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Title: Caring for bereaved family members during the COVID-19 pandemic: before and after the death of a patient

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Abstract

Bereavement care is considered an integral component of quality end-of-life care endorsed by the palliative care movement. However, few hospitals and health care institutions offer universal bereavement care to all families of patients who die. The current COVID-19 pandemic has highlighted this gap and created a sense of urgency, from a public health perspective, for institutions to provide support to bereaved family members. In this article, drawing upon the palliative care and bereavement literature, we offer suggestions about how to incorporate palliative care tools and psychological strategies into bereavement care for families during this pandemic.

Introduction

The COVID-19 pandemic has up-ended the way our society functions, including how we care for the sick, the dying and the bereaved. Palliative care clinicians have been called upon to care for patients and their families in ways we have never done before, without many of the tools we usually rely on at end-of-life. In-person patient and family meetings, conversations at the bedside, and efforts to discharge patients to home or to hospice have been replaced with remote conversations, isolation, and the very real possibility that patients will die alone, separated from their loved ones. Similarly, rituals that normally bring comfort and opportunities to access support after a death aren't possible, which can increase feelings of isolation, loss and despair in bereaved individuals.

These factors can all lead to problematic grief reactions after a patient dies. As the medical community works actively to flatten the COVID-19 curve, a sense of urgency now exists for hospitals to get ahead of the bereavement curve. In this article, drawing from the palliative care and bereavement literature, we offer suggestions that clinicians and teams can adopt before and after the death of a patient to help mitigate a difficult bereavement reaction for families impacted by this pandemic.

Background

The death of a loved one is considered the most powerful stressor in everyday life with bereaved individuals at increased risk of adverse mental and physical health outcomes (1,2). How a person copes after the death of a significant loved one is influenced by personality and coping style, the relationship with the deceased, and the circumstances of the death (3). While the majority of bereaved individuals adjust to their loss without requiring professional intervention (4), public health models estimate that approximately 10% of bereaved individuals are at 'high risk' of developing complex grief reactions possibly requiring intervention from a mental health professional, and an additional 30% are considered at 'moderate risk' and might benefit from group support (5). Risk factors for poor bereavement outcomes include a history of past psychiatric issues, lack of social support, a sudden or traumatic death, lack of preparation for the death, a hospital–based death, and a death in the ICU (2,6-8). Following a death in the ICU, specific risk factors for complicated grief reactions, such as prolonged grief disorder and posttraumatic stress disorder, include the patient dying while intubated, family members not able to say goodbye, and poor communication between physicians and the patient's family (9). Clearly, some of these risk factors are heightened for any death during this pandemic, whether the death was a direct result of COVID-19 or not. Patients with COVID-19, however, can have a clinical course that increases these risks, including a precipitous decline and death or, conversely, a prolonged ICU stay.

Families may have other stressors related to the pandemic that can also intensify their experience of a loved one's illness and death. Some families experience

multiple members falling ill and dying within a short period of time. Other families experience financial hardship and are unable to provide resources for their dying loved one. And still other families are prevented from traveling to see their loved ones during their final days, or from visiting them in the hospital, skilled nursing facility, or hospice due to visitor restrictions.

Research demonstrates that palliative care and hospice services are associated with improved family reported quality of end-of-life care (10,11), and better bereavement outcomes for family members (8,12-14). Similarly, in a bereavement study conducted at our cancer institute (15), bereaved family members were asked what they wished the clinical team could have done prior to their loved one's death that would have helped them in dealing with their loss. The most common themes identified included providing more accurate information about prognosis, the end-of-life period and the dying process, earlier referral to hospice and more caregiver support prior to the patient's death. Conversely, when asked what helped them in dealing with their loss, the family members reported compassionate care by the team, including communication that conveyed empathy, caring and concern for both the patient and caregiver. Bereavement outreach from the providers and the offering of condolences were also found to be helpful.

Given that bereavement care is best conceptualized as a preventative model of care (16) and considered a core component of palliative care (17), providing support to families before and after the death of a patient can help mitigate a poor

bereavement outcome. While the development of standardized bereavement programs has lagged behind other aspects of palliative care (16), hospitals must now implement basic bereavement outreach to help support families impacted by the COVID-19 pandemic.

Caring for families prior to the patient's death to facilitate post-loss adjustment

Palliative care provides the framework for caring for patients and their families in the most difficult of circumstances. Even without full access to all of the palliative care tools used routinely to care for patients, there is still much we can do to help families prepare for their loved one's death. Communication skills and trusting relationships are core elements of palliative care; both are even more important now given the increased distress and social distancing associated with the pandemic.

Building upon the repertoire of palliative care tools and findings from bereavement research, Table 1 outlines suggestions that can be used prior to a patient's death that can help promote post-loss adjustment. We have categorized these tools as 1. Communication Skills, 2. Care Processes, and 3. Tools to Promote Connection.

Insert Table 1 here

Caring for families after the patient's death to facilitate post-loss adjustment

It is likely that many bereaved individuals will experience great distress associated with the impact of COVID-19 on the death of their loved one and subsequent bereavement. Routines and rituals, such as wakes and funerals that normally provide comfort following a death aren't readily available, and bereaved individuals will most likely have limited access to practical support from others because of social distancing and stay-at-home orders. They might also have less access to emotional support from family and friends if those people are struggling with worries of their own. Already, mental health clinicians are beginning to see an increase in bereaved individuals seeking support. Experts predict increased rates of prolonged grief disorder and posttraumatic stress disorder in several months' time. As such, it is now crucial from a public health perspective for hospitals to adopt a proactive stance and for clinicians to intervene early.

One important tool in treating complex grief reactions, including prolonged grief disorder, is cognitive behavior therapy (CBT) (18,19). The CBT model proposes that the way we think affects the way we feel and behave. Helping people learn to evaluate their thinking and generate more realistic or accurate thinking patterns improves both their emotional state and their behavior (20). The cognitive model provides a framework for identifying and challenging unhelpful thoughts or beliefs that might result in feelings of guilt, anger or blame (21). For example, during the pandemic, a family member might blame themselves or others for their loved one's

death or feel extreme guilt about not being present when their loved one died. Helping them shift their perspective and in turn, the level of responsibility they endorse, can lead to healthier coping.

Table 2 includes CBT strategies along with other tools to help clinicians and teams support recently bereaved individuals. Based on an education, guidance and support model (16), these strategies promote a healthy integration of the loss (21). Many of these strategies are relevant soon after the death of the patient. Others are applicable at a later date and/or within the context of a therapeutic relationship.

Insert Table 2 here

Conclusion

Bereavement care is an integral component of quality end-of-life care (17). However, few hospitals and other health care institutions offer universal bereavement care to all families of deceased patients. Given the current COVID-19 pandemic, there is an urgency from a public health perspective, to expand bereavement services in an attempt to mitigate poor bereavement outcomes, including prolonged grief disorder and other psychiatric disorders. We recommend that all hospitals implement basic bereavement outreach, utilizing palliative care tools and psychological strategies to prepare families for the death of their loved ones and to support them afterwards in the initial months of their bereavement.

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Table 1: Tools for caring for families prior to the patient's death to facilitate post-loss adjustment

CATEGORY	TOOL	RATIONALE/FACTORS TO CONSIDER
Communication Skills	Acknowledge the effect of the pandemic: "These are unprecedented times."	Helps to externalize the problem, set realistic expectations within a CBT model, especially about social distancing and hospital visitor policies. (3)
	Facilitate conversations with the patient and family, or with provider, patient and family	Use virtual platforms as needed and include children as appropriate. (9,17)
Care Processes	Assign a clinician or other team member to check in with the family regularly	Provides guidance and reassurance and helps to lessen feelings of anxiety. (15,22)
	Screen family members for distress and risk factors for poor bereavement outcomes, provide support	Helps mitigate a difficult bereavement reaction, especially important during the pandemic. (17,23)
	Provide family members with up-to-date information, especially in the end-of-life period	Helps to align expectations with reality and prepare for their loved one's death. (15,17)
	If the family is not present at the time of death, have the physician call immediately to inform them, answer questions and offer condolences	Initial bereavement outreach considered an essential component of quality end-of-life care, especially important during the pandemic. (17,24)
Tools to Promote Connection	Look in the chart for hints about the patient before falling ill (occupation, family, hobbies) and refer to them in conversations with the family	Promotes connection and personalizes care. (17)
	For ICU patients, ask families for photos so teams can see who they were before becoming ill	Promotes connection and personalizes care. (17)
	Ask families if the patient has a favorite type of music and play it in their hospital room	Helps the family feel involved in their loved one's care. (17)
	Place a 'Getting to know you' poster on the patient's door, created by a staff member with a family member over the telephone	Promotes connection and personalizes care, especially because families do not want to think their loved one was 'just another number'. (15)
	Take a team photo alongside the 'Getting to know you' poster to send to the family	Promotes connection and personalizes care, and can be an important memento during bereavement within the continuing bonds framework. (3,17)
	Take a photo of the patient speaking to a family member if they are unable to visit	Helps the family member feel connected and can be an important memento during bereavement within the continuing bonds framework. (3)
	Suggest families make an audio recording that can be played by staff for the patient, telling them the	Helps alleviate guilt or regret in bereavement, especially if they were not able to be present at the time of death.

	things they would tell them in person	(17,21)
	Depending on infection status, consider tracing handprints or making hand molds of the patient	Legacy-making activity that helps families, including children, maintain a connection with their loved one after their death. (17,21,25)
	Obtain a cardiac tracing from the patient's last days to send to the family	Legacy-making activity that helps families, including children, maintain a connection with their loved one after their death. (17,21,25)

Table 2: Caring for families after the patient's death to facilitate post-loss adjustment

CATEGORY	TOOL	RATIONALE/FACTORS TO CONSIDER
Communication Skills	Respond to emotion: Name it: "This is so very hard." Explore it: "Can you tell me more?"	Helps bereaved individuals feel supported, and allows them to process information once emotion is acknowledged. (26)
	Acknowledge the effect of the pandemic: "These are unprecedented times." "The pandemic took us all by surprise."	Helps to externalize the problem and set realistic expectations about social distancing and other restrictions. Lays the foundation for challenging unhelpful thinking within a CBT model, especially in cases where individuals might feel guilt regarding the circumstances of their loved one's death. (3,21)
Care Processes	Make a bereavement call	Helps bereaved families know the patient and family are remembered, an important component of quality end-of-life care. Ideally, performed in the first week after the patient's death. (15,17)
	Send a team sympathy card	Helps bereaved families know the patient and family are remembered, an important component of quality end-of-life care. Consider including a photograph of the "Getting to know me" poster with the team. (15,17)
	Provide psycho-educational information about grief	Helps bereaved individuals have a 'roadmap' of what they might expect, (e.g., grief comes in waves). Include age appropriate information about supporting grieving children as indicated. (16,17,21)
	Refer for grief counseling	Especially for individuals at high risk for poor bereavement. (5,17,23)
	Outline strategies that help recently bereaved individuals, including adapting rituals	Helps provide structure and support during bereavement. Encourage bereaved individuals to follow a routine, pay attention to their self-care, including checking in with their doctor, and maintain social connections using technology. Suggest they consider holding a 'virtual celebration of life' with family and friends to reminisce, or writing their loved one a letter, telling them what they wish they could have said, especially if they weren't able to have a 'proper goodbye'. They can also consider planning a memorial event when able to at a later date. (15,17,21,25)
	Challenge unhelpful thinking without dismissing the emotion	Helps restructure unhelpful thinking. Within the context of a therapeutic relationship and drawing from CBT strategies, the bereaved is gently encouraged to express their thoughts and feelings, and identify and challenge those thoughts that are leading to guilt, blame or anger. A useful question to help shift perspective is: "What would you say to a friend in the same situation?" (3,21,25)
	Suggest support groups	Helps provide social connections and normalization of grieving process. Support groups require careful screening of participants to assess appropriateness, readiness and timing for a group, especially given the extraordinary circumstances of the pandemic. (5,17)

	Plan for post-COVID-19	Provides support/guidance over time. Consider offering to meet bereaved families at a later date to answer questions, or holding a team memorial service where families can come together to meet the clinicians who cared for their loved ones. (17)