

# Social Science in Humanitarian Action

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## Key considerations: health-seeking behaviours in Équateur Province, DRC

This brief summarises key socio-cultural considerations concerning health beliefs and health-seeking behaviour in the context of the outbreak of Ebola in Équateur Province, the DRC, June 2018. Further participatory enquiry should be undertaken, but given ongoing transmission, conveying key considerations and immediate recommendations related to community engagement have been prioritised.

This brief is based on a rapid review of existing published and grey literature, experience of previous Ebola outbreaks in the DRC, Uganda and West Africa, informal discussions with colleagues from UNICEF, WHO, IFRC and GOARN Social Science Group, and input by expert advisers from the CNRS-MNHN-Musée de l'Homme Paris, Institut Pasteur, University of Edinburgh, Institut de Recherche pour le Développement, Réseau Anthropologie des Epidémies Émergentes, Social Science Research Council, University of Florida, Institute of Development Studies, Anthropologica and others. Particular thanks are extended to Tatiana Carayannis, Lys Alcayna-Stevens, Jean-Benoît Falisse, Romain Duda and Alain Epelboin, and to Santiago Ripolli, Theresa Jones and Ingrid Gercama. Responsibility for this brief lies with the Social Science in Humanitarian Action Platform.

## Key considerations

### Local health beliefs

- According to local health beliefs, death and illness are seldom due to 'natural causes' alone. Even if it is accepted that an individual has a biomedical disease (e.g. malaria), people often search for the reason why that individual became sick with that disease.
- Many communities in Équateur Province consider that disrespecting or angering recently deceased parents and ancestors (*bankolo* in Lingala) can cause repercussions in life and result in illness or misfortune being bestowed on an individual, an individual's family and/or community. Illness is also thought to arise from angry water spirits (*mamiwata* in Lingala) or forest spirits (*bilima* in Lingala); jealous 'witches' that can be either male or female (*ndoki* in Lingala); diviners or healers (*féticheur* in local French, or *nganga* in Lingala) who have been paid to cause illness; divine will; the breaking of social prohibitions (related to sexual relations, menstruation, social activity time, property and sorcery associations etc.); and the failure to respect food taboos related to age, life stages, and childbirth (particularly for the Twa community).<sup>1,2</sup>
- The behaviour of others (e.g. a family member) can result in an individual becoming ill even if that individual has done nothing wrong themselves. Illness can also be directed towards a specific person. For example, in the case of interpersonal conflict or jealousy, the aggrieved party may 'direct' an illness towards a person through the use of witchcraft, or may be accused of having done so if that person becomes unwell. In order to understand the nature of an illness and the most suitable course of action, it is often necessary to identify the person or entity that is deemed responsible for causing it.

### Health-seeking behaviours and sources of care

- Evidence shows that local practices are not static but shift and evolve in response to immediate conditions. Communities are pragmatic: both individual and collective behaviours are adjusted to protect a person's own health and that of their household and community. People will try multiple courses of action in an effort to effect a cure, and will seek different types of care either consecutively or in parallel (including biomedicine, self-medication and local healing practices).
- Relatives provide constant care and companionship to help their loved ones when ill and when moving from life to death (see also the SSHAP brief on burial, funeral and mourning practices).<sup>3</sup> There is an important communal component to illness and death, and it is normal for family members to accompany a relative for treatment (from a health facility, local healer, church or other), and to gather at the health facility or hospital should a relative be admitted. As well as providing solidarity and companionship through the biomedical process, accompanying relatives play an important logistical role as they are usually responsible for providing food to the patient (meals are not provided by facilities), giving additional personal care, negotiating their treatment (including payment) and advocating with health workers on their behalf.
- Weak biomedical health structures in DRC, particularly the frontline health facilities and health posts, have been well documented. These include frequent stock-outs of essential medicines, lack of equipment, limited infection prevention control mechanisms, poor water, sanitation and hygiene, and electricity shortages. Équateur Province has 16 health zones and 284 health centres, but in Iboko health zone, the current focus of the response, there are only 16 health centres and health posts for a population of around 124,000 living in 138 villages and 48 forest camps.<sup>4</sup> Human resources for health are also strained. Health workers are often under-skilled and unpaid, and coverage is poor.
- Distrust of biomedicine should not be exaggerated, however. Whilst rural Congolese are frequently described as seeking alternative care over biomedical treatment, this is often the result of structural barriers that prevent access to biomedical services, including direct and indirect costs associated with consultations and treatment; distance from home to point of service delivery across difficult terrain with limited transport options (in Équateur Province, 50% of the population live further than 10km from their nearest health centre); lack of services (e.g. drug stockouts at health facilities); and, for women, challenges in securing permission and resources from their male household head to attend a health facility.<sup>5,6</sup>

- Self-medicating with drugs bought from pharmacies, markets and informal drug vendors (who are often more likely than health facilities to have stock) is also common.<sup>7</sup> The circulation of counterfeit, poor quality and expired drugs remains a major problem.
- Although private health facilities are reported to be well-used in urban centres across the DRC, in rural areas private healthcare is limited to small medical practices run by nurses or auxiliary health workers with limited training. It has been reported that less than 5% of the population use private health services in Équateur Province.<sup>8,9</sup>
- Knowledge about traditional medicine (*nkisi ya bokoko* in Lingala) is widespread, including medicinal herbs, fumigation, scarification, massage etc. Particularly in rural areas, many people self-treat common ailments using local herbal remedies, although these are not always pharmacologically effective. Twa communities are renowned for their knowledge of and skill with herbal treatments and local healing practices, although they are often the first to be suspected (by non-Twa communities) of witchcraft or poisoning should a family member die suddenly or under ‘suspicious’ circumstances, or should ‘misfortune’ come to the community.
- Different types of local healers can be distinguished in terms of their practice and the type of conditions they treat. *Nganga* is a generic term (in Lingala) broadly meaning ‘traditional healer’, but it covers many different types of practitioners including healers (*guérisseurs*), diviners (*devins*) and bonesetters. The *Centre de Recherches pour le Développement International* (CRDI) highlights three main categories of healer in the DRC: herbalists (*herboristes*) who provide herbal treatments; ritual herbalists (*ritualisants herboristes*) who focus on illnesses with material and/or spiritual causes and often practise divination alongside the prescription of herbal treatments; and ritual healers (*ritualisants purs*) who practise divination and use religious rites such as prayer and holy water to address not just physical ailments but areas of broader concern to the client’s life (e.g. their employment, relationships etc.)<sup>10</sup> One should not consider these categories of healer as being strictly distinct. Many healers are entrepreneurial and combine different approaches and techniques, including the use of modern pharmaceuticals, in their practice.
- It is increasingly common for people to seek care from church leaders, particularly evangelical priests. Group prayer is often blended with local divinatory practices and prescribed care can involve seclusion, fasting and purging. Illnesses perceived to be caused by witchcraft or curses are often dealt with through the church, and some congregations believe their church leaders can perform miracles. In terms of providing care, local healers and church leaders are described as having an ambivalent relationship with each other, and, as emphasised above, people move fluidly between these frontline providers in an attempt to effect a cure for their illness or misfortune. As in other areas of Africa, Islamic healing practices are in line with Islamic obligations and prohibitions and incorporate recitation of the Koran. Often, sections of the Koran are copied onto paper or parchment to be included in amulets or talismans that are either worn on the person, suspended above the threshold of a house, or hung inside a vehicle (e.g. from the rear view mirror) to bring protection. Although there is a small Muslim population in Mbandaka, it has not been possible to ascertain further information about Islamic healing practices that may be specific to the province.
- Many Congolese suspect that both biomedical practitioners and different types of local healers will try to provoke or exacerbate illness in order to render their services necessary and profitable.
- At the household level, women are responsible for caring for children and running the home, whilst men control resources and money (both income and expenditure). Female caregivers (mothers, grandmothers, aunts and older sisters) normally engage with healthcare services, both formal and informal, but must seek permission from their male household head to attend health facilities as this usually incurs expense (both direct and indirect). This has been identified as a key barrier preventing the timely utilisation of health services, particularly in relation to children’s health.<sup>6</sup>
- In Équateur Province, Twa live in Bikoro, Ingende, Iboko, Lotumbe and Ntondo health zones. Health zone data suggests that utilisation of care by Twa communities is similar to that by other ethnic groups in the province, although this may hide the higher burden of illness faced by the Twa (i.e. that they need to seek care more frequently than neighbouring Mongo communities).<sup>6</sup> Other studies have reported that only 37% of indigenous women access antenatal care compared to 94% of all Congolese women. The marginalisation of Twa groups has been well documented (see also the SSHAP brief on engaging with Twa communities).<sup>11</sup> In a recent study of five villages in Bikoro, Twa reported avoiding rural clinics because of the contempt and discrimination they encountered from health staff, preferring to go to Bikoro reference hospital where they were ‘tolerated’, although kept in separate wards to other patients.<sup>12,13</sup>

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## Health beliefs and behaviours in the context of Ebola

- Although denial of the virus (i.e. doubt that ‘Ebola is real’) is still reported, local health beliefs influence how communities perceive Ebola, its prevention, transmission and what is felt to be ‘appropriate’ care. Anthropological studies of previous outbreaks have highlighted that the diverse theories of causation used to explain other illnesses (as outlined above) are also used to explain Ebola.<sup>14</sup>
- Witchcraft – In previous outbreaks in the DRC, affected communities have made direct links between Ebola and witchcraft and curses. In Kampungu, western Kasai Province (2007), the outbreak was attributed to sorcerers who ‘ate people’ during their occult practices causing people to fall sick and die, and witchcraft was also reported as a dominant cause during the outbreak in Isiro, Haut-Uele Province (2012).<sup>15,16</sup> In Boende, Équateur Province (2014), the start of the outbreak was linked to young hunters from Inkana Mongo villages who sought to enrich their hunting through magic but failed to pay the witchdoctor who they had approached and who then cursed the village as retribution.<sup>17</sup> In discussing the outbreak in Likati, Bas-Uele Province (2017), communities explained it in terms of punishment for sorcery practices.<sup>16</sup>
- Retribution and punishment for bad behaviour – In previous outbreaks in the DRC, affected communities have also made direct links between Ebola and disorder between families and ancestors.<sup>15</sup> During the outbreak in Isiro, Haut-Uele Province (2012), deaths from Ebola were attributed to score-settling between families in conflict due to the non-payment of the bridewealth, whilst the death of the nurse who was the index case was also linked to the jealousy of her coworkers.<sup>17</sup> In Boende, Équateur Province

(2014), the outbreak was associated with the theft of fish, which led the offending family to be cursed and resulted in cases of Ebola. In Likati, Bas-Uele Province (2017), communities explained the outbreak as punishment for immoral actions.<sup>15</sup>

- Religious beliefs – In Kampungu, western Kasai Province (2007), another explanation offered was that the outbreak was a result of conflict between God and the Devil, with charismatic church and evangelical leaders fighting witchcraft whilst sorcerers demonstrated their power by killing people.<sup>15</sup>
- Suspicions of the response – Direct links have frequently been made between the transmission of Ebola and health workers and responders (as was also common in the West Africa outbreak 2013-2016). In Boende, Équateur Province (2014), surveillance teams and contact tracers were labeled as ‘blood suckers’ and communities prevented response workers from entering villages by blocking the paths with tree trunks.<sup>15</sup> It was also rumoured that health workers used ‘garawa’, a local poison, to kill people.<sup>16</sup> In the outbreak in Isiro, Haut-Uele Province (2012), affected communities referred to treatment centres as ‘death camps’, suggesting that health workers starved patients to accelerate their death (which may be connected to the fact that family members could not attend to them whilst they were admitted and were not able to provide them with food).<sup>1</sup> During the current outbreak, a doctor and nurse were reported to have been threatened after locals accused them of ‘bringing Ebola’ to their community.<sup>18</sup>
- Suspicions linked to government, political motives and financial gain – Other explanations have often suggested that Ebola is a way for the government to control the population and secure foreign aid money. In Isiro, Haut-Uele Province (2012), as in other outbreaks, Ebola and its transmission were linked to corruption by health workers and other local authorities who may have stood to benefit financially from the outbreak (e.g. to enhance their access to ‘Ebola money’).<sup>1</sup> Outbreaks have also been perceived as a way to steal blood and body parts, which may be used in witchcraft to strengthen the power of politicians or be sold to ‘the Whites’ (to give them power or for use in experiments).<sup>16</sup> In the current outbreak, rumours have circulated that the state is spreading Ebola in order to delay elections and/or control the electorate.
- Vaccine – During the current outbreak it has also been rumoured that Ebola was (re-)introduced to the DRC to enable the experimental rVSV-ZEBOV vaccine to be trialed. Although the ring vaccination campaigns have been largely successful, suspicions continue and may also be linked to other new therapeutic treatments. The fact that the DRC has successfully overcome eight prior outbreaks of Ebola since 1976 has led communities to question why the vaccine was introduced now.
- In the context of local causation theories and reliance on traditional medicine, it is likely that symptomatic patients seek care from non-biomedical sources. This has clear implications for both drivers of and barriers to transmission, as well as who to engage in the response and how. In the outbreak in Boende (2014), a number of cases were linked to a self-proclaimed healer who cut the skin of his patients and sucked out some of their blood to ‘cure’ them of Ebola. In Boende, some churches taught that only prayer could ‘cure’ people and ‘end’ the outbreak because it was ‘evil action’.<sup>17</sup> Similarly, in the Likati outbreak (2017), it was reported that sick people attended prayer groups and sought prophetic healing before presenting at health facilities.<sup>16</sup> In the current outbreak, it was reported that at least two patients were removed from the treatment unit in Mbandaka by their families in order for them to attend church and receive prayers.<sup>19</sup>

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## Recommendations

- A well-managed and transparent process will help reduce rumours associated with the cause or origins of the current Ebola outbreak and the intentions of response teams. Trusted intermediaries who are in a position to help reduce or mitigate rumours must be identified at the local level, but are likely to include local chiefs, community leaders, church leaders and imams, the Red Cross (that has a positive and well-established long-term presence), and local / community radio stations (such as Radio Okapi, a station of MONUSCO, the UN Organisation Stabilisation Mission in the DRC).
- Health beliefs and health-seeking and care-giving practices all influence and are influenced by broader determinants. When they understand the risk of transmission, communities are best placed to suggest acceptable modifications to local care practices and health-seeking behaviours.
- In engaging communities, particularly those with lower levels of health literacy, the response should avoid biomedical terms that may create unease, tension and rumour, and could be interpreted as contradicting local health beliefs. Rather, explanations about the risk of transmission, when and where to seek care, and individual and collective prevention measures should be couched in local explanatory models.
- At the community level it is important to engage decision-makers who may control whether a person with symptoms is or is not identified to response teams and presented for care. These decision-makers include male household heads, who control resources. It is also important to directly engage women, who are usually responsible for providing care at the household level of sick children and relatives. To engage women effectively, sessions should be held in their natal language and in a setting in which they feel comfortable seeking clarifications, which is not always the case in mixed-gender meetings. Women’s associations, church groups and Twa-led ‘indigenous associations’ (if they are active in the local area) can help mobilise women at the community level.
- Discussion and agreement at the local level about how frontline informal healthcare providers should be engaged by the response is critical. Individuals (e.g. traditional healers, church leaders, local pharmacists and drug vendors) need to be identified by the community. Rather than being seen as barriers to effective care, the reach and influence of frontline informal providers should be harnessed by the response, as evidence shows their positive involvement increases community trust and the reach of interventions. These providers should be provided with key information about the signs and symptoms of Ebola, and if they encounter a suspected case, they should be supported to make a timely referral to the appropriate authority. They can be positive agents for behaviour change at the community level (leading by example and conveying key health information) and can provide real-time intelligence to surveillance and contact tracing teams. This two-way flow of information is critical and should be actively facilitated and promoted, particularly as the primary focus of the response is now on expeditionary surveillance, contact tracing and

vaccination in the small market town of Itipo (Iboko health zone) and surrounding villages. Frontline informal providers should be remunerated for their time and involvement in the same way as other community-based responders.

- Structural barriers to health facility attendance are likely to be exacerbated during a health emergency. Local health structure and cadres, including community health workers (*relais communautaires* or RECO), community animation units (*Cellules d'Animation Communautaire* or CAC) and local health committees (*Comités de Développement Sanitaire* or CODESA), are important for risk communication and contact tracing, however they have limited resources and lack forms of transport needed to complete their work effectively. As well as addressing immediate need, therefore, the response should also aim to strengthen local capacity in a sustainable way.
- It is important to assess the implications of vaccine introduction in terms of its effect on care-seeking both during and after the outbreak. There have been reports of people refusing care because they were 'waiting' for the vaccine. Engagement strategies must continue to emphasise that the vaccine is not a 'magic bullet' and to stress why protective behaviours and public health control mechanisms must be continued despite vaccination (see also the SSHAP brief on vaccine introduction).<sup>20</sup> As the number of cases decline and after the outbreak is declared over, perceptions and experiences of the vaccine (as an intervention, its trial status, and how it was introduced and rolled-out, i.e. as a ring vaccination) must be carefully documented. This process should engage people who were directly involved, both in its administration and those who received it, and the broader community. The ramifications of vaccine introduction on health-seeking behaviours and engagement with health services more broadly (e.g. on routine immunisation) must also be carefully monitored and documented over the coming weeks and months.
- It is important to further understand specific practices associated with local health beliefs, health-seeking behaviour and care-giving amongst affected communities, particularly in the current hotspot areas in Iboko. Key insights are needed in relation to: how communities understand Ebola, its cause, prevention and transmission; what people consider to be 'appropriate' care; from whom people seek care, where and when; how health-seeking behaviours change or are modified in the context of Ebola; how care-giving practices at the community level change or are modified in the context of Ebola; willingness to work with response teams including surveillance and contact tracers as well as health workers; and community-led recommendations for acceptable and appropriate engagement. A series of key questions focusing on these issues has been developed, and partners are encouraged to refer to the Question Bank shared by the Social Science in Humanitarian Action Platform.

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## Contacts

If you have a direct request concerning the response to Ebola in the DRC, regarding a brief, tools, additional technical expertise or remote analysis, or should you like to be considered for the network of advisers, please contact us.

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