COVID-19 Articles Fast Tracked Articles

Grief During the COVID-19 Pandemic: Considerations for Palliative Care Providers

Cara L. Wallace, PhD, LMSW, APHSW-C, Stephanie P. Wladkowski, PhD, LMSW, APHSW-C, Allison Gibson, PhD, MSW, LISW, and Patrick White, MD, HMDC, FACP, FAAHPM

School of Social Work (C.L.W.), Saint Louis University, St. Louis, Missouri, USA; School of Social Work (S.P.W.), Eastern Michigan University, Ypsilanti, Michigan, USA; College of Social Work (A.G.), University of Kentucky, Lexington, Kentucky, USA; and Division of Palliative Medicine (P.W.), Department of Medicine, Washington University, St. Louis, Missouri, USA

Abstract

The COVID-19 pandemic is anticipated to continue spreading widely across the globe throughout 2020. To mitigate the devastating impact of COVID-19, social distancing and visitor restrictions in health care facilities have been widely implemented. Such policies and practices, along with the direct impact of the spread of COVID-19, complicate issues of grief that are relevant to medical providers. We describe the relationship of the COVID-19 pandemic to anticipatory grief, disenfranchised grief, and complicated grief for individuals, families, and their providers. Furthermore, we provide discussion regarding countering this grief through communication, advance care planning, and self-care practices. We provide resources for health care providers, in addition to calling on palliative care providers to consider their own role as a resource to other specialties during this public health emergency. J Pain Symptom Manage 2020;60:e70–e76. *© 2020 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Grief, COVID-19, end of life, loss, communication, self-care, advance care planning

Introduction

The COVID-19 pandemic has disrupted usual experiences of grief and modifications of approaches to support grief are needed. Uncomplicated grief encompasses multiple responses—emotional, cognitive, physical, and behavioral—that are common reactions after a loss.[1] We are all currently susceptible to multiple losses daily—loss of financial security, loss of social/physical connections, and loss of autonomy to move freely in the world. Many individuals are also experiencing a loss of physical/mental health and general safety and autonomy. Others are isolated in facilities where, owing to directives to limit physical contact, families are not allowed to visit. For many hospitalized patients, visitors are limited or prohibited, regardless of a COVID-19 diagnosis. For bereaved individuals, funerals and burials are postponed or held remotely, often without presence of family or the possibility of the warm embrace from loved ones. Social media feeds are full of devastating stories—families denied opportunities to say goodbye before a death, or loved ones saying goodbye over phone/video, uncertain whether each communication is the last. Clinicians are isolating themselves from their own families indefinitely owing to worry about potentially spreading infection. Individuals are urgently updating advance directives and wills, making complex decisions on ventilation and resuscitation, and considering who will care for their children if they die. Grief is inherently a normal part of this myriad of COVID-19 experiences. Here, we provide discussion to help palliative care providers consider important aspects of grief related to the pandemic, how key practices of advance care planning, quality communication, and provider self-care can help mitigate that grief, and the necessary role of palliative

Address correspondence to: Cara L. Wallace, PhD, LMSW, APHSW-C, School of Social Work, College for Public Health & Social Justice, Saint Louis University, 3550 Lindell Blvd, Office 304, St. Louis, MO 63103, USA. E-mail: cara.wallace@slu.edu

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care in serving as a resource to other specialties amid this pandemic.

Grief in Context

The complex and rapid changes from COVID-19 impact processes which are best understood through a lens of grief (see Table 1). Traditionally, anticipatory grief is the normal mourning that occurs for a patient/family when death is expected.[2] With the number of COVID-19 deaths currently doubling within days,[3] medical personnel are expecting to experience death at unprecedented rates. Viewing maps of global spread, individuals can anticipate the virus coming closer, increasing distress. Experiences of death become more personal as COVID-19 affects communities broadly. Anticipatory grief results from uncertainty as well as trying to make sense of what is coming. In response to these projected numbers, hospitals are preparing and planning for a surge of patients with potential limitations in necessary equipment, such as personal protective equipment, ventilators, and intensive care unit beds. For patients and families, there can be unsettled feelings of not knowing how disease will progress or how they will be impacted by changing hospital and facility policies. These experiences that occur before death have a lasting impact on grief experiences of loved ones and providers alike.[4–6]

In response to the spread of the COVID-19 pandemic, communities have begun implementing large-scale "stay-at-home" orders, which in many cases are mandated by local or state leaders. Hospitals and other facilities are limiting or banning the physical presence of visitors. As deaths occur, the physical, mental, and social consequences of isolation of social distancing may impact the potential for complicated grief (CG). While clinicians should not assume that all patients or family members are experiencing CG now during the height of the COVID-19 pandemic, it is important to understand how current circumstances may set the stage for CG to occur after death. CG can present symptoms such as recurrent intrusive thoughts of the person who died, preoccupation with sorrow including ruminative thoughts, excessive bitterness, alienation from previous social relationships, difficulty accepting the death, and perceived purposelessness of life.[7] Under usual/pre-COVID-19 circumstances, family members of patients who died in the hospital or intensive care unit were at a higher risk for prolonged grief.[8] In one national survey, the dying patient's inability to say "goodbye" to family before death was significantly associated with CG.[4] Other studies show that severe preloss grief symptoms,[5] lower levels of social support,[5] lack of preparation for the death,[6] and guilt[9] predicted CG and postloss depression—all relevant factors in facing death in the context of the COVID-19 pandemic.

The type[6] and volume[10] of losses a person experiences also impacts the bereavement process and likelihood for CG. Owing to COVID-19, it is not uncommon for families and communities to experience multiple losses given the methods by which the disease spreads. In one study, among home hospice patients, nearly half experienced high anxiety and/or depression during the last week of life.[11] However, symptom management and quality of care at end of life is generally better in hospice compared to hospital deaths,[8] suggesting that anxiety and depression may be even higher at the end of life in hospitals. This seems particularly likely with additional context that deaths during this time may be complicated by ethical decisions in triaging resources,[12] quick transitions between "ill" and "dying" in previously healthy patients, and limitations in visitors who can be physically present at the bedside. While research cannot yet report on psychologic processing at end of life during social isolation of the COVID-19 pandemic, one can reasonably extrapolate that many are dealing with higher levels of anxiety/depression during this uncertain time. These likely contribute negatively to the quality of the dying experience, which predicts experiences of CG.[6]

Individuals may also feel they are experiencing disenfranchised grief, when grief is not publicly mourned or socially sanctioned by the larger community.[13] For example, when an individual has not followed the social or mandated "rules" to limit exposure and becomes infected or spreads illness to others, feelings of blame, anger, and sadness, among others, will be entwined with their experience of loss of health. This experience is heightened as language used in society and media presents an emotional distance to whom will contract and/or die from COVID-19 infection. Patients can experience intense guilt and self-blame as some perceive only older adults and the immunocompromised are at risk for infection or severe outcomes. Bereaved individuals may grapple with the fact that the person they lost was so much more than a statistic and have difficulty fitting their grief within these societal messages. Disenfranchised grief can also occur when families are unable to grieve in traditional practices of funeral services or being unable to attend a loved one's burial. Many funeral and burial providers have discontinued services during the pandemic, or greatly limited the number of attendees along with other restrictions, minimizing options families have for mourning the loss of a loved one.

Though much of the grief outlined previously is focused on that of patients and families, the experiences of providers must also be considered. During times of crises, many providers rely on strategies of

Table 1
Contexts of Grief Amid Rapid Changes/Impact Due to COVID-19 and Recommendations to Mitigate Grief

Changes Due to COVID-19	Impact	Context of Grief	Recommendations
Pandemic/spread of disease	Fear, worry, anticipation of spread Multiple losses in families; communities; long-term care facilities Individuals consider updates to advance directives—considerations for ventilation and resuscitation	**Anticipatory grief** for community—will someone I love be affected? When will the spread reach MY community? **Anticipatory grief** for medical personnel—planning for the "surge" Type[6] and volume[10] of losses a person experiences can impact **complicated grief**.	Preparing patients/families for a likely death is critical part of anticipatory grief work, which can impact likelihood for complicated grief. Utilize **communication-**based management, including recognizing, responding, and validating emotional responses, to address anticipatory grief.[2] Approach difficult conversations directly and do not shy away from discussing emotions, grief, and overall patient and family distress during **advance care planning** conversations.[22] During **advance care planning**, include discussions of desired ritual or spiritual practices and funeral/memorial plans.[25] Connect patients/families to resources to help them consider postdeath planning needs and provide/refer to additional grief support through telehealth services. To enhance the role of **self-care** in overcoming accumulated stress and grief in providers, practice self-awareness.[28] Some **self-care** strategies to help individuals cope with stress during an event include the following: being able to take breaks and disconnect from the disaster event, feeling prepared and informed in facilitating their response role, being aware of local resources and services to refer patients to for additional recovery assistance, and having adequate supervision and peer support while facilitating response.[31]
Social distancing or "stay at home" orders	Loss of financial security, loss of social/physical connections and support, loss of autonomy to move freely in the world Limitations in visitors or banning physical presence of family at bedside (in hospitals, long-term care facilities) Survivors must quarantine based on exposure to loved one Changes to end of life practices—how patients/family communicate/say goodbye; communication between patients & providers, between families & providers; Delays and limitations to funerals and/or burials	Overall, **grief** is an inherent part of our experiences due to the breadth of losses individuals are experiencing to "normal" life. Increase in likelihood for **complicated grief** (CG) for bereaved family based on impact as the following factors are associated with CG—inability to say "goodbye"[4], preloss grief symptoms[5], lower levels of social support[5], lack of preparation for death[6], guilt.[9] **Disenfranchised grief** can occur when an individual does not follow social/mandated "rules" and becomes infected or spreads illness. **Disenfranchised grief** can occur when families are unable to grieve with normal practices of social support and rituals in burial and funeral services.	
Increase in deaths, overburdening of hospital systems	Ethical considerations—triaging of resources, consideration of DNRs Providers may choose to isolate themselves from personal support systems to limit risk of exposure to family Guilt may be experienced by professionals who are unable to work due to exposure/contraction of COVID-19	**Anticipatory grief** for patients, families, providers—experiences that occur before death have lasting impact on grief[4–6] Quality of the dying experience can impact occurrence of **complicated grief** in bereaved family. Potential for **moral distress** or **secondary traumatic stress** in medical personnel—use of avoidance, compartmentalization can lead to burnout and unresolved grief.[14]	

avoidance or compartmentalization to continue treating patients, which can lead to unresolved grief.[14] It is common for persons helping with response efforts to experience secondary traumatic stress, a stress response that can occur as a result of knowing or helping a person(s) experiencing trauma. Symptoms include excessive worry and fear, feeling "on guard" all the time, recurring thoughts, and physical signs of stress.[15] Within the additional context of challenging ethical decisions and impacts of new policy decisions, moral distress may be another common experience for providers. Moral distress is "the physical or emotional suffering that is experienced when constraints (internal or external) prevent one from following the course of action that one believes is right."[16] Moral distress is a significant issue facing critical care providers and is associated with burnout, where providers experience emotional exhaustion and depersonalization, or even dehumanization, of the patients and families in their care.[17] Personal challenges away from work, such as decisions to isolate oneself from personal support systems to limit risk of exposure, or feelings of guilt for those who are quarantined due to overt exposure or their own diagnosis, may cause additional grief for providers.

Recommended Practices to Mitigate Grief

With COVID-19 contributing to increasingly difficult circumstances and the potential for amplified grief, health care clinicians need tools and resources to mitigate that grief for patients/families and to cope with and process grief for themselves. Quality communication, advance care planning (ACP), and provider self-care are three recommended practices that can assist now in addressing this changed landscape of grief. Table 2 outlines relevant resources across these recommended practices.

With the likelihood of fewer (or no) family allowed to visit, clinicians must be open to having honest conversations while exploring ways to offer connection. Helping prepare for likely death is a critical part of anticipatory grief work, particularly because lack of preparedness is associated with postdeath CG.[18] Anticipatory grief work with families is a crucial component in effective ACP[19] as participation in ACP can enhance outcomes for families during the bereavement period.[20] Communication-based management, including recognizing, responding, and validating emotional responses, is one key strategy for addressing anticipatory grief among critically ill patients and their families.[2] Patients and families who are provided opportunities for cognitive and emotional acceptance of death show better outcomes in quality of life for bereaved family members six months after the loss.[21]

In addition, EOL decisions inherently impact the grief experience for all involved[13] and critical decisions are being made daily for individuals facing COVID-19 infection diagnoses. Clinicians must be ready to approach these difficult and uncertain conversations directly and should not shy away from discussing emotions, grief, and overall patient and family distress during ACP conversations.[22] Ideally, ACP conversations should occur early with the goal of avoiding unwanted/unneeded hospitalizations and intensive treatment.[23] However, the rapid clinical decline of moderate/severe COVID-19 infection presents unprecedented urgency in discussing goals of care, especially with older patients with chronic disease.[24]

ACP with patients within weeks/days of life expectancy should also include discussions of desired spiritual practices and funeral/memorial.[25] For caregivers, the unpredictable trajectory of illness, practical and emotional preparedness for death, and coping with fear of unknown factors and a future without the care recipient all contribute to tension between the present and an uncertain future.[18] Connecting patients/families to resources to help them consider postdeath planning needs and providing additional grief support is important. While forced to disengage from traditional funeral and burial services during the COVID-19 outbreak, many are turning online to telecommunication-based alternatives, which can be an effective means of extending services.[26] In addition, many licensing boards have been temporary lifting restrictions on how licensed professionals can facilitate telehealth and remote services.

Health care clinicians are often trained to put aside their own feelings and emotions to put patient well-being and care first. During a time of a crisis, this focus can be amplified, and the concept of self-care may feel counterintuitive. However, dealing with the personal thoughts and emotions that arise during care is pertinent to providing ongoing ethical care for patients and families.[27] This self-awareness, or the ability to attend to the needs of the patient, the overall work environment, and ones own subjective experience can enhance the role of self-care in overcoming accumulated stress and grief in providers.[28] In fact, personal awareness, along with inner and social self-care, is positively associated with a health care professional's ability to cope with death in their professional setting.[29] Self-care is of utmost importance to minimize potential for long-term outcome effects so that providers are able to continue caring for patients during this unprecedented strain on the health care system.[30] Some self-care strategies to help individuals cope with stress during an event include the following: being able to take breaks and disconnect from the disaster event, feeling prepared and informed in facilitating their response

Table 2
Resource List for Providers Navigating Grief Through the COVID-19 Pandemic

Topic Area	Organization, Author(s)	Title (With Hyperlink)	Purpose/Description
Communication	Vital Talk	COVID-Ready Communication Skills[33]	Practical advice on how to talk about difficult topics related to COVID-19
	Serious Illness Conversations—Kelemen, Altilio, & Leff	Specific phrases and word choices that can be helpful when dealing with COVID-19[34]	Resources include the following: helpful responses during times of restrictive visiting; guide to virtual family meetings; end-of-life topics that may arise; supporting staff; team support
	SWHPN[a]—Halpern	Working with families facing undesired outcomes during the COVID-19 crisis[35]	Tip sheet of suggestions and considerations when communicating with families
Telehealth guidance	CAPC[b]	CAPC COVID-19 Response Resources[36]	Toolkit includes communication tips, symptoms management protocols, palliative care team tools, using telehealth, among other resources
Advance care planning	Respecting Choices	COVID-19 Resources[37]	Resources include the following: those to help clinicians have conversations about treatment preferences before a medical crisis; tools to support specific treatment decisions in high-risk individuals (CPR, breathing assistance—ventilator, user guide); resources for high-risk individuals and their agents/loved ones
	NHPCO[c]	COVID-19 Shared Decision-Making Tool[38]	Includes information related to likelihood of survival, along with symptoms, statistics and facts. The tool also prompts a “decision point” about advance directives
	Aging with Dignity – Five Wishes	Five Wishes Advance Directive[39]	A complete approach to discussing and documenting care choices; document meets legal requirements for directives in 42 states
Self-care	CDC[d]	COVID-19: Stress & Coping[40]	Provides tips and resources for reducing stress
		Emergency Responders: Tips for Taking Care of Yourself[15]	Includes information on preparing for a response; understanding and identifying burnout and secondary traumatic stress; getting support; self-care techniques; and resources
	AAHPM[e]	Resilience and Well-Being[41]	Includes self-care tips, videos and presentations, articles, and other resources
	University of Buffalo, School of Social Work	Self-Care Starter Kit[42]	Includes foundational information about self-care; self-care assessments, exercises, and activities; and resources for developing a self-care plan (including for use during an emergency)

[a]Social Work in Hospice & Palliative Care Network.
[b]Center to Advance Palliative Care.
[c]National Hospice and Palliative Care Organization.
[d]Centers for Disease Control and Prevention.
[e]American Academy for Hospice and Palliative Medicine.

role, being aware of local resources and services to refer patients to for additional recovery assistance, and having adequate supervision and peer support while facilitating response[31] (see Table 2).

Conclusion

Grief is an ongoing and important factor of the COVID-19 pandemic that affects patients, families, and medical providers. Some grief processes are novel related to social distancing/isolation, uncertainty/self-blame related to infection, and inability to implement usual burials/funerals. Others are typically experienced near end of life but are occurring on an unprecedented scale that has the potential to have devastating individual/societal effects in the short and long term. Based on their training and expertise in working with patients near EOL, palliative care providers are perfectly positioned to serve as a resource to their colleagues in other specialties.[32] Understanding the complexities of this grief, in addition to accessing and sharing resources for improved communication, telehealth, ACP, and self-care, is an important component to supporting patients, families, colleagues, and ourselves.

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