



# CROSSROADS OF GRIEF PROJECT

Grieving or Bereaved Children:  
Literature Review 2015-2018

## OVERVIEW

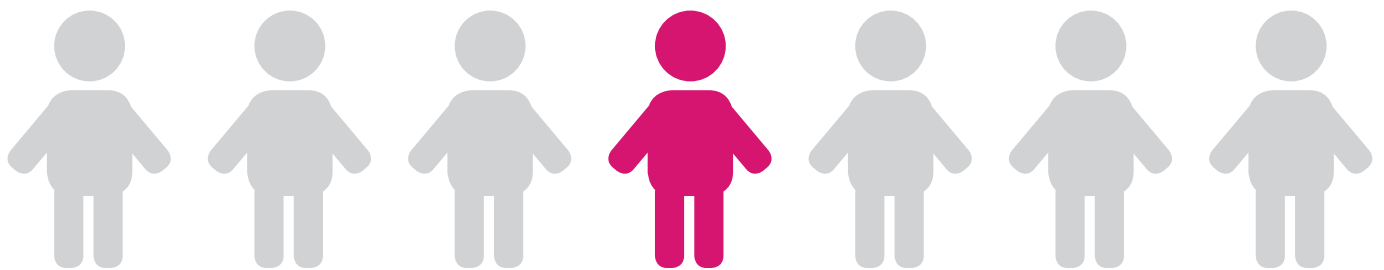
Barry R. Ashpole & Andrea Warnick RN, BA, Registered Psychotherapist  
Guelph, Canada

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*The review covers the period 2015-2018 and supplements the literature review published by the Children & Youth Grief Network of Peel Region in March 2015. The focus is on evidence-based studies published in peer-reviewed journals, reflecting current thinking on the many different aspects of grief and bereavement among children and young people. The overview of the earlier literature review makes many points that still hold currency.*

As identified in the overview to the 2015 literature review, in Western countries it is estimated that 1 out of every 7 children will experience the death of a parent or sibling before the age of 20.



Evident from the latest review of the literature is the significant increase by academia and the research community in the attention being given to how to most effectively meet the emotional and practical needs of grieving or bereaved children and young people. While the gap between theoretical knowledge and the availability of well-informed, evidence-based grief support for children and youth is narrowing, gaps nonetheless remain, particularly with respect to the unmet needs of several vulnerable populations.

To reiterate comments made in the overview of the earlier literature search, in almost all countries, the support for bereaved children remains somewhat fragmented. Meeting their needs varies greatly across all jurisdictions, underscoring the universal nature of what is emerging as a major public health issue. From an organizational (i.e., health and social services) perspective, bereaved children's needs are not recognized as the particular responsibility of any one department of government or aspect of children's services. They are more likely to be included within a wider aspect of need such as psychological health and well-being or vulnerable groups, without being mentioned specifically. Many communities lack access to any formal support for grieving children.

Much research originates from Scandinavian countries, which exhibit a more progressive outlook on many of the issues that are the focus of the literature review. Uniquely, in the Swedish health care system there are designated sibling supporters for siblings of children with cancer. In Denmark, there are standardized bereavement response plans (b-plans) throughout the school system, which has led to the majority of teachers reporting that they feel equipped to support bereavement in schools. This is in stark contrast to the literature in this area from other parts of the world.

The literature is largely rooted in research in developed countries, therefore there remains a paucity of evidence-based research with respect to children and young people living in culturally and linguistically diverse communities. There is also scant research on the bereaved children and young people of Aboriginal and First Nations communities. Children and young people within the lesbian, bisexual, gay and transgender communities, and children with intellectual or developmental disabilities, are underserved by the research community and, consequently, the community-at-large.

## Children's Understanding of Dying & Death

Cultural roots (including urban vs. rural living), maturity (i.e., cognitive ability), experience of illness and death, parents' religion and spiritual beliefs and, to a lesser degree, socio-economic circumstances, influence a child's understanding of dying and death. Today, age is considered less of a factor than, say, it was a generation ago. Children who participated in one study understood key aspects of death from as early as four-years-old and with age their explanations of inevitability, universality and causality became increasingly biological. Despite the recognition of death as a biological conception, in one study children were receptive to

an alternative concept of death which affirmed that the deceased has an afterlife elsewhere.

Researchers in a third study opined that children today have limited access to realistic information about dying and death. Alongside socio-cultural trends that have removed death from everyday life, many adults endorse attitudes of shielding children from the reality of death, but there is fairly broad consensus that parents tend to underestimate what their children know and understand about death and often discuss the topic using euphemisms that actually contradict the biological facts.

*Although not addressed specifically, it is evident that when given access to accurate information, children and young people may exhibit greater understanding and resilience with regard to dying and death than adults often expect.*



## Pre-Death

In recent years, there has been a significant increase in the attention being given in the literature to the importance of supporting families through the life-limiting illness experience and the impact that such support has on the bereavement process. The benefits of inclusion and open and honest communication with children about an anticipated death are well documented and emphasized throughout this body of work. However, many barriers are identified which unfortunately, can prevent this from happening whether the child is anticipating the death of a sibling, parent, or even their own death. While the dying or death of a family member affects the whole family, children in particular are at risk of being emotionally, albeit unintentionally, sidelined. What the death of a parent or sibling means to a child often goes unexplored; they are described in one study as "hidden mourners." The challenges faced by family dynamics – in the quest to empathetically connect – are discussed by several authors. The importance of empathetic, responsive communication is a reoccurring theme in addressing, in part, misinformation, misinterpretations or misconceptions.

Assessing a family's preparedness and assisting them in emotionally navigating their way is the focus of several studies. A few innovative pre-death initiatives are identified, such as the creation of Sibling Supporters (Sweden) and The Children and Family Services (Scotland). A number of studies strongly advocate for medical staff caring for dying adults to take a more active role in ensuring that the children who will be affected by the adults' death obtain the support they need, as indicated by the title of one article: "Think adult – think child!"

This section also touches on children's grief related to the experience of dementia in a parent. Research suggests that this type of grief experienced by family members has a distinctive nature that differentiates it from sorrow attendant on most other ill-health causes. The way in which dementia manifests in cognitive and physical changes tends to be experienced as a series of serious losses, each of which can be a source of grief leading to significant stress and emotional, mental, psychosocial and physical ill-health. Research to date has focused on spouses and adult children: one study included in the literature review adds to the grief-related perceptions and experiences of children and young people who have a parent with early onset of dementia.

## Post-Death

Research into understanding and supporting grieving and bereaved children is fertile. In the past 3-4 years, research has expanded exponentially, but most studies are based on relatively small numbers of participants. Nonetheless, research has made a significant contribution to broadening the knowledge base. Of particular interest are studies that investigate a not uncommon phenomena, the unresolved grief of adults who, as a child, experienced the death of a loved one, underscoring the critical importance of addressing grief in its earliest stages to avoid potentially negative consequences in later life. For example, children may carry into later life a distrust of health professionals and the health care system in general if they are critical or dissatisfied with the care given their dying loved one.

Two generations ago, home deaths (and births) were common occurrences. There has been a trend in recent years of returning to home deaths (and births). Running parallel with this trend is the recognition of the role of many young people as caregivers given the prolonged illness trajectories that tend to be experienced in terminal illness. Increasing attention is being paid in research circles to the impact of such responsibility on the emotional well-being of the young caregiver and, in particular, how grief manifests itself post-death.

Several studies show that when parents are supported they can demonstrate an enhanced capacity to support their children, which begs the question: to what extent is bereavement support available or offered? While this issue is beyond the scope of this literature review, research clearly demonstrates that bereavement services in hospitals and the community-at-large are fragmented.

Increasingly, the Internet offers young people in particular a platform for expressing their grief among peers.

Relationships between siblings can reflect a unique bond, and the impact on a sibling when a brother or sister is seriously ill or dying is profound. The study of sibling bereavement is growing by leaps and bounds, with particular focus on giving voice to their emotions and feelings. Siblings can emotionally get lost as a result of the illness experience and, in particular, during the period of grief when death is imminent and in the bereavement that follows. Given the far-reaching consequences of not properly supporting siblings during these times, a holistic approach is advocated. Researchers flag several predictors for unresolved grief: perceptions that it was not a peaceful death, limited information given in the last weeks or months of life, information about the impending death, sibling's avoidance of health care professionals, and a lack of communication with the extended family and people outside the family. Coined "forgotten grievers," bereaved siblings experience the long-term effects on their health and social environments, especially true when sibling bereavement occurs during formative childhood years.

Regardless of whether the death experienced is that of a sibling or a parent, there is a welcomed trend in the literature to recognize the bereaved parent(s)' own grief process as having a significant impact on the

bereaved child's experience of grief. While this issue is beyond the scope of this literature review, research clearly demonstrates that bereavement services in hospitals and the community-at-large are fragmented.

Not unique in today's society is children and young people experiencing what has been termed "double bereavement" – the impact of a divorce preceding a parental death in the family. Bereavement research and divorce research traditionally have been two separate research fields without much interchange. This is notable since both focus on profound losses within family relationships. A corresponding separation also seems to exist when it comes to support measures aiming at individuals experiencing any of these losses. Future research on double bereavement, as well as development of any support measures aiming at doubly bereaved children and adolescents, may imply more cooperation between experts of bereavement and divorce, respectively.

A relatively new area of research is the potential role of spirituality and religion in how siblings (and children and young people in general) cope with separation and loss.

While there are only a few recent studies focusing on the experience of parental suicide bereavement in children, these studies clearly articulate the

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additional challenges this group of bereaved children tend to face, such as stigmatization, feeling responsible, challenges to meaning-making and a preoccupation with the question of why the parent died by suicide. One study conceptualized the overall experience of children bereaved by suicide as a "double whammy". None of the literature in this area addressed the experience of sibling bereavement through suicide.

## In the Classroom

An extensive literature review was recently undertaken for Compassionate Ottawa as part of this group's schools initiative. An exchange/sharing of this information has been discussed with Compassionate Ottawa and the Children & Youth Grief Network. With a few exceptions, the articles listed in this latest review of the literature surfaced after that assignment for the Ottawa group was completed.

The effect of grief related to a serious illness or death on academic performance and well-being at school is well documented. Unfortunately, it is common for manifestations of grief to be misinterpreted as misbehavior. Despite this being recognized in the literature, in-school interventions are uncommon and many teachers and other school personnel consistently express self-doubt in dealing with students experiencing dying and death, and those living with a life-threatening or life-limiting illness. An exception to this is the literature on Denmark's standardized school bereavement response plans (b-plans) where the majority of educators now report that they feel equipped to support bereaved students at school.

Researchers in several studies in this section discuss a range of initiatives and strategies to address what is widely recognized as a largely unmet need in schools: to better equip teachers to support their grieving or bereaved students. Underscored is the important role for school counselling personnel, such as psychologists (where they are available), who are in a unique position to both identify and work with grieving students; to provide guidance to schools, families, and peers on approaches to support such children and youth; and, to offer training to classroom educators so that they are better prepared to support grieving students.

There is also advocacy throughout the literature for children to have structured opportunities across the whole-school curriculum to learn how loss affects people's lives and how to support themselves and others given the significant negative impact the experience of dying and death can have on a child's emotional, behavioural and academic function.

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## Intersection of Grief, Diversity & Social Barriers



### **Culturally & Linguistically Diverse Communities**

The literature on palliative and end-of-life care for children and youth of culturally and linguistically diverse communities is extensive. There is a paucity of published research, however, on grief and bereavement with respect to the expressions of loss and separation experienced by children and young people. In the case of Hindus, Jews and Muslims, culture and ethnicity are considered synonymous with faith and spiritual beliefs and, as a consequence, grief and bereavement are more family and community-based experiences compared to, say, Western societies, with their incumbent rituals and ceremonies, and periods of mourning.

### **Aboriginal & First Nations Peoples**

As with culturally and linguistically diverse communities, the literature on palliative and end-of-life care for Aboriginal and First Nations peoples is extensive, but likewise, there remains a paucity of published research on grief and bereavement with respect to the expressions of loss and separation experienced by children and young people.

A 2016 literature review, while specific to the Aboriginal population of Australia, flags issues that are universal in nature and applicable to the indigenous peoples of many countries, namely a lack of well-articulated theories, models and practice specific to the cultural and historical context of grief (as distinct from trauma). Although there is significant research on the impact of trauma in Australian Aboriginal communities, the review found little material, resources or research that focused on the complexities of Aboriginal grief. The magnitude of grief and loss experienced by Aboriginal people through loss of land, language, cultural practices, significantly higher mortality rates, suicide, incarceration and health related problems, has significantly impacted their social and emotional well-being. In Canada, the legacy of residential schools has traumatized many communities. Racial disparities in health and social services in many countries have also had a devastating impact.

### **Lesbian, Bisexual, Gay and Transgender Communities**

The literature on palliative and end-of-life care for the LGBT communities is extensive, but there is a paucity of published research specifically on bereaved and grieving children and youth in this community. Stigma and discrimination remain factors in these communities interaction with health and social services.





## Children with Intellectual/Developmental Disabilities

As one key study observes, the grieving process for children without disabilities, though personal and complex, is well described in the literature. There is less research examining the grief process and the necessary supports needed for children with disabilities.

Many children with disabilities experience the same degree of emotions and behaviour changes as those without disabilities. However, owing to difficulties with communication, comprehension, and lack of support and understanding from others, individuals with disabilities experience additional barriers to receiving grief support, which one study suggested may lead to a complicated grief process. These studies primarily take place in

schools, and they identify that students may present challenging and disruptive behaviour during periods of grief. Unfortunately, caregivers and, in particular, school personnel typically do not recognize these as expressions of grief and attribute them to the disability rather than to grief. The need for additional training for educators and therapists about grief in children with intellectual disabilities is identified.



## Faith Communities

The literature on the end-of-life (EoL) beliefs and perspectives of different faith communities is extensive, but there is a paucity of published research on the specific needs of children and youth of different faiths.

## Programs & Interventions

Of particular interest in this section are several studies showing positive 15 year post-intervention results of the well documented Family Bereavement Program (FBP). The Family Bereavement Program, which provides support to parentally bereaved youth and their surviving caregiver(s), is rather unique in children's bereavement research in that the effects of the intervention are compared with a control group. These long-term follow up studies showed significantly positive effects of participation in the FBP on the mental health of both the bereaved child and parent, as well as it's ability to reduce suicide ideation in parentally bereaved youth.

A welcome addition to children's bereavement literature is information on the Irish Childhood Bereavement Care Pyramid. This conceptual frame work was launched in 2014 and provides a comprehensive model to guide children's bereavement support based on contemporary literature, existing policy and the views of professions, volunteers and parents.

A number of additional initiatives and programs are described in this section, including 'Give us a break!' a program for children and young people who have experienced bereavement or negative change, including the impact of divorce/separation, experiences around ill health, and circumstances leading to individuals



being “looked after.” Pathfinders is a program developed in a community setting to creatively address the diverse needs of bereaved children and families, prevent complications of grief and trauma, and promote healthy adaptation. Outlined is the structure, process, and content of Pathfinders, including examples of creative interventions used within the program.

In one study, researchers observed bereavement camps through the lens of positive youth development to determine the applicability of the eight features of positive developmental settings for describing bereavement camps (safety, appropriate structure, supportive relationships, opportunities to belong, positive norms, support for efficacy, skill building opportunities, integration of family and community). Results identified how each element of positive developmental settings was exemplified in either typical camp activities or bereavement-focused activities.



### **Assessment Tools**

Researchers are focusing more attention on how to effectively assess or evaluate interventions. Promising outcomes have been reported testing, for example, ‘Screener for Bereaved Youth,’ the ‘Adolescents Grief Inventory,’ the ‘Persistent Complex Bereavement Disorder Check List – Youth Version’ and, based on the ‘Extended Grief Inventory,’ the ‘Inventory of Complicated Grief – Revised for Children’ and the ‘Inventory of Prolonged Grief for Children/Adolescents.’



### **Interventions**

There is little add to the 2015 literature research, underscoring the earlier observation that “child bereavement interventions are rarely subjected to rigorous evaluation.” The studies included, nonetheless, present a handful of interventions with promise. One in particular was a joint project run by adult and children’s services in an acute hospital trust and with a charitable organisation, which led to the development of written information to help adults prepare and support children at this challenging and uncertain time.



### **Education/Training Initiatives**

On several fronts, the need for education and a general lack of training opportunities is a common thread throughout the published literature – e.g., for parents, teachers, healthcare providers and “significant others” – and underscores what can be legitimately considered a high priority. The literature on specific education and training initiatives is light and the studies included in this section of the current review are specific to enhancing communication skills and mindfulness.