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Grief and the COVID-19 Pandemic in Older Adults

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ABSTRACT

In few periods in human history have bereavement and grief been on so many people's minds as they are today. As the coronavirus disease 2019 (COVID-19) ravages the world, we have seen many perish in a short time. Many have died alone because of requirements for physical distancing. Even more will succumb as COVID-19 continues to spread. Moreover, deaths from other causes, numbering over 50 million annually, are also happening amid physical distancing and other COVID-19-related challenges. The pandemic is affecting the way terminally ill patients are being cared for, when and how people are dying of other causes, and how bodies are being handled and bereavement rituals performed. The bereaved are required to grieve without the support of usual social and cultural rituals. Grieving is further encumbered by cascading life stressors deriving from policies needed to mitigate the pandemic. Though we are often heartened by human resilience in response to death and other hardships, for some, the burden of this pandemic will be too much. Among other mental health problems, we will likely see an increase in prolonged grief disorder. In this commentary, we review the new diagnosis of prolonged grief disorder and outline why we might anticipate increased rates of this condition on the heels of COVID-19, especially among older persons. The authors suggest ways that might mitigate this emerging problem. (Am J Geriatr Psychiatry 2020; 28:1119–1125)

Seventy-eight-year-old Alice lost her only sibling, Charles, age 69, to the coronavirus disease 2019 (COVID-19). Alice and Charles lived in different towns but were very close, speaking daily on the phone for hours. They were practicing Christians and had similar interests. He often drove to visit her. They enjoyed spending time with each other and doing things together. Despite having coronary artery disease and hypertension, Charles was independent and happy. Alice was shocked to learn he had been hospitalized for COVID-19 pneumonia and that he was intubated and on a ventilator. A bereavement coordinator reached out to her, which she very much appreciated.

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TABLE 1. Examples of PGD Risk Factors Related to Death During COVID-19

Circumstances of the death
Sudden, unexpected, seemingly preventable and random deaths
People dying alone
Restrictions on visiting policies of the dying family member
Context of the death
Physical distancing policies affecting funerals, burial, rituals, and support for the grievers
Unemployment worries
Feelings of unsafety
Financial insecurity
Consequences of the death
Being alone
Fear of contamination
Having others to care for
Financial worries

However, Alice declined an offer to visit Charles, frightened of contracting the disease herself. She understood that she, too, was at high risk for dying of COVID-19 because of her age. Although she tried to reach out to him via Skype, Charles died with only the bereavement coordinator and hospital staff at his side. Alice completed the funeral arrangements via Skype. Charles was cremated without her being present, and his ashes were delivered to her. Several weeks after his passing, Alice was plagued by remorse for abandoning her dying brother. She yearned to be with Charles and could not believe he was gone. She fluctuated between numbness, overwhelming sadness, and intense guilt. She could not stop thinking that she failed her brother during his last days. She was having trouble sleeping and was beginning to lose weight but did not meet criteria for major depression. She liked to reminisce about fond memories of Charles and knew he was with God. She had confidence in the religious belief that she would see him again one day. She also knew that she wanted to live and that she would carry Charles in her heart for the rest of her days. She continued to talk with the hospital bereavement coordinator weekly, an important source of solace. They often discussed the details of her plan to hold a memorial service in celebration of Charles' life after pandemic restrictions are lifted.

Bereavement is the experience of losing a loved one, and grief is the natural response to this loss. Typically, acute grief is intensely painful and disruptive and often feels overwhelming and unmanageable. Still, most people adapt to the death of a loved one, along with the accompanying changes in life circumstances. We accept a changed relationship to the person who died and find ways to honor them and keep them in our hearts. We restore our sense of purpose and meaning, and possibilities for happiness. Grief quiets as we do so, finding a place in our life. However, the process of adaptation takes time. Grief is complex, multifaceted and time varying; it progresses erratically. The tremendous upheaval created by losing a loved one typically produces a raft of mixed feelings and confusing thoughts. *Alice is experiencing an especially intense period of acute grief because of the sudden onset and rapid course of her brother's illness as well as deeply troubling thoughts because she was unable to be at his side when he passed*.

Bereaved people usually pass certain milestones as they adapt to their loss. They learn to understand and accept their grief and manage painful emotions. They begin to restore a sense of purpose and meaning and see possibilities for a promising future. They strengthen their ongoing relationships and restore a sense of mattering (i.e., the feeling that one's life is important and makes a significant difference) and belonging (i.e., the feeling that one fits in) in a world without their loved one present. They can tell the story of their loved one's death to themselves and share it with others. They gradually return to a world of reminders and realize they have an ongoing meaningful connection to the deceased that is internalized and permanent. Bereaved persons can use the acronym HEALING as a simple way to remember these milestones (see https://complicatedgrief.columbia.edu/wp-content/uploads/2020/06/HEALING-Milestones_-What-Grievers-Can-Expect-with-Covid-19-Addendum.pdf).

Most people adapt to a loss naturally, not easily, but often without deliberate effort. However, this process can be derailed. This usually happens because there is something about the meaning or experience of the loss that is troubling in a way that the bereaved person is unable to resolve. This might be related to characteristics of the bereaved person, the specialness of the relationship with the person who died, circumstances of the death, or the context in which the death occurred. Certain thoughts, feelings, and behaviors that occur naturally during acute grief can derail the adaptive process. The acronym DERAILERS summarizes the more common impediments to adaption (see https://complicatedgrief.columbia.edu/wp-content/uploads/2020/06/HEALING-Milestones_-What-Grievers-Can-Expect-with-Covid-19-Addendum.pdf). When adaptation is stalled or halted, the result is prolonged grief disorder (PGD),[1,2] recently included as a

new diagnosis in the World Health Organization International Classification of Diseases, 11th edition (ICD-11)[3] and now also proposed as a formal Diagnostic and Statistical Manual of Mental Disorder, 5th edition (DSM-5) diagnosis recently posted for public comment.[4] This syndrome is characterized by persistent and pervasive yearning, longing or preoccupying thoughts and memories of the deceased, accompanied by other evidence of grief-related emotional pain, causing significant distress or impairment in functioning and lasting at least 6 months and exceeding the timeframe expected by social, cultural, or religious norms. The circumstances, context, and consequences of deaths during the COVID-19 pandemic comprise risk factors that will likely elevate rates of PGD (Table 1). To understand why the pandemic holds risk factors for PGD and how they might be mitigated, we can take a closer look at the process of adapting to loss and the common ways it can be derailed.

The dramatic upheaval caused by the death of a loved one often triggers troubling feelings and thoughts. In addition to yearning and sadness, most people feel anxiety, guilt, or anger. Bereaved people are inclined to protest the death and have a natural tendency to imagine alternative scenarios in which their loved one did not die. Most feel survivor guilt. Although there is little research on the topic of survivor guilt, we believe that it is a universal human feeling. While it is widely acknowledged as a natural human response, much of the discussion about this issue is theoretical or philosophical.[5] This "guilt" can be understood as a sense of uneasiness or discomfort about having been spared from some adversity—the discomfort is about feeling it was not fair or the person did not deserve to be spared. Almost all bereaved people seek to avoid situations that trigger intense emotional pain. Although such thoughts, feelings, and behaviors are natural, if they take control, they can derail the healing process. Risk factors are characteristics of a bereavement experience that increase the likelihood of developing PGD[1,6] or another mental health problem. Risk factors make DERAILERS more difficult to resolve or set aside. Examples of risk factors include those related to the bereaved person such as previous depression or anxiety, history of insecure attachment, and previous trauma or loss. Risk factors related to the relationship to the deceased include an especially close, identity-defining relationship, such as a romantic partner or being a parent to the deceased. Other risk factors are related to circumstances, context, or consequences of death. Examples include sudden violent death, stressful life circumstances, other concurrent losses, or important secondary losses. Table 1 lists probable PGD risk factors related to the COVID-19 pandemic. Not only are the circumstances of deaths occurring during this pandemic likely to increase the risk for PGD, but the measures taken to mitigate pandemic spread may also enhance the risk.

Death from COVID-19 is often sudden and unexpected. Restrictions in place because of the pandemic have changed the experience of dying. Healthcare systems have implemented stringent limits on visiting ill patients. In acute adult inpatient settings, permission to visit in person may be granted to a loved one only briefly or not at all. As a result, it is healthcare professionals, support staff, or chaplains, and not family members, who are by the sides of dying persons. Often, too, these healthcare personnel are wearing personal protective equipment, which limits their ability to connect with their patients. These difficult circumstances increase the burden for family members dealing with the loss of a loved one during this pandemic. Comprehending the reality of a loss is difficult under any circumstances, but even more so when the death is sudden and a loved one is left to die alone.

In addition to becoming a focus of intense preoccupation and guilt after he died, Alice's inability to visit Charles left her with a strange feeling of uncertainty about his death. She had trouble understanding how her brother—her best friend—could really be gone. In her mind, he was young and healthy—the way he had been when she last saw him. She would have struggled with this had she been at his side, but not having seen him made the feeling of disbelief even stronger. His death did not compute for her.

Adding to the burden of not being with a dying loved one is the unprecedented disruption of cultural and religious rituals that provide many mourners with a supportive social context. Funeral homes are overwhelmed and sometimes unable to pick up bodies in a timely manner. In-person funeral arrangements and services are sharply curtailed during the pandemic, with additional constraints for those whose loved ones died from COVID-19. Only a limited number of family members can convene to make funeral arrangements,

and such preparations must often be completed virtually. Faith- and culture-based practices such as embalming, washing of the body, kissing of the deceased, and open casket viewing are not permitted. Private viewing is often not possible and, when allowed, is offered only to immediate family members. Close friends as well as bereaved family members who are ill, in isolation, or at-risk must stay home. Mourners must refrain from hugging or touching one another as any physical contact before, during, and after funeral services is strongly discouraged due to COVID-19. Travel restrictions create further obstacles to usual practices. Mourners and their supportive community must find new ways to observe these rituals. The bereaved must postpone conventional memorial services to an uncertain later date. Decisions are made to postpone memorials, as Alice did, or to conduct them by live stream.

Alice and Charles were religious Christians, and it troubled her that she was unable to give him the send-off she dearly wished she could. She felt awkward to make arrangements for his remains by Skype and was sad and guilty because she could not be present for the cremation. All of this weighed heavily on her mind. She did, however, gain some solace from planning a memorial for Charles when restrictions are lifted. It heartened her to discuss these plans with a bereavement counselor. Though she understood the need to forego this, she longed to have her friends and family around her as she mourned Charles. She wanted to hug them and just sit with them. She yearned for the others who loved Charles, to mourn together and share stories. Grieving alone felt almost like a physical deprivation.

The context in which bereavement is occurring also is challenging. Virtually all social gathering places have been shuttered due to physical distancing. Schools and workplaces are closed, congregations are not permitted in places of worship, and informal gatherings of large groups are disallowed. Deaths happening with stay-at-home orders in place can intensify the sense of social isolation and loneliness that is a part of the natural experience of many grieving individuals.

For Alice, the inability to spend time at church has been very painful. She regularly prays at home and she, on one occasion, was able to talk with the minister, but it was not the same as being in church. Alice believes she would be able to feel Charles' presence more strongly in the church building, and she feels she needs God now, more than ever.

COVID-19 mitigation policies are associated with other forms of loss that are also stressful. There are high rates of unemployment, furloughs, salary reductions, and an increase in homelessness. Many are experiencing disruptions in living arrangements and painful physical separation from close friends and family. There is widespread fear of contamination, possibly increased by frequent reminders of death rates and exposure to distressing stories and other emotionally activating media coverage. Such challenges can make it more difficult to resolve thoughts and feelings that can derail adaptation. In the absence of mitigating efforts, a rise in PGD cases is a likely sequel to this pandemic.

In the back of her mind, Alice had a constant fear of getting sick. She tried to ignore it but was sometimes unable to do so. She felt an urge to talk this over with Charles, and this reminded her that she and Charles will never talk on the phone again—that they will never take their favorite walks or have lunch in their favorite restaurant. She tried her best to ignore these thoughts because they evoked pain so strong that her whole body hurt. The many stresses and the need for social distancing made it more difficult for Alice to accept the reality that Charles was gone.

There is a pressing need to implement measures that might lessen the adverse consequences of COVID-19-era bereavement. We might do this by educating the lay public about grief and HEALING milestones and ways the pandemic might affect bereavement and grief. We can promote awareness of DERAILERS—the thoughts, feelings, and behaviors that can stall or halt the grieving process. These include a view of the future as empty and meaningless, a strong focus on imagining alternative scenarios and/or rewriting our role in the story of the death, excessive avoidance of reminders of the loss, social isolation, survivor guilt, or a persistent strong aversion to experiencing positive emotions.[2] Disruptions in eating, sleeping, or exercise can also make it difficult to restore a sense of wellbeing. Just as the risk of COVID-19 is greater for older people and especially those with chronic physical illness, so too the risk for PGD is likely higher in those who are older and who have a psychiatric history. Family members might be encouraged to closely monitor these vulnerable groups.

Clinicians in both primary care and mental health settings are now practicing telemedicine. There are

clear advantages to in-person visits, and many older patients currently have difficulty navigating and becoming accustomed to the digital world. However, telemedicine services can be especially convenient for some older adults, and over time, patients may become more comfortable using this modality. This could increase access to care for those for whom travel is difficult or impossible. Clinicians can learn about the natural grieving process, the HEALING milestones, and the unique challenges faced by the bereaved during the pandemic. They can learn how to promote adaptation and how to recognize and address DERAILERS. Clinicians can help by active empathic listening during virtual discussions that are warm, inviting, and open-ended. Healthcare providers can help bereaved individuals understand and accept their grief. They can assist grieving individuals to modulate their emotional pain by naming emotions, observing and reflecting on them, considering how they are affected by thoughts, mindfulness exercises, or any other emotion regulation strategies they have in their toolbox. Clinicians can invite bereaved people to talk about the story of the death and to voice and discuss any concerns they have about their loved one's illness or treatment. Sleep disturbance can be managed by providing advice on healthy sleep practices and other nonpharmacological techniques. Sedative-hypnotic medications should be avoided or used judiciously for short periods. PGD is a new diagnosis; recognizing this condition is important because it is associated with impaired physical health, cognitive decrements, mental disorders including substance use disorders and increased suicide risk, reduced quality of life, and premature mortality.[7–11] Bereavement might also trigger depression, anxiety, and trauma-related disorders without PGD. Identification of a treatable disorder and appropriate management and/or referral to mental health services is therefore important. Bereaved individuals also may benefit from referral to virtual grief counseling or psychotherapy services. Additionally, online group and self-help interventions may provide meaningful support for the bereaved.

When PGD is diagnosed, psychotherapeutic interventions are the first-line treatment. Complicated grief psychotherapy (CGT) is the best studied of these[12–14] and other similar approaches are also available.[15–19] Among these are internet-based cognitive behavioral-based therapies that use strategies to increase involvement in enjoyable activities and reduce avoidance of reminders of the deceased.[1] CGT is a short-term approach developed and tested by researchers across the country. CGT addresses derailers and fosters progression through HEALING milestones. Participants in three randomized, controlled trials funded by the National Institute of Mental Health had a substantially better response to CGT than interpersonal psychotherapy, antidepressant (citalopram) treatment, or a pill placebo.[12–14] In other words, depression-specific treatments are relatively ineffective in relieving PGD symptoms, but grief-specific interventions like CGT are effective. This observation underscores the importance of diagnosing PGD being careful not to misconstrue grief symptoms as depression. CGT is an accessible method of grief therapy that can be learned by any licensed mental health professional. By utilizing a range of training methods, such as online workshops and other methods currently offered by the Center for Complicated Grief, clinicians can learn to administer this treatment effectively. As with any grief therapy, attention to therapist self-observation, self-compassion, and self-care is important. CGT is currently being provided by trained therapists around the world, using telehealth. Learning about the HEALING milestones and DERAILERS can also be helpful for friends and family who want to support bereaved people.

In summary, the public health emergency defined by COVID-19 has brought elevated rates of bereavement as well as unique challenges that can increase the risk of the development of PGD, a new diagnosis for which proven efficacious treatments are already available. Such treatments promise to provide relief for multitudes of people worldwide who have long suffered from unending grief. Continued research in this area holds the promise of identifying protective and risk factors for PGD, especially in the context of the COVID-19 pandemic. Studies testing hypothesized mechanisms for the development of PGD and other psychiatric conditions in the wake of bereavement also are needed. Putative mechanisms of action and efficacy of in-person and remotely delivered interventions should be examined. Additionally, preventative interventions should be developed, and their mechanisms of action and effectiveness tested for use during acute grief to mitigate the mental

health consequences of bereavement, especially for older people.

COVID-19 has opened up new opportunities to deliver interventions that can alleviate the suffering of grieving individuals. The federal government has issued emergency orders to relax regulations to increase telehealth services access across the country. The American Psychiatric[20] and Psychological[21] Associations have created resources for mental health professionals to learn about developments in telehealth delivery. Alice might take advantage of this if her grief continues unabated over the next 6 months. She could contact the Center for Complicated Grief (https://complicatedgrief.columbia.edu/) to find a teletherapist trained to provide efficacious treatment for PGD.

Since COVID-19 will leave a lasting impact on our community, we call for immediate action to educate practitioners in recognition and treatment of PGD and to make telehealth policies permanent beyond the pandemic. This would ensure continued access to much-needed care for bereaved individuals, especially those like many older adults, who may be isolated with limited capacity to travel and/or inhibited by stigma in seeking mental healthcare.

AUTHOR CONTRIBUTIONS

JSG wrote the initial draft of the manuscript and case history,

MKS and JSG revised the manuscript, including all content, and provided final approval,

MKS provided the table.

DISCLOSURE

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