Comprehensive Grief Care for Children and Families: Policy and Practice Implications

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Since the 1998 publication of the groundbreaking Adverse Childhood Experiences (ACE) Study conducted by the Centers for Disease Control and Prevention and Kaiser Permanente, increased research and funding has focused on mitigating experiences that place children at risk for developmental disruption. Surprisingly, the death of a parent, sibling, or other important attachment figure—often noted as one of the most disruptive and potentially traumatic experiences for a child—has received relatively little attention in these efforts. A death of this magnitude has a profound impact on a child as well as on their surrounding family and community. Current systems of care do not adequately resource and provide access to preventive interventions that have the potential to reduce risk and promote wellbeing in youth and families adjusting to life-changing loss.

This article explores the current landscape of support for grieving children and families—including significant barriers to care and gaps in empirical knowledge. Given the complexity of the issue and the nascent state of the childhood bereavement field, it is fertile ground for social innovations that challenge current norms. An example is given of a model of care that integrates research and practice based knowledge in a community setting, allowing a broader range of individuals to access grief- and trauma-informed care. This whole-family, preventive approach offers a continuum of care that avoids pathologizing or marginalizing common grief responses without minimizing severe or disruptive grief and trauma reactions that warrant intensive intervention. The argument is made for a strengths-based, wellness approach to childhood bereavement that seizes upon opportunities to both promote adaptive adjustment and prevent further complications of unaddressed grief and trauma.

Impact of Bereavement on Children, Families, and Communities

According to the 2011/12 National Survey of Children’s Health, approximately 3% of children under the age of 18 have experienced the death of a parent or guardian with whom they have lived. This figure underestimates the true number of youth who are bereaved, as it excludes the deaths of siblings and other significant figures to children. Despite a relatively high prevalence, most grieving youth will not readily connect with peers who share this experience. As such, youth often feel isolated, alone, and different when they are bereaved. Although death is obviously a natural part of life, the death of a parent or sibling during childhood is not normative or an expected part of development.

Although numerous questions about the differential impact of childhood bereavement are not yet addressed in the empirical literature, existing findings indicate that individuals bereaved during youth are at increased risk for diverse psychological and behavioral health problems, including elevated rates of anxiety, depression, posttraumatic stress reactions, conduct disorder, substance abuse, and functional impairment. The literature focuses primarily on risk of pathology for children who have experienced the death of a parent, with large gaps in understanding the impact of diverse death losses on youth and the effects on a broader range of outcomes. There is growing recognition of the importance of exploring multiple domains of adjustment affected by bereavement in childhood, considering not only psychopathology but also other areas of developmental competence, including interpersonal relationships, academic functioning, and overall wellbeing. For instance, psychiatrist David Brent and colleagues reported that approximately five years after the sudden death of a parent, youth exhibited poorer educational aspirations, work competence, career planning, and relationships with peers than a control group of youth who were not bereaved. There is also an acknowledged need for greater understanding of positive personal or posttraumatic growth after the death of an important attachment figure and how this relates to long-term adaptation.

Children grieve within the context of their surroundings, making grief a family issue. A grieving child is most often surrounded by
family members who are also grieving, highlighting the need for a systemic approach to support. Throughout this article, family and childhood bereavement are interwoven, as a child rarely grieves in isolation. Decades of research demonstrate the effectiveness of family focused preventive interventions—approaches designed to strengthen the cognitive, emotional, and behavioral health of children within their family systems. We argue for a broader application of this preventive approach to the issue of childhood bereavement.

Any type of death can be experienced as subjectively traumatic, particularly for children.

In addition to the psychological impact of the death itself, indicators of family risk and secondary stressors are typically present in bereaved households. Children commonly experience additional changes that require adjustment after a death, such as decreased financial security or residential moves that involve new schools, neighborhoods, and unfamiliar peers and norms. The cascade of stressful life events that can follow a death, in combination with the internal and external resources possessed to adapt to these experiences, contribute to youths’ psychosocial adjustment. For example, psychologist Melissa Hagan and colleagues found that after a death, the surviving caregivers’ ability to provide warmth and consistent discipline were strong predictors of stress regulation for their children. Grief, trauma, and stress reactions after a death loss can be destabilizing, and when security is not reestablished through effective family, community, faith-based, and/or professional support, long-term behavioral health problems may result. Given the impact of context on a child’s adjustment, research and program development must address comprehensive models that understand and care for the whole child, support the whole family, and educate the whole community.

The Current Landscape of Support for Grieving Children and Families

Despite evidence of difficulties caused by bereavement in childhood, grieving families often struggle to find resources to meet their needs. A cultural avoidance of the topic of death, and a subsequent reluctance to discuss and address grief, contributes to families feeling isolated in their experiences. Children and adults alike report suppressing their reactions to the death for reasons such as not wanting to burden others, appear different, or risk appearing unstable. Consequently, grieving individuals may adopt unhealthy coping strategies such as avoidance, risk-taking, self-harm, and numbing through substance abuse. Based on the common sentiment that death is a natural part of life and humans have an inherent capacity to cope with grief, families may believe their struggles should not or do not warrant external support or professional care. However, for many, the upheaval caused by a death challenges their inherent resilience, and additional services may be necessary to maintain healthy developmental trajectories.

For those who do acknowledge the profound impact of a death on their family, barriers to care—including treatment fears, stereotypes, and social stigma—can interfere with seeking support. Families may have preconceived notions about therapy or treatment that decrease the likelihood that they will seek or follow through with referrals. This may be complicated by inequities resulting from social determinants. A lack of insurance coverage without a diagnosis, and little funding for affordable or no-cost preventive services, are additional obstacles to obtaining high quality, comprehensive grief care. Some may find connection and healing in community-based, peer support programs, while others may turn to traditional health care systems. Despite their strengths and benefits, limitations of both peer support and medical model approaches to grief—as well as a shortage of grief research and training to guide those providing services—currently limit equitable access to effective grief care for children and families.

Grassroots Grief Support Movement

For the past three decades, efforts to provide grief support to children and families have been led by a small but passionate group of community activists—many personally impacted by bereavement—who recognized the lack of societal attention to the unique needs of grieving youth. This grassroots movement has grown in strength and numbers over the years by establishing commonly held principles of grief and creating cost-effective models of largely volunteer-led, peer support programs. This approach is grounded in the belief that grief is a natural reaction to death and that adults can best support grieving children by taking a position of listener and learner. In this manner, the model aims to provide a safe place for youth and families to share their grief experiences and feel understood and less alone, offering valuable opportunities in many communities for free or low-fee support.

However, although peer support can provide normalization and helpful connections to others with similar losses, limited resources prohibit many of these programs from employing trained clinicians in their support groups. Whereas the peer support model is likely appropriate and helpful for many youth experiencing common grief reactions, those with complications of grief, trauma reactions, suicidal ideation, or other comorbid mental health difficulties may not be best served with peer connection alone. The limited amount of research on differential reactions to death circumstances indicates that even those who have had an anticipatory period prior to the death often demonstrate significant levels of clinical distress and posttraumatic stress reactions, which has been attributed to the observation of their loved one’s treatment and physical decline. Findings indicate that any type of death can be experienced as subjectively traumatic, particularly for children. This highlights the need for a trauma-informed approach—one that recognizes and responds appropriately to the varied effects of trauma—when assessing and addressing the impact of all types of death losses. Without professionals trained to assess unique therapeutic needs and provide corresponding services to address common bereavement-related complications, serious difficulties may be overlooked in peer support settings. For those difficulties that are identified as outside of the scope of peer support, it is often challenging to find referrals for grief-informed services that are palatable, affordable, and accessible.

Medical Model Approach to Grief

Families who do seek professional assistance in managing grief reactions may feel they have few options, particularly because insurance policies rarely include interventions that support those who are grieving unless their impairment meets criteria for established mental or physical health condi-
tions. In our country’s current behavioral health care system, professional services are typically covered only when criteria for a psychiatric disorder are met. This medical model approach to grief care creates a dilemma for providers, forcing them to pathologize even normative grief reactions with a diagnostic label in order to get reimbursed for services. This may result in misdiagnosis of grief-related symptoms with a proxy disorder—for example, Attention Deficit Hyperactivity Disorder (ADHD) or a mood or anxiety disorder—and may lead to inappropriate treatment that is not grief-focused. For providers who use codes from the American Psychiatric Association’s Diagnostic and Statistical Manual of Mental Disorders (DSM–5) for insurance reimbursement, revisions to the latest edition have made it both easier to diagnose depression immediately following a death by removing the bereavement exclusion, and harder to diagnose Posttraumatic Stress Disorder (PTSD) with restrictions on types of deaths that constitute a criterion stressor. An Adjustment Disorder diagnosis sometimes allows limited coverage of care, but criteria specifies symptoms must not represent normal bereavement, leaving it up to the practicing clinician to determine whether or not grief reactions are normal for that individual’s background and context.

Clinicians should use caution in interpreting psychiatric symptoms within the context of bereavement.

This question of what is normal versus pathological or disordered is one that has challenged the mental health field in general and those working in bereavement in particular. The dichotomous or categorical conceptualization of a psychosocial phenomenon is particularly challenging when it comes to an experience as personal and nuanced as grief, which is inextricably tied to relationships and all of their complexities. It is theorized that most human phenomena tend to fall along a normal distribution if measured at the population level—with some falling at the far extremes of these phenomena, but the majority falling somewhere in the middle. Although there is a relative paucity of empirical data on bereavement—particularly for children—the disruptiveness of grief reactions could theoretically be mapped onto a normal curve with more severe disruption falling on the far right end.

In recent years, researchers have made several efforts to conceptualize conditions or disorders of grief that would fall at the extreme right end of this theoretical normal curve (e.g., Complicated Grief, Prolonged Grief Disorder, Childhood Traumatic Grief, Persistent Complex Bereavement Disorder). These conditions are often referred to in the literature more broadly as pathological or maladaptive grief and are estimated to impact approximately 10% of youth and adults who are bereaved. With the exception of Childhood Traumatic Grief, most of these constructs have been based on adult data—particularly on older, White widows. Concerted efforts, such as those by Julie Kaplow and colleagues, are underway to more closely examine developmental and sociocultural differences among the constructs of maladaptive grief and adaptive grief within theoretical frameworks that encompass multiple dimensions of distress and adjustment. Such steps to enhance understanding of developmental and contextual influences are particularly salient given the inclusion of Persistent Complex Bereavement Disorder in the appendix of the DSM–5 as a condition recommended for further study.

Access to Whole-Family, Preventive Care

The push to create a bereavement-related psychiatric diagnosis is understandable in a system in which reimbursement for care is typically provided only when a disease or disorder can be defined and labeled. However, decisions regarding the lines drawn for criteria of disorders make a meaningful, real-world difference for families. If a line is drawn too far to the right on the theoretical normal curve, we risk limiting services to only those who meet certain cutoffs, creating access to care for only identified patients in families who have experienced a death. This can result in pathologizing and/or marginalizing individuals from the rest of their family and peers. For instance, if the severity of their symptoms excludes them from participating in peer support groups because of the aforementioned lack of behavioral health professionals in these settings, these individuals may miss valuable opportunities to connect with others who are grieving. Focusing on only those with the most severe or identifiable difficulties can also minimize the struggles of other family members in need of support and detract from whole-family care.

On the other hand, if diagnostic lines are drawn too far to the left, we risk pathologizing normative grief reactions and inappropriately attaching psychiatric labels to them. Families seeking support with coping after a loss are often comforted by normalization and validation—knowing they are not the only ones who have struggled with grief and its complexities. Although a grief-related diagnosis might be comforting for some, for others receiving a message that their natural grief reactions constitute a mental disorder can be experienced as stigmatizing, thus exacerbating distress or deterring families from continuing services. This label can be particularly alarming for parents or caregivers who are already worried about the detrimental impact of the death on their child.

In reality, there are many dimensions and possibilities between normal and pathological, and clinicians should not be restricted by evolving diagnostic criteria when working with children and seeking grief services and supports in real-world contexts. Careful assessment of experiences, difficulties, and needs is crucial to tailoring services appropriately; however, clinicians should use caution in interpreting psychiatric symptoms within the context of bereavement. Although a bereavement-related diagnosis might be one path toward increasing access to grief-focused and trauma-informed care, grieving families should not have to wait until someone meets criteria for a psychiatric disorder to have access to effective bereavement services.

Equitable access to services should be available based upon the individual’s experience of grief after a death, respecting self-determination and families’ perceptions of whether they want and need support. To limit access to professional services and assume that anyone whose difficulties are not at the more extreme end of the spectrum will be fine with the passage of time places the decision-making power in the hands of the expert, rather than empowering individuals with information and resources that will help them best support their own family. We need to see families holistically, meeting each individual—and the family as a whole—where they are. When we are able to do this, we have an opportunity to prevent the development of more significant disruption.
We need to see families holistically, meeting each individual where they are.

Research and Education for Grief- and Trauma-Informed Systems of Care

In both the peer support and medical model approaches to helping grieving children and families, the common denominator is the need for more research and education aimed at growing a grief- and trauma-informed, whole-community response to bereavement. Peer support programs need to have ready access to evidence-based assessment tools and professional resources that help them safely support families who come to them. Professionals in health and mental health settings need to be trained to be both trauma- and grief-informed in their care. Even within established health care systems, families often encounter clinicians who are not properly prepared to identify and address grief and trauma reactions associated with bereavement. Although there is recognition of a continuum of need, our under-trained workforce limits access to the full continuum of care. Without adequate training, primary and behavioral health care professionals may fail to identify bereavement’s role in the etiology of presenting symptoms. Further, providers may fail to see the impact of grief throughout the family and instead default to more traditional approaches focused on individual treatment of only reimbursable physical and mental health diagnoses, missing a critical opportunity to support the entire family system and prevent further complications. When grief is identified as a presenting concern, professionals may not be equipped to address the complex needs of families. There is a great need for translational research findings, accessible training, and practical tools that guide practitioners in making evidence-driven decisions that promote wellness in grieving children and families in their care.

Opportunities for Social Innovation: Judi’s House/JAG Institute and Comprehensive Grief Care

Given the unique complexities of grief and the developing state of the childhood bereavement field, there is tremendous opportunity for social innovation in the approach to this public health issue. Innovation in this arena calls for collaborative efforts from researchers, clinicians, educators, and policymakers committed to understanding and addressing the needs of grieving children and families in ways that are compassionate, comprehensive, and accessible. Rather than maintaining a divide between grassroots community approaches to grief support and evidence-driven approaches drawn from academic and medical models, the field has an opportunity to come together in ways that close current gaps in knowledge and access. By bridging rigorous research, professional training, and community-based services, a unified field will create a more robust safety net for grieving children and families.

In Colorado, one such effort at integrating research and practice in the community has developed out of the work at Judi’s House (JH) and JAG Institute, both named in memory of Judith Ann Griese. JH, a nonprofit bereavement center founded in 2002, has spent more than a decade folding scholarly research and evidence-based clinical practices into a peer support framework. Closely integrated with the direct services of JH, JAG Institute houses training and research initiatives focused on disseminating knowledge and resources to build workforce capacity and advance the field. Through three core initiatives—direct service, evaluation and research, and training and education—JH and JAG Institute integrate collective knowledge drawn from community, practice, and research partners to impact social change around the issue of childhood bereavement. This collective knowledge culminates in the Comprehensive Grief Care Model (CGC; See Figure 1) and allows for continuous development and evaluation of programs and resources that improve education and care coordination efforts. The resulting continuum of preventive, whole-family and whole-community services provides accessible entry points while reducing barriers to resources and care (see Figure 2).

The CGC Model is influenced by classic psychological and developmental theories, such as Bronfenbrenner’s ecological systems models, Yalom’s therapeutic group factors, and Maslow’s hierarchy of needs; contemporary grief, trauma, and attachment theories, including Dual Process and Continuing Bonds; empirically supported trauma and grief interventions, such as Trauma-Focused Cognitive Behavioral Therapy and the Family Bereavement Program; and, most importantly, the voices and lived experiences of the children and caregivers seeking care at JH for over 14 years. Growing from our foundation as a peer support model, the strengths-based perspective of the CGC approach views grief as a universal and natural reaction to a death, and each individual is believed to have the capacity to adjust to loss with appropriate support and care. As we learned about the diverse needs of the population seeking services at JH, we saw a need to intentionally integrate clinical practices, such as assessment and evidence-based approaches, to more effectively address the complications observed.

Direct Service: Providing Comprehensive Grief Care

Since opening its doors, JH has served more than 8,000 children and caregivers free of charge. In 2015 alone, the organization provided care to more than 1,200 clients, addressing disparities in the availability of preventive services and filling an unmet need in the community. The CGC Model takes a systems approach to providing care to a demographically diverse population of youth ages 3–25 and their caregivers. Although JH serves youth grieving any type of death, typically more than 70% are grieving the death of a parent and over 10% the death of a sibling. Tables 1 and 2 provide a snapshot of the population accessing support and the services provided during a typical year. This does not include the additional countless hours of phone consultations with concerned individuals who did not directly participate in services at JH. Previous JH clients, friends, and family members refer the majority of our families, and we receive numerous referrals from the community, including schools, mental health centers, victim services, hospice, and primary care. Although most families live within the Metro Denver area, some drive long distances from remote rural and mountain areas to participate in services. All services are provided free of charge regardless of ability to pay, resulting in a diverse range of socioeconomic status among program participants.

Services are provided by licensed clinical staff (e.g., licensed professional counselors, licensed clinical social workers, licensed psychologists) and trainees at the master’s, doctoral, and postgraduate level. Through an integrated intake assessment of each family
member, and ongoing assessment throughout services, clinicians identify and address potential unique complications of bereavement. By targeting disruptive grief reactions with evidence-informed interventions, and encouraging restorative grief experiences, families are supported in staying on track developmentally and strengthening their connections to supportive peers and adults.

Team-based care with internal collaboration facilitates a systems approach to serving families, and strong cross-referral relationships with community and practice partners aid in meeting clients’ needs that are outside of the scope of our expertise and mission (e.g., domestic violence, substance abuse).

A majority of families who engage in CGC services at JH participate in the core program, Pathfinders, a 10-week preventive intervention developed, evaluated, and refined for more than a decade at JH in collaboration with the University of Colorado Boulder and now JAG Institute. The onsite, multifamily program utilizes a structured curriculum with youth divided into age-appropriate groups, while caregivers participate with other adult peers grieving similar

Figure 1. Comprehensive Grief Care integrates and shares collective knowledge to increase grief- and trauma-informed responses for children and families who have experienced a death loss.

Figure 2. Continuum of whole-family, whole-community preventive intervention services provided through Judi’s House and JAG Institute. Sound evaluation and research methods establish the foundation for ongoing development and improvement across the spectrum.
The parallel child, adolescent, and adult versions of the Pathfinders curriculum each include education, adaptive coping skills, opportunities for expression, narrative exploration, and memorializing, as well as parenting support for adults. The same core topics and coping strategies are introduced in developmentally tailored ways in all age groups, encouraging continued family dialogue and modeling of skills at home. Pathfinders also includes activities and discussions geared toward reflecting on personal growth after a death, as described in Ryan Kilmer and colleagues’ 2014 article on promoting posttraumatic growth in youth.

Although a majority of families choose only to participate in this time-limited group intervention, ongoing Connections groups meet bimonthly to provide continued support that builds upon the skills and topics covered in Pathfinders. Individual and family therapy is also available for those who need more intensive care. As youth encounter different developmental milestones, such as adolescence or graduation, they may return for additional grief support services. Knowing that JH is an easy door to walk through at any time is an important aspect of this accessible, preventive model of community-based care.

This initiative has yielded the largest known dataset on children and families who have experienced a death.

In addition, the Community-Based Care team facilitates Pathfinders groups in schools and other community organizations. In each situation the team takes into consideration the uniqueness of each community setting when implementing the CGC Model. For example, accommodations for after-school programming at an urban Boys and Girls Club differ from those established in a middle school in a suburban school district. When possible, the Community-Based Care team provides grief and trauma education

Table 1. Judi’s House 2015 Clients at a Glance

<table>
<thead>
<tr>
<th>Client demographics</th>
<th>Children</th>
<th>Adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>358</td>
<td>397</td>
</tr>
<tr>
<td>Male</td>
<td>371</td>
<td>140</td>
</tr>
<tr>
<td>Total unduplicated clients served</td>
<td>729</td>
<td>537</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
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<td></td>
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<tr>
<td>African American</td>
<td>46</td>
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<tr>
<td>Asian/Pacific Islander</td>
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<td>2</td>
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<tr>
<td>Hispanic/Latino</td>
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<td>96</td>
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<td>Multiracial</td>
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<td>40</td>
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<tr>
<td>Native American</td>
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<tr>
<td>White</td>
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<td>341</td>
</tr>
<tr>
<td>Other</td>
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<td>3</td>
</tr>
<tr>
<td>Not indicated</td>
<td>70</td>
<td>20</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 to 6 years</td>
<td>99</td>
<td>—</td>
</tr>
<tr>
<td>7 to 10 years</td>
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<tr>
<td>11 to 13 years</td>
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<td>—</td>
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<tr>
<td>14 to 18 years</td>
<td>207</td>
<td>—</td>
</tr>
<tr>
<td>19 to 25 years</td>
<td>—</td>
<td>44</td>
</tr>
<tr>
<td>25+ years</td>
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<td>493</td>
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<tr>
<td>Information about the death</td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Average age of deceased (years)</td>
<td>38.62</td>
<td>16.45</td>
</tr>
<tr>
<td>Average time since death to intake (months)</td>
<td>11.02</td>
<td>15.91</td>
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</table>

Table 2. Judi’s House/JAG Institute 2015 Comprehensive Grief Care Service Provision

<table>
<thead>
<tr>
<th>Service</th>
<th>Individuals reached</th>
<th>Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public awareness</td>
<td>436</td>
<td>31</td>
</tr>
<tr>
<td>Grief and trauma education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Intensive in-house training</td>
<td>20</td>
<td>5,853</td>
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<tr>
<td>Community training</td>
<td>1,389</td>
<td>71</td>
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<tr>
<td>Training and education totals</td>
<td>1,845</td>
<td>5,955</td>
</tr>
<tr>
<td>Consultation, assessment, and care coordination</td>
<td>812</td>
<td>1,172</td>
</tr>
<tr>
<td>Group counseling</td>
<td>956</td>
<td>9,621</td>
</tr>
<tr>
<td>Individual and family therapy</td>
<td>78</td>
<td>548</td>
</tr>
<tr>
<td>Direct service totals (unduplicated)</td>
<td>1,266</td>
<td>11,341</td>
</tr>
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Research and Evaluation: Advancing the Field

Early in the development of JH, the dearth of childhood bereavement research to inform practice inspired the creation of a large-scale evaluation and research initiative in collaboration with university researchers. The aim of the CGC Research Initiative has always been to conduct rigorous research about childhood bereavement in a community-based setting to improve care and strengthen the field. Since its inception in 2005, the research initiative has established a collective knowledge base by engaging multiple stakeholders, including clinical practitioners, academic researchers, and the community of children and families participating in bereavement services. As a result, this initiative has yielded the largest known dataset of its kind, including data on thousands of children and families who have experienced a death.

Utilizing a health services approach, data extracted from available clinical records for this service-seeking population are used for the purposes of systematic research and program evaluation. Records are comprised of comprehensive assessments that include standardized and grief-specific measures yielding qualitative and quantitative indicators of adjustment from multiple informants. Assessments are conducted longitudinally, including up to three preintervention and two postintervention time points. The data reflect diverse children and families and can be clustered by family unit, group cohort, individual client, or demographic or clinical characteristics such as race, gender, age, time since death, cause of death, or adjustment. This allows the CGC Research Initiative to investigate nuanced patterns regarding the needs, grief experiences, and adjustment over time for children and families. Shared broadly and translated across other settings, such findings will help characterize the needs of grieving children and families and provide detailed practical guidance to the field.

Preliminary data findings from the CGC Research Initiative suggest families seeking bereavement services at JH are heterogeneous in clinically important ways, including diverse racial and ethnic identities representative of the community, and wide-ranging reported causes of death and relationships to the deceased. As mentioned above, Table 1 provides a breakdown of the population seeking care in this community based grief center in 2015. Of note, the average age at death reported at JH is less than 40 years old, compared with the 78.6 years average life expectancy in the United States, highlighting how unexpected and untimely the deaths are for most families served by JH. Findings presented by the authors elsewhere indicate that the majority of participants at JH report symptom levels that could warrant professional services. However, most would not meet criteria for a diagnosis, and withholding services until symptoms reach diagnostic levels could result in missed opportunities to prevent further disruption to their lives.

The evidence base for the value of preventive interventions for grieving families was spearheaded by the seminal work of Arizona State University researcher Irwin Sandler and his colleagues. Their randomized control trial of the Family Bereavement Program demonstrated that participants in a preventive intervention—which included psychoeducation, coping skill development, and positive parenting skills—showed less psychological problems than those who did not participate in the program, even several years after the initial intervention. Although this body of research on a recruited sample of children who were parentally bereaved and their surviving biological parent is a tremendous contribution to the field, studies on larger samples of children with different types of deaths and diverse family constellations are necessary to strengthen the case for preventive intervention services. In particular, there is a need for translational research on families seeking services in the community to inform the real world provision of care.

In our own preliminary evaluation findings, data about 2015 Pathfinders participants indicate that at the end of the 10-week intervention, 87% of adult participants who initially presented with clinically significant levels of depressive symptoms on the Beck Depression Inventory (BDI-II) and 74% who initially presented with clinically significant symptoms on the Inventory of Complicated Grief (ICG) showed improved scores on these scales. The average score across all participants dropped from above to below clinical cutoffs on both measures. Similarly, 60% of youth participants who initially presented with disruptive levels of grief-related distress showed improvement. Future directions for the CGC Research Initiative include evaluating the immediate and long-term preventive impact of our whole-family approach for varied types of death losses and surviving family members.

Future directions also include continuing to evaluate the expressed need for grief support in the community, gaps in service delivery, and differential effectiveness of services for diverse populations. This includes examining the impact on program effectiveness when it is delivered in schools and youth agencies with limited parent involvement, as opposed to onsite with the whole family. By examining the numerous diverse families served, JAG Institute will be able to provide in-depth analyses of individual differences in grief reactions and intervention responses for a broad range of relationships and causes of deaths. Understanding unique reactions and needs related to specific demographics and types of deaths will help guide the ongoing development of programs and the training and education of those caring for the bereaved.

Training and Education: Strengthening the Workforce and Increasing Community Capacity

In response to increased need for high quality grief care, and a trained workforce to provide such services, JH/JAG Institute is investing substantial resources in the expansion of the Comprehensive Grief Care (CGC) Network through training and education efforts. Although creating additional grief centers would incrementally increase access to care, this approach to expansion is limited by the need to fund facilities and operations in addition to services and supports. The organization is committed to disseminating knowledge and building workforce capacity and public awareness in ways that can potentially impact the lives of grieving children and families anywhere.

Annually, JH/JAG Institute provides in-depth clinical training to more than a dozen interns and early career mental health professionals. Each trainee engages in a minimum of 1,000 hours of training ranging from developing basic clinical judgment and therapeutic skills to assess-
grief-focused and trauma-informed care. In addition, public awareness and education efforts reach many thousands of professionals and community members who are in contact with grieving youth and families. For instance, in 2015 alone, our professionals presented to more than 1,800 individuals at more than 60 local and national presentations and events (see Table 2). By leveraging technology and designing Web-based resources for professionals who seek to implement grief-focused, trauma-informed practice standards, we will increase families’ access to effective grief care while informing regional, state, and national policy.

Ultimately, the goal is to establish a proof of concept of an effective system of care in a metropolitan area that can be shared and adapted by other communities. By engaging providers in other locations in collaborative community-based research, we will grow our collective knowledge about the diverse needs of grieving families so that individualized services and helpful resources are accessible to all. We are looking to existing models to apply best practices in dissemination science. However, we recognize that to train more providers in this model, grief needs to be more of a priority in our society. At the policy level, this requires substantial changes that allow for the financial sustainability of providing comprehensive, grief-focused and trauma-informed care.

A Call to Action for Policy and Practice Innovation

We have a tremendous opportunity, as a field and as a society, to chart a different course for the study and support of childhood bereavement than current policies and systems of care permit. Childhood bereavement is a critical public health issue and greater resources should be directed toward developing, evaluating, and disseminating comprehensive grief-focused, trauma-informed models of care to serve grieving families across a broad spectrum of needs. Most communities do not currently have adequate systems or resources in place to support families after a death, and significant modifications of our current health care system’s approach to bereavement are needed to improve wellbeing and outcomes for all grieving children and families. The example of JH/JAG Institute demonstrates how a comprehensive, whole-family and whole-community approach to grief care can help wrap around bereaved youth and their caregivers in ways that promote well-being without minimizing or pathologizing diverse grief reactions.

At present, a comprehensive grief center as a hub for the community might not be possible in many cities and rural communities because of logistics and limited resources invested in addressing childhood bereavement. However, as long as there are professionals who are well-trained in grief care, and research and practice based knowledge is accessible, these services can also be provided in schools, churches, and other community settings in affordable, sustainable ways. Indeed, when it comes to sustainability of effective grief services, part of the solution is increased training, education, and research—mobilizing and reinforcing the existing workforce and available resources. Instead of merely citing financial barriers as a rationale for an inadequate response, health systems, researchers, and policymakers need to evaluate the cost of inaction when bereaved youth and families do not have access to appropriate support, so that greater funding is directed to this issue. Without any state or federal funding and no insurance reimbursement, JH, like most grief centers, must rely on the generosity of the community until other sustainable funding sources are identified to support preventive grief services. JH/JAG has been fortunate to receive substantial financial support from numerous community members, corporate sponsors, and local and national foundations. These funders see the value of

Suggestions for Further Reading

investing in prevention that mitigates costly negative outcomes for this vulnerable population. Meanwhile, we continue to explore other viable options for sustainable funding, reimbursement, or subsidization with community, policy, and health care leaders.

As decision makers work to improve behavioral health care policies more broadly, the complex issues faced by the bereaved should be addressed in ways that differ from traditional medical model approaches. For instance, although there are certainly practical advantages to creating a bereavement-specific diagnosis within our current health care landscape, when considering what is best for grieving children and families we need to think of the broader implications. People should not have to wait until they reach significant impairment in functioning to have access to grief support, nor should they have to be diagnosed with a psychiatric disorder to receive evidence-based care. Although free peer support groups are an invaluable service and opportunity for connection in the community and remain important resources in the continuum of care, they might not be able to adequately address the complex needs of some families seeking their support. Careful assessment and trauma- and grief-informed professional interventions should also be readily, if not universally, accessible and affordable for the bereaved. The following recommendations are designed to serve as guideposts in ensuring equitable access to effective services for grieving children and their families:

- Provide and sustain a continuum of established preventive intervention services that reduce risk and promote coping and wellbeing for all children and families seeking grief support. This could include state or federal subsidization of services, or insurance policies that reimburse grief care for the bereaved regardless of diagnostic status, offering such interventions as prevention or wellness services.
- Advance the field through research efforts that build the knowledge base about the diverse needs of grieving children and families and produce findings that translate into practical strategies and solutions. We must grow an evidence base for the differential effectiveness of varied prevention and intervention approaches in community settings where grieving children and families are seeking services.
- Strengthen workforce and community capacity by developing and providing trainings, tools, and resources for clinicians and the community. Broadening public awareness, education, and advocacy efforts that share information about the needs of grieving children and families will help assure that those coping with a death are met with sensitivity and responsiveness. In addition to the popular push for a trauma-informed workforce, we need grief-informed professionals, schools, and communities that can appropriately address the unique needs of children and families in the places they live, study, work, and seek care.

Experiencing a significant death during childhood often presents profound stress, adversity, and trauma—potentially derailing developmental trajectories without appropriate support. For the millions of children who are bereaved annually, a comprehensive approach to the development and implementation of resources, supports, and services within a system of care is an essential public health need. Now is the time for researchers, practitioners, educators, policymakers, and advocates to unite in support of this population. By investing in prevention, we can create social change that ensures a compassionate response to all grieving children and families.

Keywords: behavioral health; childhood bereavement; grief; prevention; trauma