Consent, Ebola, and the fine line between collaboration and exploitation in research conducted during public health emergencies

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THANK YOU!

- Lisa Schwartz PhD, Ani Chénier, MA, John Pringle, PhD, Matthew Hunt PhD, Oumou Bah-Sow, MD, PhD, Sékou Kouyaté, MA, Sonya De Laat, PhD, Gautham Krishnaraj MSc, Carrie Bernard, MD, Lynda Redwood-Campbell, MD, FCFP, DTM&H, MPH, Laurie Elit, MD, MSc FRCS

- Colleagues (many in room)

- Study participants

- $ Funders $ 😊😊 : R2HC & CIHR
The weight of consent (structure of talk)

1. Overview of project and ‘data’ that is pt of departure for this talk

2. Slowing down, really listening to and thinking with West African study participants’ social rationales for participation in research

3. Consent and (mis)recognition
Part I:

Ebola and one Canada-West Africa R2HC-funded project
The West Africa Ebola Virus Disease epidemic

<table>
<thead>
<tr>
<th>Country</th>
<th>Reported cases</th>
<th>Deaths</th>
</tr>
</thead>
<tbody>
<tr>
<td>Guinea</td>
<td>3,814</td>
<td>3,956</td>
</tr>
<tr>
<td>Liberia</td>
<td>10,678</td>
<td>3,956</td>
</tr>
<tr>
<td>Sierra Leone</td>
<td>14,124</td>
<td>4,810</td>
</tr>
</tbody>
</table>
Perceptions and moral experiences of EVD research
Humanitarian Healthcare Ethics, Guinean National Health Research Ethics Board, R2HC
Density of physicians per 1000

Canada (2015): 2.539

© World Health Organization 2018 | Source: Global Health Observatory (http://www.who.int/gho/en/)
Density of physicians per 1000

- Guinea (2016): 0.075
- Sierra Leone (2010): 0.024
Perceptions and Moral Experiences of Ebola Research

Study objectives:

1) To deepen understanding of challenges and strategies for the ethical conduct of research during public health emergencies, with particular attention to the rolling out of clinical trials.

2) To learn how Ebola quarantine and isolation disease control measures, such as voluntary consent, interacted with ethical standards of research interventions in Sierra Leone, Guinea, Liberia.

3) To add evidence to existing recommendations for the ethical conduct of research in public health emergencies.
The *oughtness of care*: Fear, stress, and caregiving during the 2000–2001 Ebola outbreak in Gulu, Uganda

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Who did we interview?

- 65 men, 43 women
- 91% West African
Research studies discussed by our participants

- **Vaccine(s)**: 30
- **Conv. Blood &/or plasma**: 22
- **Drugs (zmapp, TKM, interferon)**: 18
- **Survivor**: 15
- **General**: 8
KEY QUESTIONS

• “What motivated you to support, participate in, or decline participation in this research?”

• “Did anything make you uncomfortable or leave you feeling troubled?”

• “What was done well?”
“Doctor, do whatever you want to do, as long as I get better.”
(P72)
“...those taking consent should exercise more time. Which unfortunately was not the case in the Ebola business...in that kind of situation, you just want to talk less and start the treatment.”

(P80)
Therapeutic optimism framing recruitment as the only ethical objective

• “You need to cajole them”
Tx Misconception - vaccine

“They told us that if we got vaccinated, even if Ebola is in this area, we will be sheltered. That we will never again be able to get Ebola.”
NEED

Access to otherwise inaccessible healthcare services
“During the outbreak, a lot of people came to help. It’s like somebody drowning and you are given a knife to hold. What do you do? You just have to hold a knife.” (P62)
INADEQUATE COMMUNICATIONS

• Trials started before final ethics approval

• Lack of clear info

• Survivors wanted to be and not consulted before studies approved

• Lack of post-trial communication = feeling used
Tx misconception

• Ethical / practical problem b/c

  • Decision-making based in delusion/mis-information

  • Can result in disappointment and loss of trust
“Consent or collaboration misconception”

Harm –

disappointment, loss of trust feeling objectified and misled –
comes from entering research with (mi)sconception that this is collaboration
Consent complexities

LRs enhance recruitment

Low rates of literacy, medical literacy, distrust

Relationship between LRs and community

Best practice?

Trauma related to EVD, losses

Compensation inflation
Part II:
Social connection rationales animating participation in research
In ETU: "Emmanuel"

-Nurse recognizes family name: her family is from the same village

“On the outside, I know you people have heard a lot of rumours, that the drugs that they offer you are going to kill you. You’re going to die. So I beg you, this is the drug that we give. It is an experimental drug that we are giving. But we know it is saving people. It is helping people to regain their strength, to regain their life. ... So take it in."
• Nurse: “I am not here to harm you, I’m not here to kill you. I am your relative. I am your sister. So take it in. So I said OK, and I took it in.”
“...since I am an Ebola survivor, I know what was going on in the ETC, I could not just stay there like that, standing idly by with my arms crossed, refusing to give life to other people who were still suffering.”

(P11)
...I had to contribute, in my way, to researching the disease.

(P34)

I know what I’ve undergone, I don’t want this disease affect any other citizens.

(P55)
Why is this interesting?
"It's got to be altruism," he told The Globe and Mail.
Ebola and Learning Lessons from Moral Failures: Who Cares about Ethics?

Maxwell J. Smith*, University of Toronto
Ross E.G. Upshur, University of Toronto
Part III:

(Mis)interpreting Consent & (Non)recognition
Nancy Fraser 2001, p. 6
“Recognition or redistribution?”

• Recognition is fundamental to any redistribution

• (Mis)recognition of those with less resources as not our peers at core of why and how inequities persist

• Recognition is fundamental to the sharing of power and to transformative politics/policy
recognition
/ˌrekəgˈniSH(ə)n/

noun
noun: recognition; plural noun: recognitions

1. identification of someone or something or person from previous encounters or knowledge.

2. acknowledgment of something's existence, validity, or legality.
   - appreciation or acclaim for an achievement, service, or ability.
   - formal acknowledgment by a country that another political entity fulfills the conditions of statehood and is eligible to be dealt with as a member of the international community.
Ebola and the production of neglect in global health

João Nunes
“Systematic mis-recognition has led to forgetting or to the imposition of narratives that do not correspond to actual lived experiences. This in turn has had an impact upon how injustices and suffering are dealt with.”

(p. 542)
recognition
/ˌrekəɡˈniSH(ə)n/

1. identification of someone or something or person from previous encounters or knowledge.

"he stared at her, but there was no sign of recognition on his face"
Thank you!
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Participants’ Perceptions of Ebola Research
Report to participants

What is the purpose of this report?

In 2016, we launched the "Perceptions and moral experiences of research conducted during the West Africa Ebola outbreak" study (the "Perceptions" Study). This study seeks to better understand the practical and ethical issues of research conducted in public health crisis situations. To this end, we conducted 108 individual interviews in Guinea, Liberia and Sierra Leone with 3 categories of people: (1) participants in clinical trials and other studies conducted between 2014-6; (2) researchers, and; (3) African and foreign leaders who supported or evaluated these studies (e.g.: government representatives, scientific committee members).

This report looks at category (1), people who participated in research, and answers the following questions:

- How did the people who participated in research conducted during the West Africa Ebola crisis experience the research?
- How did the conducted research impact their lives?