OPEN LETTER

Invisibility in global health: A case for disturbing bioethical frameworks [version 1; peer review: awaiting peer review]

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Abstract
In recent years, the global health community has been increasingly reporting the problem of ‘invisibility’ as aspects of health and wellbeing that are often overlooked and ignored, and predominantly affects the most marginalized and precarious people. However, it is unclear how to realistically manage global health invisibility and move forward. In this letter, we reflect on several case studies of invisibility experienced by people in Brazil, Malaysia, West Africa and other transnational contexts. Highlighting the complex nature of invisibility and its interconnectedness with social, political and economic issues and trends, we argue that while local and targeted interventions might provide relief and comfort locally, they will not be able to solve the underlying causes of invisibility. Moving forward, we argue that in dealing with an intersectional issue such as invisibility, twenty-first century global health bioethics could pursue a more ‘disturbing’ framework, challenging the narrow comforting solutions and sociomaterial inequalities of the sociopolitical status quo. We highlight that comforting and disturbing bioethical frameworks should not be considered as opposing sides, but as two approaches working in tandem in order to achieve the internationally set global health milestones of providing better health and wellbeing for everyone. In doing so, we call for taking seriously insights from sociology, anthropology, postcolonial studies, history, feminist studies and other styles of critical reasoning that have long been disturbing the grand assumptions about people and their conditions, and, practically, to rediscover the ethos of the WHO Alma Ata Declaration, calling for cooperation and support beyond the narrow market logic that dominates the landscape of contemporary global health.

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Any reports and responses or comments on the article can be found at the end of the article.

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Encountering global health invisibility: a few empirical snapshots

Global health is increasingly acknowledging the existence of many social, political and economic aspects of health that often remain structurally overlooked, underappreciated, ignored—and are thus invisible. The literature reports this 'invisibility' unfolding in unequal or otherwise divided environments marked by asymmetrical power relations, which characterizes most—if not all—global health contexts (Davis, 2017; Harman, 2016; Mac-Seing *et al.*, 2019; The Lancet Global Health, 2019). This means global health invisibility offers sharp challenges for theory and practice, requiring careful transdisciplinary examination.

In 2022, the Oxford-Johns Hopkins Global Infectious Disease Ethics Collaborative (GLIDE) organized a forum examining invisibility across a variety of global health contexts. The aim was to gain diverse perspectives to shift attention from the question of '*What* is invisibility?' to '*How* is invisibility made and unmade in practice?' and 'How should ideas of invisibility be addressed in policy?' In this letter, we reflect on the invisibility case studies and suggest the distinction between 'disturbing' and 'comforting' global bioethics as an analytic lens for engaging with invisibility. Moving forward and looking back, we argue that the ethos of the Alma Ata declaration could be rediscovered and reinvigorated for tackling global health invisibility and disturbing the comforting yet limited solutions to chronic intersectional issues.

In this section, we briefly introduce five examples of Global Health invisibility that reveal only the tip of an iceberg, with far more serious problems lying underneath. Firstly, in Malaysia, since the turn of the century, invisibility has unfolded as an institutionalized practice, wherein undocumented migrants, subjected to a spectrum of health problems and especially mental health issues, were not identifiable in any registries, and nor did their health issues in effect 'exist', effectively turning invisibility into a local determinant of health and wellbeing. Secondly, In Brazil, in the context of the response to COVID-19, layers of invisibility came to the fore with the lack of gender-specific policies and institutionalized processes that oversimplified continuums of inequalities and rendered vulnerable populations invisible.

Thirdly, we discussed how internationally praised collaborative partnerships for Ebola research in West Africa contained invisible forms of precarity stemming from a dependency on Northern funding. As a result, the entire local research and health care systems relied on its presence and constant flow, creating cycles of unresolved and unsustainable issues. This unseen phenomenon was in sharp contrast to the formal rhetoric of building local capacity and equal partnerships between the North and South. Moreover, we discussed how the US-led, North-South collaborative partnerships on global health and bioethics contained hidden layers of inequality that proliferated despite attempts to achieve benchmarks of fairness, empowerment and egalitarianism. Finally, zooming out at the international level, invisibility was traced with regard to the unseen politics of death and dying, spanning global health as a whole. There are millions of dead bodies across the globe that remain unidentified, and this number is steadily increasing due to humanitarian disasters, infectious disease outbreaks and mass migrations. In such contexts, people from poorer and marginalized backgrounds are likely to be invisible in their death and dying.

Rethinking global bioethics: the case for disturbing and comforting methods

The collective discussion of such case studies brought up a key theme; namely, that topical and narrow solutions to invisibility will likely not be able to address the root causes of invisibility, however, they might be able to alleviate tensions locally. In this letter, we, the presenters and the organizers, further develop this idea and suggest that in order to address a complex issue such as global health invisibility it might be useful to maintain the analytic distinction between what we term 'comforting' and 'disturbing' global health bioethics. We argue that if it is true that invisibility is a function of coloniality within bioethics and global health, a two-pronged strategy of comforting and disturbing bioethics must be pursued, lest global health bioethics reproduce regimes of visibility and invisibility and the structural injustices they maintain.

Reflecting on the snapshots of the case studies, we suggest that comforting bioethics builds upon the premise of creating new forms of engagement based on amendments to existing power structures, while effectively maintaining the status quo. In doing so, comforting bioethics effectively reproduces the idea of ethical commensurability, progress and Whig historiography (Lerner & Caplan, 2016) in suggesting that ethicality is being gradually accumulated over time. Hence, the solutions are 'comforting' as they address issues locally and do not intend to fundamentally challenge the features of the entrenched power structures and socio-political determinants of health inequities. While we are sympathetic and advocative for a comforting action, nevertheless we cannot ignore the fact that all of the cases above, one way or another, are linked to global patterns of social stratification, distress and disparity existing beyond bioethics and global health. Colonial history, the global acceleration of neoliberalism as the dominant political, economic and cultural vector, and the neo-colonial integration of the Global South into global markets of unequal exchange, as well as patriarchal power dynamics, all play a role in creating invisibility that we can no longer afford to overlook and oversimplify. Disturbingly, this could suggest that isolated attempts to address global health invisibility—without addressing or at least acknowledging the core issues and overarching patterns—risk misrepresenting the sheer magnitude of the problem. This, in turn, risks producing 'cruel optimism' (Berlant, 2011): a social change that is simultaneously desired but is not attainable within a given socioeconomic system and the solutions it offers.

While comforting bioethics is well represented in applied bioethics and global health, we argue that the international community should practice more disturbing bioethics in order to achieve the internationally-postulated milestones for global health in the 21st century. Disturbing bioethics offers a different proposal; namely that ethicality can be achieved when power structures are challenged and reassembled in a structurally competent way. This simple yet crucial analytic point creates a justification for disturbing the comforting solutions and the sentimental morality they might entail. We suggest that disturbing bioethics could be enacted by drawing on insights from anthropology, sociology, studies of international development and globalization, postcolonial studies and other styles of reasoning that have a record of disrupting power structures and challenging grand assumptions about people and their conditions. Disturbing bioethics, in essence, is an exercise in reflexivity and a reminder that the contemporary world is marked by contingency, crisis and precarity. Such processes have been accelerating in recent years and now, without exaggeration, they pose an existential threat to humanity as a whole.

As a result, we encounter a timely and uneasy question for global health and bioethics: What are the ethical implications for offering reassuring and comforting interventions and frameworks to intersectional issues such as invisibility, knowing that it will, after being supposedly addressed in one given context, simply manifest somewhere else?

Disturbing guidance: The Alma Ata declaration revisited

Fortunately, we already have a milestone document that supports the claims of disturbing bioethics: WHO's Alma Ata declaration (1978), which formulated health care as a fundamental human right that care should be available to all people regardless of their socio-economic status. The declaration called for a more horizontal approach to the structuring of infrastructures providing health care, education and wellbeing. Since this document was signed in the presence of 3,000 delegates from 134 countries and 67 nongovernmental organizations, the global rise of neoliberalism has resulted in the rapid marketization of health care, reductions in public expenditure, and the greater involvement of the private sector in public services (Exworthy, 2008) and the WHO played an instrumental part in this transformation (Navarro, 2008). At the same time, despite economic growth, the Global South remained unable to invest the necessary resources into building effective, responsive and adequate health systems, and many post-independence countries were further crippled by debt and structural adjustment policies imposed by the transitional organizations, such as the World Bank and the International Monetary Fund (Siddiqui, 2012). Under such a regime, the Declaration's ethos of 'health for all' has been replaced with 'health insurance for all' (Pandey, 2018). Fifty years later, principles of horizontality and social change outlined by the Alma Ata declaration are truly disturbing—some might even say radical—in the hegemonic global health prioritizing top-down, technologically driven health programs and market-based solutions to chronic health and social issues (Holst, 2020). Numerous academics and practitioners have expressed the concern that contemporary global health is rapidly departing from the principles of the declaration, and that now, more than ever, we need 'reinvigorated social justice–based on political and social movements—an uphill struggle, to be sure, but a healthy one indeed'(Birn, 2018). Reflecting on the concerns of invisibility in global health, the colonized state of both global health and bioethics, we suggest that the ethos of the Alma Ata Declaration could be reintroduced through the notion of disturbing bioethics and its central aim of challenging comforting yet heuristic solutions to chronic social and health care issues.

Moving forward and looking back

Taken together, in pursuing the exercise in 'comforting' bioethics, we suggest that invisibility should be made central to normative action in accordance with the best practices in the field. More specifically, we suggest that funders and institutions could

- increase the funding of studies of invisibility in various global health contexts to gain a better understanding of the problem;
- establish local bottom-up collaborative partnerships to empower invisible communities and address invisible problems;
- collect qualitative, quantitative or mixed-methods data and prepare it for evidence-based policymaking, with the goal of reaching national and international regulators; and
- perform stakeholder analysis, review gaps in evidence concerning invisibility and identify topics for advocacy.

While we are sympathetic and advocative for a comforting action, nevertheless we call for approaching global health invisibility as a product of global health political economy, or at least as a phenomenon unfolding in a political context. Accordingly, we would like to add three disturbing conceptual points to the list above, to make a grand total of seven:

- Politicize the emergence of global health invisibility and oppose the depoliticized operationalization of the term, further linking it with the notions of coloniality, precarity and neoliberalization
- Acknowledge that intersectional issues cannot be easily resolved by the vertical approaches that currently dominate the landscape of contemporary global health and applied global health bioethics
- Advocate for distributive justice and a more horizontal approach to the conduct of health interventions as initially proposed by the WHO Alma Ata declaration, prioritizing cooperation, resistance and solidarity beyond the market logic.

Data availability

No data are associated with this article.

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