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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.

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Competing interests

None declared.

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.

Keywords

Ebola; social protection; symbolic violence; survivor; outbreak; apomaafa; amgits

Main Text

> “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)

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 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 survivor 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 breadwinning 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 also 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.

Methods

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.

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 survivor 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).

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 with food secure/insecure as the dependent variable to assess the impact of the amount of social protection received. To account for the clustering effect of the district variable, we fit models using the generalized estimating equation (GEE) approach (Liang and Zeger, 1986). Covariates with a p-value < 0.2 in bivariate analysis were included in adjusted multivariate models. Covariance structure for each model was chosen by selecting those with the minimum quasi-likelihood under the independence model criterion (QIC) (Pan, 2001). Data were analyzed using STATA/IC 12.1 (STATA Corporation, College Station, TX).

We randomly chose 10 participants per social protection category to participate in an approximately 1–2 hour in-depth interview (IDI), where we explored his/her experience as an Ebola survivor (total = 40 IDIs). Three interviewers (ETR, MBB, OS) took detailed notes during each interview and discussed their notes immediately post-interview to determine themes. The themes that they agreed upon unanimously were recorded, and, during data analysis, they searched for both similarity and variance in the resulting themes by social protection category.

Lastly, we combined a genealogical approach with critical social theory to interpret the study data. In particular, we proceeded from the Bourdieusian notion that that actors “mis-recognize” the role that symbolic forms play in the maintenance of power structures (Swartz, 1997).

Results

Quantitative

Table 1 shows socio-demographic characteristics categorized by the amount of social protection received. The only significant difference between study participants was that individuals who received jobs for longer than six months were more likely to have a tertiary education ($p<0.001$).

Sex, age, education, marital status, and the number of relatives lost to EVD were not associated ($p<0.2$) with wellbeing in the bivariate GEE analysis. Social protection categories II-IV (moderate to extensive) were each significantly associated with 15–22% higher wellbeing scores compared to minimal social protection ($p<0.001$) (Table 2).

Education and marital status were associated ($p<0.2$) with food security in the bivariate GEE analysis and were included in the multivariate model. 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) compared to minimal social protection (Table 3).

Qualitative (Quotes and paraphrases translated from Krio, Temne, and Mende)

Several themes were persistent across our interviews. First, survivors who received jobs or monetary support used the additional income in novel and creative ways. For example, some invested the money in their petty trade such that they were earning more after recovering from EVD compared to before. Others used the monthly stipends as capital to start their own small businesses. Second, survivors who chose to attend literacy and vocational classes (which included banking and business skills training) noted benefits they would not have been able to purchase. For example, several participants discussed their path to partial literacy through courses organized according to Paulo Freire's literacy teaching methodology. Third, almost all survivors who received jobs (categories III and IV) spoke of a sense of purpose and fellowship that helped them cope with their losses. Some remarked how survivors they had met through SLAES took the place of relatives they had lost. Fourth, many survivors discussed in detail the exponential devastation caused by the loss of a breadwinner; however, those who received jobs and longer-term cash transfers were able to take over this role. One survivor remarked, "My father passing from Ebola could have left our entire family starving—my new job at the ETU saved us from that." Fifth, survivors who had higher levels of social protection (categories III and IV) narrated their experiences with 'stigma' as less traumatic than those who received minimal support. One middle-aged female noted she was shunned after being discharged a survivor. "It didn't hurt as much when I wasn't hungry, and after a year we were friendly again anyway," she shared. Lastly, those we interviewed made it clear that suffering in Sierra Leone did not begin with Ebola, nor had specific clinical and social sequelae related to EVD ended despite multiple declarations that West Africa was "Ebola-free" (MacDougall, 2016).

Discussion

This study makes use of the quasi-experimental conditions created by aid delivery during heightened transmission of Ebola virus in Sierra Leone to investigate the role of instrumental social protection in survivors' wellbeing. Our results demonstrate that, for EVD survivors, short-term instrumental social protection during the vulnerable period post-discharge can pay positive dividends with respect to wellbeing and food security two years later. These results are potentially generalizable to survivors of the 2017 landslides in Sierra Leone, where cash transfers are being provided directly to affected households by the United Kingdom's Department for International Development (United Nations Sierra Leone, 2017).

The study findings also support our claim that the word "outbreak" (which comes from the Old English *utbræcan* - "to break out") (Oxford English Dictionary, 2017) does symbolic violence (Bourdieu and Passeron, 1977) by creating the illusion that social suffering (Kleinman et al., 1997) ends when transmission of a pathogen ceases. As an example, millions of dollars earmarked for the Ebola response dried up when West Africa was declared free of transmission (Davis, 2016). Could it be that the categories we use to describe natural phenomena determine our responses to them (Richardson and Polyakova, 2012)? That is, is the finality of the word *outbreak* enough to blunt our appreciation that the suffering related to Ebola endures? The EVD survivors we interviewed are testament to the

fact that suffering certainly continues—in the form of clinical sequelae, lost livelihoods and loved ones, broken communities, food insecurity, and 'stigma.'

There is potential resource-mobilization benefit to the proclamation, *Outbreak!:* however, by bracketing an arbitrary fragment of social suffering in geo-microbiological terms, the word raises funds of considerably less value than the depredations of resources it obscures. That is, by distilling the virological consequences of centuries of human and natural resource extraction into a circumscribed event of public health concern, uncritical use of the term depoliticizes our understanding of the phenomenon (Escobar, 2011; Ferguson and Lohmann, 1994) and stymies transformative challenges to status-quo transnational relations of inequality by reinforcing technical solutions for all crises (Agrawal, 1996).

Like outbreak, the word "epidemic" (from the Greek *epi* [on] plus *demos* [people]) creates fictitious boundaries in our minds; however, it obscures even more by positing ahistorical *locationality* to the spread of pathogens. In other words, it elides the global forces that shape every localized occurrence of infectious disease (Richardson et al., 2016a). We thus prefer the term "apomaafa" (from the Greek *apo* [derived from; related to] plus the Kiswahili *maafa* [disaster; calamity; terrible occurrence (Ani, 1994)—but also denoting the African Holocaust: the ongoing effects of atrocities inflicted on African people through the Atlantic slave trade (Morrison, 1987), and continued through exploitative colonialism (Césaire, 1972), symbolic violence (Fanon, 2005; Said, 1979; Swartz, 1997), purposeful underdevelopment (Akyeampong et al., 2014; Amin, 1973; Rodney, 1972), structural adjustment (Kim et al., 2002), resource extraction and tax evasion (Campaign, 2017), and enabled civil war (Abdullah, 2000)] as it provides a hybrid (Bakhtin, 1981), postcolonial (Mbembe, 2001) symbolling for infectious disease analyses in sub-Saharan Africa with regard to time and place. By displacing the coding apparatus (Spivak, 1990) of epidemiology, it transforms facile claims of association by accounting for the often-violent historical and structural determinants of communicable disease occurrences (Farmer, 1996; Richardson et al., 2016c; Singer, 2015).

In this way, we see how a word like epidemic and the containment-by-isolation fetish it inspires are not adequate to describe, nor address, the continuing Ebola-related suffering described by our study participants. Would the U.S. government have pulled funding for post-Ebola health systems strengthening (Cancedda et al., 2016; Davis, 2016) had they cognized what happened as an Ebola apomaafa (i.e., something still ongoing) rather than as an epidemic (where transmission had ceased)?

Also inutile is the term 'stigma.' Our handling of the term in inverted commas indicates our ambivalence towards its conventional usage. Erving Goffman traced the term to the ancient Greek practice of marking the skin of slaves and criminals to denote them as 'undesirable' persons (Goffman, 1963). We find that international NGOs and associated academics similarly approach 'stigma' as a characteristic or attribute that is undesirable and separates an individual or a group from others, resulting in 'avoidance, dehumanization, social rejection, labelling, and stereotyping' (Tenkorang, 2017). In other words, 'stigma' is conceptualized as an intersubjective process of discrimination and hostility between Africans, one that needs to be combatted through social science and advocacy.

Yet, like outbreak and epidemic, the word obscures more than it reveals: If one recognizes that the real ‘stigma’ at play is the centuries of virulent racism from the global north [i.e., the Western consciousness of blackness (Mbembe, 2017)], then the term is exposed for the domination it leaves uncritiqued. That is, by omitting analytically the deeming of an entire continent as ‘undesirable’, the word does discursive violence. We thus propose the term ‘amgits’—literally and post-structurally as a form of strategic reversibility (Foucault, 1991)—to remind us that conventional use of the word ‘stigma’ represents a backwards, counterproductive approach to combatting the actual roots of the prejudice. Going a step further, one could posit ‘stigma’ as a false-consciousness of [the Marxist view (Eyerman, 1981)] or a less useful vocabulary for [the pragmatist view (Rorty, 1989)] the structural forces that result in the human-cum-pathology an actor is maligning.

In addition to symbolic reparations, our study’s findings lend support for an additional method of combatting the consequences of amgits: the provision of social protection (or instrumental micro-reparations). During and after the West Africa Ebola outbreak, as conventionally defined, some international NGOs employed survivors, offering them formal opportunities to contribute to outbreak-response activities and health-systems-strengthening efforts (Hayden, 2014), from contact tracing and community-based health initiatives to various caregiving roles within and outside of health care facilities. EVD survivors across the three most affected countries expressed significant interest in such opportunities and considered themselves vital contributors to efforts to improve their national health systems and the situation of EVD patients and survivors (Lee-Kwan et al., 2014). A group interviewed in Sierra Leone, for example, stated that “supporting themselves with this work would help restore their own dignity” (Delamou et al., 2017; Karafillakis et al., 2016; Lee-Kwan et al., 2014), and those surveyed in another study in Sierra Leone found that job opportunities could help “financially and emotionally sustain them as they adjust to being a survivor” (Karafillakis et al., 2016). It was therefore not surprising to find in our study that survivors who received moderate to extensive instrumental social support reported less stigma, or better overcame it, than those who did not. Instrumental social support may therefore provide a mechanism to not only boost survivors’ financial security, but also nurture personal, emotional, and psychological wellbeing.

In this study, our uncritical adoption of how “survivors” are designated is similarly problematic. The use of Ebola virus polymerase chain reaction positivity to bracket a community of suffering neglects other forms of suffering also related to the Maafa. What is the risk of reconstructing identities from what we know will be a transient biofad? Sierra Leone civil war amputees were caught up in a similar global show-and-tell (Berghs, 2007) and are now bereft of the resources such biological citizenship (Petryna, 2003) once provided. This leads us to question, does the transient attention focused on EVD survivors attenuate demands for reparations by obscuring the fact that many can claim surviving the Maafa? Many of the “non-infected” we interviewed as part of other projects expressed this very sentiment: “We are all survivors.”

Furthermore, what are the ramifications of the World Health Organization’s description of the Ebola apomaafa as a Public Health Emergency of International Concern (PHEIC) (World Health Organization, 2014)? Sierra Leone has had one of the highest maternal mortality

rates in the world for many years (Amnesty International, 2009), without sounding similar alarms in Geneva. How is it that the agency tasked with the health of the world reserves its most powerful symbolling (and the consequent resource outlays) for the swaths of death and suffering that have potential for spillover into high-income countries [Zika presents another example (Adams and Nutt, 2016)]? By framing the way the world thinks about a particular phenomenon in terms that cater to dominant country interests (Marx and Engels, 1998), such symbolling performs violence by relegating other forms of suffering—suffering no less linked to the African Holocaust—to a Public Health Nullity of Local Concern (PHNLC).

In conclusion, the combination of critical theory from the South (Comaroff and Comaroff, 2012) with mixed-methods empirical research can challenge the impoverished discursive infrastructure of contemporary public health (Farmer, 2001; Good, 1994; Jones, 2011), in effect, transforming health policy by transforming its representations (Bourdieu, 1981). While other authors have analyzed the role of local discursive power in perpetuating underdevelopment in Sierra Leone (Ferme, 1998; Hoffman, 2011), our study explores more distal pathogenic symbolling, wrought in the Global North. The evidence-based re-descriptions (Cornwall and Eade, 2010; Richardson et al., 2017; Rorty, 1999; Sachs, 2009) of epidemiological discourse presented in this paper vitiate the crisis-caravan approach to global health (Packard, 2016; Polman, 2010), foreground subaltern demands for health systems strengthening, and provide a point of departure for a mobilization of symbolic reparations.

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Highlights

- A critical theory of the symbolic violence of public health discourse is proposed.
- For Ebola survivors, short-term social protection can pay dividends two years later.
- Symbolic reparations are a crucial component of global health equity.

Table 1

Socio-demographic characteristics by social protection category (N=200).

		Social Protection Categories			
Covariates		**Minimal (I) n=50**	**Moderate (II) n=50**	**Substantial (III) n=50**	**Extensive (IV) n=50**
Sex	Female	33 (66%)	33 (66%)	30 (60%)	22 (44%)*
	Male	17 (34%)	17 (34%)	20 (40%)	28 (56%)*
Age	18–40	35 (70%)	42 (84%)	33 (66%)	39 (78%)
	>40	15 (30%)	8 (16%)	17 (34%)	11 (22%)
Education	None	28 (56%)	21 (42%)	32 (64%)	6 (12%)*
	Primary	4 (8%)	8 (16%)	4 (8%)	7 (14%)
	Secondary	14 (28%)	16 (32%)	14 (28%)	17 (34%)
	Tertiary	4 (8%)	5 (10%)	0 (0%)	20 (40%)*
Marital status	Single	14 (28%)	20 (40%)	12 (24%)	13 (26%)
	In union	16 (32%)	20 (40%)	20 (40%)	26 (52%)
	Widowed	20 (40%)	10 (20%)	18 (56%)	11 (22%)
Religion	Muslim	41 (82%)	36 (72%)	45 (90%)	41(82%)
	Christian	9 (18%)	14 (28%)	5 (10%)	9 (18%)
# of relatives who died from EVD	< 5	25 (50%)	23 (46%)	19 (38%)	23 (46%)
	≥5	25 (50%)	27 (54%)	31 (62%)	27 (54%)

Table 2

Summary of general estimating equation (linear) regression statistics predicting wellbeing (quality of life) scores by social protection category. Reference: Social protection category=I (minimal). SE=standard error. CI=confidence interval.

Variable	Coefficient	95% CI	p-value
Social Protection Category			
II	10.94	7.61–14.28	<0.001
III	12.15	8.20–16.11	<0.001
IV	14.50	10.88–18.12	<0.001

Table 3

Summary of general estimating equation (logistic) regression statistics predicting dichotomous food security/insecurity by social protection category, education, and marital status. Reference: Social protection category=I (minimal); Education=none; Marital status=single. SE=standard error. CI=confidence interval.

Variable	Odds Ratio	95% CI	p-value
Social protection category			
II	1.28	0.59–2.78	0.540
III	1.39	0.65–2.98	0.393
IV	6.11	2.85–13.10	<0.001
Education			
Primary	0.62	0.24–1.56	0.305
Secondary	1.47	0.79–2.73	0.219
Tertiary	0.70	0.31–1.57	0.39
Marital status			
In union	0.65	0.36–1.16	0.141
Widowed	0.68	0.35–1.33	0.261