MHPSS considerations in burial practices and responses to grief and loss during COVID-19
MHPSS Technical Working Group South Sudan

(June 2020)

This guidance note aims at presenting key MHPSS considerations to help patients in palliative care due to COVID-19, workers confronted with grieving families and people experiencing the loss of loved ones. Different topics are addressed including:

1. **MHPSS support for patients at the end of life and their families**
2. **MHPSS considerations for burials and funeral rites/ ceremonies**
3. **MHPSS recommendations during grieving and mourning**
4. **Stress Management for Safe and Dignified Burial Teams**

1. Key MHPSS considerations for dying patients and their families

COVID-19 is an infectious disease that is not only posing significant risks to public health, but also challenging the way people die and are mourned by their loved ones. The COVID-19 pandemic has created concerns relating to visiting patients, preventing the opportunity to hold someone's hand, have a last meaningful conversation, affirm a bond, make amends, or simply say good-bye. Further causing distress is the haste with which the dead bodies are handled.

The presence of family is vital to ensure an end of life that is dignifying, at a crucial time of the human experience. It provides comfort not only to the dying patient, but also to those present, and the inability to be present can be a source of anxiety, distress and moral injury. Physical distancing restrictions related to COVID-19 have meant that many individuals are dying – or facing the prospect of dying - without the presence of loved ones around them, causing them feelings of isolation and psychological distress.

Psychosocial impact of COVID-19 restrictions in South Sudan.

In South Sudan, family members are an integral part of patient care and support. Family members accompany patients to health facilities and support them emotionally and logistically, providing food and negotiating treatment with health workers. Preventing visitors can adversely affect trust in the health response teams and can be a major deterrent to engagement with response actions and precautionary measures applied.

Mitigation measures

In response to concerns about the psychosocial impacts of restrictions, many countries have implemented approaches that facilitate a level of connection between the dying person and their loved ones. Some countries allow family members to enter the patient's room to say goodbye, provided that Personal Protection Equipment (PPE) is worn. Other countries rely on remote means of communication such as mobile phones. Donated phones and tablet devices have made it easier for coronavirus patients at hospitals around the world to communicate with their loved ones, and for priests, imams and other religious leaders to provide the last rites remotely. In other cases, healthcare workers are themselves standing vigil for dying patients, to ensure that they do not die alone.

The level of psychosocial support available for patients and family members needs to be carefully considered and provided to the right people at the appropriate time. A major role of MHPSS workers in this context is to provide support to healthcare staff, and to help create a protective and humanized environment. The latter refers not only to facility –based but also home-based care as most of the patients suffering from Covid 19 in South Sudan may be taken care of at home and in their respective communities.

Key considerations

1. Explore ways of enabling interaction between a patient and loved ones and/or spiritual advisors in a manner consistent with physical distancing guidelines. Approaches should be developed in consultation with the wider community, including local leaders, religious leaders and influential organizations and associations. They may include the facilitation of virtual visits or the use of PPE for in- person visits. Family should be supported to minimize harm to themselves and those they subsequently come in contact with. Some **safeguarding recommendations** include:

    - All patients dying from COVID-19 within hours or days should be entitled to contact with family members, with his/her consent.
    - Visitors should provide informed consent that they understand the personal risks associated with visiting, after being informed of all precautionary measures.
    - If a PPE is not available, visitors must agree to undertake the subsequent isolation and quarantine restrictions appropriate to the contact that has occurred in association with their visits, to protect others they come in contact with.
    - In all cases, visitors must consent to wear Personal Protective Equipment and undertake all other relevant hygiene requirements equivalent to that used by care staff in the specific care facility. Support should be provided to put on and remove equipment as necessary.

2. A patient's current or previously known wishes about their own end of life should be taken into account (preferred location for burial, funeral rites, etc). However, honesty and integrity about the restrictions regarding the end of life must be communicated transparently to avoid frustrated expectations ofboth patients and families.
3. If arrangements cannot be made for virtual or other visits, healthcare workers or other care staff should be present to provide end-of-life companionship and family members should be informed of this.
4. Adequate psychosocial support should be available for patients, families and healthcare staff involved.
5. Clinical teams in more acute settings, particularly Intensive Care Units, should receive support by MHPSS counsellors in communicating with a patient's family , enabling them to focus on direct patient care.
6. Care facilities should support families who cannot visit by providing access, or facilitating referral to those who can do it, to and support in the use of mobile or handheld communication devices to patient and family, particularly if a family cannot provide these for themselves.

2. MHPSS considerations for burials and funeral rites/ ceremonies

As countries face rapidly increasing numbers of deaths by COVID-19, guidelines for management of dead bodies may change rapidly and entail practices that were previously uncommon or unnecessary. Physical distancing measures have limited the numbers of mourners allowed to attend funerals and other burial rites; in some cases,

these gatherings have been prohibited altogether. Such changes to customary practices can have profound psychosocial and wider cultural impact.

Psychosocial impact of changes in mortuary practices.

In times of grief, people expect and rely on a degree of certainty regarding what will happen to their loved ones. Changes in mortuary practices during the COVID-19 pandemic have altered normal and predictable care for the deceased. Engagement with communities and good communication are essential and will encourage acceptance of changes in mortuary practices.

Physical distancing restrictions are making it hard for people to come together socially with other mourners to grieve, spend time with or pay their final respects to the deceased, provide support to one another, and/or find comfort in their cultural or secular traditions, thereby contributing to grieving challenges and feelings of isolation.

Given the serious psychosocial impact and distress caused by uncertainty associated with care for the deceased, it is important that communication between the family and those caring for the deceased be ongoing, open and detailed to remove as much uncertainty as is possible. Acceptable care for the deceased may differ according to religious, ethnic and cultural group and it is essential to guard against actions that may be perceived as disrespectful or contrary to existing traditions.

When loved ones do not have the opportunity to say good-bye and cannot come together to provide physical comfort, they may not have the necessary closure – mourning without a dead body is an **ambiguous loss**. Family members may feel anger at those that have put the restrictions in place; regret at not having had a chance to hold someone's hand or make amends; worry that a loved one may not be given appropriate care or necessary pain relief; and guilt over one's own powerlessness and inability to be with a loved one in their time of need.

Preparing the deceased (washing, dressing and/or shrouding the body) has great significance in many religious practices. International guidelines are not clear of the risk of posthumous transmission of COVID-19, although some reports suggest the virus may survive on clothes in the immediate hours after a person's death. Such inconsistencies have led to confusion about what constitutes safe procedures, despite the low risk of transmission after death. In response, countries have introduced a wide range of policies and recommendations[1] for caring for the deceased by mortuary personnel and family members.

Community acceptance is essential to the successful uptake of any policy related to burials, particularly in an emergency context. Opposition to funeral practices may result as part of broader resistance to epidemic response measures, particularly when there is lack of trust or misinformation. Opposition to changes in funeral practices during a pandemic may also result from the failure to fully understand local customary practices, to involve community members in planning alternative practices, or to fully explain modifications and why they are needed. Working with community members helps to balance their needs and public health measures, creating more acceptable guidelines.

[1] Standard Operating Procedures for Dead Body Management in South Sudan. Juba: June 2020

Key Considerations

1. Up-to-date and accurate information regarding the handling of those who have died from COVID-19 should be clearly communicated to people who care for the deceased.
2. Families should be informed in a careful, timely and compassionate manner about what will happen with the remains of their relative and expectations must be sensitively managed. Community and faith leaders can support this process.

Changes to established funerary practices as a result of an epidemic response have sometimes elicited community opposition. Evidence from previous epidemics demonstrates that people are willing to adapt practices, provided ***(i) the new practices meet the symbolic, social and emotional needs of the original ceremonies and practices, and (ii) affected communities themselves are involved in the formulation of any proposed changes.***

3. Families should understand the different steps that will be followed and be assured that they will be able to retrieve their loved ones' ashes or identify the burial site. Family members should be encouraged to ask questions and fully participate in decisions regarding the deceased, within appropriate safeguarding measures.
4. Identifying a representative/spokesperson for the family may facilitate communication regarding burial aspects and concerns, by focusing on one individual only for providing information and receiving feedback, other than managing different family members in an already stressful situation.
5. During COVID-19 there have been numerous examples of **rituals and ceremonies** taking place remotely (e.g. memorial between family members in a different location; lighting candles and putting flowers around patient's picture; writing a letter to say goodbye, reading it out loud and burning it; burying a dear possession of the patient, etc.).
6. In many settings, the bereaved are encouraged to plan a ceremony or memorial, to be held once restrictions are lifted in the cases where it entails gatherings or traveling. The act of planning such an event may provide some immediate support. Practices that are chosen and managed by the family and their community, aligned with cultural values, will be the most beneficial.

3. MHPSS recommendations during grieving and mourning

Grief is a normal response to loss, and for many, coming together for a funeral or other cultural ritual to honor the death of their loved one is an essential part of the bereavement process. COVID-19 has complicated the process of mourning due to the ambiguous loss (grieving without a body). These circumstances may increase the likelihood of one experiencing disrupted, complicated or prolonged grief.

Identifying Psychological Distress

Individuals experiencing disrupted, complicated or prolonged grief are at increased risk of **substance use, sleep disorders, impaired immune functioning and suicidal thoughts.** While spiritual leaders are themselves being restricted from being with individuals as they pass and performing any last rites of passage, they can be a source of comfort to loved ones to help them cope with the loss. Mental health providers can help with disrupted, complicated or prolonged grieving, by supporting family members with psychological interventions or counselling services.

Psychoeducation key messages for people experiencing Grief and Loss:

- **Normalizing grief**: Emotional pain is inevitable after experiencing the loss of a loved one, so mourners should be encouraged to accept their feelings and rely on the support of their friends and family during the grieving process. Each person takes different time to mourn, and no one should be pressured to recover, but rather take his/her own time to recover and ask for support if needed.
- **Holding on to believes and faith** (if the person/family is religious): Faith and believes about the meaning of life and death can help mourners to find emotional peace.
- **Normalizing Guilt and Anger**: People can feel guilty and/or angry about the death of their loved. They may feel that the person did not receive enough care or feel guilty for being distant. Explaining that guilt is as normal human reaction to loss and helping the person to focus on the good memories he/she has from his/her loved one could help to relieve the pain of the mourner.
- **Advising family members to maintain social connectedness** (while applying physical distancing measures for those living in different households, e.g. using phone, whatsapp, etc.).
- **Inform people of where they can be supported** for basic needs (provisions, medicines, etc.), if needed, as well as how to access counselling or mental healthcare.
- **Remind mourners and their families to stay healthy**: While sleeping patterns and appetite may become affected as a consequence of the loss, people should know this is a natural and otherwise expected consequence, while also being encouraged to try to resume their normal patterns, namely by going to sleep and going out from bed at usual times, and not skipping meals.

Counselling recommendations during Bereavement

- Normalizing the grieving process
- Allowing for the memories and stories of the deceased person to be verbalized
- Allowing for emotional ventilation and validation of the emotional experience
- Helping the person to find closure, and emotional peace
- Activating support systems – faith leaders, family members, community - to accompany the person throughout the process, provided the necessary physical distance
- Regular follow-up to check in on mental health and assess any risks

If symptoms like the ones listed below appear, or the experience of pain and depression intensifies over time, impairing the overall functioning (e.g. preventing to carry out normal activities); the person will need a referral to **specialized mental healthcare**:

Red Flags:

- ***Sleeping poorly, too much (not wanting to get out of bed) or too little, for more than 2 weeks***
- ***Avoiding others, becoming progressively isolated or withdrawn to the point of not taking care of self/others***
- ***Feeling disconnected from reality or acting in an unusual and bizarre way***
- ***Feeling anxious or alert all the time***
- ***Having panic attacks***
- ***Uncontrolled anger or using violence towards others***
- ***Drinking more alcohol or taking more drugs than prescribed***
- ***Having little patience for children, to the point of hitting them or being unable to care for them***
- ***Intense feelings of despair, leading to suicidal thoughts***
- ***Self-harming and/ or Suicide attempt***

4. Stress Management for Safe and Dignified Burial Teams

In specific Protection of Civilian (PoC) sites in South Sudan burials are organized by teams which follow standard operating procedures on "Safe and Dignified Burials (SDB)". In South Sudan, the Camp Coordination and Camp Management (CCCM) cluster has further specified responsibilities for each settlement location. The SDB teams must receive training including MHPSS considerations, community and family engagement and stigma reduction.

Despite the preventative and safeguarding actions taken, safe and dignified burial teams are exposed to high levels of stress, as well as conflicts and misunderstandings with family and community members. Dealing with burials and the grief of family members is likely to exacerbate stress levels, including **sleeping difficulties, nightmares or negative thoughts.** Volunteers and staff should have a **self-care plan in place** that includes scheduling time for rest, relaxation and leisure; and regularly monitoring negative emotions, psychological and physical discomfort. Other recommendations to manage the stress of SDB teams are the following:

- Managers should provide basic support such as transport, PPE kits, materials and tools, incentives, etc. to staff and volunteers. These should include MHPSS considerations (e.g. paying for coffee, sugar or other materials that are used during the burial and mourning ceremonies).
- Training in MHPSS considerations, stress management and conducting regular meetings to review guidelines, community leaders' suggestions, concerns, fears, threats and ethical dilemmas are advised.
- The creation of a peer support group and/or a buddy system can help to create safe spaces where staff and volunteers can listen and support each other.
- A supportive supervision for staff and volunteers is highly recommended, highlighting aspects of self-care and stress management.

MHPSS Resources for Burial Practices, Grief and Mourning

- Key Considerations: Dying, Bereavement and Mortuary and Funerary Practices in the Context of COVID-19 Author: Social Science in Humanitarian Action (April 2020)
- Assessing Key Considerations for Burial Practices, Death and Mourning in Epidemics Author: Social Science in Humanitarian Action (April 2020)
- 'We hear you, Dad' A Daughter Stays on the Phone for Hours and Hours as Her Father Dies Alone From Coronavirus Author: Trevor Hughes (20 April 2020)
- Relearning Ways to Grieve Author: Harvard Gazette (21 April 2020)
- Palliative Care Guidelines for COVID19 Author: Task Force in Palliative Care (April 2020)
- How to Tell Children That Someone Has Died Author: University of Oxford (March 2020)
- Contacting Relatives by Phone to Report Death Author: University of Oxford (March 2020)
- Implications of COVID19 – Patients and Family at the End of Life Author: Marie Cure (April 2020)
- Management of the Dead Under Islamic Law Author: ICRC (21 April 2020)
- Communicating with Children About Death, and Helping Children Cope With Grief – English French Portuguese Spanish Authors: The MHPSS Collaborative for Children & Families in Adversity and Child Protection (24 April 2020)
- Guidance on Safe Religious Practice for Muslim Communities During the Coronavirus Pandemic Author: Islamic Relief Worldwide (April 2020)
- Mourning for a Loved One When You Cannot Attend Funeral Services Authors: Save the Children & Child Protection (10 May 2020)
- "Psychology Works" Fact Sheet: Grief, Bereavement and COVID-19 Author: Canadian Psychological Association.