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Social Science Support for COVID-19: Lessons Learned Brief 4

Social sciences evidence on barriers to healthcare seeking during the DRC Ebola outbreak

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Context

Since August 2018, an Ebola epidemic has continued to spread throughout the east of the Democratic Republic of the Congo (DRC), resulting in 3404 cases and over 2240 deaths, including many women and children. Despite cases continuing into 2020 (including new cases in April, two days before the anticipated declaration of the end of the outbreak) a new world-wide pandemic began. COVID-19, a novel coronavirus, originated in Wuhan, China, and has since spread to 213 countries, areas or territories and infected over 2.7 million people[1], including healthcare workers (HCWs).

In February 2020, the first case was announced in Africa, and as of April 2020, cases have been confirmed across 52 countries.

While prediction models for the spread of COVID-19 across the continent vary, the forecasting of the secondary impacts of the outbreak on health, poverty and stability of already fragile settings are consistent. COVID-19 adds to the burden of endemic infectious diseases and conflict facing many countries in the region, with impacts compounded by conditions of limited water, sanitation and hygiene (WASH) coverage, and population overcrowding. Communities and humanitarian actors working to support the COVID-19 response within these contexts are presented with the challenge of preventing the overwhelming of health systems and diversion of resources critical to addressing existing needs.

The Social Sciences Analysis Cell (CASS)

The Social Sciences Analysis Cell (CASS), established during the DRC Ebola outbreak (2018-present), is a unit set up by UNICEF, together with national and international, operational and academic partners to operate under the Ministry of Health (MoH) response lead. The Cell conducts mixed methods, operational social sciences analyses to support the response actors, strategies and interventions. The purpose of this Cell is to provide integrated analysis to facilitate understanding and monitoring of epidemiological, behavioural and perception trends as the outbreak and its responses evolve, and together with partners, apply results of analyses to motivate real operational change and improved community health outcomes. As part of the Ebola outbreak response, the CASS **conducted 57 field studies, and together with the MoH and response actors, developed 112 recommendations.**[2] Following from the success of this model, the CASS aims to replicate this role across several countries in Sub-Saharan Africa, adapting to new contexts presented by outbreaks such as the current COVID-19 pandemic.

Lessons learned briefs

The CASS has drafted a set of briefing documents outlining key lessons learned from social sciences analyses during the DRC Ebola outbreak response, aiming to connect findings from the research conducted by the CASS with recommendations for supporting and improving the approach to tackling COVID-19 and its secondary impacts in Sub-Saharan Africa.

The CASS Briefs do not imply comparatives between the diseases. While the Ebola virus has a higher mortality rate than COVID-19, it is far less transmissible being a disease where a reasonable level of physical contact with a symptomatic person is required in order to contract the virus. Conversely, COVID-19 is spread via droplets, up to two metres from one person to another, often before the onset of symptoms. This presents challenges for containment and prevention activities and elevates the risk of exposure to outbreak responders.

Despite these differences, the social and behavioural sciences studies, recommendations, and resulting documented lessons learned can **provide key guidance and important considerations for COVID-19 response and research teams operating in similar contexts across the continent.**

The briefs address the following topics:

Brief 1: Social Sciences Research questions we should be asking in humanitarian contexts under COVID-19

Brief 2: Gender inclusiveness in COVID-19 humanitarian response operations

Brief 3: Humanitarian programme recommendations for COVID-19 based on social sciences evidence from the DRC Ebola outbreak response

Brief 4: Social sciences evidence on barriers to healthcare seeking during the DRC Ebola outbreak

CASS research tools, raw data, presentations, analysis and monitoring of research recommendations to action (MONITO) are available online: Ebola drive and COVID drive.

1 Updated case number statistics are provided daily by the World Health Organisation

2 For a complete list of all CASS Studies conducted during the Ebola outbreak response, please consult the study tracker (LINK)

Brief 4: Social sciences evidence on barriers to healthcare seeking during the DRC Ebola outbreak

This brief was developed for actors working "on the ground" in humanitarian response programmes. It **focuses on the importance, reasons and recommendations for minimising barriers to healthcare seeking in outbreak settings based on social sciences evidence from CASS studies undertaken during the Ebola outbreak response in the DRC.**

The recommendations outlined are based on social sciences evidence from Ebola and do not cover all recommendations in mitigating barriers to health seeking behaviours related to COVID-19 that will undoubtedly emerge as more is understood about care and Infection Prevention Control (IPC) best-practice. For example, it is important to note that the recommendations for home care for Ebola and COVID-19 do vary (by outbreak and by location of outbreak). While home care has not been recommended for Ebola, in COVID-19, unless severely sick, home care is suggested. The recommendations outlined below may be applied to multiple, if not all barriers, but for the purpose of this report only one recommendation is proposed alongside each barrier.

Key barriers identified during the DRC Ebola outbreak and implications for the COVID-19 response

Barrier 1: Fear of being sent to an Ebola treatment centre (ETC)

Evidence from the DRC Ebola outbreak response

Early Ebola messaging focused on the severity of Ebola; messaging concentrated on ensuring people understood "Ebola is Real" and "Ebola kills"[3]. Such information, however, caused increased fear that anyone sent to an Ebola Treatment Centre (ETC), whether a confirmed case or not, would die. Evidence from the DRC Ebola outbreak suggests that many people may have delayed or avoided seeking care for fear of being sent to an ETC[4]. In a CASS study looking at community perceptions of the ETC, a lack of understanding of symptoms of Ebola led to the belief that regardless of infection status, all symptoms would be diagnosed as Ebola, and all sick individuals would be transferred to an ETC, even those with only a slight fever. Women were particularly vulnerable to this kind of misunderstanding due to unclear communication; in a TWB study, many described not seeking professional care for fear of misunderstandings that could result in misdiagnosis. An IRC study on access to sexual and reproductive health (SRH) services during Ebola documented cases where pregnant women experiencing complications such as spontaneous abortion or bleeding would delay seeking care for fear of being sent to an ETC.

A CASS study on health seeking behaviours found *fear* to be the most prominent barrier. In areas reporting longer delays in treatment seeking (7-9 days after the onset of symptoms), fear and rumours around the ETC were found to be the main barriers and cause for delay. This study, in addition to a study on perceptions of the ETC identified many rumours at community level about ETCs, which seemed to increase the level of fear associated. In these studies, fear was related to the perception of the ETC as a "mouroir"[5], a lack of information about treatment methods and fear of poor quality of care inside the ETC. The CASS study on health seeking behaviours also showed that important motivators to health seeking were the diffusion of positive messages about the ETC (including the number of Ebola survivors), and community sensitisation about the importance of early treatment seeking. A further quantitative population survey[6] conducted by the CASS found that between 23-37% of participants delayed seeking treatment for fear of being sent to an ETC.

Recommendations for COVID-19 response

Work within existing healthcare systems

During the DRC Ebola outbreak, population surveys found that the primary reason for reticence around ETCs was because they were not associated or affiliated with the regular health facilities[7] familiar to communities. Early contextual analysis during COVID-19 response efforts should focus on monitoring population perception to understand whether fears around this novel disease exist to the same extent. When and where possible, COVID-19 response activities should take place in known and trusted health facilities recommended by communities, and thus contribute to mitigating fears impacting health seeking behaviour. It is key to ensure early engagement of both public and private health facilities (including traditional healers and pharmacies), facilitating and encouraging their involvement in local intervention design and implementation from onset.

3 In Kinshasa April 2020, megaphone alerts in front of supermarkets continue to alert "beware of Coronavirus, a lethal disease!"

4 Social sciences analyses of the West African Ebola outbreak found similar behaviour; communities would delay going to a healthcare centre for fear of being sent to an ETC, which was believed to result in death.

5 "Mouroir" is a recurrent expression used by participants in CASS studies, referring to a place those who are waiting to die will go, or a place where everyone dies

6 Population surveys are conducted using representative sample sizes 95% CI and 5% ME based on Health Zone population sizes

7 A health facility refers to any structure providing formal or informal healthcare, including state-run health centres, hospitals, private health centres, traditional healers and birth attendants, and pharmacies

Barrier 2: Mistrust of healthcare workers

Evidence from the DRC Ebola outbreak response

In November 2019, a perceptions and practice population survey found that between 47-51% of respondents no longer trusted HCWs to treat their children. In a CASS study on how to rebuild trust in the healthcare system, participants' mistrust of HCWs was often related to the perceived high salaries of HCWs working for the response. Qualitative data highlights community sentiment that HCWs, believed to receive payments for transferring patients to ETCs or for making alerts, were betraying their community. Several CASS quantitative population surveys found communities reporting that, since Ebola, everyone who visits a health centre for any health condition will be diagnosed with Ebola, and will be sent to the ETC, thus financially rewarding HCWs. This fuelled the perception that the Ebola outbreak response was a business, and that HCWs were only working for the money. The fact that HCWs did not always speak the local languages and often used technical terms in French compounded community concerns and mistrust. This was further demonstrated through a population survey in which 47% of respondents did not believe that the propagation of Ebola was real, and that the outbreak continued to be spread for individual financial gain.

Recommendations for COVID-19 response

Focus on healthcare systems strengthening

In low income humanitarian settings, COVID-19 risks overburdening already fragile healthcare systems. It will be critical to mitigate greater risks of nosocomial infections that could result from increased use of health services. Strengthening HCW capacity through provision of equipment and training will support not only the COVID-19 response, but also those for other diseases, and would hopefully limit the risk of diversion of health services from other areas of need. In addition, existing networks of Community Health Workers (CHWs) should be trained and mobilised in order to address aspects of the response relating to community-based IPC. This will support clinical activity and may help to reduce the strain on already stretched health systems.

Barrier 3: Fear of contracting Ebola at a healthcare facility

Evidence from the DRC Ebola outbreak response

Epidemiological analysis from December 2019 showed that an estimated 16% of Ebola infections throughout all affected health zones were a result of nosocomial transmission. A perceptions and practice population survey among HCWs found that between 12-72% of HCWs surveyed felt unable to identify a suspected Ebola case. Additionally, most HCWs perceived healthcare facilities as a place where Ebola could be transmitted. Fewer than 80% of health centres surveyed in affected zones reported having protocols in place to deal with a suspected Ebola case. A community population survey found that between 24%-49% of participants delayed seeking treatment out of fear of contracting Ebola at an ETC.

Recommendations for COVID-19 response

Improve infection prevention and control (IPC) standards at health facilities

Given the risk to patients, carers and HCWs of exposure to COVID-19, health facilities, both formal and informal, must be supported in order to prevent nosocomial transmission, whilst maintaining service delivery through appropriate training, provision of personal protective equipment (PPE), adequate water, sanitation and hygiene (WASH) infrastructure, and screening and testing of clients.

Barrier 4: Perceptions of reduced quality of care

Evidence from the DRC Ebola outbreak response

Qualitative CASS studies looking at perception and usage of healthcare services, and how to rebuild trust in the healthcare system suggested that a perceived reduction in quality of care at health facilities could influence health seeking behaviours. One study highlighted the perception that, since Ebola, healthcare services were no longer effective, HCWs were no longer welcoming, and service was slower. Findings also demonstrated community distrust and aversion to the physical distance between HCWs and patients, resulting from HCW use of PPE, and the physical distance they now kept from patients.

In qualitative studies looking at rebuilding trust in the healthcare system, perceived declines in quality of care were often associated with the fact that services offered by the Ebola response were free. A perceived reduction in care was also related to a lack of welcome by HCWs, and the use of PPE, which the patients perceived as distancing the HCWs from patients. Respondents also discussed a mistrust in HCWs as a result of Ebola. A minority felt that the quality of care had improved. This perception tended to be related to improved hygiene facilities at health structures (capacity for handwashing etc.).

Recommendations for COVID-19 response

Ensure access to essential healthcare services (beyond COVID-19) continues

Several reports have urged the critical need to continue essential health services, and yet despite this, vaccination campaigns in many countries are at risk as a result of redirecting public health resources towards the COVID-19 response. Not only is it important to ensure the continuation of existing healthcare services, it is critical to ensure that communities are aware of how and where they can safely access services, notably if there are confinement or quarantine measures in place.

COVID-19, while an important disease that requires due care and attention, is just one of many health and life concerns of individuals in Sub-Saharan Africa. Efforts to combat COVID-19 should be integrated and aligned with response efforts for other diseases that may be more common and impactful on the lives of people.

Impacts on behaviour

Delays in seeking healthcare

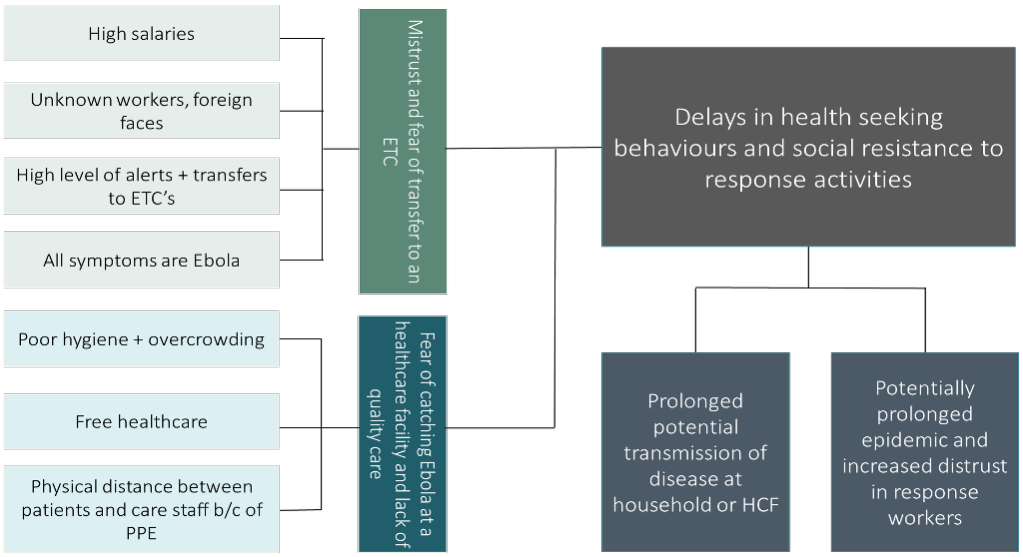
As outlined through each barrier highlighted above, community perceptions of poor quality of care, fear and mistrust may all cause critical delays in healthcare seeking, or in worst-case scenarios, prohibit those in need from seeking healthcare at all.

During the DRC Ebola outbreak response, medical experts highlighted that, if those delaying their care were ill with Ebola, these prolonged delays in healthcare seeking could lead to higher household or health facility transmission (if the health facililty does not transfer the patient to an ETC), resulting in potentially worse health outcomes for the patient.

Community reticence and resistance to response activities

During the Ebola outbreak in the DRC, at a community and social level, mistrust and fear of Ebola response and healthcare workers lead to reticence and resistance to response activities, as well as caused rumours to circulate in communities, and in some cases even resulted in violence. In 2019 alone, over 300 attacks on Ebola response workers were recorded, including targeted attacks on ETCs and attacks on other response structures. These attacks left 6 dead, and over 70 wounded. Additionally, studies have reported links between such events and transmission, and suggest that social resistance perpetuated the continued spread of Ebola in the DRC. 12% of study respondents felt that the outbreak was fabricated, and 72% were mistrustful of the response. Socially resistant behaviours included touching dead Ebola victims' bodies, hiding from health authorities, and refusing safe and dignified burials.

Figure 1 shows a conceptual framework developed by the CASS on the potential causes of healthcare barriers and the impact these have had on the response and the community.



COVID-19 programmatic recommendations based on DRC Ebola outbreak response analysis

Communication to promote positive, practical action

Central to addressing each of the barriers outlined above is the importance of emphasising clear communication to minimise fear and propagation of rumours[8]. During the DRC Ebola response, negative and fear-based messaging was found to increase community perception of fatality, and that Ebola infection was equal to a death sentence. Communication on the severity of COVID-19 should be clear, and messaging encouraging appropriate health seeking behaviour should be motivating, inspiring positive action. Comparisons between COVID-19 and other familiar conditions regarding symptoms, severity and processes for prevention and treatment should be clearly provided, in addition to practical and realistic actions that individuals, households and communities can take ownership of. Messaging around the response should evolve in tandem with evolving information needs highlighted through CASS social sciences research.

Risk Communication and Community Engagement (RCCE)

- Work with social scientists to understand local practices around health-seeking, who are the trusted sources of care, and how best to engage them in RCCE activities
- Promote positive messages in local languages and through trusted channels about the response and IPC guidelines, and the support that communities can provide
- Ensure communities understand the signs of severe disease that may require case management (health care seeking) versus the symptoms for which self-isolation is encouraged (this will vary by country)
- Ensure IPC measures are fully understood, including their justification in the response, given the disruption they may cause to daily life
- Target RCCE activities towards high-risk groups to support positive health seeking behaviour (including community surveillance and screening)
- Hire local community health workers with relevant language skills (ensuring appropriate training and materials are provided on IPC and individual protection and safety) to lead COVID-19 health promotion activities, and to encourage communities to continue to seek care for routine health needs
- Train and brief all HCWs (public and private), and equip them with relevant health promotion materials to facilitate RCCE activities in health structures
- Engage local women's and youth organisations and local leaders to ensure messaging and behavioural best-practice is promoted through trusted sources

Testing

- Depending on testing capacity in country, try to integrate testing in with other "routine" tests (malaria, dengue, cholera) to reduce the fear around COVID-19
- Ensure testing is conducted in ways similar to other testing (e.g. location, by local teams) to mitigate distrust in the process

Treatment (COVID-19 and otherwise)

- If setting up COVID-19 treatment centres, set them up adjacent to routine health facilities, or in areas proposed and supported by communities[9]
- Focus on building local capacity (instead of importing foreign health workers- when travel is feasible)
- Provide IPC supplies and PPE to healthcare facilities and community health workers to reduce risks of nosocomial transmission and to increase the trust in health services of those accessing care
- Do not forget routine health services: be creative in considering how to keep services open in hotspot areas (i.e. use school buildings to deliver care if the health facility is closed, consider how to do phone consultations for routine health needs)
- Train healthcare workers on supportive communication skills and promote a compassionate, human centric response

Conclusions

Barriers to care identified through CASS social sciences research during the DRC Ebola outbreak response likely contributed to considerable delays in healthcare seeking by both positive Ebola cases and people with different clinical and prophylactic needs.

As the response to the COVID-19 outbreak across Sub-Saharan Africa evolves, these barriers should be addressed in order to mitigate any negative primary and secondary impact and ensure that populations can continue to access and receive the care that they require.

8 See CASS Brief 3: Humanitarian programme recommendations for COVID-19 based on social sciences outbreak evidence

9 It will be critical to rapidly assess community perceptions and suggestions around the setup of new facilities or use of existing ones for COVID-19 treatment

The Social Sciences Analysis Cell- CASS: contact and brief development

If you have a direct request concerning the CASS, regarding a brief, tools, additional technical expertise or remote analysis, or should you like to be included in CASS research, network, partnerships or team, please contact the CASS by emailing Simone Carter (scarter@unicef.org) and Jerome Pfaffman Zambruni (jpfaffmann@unicef.org). Key contributing CASS members include GOARN Research (nina.gobat@phc.ox.ac.uk), Anthrologica (oliviatulloch@anthrologica.com), MSF-Epicentre (Pascale.LISSOUBA@epicentre.msf.org), HHI (ppham@hsph.harvard.edu; pvinck@hsph.harvard.edu), Gillian McKay from LSHTM (Gillian.Mckay@lshtm.ac.uk), TWB (christine@translatorswithoutborders.org), ITM (WVDamme@itg.be, vvanlerberghe@itg.be), IFRC (ombretta.baggio@ifrc.org), NOVETTA (roneill@novetta.com)