Death, Dignity and Palliative Care during a Pandemic

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During the current global pandemic, the world is facing devastating loss of life, often under difficult and unprecedented circumstances. COVID-19 has caused 400,000 reported deaths worldwide to date (08/06/20). During our COU**NTD**OWN cross-country call with partners from Liberia, Cameroon, Nigeria and Ghana, we discussed the impact of COVID-19 in our specific country settings. Questions around burial guidelines were raised and its impact on communities. This blog will reflect on how COVID-19 has changed funeral practices across the world, the impact this has had within communities, including implications and considerations around palliative care.

COVID-19 has presented exceptionally challenging circumstances around the loss of life. Compounded by physical distancing and limits on visitation in preventing transmission, many patients have passed away, isolated and without the physical presence of their relatives. While the statistics are staggering, each number represents the loss of a loved one, leaving behind family, friends and communities who have been unable to grieve through traditional funeral and burial practices. Funerals are rooted in tradition, ceremony, and often encompass sacred and spiritual elements. In every culture, funerals bring communities together; mass funerals are commonplace in West Africa. Many customs and burial rites have been practiced for centuries and play an important role in the process of grief. However, social distancing regulations around COVID-19 have placed restrictions on funerals across the globe, with many cultural traditions being unable to be fulfilled, resulting in further distress of bereaved individuals.

Funeral and burial guidelines during COVID-9 vary country to country. However, general guidelines include holding ceremonies in well-ventilated spaces, limiting the number of attendees, with social distancing in place and ensuring hand hygiene. In the UK, the number of mourners has been recommended to be kept as low as possible and to maintain a minimum distance of 2 metres between attendees. Gatherings of no more than 20 people have been prohibited in Nigeria, while in Cameroon, the limit is 50. Although families can prepare the grave in Cameroon, the bodies of the deceased are solely handled by health workers. Across all country contexts, due to physical distancing, mourners are forced to attend without the usual comforts and simple gestures of a hug or handshake. Within West African culture, food and drinks are often exchanged, and singing and communal prayers take place during funerals. However, it is now not possible to follow these practices. It has been reported that these restrictions have caused distress to many communities; as Ramtin Arablouei puts it, 'Coronavirus is stealing our ability to Grieve'.

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Our partners in Cameroon mentioned that restrictions around visitations and burials have resulted in denial of COVID-19 and mistrust within communities of health workers. Many are reluctant to accept that they cannot attend to sick family members or bury those who have died. This situation is not unique to COVID-19 as issues of mistrust and denial occurred during the Ebola outbreak. In the case of Ebola, bodies remained highly infectious therefore most burials were conducted by Ebola response teams and the Ministry of Health prohibited traditional funerals in Liberia. Initially,

cremations were mandatory and often conducted hastily, which went against religious and traditional Liberian practices. This was met with staunch opposition from community members who were highly disturbed and upset by these policies, resulting in significant psychosocial impacts on many bereaved members. However, as the epidemic progressed and opposition from the public increased, NGOs such as the Red Cross and Red Crescent adapted protocols to allow for safe and dignified burials, balancing needs of the community and ensuring public health priorities. Adapted World Health Organisation guidelines focused on inclusion of family members and local faith leaders in the burial process, honouring cultural and religious practices where possible. Customs, particularly within Islamic communities, often include relatives washing and preparing bodies of loved ones for funerals. The WHO guidelines suggested adapting these practices to create safe alternatives. For example, although washing and contact with the body was prohibited, family members were allowed the option to sprinkle water over the body to allow some semblance of traditions to continue.

Lessons learned from Ebola demonstrate that mistrust and opposition to protocols and guidelines occur amongst the public when they are implemented by external entities, without engaging the community. In the context of COVID-19, this has also been suggested as good practice with a focus on collaboration with families, community and religious leaders in order for adaptations to be culturally sensitive and context specific.

Other adaptions to traditional funeral practices have also been practiced in the wake of COVID-19. For example, people have adapted by using virtual platforms, such as Zoom to livestream funerals or memorials. However, this may not be possible where there is a shortage of smart technology and internet connection, particularly in low resource settings. In the Democratic Republic of Congo, experiences from Ebola have been reflected in how traditional funeral practices of the Nande culture have been adapted by a group of Congolese counsellors and a psychologist, the Bethesda Counselling Centre. This includes gathering relatives to pray, share stories, music and photos of their loved ones. Writing letters to the deceased is encouraged as a form of closure, which many are denied in the context of epidemics. Planting trees or flowers in the memory of loved ones has also been practiced as an adapted ceremonial rite. Ebola responses in Uganda also included grief counsellors who had previously supported patients dying from HIV/AIDS.

The pandemic has highlighted the need for palliative care. In Pursuing a Good Death in the Time of COVID-19, Wang et al (2020) recommend that communication is key regarding options on end of life care with patients identified as being at high risk of deteriorating conditons, and including their next of kin in these discussions. Video calls have been used as a way for patients to communicate with relatives and friends, as well as providing PPE for visitors where possible. However, health workers in the Global South often have little or no training on palliative care. The African Palliative Care Association advocates for the integration of palliative care into health systems. Recommendations for training on palliative care include communication skills, and symptom management such as breathlessness, agitation, delirium, fever and pain to improve the quality of life for patients. However, there are often shortages of medication such as opioids used in palliative care in low and middle-income countries. Thus, training needs, resources and psychosocial support for health workers must also be addressed.

"How people die remains in the memory of those who live on." ***(Dame Cecily Saunders)***

The magnitude in the loss of lives due to the pandemic has forced many of us to reflect on mortality. 'The new normal' comes with adjustments on how we live day to day but also in how we experience death and grief. COVID-19 has reshaped culture and traditions of funeral and burial practices around the globe. Community engagement and consultation with next of kin is crucial when adapting public health guidance. However, the difficult, unprecedented circumstances surrounding loss during COVID-19 is likely to have enduring psychosocial impacts on individuals and communities. Therefore, holistic care including mental health needs and dignity should be central in pandemic responses, in both life and in death.