An Overview of Bereavement and Grief Services in the United States

Report to Congress, 2023

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Abstract

The Consolidated Appropriations Act of 2023 P.L. 117-328, Explanatory Statement, Division H directs the Department of Health and Human Services to produce a report on bereavement and grief services. The Explanatory Statement specifies that the report should aim to address:

> … the scope of need for high quality bereavement and grief services… the growing need for these services. The report shall provide a holistic evaluation of populations impacted and the scope of necessary interventions, including: (1) the prevalence of certain disorders (e.g. post-traumatic stress disorder, complicated grief) that are resulting from both emergencies; (2) the need for support for health care workers and other highly impacted populations; and (3) the prevalence and outcomes of bereavement and grief services. Part of this work should focus on the role of hospice programs in supporting community bereavement and grief services. (p. 124)

This report presents findings of an environmental scan and semi-structured interviews with key contributors, including governmental and non-governmental contributors, such as researchers, clinicians, advocates, service provider/payers, and policy experts. The findings included in this report are organized by specific domains and themes found within the peer-reviewed and grey literature. Specific topics include: the typical grieving process; defining and identifying prolonged grief disorder (PGD) and complicated grief (CG); PGD Comorbidities; the impact of the COVID-19 pandemic on PGD; the impact of PGD on substance use; the impact of grief on suicidal behaviors and ideation; social factors impacting bereavement; equity implications of bereavement and grief services; the current state of bereavement and support services; approaches to and effectiveness of services for PGD and CG; and barriers to seeking bereavement support. The report concludes with recommendations for enhancing health systems and services.

Principal Findings

The results of the environmental scan and key contributor interviews reveal the following key points:

- The literature suggests that an estimated one in ten bereaved adults will develop PGD or CG after a loved one dies. However, key contributors interviewed for this study indicated that diagnosing PGD and CG is challenging because of potentially overlapping mental health conditions which suggest that the rates of PGD and CG may be underestimated.
- PGD is often comorbid with post-traumatic stress disorder (PTSD), depression, substance use disorder (SUD), and anxiety, making treatment and recovery challenging. Despite this challenge, key contributors conveyed the importance of access to bereavement services to help prevent longer-term conditions associated with PGD.
- Populations highly impacted by PGD include children, caregivers, veterans, and those bereaved in traumatic ways. Key contributors interviewed clearly conveyed that grief is highly individual, and although many experience bereavement lasting over one year, many individuals recover within one year of a death event; furthermore, grief reactions may present differently in children than adults.
- There are many types of bereavement support services targeting PGD, ranging from phone calls and traditional psychotherapy to services such as music therapy. According to key contributors,

incorporating trauma-informed care is essential for treating bereaved individuals. Populations with high need can be identified through schools, data, and mental health settings.

- Hospice can play a crucial role in promoting healthy bereavement by offering support before, during, and after a loved one passes to facilitate coping mechanisms to navigate loss. While key contributors support hospice, some expressed concern about inequity in accessing services and transitioning to for-profit models within the hospice industry.
- Research indicates that disparities in bereavement service utilization exist due to individual characteristics and social determinants of health (SDOH). Key contributors expressed that SDOH, including systemic racial discrimination, requires examination of grief experiences in communities of color. Additionally, bereavement and grief services are disjointed and can exacerbate inequities based on race, socioeconomic status, and geography.
- More than 50 percent of key contributors reported that the COVID-19 pandemic reduced stigma and encouraged discussions about loss and grief; and concurrently increased the need for services, especially in under-resourced communities and communities of color.
- There is debate among key contributors regarding the medicalization of bereavement and grief; most key contributors reported a need for a more comprehensive approach to managing grief beyond medicalization.

Acronyms

ACE	Adverse Childhood Experiences
APA	American Psychological Association
ART	Accelerated Resolution Therapy
ASPE	HHS Office of the Assistant Secretary for Planning and Evaluation
BIPOC	Black, Indigenous, and People of Color
CBT	Cognitive Behavioral Therapy
CD	Conduct Disorder
CDC	HHS Centers for Disease Control and Prevention
CG	Complicated Grief
COVID-19	Coronavirus Disease of 2019
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM-5-TR	Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision
EAP	Employee Assistance Program
FARS	Fatality Analysis Reporting System
FMLA	Family and Medical Leave Act
GAD	Generalized Anxiety Disorder
HCBS	Home and Community-Based Services
HHS	U.S. Department of Health and Human Services
ICBGT	Internet-Based Cognitive Behavioral Grief Therapy
ICD-11	International Classification of Disease 11th Revision
ICG	Inventory of Complicated Grief
ICU	Intensive Care Unit
IHF	Irish Hospice Foundation
ILOS	In Lieu of Services
IPV	Interpersonal Violence
LMIC	Low and Middle-Income Countries
MCGT	Meaning-Centered Grief Therapy
MDD	Major Depressive Disorder

NHPCO	National Hospice and Palliative Care Organization
NVDRS	National Violent Death Reporting System
P.L.	Public Law
PGD	Prolonged Grief Disorder
PG-13	Prolonged Grief-13
PG-13-R	PG-13-Revised
PPE	Personal Protective Equipment
PRACTICE	Psychoeducation and parenting skills, Relaxation (R) Affective modulation, Cognitive coping, Trauma narrative, In vivo exposure, Conjoint parent-child sessions, and Enhancing safety and development
PTG	Post-Traumatic Growth
PTSD	Post-Traumatic Stress Disorder
PWUO	People Who Use Opioids
RCT	Randomized Controlled Trial
SARS-CoV	Severe Acute Respiratory Syndrome Coronavirus
SDOH	Social Determinants of Health
SES	Socioeconomic Status
SUD	Substance Use Disorder
TF-CBT	Trauma-Focused Cognitive Behavioral Therapy
TIC	Trauma-Informed Care

Executive Summary

The American Psychological Association (APA) defines bereavement as the condition of having lost a loved one to death and defines grief as the anguish experienced after significant loss, usually the death of a beloved person.[1,2] The characteristics of bereavement and grief are similar but may not be mutually exclusive; for example, not all bereavement results in a strong grief response and not all grief occurs after bereavement.[1,2] According to the APA, a bereaved individual may experience emotional pain and physiological distress.[1,2]

Bereavement and grief are complex and individualized experiences. Most who are bereaved or grieving will not need access to formal services; frequently they are resilient and/or will rely on their existing family and social networks. For those individuals who require more formal support, bereavement and grief services play a crucial role in mental and emotional well-being. In recent years, the need for bereavement and grief services became more critical due to the COVID-19 pandemic and the simultaneous epidemics of deaths secondary to suicide, overdose, and community violence.

This report presents a comprehensive examination of the current state of bereavement services in the United States, encompassing a thorough environmental scan and insightful interviews with diverse key contributors. The study explores existing research to shed light on the landscape of bereavement and grief services and highlights gaps and challenges within. Through a series of semi-structured interviews, a diverse group of participants engaged in thoughtful discussions, offering multifaceted perspectives on the efficacy and accessibility of available services.

The environmental scan delves into various aspects of bereavement services, emphasizing the need for comprehensive services. It examines typical grief, discusses prolonged grief disorder (PGD) and comorbidities, identifies effective treatment models, and addresses prevailing disparities in service availability. The review underscores the importance of recognizing grief as a nuanced process that interacts with multiple factors, including cultural norms, socioeconomic status, and community dynamics.

The interview component of the study captures firsthand insights from key contributors representing a range of backgrounds and professions. These conversations reveal the inadequacies and fragmentation of the current bereavement support infrastructure, but also emphasize initiatives that are working well. Participants highlighted the organic development of grassroots grief centers, emphasizing their role as community-driven responses to unmet needs. The interviews further delve into the unique challenges faced by specific populations, such as children, racial and ethnic minorities, and those lacking access to formalized support networks.

One recurring theme throughout the report is the fragmented, unresponsive nature of current bereavement systems. This study identifies the pivotal role that community-specific grief centers play in serving diverse populations, recognizing that cultural nuances impact grief experiences and coping mechanisms. Moreover, the report emphasizes the significance of integrating culturally sensitive training into mental health education to address the prevailing lack of standardized training on grief and bereavement.

In conclusion, this report offers a comprehensive analysis of the current state of bereavement services in the United States, drawing from a synthesis of existing literature and illuminating interviews. The findings underscore the need for a more inclusive, accessible, and culturally attuned approach to bereavement support. By recognizing the unique needs of diverse populations and prioritizing community-based interventions, this report aims to contribute to the development of more effective and equitable bereavement services in the United States.

I. Overview: Bereavement and Grief Services in the United States

As defined by the American Psychological Association (APA), bereavement is the condition of having lost a loved one to death, while grief is the anguish experienced after significant loss, usually the death of a beloved person. Both share similar characteristics but may not be mutually exclusive; for example, not all bereavement results in a grief response and not all grief occurs after bereavement.

Bereavement and grief are two experiences that are inextricably linked to the human experience. The loss of someone close to an individual can bring on intense emotional and physical pain to the bereaved, who will require time to integrate this loss into their lives.[3] To aid the process of integrating the loss, bereavement and grief services may be needed for some individuals, but not all, and the best types of services and interventions will vary by the individual. Bereavement and grief services should be trauma informed[4] and may include psychotherapy such as cognitive behavioral therapy (CBT), social support, spiritual support, hospice, and innovative services like bereavement camps, music and art therapy, and care farming.

Little is known about the current state of bereavement and grief services available in the United States, the extent to which they are needed, and if certain portions of the population have disproportionate needs for these services. The Consolidated Appropriations Act of 2023 (P.L. 117-328) Explanatory Statement, Division H requested the U.S. Department of Health and Human Services (HHS) to produce a report on the scope of need for high quality bereavement and grief services available within the United States. Mathematica assisted the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in writing this report in conjunction with an HHS Advisory Group that consists of a multi-agency team from ASPE's Office of Behavioral Health, Disability, and Aging Policy; the Centers for Disease Control and Prevention (CDC); the National Institutes of Health; the National Institute of Mental Health; and the Substance Abuse and Mental Health Services Administration (SAMHSA). This report includes the findings from an environmental scan and key contributor interviews with both government and non-governmental contributors, such as researchers, clinicians, advocates, service providers/payers, and policy experts.

Published data provide a sense of the level of demand for bereavement and grief services in the United States. According to CDC data there were over 3.4 million deaths in 2021 in the United States, with a rate of 1,043.8 deaths per 100,000 population.[5]

The COVID-19 pandemic has likely exacerbated the need for bereavement and grief services, given its sheer impact: as of July 2023, there have been over 1.1 million deaths from COVID-19[6] and for every COVID-19 death there are an average of nine individuals who are bereaved.[7] Further, Burns et al. found that overall more than 700,000 United States children were newly bereaved due to a parent's death in 2020 and 2021 and among these children there was a disproportionate impact on BIPOC (Black, indigenous, and people of color) and Latinx communities.[8] Additionally, studies have documented that health disparities were exacerbated during the pandemic, with higher infection rates in the BIPOC and Latinx communities. Specifically, Black counties had infection and death rates that were three and six times higher than those in predominately White counties, respectively.[9,10] Furthermore, Basset et al. compared the differences in COVID-19 mortality by race/ethnicity and age and found that non-Hispanic Black, non-Hispanic American Indian/Alaskan Native, and non-Hispanic Asian/Pacific Islander populations had higher mortality rates compared to non-Hispanic White populations.[11] Both non-

Hispanic Black and Hispanic populations had a higher risk of premature death before the age of 75 compared to non-Hispanic White populations.[11]

The COVID-19 pandemic placed a spotlight on the need for bereavement and grief support services in the United States. Furthermore, increases in mortality related to the pandemic placed more people at risk for prolonged grief disorder (PGD) and other mental health conditions due to the loss of loved ones.

Moreover, while rates of social participation were declining meaningfully before the COVID-19 pandemic, the pandemic accelerated these trends with one study finding a 16 percent decrease in social network size from June 2019 to June 2020.[12] In 2021, approximately half of Americans reported having three or fewer close friends, which is almost a 50 percent increase in the percentage of Americans having three or fewer friends since 1990.[12] Like bereavement and grieving, the harms associated with loneliness and isolation are often underappreciated. The U.S. Surgeon General's report on loneliness and isolation found that approximately half of United States adults report experiencing loneliness with some of the highest rates among young adults.[12] While loneliness and isolation are distinct from bereavement and grief, they can coexist for a portion of the population and result in fewer people having access to the social support networks necessary to assist people through typical grieving.

In addition to the COVID-19 pandemic, high numbers of deaths related to overdose and suicide, and community violence are also contributing to the need for bereavement and grief services. In 2021, drug overdose accounted for 106,699 deaths,[13] suicide accounted for 48,183 deaths,[14] and homicide accounted for 26,031 deaths.[15] In 2020, some groups had disproportionate increases in drug-related mortality rates; for example, there were 54.1 fatal drug overdoses for every 100,000 Black men in the United States, which surpasses the American Indian or Alaska Native rate of 52.1 deaths per 100,000 people. This represents a 213 percent increase in fatal drug overdoses in Black men since 2015.[16]

Evidence from a small study of people who use opioids (PWUO) suggested that they are more likely to be bereaved when a death by drug overdose occurs in their social network.[17] Grief and bereavement may also create conditions in which substance use is exacerbated, thus potentially adding to the increase in deaths related to substance use, creating a negatively reinforcing cycle. For example, after the death of a loved one, some may manage their grief by coping through use of substances, possibly developing a mental health condition or substance use disorder (SUD) or exacerbating a pre-existing mental health condition or SUD.[18] Additionally, the circumstances around the death of a loved one -- for example an unexpected loss, a child's loss of a parent or parents, or a homicide -- can modify the nature of the distress and may influence whether substances are used during bereavement.[19]

Increases in death by suicide have also resulted in greater numbers of people experiencing grief and bereavement. During 2021, there was one death by suicide every 11 minutes in the United States, 12.3 million adults seriously thought about suicide, 3.5 million adults made a suicide plan, and 1.7 million adults attempted suicide; from 2000 to 2022 overall rates increased by 36 percent.[20] Youth and young adults ages 10-24 years represent 15 percent of all suicides, and suicide is the second leading cause of death for this age group.[21] The Congressional Black Caucus Emergency Task Force on Black Youth Suicide and Mental Health released a report in August 2023 exposing the fact that Black youth have the fastest rising rate of suicide with a 144 percent increase between 2007 and 2020 in Black youth ages 10-17.[22] The report notes that the number of suicides in Black youth may be underrepresented because suicidal ideation, attempts and deaths may be misclassified. The rates of suicide among Black Americans are lower compared to other races and ethnicities; however this data on Black youth suggests more research is needed to best understand the issue and the resources to combat it.[23]

The purpose of this report is to outline the landscape of what is known about bereavement and grief services available through peer-reviewed and grey literature as well as semi-structured interviews with key contributors to address the key questions posed by ASPE and the HHS Advisory Group.

Key Questions

The key questions proposed by ASPE and the HHS Advisory Group are listed in the table below (**Table 1**).

Table 1. Key Questions

Key Question proposed by ASPE and HHS Advisory Group
• What is the typical grieving process, and what services can support people experiencing grief and loss? How are these services typically accessed?
• To what extent have the crises of COVID-19, violence, suicide, and increased mortality associated with substance use resulted in increased needs for bereavement care and grief support?
• Given bereavement has a strong cultural element, how broadly are these impacts shared by the US population and are certain groups experiencing greater need?
• To what extent have the current crises resulted in grief that has persisted, resulting in impaired functioning and conditions such as depression, post-traumatic stress, and prolonged grief?
• To what extent is there a need for support for health care workers and other highly impacted populations?
• To what extent are bereavement and grief support services being utilized and is there evidence indicating that these services are effective? Are there differences among groups?
• How can the health care system be improved to be more trauma-informed to provide a more functional context for grief and bereavement services?
• What role does hospice currently play in supporting people who are grieving and what services might they provide to support community needs more broadly?

Source: ASPE and HHS Advisory Group.

COVID-19 = Corona Virus Disease of 2019.

Appendix A includes a crosswalk of the key questions and literature used (identified by article number) to address each key question.

II. Data Sources and Methods

A. Environmental Scan Methods

We conducted a systematic review of literature, including grey literature, published in the last ten years, as well as any seminal articles outside of that time range. Grey literature refers to research and information materials produced and published outside of traditional academic or commercial publishing channels. Our review of the grey literature did not identify relevant information to include in the environmental scan. We searched PubMed, Sagepub, the National Center for Biotechnology Information, the American Journal of Psychiatry, International Journal of Palliative Nursing, Science Direct, Research Gate, and Wiley databases on April 13, 2023, with further updates to search criteria on May 5, 2023. The search criteria included key words such as bereavement, PGD, grief, and bereavement services. We identified additional literature through searching Google Scholar and reference lists from the studies included in the environmental scan sample.

We drew key topics from the key questions to inform the search terms. **Table 2** presents the key topics and related search terms used to inform the analysis.

Table 2. Key Topics and Related Search Terms

Key Topic	Related Search Terms
Grief	• Grief, Bereavement, Prolonged Grief Disorder, Disenfranchised Grief, Grieving
Service/Support	• Service, Program, Intervene, Support, Hospice, Approach, Strategy, Training, Tutorial, Counsel, Evaluate, Predict, Care Plan, Experiment, Policies, Policy, Trial, Trials, Burden, Need, Necessity
Bereavement	• Bereave, Grief, Grieving, Complicated Grief, Prolonged Grief
Services	• Service Program, Intervention, Support, Hospice. Approach Strategy, Training, Tutorial, Counsel, Evaluate, Predict, Care Plan, Experiment, Policies, Policy, Trial, Trials, Process, Access, Increase, Need, Current, Changing, Evolve, Impair, Function, Diminish, Health Care, Use, Used, Utilize, Different, Coping, Outcome
Disorders (+COVID-19)	• Post-trauma, Post trauma, PTSD emergency, Mental Health, Depress, Anxiety, Stigma, Crisis Disorder, Symptom, Substance, Medication, Alcohol, Drugs, Drug, Tobacco, Firearms, Prescription, Medication, Opioid, Exposure, Use, Abuse, Misuse, Addict • Covid, Coronavirus, SARS-CoV OR Covid-19, Pandemic
Trauma-Informed	• Trauma and Stressor Related Disorders, Survivors, Crime Victims, Crime, Social Problems, Substance-Related Disorders, Compulsive Behavior, Community Violence, Alcohol, Tobacco, Drug, Substance, Solvent, Opioid, Prescription, Benzodiazepine, Illicit, Illegal, Opiate Pills, Stimulants, Marijuana, Hallucinogenic, Use, Misuse, Abuse, Addict, Depend, Disorder, Legal High, Trauma-Informed, Trauma, Abuse, Violent, Crime, Criminal

Note: We further specified the search by changing the pairings of words and themes. For example, we searched "Grief" OR "Bereavement" OR "Prolonged Grief Disorder" AND "Service" OR "Intervention" OR "Trauma-Informed."
COVID-19 = Corona Virus Disease of 2019; PTSD = Post-Traumatic Stress Disorder; SARS-CoV = Severe Acute Respiratory Syndrome Coronavirus.

To complete the environmental scan, we developed an abstraction tool for uniform information gathering (**Appendix B**). This tool summarizes the study's purpose, methods, data sources, study sample information, and key findings from the analysis. We summarized information from 66 sources to guide the analysis. The environmental scan included randomized controlled trials (RCTs), cross-sectional and

case-control studies, meta-analyses, and qualitative studies composed of surveys, semi-structured interviews, and questionnaires. Meta-analysis articles were limited to those focused on the availability and use of bereavement services in the United States; however, we also included studies from other English-speaking countries (such as the United Kingdom and Canada). Sample sizes and composition varied from as few as five hospice organizations to a nationally representative study of 2,441 U.S. veterans. We focused our analysis on articles published after 2013. However, we included two articles dating from 1992 because they were either: (a) seminal literature; or (b) supplemental to our knowledge of bereavement services in hospice facilities, as the research in this area has been limited. **Table 3** summarizes the studies used in the analysis by study type.

Table 3. Environmental Scan Summary

Study Method	Number of Articles
Randomized Controlled Trial	3
Cross-Sectional Study	10
Meta-Analysis	6
Qualitative Studies (interviews, surveys, questionnaire, focus groups)	22
Case-Control	2
Secondary Data Analysis	3
Mixed Methods	1
Descriptive Study	7

Source: Mathematica analysis of bereavement and grief support literature.
Note: The study method is defined by each study and was not assessed by the research team.

While conducting the environmental scan, we applied several exclusion criteria to refine the selection of relevant articles. The three specific exclusion criteria applied include: (1) articles not written in English; (2) studies conducted in low and middle-income countries (LMICs); and (3) articles published more than ten years ago with the exceptions described previously. The exclusion of studies conducted in LMICs helped maintain the focus on research applicable to the United States. These carefully applied exclusion criteria helped streamline the environmental scan process, allowing the researchers to focus on current, relevant literature for analysis.

Table 4. Study Domains

Domain	Number of Articles
PGD/CG Awareness	20
Individual and Family Characteristics	32
Intervention Recommendations	40
Cultural Factors	5
Barriers in Seeking PGD/CG Treatment	10
SUD (including overdose)	6
Trauma-Informed Care	5
Grief/PGD Comorbidities	27

Source: Mathematica analysis of bereavement and grief support literature.
CG = Complicated Grief; PGD = Prolonged Grief Disorder; SUD = Substance Use Disorder.

The themes and domains in this study were based on the key questions the study team identified. The domains capture overarching themes. **Table 4** and **Table 5** summarize the studies used in this analysis by domain and theme, respectively.

Table 5. Study Themes

Theme	Number of Articles
Impact of COVID-19 on PGD Prevalence	9
Difficulties Recognizing PGD/CG	12
Bereavement Supports in Hospice/Palliative Care	8
Impact of Community Violence, Trauma, and/or Suicide	26
Populations Experiencing Increased Need for Bereavement Supports	40

Source: Mathematica analysis of bereavement and grief support literature.
CG = Complicated Grief; COVID-19 = Corona Virus Disease of 2019; PGD = Prolonged Grief Disorder.

B. Key Contributor Interview Methods

1. Developing the Interview Protocol

The interview protocol was based on the themes and domains that were used in the environmental scan. The interviews with key contributors focused on the following topics: (1) their experiences with and perspectives on current bereavement support services available; (2) insights into gaps or challenges in accessing bereavement or grief services; (3) understanding the specific needs of different populations; (4) insights into barriers to seeking bereavement support; and (5) recommendations for improving existing health systems and services. Some questions were modeled after questions from the existing literature. We designed the interview protocol to be dynamic; that is, to provide flexibility and a focus on contributor expertise, not all respondents were asked all questions and questions were tailored to the contributor's expertise.

2. Recruiting Key Contributors

The study team prepared a list of potential key contributors to interview. This list included both governmental and non-governmental contributors, such as researchers, clinicians, advocates, service providers/service payers, and policy experts. The study team also consulted the HHS Advisory Group to review the list and add any additional key contributors. In July 2023, we conducted one-hour semi-structured telephone interviews with nine key contributors. One researcher led these interviews, and another took notes. We recorded each interview to verify the accuracy of the notes. We reviewed the process after the first interview to determine whether any changes to the protocol were required; no revisions were considered necessary, and none were made. To supplement the information learned through formal interviews, we held five informal discussions with key contributors that were 30 minutes in length and did not use the study protocol. Instead, these discussions started with the interviewee's experience as it related to bereavement and grief, and follow-up probes were asked based on the items in the formal protocol.

3. Qualitative Analysis

We created a qualitative analysis table (using Microsoft Excel) organized by interview topic and question. We used this table to synthesize common themes within and across responses.

III. Findings

In this chapter, we present our findings on the grief and bereavement landscape in the United States. These findings were developed through the above-mentioned environmental scan and formal and informal interviews. We then provide recommendations based on the findings in the next section.

A. Typical Grieving Process

Grief is defined as the anguish experienced after a significant loss, usually the death of a beloved person.[2] The past two decades of grief research has revealed that grief, while deeply individual, is not linear from the death event to a return to regular life.[3] For most individuals, grief in the context of the loss of a loved one is experienced in waves, with the largest swells closer to the death and smaller ripples as one becomes further removed from the event.[3]

The Kübler-Ross Stages of Dying is a well-known model that forced a cultural shift in how we talk about death and dying in the United States. This model focuses not only on dying patients but also on their families and the need to help them adjust to the reality that their loved one is dying. The model's five stages are: (1) denial; (2) anger; (3) bargaining; (4) depression; and (5) acceptance.[24] The model has an important place in history as, when it was presented in 1969, it shed light on bereavement in a way that had not been done before. However, the model was never independently confirmed to be reliable, valid, or efficacious.[25] Newer grief research has since discovered that individuals may feel different symptoms, such as emotional numbness and yearning, and that not everyone experiences all of the symptoms of the Kübler-Ross model, nor do they necessarily experience them in the prescribed order.[3] There are specific points along the process where grief may become more intense, for example around holidays, the deceased's birthday, and the anniversary of their death. During such times, bereaved individuals may rely on their family, friends, religion, and community to "ride" the wave of grief.

Research has established that most bereaved individuals do not require help from formal services, and instead find other ways to recover. The latest research has concluded that most adults (66.4 percent) have recovered at the one-year mark and 25 percent of those with initially elevated grief were recovered in the period of 6-12 months post-bereavement.[3,26,27] Adults attribute their improved outcomes to a variety of factors including positive coping styles leading to a healthy adjustment, such as remembering the loved one fondly, and the ability to experience and express positive emotion.[3] Some bereaved adults may experience feelings of relief after the passing of a loved one due to the resolution of some of the stress they experienced prior to the loss. In a study of bereaved spouses, participants reported feeling comfort from memories of their loved ones, finding meaning in the loss, and perceived benefits from dealing with the loss.[28]

The literature reports that most adults will recover within a year without clinical intervention; however, approximately 7-10 percent of the United States population will continue to experience symptoms of grief and may develop PGD and/or CG.[29] There is debate in the literature about whether grief should be a diagnosable condition, and about the most appropriate criteria for diagnosing PGD and CG.

Although bereaved individuals can experience common grief symptoms, several key contributors described grief as a highly individualized process influenced by various factors. Those interviewed emphasized that although grief is a natural response to the death of a loved one, the grief process can

differ significantly depending on an individual's relationship to the deceased, the cause of death, and the bereaved individual's stage of life.

The most contemporary theoretical understanding of grief suggests that it is not a linear process and requires oscillating emotions to promote healthy coping mechanisms. One participant described oscillation through the dual-process model. The dual-process model,[30] also known as dual-system theory or dual-process theory, is a psychological framework that has been directly applied to how we process the thinking and emotions associated with grief. Loss-orientation involves focusing on the emotions and thoughts associated with the loss itself. This includes activities like reminiscing about the person who is no longer present and experiencing the sadness and pain that come with the loss. During this phase, the person acknowledges and processes their grief, allowing themselves to mourn and remember. Restoration-orientation, on the other hand, centers around engaging in activities that help the person adapt to the changed circumstances after the loss. This could involve concentrating on work, relationships, or new experiences. By shifting their attention to these restoration-oriented activities, individuals can create a sense of consistency and control in their lives. This alternation allows individuals to process their emotions while also gradually adjusting to life without the presence of the person they have lost. In essence, the model emphasizes that grief is not a linear process but a fluctuation between addressing the emotional impact of the loss and finding ways to adapt and move forward. This balanced approach helps individuals navigate the complexities of grief in a constructive manner.

One key contributor stated that in the typical trajectory of grief reactions, bereaved individuals may initially experience acute grief, marked by yearning, extreme sadness, and preoccupation with the deceased. The participant described that the bereaved may experience a period of shock or numbness, particularly while dealing with the affairs of the deceased, such as funeral planning. As time passes, grief typically transitions into a more emotionally expressive process, often accompanied by physical symptoms like increased susceptibility to colds, headaches, stomach aches, loss of appetite, or numbness in fingers or toes. During this phase, there may be a defense mechanism involving a temporary exclusion of reality as individuals cope with the intense emotions. Common experiences include feelings of disbelief and imagining alternative scenarios, coupled with attempts to avoid reminders of the loss through sensory experiences, such as avoiding pictures of the deceased or listening to their voice.

Another participant discussed the trajectory of a typical grief response. In her clinical experience, she found that about 3-9 months after the loss, individuals tend to experience fewer acute symptoms, but there may be a resurgence of grief around the anniversary of the death. This cyclical pattern of grief underscores the importance of recognizing the uniqueness of each individual's grief journey and the need for personalized support throughout the bereavement process. In the first year or two after the loss, the grief focuses on the nature of the loss itself, such as whether it was a prolonged illness or traumatic accident.

Moreover, some key contributors described grief reactions as presenting differently in children as compared to adults. In children, typical grief responses include separation distress and a preoccupation with any traumatic circumstances surrounding the death. However, children may exhibit externalizing behaviors in atypical grief reactions, which a participant called "disenfranchised grief." A key contributor found that childhood bereavement was associated with other mental health disorders such as depression, post-traumatic stress disorder (PTSD), separation anxiety, and conduct disorder (CD).[31] CD is a behavioral health disorder diagnosed in children and adolescents that involves a persistent pattern of violating societal norms, rules, and the rights of others.[31] Additionally, individuals may be diagnosed with adjustment disorder with disturbance of conduct that develops after a critical life event and is

characterized by disruptive or oppositional behavior, hyperactivity, irritability, concentration problems, increased clinginess, tantrums, regression, sleep disturbances, or bedwetting.[32] Adjustment disorder typically resolves after the critical life event has ceased.[32]

The absence of a support system due to the loss is a crucial factor in children's grief reactions. One participant discussed the impact of a grandparent's death on children's outcomes indicating that children who experience such losses tend to have worse early, middle, and adolescent outcomes compared to non-bereaved children. This contributor also considered grief in the context of parental death, recognizing that several types of deaths can affect children. Furthermore, the effects of grief may not always be immediate, sometimes manifesting 5-6 years later, resulting in persistent disadvantages.

Although bereavement and grief have distinct definitions, they are often interconnected to such an extent that their services and support systems can be shared. People experiencing normative grief responses can still use bereavement support in the forms of support groups, including community and faith-based support, grief-focused books or articles, or bereavement hotlines. It is important to remember that each person's grief journey is unique, and what works for one individual may not be suitable for another. Exploring different support options and finding the right fit is essential in navigating the grieving process effectively.

B. Defining and Identifying Prolonged Grief Disorder and Complicated Grief

Typical grief is characterized by intense pain that decreases over time, allowing bereaved individuals to return to regular life.[29] Although grieving periods can vary based on cultural or religious context, persistent or excessive preoccupation with a loved one's death could signal a grief disorder such as CG or PGD.[33] Although individuals may have always been suffering from bereavement, a diagnostic code for PGD was not established until the International Classification of Disease 11th Revision (ICD-11) introduced a PGD code in 2018. In March 2022, a new diagnosis of PGD was added to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR). Previously, the DSM-5-TR acknowledged persistent complex bereavement disorder as a possible focus of clinical attention or as a reason that individuals may seek mental health care but did not formalize this as a disorder. Throughout the literature CG preceded PGD and the research around the CG construct informed the formalization of the PGD diagnosis, thus these terms are often used interchangeably. Therefore, we use these terms interchangeably throughout the report as well.

Grief in the United States

"I think a lot of our issues as a nation actually stemmed from some unresolved grief[...] that's happening on a lot of different levels and coming out as anger."

-- Interview Participant

The DSM-5-TR describes PGD symptoms as "identity disruption (such as feeling as though part of oneself has died), marked sense of disbelief about the death, avoidance of reminders that the person is dead, intense emotional pain (such as anger, bitterness, sorrow) related to the death, difficulty with reintegration (such as problems engaging with friends, pursuing interests, planning for the future), emotional numbness (absence or marked reduction of emotional experiences, feeling that life is meaningless), and intense loneliness (feeling alone or detached from others).[34] Although the DSM-5-TR and ICD-11 identify common criteria -- such as longing for the deceased, denial, and difficulty with reintegration -- their criteria also differ in certain aspects. For example, according to the DSM-5-TR diagnostic criteria, bereavement had to occur at least 12 months ago; while for the ICD-11 it had to occur at least six months ago and the individual must experience additional symptoms related to identity

disruption, disbelief about the death, and a sense of meaninglessness in life. **Table 6** describes key differences in ICD-11 and DSM-5-TR PGD diagnostic criteria.

Table 6. ICD-11 and DSM-5 PGD Diagnostic Criteria

Criteria	ICD-11 Criteria for PGD	DSM-5-TR Criteria for PGD
Symptoms	Intense and pervasive grief response	Persistent and pervasive grief response
Duration	Lasting for at least 6 months after a significant loss	Lasting for at least 12 months after a significant loss
Cognitions and Emotions	Preoccupation with the deceased person, avoidance of reminders, difficulty accepting the loss	Preoccupation with the deceased, emotional pain associated with the loss
Functional Impairment	Impaired daily functioning, social withdrawal	Significant impairment in daily functioning
Identify Disturbance	May experience a sense of being "partially dead"	Not a criterion in DSM-5-TR
Children-Specific Criteria	May include somatic complaints, clinging behaviors; behavioral symptoms (irritability, tantrums, conduct issues)	Lasting for at least 6 months after a significant loss

Sources:
World Health Organization. International Statistical Classification of Diseases and Related Health Problems. Geneva, Switzerland: Author, 2018.
P. Appelbaum, M.D., and L. Yousif, M.D., Ph.D., M.Sc. "Prolonged grief disorder." *Psychiatry.org – Prolonged Grief Disorder*, https://www.psychiatry.org/patients-families/prolonged-grief-disorder.

DSM-5-TR = Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision; ICD-11 = International Classification of Disease 11th Revision; PGD = Prolonged Grief Disorder.

Groups that may be at greater risk of developing PGD include bereaved children,[35] veterans and their families,[36] caregivers,[37] health care providers, and those bereaved by a particularly traumatic event such as suicide[38] or overdose,[17] among others. However, grief extends beyond bereavement and can occur in losses unrelated to death. Such losses include the end of a significant relationship, a decline in health, financial setbacks, or the effects of a worldwide pandemic. However, while distressing, these losses do not meet the diagnostic criteria for PGD in the ICD-11 or the DSM-5-TR which requires the death of a person. Grief unrelated to death involves similar emotional, cognitive, and behavioral responses as bereavement grief, including sadness, yearning, disbelief, and changes in daily routines.[39]

Acknowledging and addressing grief in these contexts is essential for promoting emotional well-being and facilitating healthy coping strategies. For example, caregivers of people with SUD often experience grief prior to a death,[37] and because this grief is unrelated to death, they are often unaware of it even if they are experiencing psychological distress and coping poorly.[37] Similarly, pre-loss grief is often expressed in caregivers of terminally ill loved ones. One study found that caregivers of terminally ill cancer patients may experience high levels of pre-loss grief which is a risk factor for post-loss adjustment.[40] Thus, identifying groups at increased risk of PGD is essential in decreasing the potential for severe grief reactions. While the examples highlight people experiencing grief related to terminal or other serious conditions that can result in a person's death, it is important to note that grief is experienced in other ways as well.

Approximately 7-10 percent of bereaved individuals experience PGD symptoms.[33] The characteristics that differentiate PGD from typical grief are pervasive emotional pain, persistent preoccupation with the deceased, and significant disruption to individual, family, social, educational, or occupational functioning.[41] The way PGD manifests varies significantly across cultures. The ICD-11[17] describes

culture-related features associated with PGD. Culture-related factors can play either an adverse or protective role in the development of PGD. For example, in many cultures, nightmares about the deceased may be distressing, thus contributing to symptoms of PGD. Conversely, in many Southern European and Latin American cultures, visitation from the deceased may provide comfort to the bereaved, which may provide protection and/or relief from PGD symptoms.[42] Culture plays a crucial role in the diagnosis of PGD. Cultural norms and expectations around grief, mourning rituals, and expressions of emotions can vary widely across different societies. This diversity can affect how individuals perceive and cope with grief, making it challenging to establish universal diagnostic criteria for PGD. Cultural factors can influence the duration considered typical for mourning and the extent to which grieving individuals seek professional help. Clinicians need to be culturally sensitive to and aware of these variations when assessing and diagnosing PGD to avoid potential misdiagnosis or stigmatization based on cultural differences in grief response.

Several tools used to collect self-reported information have frequently been used to measure PGD; these include the Inventory of Complicated Grief (ICG), the Prolonged Grief-13 (PG-13) scale, and the PG-13-Revised (PG-13-R) scale. These tools have also been frequently used to measure the presence and severity of CG symptoms. The ICG[43] was determined to be a reliable source for testing increased levels of maladaptive grief symptoms since 1995. However, additional scales including the PG-13 scale[43] and the PG-13-R scale[42] have grown in popularity for assessing elevated levels of complicated or prolonged grief. Notably, the duration of grief expression varies by culture. Researchers have therefore tailored PGD measurement tools to improve cross-cultural validity. The International Prolonged Grief Disorder Scale includes culturally specific items to measure PGD symptoms across cultures.[44]

Of note, establishing specific diagnostic criteria for PGD is particularly important for increasing PGD awareness and enhancing treatment options and interventions. The new DSM-5-TR criteria or ICD-11 code for PGD facilitates the identification and diagnosis of individuals experiencing PGD, helping to provide appropriate and focused care.[45] These new diagnostic criteria allow for improved documentation and communication among health care providers, facilitating a better understanding of PGD as a distinct mental health condition. While there are debates around labeling PGD as a mental health condition due to the complexity of grief reactions, recognizing PGD as a specific diagnosis opens up treatment options that can be tailored to address the unique needs of individuals with prolonged grief symptoms -- potentially leading to more effective interventions and improved patient outcomes.[45] Moreover, diagnostic criteria and diagnostic codes may increase access to treatment options by facilitating insurance coverage for individuals seeking care. In addition to nuances related to PGD identification and classification, there are significant PGD comorbidities to consider during the diagnosis period, as discussed in the next section.

C. Prolonged Grief Disorder Comorbidities

Grief can manifest both as a response that follows a death or as an anticipatory reaction connected to various types of loss. PGD often co-occurs with other mental health conditions such as PTSD, depression, anxiety, and other trauma induced conditions.[46] Several studies included in this analysis found comorbidities associated with CG or PGD such as adverse childhood experiences (ACEs), PTSD,[47] anxiety, depression,[39] and suicidal ideation.[48] United States children who experience the loss of a primary attachment figure, such as a parent, sibling, or caregiver, may face a higher risk of developing PGD. Although the World Health Organization advises that PGD should only be diagnosed in children and adolescents with caution after losing a primary caregiver, because intense grief reactions are anticipated

and may reoccur along the course of further development.[42] The DMS-5-TR does not include similar cautions for PGD diagnoses in children.

Studies have also found associations between PGD and other mental health disorders such as major depressive disorder (MDD), generalized anxiety disorder (GAD), and PTSD in certain populations. In a nationally representative study of U.S. veterans, the authors found that approximately 7 percent of veterans screened positive for PGD symptoms and were "5 to 9 times more likely to screen positive for PTSD, MDD, and GAD symptoms".[36] In another study related to military veterans, Simon et al. found that comorbid CG is associated with increased PTSD severity.[49] For families bereaved by a traumatic death that occurred in a workplace "61 percent of participants had probable PTSD, 44 percent had probable major MDD, and 43 percent had probable PGD".[50] In addition, individuals in the process of a SUD recovery are vulnerable to grief disorders.[49] In one study, the authors found that bereaved individuals in the process of recovering from a SUD can experience CG due to the co-occurring loss of a loved one and also from the loss of discontinuing the substance itself, something that held a great significance in their life.[51] Finally, individuals with existing mental illnesses, such as a serious mental illness, may experience increased rates of co-occurring PTSD and PGD.[48] In a study of individuals receiving community mental health services, the authors found that nearly half of participants met criteria for probable and provisional PTSD, and approximately 12 percent of participants had probable co-occurring PTSD and PGD.[48]

The study team conducted semi-structured interviews to gain insights into the complexities of PGD in the United States. Interviews highlighted that differentiating PGD from other mental health conditions can be challenging due to overlapping symptoms in the context of grief and loss. For example, bereaved individuals may experience fatigue, appetite changes, or withdrawal from daily activities, all of which are symptoms of both PGD and MDD. While some participants emphasized the significance of sequential treatment -- addressing mental health conditions before dealing with grief -- another participant highlighted integrated treatment by suggesting that mental health conditions and grief should be treated simultaneously. Regardless of the sequence, addressing mental health conditions, such as PTSD, is critical as grief often exacerbates mental health conditions. One contributor conveyed that some bereaved children also experience trauma associated with PTSD, such as interpersonal violence (IPV) or sexual violence, then must cope with the additional burden of loss.

D. Impact of the COVID-19 Pandemic on Prolonged Grief Disorder

The COVID-19 pandemic has been described as a mass bereavement event[52] due to the dramatic increase in deaths it caused around the world.[53] Consequently, there is now an increase in the number of people at risk for developing PGD[18,54] and other mental health conditions. Bereavement caused by the COVID-19 pandemic has taken many forms. In addition to causing the loss of loved ones, the COVID-19 pandemic disrupted social networks and individual autonomy due to lockdowns, travel bans, and social distancing efforts. For example, policies around funeral practices restricted the number of mourners who could be present and social distancing guidelines limited expressions of physical comfort (for example, discouraging hugs and handshakes, etc.).[55]

By disrupting regular life, the COVID-19 pandemic created unique PGD risk factors.[18] For young adults who lost a close friend or family member during the pandemic, more time spent with the deceased before their death was associated with increased PGD symptoms and a greater likelihood of meeting PGD diagnostic criteria.[18] In addition to increased PGD symptoms, the COVID-19 pandemic affected typical

grieving practices in multiple ways. For example, bereaved individuals may have felt guilty for not being present at the time of death[18] and may have experienced survivors guilt and guilt over transmission of the virus.[56]

Due in part to the greater likelihood of Black and Hispanic families in the United States living in multigenerational households, the effects of COVID-19 disproportionately affect minoritized communities.[57] Black and Hispanic individuals are also more likely to work in jobs deemed essential, such as health care, childcare/social services, public transportation, and building cleaning services.[58] These individuals therefore faced higher risks of exposure to the virus, and as a result experienced high hospitalization and death rates due to their roles on the front lines of the pandemic response, exacerbating existing health and economic disparities within these communities. The pandemic has underscored the urgent need for addressing such systemic disparities in order to ensure equity in both essential workforces and access to health care.[58]

The COVID-19 pandemic has significantly impacted the mental well-being of health care workers[59] such as doctors, nurses, and social workers.[60] Given the severity of the pandemic and stress associated with caring for COVID-19 patients, health care workers may be at increased risk for PGD and PGD comorbidities. In a study evaluating the impact of the pandemic on post-traumatic stress, burnout, and secondary trauma at work, researchers found that approximately 26 percent of social workers met PTSD diagnostic criteria, about 16 percent reported severe grief symptoms, and 50 percent reported secondary trauma, which is similar to experiencing PTSD, but through vicarious exposure to the trauma of others.[60] In the first few months of the pandemic, front-line workers experienced challenges such as personal protective equipment (PPE) shortages, changing PPE guidance, anxiety and fear, and testing delays.[61] Researchers have identified five important themes related to future PGD research in the wake of the COVID-19 pandemic.[26] Djelantik et al. recommend more research to: (1) reconcile PGD diagnostic criteria in the ICD-11 and the DSM-5-TR; (2) develop better screening tools and interventions based on one's severity of PGD symptoms; (3) identify additional pharmacotherapies; (4) better understand the needs of higher risk populations such as children and older adults; and (5) understand grief as a conceptual model of causal factors rather than an underlying disease.[26]

The COVID-19 pandemic has had an impact on how people talk and think about grief and bereavement. Several interview participants and key contributors highlighted the changing nature of the bereavement and grief landscape caused in part by the COVID-19 pandemic. Several key contributors said the pandemic reduced stigma and encouraged open discussions about loss and grief. For example, participants noted that there has been increased media attention to grief and an increase in the number of people openly sharing their grief experiences. However, the pandemic has had a disproportionate impact on under-resourced communities and communities of color, where COVID-related deaths pose unique challenges for those left behind. One contributor described being approached by a local school district seeking effective support for grieving children -- mainly youth of color -- who lost loved ones to COVID-19. According to this contributor, these deaths in under-resourced communities of color have been particularly complex, with children grappling with feelings of guilt, shame, and even self-blame for transmitting the virus. In the United States, within the literature and key contributor interviews, evidence suggests that the pandemic has created a "shadow population" of bereaved individuals and families. In this context, the "shadow population" refers to individuals who have directly and indirectly experienced emotional impacts associated with the death of a loved one. In fact, a key contributor noted that for every COVID-19 death, approximately nine people lose a relative. The loss of adult relatives has led to a lack of social support for many children, making the grieving process even more challenging.

Despite these challenges, study participants emphasized that the COVID-19 pandemic has also fostered innovation relating to seeking support and care. Virtual platforms, such as Zoom and Facebook support groups, have become instrumental in connecting people during times of isolation, providing a valuable resource in helping grieving individuals find solace and community. Thus, a study participant highlighted how the pandemic has, in a way, opened new avenues for support and care that were not as widely explored before. Additionally, she noted that while innovative ways to seek mental health care exist, the volume of individuals seeking care during the COVID-19 pandemic disrupted access to care. An informal conversation by a key contributor in hospital administration during the pandemic led to the creation of a hospital-based task force focused on addressing grief, which emerged during the pandemic, coinciding with a surge in demand for bereavement services. As a clinician based in a hospital setting, the contributor became acutely aware of the overwhelming demand for her services, particularly among grievers, cancer patients, and individuals facing isolation due to immunocompromising conditions. The intensity of the grief she observed surpassed anything she had previously encountered, resulting in a waitlist exceeding six months for her assistance. Thus, some of our interviews suggest that although the pandemic opened the conversation around grief, the existing infrastructure could not meet the demand.

E. Impact of Prolonged Grief Disorder on Substance Use

In the overview section of this report, we detailed the statistics on SUD and overdose deaths and how the trends represent a potential unmet need for bereavement and grief services. Several studies included in the analysis found that grief may impact substance use, especially among people with a pre-existing SUD and their families.[19] In the ICD-11, clinical features of PGD include the increased use of alcohol, tobacco, and other substances.[42] In one study, bereaved college students conveyed that grief and mental distress contributed to an increase in their substance use.[62]

The complex, bidirectional relationship between grief and substance use/SUD is illustrated by the literature on grief among PWUO. PWUO report complex grief experiences and significant distress when they lose friends and family to drug overdose.[19] There are several behavioral and psychological effects for grieving PWUO when someone close to them has a drug-related overdose. For example, in a qualitative study evaluating the impact of overdoses of friends and associates for PWUO, researchers found that three out of four PWUO knew someone within their social network who died by overdose.[19] Furthermore, the study participants indicated that the overdose affected their drug use. Although some PWUO adopted safer drug practices, others increased their drug use. One participant justified their increased drug use as a way to cope with their pain and distress after the death of a family member. In another qualitative study evaluating drug use behavior, trauma, and emotional affect among people bereaved by an overdose in their social network, researchers found that subsequent overdose risk depended on whether the individual witnessed the drug overdose and how drug use behaviors changed because of the overdose in their network.[17]

F. Impact of Grief on Suicidal Behaviors and Ideation

Suicidal ideation commonly co-occurs with PGD symptoms.[42] For example, veterans with PGD were two to three times more likely to have suicidal behaviors and thoughts compared to veterans without PGD.[63] In addition, childhood bereavement is associated with increased suicide-related behaviors in early adolescence and adulthood.[35] Bereaved youth reported feeling burdensome to family and loved ones which led to an increase in suicidal ideation.[38] Individuals bereaved by suicide may experience emotions of guilt and stigma as survivors face the aftermath of suicide. One study found that people bereaved by

suicide expressed feelings associated with stigma, such as feelings of social disapproval, long after the event has taken place; an experience that was further magnified if they also reported higher levels of depressive symptoms.[64] Bereavement when a loved one dies suddenly and unexpectedly is also associated with increased suicide risk. In one study, researchers found that individuals who experienced a sudden suicide death of a relative in the past five years have the highest risk of attempting suicide themselves.[64] Finally, bereavement and drug overdose exposure were found to impact suicidal ideation: for "participants who engaged in risky behaviors following the overdose of someone they knew, a subset described increasing their drug use with suicidal intention and increased suicidal ideation".[17] Therefore, bereavement due to loss from suicide should be recognized as a suicide risk factor.

G. Social Factors Impacting Bereavement

Sargent et al. examined the effects of family and community violence on African American adolescents. The study reported on characteristics of stressors, like proximity to violence (meaning physical proximity, or emotional or relational proximity to the victim of a violent event) and type of violence, and concluded that community violence is a social risk factor that contributes to bereavement and grief through direct victimization, and/or vicarious experiences of exposure to violence in the community.[65] Kennedy & Ceballo's findings indicate the closer the relationship between the bereaved and the victim of violence is related to increased risk for mental health symptoms.[66] Another study found that violence exposure can predict mental health outcomes including internalization of symptoms like grief.[65]

In a study of men who lost relatives in use of force incidents with law enforcement, the authors reported that the survivor's grief was intensified by traumatic experiences with law enforcement both before and after the fatal incident.[67] Therefore, people who are bereaved by deaths occurring in the context of use of force incidents with law enforcement may be further distressed by subsequent interactions with the criminal justice system and over-policing, especially in neighborhoods of color.67

George Floyd's death at the hands of police has brought considerable attention to a long-standing experience of grief and bereavement within Black and Brown communities secondary to traumatic encounters and deaths from use of force by police. Some interview participants identified George Floyd's murder as a pivotal event that prompted further examination of grief experiences in communities of color. The respondents conveyed that many Americans including members of communities of color who saw George Floyd's murder broadcast on national television may have experienced profound feelings of grief despite not knowing George Floyd personally. Further, study participants indicated that grief in these communities has been particularly profound, accompanied by feelings of helplessness, persecution, and the effects of racism, resulting in significant suffering. As a result, a study participant noted an increase in demand by community members who are seeking bereavement support services to address their grief, but often resources are unequipped to meet this demand. One participant noted that the pandemic and social crisis coincided, creating complex grief experiences for survivors due to COVID-related losses and increased isolation. Despite these challenges, a common response and community support provided some solace during this period. One participant noted that to better support communities through their grief, it is important to consider cultural aspects, especially in the preliminary period of grief.

H. Equity Implications of Bereavement and Grief Services

The loss of a loved one during childhood could be recognized as a significant Adverse Childhood Event due to its profound and enduring impact on a child's developmental trajectory. Numerous studies

underscore the far-reaching implications of childhood bereavement on psychological, emotional, and social well-being.[68] For example, one study found that the premature loss of a parent was associated with poverty, decreased global functioning (the ability to manage the demands and challenges of daily life), and increased likelihood of a SUD.[31] Moreover, childhood bereavement was associated with other mental health conditions such as depression, PTSD, separation anxiety, and CD. Moreover, Black and Hispanic youth experienced higher rates of parental death and were at elevated risk of a psychiatric disorder compared to non-bereaved White youth.[69]

Furthermore, bereavement can sometimes be viewed through the lens of racial discrimination due to disparities in how different racial and ethnic groups are affected by such losses. Racial discrimination and systemic inequalities can impact access to resources, support systems, and quality health care, all of which play a pivotal role in an individual's ability to cope with grief. Minoritized communities often face barriers that limit their access to mental health services, counseling, and culturally sensitive support networks, exacerbating the challenges of bereavement.[70,71] Moreover, systemic racism can contribute to higher rates of deaths in certain racial groups, such as deaths resulting from inadequate health care or unequal socioeconomic opportunities. Similarly, structural violence, which encompasses systemic injustices and inequalities, can lead to an environment where crime and violence are more prevalent. This can disproportionately impact minoritized communities, leading to a higher risk of homicide and subsequent bereavement.[72] Recognizing bereavement as a potential outcome of racial discrimination underscores the need to address underlying systemic inequalities, promote inclusive support services, and foster a greater understanding of how various societal factors intersect to influence individuals' grieving experiences.

In the United States, differences in access to bereavement support services contribute to health inequities among certain populations. One interview participant expressed concern that, despite substantial evidence highlighting the physical and mental health impact of untreated PGD, there is a failure to recognize bereavement as a social determinant of health. For example, research has found that bereavement has significant effects on mortality for the bereaved. Bereaved individuals are at greater risk than the non-bereaved of dying from any cause such as cardiovascular disease, stroke, or cancer.[73] The contributor advocates for at least recognizing bereavement as one of the most significant ACEs, particularly in cases involving the loss of a parent or sibling.

Another contributor emphasized that bereaved individuals may experience loss differently due to racial inequities and discrimination in the United States, as it perpetuates poverty and extreme disadvantages in affected communities. The cost of a funeral can lead to extreme debts, compounded by high interest rates, which can continue to plague families long after the death. The financial, social, and health implications of bereavement create long-lasting challenges for affected families.

I. Current state of bereavement and support services

There are a variety of bereavement- and grief-related support services available, including CBT and CBT variations, trauma-informed care (TIC), social support, spiritual support, hospice, and other interventions such as bereavement camps, music and art therapy, and care farming. **Table 7** defines each of the interventions described in this section.

Table 7. PGD Interventions and Descriptions	
Intervention	**Description**
Psychotherapy	Psychotherapy, including cognitive behavior therapy (CBT) and trauma-focused cognitive behavior therapy (TF-CBT), meaning-centered grief therapy (MCGT), and accelerated resolution therapy (ART), is typically offered in various formats, including individual therapy, group therapy, and family therapy, allowing individuals to choose the approach that best suits their needs. It provides a structured and supportive framework for navigating the complex emotions and challenges associated with prolonged grief, ultimately promoting healing and emotional well-being.
Social Support	The provision of emotional, practical, and informational assistance from individuals, groups, or communities. Social support can come from friends, family, support groups, online networks, or pets. It plays a crucial role in mitigating PGD symptoms and promoting overall well-being.[a,b]
Spiritual Support	Spiritual support in grief intervention acknowledges that individuals experience and navigate grief through their unique spiritual or religious perspectives. It provides a safe and compassionate space for individuals to explore and express their spiritual beliefs, find comfort in their faith, and address existential questions related to life, death, and the afterlife. This intervention can be facilitated by spiritual leaders, chaplains, counselors, or trained bereavement professionals who respect and honor the individual's spiritual or religious background.[c,d]
Bereavement Camps	Programs or retreats specifically designed for bereaved individuals, particularly children. Bereavement camps provide a supportive environment where participants can engage in various therapeutic activities, share their grief experiences, and connect with others who have also experienced loss. These camps aim to reduce PGD and other grief symptoms.[e,f,g]
Music and Art Therapy	Therapeutic interventions that utilize music or art forms to facilitate expression, emotional processing, and healing. Music and art therapy can help individuals cope with grief, trauma, and emotional distress, promoting self-discovery and emotional well-being.[h,i]
Care Farming	An innovative approach that combines farming activities with therapeutic interventions. Care farms provide a nurturing environment where individuals can engage in nature-related activities, interact with animals, and participate in ecotherapy. Care farming has shown positive effects on physical and mental health, including grief-related symptoms.[h,j]
Hospice Bereavement Support	Specialized support services provided by hospice facilities to individuals and families during and after the end-of-life process. Bereavement support in hospice may include counseling, educational resources, assistance with funeral arrangements, and ongoing emotional support. These services aim to help individuals navigate their grief journey and adapt to life after the loss.[k]

Source: Mathematica analysis of PGD interventions.

Notes:

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ART = Accelerated Resolution Therapy; CBT = Cognitive Behavioral Therapy; MCGT = Meaning-Centered Grief Therapy; TF-CBT = Trauma-Focused Cognitive Behavioral Therapy; TIC = Trauma-Informed Care.

All key contributors expressed their concerns about the current state of bereavement services, describing them as lacking, inaccessible, and fragmented. One participant highlighted the emergence of a loose and organic network of community-based grief centers that have arisen out of necessity. When individuals find that existing grief services do not adequately meet their community's needs, they often take matters

into their own hands and start their own programs such as grief centers. Although these centers may vary in quality and the types of relationships they offer, they all share a common goal of recognizing the need for support and serving their community.

Other participants highlighted the lack of awareness about and availability of bereavement support services, particularly for children and adolescents. One participant suggested that American culture has not fully embraced the idea that children experience grief, indicating that grief manifests differently in youth compared to adults. One study found that while the majority of children bereaved by a sudden parental death coped with their grief within one year, nearly a third of children gradually resolved their grief and approximately 10 percent of children showed symptoms of prolonged grief.[74] Consequently, it seems that there is a lack of interventions designed specifically to address grief in children. In the United States, there are only six evidence-based interventions for childhood grief, and approximately four of them combine grief and trauma treatment. One notable intervention, Trauma and Grief Component Therapy, acknowledges the distinction between grief and trauma. This therapy is flexible and adaptable, and it can be tailored to meet an individual's unique needs, making it suitable for addressing various traumatic and grief experiences. Another intervention is designed to assist children in developing basic coping skills related to grief. Despite the variety of bereavement services available, a contributor highlighted that many clinicians, particularly those working in school or community-based settings, report not receiving adequate training to treat grief in children effectively. There is a need for improved training and resources to ensure that bereavement support services are more accessible and effective for children experiencing grief.

Additionally, most key contributors expressed concerns about the limited training available to help mental health professionals effectively address grief in both children and adults. Although many mental health care providers believe they can manage grief-related concerns, training and education on grief and bereavement in graduate school programs is often insufficient, leaving practitioners ill-equipped to identify and treat PGD. Key contributors specifically criticized the absence of standardized training protocols for addressing death and bereavement. For instance, some mental health care providers are taught to watch for signs of poorly managed grief, while others only learn about the outdated stages of grief or are trained using pathology-based approaches. The absence of standardized credentialing and quality certification for providers further hinders the consistency and effectiveness of care. According to one participant, grief knowledge and support within the mental health community are limited. Specifically, there is a lack of grief literacy among individuals experiencing grief and mental health practitioners, leading to challenges in understanding what is typical and when to seek help in providing care to the bereaved.

Finally, contributors mentioned a noticeable absence of community-based services that cater to both clinical and non-clinical bereaved populations. One participant emphasized the importance of extending support to people diagnosed with PGD and those who are not formally diagnosed with PGD and do not receive professional care. Communities require accessible bereavement support, especially if they face multiple, concurrent, challenging events, such as increased gun violence deaths in their community coupled with COVID-19 deaths. The contributor believes that community resources are often underutilized due to the increased pathologizing of grief disorders. For instance, he emphasized that while certain individuals may perceive the health care system as untrustworthy, there is an opportunity for many to find support in non-professional, community-based organizations like faith groups, grief centers, or local support groups for those experiencing PGD and normative grief. Therefore, community-based services have the potential to significantly improve health outcomes.

J. Approaches and Effectiveness of Services for Prolonged Grief Disorder and Complicated Grief

1. Psychotherapy

Psychotherapy is crucial in the treatment of PGD due to its role in addressing the continuum between typical grief and pathological grief responses. Providing individuals with information about grief, its natural progression, and the potential signs of PGD helps them understand their own experiences. This understanding allows individuals to distinguish between expected grief reactions and those that may indicate a need for specialized intervention. By promoting awareness and knowledge about PGD, psychoeducation contributes to early intervention and improved treatment outcomes for those experiencing this challenging condition.

2. Cognitive Behavioral Therapy (CBT)

Studies included in this analysis frequently suggested CBT as an effective intervention for treating PGD in children, adolescents, and adults.[49,75] In a RCT for children, CBT Grief-Help was an intervention used to treat children and caretakers.[27] Aspects of the intervention included: narrative reconstruction (describing the death in detail), visiting the scene of the death, writing, and various other coping mechanisms to mitigate PGD symptoms. At the 3-month, 6-month, and 12-month follow-up, CBT was found to decrease PGD symptoms through "yielding positive changes in negative thinking patterns, decreasing maladaptive coping, increasing pleasant activities, and strengthening social problem-solving skills".[27] While CBT Grief-Help was more effective in decreasing PGD symptom severity compared to children who received supportive counseling, CBT also decreased PGD comorbidities such as PTSD and depression in parents, caretakers, and children.[27] In a RCT, Lacasta et al. found that cognitive behavioral group therapy is another effective treatment for CG, depression, and anxiety, and is more effective than traditional psychoeducational therapy.[76]

Furthermore, research has demonstrated the effectiveness of CBT-based treatments for PGD in adults. In a study involving adults with PGD due to suicide, participants underwent Internet-based cognitive behavioral grief therapy (ICBGT). The program includes three phases: (1) the self-confrontation phase is designed to address loss-related aspects; (2) the cognitive restructuring phase aims to promote restoration-oriented thinking; and (3) the social sharing encourages integration and reflection on strategies to improve coping post-loss. Through written assignments, ICBGT effectively reduced the severity of grief and associated conditions like depression. Therefore, both traditional CBT and its variations, such as ICBGT, have shown efficacy in treating PGD in both children and adults. Additionally, Internet-based interventions can expand access to bereavement care, particularly for individuals who might face challenges accessing traditional mental health care settings.[77]

3. Trauma-Informed Care (TIC)

There are opportunities to incorporate trauma-informed care (TIC) to treat PGD and related grief disorders. TIC is a framework that recognizes and acknowledges how trauma impacts physical and behavioral health, and practitioners have developed a continuum of care approach to promote resilience and avoid retraumatizing patients.[4] In a pilot study that examined the relationship between TIC and post-traumatic growth (PTG) in bereaved children, researchers found that children who took part in a bereavement camp experienced a statistically significant decrease in PGD symptoms.[78] PTG refers to the positive psychological changes that can arise in individuals after experiencing a highly stressful or

traumatic event.[78] TIC has the potential to significantly affect grief and secondary grief outcomes in communities experiencing increased violence or trauma. When social media posts indicate increased traumatic grief among community residents, TIC targeted to specific populations could serve as a useful tool.[79] Lastly, the Grief Recovery Method is an online blog platform that incorporates TIC. Although the Grief Recovery Method is not a commonly cited PGD intervention, the program is highly rated by users and could serve populations that are not able to access traditional PGD interventions. The Grief Recovery Method can be adapted to one-on-one grief support, group grief support, grief support for children, or support for those experiencing a pet loss.[79]

Mental health practitioners have developed a short-term treatment model for children and adults who experienced trauma, which includes the death of a loved one, in an intervention known as trauma-focused CBT (TF-CBT).[80] Typically, TF-CBT interventions involve both a child and a caregiver, aiming to address the child's trauma impacts while also assisting the caregiver in coping with their own distress related to the traumatic experience and enhancing their parenting skills.[81] TF-CBT includes nine steps that use the acronym PRACTICE, meaning "psychoeducation and parenting skills (P), relaxation (R) affective modulation (A), cognitive coping (C), trauma narrative (T), in vivo exposure (I), conjoint parent-child sessions (C), and enhancing safety and development (E)".[80] Based on previous research and a meta-analysis of 61 RCTs evaluating TF-CBT for children, TF-CBT was found to be effective in treating post-traumatic stress symptoms and secondary outcomes such as depression, anxiety, and grief.[75] Moreover, researchers have evaluated TF-CBT for both veterans and their families, including their children, within U.S. Department of Veterans Affairs facilities.[82] As previously mentioned, military members and their families are a vulnerable population because of their increased exposure to violence and trauma. For example, studies have documented increased exposure to maltreatment and IPV for military children.[82] Therefore, TF-CBT is a potential intervention for military members, their families, and other individuals bereaved in traumatic ways.

One participant discussed a case study in which her mental health colleagues, including a bereavement counselor, used a creative approach blending therapeutic interventions such as accelerated resolution therapy (ART) and trauma-focused therapy. ART aims to help individuals process and resolve traumatic memories in a safe and effective manner. Recognizing that the bereavement counselor was unequipped to treat the traumatic elements, they referred the patient to another counselor before addressing the grief-related elements. Furthermore, the participant highlighted the value of preventative mental health support, such as palliative care social work, with mental health providers who can recognize symptoms and provide support. Thus, addressing grief and trauma may require a comprehensive, multifaceted approach.

4. Meaning-Centered Grief Therapy (MCGT)

In an informal discussion, a key contributor described another mental health intervention to treat grief: Meaning-Centered Grief Therapy (MCGT).[83] MCGT is a therapeutic approach designed to help individuals who are experiencing grief and loss find meaning and purpose in their lives after the death of a loved one. It can help individuals make sense of their grief, find new directions, and develop a greater sense of hope and purpose as they navigate through their grief journey. It emphasizes the importance of finding meaning and purpose as a fundamental human motivation and incorporates CBT. The therapy addresses existential themes such as purpose, values, beliefs, legacy, and connections to others, encouraging individuals to explore the existential questions that arise from their loss. Through reflection and narrative techniques, individuals construct a coherent and meaningful story around their grief experiences, integrating them into their overall life narrative. Psychoeducation about grief and the process

of finding meaning is often provided, helping individuals understand the universality of their grief reactions and providing coping tools. MCGT can be delivered in both group and individual therapy settings, allowing for shared experiences and support. One study evaluated the efficacy of MCGT for parents who lost their child to cancer. Participation in the intervention, which included 16 sessions, was associated with decreased PGD, depression, and hopelessness and increased sense of meaning and PTG.[84] By promoting meaningful reconstruction and PTG, MCGT aims to help individuals discover renewed purpose, hope, and resilience in the face of loss.

5. Hospice and Clinical Support

Hospice care plays a significant role in providing bereavement support in the United States, offering comprehensive assistance to individuals and families coping with impending loss and the subsequent grieving process. Hospice care extends beyond the patient's medical needs to address the emotional, psychological, and spiritual well-being of both patients and their loved ones. Through counseling, support groups, and educational resources, hospice programs offer guidance and preparation for the bereavement journey ahead. According to the National Hospice and Palliative Care Organization (NHPCO), most hospice programs in the United States include bereavement services as a core component of their care model, recognizing the importance of supporting families before, during, and after the patient's passing. These services not only facilitate healthy coping mechanisms for grieving individuals but also help them navigate the complex emotional landscape of loss.[85] By intertwining end-of-life care with bereavement support, hospice programs contribute significantly to the overall well-being of patients and their families during a profoundly challenging time.

Moreover, one contributor noted that while hospice can provide quality bereavement support, the typical time spent in hospice is short. Thus, there is a need for a more comprehensive approach to bereavement support. To address bereavement needs, one participant mentioned two grief models -- the Canadian Grief Model and the Irish Hospice Foundation Model -- which provide valuable resources for grief support. These models can contribute to enhancing the bereavement experience for individuals and families facing loss. In general, interview participants recognized positive outcomes for bereaved individuals who sought support through hospice institutions, however, some participants highlighted the changing nature of hospice services. More specifically, some hospice institutions are transitioning to for-profit models, which interview participants hypothesized might impact the quality and availability of bereavement services.

By providing pre-bereavement interventions that can mitigate severe grief symptoms post-bereavement, frameworks like the Canadian Grief and Bereavement Model and the Irish Hospice Foundation's (IHF) initiatives offer valuable insights for the United States to consider. The Canadian Grief and Bereavement Model[86] is a framework developed to understand and support individuals experiencing grief and loss. This model outlines four main tasks that individuals typically need to cope with their bereavement effectively. The four tasks include accepting the reality of the loss, processing the pain of grief, adjusting to a life without the deceased, and finding ways to maintain a connection with the deceased while continuing to live a fulfilling life. The model emphasizes that grief is a dynamic and evolving process, and individuals may revisit these tasks at various times as they move through their grief journey. The Canadian Grief and Bereavement Model has been widely adopted and recognized as a valuable resource for clinicians, counselors, and individuals dealing with grief, providing a roadmap to understand and cope with the complex emotions and challenges that accompany loss.

The IHF[87] is a leading non-profit organization dedicated to improving end-of-life care and support for individuals and families facing serious illness and bereavement in Ireland. Established in 1986, the IHF

works collaboratively with health care providers, policymakers, and the public to promote palliative care, education, and advocacy. The organization focuses on enhancing the quality of life for those with life-limiting conditions, ensuring access to compassionate and appropriate care. The IHF offers a wide range of services, including training for health care professionals, support for bereaved families, research initiatives, and public awareness campaigns. Through its diverse efforts, the IHF continues to play a vital role in advancing end-of-life care and raising awareness about the importance of compassionate and dignified support for individuals and families during challenging times. Thus, the two models serve as meaningful examples for the United States to consider when designing services.

Bereavement services have also been evaluated in the intensive care unit (ICU) setting.[88] Bereavement services in the ICU include providing support to bereaved family members, providing information about services, following up with the family, and providing individualized care. One study found five themes related to bereavement care within the ICU: (1) Participants indicated that discussing bereavement support services should occur as soon as possible. (2) Participants highlighted that services should prioritize care, dignity, and respect for the family. (3-4) Other important themes were information and education and making memories, such as bereavement box making. (5) Lastly, one participant said the bereavement services included providing "support to patient and family, nursing care,[…] identifying psychological and psychosocial needs of the family, [and] spiritual care".[88]

In addition to hospice facilities, traditional primary care and specialty behavioral health care settings can play a significant role in providing bereavement support for families and their loved ones. Identifying risk factors and PGD symptoms in a primary care setting can significantly affect PGD severity and rates. In a literature review of bereavement care in primary care in the United Kingdom, researchers found that primary care doctors and nurses recognized bereavement support as important, however, they were cautious in pathologizing normal grief reactions. The common forms of bereavement support included telephone calls, home visits, and condolence letters.[89] Nevertheless, there is a call for further research into bereavement support within United States primary care, given the limited existing literature on this subject.[90] In contrast, most hospice organizations provide bereavement support in the United States. According to Medicare Hospice Regulations, bereavement services must be available to loved ones for up to one-year post-death.[91] However, bereavement support services in hospice facilities vary significantly in terms of service types and accessibility in the United States. Some examples of hospice services include telephone calls or letters sent to bereaved family members, providing educational materials related to grief, pre-death planning, or therapy.[92] For informal hospice caregivers, one study discussed using music therapy prior to bereavement.[93] Through music therapy, participants in the study became more resilient and strengthened relationships with hospice patients (e.g., spouse, parent, or child) prior to bereavement. However, certain illnesses treated in hospice facilities may result in increased necessity for bereavement support services post-death.[94] In a matched pair case-control study, Jones et al. found that patients bereaved by Alzheimer's disease, lung cancer, and renal failure required increased bereavement services at least 50 percent of the time.[94] Regardless, hospice facilities are in a unique position for providing pre-bereavement interventions that can mitigate severe grief symptoms post-bereavement.

6. Social Support

Social support refers to the assistance, comfort, and resources that individuals receive from their social networks, such as family, friends, coworkers, and community members. Social support can be effective in mitigating PGD symptomology. Individuals bereaved by the suicide death must strike a balance between remembering their loved one in a non-traumatizing way and releasing feelings of self-criticism, blame,

and guilt. In addition to empathy, social support has been cited as an important intervention in the wake of a traumatic loss.[95] In the study, participants indicated their satisfaction level for various social support networks. Perceived social support in the context of having pets received the most positive ratings, with 89 percent of participants reported being extremely satisfied or satisfied with pets/animals, followed by 67 percent for online grief groups, 58 percent for in-person grief groups, and 52 percent and 40 percent for friends and family, respectively.[95] Groups that provide social support but received the highest percentage of extremely dissatisfied or dissatisfied ratings include faith leaders at 41 percent, followed by 42 percent and 36 percent for neighbors/communities and colleagues, respectively.[95] For one participant, emotional support means "having a community of people who are safe to share your journey of grief with, who don't try to fix you or hurry you… people who let me say her name and tell stories about her".[95] Thus, while social support can vary significantly, good social support has the potential to positively impact grief outcomes.

As previously mentioned, people who lose a loved one to suicide are at increased risk for suicide themselves[96] and other mental health conditions. Therefore, it is important that these survivors develop coping mechanisms that can mitigate the risk of developing a grief disorder such as PGD or CG. People who lose a loved one to suicide frequently experience depression, stigma,[64] guilt, self-blame, and social criticism.[97] One study that examined coping in people who had lost a family member to suicide found that empathizing with other survivors allowed them to "regulate their adverse emotions, regain self-worth and every-day routines, but also underpinned a state of elevation and self-growth by transforming their traumatic experience of loss into empathy and support for others in need".[97] Thus, support groups serve as a potential intervention to improve grief reactions for people who lose a loved one to suicide.

7. Spiritual Support

Religious and faith-based organizations can play an instrumental role in supporting bereaved individuals through the grief process. In a meta-analysis of 73 studies regarding bereavement and religiosity, researchers found that, generally, spirituality has a positive effect on bereavement. However, the authors noted significant gaps in literature around this topic.[98] Lillig highlighted the often-overlooked role of spirituality in secular counseling, underscoring an opportunity for non-faith-based mental health professionals to integrate spirituality into their bereavement support services. The author suggests incorporating therapeutic elements such as music therapy, bibliotherapy, and prayer/meditation, which can be customized to aid bereaved individuals or groups. Given the existing gaps in the literature concerning grief and faith, there is a pressing need for further research in this area, as it may introduce opportunities for organizations able to incorporate such elements.[16,20]

8. Other Supportive Interventions

While CBT appears to be the most cited treatment for PGD, recent research has studied novel PGD treatments including bereavement camps, music and art therapy, and care farming. Several studies have cited bereavement camps for bereaved children as an effective intervention for PGD, CG, and other grief symptoms.[91,99,100] At one camp, Healing Hearts, trained volunteers led bereaved children through various group activities in which children were able to talk about their grief and gain trust.[99] Care farms have been described as therapeutic landscapes[101] with the power to impact physical and mental health including trauma and grief.[100] The Green Care Model for traumatic grief has three components: care farming (e.g., rescuing animals, nature immersion, and ecotherapy), contemplative connection (e.g., rituals and

mindfulness), and physical well-being (e.g., sleep hygiene, psychoeducation, and a healthy diet). After pre-tests and post-tests, care farming participants exhibited a significant reduction in grief intensity.[100]

There are several effective ways to identify populations with high needs for bereavement support, including utilizing schools, data, and mental health institutions. As noted by some key contributors, schools serve as a clear entry point to reach grieving children. For example, one participant was approached by a school district to assist grieving children following COVID-19 deaths. One way in which children grieve is by "acting out" in school. One contributor pointed out that children and youth, including youth of color, may express their grief through externalizing behaviors, often leading to misdiagnosis with other behavioral conditions, such as CD. CD is a psychiatric condition that typically manifests in childhood or adolescence and is characterized by a pattern of persistent and repetitive behaviors that violate the rights of others, societal norms, and age-appropriate rules. According to the DSM-5-TR, CD often includes disregarding rules, deceitfulness, and academic issues, such as frequent disruptions and poor impulse control.[102] CD often leads to misdiagnosis with other behavioral conditions, such as adjustment disorder and can have negative consequences, potentially involving the criminal justice system.

To address the impact of home and community-based events on a youth's mental health and school engagement, the "Handle with Care" program[1] was developed. The program involves law enforcement officers notifying a child's school when they respond to a home, because the presence of law enforcement indicates that a potentially traumatic incident, such as a death, domestic violence situation, overdose or shooting, has occurred in the presence of the child. This program is designed to improve the collaboration between law enforcement agencies and schools to support the emotional and psychological well-being of children who may have experienced trauma at home or in their communities. This helps identify children at risk and provide appropriate support. The program's primary goal is to promote the well-being and resilience of children during difficult times in their lives. Additionally, another interview participant emphasized the importance of targeting children of color for grief and bereavement support services, especially boys, to enhance health equity. Schools in areas with racial segregation, extreme poverty rates, and elevated violence should be directly targeted for grief support because of high rates of exposure to violence that has resulted in the death of loved ones and others in the community.[65]

Outside of clinical PGD treatments, there are opportunities to strengthen the bereavement system to support the population prior to a bereavement event. One participant discussed the importance of increasing stability in the general population by improving economic conditions and housing stability. By helping families meet their basic needs and achieve greater independence, they can better address the stressors that arise from grieving and loss. Moreover, another participant emphasized the opportunity to reinforce existing home and community-based services (HCBS). He stated that bereavement support should be considered through the lens of Medicaid "in lieu of services" (ILOS). Medicaid "in lieu of services" provisions[103] allow states to offer alternative forms of care and support to beneficiaries in certain situations instead of providing traditional Medicaid-covered services.[2] The ILOS provision is often covered under Medicaid 1115 demonstration waivers, which allow states to use Medicaid funding outside of services traditionally covered by Medicaid. When a state implements an ILOS provision, it means that

[1] Handle with Care is often associated with programs aimed at providing support to children who have experienced trauma or adverse events. These programs typically involve communication and coordination between law enforcement, schools, and other community organizations to ensure that children exposed to traumatic situations receive appropriate support and accommodations in their educational environment.

[2] See https://www.federalregister.gov/documents/2024/05/10/2024-08085/medicaid-program-medicaid-and-childrens-health-insurance-program-chip-managed-care-access-finance#h-62.

certain Medicaid beneficiaries may receive alternative services that are determined to be more appropriate or cost-effective for their specific needs; the beneficiary may choose this alternative service or setting or what is ordinarily covered in the state plan. The ILOS provision allows states to tailor their Medicaid programs to better meet the diverse needs of their beneficiaries, promote community integration, and potentially control costs by providing services that prevent or reduce the need for more expensive institutional care. HCBS, such as those covered under the ILOS provision, can serve as a useful intervention for individuals who are grieving but do not meet PGD diagnostic criteria.

In New York State, there is a palliative HCBS care program specifically designed for children diagnosed with terminal conditions. When a family opts for bereavement counseling, they undergo an interview to evaluate their counseling requirements, encompassing an assessment of various factors like their social, spiritual, and cultural influences that could impact the grieving process.[104] After the child's passing, grieving family members can access bereavement counseling for a duration of up to six months and receive health home care management one month after the passing.[104] Health home care management includes but is not limited to: notifying schools, physicians, and pharmacies of the passing; connecting family members with bereavement support groups; and removing home modifications.[104] However, the specific ILOS options and eligibility criteria can vary across states based on their individual Medicaid programs and available waivers.

K. Barriers to Seeking Bereavement Support

According to recent studies, the utilization rate of bereavement services in the United States varies considerably both demographically and geographically. One study reported a low utilization rate, noting that 10 percent of bereaved individuals with PGD access formal support services.[105] Another study found that nearly 90 percent of parents who experienced severe PGD symptoms reported wanting bereavement support, but only 56 percent used mental health services.[106] Some populations that are more likely to use bereavement services at higher rates are those that are of cis-female gender, younger in age,[107] and insured.[96]

Variations in service utilization rates can be attributed to several factors. Cultural and societal norms around grief may influence an individual’s grief experience and their willingness to seek professional help. For example, individuals from some cultural backgrounds may rely more on informal support systems within their communities rather than formal services.[88] In addition, several barriers can contribute to the underutilization of bereavement services; these include lack of awareness about available services, financial constraints,[96] and stigma[64] associated with seeking mental health support. Among parents who experienced the loss of a child due to cancer, 64 percent reported it was too challenging to discuss the death of their child, and 60 percent said it was difficult to find the necessary support.[106] Other barriers included lack of time, financial barriers,[96] or transportation concerns. In a study on barriers to care and service satisfaction for people bereaved by homicide, approximately 32 percent said having no insurance made it difficult to schedule or keep mental health appointments.[96]

Furthermore, hospice can play a vital role in promoting healthy bereavement -- as a better end-of-life experience can lead to improved bereavement outcomes. However, key contributors noted that the relevance of hospice in bereavement support depends on specific cases and populations. Inequities in hospice access were highlighted, with White Medicare beneficiaries being more likely to receive hospice services and in a timelier manner compared to Black Medicare beneficiaries.[108] Thus, bereavement service utilization is impacted by several factors.

One participant in our study emphasized the importance of culturally sensitive interventions in bereavement support. Individuals from diverse racial and ethnic backgrounds may be hesitant to seek help for several reasons, such as limited English proficiency, which can be a barrier to accessing support. Additionally, diverse cultures have unique views of and experiences with grief. It is therefore important to let people express their support needs and preferences. Given the diverse population within her community, this contributor highlighted the significance of cultural specificity. For instance, she observed that grief unfolds differently in different cultural contexts, such as Indigenous, Muslim, and Hmong communities, where there are distinct practices and beliefs around grief. In certain Indigenous communities, it is common to stop saying the deceased's name and crying after a specific period. Notably, the contributor indicated that grief is less likely to be seen as a medical issue in these populations. Given the multicultural composition of the United States, she also stressed the need to develop culturally sensitive interventions by supporting more mental health practitioners from diverse communities.

Social determinants of health, which are defined as social or economic factors that influence one's health and well-being, can also function as barriers to seeking bereavement services. For example, geographic disparities in the availability of support services acts as a barrier in service access and utilization.[109] A Chicago-based study evaluating access to bereavement support among people bereaved by a child's death found that in addition to a lack of access to support in geographic areas with the highest prevalence of child deaths, areas where child mortality rates were higher had higher proportions of low-income, Black, or Hispanic residents.[109] Another social determinant that acts as a barrier to accessing mental health services is Internet access,[62] which, along with a lack of awareness of available services, a lack of access to necessary technology, and personal mental health barriers, contributes to digital exclusion faced by individuals with mental health conditions. With the rise in telehealth services during the COVID-19 pandemic, digital exclusion has the potential to significantly affect mental health outcomes in areas in need of mental health services.

Health care providers' ability to recognize symptoms may also be an important contributor to identifying PGD and linking individuals to needed services. Until recently, the absence of a formal diagnosis posed challenges for clinicians in identifying, managing, and studying PGD.[63] Identifying people at risk of PGD, CG, or other grief disorders is one of the first steps in helping them seek out support. Moreover, there is limited research regarding identifying high-risk family members, their bereavement service utilization, and whether sociodemographic factors play a role in service utilization.[107] However, one study found that approximately 55 percent of United States hospice facilities regularly screen caregivers for CG or PGD,[110] but fewer than half of caregivers identified as high-risk utilize bereavement services.[107] Although it can be difficult to identify populations at risk of PGD, one study found a novel way to identify grief on a community level. Researchers used social media to identify signals of elevated traumatic grief in Chicago gang territories.[111] Thus, social media could be a useful tool in targeting interventions.

In addition to social media, multiple data sources can be utilized to identify populations in need of bereavement support. One study participant suggested utilizing existing data from various sources, including emergency departments, the Fatality Analysis Reporting System (FARS),[112] vital statistics, and the National Violent Death Reporting System (NVDRS),[113] to identify individuals who have died and connect their social networks with bereavement support. The FARS, as described by the National Highway Traffic Safety Administration, provides a comprehensive yearly census of fatal injuries occurring in motor traffic accidents. Vital statistics are essential government records that track vital events such as births, deaths, marriages, and divorces, and they also capture details about the cause of

death, underlying cause of death, and multiple causes of death when applicable. The NVDRS captures violent deaths, including homicides, suicides, deaths from legal intervention involving law enforcement officers, unintentional firearm injuries, and deaths of undetermined intent. The system aggregates data from various sources, such as death certificates, law enforcement reports, medical examiner and coroner reports, toxicology reports, and other relevant records.

Interview participants emphasized additional gaps in accessing bereavement and grief support services, complementing the gaps and challenges discussed in the literature. One key gap identified was a fragmented and inattentive system with inadequate funding. One participant pointed out that the existing bereavement system is inattentive, leading to the oversight of crucial cues. For instance, two out of nine key contributors referenced studies on incarcerated youth, revealing that a significant proportion (40-90 percent) of incarcerated youth had experienced bereavement, often involving the loss of a parent or caregiver, prior to incarceration. Consequently, another participant stressed the need to "bereavement-proof existing systems" by identifying and addressing people's needs when they are bereaved. Bereavement-proofing existing systems could involve a comprehensive, multifaceted approach, recognizing that grief is a natural part of life and that systems should be designed to support individuals and families during their grieving journey. Collaboration among government agencies, health care providers, employers, schools, and community organizations could play a vital role to achieve a more grief-sensitive society in the United States.

The lack of insurance funding for bereavement support systems and the characteristics of the existing insurance system negatively impact access to services. While several study participants criticized the inclusion of PGD into the DSM-5-TR, many recognized it as necessary because diagnoses and associated codes are essential for accessing insurance funding for mental health services in the current system. However, a significant challenge arises as many mental health practitioners do not accept insurance, requiring individuals to pay out-of-pocket or require a philanthropic donation to access affordable bereavement support. In fact, in a study of over 500 provider networks in the Affordable Care Act Marketplaces, only 43 percent of psychiatrists and 19 percent of non-physician mental health practitioners participated in any network.[114] Therefore, accessing mental health care can be complicated by costs and network availability. It should be noted that novel supports, like bereavement camps and farms may not require patients to meet criteria of medical necessity, therefore providers of these services would not necessarily be able to bill within the existing insurance system for all the clients they serve. Individuals seeking care from novel supports would have to pay out-of-pocket; however, the populations that seek novel supports may not be the same as those who seek bereavement support from the medical community.

Furthermore, another participant stressed the need for more research and an evolving understanding of grief over time. Another study participant highlighted the collaborative development of the DSM-5-TR criteria by researchers in the field of bereavement. These criteria represent a reasonable consensus and have been validated globally. However, she acknowledged the potential for modification as added information and insights emerge over time, indicating a willingness to adapt the diagnostic criteria to better address bereavement needs effectively. Conversely, research has found clinical utility in the PGD diagnostic criteria and codes.[115] One RCT found that clinicians who received information about PGD and PGD risk factors were nearly five times as likely to correctly diagnose PGD and were more likely to recommend psychotherapies aimed at addressing PGD and grief symptoms.[115]

Therefore, the incorporation of PGD into the DSM-5-TR has the potential to improve PGD outcomes by enabling clinicians to more effectively identify and diagnose PGD and link individuals with specialized bereavement support services.[115] However, labeling grief as a mental health disorder was deemed

problematic by another participant due to the concrete nature of DSM-5-TR criteria, thereby dismissing the complexity of emotions individuals experience after a loss. The participants criticized the pathologizing and over-medicalizing of grief reactions, emphasizing the need to find a balance between providing support without labeling a response as problematic. Additionally, one participant mentioned that she would consider grief lasting for a year or a year and a half as typical, depending on the level of difficulty experienced. Overall, these insights underscore the importance of continually examining and improving bereavement support systems to better meet the diverse needs of individuals coping with grief and loss.

While a PGD diagnosis is often necessary to access care, Medicare reimbursement rates can impact provider availability and accessibility and create barriers to care. Contributors raised concerns about Medicare reimbursement rates, which may not adequately cover the cost of bereavement services, potentially limiting access for some Medicare beneficiaries despite having insurance coverage. Almost all participants highlighted the need for a more comprehensive approach to addressing grief, expressing concern about the over-medicalization of grief and its potential negative consequences. Key contributors emphasized that people experiencing severe grief reactions still have important needs, such as financial support after the loss of a spouse or access to food assistance. This underscores the importance of addressing grief from a holistic perspective, considering the diverse needs of individuals experiencing loss.

Social determinants of health (SDOH), such as socioeconomic status (SES) and English proficiency, can function as barriers to accessing bereavement services. Several participants pointed out how SES plays a significant role in a person's ability to access services. When individuals are struggling to meet basic needs, seeking mental health care may become a secondary concern. In fact, grief events can exacerbate these challenges. Additionally, disparities in bereavement support were noted across different demographics and regions in the country. Vulnerable populations, such as undocumented individuals, runaway and youth experiencing homelessness, and migrant farm workers, may be disconnected from service systems due to fear, lack of access, or language barriers. Geographic location also influences the availability of resources in communities, highlighting the importance of understanding and addressing the unique needs of impacted individuals. However, one participant expressed that the lack of grief-focused practitioners limits discussions about gaps and challenges in bereavement support. Furthermore, stigma can impact one's willingness to seek bereavement support. Some people may not seek or desire help, and certain communities may be wary of support services. Due to the sensitive nature of bereavement, individuals may feel uncomfortable sharing their experiences, necessitating sensitivity when working with bereaved individuals.

IV. Opportunities for Enhancing Health Systems and Services

Key contributor interviews yielded several recommendations to implement and improve a bereavement system. However, it is important to reiterate that most individuals do not require any formal bereavement or grief support services. One key suggestion was to implement policies that support bereavement, such as medical, government, and workplace policies, leave and economic functional support. Economic functional support is critical for individuals who are bereaved or grieving because, depending on their relationship to the deceased, they may be at risk of losing their entire livelihood. Economic functional support involves assistance to individuals or households to help them meet their economic needs and maintain financial stability. This support can take various forms, including financial or food assistance programs, housing support, and childcare assistance, among others. Such support is vital for reducing poverty, promoting economic mobility, and improving the overall quality of life for those in need.

Key contributors emphasized the numerous benefits of guaranteed bereavement leave for both employers and employees. Bereavement policies in the United States vary significantly based on employer and state. Currently, workplace bereavement policies may include requirements to determine eligibility such as: (a) needing to prove the death; and (b) consideration of the degree of separation from the loss for both friends and family. They may also vary based on minimum bereavement leave allowances and flexibility to use other leave options (e.g., paid time off), or of the Family and Medical Leave Act (FMLA), access to Employee Assistance Programs (EAP). FMLA provides eligible employees with job-protected leave for specific family and medical reasons. FMLA was enacted to balance the demands of the workplace with the needs of employees to attend to their own health conditions or those of their family members. However, minimum working requirements and unpaid leave may prevent employees from accessing FMLA services.[116]

Similarly, an EAP is a workplace benefit program offered by many employers to support their employees' well-being and address various personal and work-related challenges they may face. Bereavement support in EAPs typically involves providing employees and their immediate family members with access to licensed counselors or therapists who can offer guidance and assistance when dealing with grief and loss.[117] This may include counseling services, support groups, referrals to grief therapists or other support organizations, and crisis intervention for those suffering from a sudden or traumatic loss. Moreover, EAP policies could be strengthened by increasing the number of counseling sessions available, ensuring counselors have cultural humility and have specialized training in grief support, and partnering with community-based organizations to connect employees with affordable support.[117] While policies exist, none of the key contributors discussed these policies in their interviews.

By recognizing the emotional impact of losing a family member or close friend, bereavement leave contributes to improved employee well-being, reduced stress, employee retention, and an enhanced organizational reputation. Bereavement leave also helps in reducing presenteeism, where employees come to work but are not fully engaged or productive due to personal issues. By allowing employees the time they need to heal and recover, bereavement leave fosters a compassionate and supportive workplace culture, leading to increased employee satisfaction, loyalty, and overall organizational success.[118]

Key contributors in the study urged health systems to provide grief and bereavement support. The suggested health system policies encompass a continuum of services for bereavement support. In an informal conversation, a key contributor observed the dependency parents develop on health care providers and emphasized the importance of promoting continuity of engagement for bereaved parents at

cancer centers. Sudden changes like the loss of support from providers in the wake of a child's death can lead to feelings of abandonment. This has a particular impact on caregivers, who lose not only their loved ones but also their support network and community.

In an informal conversation, a contributor noted that the medicalization of the dying process has shifted death from a community-oriented experience to an institutionalized one, resulting in a loss of embedded support within families' communities. Grief-literate communities support individuals and families in the transition of dying at home rather than in a hospital setting and are often places where people confidently offer social support because they are knowledgeable about its importance and how to offer it to someone after a loss. These communities need to continue to support the families after the loved one is gone and emphasize attachment and ongoing support. Grief-literacy also helps those providing social support know how to identify when someone needs more support and connect them to more formal services if needed. Another suggestion for a vital health system policy is allocating adequate resources -- including sufficient staff -- to incentivize providers to better support people who are grieving. Despite the recognized importance of addressing grief and bereavement needs in hospitals and health care facilities, bereavement services are often underfunded and understaffed, making it challenging for these institutions to meet the needs of patients and their families effectively.

Furthermore, key contributors suggested several ways for insurers to improve the accessibility of grief services. Emphasizing the importance of preventive community-based efforts, one contributor proposed that insurers should reimburse care for bereavement support, regardless of a formal diagnosis. Some key contributors cautioned against involving profit-driven institutions and providers in these arrangements, particularly the growing number of for-profit hospice providers, where practitioners might lack the qualifications to differentiate between grief, trauma, and other mental health conditions and potentially over market and utilize services by pathologizing processes that would be considered more typical grieving. Instead, one interviewee suggested reimbursing community-based initiatives from faith-based organizations and grief centers.

Another contributor highlighted the significance of community-level control to prevent monopolization of bereavement services by insurance providers that may affect access to and quality of care for bereaved individuals. Issues with insurers were mentioned, including issues observed across behavioral health care more generally such as "ghost networks" where provider lists are out-of-date or inaccurate. For example, some of the phone numbers listed for providers were to McDonald's locations instead of medical facilities.[119] One study revealed that 51.8 percent of providers listed in Medicaid directories had no evidence in the claims data of having seen patients within the study period, with these ghost providers accounting for up to 90.3 percent of some coordinated care organization's provider lists.[119] Risks associated with ghost networks include limited access to care and inadequate provider choice due to the lack of providers within the network, thus leading bereaved individuals to stop seeking care.[119] This contributor noted the need for bereavement policies to be smart, protective, person-centered, and affirming for those seeking bereavement care. Exploring opportunities to enhance bereavement care through mechanisms such as federal CMS Section 1115 waivers was also suggested as part of the policy development process.

To ensure the well-being of those seeking bereavement care, one contributor stressed the importance of a protective and person-centered approach to designing any policy or system. Another contributor suggested that health insurance companies could be required to cover a certain number of grief sessions. The contributor also suggested foundations and other philanthropic organizations could establish more focused fundraising efforts and funding streams designed to support bereavement services for those

individuals who do not meet clinical criteria. Another contributor highlighted the need to recognize that younger, working-age people also require bereavement services and advocated that employer-sponsored insurance include bereavement care coverage (similar to life insurance benefits) to reduce absenteeism. However, increasing awareness of the need for and demand associated with bereavement services in the insurance industry remains a challenge. Overall, the study participants underscored the pivotal role insurers play in improving the access to grief services. Key contributors also highlighted the importance of reducing the administrative burden in accessing insurance benefits. For example, many bereaved children can access their parent's social security benefits, but two key contributors mentioned that more would benefit from doing so. Thus, although some bereavement supports exist to reduce burden, these systems are often inaccessible.

Several segments of the population, particularly vulnerable communities, may require more or different bereavement and grief services. It is crucial to understand and address the needs and perspectives of the most directly impacted individuals. For instance, the rates of juvenile incarceration and orphanhood[120] in Indigenous communities are noteworthy resulting in greater need for bereavement services. Historically marginalized populations and communities with higher rates of homicide or gun violence are also in greater need of bereavement support. Addressing coping mechanisms and challenges faced by families impacted by gun violence or drug-related deaths, given the stigmatization these populations often face and their risk of poor outcomes, was considered vital. One participant suggests that schools in areas with a higher concentration of violence and poverty could be targeted for bereavement and grief support. Addressing bereavement needs in these communities can be beneficial.

Additionally, the impact of child death on mid-life parents, typically between the ages of 35 and 50, may lead to a loss of productivity, necessitating services to help provide stability to bereaved mid-life parents. People with underlying mental health conditions and the potential complications in their grief process was underscored. Consideration should also be given to immunocompromised individuals and hospitalized psychiatric populations to provide appropriate support in the wake of the COVID-19 pandemic due to the isolation and grief they may be experiencing. First responders and front-line workers, such as health care workers, mortuary workers, or emergency responders, also face emotional challenges due to delivering life-saving services or witnessing traumatic events. A comprehensive approach recognizing the unique impact of adverse death events on anyone connected to them is essential.

Key contributors suggested the involvement of several key actors to elevate priority around national bereavement and grief policy. One idea would be the establishment of a government-wide office whose focus would be bereavement issues spanning multiple agencies that would coordinate efforts across the federal system. Establishing an intragovernmental approach is one way to address bereavement and grief support issues comprehensively and encourage greater collaboration.

Emphasizing the cross-cutting nature of bereavement, one participant advocates that the government, and specifically HHS, should play a leading role in addressing bereavement care across all agencies that impact community conditions. Adopting a "bereavement lens" can address unmet needs that contribute to outcomes like homelessness and incarceration. The conversation should include representation from groups providing clinical care, the military community, affected individuals, researchers, and hospice representatives to ensure a clear and significant voice in discussions.

Key contributors highlighted the importance of interdisciplinary representation in the discussion of bereavement and grief. In particular, they emphasized: (a) involving scientists and mental health providers; and (b) considering economic policies such as guaranteed time off or additional compensation

to support funerals. Representatives from various groups, including hospice, national organizations, and thought leaders in the field, should be included in the conversation. Furthermore, the need to address children's grief within family systems and diverse populations affected by COVID-19 is crucial to minimizing many significant avoidable negative health and other outcomes.

Moreover, participants emphasized that private equity firms and for-profit entities, like funeral homes and hospice, should be part of the solution in building a bereavement infrastructure. However, it is important to ensure access to and quality of care for these services to support bereaved individuals and that the services are appropriately offered to people who need them without pathologizing otherwise typical grieving patterns. Participants discussed the importance of collaboration between the for-profit entities to focus on helping bereaved and grieving individuals. While valuable opportunities may be offered, a comprehensive response to bereavement requires coordination at both federal and state levels, with potential policy responses at the federal level and opportunities for innovation at the private, state and local levels.

V. Limitations

A. Environmental Scan

The results of our environmental scan were subject to several limitations. Our search criteria and search terms may not have captured all relevant studies. The studies identified were published from 2013-2023, and we included two studies published in 1992 because they were either: (a) seminal literature; or (b) supplemented our knowledge on bereavement in hospice facilities given that research is limited in this area, however there may have been considerable changes regarding data accuracy during this time. The articles were limited to those in English and studies conducted in developed countries similar in composition to the United States, and those we could access. Although these search parameters helped focus the analysis, it is still possible that informative research was not included in the analysis.

Furthermore, due to the novelty of the COVID-19 pandemic, more research regarding long-term physical and mental health effects of the pandemic on grief and bereavement is necessary. While some health outcomes related to COVID-19 infections have been studied over the last three years, there are still significant gaps in the research on the virus, health outcomes, and effective services. Future research may have more definitive answers regarding the long-term effects of the pandemic.

B. Key Contributor Interviews

We were only able to formally interview nine individuals, which may have limited the breadth of the insights that we were able to obtain from our key contributors.

VI. Conclusion

The impacts of the COVID-19 pandemic and the SUD and opioid crises -- as well as the high prevalence of suicidal behaviors and suicidal ideation -- have each underscored the burden of bereavement and grief on the nation. Each pandemic and epidemic listed has unique characteristics; however, this report reveals that there are shared equity implications to be considered when creating and implementing bereavement and grief services related policy. The current state of bereavement and support services was characterized by key contributors as lacking, inaccessible, and fragmented; however supports do exist. Individuals that require bereavement and grief services can access a variety of supports including psychotherapeutic interventions, especially those grounded in CBT and CBT variations, psychotherapy, social support, spiritual support, hospice, and other interventions such as bereavement camps, music and art therapy, and care farming.

There is large variation in the utilization rates of bereavement services in the country. Individual factors that may explain the variation include cultural and societal norms around grief and the willingness to seek professional help, lack of awareness of services, financial constraints, stigma associated with seeking support, lack of time, transportation issues, culturally appropriate treatment, and SDOH. Two potential ways to identify populations at greater risk for PGD are via health care providers and social media. Health care providers in hospice could screen caregivers for PGD and CG. Health systems could use social media to identify signs of elevated traumatic grief, and targeted interventions could be deployed by providers and or health systems.

This report offers key insights and recommendations around expanding access to bereavement services in the United States. To implement policies that support bereaved individuals, policymakers should consider how bereavement intersects with health systems, government and workplace policies, and economic support. Policies could include economic approaches that would guarantee time off or compensation for funerals, housing and food support, as well as reimbursement for bereavement services regardless of formal diagnosis. Key contributors to this study emphasized the importance of having a diverse group of key actors that could help address the issues discussed in this report. Lastly, targeted interventions for populations experiencing higher rates of -- and more severe -- grief events are imperative to improving health equity.

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Appendix A. Key Questions and Corresponding Literature

For each key question, **Table A.1** lists the corresponding article number as listed in **Appendix B**.

Table A.1. Key Questions and Corresponding Articles

Key Questions	Corresponding Article Numbers
What is the typical grieving process, and what services can support people experiencing grief and loss? How are these services typically accessed?	3, 8, 12, 24, 25, 26, 28, 30, 35, 36, 37, 38, 41, 42, 44, 46, 47, 48, 49, 51, 52, 54, 55, 56, 57, 58, 59, 60, 61, 63, 64, 70, 71, 76, 77, 82, 96
To what extent have the crises of COVID-19, violence, suicide, and increased mortality associated with substance use resulted in increased needs for bereavement care and grief support?	3, 26, 30, 35, 36, 40, 42, 44, 48, 49, 50, 54, 55, 57, 59, 65, 66, 67, 69, 70, 73, 90, 91, 93, 100
Given bereavement has a strong cultural element, how broadly are these impacts shared by the US population and are certain groups experiencing greater need?	8, 40, 44, 55, 99
To what extent have the current crises resulted in grief that has persisted, resulting in impaired functioning and disorders such as depression, post-traumatic stress, and prolonged grief?	35, 61, 68, 72
To what extent is there a need for support for health care workers and other highly impacted populations?	3, 8, 11, 12, 25, 26, 28, 35, 36, 37, 38, 40, 41, 42, 44, 48, 49, 51, 54, 57, 58, 59, 61, 62, 63, 64, 65, 66, 69, 70, 73, 74, 77, 93
To what extent are bereavement and grief support services being utilized and is there evidence indicating that these services are effective? Are there differences among groups?	12, 25, 28, 36, 37, 38, 46, 47, 51, 52, 53, 56, 59, 60, 63, 64, 70, 71, 76, 77, 99
How can the health care system be improved to be more trauma-informed to provide a more functional context for grief and bereavement services?	30, 35, 36, 44, 47, 51, 86
What role does hospice currently play in supporting people who are grieving and what services might they provide to support community need more broadly?	8, 11, 25, 28, 64, 75, 76, 77, 89, 95

Source: Mathematica analysis of key questions with corresponding articles.

Appendix B. Abstraction Tool

Please see “BRTC Abstraction Tool-6-19.xlsx,” the abstraction tool, an excel document that accompanies this summary report which outlines each of the pieces of literature included in this environmental scan.

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