

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 Abye, one in the Abye 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.