BECOMING GRIEF-INFORMED: A CALL TO ACTION

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Dougy Center: The National Grief Center
for Children & Families

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Introduction

Is grief a mental condition which needs to be assessed, diagnosed, and treated? Or is grief a universal, normal experience that is adaptive and nonpathological, interwoven in a sociocultural context, influenced by family, community, and other social systems? The current hegemony of grief in the field of thanatology[1] in America overly defines grief as an individual problem needing treatment rather than a response to loss that is inextricably interwoven in sociocultural and historical contexts. Attempts to understand and categorize the human experience of grief have been influenced by misassumptions such as: (i) there are universal standards in how we respond to loss, (ii) "normative" responses are best defined by stages, phases, or tasks the griever ought to attend to, and (iii) deviance from "mainstream" standards results in pathology such as "complicated grief" or "prolonged grief disorder" which must be diagnosed and treated by professionals. This hegemony over grief has paid credence to an ethnocentric model, resulting in a "dominant" narrative that has failed to adequately account for and include the sociocultural context of being human. In this paper, we challenge the "dominant" discourse of what it means "to grieve" and how to "grieve correctly," extending a call to action for the resurgence of understanding grief in its normal and natural state. The lack of grief education and diverse ethnic representation among helping professionals further perpetuate institutional and societal policies and practices which fail to address the fundamental and unique needs of people who are grieving. We argue for the need to deconstruct the hegemony of grief in the field of thanatology and propose core principles and tenets of becoming grief-informed based on human welfare, humanistic values, social justice, and the dignity and worth of every person.

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[1]Thanatology is "the description or study of the phenomena of death and of psychological mechanisms for coping with them." (Thanatology, n.d.).

The Hegemony of Grief in "Mainstream" American Society: Historical and Cultural Shifts in Responding to Death

A Historical Understanding of Grief in the United States

To set a context for our argument, we begin by highlighting a few important examples about how "mainstream" beliefs and assumptions in American society have resulted in significant shifts in how American society views and responds to death. One such shift relates to the practices associated with caring for and tending to the deceased. Although most modern Western funeral practices utilize the services of funeral homes for preparation and disposition of a body, in the past, the tending to and care of the deceased was traditionally done by family and friends (Brennan, 2014). Tradespeople, known as "undertakers," generally built caskets and supplied materials for funerals (e.g. clothing, announcements, and candles). The deceased was laid out in their home's 'parlor,' or formal front room, and relatives, friends, and members of the community paid their respects by viewing the deceased and mourning with the family. Grieving and mourning were shared social events, and at the turn of the century in 1900, as many as 80% of deaths in the United States occurred at home (Corr, Corr, & Doka, 2019). By comparison, in 2014, more than 64% of people who died in the U.S. died in a hospital, long-term care facility, or hospice (Corr et al., 2019).

> The communal experience shifted to the purview of professionals, ultimately altering the intimate personal experience of coping with death and loss.

In the latter 1880s, the trade industry of "undertakers" expanded as they took on increasing roles in attending to the preparation and disposition of the body, moving from "undertakers" to "morticians" and "funeral directors." (Despelder & Strickland, 2020). Thus, the business of funeral "parlors" began to replace the home's formal front room "parlor." People became more distanced from death as many of the routines and rituals at the end of life shifted from the family's role to outsiders, and fewer people died at home. The communal experience shifted to the purview of professionals, ultimately altering the intimate personal experience of coping with death and loss.

With the advent of psychology and psychiatry as disciplines, which trace their origins to

Wilhelm Maximilian Wundt and Sigmund Freud respectively, the internal experience of an individual's grief began to gain prominence over the communal experience. Freud proposed in his essay *Mourning and Melancholia* (1917/1963) that the task of the mourner was to sever emotional attachments to the deceased. This has often been interpreted to mean that failing to do this work could result in a psychiatric illness (Granek, 2010). This is ironic because Freud clearly stated that he did not support pathologizing grief (Freud, 1917/1963).

The path to pathologizing grief widened as Freud's colleague, the Polish-American Psychoanalyst Helene Deutsch (1884-1982) articulated the conceptualization of grief as pathology in her essay *The Absence of Grief*: "It is well recognized that the work of mourning does not always follow a normal course. It may be excessively intense, even violent, or the process may be unduly prolonged to the point of chronicity when the clinical picture suggests melancholia." (Deutsch, 1937, p. 12). We want to draw special attention to her language here, especially noting the words "prolonged" ("continuing for a notably long time: extended in duration") and "chronicity" ("continuing or occurring again and again for a long time") as these terms re-emerged over 60 years later in more modern efforts to pathologize grief ("Chronicity," n.d..; "Prolonged," n.d.) It is important to note that Deutsch does not offer any basis or citations in her statement that "it is well recognized," other than her own opinion.

The shift and movement to view grief through a Western medical lens as a pathology needing diagnosis and professional treatment accelerated through the initial work and writing of German-American psychiatrist Erich Lindemann (1900-1974). Lindemann diagnosed and treated survivors and bereft family members from the 1942 Cocoanut Grove nightclub fire which killed 492 people. He diagnosed them as suffering from a "syndrome" of "acute grief" and, after his 12-week treatment, asserted that they would attain "a normal grief reaction with resolution." (Lindemann, 1944, p. 141). However, as he worked with WWII soldiers diagnosed with "battle fatigue," it became evident to him that taking soldiers away from their platoons for treatment increased their isolation and grief, and he concluded they were more likely to recover if their treatment occurred on site and/or if they were told they would be returned to their platoon as soon as possible (Rosenfeld, 2018). He moved from his previous focus on the pathology of the individual to a wider recognition of the social needs and social context of persons experiencing loss and grief.

Years later at Harvard, Lindemann expanded beyond psychiatry and integrated anthropology, sociology, and social psychology into mental health education and research, for which he received criticism from many in the psychiatric community.[2] (Rosenfeld,

[2] David G. Satin, a student of Lindemann's who went on to teach psychiatry at Harvard Medical School, characterized the criticism Lindemann received in this way: "People began to disapprove of this expansion. They felt he was getting into things that were not psychiatric, that were not medical. That were getting into fields that were politics, that were sociology, and physicians should stay out of that…And when he involved non-medical people, in psychology, anthropology, sociology… the medical people were just outraged — letting all these non-medical people into our citadel, and polluting the purity of medicine."

2018). He dedicated the rest of his career to community psychiatry (Fried & Lindemann, 1961). When 3,000 residents were evicted from Boston's West End to build high-rises, he and others studied how the mass eviction impacted families. During this time, community support was essential for individuals who were grieving because grief was occurring at the community level, and people needed their community to "recover." (Rosenfeld, 2018). This was the foundation of the movement called Community Mental Health, and in 1948 Lindemann founded the nation's first community mental health center. Lindemann's shift is important in two ways: First, he recognized the limitations of looking at grief only through the lens of one discipline, in his case, psychiatry, and he incorporated the evidence from multiple disciplines into his practice. Second, he saw the value and importance of working with people within their full context, not just through evaluating an individual's mental state.

The "dominant" narrative. The examples above are but a few of the significant influences on how grief has been conceptualized and addressed in America. It would be remiss of us not to acknowledge that our recollection of the historical understanding of grief is recounted through the lens of accounts dominated by Eurocentric/white narratives and worldviews. Much of what has been written in textbooks and articles throughout the history of thanatology fails to appropriately and adequately incorporate the narratives of grief from individuals and communities of various ethnicities, beliefs, genders, socioeconomic statuses, and other attributes which make people diverse, unique, and worthy of inclusion. The awareness of these limitations compel us to challenge the existing norms and standards set in "mainstream" American society regarding grief, what it means to grieve, "abnormal" responses to grief, and the hegemony of the biomedical model on people who are grieving.

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Grief in Contemporary American Society and Policy

Our look at how grief is viewed and responded to in contemporary American society involves unpacking the dominant societal assumptions which dictate how people should grieve in "mainstream" American culture. These attitudes and ideas are "normed" by convention and encapsulated by social context and policies. Although the range of examples could generate an article on its own, we have chosen to look at three areas in which these norms influence and impact people who are grieving in the United States: inequities in the health care system; inequitable and culturally irrelevant access to mental health care; and federal and employer policies related to bereavement leave and care.

Inequities in the health care system. The health care system in the United States is largely composed of health care providers who are white. This lack of diverse ethnic representation is extremely problematic; our society, which consists of people of various cultures and ethnicities, should consist of care providers who can be attuned to the physical, psychological, emotional, social, and cultural needs of the individuals they serve (Hardy-Bougere, 2008).

This gap becomes even more problematic when we look at the glaring contrasts in morbidity and mortality rates between African Americans[3] and white Americans, for example, in life expectancy, infant mortality, heart disease, and other measures of health. These disparities have been consistent throughout U.S. history, despite occasional strides toward equitable progress. Factors such as racial discrimination, cultural barriers, and inadequate access to health care contribute to these disparities. Because of the homogeneous makeup of the American health care system, its oppressive history on African Americans (i.e., The Tuskegee Experiment), and the ongoing presence of structural and institutional racism, many African Americans are not trusting of the "mainstream" power structure, and rightfully so, which has not focused on or attended to their fundamental needs (Brennan, 2014; Hardy-Bougere, 2008).

In addition to higher mortality rates from disease, consider these disparities in other modes of death: Black Americans are eight times more likely to die by homicide than white Americans (Silver, 2015). Young Black men are five times more likely to be killed by police than young white men. A study in 2015 indicated that Black people were killed at twice the rate of white, Hispanic, and Native American peoples (Swaine, Laughland, Lartey, & McCarthy, 2015). Clearly, the combined systemic issues of racism, lack of equal access to quality health care, the lack of trust in the medical system, and other social issues prohibit equitable access to quality medical care as well as quality end-of-life care.

[3]Being person-centered involves acknowledging and recognizing that labels can be limiting, restrictive, and misrepresentative. Each person is unique and should be empowered to identify if and how they want their identity categorized. Because our sources for this article are written texts and not written by the individuals themselves, we are utilizing the identity categories stated by the authors of the resources being cited to reflect the language presented by the authors.

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Inequitable and culturally irrelevant access to mental health care. When it comes to equitable and culturally relevant access to mental health care in the U.S., the reality is no better than access to physical health care. For example, in 2018, 84% of psychologists identified as white, 5% as Hispanic, 4% as Black/African American, 4% as Asian, and 2% identified with other races/ethnicities (American Psychological Association, 2018). In the 2017 Medscape Psychiatrist Lifestyle Survey, American psychiatrists identified their ethnicity as white (69%), Asian Indian (9%), Hispanic/Latino (7%), Black/African American (3%), Chinese (3%), Other Asian (2%), Filipino (2%), Korean (1%), Japanese (1%), and Vietnamese (0.3%) (Peckham & Grisham, 2017). Numerous issues contribute to these numbers, including systemic racism which establishes and perpetuates multiple systems and structures of injustice in American society. As one example, the Black Psychiatrists of America (BPA), formed in 1969, was founded due to "The struggles, social conditions of Black Americans, professional experiences, and the barriers faced by black psychiatrists... The founders of the BPA understood the importance of moving progressively to ensure the emotional and psychological development of African Americans, affording them the tools to cope and succeed in the face of persistent racism." (Black Psychiatrists of America, 2020). Rosenblatt & Wallace (2005) stress the need for society to pay attention to the racial struggles and complexity embedded in the grief of African Americans. Their study demonstrates how the racism experienced during the life of the deceased or the racism which contributed to a person's death (which was the case for more than half of those interviewed) can evoke feelings of anger and frustration due to the injustices and atrocities experienced by African Americans. These injustices were further evidenced in 2020 after the killings of Breonna Taylor, Ahmaud Arbery, and George Floyd, among the growing number of African Americans who died by the hands of the police; re-emphasizing society's need to prioritize the Black Lives Matter movement across the U.S. and beyond.

Federal and corporate policies on bereavement leave. Another area in contemporary American society where disparity and inequity exist is in federal, state, and agency policies regarding bereavement leave. On the federal level, there are currently no nationwide laws that require employers to provide employees either paid or unpaid

leave after a death. The U.S. Department of Labor states that "the Fair Labor Standards Act (FLSA) does not require payment for time not worked, including attending a funeral. This type of benefit is generally a matter of agreement between an employer and an employee (or the employee's representative)." (U.S. Department of Labor, 2020). It is noteworthy that this policy is listed under the heading "Funeral Leave," not "Bereavement Leave," as it is defined in most employment policies.

On the state level, Oregon is currently the only state that requires employers with more than 25 employees to offer bereavement leave for the death of a family member within 60 days of the death, through their Family Leave Act of January 1, 2014 (Oregon Bureau of Labor & Industries, 2020; State of Oregon, 2019). In Illinois, the Child Bereavement Leave Act became law on July 29, 2016, requiring companies that employ 50 or more employees up to 10 days of unpaid leave, but only after the death of a child (Illinois Department of Labor, 2020). The other 49 states, plus the District of Columbia, do not require employers to provide employees either paid or unpaid bereavement leave (The Lunt Group, 2020).

On the corporate level, a survey by the Society for Human Resource Management indicated that 89% of respondent companies provide paid bereavement leave to full-time employees. The average length of leave was four days for the death of a spouse or child; three days for the death of a same-sex or opposite-sex domestic partner, child in foster care, grandchild, parent, sibling,

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or grandparent; two days for a death from miscarriage, or the death of a relative of a spouse or relative of a same-sex domestic partner; and zero days of leave after the death of a friend or colleague (Society for Human Resource Management, 2019).

These policies create a structure regarding "eligible" and "ineligible" losses which are "acceptable" or "unacceptable" for approval to grieve. In other words, bereavement leave is only afforded to those who have had a certain type of loss, a certain type of relationship, and a certain duration of time to grieve. Non-death losses like divorce do not qualify. Many agencies grant bereavement leave to an employee only when someone in their "immediate family" dies (e.g. a spouse or a child). Consider how these policies create inequities for people and communities who define "immediate family" differently (e.g. people whose "immediate family" are aunts, uncles, grandparents, cousins, other relatives, pets, and/or people other than biological kin) and for the many other diverse family structures that exist in American society.

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Obviously, there are inequities, power imbalances, and oppressive and racist structures that are being perpetuated by and within our political systems, health care systems, employment systems, and social systems. We need to consider how the dominant beliefs about death, loss, and bereavement further shape and oppress people, cultures, and communities whose narratives are not being included in the decisions which dictate how grief will be addressed by society.

Medicalizing and Pathologizing Grief

Before taking a brief look at the history of how grief became pathologized and medicalized, it is worth noting how the social construction of pathologies are devised:

> Someone observes a pattern of behaving, thinking, feeling, or desiring that deviates from some social norm or ideal or identifies a human weakness or imperfection that, as expected, is displayed with greater frequency or severity by some people than others. A group with influence and power decides that control, prevention, or 'treatment' of this problem is desirable or profitable.... The new disorder then takes on an existence of its own and becomes a disease-like entity. As news about 'it' spreads, people begin thinking they have 'it'; medical and mental health professionals begin diagnosing and treating 'it'; and clinicians and clients begin demanding that health insurance policies cover the 'treatment' of 'it'. Once the 'disorder' has been socially constructed and defined, the methods of science can be employed to study it, but the construction itself is a social process, not a scientific one. In fact, the more 'it' is studied, the more everyone becomes convinced that 'it' really is 'something.' (Maddux, 2008, p. 62)

German psychiatrist Emil Kraepelin (1856-1926) influenced the field of psychiatry in ways which still reverberate today (Engstrom & Kendler, 2015). The influence most relevant to medicalizing and pathologizing grief was his attempt to classify mental disorders into common patterns, which was in opposition to the leading theories of his time. To be "Kraepelin" meant to operate from a medical model rather than a biopsychosocial model (Shorter, 1997). His drive to find new ways to classify illness built the foundation for the

development of the Diagnostic and Statistical Manual of Mental Disorders (DSM), published by the American Psychiatric Association (APA). Both the DSM and the International Classification of Diseases (ICD), published by the World Health Organization, "still rely on Kraepelin's concept." (Ebert & Bar, 2010, p.191).

International Classification of Diseases (ICD). The ICD is a document which is used by more than 100 countries to classify diseases and to report mortality data, a primary indicator of health status. About 70% of the world's health expenditures, an estimated $3.5 trillion in the U.S., are allocated using the ICD, and it is increasingly used in both clinical care and research (World Health Organization, n.d.).

The ICD-11 includes a new disorder category, *Prolonged Grief Disorder* (PGD), and describes the responses which characterize the disturbance for PGD (World Health Organization, 2018). These responses include preoccupation with or longing for the deceased accompanied by intense emotional pain, difficulty accepting the death, and feeling like a part of one's self has been lost (World Health Organization, n.d.). Although the need to attend to variations in social, cultural, and religious norms in terms of the duration of symptoms is acknowledged and a minimum of 6 months prior to eligibility for diagnosis is suggested, Killikelly and Maercker (2018) point out that the length of time post-death for distinguishing PGD from "normal" bereavement has not been scientifically validated. We argue that PGD, as well as the post-death time-point for diagnostic consideration, are social constructs which have not been and cannot be scientifically validated, nor can any of the hundreds of "mental disorders" listed in the APA's DSM-5 be scientifically validated.

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Bereavement and the DSM. In 1952, the first Diagnostic & Statistical Manual of Mental Disorders (DSM-I) was published by the American Psychiatric Association, with 106 mental disorders, 86 pages in length. DSM-II followed in 1968 and was referred to more as an update than an overhaul. In 1980 when DSM-III was published, it had grown to include 265 mental disorders, and was 400 pages in length. "Uncomplicated Bereavement" was added as a V-code, a clinical condition that was not considered a mental disorder. The DSM also included a "bereavement exclusion" for Major Depressive Episode (MDE), stating that "'uncomplicated bereavement' can be

used when a focus of attention of treatment is a normal reaction to the death of a loved one. A full depressive syndrome is a normal reaction to such a loss, with feelings of depression and such associated symptoms as poor appetite, weight loss and insomnia." (p.333). It added that "the duration of normal bereavement varies considerably among different subcultural groups."

In 1993, the first diagnostic criteria for a bereavement-related disorder was developed, termed 'pathological' then 'complicated' grief (CG) (Horowitz, Bonanno, & Holen, 1993; Horowitz et al., 1997). "Disordered grief" was originally conceptualized as a reaction to a stressful life event. Research in the field accelerated and over the following years various groups have used differing terminology to describe this "mental disorder," including pathological, complicated, traumatic, prolonged, chronic, or morbid grief (Wagner & Maercker, 2010).

The movement to consider including a "mental disorder" related to grief in the DSM accelerated in the mid-to-late '90s. Two conceptualizations of grief as a mental disorder developed over the ensuing years: "Complicated Grief" (CG) and "Prolonged Grief Disorder" (PGD). The main differences between the two were that CG emphasized the depth of symptoms and when "normal" symptoms of grief become complicated, whereas PGD emphasized that the length of time for grief could be problematic and that not all symptoms of grief are "normal."(Maciejewski, Maercker, Boelen, & Prigerson, 2016). Prior to the publication of DSM-5 in 2013, the American Psychiatric

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Association provided a public comment period for various proposed new mental disorders, including "Prolonged Grief Disorder." After review, both PGD and CG were deemed to have "clear merit but ultimately were judged to need further research before they might be considered as formal disorders." Instead, a hybrid compromise named "Persistent Complex Bereavement Disorder (PCBD)" was placed into the DSM-5's "Conditions for Further Study." (APA, 2013). More recently, a new proposal was submitted to the DSM-5 Steering Committee to modify the criteria for PCBD and create a new formal DSM diagnosis of "Prolonged Grief Disorder." As with the previous proposed bereavement-related mental disorder diagnoses, the criteria proposed for PGD establish that grief adheres to a specified timeline (i.e., grief that lasts longer than 12 months is problematic), should be finite (i.e., grief that is characterized by yearning/longing for the deceased for long periods of time is "abnormal'), and that expressions of grief are primarily a result of mental conditions occurring within, and as a result of, an individual, with only passing mention of the normative expressions of grief in various socio-

cultural contexts[4] (APA, 2020). The criteria regarding duration of grief may wrongly and ethnocentrically impose a "standard" of what is "normal" for grief on cultures and societies that do not align with these views. For example, some cultures endorse the practice of grieving socially, publicly, and personally beyond a year after a death (Rosenblatt, 2017). Therefore, is it possible that these standards may actually contribute to bereaved people experiencing more distress and impairment in social functioning? Is it not feasible that social and political conditions themselves cause or contribute to what are being labeled "mental disorders?"

Another relevant change in the DSM-5 included an expanded definition of a mental disorder, as "a syndrome characterized by clinically significant disturbance in an individual's cognition, emotional regulation, or behavior that reflects a dysfunction in the psychological, biological, or developmental processes underlying mental functioning. Mental disorders are usually associated with significant distress in social, occupational, or other important activities." We invite the reader to consider their use of the term "associated with" and counter-propose that the social and occupational distress experienced by people who are grieving may be perpetuated by social conditions which contribute to alienation and

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estrangement, including unsupportive cultural norms and employment policies. Furthermore, there is also the possibility that "diagnosing" a person from any community who has experienced oppression, discrimination, and/or marginalization with a "mental disorder" could further the mistrust which already exists between health care provider "experts" and communities who have historically been, and currently are, marginalized and oppressed.

[4] Although the criteria observe that the "duration of the bereavement reaction" may vary from culture to culture, there are no criteria that acknowledge how peoples' experiences of bereavement are impacted by and will vary based on the sociocultural contexts in which they interact.

Grief Education and Training, or Lack Thereof

All individuals, regardless of age, ethnicity, ability, gender, culture, and sexual orientation, will experience loss. Considering that death and loss are inevitable, it is disconcerting that most helping professionals are not grief-informed. An extensive review of grief-related training worldwide for medical students, residents, and practicing physicians in psychiatry, pediatrics, and family medicine reported there is "a curious lack of training for physicians about what grief is and how it might impact patient care and their own well-being." (Sikstrom et al., 2019, p. 12). In a study of 369 counselors, most reported they had not received adequate training on grief (Ober, Haag Granello, & Wheaton, 2012). When 161 counselors from the American Counseling Association were surveyed, 84% reported that their graduate education did not include a single course on loss and grief (Doughty Horn, Crews, & Harrawood, 2013). Unfortunately, because the Council for Accreditation of Counseling and Related Educational Programs (2016) and the Educational Policy and Accreditation Standards for Baccalaureate and Master's Social Work Programs (2015)[5] make no mention of loss or grief in their requirements for accreditation in either profession, it is apparent we still have a long way to go before helping professionals trained in the United States are grief-informed.

Psychiatrists and other physicians, counselors, and social workers are not the only professionals who are lacking training in grief education. A study by the American Federation of Teachers and New York Life Foundation (2012) reported that only 7% of classroom teachers ever received training in grief education, less than 5% of schools and districts offered any grief training, and only 1% of teachers received training on bereavement during their undergraduate or graduate studies.

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With more than 4.9 million youth who are bereaved in the United States and 1 out of 14 children experiencing the death of a parent or sibling before the age of 18 (Judi's House, 2020), there is a clear need for clinicians and educators to be grief-informed. And these statistics only capture children who are bereaved; they do not account for all the adults in the United States who experience the death of a friend, a partner, a parent, a child, and all the other death and non-death losses that consume the everyday lives of millions of people. Furthermore, being grief-informed is not just limited to the United States. Of the nearly 8 billion people in the world, every one of us will experience loss and death. Clearly, there is a need for our helping professionals to become grief-informed.

[5] It is worth noting that the Educational Policy and Accreditation Standards for Baccalaureate and Master's Social Work Programs (2015) also made no mention of the term "trauma" or "trauma-informed" anywhere in the standards.

Grief-Informed and Trauma-Informed

Although there is overlap between being grief-informed and being trauma-informed, they are not one and the same. Traumatologists (professionals who study and counsel people who are exposed to highly stressful and traumatic events) have done an excellent job explaining and developing trauma-informed principles and practices. Unfortunately, thanatologists (professionals who specialize in the topics of dying, death, loss and grief, and bereavement) have not made as much progress in this area.

There are overlaps in trauma-informed and grief-informed approaches. Both approaches acknowledge that the person experiencing trauma and/or grief is embedded within a sociocultural context in which the trauma or loss has taken place. A trauma-informed approach acknowledges this by asking, "What happened to you?" (i.e. the problem happened to the person) rather than "What is wrong with you?" (i.e. the problem is the person). Similarly, grief-informed approaches recognize the inevitability of loss, and the individuality of each loss relative to the relationship and circumstances surrounding it. By acknowledging that grief is both individual and interwoven into a sociocultural context, a grief-informed response states, "Grief is complex. You are having a normal response to a complex situation." (i.e. the situation/problem happened to the person) instead of, "You are having an abnormal (disordered/complicated) response to a normal situation." (i.e. the problem is the person).

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A central component of a trauma-informed model and a grief-informed model is the emphasis on acknowledging events as person-centered. Trauma-informed models are grounded in a strengths-based framework, focus on the physical, psychological, and emotional safety of the individual, and promote capacity building for personal control and empowerment (Hopper et al., 2010); a humanistic grief-informed model shares this grounding, focus, and promotion. Both models emphasize that people's experiences and perceptions of events are subjective and unique to each person. It is interesting, then, to consider how the focus shifted from viewing trauma and grief as person-centered (subjectively-defined) to incident-centered (objectively-defined) when the terms "trauma" and "death, loss, and bereavement" were compounded and introduced as theoretical constructs in the field of thanatology.

Terms such as "traumatic death," "traumatic loss," and "traumatic bereavement" are interwoven throughout thanatological

> There are overlaps in trauma-informed and grief-informed approaches. Both approaches acknowledge that the person experiencing trauma and/or grief is embedded within a sociocultural context in which the trauma or loss has taken place.

literature and often deviate from the person-centered approach of a trauma-informed and grief-informed lens. The term "traumatic death" has been customarily associated with a loss that was preventable, premature, or catastrophically horrific.[6] Therefore, this definition moves away from being person-centered by asserting that an incident, in and of itself, is traumatic. Schuurman & DeCristofaro (2010) caution us to be more discerning and recognize that it is the individual's perception of a loss, and not the nature of the loss itself, that lends itself to whether a loss is "traumatic." Other studies have further emphasized that events, in and of themselves, are not interpreted uniformly by all people. Rather, individuals engage in a transactional process whereby events are appraised in relation to their potential to benefit or threaten personal well-being (Lazarus & Folkman, 1984). Events, in and of themselves, are not traumatic or ambiguous; it is an individual's subjective interpretation of an event in relation to their personal well-being which determines the nature of the event (Mitchell, 2010). Furthermore, the Substance Abuse and Mental Health Services Administration (SAMHSA, 2014) also regards trauma as subjectively-identified. SAMHSA (2014) states "Individual trauma results from an event, series of events, or set of circumstances experienced by an individual as physically or emotionally harmful or life-threatening with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being." (p.7). In other words, similar to Schuurman & DeCristofaro (2010) and Mitchell & Kuczynski (2010), SAMHSA advises that an individual must experience an event, series of events, or set of circumstances as harmful or life-threatening before identifying it as "traumatic." By identifying specific criteria for "traumatic deaths" or "traumatic losses" and stating that some deaths and losses are inherently "traumatic" whereas others are not, we disregard the dignity and worth of each human being's experience of loss and their perception of what is traumatic to them.

[6] We note that the criteria for identifying or labeling grief as "traumatic", again, has been informed by the dominant narrative of a largely monoethnic perspective which requires further scrutiny and consideration, as does all and any of the existing criteria for types of grief that are considered to be pathological or "abnormal."

The Core Principles and Tenets of Grief-Informed Practice[7]

It is critical to recognize that how "mainstream" society understands grief will have a direct impact on how we address grief in our policies and practices, and vice versa. Everything we have discussed in this article sets a foundation for why an alternate paradigm of grief is needed for society. In this section, we address some of the common misassumptions that perpetuate the hegemony of grief in American society, the challenges they portend, and the injustices and inequities they perpetuate. We propose ten core principles and tenets of grief-informed practice which are based on the core values of human welfare, humanistic values, social justice, and the dignity and worth of every person.[8]

> It is critical to recognize that how 'mainstream' society understands grief will have a direct impact on how we address grief in our policies and practices, and vice versa.



Natural

Loss is a normal, inevitable, and universal human experience. To be human means that loss will occur. Grief is a natural response to loss. All people, regardless of nationality, ethnicity, gender, sexual orientation, and socioeconomic status will experience loss and grief.

People have an innate capacity to adapt to loss and function healthily. Since the beginning of humanity, well before pharmaceuticals and the "mental health" profession, human beings have been exposed to loss. The misassumption that grief is a mental condition that may require medication to "correct" or "order" one's grief is imposed by American ethnocentrism. As history, culture, and lived experience have shown us, people have an innate capacity to adapt to loss without medical interventions, especially when they have the relational and sociocultural support they need.

[7] These principles and tenets also inform the Dougy Center Model, originated by Dougy Center, the first children's bereavement center in the United States, which has been used to train over 500 sites worldwide since 1982.

[8] This paper proposes an alternate paradigm to the bio-medical model of grief and introduces ten core principles and tenets to provide a philosophical foundation to becoming grief-informed. The application of these principles and tenets in practice is beyond the scope of this paper.



Nonpathological & Complex

Grief is an adaptive, nonpathological response to loss. A common misassumption is that grief can be pathological. As discussed earlier in this paper, this misassumption is based on criteria which determine when grief should be labeled as a mental disorder. For example, what the dominant "narrative" identifies as pathological or deviant responses to grief may be completely normal reactions to grief, especially for people who have had to endure historical trauma and injustices throughout American history. And, to that, we are deeply concerned with how pathologizing grief will further marginalize already marginalized populations by creating even more labels, stereotypes, and barriers for individuals and communities to overcome.

Contrary to the bio-medical model of grief, in our model, expressions of grief are not considered "symptoms" of pathology, but rather, attempts to cope with distressing life circumstances. Adapting to the many changes that occur after a loss should not be viewed as pathological (Jacobs & Cohen, 2010). The changes and accommodations to loss vary by individual and cannot be assessed by checking off a list of symptoms as proposed by the Western medical model of pathology. This tenet should not be misconstrued to imply that people who are grieving never need or cannot benefit from professional help. Rather, it advocates for trained therapists and counselors to assist bereaved individuals holistically in the full context of their unique loss circumstances, without the need to diagnose them with a "mental disorder".

"Contrary to the bio-medical model of grief, in our model, expressions of grief are not considered 'symptoms' of pathology, but rather, attempts to cope with distressing life circumstances."

Grief is complex and complicated because people and relationships are complex and complicated. A common misassumption is that certain experiences and expressions of grief should be categorized as "complicated." There are numerous reasons why categorizing certain expressions of grief as "complicated" is problematic, and we, as well as others, have elaborated on these reasons in other publications (Schuurman, 2017; Schuurman, 2018; Frances, 2013; Granek, 2010).

The most basic reason for this conundrum is the fact that grief, in and of itself, is complicated because human beings are complicated, and relationships are complex. We have yet to meet an individual who is bereaved who says grieving is easy, simple, or uncomplicated. In fact, from the more than 55,000 children and their families that have been served by Dougy Center since 1982, it is far more common to hear statements such as: "This is hard." "This is unreal and confusing." "This is complex." To state that

some grief is "complicated" while other grief is "uncomplicated" contradicts the lived experience of the thousands of children and families we, and others, have served.



Contextual

Grief is not solely an individual experience; grief is interwoven in a sociocultural context, influenced by family, community, and other social systems. Grief does not occur in a vacuum; we are interconnected in local and global community. As human beings, we are embedded within individual, social, cultural, spiritual, and political contexts that shape who we are (Bradford, 2007; Jacobs & Cohen, 2010). Similarly, how people express their grief (which some refer to as "mourning") is impacted by the community and society in which they live. As we have learned from the thousands of children and families we have served at Dougy Center, how one's family, community, and other social systems to which they belong or are a part of respond can have positive and/or negative impacts. These responses can assist or hinder how a person copes with loss and subsequent grief. Therefore, it is not simply the individual who determines their coping response; an individual's sociocultural environment, and the people within that environment, contribute significantly to how a person copes with loss. The DSM diagnostic model is reductionistic, reducing grief to a list of symptoms qualifying as "mental disorders" that exist "within the individual." (Bradford, 2007; Jacobs & Cohen, 2010). American "mainstream" norms fail to account for the various contextual factors which shape and impact their lives.

"The DSM diagnostic model is reductionistic, reducing grief to a list of symptoms qualifying as "mental disorders" that exist "within the individual." (Bradford, 2007; Jacobs & Cohen, 2010).

Acknowledging and addressing the sociocultural and historical factors that impact grief can reduce disparities and promote equity and inclusion. "Grief is not a universal process with typical symptoms. There are a wide range of individual and cultural differences in the way people grieve. What is normal in one culture may be quite aberrant in another." (Connor, 2009, p.88). Individuals' expressions of grief are further nuanced by issues of privilege, language, social norms, and expectations. As highlighted throughout this paper, the systemic and institutional racism and ethnocentrism that continue to dominate and influence the contemporary practices and beliefs that impact grief must be acknowledged and addressed to reduce disparities and promote equity and inclusion for all people.



Disruptive

Grief challenges our identity, relationships, beliefs, and assumptions about the world and our role in it. The death of someone in our lives is often described as life "before and after." Is a parent whose child died still a parent? When a spouse dies after 50 years of marriage, how does the surviving spouse recalibrate their life and their relationships? When death feels unfair, preventable, premature, or traumatic, our assumptions about the world and our place in it may be shattered (Janoff-Bulman, 1992). Grieving disrupts our patterns, and often, our core beliefs. Grief is a human distress, but not an illness. We are not suggesting that people do not struggle, nor are we opposed to quality professional help. Rather, we are asserting that people who are grieving attempt to adapt to their losses through means that may be helpful, and through means that could be harmful.

> Grief is a human distress, but not an illness.

Neither they nor their grief should be pathologized because they are not conforming to the consensus of professionals around the course of "normal" grief. Death is a life-altering event, but grief is not a pathological condition. Numerous influential people in the field have raised red flags about

> Death is a life-altering event, but grief is not a pathological condition.

the pathologizing and medicalizing of normal sorrow and ordinary life challenges (Bradford, 2010; Caplan, 1995; Frances, 2013; Greenburg, 2013; Horwitz & Wakefield, 2007; Jacobs & Cohen, 2010; Whitaker, 2010).



Relational Connection & Perceived Support

Healthy adaptation to loss is fostered by supportive relationships. "Mainstream" American society has fostered a climate where grief is a personal/family private matter, notwithstanding social and other media. In our practice, most youth and adults who are bereaved report feeling abandoned and misunderstood by friends, their communities, and the larger society due to their lack of education around the needs of people who are grieving. Students training as helping professionals, as well as seasoned professionals, report that they do not feel adequately prepared to respond to individuals coping with a death. As a result, many individuals who are grieving are avoided, misunderstood, or ex-communicated by family and friends.

Relational support has been shown to be a basic need for healthy adaptation following bereavement (Sandler, et al 2008). Perceived

> In our practice, most youth and adults who are bereaved report feeling abandoned and misunderstood by friends, their communities, and the larger society due to their lack of education around the needs of people who are grieving.

relational support (e.g. from peers, family, neighbors, and community members) can increase well-being, enhance personal growth, and mediate the relationship between anxiety and depression for individuals who are grieving (Barenbaum & Smith, 2016; Bartone, Bartone, Violanti, & Gileno, 2019; Jacobson, Lord, & Newman, 2017). Considerable evidence supports the importance of addressing social [relational] support and its impact on mental health, but standard clinical practice rarely includes such screening (Mental Health America, 2020). Some people who are grieving find solace and support through their faith community and shared beliefs; others experience detachment or ostracizing from their spiritual community. Either experience may have a lifelong influence on how they perceive and respond to previously held beliefs and assumptions about meaning, a Higher Power or Supreme Being (e.g. God, Allah, and Yahweh), and their community response in their time of need.



Personal Empowerment & Agency

Healthy adaptation to loss is fostered by personal empowerment and agency. When loss occurs, people often lose a sense of control, feel powerless, and experience a lack of agency (Attig, 1996). Additional changes in roles, responsibilities, as well as income, place, and status may contribute to feeling unbalanced while navigating a new life without the physical presence of the person who has died or from whom one has been estranged. For youth and adults, cultivating a sense of control and personal empowerment (as opposed to a "victim" stance) can help to foster healthy adaptation to life stressors (Gutierrez, 1994). For some, that route is through political action, or advocating for a cause in the person's memory. For others, it may be through more personal means, such as re-prioritizing one's time, changing employment, engaging in more self-care, and other decisions that enhance agency and personal empowerment. The importance of accessing one's personal choice and power in attaining healthy adaptation to loss cannot be overemphasized. A protective factor in healthy adapting after trauma and loss is having a strong sense of control over one's life (Cassels, 2008). Being grief-informed involves understanding that individuals who are grieving need supportive relationships and environments (i.e., systems, structures, policies, etc.) to facilitate personal agency, control, and empowerment.



Safety

Healthy adaptation to loss is fostered by psychological, physical, emotional, and spiritual safety. Being grief-informed requires understanding the vulnerability of individuals who are grieving and their need for safety physically (being out of harm's way), psychologically (understanding and coping with what has happened), emotionally (allowing for positive experiencing of feelings, including the difficult ones), and spiritually (one's inner life and existential beliefs). Factors that foster safety for individuals who are grieving include truthfulness and honesty about the deceased and circumstances of the death; holding a non-judgmental stance in relationship to whatever the person is experiencing, and allowing for individual responses that are not required to conform to standards set by others (Schuurman, 2003; McNiel & Gabbay, 2018).



Person-Centered

The duration, intensity, and experience of grief are unique for every individual. Most trained grief professionals would agree that each person's grief experience is unique, but most models of grief and their respective treatment protocols fall into categories of tasks that should be accomplished within a socially-constructed time period or the person is diagnosed with a "disorder."

> To assert that our grief responses will vary dramatically based on numerous issues while creating unscientific and socially constructed parameters around acceptable lengths of time for grief, or depths of grief, is contradictory.

Responses such as "intense yearning" or "preoccupation with the deceased" become "symptoms" in "Prolonged Grief Disorder," which begs many questions: Who decides when "intense yearning" is too intense, or has lasted too long? Who determines the dividing line between missing and remembering the deceased, and "preoccupation"? Another symptom, "feeling alone or detached from others" is interpreted through a mental illness lens when the reality may be that a griever is feeling alone or detached from others because people have deserted them.

The duration, intensity, and experience of grief are unique for every individual because every relationship is also unique based on multiple factors including the mode of death, the quality of the relationship before the death, the developmental and emotional age of the griever, the support or lack of support received, etc. To assert that our grief

responses will vary dramatically based on numerous issues while creating unscientific and socially constructed parameters around acceptable lengths of time for grief, or depths of grief, is contradictory.



Dynamic

The dynamic nature of grief cannot be captured by stage, phase, or other prescriptive models. There are no universally acceptable or "correct" ways to grieve. One of the greatest misassumptions about grief is that there are stages to grief which individuals must process and experience. This misassumption is primarily a result of the seminal work of Elisabeth Kübler-Ross (1969) and her model outlining five stages patients who are dying seemed to experience. It is beyond the scope of this paper to discuss the evolution and influence of Kübler-Ross's work. It is important, however, to note that the misinterpretation of this model within "mainstream" society has shaped the belief that grief is linear or happens in certain stages. Being grief-informed involves recognizing and acknowledging that grief is dynamic and person-centered. Grief does not follow a specific set of rules or stages or processes that can be generally applied to all individuals who are grieving.

Another misassumption that exists in "mainstream" society is the belief that there is a correct and an incorrect way to grieve. We hear people telling others that the way in which they are grieving is not the "right" way. Because each person's experience of loss is unique and because each person has their own beliefs, assumptions, and experiences, it would be illogical and inherently contradictory to assume that there are "correct" and "incorrect" ways to grieve. This misassumption results in many people who are bereaved receiving unsolicited advice about how long and in what ways they "should" grieve, including disapproval for being "stuck," advising mourners to "move on," to start new romantic relationships, to dispose of the deceased's belongings or re-do the deceased's room, among other common areas of unhelpful advice.

> Because each person's experience of loss is unique and because each person has their own beliefs, assumptions, and experiences, it would be illogical and inherently contradictory to assume that there are 'correct' and 'incorrect' ways to grieve.



Nonfinite

Loss is interwoven into our identity; therefore, the act of grieving is not a finite experience. Grief is ongoing. The misassumption that grief is time-limited permeates our everyday discourse. Individuals and families who are grieving are evaluated on the time that has passed since the person's death and whether the person who is grieving has "gotten over it." There is the misassumption that grief should only last for a certain period and anything after this timeframe is considered problematic. Important questions of consideration which further elucidate the hegemony of the grief narrative in U.S. society are: Who decides how long someone should grieve? Who determines that grief should be time-limited? Who asserts that all people should grieve on a specific timeline, irrespective of culture, experiences, relationship to the deceased, personal history and so forth?

Terms ascribed to grief such as "recovery" and "resolution" imply that grief is something that does or should come to end. These terms suggest that a goal of grief should be finding a fixed end point (Corr et al., 2019). Rather, grieving a death or loss will influence a person throughout the rest of their lives; grief does not have a magical finish line.

"Grieving a death or loss will influence a person throughout the rest of their lives; grief does not have a magical finish line."

Concluding Thoughts

This paper is a call to action to challenge the current hegemony of grief in the field of thanatology and to become grief-informed. We have only begun to touch upon the many examples that display inequities in the health care system, inequitable and culturally irrelevant access to mental health care, and unaddressed needs in federal and corporate policies on bereavement leave. As a society, we have moved away from experiencing grief as a communal experience to experiencing grief as "a private matter." (New York Life Foundation, 2017). The hegemony of grief in American society, aligning with the biomedical model and "dominant" grief narrative, dictates that grief is an individual problem instead of a response to loss that is interwoven in a sociocultural context. This hegemony has established norms that are monoethnic and discriminatory, failing to incorporate the lived experience of people from various cultures, ethnicities, and beliefs.

The 2020 global pandemic of COVID-19 has brought the normally avoided topic of grief from the background to the foreground, highlighting the need for all of us to become grief-informed. Most helping professionals have no formal training in grief education, are mired down in society's misassumptions about loss and grief, and lack the information needed to appropriately support individuals who are grieving. Now, perhaps more than ever, we need to deconstruct the "dominant" narrative about grief as "normal" and "abnormal," which discriminates against peoples and creates further divides. Together, as a human race, it is time to advocate for the lives of people who are grieving, base our assumptions on human welfare, humanistic values, social justice, and the dignity and worth of every person, and work as allies to become grief-informed.

> "Together, as a human race, it is time to advocate for the lives of people who are grieving, base our assumptions on human welfare, humanistic values, social justice, and the dignity and worth of every person, and work as allies to become grief-informed."

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Appendix A



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Appendix B

10 CORE PRINCIPLES & TENETS OF **GRIEF-INFORMED PRACTICE**

	PRINCIPLES	TENETS
	**Natural**	Loss is a normal, inevitable, and universal human experience. People have an innate capacity to adapt to loss and function healthily.
	**Nonpathological & Complex**	Grief is an adaptive, nonpathological response to loss. Grief is complex and complicated because people and relationships are complex and complicated.
	**Contextual**	Grief is not solely an individual experience; grief is interwoven in a sociocultural context, influenced by family, community, and other social systems. Acknowledging and addressing the sociocultural and historical factors that impact grief can reduce disparities and promote equity and inclusion.
	**Disruptive**	Grief challenges our identity, relationships, beliefs and assumptions about the world and our role in it.
	**Relational Connection & Perceived Support**	Healthy adaptation to loss is fostered by supportive relationships.
	**Personal Empowerment & Agency**	Healthy adaptation to loss is fostered by personal empowerment and agency.
	**Safety**	Healthy adaptation to loss is fostered by psychological, physical, and emotional safety.
	**Person-Centered**	The duration, intensity, and experience of grief are unique for every individual.
	**Dynamic**	The dynamic nature of grief cannot be captured by stage, phase, or other prescriptive models. There are no universally acceptable or "correct" ways to grieve.
	**Non-Finite**	Loss is interwoven into our identity; therefore, the act of grieving is not a finite experience. Grief is ongoing.

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Appendix C

About the Authors

Donna L. Schuurman, EdD, FT is an internationally recognized authority on grief and bereaved children, teens, and families, and the author of *Never the Same: Coming to Terms with the Death of a Parent* (St. Martin's Press, 2003), among other publications. In addition to her work as the Executive Director of Dougy Center in Portland, Oregon from 1991 - 2015 and currently as Dougy Center's Senior Director Advocacy & Training, Dr. Schuurman has written extensively on topics related to bereaved children. Her articles and other contributions have been published in scholarly journals and textbooks, and she has been interviewed as an expert on the subject by *Redbook, The New York Times, SmartMoney, USA Today*, and many other consumer publications. She has worked on the ground with families and communities impacted by large-scale tragedies including the Oklahoma City bombing, 9/11, the Sandy Hook school shootings, Japan's Great Hanshin Earthquake (1995) and Tohoku Earthquake (2011), among natural and man-made disasters.

Dr. Schuurman earned her master's degree in communications from Wheaton Graduate School, and her doctorate in education from Northern Illinois University's Department of Psychology, Counseling, and Special Education. She served for eight years on the Board of Directors of the Association for Death Education & Counseling (ADEC), including as President in 2001/2002. In 2003, she received ADEC's Annual Service Award, and in 2013, their Annual Clinical Practice Award. She has also served on the Board of Directors of the American Foundation for Suicide Prevention-NW, The Compassionate Friends, Inc., and The Compassionate Friends Foundation. Dr. Schuurman is a member of the invitation-only International Work Group on Death, Dying and Bereavement (IWG), serving as Board Vice-Chair (2016-2021). She is a Founding Board member of the National Alliance for Grieving Children (NAGC) and serves on the FBI's Mass Violence and Children Work Group, and as an Expert Witness in legal cases related to wrongful death.

Monique B. Mitchell, PhD, FT is a nationally recognized authority on children, teens, and families who are grieving in foster care, and the author of *The Neglected Transition: Building a Relational Home for Children Entering Foster Care* (Oxford University Press, 2016) and *Living in an Inspired World: Voices and Visions of Youth in Foster Care* (Child Welfare League of America Press, 2017), among other publications. Dr. Mitchell has trained and researched extensively on topics related to the lived experience of children and youth in the foster care system, taught undergraduate and graduate courses on loss and grief, and developed child-centered curricula to serve children who are grieving. Dr. Mitchell has partnered with national agencies such as the United States Children's

Bureau, American Bar Association, the Child Welfare League of America, the National Foster Parent Association, and numerous child welfare agencies. She has worked on the ground with children, youth, and young adults who have been impacted by death and non-death losses in Canada, Honduras, and the United States.

Dr. Mitchell has earned a Master of Science (MSc) degree in Capacity Building and Extension, a Doctor of Philosophy (PhD) degree in Family Relations & Human Development, a Fellow in Thanatology (FT) from the Association for Death Education and Counseling, and an Academic Associate credential from the Viktor Frankl Institute of Logotherapy. She was invited to serve as a scholar for the international Enhancing Life Project (2015-2017) and currently serves on national committees for the Association for Death Education & Counseling and the National Alliance for Grieving Children.

Appendix D

About Dougy Center

The mission of the Dougy Center is to provide grief support in a safe place where children, teens, young adults, and their families can share their experiences before and after a death. We provide support and training locally, nationally, and internationally to individuals and organizations seeking to assist children in grief.

Founded in 1982, Dougy Center was the first center in the United States to provide peer support groups for children who are grieving. Dougy Center's name honors Dougy Turno who died of an inoperable brain tumor at the age of 13, and whose ability to speak openly and honestly with others about death inspired our founder, Beverly Chappell.

On average, Dougy Center serves over 1,000 children and their adult family members each month via open-ended bi-weekly peer grief support groups. Groups are divided by age, type of death (illness, sudden death, murder, suicide) and who died (parent, sibling, friend). Concurrent adult caregiver support groups are held for the parents or adult caregivers of the children and teens. Since its founding, Dougy Center has served more than 55,000 children, teens and their families and has received national and international acclaim for The Dougy Center Model, a pioneering peer grief support model which helps children cope with the death of a family member.

Dougy Center provides educational materials about children and grief and training opportunities to local, national, and international agencies in need of grief expertise. Dougy Center's annual International Summer Institute draws participants from around the world for a week-long intensive training in Portland, Oregon. In Dougy Center trainings, participants representing hospices, hospitals, funeral homes, and/or independent non-profit organizations learn how to apply the core grief-informed principles and tenets to their practice settings. Over 500 sites have developed and implemented peer grief support groups for children and families based on The Dougy Center Model.

As an independent 501(c)3 non-profit, Dougy Center operates through the generous contributions of individuals, businesses, and foundations. Dougy Center receives no government funding and is supported entirely through charitable donations and professional training fees. Dougy Center never charges families for services. For more information, go to dougy.org or contact Dougy Center through help@dougy.org.

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