SUPPLEMENT ARTICLE







Where Caring Is Sharing: Evolving Ethical Considerations in Tuberculosis Prevention Among Healthcare Workers

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In many settings, the dedication of healthcare workers (HCWs) to the treatment of tuberculosis exposes them to serious risks. Current ethical considerations related to tuberculosis prevention in HCWs involve the threat posed by comorbidities, issues of power and space, the implications of intersectoral collaborations, (de)professionalization, just remuneration, the duty to care, and involvement in research. Emerging ethical considerations include mandatory vaccination and the use of geolocalization services and information technologies. The following exploration of these various ethical considerations demonstrates that the language of ethics can fruitfully be deployed to shed new light on policies that have repercussions on the lives of HCWs in underresourced settings. The language of ethics can help responsible parties get a clearer sense of what they owe HCWs, particularly when these individuals are poorly compensated, and it shows that it is essential that HCWs' contribution be acknowledged through a shared commitment to alleviate ethically problematic aspects of the environments within which they provide care. For this reason, there is a strong case for the community of bioethicists to continue to take greater interest both in the micro-level (eg, patient–provider interactions) and macro-level (eg, injustices that occur as a result of the world order) issues that put HCWs working in areas with high tuberculosis prevalence in ethically untenable positions. Ultimately, appropriate responses to the various ethical considerations explored here must vary based on the setting, but, as this article shows, they require thoughtful reflection and courageous action on the part of governments, policy makers, and managers responsible for national responses to the tuberculosis epidemic.

Keywords. bioethics; community health workers; healthcare worker-patient transmission; prevention; tuberculosis.

Healthcare workers (HCWs) working in areas with high tuberculosis prevalence often act as a bridge between the various stakeholders involved in the provision and reception of care [1]. Their dedication, however, exposes them to serious risks. For far too long, bioethics has paid too little attention to the structural factors that have perpetuated those risks among HCWs—volunteer or paid, lay or professionals, clinic- or community-based.

Over the past 20 years, several scholars have expressed concern about the narrow focus of bioethics and the neglect of ethical considerations in relation to health in a broader sense [2–6]. Leigh Turner [5] recognized that many bioethics scholars were "deeply embedded in a global economic system that depends on the continued existence of impoverished societies," and he chastised them for focusing on issues such as cloning, euthanasia, genetics, and stem cell research to the neglect of the more mundane, but vastly more important topic of access to the social determinants of health. Michael Selgelid subsequently took umbrage to the fact that the topic of infectious diseases, so closely intertwined with the issue of resource deprivation, had

health [8].

Since the ability to control the scourge of tuberculosis may be within our reach [9, 10], discussions of the intricacies of tuberculosis control should not ignore the fact that simply facilitating access to good nutrition and decent housing has tremendous impact on transmission rates. Instead, such discussions should engage heavily with notions of fair distribution of resources at both the meso (eg, regional programs) and macro (eg, national or international programs) levels. But bioethics can make an additional contribution to discussions of tuberculosis control by

shedding light on the ethical considerations that often go unno-

ticed. Bioethics, as a discipline of applied ethics, is concerned with "systematising, defending, and recommending concepts

received less than its fair share of attention from the bioethics

community [7]. He argued that one of the reasons why

"infectious diseases warrant more of bioethics' attention is

that they raise serious, difficult philosophical/ethical questions of their own" [7]. A lack of moral imagination—that is, one's

ability to empathize with others—was implicated in the neglect by bioethicists of the major forces that aggravate disparities in

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of right and wrong" in the context of controversial issues in health [11]. Such issues include the resource reallocation that would be necessary to rectify the structural factors allowing the tuberculosis epidemic to continue. Although encouraging an overhaul of the sociopolitical structures that perpetuate the transmission of tuberculosis is a crucial goal—and one we have

wholeheartedly embraced [9]—we submit that it is no less essential that HCWs' contribution be acknowledged through a shared commitment to alleviate ethically problematic aspects of the environments within which they provide care. Without offering a detailed ethical analysis of the reasons why we are morally compelled to protect HCWs from tuberculosis infection, we note that these include fiduciary, duty-based, and utilitarian obligations. We suspect that the utilitarian public health argument is so strong that almost all people would intuitively agree that protecting HCWs from tuberculosis should be a priority. Put simply, HCWs play a key role in ensuring the well-being of others and, should they become infected with tuberculosis, they might spread the disease further.

The literature on ethical considerations surrounding the exposure of HCWs to tuberculosis is limited. Of course, the way we define HCWs has crucial implications, as the papers presented in this special issue have highlighted. For instance, the issue of lack of occupational compensation for students and volunteers who contract tuberculosis in the workplace has been cited by van Delft et al. Similarly, the magnitude of the dilemmas faced by HCWs who visit the homes of patients is likely to be amplified. In general, however, we fundamentally believe that addressing global health disparities, such as the greater risk of exposure to tuberculosis of some HCWs, requires that we reconsider the way we think about global health and progress more broadly [12]. In this article, we seek to bring attention to some of the ethical considerations surrounding HCWs' exposure to tuberculosis without offering detailed ethical analysis of each one. Several approaches to ethical analysis exist [13-15], and applying just one to each of the considerations we raise would require far more space than is available. The synopses of ethical analysis we propose are useful, we hope, in showing how the considerations discussed, which might at first glance appear to be of a very localized nature, in fact point to the impact of structural factors on the experience of HCWs in underresourced settings.

CURRENT ETHICAL CONSIDERATIONS

Comorbidities

Tuberculosis infection has synergistic relationships with other diseases, including human immunodeficiency virus (HIV)/ AIDS and diabetes. It has been repeatedly shown that individuals with HIV/AIDS are at higher risk of being infected by tuberculosis [16,17]. At the same time, HIV-infected patients who also suffer from tuberculosis may present a challenge to tuberculosis control programs, as they tend to more frequently be sputum negative (yet still infectious) than HIV-uninfected patients [18]. Diabetes, a rising health concern in much of the world, similarly increases the likelihood of tuberculosis infection [19, 20]. This poses intricate ethical challenges for tuberculosis control programs, for comorbidities might amplify the risk faced by HCWs in the course of their normal functions. On one

hand, in underresourced settings, occupational exposure of HCWs to HIV is a documented concern. Although HIV transmission is normally unlikely in the course of treatment for drug-sensitive tuberculosis, the use of injectable drugs for resistant strains can increase that risk for HCWs. On the other hand, assessment of risks related to tuberculosis and comorbidities need to also take into account potential interactions with preexisting conditions of HCWs delivering care. For example, additional precaution is needed for HCWs with diabetes to minimize the likelihood that they will develop tuberculosis after providing care to patients. Finally, there are several other risk factors yielding compromised immune systems—including poor nutritional status and stress—that may be a concern in locales where HCWs' working conditions are suboptimal. Although these risk factors tend to be invisible, they should not be overlooked by healthcare programs.

Ethical considerations related to comorbidities also arise in the conduct of biomedical research, a topic discussed in more detail below. Research ethics committees overseeing studies that have the potential to put HCWs at increased risk of tuberculosis infection should require that research protocols include relevant mitigating measures [21].

Power and Space

All provision of care is shaped by power relations, and tuberculosis care is no exception [22]. But power takes on a particular significance when care is provided outside of formal institutions such as hospitals and clinics, where high-ranking HCWs tend to operate [23–25]. When the home is the site of care, it becomes a site of conflict "in which 2 social groups [ie, frontline HCWs and clients], both of whom suffer from a wider social diminishment, struggle to establish autonomy and personal esteem" [23]. When HCWs are required to travel to the home of patients to observe tuberculosis treatment, they enter a space that was not designed and standardized to meet their needs and favor their protection the way hospitals are. For example, patients' homes may be poorly ventilated. Whereas in clinic settings HCWs have more authority over the space they occupy, HCWs who travel to the patients have little control over their working environment. The limited credentials of many frontline HCWs in underresourced settings might further contribute to their lack of leverage, making it difficult for them to negotiate adaptations to the environment that would be more conducive to their protection.

That is not to say that the experience is necessarily positive for patients receiving care in their homes. Some of them refer to a loss of control [22], even when no major accommodations are required to ensure the protection of HCWs. Qualitative research has demonstrated that patients are often expected by HCWs to accept a form of emotional infantilization in exchange for receiving care [23]. In tuberculosis specifically, the inflexibility of in-clinic treatment schedules is not necessarily alleviated when treatment is provided in the home. As a result, the

employability of patients treated in their homes may not be much improved over that of patients having to travel to meet HCWs [22]. These realities can lead to heated confrontations between patients and HCWs.

Policy makers must not underestimate the impact of issues of space and power on the morale of HCWs and on the risks they face. If there is now an expansive literature detailing the ethical dilemmas encountered by HCWs in high-income countries—particularly in the field of nursing—the moral plights faced by HCWs in underresourced settings remain an under-investigated topic. Policy makers should endeavor to provide opportunities for HCWs to raise red flags about ethically charged situations in their work environment so that these situations can be discussed—and improvements proposed.

Intersectoral Collaborations

One of the ways through which the sociopolitical context in which HCWs operate affects their experience is the role played by the private sector in the provision of tuberculosis care. Reliance, even partial, on the private sector has been extensively contested by those who view the private sector with suspicion, as well as by those committed to the strengthening of public health apparatuses and who see private sector involvement as undermining this objective. The extent to which public-private collaborations are useful is also debated. For example, there are concerns related to the resources that need to be expanded to ensure communication and coordination between all stakeholders, as well as to mitigate conflicts [26]. Yet public-private partnerships have been shown in some circumstances to improve case detection, achieve acceptable treatment results, and increase equitable access to treatment [26]. Because of this, intersectoral collaborations have been touted as holding "considerable potential to improve tuberculosis control" [27]. Unsurprisingly then, there is in some countries a programmatic openness to collaborations between the private and the public sectors—an interest that has been renewed because of the emergence of multidrug-resistant tuberculosis, suggest some observers [1].

Although the issue of efficiency and effectiveness of intersectoral collaborations are issues worthy of consideration by those concerned with ethical decision making, attention must also be paid to the way those collaborations play out at the micro level. Some partnership efforts are indeed thought to have failed to successfully integrate the private sector because of their lack of attention to the working relations of those on the ground [1]. At the micro level, HCWs become agents of the public-private collaboration. As such, it is important that issues of hierarchy between private and public HCWs not be underestimated. There have been numerous reports of lapses in treatment recommendations offered by private practitioners to patients [28, 29]. Frontline HCWs may find themselves in the uncomfortable position of having to navigate between official treatment guidelines and private practitioners' prescriptions.

When private practitioners offer suboptimal care, this may increase HCWs' risk of exposure to tuberculosis. Similarly, pressures toward cost reduction may be felt particularly heavily in profit-driven organizations. In settings where the public health system apparatus envisages a collaboration with the private sector, tempting shortcuts when it comes to safety procedures should be prevented.

(De)Professionalization

Over the past 2 decades, there has been a trend toward the decentralization of tuberculosis control efforts to maximize reach and efficiency. In Malawi, the surge in case detection—linked to the HIV epidemic—led the Ministry of Health to explore alternatives to directly observed therapy in hospital settings [30]. But this push for decentralization has raised questions about the issue of professionalization. Early results from the Malawian experience suggested that nonprofessional care providers could be as, if not more, effective in ensuring patients' adherence to treatment [30]. Such results were in part attributable to the documented role that social support plays in influencing behaviors. Given their high cost-effectiveness, "lay" HCWs (ie, providers of care who have not completed training within a healthcare profession and who work on the frontline) continue to be promoted in many underresourced settings. What is less clear is the extent to which deprofessionalization might be associated with increased risk for lay HCWs. To ensure that the burden of prevention is not unjustly shifted onto lay HCWs, monitoring mechanisms should be put in place in locales pushing for decentralization and deprofessionalization of tuberculosis

A more systemic ethical consideration is that the burden of nonprofessional care provision is not distributed in an equitable fashion. In many societies, higher rates of unemployment among women, combined with cultural expectations regarding their role as caregivers, are likely to result in men assuming less frequently the tasks of volunteer care provision [31]. For this reason, the risk that the deprofessionalization of tuberculosis control perpetuates gender disparity must not be ignored by policy makers.

A similar ethical consideration arises when paid and unpaid HCWs coexist in a given setting. Striving for equity would suggest that equal compensation should be provided for equal work, unless other factors justify differential treatment. When a relative is expected to play the same role as a professional HCW but does not receive an equivalent compensation, policy makers should be able to offer relevant justifications for these differences.

At the other end of the spectrum, there appears to be a recent retreat from deprofessionalization in some high-resource settings. For example, in a Massachusetts community HCWs have led a successful movement toward the establishment of certification [32]. Should similar movements for (re)professionalization emerge in other regions, it would be important

to consider measures to ensure they do not constrain the emancipation of the more marginalized care providers—for example, by requiring examination fees that would be prohibitive.

Remuneration

There is both a large spectrum of approaches to HCW remuneration and incentivization, particularly of lay HCWs, and a long-standing debate about best practices [33]. Perspectives on remuneration vary greatly, from fears that it is unsustainable to the view that it is a basic human right and a mechanism to achieve greater gender equity. For example, the nongovernmental organization Partners in Health (PIH) is known for its clear stance on remuneration for community health workers (CHWs):

"There is no excuse for withholding payment for the highly skilled services of CHWs, who accompany patients through their greatest struggles and put themselves at daily risk of contracting deadly diseases. Furthermore, payment directly benefits the health and welfare of the community by providing jobs to local people. PIH provides and advocates for professional treatment of CHWs—including fair payment, ongoing training, and provision of necessary supplies—so they may perform their vital work to the highest standards." [34].

Just as there is debate about the best approaches to remuneration and incentivization, there are conflicting ethical considerations attached to both [35]. On one hand, wages may contribute to poverty reduction and human development in disadvantaged areas, an objective supported by redistributive principles of justice. Some suggest that remuneration is in fact integral to the duty not to be exploitative [36]. This may be particularly true when lay HCWs are involved, for agreeing to supervise the completion of tuberculosis treatment is a commitment that extends over the course of several months, and, as such, might limit one's ability to seek employment opportunities. There is also evidence to suggest that wages might be an effective retention factor, especially in rural areas and among marginal communities [35]. Retention is especially important, as studies have shown that a lack of continuity can make it difficult to build trusting relationships [22]. Lack of trust can, in turn, be associated with poorer adherence and outcomes [37-39]. Adequate remuneration can also have a protective effect for HCWs, for it may help them secure access to the social determinants of health that are so crucial in limiting the transmission of tuberculosis.

On the other hand, there is agreement that challenges exist to securing resources to sustain the long-term financing of the healthcare sector. The comprehensive review by Bhattacharyya et al illustrates well the complexity of striking a balance between concerns for sustainability and the various factors known to affect motivation and attrition of CHWs [40]. Threats to tuberculosis program sustainability can translate into health threats: If there is inconsistency in the services provided to patients (eg,

because tight resources mean that HCWs go without pay for extended periods), drug resistance might emerge and, therefore, HCWs may be put at increased risk. As such, it is possible to imagine that in locales with extremely limited resources, insisting on HCW remuneration in exchange for the provision of tuberculosis care could eventually lead to counterintuitive harms. At this time, however, this line of reasoning seems so hypothetical, and the conclusion so uncomfortable, that rigorous data and diligent ethical reasoning would need to be provided for this argument to be invoked.

Duty to Care

The dilemma around providing care in circumstances that do not favor personal safety is but one of the vexing ethical dilemmas faced by those providing frontline care and services to tuberculosis patients. The extent to which HCWs are required to expose themselves to risk is a hotly debated topic, both within the medical professions and the bioethics community [41, 42]. The issue of duty to care during public health emergencies—especially during epidemics of influenza—has received significant attention in the past decade [43, 44], and meticulous analyses of the issue are available. The phenomenon has also been studied from the perspective of HCWs in high-income countries [45]. However, the experience of HCWs in underresourced settings, where risks tend to be much higher, remains understudied.

Whereas commentators disagree with regard to the extent to which it is reasonable to expect HCWs to expose themselves to risk, most agree with some form of the risk minimization principle. This principle mandates that, at a minimum, special measures should be put in place by various parties (eg, governmental organizations) to protect HCWs at greater risk due to comorbidities [46]. Ideally, these additional measures should be such that they do not unnecessarily increase stigma (eg, by making public an HCW's HIV status).

Involvement in Research

After several years of inactivity, the tuberculosis research pipeline became more promising shortly after the turn of the millennium [47]. The rebirth of tuberculosis research—ephemeral as it appears to be, given recent setbacks in funding [48]—is not without ethical implications for HCWs. Much has been written on the ethical conduct of biomedical research, including tuberculosis research [49]. In general, the emphasis in regulations and guidance documents is on the protection of research participants. And so, whereas investigators are now expected to think carefully about the safety of study participants, investigators' obligations with regard to HCWs taking an active role in research activities are much less clear cut [50]. As C. L. Heidebrecht rightly points out, biomedical research relies on staff members to recruit participants, collect data and biological specimens, and administer treatment [50]. Each of these activities represents a risk to research staff—who often play the dual role of being HCWs—especially in underresourced settings. For example, gathering participants as part of a study on HIV/AIDS could increase the risk of tuberculosis transmission to participants, as well as to research personnel [21]. Steps to protect research participants, HCWs, and other personnel in the course of research have been proposed. These include conducting a preliminary risk assessment, putting in place administrative and environmental controls, and ensuring adherence to the use of protective equipment [21].

We disagree with a reductionist view that would suggest that the apparatus of research ethics oversight should limit its mandate to the protection of the well-being of study subjects [51]. Part of the reason why injustices tend to persist is precisely because of the ease with which lines are drawn between different groups. Research ethics processes should not encourage investigators to protect participants merely because they are mandated to do so, or because it is instrumentally useful (by easing recruitment, for instance). Instead, research ethics oversight should favor the development of solidarity and moral imagination—that is, the capacity to imagine oneself in the shoes of others [8]. Of concern is the fact that there is currently a scarcity of data about the experience of HCWs who engage in research [50].

At a broader level, it is important that policy makers also think through the ethical considerations associated with the development of new therapies and vaccines. HCWs are often good candidates to gain early access to novel mechanisms for care and prevention. However, there can be a concern that this sort of early access leads to increased disparity between the public and HCWs. Indeed, HCWs tend to be relatively privileged when it comes to access to health resources, in part due to connections and relationships [52]. On the other hand, ensuring that HCWs have access to the latest gold standard in tuberculosis prevention and treatment might help improve efficiency of he public health system's response by halting an easy source of transmission and thus decreasing risk of harm for the population.

EMERGING CONSIDERATIONS

Mandatory Vaccination

Because many of the ethical conundrums posed by tuberculosis would be avoided if its transmission were stopped [53], there is a strong incentive to push for the development of a more effective vaccine and to ensure high coverage subsequently. In general, there has been some sympathy toward the mandatory vaccination of HCWs for diseases such as influenza [54, 55]. Because there is no highly effective vaccine against tuberculosis, current recommendations regarding tuberculosis vaccination for HCWs are quite lax in high-resource settings. For instance, the Public Health Agency of Canada recommends BCG vaccination for HCWs only when 3 conditions are met: (1) HCWs are likely to be repeatedly exposed to persons with untreated, inadequately treated, or drug-resistant active tuberculosis; (2) HCWs work in conditions where protective measures against infection cannot appropriately be taken; and (3) early identification and

treatment of latent tuberculosis infection are not available [56]. The US Centers for Disease Control and Prevention shares a similar stance [57].

If having a new, effective tuberculosis vaccine could eliminate many ethical concerns, the rollout of such product would likely itself be fraught with ethical conundrums, including the likelihood that at least some form of prioritization would be inevitable at first [53]. HCWs could be seen as particularly good candidates to receive privileged access to a new vaccine given their importance for the well-being of populations, their increased exposure, and their potential role in further transmission. However, policy makers need to evaluate mandatory vaccination policies very carefully, especially when access to the product is limited. In such cases, mandatory vaccination of HCWs risks simultaneously to antagonize HCWs-whose autonomy is infringed upon—as well as members of the public, who may be upset by the appearance of unjust distribution. Policy makers must also warily review the empirical data provided by vaccine developers before adopting new vaccines. There is no lack of evidence that publication biases are strong [58], and the concerns that they might result in tremendous waste of resources [59] in the case of other diseases might transfer to tuberculosis.

Geolocalization Services and Information Technologies

The use of new technologies to improve the delivery of care in underresourced settings is rapidly taking off. For example, since the 2010 Haiti earthquake, humanitarian organizations have incorporated many new digital technologies in their field operations [60], including crowd-sourced live mapping [61], drone imagery [62], and SMS messages [63] to guide humanitarian responses to disease outbreak, war, and disaster. There is also some appetite for the use of new information technologies in tuberculosis control.

Interest in these new technologies can be partly explained by the rise of an efficiency paradigm in which accountability tends to be measured in technical rather than social outcomes [1]. For healthcare systems, the appeal of being able to monitor the progress of HCWs in real time may be particularly alluring. However, this raises important questions about the right to privacy of HCWs, even during work hours. The question is amplified in settings where HCWs are unpaid or minimally compensated. Aside from concerns around privacy, geolocalization tools raise deep questions about the notion of efficiency. Geolocalization services might make it possible, for example, to keep track of how long a frontline HCW stays in the house of a patient. Although such data could prove useful in detecting problems in the delivery of services, there is a risk that this kind of monitoring would put deleterious pressure on HCWs. The importance of cordial relationships has repeatedly been shown to play a key role in the healing relationship relevant more broadly than just tuberculosis. If a HCWs feels she is unable to tend to a patient holistically because she is monitored by GPS-knowing, for example, that justifying the deviation in time spent with the patient will mean having to write a report—then the quality of the healing relationship might suffer.

The detrimental effect of the "institutionalised privileging of statistical evidence over field-based knowledge" [64] might be felt at a more structural level, too. Arima Mishra reports that the focus on indicator reporting eliminates "any opportunity for the workers to share broader feedback from their practice . . . despite the fact that their experiences from the field would help to explain the mechanisms through which outputs are achieved (or not) and how" [64]. Privacy concerns, combined with the precautionary principle, might hint at the importance of taking a rationalized approach to new technologies, and of subjecting proposals to integrate new technologies for tuberculosis control efforts to ethics appraisal.

CONCLUSIONS

The persistence of tuberculosis and the development of multidrug-resistant strains, despite the fact that for many decades we have had the tools to achieve global control, is symptomatic both of the inadequate use of biomedical treatments available at low cost and of the refusal to recognize the disease as one that is essentially social [65]. Here, we have offered an overview of some of the most important ethical considerations related to tuberculosis prevention, including emerging ones, from the perspective of HCWs in underresourced settings. Through the provision of care to individuals battling tuberculosis, HCWs are de facto exposed to risks. Although there are highly effective measures to prevent the transmission of the disease to care providers, as discussed in this special issue, these measures are often not available to HCWs working in underresourced settings. Lack of access to protective measures adds to the threat posed by the considerations explored here, such as suboptimal private practices, issues of power and space, and deprofessionalization.

We recognize that these ethical considerations will require thoughtful reflection and courageous action on the part of governments, policy makers, and managers responsible for national responses to the tuberculosis epidemic. The appropriate responses to the various challenges are likely to vary based on the setting. However, it is important that the language of ethics be actively deployed when policies that have repercussions on the lives of HCWs are developed. As such, we dually call for policy makers to pay attention to the rising voice of tuberculosis advocates [66] and to the ethical issues with which tuberculosis control is fraught, and for bioethicists to continue to become more engaged with the plight of HCWs working in areas of high tuberculosis prevalence. The emergence of global health ethics as a distinct subdiscipline [67-69] holds promises for the clarification of what responsible parties owe HCWs, especially when these individuals are poorly compensated for their important work. For this reason, we conclude that to have hope for progress in the fight against tuberculosis (and multidrug-resistant tuberculosis in particular) demands that we continuously reexamine our values [12], and combine profound engagement with philosophical analysis [70] with immediate pragmatic approaches that can make an immediate difference on the ground.

Notes

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