



The symbolic violence of ‘outbreak’: A mixed methods, quasi-experimental impact evaluation of social protection on Ebola survivor wellbeing



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ABSTRACT

Despite over 28,000 reported cases of Ebola virus disease (EVD) in the 2013–16 outbreak in West Africa, we are only beginning to trace the complex biosocial processes that have promoted its spread. Important questions remain, including the effects on survivors of clinical sequelae, loss of family and livelihood, and other psychological and social trauma.

Another poorly understood question is what effect social protection and job creation programs have had on survivors' wellbeing. Several clinical and social protection programs have been developed to respond to the needs of EVD survivors; however, little in the way of impact evaluation has taken place.

We enrolled 200 randomly selected EVD survivors from Port Loko, Kenema, and Kailahun districts in Sierra Leone and stratified them based on the amount of instrumental social protection received post-discharge from an Ebola Treatment Unit. We then conducted a survey and in-depth interviews to assess participants' wellbeing and food security.

Social protection categories II–IV (moderate to extensive) were each significantly associated with ~15–22% higher wellbeing scores compared to minimal social protection ($p < 0.001$). Only social protection category IV (extensive) was significantly associated with being food secure (adjusted odds ratio 6.11; 95% confidence interval, 2.85–13.10) when compared to minimal social protection.

Qualitative themes included having a sense of purpose during the crisis (work and fellowship helped survivors cope); using cash transfers to invest in business; the value of literacy and life-skills classes; loss of breadwinners (survivors with jobs were able to take over that role); and combating the consequences of stigma.

We conclude that, for EVD survivors, short-term social protection during the vulnerable period post-discharge can pay dividends two years later. Based on the empiric evidence presented, we discuss how terms such as “outbreak” and “epidemic” do symbolic violence by creating the illusion that social suffering ends when transmission of a pathogen ceases.

“One of Said's decisive contributions was to show, in opposition to the Marxist doxa of the period, that the colonial project was not reducible to a simple military-economic system, but was underpinned by a discursive infrastructure, a symbolic economy, a whole apparatus of knowledge the violence of which was as much epistemic as it was physical.”

–Achille Mbembe, *What is Postcolonial Thinking* (2008)

1. Background

The 2013–16 Ebola virus disease (EVD) pandemic was the longest and largest on record (World Health Organization, 2016), yet we are only beginning to parse the complex biosocial processes that eventuated in its surge across West Africa (Benton and Dionne, 2015; Brown and Kelly, 2014; Richardson et al., 2016a). Important questions remain, including the effects of clinical sequelae, loss of family and livelihood, and other psychosocial burdens on EVD survivors.

On account of the tragic loss suffered by tens of thousands of West

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Africans, a number of international non-governmental organizations (INGOs), in partnership with Ministries of Health and foreign donors, created clinics and social protection programs which delivered medical and material support to EVD survivors and their families, as well as children orphaned by the disease. Small sums are currently being invested in such programs—including *symbolic* resources in how “survivor” is actually defined (Richardson et al., 2016b)—yet little in the way of impact evaluation has taken place. Such evidence is important to understand the experience of survivors as well as to guide funding decisions for survivors’ programs.

Social protection has been defined as the provision of safety nets to individuals and households during periods when they cannot engage in gainful employment or obtain enough income to secure their livelihoods—due to unemployment, sickness, chronic ill health, disability, old age, or care responsibilities (United Nations Research Institute for Social Development, 2010). A growing body of evidence demonstrates that social protection alleviates poverty, reduces inequality and promotes social stability, improves government’s capacity to respond to shocks, and improves wellbeing and health outcomes (The World Bank, 2012).

While several recent studies have documented the clinical sequelae of EVD in the West African outbreak, few have examined the social and economic challenges experienced by its survivors, or the optimal interventions to address them. Survivor programs have varied widely within and across the three most affected countries. According to interviews with survivors discharged from Liberia’s largest Ebola treatment unit, for example, many survivors lost jobs and housing, were separated from bread-winning family members, and were excluded from markets in which they could buy and sell products (Rabelo et al., 2016). Similar economic concerns have been documented in Guinea: a study of 121 Ebola survivors in urban parts of that country found most in poorer socioeconomic conditions, work situations, and workplace relationships following their acute illness than before it (Delamou et al., 2017). Many survivors across West Africa also lost material possessions, often destroyed in the course of infection-control efforts (Lee-Kwan et al., 2014), and have faced difficulties paying children’s school fees, starting new businesses, and maintaining existing ones (Karafillakis et al., 2016). In a survey of 28 survivors from five districts of Sierra Leone, most experienced job loss and lacked the means to care for their families; almost all of these survivors contended that their government ought to “help them by providing jobs, microcredit or training so they could develop necessary skills for employment” and emphasized their “need for financial help and their desire to receive money, scholarships and other incentives,” along with “the provision of food and supplies as well as housing” (Karafillakis et al., 2016).

With reports of widespread discrimination against Ebola survivors, much has been made of the need to mitigate ‘stigma,’ better reintegrate survivors into their communities, and address survivors’ guilt. In Liberia, for example, the Firestone Natural Rubber Company established a reintegration program in which the company’s medical personnel held meetings with survivors’ communities to allay concerns regarding the risks of Ebola transmission, organized community-wide celebrations to welcome survivors home, and visited survivors weekly for three months following discharge (Arwady et al., 2014). Counseling and other forms of psychosocial support have also been proposed as interventions to help survivors better cope with feelings of marginalization, isolation, guilt, distress, and shame (Mohammed et al., 2015; Rabelo et al., 2016), as have media engagement and public messaging to more broadly convey survivors’ stories and build acceptance (Karafillakis et al., 2016). Throughout West Africa, Ebola survivors and their supporters have created survivor networks, such as the Sierra Leone Association of Ebola Survivors (SLAES), to promote group healing and peer support, while advocating against stigma and drawing government and public attention to the unmet needs of thousands of survivors (Acland, 2016; SLAES, 2017; World Health Organization, 2015).

In the following study, we evaluate the impact of instrumental social protection (including monetary stipends, food rations, educational support, and/or jobs) on the wellbeing of EVD survivors, approximately two years after they were initially infected. By choosing study participants at random, and thus potentially controlling for non-material forms of social support which are more difficult to quantify (Cohen and Wills, 1985), we hypothesized that EVD survivors who received high levels of instrumental social protection would have significantly higher indicators of wellbeing and food security two years post-discharge compared to those who had access to minimal aid.

2. Methods

2.1. Ethics statement

The study protocol was approved by the Sierra Leone Ethics and Scientific Review Committee and the Partners Human Research Committee (Protocol ID: 2016P001766). Individuals provided written informed consent or placed a thumbprint after hearing a consent script read in the Krio, Temne, or Mende languages. Subjects received 25,000 Leones (~\$5 US) for transportation.

2.2. Selection and recruitment of study participants

After obtaining district survivor lists from the respective District Ebola Response Centers, we enrolled 200 randomly selected EVD survivors from three of the hardest-hit districts in Sierra Leone—Port Loko, Kenema, and Kailahun (World Health Organization, 2016)—based on a random numbers list generated in the R programming language. Recruited participants were screened based on the “amount and type of social protection received” and were subsequently enrolled if we had not yet reached 50 participants for their assigned category (minimal, moderate, substantial, extensive). Although participants were not randomized prospectively by the various survivors’ programs that administered social protection, the differing amounts of resources meted out by these programs allow for a quasi-experiment which potentially controls for unmeasured confounders including the mechanisms for delivering support (White and Sabarwal, 2014).

2.3. Survey and in-depth interviews

We asked participants their demographic information as well as the amount of instrumental social protection they received since they were initially infected with Ebola virus. Instrumental social protection was ranked into a four-tier variable:

- I Minimal (single food ration or single monetary stipend);
- II Moderate (multiple food rations OR educational support or job/stipend < 3 months);
- III Substantial (multiple food rations or educational support AND job/stipend < 3 months OR job/stipend for 3–6 months);
- IV Extensive (job/stipend > 6 months).

We evaluated wellbeing by a 20-question Likert survey adapted from the World Health Organization quality of life instrument, WHOQOL-HIVBREF (a standard, global instrument available in Krio) (World Health Organization, 2002), and food security with the Household Food Insecurity Access Scale (HFIAS) for Measurement of Food Access (Coates et al., 2007). Lastly, we conducted in-depth interviews with 40 participants, 10 from each social protection category.

We summed the Likert responses to all 20 survey questions and treated the outcome as a continuous variable on a 20–100 scale (there were no missing data), whereby higher scores indicated better function and wellbeing. We then used this value as the dependent variable in a linear regression model to assess the impact of the amount of instrumental social protection received. We used a logistic regression model

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