what its title calls for. The authors explain the ethical justifications for DEI, describe several kinds of efforts that fall under that descriptor, and dismantle the main critiques of DEI being advanced currently. These authors are not simply "taking a stand" in the political sense. They are calling for holding fast to policies that advance the values of healthcare professionals such as respect for the dignity of all persons. Such a piece is prophetic in the sense of illuminating the moral truths contained in DEI efforts, calling for professionals to be true to their identity, and thereby advocating for health of the communities that healthcare professionals serve.

Scholarship that advances the values of healthcare professionals and institutions, whether original data gathering or perspective pieces that develop an argument based on accumulated data, is clearly an important aspect of the bioethicist's prophetic role. Bioethicists also make a valuable contribution when they promote such arguments and conclusions in trade and popular media. This is also a part of the educational vocation of bioethicists.

THE DUTY TO EVERYDAY PROPHETIC EDUCATION

I would like to suggest that we have often underestimated the moral importance of our educational role. As I have illustrated, there are many important ways that bioethicists can service moral truth, such as through consensus statements of the Association of Bioethics Program Directors, scholarly articles, contributions to popular publications, and by our role in influencing institutional policy. While such efforts are quite laudable and important, we should also ask ourselves how we can do more to directly educate healthcare professionals and assist their professional ethical formation. For instance, have we done talks on key issues for our colleagues in their common continuing education venues, such as grand rounds? These educational venues provide an opportunity to pierce the institutional silence in an informative way that is not especially threatening. Such presentations are expressions of our academic freedom and are not a statement by the institution. Furthermore, such presentations have their own important sphere of effectiveness.

My work has largely focused on supporting patients who are immigrants to the US. It is an area that is opaque to most Americans, including many healthcare professionals. Immigration is perhaps the most politicized issue of the present era and misinformation abounds. We have witnessed a ceaseless vilification of these patients as criminals and as people who unjustly use benefits to which they are not entitled. We have even watched them be characterized as some kind of subhumans who eat their neighbours' pets (11). Because this population is so widely demonized in our politics, healthcare professionals (and most Americans) need basic knowledge and attitudinal education.

In this environment, I usually begin my talks on serving immigrant patients by reviewing the basic values of the healing professions. These values apply to the care of all patients. In order to secure a least common denominator among those of varying attitudes toward immigrants, I sometimes consider how professionals deal with any patient who they think may have committed a crime. I reinforce the common institutional protocols. For instance, if the patient poses no immediate danger to others in the clinic and the suspected crime is not mandated by law to be reported, healthcare professionals and their institutions generally see the duty of patient confidentiality as paramount. Healthcare institutions generally require a warrant signed by a judge to disclose information about that patient and would discipline staff who contacted law enforcement on their own. This lays a baseline that establishes that all staff must treat immigrant patients primarily as patients.

Once one establishes clearly that the vocation and mission of healthcare professionals must be to treat patients and to address obstacles to accessing timely and effective health care, other kinds of support become clearly appropriate. For instance, reassurances that the clinic respect patient privacy and not cooperate with immigration authorities unless compelled by a judicial warrant are expressions of the healing mission, not politics. Similarly, offering information regarding other available social supports such as reputable legal resources are about empowering patients to move beyond fear and take positive steps that are supportive of their mental and physical health.

I also raise the historical analogy to treating patients who are Black during the era of Jim Crow in the US. I ask them to consider what the obligations of the medical profession are when patients are routinely characterized as inferior and segregated from other Americans and opportunities to achieve a full and healthy life. This line of discussion suggests that the healing professions' commitment to the dignity — literally, the worth of each person — raises some additional duties, such as fostering the truth of human equality and the contributions to society of these neighbours and colleagues. Following out of such lines of reasoning in educational sessions is an effort at professional formation — developing and refining the virtues of these professionals.

CONCLUSION

What these times require of bioethicists is not so different from what we have long been doing. In past years, I have argued that we underestimate our service role as institutional influencers. As influencers, we can affect many lives through organizational policies and clinical protocols. I have not always placed the same emphasis on matters such as public statements and scholarship. But this year, the bioethicist must preserve the space for the fundamental values of the healing professions and institutions by giving voice to those values and illuminating how they are being threatened. I have adorned this role with the noble metaphor of the prophetic voice because of its place in calling our colleagues to what is best in their professional traditions.

I have followed this somewhat grandiose characterization with a request that bioethicists execute this noble function in the most mundane of ways — by doing presentations in everyday educational venues. Sometimes prophetic voices cry in small venues if not completely in the wilderness. I believe that this work is essential because articles and position statements are often not widely read or only read by those who are expert on the topic. We must also build from the ground up. Professional formation often takes place within one's immediate learning community. Promulgating and reinforcing the cherished values of the healthcare professions in those communities is a foundational moral activity.

In closing, it is clear that I have not answered many of the questions that will continue to be urgently discussed among bioethicists. In a sense, I have said little more in response to the question of what this year's bioethicist should do than to answer: service, scholarship, and education. However, I have tried to show the urgency to carry out these functions and the significant stakes in doing so. We will continue to come under pressures to not discharge these functions. And the need of the professions and society for this kind of work is far beyond the capacity of bioethicists alone. But we would not be worthy of the name of our profession if we did not do all we could to advance these goals.

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TÉMOIGNAGE / PERSPECTIVE

Fair Trade: The Legacy of Osler and Penfield for Neuroscience and Ethics

Joseph J. Fins^a

Résumé

Dans cet essai, j'explore les contributions transfrontalières de William Osler et Wilder Penfield aux neurosciences et à l'éthique, et je plaide en faveur d'une collaboration continue entre le Canada et les États-Unis.

Mots-clés

William Osler, Wilder Penfield, neuroéthique, neurosciences, collaboration internationale, histoire de la médecine

Abstract

In this essay I explore the cross-border contributions of William Osler and Wilder Penfield to neuroscience and ethics and make the argument for continued collaboration between Canada and the United States.

Keywords

William Osler, Wilder Penfield, neuroethics, neuroscience, international collaboration, medical history

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The great physician Sir William Osler and the renowned neurosurgeon Wilder Penfield are both thought to have been Canadians. Osler, the father of internal medicine, was certainly Canadian, hailing from Bond Head, a small town in Ontario and part of a long line of distinguished family members (1). But Penfield, a neuroscience pioneer and epileptologist, was an American. He was born in Spokane, Washington (2,3).

The mistake is understandable because the two are national heroes in Canada. Their lives intersected in so many ways just as streets named "Sir William Osler" and "Doctor Penfield" intersect in Montréal at the foot of Mt. Royal, running through the heart of McGill University. Penfield was a student and protégé of Osler and both have been honoured with Canadian postage stamps. The Penfield papers are housed in the Osler Library of the History of Medicine at McGill. But truth be told, Penfield was indeed a Canadian. He became a naturalized citizen in later life.

But what is truly noteworthy is their respective trajectories in America and Canada. Osler, the Canadian, made his mark in the United States as one of the four founders of Johns Hopkins School of Medicine, the medical school that was the model for the Flexner Report (4) and for the origins of modern medical education. While future reforms would follow, Osler's pedagogical contributions to that early template were enduring. Penfield, the American, founded the venerable Montreal Neurological Institute (MNI) (5), a truly innovative place which engaged in both basic and clinical neuroscience research. A stone bridge stretching between the Royal Victoria Hospital and the MNI remains a concrete and metaphorical connection between the laboratory and the clinic (6). Penfield's vision for translational neuroscience became the model for the US National Institute of Neurological Diseases and Stroke, a component of the National Institutes of Health.

What is interesting, and indeed paradoxical, is their mix of geography and biography. Osler, the Canadian, had his most productive years in Baltimore while Penfield, the American, spent his professional life nestled in Montréal. Contrary to their place of birth, each country benefitted from the contributions of one of its neighbour's sons. America enjoyed the fruits of Osler's ministrations in Baltimore and Canada from the generative creativity of Penfield in Montréal. The irony could not be clearer: Considering the current disputes over tariffs, one could say the Osler-Penfield exchange was a fair trade.

And that's the point. Fair trade benefits both sides. The contributions of that early exchange continue to accrue since the founding of Johns Hopkins in 1893 (1) and the MNI in 1934 (5). They extend today to bioethics and modern neuroethics where there is a deep collaboration between our countries in joint scholarship and in a legacy of binational leadership of the International Neuroethics Society (INS), the field's leading membership organization.

As INS president, I was delighted to have brought our first non-US based meeting to Montréal, where we were graciously hosted by the Institut de Recherches Cliniques de Montréal (ICRM). On a personal level, the implicit strain of clinical neuroethics that threads through the work of Osler and Penfield informed my own writings on disorders of consciousness (7) and neuromodulation (3,8). In the face of nihilism in neurology and neurosurgery, Penfield was more optimistic about the emerging therapies he was developing, including the electrical stimulation of the brain in his work on epilepsy (9). His writings have been an inspiration to me and my colleagues (10).

I have been honored to write the epilogue for two editions of the Oxford Textbook of Neuroethics (11,12), co-edited by University of British Columbia's Judy Illes, herself a former INS president. Closer to the East Coast, I have shared a pragmatic approach to ethics and neuroethics with Montreal's Eric Racine (13) and legal scholarship with Ottawa's Jennifer Chandler (14). Most recently, I co-authored an essay in JAMA with Harvey Chochinov on medical aid-in-dying and its relationship to palliative care (15). As chair of the Hastings Center board of trustees, I am honored to work with our president, Vardit Ravitsky, who is Canadian (16). I share these personal connections because they have been incredibly meaningful, and I hope led to important scholarship that we couldn't have done without expanding our horizons and crossing borders.

These relationships speak to the molecular nature of life. As individual academics, we are connected to each other like atoms within molecules. The bonds are tight, and it is all about relationality and connections that grow stronger over time. It's no accident that Penfield's memoir, *No Man Alone* (2), reflected on all those who contributed to a life well led. While I would make the title more inclusive, the sentiment is correct and instructive.

In response to tariffs and other barriers to the free exchange of ideas and scholars, we must reaffirm the strong connections between our two academic communities that the democratic exchange of ideas is a predicate for learning and progress. We must be free to think and collaborate as we choose and do so transnationally, especially with our Canadian friends. Academic discourse between our countries is particularly valuable because we share so many common values but are nonetheless different enough to reflect knowingly on each other's idiosyncrasies. Each country can provide an outsider/insider perspective on the other. This is immensely valuable in volatile times. And this is precisely what good friends are for.

To neuroscientists, Penfield is best known for his brain mapping. He charted the motor and sensory homunculus which are cortical strips in the brain that are primary motor and sensory cortex, respectively. It was a masterful act of cortical cartography. Both our motor actions and our bodily sensations are processed in discrete provinces or states which correspond to an area of the body.

As a mapper of the mind, Penfield might also have had something to say about the border that Canada and the United States share. I suspect he would see it as a liminal space, one that he traversed personally and professionally, one which both separates and connects, and like the nervous system itself is fully integrated in ways we can yet apprehend. To sever these connections would be to disrupt networks that have taken centuries to cultivate, and which have the potential for further plasticity and growth. Perhaps to stretch a metaphor beyond its membrane, severing these connections would be ablative and akin to the horrors of psychosurgery, a destructive act with enduring consequences. It would evoke changes in our national character, of our personalities, on both sides of the border that we would certainly regret.

Of course, geopolitics is distinct from the body politic, and it is important not to overindulge in analogic reasoning. But just as Penfield's life and work prompted him to title his memoir, *No Man Alone* (2), his ties to both Canada and the United States might lead to another admonition: "no country alone." That counsel is especially true when we think of our two countries and the bonds that have served us both so very well.

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