

Grief and Memorialisation: Beni, North Kivu

BACKGROUND AND CONTEXT

As of 6 October 2019, the WHO report that a total of 2142 individuals have died from Ebola in North Kivu, DRC. Whilst much attention has been paid to identifying cases, vaccinating, treating and hygienically burying those who die, less focus has been given to the aftermath of Ebola. In particular, families of those who die from Ebola tend to garner less attention from the international response.

One of the dominating issues in an Ebola outbreak response is that ‘safe and dignified burials’^{iv} (SDB) can deny families the chance to say goodbye in a way they would choose, and in-line with their cultural values. The psychological and social consequences of this can be many. An immediate impact of this can be so-called ‘community resistance’ as people reject the actions of burial teams, and the wider Ebola response. In the long-term, it can manifest as mental health issues related to unresolved grief and ‘ambiguous loss’^v. As outlined by the IASC guidelines (2015) for mental health and psychosocial support in Ebola, lessons learnt from the West Africa outbreak: *‘the bereaved need to have the opportunity to mourn’*. In cases where important funeral rites, mourning ceremonies and rituals are not allowed due to infection, prevention and control mechanisms, then dignified and meaningful alternatives should be found.

That has not always happened in the North Kivu Ebola response. Reports of community feedback by the IFRC^{vi} indicated frequent delays between the notification of a death and burial teams arriving: *‘Whilst the body is decomposing’*, or not arriving at all. Reports of burials teams not showing respect to families have also been consistent: *‘Why are you burying people who died from Ebola without showing respect?’* (SSHAP, 2019). Data collected from communities between August 2018 to May 2019 highlighted a strong sense of disruption and loss amongst families, and an overarching resentment that the response had not acknowledged this aspect of the outbreak. Families were feeling ignored: *‘To families who haven’t lost a loved one in this outbreak Ebola is a joke’* (IFRC, 2019).

Loss is just one side of the complex, heterogenous experiences of Ebola deaths. Many families also reported experiencing stigma at the Ebola Treatment Centres (ETCs) or as a result of their having received Ebola care. In community feedback collected by Oxfam in Katwa in April 2019, one community member explained: *‘All my neighbours hate me saying that I was corrupted by the response because after the death of my child at the ETC, I accepted decontamination, safe burials, vaccination and other things’* (SSHAP, 2019). This lack of understanding and social support from fellow community members presents a further impediment to healing.

Changing trends in the community feedback, however, suggest that there have been recent important improvements: *‘Before, the responders would hide the dead bodies, but today it’s good because they’ve just agreed to bury the dead where the family wants, thanks for that’* (SSHAP, 2019). This reflects the commendable efforts of the Ebola Response sub-commission in charge of SDB and the Psychosocial Commission^{vii}, who have worked to ensure that particular funeral rites of specific ethnic groups (such as the Nande) are included in SDBs, and when possible, that family are involved during the preparation of the body and during the burial itself. Moreover, locally recruited psychosocial agents or psychologists who work through the Psychosocial Commission are now linked to the organisation of the SDB to emotionally support the family. The Child Protection and Psycho-Social Support (CPPSS) strategy of the Psychosocial Commission is comprehensive and seeks to respond to the specific needs of Ebola confirmed and suspect cases and their family members^{viii}. Affected families (families who have one member who went through an Ebola Treatment Centre (ETC), or families who lost a relative from Ebola) are followed up by a psychosocial agent and can

be supported through material assistance which include a funeral kit (food assistance or cash) to support the organisation of a subsequent ceremony. To date 10,570 affected families and 1,806 orphans have been assisted by the Psychosocial Commission^{vii}. However, this support can take a long time to reach families, or they can be requested by response teams at the last minute when ‘community resistance’ is already happening. Furthermore, the overall improvements come too late for some families.

These issues remain a priority for North Kivu communities who request additional support to bereaved and affected families. Direct appeals to the IFRC have included families wanting to feel that deaths ‘mattered’ to the response teams and for more formal memorialisation of deceased loved ones (SSHAP, 2019). There is a need for further investment into community-based, contextually appropriate grief and memorialization efforts in order to respond to these requests. Mental health and psychosocial support actors who have the technical skills to guide families through such a process are best placed to provide the support. Ideally, these should be local people who are aware of the socio-cultural sensitivities and specificities of this work.

BETHESDA SUPPORT TO GRIEVING FAMILIES

Bethesda is a counselling organisation, part of the Congo Initiative, based in Beni. It is a faith-based organisation, but services are offered to all. Having operated in Beni and the surrounding areas since 2016, they have expanded their services to meet needs relating to Ebola. Activities have included group counselling for Red Cross International workers involved in SDB, community engagement initiatives with local transport providers (mostly taxi drivers), psychoeducation activities for children, distribution of hygienic washing kits to schools, distribution of Ebola messaging materials and weekly music programmes to local communities.

Having identified a gap in support to families who have lost members to Ebola, Bethesda designed a process through which ‘to walk alongside grieving families in Beni and Mangina and provide care and healing in the aftermath of Ebola Virus’. This involves guiding small groups of families through the following stages:

Stage 1 – Relationship / trust building

- Introduce Bethesda - who they are, what they stand for, and why they care about grieving families
- Communicate a sense of honesty and humility
- Invite questions about Bethesda and their connection to the Ebola response
- Describe the support process to grieving families and discuss why such a process may or may not be important
- Give families a choice to participate
- Set group boundaries for those who choose to take part
- Discuss Ebola perceptions through questions and answers

Stage 2 – Sharing stories and coping mechanisms

- Discuss the impact of Ebola on the families, including stigma, shame, stress etc.
- Invite families to describe one or two items that have personal significance or held personal memories, items that may have been incinerated or destroyed through the Ebola hygiene activities
- Share stories of loved ones who died
- Write or narrate a goodbye letter to their loved one
- Share strategies around individual/community coping mechanisms and skills – what are people doing now? Can they re-find old ways? What are some new or different ways that can emerge?
- Discuss and practice approaches to relaxation and affect modulation, encourage participation in social activities within the community: prayer, songs, music etc.

Stage 3 – Memorialisation ceremony

- Discuss the importance of family and community support systems
- Agree strategies to support one another in future
- Discuss what a memorialisation ceremony is and means to the community.
- Agree what the ceremony for memorialisation will look like. Choose where, when and how it will happen.

There has been no prescribed amount of time for each stage, each takes as long as necessary, although the Bethesda team spend a minimum of five weeks with each group of families. To date, 46 families in Beni have decided to plant trees collectively on a shared plot of community land. In Mangina, 49 families chose to plant trees in their own land where they live as part of the memorial process.



Mangina tree planting program in Masimbembe and Manzanabala - Families chose the types of trees they want

FAMILY TESTIMONIES + SELF-REFLECTION

Whilst a full impact evaluation has not been done, Bethesda have been systematically documenting families' experience of the process. The following are key themes to emerge from the comments, illustrated with key quotations.

Feeling cared for and comforted

'We were very angry as since we have been grieving, we have seen nobody coming here to comfort us. They were coming here often only to record names'

'Living on this earth, we all have an end; the sessions have been my first time I have felt comforted, these sessions have helped me. You have done a good thing to bring us to these sessions.'

The value of remembrance

'Ah now these are the people who have thought about us and have touched an aspect of life that was forgotten.'

'From this tree we will tell our girls and boys what happened in Masimbembe.'

'This tree will help us to remember brothers, sisters and parents taken by the Ebola virus.'

Healing as a process

'What I have gained from these sessions. The first day I attended the group, there was time when I felt like the session was touching my heart and directly to my personal issues. When we worked on the goodbye letter, this was the beginning of hope for me. This letter helped me so much and after completing it I felt so much better. The following day was Sunday, I woke up a bit tired, I went into my room and read the letter again. After the reading I again felt so comforted. I came to this last session with so much joy within me.'

'Our healing will be connected to the growth of this tree.'

In efforts to understand the impact of their work, the Bethesda team reported several key inter-related principles of their approach:

- **Being identified as neutral** – to avoid politicisation of the work, which has been a prominent issue in the Ebola outbreak to date, Bethesda makes sure to explain their long history supporting grieving communities in Beni, from before the onset of this Ebola outbreak. Many families report feeling safer to engage with Bethesda staff as they are not connected with the Ebola response and are already accepted as part of their community. This allows families to share and express themselves knowing that it won't bring *'trouble'*.
- **A light touch approach** – being humble and sitting with people, without being associated with expensive cars or equipment, has been central to this process. Not only does this draw less attention and protect the privacy of families, it sends a message that Bethesda are there only to be with them, without other intentions.
- **Showing we care** – being present with families over a period of multiple weeks without interruption, empathising with their pain and grief, helps them experience another level of *'care'*. Through understanding in the very first meeting that Bethesda care and want to listen to them, families are been willing to engage in the process.
- **Localised, cultural expertise** – being familiar with the cultural customs of the area, whilst having mental health and psychosocial support expertise has been crucial. Families are planting trees at the culmination of the process, as part of the memorialisation ceremony. In the Nande culture, a *'mahero'* is considered a secret place, a place of honour for those who have died. A tree that is planted to represent *'mahero'* is called *'muhumo'* or *'mulubma'* - and is believed to have both cultural and spiritual meaning, which has been central to the significance of the tree-planting ceremony.
- **Facilitate the supportive power of family and community** – the natural support systems within family and community networks are often the most powerful, but are easily unsettled in times of crisis (IASC, 2007). One of the challenges Ebola has brought to North Kivu is the disruption of normal social and cultural ways of living. Bringing grieving families together can communicate a sense of togetherness as coping mechanisms are shared, new meanings are co-created, and the foundation for ongoing practical and emotional support is set. The sessions become a unique place to reconstruct, even on a small scale, the needed sense of community.
- **Let them lead** – where possible in the process, the family groups decide and lead the action. This involves the choice to participate, the decision of where the family meetings should take place, the decision of what the ceremony for memorialization will look like – including where, when and how it will happen, what food will be shared and what type of tree will be planted. In this way families lead how they would like to be worked and the sessions are ultimately *'about them'*.

RECOMMENDATIONS

Bethesda will continue to provide these support processes to affected families in Beni and Mangina. However, as a relatively small organisation they recognise their capacity is limited, and therefore advocate for the reinforcement of current capacity within the Ebola response to bolster these initiatives. Families recommend that memorialisation processes should include the construction of graves, with a cement or tile grave marker, as is customary within a year of the person's death. This can give families another chance to come together, mourn and remember their loss. The process could be supported by government or other actors, to show further solidarity with families of Ebola victims, and be a positive action to the wider community.

The CPPSS needs to continue to be well-funded and equipped in order to fulfil its function in the Ebola response. Contextually appropriate grief and memorialisation work could become more emphasised in their work, perhaps learning from the experience of Bethesda and other actors in this space.

Building on recent improvements to SDB practices and related psychosocial support, various activities are recognised as having critical importance: a) involving communities in the adjustment of burials protocols to ensure they are locally appropriate and acceptable, b) keeping family members well informed and facilitating their direct engagement with

burial practices, and c) providing additional, sustained and culturally appropriate psychosocial support. These actions should continue moving forwards, supported by excellent communication and coordination between the SDB and Psychosocial Commissions. Importantly, psychosocial considerations should always be integrated from the outset of SDB activities, rather than as a reactive response ‘when things go wrong’.

Importantly, due to cumulative stressors resulting from years of conflict and poverty, and the relative absence of mental health services in North Kivu, Ebola should not be only the focus of funding, individuals and families need ongoing and long-term support beyond the emergency programs (see further discussion in Jones & Bedford, 2019). This may require a strategic mental health and psychosocial support recovery funding plan that builds the efforts of local initiatives, not only outside or international initiatives.

Finally, through the thorough dissemination of this document, the core principles identified through the process should be taken on-board by all sectors of the Ebola response. Identifying as neutral, taking a light touch approach, showing you care, localised and cultural expertise, facilitating the supportive power of family and community and letting communities lead - are all key to curtailing the outbreak.

REFERENCES

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ⁱ Number of suspected and confirmed cases. WHO, External Situation Report 60, 8 October 2019. file:///Users/tj/Downloads/SITREP_EVD_DRC_20191008-eng.pdf

ⁱⁱ In order to prevent the spread of Ebola through the handling of dead bodies, burials are carried out by teams who trained to bury the body in a ‘safe yet dignified’ manner, in-line with Infection Prevention and Control measures. <https://www.who.int/csr/disease/ebola/training/safe-burials/en/>

ⁱⁱⁱ ‘Ambiguous loss’ refers to when an experienced loss is not verified, the grieving process is frozen and the natural human need for meaning, sense, knowledge, connection and ritual is denied. This void and the ‘presence of absence’ can have a continuing and devastating impact on everyday life and long-term mental health. Although ‘ambiguous loss’ is most often reported in conflict settings, it is also evident in communities affected by Ebola when ‘normal practices’ are disrupted, as when a person is admitted to an ETU and their family is not informed of his / her death before burial; the family cannot engage with the body (e.g. to view it after death) or be involved in SDB practices; and/or the body is buried away from their community.

^{iv} Multiple organisations including the IFRC and the National Society of the Red Cross in DRC, UNICEF, WHO, Oxfam, other INGOs and local partners are compiling community feedback and conducting operational research in North Kivu and Ituri provinces. According to organisations working on the ground, community feedback and research findings are analysed and discussed in Ministry of Health-led Ebola coordination structures to adjust and improve response actions. These structures include the Emergency Operations Centre, various Commissions (particularly the Communication Commission), and working groups on community feedback established in Butembo and Katwa. The IFRC (with support from CDC) has been systematically collecting and analysing community feedback gathered from the National Society of the Red Cross since August 2018.

^v UNICEF is co-leading the Psychosocial Commission with the Ministry of Health. Partners include: Danish Refugee Council (DRC), Alliance for International Medical Action (Alima), Division Provinciale des Affaires Sociales (DIVAS), Division de l’Interieur (DIVInter)

^{vi} The key elements of the CPPSS strategy include the provision of: 1) psychosocial support for Ebola confirmed and suspected cases, including children, in the ETCs; 2) material and psychosocial assistance to affected families to better support children; 3) psychological support of contacts to support the Surveillance Commission in their listing and follow up; 4) psycho-social assistance, socio-culturally appropriate care and research for long-term solution to orphans and unaccompanied children; 5) support to specialized staff for assisting children and families with more severe psychological or social needs, especially regarding Ebola survivors; and 6) integrating mental health and psychosocial support in the different components of the response (vaccination, decontamination procedures and organization of SDB etc.).

^{vii} Réponse Ebola EOC – Commission Psychosocial. Nord Kivu, Sud Kivu et Ituri – Aout 2019.