

BMJ Open Mixed-methods assessment of health and mental health characteristics and barriers to healthcare for Ebola survivors in Beni, Butembo and Katwa health zones of the Democratic Republic of Congo

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ABSTRACT

Objectives Health and mental health characteristics of all respondents, barriers to accessing health and mental health services and the characteristics and those most at risk for mental health disorders.

Setting Beni, Butembo and Katwa health zones in the Democratic Republic of Congo.

Participants The sample contained 223 Ebola survivors, 102 sexual partners and 74 comparison respondents living in the same areas of the survivors. Survivors were eligible if aged >18 years with confirmed Ebola-free status. The comparison group was neither a survivor nor a partner of a survivor and did not have any household members who contracted Ebola virus disease (EVD).

Primary and secondary outcome measures Health and mental health characteristics, barriers to care and the association of association of mental health disorders with study population characteristics.

Results Funding was a barrier to accessing needed health services among all groups. Nearly one-third (28.4%, 95% CI 18.0% to 38.7%) of comparison households avoided getting injections for their children. Although most pregnant women were attending antenatal care, less than 40% of respondents stated EVD precautions were discussed at those visits. Trouble sleeping and anger were the strongest predictors of post-traumatic stress disorder, major depressive disorder (MDD), anxiety and suicide attempts with 3-fold to 16-fold increases in the odds of these disorders. There was a 71% decrease in the odds of MDD if current substance abuse (aOR 0.29; 95% CI 0.13 to 0.67; $p<0.01$) was reported.

Conclusions Specialised mental health services were limited. Fear of contracting EVD influenced vaccine compliance. Anger and sleep disorders significantly increased the odds of mental health disorders across all groups. Respondents may be using substance abuse as self-medication for MDD. Ebola outbreak areas would benefit from improved screening of mental health disorders and associated conditions like anger and sleep difficulties and improved mental health services that include substance abuse prevention and treatment.

Strengths and limitations of this study

- This randomly sampled study of adult Ebola survivors represents the entire adult survivor population in Beni, Butembo and Katwa health zones or 52% of all survivors in the 10th Ebola outbreak in the Democratic Republic of Congo.
- This cross-sectional study assesses health and mental health among Ebola survivors and their sexual partners and compares outcomes to a non-Ebola comparison group.
- The study reveals novel characteristics that increase the odds of mental health disorders among Ebola survivors and links them to known characteristics common in post-Ebola syndrome.
- The weighted findings of this study cannot be generalised to the entire population of survivors in other health zones or child survivors.
- Some outcomes of interest, when stratified by specific categories, had very small sample sizes, potentially affecting the precision of estimates.

INTRODUCTION

The Ebola virus disease (EVD) was first described in the Democratic Republic of Congo (DRC) in 1976 (then Zaire) and has occurred regularly throughout central Africa.¹ The largest outbreak of EVD occurred 2104–2016 in Guinea, Sierra Leone and Liberia and caused more than 11 000 deaths.¹ The second largest outbreak occurred over a 22-month period (August 2018–June 2020) in the North Kivu, South Kivu and Ituri provinces in Eastern DRC.² There were 2287 deaths reported among 3470 confirmed and probable cases, with an overall case fatality ratio of 66%.² The case fatality rate (66%), despite ring vaccination, was higher than the

50% case fatality rate in the West Africa epidemic.¹² More than half (57%) of those infected were women.²

North Kivu province had some of the best health indicators and preventive services of all provinces in DRC prior to the EVD outbreak.³⁻⁵ Mental health services, in part due to previous and continued international support of services addressing gender-based violence (GBV), conflict and the EVD outbreak, can be accessed at hospitals, health facilities and in the community which is provided by locally trained religious groups and lay providers.^{6,7} However, there is a paucity of psychologists and psychiatrists able to treat serious mental health disorders other than those focused on GBV survivors.^{6,7}

Although it is impossible to assign Ebola as the cause of the higher rates of mental health disorders, retraumatisation that may occur from an event like an EVD outbreak can exacerbate symptoms of mental illness, become socially disabling, and contribute to the higher suicide attempt rates among survivors.^{6,8,9} In a previous study, four times as many survivors (23%) met statistically significant symptom criteria for major depressive disorder (MDD) than partners (6%) and post-traumatic stress disorder (PTSD) symptom criteria for survivors (24%) and partners (17%) was four times higher than the comparisons (6%). [9] In addition, suicide attempts among survivors was six times higher than the comparison group.⁹ Substance abuse ranged from 23% among survivors and up to 51% of partners and comparison respondents.⁹ Data from previous studies of EVD have shown that in postconflict settings, retraumatisation and mental health problems are associated with health behaviours that hinder combatting and preventing EVD and limit access to preventive care services.^{8,10} To further investigate this association in the context of the eastern DRC Ebola outbreak, we conducted a cross-sectional study of EVD survivors, their sexual partners, and a comparison population in health zones (HZ) of North Kivu province with the highest numbers of EVD survivors. The specific aims of the study were to: (1) understand the health and mental health characteristics of the study sample, (2) identify barriers to accessing health and mental health services and (3) using a secondary analysis of previously reported rates of mental health disorders among the study population, define the characteristics and those most at risk for mental health disorders to make recommendations for the care of survivors and partners post-EVD.⁹ These data also identify opportunities to integrate EVD prevention and screening for postinfection health issues into existing health services. Given the rate of EVD infection among females (57%), maternal, newborn, child health (MNCH) services may be a particularly important point of integration.^{2,11}

METHODS

Survey sites and sample selection

This cross-sectional survey was conducted in Beni, Butembo and Katwa HZ in DRC. Surveying of comparison

households began in Beni in early February 2020 with the remaining surveys completed in Butembo and Katwa occurred between July and September 2020. The lag in survey completion was due to delays in study approvals from government officials as their focus shifted from the EVD response to the COVID-19 in 2019.

Male and female EVD survivors were eligible if aged >18 years and were able to present a certificate from an Ebola Treatment Centre (ETC) that confirmed Ebola-free status. Complete lists of survivors collated by the Ebola Survivor Associations contained the names and contact information for 427 eligible adult survivors (52% of all survivors) in Beni, Butembo and Katwa HZs and were used to randomly and/or systematically select survivors for the study.¹² Mabalako HZ, another area with high numbers of survivors, was excluded due to insecurity. We attempted to interview a representative number of female survivors (~57%) as they had higher infection rates than males during this outbreak.¹³ Comparison interviews were randomly selected within the same villages or on the same avenue as the survivor (after every third survivor interview) using a random number skip pattern from the household of the survivor (eg, the 5th house to the right). If no one was home, the data collector moved, via the same skip pattern, to the next house to the right until someone was home and could serve as a comparison. The comparison group was neither a survivor nor a partner of a survivor and did not have any household members who contracted EVD.

Instruments

We used epidemiological instruments previously developed, implemented and validated for DRC to develop a survey for survivors and their sexual partners and a similar version for the comparison group.^{6,14,15} The major domains of these instruments included demographics, experiences during discharge from the ETC, EVD knowledge, stigma, condom use and risky sexual behaviours.⁹ Symptom assessment of mental health was measured by the Hopkins Symptom Checklist (HSCL-25) used to assess MDD (15 items) and anxiety (10 items) and by the Harvard Trauma Questionnaire (HTQ) to assess PTSD symptoms (16 items).^{16,17} Both the HSCL-25 and the HTQ have been used internationally and in conflict-affected samples.¹⁸⁻²⁰ These scales were previously tested and validated in DRC.^{6,21} Questions about suicidal ideation and suicide attempts among respondents were asked and reported as yes or no responses.²²

The survey was written in English and translated to Kiswahili and back translated to account for culturally sensitive wording and reviewed for content validity. Although French is the lingua franca of DRC, the areas of the survey are largely Kiswahili and Kinande speaking. The survey questions, other than EVD-related ones, had been previously pilot tested and validated among more than 2000 participants in previous studies in the same survey areas.^{6,14,15} EVD-specific questions were pilot tested among eight community members in Beni.

Semi-structured interviews

In-depth key informant interviews were used to provide additional insights into the themes and findings that emerged from the quantitative survey. Across all 3 HZ, 8 EVD survivors, partners and community members, 6 community leaders and 15 healthcare providers and non-governmental organisation (NGO) staff were interviewed. Convenience, purposeful and snowball sampling (non-probability sampling) methods were used to allow flexibility in accessing individuals who might be important for informing the quantitative data. Interviews were conducted in French, Kiswahili or Kinande, and notes were taken during the interview on a computer to allow for simultaneous transcription, being careful to write exactly how issues and concerns were expressed by the respondent. The topics discussed included awareness of the causes of EVD, concerns since discharge or concerns about survivors in the community after discharge, postrecovery services offered, changes in sexual behaviour and stigma. Respondents were also given the opportunity to discuss other issues. Additionally, a subset of short qualitative responses was obtained from the quantitative survey (n=399).

Interviewers

Four locally hired and EVD vaccinated data collectors were trained by one expatriate researcher and one Congolese supervisor over 3 days to conduct one-on-one interviews. Training included a combination of classroom teaching, experimental role-play and field testing. Data collectors learnt to verbally administer the survey in Kiswahili and Kinande. The verbal translations from Kiswahili into Kinande were checked for accuracy by members of the research team. Interviews were conducted anonymously in a setting that offered privacy and confidentiality, typically inside the housing unit if masks were available and social distancing could be maintained. If not, interviews were completed outside away from others to preserve confidentiality and ensure social distancing. Oral rather than written consent was obtained because of the high illiteracy rate and the need for confidentiality. Participants did not receive any material compensation. They were informed that participation or lack thereof would not affect their access to or the quality of the care they receive and were explicitly given the right to refuse participation. Password-protected tablets were used with the Kiswahili translation of the survey for data to limit data loss and to allow for remote monitoring. The data collectors were supervised throughout the survey period, and data was uploaded at the end of the day and reviewed by the study team nightly.

Data analysis

Quantitative analysis

Sample size was determined by the known prevalence of major depression of 0.4.⁶ The sample size required to estimate that prevalence via a simple random sample, to within 0.05 with 95% confidence, was 199 survivors. The

study targeted 225 EVD survivors (of the 427) in the 3 HZs to account for refusals and to ensure representativeness of the sample. A subset of sexual partners of the randomised survivors were also surveyed. The original target sample size for partners was 225. Only 45% (110/225) of those were interviewed, due to partners being away from households for work, not wanting to participate in a lengthy interview, and/or not wanting to talk about their experiences due to stigma. XLSTAT and STATA 16 were used to perform the statistical analyses. Analysis involved the estimation of weighted population and subpopulation means and percentages. As previously described, 58% of the survivor sample was female and 42%, male.⁹ The mean age (range 33–38 years) was not statistically different across respondent groups.⁹ The majority reported to be married, Christian, Nande ethnic group, farmers/herders and Kiswahili speakers.⁹ An average HSCL-25 score of 1.75 or higher and an average HTQ score of 1.75 or higher was considered predictive of clinically significant depression or anxiety and PTSD, respectively, based on data from other conflict-affected populations.^{19 23 24} Data were weighted to account for population differences of the HZ and numbers of survivors.⁹ Multivariate logistic regression models were used to investigate the association of mental health disorders with study population characteristics. Variables found to be significant in bivariate analysis were included as cofounders in the multivariate model. Because missing data were minimal for relevant variables (<5%), observations with missing data were dropped from analyses.

Qualitative analysis

Qualitative data were translated into English. In-depth narratives from the key informant interviews and qualitative data from the quantitative surveys were summarised and compiled into a master Excel spreadsheet by outcomes and questions on the instruments. Qualitative data were collected to complement and triangulate the quantitative data. All data were analysed using content analysis (specifically conceptual content analysis).²⁵ Themes, developed collaboratively with local field staff to ensure culturally and contextually appropriate interpretation of the analysis, were hand-coded, analysed, categorised by the first author and reviewed by additional authors for concurrence.

Patient and public involvement

The Ebola Survivor Associations of Beni, Butembo and Katwa were involved in recruiting participants and in dissemination of the results.

RESULTS

Health services accessed

The most accessed health services by all respondents included pharmacies, health centres and hospitals (table 1). The most stated barrier to accessing needed health services among survivors (57%), partners (70%) and the comparison group (49%) was the lack of money to pay for such

Table 1 Health services accessed

	EVD survivors (n=223)	Partners (n=102)	Comparison group (n=74)	P-value*	P-value*
	Weighted % (95% CI)	Weighted % (95% CI)	Weighted % (95% CI)	Survivor versus partner	Survivor versus comparison
Medical services accessed†					
Hospital	85.3 (80.7 to 90.0)	65.6 (56.4 to 74.8)	59.3 (48.1 to 70.5)	<0.001	0.00
Health facility	74.0 (68.3 to 79.8)	79.1 (71.3 to 87.0)	83.6 (75.2 to 92.1)	0.32	0.28
Pharmacy	70.3 (64.3 to 76.3)	76.8 (68.7 to 85.0)	80.8 (71.8 to 89.7)	0.22	0.71
Traditional healers	4.42 (1.7 to 7.1)	1.21 (0 to 3.3)	2.7 (0.6.4)	0.14	0.07
Feeding centre	1.59 (0.3.2)	4.1 (0.3 to 7.9)	3.2 (0.7.2)	0.17	0.36
Why medical services were not used if needed				0.00	0.03
No money for services	57.2 (50.7 to 63.7)	69.8 (60.9 to 78.7)	48.9 (37.4 to 60.4)		
Discrimination/stigma	10.5 (6.5 to 14.5)	1.8 (0 to 4.4)	0 (0 to 0)		
Fear of infection with EVD	5.6 (2.6 to 8.7)	17.0 (9.7 to 24.3)	18.8 (9.8 to 27.8)		
Too far away	4.9 (2.1 to 7.8)	0.59 (0 to 2.06)	0 (0 to 0)		
No money for transportation	2.4 (0.4 to 4.4)	0.59 (0 to 2.1)	8.5 (2.1 to 14.9)		
Fear of dying at a health facility	2 (0.2 to 3.8)	1.1 (0 to 3.1)	6.0 (0.5 to 11.5)		
Other	17.3 (12.3 to 22.3)	9.1 (3.5 to 14.7)	17.8 (9.0 to 26.7)		

Bold/italicized P-values denote statistical significance

*Pearson χ^2 test.

†Other: survivors and partners: nothing n=38, prefer traditional medicine n=2, no time n=2, spouse refused n=1, lack of quality care/distrust n=4; comparison: nothing n=12, fear of health facility n=4.

EVD, Ebola virus disease.

services ($p<0.05$). Stigma was not a commonly stated barrier to care. However, 10% of survivors did report stigma as a reason for not accessing services if they were needed. Among partners (17%) and the comparison group (19%), fear of EVD infection was the second commonly stated barrier to accessing healthcare services.

Maternal and child healthcare access and characteristics

During the EVD epidemic, nearly a third (28.3%, 95% CI 18.0% to 38.7%; $p<0.001$) of comparison households stated they avoided getting injections for their children compared with 4.5% (95% CI 1.8% to 7.2%) of survivors and 9.4% (95% CI 3.7% to 15.1%) of partners (table 2). Of those pregnant at the time of the study ($n=34$), planned pregnancies were more than twice as common among survivors (83.6%, 95% CI 66.5% to 100%) and partners (72.8%, 95% CI 48.6% to 96.9%; $p=0.05$), than comparison women (36.2%; 95% CI 0% to 83.9%). Forty per cent of pregnancies among the comparison group were due to violence. Less than half of survivors (47.9%, 95% CI 24.9% to 71.0%) stated they planned to breastfeed. Although most pregnant individuals surveyed were attending antenatal care visits (ANC), only 7% survivors, 19% of partners and 39% of community comparisons reported that EVD precautions were discussed at those visits.

Mental healthcare access

Clinics and hospitals across the three HZs were reported to have mental health services (table 3). Respondents in Beni stated that religious groups and traditional healers

were involved in mental healthcare. Among respondents, up to 21% did not know if services were available in their HZ. Post-Ebola psychosocial support was reported as available in each HZ.

Most of the survivors 87.0% (95% CI 82.6% to 91.4%) and one-third of partners (33.5%, 95% CI 24.3% to 42.6%) had received mental health counselling since August 2018 compared with 16% of the comparison group (online supplemental table 1). More than 50% of all respondents stated there was 'nothing' that would stop them accessing mental health services, although 13.2% (95% CI 6.7% to 19.8%) of partners stated that shame would stop them and 25.6% (95% CI 15.6% to 35.5%) of comparison respondents stated they believed services were not necessary. Religion, discussions with friends and family support were reported as the most helpful means for dealing with their experiences during EVD across all three groups. One-third of survivors (31.9%, 95% CI 25.8% to 38.0%) stated 'trying to forget about it' was helpful while employment was more frequently stated by partners and comparisons.

Mental health characteristics

More than half of survivors and partners self-reported anger compared with one-third of the comparison group (table 4). More than half of all respondents also reported sleep difficulties. More comparison households (5.4%, 95% CI 0.2% to 10.5%) and partners (4.7%, 95% CI 0.6% to 8.9%; $p=0.05$) reported a household member

Table 2 Maternal child health access and characteristics

	EVD survivors (females; n=134)	Partners (females; n=45)	Comparison group (females; n=34)	P-value*	P-value*
	Weighted % (95% CI)	Weighted % (95% CI)	Weighted % (95% CI)	Survivor vs partner	Survivor vs Comparison
Since the start of EVD, avoided getting injections for children	4.5 (1.8 to 7.2) (n†=223)	9.4 (3.7 to 15.1) (n†=101)	28.3 (18.0 to 38.7) (n†=73)	0.06	<0.001
Pregnant at the time of the survey	13.6 (7.7 to 19.4)	28.9 (15.7 to 42.1)	11.3 (0.7 to 22.0)	0.02	0.73
Number of miscarriages since the start of EVD‡	0.2 (0.1 to 0.3)	0.3 (0.2 to 0.5)	0.2 (0.0 to 0.4)	0.19	0.99
	Pregnant survivors (n=17)	Pregnant partners (n=13)	Pregnant comparison group (n=4)		
Pregnancy was planned	83.6 (66.5 to 100)	72.8 (48.6 to 96.9)	36.2 (0 to 83.9)	0.46	0.05
Pregnancy was the result of violence	3.3 (0 to 11.6)	0 (0 to 0)	39.5 (0 to 88.1)	0.51	0.03
Had a miscarriage due to violence§	12.1 (0 to 25.0) (n¶=23)	0 (0 to 0) (n¶=13)	22.5 (0 to 62.3) (n¶=6)	0.20	0.57
Planning to breastfeed	47.9 (24.9 to 71.0)	95.4 (84.1 to 100)	100 (100 to 100)	0.01	0.06
Planning to deliver at a health facility	100 (100 to 100)	100 (100 to 100)	100 (100 to 100)	NA	NA
Attending ANC visits	69.8 (48.6 to 91.0)	72.4 (48.2 to 96.7)	75.6 (32.9 to 100)	0.87	0.82
Ebola precautions were discussed at antenatal care visits	6.9 (0 to 18.6)	19.0 (0 to 40.3)	39.5 (0 to 88.1)	0.59**	0.21**

*Categorical variables: Pearson χ^2 test; continuous variables: two tailed t-test, prior use of an F-test to determine whether variance can be assumed to be equal.

†n=all participants and therefore includes men and women.

‡Continuous variable.

§n=among all women reporting a miscarriage; limits to p values due to small sample size and CIs.

¶n=the number of women who reported at least one miscarriage since August 2018.

**Limitations to p values due to small sample size and CIs.

ANC, antenatal care; EVD, Ebola virus disease; NA, not available.

committed suicide when compared with survivor households (1.1%, 95% CI 0% to 2.5%; $p=0.03$). Fear of EVD (88%–98%) and fear of sexual violence by combatants (73%–83% among all respondents) was high. Most

households feared EVD as much as they feared sexual violence by combatants and feared sexual violence by combatants approximately eight times more than sexual violence by others. Substance use largely decreased

Table 3 Mental health services reportedly available by health zone (HZ)

	Beni (n=145)	Butembo (n=128)	Katwa (n=126)	P-value*
	% (95% CI)	% (95% CI)	% (95% CI)	By HZ
Mental health services available				
None	40.7 (32.7 to 48.7)	4.7 (1.0 to 8.3)	27.0 (19.2 to 34.7)	<0.001
Hospital	44.8 (36.7 to 52.9)	43.0 (34.4 to 51.5)	51.6 (42.9 to 60.3)	0.35
Clinic	17.2 (11.1 to 23.4)	42.2 (33.6 to 50.7)	16.7 (10.2 to 23.2)	<0.001
Witch doctor, traditional healer	15.2 (9.3 to 21.0)	5.5 (1.5 to 9.4)	5.6 (1.6 to 9.6)	0.01
Religious support	13.1 (7.6 to 18.6)	3.1 (0.1 to 6.1)	6.3 (2.1 to 10.7)	0.01
I don't know	11.7 (6.5 to 17.0)	21.1 (14.0 to 28.2)	17.5 (10.8 to 24.1)	0.11
Ebola/post-Ebola psychosocial support	10.3 (5.4 to 15.3)	24.2 (16.8 to 31.6)	19.0 (12.2 to 25.9)	0.01
One-on-one counselling	2.07 (0 to 4.4)	8.6 (3.7 to 13.4)	7.9 (3.2 to 12.7)	0.04
Rehabilitation centres	0.7 (0 to 2.0)	2.3 (0 to 5.0)	2.4 (0 to 5.0)	0.47
Group counselling	0.7 (0 to 2.0)	3.9 (0.5 to 7.3)	1.6 (0 to 3.8)	0.15
Community health worker	0 (0 to 0)	2.3 (0 to 5.0)	0.8 (0 to 2.3)	0.15

*Pearson χ^2 test applied to compare reported service availability by HZ.

Table 4 Mental health characteristics

	EVD survivors (n=223)	Partners (n=102)	Comparison group (n=74)	P-value*	P-value*
	Weighted % (95% CI)	Weighted % (95% CI)	Weighted % (95% CI)	Survivor vs partner	Survivor vs comparison
Feeling irritable or having outbursts of anger	60.9 (54.5 to 67.3)	56.0 (46.4 to 65.7)	26.2 (16.2 to 36.2)	0.40	<0.001
Trouble sleeping	57.6 (51.1 to 64.1)	55.7 (46.0 to 65.3)	52.1 (40.7 to 63.5)	0.75	0.41
Household member committed suicide since August 2018	1.1 (0 to 2.5)	4.7 (0.6 to 8.9)	5.4 (0.2 to 10.5)	0.05	0.03
Sexual violence by combatants is something feared for self and family	83.1 (78.2 to 88.2) (n=218)	72.6 (63.9 to 81.4) (n=100)	82.5 (73.7 to 91.2) (n=74)	0.01	0.82
Sexual violence by family members, friends, or civilian strangers is something feared for self and family	18.5 (13.4 to 23.7) (n=219)	8.2 (2.8 to 13.6) (n=100)	4.0 (0.0 to 8.5) (n=74)	0.02	0.00
Ebola is something feared for self and family	97.9 (95.9 to 99.8) (n=219)	94.1 (89.5 to 98.7) (n=100)	88.0 (80.5 to 95.5) (n=74)	0.01	0.00
Change in substance use since August 2018					
Increased	3.4 (1.0 to 5.7)	8.0 (2.7 to 13.3)	9.3 (2.6 to 16.0)	<0.001	<0.001
Decreased	35.3 (29.0 to 41.5)	16.0 (8.9 to 23.2)	9.1 (2.4 to 15.7)		
Remained the same	6.8 (3.5 to 10.1)	35.3 (25.9 to 44.6)	23.5 (13.8 to 33.3)		
Never used	54.0 (47.5 to 60.5)	40.7 (32.1 to 50.3)	55.3 (43.9 to 66.8)		

*Pearson χ^2 test.

EVD, Ebola virus disease.

among survivors since the start of the outbreak. Comparison respondents had the highest rate of increase in substance use since the start of outbreak.

Respondent group, sex, education, employment status and reported stigmatisation had no statistically significant associations with MDD, PTSD, anxiety or lifetime suicide attempts (table 5). Trouble sleeping and anger were the strongest predictors of PTSD, MDD, anxiety and suicide attempts. For those with PTSD, after adjusting for confounders, the odds were 16-fold higher (aOR 17.8, 95% CI 6.1 to 52.1; $p<0.001$) for those who reported trouble sleeping and 15-fold higher (aOR 16.1, 95% CI 4.5 to 47.3; $p<0.001$) if they reported anger.

For those who made symptom criteria for MDD, there was a 2% increase in the odds of MDD for every 1-year increase in age ($p<0.05$), an 88% decrease in the odds of MDD if you were a partner of a survivor ($p<0.01$), a 49% decrease if married ($p<0.05$) and a 71% decrease if substance abuse was self-reported ($p<0.01$). Like PTSD, with self-reported trouble sleeping (aOR 3.89, 95% CI 1.9 to 8.1; $p<0.001$) and anger (aOR 6.2, 95% CI 2.7 to 13.8; $p<0.001$) there was a threefold to fivefold increase in the odds of MDD.

Trouble sleeping increased the odds of anxiety six-fold and (aOR 6.73, 95% CI 2.5 to 18.0) and lifetime suicide attempts three-fold (aOR 3.53, 95% CI 1.4 to 8.8). The odds of anxiety were 12 fold higher if respondents reported anger (aOR 12.57, 95% CI 3.7 to 43.1) and

associated with a threefold increase in lifetime suicide attempts (aOR 3.76, 95% CI 1.5 to 9.4).

Qualitative findings

In-depth interviews revealed that healthcare access for preventive care had suffered during the EVD emergency. Community health workers (CHWs) were paid US\$300–US\$350 during the epidemic for EVD case referrals and for community messaging. Participants were asked if they would return to their normal volunteer roles in the community, given their CHW positions became paid as part of the emergency response. The US\$300 per month stipend given to CHWs is half of an average yearly salary of most Congolese households.²⁶ It is likely that volunteers who were paid for the emergency response will put the health prevention and promotion role of volunteer CHWs at risk and potentially decrease available preventative services especially for women and children:

When I see other people [communicators and people working in offices] being paid why should we not be paid? When the response teams came, they were giving money to everyone; we realized that Ebola was all about money (Male Community Health Worker—Beni)

If they stop paying me to do sensitization, I will just go back to farming...everyone knows Ebola is money (Female Community Health Worker—Beni)

Table 5 Adjusted ORs (aORs) for the associations of study sample characteristics with mental health disorders

Study characteristic*	PTSD			MDD			Anxiety			Suicide attempt		
	N (%)†	aOR (95% CI)	P-value	N (%)†	aOR (95% CI)	P-value	N (%)†	aOR (95% CI)	P-value	N (%)†	aOR (95% CI)	P-value
Survivor	-	-	NS‡	54/221 (24%)	0.12 (0.03 to 0.4)	0.005	-	-	NS	-	-	NS
Married	-	-	NS	35/233 (15%)	0.51 (0.3 to 0.9)	0.04	-	-	NS	-	-	NS
Age	-	-	NS	-	1.02 (1.0 to 1.1)	0.01	-	-	NS	-	-	NS
Substance abuse§	-	-	NS	13/140 (9%)	0.29 (0.1 to 0.7)	0.004	-	-	NS	-	-	NS
Trouble sleeping	64/214 (30%)	17.85 (6.1 to 52.1)	<0.001	55/214 (26%)	3.89 (1.9 to 8.1)	<0.001	42/214 (20%)	6.73 (2.5 to 18.0)	<0.001	27/214 (13%)	3.53 (1.4 to 8.8)	0.007
Anger	64/209 (31%)	16.11 (4.5 to 47.3)	<0.001	56/209 (27%)	6.15 (2.7 to 13.8)	<0.001	46/209 (22%)	12.57 (3.7 to 43.1)	<0.001	27/209 (13%)	3.76 (1.5 to 9.4)	0.005

Bold aORs denote statistical significance
 *aORs are only presented for characteristics found to be significant in bivariate analyses.
 †Unweighted percentages.
 ‡Not significant; the aORs for these characteristics were not significant in bivariate analyses.
 §Current substance abuse.
 MDD, major depressive disorder; NS, not significant; PTSD, post-traumatic stress disorder.

Interviews also revealed that healthcare providers and NGO personnel had frustration with the ‘all-consuming nature of the response’, leaving programming gaps, such as childhood vaccines, malaria and diarrhoea prevention campaigns. They expressed worry about the long-term effects of the gaps in coverage over the 22 months of the epidemic response. One HZ chief doctor stated he spent all his time on Ebola, leaving little to no time to address health issues like tuberculosis, MNCH or vaccinations. He stated that ‘Ebola broke the system’ when referring to the decision to pay CHWs and other volunteers who were the ‘backbone of the preventive healthcare system’.

Short answer qualitative findings and in-depth interviews revealed that refusing injections (vaccines) for children was driven by a fear of infection, fear of contracting EVD at a health facility and/or the belief that EVD was being purposely injected at health facilities. As one participant stated, ‘I hear they are infecting people with the virus, so I am afraid’. (Male Comparison Respondent)

In-depth interviews added important context to the mental health data. During key informant interviews, many of the survivors and partners interviewed appeared angry. When asked about the anger, it stemmed from home life issues, including the lack of employment, loss of a child, financial deprivation after infection, taking in orphans with no support and ongoing stigma and discrimination. One respondent, when asked why she was angry stated the following:

I am very angry, and because I lost a child [to Ebola] and then I got Ebola...many people talk about Ebola but they don't know what it really is. They don't understand my pain and I feel stigmatized. (Female Survivor—Butembo)

Compounding the anger was the reality that more than half of the survivors and partners that reported having to move households after contracting Ebola, also had to leave their communities because of violence. A female survivor stated:

One of my neighbours died of Ebola and then they said that if I was healed why did I give her Ebola so they attacked my house and demolished it by burning it with all my things. (Female Nurse Survivor—Beni)

DISCUSSION

Healthcare access

Two decades of continuous violent civil conflicts and insecurity in North Kivu have created significant government health system weaknesses, particularly at the HZ level where planning of healthcare services is implemented.^{3 5 7 27 28} Thus, North Kivu is one of two provinces with the highest percentage of for-profit and humanitarian assistance run health services.³ Given these challenges, EVD survivors are monetarily incentivised by third party providers such as WHO and the Ministry of Health for monthly post-EVD care. This care includes medical care,

psychological counselling for survivors and partners, and medical follow-up of children under 15 years of survivor families and is expected to continue through March 2022.^{2 29} Since access to medical care and psychological services for survivors are monetarily incentivised and provided cost-free, it is not clear why over half of survivors state they were unable to access services due to lack of funding. Health financing is dependent on household out-of-pocket payments, so it may be that the financial barrier applies to care for other family members.² In a previous study more than one-quarter of survivors stated they were stigmatised by facilities and/or healthcare staff, their expressed fear regarding stigmatisation in health facilities (10%) was worse in practice.⁹

Maternal and child healthcare access and characteristics

Vaccines remain one of the most efficient and cost-effective public health interventions to reduce child mortality.³⁰ Vaccination rates in DRC improved between 2007 and 2014 and North Kivu had the highest prevalence of full vaccination (66%).³¹ However, that still means that 44% of infants and children did not have full vaccination.³¹ During the EVD outbreak, vaccination rates for early childhood diseases began declining in 2019, with decreases of 10% reported.^{32 33} With these decreasing rates now compounded by COVID-19, vaccine hesitancy, based on fears and misinformation, could have a further deleterious effect on infants and children.^{32 34}

Mortality rates among women and children in DRC have decreased over the last decade but remain high. Contributions to the high maternal mortality rate include preventable diseases, inadequate prenatal and postnatal care, unequal power dynamics and decision making between women and men, and harmful practices such as early marriage.^{6 30 31} These factors contribute to the high GBV rate in the areas and may explain the high number of unplanned pregnancies and miscarriages due to violence among the comparison group.^{6 31} Higher rates of planned pregnancy among survivors and partners is likely due to the requirement to have viral clearance before planning or getting pregnant as per their monthly follow-up. Focused ANC is essential to decrease newborn mortality.³⁵ During the EVD outbreak and in this sample, between a quarter and one-third of pregnant women were not attending ANC visits which is similar to decreases in ANC visits in the West Africa EVD outbreak.^{34 36} Among those who attended ANC, the lack of EVD precautions discussed at these visits suggests patients are not receiving important, and potentially life-saving, information about infection prevention control measures, condom use, and means to combat myths and misinformation. Providing accessible information on these topics is important for addressing barriers to maternal and child healthcare seeking and utilisation especially for EVD survivors and partners.³⁶ Despite lessons learnt from the West Africa EVD outbreak, some of the same mistakes such as decreased access to and utilisation of ANC and other important services for endemic diseases like malaria,³⁴ and failing to prevent

excess deaths among pregnant, non-EVD infected individuals, were repeated in DRC.^{36–38} Integrating EVD awareness into maternal and child health services at the outset, in addition to community messaging, is prudent to decrease mortality and morbidity for women and children resulting from lack of preventive care.^{34 39 40}

Exclusive and immediate breast feeding is known to prevent 38% of neonatal deaths.^{31 40} Despite a lack of evidence that breast milk can transmit EVD from mother to child, DRC recommendations state that EVD survivors with cleared viraemia should wait for two consecutive negative tests to resume breast feeding.^{41–43} Thus, nearly half of the pregnant survivors are planning to breastfeed even with guidelines that suggest they should not. And without evidence-based research on EVD and breastmilk, discouraging breast feeding can have significant effects on infant mortality and morbidity and setback public health efforts and gains in promoting breast feeding especially within the DRC context.⁴³

Mental healthcare access

Those living in outbreak areas had poor mental health at baseline, partly due to these areas being postconflict and chronically insecure with a high prevalence of sexual violence.^{6 44} There is a lack of specialised mental health services in North Kivu, and community members have little choice in service and treatment options.⁷ Mental healthcare is largely provided by lay personnel such as religious leaders or trusted community members using active listening, feedback or in special circumstances cognitive processing therapy (CPT) for sexual violence survivor programmes.^{21 44 45} Survivors and partners are offered limited psychological evaluations and care during their monthly follow-up appointments.⁴⁵ The availability and quality of treatment for more severe mental health disorders such as suicidal ideation, suicide attempts and PTSD in Ebola affected HZs remains unclear.

Mental health characteristics

Anger and sleep quality index scales have not, to the authors' knowledge, been used in DRC and would require adaption and validation.^{46 47} Anger among the study population was significantly associated with PTSD, MDD, anxiety and suicide attempts. Mental health screening should include anger scales, given their association with these and other mental health disorders.^{48 49}

Furthermore, collective community anger should be addressed in the EVD outbreak areas given the chronic conflict, rates of GBV and associated mental health disorders.⁶ Addressing anger broadly among entire communities will serve to help everyone, not just survivors and partners, and may help to prevent further traumatisa-tion and the severity of mental health disorders in future outbreaks of EVD.^{50 51}

Across Africa, sleep disorders are theorised to be caused by genetic predisposition, testosterone and oestrogen decline, inflammation, obesity, environmental factors and are common among HIV-positive patients and

in areas where African Trypanosomiasis is endemic.^{52 53} And although sleep disorders among EVD survivors is a common complaint of the post-Ebola syndrome, the cause of the reported sleep disorders remains unknown.^{54 55} It is possible the erectile dysfunction and menstrual changes commonly seen among survivors post-Ebola are hormone related which contribute to the sleep disorders.^{54–56} Given the strong association of sleep difficulties with mental health disorders in this study, sleep quality scales should be administered to identify those at risk for mental health disorders.^{46 56 57} Additionally, further research to better define the causes of the sleep disorders may help to identify, treat, and alleviate the burden and severity of mental health disorders. The protective effects of substance use/abuse for MDD suggests that alcohol and or drugs are being used to self-medicate (SM), a well-established phenomenon among those with MDD and anxiety.^{58 59} Screening for and addressing substance abuse and SM behaviours should be concurrent with the treatment of MDD and anxiety in this population.^{58 59}

It is also possible that the effects of fear and death around survivors and their families is exacerbating symptoms of mental health disorders stemming from trauma from GBV and conflict/insecurity in outbreak areas. Exacerbation of symptoms can become socially disabling and may be a reason for the higher suicide attempt rates among household members.^{9 10}

With a dearth of specialised psychiatric practitioners in DRC, some of the already trained lay providers could be helpful in screening and treatment of survivors, partners and the community for specific mental health disorders, like PTSD, MDD and anxiety. By using CPT or psychological first aid, they may be able to address symptoms such as anger which increase the odds of significant mental health disorders and treat the substance abuse concurrently.^{7 21 44 48–51 60}

LIMITATIONS

The weighted findings of this study represent the adult survivor populations in Beni, Butembo and Katwa HZs and cannot be generalised to the entire population of survivors in other HZs or child survivors. The sample weights are based on population estimates from the DRC, District Health Information Service 2.0, and therefore, may introduce bias given there is no census data to rely on. Some outcomes of interest, when stratified by specific categories, had very small sample sizes, potentially affecting the precision of estimates. The design of this study allows for the determination of population characteristics but not causality between those characteristics and outcomes of interest. Interviewers were careful to explain there would be no material gain by participation in the study; however, respondents may have underestimated or exaggerated responses if they thought it would be in their interest to do so. The mental health instruments used to determine the prevalence of symptom criteria for mental health disorders do not substitute for clinician diagnosis.

CONCLUSION

This study suggests the inability to pay for services, fear of being stigmatised or contracting EVD had a role in limiting access for all health services. Sustainable, affordable and accessible healthcare, including specialised mental healthcare, in North Kivu must continue to be prioritised by both the government and donors. EVD awareness should be integrated into preventive care such as MNCH care. The community would benefit from improved screening of mental health disorders including anger and sleep difficulties and improved mental health services should integrate substance abuse into treatment. Community based trauma healing may improve community health after EVD and perhaps prevent further trauma induced exacerbation of mental health disorders and address the anger in communities. Lay counsellors, trained in CPT for GBV survivors, could be an effective and efficient means of screening and addressing a range of mental health issues in EVD outbreak areas to fill the void of specialised services necessary for EVD outbreak area populations. Further research using clinical reasoning that deciphers and ties post-Ebola syndrome symptoms to clinical outcomes is necessary to better meet the medical needs for survivors and outbreak area communities at large.

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Supplemental Table 1. Mental Health Care Access

	EVD Survivors (n=223)	Partners (n=102)	Comparison Group (n=74)	p-Value ^a	p-Value ^a
	Weighted % (95% CI)	Weighted % (95% CI)	Weighted % (95% CI)	Survivor vs Partner	Survivor vs Comparison
Received mental health counselling or psychosocial support since EVD	87.0 (82.6,91.4)	33.5 (24.3,42.6)	16.2 (7.7,24.7)	< 0.001	< 0.001
Issues that would make accessing mental health services difficult					
Nothing	62.2 (55.8,68.5)	46.4 (36.7,56.1)	54.1 (42.8,65.5)	0.01	0.22
Access to a program or facility	8.1 (4.5,11.7)	4.1 (0.3,7.9)	1.3 (0,3.8)	0.18	0.04
Fear of family non-acceptance	6.8 (3.5,10.1)	0.6 (0,2.1)	0 (0,0)	0.02	0.02
Not necessary	5.3 (2.4,8.3)	21.4 (13.4,29.3)	25.6 (15.6,35.5)	< 0.001	< 0.001
Concerns about confidentiality	4.5 (1.8,7.3)	7.6 (2.5,12.78)	5.2 (0.2,10.3)	0.26	0.80
Feeling ashamed	4.3 (1.6,6.9)	13.2 (6.7,19.8)	3.9 (0,8.4)	0.00	0.90
Interfere with responsibilities at home	4.1 (1.5,6.8)	2.8 (0,5.9)	4.6 (0,9.4)	0.54	0.87
Fear of stigma or community non-acceptance	2.7 (0.6,4.9)	0.6 (0,2.1)	0 (0,0)	0.21	0.15
Do not believe this would help	2.3 (0.3,4.2)	6.5 (1.7,11.3)	1.3 (0,3.8)	0.06	0.60
Services that helped get through their experiences since EVD					
Trying to forget about it	31.9 (25.8,38.0)	22.2 (14.1,30.2)	2.1 (0,5.3)	0.07	< 0.001
Religion	30.7 (24.6,36.7)	28.0 (19.3,36.7)	44.9 (33.6,56.2)	0.62	0.03
Discussions with friends	22.2 (16.7,27.6)	41.1 (31.5,50.6)	41.7 (30.5,53.0)	0.00	0.00
Support of family	21.5 (16.1,26.9)	20.1 (12.3,27.9)	26.9 (16.8,37.0)	0.78	0.33
Employment	20.1 (14.8,25.4)	42.0 (32.4,51.6)	36.5 (25.5,47.5)	< 0.001	0.00
Discussions with other survivors	19.1 (13.9,24.2)	2.3 (0,5.1)	0 (0,0)	< 0.001	< 0.001
Medical care provider	19.0 (13.9,24.2)	5.7 (1.2,10.2)	5.9 (0.5,11.2)	0.00	0.01
Taking care of the household	15.5 (10.8,20.3)	13.5 (6.9,20.1)	16.8 (8.3,25.3)	0.63	0.79
Not telling anyone about my infection	8.7 (5.0,12.4)	17 (9.7,24.3)	0 (0,0)	0.03	0.01
Discussions with family members	7.2 (3.8,10.6)	5.2 (0.9,9.5)	14.3 (6.3,22.3)	0.49	0.06
Assistance from NGO workers	7.0 (3.6,10.3)	6.3 (1.6,11.0)	0 (0,0)	0.81	0.02
Healing ceremonies	2.1 (0.2,4.0)	0.6(0,2.1)	0.6 (0,2.4)	0.31	0.39
Traditional medicine/healer	1.8 (0.1,3.5)	1.1 (0,3.1)	0 (0,0)	0.63	0.24
Services that would be most helpful					
Income generating projects	78.0 (72.6,83.4)	77.5 (69.5,85.6)	71.2 (60.9,81.5)	0.93	0.23
Medical care	77.2 (71.7,82.7)	60.8 (51.4,70.3)	44.7 (33.4,56.1)	0.00	< 0.001
Psychosocial support	52.4 (45.9,59.0)	38.5 (29.0,47.9)	8.6 (2.2,15.0)	0.02	< 0.001
Mental health counselling	48.3 (41.8,54.9)	35.5 (26.3,44.8)	10.7 (3.6,17.7)	0.03	< 0.001

Religious counselling/support	43.0 (36.5,49.5)	40.7 (31.2,50.2)	37.6 (26.6,48.6)	0.69	0.41
Vocational/skills training	39.8 (33.4,46.3)	33.9 (24.7,43.0)	48.5 (37.1,59.9)	0.30	0.19
Support groups	11.9 (7.6,16.1)	7.0 (2.1,12.0)	22.1 (12.7,31.6)	0.18	0.03
Education (primary/secondary)	7.9 (4.3,11.4)	5.3 (1.0,9.7)	9.6 (2.9,16.3)	0.40	0.65
Rehabilitation centres	4.2 (1.6,6.9)	4.2 (0.3,8.1)	14.2 (6.2,22.1)	0.99	0.00

Abbreviations: CI, confidence interval; EVD, Ebola virus disease.

^a Pearson χ^2 test

^b Missing values excluded from test calculations (4 missing values in survivor group, 2 missing values in the partner group, 1 missing value in the comparison group)

^c p-value=0.046<0.05 therefore significant