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Bereavement support on the frontline of COVID-19: Recommendations for hospital clinicians

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Abstract

Deaths due to COVID-19 are associated with risk factors which can lead to prolonged grief disorder, post-traumatic stress and other poor bereavement outcomes among relatives, as well as moral injury and distress in frontline staff. Here we review relevant research evidence, and provide evidence-based recommendations and resources for hospital clinicians to mitigate poor bereavement outcomes and support staff. For relatives, bereavement risk factors include dying in an intensive care unit, severe breathlessness, patient isolation or restricted access, significant patient and family emotional distress, and disruption to relatives' social support networks. Recommendations include advance care planning; proactive, sensitive and regular communication with family members alongside accurate information provision; enabling family members to say goodbye in person where possible; supporting virtual communication; providing excellent symptom management and emotional and spiritual support; and providing and/or sign-posting to bereavement services. To mitigate effects of this emotionally challenging work on staff, we recommend an organisational and systemic approach which includes access to informal and professional support.

Key words: Bereavement, Grief, Coronavirus, Pandemics, Palliative Care, Family Caregivers

Running title: Bereavement support in COVID-19

Introduction

At the time of writing, there have been over 190,000 deaths globally from COVID-19, with an estimated 0.95 million people bereaved. Although the true impact of COVID-19 is as yet unknown, considerable levels of grief and bereavement will follow.

Bereavement is a natural part of the human experience, but can be intensely painful and negatively impact on physical and mental health. Approximately one in ten bereaved adults develop Prolonged Grief Disorder (PGD)(1), which involves intense symptoms of grief that endure for more than six months post-loss, separation distress, intrusive thoughts, and feelings of emptiness or meaninglessness.

Wallace et al. describe the types of grief associated with the COVID-19 pandemic and provide useful general guidance for its mitigation(2). Here, we review bereavement risk factors in COVID-19, provide evidence-based recommendations for how to support bereaved relatives (Table 1), and highlight additional resources (Table 2).

Dying in hospital, advance care planning and communication

Most deaths from COVID-19 currently occur in hospital. Advance care planning (ACP) discussions would ideally have been documented prior to admission and revisited in hospital(3). However, if ACP has not yet occurred, then at this stage ACP and parallel planning (preparing for the worst while hoping for the best) are essential(2, 4) (Table 1). ACP aims to understand patients' unique perspectives on what gives life meaning and helps ensure care is consistent with their values. This includes helping patients avoid unwanted or non-beneficial high-intensity treatments(5). Planning for future care also prepares family members for the death of their relative and leads to better outcomes after death(6).

INSERT TABLE 1

Some of the most critically ill patients with COVID-19 are admitted to and may die in intensive care units (ICUs). While for some patients this will be clinically appropriate and in line with their preferences, among surviving relatives ICU bereavement is associated with poor mental health outcomes including PGD (5%–52%), post-traumatic stress disorder (PTSD) (14%–50%) and depression (18%–27%)(7-9).

Whether or not a patient dies in ICU, we know that clear, complete communication by healthcare providers improves bereaved relatives' satisfaction with end-of-life care(6), and that families appreciate proactive, regular and sensitive communication and accurate information(6, 10, 11). Conversely, poor communication with relatives is associated with PGD(7).

Specific communication strategies that increase family satisfaction include: empathic statements assuring non-abandonment, assurances of comfort, and provision of written information(12). Conversation Analytic research has identified communication practices useful in end of life care(13) and has been incorporated in COVID-19 training (Table 2). Family conferences informed by the "VALUE" mnemonic have been found to lessen bereavement burden(10).

INSERT TABLE 2

In COVID-19, communication at the bedside is challenging, as health professionals need to wear personal protective equipment (PPE). The de-personalisation of protective clothing and communication through a mask and visor is testing, particularly when a patient is frail or hearing impaired; however, guidelines and flashcards are now available (Table 2). Regular telephone communication is vital, with Swiss guidance recommending twice-daily calls to family members when a patient is seriously ill or dying, and families being told when a patient is "sick enough to die"(14). Telephone communication is understandably difficult, particularly when breaking news of a death, but there are resources to support staff (Table 2).

Palliative care, whether generalist or specialist, plays a central role in responding to COVID-19. Specialist palliative care involvement in the emergency department reduces hospital length of stay and ICU admission(15), while in the ICU it decreases hospital and ICU stays(16). Early palliative care consultations also improve bereaved relatives' perception of the quality of end-of-life care(17). However, as specialist palliative care is a limited resource, consultation and referral will need to be triaged(18), with input focussed on supporting and coaching primary teams, often digitally or via telephone(19).

Patient isolation, family access and virtual communication

An additional risk factor for poor bereavement is the need to isolate patients to control the spread of COVID-19. Restricted access to a patient and not being able to say 'goodbye' are distressing to relatives(9) and associated with PGD and PTSD in bereavement(7).

If relatives are not in a high-risk category, in quarantine or unwell themselves, it is therefore recommended that access be granted for short periods(14). Ideally, patients will have single-occupancy rooms to allow quiet and privacy to spend time with relatives(11). However, for many relatives visiting may pose a significant health risk. There may also be shortages of PPE for relatives or a lack of staff to assist relatives with donning PPE, particularly where testing of healthcare staff is insufficient.

It is therefore also recommended that clinical teams help enable patient-family communication via virtual means, following infection control guidelines for devices – particularly if an in-person visit is not possible (Table 1). However, Swiss guidance does not recommend virtual contact between patients with COVID-19 and their families when a patient is actively dying(14); previous studies have found an association between relatives witnessing death in ICU and higher rates of both PGD and PTSD(7, 8).

Symptom management

The breathlessness(4) associated with COVID-19 may also be problematic for bereavement. Severe shortness of breath in patients can be highly distressing to relatives(9). Among bereaved caregivers, the perception that a patient could not breathe peacefully is associated with a higher risk of PTSD, and a patient dying while intubated is associated with both PGD and PTSD(7). Conversely, there is evidence that withdrawal of life-prolonging interventions and extubation before death increase satisfaction among bereaved family members(12); withdrawal should be clearly explained and in the context of good symptom control(20).

Emotional and spiritual distress

Patients who are seriously ill with COVID-19 and their families are inevitably anxious, afraid, alone and in need emotional support, yet this is an area in which hospital care has been found lacking(11, 21). In addition to considering pharmacological and non-pharmacological interventions(4), attending to the tenor of care is key. Care for the patient and family should provide for physical comfort, autonomy, meaningfulness, preparedness, and interpersonal connection(22) and be mindful of the "ABCDs" of dignity-conserving care (attitudes, behaviours, compassion, and dialogue)(23). Care must also respect cultural and religious diversity, and staff require cultural competence to provide appropriate support to families whose cultural and faith background is different from their own.

Bereaved family members may question why they have survived when their loved-one did not, feel guilt over possibly transmitting the disease and a loss of coherence or meaning, and mourn the loss of future dreams and hopes(4, 24). Relatives' perception of whether a patient received emotional support at the end of life is a determinant of their experience of bereavement(21). Greater attention to the dying patient's emotional well-being help limit relatives' distress(9). Showing respect and compassion and comforting bereaved relatives mitigate poor outcomes and dissatisfaction(6). All frontline staff should be able to provide the basics of culturally sensitive bereavement support and signpost to specialist services(25).

Access to spiritual support at the end of life is important for many patients and families, whether or not they are religious, but this is an aspect of care somewhat neglected in acute hospitals(26). As in humanitarian crises, spiritual care during COVID-19 will include helping individuals face and overcome fears and find hope and meaning; attending to existential suffering; addressing feelings of punishment, guilt, unfairness, and remorse; assisting when people need to confess or reconcile; and offering grief support and death preparation assistance(24). While chaplains can play a crucial role in the team and have specialist skills, "spiritual first-aid", based on skilled listening and expressing kindness and compassion, can also be provided by other staff(24).

Grieving in isolation and bereavement support

A common impulse for those experiencing grief is to seek comfort in the arms of family, friends and community. Yet in the context of COVID-19, bereaved family members may have limited social support due to physical distancing requirements, and be forced to grieve alone. Loss of social and community networks, living alone and loss of income are known to exacerbate psychological morbidity in bereavement(7, 27).

Health and social care professionals, and those supporting the bereaved informally, can encourage those who are grieving to express their grief and reach out to others, however they can – online or via telephone, letters and videos. Although these cannot replace face-to-face conversation and physical affection, they nevertheless enable connection in the interim.

While family, friends and existing networks are the foundation of bereavement support, and for many people the only support needed, formal bereavement services play a central role in supporting individuals and families. Poor bereavement outcomes are associated with being a female relative, a spouse, older age, trauma, and lower educational attainment, socioeconomic status and social support(28-30). Awareness of these risk factors can guide information provision and support.

A systematic review of bereavement support in adult ICU identified several interventions: a personal memento, a handwritten condolence letter, a post-death meeting, storytelling, research participation, use of a diary and a bereavement follow-up program. Although evidence for effectiveness was weak, all interventions were well accepted by families(31). Bereaved relatives report that they prefer hospital staff make contact with them following the death of their family member(11). A personalised condolence letter can help to humanise the medical institution, but might also highlight the absence of further support(32), hence bereavement support leaflets sign-posting to services are also important(11). While the best timing of a condolence letter is unclear, it is crucial that letters avoid making commitments (e.g. to provide further information) which cannot be met(33). Organised bereavement support evenings can be a form of comfort and have a positive impact on relatives' grieving process(34).

Another way a pandemic such as COVID-19 disrupts the process of bereavement is by impacting families' ability to hold funerals and other ceremonies(2, 25). Funerals play a key role in mourning, bringing together those who remember the deceased to celebrate their life and creating a supportive network for the bereaved family. Restrictions during the pandemic mean that funerals carried out in this time are unlikely to match the wishes of the bereaved or the deceased. However, it is possible to adapt funeral services using online methods to ensure important people are included, even if attendance isn't possible (Table 2). After the crisis, relatives can ceremonies to remember their loved one, and culturally sensitive bereavement services held in hospitals may be helpful in for closure and to show respect for the dead(11).

The impact of deaths from COVID-19 among staff

In the COVID-19 pandemic, the ICU has been described as the 'frontline of a war' against the disease, with clinicians the 'soldiers in the trenches'. While war metaphors have limitations, we know from the experiences of clinicians in China, Italy, and Switzerland that care of patients with COVID-19 results in major ethical dilemmas and a psychological toll on the health care teams caring for them,

in part due to limited resources(14, 35). Frontline staff are at risk of secondary or vicarious trauma, as a result of repeated empathic engagement with sadness and loss(36), as well as moral injury(37), resulting from actions, or the lack of them, which violate one's moral or ethical code. This can lead to depression, anxiety and post-traumatic distress(38).

We recommend that healthcare leaders and organisations take responsibility and ensure staff are prepared for the emotional consequences of their work, and that resources, guidance and training are in place to safeguard healthcare providers' health(37). Self-care strategies and individual 'resilience tools' such as mindfulness and reflective practice are insufficient; resilience should not become another responsibility of staff working in traumatic conditions, but requires an organisational and systemic response(40). Organisations should actively monitor frontline staff, facilitate effective team cohesion and implement strategies to support teams' day-to-day work, including informal debriefing and peer support. Single-session psychological debriefing approaches should be avoided as they may cause additional harm(39). Leaders and organisations should also make professional sources of support readily available; this includes formal bereavement counselling, which can enhance awareness about vicarious traumatisation and encourage adaptive coping strategies(36).

Conclusions

COVID-19 brings with it new challenges and difficulties in caring for patients and their loved ones, and supporting staff. Evidence suggests several risk factors for poor bereavement outcomes in COVID-19, including severe breathlessness, patient isolation, and disruption to relatives' social support networks. Understanding the risk of trauma and moral injury to staff in the current pandemic is essential for the early identification and prevention of harm. Drawing on best available evidence, we have made recommendations for mitigating negative effects on bereaved relatives and healthcare professionals. These include proactive, sensitive and regular communication with family members alongside accurate information provision; enabling family members to say goodbye in

person and supporting virtual communication; providing excellent symptom management and emotional and spiritual support; sign-posting to bereavement services; and supporting bereaved relatives to adapt funerals and seek appropriate bereavement support, as well as consistent leadership and support for health professionals in the frontline.

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Table 1: Evidence-based recommendations for mitigating poor bereavement outcomes in relatives

Before a patient's death
• Early Advance Care Planning discussions and parallel planning with patients and families
• Timely, proactive and sensitive information provision and communication with families, guided by the VALUE mnemonic: value and appreciate what family members say; acknowledge family members' emotions; listen to their concerns; understand who the patient was in active-life by asking questions; elicit questions from family members
• Where possible, assign a specific contact person for each patient to help ensure continuity of care and timely communication with families before and after death
• Follow expert guidance on tele-communication and communication with PPE (see Table 2)
• Specialist palliative care collaboration, referral and advice; use triage and remote communication where needed
• Optimise symptom management
• Where possible, allow and facilitate a family member to visit a deteriorating patient
• Facilitate virtual communication using smartphones, tablet computers and other technology. Enlist donations to source tablets, smartphones and charging devices (patients are often admitted to hospital with their phones but not chargers). Dedicated equipment with appropriate applications can then be loaned to patients and families in COVID-19 areas.
• To avoid distress, be cautious about virtual communication when a patient is actively dying
• Ensure patients and families have access to emotional, psychological and spiritual support, including access to chaplaincy
After a patient's death

• Some families may want mementoes or keepsakes (e.g. locks of hair, handprints etc.). Local practice may vary; in the UK, these can be taken at the time of care after death, but not at a later date, placed in a sealed bag and not opened before 7 days(41).
• Ensure an involved clinician is available post-mortem to speak and listen to family members, discuss what happened and answer questions via telephone.
• Identify relatives who may be at particular risk of poor bereavement outcomes (e.g. due to social isolation) for enhanced follow-up and support.
• Enlist the support of allied health professionals from other specialties within the hospital, whose workload may have decreased during the pandemic, to help provide psycho-social support to bereaved families.
• Create a COVID-19 bereavement leaflet which sign-posts relatives to local bereavement support available via email, telephone, mobile Apps, web forums, web chats and virtual peer support, and where to get faith-specific advice. These should be given to the family as soon as possible after the patient's death.
• Send a personalised condolence letter. The best timing of a condolence letter is not currently known, however it should be personalised and not make commitments that cannot be met, and include information regarding further support.
• If needed, provide a list of local support services which may be able to provide practical help and support to people who are suddenly vulnerable due to a bereavement and may be self-isolating.
• Provide up-to-date information and guidance on arranging a funeral or other religious ceremony and registering a death, with suggestions and resources for future ceremonies. Funeral poverty may be a concern for many relatives, so signposting towards organisations who can advise on this issue may be helpful.
• Consider providing bereavement support evenings and/or culturally sensitive bereavement services for relatives after the immediate crisis.

Table 2: Resources

Advance care planning in COVID-19	Respecting Choices (US): https://respectingchoices.org/covid-19-resources/#planning-conversations Compassion in Dying (UK): https://coronavirus.compassionindying.org.uk/making-decisions-about-treatment/
COVID-19 communication	Center to Advance Palliative Care (CAPC) COVID-19 Response Resources – includes communication guidance from VitalTalk, the Serious Illness Program and others (US): https://www.capc.org/toolkits/covid-19-response-resources/ Discussion of unwelcome news during Covid-19 pandemic: A framework for health and social care professionals, E-learning for Health (UK) https://portal.e-lfh.org.uk/LearningContent/LaunchFileForGuestAccess/611123
Telephone communication	Patient Safety Learning (UK). Talking to relatives: A guide to compassionate phone communication during Covid-19. 2020. https://www.pslhub.org/learn/coronavirus-covid19/tips/talking-to-relatives-a-guide-to-compassionate-phone-communication-during-covid-19-r2009/
Communication via PPE	CARDMEDIC – Flashcards for communicating with patients in the ICU during the COVID-19 pandemic. 2020. https://www.cardmedic.com/
Information leaflets for hospital admission	Editable leaflets to provide to patients and families (Europe): https://erj.ersjournals.com/content/early/2020/04/07/13993003.00815-2020
Supporting staff	Strategies for Public Service Personnel Leadership (Canada): https://www.cipsrt-icrtsp.ca/covid-19/strategies-for-psp-leadership/ King's Fund (UK): Responding to stress experienced by hospital staff working with Covid-19 https://www.kingsfund.org.uk/audio-video/stress-hospital-staff-covid-19