BC Centre for Palliative Care

Impact of the COVID-19 Pandemic on Grief & Bereavement

Literature Review Report

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For More Information:

For more information about this report, please communicate with:

Dr. Eman Hassan
Executive Director
BC Centre for Palliative Care
Email: ehassan@bc-cpc.ca

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Territory Acknowledgement

The BC Centre for Palliative Care respectfully acknowledges that its office is located on the unceded, ancestral, and traditional territories of the Coast Salish People, including the territories of the xʷməθkwəy̓əm (Musqueam), Skwxwú7mesh (Squamish), and Sḵwx̱wú7mesh (Squamish), and Sḵwx̱wú7mesh (Squamish), and Səl̓ílwətaʔ/Selilwitulh (Tsleil-Waututh) Nations.

Gratitude to Our Collaborators

We are thankful and appreciate all those who gave of their time and shared their knowledge and experience to create this resource.

The Impact of the COVID-19 Pandemic on Grief & Bereavement: Literature Review is the result of a collaboration between the project team at the BC Centre for Palliative Care and a steering committee comprising representatives of provincial and national leaders in the provision of grief and bereavement support services and representatives of people with lived experience.

Project Team:

- Anica Butters, HBSc, Research Assistant, BC Centre for Palliative Care
- Joshua Black, PhD, Bereavement Initiative Manager, BC Centre for Palliative Care
- Rachel Carter, PhD, Division of Palliative Care, UBC; Research Manager, BC Centre for Palliative Care
- Principal Investigator: Eman Hassan, MD, MPH, Executive Director, BC Centre for Palliative Care

Steering Committee

- Shelly Cory, MA, Executive Director, Canadian Virtual Hospice
- Jessica Lowe, Executive Director, BC Bereavement Helpline
- Heather Mohan, PhD, RCC Executive Director, Lumara Grief & Bereavement Care Society
- Marney Thompson, MA, RCC, Director Bereavement Services, Victoria Hospice
- Annette Berndt - Public Partner
- D’Arcy Wingrove - Public Partner

GLOSSARY & ABBREVIATIONS

Definitions of Key Terms

Bereaved means suffering from being deprived of someone you care about because of their death.[1]

Bereavement is the condition of being bereaved, defined as the period of time following a death, during which a person experiences grief and mourning.[2]

Grief includes a wide variety of responses to loss (including losses other than through death), categorized into six domains:

- Emotional: for example, sadness, anger, regret [3-8]
- Cognitive: for example, difficulty concentrating, rumination, dreaming of the deceased [6,9-13]
- Physical: for example, illness, headaches, sleep changes [7,11,13,14]
- Behavioural: for example, crying, keeping busy, avoiding reminders of deceased [3,6-8, 11]
- Social: for example, isolating from others, continuing a bond with the deceased [6,7,9,11,15]
- Spiritual: for example, searching for meaning and purpose, questioning existence of a higher power [7,11,16,17]

Although grief can occur as a response to many losses, this review will focus on grief following a death.

Mourning is the outward expression of grief.[6]

List of Abbreviations

Abbreviation	Definition
BC	British Columbia
CBT	Cognitive Behavioural Therapy
COVID-19	Coronavirus Disease 2019
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition
ICU	Intensive Care Unit
PGD	Prolonged Grief Disorder
PGS	Pandemic Grief Scale
PPE	Personal Protective Equipment
PTSD	Post-Traumatic Stress Disorder

BACKGROUND

The review is part of a bigger initiative

The literature review is part of an initiative led by the BC Centre for Palliative Care in collaboration with key bereavement service providers, which include Victoria Hospice, BC Bereavement Helpline, Lumara Grief & Bereavement Care Society, and Canadian Virtual Hospice. The initiative aims to develop a provincial evidence-informed approach to supporting people experiencing bereavement in British Columbia (BC). In addition to the literature review, the initiative's key activities include several research studies that assess the current state of bereavement experience and services in BC from different perspectives. The results of this bereavement research informed a province-wide roundtable discussion with key stakeholders to identify the actions required to improve bereavement experiences and services in BC.

The need

In March 2020, the outbreak of the novel coronavirus (SARS-CoV-2) was declared a pandemic by the World Health Organization (WHO). Numerous restrictions were established to protect the health and safety of individuals around the world, with a primary focus on restrictions related to social interactions.[18–25] Despite these efforts, at the time of writing (July 20, 2022), COVID-19 has been responsible for the deaths of over 6.3 million people worldwide, including over 42,414 people in Canada.[26,27] In Canada, it was further noted that COVID-19 mortality rates were higher in neighbourhoods with a higher proportion of people who identify as a racial minority.[28] It is estimated that for every COVID-19 death, nine people are affected by bereavement.[29] Together, public health restrictions and the increased mortality rate have contributed to changes in how people have experienced death and bereavement.[30]

Objectives

The purpose of this literature review is to:

1. Understand how the COVID-19 pandemic has affected grief and bereavement experiences.

2. Identify best practices that have been effective in supporting people experiencing bereavement during the COVID-19 pandemic, and in other relevant situations such as previous epidemics or large-scale crises.

3. Use knowledge gained to inform best practices for bereavement support in British Columbia, both during and beyond the current pandemic.

Methods

Articles published between March 1, 2020 and July 20, 2022 were searched using the following databases: OVID, APA PsycInfo, PubMed, Scopus, and Google Scholar. The terms used in the search were: bereavement, grief, or mourning, and COVID, COVID-19, or coronavirus. A total of 59 articles (56 peer-reviewed) were reviewed that addressed bereavement during the COVID-19 pandemic. There were 143 articles total (126 peer-reviewed) that were included in the reference.

INTRODUCTION

Bereavement Experiences During the Pandemic

1. Grief

Most people experience and express their grief following a significant death in a variety of ways, which are captured in the six domains described in the glossary. However, it is important to understand that grief responses are unique for each person. While there are elements of grief that are seemingly universal, natural variations exist, and not everyone will feel, think, or behave in the same way following a major loss.

For many bereaved individuals, grief is a lifelong process that changes over time.[6] In the time immediately following a death, grief may be experienced acutely.[13] Individuals may experience a more intense "blend of yearning and sadness," in which there may be a greater desire to be removed from daily activities to be with the thoughts and memories of the deceased.[31] It is estimated that approximately 90% of people experience grief acutely, then gradually move toward a situation where grief becomes an integrated and less disruptive part of their lives.[32–34] Thus, some form of grief remains; however it is less intrusive in daily life.[35] Bereaved individuals may use a wide variety of supports, including family members, friends, animals, professional counselling, and peer support to help them process their grief.

The COVID-19 pandemic posed new challenges for the bereaved, primarily in relation to public health restrictions and policies.[18–25] These included social distancing, stay-at-home orders, travel bans, isolation for exposed or infected individuals, limits on the number of visitors at hospitals or care homes, use of personal protective equipment (PPE), and limits on the number of attendees at religious ceremonies, funerals, and post-death rituals.[18–25,36]

These restrictions had a direct impact on many areas significant to the bereaved, such as end-of-life moments, mourning rituals such as funerals or celebrations of life, informational supports, social circles, and changes to their typical ways of coping.[18,21–25,36]

Anger, while not uncommon in grief, has been an identifiable feature of grief during the COVID-19 pandemic.[37] This is in part due to characteristics of the pandemic, such as the infectious nature of the virus and the restrictions on visitors in hospitals, causing feelings of anger as a grief response.[37,38] Feelings of anger were directed toward governments for inaction, healthcare institutions and providers for delays in treatment and visiting restrictions, and the public for not complying with public health restrictions.[37]

Guilt and regret, also common emotions in grief, have been identified during the pandemic, with one study reporting over a third of participants experiencing these emotions.[39] Some bereaved individuals expressed guilt for being physically and psychologically absent during the final days before the person's death.[40] Other articles identified that guilt may be felt due to a feeling of failing to prevent the death, and an overall sense of unease about surviving a pandemic that claimed the life of someone close to them.[40–42]

2. Prolonged grief disorder

Prolonged grief disorder (PGD) is a maladaptive grief response that has recently been added to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) as part of its March 2022 revisions.[43] PGD is characterized by yearning and longing for the person who has died, alongside a preoccupation with thoughts of the person who has died. As discussed by Prigerson et al.[43], specific criteria for the DSM-5 diagnosis include the presence of at least three of eight symptoms as a result of the death:

1. Identity disruption;
2. Marked sense of disbelief about the death;
3. Avoidance of reminders that the person is dead;
4. Intense emotional pain related to the death;
5. Difficulty with re-integration into life after the death;
6. Emotional numbness;
7. Feeling that life is meaningless; and
8. Intense loneliness[43]

PGD is considered a disordered grief response due to impairment in many areas of, and the duration and severity of the symptoms, which must be considered to exceed the norms of the context in which the bereaved individual lives. PGD can only be diagnosed in adults 12 months after the death, although for children and adolescents this is shortened to six months. It must also be ascertained whether the symptoms can be better explained by a different mental disorder, a medical condition, or substance use.[43] PGD can potentially last decades, and reduces a person's capacity to enjoy social activities and to feel positivity.[31] PGD is reported to impact approximately 10% of all bereaved individuals.[32]

There are several proposed ways to treat PGD in bereaved individuals. First is the use of cognitive behavioural therapy (CBT), which can be particularly beneficial when it addresses feelings of self-blame with which many individuals with PGD struggle.[44–46] Other suggestions include exposure therapy to encourage emotional processing of the death, individual psychotherapy, group psychotherapy, internet-based exercises, and the use of antidepressant medications.[44,47,48] Further clinical trials investigating pharmaceutical treatments for PGD have also been proposed.

Prior to the COVID-19 pandemic, PGD was reported to impact approximately 10% of all bereaved individuals.[32] During the first year of the pandemic, one study found PGD to occur in 49% of individuals bereaved by COVID-19.[49] However, it is still possible that the full extent of PGD resulting from the pandemic has yet to unfold.

Events in the initial years of the pandemic predisposed people to some of the known risk factors for PGD, such as multiple losses in a short time, untimely or unexpected death, and reliance on maladaptive coping behaviours (e.g., increased substance use and overuse).[22,50–53] However, individuals bereaved during the pandemic from COVID-19 and non-COVID-19 causes are both at risk of PGD, particularly those with limited social support, those who are older, and those who have a previous history of mental illness.[42]

3. Disenfranchised grief

Any grief that is unrecognized by societal norms is considered disenfranchised and can exacerbate the individual's struggle to cope following the death.[54] Because the grief is unrecognized, the individual may feel unable to publicly mourn or ask for social support from others. Doka[12] identifies three ways grief can be disenfranchised as:

1. The relationship is not recognized – for example, an ex-spouse, a same-sex partner;
2. The loss is not recognized – for example, death of a pet, after the loss of a pregnancy; and/or
3. The griever is not recognized – for example, grief felt by children or people with mental disabilities.[12]

Overall, the disenfranchisement of grief poses a problem to the individual who is bereaved, as it creates additional barriers to their grieving and often removes much-needed avenues of support.[54]

Suicide and toxic drug-related harms and deaths

As both suicide and toxic drug-related harms and deaths are stigmatized, they can be associated with disenfranchised grief.[55] It can be difficult for individuals who have had someone die in these ways to feel their grief is recognized. The COVID-19 pandemic has led some regions to experience an increase in the number of toxic drug-related and suicide deaths.[56–59] Reasons suggested for the increase in suicide deaths included financial difficulties brought on by loss of employment, the increased prevalence of mental health issues (e.g., stress, anxiety, and depression), and maladaptive coping strategies (e.g., alcohol and drug use).[19,60,61] In other areas, the suicide rate stayed the same or even decreased.[62,63] Some factors suggested the absence of an increase in the suicide rate included an increase in calls to suicide hotlines and increased use of and requests for telemedicine and counselling.[64]

In Canada, there is inconclusive evidence that the pandemic affected the number of suicide deaths.[65] One Canadian study provided evidence for a decrease in suicide mortality during the pandemic.[66] Yet, data from the Survey on COVID-19 and Mental Health conducted by Statistics Canada indicated that suicidal ideation increased among adults, compared to both pre-pandemic and early pandemic numbers.[67]

In Canada, there was an increase of 91% in the number of opioid-related deaths between April 2020 to March 2022 compared to two years earlier (between April 2018 to March 2020).[59] A similar trend was identified in a study of Jefferson County in Kentucky, United States, which saw an increase in toxic drug-related deaths of 88.6% during the short period between March and June 2020 compared to the same period in 2019.[56]
It is believed that in addition to general stress caused by the pandemic, the disruption of traditional routines challenged individuals who were using or had historically used substances, including those who were abstaining or reducing their use prior to the start of the pandemic.[68] For others, accessing treatment or safe injection sites became difficult with the need for social distancing, or for treatment centres to have limited hours and fewer staff onsite.[68] These findings signal a need to prepare to support a larger number of individuals bereaved from toxic drug-related harms and deaths, who may feel disenfranchised in their grief.

Unvaccinated people

As the COVID-19 vaccine roll-out occurred in Canada, a group that experienced disenfranchised grief were those who experienced the death of a person unvaccinated against COVID-19. While there is limited academic literature on the topic, some anecdotal evidence was reported.[69,70] Personal stories shared by those bereaved by the death of an unvaccinated person reflected the unique challenges associated with these circumstances, such as anger at the deceased for choosing to not be vaccinated, or guilt for not being able to convince them to become vaccinated.[69] Others have shared stories of unwelcome or hurtful comments from friends, family members, or strangers on social media, such as questions about the medical decisions of the deceased person.[70] In a survey conducted by the Angus Reid Institute, 75% of Canadians were found to be unsympathetic to those who contracted COVID-19 while unvaccinated.[71]

Healthcare workers and older adults

Disenfranchised grief is expected to have increased as a result of the COVID-19 pandemic.[50,51] Two additional groups at risk of disenfranchised grief are those bereaved following the deaths of healthcare workers and older adults.[51] The use of metaphors like “angel” or “hero” when referring to healthcare

workers at the front lines of the pandemic has led to their deaths being framed as heroic, as they 'knowingly' risked their lives to save others.[51,72,73] By constructing their deaths as heroic and sacrificial, those who are bereaved are limited in their ability to feel certain emotions, like anger, in their grief.[51] This may disenfranchise and silence their grief.[51] The deaths of older adults from COVID-19 are sometimes framed as inevitable due to the knowledge that older adults are more susceptible to severe outcomes resulting from COVID-19.[51] Media and government messages reinforce these narratives, and while intended to reassure the larger population, they may have the unintended consequence of some individuals feeling their grief is not valid, or of significance.[51]

Bereavement Support Challenges During the Pandemic

The COVID-19 has had many unique characteristics that have affected the grief individuals have experienced following a death.[74] Deaths from COVID-19 are often sudden, while those bereaved by deaths from both COVID-19 and non-COVID-19 causes have been subject to social isolation and limitations with regard to traditional ceremonies and rituals relating to death and grief.[18,75–77] During the pandemic, people have also been exposed to multiple losses, contributing to the presence of grief symptoms.[76]

1. Pre-death factors

Unable to visit the dying

Restrictions from the COVID-19 pandemic affected relational and cultural activities that might normally happen before or near death. Social distancing and restrictions on gatherings impacted the ability to visit people in hospices, hospitals, and care facilities.[21,36,78] While these restrictions helped reduce the risk of infection, the inability to say goodbye to someone you care about who is dying is a risk factor for complicated grief, and forced separation may have led to feelings of guilt, yearning, anger, or bitterness.[24,50] Individuals may have felt as though they should have made more effort to see the dying, and to make sure they were comfortable and that their wishes for care were being followed.[24]

Often, video calls were used to stay in touch with family members unable to visit, but requests for video calls were difficult to facilitate when staff were busy with other tasks.[79] For patients with cognitive impairments or who were unable to speak due to intubation, their families were not always offered the opportunity to video call, due to concerns over increased distress for both the patient and their relatives.[78,80] Video calls were also not a feasible method of communication for all family members, due to issues with access to the internet and necessary technology.[78,81,82]

Restrictions on visits also prevented family members and friends from being able to visit until the patient was close to end-of-life, which often meant they were unable to fully interact with those who came to visit them.[78]

Mental health

Mental health is defined as the condition of a person's mind, and it is normal for it to change over time.[83] Mental health disorders are absent or present, and are based on sets of distinct symptoms that affect a person's thoughts, emotions, and behaviors, and are often associated with significant distress and ability to function in daily life.[83] The pandemic increased both the difficulty in maintaining good mental health and the prevalence of mental health disorders in adults and children.

Adult mental health

Necessary public health measures like quarantine, lockdown, and social distancing negatively affected individuals' mental health. Feelings of loneliness and isolation have been linked to worsening mental health.[84,85] These public health measures also reduced or eliminated many of the strategies people employed to cope with stress (e.g., going to the gym, in-person gatherings, eating at restaurants).[20] New or heightened fears surfaced because of the pandemic including fear of personal illness or death of someone important, loss of income or employment, social isolation, and separation from friends or family.[20,52,53,84] Individuals who tested positive for COVID-19 or who worked in close contact with sick individuals may have experienced anxiety regarding their prognosis, as well as stigmatization from the public.[52,53] Unsurprisingly, maladaptive coping

behaviours, such as excessive gambling and/or alcohol and drug use, increased in prevalence.[52] This rise in mental health issues and maladaptive coping behaviours during the pandemic is also reflected in the growing incidences of suicide and substance use-related harms and deaths in some geographic regions.[56–58,60]

Throughout the COVID-19 pandemic, the incidence of mental health disorders in adults has risen, which may complicate the grieving process.[86] Mental health disorders in adults that increased during the pandemic include anxiety, sleep disorders, suicidal ideation, and depression.[67,87–89]

Child mental health

Children's mental health has been impacted by the pandemic. For young children, their often-limited understanding of the pandemic created confusion and uncertainty.[20] Older children experienced worsened stress and anxiety.[20] Oftentimes, lockdowns meant children were not present in the physical school environment with their friends, contributing to a lack of social connectedness.[20] Some children may have been living in a home environment where abuse, neglect, or addictive behaviours were present and, with lockdown, faced extended periods of time in such an environment with no relief through school or other outings.[20] Fortunately, children and young adults were more often willing than older age groups to access online mental health support, which may have mitigated some of these concerns.[90] However, online mental health support may not be beneficial for some children, including very young children and those who are technologically disadvantaged.[90]

Throughout the COVID-19 pandemic, mental health disorders in children also have become more prevalent.[20] The increase in mental health disorders for children may mean that, like adults, those bereaved during the pandemic may have additional challenges in coping with the death due to new or worsened mental health disorders.[20] Certain mental health disorders that have increased in children during the pandemic are anxiety, behavioural disorders, and depression.[20,91,92]

Access to healthcare professionals

There also has been an impact on the ability of relatives of the patient to build a relationship with the healthcare professionals caring for the dying.[36] Conversations that previously occurred in-person with healthcare professionals were required to take place over the phone or video call.[36] This lack of connection may have led to a sense of uncertainty with the care choices they have made.[36] In one survey completed in the United Kingdom, over a third of respondents indicated they did not feel involved in decisions regarding the care or treatment of their family member.[93]

2. Post-death factors

Isolation and stigmatization

Public health measures enacted to limit the spread of COVID-19 (e.g., lockdowns and social distancing), have increased isolation for individuals who are bereaved. If the death was the result of COVID-19 and the family was able to visit the person in hospital, there were often requirements to self-isolate afterward. This reduced opportunities to receive grief support in the immediate days following the death.[24] It is important to note that the isolation felt during COVID-19 not only impacted individuals bereaved during the pandemic, but those who were bereaved before the start of the pandemic as well.[24] Individuals who were accessing bereavement care may have had this care interrupted by pandemic measures, affecting their progress in understanding and working through their feelings of grief.[24]

Isolation can also impact bereavement support from the perspective of bereavement care providers. Without being able to connect in-person with bereaved individuals, there were limited opportunities to identify who needed further support.[24] As a result, many bereavement care providers took on a proactive approach in contacting families of

the person who died, in recognition of how social isolation was affecting bereavement.[24]

Another factor negatively impacting bereavement during the pandemic has been stigmatization.[24,77] COVID-19 is an infectious disease, thus there is potential for surviving family to be seen as carriers of disease.[77] Out of fear for their own safety, and based on reports from the media and others, people who may have otherwise supported the bereaved family avoided them.[42,77] A lack of social support can impact bereavement and is a risk factor for PGD.[76,77] Additionally, stigmatization of the virus was noted when families did not want the cause of death on the death certificate to be listed as COVID-19.[24]

Mental health disorders

For individuals bereaved during the COVID-19 pandemic, co-morbid mental health disorders (e.g., anxiety and depression) may be more common.[49] Tang et al.[49] reported that clinical anxiety and depression are present in 70% and 65% of individuals bereaved by COVID-19, respectively, compared to 58% and 48% of individuals bereaved in pre-pandemic times.[94] The location of the death is a pandemic-related factor linked with the increase in mental health disorders seen in those who have been bereaved.[76] Often, deaths from COVID-19 occur in the intensive care unit (ICU), a location of death linked to depression and more complex grief.[76,95] Post-traumatic stress disorder (PTSD) is also associated with deaths occurring in the ICU, particularly if the patient was intubated and families expressed concerns about whether the patient could breathe.[96,97]

Lack of access to routines and rituals

Throughout the COVID-19 pandemic, public health restrictions surrounding social distancing and crowds impacted traditional bereavement practices that normally occur post-death.[18,25] While the restrictions limiting post-death rituals were necessary to protect the health and safety of the bereaved, these rituals provide an important opportunity for individuals to engage in meaning-making following the death.[18] The loss of such events impacted grieving, as families struggled to make sense of the death.[77,98]

Funerals provide an opportunity for the bereaved to honour the person who died, and to say goodbye in meaningful ways.[18] Funeral providers are a frequently used source of support for bereaved individuals, and are perceived as highly helpful during bereavement.[99] Having the opportunity to attend a funeral has also been identified as a protective factor against complicated grief reactions, while feeling upset about the inadequacy of the memorial service was identified as a risk factor for grief disorders.[40,41]

While funerals have typically been permitted during the pandemic, it is often with guidelines in place regarding the number and type of guests, as well as the specific practices that can take place.[18] Children, individuals who display symptoms of COVID-19, and individuals at-risk of severe outcomes of the disease may have been restricted from attending.[18,22] For individuals living in the same household, a positive test for COVID-19 around the time of death resulted in the inability to attend an in-person funeral.[100] While these decisions are often made keeping health and safety in mind, there is a likelihood that they impacted the bereavement process of these groups.[18,22] In some regions, due to the increased death rate during the pandemic, it was requested that funerals were held immediately, rather than being delayed until restrictions were lifted; however, this was not universal.[18]

Yet, there remains a lack of consensus in how the restrictions surrounding funerals affected bereavement, as the impact may vary between bereaved individuals and families.[18] For example, Burrell and Selman[18] suggest that funerals may not be directly linked to difficulties during the bereavement process, with the meaning of the funeral experience having more of an impact than the presence or absence of a funeral. This ability to make important decisions about the ceremony, and to personalize what rituals take place could be beneficial, but may have been impacted by public health restrictions.[18]

As a result of pandemic restrictions, many families made the decision to use a virtual or modified format for funerals. Often, funerals and other rituals were held using video-conferencing technology, which allowed individuals to memorialize the deceased together, without the risk of infection.[101,102] Another funeral format used during the pandemic was a "drive-through funeral" in which the bereaved individuals drove in a procession through a funeral home parking lot or other site, stopping beside the casket to pay their respects.[103] Outdoor funerals, hybrid options, or in-person funerals held in large indoor spaces were also options.[104] For some, the ability to have a virtual ritual may have been appreciated and beneficial, yet others described virtual funerals as "unbearable" and a poor substitute.[37,105]

Lack of access to culturally sensitive supports

Throughout the pandemic, individuals belonging to a racial and/or ethnic minority group have been more likely to experience multiple deaths and secondary losses (e.g., loss of housing and/or employment).[51,106,107] Furthermore, cultural and/or religious rituals that normally provide comfort following a death have been restricted by social distancing requirements and other public health measures. It was identified in the literature that there is a gap in providing culturally appropriate resources and care in bereavement support, and that has been brought to the forefront by the pandemic. There is a need to make space for the facilitation of traditional cultural and/or religious bereavement practices wherever possible and to provide support in the bereaved person's preferred language.[18,50,77,108,109] However, there is undeniably further research and work required not only to address the inequities at the root cause of the aforementioned disparities, but also to develop culturally appropriate practices and resources to support individuals belonging to racial and ethnic minorities in their bereavement beyond the pandemic.[18,50,77,108–110]

Access to healthcare and bereavement care professionals

Healthcare providers

Healthcare providers also faced difficulties when working with bereaved individuals during the pandemic.[24] When working with families face-to-face, the use of PPE has inhibited communication, including non-verbal cues of support and empathy.[24,42] In some instances, there was hostility and anger toward healthcare providers, with bereaved family members placing blame on nursing home workers for the deaths of residents from COVID-19, as they were concerned that workers may have been spreading the virus among themselves and residents.[111]

Furthermore, the economic impact of COVID-19 meant some healthcare workers were laid off, while others were re-deployed to serve other understaffed facilities.[24] In facilities where volunteers had some responsibility for bereavement support, volunteer support was reduced or suspended by restrictions.[24] This limited access to individuals who may have been able to support families in their grief, and placed more responsibility on those around to help.[24]

Throughout the pandemic, healthcare providers themselves have been at a heightened risk of experiencing bereavement of their own, through the death of a patient, colleague, family member, friend, or another person known to them.[73] The demand of working during a pandemic, while simultaneously grieving the death of someone known to them (or another loss) has created emotional difficulties for healthcare providers in their work.[24,80] Healthcare providers deployed to roles in which they had not worked prior to the pandemic may have been exposed to death at a rate not previously seen in their work.[112] They may also feel guilt or distress about the deaths that occurred in healthcare settings, particularly in the early days of the pandemic when limited treatment options were available.[112] Similar to those who do not work in healthcare, healthcare providers may be at risk of developing PGD due to the challenges of bereavement during the pandemic.[76]

Virtual bereavement support for adults

Individuals and organizations who have traditionally provided support to bereaved individuals have faced many barriers to successful bereavement support throughout the pandemic.[24,75] The inability to physically comfort those who are bereaved has led to a need for creative measures, including services provided over phone and video calls.[24]

In many instances, phone and video call supports had rarely been used prior to the pandemic but are now seen as a useful form of outreach.[24] Learning how to effectively assist bereaved individuals required additional time and effort on the behalf of bereavement service providers at the onset of the pandemic, to learn how to effectively assist bereaved individuals.[24]

While these supports have been shown to be beneficial, there are also limitations to using these methods.[24,113] Difficulties identified by facilitators of online bereavement programs included having initial trouble with managing emotions and distress during a video call, and developing a supportive group environment.[75,113] It was identified that developing a supportive virtual environment required a longer amount of time for individuals to feel comfortable sharing their bereavement experiences.[113] For bereavement care providers, these challenges combined with their desire to continue to support the bereaved led to increased burdens of time and effort that contributed to their feelings of exhaustion.[24]

In order to comprehensively identity further challenges in using video and phone supports, the literature on both bereavement and mental health support during the COVID-19 pandemic was reviewed. While specific groups like children and young adults were identified as having remarkable success in switching to an online environment, it is worth noting that very young children or individuals with certain mental health disorders (e.g., eating disorders) were not perceived to benefit as much.[90]

A common challenge voiced with regard to the effectiveness of support provided through a video or phone call is the perceived absence of or difficulty in developing a human-to-human connection that is usually facilitated in an in-person setting.[90,114] This may interfere with the development of an effective working relationship, or with the ability for the service provider to read signals like body language to determine how the client is feeling.[90,114–116]

Another concern raised about using virtual support was privacy.[114] For example, among undocumented immigrants or relatives of undocumented immigrants, there was fear that virtual support would reveal their location.[115] Additionally, it was found that reasons for preferring in-person support over virtual ranged from personal preference to issues such as the lack of high quality internet, an operating system that supported video calls, or limited use available on prepaid phones.[90,115] Technology disruptions were also a common issue raised.[90,114,115]

Virtual bereavement support for children

In the context of the COVID-19 pandemic, it was estimated that between March 2020 and April 2021 alone, 1.56 million children experienced the death of a parent, guardian, or older family member, indicating a widespread need for child-centred bereavement support.[117] With bereaved children, certain challenges were identified like whether virtual bereavement support would address the isolation and loneliness children were feeling, due to limited connections to support networks like friends, teacher, or caregivers.[20,90,118,119] Thus, virtual bereavement support may address some concerns for bereaved young people, but challenges exist in other aspects.[90]

Other mediums like children's books and storytelling on grief and bereavement may have been useful in the context of the pandemic, although parents needed advice on facilitating conversations about death with their children, both before and after the death.[79,104,120]

Another venue where young people may seek support in their bereavement is social media.[119] A post about a death can garner comments and offers of assistance from friends and acquaintances.

However, social media is an unpredictable environment in which to seek bereavement support.[119] Where support may be offered in one moment, a hurtful comment or emotional post may lead to upsetting feelings in the next.[121]

Children must be given much consideration in the context of virtual bereavement support. Their generalized knowledge and comfort with online media can be both a benefit and a risk in providing bereavement support.[90,119] While virtual bereavement sessions can be a support system for individuals and families, clear practices need to be identified that address these barriers to effective assistance.[113]

Bereavement Support Successes During the COVID-19 Pandemic

Undeniably, there have been difficulties managing bereavement support during the COVID-19 pandemic; yet, the literature has identified several successes.

1. Pre-loss successes

Creative connections

Social workers have organized many important moments for both the dying individual and those who care about them.[21,22] Organizing virtual bedside visits to provide a moment of connection has been beneficial to individuals who would otherwise not be able to say goodbye.[21] Social workers were also able to provide updates to worried family members who were not

able to be there in person and were able to serve as a mediator between the patient and physician.[122] When social workers were limited in their physical contact with patients, nurses, healthcare assistants, and other practitioners worked alongside social workers to implement support programming, such as assisting families in creating and delivering letters and drawings to those important to them.[21,80]

Memory-making

While historically associated with the death of a child in hospital, memory-making has been used throughout the pandemic due to limitations to in-person visits.[21] Creations like cardiac tracing (tracing the electrical signature of the heart), handprint moulds (creating a plaster mould of the individual's hand), or video messages from the person dying were provided to families to support them in their bereavement, and in remembering the deceased.[21,23] Social workers often were a key facilitator of such activities in hospital settings.[21]

2. Post-loss successes

Healthcare workers

Clinicians, like doctors and nurses, are responsible for the medical care of the sick individual, but they are also an important resource in the provision of bereavement support.[23,123] Telephone conversations from clinicians to notify families of the death were beneficial to bereaved family members, as they have provided an opportunity for the bereaved to receive details about the patient's care and death.[123,124] Family members may be reassured, for example, to learn if their relative was in the company of a doctor or nurse as they died.[37] In these calls, appropriate, empathetic, and personalized condolence communications are beneficial. Doctors, or any other healthcare staff, are also able to utilize these calls to identify any concerns with an individual's mental health during bereavement.[123,124]

In instances where clinicians were not able to mitigate the impact of restrictions, their efforts were nevertheless appreciated by the family members of the patient.[122] There has been and continues to be a reliance on the work of healthcare providers, clinicians especially, in bereavement support during the pandemic.[21,25,123]

Bereavement packages

In the context of the COVID-19 pandemic, bereavement packages may include a condolence letter, grief guide, a list of community resources, a social work contact, and a COVID-19-specific grief sheet.[75] Bereavement packages have been identified as a supportive resource during the pandemic, as they assist families in identifying what supports are available to them, should they be required.[75] Other supports included in the bereavement package can be suggestions of cognitive behavioural therapy (CBT) strategies and how to adapt personal bereavement rituals.[75] Hospitals have also provided further gestures of support, like small mementos given to bereaved families.[24]

Remote support

A prominent theme was the success of the translation of traditional bereavement supports to an online environment, including bereavement therapy groups which were facilitated over video call platforms, albeit with some identified challenges.[24,108,113] Research on remote bereavement support during the COVID-19 pandemic was examined to identify further successes in using video and phone support. There are many additional relevant findings from the mental health support literature, which were also examined to gain a comprehensive picture of remote support successes.

Common strengths of remote support include:

- A higher likelihood of individuals attending scheduled appointments[115];
- Greater accessibility, which can reduce costs of travel and absence from work[90,115,125,126];
- Lower costs for provision of remote support, reducing overall treatment expenses and increasing accessibility[127]; and
- The ability for people to feel more open and relaxed, as virtual support can reduce the stigma of seeking support.[126]

It was found that clients were generally highly satisfied with virtual support services.[125,126] Challenges were offset by advantages gained in the video call format.[114] Furthermore, it was identified that a brief glimpse into the home environment could allow for identifying any ongoing issues at home that may need to be addressed.[114] However, these benefits only occurred when a video call was the medium of choice. Over the phone, service providers are further limited, and there was still a preference among some people for in-person support.[114,115] There is also the potential for remote bereavement support to include self-directed activities such as audio diaries or journaling, which may be of particular use when other methods of support are unavailable.[128]

Community-based initiatives for remote bereavement support is also important. In Quebec, J'accompagne (I'm with you) is an online support community developed to support those bereaved during the pandemic.[129] J'accompagne has provided a space for bereaved individuals to connect with others, and to express their feelings using art and storytelling, while also providing death education and available resources to the wider community.[129] Dedicated websites like these may provide a space for collective grief and may allow for the involvement of those who are bereaved in providing feedback for new ideas.[73]

Adaptation of traditional experiences

By personalizing funeral experiences within the context of public health restrictions, meaning-making can take place.[18] There has also been a benefit in facilitating viewing of the body, which was restricted with individuals who died from COVID-19 due to risk of infection.[21] Practices like 'double bagging' the body, requiring visitors to wear full PPE, or virtual viewings have supported families in having a meaningful opportunity to say goodbye to the person they cared about.[21]

Rapid grief assessment tool developed

A rapid grief assessment tool was developed during the pandemic to quickly identify possible cases of disordered grief after experiencing a death from COVID-19.[130] The Pandemic Grief Scale (PGS) is a five-item scale that has the potential to assist healthcare providers in making decisions about resource allocation, particularly in environments where resources are limited.[131] Studies have indicated its usefulness as a rapid assessment tool, such as a study examining its use in ten Latin American countries that demonstrated promising reliability.[131,132] Of note was its potential to be used in cross-cultural studies, as uniform meaning was found across all ten Latin American countries.[132] The PGS represents a new innovation in bereavement support during the COVID-19 pandemic.[130]

Key Bereavement Learnings from Past Outbreaks and Disasters

While the COVID-19 pandemic has been caused by a novel form of the coronavirus, there are many similarities from this pandemic to past outbreaks of disease and disasters.[76,109] Similarities to the COVID-19 pandemic include the events being sudden and traumatic, as well as creating multiple deaths and secondary losses (e.g., income).[76] Exposure to traumatic events is often multiplied by constant news and social media coverage of ongoing events, as was seen during COVID-19.[42] There is thus a potential for similar bereavement experiences to occur during COVID-19.[76,109] Ultimately, there is a benefit in considering how bereavement services supported individuals in these moments, as well as past inadequate support, to investigate what practices may be useful to bring forward into the current pandemic.[74,76,109]

1. Bereavement support in past disease outbreaks

Many successes were identified in bereavement support during past disease outbreaks, epidemics and pandemics. Similar to COVID-19, past disease

outbreaks like the West Africa Ebola virus epidemic and the Haitian cholera outbreak had an impact on how bereavement support was provided.[74,133–135] For both Ebola and cholera, the risk of contagion from the body to living individuals required either rapid burials or cremation.[134,135]

Rituals

Challenges identified in several past disease outbreaks included an inability to meet cultural expectations for burials and limited opportunities for the bereaved to connect with other family and community members for support, both of which raised concerns about how they may impact the grieving process.[134,135] These challenges were addressed within the context of the Haitian cholera outbreak by prioritizing the creation of opportunities for family members to say goodbye to the dying.[134] A mourning tent was established outside a cholera treatment centre, where families could gather.[134] At the family's request, a religious leader of their choice was allowed to be present to lead short prayers or rituals.[134] It has been suggested that respect or rituals and giving of space for emotions should be allowed.[134] Although it may not always be permissible within public health restrictions, wherever possible a mourning opportunity should be facilitated.[134]

Healthcare providers

In the face of enforced isolation and limits to social gatherings, healthcare providers in hospitals, including mental health and social work departments, were seen as useful resources to provide practical and emotional support to bereaved individuals, especially those who live alone.[76] These departments also can provide beneficial care not only to those who are sick, but also to their coworkers, alleviating their stress levels and allowing them to provide better care to those who are sick.[76]

Bereavement care for survivors

A consideration to be noted for COVID-19, based on research from the Ebola epidemic, is how to provide bereavement support for individuals who were diagnosed with the illness and survived, while someone they cared about who was also diagnosed with the illness died.[135] During the Ebola epidemic, survivors of the virus were unable to grieve with their families due to being in hospital or in isolation with the illness.[135] Furthermore, due to the need to cremate the bodies of Ebola victims and the lack of formal burials, there was often no grave for the survivors to visit to pay their respects, meaning they often had no opportunity to take part in collective grief rituals.[135] These survivors dealt with complex feelings of grief, which bear similarity to PTSD, including flashbacks to their time in hospital.[135] Solutions used to address these issues included community-based approaches that were developed in cooperation with survivors, who can provide input on what resources and support would serve them best.[133,135]

2. Bereavement support in past disasters

Natural disasters (e.g., 2004 Indian Ocean tsunami) and human-made disasters (e.g., 9/11 and 2011 Norway terrorist attacks) have also been examined to identify beneficial practices, such as widespread organized responses, gatherings and memorials, proactive outreach, and support systems.[76,109] Like the COVID-19 pandemic, natural and human-made disasters can create multiple secondary losses (e.g., housing and job loss), and deaths from the disaster will likely be sudden and traumatic.[76]

Widespread organized responses

Following the 9/11 terrorist attacks, a program called Project Liberty was launched to provide crisis counselling and support for residents of New York City and surrounding counties.[136] The program was found to reduce depression, grief, traumatic and severe stress for bereaved individuals. In 2003, two years after the attacks, the decision was made to expand Project Liberty to develop long-term counselling supports.[137] It was recognized that some individuals were experiencing grief and mental health disorders (e.g., depression and PTSD) beyond what could be addressed with short-term counselling.[137] Research that surveyed individuals who received counselling from Project Liberty led to the development of the Brief Grief Questionnaire, which is used to screen for complicated grief.[138]

Gatherings and memorials

Echoing the findings of Project Liberty that long-term services may be required, a study on a program developed after the 2011 Norway terrorist attacks suggest that weekend bereavement support gatherings at 4, 8, 12, and 18 months following the attack are beneficial for the bereaved.[139] These gatherings consisted of plenary sessions, group discussions, and activities for children.[139] The events were very successful, with 90% of attendees reporting the gatherings as helpful or extremely helpful, and none reporting them as counterproductive or unnecessary.[139] Helpful supports in Sweden following the 2004 Indian Ocean tsunami included annual memorials to remember the victims of the event.[140] The ability for survivors to come together to remember someone important to them was echoed across many studies, as the unique ability to reflect together on similar experiences is invaluable.[139–141]

Proactive outreach

A study conducted with bereaved individuals of the 2011 Norway terrorist attacks indicated a preference for proactive outreach from professionals to bereaved individuals.[141] If the bereaved person initially refused help, repeated contact or the provision of a contact person may be beneficial.[141]

Support systems

A significant need was identified for strong social supports.[139–141] Group support with individuals bereaved by the same event was also identified as important.[139–141] However, a challenge was identified in that bereavement service providers may not be educated on how to best provide support for individuals bereaved from rare events like pandemics or natural disasters.[141] Further training on working

with individuals bereaved by traumatic events could be beneficial in improving the support they provide.[141] Obstacles for the bereaved in receiving help included low energy, limited ability to miss work, and not being able to travel.[141] One strategy to address these challenges is offering support at school or work. One study examining those bereaved by the 2011 Norway terrorist attacks identified the potential for work and school to be supportive environments, but emphasized the need to address gaps regarding flexibility and understanding of how to support grievers in the workplace.[141]

CONSIDERATIONS FOR THE FUTURE

This literature review has identified many successes and challenges in bereavement support throughout the pandemic, as well as the impact on grief. However, it is important to acknowledge what has been identified as necessary for future bereavement supports, both throughout the remainder of the pandemic and beyond. A general emphasis was the importance of continuing the desire to improve bereavement support beyond the pandemic.[24,50]

The current global pandemic has raised the profile of bereavement like never before. Prior to the pandemic there was a consistent identification that available bereavement support was insufficient.[24] Thus, emphasizing the importance of developing and implementing appropriate and successful bereavement supports must continue.[50]

Despite only a few studies in this review involving a Canadian sample[95,122,129], this knowledge will inform best practices for bereavement support in British Columbia, both during and beyond the pandemic.

Based on this review, suggested considerations for the future can be divided into increasing quality of supports available to the bereaved, grief and bereavement literacy and training, and collaborations between bereavement and non-bereavement organizations.

Increase Quality of Supports Available to the Bereaved

1. **Offer culturally tailored bereavement support.** The bereaved need to receive supports that are tailored to their unique needs and experiences, and that are respectful of their diverse cultures, beliefs, religions, traditions, and worldviews. There is and will continue to be a need for cultural sensitivity in all bereavement support, as well as providing bereavement support in the person's preferred language. Translating websites, information sheets, or bereavement packages into multiple languages will be beneficial for the bereaved.
2. **Utilize technology for bereavement support.** Virtual one-to-one and group bereavement supports were seen to be helpful for many people and this support should continue as an option beyond the pandemic. It is important to consider that many Canadians do not have access to the required technology (e.g., owning a mobile phone, having a sufficient internet connection), so in-person support is also needed and may be a preferred choice for certain people beyond the pandemic. Additionally, the use of social media can help normalize grief. Social media can provide a place for collective grief, giving opportunity for grassroots bereavement support movements to develop, and for a greater acceptance and normalization of grief to occur. Social media also has been a method of sharing resources about bereavement, personal feelings, and a place to pay tribute to those who have died.
3. **Factors impacting bereavement.** Enabling people to visit or see those they cared about before death, as well as facilitating post-death rituals makes a significant difference in the bereavement process for the bereaved. The absence of these can exacerbate complexity in a person's grief. Additionally, the necessary public

health measures like quarantine, lockdown, and social distancing may have negatively affected bereaved individuals' mental health. These factors need to be considered when understanding the impact that the pandemic will have on how people will be able to process their grief. There may be more people experiencing complex grief that will require a greater amount of support. It is encouraged that organizations provide proactive outreach to the bereaved.

4. **Group supports.** When designing bereavement support groups, it is important to understand the benefits of having groups with people who are bereaved by the same event (e.g., COVID-19), same type of loss (e.g., child loss), and age of participants (e.g., children). We need to continue creating supportive environments for bereaved children and youth. Children and youth experience grief differently and require supports that meet their developmental needs (in group or one-to-one).

Increase Grief and Bereavement Literacy

5. **Additional bereavement education and training for those who work with the bereaved.** It is important to recognize that people can feel uncertain in how to approach working with people who are bereaved, and to develop brief training for them to gain confidence in this area of support. There is benefit in promoting the implementation of grief and bereavement literacy and training to professionals who encounter the bereaved (especially healthcare workers, counsellors, frontline workers, workplaces, schools, etc.). Training for professionals should cover typical distress and bereavement symptoms, as to avoid pathologizing normal distress. With the risk and prevalence of PGD increasing due to the pandemic, it is necessary to ensure competency in supporting individuals showing symptoms of PGD.

   Since it is common for the bereaved to experience grief months and years after the death, supporting bereaved workers is essential for helping people adjust to the loss. Research prior to the pandemic has found that grief following a death can impact the bereaved in returning to work, taking sick time and their productivity and safety at work.[142,143] The bereaved having a workplace that supported them in their grief aided them in their grief processing, whereas poor support negatively impacted them.[143] Workplaces need to provide better bereavement support training for managers, supervisors, and Human Resources staff, as well as develop bereavement policies and procedures specific to the workplace.[142,143]

Increase Collaborations

6. **Increase collaborations between bereavement and non-bereavement organizations.** The expansion of bereavement support will need to be supported by a collaborative approach among organizations with the interest and ability to address the issue. There will be opportunities for partnerships between bereavement and non-bereavement service providers to create a structure of bereavement support that incorporates many of the resources a person experiencing bereavement may access. Throughout all multi-sectoral approaches, government assistance will be critical in providing funding and resources for building a strong infrastructure of bereavement support and developing a large-scale organized bereavement response for future pandemics.

RECOMMENDED STRATEGIES

As stated in the beginning of this report, in 2021 the BC Centre for Palliative Care undertook an initiative to improve the grief and bereavement experience for all British Columbians. The findings from this literature review were used to inform this bereavement initiative, which included multiple research activities aimed at better understanding the needs and experiences of the bereaved in BC.

Leveraging a human-centred design approach, the BC Centre for Palliative Care in November 2022 brought together key stakeholders including individuals who had experienced the death of someone they cared about, grief and bereavement service providers, researchers, community leaders, and policy decision-makers to co-create a province-wide, evidence-informed collaborative action plan toward accessible, appropriate, and equitable grief and bereavement supports for all British Columbians.

The action plan has three pillars, under which there are several specific action items. To view the action plan titled ***"Collaborative Action Plan for Accessible, Appropriate, and Equitable Grief and Bereavement Support in British Columbia: An Evidence-Informed Approach."*** click here.

CANADIAN RESOURCES

If you are interested in increasing your knowledge about grief and bereavement, the Canadian Virtual Hospice (virtualhospice.ca) and Canadian Alliance for Children's Grief (grievingchildrencanada.org) have excellent information and support for both individuals and professionals. Additionally, the Canadian Virtual Hospice has specific grief websites for adults, kids, and youth:

- mygrief.ca
- kidsgrief.ca
- youthgrief.ca

If you need to speak to someone to direct you to helpful bereavement resources (e.g., service providers and informational supports) in British Columbia (Canada), the BC Bereavement Helpline provides this service. Additionally, they offer a free service that provides a compassionate ear to the bereaved.

Here is their contact information:

Helpline: 604-738-9950

Toll-Free: 1-877-779-2223

Website: https://bcbh.ca/

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of innovation and best practices
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