

PLOS Science Wednesday: Hi reddit, we're Ruth and Sophie and we investigated how media coverage of Ebola survivors addressed the issues of stigma and discrimination against survivors – Ask Us Anything!

PLOSScienceWednesday¹ and r/Science AMAs¹

¹Affiliation not available

April 17, 2023

[REDDIT](#)

PLOS Science Wednesday: Hi reddit, we're Ruth and Sophie and we investigated how media coverage of Ebola survivors addressed the issues of stigma and discrimination against survivors – Ask Us Anything!

PLOSSCIENCEWEDNESDAY [R/SCIENCE](#)

[removed]

[READ REVIEWS](#)

[WRITE A REVIEW](#)

CORRESPONDENCE:

DATE RECEIVED:
September 07, 2017

DOI:
10.15200/winn.150470.02268

ARCHIVED:
September 06, 2017

CITATION:
PLOSscienceWednesday ,
r/Science , PLOS Science
Wednesday: Hi reddit, we're
Ruth and Sophie and we
investigated how media
coverage of Ebola survivors
addressed the issues of stigma
and discrimination against
survivors – Ask Us Anything!,
The Winnower
4:e150470.02268 , 2017 , DOI:
[10.15200/winn.150470.02268](https://doi.org/10.15200/winn.150470.02268)

© et al. This article is distributed under the terms of the [Creative Commons Attribution 4.0 International License](#), which permits unrestricted use, distribution, and redistribution in any medium, provided that the original author and source are credited.



It sounds like the virus can survive an incredibly long time in sperm when the survivor is otherwise Ebola free. Is this a part of what drove the stigma? Someone could masturbate and not wash their hands and start a whole new outbreak months later?

[YoullShitYourEyeOut](#)

Ruth: Yes, there are several studies ongoing to determine in what way and for how long the virus is able to survive. Stigma was present even before it was known that the virus can survive in certain body fluids. We also know that stigmatization took place during other EVD epidemics in Africa. And let us not forget the stigmatization of health workers returning from the response to Europe and the US, even without them having Ebola ... I think partly stigmatization and discrimination has to do with (one could say a very understandable) fear of a deadly disease (high case fatality rate of over 40%). Probably also the negative messaging that “Ebola is deadly” which left no space for hope, might also have been a contributing factor. One Liberian health worker, who was a survivor, told me that if he mentioned he was a survivor he would not be treated by hospital staff. So also structural factors, low levels of education, little health literacy, poor public health infrastructure are important when we discuss issues of stigma and discrimination.

The outbreak affected both rural and urban communities. Is there a difference in the way survivors were seen between these communities?

[Doktor_Wunderbar](#)

Ruth: Thank you, excellent question. In the media we could not see any difference in the perception of Ebola survivors in rural or urban communities. But we have to consider that the Liberian Observer is rather read by urban consumers than rural ones and the picture shown might be biased. In terms of effect of stigma on survivors I would say that there is a difference. In another study (yet to be published) we found that almost half of our interview partners who lived in Montserrado (an urban area which includes the capital Monrovia) have moved to another area in the city where they are not known as survivors. In urban communities it might be easier to deal with discrimination than in rural ones.

In a precursor to your research question, what led the Liberian media to adopt a positive tone about Ebola survivors?

[sanity_incarnate](#)

Sophie: Good question, that was also something we discussed among ourselves. Among so many things that went wrong during the response to the outbreak in West Africa the reporting in the Daily Observer was quite well-balanced and empathic. Actually, we don't know! What do you think?

okay. a flat-out blunt question - are there any risks to other people coming into contact with survivors of the disease, what are they, and what can be done to minimize them?

and an optional follow-up question in case the first answer is a nice and satisfying flat "no" - are there any long-term negative health effects for survivors, what are they, and what can be done to minimize them?

[thesuperevilclown](#)

Ruth: Normal day-to-day contact with survivors (e.g. shaking hands, eating from the same plate) is harmless. Ebola virus can remain in the semen for several months and survivors are recommended to use condoms. There are several long-term effects reported: joint pain, muscle pain, headaches; treatment currently is symptomatic.

Do Ebola survivors become healthy? Do they regain their previous strength?

[hawkwings](#)

Ruth: Some do. Many survivors, however, suffer from physical and mental after effects. The reason why we know so little about all this is that before this large epidemic in West Africa with more than 28.000 cases and an estimated 10.000 survivors, all other outbreaks were relatively small and confined, with few survivors. Research on the after effects of the disease is only beginning.

Hi there, what made the ebola virus spread much more effectively and pose such a greater threat than any other virus? Thanks a lot for you time

[the-pinnacle](#)

Sophie: Hello! Well, for the recent Ebola epidemic in West Africa I would say that it is relevant to consider that the countries had quite weak primary health care systems even before EVD was detected, this weakened with the spread of the disease. Secondly, the number of health care workers infected with the virus was quite high, this was related to lack of protective equipment and unclear evidence of all possible transmission routes (more research was done after it became clear how severe this crisis had become).

is it true you can be an asymptomatic carrier of the disease? how long should these people be quarantined

[Alexandertheape](#)

Ruth: In one study last year Richardson et al. found that Ebola can cause a broad spectrum of manifestations, some of them minimally symptomatic. A more recent study by Glynn et al. showed that „asymptomatic infection with Ebola was uncommon“ and that it would „account for few transmissions“.

Is there a higher or lower incidence of survivor discrimination in more highly educated areas? Has the government in Liberia set up a public information campaign explaining how the disease is spread and that those who have cleared an infection are no longer dangerous?

[Bskinz](#)

Ruth: Actually there is no data on discrimination in different social contexts but this would be an interesting research question to explore! There has been research carried out by Fallah et al. (<http://journals.plos.org/plosntds/article?id=10.1371/journal.pntd.0004260>) that economically more deprived areas were more affected by the disease. There was large scale campaigning on disease transmission, hand hygiene etc. carried out in collaboration with NGOs, UN organizations etc.

Hi there, have you studied or noticed any misinformation regarding the connection of Ebola and HIV, and have you noticed similar stigmas between the two diseases?

[lordofbluefalcons](#)

Ruth: No, we have not studied links between Ebola and HIV. But we noticed similarities in how stigma and discrimination are enacted, specifically at the beginning when HIV was discovered, e.g. that affected persons are not touched, they lost their jobs, people refused to house them etc. These are the things we see with Ebola survivors today.

While there is a major focus with ebola on the victims, what are the effects of the community that surrounds the victims?

[1snowwolf](#)

Ruth: Stigmatization is not only confined to survivors, also frontline workers were and are stigmatized, for instance health workers and members of burial teams. Some communities which were highly affected by the disease were supported by NGOs to do so called “community healing dialogues” to deal with the massive traumatization of some of its members who lost loved ones or became sick themselves. There are also many children who lost one or both parents who have to be taken care of.

How does media coverage of Ebola survivors address the issues of stigma and discrimination against survivors?

[Balsamicon](#)

Sophie: In short, we found that the Daily Observer Liberia explicitly mentioned stigmatization or stigma in almost 50% of the selected articles between 2014-2016. The articles describe that stigmatization resulting in discrimination was experienced as a community attitude and ostracism was often expressed by shunning individuals. It was experienced at work-places, at home or in public spaces and also related to health seeking behaviour. The newspaper took a clearly supportive stance towards Ebola survivors and gave survivors a strong voice. It took an educational role towards its readership and provided an overview what factors contributed to stigma, i.e. failing communication, fear of contracting the disease in light of (back then) uncertain evidence on transmission routes, absence of a cure and

high case fatality rates.

What's the survival rate? Are there any long-term effects of living through?

[MadroxKran](#)

Ruth: According to WHO the average case fatality rate is around 50%. There are several long-term effects reported: joint pain, muscle pain, headaches, eye complications.

What percentage of people believe that Ebola virus is just a hoax?

[Lowcrbman](#)

Sophie: We do not have numbers on how many people believe that the Ebola virus is just a hoax, neither for Liberia nor for any other countries globally.

Of what practical implications is your research?

[quyax](#)

Sophie: Thank you for your question! To the best of our knowledge this study is the first analysis of media reporting on the situation of EVD survivors in one of the most affected countries. One of the practical implications is that well-balanced media reporting might not be sufficient as a corrective to what the larger public believes. On the ground there are reports that survivors are still highly stigmatized and discriminated against. Thus specific interventions are required to increase health literacy and strengthen the capacity and access to the health system. Media reporting is crucially important but only one part of an effective response in infectious disease outbreaks.

What are the most common misperceptions about Ebola survivors in Liberia? In most western countries?

[latenerd](#)

Sophie: What we found through the analysis of the media reporting was that there are misconceptions about Ebola survivors such as:

- they are not free from the virus
- that something is wrong with them, that they have occult power for example, related to the question why they survived

For western countries I am not sure if there was anything published/written about that? Please let me know if you know of anything!

This is a three part question:

-How does one determine that discrimination is occurring against an Ebola survivor? -How would people who were not infected with Ebola virus be able to identify a person that survived Ebola virus? - In which ways are people stigmatized or discriminated against after having survived Ebola?

[queenofdragons00](#)

Ruth: Discrimination is reported by Ebola survivors in many forms: they are evicted from their houses, lose their jobs, they are shunned by their families. You cannot see if someone is an Ebola survivor, but people in their communities know, that's why survivors often move to other areas in town where they are not known as survivors.

Since treatment of catastrophe survivors is a very subjective, cultural affair and your analysis mainly focused on Liberia, what would the outcome of this research be for the rest of Africa and/or the rest of the World?

[bassow](#)

Ruth: Treatment of survivors is (or should not be) subjective, there are clear guidelines e.g. by WHO. This is a useful link

http://apps.who.int/iris/bitstream/10665/204235/1/WHO_EVD_OHE_PED_16.1_eng.pdf I think it is very important to consider media reporting in public health emergencies and to include them in the response to raise awareness and disseminate important information.

How has the virus not spread to the U.S.A. now? What is the likelihood of that happening (again), and how are authorities effectively preventing its spread to the U.S.?

[kuhataparunks](#)

Ruth: There were several confirmed cases of EVD in the US. The US is a developed country with enormous economic and human resources. Ebola in Africa spread because of a poor health infrastructure, very few resources, little health literacy, poor and congested housing, poor sanitation, you name it.

Can you explain the rationale behind discrimination against Ebola survivors? I don't understand why they would be discriminated to begin with.

Anyone can get infected by Ebola (no *immoral lifestyle* rationalization here), and Ebola survivors are no longer contagious. They should therefore be treated like how we treat cancer survivors.

[vader1941](#)

Sophie: Thanks for your question. Explaining the rationale behind discrimination - would you say discrimination is based on rational or rather on prejudice of belief which is not rational?

I would like to add to your point, Ebola survivors should be treated with dignity and must not be discriminated or stigmatized.