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Stigma among Ebola Disease survivors in Mubende and Kassanda Districts, Uganda, 2022

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Summary

Background: On September 20, 2022, Uganda declared a Sudan Ebola Virus Disease (SUVD) outbreak after a case was detected in Mubende District. The outbreak eventually spread to 8 other districts during September-November 2022. Ebola survivors often experience stigma in multiple formats, including felt (perceived) stigma, enacted (action-based) stigma, and structural (institutional) stigma. We examined the types of stigma experienced by survivors and their household members and its effect on their well-being to inform ongoing interventions.
Methods: We conducted a qualitative study during January 2023 in Mubende and Kassanda Districts. We conducted in-depths and key informant interviews with ten SUDV survivors, ten household members of SUDV survivors, and ten key informants (district officials and health workers in the affected communities). Interviews were recorded, translated, transcribed, and analyzed thematically.
Results: Survivors reported experiencing isolation and rejection by most community members, as well as loss of business or their jobs. They reported being denied goods at shops and, when their purchases were accepted, having their money collected in a basket and disinfected (enacted Stigma). Due to this enacted stigma, survivors resorted to self-isolation (felt stigma). Educational institutions denied some students from affected homes access to school, while some parents stopped sending children to school due to verbal abuse from students and teachers (structural stigma). Prolonged EVD symptoms as well as additional attention to survivors, including home visits by health workers, public distribution of support items, and conspicuous transport from home to the survivor's clinic aggravated both felt and enacted stigma. Despite a number of community engagement activities by the response team to reduce stigma, survivors felt they were still considered a threat to the community.

Conclusion: Survivors experienced felt stigma, enacted stigma, and structural stigma that persisted even after implementation of control measures. Strengthening community engagement to counteract stigma, rethinking response activities that aggravate stigma, management of long-term SUDV symptoms for survivors, integrated response interventions by partners, private distribution of support items, and increasing awareness and sensitization through video messages could reduce stigma among the SUDV survivors.

Introduction

Ebola disease (EBOD) is a severe and frequently lethal disease caused by Ebola virus. EBOD outbreaks typically start from a single case of probable zoonotic transmission, followed by human-to-human transmission via contact with infected bodily fluids or contaminated fomites[1]. There are 6 species of Ebola virus: *Bundibugyo ebolavirus*, *Zaire ebolavirus*, *Sudan virus*, *Reston ebolavirus*, *Bombali ebolavirus*, and *Taï Forest ebolavirus*. Three species, Bundibugyo ebolavirus, Zaire ebolavirus, and Sudan virus, cause epidemics in Africa, resulting in severe hemorrhagic diseases with high case fatality rates (CFR)[2]. Zaire ebolavirus has an average case fatality rate (CFR) of 60–90%, while the Sudan virus has a CRF of 40-60%, the Bundibugyo ebolavirus has caused only one outbreak to date with a CFR of 25%[3]. Several Ebola outbreaks have been registered in Africa in the last three decades[4], of these Uganda has registered five Ebola outbreaks since 2000, with the largest being the Gulu Outbreak in 2000[5, 6].

Despite the high fatality rates, Ebola usually records a high number of survivors; based on the 2014–2016 West African Ebola outbreak, 35% of the recorded 28,646 cases survived while during the Gulu Uganda outbreak in 2000, 47% of the 425 clinical cases survived [5]. Despite the scary Ebola disease experience for all patients, many EVD survivors are known to suffer from short- and long-term physical symptoms and mental complications. Psychosocial consequences of EVD survivorship can be traumatic due to experiences during infection, treatment, and post-discharge. These may include but are not limited to depression, anxiety, grief, and stigma[7]. According to a study in West Africa, shame or disgrace was felt by people who had any association with EVD, regardless of whether they themselves had been sick or not[8], while in another study, survivors felt supported through engagement in religious faith activities and in Ebola response [9].

Addressing disease-associated stigma early in an epidemic has been identified as an important intervention in the containment of epidemics and pandemics because it affects the willingness of affected communities to seek care and their acceptance of prevention and case management packages [6]. The stigma attached to Ebola survivors largely stems from fear of contagion and has led to evictions, intimate partnership

dissolution, termination of employment, abandonment, and physical violence[10]. Ebola survivors need comprehensive support for the medical and psychosocial challenges they face and to minimize the risk of continued Ebola virus transmission [6]. The support given to survivors has been linked to better coping, faster restoration of their dignity and quick recovery to full potential following discharge [11].

On September 20, 2022, Uganda declared an EBOD outbreak (Sudan virus) that started from Mubende District and spread to Kassanda, Kampala, Wakiso, Kyegegwa, Bunyangabu, Kagadi, Masaka, and Jinja Districts, with Mubende and Kassanda being the most affected. The outbreak led to 142 cases, 55 confirmed deaths, 22 probable deaths, and 87 survivors[12]. Due to the anticipated stigma, the Uganda ministry of health and a number of partners invested in community engagement dialogues to control stigma and quicken reintegration of survivors in the communities, four meetings had been held in each district by the time of the study. Furthermore, implementing partners supported survivors with cash and household items like mattresses, clothes, and food which were issued out at the subcounty headquarters which is a public place. Additional support included: psychosocial support at the survivor's clinic and in the community. To the survivor's clinic, survivors were picked and returned to their homes by branded organization vehicles while in the community, various stakeholders visited survivor's homes for psychosocial support. To ascertain the effectiveness of the stigma control measures and to promote the well-being of EVD survivors in Uganda, we examined the types of stigma experienced by EBOD survivors and their household members, how it affected their lives and the possible drivers to inform stigma control measures for improved epidemic response and survivor support.

Methods

Study design and setting

We conducted a qualitative study to explore the perceptions and experiences of survivors and their household members. We focused on Mubende and Kassanda districts since these were the most affected areas with a significant number of Ebola survivors. Important to note is that these districts had never experienced an EBOD outbreak before.

Study population

Participants for this study were Ebola disease survivors, members of the same household as the survivor above the age of 18 years. However, an exception was made to include emancipated minors (Children above 16 years living independently). Children living with their parents or guardians and individuals whose physical and psychological health limits them from providing information through the interview process were excluded from this study. While the experiences of these groups are valuable and worthy of study, they required specially developed and tested data collection methods

that would go beyond the resources available. We identified survivors using a discharge list from the ETU and located them in the communities with the help of community health workers (CHW).

Sample size considerations

We recruited survivors and household members from each district for in-depths interviews (IDI). Similarly, household members were recruited from each district, only one survivor or household member was recruited per household for IDIs to increase the variability of findings. We also engaged district local government leaders from each district as key informants on how stigma could be reduced for improved wellbeing of the Ebola survivors. These included health workers attached to health facilities in Ebola affected communities, the District Health Officer (DHO), Resident District Commissioner (RDC), and the District Surveillance focal person (DSFP). Saturation was reached with 20 in depth interviews; 10 survivors, 5 from each district and 10 household members and with 10 key informant interviews.

Study variables and data collection

Using an interview guide, we conducted in-depth interviews in the local language (Luganda) with the EVD survivors and their household members. We also used an interview guide to interview the key informants. Variables explored for IDIs included: experiences of stigma, possible stigma instigating factors or actions, how stigma affected their lives, possible suggestions for the control of stigma and any additional support required. In addition, we collected data on age, sex, place of residence, EVD status (survivor or household member), number of EVD patients in household, presence of EVD death in household from the survivor and household members. Key informant interviews explored community perceptions and actions towards EBOD survivors and their household members, health concerns of EBOD survivors, and recommendations for improvement. Information from the interviews was recorded in electronic form using audio digital recorders. Data was collected from participants in both districts concurrently until saturation was attained.

Data analysis

Recordings were translated to English and transcribed at the end of each data collection day and stored safely by the project PI in soft copies in a password protected computer. Participants were identified based on the type of interview, an example is SKR1, SMR2…. for survivors, HHM1, HHK1 …. for household members and KIIK1, KIIM2…. for key informants. This code was applied for both transcripts and demographic forms. After data collection, transcripts were reviewed by the PHFP fellows, coded and analyzed thematically using the CDC Excel tool for thematic analysis Ver. 10.18.22. to bring out the story of lived experiences and recommendations.

Ethical considerations

Before starting the project, a non-research determination form was submitted to the US Centers for Disease Control and Prevention (CDC) as a requirement. The Office of the Associate Director for Science at the CDC determined that the project did not involve human subjects research. This determination was made because the project aimed to address a public health problem and had the primary intent of public health practice. Further administrative approval to conduct this study was obtained from Mubende and Kassanda District offices, Mubende regional referral hospital case management team, the National Institute of Public Health, and Uganda Ministry of Health. Before data collection, written informed consent was sought from respondents, they were informed that their participation was voluntary and their refusal would not result in any negative consequences. To protect the confidentiality of the respondents, each was assigned a unique identifier which was used instead of their names. This activity was reviewed by CDC and was conducted consistent with applicable federal law and CDC policy. § §See e.g., 45 C.F.R. part 46, 21 C.F.R. part 56; 42 U.S.C. §241(d); 5 U.S.C. §552a; 44 U.S.C. §3501 et seq.

Results

Type of stigma experienced by Ebola disease survivors and their household members, Mubende and Kassanda districts, Uganda, September 2022-January 2023

Ebola virus survivors experienced various forms of stigma.

Enacted Stigma

All Ebola survivors experienced enacted stigma in the first 2 months after discharge most especially those that were discharged during the peak of the outbreak. The stigma was mainly from community members and this made the survivors feel so terrible.

> *"….. I was treated so badly, people feared and isolated me, when I would go to the shop, they could not touch the money, they put a basket where we would drop the money and they later washed it…" a survivor from Kassanda District.*
>
> *"……they treated us very badly, the shop attendants would refuse to hold our money, we were ignored by everyone. At the borehole we always fetched water last because no one wanted to pump water after we had pumped…". Another survivor from Mubende District.*

However, it was noted that survivors discharged in the early stages of the epidemic were less likely to be stigmatized, this was related to the limited knowledge about the seriousness of the disease by the community members.

"…. I was welcomed well by the community and I integrated well, it was still early and the community was not yet tired of ambulances. My boss offered my job back but I could not do it because I was weak…." a survivor in Mubende District

Despite the support provided to survivors to control stigma like the community engagements for acceptance, survivors were still considered a threat to the community and some families had not yet fully accepted their survivors, this was most times not said but implied.

"…. survivors are still stigmatized in the communities although people cannot openly come out to talk about it but it is implied in how they relate to them…" a key informant in Kassanda District

"…. we are still rejected, it will take several months because now it's been 3 months. Maybe after 6 months they will be free with us…." A survivor in Mubende District

"….to date some people still fear and discriminate us, some times when you come where they are they don't offer you a seat so you automatically understand they still fear you…." a survivor in Mubende District.

Institutional stigma

Survivors further experienced institutional stigma with the educational institutions being the most involved. Respondents reported that children from Ebola survivors home steads were denied access to schools while others were stopped from attending school by their parents due to the immense rejection and verbal abuse from the teachers and fellow students.

"…... we received reports that some students from affected homesteads were denied end of term promotion exams, teachers fear to touch their books and fellow students also stigmatize them....." a key informant from Mubende district

"….my children were discriminated by their friends; a time came when they did not want to go to school so they stayed home until examination period …" revealed a household member in Kassanda District

Felt Stigma

Following the intense stigma from the community, survivors felt it was best to keep to themselves. A survivor from Mubende district revealed that:

"…. I have not started going to the mosque, I fear to scare people when they see me coming, it's better not to go until when the situation is better…."

In Kassanda district, survivors kept to themselves and developed a very strong bond because they frequently spent time together due to the rejection from the community. This helped them console each other in case of any form of abuse.
However, for a few survivors, felt stigma started from discharge due to the long EVD signs and symptoms, they felt unwell and thought they could still be infectious.

> *"….. after discharge I was so happy but I feared to go home because I was still weak and thought maybe the disease was still there. I didn't want to go home because my body was still swollen …." a survivor from Mubende District*

Reasons for the aggravated stigma among Ebola disease survivors and their household members in Mubende and Kassanda districts, Uganda, September 2022-January 2023

Prolonged EVD symptoms

Stigma among EVD survivors was aggravated by the prolonged EVD symptoms and the fear for the disease due to its high fatality rate. Sickly survivors were perceived as "still infectious".

> *"…….many of them still have health problems like: scrotal swelling and pain, hearing problems, back pain mainly for the women, headache and easy irritability. The residual symptoms confirm the community's myths that Ebola cannot heal further increasing the stigma among Ebola survivors…." a key informant in Mubende District*
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> *"…….....it was hard to explain to the children why their father was still weak following discharge, so any sign like vomiting or coughing they would run away from him...." a household member from Kassanda District*

Extra attention to the survivors

Partners provided a number of services to the EVD survivors and majority of these were considered extra attention that aggravated both felt and enacted stigma among EVD survivors and their household members. The frequent community visits by supporting partner organizations with so many cars raised the attention of the community, the pickups from the community to the survivor's clinic. Other services provided included public distribution of support items (public in-kind and monetary support issued at subcounty offices) and conspicuous transport from home to the survivor's clinic.

> *"……use of ambulances to pick survivors for review, people in the community think they are still sick. It is making it hard for the community to accept them as survivors. .." a key informant from Kassanda District*

"…. visiting their homes with so many cars, the neighbors wonder if somebody has become sick again, the frequent visits, frequent clinic reviews, the special attention with support, there is some level of stigma we bring....." a key informant from Kassanda District

Public monetary and in-kind support

Various partners supported survivors with cash and house hold items like mattresses, clothes, and food. All these were provided in public at the respective sub county offices. It was noted that publicizing support aggravated stigma to the survivors as reported by some respondents.

"…. giving them material and monetary support in public…. the community segregates them because they assume they have more than other members in the …." a key informant Kassanda District.

Risk communication

During health education and community sensitization, it was noted that a lot of information was provided to the community which they could not comprehend. This included messages like the presence of the virus in the body fluids of survivors for 1 year after discharge.

"…..a lot of stigma which was promoted during health education .....the message that these are survivors but they still have a risk, they still have the virus in their semen and tears…." a key informant in Kassanda District

Furthermore, the mode of sensitization was considered ineffective to the community. The moving mobile vehicles were not audible and the information was not well received.

"……I can remember the education I received as a youth about prevention of HIV because they were showed in video form in the community squares but I cannot remember all that was said a few months back when the Ebola treatment unit was opened…." - A key informant in Mubende District

***Effects of stigma to the* Ebola disease survivors and their household members in Mubende and Kassanda districts, Uganda, September 2022-January 2023**

Economic effects

Stigma mainly affected the economic aspect of the survivors and their household members lives. A household member in Mubende revealed that:

"…..the herdsman was not allowed to cross the compound to take the cows for grazing so he run away and the cows died……".

While a key informant from Mubende revealed that:

"……most of them have lost their jobs, for the few that maintained their jobs, their physical health is limiting their engagement in day to day activities….".

Effects on education

Additionally, stigma affected the education of school going household members to EVD survivors as noted by respondents.

"…… we received reports that some students from affected homesteads were denied end of term promotion exams, teachers fear to touch their books and fellow students also stigmatize them....." A key informant from Mubende district

"….my children were discriminated by their friends; a time came when they did not want to go to school so they stayed home until examination period and so my children did not perform well this last term…". A report from a household member in Kassanda District

Social effects

Families broke down due to stigma, in polygamous families where only one family was affected, the heads of family have refused to go back and denied them support. For other families where one parent died, the other divorced and refused to return home for fear of getting infected resulting in child headed homes and elderly headed homes where children were left with their grandparents.

For such homes, the subcounty in Mubende has tried to offer some support.

"…. some families are now headed by children, the father died, the mother divorced and has refused to return in fear of getting infected…." a key informant in Mubende District

"…. the subcounty has taken on support for child headed homes and homes headed by the elderly. we plan to pay the little school fees for them in government schools using the subcounty budget… for child headed homes we have identified a relative or neighbor to watch out for them…" a key informant in Mubende District.

Additionally, there was an increase in marital conflict caused by the close interaction among survivors. Wives and husbands were closer to fellow survivors than their spouses.

"…. survivors interact more, they have maintained the friendship to help console each other in case of any form of abuse… However, this close interaction among survivors has resulted in marital conflicts as wives and husbands are closer to fellow survivors than their spouses…." A Key informant in Kassanda District

Proposed measures to control stigma among **Ebola disease survivors and their household members in Mubende and Kassanda districts, 2022**

Respondents proposed a number of measures needed to control stigma. Among them was to intensify efforts to reintegrate survivors back to the community. A key informant from Kassanda District noted that:

> *"…intensify the integration of survivors in the community. We need to show that they are as normal as us and reduce on the extra attention..."*
> *"…. allow survivors use public means to the survivors clinic and have their transport refunded, this will reduce on the attention during pickups and drops from the clinic which causes extra attention…" a key informant from Mubende District.*

Use of visual messages for health education and sensitization in the communities. A key informant in Mubende District revealed that:

> *"……I can remember the education I received as a youth about prevention of HIV because they were showed in video form in the community squares but I cannot remember all that was said a few months back when the ETU was opened….".*

Additional measures suggested to control stigma included supporting survivors in management of their long Ebola signs and symptoms and integrated management of interventions to avoid frequent visits to survivors and their households in the community by different teams. It was suggested that all teams should move to the field together to avoid frequent visits and the so many cars that park in survivors' compounds.

Additional support required to improve the well-being of survivors and their household members

Respondents revealed the need for additional support for improved wellbeing of survivors and their household members. These included: help to achieve a sustained livelihood through startup capital, school fees support for at least 6 months to allow them regain financial stability since majority lost their jobs or cannot work due to long Ebola symptoms and replacement of destroyed phones in the Ebola treatment unit.

Discussion

Our study revealed that survivors and their household members faced enacted, institutional, and felt stigma that persisted despite control measures. It was aggravated by the prolonged EVD symptoms, extra attention given to the survivors and some health workers activities intended to control the disease and to support the survivors like risk communication. Despite the fact that stigma control measures were in place, survivors were still considered a threat hence the need to strengthen stigma control measures.

Our findings noted enacted, institutional, and felt stigma as the forms of stigma faced by EVD survivors and their household members; the enacted stigma being the most greatly experienced. This finding is similar to other studies conducted in Liberia and Sierra Leone where EVD survivors encountered primarily enacted and perceived external stigma rather than internalized stigma[11, 13-15]. Contrary to this finding, a study conducted in Sierra Leone among EVD survivors reported higher levels of felt stigma (0.92 ± 0.77) compared to total enacted stigma (0.71 ± 0.61) and social isolation was the highest reported enacted stigma subscale [7]. Strengthening community engagement and psychosocial support would help reduce stigma among EVD survivors and their household members.

Among the reasons for aggravated stigma was prolonged EVD symptoms that persisted after discharge. This finding is similar to other scholars where survivors reported health problems; the most common symptoms being blurred or partial loss of vision, dizziness, headache, sleeplessness, and myalgia[11, 16, 17]. These were perceived as active disease and a confirmation to the community that EVD does not heal. Other causes included activities and messages passed by health workers to contain the disease like health education, home visits, transportation from the community to the survivor's clinic and offering of support items like food among others in public. In a research conducted on unpack causes and consequences of EVD stigma on the children, children drew images and wrote vividly about health campaigns initiated to contain the epidemic, such as the 'no touch' policy as the main cause of stigma[18]. Repackaging health education messages to the community for appropriateness, integrated response interventions by partners and private distribution of support items would help control stigma in addition to community engagement.

The stigma has affected survivors economically, socially and has also affected the education of the school going household members. This is similar to other studies where EVD survivors have suffered from after-effects, social and economic consequences and have emphasized the critical need for the provision of a packet of materials, including clothing and cash [11, 19]. Various partners came in to support with material items like food stuffs and household items including monetary support. However, they expressed a need for startup capital to enable sustained self-reliance and support with children's school fees for a few months as they get financially stable. Support was provided to EVD survivors to improve stigma among EVD survivors which included psychosocial support and community engagements to improve acceptance. Despite these efforts, stigma persisted requiring strengthening of these control measures. Similar findings have been noted in other studies where survivors emphasized the critical need for comprehensive discharge counseling as well as facilitation of reentry into the community by professional psychosocial support counselors[11]. Contrary to this, other researchers have reported better coping for EVD

survivors following similar support by family, friends, and prayer groups [15, 20]. Strengthening community re-entry engagements and increasing awareness and sensitization through video messages could reduce stigma among the SUDV survivors.

Study limitations

We might not have sampled the most severely affected survivors, some families had survivors who had endured enormous but did not wish to tell their story. However, the recruitment of participants until saturation may have minimised this limitation.

Conclusion

Survivors experienced felt stigma, enacted stigma, and structural stigma that persisted even after implementation of control measures. Strengthening community engagement to counteract stigma, rethinking response activities that aggravate stigma, management of long-term SUDV symptoms for survivors, integrated response interventions by partners, private distribution of support items, and increasing awareness and sensitization through video messages could reduce stigma among the SUDV survivors.

Conflict of Interest

The authors declare no conflicts of interest.

Author contribution

GMZ, BS, ZK, JFZ, PCK, MWW, PK, SNK, HNN, BA and RZ collected data under technical guidance and supervision of JH, ARA, DK, RM, BK, JG, SP, ERG, EJN, AA and JK. GMZ analyzed and interpreted the data. GMZ drafted the bulletin. GMZ, LB, and ARA critically reviewed the bulletin for intellectual content.

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