

Abstracts of Scientific Papers-WADEM Congress on Disaster and Emergency Medicine 2017

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 two case studies: one showing gaps in guidelines and resources available to support the ethical conduct of research, the other illustrating the importance of creative, context-tailored responses to exceptionally challenging clinical research settings.

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.

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Ethical Dilemmas during a Refugee Crises

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Study/Objective: Describe why humanitarian actors should prioritize the welfare of the community, and decline transfers of critical patients in a refugee camp through a case study.

Background: While providing care in a Syrian refugee camp in Greece, referrals were frequently received for transfer of critical patients to our camp given superior infrastructure. One such referral was of a 5 year-old child in end-stage heart failure.

Methods: Evaluation of current ethics literature to justify decline of transfer of this patient.

Results: The Sort, Assess, Lifesaving Interventions, Treatment/Transport (SALT) system, in disaster settings, is the most ethically accepted rapid assessment triage system. Its ethical foundation is no different during a prolonged humanitarian crisis. Under utilitarianism, critical patients should not be allowed to be transferred given the constraints placed on resources, because they should be used to maximize life years and Quality-Adjusted Life Years (QALYs) saved. One cannot justify the consumption of resources to save a single life for a short period of time, when they could be used to care for many for a prolonged period of time. Egalitarians would support the care of patients that are worse off, yet, the principles of prioritarianism places weight on the ability to provide the greatest benefit. One would argue that such patients should not receive priority of care. Although having the fewest lifetime QALYs, one is unable to provide the greatest benefit. Finally, we are ethically responsible to practice international medicine within the standard of care. Critically-ill patients require advanced specialty care, which would require advanced tools not available.

Conclusion: The ethical arguments as to why it is our responsibility, as humanitarian actors, to prioritize the welfare of the entire community in these complicated situations has been outlined. During a humanitarian crisis, our responsibility is to provide the best care possible. This task is frequently difficult and comprised of a magnitude of ethical dilemmas.

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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.

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Ethical Challenges of Providing End of Life Care in an Ebola Treatment Unit (2014–2015)

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Study/Objective: To identify and explore the ethical challenges faced by UK Defence Medical Services personnel working in an Ebola Treatment Unit (ETU) established in Sierra Leone.

Background: British military were deployed as part of the UK Government's response to the Ebola outbreak in West Africa (Op GRITROCK). This included establishing a small, well-resourced ETU for Ebola-infected international responders and local healthcare workers. The End of Life Care (EoLC) provision in humanitarian disaster response is discussed very little in bioethics.

Methods: Twenty personnel who deployed between October 2014 and April 2015 were interviewed about the ethical challenges they faced. Participants included doctors (7), nurses (6) and other healthcare related (7). A largely conventional approach to content analysis was taken using the data to draw conclusions about themes in the participants' thinking. Data was organized using NVivo. Only the EoLC theme is reported here.

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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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: 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.