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Responding to Ebola in DRC: when will we learn the lessons from Sierra Leone?

Ebola Gbalo research team:

London School of Hygiene & Tropical Medicine and Njala University, Sierra Leone

Latest reports from the WHO suggest that the Ebola outbreak in North Kivu and Ituri Provinces, Democratic Republic of Congo (DRC) is serious and rapidly escalating. As of May 13th 2019, there were 1,800 confirmed cases, 1,218 of whom had died, making it the second largest outbreak (so far) in history with a case fatality rate of 66% - much higher than previous outbreaks [1]. Jeremy Farrar, the head of the Wellcome Trust has called the situation “terrifying” [2]. Although Ring Vaccination is helping endeavours to contain transmission, it requires a sufficient coverage of contact persons and efficacy has been demonstrated only beyond 10 days after vaccination [3]. All critical response interventions (case and contact detection, community education, treatment and vaccines) are being severely impeded by the exceptionally difficult setting of armed violence: there are many active militia groups in North Kivu and Ituri Provinces in DRC [4], and the political instability and violence make it difficult to establish secure bases. The problem is complicated by high degrees of local distrust in the work of Ebola responders. The recent armed attacks on Ebola Treatment Centres in Butembo and Katwa and the killing of a WHO epidemiologist highlight the gravity of the situation [5]. Jeremy Farrar, of the Wellcome Trust has called for a six-nine month ceasefire to allow treatment teams into communities and Dr Tedros, Director-General of the World Health Organisation, has called for international donors to urgently commit to filling the funding gap to support these efforts [2]. These steps are important, but they address only part of the problem. There are numerous armed militia groups in the region and it is far from clear how much support they have, or how they relate to other kinds of authority within the region. To work in these spaces is exceptionally difficult and few people have the local knowledge, language skills, experience and networks to do so effectively. The situation is complicated by widespread distrust of “outsiders” and of western-led emergency-response systems as well as manipulation of these fears by those seeking to consolidate political or military power. Violence against local and international health workers is an expression of this distrust. But what can be done about it?

Distrust and misunderstanding were also features of the Ebola epidemic in Sierra Leone (2014-15) and subsequent research has shown very clearly the need to work closely with frontline health responders and other authorities perceived locally to be legitimate, yet these lessons appear not to have been put into practice in DRC. Responders from the field, including Alima and Médecins Sans Frontières, recognise this more than most. On 10th May one of MSF’s field coordinators, Karin Huster, called for a rethink on

the Ebola response in DRC, by lowering its “emergency” profile to reduce suspicion and distrust in the isolation procedures that “scream Ebola” [6]. Kate White, another MSF emergency manager calls for closer work with communities where most of the deaths are happening. David Miliband, head of the International Rescue Committee, has also called for a “rethink” on the DRC response [2]. Augustin Augier, CEO of Alima, articulates a possible rethink observing that *“the best way to overcome this distrust is to trust the community [...] if we trust them and give them the means, we can do it.”* [7]. Yet among too many international response agencies this rethink is slow in coming. A policy panel discussion in Geneva on 13th May suggests the continued focus is on international responders and WHO’s coordination efforts [8]. Many of these efforts regard communities as recipients and supporters rather than owners of the response. The effort is to do more of the same rather than a commitment to finding completely new ways to work with communities, involving them directly in decision making. On the Geneva panel were researchers from the Ebola-Gbalo (“Ebola Troubles”) research project who discussed their recent analysis of responses to the Ebola outbreak in southern Sierra Leone. They underlined the critical importance of learning from local frontline responders and working closely with and through communities (chiefs, herbalists, youth leaders, traditional health attendants, community health workers, teachers and others) to promote locally acceptable treatment and burial practices, including offering “as-safe-as-possible” options for home-care where access to care centres is impossible. The multi-disciplinary Ebola-Gbalo study reconstructs the history of the epidemic and the work of responders in Bo and Moyamba districts who were working successfully before national or international responders came to support them. For example, Bo district fundraised locally and created their own surveillance protocols based on relationships with the communities. Much can be learned from this for North Kivu and Ituri Provinces where it seems likely that it will be local responders, not the international community, who play the critical role in turning the epidemic around in an exceptionally difficult setting in which community isolation is increased by activities of insurgent groups. We summarise the lessons of the Ebola-Gbalo study here and lessons already learnt from DRC.

Establishing trust

In Sierra Leone, our data show that community-level distrust was related to the nature of the response, and the distance to the locus of operational decision making. Large and distant Ebola Treatment Centres were distrusted because families could not follow patients and monitor their progress – rather patients were seen to be taken away, by hazmat-suited strangers, to die in unknown locations (many bodies were never returned, their graves unknown). Village-based Community Care Centres were preferred as triage facilities because community members knew the staff and could literally see inside [9]. Burial teams and contact tracing worked best when the recruits were local. Panic and confusion were alleviated when home carers were given clear instructions about how to care for their loved ones safely while waiting for help to arrive [10]. Where local agents, including health personnel, government agents and families, were strongly involved in planning and implementing the response it was more effective. Families were recognized as essential to the survival of their loved ones, and local health personnel felt fully valued. Our findings suggest that in Bo and Moyamba districts the response succeeded when community and district leaders were fully engaged. The actors differed in each district; international responders need to work with district and traditional authorities, as well as health workers embedded in communities to discover

other local leaders and figures of influence including women's groups, secret societies and religious groups, traditional healers, citizen welfare groups, youth organisations and so on.

From the outset, international and national responders in North Kivu and Ituri Provinces in DRC have recognized the importance of working with people who are perceived to be legitimate figures of authority, even if they do not have legislative or official authority. Considerable effort has also been given to working with researchers (social scientists, including anthropologists and health systems researchers) with extensive knowledge of the region to map out different kinds of public authority [11]. Recording how these different authorities relate to each other, enabled responders to identify, and establish, effective working relationships with, for example, particular youth groups and militia groups in parts of North Kivu and Ituri Provinces. However, critical gaps in the response remain. There still appears to be lack of ownership of the response in some communities.

Understanding reasons for this lack of ownership is crucial. In Sierra Leone, the earliest affected communities had no options but to engage with the disease. Our data illustrate how active local involvement promoted understanding. By whatever means, the sick had to be quarantined and the dead buried, even though the risks associated with these activities were known. Steps were then taken to improvise protective clothing and implement prevention measures. Carers and burial teams began to use plastic bags and coats worn backwards. Chiefs formulated Ebola by-laws, to restrict movement, and fine those not reporting cases of sickness. Volunteer youth groups mobilised to block roads, trace contacts, and safely bury the dead.

In North Kivu, by contrast, the prompt arrival of international help may (perversely) have served to close down the available space for local agency. It is perhaps telling that much of the response (and training of locals) is conducted in French – a language not understood by many villagers [12]. Instead, a counter-discourse of Ebola denial has taken root in homes and villages, feeding attacks on Ebola facilities and staff. MSF's General Director noted: "what we know is that organisations involved in the Ebola response – MSF included – have failed to gain the trust of a significant part of the population." [13] Perhaps what is now needed is for the international response to step back and debate with communities and local responders about what they could do for themselves. In Sierra Leone, where jobs for young people are scarce, paying "volunteers" a modest stipend proved an effective way of gaining community engagement.

Learning from local frontline health staff and others attempting to care for the sick

Local learning in Sierra Leone was rapid among health workers and villagers alike [14]. In the absence of a functioning, well-resourced health system, people drew on their own empirical observations about how Ebola was transmitted as well as any previous experiences they had had responding to cholera and smallpox. Our interviews report how infected health workers in Kenema (the site of an isolation facility to which many early Ebola cases were sent) phoned their colleagues in neighbouring Bo District (and elsewhere) to tell them they were seeing different symptoms from the ones being cited nationally, enabling staff to be prepared. This information was acted on by Bo district authorities and there are examples of prepared staff being able to stop infection spread as a result. In some instances, villagers adapted past knowledge to deal with the virus, including in some remote areas local efforts to quarantine affected houses and villages, rehydrate sick relatives and make impromptu PPE to safely bury their dead. A feature of the response in Sierra Leone, however, was the lack of attention given by national and international responders to the learning of these frontline and district-based responders. Had there been

a different mindset in action than guidelines and information on local Ebola symptoms, dignified burials, home-care and acceptable siting of treatment centres would have been corrected and agreed much earlier.

By all accounts, the Ebola control on north-eastern Congo poses even more daunting challenges than in Sierra Leone, where war and outbreaks came separately and not conjoined. The region has been affected by protracted insecurity and conflict for decades, biomedical health care facilities vary widely in terms of capacity and adequacy of care, mortality and morbidity from other infectious diseases are rife, including on-going outbreaks of polio, cholera and yellow fever. Surviving in such circumstances requires skill and tenacity, a capacity to learn from the past and to draw on local knowledge. Communities (however defined) are learning rapidly, and so are responders, with safe burials, for example, being adapted to accommodate local practices [15]. Placing greater trust in communities to identify effective solutions is likely to pay dividends [16, 17]. Ebola in Sierra Leone taught international responders never to underestimate the levels of skill, common sense and adaptive ingenuity of local agents (from health workers and district managers to family members) to respond to Ebola once they understood the nature of the challenge, provided there was a real attempt to build working alliances between local and international partners based on mutual respect. Far greater efforts are now needed in DRC to engage with community members, local governance structures and district health authorities, and see them not only as implementers of an international emergency response, but involve them equally in decision making about how to roll-out vaccination and treatment. This will need to include home care and the establishment of locally staffed and managed burial teams, as well as a complete change of mind-set from international agencies.

Supporting homecare

Home care in managing Ebola is controversial. For many, the risks of infection are too high, especially where supplies and support for the families is inconsistent. Another perspective is that in some circumstances it is unavoidable. Our data show that families often had to wait long periods for help, and beds in Ebola treatment centres were not always available. In these circumstances, families refused to abandon their loved ones, but coped as best they could often only with their own resources. Given the inadequate infrastructure and reach of the official response, there is always the issue of how care is to be given while waiting for help and in settings where no help is likely to arrive. In Sierra Leone, international NGOs and donors as well as government persistently overruled the suggestion to provide information and resources to enable people to care for loved ones within their homes [18].

Yet, Ebola is fundamentally a “family disease”. In contexts of profound distrust, it is an illusion to expect mothers to willingly allow their children – or any family member – to be taken by health personnel in hazmat suits to barricaded emergency-response medical facilities regarded as places from which no-one returns alive. It is no surprise that most deaths in DRC have been in family homes, not in treatment centres. In Sierra Leone it will never be known how many people might have been saved if boots, chlorine and rubber gloves had been freely and widely available in health centres, markets, and households, allowing families to take basic precautions in caring for their sick, but almost certainly these items would have had a positive impact. While improving local trust in health centres is essential since specialised care in local, trusted treatment centres improves survival chances, improving the safety of home care with good advice may be the only realistic option in the more inaccessible villages in North Kivu and Ituri

Provinces, particularly in places isolated by fighting or characterised by high levels of distrust in the formal health system. One possible way forward might be to pre-emptively mass-vaccinate people who are identified locally as likely carers, though identification of these potential carers could be challenging and needs to be driven locally. The use of the CDC guidelines on home-care (developed in Sierra Leone) could be very effective with backup radio discussions. If necessary, home-care leaflets could be dropped by drone, along with gloves, boots and possibly even chlorine – as local need arises.

Engaging the military and security forces to contain Ebola

The Sierra Leonean armed forces played a major role in enforcing quarantine. In particular, they provided 24-hour armed guard for 21 days in houses where a person had become infected with Ebola. The results were mixed across our fieldwork area, with some of our study participants saying it was necessary to enforce compliance in this way, and others finding enforced quarantine counterproductive. There were multiple examples of by-laws and quarantine being broken, suggesting that it may be better to engage with populations in such a way that they take responsibility for their own quarantine rather than relying on external military forces. External actors could support such an approach by helping to provide food and medical supplies for a range of ailments. In the uncertain and fragmented context of DRC it is highly unlikely that any general restriction of movement could be enforced while the military is a major actor, furthermore stepping-up military presence is likely to further exacerbate suspicions of political manipulation and could possibly increase violence. The priority for DRC should be to support endeavours to negotiate a peace-deal and broker a ceasefire to encourage all armed groups to unite in the Ebola response. These endeavours are made harder by the corruption associated with local “business” interests from the influx of money and goods for the response; corruption that must be tackled.

Some conclusions

Recognising differences between settings, we feel, nevertheless, that it is urgent that the lessons from Sierra Leone help to rethink the response to the significantly worsening outbreak in North-Eastern DRC. These are: 1) to work closely with the different forms of local authority, including recognizing heterogeneity and different capacities among those authorities, with a commitment to allowing local authorities to shape the response ; 2) to allow local frontline health workers to advise international responders on the best means to reach and encourage cooperation from affected communities; 3) to disperse resources and basic life-saving equipment (including gloves, boots and chlorine) to communities, particularly in remote locations beyond formal health systems; frontline health workers and distant village/community leaders should also be provided with communication tools to expand the surveillance area beyond those reached by formal health systems; and 4) to recognise that in the highly politicised context of the Ebola outbreak in DRC, securitisation of response is problematic and will require reflection. If international agencies are to provide effective support to local responders, then serious efforts need to be given to peace-negotiations and brokering a ceasefire or securing safe corridors for aid delivery. But even if this does not happen, the situation could be transformed if international agencies, including WHO, “let go” of their control and trust community responders to take the lead. While acknowledging the enormous courage, commitment and hard work shown by responders to date, we share these reflections

in the hope that new ways can urgently be found to support communities to tackle the devastating outbreak in northern DRC.

Authors

Ebola Gbalo Research Group: Lawrence S. Babawo, Dina Balabanova (Co-I), Johanna Hanefeld (Co-I); Tommy M Hanson; Bashiru Koroma; Susannah H. Mayhew (**PI and corresponding author*); Alfred Mokuwa; Esther Yei-Mokuwa; Melissa Parker (Co-I); Paul Richards; Ahmed Vandri.

* Susannah.Mayhew@lshtm.ac.uk

Project website

www.responding-to-ebola.org

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