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Advocates, Activists, Architects of Moral Space?

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[See table of contents](#)

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Article 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.

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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 (EDI). 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 decentering 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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