From the Front Lines: Trialing Research Ethics in the Time of Ebola
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Study/Objective: Focused on first-person accounts of clinical trials conducted during the West Africa Ebola outbreak, this study unpacks challenges and strategies for the ethical conduct of research during public health emergencies, adding evidence to existing recommendations for the ethical conduct of research in public health emergencies.

Background: Research conducted during the 2014-15, West Africa Ebola outbreak presented a number of documented, ethical and practical challenges. Alongside the recruitment and consenting of participants amongst patients subject to isolation and quarantine, research involved the testing of unproven agents with no known alternative. Research occurred in the context of widespread fear, distrust of hospitals, foreigners, vaccines, and/or local authorities. It involved a little, understood Level 4 Pathogen. The Ebola research context presented the coexistence of all these challenges in one research context, and the possibility – due to the number and variety of studies carried out in three countries – to compare experiences and innovations to the challenges of upholding ethical standards during an emergency of this scale.

Methods: Data was gathered through Skype and in-person semi-structured interviews (N = 110) with stakeholders directly involved in research at trial sites in Guinea, Sierra Leone, and Liberia (as survivors, proxy decision-makers local and international research ethics board members members, research and Ebola Treatment/Management Center staff).

Results: Different trials and trial contexts presented some similar, but also unique ethical challenges. Examined in depth are the number and variety of studies carried out in three countries – to compare experiences and innovations to the challenges of upholding ethical standards during an emergency of this scale.

Conclusion: This study builds on a growing body of knowledge directly engaging ethical and practical experiences and challenges, of conducting ethical research during public health emergencies.

Moral Entanglement and the Ethics of Closing Humanitarian Medical Aid Projects
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Study/Objective: We aim to clarify the obligations that humanitarian medical organizations hold towards recipients of aid when a decision is made to end a humanitarian project.

Background: Humanitarian organizations and their staff regularly make and implement decisions to close projects.
Such decisions are frequently challenging to make, and may be contested within an organization. They also have enormous ramifications for the communities who are receiving assistance.

**Methods:** Drawing on field cases of project closure, and an examination of the literature around this topic, we conducted a normative and conceptual analysis of humanitarian organizations' obligations.

**Results:** Humanitarian projects have intrinsic, as well as instrumental value, and thus create moral entanglements between humanitarian actors and local communities that require careful consideration due to the responsibilities that ensue. Basing our proposal on an analysis of the nature of relationships between providers and recipients of humanitarian aid, we argue that ethical exit strategies should reflect five commitments. In closing projects, humanitarian organizations should demonstrate respect for recipients of care, and seek to minimize harm and disruption by acting in ways that are characterized by: (1) transparency, (2) predictability, (3) adaptability, (4) participation, and (5) evaluation. In addition, humanitarian organizations have responsibilities toward their staff who will implement the closure of a project. These responsibilities include ensuring that relevant policies and resources are in place, and that training and support are provided to those who require it.

**Conclusion:** Closing projects is an inescapable aspect of humanitarian action – indeed, almost all humanitarian projects will come to an end. Making and enacting such decisions is ethically fraught, and may be a source of distress for humanitarian workers and local communities. Careful attention to ethical exit strategies that follow through on obligations toward local communities is therefore a vital component of ethical humanitarian action.

**Ethical Challenges at the Intersection of Policy and Practice in Humanitarian Contexts**

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**Study/Objective:** To explore how policies and ethics inform each other, in order to better understand where problems arise in humanitarian healthcare organizations, and how policy can be improved in this regard.

**Background:** Researchers have just begun to understand the range of ways in which humanitarian healthcare organizations' policies can shape ethical dilemmas in the field. This study lays out some of the ethical tensions that affect the profession by identifying ethical challenges that arise from aid agency policies and practices, or that trigger the need for improved policy development.

**Methods:** We interviewed 14 Organizational Members (OMs) from Canadian and international offices of humanitarian healthcare organizations to explore the questions and objectives guiding our study. In order to understand how problems and ethical issues are identified in humanitarian aid organizations, and their relationship to policies and practices in this regard, we used interpretive description (ID) methodology. We prioritize understanding to go beyond description and more deeply into the interpretive aspect of ID, in order to unpack problems and ethical issues in humanitarian aid.

**Results:** EoLC caused particular ethical difficulties, even though most participants were accustomed to dealing with the dying and dead. Specific issues included: uncertainty about the course of the disease in individuals, which resulted in, amongst other things, a ‘hybrid’ approach to palliation; the trade-off between infection control and providing ‘normal’ end of life care and comfort; moving dying patients long distances to receive palliative care; preparation of the dead for burial. The duty to care for patients (‘normal’ professional obligations) was constrained by public health measures (containment) and the need to protect staff from infection (obligations to employees/self/colleagues). End of life care, where human contact seems especially important, was particularly impacted.

**Conclusion:** Meaningful end of life care is difficult to provide during a mass outbreak of a highly infectious and serious disease. The difficulties of providing meaningful care need to be taken into account when deciding how to prioritize and deliver EoLC in a disaster response.

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Ethical Challenges at the Intersection of Policy and Practice in Humanitarian Contexts

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**Results:** Three key themes were identified: participant perceptions of tensions related to 1) institutional memory loss; 2) priorities within different departments of humanitarian healthcare organizations; and, 3) social norms and expectations of humanitarian healthcare organizations and local communities.