Changes in Health-Seeking Behavior Did Not Result in Increased All-Cause Mortality during the Ebola Outbreak in Western Area, Sierra Leone

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Abstract. Little is known about the residual effects of the west African Ebola virus disease (Ebola) epidemic on non-Ebola mortality and health-seeking behavior in Sierra Leone. We conducted a retrospective household survey to estimate mortality and describe health-seeking behavior in Western Area, Sierra Leone, between May 25, 2014, and February 16, 2015. We used two-stage cluster sampling, selected 30 geographical sectors with probability proportional to population size, and sampled 30 households per sector. Survey teams conducted face-to-face interviews and collected information on mortality and health-seeking behavior. We calculated all-cause and Ebola-specific mortality rates and compared health-seeking behavior before and during the Ebola epidemic using χ^2 and Fisher's exact tests. Ninety-six deaths, 39 due to Ebola, were reported in 898 households. All-cause and Ebola-specific mortality rates were 0.52 (95% confidence interval [CI] = 0.29–0.76) and 0.19 (95% CI = 0.01–0.38) per 10,000 inhabitants per day, respectively. Of those households that reported a sick family member during the month before the survey, 86% (73/85) sought care at a health facility before the epidemic, compared with 58% (50/86) in February 2015 ($P = 0.013$). Reported self-medication increased from 4% (3/85) before the epidemic to 23% (20/86) during the epidemic ($P = 0.013$). Underutilization of health services and increased self-medication did not show a demonstrable effect on non-Ebola-related mortality. Nevertheless, the residual effects of outbreaks need to be taken into account for the future. Recovery efforts should focus on rebuilding both the formalized health system and the population's trust in it.

INTRODUCTION

Since being declared on March 21, 2014, the west African Ebola virus disease (Ebola) epidemic has caused over 28,602 cases and 11,301 deaths in the most affected countries, Guinea, Liberia, and Sierra Leone,¹ with a case fatality rate of approximately 40%.² The outbreak was officially declared in Sierra Leone on May 25, 2014, and peaked at the end of 2014.³ By November 2015, the end of the outbreak in Sierra Leone, the World Health Organization had reported a total of 8,704 confirmed cases and 3,589 confirmed deaths.² Health structures were overwhelmed by Ebola patients at different points during the outbreak and over 300 health-care workers were infected.⁴ Compounded with fewer staff available to see patients, individuals in the community feared becoming infected with Ebola in health-care facilities.⁵ As a consequence of these and other factors, it was suspected that access to health care for other illnesses such as malaria had been compromised.^{6,7}

We conducted a retrospective household survey to estimate both the all-cause and the cause-specific (Ebola related) mortality rates in Western Area from May 25, 2014, to February 16, 2015. In addition, we describe the principal self-reported causes and places of death, in addition to health-seeking behavior before death or during a recent illness before and during the Ebola outbreak.

METHODS

Survey design, setting, and period. We conducted a retrospective household survey using two-stage cluster sampling

in Sierra Leone in February 2015. The recall period was from May 25, 2014 (the day before the first Ebola case was confirmed in Sierra Leone), to February 16, 2015 (the date the survey began). Locally salient events occurring at the beginning, middle, and end of the recall period were used to aid respondents with recall.

Sampling procedures. Western Area is comprised of 86 sectors spread among urban and rural areas. The primary sampling unit was the sector; a list of sectors served as the sampling frame. We selected sectors with probability proportional to their population size. Sector-specific population estimates were obtained from Statistics Sierra Leone. Second-stage sampling was carried out within each selected sector to sample 30 households. One global positioning system (GPS) point was randomly selected; surveyors located the point using a handheld GPS, and the household closest to the GPS point was the first to be surveyed. Subsequent households, the 25th household to the right of the last household surveyed, were systematically selected. Each day, survey teams received a map of their assigned sectors with clearly defined boundaries to ensure they remained in the area to be surveyed. All residents of the survey area were eligible to participate if they were 18 years of age or older. Information was collected at the household level from the head of household or from another adult member of the household. If all members of a household were deceased, the household composition at the beginning of the survey period was reconstructed with help from neighbors and/or family members who also responded to the questionnaire.

Sample size. The sample size for the all-cause mortality rate (acMR) was calculated based on an estimated acMR of 0.52 deaths/10,000 individuals/day with a recall period of 267 days, precision of 15%, and a design effect of 1.5 and 10% for refusals and nonresponse. This yielded a sample of 4,943 individuals, 898 households (assuming a mean household size of 5.5) to be sampled in 30 clusters.

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Data collection and variables. Over 3 days, surveyors were trained on the survey protocol, survey procedures, and protective measures to take while in the field during an active Ebola outbreak to ensure safety for themselves and survey respondents. The data collection materials including the use of handheld GPS devices and informed consent were piloted during a pilot survey on the final day. For 6 days, five teams of two people conducted face-to-face interviews in the community using a structured questionnaire. Survey teams were supervised by an epidemiologist who ensured respect of the survey procedures, including informed consent. All survey teams were provided with personal protection equipment while in the field (gum boots and chlorine spray bottles).

A household was defined as all family members sleeping under the same roof and sharing the same meal in the 3 days before the survey. A death due to Ebola was considered to be any death reported by the family of the deceased as due to Ebola.

The questionnaire covered 1) household composition at the beginning and at the end of the recall period (births and new arrivals, departures and deaths with dates), 2) cause and place of death including history of contact with an Ebola case, if applicable, and 3) health-seeking behavior and access to health care (if there was a sick household member during the last 30 days before the interview and, if so, self-reported disease and health-seeking behavior of this person (Did the person seek health care? If yes, where? Was the person able to receive the desired care at this location? If yes, what care did they receive? If not, why not? If no, did they go elsewhere?), and health-seeking behavior of household members before the Ebola epidemic (Where do you normally go for help first if somebody is sick in the family?). If there had been more than one person sick in the household in the past 30 days, the survey team randomly selected one of the sick individuals for inclusion. Surveyors were instructed to record any refusals to participate in the survey on the household tally sheet.

Data management and analysis. Data were entered into an EpiData (The EpiData Association, Odense, Denmark) mask. The database was cleaned and questionnaires reviewed for missing and/or conflicting answers. Data analysis was conducted in Stata 12 (Stata Corp, College Station, TX) using “svy” commands to account for complex survey design.

All-cause and Ebola-specific mortality rates were calculated as the number of deaths per 10,000 inhabitants per day and presented with 95% confidence intervals. The numerator included all deaths recorded during the recall period; the denominator was the average population during the recall period.

Proportions of the population which reported any mortality were compared with the proportions reporting Ebola deaths. χ^2 and Fisher's exact tests were used to compare differences in reported health-seeking behavior, whereas means were compared using Student's *t* test. Differences were considered statistically significant at $P < 0.05$.

Ethical considerations. All permanent residents of the survey area were eligible to participate if they were 18 years of age or older. The surveyors read and explained the consent form to the respondents who provided oral consent. Consent for each household was documented on a tally sheet. Written consent was not obtained from survey participants due to restrictive infection prevention procedures that were put in

place to ensure the safety of surveyors and survey participants. Participation was voluntary and could be withdrawn at any time; surveyors were instructed to record all refusals on the tally sheet. Data were anonymous and only aggregated data were reported. All survey documents were stored in a locked cabinet or electronically in a password-protected computer with access available only to the survey team. Authorization to conduct the survey was obtained from the Sierra Leone Ministry of Health and Sanitation who reviewed the survey protocol including the use of oral consent.

This survey was conducted by Epicentre, Paris, France, and Médecins Sans Frontières (MSF), Geneva, Switzerland, and the Ministry of Health and Sanitation of Sierra Leone.

RESULTS

Response and household size. In total, 898 households were surveyed and no refusals to participate were reported. The mean household size and total number of household members were 6.70 (± 3.88) and 5,976 persons at the beginning of the epidemic (May 25, 2014), and 6.66 (± 3.79) and 6,019 persons at the moment of the survey, respectively.

Mortality. During the recall period, 96 deaths were reported in 68 households. Demographic information and date, place, and cause of death were available for 95 (Tables 1 and 2). Sixty-eight (7.6%) households reported one death, whereas 14 (1.6%) households reported more than one death (range 2–6).

The acMR was 0.52/10,000 inhabitants/day (95% confidence interval [CI] = 0.29–0.76). The most frequently reported causes of death were Ebola (41.1%, $N = 39$) and malaria (9.5%, $N = 9$). For 11.6% ($N = 11$) of cases, the cause of death was unknown to the respondent (Table 1).

The Ebola-specific mortality rate was 0.19/10,000/day (95% CI = 0.01–0.38), and the crude mortality rate (CMR) excluding Ebola cases was 0.33/10,000 inhabitants/day (95% CI = 0.24–0.42).

A total of 39 deaths (40.6%) were attributed to Ebola and occurred in 24 households (2.7%). Four Ebola-related deaths occurred outside a health facility (Table 2). Of the 39 Ebola deaths, 25 (64.1%) were reported to have had contact with an Ebola case before falling ill. Eight respondents stated that they were not aware of any contact with an Ebola case, whereas this information was not available for six

TABLE 1
Causes of death as reported by a family member from May 25, 2014, to February 16, 2015

Reported cause of death	<i>n</i>	%
Ebola (suspected, probable, or confirmed)	39*	41.1
Unknown	11	11.6
Fever and shivering (malaria)	9	9.5
Injury/accident	6	6.3
Cough, difficult breathing	4	4.2
Newborn death	4	4.2
Still birth	1	1.1
Watery stool/diarrhea	2	2.1
Death of a mother during pregnancy or childbirth	2	2.1
Hunger (malnutrition)	1	1.1
Rash and fever (measles)	1	1.1
Other	15	17.9
Total	95	100

Retrospective household survey, Western Area, Sierra Leone, February 2015.

*Two reported Ebola deaths were neonates, and are not double counted under “newborn death.” Three Ebola deaths were children < 5 years of age and beyond neonatal age.

TABLE 2
Place of death and characteristics of cases as reported by a family member

	All deaths (N = 95)		Ebola-related deaths (N = 39)		Deaths from other causes (N = 56)		P value†
	n	%	n	%	n	%	
Sex male	53	55.8	19	48.7	34	59.7	0.34
Places of death							
Hospital	37	39.0	14	35.9	23	41.1	< 0.0001‡
Home	36	37.9	4	10.3	32	57.1	
Health facility	2	2.1	2	5.1	0	—	
Another location	1	1.1	0	—	1	1.8	
Ebola treatment/holding center	19	20.0	19	48.7	0	—	0.004
Age (mean ± SD*)	34.1 (±23.8)		25.6 (±15.2)		39.9 (±26.8)		

Retrospective household survey, Western Area, Sierra Leone, February 2015.

*SD = standard deviation.

†P values in this table compare Ebola-related deaths and deaths from other causes.

‡This P value refers to place of death “home” compared with all other places.

individuals. Individuals who died of Ebola were significantly younger than those who died of other causes ($P = 0.004$).

Overall, nine children < 5 years of age died during the survey period, including six neonatal deaths. One stillbirth was reported. Five children < 5 years of age were reported to have died of Ebola; of those, two were neonates. Three of the Ebola-related deaths in children < 5 years of age were reported from the same household (two neonates and a 1-year-old child). All Ebola deaths reported in children < 5 years of age had a known contact with an Ebola case before death.

Non-Ebola related deaths were more likely to have died at home than Ebola-related deaths ($P < 0.0001$) (Table 2).

Morbidity and health-seeking behavior. One hundred and twenty-three (13.7%) respondents reported having had at least one sick person in their household in the 30 days before the survey. For 105 (85.4%) of these cases, the respondents were able to provide additional information on the illness as seen in Table 3. The most frequently reported illnesses were malaria (40.5%), headache (10.8%), common cold (10.8%), and chronic illnesses (7.2%).

Eighty-eight (71.5%) respondents reported that a sick family member had sought medical care “somewhere” during a reported illness, the location was available for 86.

TABLE 3
Reported illnesses during the 30 days before the survey

Reported illness	n*	%
Fever and shivering (malaria)	45	40.5
Cold	12	10.8
Headache	12	10.8
Chronic illness (diabetes, hypertension, etc)	8	7.2
Body pain without fever	7	6.3
Injuries	6	5.4
Abdominal pain	4	3.6
Typhoid fever	3	2.7
Bloody stool/dysentery	2	1.8
Ebola	2	1.8
Ulcer	2	1.8
Dental problem	2	1.8
Diarrhea	1	0.9
Liver problem	1	0.9
Measles	1	0.9
Chicken pox	1	0.9
Tuberculosis	1	0.9
Dizziness	1	0.9
Total	105	100

Retrospective household survey, Western Area, Sierra Leone, February 2015.

*More than one response was possible.

Seeking care at a health facility was reported as the first health-seeking behavior for 50 (58.1%) individuals who experienced an illness during the Ebola epidemic compared with 73 (85.9%) before the Ebola epidemic. Reported self-medication increased from 3.5% (3/85) before the epidemic to 23.3% (20/86) during the epidemic ($P = 0.013$) (Table 4).

DISCUSSION

An increase in all-cause mortality was anticipated in countries heavily affected by the Ebola epidemic as a consequence of its disruption of the health-care system.⁶ However, this survey estimates the acMR during the Ebola epidemic in Western Area, the location of the capital Freetown, to be well under 1.04/10,000/day, two times the acMR before the Ebola outbreak, a threshold for comparison as proposed by Toole and Waldman⁸ despite changes in health-seeking behavior. The recall period for this survey began the day the Ebola outbreak was declared in Sierra Leone (May 25, 2014), and the epidemic was ongoing when the survey was conducted (February 2015), yet the acMR did not document mortality in excess of what would have been expected before the outbreak. Instead, this survey's acMR estimate, 0.52/10,000 inhabitants/day (95% CI = 0.29–0.76), is similar to the country-wide acMR for Sierra Leone before the Ebola outbreak (0.56 deaths/10,000 women and 0.5 deaths/10,000 men).⁹

After excluding deaths reported as due to Ebola, the CMR in our survey was 0.33/10,000/day. We suggest three partially contrasting explanations for this lower than anticipated mortality rate: 1) Deaths, particularly for children under 5 years of age, may have been underreported by survey respondents, and therefore, underrepresented in our estimate. Nevertheless, respondents reported 11 deaths in children under 5 years of age and two maternal deaths. Deaths in these vulnerable groups may have been related to a lack of access to antenatal care and safe deliveries, hesitancy to seek care in health facilities, or even unknown Ebola infection. 2) The CMR estimate excluding Ebola mortality, may more accurately represent Western Area-specific mortality than the Sierra Leone wide figure, which was the only mortality figure available for comparison. Urban populations in sub-Saharan African countries, similar to that in Western Area, generally have better access to health services, and by consequence, lower baseline mortality than rural populations.¹⁰ 3) Improved hygiene practices in the population, such as frequent hand washing, could have led to

TABLE 4

Reported health-seeking behavior before and during the Ebola epidemic, for households with a sick family member who sought care for their illness

Reported places for health seeking	Before the Ebola epidemic (<i>N</i> = 85*)		30 days before survey (<i>N</i> = 86)		<i>P</i> value
	<i>n</i>	%	<i>n</i>	%	
Health facility	73	85.9	50	58.1	0.013
Traditional medicine	1	1.2	2	2.3	
Private pharmacy	5	5.9	12	14.0	
In the market/self-medication	3	3.5	20	23.3	
Private or family doctor/private hospital	3	3.5	1	1.2	
Other not specified	0	—	1	1.2	

Retrospective household survey, Western Area, Sierra Leone, February 2015.

*Information missing for one respondent.

a lower incidence of gastrointestinal morbidities and thus lower mortality from such causes. Hand washing was hypothesized to have impacted the lower than expected gastrointestinal disease burden in a military population deployed in west Africa during the Ebola outbreak.¹¹ It is conceivable that this may also have played a role in the general population though to a lesser extent as access to water and hand washing discipline might not have been as good as for the military personnel. Unfortunately, we are unable to quantify the extent to which each of these factors may have influenced our estimate.

Ebola was the most frequently reported cause of death in this survey, and was more frequently reported than malaria, the leading cause of morbidity and mortality in Sierra Leone for children under 5 years of age and pregnant women.⁹ Unfortunately, the figures provided by this survey are too small to provide cause-specific prevalence estimates for comparison with national statistics. Nevertheless, the most frequently reported causes of death reported here correspond with the most frequently reported causes of death in Sierra Leone.¹²

The majority of individuals reported as having died of Ebola were reported to have died in a facility for Ebola-infected individuals. Reports of location of death presume that deaths reported by the family as both due to Ebola and/or occurring in an Ebola center were actually due to Ebola. However, Ebola symptoms, especially in the early state of the illness, are unspecific and may have easily been confounded with malaria or other diseases presenting with fever. Some deaths occurring in Ebola holding or treatment centers may not have been due to Ebola unbeknown to the family of the deceased. In addition, families of patients sent to Ebola centers were not systematically informed of their family member's Ebola test result. We also received anecdotal reports of individuals being admitted to Ebola centers, being discharged negative, and never returning to their place of residence. Thus, these families may believe their family member died of Ebola because they never returned home. Consequently, the number of deaths due to Ebola may be overestimated. However, we did not collect identifying information for the deceased, and did not have access to patient and laboratory databases; thus, we were unable to quantify this phenomenon retrospectively.

Nevertheless, the results from this survey are similar to those from another retrospective mortality survey in Monrovia, Liberia (A. Kuehne, E. Lynch, E. Marshall, and others, unpublished data), where, similar to the results presented here, Ebola accounted for an important proportion of mortality, and yet there was no demonstrable increase in all-cause mortality during the Ebola outbreak.

More than one-third of all deaths reported during the survey occurred at home. Although this may seem high, data on common places of death before the Ebola epidemic in Sierra Leone were not available for comparison. Four Ebola-related deaths occurred at home. Despite being a relatively small number, they are important to note as those cases may have provided an opportunity for Ebola transmission to continue. In addition, three of the four died at home five or more months into the epidemic (data not shown); a time at which messages on Ebola care facilities and the risk of transmission should have been well known. This highlights the importance of continuous health education and community awareness programs to convince communities to make use of Ebola centers and safe burial teams.

This survey indicates that health-seeking behavior in Western Area changed during the epidemic. Survey respondents reported a decrease in utilization of health facilities during the Ebola epidemic, a phenomenon that was also documented in Monrovia, Liberia,¹¹ and in Guinea.⁶ Although health facilities were never officially closed in Sierra Leone, their functioning was greatly affected by the loss of health workers due to Ebola infection.⁴ This was not unique to Western Area; similar observations were reported by Bolkan and others who reported decreased functioning of health facilities in addition to declines in inpatient admissions and major surgery across Sierra Leone.⁵

Herein, we document an increase in reported self-medication for illness occurring during the Ebola epidemic. It is likely that the population hesitated to seek care at health facilities due to fear of infection, lack of available staff, and/or the reluctance of facility staff to see patients who could not prove their Ebola serostatus with a negative laboratory test. Unfortunately, although important for our understanding of the secondary impacts of the Ebola epidemic, it is difficult to quantify the extent to which these different factors influenced the change in health-seeking behavior. Nevertheless, despite changes in health-seeking behavior, our results do not provide evidence of an increase in all-cause mortality in the short term.

Our survey is subject to limitations. All information was self-reported or reported by the family of the deceased, generally nonmedical people, and consequently, cause of illness and death in some cases may be imprecise or misclassified. We compared reported health-seeking behavior for any illness in the 30 days before the survey and before the Ebola outbreak. Health-seeking behavior for more severe illness may have been recalled more easily than that for less severe illness before the outbreak. Due to limitations of recall, particularly for nonsevere illness, we may have overestimated

the change in health-seeking behavior. To mitigate any impact of recall difficulties, we used locally salient events to aid the memory of survey respondents.

This survey provides evidence that health-seeking behavior in the population of Western Area, Sierra Leone, changed during the Ebola epidemic. At the same time, in the short term, reduced utilization of health services and increased self-medication did not impact all-cause mortality. Nevertheless, these findings highlight the importance of considering the potential impacts of outbreaks on health-seeking behavior now as the Ebola-affected countries begin to recover and for the future. Concerted recovery efforts need to focus on rebuilding both the formalized health system and the population's trust in it.

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