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In the midst of a 'perfect storm': Unpacking the causes and consequences of Ebola-related stigma for children orphaned by Ebola in Sierra Leone☆

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ABSTRACT

The West African Ebola virus epidemic resulted in the deaths of more than 11,000 people and caused significant social disruption. Little is known about how the world's worst Ebola outbreak has affected the thousands of children left orphaned as their parents or caregivers succumbed to the virus. Given the infectious nature of Ebola, and numerous anecdotal accounts of stigmatisation, we set out to examine children's social representations of peers orphaned by Ebola, unpacking the causes and consequences of Ebola-related stigma. The study was conducted in 2015 in Freetown, Sierra Leone. Data was generated through drawings and captions from 24 children living in four different communities in Freetown and interviews with four key informants. The children were first invited to draw *a child whose family has been affected by Ebola* and subsequently asked to write 3–10 phrases explaining the drawing. The drawings and captions were thematically condensed and key thematic areas were identified. The thematic areas emerging from the drawings were subsequently used to frame the interviews with practitioners. Unsurprisingly, Ebola was represented as a highly stigmatized and feared disease. Children drew and wrote vividly about health campaigns initiated to contain the epidemic, such as the 'no touch' policy and quarantine of suspected Ebola cases. Although important, the health campaigns appeared to cement an 'othering' of anyone associated with Ebola. Children orphaned by Ebola were depicted as excluded from social interaction due to the association with Ebola. This prevailing fear and stigma of Ebola were described to undermine the willingness of community members to help orphaned children and described to have severe psychological repercussions for children orphaned by Ebola. Many of our findings resonate strongly with the experiences of children orphaned by AIDS, calling for a greater focus on the risk of Ebola-related stigma and further discussion on the transferability and applicability of lessons learned from research on HIV-related stigma.

1. Introduction

The most persistent and widespread outbreak of Ebola Virus Disease (EVD, known as Ebola) began in West Africa in December 2013 (Stein, 2015). Already by mid-September 2014, the number of cases exceeded the cumulative number from all previous outbreaks (Stein, 2015). In November 2015, the World Health Organization (2015) estimated that the epidemic had caused more than 11,000 deaths and more than 28,000 cases, making it one of the deadliest viral epidemics in recent history. Sierra Leone experienced the highest number of cases and faced some of the greatest challenges in containing the virus compared to neighbouring Liberia and Guinea (WHO, 2015). Many children have been at the frontline of the Ebola epidemic, facing the consequences of parental death. The exact number is unknown and estimates vary greatly. In 2015, Street Child, a non-governmental organisation (NGO), claimed they had documented more than 12,000 children in Sierra Leone who had lost a primary caregiver to Ebola (Street Child, 2015). Estimates from the World Bank are significantly lower at 3300 children, making up 1.5% of the total 'orphan burden' in Sierra Leone (Evans & Popova, 2015). Interim reports from relief organisations and news agencies describe children orphaned by Ebola as vulnerable and in risk of experiencing hunger, malnutrition, exploitation and child labour (Al Jazeera America, 2014; Mail Online, 2014; Street Child, 2015). Early reports also suggest that orphaned children face abandonment and stigma due to their association with Ebola (Mail Online, 2014; Street Child, 2015).

Historically, disease outbreaks that have contributed substantially to mortality and morbidity, have also contributed to the ostracisation of people affected by the illnesses. A contemporary example includes the human immunodeficiency virus (HIV) epidemic, which the former Secretary-General of the United Nations, Ban Ki-Moon (2008), argues is partly fuelled by stigma. Moreover, epidemics that constitute an overt threat to human life and ways of living, are especially likely to evoke

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social processes that isolate people affected by the epidemic (Gilmore & Somerville, 1994). The circumstances surrounding Ebola are particularly conducive for stigma. Ebola spreads relatively easily between humans through direct contact with infected bodily fluids or contaminated fomites (WHO, 2016; Osterholm et al., 2015). As a result, even every day practices, such as shaking hands, can suddenly become a potential source of infection. Ebola has a short incubation period, anything between 2 and 21 days, with symptoms such as fever, muscle pain, sore throat, nausea, vomiting and diarrhea, mimicking those of other endemic diseases, including malaria, typhoid or Lassa fever. Consequently, anyone with these ordinary symptoms can be suspected and accused of having Ebola and seen as a potential threat. As there is no cure for Ebola, and only limited treatment options, the fatality rate in West Africa averaged around 50% (WHO, 2016), making it a particularly lethal disease. These factors provide a 'perfect storm' for fear and stigma, and according to Davtyan, Brown, and Folayan (2014), they are not too dissimilar to the HIV context, where stigma has been rife. They note a number of similarities, including irrational and unfounded fears of pathogen transmission as well as fear of health care providers. They also comment on the role of poverty and political conflict in providing context for stigma, and how both epidemics create an environment for blaming and shaming particular population groups. In the midst of this 'perfect storm', we set out to explore how the epidemic manifests in the daily lives of children living in low resource and Ebola-stricken communities. How does stigma affect children who have lost their primary caregivers to Ebola? How does these experiences relate to children affected by HIV? These are some of the questions we seek to address in this paper. We hope to provide empirical insight to the applicability and transferability of lessons learned from the HIV epidemic to a long-term Ebola response.

2. Theoretical framework: explanations of stigma

To address the questions above we position the study in the theoretical arena of stigma. The influential work on stigma by Erving Goffman (1963) guides this study. Goffman defines stigma as a discrediting attribute that isolates individuals or communities of people who are perceived to be a threat to public order. Such primary stigma involves a process of 'othering' that results in individuals being disqualified from full social acceptance (Goffman, 1963). As children orphaned by stigmatized illnesses, such as Acquired Immune Deficiency Syndrome (AIDS) or Ebola, may not be considered a primary threat, their association with stigmatized individuals, such as their sick or deceased parents, can result in forms of stigmatisation that are detrimental to their psychosocial well-being, food security, access to health services and rights to inheritance (Mo, Lau, Yu, & Gu, 2015; Boyes & Cluver, 2013; Yassin & Erasmus, 2016; Fielding-Miller, Dunkle, & Murdock, 2015; Nayar, Stangl, De Zalduondo, & Brady, 2014; Evans, 2015). Goffman (1963) refers to 'stigma by association' as 'courtesy stigma'. Related to 'courtesy stigma', is the concept of 'secondary stigma'. Writing from the context of HIV, Deacon and Stephney (2007) define secondary stigma as attached to other things (diseases, objects and practices) because of their association with HIV/AIDS. This means certain items and practices (e.g. sharing of cutlery) or illnesses (e.g. skin rashes), can become symbols of potential contamination, sparking negative social responses. These distinctions help us disentangle how Ebola-related stigma, whether primary, secondary or courtesy, or a combination, manifests in the lives of children orphaned by Ebola and resonate with HIV-related stigma.

Goffman, and much HIV-related stigma research, has been criticised for not doing enough to highlight the social processes in play to reproduce social differences (Parker & Aggleton, 2003). Taking a structural approach, Parker and Aggleton (2003), also reflecting on the HIV response, call for greater attention to how stigma interplays with forms of power and domination to maintain social inequalities. Although we fully agree with this approach, and will actively use this structural conceptualisation of stigma in our discussion, we adopt a social psychological approach to disentangle social processes that lead to stigma. Specifically, we draw on the Social Representations Theory (SRT) (Sammut, Andreouli, Gaskell, & Valsiner, 2015). Moscovici (1973) defines social representations as systems of values, ideas and practices with two functions; first, they establish an order that will enable individuals to orientate themselves in their material and social world and to master it; secondly, they provide communities with a code for social exchange and for classifying the various aspects of their world and their individual and group history. SRT can thus be seen as a specific way of understanding and communicating collectively constructed meanings, or codes, that are embroidered into people's social worlds. By unpacking these social representations we hope to develop an understanding of the causes and consequences of stigma associated with children orphaned by Ebola. SRT is particularly useful for studying stigma, shedding light on the representational construction of 'boundaries' between the 'normal' and those who are 'discredited within a local moralistic system' (Jaspal & Nerlich, 2016; Beres, Winskell, Neri, Mbakwem, & Obyerodhyambo, 2013; Joffe, 1995). SRT have been used in research that uses drawings by children to unpack the systems of social knowledge which drive or mitigate HIV-related stigma (Campbell et al., 2012; Beres et al., 2013; Winskell, Hill, & Obyerodhyambo, 2011). As an example, Campbell et al. (2012) explored the stock of symbolic resources that guide how children in Zimbabwe make sense of the HIV epidemic. They found that children represented HIV-affected children as alone and bullied, with other children refusing to play with them, actively keeping their distance. They also identified poverty-related stigma in children's drawings (Campbell et al., 2012). This suggests that children affected by poverty and Ebola may be socially rejected from two fronts.

3. Methodology

We draw on a qualitative study that used the draw-and-write method to elicit children's representations of children orphaned by Ebola and in-depth interviews with adults to contextualise and triangulate these representations. We adhered to UNICEF's's (2002) guidelines on undertaking research with children. Oral consent was obtained from all participating children and interview informants and written consent was collected from the children's parents/guardians. Pseudonyms are used in the analysis to conceal the children's identities.

3.1. Study participants

Two different target groups were included in the empirical material; children from Freetown and key stakeholders working with children orphaned by Ebola in Freetown. In total 31 children participated. However, we excluded seven children, as they did not provide a caption with their drawing, leaving a total of 24 child participants. The study took place in four different districts in Freetown; Aberdeen, Hill Station, Kroo Bay and Wilberforce community – all of which saw a number of Ebola cases and experienced government lock downs.

Representatives from the organisation Football for A New Tomorrow (FANT) assisted with the collection of drawings and captions. A detailed introduction letter to the drawing exercise was prepared for the local staff in order to ensure that the same framework was used to generate the empirical material. Children participating in the study were between 8 and 14 years of age. They were recruited by FANT staff using convenience sampling. FANT staff asked a group of children in their programme if they would be willing participate in this study. Criteria for inclusion were age, willingness to participate, consent from a guardian as well as living in a low resource and high Ebola prevalence area.

Interview informants were chosen on the basis of their knowledge about children orphaned by Ebola, as well as their contextual knowledge of Sierra Leone. Four key informants were included in the study; three informants from three international non-governmental organisations (INGO) (one child protector advisor, one monitoring and

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