

Meeting the Moment: Bioethics in a Revolution

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Advocates, Activists, Architects of Moral Space?

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Article abstract

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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, partisanerie, 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 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 from 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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