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Ethical guidance or epistemological injustice? The quality and usefulness of ethical guidance for humanitarian workers and agencies

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ABSTRACT

This paper explores the quality and usefulness of ethical guidance for humanitarian aid workers and their agencies. We focus specifically on public health emergencies, such as COVID-19. The authors undertook a literature review and gathered empirical data through semi-structured focus group discussions amongst front-line workers from health clinics in Cox's Bazar, Bangladesh and in the Abyei Special Administrative Area, South Sudan. The purpose of the project was to identify how front-line workers respond to ethical challenges, including any informal or local decision-making processes, support networks, or habits of response.

The research findings highlighted a dissonance between ethical guidance and the experiences of front-line humanitarian health workers. They suggest the possibility: (1) that few problems confronting front-line workers are conceived, described, or resolved as ethical problems; and (2) of significant dissonance between available, allegedly practically oriented guidance (often produced by academics in North America and Europe), and the immediate issues confronting front-line workers. The literature review and focus group data suggest a real possibility that there is, at best, a significant epistemic gulf between those who produce ethical guidelines and those engaged in real-time problem solving at the point of contact with people. At worst they suggest a form of epistemic control—an imposition of cognitive shapes that shoehorn the round peg of theoretical preoccupations and the disciplinary boundaries of western academies into the square hole of front-line humanitarian practice.

Summary box

- Few problems confronting front-line humanitarian workers are conceived, described, or resolved as ethical problems by the workers themselves.
- There is significant dissonance between available, allegedly practically oriented guidance and the immediate challenges confronting front-line workers.
- Academics and policy experts from resource-rich Northern countries who produce ethical guidance for front-line humanitarian workers urgently need to explore the extent to which such guidance addresses the real world needs of those to whom it is addressed.
- Front-line humanitarian workers report that collegial relationships and supportive behaviours provide space for resolving dilemmas encountered in the workplace.

INTRODUCTION

In early 2021, the authors undertook a WHO-funded project designed to understand the quality and usefulness of ethical guidance for front-line humanitarian aid workers, with a focus on responding to public health emergencies, such as COVID-19. This project emerged from earlier, pandemic-focussed research by the authors which identified significant gaps in ethical awareness in humanitarian health praxis.[1] We concluded from that earlier research that although ethical reflection on humanitarian practice is increasingly rich,[2] offering important insights into moral challenges in the field, it is not designed to guide practical decision-making in humanitarian crises.[1] As such, we designed this study with the following objectives: (1) to identify and describe existing ethical guidance, (2) to create a typology of ethical problems experienced by front-line humanitarian heath workers (FHWs) and (3) to identify how FHWs respond to these challenges (including any informal or local decision-making processes, networks or habits of response).

Our method involved a preliminary two-stage data-gathering process which included a literature review and semi-structured focus group discussions (FGDs) involving front-line humanitarian health staff from health clinics in Cox's Bazar, Bangladesh and in the Abyei

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Special Administrative Area, South Sudan (for detail of methods, see online supplemental appendix A).

LITERATURE REVIEW

We searched MEDLINE, EMBASE and PsycINFO for COVID-19-related ethics guidance or commentary published between January 2019 and 11 March 2021. We limited our search to sources in English that referenced COVID-19 for multiple reasons: (1) to get a sense of the relevance of the literature to the ethical challenges presented by COVID-19 in the study settings, (2) because the COVID-19-related literature was overwhelming, and (3) because funding required a focus on COVID-19-related ethical challenges.

Our literature search resulted in 737 articles following deduplication. Following disaggregation into broad themes, three types of articles were chosen for closer scrutiny: (1) those containing action-guiding ethical content, (2) those focussing on resource-poor settings, and (3) those referring to humanitarian crises or response. Seventy-nine papers were identified and then screened for material of action-guiding relevance for front-line workers in low-income and middle-income countries. We also searched for grey literature using Google and DuckDuckGo to identify additional sources of COVID-19-related ethical guidance for humanitarian and resource-poor settings; including from WHO, the International Committee of the Red Cross, and Humanitarian Health Ethics.

We found that the practically oriented guidance, such as that developed for the WHO,[3] is largely aimed at high-level actors—those responsible for country-wide responses to humanitarian challenges (e.g. governments, strategic decision makers) and more senior clinicians and humanitarian workers. Much of the recent material responding to the ethical challenges of COVID-19 has been focused on hospital-based decision making in resource-rich settings, with little application for FHWs.[4] Even when designed to inform front-line ethical deliberation, the tools that exist have been developed and assessed using the experience of Western healthcare staff, albeit some with overseas experience.[5]

FOCUS GROUP DISCUSSIONS

We carried out six semistructured FGDs with FHWs from health centres, or community health posts in Cox's Bazar, Bangladesh and Abyei, South Sudan in early 2021. Both Cox's Bazar and Abyei are characterised by extreme humanitarian need. Four FGDs were carried out in Cox's Bazar. Two of these were facilitated and attended by Save the Children International (SCI) staff (in one, participants included Rohingya FHWs, the other included FHWs from the host population), whilst the other two FGDs were facilitated by Médecins Sans Frontières (MSF) staff (in one, participants included MSF FHWs, the other included MSF volunteers from the Rohingya community). In Abyei, South Sudan two FGDs were facilitated and attended by FHWs from SCI. A total 50 FHWs participated in the FGDs. Owing to time pressures, and to ensure FGDs could take place in a single language, convenience sampling was used.

The FGDs were carried out by Bangladeshi and South Sudanese study team members who are experienced FGD facilitators. Together, we developed a location-specific topic guide to help elicit examples of the types of challenges encountered by participant FHWs including follow-up prompts. Assuming that not all participant FHWs were familiar with Western-oriented bioethics, facilitators used a variety of descriptors (eg, 'ethics', 'values', 'conflict' 'doubt', 'problems', 'religious views') and other prompts to identify problems confronted by FHWs involving a value-oriented dimension.

Facilitators were accompanied by a note-taker. Audio-recordings were transcribed and translated into English. Transcripts were coded using a thematic content analysis approach by CM using NVivo V.12. Codes were reviewed, discussed, and revised with JS and MD.[6] A typology of the challenges described by FGD participant FHWs was developed alongside an analysis of their experiences resolving these challenges.

Although Abyei and Cox's Bazar are radically different settings, there was considerable overlap in the problems confronted by participant FHWs. Thematic coding identified a 23-part typology of challenges. The most frequently referenced challenges fell into the following six themes: (1) resources to support patient care; (2) resources to support staff; (3) affected people dissatisfied, mistrustful or unhappy; (4) challenges or constraints caused by policies, protocols, and/or established ways of working; (5) public health rules or expectations not feasible or acceptable to affected people; and (6) contextual challenges (including safety and security). We have grouped these themes as follows: (1) resource-based challenges, (2) terms and conditions of employment, (3) working in challenging settings, and (4) inflexibility of policies/protocols.

RESOURCE-BASED CHALLENGES

In line with our own experience - that includes both working in humanitarian settings and reflecting on ethical issues that arise in these settings - resource-based challenges featured highly among the major challenges facing FHWs in both Bangladesh and South Sudan. Importantly, FHWs can also be the 'local' face of large and well-financed humanitarian organisations and can therefore be held — or can perceive themselves to be held — accountable for resource allocation decisions made in distant countries or European capitals.[7] One example of resource-based challenges identified by FGD participants relates to the 'vertical' programmes of humanitarian organisations and the specific assistance on offer in particular projects (e.g., MSF's focus is on medical interventions). Following the fires in Cox's Bazar in March 2021, some Rohingya refugees did not view healthcare

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as a priority despite the presence of COVID-19 in the camps. One participant paraphrased his interaction with people in the camp who had been affected by the fires:

> Our house has burned about 20 days ago and we don't have food to eat and don't have a place to sleep. If you call us to your health [education] session, how can we respond to you as we are in problem. … If [your agency] talks to other NGOs like [names of agencies] and provides us our necessary things as soon as possible, it would be better for us.

Healthcare workers, therefore, report becoming targets for frustration at resource allocation decisions made a considerable distance from their workplace. Similarly, participant FHWs indicated that people affected by crisis express frustration when INGO staff provide hygiene and sanitation advice without providing basic materials:

> When talking with the community about hygiene, it will be good if we can distribute soap and pot to keep water. If we cannot give these to people, they become upset.

Another participant stated:

> I say [to affected people] that if you face any problem at night, you can go to our hospital. Then they ask me, 'how we can go there as there is not any kind of transport system or vehicle like van or ambulance…the surrounding condition is not good, that's why we are afraid to go anywhere' .

Pressure on resources often translates into long waiting times at health facilities:

> It happens that many patients left after waiting for 1 to 1.5 hours . As our facility is people-centred, we must be friendly with them. Moreover, we have to be time-convenient. Many times many patients left the clinic just because of prolonged waiting time.

Many FHWs argued that they could be more effective — and more resilient — if they were better resourced. The demands were hardly extravagant: wellington boots, umbrellas, T-shirts and proper name badges were items respondents suggested would make their working lives safer and less challenging.

Although resource allocation decisions — such as the shortage of ventilators during COVID-19 — are properly an area of considerable focus in bioethics, these excerpts show such abstract reflection is of little practical benefit to FHWs. Their challenge is to absorb both their own frustration (and that of people affected by crisis) at lack of resources the lack of resources resulting from allocative decisions made far higher in the institutional apparatus of humanitarian work.

TERMS AND CONDITIONS OF EMPLOYMENT

Many FGD participants experienced frustration with their conditions of employment, particularly the level of support they receive from employing INGOs:

> It [was] not long time that we [had] a water bottle; but it also burnt with our house, or someone lost their bottle. I think they should get bag and water bottle who don't have one, or lost [it] . And we badly need umbrella as well as saline because sun is so hot and we sweat much when we work.

Staff also compare their working conditions with staff from other agencies:

> Others got good visibility who work in other NGO. They got vest, t-shirt, and very strong [ID] card. We also got card from [agency], it will be good if we would get more good visibility from [agency] . Community people would respect us more. T-shirt like other NGO volunteer got will be best for us.

> We work with risk, but we didn't get supportive item like umbrella, sanitiser. Also [we] faced challenges from [affected people] ; they said [why don't we give] them like mask, soap, or related item for being safe.

Working for an INGO headquartered outside of the country also presented challenges, with tensions arising between local approaches and solutions and the demands of some international managers:

> Sometimes some expats are so friendly, they do open discussion, take suggestion from us, after [that] they come to a decision. In some cases some expats come and he approaches that everything [that] was going on before [he came] was wrong. So, this is a huge mental stress for us.

To require local FHWs to work without basic materials, or the respect of international managers, can undermine their agency and confidence, create moral dissonance—they are prevented from doing their jobs by the organisations employing them—and have serious reputational consequences for individuals and INGOs.

WORKING IN CHALLENGING SETTINGS

Many FHWs are employed locally, often living in pressurised circumstances, and are immersed in responding to human suffering in emergency settings. Travel to and from work can be challenging, as can lack of acceptance from crisis-affected people. Fear inevitably plays a significant part in their concerns. Conflict, instability, factional tensions, and the omnipresence of COVID-19 add further challenges. Gender can lead to vulnerabilities, particularly when linked to resourcing issues:

> In the evening or at night when someone's shift is over and someone is about to start at 7 pm, it becomes dark outside. It is natural to be challenging for the nurse, midwife, or other female staff. So, if there would have shuttle service, then it would be better.

Tensions were reported between fears for personal safety and the requirement to ensure money for families. Although front-line work increased risks of exposure to COVID-19, in the absence of other employment, choices are highly restricted:

> One of our colleagues left his job due to the fear of COVID. When he left the job, then I was in a dilemma thinking what should I do now? As I have family, if I leave the job, how I will contribute there?

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Many of those living in the refugee centres are frightened, which can seriously inhibit their willingness to interact with FHWs or to engage in health promoting behaviour.

> Beneficiaries do not respond and open up themselves easily because of the unstable camp situation. They have this fear that people from [name of militant group] are always following them and if they utter any words, those people will cause them harm.

Navigating the complex political alliances within refugee camps, and between camps and host communities, can clearly present major challenges, as can ethical tensions between duties to support beneficiaries and obligations on FHWs to protect themselves. Our literature search suggests that these complex and urgent challenges, which combine normative, administrative and prudential questions are not directly addressed in the existing guidance.

INFLEXIBILITY OF POLICIES/PROTOCOLS

Humanitarian settings are often characterised by disruption, urgency, and extreme need. Given the urgency of the demands, FHWs are aided by protocols, guidance notes and other supports for decision making. These aids can be vital but also concerning for front-line workers where they don't 'fit'.

> Some standard operating procedures/[agency] clinical guidelines doesn't match for some disease. In that case, we do Google search sometimes. I personally think that [these standard operating procedures] are not a good reference actually…[they] should be checked after every three or six months . This is one thing. Another thing is, the diseases that we are getting [that are not included in] these guidelines, there should have an individual portal/guideline for that.

Another frequent area of tension is between patient expectations and the treatment or intervention supported by institutional protocols.

> Another problem is that we send many patient to health centre like [sexual and gender-based violence], [haemophilus influenzae], etc. If a patient doesn't have fever, doctors don't give medicine and if an [acute watery diarrhoea] patient doesn't defecate two or three times in front of doctors, they don't give medicine. When we do work there next time, they tell us, " yYou sent us to hospital but they didn't give medicine. Why you sent us" ?

For those with experience in humanitarian settings, the practical focus that emerged from the FGDs may not be surprising. Lack of resources is at the heart of humanitarian work. But it remains striking how little FHWs were concerned by the kinds of ethical challenges that routinely exercise western ethicists in reflection on humanitarian practice. Furthermore, where ethical questions would seem to arise, such as how FHWs should respond where protocols do not match reality — whether they should adapt or extemporise, and based on which criteria — we found no evidence that they were addressed in available ethical guidance.

RESOLVING WORKPLACE CHALLENGES

Despite the lack of ethical guidance adapted to workplace challenges identified, it was evident from the FGDs that problems were not left unresolved. Formal and informal procedures — whether involving discussion with line managers or more collegial and informal relationships — were used to manage problems. Interviewees mentioned the importance of innovation, kindness, generosity and collegiality in the resolution of workplace challenges. It must not be presumed that because these support systems do not comport with external—Western—standards, they do not exist, or are ineffective, although this is potentially an area for further investigation.

CONCLUSION

The urgency of the humanitarian crisis in both locations and the restrictions imposed by COVID-19 limited staff availability and the conduct of the FGDs. As a preliminary scoping study with a small convenience sample of FGD participants — involving FHWs exclusively — the data are therefore suggestive rather than determinative. It is clear however that the FHWs who participated in the FGDs did not classify the challenges they face as ethical or normative despite prompting. The strength of this study lies in the skilled facilitation by members of the study team who live and work in the study settings, and our confidence that our qualitative data accurately reflect the lived experience of our FGD participants.

The findings of the literature review and the FGDs were concerning. Although we expected practical challenges to be raised, we were surprised that few obviously ethical or normative challenges were described by participants. Our findings suggest the possibility: (1) that few problems confronting FHWs are conceived, described, or resolved as ethical problems and, (2) there is significant dissonance between available, allegedly practically-oriented guidance (often produced by academics in North America and Europe) and the immediate issues confronting FHWs. We were also surprised by the absence of academic literature interrogating the questions our research prompted.

The FGD data further suggest that much of the ethical guidance developed in high-income settings does not capture or reflect the nature of the choices confronting FHWs and local populations. Instead, this guidance often occupies the meta/abstract, macro/global and meso/national levels. Despite the richness and variety of the material we discovered during our literature search, very little was directly applicable to the day-to-day challenges facing FHWs.

The findings of the FGDs also invite reflection on the extent to which ethical guidelines serve the theoretical paradigms — and professional interests — of largely Northern academic institutions, rather than the needs of

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FHWs. To begin with, these guidelines miss how FHWs lack agency within the top-down distribution of authority or power within their large humanitarian institutions. Seemingly outside these ethical frameworks, their descriptions of difficult conditions of employment and resource allocation challenges reflect how the agency's duty of care and distribution of goods signal the participants' status as local, community-level employees. Furthermore, though it is possible to frame some of the issues raised as 'ethical' problems, the ease with which many of the issues could be addressed suggests that contemplating ethics guidance, or engaging in moral deliberation, may not be the best use of time or resources. Critically, at a time when NGOs are being asked to challenge their own ethics, so too should institutions and academics who position themselves as moral authorities in the humanitarian space.

The data from the FGDs and literature review suggest a real possibility that there is, at best, a significant epistemic gulf between those who produce ethical guidelines and those engaged in real-time, community-facing problem solving. At worst they suggest a form of epistemic control[8]; an imposition of cognitive shapes that shoehorn the round peg of theoretical preoccupations and boundaries of western academies into the square hole of front-line humanitarian practice.

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Sheather et al. Ethical guidance or epistemological injustice? The quality and usefulness of ethical guidance for humanitarian workers and agencies

Appendix A - methodology

By way of background, as part of an earlier project to produce ethics support for epidemic response in humanitarian action, we conducted a literature review in the first half of 2020. There, the questions we ask in this research as to the relevance of the guidance for frontline staff first emerged. In this study, we undertook a literature search to identify practically-oriented COVID-related ethics material for the purpose of identifying gaps in the literature and determining whether the available literature was likely to be practically useful (particularly for those without a professional training in ethics). We searched MEDLINE, EMBASE, and PsycINFO for COVID-related ethics guidance or commentary published between January 2019 and 11 March 2021. We used a combination of search terms as follows: coronavirus – and correlates – ethics, bioethics, ethical, bioethical, developing countries, third world, developing nations, resource poor, low income, LMICs, undeveloped, humanitarian, refugee, displaced people, refugees.

Our literature search resulted in 737 articles following de-duplication. Of these 658 were deemed not relevant for inclusion (reasons included: lack of practically-oriented guidance and irrelevance to humanitarian settings. Following initial screening we disaggregated the remaining 79 papers into broad themes, three types of articles were chosen for closer scrutiny: a) those containing action-guiding ethical content, b) those focussing on resource-poor settings, and c) those specifically referring to humanitarian crises or response. Seventy-nine papers were identified and then screened for material of any action-guiding relevance for frontline workers in low- and middle-income settings (LMICs). We also searched for grey literature in Google and DuckDuckGo to identify additional sources of COVID-related ethical guidance for humanitarian and resource-poor settings, including from the World Health Organization, the International Committee of the Red Cross, and Humanitarian Health Ethics.

COVID-19 has seen the publication of a significant body of material describing the ethical issues related to the pandemic. Overwhelmingly, the focus was on hospital-based medicine and concerned with the impact on speciality-specific practice, as well as the ethics of research and resource allocation. The material produced by clinicians and ethicists in LMICs also reflected this bias. Normative work was almost entirely rooted in western bioethics. Among the normative concerns, questions of justice and equality were prominent.

In addition, we carried out six semi-structured FGDs with frontline humanitarian workers from health centres, health posts, or mobile clinics in Cox's Bazaar, Bangladesh and Abyei, South Sudan in

February/March 2021. Four FGDs were carried out in Cox's Bazar: two facilitated and attended by SCI staff (the participants in one were drawn from the refugee/Rohingya population and in the other from the host population); one facilitated and attended by MSF staff; one facilitated by MSF staff and attended by MSF volunteers from the Rohingya community); two FGDs were carried out in Abyei, one in the Abyei town and the other in Juljok (both facilitated and attended by SCI staff). A total 50 frontline health workers and six health volunteers participated in the FGDs.

In both locations, particularly in Cox's Bazaar, community health work involved sensitisation and response to COVID-related issues. Each FGD comprised a mixed group of five to ten participants. Participants were employees of Save the Children International (SCI) or employees and volunteers of Médecins Sans Frontières (MSF). Owing to time pressures and the necessity to ensure FGDs could take place in a single language, convenience sampling was used.

The FGDs were carried out by study team members who are experienced FGD facilitators and who were from Bangladesh and South Sudan, respectively. Together, we developed a location-specific topic guide to help elicit examples of the types of challenges encountered by participants in the course of their work, including follow-up prompts. Assuming that not all participants were familiar with Western-oriented bioethics, facilitators used a variety of descriptors (e.g., 'ethics', 'values', 'conflict' 'doubt', 'problems', 'religious views') and prompts to identify problems confronted by health workers involving a value-oriented or normative dimension. We also encouraged participants to identify how they responded to challenges, and to describe what resources were available to support those responses.

Facilitators were accompanied by a note-taker. Audio-recordings were transcribed and translated into English. Transcripts were thematically coded using NVivo 12 qualitative research software (QSR International. 2021. NVivo: Release 1.0. Melbourne, AU: QSR International, LLC). A typology of ethical challenges was developed alongside an analysis of participants' experiences resolving ethical challenges. A positive deviance approach was used to identify potential staff-generated solutions or responses to the ethical challenges faced.

Participants provided verbal consent to participate in the FGDs and to their recording. No personal identifying information was divulged during the interviews. Recordings were destroyed following transcription. Ethics approval was obtained from the Save the Children UK research ethics committee; the MSF Operational Centre Amsterdam research committee waived ethics review on the grounds that the work constituted service evaluation and improvement. The locations and names of agencies have been removed to increase anonymity.