Between Rigor and Reality: Ethical Challenges in the Conduct of West African Ebola Research

Nicola Gailits
PhD student, Dalla Lana School of Public Health
University of Toronto
Conducted narrative review with aim to identify key ethical and practical challenges in the scholarly literature emerging from research conducted during the 2014-2016 West Africa Ebola outbreak.

(Antierens & Frontières, 2014)
Methods

- **PUBMED**: 739 Citation(s)
- **EMBASE**: 1700 Citation(s)
- **CINHAL**: 229 Citation(s)
- **JSTOR**: 35 Citation(s)
- **Philosophers Index**: 27 Citation(s)

2062 Articles Retrieved
Removed duplicates (668)

Excluded articles not reporting on research with human subjects during 2014-16 EVD outbreak

1636 Articles excluded after title/abstract screen

427 Articles Included

Included articles mentioning ethical or practical challenges

280 Articles excluded after full text screen
2 Articles excluded during analysis

145 Articles included in review
Results: Interlocking Levels of Ebola Ethical Challenges
Results

1) **4 Interconnected Levels** of ethical challenges

2) **Impact of Global Inequities:** Weak health systems + lack of resources result of:
   - Under-investment, postcolonial political instability, armed conflict, and externally imposed structural adjustment programs

3) **Flexibility and Rigor:**
   - Tension between ideals of rigorous research and practical realities on the ground
   - Flexible approaches and innovative thinking needed
NATIONAL LEVEL CHALLENGES

Lack of human and technical resources:
• ETC workers trained as frontline responders not researchers
• Poor infrastructure
• Few courses of treatments available

Nearly impassable bridge on the road to Monrovia, Liberia. (Summers et al., 2014)
NATIONAL LEVEL CHALLENGES

• number of infected individuals had declined by the time some trials started, =competition between trials
• REBs often had limited trial experience
• Weak documentation practices reported

Empty shelves in clinic in Liberia. (Summers et al., 2014)
COMMUNITY LEVEL CHALLENGES: DISTRUST IN A POSTCOLONIAL CONTEXT

- Widespread panic and confusion
- Belief that national/international governments had created Ebola to infect West Africans

Postcolonial Context:
- Decades (and centuries) of distrust built up through colonialism

(Antierens & Frontières, 2014)
COMMUNITY LEVEL CHALLENGES

Panic, Confusion, and Stigma:

+ Cross-cultural and language confusions during engagement
+ Fear/violence: Participants violently freed from ETCs
+ Stigma: Not sharing home addresses for follow up

Riots in Guinea
(Antierens & Frontières, 2014)
TRIAL DESIGN CHALLENGES: GLOBAL DEBATES

Two main areas of debate emerged:

1) **Experimental Interventions**: Whether it was ethical to use interventions previously untested.

2) **Randomization Debate**: revealed two groups—RCT group arguing for their scientific rigor, and opponents of RCT insisting treatments should be made available to all patients.
TRIAL DESIGN CHALLENGES

Debates as Distraction

- Authors arguing these two debates were distractions from outbreak and trial response efforts needed
- Debates of use of exp interventions “sidetracked relief efforts” (Gericke, 2015)

CNN, 2014
PARTICIPANT LEVEL CHALLENGES

Vulnerable Populations:
+ Many studies excluded pregnant women
+ Seen as a breach of equity

Informed consent:
+ Unclear if participants could consent in their psychological state
+ Large potential for therapeutic misconception
Next Public Health Emergency: Recommendations

1) **Global inequities**: Ethical challenges embedded within global inequities
2) **Interconnections**: Connections across 4 levels of ethical challenges
3) **Rigor vs Reality**: Be ready with **flexible** and adaptable study designs

Discussion with a paramount chief in Sierra Leone (WHO, 2017)

(Antierens & Frontières, 2014)
Acknowledgements

- Co-authors: Dr. Elysée Nouvet, Dr. Lisa Schwartz, Dr. John Pringle, Dr. Matthew Hunt, Daniel Lu, Dr. Carrie Bernard, Dr. Laurie Elit

- Humanitarian Healthcare Ethics Team

- Funders:
  - R2HC (Research for Health in Humanitarian Crises) and Elrha

Paper coming out! Keep in touch: nicola.gailits@mail.utoronto.ca
References


