UGANDA

Strengthening Community Linkages to Ebola Virus Disease (EVD) Outbreak Preparedness: Anthropological research on the socio-cultural context of EVD in the most-at-risk districts in Uganda

What can community perspectives bring to Ebola virus disease preparedness in Uganda?

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EDITORIAL INSIGHT

Reviewers commended this "excellent" piece of research for the deep insights into how unequal social structures and underlying structural violence shape community responses, and how epidemics can exacerbate pre-existing inequalities. The study's participatory approach, appreciation of cultural diversity and human rights, and engagement with local communities and agencies, were also highly praised by reviewers.

Additional strengths noted comprise its transparent and ethical methodology and its well-substantiated conceptualization of the research purpose. The potential for impact is strong since the findings are highly relevant to the development of policy responses in the ongoing COVID-19 pandemic.

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Drama group at Nyakabira village, in the Kabarole district of the Democratic Republic of the Congo, delivers messages on positive behaviour change and how to avoid Ebola Virus, as part of the activities for Interventions for Ebola Virus Disease.

In June 2019, an Ebola epidemic was declared in Kasese District, southwestern Uganda. This was traced, in part, to the porous border between Uganda and the Democratic Republic of the Congo, where an epidemic had been ongoing since August 2018. The epidemic was exacerbated by political instability in affected areas, leading to an influx of refugees to Uganda.

The Ugandan outbreak developed in a region characterized by frequent cross-border movements, low community engagement with prevention measures, and social and cultural practices that limited the uptake of robust Ebola virus disease preparedness practices.

In this context, UNICEF Uganda and Makerere University carried out anthropological research to better understand Ebola preparedness response uptake, particularly in relation to cultural norms governing health-seeking, caregiving and preventive behaviours. The research aimed to further understand how these behaviours are influenced by livelihoods, religious and spiritual beliefs, funeral and burial practices, caregiving practices, and trust in the health system – as each factor plays out across specific social, political and economic contexts.

PURPOSE

At the onset of the outbreak, the Ugandan National Task Force on Disease Outbreaks and Response called for a strategy for border health, cross-border cooperation and scaled-up risk communication, grounded in an understanding of the sociocultural context prevailing in high-risk border areas.

FIGURE 1
Ebola outbreaks in Uganda
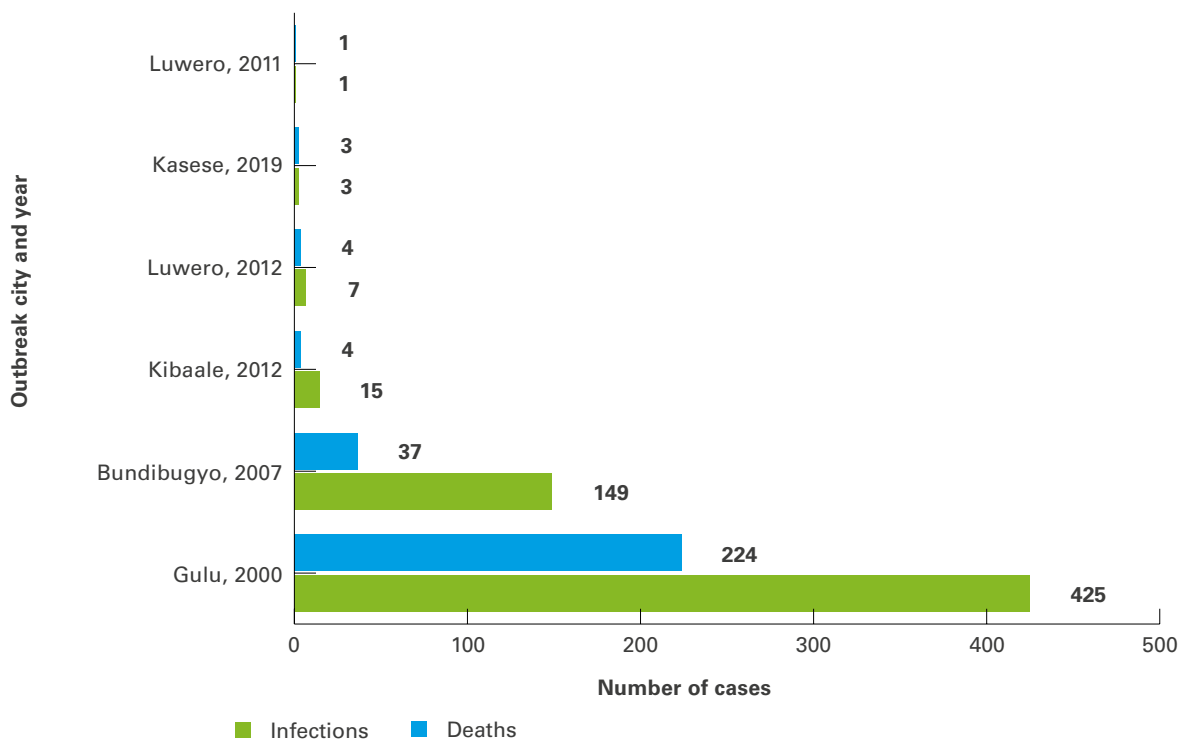
Source: Adapted from Uganda, Ministry of Health, *National Ebola Virus Disease Contingency Plan*, 2018; and World Health Organization, 'Disease Outbreak News: Ebola virus disease – Republic of Uganda', 2019.

This research aimed to investigate community dynamics and cultural factors that may affect health-seeking and preventive behaviours by identifying possible areas of cultural resistance to information, and by assessing the appropriateness and acceptability of Ebola prevention and control activities.

In describing the sociocultural context of behaviours that may affect Ebola preparedness, the study sought to inform culturally sensitive Ebola preparedness planning, including public health messaging and social mobilization around protective health behaviours, particularly in high-risk border areas.
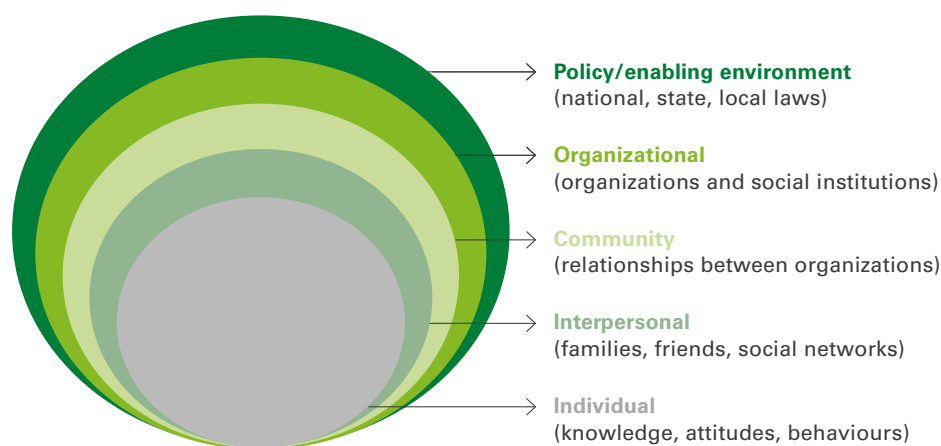
APPROACH

The research used an anthropological approach and drew on an adaptation of the socioecological model of communication and behaviour that proved previously effective in Ebola containment in West Africa. This model has been used to understand the multifaceted and interactive effects of personal and environmental factors that affect behaviours. In the context of Ebola preparedness, the model has helped to identify social and cultural leverage points thought to influence positive health-seeking behaviours and effective risk communication.

FIGURE 2
Socioecological model of communication and behaviour

Policy/enabling environment
(national, state, local laws)

Organizational
(organizations and social institutions)

Community
(relationships between organizations)

Interpersonal
(families, friends, social networks)

Individual
(knowledge, attitudes, behaviours)

Source: Centers for Disease Control and Prevention 2014.

Inclusive and locally grounded
Study sites were established across Uganda by engaging local councils in districts at high to moderate risk for the spread of Ebola. An inclusive approach to qualitative data collection was taken to incorporate local voices. Interviewees included a variety of community stakeholders: religious leaders, traditional leaders and healers, community influencers, front line health workers, local political leaders, civil society organizers, and members of District and National Task Forces.

Community members were recruited for focus group discussions from five cultural groups to account for differences in the sociocultural contexts of Ebola in Uganda. Female moderators conducted focus groups composed of women. Twenty local research assistants with comprehensive knowledge of the languages and cultural practices of each study site were recruited.

> **This research provides a missing part of the Ebola story, by situating narratives of local Ugandans in epidemic preparedness and control.**
> – Research report

Participant observation – whereby the researchers actively participated in Ebola preparedness activities and local events such as market days – supplemented the qualitative data collection around sociocultural contexts.

Ethically sound
An ethics committee from Makerere University approved the research design, and the Uganda National Council for Science and Technology registered the study protocol. Written informed consent was obtained from all participants, who were given the option to access counselling in case of distress. Individual interviews and focus group discussions were conducted in venues that minimized privacy concerns.

KEY FINDINGS

Research findings revealed that Ebola was known and feared across Uganda. Nevertheless, many interviewees, even in border districts, considered the risks remote and unclear. Preparedness was mediated by a range of contingent factors, some of which were perceived as higher priority than Ebola. Seven major drivers were identified.

Livelihoods and health
Although community members were afraid of Ebola, they could not easily change their behaviours because of economic constraints. For example, people living in border districts reported moving regularly between Uganda and the Democratic Republic of the Congo to tend crops, fetch water and trade at markets, while truck drivers and motorcycle taxi riders based in Uganda continued to cross the border to earn a living. Often, such activities meant traversing the border several times a day, using informal crossing points less well equipped to prevent Ebola spread.

Traditional healers and religious leaders
In rural areas, traditional healers were respected and trusted sources of health information in their communities. The healers interviewed for the study described advising their communities on Ebola prevention, including on the use of screening and handwashing facilities and the need to report cases immediately. Religious leaders such as imams, sheikhs and pastors also had a good level of knowledge about Ebola, how to prevent it and what to do with suspected cases. Churches and mosques were considered excellent channels for disseminating Ebola information.

Funeral rituals and burial practices
While burial practices were found to be of great importance in all research districts, they were also associated with substantial risks of contamination. Across cultural groups, bodies were kept at home and cleansed before burial, a task with substantial potential for contact with virus-contaminated bodily fluids. Some cultures required the body to be returned to the father's ancestral land, potentially across borders. In general, communities went to great lengths to ensure that the soul of every deceased person would rest in peace.

The research evidenced a strong cultural resistance towards changing deep-rooted traditional practices. Government health messages that did not take into account local traditions were perceived as unhelpful and disrespectful, and resulted in low uptake. Results suggest that communication around disease prevention is more effective when it offers solutions – such as ways to safely conduct burials – and that a culturally sensitive disease response needs to be informed by both medical and anthropological evidence.

In our cultures, some people believe that when they get sick, they have been bewitched. Instead of going to health centres, they go to traditional shrines.

– Local leader participating in focus group discussion in Luwero

Students from Mushangi Primary School in Rubirizi District, Uganda, perform a song as part of the preparedness activities of the Ebola response interventions in schools, communities and health facilities.

Caregiving practices

Community and gender norms shaped caregiving practices during the Ebola outbreak, with the burden of care mainly falling on women. Unsurprisingly, 70 per cent of Ebola-affected individuals in the 2014–2015 West African epidemic were women. In cases of severe illness, community-based Village Health Teams were consulted to guide families in decision-making around care.

Health beliefs and health-seeking behaviour

Government health facilities usually had a poor reputation among participants, primarily because of health workers' perceived negative attitudes towards patients and mistrust in hospital treatments. In particular, pregnant women were reportedly sceptical about some preventive measures such as handwashing in chlorinated water, which they supposed to be potentially harmful to their pregnancy.

A predominant response of community members was that government health facilities were too far away and too expensive to access. Rural areas of border districts were particularly disadvantaged and underserved. Hence, participants reported a preference to seek care from more accessible local private health facilities or lower-cost traditional healers.

In this pre-crisis phase in Uganda, we see an opportunity to prepare and produce risk communication and social mobilization activities that are locally relevant.

- Key informant quoted in research report

Trust between communities and authorities

The sociocultural context of trust between communities and authorities, such as local leaders and health workers, has implications for Ebola preparedness. Trust in local leaders was generally said to be good, especially regarding information on Ebola prevention and control. Red Cross and UNICEF staff were seen as impartial mediators and an important source of support.

However, formal government health facilities were often perceived by communities as untrustworthy. Hearing that many patients suspected of having Ebola had died shortly after reaching hospital raised alarm and fostered mistrust in the health care system. Marginalized communities such as fishing communities reported widespread mistrust of authorities, including security officers, customs officers and the army.

Social, political and economic context

The broader context shapes how a community copes with disadvantage and vulnerability, with implications for Ebola. The study identified communities – from rural poor to fishing communities – that were particularly vulnerable owing to experiences of structural violence. Issues such as lack of water and sanitation, ongoing violence and health threats, food insecurity, and poverty contribute to both community vulnerability to epidemics and low uptake of preparedness practices. Unequal social structures shape community responses to Ebola and demonstrate how epidemics tend to exacerbate pre-existing inequalities.

BOX 1
KEY RECOMMENDATIONS TO IMPROVE EBOLA PREPAREDNESS

- Deploy participatory social mobilization practices (e.g., involving local leaders) as a sustainable means of supporting improved uptake of messages to counter the spread of Ebola.
- Emphasize that Ebola can be spread by anyone and address the stigmatization of migrants from the Democratic Republic of the Congo.
- Pay special attention to local dynamics (including to avoid conflict between fishing communities and authorities) so that preparedness efforts are not derailed.
- Design posters that are accessible to illiterate individuals and which use local languages and child-friendly messaging.
- Address the concerns of pregnant women, particularly around the use of chlorine for handwashing.
- Design youth-friendly mobilization practices, with the involvement of local youth.
- Chlorine for handwashing in hospitals.

INFLUENCE ON POLICY AND PROGRAMMING

The research study provides specific recommendations that can inform UNICEF Communication for Development (C4D) efforts to scale up risk communication and social mobilization – including to train teams to educate communities about safe, respectful burials. It also grants insights into potential areas of cultural resistance to health information around Ebola; how to leverage cultural assets in support of Ebola risk communication; and the cultural appropriateness and acceptability of Ebola prevention and control activities.

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Students from Kamabale Primary school, in the Kabarole district of the Democratic Republic of the Congo, participate in activities related to the Interventions for Ebola Virus Disease campaign.

The findings have already led to adjustments in the Ugandan risk communication strategy around improved and targeted messaging (e.g., translation into local languages) and use of trusted sources of information (e.g., village health workers, local leaders). Cognizant of the need for sensitivity to local conditions and to use existing structures to deliver messages, health workers have engaged with caregivers (typically women) and traditional healers to provide training and enhanced collaboration with local leaders.

LOOKING AHEAD

Results will be disseminated at briefings with appropriate implementing partners in Uganda, to facilitate the integration of social and cultural information into risk communication and social mobilization programming. Results will also be shared in relevant health and social research forums, to streamline research on Ebola virus disease on the Uganda–Democratic Republic of the Congo border. Efforts should be made to connect with social science researchers in the Democratic Republic of the Congo to share knowledge and findings across the border.

The study's approach and findings are potentially applicable to other epidemic situations, including the COVID-19 pandemic. Its conceptual model provides a framework for a multilayered policy response that balances both human rights and cultural sensitivities with the urgent need to control disease outbreaks.

Ebola is, similarly to HIV, an 'epidemic of opportunity' that is visible in communities most affected by structural violence.
– Research report

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