Hindsight is 2020: Lessons Learned from the COVID-19 Pandemic on Death, Dying, and Grief

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Abstract

The severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) pandemic has led to significant changes not only in the way we live, but also in the way we die. Visitor restrictions mean that patients are dying alone, and that families and loved ones are often unable to say goodbye or visit in the days and hours preceding death. Further, limitations on various cultural norms and rituals following death, such as the ability to hold funerals or wakes, are also influencing the experience of death and dying. The impact of these changes on bereavement and grief remains unknown, but it has been speculated that such changes may lead to adverse bereavement and grief experiences. There is an urgent need to establish a national grief strategy to ensure sufficient resources and supports for people experiencing the loss of a loved one, be it from coronavirus disease-19 (COVID-19) or another cause, during and beyond the pandemic.

It was January 1, 2021. The start of a new year that held more anticipation and promise than that of New Years past. This new year, to me, heralded the promise of hope and optimism, particularly as the COVID-19 vaccines were starting to roll out. I was sledding with my two girls, and we somehow found ourselves on a particular section of the hill with so many jumps that made it seem as if we were sledding down a mogul-covered ski hill. Every bump made me question my sanity, and my bone density.

As we sat at the top of the hill playing in the snow, the cold permeating my snow pants, I felt it. The silent vibration of my phone ringing. Not once, not twice, but repeatedly. I answered on what must have been the 3rd or 4th attempt, and I immediately sensed that something was wrong. It was a long-time family friend, M, who had metastatic breast cancer. She was speaking rapidly. I could hardly make out her words and I suspected she was moving between English and Farsi. She sounded scared and confused. She was in the Emergency Room (ER) at one of the acute care hospitals in the city, and she wanted me to come to her. She wanted to go home. A million thoughts raced through my head: would they

let me see her, given the COVID-19 visitor restrictions? How could I help? Who was on-call for palliative care? We immediately left the hill and made our way home. On the walk back home, I was slightly out of breath as I was moving quickly and carrying all the sleds. I spoke first with her husband. Then, M's daughter called. In those few minutes on the way home, I had a conversation with her about goals of care and what her mom would want if time was short, which I was sure it was.

After several calls to the hospital, I was able to speak with M's nurse in the ER. At first, it sounded as if things were perhaps not as dire as I had envisioned. They were already talking about discharging her. Relief. I relayed what M's husband and daughter had told me about her uncontrolled symptoms and the reasons why she had been taken to the ER two days in a row. I asked the nurse if they would let me see her if I were to come to the hospital. The nurse was firm; it was an unequivocal 'no'. My worry was compounded by the fact that I thought M might be in a delirium, and the language barrier might be problematic. She needed someone there to advocate for her. She needed someone there to be her voice. I spoke again with her husband and daughter. I also spoke with the physician who was oncall for palliative care at the hospital. I tried to call M again, but she didn't answer. That's good, I thought. She's probably sleeping. I went to bed worried but hopeful. I would check in first thing in the morning.

I woke up on Saturday to a quiet house. I had slept restlessly; my slumber had been interrupted by many dreams but none foreboding. I sent the text just after 9 am. The response came back swiftly: we lost her. Lost. Where? Why? How? I was just talking to her. How could it be that she was just here, and now, she is so gone? Again, a million thoughts raced through my mind. What happened? Was she in pain? Was she scared? And almost unbearable to think, did this incredibly generous, kind, loving, selfless human being die alone? My girls wanted me to ask. They wanted to know. But even now, more than a month later. I cannot bear to think about it. I don't want to know. I don't want to think for a second that she was alone. I want to imagine that she was calm and ready. I want to imagine that her family made it in time. Or if not, that a caring nurse was by her side until the very end, stroking her hand, even if through the impersonal, impervious layers of latex. I hope she wasn't scared. I hope she felt peace. I hope.

In the time since M died, I've been going through the usual stages of grief, but not in a linear fashion, and always with an undertone of anger. M deserved better. Her family deserved better. In replaying the events of January 1 in my mind, I have distilled down what I believe to be the core issues, along with opportunities for improvements in the healthcare system and how these opportunities might help us die better, whether from COVID-19 or anything else.

Grief

Grief is a natural and expected response to loss ^{1,2}. Previous research has revealed that people who experienced the loss of a loved one went through a period of acute grief that subsided as time passed, due to the adaptation to the loss ^{1,2}. However, the potential for grief to evolve into a grief-related disorder, even in pre-pandemic times, has been well recognized. Disordered grief, such as complicated grief (CG) and prolonged grief disorder (PGD), was estimated to affect approximately 10-15% of the bereaved prior to the COVID-19 pandem-

ic ^{3,4}. Grief experts have reported that disordered grief may be on the rise, now and in the future, as a consequence of an array of factors related to the COVID-19 pandemic to be explored in further detail below ^{5,6}. Complicated grief has been described as grief that persists beyond what would be expected based upon cultural norms, and that interferes with daily functioning⁷. The ICD-11 describes this grief as a "persistent and pervasive grief response characterized by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain"². Complicated grief can impact one's physical and mental health, the ability to work, and the ability to maintain relationships. Moreover, CG has the potential to increase pressure on the healthcare system⁸. Complicated grief has been found to be associated with depression, suicidality, social isolation, and post-traumatic stress disorder. In addition, CG can manifest as panic attacks, excessive worry, and impaired function ⁹. Disenfranchised grief encompasses psychological, sociological, and political aspects of loss and describes the experience of grieving losses that are unacknowledged or unsupported by social systems ¹⁰ such as the absence of funerals and the lack of social or cultural recognition of death ^{11, 12}. Grief in the context of a pandemic

As of May 6, 2021, more than 3.2 million people worldwide have died of COVID-19¹³. Verdey et al.¹⁴ created a COVID-19 bereavement multiplier to estimate the average number of people who will experience the death of a close relative for each death due to COVID-19. The authors estimated that for every person bereaved due to a COVID-19 death, there could be up to 9 people who grieve the loss ¹⁴. Many countries, including Canada and the United States, have reported excess mortality in 2020 due to COVID-19 related deaths and other causes ¹⁵⁻¹⁷. According to Statistics Canada, there were an estimated 309,912 deaths in 2020¹⁵, leaving more than 2.78 million people grieving the death of a loved one. It is unknown how many of these individuals will experience complicated grief, but the changes in how people have been dying since the pandemic began will undoubtedly impact the bereavement experience and grief response of many. Factors related to the COVID-19 pandemic that might influence grief and bereavement.

The experiences that occur as someone is dying have the potential to impact the subsequent grief experience of family and loved ones ¹¹. It can be expected that the grief experience of someone who loses a loved one during the pandemic may be adversely impacted by the restrictions and limitations imposed by the pandemic. In a review article on the impact of previous pandemics on grief and bereavement, Maryland et al.¹⁸ reported that the COVID-19 pandemic is "likely to have a major impact on the individual and societal experience of death, dying, and bereavement". Grieving alone and in isolation has been described as a "uniquely different, unnatural feature of bereavement" during the pandemic, which is not limited to deaths from COVID-19¹⁹. For those who lose a loved one to COVID-19, the nature and experience of such a death may contribute to the bereaved person's grief ²⁰⁻²². For example, death in an intensive care unit may impact the bereaved person's grief by factors such as rapid decline and subsequent lack of preparation for the loved one's death, and the inability to be with the dying person due to isolation requirements 6,22-25. Further, while it has not been expressly discussed in the literature to date, there may be profound guilt if the bereaved person may have been the source of infection of the dying person. All of these factors may contribute to disordered grief for someone who loses a loved one to COVID-19. The bereavement experience of deaths that are not due to COVID-19 may also be influenced by pandemic-related factors ^{25,26}. Apart from COVID-19 related deaths, other deaths may occur during the pandemic where family and loved ones are unable to be with the dving person due to visitor restriction policies 3,6,25. Therefore, family and loved ones may be unable to say goodbye to, pay their respects to, or make amends with the dying person ^{22,25,27,28}. Public health restrictions have also limited gatherings for funerals or precluded the ability to honour other practices and traditions held after someone dies, potentially impeding a sense of closure and importantly, decreasing the social support for the bereaved ^{6,22,24,25,28}. Furthermore, people may experience multiple concomitant losses during the COVID-19 pandemic, including the loss of human lives, property, financial security, social and physical connections, sense of safety and security, and the autonomy to move freely in the world ^{3,9,11,22,25,29}.

Altered or absent customs and rituals

In addition to the impact of visitor restrictions, many usual customs and rituals surrounding death, including funerals and wakes, have been constrained or prohibited due to the pandemic 9,10,18,30. Travel restrictions and limitations on social gatherings have reduced the social supports to bereaved people ⁹. Practices surrounding death are shaped by culture and religion and may include body preparation, viewing of the body, funerals and wakes, cremation, and burials, to name a few ²⁴. Public health guidelines have limited or changed many of these rituals such as the shift to virtual funerals rather than in-person funerals^{22,24,28,31}. The consequences of the altered or absent rituals on the bereaved person's mental well-being remain unknown, but some studies suggested that the inability to attend a funeral, or the reduction in numbers of people who can attend, may adversely influence bereavement outcomes ^{24,32}. In a review, Burrell and Selman²⁸ identified 17 articles, including both quantitative observational and qualitative studies, that addressed the impact of funeral practices on bereaved relatives' mental health, grief, and bereavement. Overall, the authors found that the evidence on the impact of funerals on bereaved relatives' mental health and bereavement outcomes was equivocal and that ultimately, the "benefit of after-death rituals, including funerals, depends on the ability of the bereaved to shape those rituals and say goodbye in a way which is meaningful to them, and on whether the funeral demonstrates social support for the bereaved" ²⁸.

Lessons from previous mass bereavement events Harrop et al.²² conducted a systematic review to synthesize the evidence on system-level responses to mass bereavement events, including the terrorist attacks in the United States on September 11, 2001, the terrorist attacks in Norway in July 2011, the Norwegian Maritime disaster in 1999, Hurricane Katrina in August 2005 in the United States, and the tsunami in South East Asia in 2004. The review included twelve papers from six studies. The authors reported that while there were limitations in the quantity and quality of the evidence base, there had been commonalities among the studies in terms of key features of bereavement service delivery. In particular, the authors found that a proactive outreach approach, a centrally organized but locally delivered program, event-specific professional competencies, and psycho-educational content were essential ²². Additionally, the authors identified the need for crisisor event-specific competencies, which included the factors discussed above related to the COVID-19 pandemic. Cultural sensitivity and multilingual support should be integral to any program or service that is offered ²².

Similarly, Killikelly et al.⁴ recommended a three-tiered approach to addressing prolonged grief disorder during the COVID-19 pandemic. For low-risk individuals, the authors recommended general interventions, such as basic, self-help guidance. For at-risk groups, the authors suggest selective interventions such as non-mental health specialist support, community groups, trained volunteers, and engagement with clergy and chaplains. For individuals deemed to be at high risk of PGD, the authors advocate for indicated interventions, such as support provided by trained clinicians, psychologists, psychiatrists, and grief/bereavement counsellors ⁴. These recommendations mirror those delineated by Palliative Care Australia 5, who categorized their recommendations for support as follows: informal support, community support (generalist or specialist), and specialised professional bereavement support.

There is a need to educate healthcare providers and the public alike on the possibility of prolonged and complicated grief during and following the pandemic ⁹. Media campaigns and public education on grief during the pandemic may help to mitigate disenfranchised grief by providing acknowledgment and validation of grief. Evidence-based interventions to help manage prolonged and complicated grief are needed ³³. A national strategy on grief has been recommended by the Canadian Grief Alliance (CGA), a coalition of national leaders in grief and bereavement, and it has been supported by over 150 professional organizations and associations across the country ³⁴. The CGA is calling for the development of a National Grief Strategy to identify gaps, best practices, and priorities, an investment by the government of \$100 million over 3 years to expand and sustain grief services, \$10 million to fund grief research, and a public awareness campaign to increase Canadians' awareness and understanding of grief and coping strategies ³⁴.

Likewise, other organizations have recognized the need

for a concerted, systematic approach for dealing with grief in the context of the pandemic. In January 2021, the National Hospice and Palliative Care Organization and the Social Work Hospice and Palliative Care Network in the United States put out a joint call for a national bereavement response for COVID-19 related grief in the US²⁶. In February 2021, Carroll et al.³ sent a letter to United States President Joe Biden calling for a national grief strategy. Attention to underserved, racial, and marginalized populations will be critical, especially given that these populations have already been disproportionately affected by the pandemic ^{35,36}. The COVID-19 pandemic has emphasized how important it is for people to think about their goals and wishes for medical care, including their care at the end of life. There is recognition that all clinicians, not only those trained in palliative care, should possess the skills to discuss advance care planning and preferences for EOL care with patients and their loved ones ¹¹. Similarly, all clinicians should have the capacity to provide exemplary symptom management and be proficient in holding difficult conversations. Bereavement care, a key component of palliative care, should be incorporated into EOL care and provision of support to families should occur prior to and following the death of a loved one ³⁷.

Finally, just as there has been worldwide collaboration on many aspects of the pandemic response thus far, I would like to see international collaboration on developing strategies and sharing knowledge and resources to address grief and bereavement during and after the COVID-19 pandemic.

Conclusion

The COVID-19 pandemic has impacted the way that people are dying, and the way that people are experiencing bereavement and grief. While it may not be possible to prevent the inevitable grief that comes with losing a loved one, there are ways to help diminish the associated distress and help ensure that people experience uncomplicated grief. A national grief strategy is urgently needed to prevent unimaginable and protracted suffering. Such a strategy should outline interventions, including educational initiatives for the general public to help improve grief literacy and to increase awareness of available supports, as well as for healthcare providers to ensure that they are prepared to recognize and respond to disordered grief. In addition, the strategy should include interventions, such as general interventions, targeted interventions, and specialized interventions. Interventions should also be tailored to the local context and reflect of the unique issues of the COVID-19 pandemic. Research to assess the impact of the pandemic on grief and bereavement as well as on interventions that may help address grief and bereavement should also be included in the strategy. Of note, this paper did not address grief in healthcare providers, a topic that warrants a separate paper altogether. Unequivocally, the moral injury and distress that many healthcare providers have experienced since the beginning of the pandemic has the potential to influence the mental health of healthcare providers, which is worthy of considerable attention ³⁸.

I think of M and her family often. I wish things would have been different for her. I wish she would have been surrounded by a room full of people. I wonder how that would have changed her experience, her family's experience, and even my experience. I know that the pain of losing her wouldn't be allayed, though I can't help but wonder if this gnawing sense of regret would be replaced by a sense of peace. Death may be inevitable but dying and grieving alone shouldn't be.

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