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Bereavement in the Time of Coronavirus: Unprecedented **Challenges Demand Novel Interventions**

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ABSTRACT

COVID-19 fatalities exemplify "bad deaths" and are distinguished by physical discomfort, difficulty breathing, social isolation, psychological distress, and care that may be discordant with the patient's preferences. Each of these death attributes is a well-documented correlate of bereaved survivors' symptoms of depression, anxiety, and anger. Yet the grief experienced by survivors of COVID-related deaths is compounded by the erosion of coping resources like social support, contemporaneous stressors including social isolation, financial precarity, uncertainty about the future, lack of routine, and the loss of face-toface mourning rituals that provide a sense of community and uplift. National efforts to enhance advance care planning may help dying patients to receive care that is concordant with the preferences of them and their families. Virtual funeral services, pairing bereaved elders with a telephone companion, remote counseling, and encouraging "continuing bonds" may help older adults adapt to loss in the time of pandemic.

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KEYWORDS

Bereavement; coping; death and dying; COVID-19; mental health; stress

More than 75,000 people in the U.S. have died of COVID-19 as of May 6, 2020, with fatalities climbing daily (Centers for Disease Control and Prevention, 2020). COVID-related deaths can strike anyone, although this risk rises dramatically with age. Older adults ages 65 years and older make up 16% of the U.S. population, yet account for 31% of all cases, 45% of hospitalizations, 53% of ICU admissions, and 80% of deaths associated with COVID-19. Oldest-old persons are especially vulnerable; the COVIDrelated death rate for people ages 85+ is three times higher than among persons ages 65 to 84 (CDC COVID-19 Response Team, 2020).

While daily statistics focus on the decedents, less attention is paid to the loved ones they leave behind. In this Perspective, we argue that COVIDrelated fatalities embody the attributes of a "bad death," making them particularly devastating for bereaved kin, whose grief may be compounded by their own social isolation, lack of practical and emotional support, and

high-stress living situations marked by financial precarity, worries about their own or other family members' health, confinement to home, and the loss of routine and activity that once structured their days. New models of support must be implemented to meet the emotional needs of bereaved persons in the wake of COVID-19.

COVID-19 fatalities epitomize "bad deaths"

"Bad" or poor quality deaths are marked by physical discomfort, difficulty breathing, social isolation, psychological distress, lack of preparation, being treated without respect or dignity, and the receipt of unwanted medical interventions or being deprived of treatments one desires (Krikorian et al., 2020). "Good deaths," conversely, are distinguished by physical comfort, emotional and spiritual well-being, preparation on the part of patient and family, being surrounded by loved ones in a peaceful environment, being treated with respect and dignity, and receiving treatments concordant with one's wishes (Gawande, 2014; Steinhauser et al., 2000). Due to the excessive burden on the health care system, deaths thus far from Coronavirus have exemplified "bad deaths."

Roughly three-quarters of all COVID-related deaths take place in hospitals or nursing homes, although surveys consistently show that more than three-quarters of older adults would prefer to die at home (Centers for Disease Control and Prevention, 2020). Physical and cognitive aspects of COVID-19 deaths, including discomfort, difficulty breathing, lack of awareness, and reliance on mechanical ventilation are hallmarks of a "bad death" (Steinhauser et al., 2000). Because of the highly contagious nature of the virus, hospital and nursing home rules now prevent all patients from having visitors. As such, they are dying in isolation, separated from their loved ones; the best case scenario is that staff members facilitate family conversations via phone or video chat apps (Wakam et al., 2020). For those dying in over-crowded or overwhelmed facilities, bodies may not be treated with the dignity they would ordinarily receive, as beleaguered staff quickly make beds available for patients, with dead bodies "piling up" in hallways or refrigeration trucks (Young et al., 2020).

Why "bad deaths" are so difficult to grieve

Death context predicts survivors' symptoms of depression, anger, anxiety, and risk of complicated grief. Bereaved family members have heightened psychological symptoms when they did not have an opportunity to say "good bye" to the decedent, when the decedent was in pain, when the death was unexpected, when they perceive that the death was unjust and could have been prevented, when the death occurred in an ICU or hospital rather than at

home, and the treatments received were intrusive or discordant with the patient's preferences (e.g., Carr, 2003; Chi & Demiris, 2017; Wright et al., 2010). Dying patients' moves from home to hospital in their final days are a source of distress to family members both during the transition and after the death (Coleman, 2003).

"Bad deaths" are distressing because they challenge notions of an idealized death, they prevent family members from having meaningful conversations and resolving "unfinished business," they trigger pain in seeing a loved one suffer, and they may make family members feel guilty that they could not protect their loved one from the devastating situation (e.g., Carr, 2003; Li et al., 2019). Bereaved persons who believe their loved one's death came too quickly, too young, or unjustly due to a lack of appropriate care, may experience anger and a desire to cast blame, in order to make sense of or seek retribution for their loss (Carr, 2009; Neimeyer, 2000).

Bad deaths are distressing under normal circumstances, yet the pandemic has created a context in which the pain of loss is amplified by concurrent stressors. These stressors include social isolation, financial precarity, health concerns, worries about other family members, deaths of other friends and family, and anxiety about one's own mortality (World Health Organization, 2020). This accumulation of stressors within a relatively short time period can overwhelm one's capacity to cope (Folkman, 2011).

Social and emotional support from friends and family are essential for bereaved persons' adjustment to loss (Ha, 2008). However, most older adults are now self-quarantining, so their loved ones must offer support remotely, which may not adequately meet bereaved elders' emotional and physical needs (Peek et al., 2014). Additionally, the persons upon whom older adults rely may be beset with their own struggles regarding family relationships, financial security, employment, and other losses which undermine their capacity to support their aged bereaved relatives. Many of the face-to-face interactions that support older adults as they mourn, including funeral services and religious rituals like sitting shiva, are prohibited in most U.S. states, forcing families to turn to remote memorial services (Pauly, 2020; Waters, 2020). As such, the pain of loss is compounded by cooccurring stressors, and the erosion of supports, coping resources, and rituals that are essential to bereaved persons' well-being.

Proposed practices

The best way to mitigate against survivor grief is to alter the quality of deaths experienced by those dying of Coronavirus, although such solutions will be impossible in the short and intermediate term in the absence of major investments in the health care systems caring for the dying (Murthy et al., 2020). However, efforts to increase rates of advance care planning (ACP), including living wills and durable power of attorney for health care (DPAHC) designations, may help to ensure that more COVID-19 patients can convey their treatment preferences to health care providers, even if they lack decisionmaking capacity at the moment a decision is required. Many health and palliative care organizations like Respecting Choices (2020), Compassion in Choices (2020), and Center to Advance Palliative Care (2020) have created documents to assist with ACP and guides for effective end-of-life conversations.

Small-scale interventions may be effective in mitigating bereavement symptoms, at least in the immediate aftermath of loss. (Major investments in social programs and infrastructures will be required in the longer term, a topic beyond the scope of this brief essay). Health care workers can share respectful digitized photos of the decedent's face to provide evidence of the death and protect against the pain of ambiguous loss (Boss, 2009; Wang et al., 2020). Virtual memorial services and celebrations of the decedent's life have become the norm, yet older adults may require assistance in learning to download and use streaming services; the bereaved person's kin and support personnel like social workers or home health aides could provide this guidance. More generally, family members could encourage older adults to talk about the kind of memorial service they want for themselves someday, helping them to celebrate their loved one's life in a way that accords with their wishes.

Both professionals and volunteers can be enlisted to help bereaved older adults cope in the immediate aftermath of the loss. Supports typically provided by hospice workers could be deployed remotely to be reaved persons, such as counseling via telephone or web-based telemedicine. Community programs that connect volunteers with isolated older adults for daily telephone calls could provide special training for volunteers who are assigned to work with bereaved persons, or could recruit bereaved persons to serve as the contact for the newly bereaved, similar to the highly effective Widow to Widow program (Naylor, 2020; Silverman, 2004).

However, such programs should recognize that older persons value close ties with fewer confidants rather than many ties with fleeting acquaintances, so every effort should be made to ensure continuity of relationships (Charles & Carstensen, 2010). Additionally, practitioners who provide remote counseling to older adults must be careful to discern whether the patient's distress symptoms are grief reactions to the loss, which will fade over time, versus more serious symptoms of long-standing depression that one suffered prior to the loss. The latter require more intensive treatments, as persons with underlying depression are particularly vulnerable in times of crisis (Bonanno, 2004). For some older adults, financial insecurity may increase anxiety and require material assistance. Both professional and lay support persons also should recognize the importance of and encourage "continuing bonds" (Klass et al., 2014). Encouraging the bereaved person to recall positive memories and share stories of the decedent, to write down their memories, and to think about the



conversations they might have with the decedent may provide a source of uplift and inspiration. Remembering that grief is the "price we pay for love" may provide a glimmer of solace during these bleak times (Parkes, 2014).

Conclusion

The COVID-19 pandemic has dramatically altered how older adults live, die, and mourn. Persons dying of the virus spend their final days in hospitals and nursing facilities, separated from their families. Their bereaved kin must mourn the loss without the comforting embrace of loved ones, or the support of mourners who show their respect for the deceased at funerals. The symptoms of grief, sadness, and anger experienced by bereaved family members will ultimately diminish, a reflection of human resilience in the face of loss (Bonanno, 2004). The recovery process will require innovative modes of support from professionals, family members, and community volunteers who come together to nurture the most vulnerable in their time of need.

Key Points

- COVID-19 deaths exemplify "bad" deaths: discomfort, difficulty breathing, social isolation, and treatments discordant with one's wishes.
- "Bad deaths" are especially distressing because they violate cultural expectations for a peaceful death, and involve awareness of a loved one's suffering.
- Distress associated with bereavement is compounded by older adults' social isolation, co-occurring stressors, and loss of face-to-face mourning rituals.
- Virtual memorial services, telephone support groups, and other innovations may provide short-term support for survivors of COVID-19 deaths.
- National efforts to promote advance care planning may help dying patients to receive care concordant with their wishes.
- Programs targeting the grief of older bereaved persons must take into account their distinctive needs, preferences, and anxieties.

Disclosure statement

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