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From the Front Lines: Trialing Research Ethics in the Time of Ebola

Elysee Nouvet, Lisa Schwartz

Clinical Epidemiology And Biostatistics, McMaster University, Hamilton/Canada

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

Nirma D. Bustamante¹, Bryant Shannon²

- Emergency Medicine, Brigham and Women's Hospital, Boston/ AL/United States of America
- 2. Massachusetts General Hospital, Boston/MA/United States of America

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

Matthew Hunt¹, Jingru Miao²

- School Of Physical And Occupational Therapy, McGill University, Montreal/QC/Canada
- 2. McGill University, Montreal/QC/Canada

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.