Support Services for Grieving or Bereaved Children: Needs Assessment

Overview of Literature Search

1

Barry R. Ashpole
Guelph, CANADA

Andrea Warnick RN, MA
Toronto, CANADA

Introduction

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. The distressing effects of such an experience are well documented ...but, despite the solid research base in the field of children's grief, there remains a wide gap between this theoretical knowledge and the availability of well-informed, evidence-based grief support for children and youth. The literature search identified key articles, reports, etc., published between 2010 and 2015 that reflect current thinking on the many different aspects of grief and bereavement among children and young people.

**Access to/Availability of Support Services for Bereaved Children:
Assessments, Environmental Scans, Evaluations, Surveys**

In almost all countries, the support for bereaved children is fragmented. Meeting the needs of this vulnerable population varies greatly across all jurisdictions, underscoring the universal nature of what is emerging as a 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.

One region in the U.K. identified gaps in services and developed a Children's Bereavement Service with the mandate of offering support to professionals working with bereaved children and their families. They quickly found referrals to be higher than anticipated, expecting 60 per year and receiving 255 in the first year alone.

Children's Understanding of Dying & Death

This is a topic not without controversy and one that is difficult to research. The findings of one study suggests that children may know more about death than their parents expect, and that even children within a given community vary a great deal in their access to information about death. Although a biological understanding of death increases in accordance with cognitive development, biological and supernatural explanations of death co-exist in a complementary manner, being deeply imbedded in cultural contexts and heavily influenced by the information available to them from the adults around them. Children's thinking is embedded in both cultural practices and religious ideas, and children with death experience seem to have a more realistic understanding of death than their inexperienced age-mates.

Pre-Death

Communicating with children about the anticipated death of a parent, sibling or loved one is recognized in the literature as being incredibly challenging for parents and even experienced health care or social service providers. Consequently, parents tend to adopt an overly positive stance in order to shield their children from the truth. Although the literature strongly encourages parents to take an open and honest approach to supporting children and youth prior to a death, many barriers remain to them doing so. One nation-wide study found that up to a couple of hours before a parent's death, 43% of teenaged children were not aware that the death was imminent.

Research suggests that when during the terminal phase of a parent's illness children and youth are provided with regular information and are involved in discussions about the situation, they would be able to cope more effectively with the uncertainty and upheaval within their lives. Yet many parents lack access to well-informed advice on the topic of preparing children for a death; they are unaware of this information.

Parents in one study, as an example, engaged in the process of disclosure in one of four ways: 1) measured telling; 2) skirted telling; 3) matter-of-fact telling; and, 4) inconsistent telling. Frequent reasons for why the teenager and parents did not talk about imminent death, however, were that one of the parents together with the teenage child had pretended that the illness was not that serious or that none of the parents had been aware that death was imminent.

Evidence suggests that having dependent children influences parents' treatment decisions at the end of life and that a central concern for children and parents is optimizing time spent together. Parents may feel an urgency to engage in accelerated parenting, and maintaining normalcy remains a consistent theme for the ill and healthy parent alike. Yet researchers agree that avoiding talking to their children about an impending death will not protect them from their thoughts about death. One study highlighted that when children are unable to understand what is happening within their family, they often blame themselves for the parent's illness.

While open and honest communication, even with very young children, is consistently found to lead to beneficial outcomes in terms of bereavement, there is a paucity of information on how to talk to children when a parent is dying. Practitioners from health, education and social services are identified as having a central role to play in providing support to grieving children and youth, yet multiple barriers prevent them from doing so. One of the most common cited barriers is a lack of training opportunities on the topic.

Identified as being of particular import, are the needs of siblings of children with life-threatening or life-limiting illnesses, a group that is often unacknowledged as needing specific support (see 'Post Death' for further discussion of this unmet need).

Post-Death

There is a significant amount of literature on the topic of supporting children after a death. The death of a parent or sibling has been found to be one of the most stressful life events that a child or youth can experience. The literature clearly documents the emotional toll that such a death takes on children and youth. Yet, unfortunately, the needs of grieving children are consistently found to be overlooked or unmet due to a variety of barriers. Parents and professionals struggle to know what to say, how much information to provide, and how to best support the grief process of children and youth.

The literature suggests that while many professionals (in health care, social services, education) express a desire to communicate with grieving children and their families, both their initial training and ongoing professional development fails to equip them with either the confidence or competence to engage in such conversations. Lack of awareness of available resources, support services and referral processes are also cited as common barriers to providing support to grieving children and youth.

A welcome development in this area is that current research is increasingly engaging the voice of bereaved youth in their studies; a refreshing change from previous generations of literature. Youth are clear in their desire for inclusion and honest information both prior to and following the death of someone close to them.

Some of the studies in this area focus on ways to support children. Others offer practical ways to help adolescents in coping with their normal grief reactions of sadness, anxiety, anger, feelings of rejection, and sense of worthlessness. A child's adjustment to the death of a parent is greatly influenced by the surviving parent's ability to attend to his or her own grief-related needs, to create and sustain a consistent and nurturing environment, and to encourage the child to express distressing or conflicting thoughts, feelings, and fantasies about the loss. Yet, the surviving parent's grief often compromises their ability to parent consistently and empathically.

Researchers illustrate how discontinuity, a lack of appropriate social support for both the child and surviving parent, and a failure to provide clear and honest information at appropriate time points relevant to the child's level of understanding can have serious implications for grieving children. These might include

negatively impacting the grieving child/youth into adulthood with regards to trust, relationships, self-esteem, feeling of self-worth, loneliness and isolation, and the ability to express feelings.

There has been growing recognition that the experience of having a sister or brother die is different from that of the death of a parent/caregiver. One study suggests that sisters are far more affected than brothers and that the cause of death is an important factor in sibling effects. Siblings in another study who reported dissatisfaction with communication, poor preparation for death, missed opportunities to say good-bye, and/or a perceived negative impact of the cancer experience on relationships tended to have higher distress and lower social support scores. Almost all siblings reported that their loss still affected them (in one study 12 years after the fact); half stated that the experience impacted current educational and career goals. The majority of bereaved young adults in one study had not worked through their grief over a sibling's death.

A limitation in this area of research, identified by one researcher, is the fact that child bereavement interventions are rarely subjected to rigorous evaluation. There is, nonetheless, encouraging evidence emerging regarding the efficacy of certain interventions for bereaved youth, at least one of which has been rigorously evaluated, representing an important development in this area.

An area in which there is little research available involves the impact on children and youth who experience multiple deaths.

Post-Death: Culturally & Linguistically Diverse Communities

There is a paucity of literature on this topic. The three studies noted offer some insight, primarily from the perspective of Islamic doctrine and Islamic traditions. An Iranian study looked at the effects of an Islamic model of grief intervention on adolescent girls grieving the death of close loved ones. The support intervention was found to be effective when compared to the control group who did not receive the intervention. This paper also highlights that the rate of children experiencing the death of a parent before the age of 18 is likely much higher in developing countries than it is in Western countries.

Another paper describes Sunni Muslim's view of death, mourning, and burial rituals and the implications for providing counselling to grieving Muslim pre-school and elementary children. This paper urges counsellors to promote social justice through equity in resources and services for marginalized groups. It also emphasizes the importance of counsellors receiving training in cultural competence.

The change, loss and grief experiences of children and young people with refugee backgrounds is explored in one study through a consideration of their resilience and also the challenges they have faced during their life in their home country, exile and resettlement, and the normal day-to-day experiences.

This section includes a listing of journal articles on end of life from the Jewish, Hindu, Muslin and Buddhist point of view.

Post-Death: Faith Communities

There is also a paucity of literature on this topic. The article found examines the Christian church's responses to childhood grief and includes a comprehensive review of childhood grief and highlights the importance of directly engaging past childhood grievers in order to gain an accurate evaluation of the support they receive. The article also emphasized the benefits of providing children with honest information about a loved one's death as opposed to leaving them with unanswered questions, in which case they often use their imaginations to come up with answers. The study concludes that a gap exists between what is needed to support grieving children and what is currently being provided in a large number of church communities. The need for training of church leadership as well as lay members on issues related to childhood grief is stressed.

An additional area that was found to require significant emphasis was how to best educate parents on the importance of explaining in child-appropriate terms the viewing of the person who died.

Post-Death: Children with Developmental Disabilities

Although a sizable literature investigates and describes children's grief, the majority of information focuses on typically developing children. Far less has been published about the loss and grief of children with developmental disabilities, even though this population experiences significant and multiple losses, increasing their vulnerability to negative outcomes such as pathological grief. One article explicates common losses and important grief-related challenges experienced. An overview of recommendations for supporting this population is included, such as how to communicate in an honest and concrete manner about concepts related to death and grief.

Post-Death: In the Classroom

A significant amount of literature was found in this area. Regardless of where in the world the research was conducted, many similar themes were identified. Teachers play a significant role in the lives of grieving students, yet they often feel ill equipped to support the grieving process of their students due to factors such as lack of training and a concern about saying the wrong thing. The desire for further support in terms of policy, curricula materials, practice direction, staff support, and continuing professional development programs is documented in many of the papers.

Most of the studies reported childhood grief related to the death of a close family member as having a significant impact on the school experience of students. One study perceived bereaved boys as more sensitive-isolated and victimized, while bereaved siblings in elementary grades were perceived by peers as less pro-social, more sensitive-isolated, less accepted, and as having fewer friends. Another study addresses the rarely mentioned, minimally investigated topic of peer taunting of parentally bereaved children.

Although school personal are found to express high levels of empathy and commitment toward grieving students, they also express limited knowledge about how child bereavement affects school performance, concentration, learning, and guilt for not doing more for bereaved children at school.

The importance of educators needing to be able to identify traumatic grief symptoms in children is also identified in the literature.

Post-Death: Suicide

While much has been written about the devastating experience of suicide loss in the adult population, the impact on sibling survivors of suicide is often overlooked, leading one article to refer to them as the "forgotten mourners." A reoccurring theme in the articles is the tendency of the needs of the grieving parent to overshadow the needs of the grieving sibling.

The authors of one study found that the perception of health services as being helpful was influenced by both the participants' and by the deceased siblings' experiences with health services. Still, almost all of the participants stated that health services should initiate contact with a bereaved sibling immediately after a suicide death to offer psychological support. Several participants also identified that they would have appreciated guidance from a professional about how to talk with their own children (when the time came) about their sibling's death by suicide.

The studies in this section document the significant levels of distress experienced by both siblings and friends of those who have committed suicide. The benefits of open communication among family mem-

bers and practitioners as a way of counteracting the stigma and silencing of the topic of suicide are stated and the need for a more proactive response from health and support services is strongly emphasized.