Key sociocultural dimensions of scientific research and response to the West African Ebola outbreak

Briefing Note for WHO Ebola Science Committee, 04/06/2018

Ebola Response Anthropology Platform

Key points

1. **Caring is human, and intensely practical. Yet scientific discussions concerning the current Ebola virus disease (EVD) epidemic frequently portray caring practices, including burial, as irrational or immutable traditions.**

2. **Rumours, resistance or continued at-risk practices are more helpfully interpreted as evidence of genuine concerns with the quality of the response as implemented on the ground, or a pointer to the irrelevance of the response to people's most pressing health or livelihood concerns**

3. **Current fears and uncertainty are influenced by historical experiences of external predation (slave traders, colonial regimes, recent warlordism). There is potential for people in Guinea, Liberia and Sierra Leone to mistrust the motives of anyone outside their communities. This risk needs to be taken seriously and explicitly addressed at all stages of the design, implementation and oversight of research and infection control**

While this briefing note identifies arenas of particular significance with regard to burial practices and clinical sampling, **such practices and perceptions are not standardised and are likely to change as social responses to EVD evolve. Mechanisms therefore need to be put in place to identify and respond flexibly to varied and shifting local concerns**.

Burial Practices

Funeral and burial practices vary according to religion and across the region. Whilst a many profess Christian and Muslim faiths, many also adhere to local beliefs. In the region surrounding the Ebola epicentre, local cult practices dominate despite a century of attempts by colonial and post-colonial governments and missionaries to suppress them. Funeral and mortuary practices are central to these cults and consequently are important not only to personal life but also social and political identity. These practices are deemed to be essential to the prosperity of people, businesses, crops etc. and to ensure proper moral and social conduct.

Mortuary and funeral practices help the dead to join the ancestors. If the correct funeral practices are not made, the spirits of the dead are deemed liable to wander eternally and may torment or punish their descendants. These are good reasons why people are so concerned by the proper conduct of funerals, and why the ill should die among respectful friends and family.

4. ‘Funeral practices’ conflate several processes and events. First, families care for the mortally ill to the very end. As serious illness can be caused by social faults, confession may be thought important to healing. If curses or malicious sorcery are suspected, a healer may be sought to identify the cause and address it. Second, for influential people, associates need to gather to hear last wishes of the dying and resolve inheritance questions. Thirdly, debts (bridewealth etc., commercial debts etc.) must be settled. Fourth, when curses or sorcery is a suspected cause of death, or when the dead are themselves suspected of sorcery (for Ebola, both may occur), specialists endeavour to discern the cause. All those who can and should mourn the dead will attend the funeral or risk being suspected of malice. Sixth, the body should be prepared for the difficult journey ahead, which for all involves washing, closing eyes, and clothing properly, but for some can be more elaborate - for example, throughout much of the region women’s societies must remove a fetus from a woman who died pregnant and bury both separately. Seventh, the location of the grave is highly significant, differentiating the powerful and socially insignificant; locals and strangers, good and bad deaths, sorcerers and the good; ‘first’ deaths and the normal. Eighth, for loved people, sacrifices must be made over the grave to help the dead to attain peace and thus to continue to support the living. In general, it is most important for burial to be witnessed. Chiefs need to be informed in the proper manner, and people need to follow their loved ones to the grave site, to know its location, and know that the body was handled correctly. If the family does not carry out the burying (for reasons of protection from Ebola) then the trained and equipped burial teams should at least be made up of local people, familiar with requirements for decent burial in that place.

5. Many people are highly sensitive that they are being unfairly blamed for "spreading Ebola" by adhering to "strange customs" they suspect outsiders may disapprove. Burial rituals are often secret, and people resent being asked about them and do not want the rituals, especially those associated with burial of cult elders, publicized or interpreted to the world. In general, the approach to village communities in such traumatic circumstances should be to ally with them in expressions of grief, concern and solidarity, and to recognize that cultural and behavioural change will come most effectively if they are offered space in which to exercise their own collective understanding of ways to mitigate the moral and societal risks mentioned. Villagers will change rituals in line with protecting their own health, once they understand the risks, provided non-members respect the law of secrecy. But *only villagers themselves can balance social protocols with those minimising infection risk*. Any "disrespect" in this area risks prejudicing the engagement of local agency for Ebola control. It is less important to know ‘what people do where’ that to appreciate that it is important to them, that it varies, and that it is amenable to internal change, but much less amenable to change directed by outsiders, perhaps especially where that involves the threat of force.

6. Death threatens the social fabric, and people feel moved and impelled by death to express their feelings. These expressions are intended to set social relations back on track, and allow the spirit of the dead person to move on, untrammelled by lingering concerns and commitments to those who remain.

7. These are universal human concerns. There are myriad particular ways in which feelings and concerns focused on death find detailed cultural expression but it is often not helpful to dwell on the details, since this risks seeing cultural minutiae as "causes" of EVD. The objective is to combat a virus, not local customs.

8. Not attending a funeral, or not carrying out procedures deemed to be correct or necessary creates a huge burden of guilt among the survivors. They often feel they may have sinned. No

amount of "health education" about risks of EVD will alter this burden of guilt. People retain a strong motivation to bury their dead in a correct and respectful manner.

9. Important progress has been made to improve how burial management teams attend to the dead in a safe but respectful manner, including the recent WHO burial guidance. There is evidence that acceptance of the infectiousness of the recently deceased and the necessity of instituting protective changes to burial practices are becoming more widespread ideas.

10. There continue, however, to be field reports of people burying Ebola deaths themselves whether for practical reasons, principally delays to the arrival of burial management teams, or due to concerns around the fate of bodies being 'lost' in the formal care system, and/or ongoing spiritual concerns about, for example, mass cremation (an issue in Liberia)..

Clinical Sampling, blood donation and transfusion

11.Blood donation is not a trivial act in West Africa. Concerns about the impact of reducing the quantity of the blood should not be dismissed.

12.The significance of blood varies between West African groups and ethnicities. However anthropologists working across the region have noted that blood is understood as a 'vital force' associated not only with good health but with individual strength and prosperity. A similar set of logics link illness and misfortunate to reductions in the quality and quantity of blood.

13. The importance of clean or strong bodily fluids can attribute to the popularity of interventions such as vaccines that injected directly into the bloodstream; while the emphasis on a limited 'economy of blood' can also generate fears and anxieties of blood giving – whether for research or transfusion – which can render the patient vulnerable to other diseases.

14. This is particularly true of women and children who are often understood to have less blood to begin with and, in the case of the latter, a greater need due to their workload.

15.Concerns about blood theft, sale and vampirism are common across the Africa continent. Anthropologists have shown that these anxieties are often linked to medical research contexts, where populations perceive imbalance and inequity in exchange.

16.Attempting to dispel rumours by teaching or 'sensitizing' populations to the procedures of medical research often make little difference in the acceptability of research. Anxieties of blood theft are rarely due to a lack of education or misinformation but rather articulate cultural perspectives, often grounded in long-term engagements with biomedicine, legacies of unequal relations of power, extraction and exchange.

17.In some cases, certain foods are regarded replenish blood and build strength, for example groundnuts or milk. Local perceptions of the association between different foods and blood should, however, be checked locally.

18.There should be as much clarity as possible regarding the destination of blood; if samples have to be processed at a distance from the hospital that is it important to reinforce the altruistic nature of the donation.

19. We are not aware of any particular significance attributed to other clinical samples. It is, however, entirely plausible that any sample that comes to play a central role in the diagnosis or

management of EVD patients will gain significance with time. Mechanisms should be put in place to identify and respond to any emerging concerns regarding this, and indeed all aspects of research and health care.

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This briefing note represents the views of the Ebola Response Anthropology Platform. The above contributors do not necessarily agree with all of the briefing note's contents.