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Publication Date

2022-12-01

DOI

10.1016/j.ssmmh.2022.100064

HHS Public Access

Author manuscript

SSM Ment Health. Author manuscript; available in PMC 2022 December 01.

Published in final edited form as:

SSM Ment Health. 2022 December ; 2: . doi:10.1016/j.ssmmh.2022.100064.

A post-outbreak assessment of exposure proximity and Ebola virus disease-related stigma among community members in Kono District, Sierra Leone: A cross-sectional study☆

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Abstract

Background: Based on findings from other contexts, informed by intergroup contact theory, that more contact is associated with less stigma, we hypothesized that community members with greater exposure to cases of Ebola virus disease (EVD) were less likely to report EVD-related stigma towards EVD survivors. We assessed personal stigmatizing attitudes towards Ebola survivors, which reflects personal fear and judgement, as well as perceived stigma towards EVD survivors, which reflects an individual's perception of the attitudes of the community towards a stigmatized group.

Methods: From September 2016 to July 2017, we conducted a cross-sectional, community-based study of EVD-related stigma among individuals who did not contract Ebola in four EVD-affected

☆**Presentations at meetings:** This work has not been presented.

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Declaration of interests

ACT reports receiving a financial stipend from Elsevier, Inc. for his work as Co-Editor in Chief of the journal *SSM-Mental Health*. All other authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.ssmmh.2022.100064.

rural communities of Kono District, Sierra Leone. We identified individuals from all quarantined households and obtained a random sample of those who were unexposed. Exposed individuals either lived in a quarantined household or were reported to have been in contact with an EVD case. Our explanatory variable was proximity to an EVD case during the outbreak. Our primary outcome was stigma towards EVD survivors, measured by a 6-item adapted HIV-related stigma index validated in Zambia and South Africa, with 1 item reflecting personal stigmatizing attitudes and 5 items reflecting perceived community stigma. The 6-item EVD stigma index had good internal consistency (Cronbach's alpha=0.82). We used modified Poisson and negative binomial regression models, adjusting for potential confounders, to estimate the association between exposure proximity and EVD stigma.

Results: We interviewed 538 participants aged 12 to 85 years. Most (57%) had been quarantined. Over one-third (39%) reported personal stigmatizing attitudes or perceived community stigma; the most frequently endorsed item was fear and judgment towards EVD survivors. Having contact with someone with EVD was significantly associated with a lower likelihood of perceived community stigma (prevalence ratio [PR], 0.26; 95% CI, 0.13–0.54) and personal stigmatizing attitudes (PR, 0.44; 95% CI, 0.29–0.65). In contrast, being quarantined was significantly associated with a higher likelihood of perceived community stigma (PR, 3.9; 95% CI, 1.5–10.1)

Conclusions: In this cross-sectional study, we found evidence of an inverse relationship between EVD-related stigma and contact with an EVD case. This finding substantiates intergroup contact theory and may form the basis for anti-stigma interventions.

Keywords

Ebola; Social epidemiology; Sierra Leone; Stigma; sub-Saharan Africa

1. Introduction

The 2013–2016 Ebola virus disease (EVD) epidemic in West Africa was the largest in history, introducing lasting impacts on survivors and communities (Jalloh et al., 2018; James, Wardle, Steel, & Adams, 2019; Rabelo et al., 2016; Tambo et al., 2017). It is widely recognized that stigma existed towards EVD survivors in Sierra Leone during the outbreak (Jalloh et al., 2017; James et al., 2019; Kelly et al., 2019; Mayrhuber, Niederkrotenthaler, & Kutalek, 2017; Nuriddin et al., 2018; Overholt et al., 2018), with upwards of 95% of community members reporting some discriminatory attitudes early in the outbreak (Jalloh et al., 2017). EVD-related stigma has been shown to have negative impacts on not only income, housing, social relationships, and psychological well-being (Jagadesh et al., 2018; James, Wardle, Steel, & Adams, 2019; Karafillakis et al., 2016; Lee-Kwan et al., 2014; Mayrhuber, Niederkrotenthaler, & Kutalek, 2017; Van Bortel et al., 2016), but also on health outcomes (Hatzenbuehler, Phelan, & Link, 2013; Hotez, 2008; Stangl et al., 2019). Despite the public health implications of EVD-related stigma, comprehensive measurements of personal and perceived EVD-related stigma are limited. Expanding upon these measurements and implementing evidence-based stigma-reduction interventions provide an opportunity to improve the well-being of survivors and their communities.

As described by Goffman, stigma refers to “an attribute that is deeply discrediting” and leads to discriminatory attitudes, preventing individuals from gaining full social acceptance (Goffman, 2009). Personal stigmatizing attitudes reflect an individual’s own attitudes of fear and judgment towards a certain group, while perceived community stigma reflects the perceived attitudes of other community members towards the stigmatized group (Batterham, Griffiths, Barney, & Parsons, 2013; Tsai et al., 2021; Busby Grant, Bruce, & Batterham, 2016). In the context of infectious disease outbreaks, stigma and social exclusion often stem from fear of infection (Oaten, Stevenson, & Case, 2011; Sow, Desclaux, & Taverne, 2016; Stangl et al., 2019); however, stigma actually undermines infection control measures, slows the adoption of healthy behaviors, and increases the severity of health problems (Fischer, Mansergh, Lynch, & Santibanez, 2019; Lee-Kwan et al., 2017). Insufficient communication of outbreak-related information perpetuates this stigma and fear (Kinsman, 2012; Mayrhuber et al., 2017; Okware et al., 2002; Pellecchia, Crestani, Decroo, Van Den Bergh, & Al-Kourdi, 2015; Tenkorang, 2017).

Stigma exists when the four components of labeling, stereotyping based on this label, separation, and status loss and discrimination converge in an environment where differences in power allow stigma to arise (Link & Phelan, 2001). This is relevant to the occurrence of personal stigmatizing attitudes as individual feelings of fear may develop in response to these combined components. This is also relevant to perceived stigma as community members observe labeling, stereotyping, separation, and status loss within their community and subsequently develop beliefs about the community’s attitudes towards the stigmatized group. Perceived stigma can likely occur in the presence of any one or more of these four components. EVD survivors experiencing continued clinical sequelae, and therefore more visible signs of disease, experience greater stigma as suggested by a previous study of EVD-related stigma in Liberia (Kelly et al., 2021). It is theorized that disease avoidance has an evolutionary basis and is rooted in automatic emotional reactions to threat of infection (Oaten et al., 2011; Phelan, Link, & Dovidio, 2008). EVD survivors with visible signs of disease may be more likely to be labeled and experience subsequent stereotyping (e.g., diseased or dangerous), separation (e.g., avoidance), and status loss and discrimination (e.g., difficulty returning to work). Some level of power is often removed from people with EVD, given that they are often required to be separated (through quarantine and/or isolation) from the community. Unfortunately, what is intended to be a temporary separation from society can remain unresolved after recovery from EVD. In a study exploring community perceptions of Ebola survivors in Sierra Leone, participants endorsed isolation of survivors for 90 days or more to prevent further transmission, demonstrating potential resistance to accepting survivors back into the community (Nuriddin et al., 2018).

Intergroup contact theory posits that greater contact with someone belonging to a stigmatized group, under certain conditions, is associated with reduced levels of prejudice (Miller & Brewer, 2013; Pettigrew & Tropp, 2005) and may influence disease-related stigma. Social contact facilitates an increase in knowledge and a disruption of stereotypes, thereby reducing discrimination (Chan & Tsai, 2017). These processes may occur through direct contact, such as face-to-face interactions, and indirect contact, such as through testimonials in the media (Brown, Macintyre, & Trujillo, 2003; Heijnders & Van Der Meij, 2006). While Allport’s original contact hypothesis focused on racial and ethnic groups

(Pettigrew & Tropp, 2005), a meta-analytic test of intergroup contact theory found that intergroup contact tends to reduce intergroup prejudice across many contexts – suggesting that contact theory can be applied to a range of groups (Pettigrew & Tropp, 2006). Additionally, contact theory specifies that reduction of intergroup prejudice is enhanced when the groups in contact have equal status, shared goals, cooperation, and support of authorities; however, a range of studies have demonstrated that successful reduction in prejudice is possible even in the absence of these optimal conditions (Pettigrew and Tropp, 2005, 2006). Studies investigating the impact of interacting with people living with HIV (PLHIV) on stigma found that increased contact with PLHIV is associated with reduced stigma. Multiple studies have also shown that interventions utilizing social contact are associated with improved attitudes towards people with mental illness (Clement et al., 2012; Evans-Lacko et al., 2012a, 2012b; Heijnders & Van Der Meij, 2006), further supporting the hypothesis that contact theory could extend to the development of EVD-related stigma interventions (Brown et al., 2003; Chan & Tsai, 2017; Coleman, Tate, Gaddist, & White, 2016). There are three potential groups within close proximity to an EVD case with different experiences of stigmatizing attitudes and perceived stigma towards EVD survivors: those who had contact with an EVD case, those who were quarantined during the outbreak, and those who had a relationship with an EVD case. While these partially overlap, with some individuals belonging to multiple or all of these three groups, there are also individuals who fall into only one of these groups. For example, having contact with an EVD case does not require having a relationship with an EVD case and being quarantined does not require having contact with an EVD case. Houses in close proximity to a house with an EVD case or that shared an outdoor toilet with the house of an EVD case were quarantined even if they did not have any contact or relationship with members of the neighboring EVD household. Based on contact theory, we expect that being within close proximity to an EVD case by belonging to any of these three groups reduces EVD-related discriminatory attitudes. Notably, while contact is associated with reduced personal stigmatizing attitudes, some studies demonstrate greater perceived community stigma when participants shared an experience with the stigmatized group (Batterham et al., 2013; Busby Grant et al., 2016; Pedersen & Paves, 2014). Similarly, being quarantined or having a relationship with someone with EVD may increase perceived EVD-related stigma, as these individuals may have personally experienced stigma or witnessed stigma towards EVD survivors despite being free of EVD themselves. Though studies have shown that stigma towards EVD survivors existed during the West African outbreak, the relationship between contact with EVD cases and personal and perceived stigma is not well understood.

In light of the ongoing need for effective Ebola preparedness and stigma-reduction strategies, we sought to understand EVD-related personal stigmatizing attitudes and perceived stigma based on exposure to EVD-infected individuals. We administered an EVD-related stigma questionnaire to community members across Kono District, Sierra Leone—a rural district that was affected heavily by the 2013–2016 outbreak. Based on intergroup contact theory, we hypothesized that community members with greater exposure to EVD cases and survivors were less likely to report EVD-related personal stigmatizing attitudes and perceived community stigma. By improving our understanding of the impact of exposure on stigma towards EVD survivors, we can develop anti-stigma interventions rooted

in contact theory for future EVD outbreaks. This need is ongoing given the recurrence of EVD outbreaks in Central and West Africa (Calnan, Gadsby, Kondé, Diallo, & Rossman, 2012; Richardson et al., 2017; Tambo et al., 2017; Van Bortel et al., 2016).

2. Materials and methods

2.1. Ethics statement

The Sierra Leone Ethics and Scientific Review Committee and the University of California, San Francisco and Harvard University Institutional Review Board approved the study protocol. Participants provided written informed consent before participating in study-related procedures, with parental consent provided on behalf of minors. The Kono District Ebola Response Center (DERC), a government facility responsible for coordinating Ebola-related activities, provided permission to access the viral hemorrhagic fever (VHF) database.

2.2. Study design

We conducted a cross-sectional, community-based study of EVD-related stigma in rural areas of Sierra Leone that were affected by the 2013–2016 EVD epidemic.

2.3. Subjects and setting

From September 2016 to July 2017, we identified four rural communities in Kono District, Sierra Leone that were heavily affected by the outbreak of EVD: Ngo Town, Ndorgboi, Bumpeh, and Joe Town. These four towns collectively experienced 76 EVD cases. Individuals over 12 years of age were eligible for our study if they were physically present in their respective communities at the time of the local EVD outbreak. Eligibility for this particular study excluded EVD survivors and was limited to those who had not contracted EVD. We attempted to recruit all non-cases in these communities who had been exposed to EVD during the outbreak. Exposure was defined as either having lived in a quarantined household or having been identified as a close contact by an EVD case, as a household surrogate of EVD deaths, or as a close contact in the VHF database. We then recruited unexposed individuals by randomly sampling households with individuals who did not meet the exposure criteria and confirmed the absence of EVD exposures. All participants could therefore fall into one of the following four categories, with those in the first three categories considered exposed to EVD: 1) lived in a quarantined household and had close contact with an EVD case, 2) lived in a quarantined household but did not have close contact with an EVD case, 3) did not live in a quarantined household but had close contact with an EVD case, or 4) did not live in a quarantined household and did not have close contact with an EVD case. In order to confirm that our sampling strategy for recruiting quarantined vs. non-quarantined households did not affect internal validity, we conducted a sensitivity analysis restricting our models to quarantined individuals only, which indicated no substantial difference in our results (Supplemental Table 1).

With the support of the Kono District Health Management Team (DHMT) and paramount chiefs, and in collaboration with the Sierra Leone Association of Ebola Survivors (SLAES), local study staff worked with EVD survivors, local chiefs, and community members to identify the sampling frame and recruit participants. We used images of the communities

from Google Earth to number each household and identify which households had been quarantined. We identified 29 quarantined households and 124 non-quarantined households. First, we recruited participants from quarantined households. We interviewed at least one individual from every quarantined household and attempted to interview as many individuals from these households as possible by creating a list of all household members at our initial visit and making a series of attempts to locate and interview each individual. While enrolling these households, we generated a list of close contacts and identified where the close contacts lived. We used other sources such as the VHF database to extend and confirm the list of close contacts and recruited households identified to have a household member with close contact to an EVD case. To enroll our unexposed group, we recruited a random sample from the remaining non-quarantined households, which were considered to be unexposed. We used a computerized random number generator to select non-quarantined households from our Google Earth image. We recruited and enrolled as many individuals from the selected households as possible based on consent to participate.

After enrollment, we administered an epidemiological questionnaire and obtained a blood sample. The questionnaire captured sociodemographic, relationship, exposure, quarantine, symptom, and stigma data. We used the blood samples to test for Ebola-specific antibodies to achieve the objectives of the larger sero-epidemiological investigation.

2.4. Measurements – EVD stigma index

Our primary outcome was stigma towards EVD survivors, measured by a 6-item index adapted from an HIV-related stigma index validated in Zambia and South Africa (Hargreaves et al., 2018). Given the urgent need to assess EVD-related stigma among Ebola-affected communities and the lack of stigma measurement tools, we decided to adapt stigma questions from this pre-existing HIV-related stigma index rather than develop a *de novo* EVD-related stigma index. The EVD-related stigma questions originated from an 8-item HIV-related stigma index developed to assess personal stigmatizing attitudes and perceptions of stigma in the community that was used in the PopART (HPTN071) trial. The original 8 items were as follows: 1) 3 items eliciting HIV-related fear and judgment (personal stigmatizing attitudes), and 2) 5 items eliciting study participants' perceptions of stigma towards PLHIV by other community members (perceived stigma).

In collaboration with the SLAES, the investigators and local study team considered the construct and face validity of the HIV-related stigma items in the setting of the EVD outbreak and stigma observed in the communities. Using focus groups of individuals living in other Ebola-affected communities, we confirmed the presence of stigmatizing attitudes and perceived stigma, which was consistent with the construct of the psychometric domains in the HIV-related stigma index. Instead of Likert responses, the focus groups advised that the EVD-related stigma index offer binary responses (yes/no) as a preferred culturally-appropriate format to clearly and accurately collect participant responses.

Of the 8 items in the HIV-related stigma index, 6 were considered by our team to have face validity and were thus considered to be applicable to the Ebola-affected communities in Sierra Leone and were pilot tested in the field. We selected and adapted 1 item that assessed EVD-related personal stigmatizing attitudes: "I would not like to sit close to an Ebola

survivor, for example on public transport, at church or in a waiting room." We selected and adapted 5 items that assessed perceived stigma: 1) I would be ashamed if someone in my family was an Ebola survivor; 2) people sometimes talk badly about people living with or thought to be living with Ebola survivor(s); 3) people living with or thought to be living with Ebola survivor(s) lose respect and standing; 4) people living with or thought to be living with Ebola survivor(s) are verbally insulted, harassed, and/or threatened; and 5) people sometimes disclose that other people are Ebola survivors without their permission. Participants were asked to respond to the EVD-related stigma items based on their attitudes and perceptions in the past one month.

We assessed the internal reliability of our adapted scales in order to ensure the final items appropriately measured EVD-related stigmatizing attitudes and perceived stigma in our study population. The estimated Cronbach's alpha for the complete 6-item index, comprised of the two subscales, was 0.82. Based on the structure of the original HIV stigma scales, we initially anticipated that the item "I would be ashamed if someone in my family was an Ebola survivor" would reflect stigmatizing attitudes alongside the item "I would not like to sit close to an Ebola survivor, for example on public transport, at church or in a waiting room" (Hargreaves et al., 2018). However, analyzing the scale reliability of these two items together demonstrated a low Cronbach's alpha of 0.46. We instead found that the item eliciting shame more reliably measured perceived stigma alongside the remaining 4 items, with an estimated Cronbach's alpha of 0.85 for this 5-item perceived stigma subscale. Therefore, our assessment of scale reliability demonstrated that personal stigmatizing attitudes towards EVD survivors was best reflected by the single item, "I would not like to sit close to an Ebola survivor, for example on public transport, at church or in a waiting room," and perceptions of community stigma were reliably reflected by the remaining five items, including the item "I would be ashamed if someone in my family was an Ebola survivor."

2.5. Measurements – exposures

We investigated three measures of exposure to an EVD case—contact with an EVD case, being quarantined at any point during the outbreak, and having a relationship with an EVD case. Our main explanatory variable was contact with an EVD case during the outbreak. We defined contact as having been within close proximity to an EVD case during the conduct of various activities, including going within six feet, sharing a meal, sleeping in the same room, caring for that person, washing that person, or attending a traditional burial. This variable was binary, with a participant considered exposed by reporting one or more of the contact behaviors.

We considered quarantine status and having a relationship with someone with EVD as two other independent explanatory variables. Quarantine status was an objective measurement, but we still confirmed whether each participant had been quarantined by self-report in our questionnaire. Reasons for being quarantined included having lived with an EVD case, having shared a toilet with an EVD case, having been tested for Ebola, or having other forms of close contact with an EVD case. Our questionnaire also asked participants whether they had friends or family members who had been diagnosed with EVD, and if participants

endorsed a relationship, we further classified their relationship. We defined a participant as having had a relationship with someone with EVD if they endorsed any type of relationship.

2.6. Analysis

We evaluated descriptive characteristics of participants who were administered the EVD-related stigma items. We then estimated the association between exposure proximity to an EVD case and EVD-related stigma, using separate models for each of the three exposure proximity measurements—contact, quarantine status, and relationship with an EVD case. Prior to building our models, we created directed acyclic graphs (DAGs), considering potential confounders, mediators, and colliders. Based on a review of the literature, we identified age, sex, and education as potential confounders of the association between exposure and EVD-related stigma (Aromaa, Tolvanen, Tuulari, & Wahlbeck, 2011; Batterham et al., 2013; Griffiths, Christensen, & Jorm, 2008; Ndetei et al., 2016; Visser, Makin, & Lehobye, 2006; Zaninotto et al., 2018). Additionally, we identified relationship with an EVD case as a potential confounder, and quarantine status as a potential mediator, of the relationship between having contact with an EVD case and reporting EVD-related stigma (Supplemental Fig. 1a). We utilized a similar process to assess the path between quarantine status and EVD-related stigma as well as the path between having a relationship with an EVD case and EVD-related stigma (Supplemental Figs. 1b and 1c). We used the anticipated relationship between each factor illustrated in the DAGs to determine which factors to control for in each model. We therefore adjusted for age, sex, and education in all models. The model for contact was also adjusted for relationship with an EVD case. The model for quarantine status was also adjusted for contact with an EVD case and relationship with an EVD case.

In addition to specifying the overall stigma index as the dependent variable, we also specified personal stigmatizing attitudes and perceived stigma as separate dependent variables. For the analysis of stigmatizing attitudes, the dependent variable was specified as the single binary item on stigmatizing attitudes. For the analysis of perceived stigma, the dependent variable was specified as the sum of affirmative responses to the 5 items on perceived stigma. We used modified Poisson and negative binomial regression models, adjusted for potential confounders and clustered by household, to assess the prevalence ratio of EVD-related stigma due to the exposure proximity variables. For our binary dependent variable (stigmatizing attitudes), we used a generalized linear model (GLM) with log-link and a Poisson distribution with robust standard error. For our count dependent variable (perceived stigma), we used a negative binomial regression model to estimate the association between exposure proximity and EVD-related stigma. Analyses were performed using Stata software (version 17, Stata Corporation, College Station, Texas, USA).

3. Results

3.1. Characteristics of the study population

The general questionnaire for this study was administered to 640 community members living in 106 households. We excluded 98 individuals under age 12 and four individuals without responses to the stigma questions or without a known quarantine status. This left a total

of 538 participants from 106 households. Our study population included a wide range of ages from 12 to 85, with a median age of 28 years (interquartile range [IQR] 18–42). A large proportion of participants had no formal education (42%). More than half (57%) of participants had been quarantined during the Ebola outbreak in their community. Other characteristics of the study population are described in Table 1.

3.2. Description of personal stigmatizing attitudes and perceived stigma

More than a year after the EVD outbreak in the community, there was still a substantial level of stigma reported, with nearly one-third of participants reporting personal stigmatizing attitudes, one-fifth of participants reporting perceived stigma in the community, and 39% reporting either personal or perceived stigma (Table 2). The item reflecting fear and judgment towards EVD survivors was the most frequently endorsed. Among those with perceived stigma, community members most commonly reported that they would be ashamed if a family member was an Ebola survivor. These high levels of stigma were observed regardless of the exposure proximity mechanism (contact, quarantine, relationship). Few community members perceived that people sometimes talked badly about or verbally insulted, harassed, and/or threatened households of Ebola survivors.

3.3. Correlates of personal stigmatizing attitudes

Based on our multivariable regression model adjusted for age, sex, education, and relationship with an EVD case, having contact with an EVD case was significantly associated with a lower likelihood of personal stigmatizing attitudes towards survivors (adjusted prevalence ratio [PR], 0.44; 95% confidence interval [CI], 0.29–0.65; $p < 0.001$) (Table 3). Being quarantined, however, was not significantly associated with personal stigmatizing attitudes when adjusted for age, sex, education, contact with an EVD case, and relationship with an EVD case. Having a relationship with someone with EVD was also not significantly associated with stigmatizing attitudes.

3.4. Correlates of perceived stigma

Similar to the relationship observed between contact and stigmatizing attitudes, having contact with someone with EVD was significantly associated with a lower likelihood of endorsing perceived community stigma (PR, 0.26; 95% CI, 0.13–0.54; $p < 0.001$) (Table 3). In contrast, being quarantined during the outbreak was significantly associated with a higher likelihood of perceived community stigma (PR, 3.9; 95% CI, 1.5–10.1; $p=0.01$). As was seen with relationship to an EVD case and stigmatizing attitudes, we did not observe an association between having a relationship with someone with EVD and this psychometric domain of stigma.

4. Discussion

In a cross-sectional assessment of communities heavily affected by the 2013–2016 EVD epidemic in Sierra Leone, we found evidence of an inverse association between EVD-related stigma and contact with an EVD case that substantiates the role of intergroup contact theory in this context. The higher level of perceived community stigma in those who were quarantined demonstrates ongoing post-outbreak stigma and an opportunity for potential

benefit through interventions. While adapting a validated quantitative measurement to report levels of personal stigmatizing attitudes and perceived community stigma, we identified intergroup contact theory for consideration when conceptualizing anti-stigma interventions. Quarantined individuals and those without contact with EVD cases were identified as potential target populations.

These findings are potentially consistent with Allport's contact hypothesis. Previous studies of other infectious diseases (e.g., HIV) and other disease conditions (e.g., mental illness) found a reduction in stigma towards various stigmatized groups with increased contact (Brown et al., 2003; Chan & Tsai, 2017; Coleman et al., 2016). Our findings have practical implications for addressing stigma towards EVD survivors. Contact interventions create an environment where the community can interact with the stigmatized group, either directly or through the media (Brown et al., 2003; Clement et al., 2012). Studies have found that filmed interactions are equally as effective as direct social contact at reducing stigma, providing flexibility for potential strategies, including the use of direct interaction or testimonials from affected individuals (Clement et al., 2012). It is theorized that interacting with or hearing from infected or affected individuals can generate empathy, dispel misinformation, and subsequently reduce stigma. Reduction in stigma through contact is most successful if paired with an improved understanding of the disease (Brown et al., 2003), emphasizing the importance of providing education along with facilitating interpersonal interaction (Link & Phelan, 2006). One possible approach to reducing EVD-related stigma is involving survivors in implementing anti-stigma interventions. This has shown promise for reducing stigma towards PLHIV in sub-Saharan Africa by increasing opportunities for meaningful interactions between PLHIV and the community (Chan & Tsai, 2017). Including survivors in the Ebola response can help survivors regain livelihood, reduce stigma, and provide opportunities for inclusion as trusted community members aiding in Ebola prevention and response (Davtyan, Brown, & Folayan, 2014; Karafillakis et al., 2016; Lee-Kwan et al., 2014; Nuriddin et al., 2018). Communities in West Africa and the DRC affected by Ebola have informally implemented strategies to improve dialogue and reduce stigma through various approaches, including media campaigns that share survivors' stories and educate the public about Ebola (Vulcan Productions, 2014), facilitated community discussions focused on healing and addressing challenges faced by survivors (Aidoo, 2014; Reliefweb, 2018), and outreach efforts led by survivors to raise awareness of the disease (Bahati, 2021). These approaches have shown promise with an ability for communication campaigns to reach 50% of West Africa's population (Vulcan Productions, 2014) and many personal reports of improved reintegration by survivors (Bahati, 2021; Reliefweb, 2018). Further development and formal evaluation of contact interventions in these settings offers opportunities to scale up the most effective components for reducing EVD-related stigma.

We did not find evidence that a relationship with an EVD case reduced personal stigmatizing attitudes. This is consistent with our observations during the outbreak because some family members, for example, were avoidant when their relative was infected with EVD. There was often resentment towards and continued avoidance of the EVD case for the trauma occurring in the community or due to the perceived infectiousness of the survivor. While there are theories that stigma reduction through increased contact is in part due to relationship development (Brown et al., 2003), many community-level interventions, particularly through

mass participation or media campaigns, have demonstrated a benefit to interaction even if a more established relationship is not developed (Batterham et al., 2013; Clement et al., 2012; Evans-Lacko et al., 2012a, 2012b). This is reinforced by our findings that contact, regardless of relationship, is associated with lower stigma towards EVD survivors.

The greater perception of stigma in those who were quarantined is in line with the existing literature on mental health stigma. Previous studies show that having contact with people with mental health disorders is associated with lower levels of personal stigma towards these individuals, but having a prior history of mental illness and greater levels of depression symptomatology are associated with greater perceived community stigma (Batterham et al., 2013; Busby Grant et al., 2016; Griffiths et al., 2008; Pedersen & Paves, 2014). This relationship suggests that those who identify more closely with the stigmatized group may be more likely to perceive stigma from the community at large. Those who were quarantined during the EVD outbreak may have experienced or feared EVD-related stigma from the community, witnessed discrimination, or more closely identified with the stigmatized group, thereby increasing their perception of stigma from the community. The perceived stigma from the community among quarantined individuals allows for potential stigma-reducing interventions. For example, providing education and clear messaging on the safety of ending quarantine, or marking the end of a home's quarantine period with a ceremony recognizing they can safely reintegrate, may help to mitigate stigma experienced by quarantined individuals. While quarantine is an important public health measure during an outbreak, it is important to address the complex ways in which it affects individuals and the community.

While this study has several strengths, there are also several limitations. First, when we started designing the study, we were still in a humanitarian crisis and rapidly attempting to adapt this stigma measurement from a validated tool, using face and construct validity. Second, there was a period of time between the EVD outbreak and enrollment of participants, during which the composition of the villages may have changed through migration or deaths. Third, there may be unmeasured, unknown confounders. The communities included in this study were rural and affected later in the epidemic, influencing the external validity. Additionally, social desirability bias may have influenced participant responses. Those with close relationships with EVD survivors may have particularly felt pressure to report acceptance of survivors, leading to under-reporting of stigmatizing attitudes. As this study had a cross-sectional design, we are unable to rule out reverse causation for the observed relationship between contact and EVD-related stigma. For example, those with lower levels of stigma towards EVD cases and survivors may have been more likely to come into contact with cases, rather than the reverse (more contact causing lower levels of stigma).

5. Conclusions

This study suggests intergroup contact theory may be useful as part of the conceptual framework of EVD anti-stigma interventions combatting personal stigmatizing attitudes and perceived community stigma. Addressing disease-related stigma in populations such as those quarantined and those lacking close contact to EVD cases has important public health

implications, as stigma contributes to increased stress and other negative health outcomes, prevents reintegration into society, and perpetuates inequity (Hatzenbuehler et al., 2013; Karafillakis et al., 2016; Link & Phelan, 2006; Muela Ribera et al., 2009; Rabelo et al., 2016). Along with the recurrent nature of EVD outbreaks in West and Central Africa (Calnan et al., 2012; Richardson et al., 2017; Tambo et al., 2017; Van Bortel et al., 2016), EVD-related stigma will continue to be an important issue, requiring a call to action for continued development and evaluation of anti-stigma interventions, even in the absence of a current outbreak. Interventions rooted in contact theory have shown success in reducing disease-related stigma (Brown, Macintyre, & Trujillo, 2003; Coleman, Tate, Gaddist, & White, 2016; Evans-Lacko et al., 2012a; Heijnders & Van Der Meij, 2006). and provide meaningful opportunities to engage EVD survivors in the Ebola response, education efforts, and their communities. Developing a deeper understanding of the impact of social contact on stigma towards EVD survivors has meaningful implications for future interventions aimed at countering the harmful consequences of Ebola-related stigma.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgements

We are grateful to the staff of Wellbody Alliance and Partners In Health for their dedication to health equity in Sierra Leone.

Funding sources

This work was supported by UCSF Institute for Global Health Sciences, Partners In Health – Sierra Leone, the National Institute of Allergy and Infectious Diseases (K23AI135037 to JDK), and the National Institute of General Medical Sciences (R01GM130900 to JDK).

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Table 1

Sociodemographic characteristics of community members.

Individual characteristics	**N = 538**
Sex	
Male	57.3%
Female	42.6%
Age (years)	
12–19	29.6%
20–29	23.8%
30–39	15.8%
40–49	16.2%
50+	14.7%
Education	
No formal education	42.1%
Primary school	19.8%
Secondary school or beyond	38.1%
Quarantined during outbreak	
Yes	56.7%
No	43.3%

Table 2

Responses from community members to stigma items.

	Overall (n = 538)	Contact		Quarantine status		Relationship with EVD case	
		No contact (n = 274)	Contact (n = 264)	Not quarantined (n = 233)	Quarantined (n = 305)	No relationship (n = 207)	Relationship (n = 331)
Personal stigmatizing attitudes							
I would not like to sit close to an Ebola survivor, for example on public transport, at church or in a waiting room	166 (31%)	105 (38%)	61 (23%)	87 (37%)	79 (26%)	68 (33%)	98 (30%)
Perceived community stigma							
≥1 perceived stigma item endorsed	102 (19%)	65 (24%)	37 (14%)	48 (21%)	54 (18%)	46 (22%)	56 (17%)
I would be ashamed if someone in my family was an Ebola survivor	60 (11%)	43 (16%)	17 (6.4%)	28 (12%)	32 (10%)	27 (13%)	33 (10%)
People sometimes talk badly about people living with or thought to be living with Ebola survivor(s)	32 (6.0%)	19 (6.9%)	13 (4.9%)	4 (1.7%)	28 (9.2%)	4 (1.9%)	28 (8.5%)
People living with or thought to be living with Ebola survivor(s) lose respect and standing	35 (6.5%)	23 (8.4%)	12 (4.5%)	11 (4.7%)	24 (7.9%)	10 (4.8%)	25 (7.6%)
People living with or thought to be living with Ebola survivor(s) are verbally insulted, harassed and/or threatened	23 (4.3%)	18 (6.6%)	5 (1.9%)	3 (1.3%)	20 (6.6%)	4 (1.9%)	19 (5.7%)
People sometimes disclose that other people are Ebola survivors without their permission	43 (8.0%)	30 (11%)	13 (4.9%)	17 (7.3%)	26 (8.5%)	16 (7.7%)	27 (8.2%)

Table 3

Associations with stigma outcomes (N = 538).

	Overall		Personal stigmatizing attitudes		Perceived community stigma	
	Adjusted PR (95% CI)	**p-value**	**Adjusted PR (95% CI)**	**p-value**	**Adjusted PR (95% CI)**	**p-value**
Contact	0.32 (0.18–0.55)	<0.001	0.44 (0.29–0.65)	<0.001	0.26 (0.13–0.54)	<0.001
Quarantine status	1.9 (1.2–2.8)	0.01	0.75 (0.45–1.3)	0.27	3.9 (1.5–10.1)	0.01
Relationship with EVD case	1.1 (0.67–1.8)	0.72	0.92 (0.64–1.3)	0.63	1.3 (0.64–2.7)	0.46

*Each cell in this table represents the output of a multivariable Poisson (personal stigmatizing attitudes) or negative binomial (overall stigma and perceived community stigma) regression model, adjusted for the following covariates: age, gender, and education. The model for contact also adjusted for relationship with EVD case. The model for quarantine status also adjusted for contact with EVD case and relationship with EVD case. Thus, the adjusted prevalence ratios (PR) above reflect the output of 9 regression models total, with the coefficients on the other covariates excluded for ease of exposition.