



CROSSROADS OF GRIEF PROJECT

Grieving or Bereaved Children: Literature Review 2015-2018

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Guelph, Canada

December 2018



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Foundation



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Preface

The Children & Youth Grief Network would like to acknowledge that this Literature Review, while covering studies inclusive of 2018 is neither fully comprehensive nor the sole source of the networks attempts to improve equity, systems change and cultural humility in the grief space.

The network accepts that the production and access to research, studies, data and publications is a continual process requiring ongoing and intentional funding and sourcing, both of which are beyond the scope of this review. In addition, the network understands that it is difficult and problematic to categorize individual circumstances and experiences of death and grief, such as the "categories" in the Table of Contents. Such categorization is intended to organize the review for useful reference but the network acknowledges that an individual's understanding of their own social location and self-identity will greatly influence their experience of grief and community resources and supports. It is likely that most individuals identify with multiple barriers at the same time and these identities may crossover, are fluid and can change over the life span.

It is the intention of the network to be mindful of the historical and prevailing context of oppression, exclusion and discrimination experienced by many and the pervasive role that mainstream systems often play in the perpetuation of inequity and injustice. By increasing knowledge of the current literature on the intersection of diversity and grief, the network continues a learning journey rooted in cultural humility and an intentional stance of receiving knowledge from other's experiences and withholding personal bias.

The Children & Youth Grief Network is committed to advancing its mission to advocate for educational opportunities and support services that will benefit all children and youth who are grieving the dying or the death of someone they care about. The network strives to achieve this by combining future research, advocacy, data collection, policy and best practices, education and most critically, hearing people most proximal to the social issues we are exploring.

The Children & Youth Grief Network recognizes that there is an historical lack of consistent terminology used to identify individuals in social categories and this will continue to change. We acknowledge that a variety of language/terms are used and we understand that literature reflects this variety. The Children and Youth Grief Network's intention is to be inclusive of different language used in all literature and attempts to explore experiences of all people.

Introduction

This 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 main focus is on evidence-based studies published in peer-reviewed journals, reflecting current thinking on the issues identified. A companion to this document is an 'Overview of the Literature,' summarizing key findings of the literature published to date and identifying gaps in research, e.g., specifically with respect to what can be described as vulnerable populations.

At a minimum, abstracts or summaries of the journal articles included in this review can be accessed online. Some journals also include with an abstract a list of (or a link to) authors' footnotes or references, providing additional information and/or resources.

Free online access to the full text of a number of the articles is indicated. Where this is not the case, there are a number of access options, including a subscription to the publication in question, payment of a one-time fee for access to the article of interest, or a request of the corresponding author for a copy of the article. An alternative is the possibility of obtaining a copy of an article through a university or hospital library with the necessary publisher's licensing agreement.

It must be emphasized that failure to obtain the necessary permission to reproduce or circulate/distribute an article would be in violation of any copyright protection with potential legal or financial consequences.

Regarding meeting the needs of vulnerable populations, there remains a paucity of evidence-based, published studies with respect to culturally and linguistically diverse communities, Indigenous and First Nations peoples, children within the lesbian, bisexual, gay and transgender communities, and children with intellectual or developmental disabilities. And, as pointed out further on in this document, it is important to acknowledge that culture and faith for some communities are synonymous, e.g., Hindu, Muslim.

It should be pointed out that in the academic literature there is little consistency in terminology when referring to indigenous peoples. In Canada, for example, First Nations is most widely (but not exclusively) used, but this does not necessarily include the Inuit or Métis.

A review of the literature was recently undertaken for Compassionate Ottawa as part of this group's schools initiative entitled: *Dying, Death, Loss and Grief: Building a Shared Language for School Communities*. This review for the Child & Youth Grief Network includes several articles from the review for Compassionate Ottawa in section 3.3. For more information, please visit *Compassionate Ottawa* at compassionateottawa.ca.

In the course of the search of the literature, a number of online sources were identified, some of which may already be familiar to the network and its partners. These are listed under 'Resources.'

Barry R. Ashpole

1. Children's Understanding of Dying & Death

2018

Children's and adults' understanding of death: Cognitive, parental, and experiential influences

JOURNAL OF EXPERIMENTAL CHILD PSYCHOLOGY, 2018;166(2):96-115. This study explored the development of understanding of death in a sample of 4 to 11-year-old British children and adults. It also investigated four sets of possible influences on this development: parents' religion and spiritual beliefs, cognitive ability, socio-economic status, and experience of illness and death. Participants were interviewed using the "death concept" interview that explores understanding of the sub-components of inevitability, universality, irreversibility, cessation, and causality of death. Children understood key aspects of death from as early as 4 or 5 years, and with age their explanations of inevitability, universality, and causality became increasingly biological. Understanding of irreversibility and the cessation of mental and physical processes also emerged during early childhood, but by 10 years many children's explanations reflected not an improved biological understanding but rather the co-existence of apparently contradictory biological and supernatural ideas – religious, spiritual, or metaphysical. Evidence for these coexistent beliefs was more prevalent in older children than in younger children and was associated with their parents' religious and spiritual beliefs. Socio-economic status was partly related to children's biological ideas, whereas cognitive ability and experience of illness and death played less important roles. There was no evidence for co-existent thinking among adults, only a clear distinction between biological explanations about death and supernatural explanations about the afterlife.

Abstract: <https://goo.gl/CsuPSU>

Children's understanding of death: From biology to religion

PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B, 2018;373(1754). Young children construct a biological conception of death, recognizing that death terminates mental and bodily processes. Despite this recognition, many children are receptive to an alternative conception of death, which affirms that the deceased has an afterlife elsewhere. A plausible interpretation of children's receptivity to this alternative conception is that human beings, including young children, are naturally disposed to remember and keep in mind individuals to whom they are attached even when those individuals leave and are absent for extended periods. This disposition is reflected in the pervasive tendency to talk about death as a departure rather than a terminus. It also enables the living to sustain their ties to the dead, even if, in the case of death, the departure is permanent rather than temporary. Linguistic and developmental evidence for these claims is reviewed. Possible biological origins and implications for archaeological research are also discussed.

Full text: <https://goo.gl/KtppNe>

Sources of children's knowledge about death and dying

PHILOSOPHICAL TRANSACTIONS OF THE ROYAL SOCIETY B, 2018;373(1754). Modern children have limited access to realistic information about death and dying. Alongside socio-cultural trends that have removed death from everyday life, many adults endorse attitudes of shielding children from the reality of death. Furthermore, it appears parents tend to underestimate what their children know about death, and often discuss the topic using euphemisms that actually contradict the biological facts. While media exposure is an increasing influence on children's learning, there is no research to date investigating how media portrayals influence children's developing death concepts. Drawing together the limited evidence reviewed above, and the advice of bereavement experts and clinicians, the authors offer tentative recommendations about how to teach modern children about death and dying can be made:

Full Text: <https://goo.gl/FNL27F>

2017

End-of-life in Disney and Pixar films: An opportunity for engaging in difficult conversation

OMEGA – JOURNAL OF DEATH & DYING | Online – 17 August 2017 – This study expanded upon previous scholarship by examining end-of-life (EoL) depictions and messages of death within Disney and Pixar animated films. The authors argue Disney and Pixar depictions of EoL and death can provide critical opportunities for discussing death and dying processes with children and adults alike. A content analysis of 57 movies resulted in a total of 71 character deaths. These instances of death became the discourse used for analysis. The EoL discourse was coded based on five categories: 1) Character status; 2) Depiction of death; 3) Death status; 4) Emotional reaction; and, 5) Causality). After quantitative analysis, the films were qualitatively analyzed. Four themes emerged from analysis: unrealistic moments, managing EoL, intentions to kill, and transformation and spiritual connection. Discussion of results, limitations, and directions for future research are included

Abstract: <https://goo.gl/QZLFTj>

Communication about dying, death, and bereavement: A systematic review of children's literature

JOURNAL OF PALLIATIVE MEDICINE, 2017;20(5):548-559. Children's books have the potential to facilitate communication about death for children living with a serious illness and for children coping with the death of a loved one. Two-hundred-ten books met inclusion criteria. The dying subject was primarily a grandparent or pet. Books on the experience of a child dying were scarce. The word death or dying was used in 75% of the books, while others utilized euphemisms. The majority of books featured animals or Caucasian subjects and included spiritual elements such as heaven. Less than one-quarter of the books included tools for readers to address the topic of death. Storybooks can be a helpful tool to introduce communication about dying and death with children. Gaps exist in current children's literature to effectively enable children to reflect on their own dying process. A general summary of available books is provided to assist those caring for children and families facing end-of-life issues.

Full Text: <https://goo.gl/EEbSzD>

A socio-cultural approach to children's perceptions of death and loss

OMEGA – JOURNAL OF DEATH & DYING, 2017;76(1):53-77. By employing the phenomenographic approach, the present study explored children's cognitive understanding of and emotional responses to death and bereavement. Participants included 52 Korean, 16 Chinese, and 16 Chinese American children ages 5-6. Thematic analysis of children's drawings and open-ended interviews revealed that most children associated death with negative emotions such as fear, anxiety, and sadness. The majority of children used realistic expressions to narrate death. The core themes from their drawings included causes for death, attempts to stop the dying, and situations after death. This study contributes to the literature by targeting young children who have been relatively excluded in death studies and provides evidence in the usefulness of drawings as a developmentally appropriate data collection tool. The findings also enrich our knowledge about children's understanding of death and bereavement, rooted in the inductive analysis of empirical data with children from culturally diverse backgrounds.

Abstract: <https://goo.gl/deXN3Z>

2016

Tales: A tool to address death with children

JOURNAL OF HOSPICE & PALLIATIVE NURSING, 2016;18(5):429-435. Children are curious about death, but it is also one of their biggest fears and a primary cause of sadness. Several authors argue that tales are an appropriate tool for addressing concepts of death. This article summarizes and evaluates 23 tales dealing with death in terms of their usefulness in helping 3 to 9-year-old children understand and cope with the concept of death.

Abstract: <http://goo.gl/gWyWda>

2015

Children's earliest experiences with death: Circumstances, conversations, explanations, and parental satisfaction

INFANT & CHILD DEVELOPMENT, 2015;24(2):157-174. Parents of children 2 to 7 years responded to an online survey regarding their children's experiences and conversations about death. A total of 75% of parents indicated that they had spoken to their child about death, and the majority of conversations were first initiated when children were between 3 and 3.5 years of age. Binary logistic regression analysis was used to explore factors that could predict conversations about death. Parents provided narratives of the explanations of death that they gave their child and subsequently reported their level of satisfaction with their explanation. The content of the explanations was coded and examined in relation to children's age and parental satisfaction. Results revealed that parents who provided explanations to a continued existence after death reported significantly higher levels of satisfaction than those parents who discussed the absence of a future physical relationship after death. Finally, explanations of a continued existence were not always in reference to an afterlife and could include discussing the memory of the deceased or their continued impact even after death. Thus, when talking to young children about death, parents may feel greater satisfaction in finding ways to discuss the continued legacy of those who have died compared to more biological explanations.

Abstract: <https://goo.gl/HJR74X>

British and Pakistani children's understanding of death: Cultural and developmental influences

BRITISH JOURNAL OF DEVELOPMENTAL PSYCHOLOGY, 2015;33(1):31-44. This study explored British and Pakistani 4 to 7-year-olds' understanding of death. The aim was to examine possible influences on the acquisition of the sub-components of the death concept by investigating how they are understood by children of different ages and cultural and religious backgrounds. Three groups of children were compared: White British and British Muslim living in London, and Pakistani Muslim living in rural Pakistan. In line with previous research, irreversibility of death was one of the first sub-components to be acquired, while causality was the last. The two groups of British children shared many similarities in their understanding of inevitability, applicability, irreversibility, and cessation. Pakistani Muslim children understood irreversibility earlier than did children in both British groups. In all three cultural groups, children's responses demonstrated very limited understanding of causality. The authors' findings support the view that aspects of a mature understanding of death develop between the ages of 4 and 7 years and that the process of understanding death as a biological event is, to a great extent, universal. They also suggest that aspects of children's reasoning are influenced by culturally specific experiences, particularly those arising from living in rural versus urban settings.

Abstract: <https://goo.gl/3oi6Yb>

2. Pre-Death

2.1 End-of-Life Care in Children and Adolescents

2018

“Will you remember me?”: Talking with adolescents about death and dying

CHILD & ADOLESCENT PSYCHIATRIC CLINICS OF NORTH AMERICA, 2018;27(4):511-526. This article describes the preparation, rationale and benefits of talking with adolescents who have life-threatening or life-limiting illness about advance care planning (ACP) and end-of-life concerns in a developmentally sensitive manner. The first step is to ensure a health care provider is ready to work with adolescents in ACP by taking a self-inventory, learning communication skills, and understanding individual barriers. The authors outline how to assess patient and family readiness, including developmental, cultural, personal, and psychosocial considerations. Evidence-based techniques for respectfully and productively engaging adolescents in ACP conversations are discussed.

First page review: <https://goo.gl/cpmEAG>

2015

Understanding death with limited experience in life: Dying children's and adolescents' understanding of their own terminal illness and death

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2015;9(1):40-45. Clinicians still find it difficult to speak with pediatric patients about death even though guidelines for facilitating communication on the topic exist. As a result, pediatric patients are less likely to develop a clear understanding of their illness and there is a disconnect between clinicians and parents about prognosis, even when clinicians have concluded there is no longer possibility for cure. Insufficient communication and poor understanding may increase the risk of patients feeling isolated, mistrustful and anxious, and deprive them of a role model who can communicate about painful issues or share difficult feelings. Despite these complexities, young people often show remarkable resiliency in the face of death and want to get the most out of the remaining time they have. The authors provide an up-to-date summary of the literature on children's and adolescents' understanding of their own terminal illness and death. They examine the challenges in researching this topic, obstacles to patients receiving information about prognosis, and how physical symptoms affect patients' ability to develop an understanding. The authors review sources of insight into pediatric patients' understanding, including the development of concepts of death, fears about their own death, legal interpretations of what patients understand, and how terminally ill young people continue to treasure life. The article addresses ways clinicians can use the knowledge they have to communicate well with dying children and adolescents and their families.

Full text: <https://goo.gl/aRihnZ>

Obstacles to the promotion of dialogue between parents, children and health professionals about death and dying in pediatric oncology

INTERNATIONAL ARCHIVES OF MEDICINE, 2015;8(126):1-5. Despite advances in cancer treatments and improved prognosis, the number of deaths from the disease is high in the world. In Brazil, cancer is the second leading cause of death among children and adolescents, forcing family members, patients and professionals to deal with the issues of human finitude. The multidisciplinary team considers the discussions at the end of life (EoL) as a difficult task to be performed on pediatric patients. The family is essential to overcome the communication barriers, acting as liaison between the multidisciplinary team and the patient. Children should be invited to participate in the decision-making process and their wishes should be honored at the EoL. Professionals should be able to meet the physical, psychosocial, spiritual, social and cultural rights of patients and families. Discussions at the EoL with pediatric patients are key to promoting a "good death," however there are few studies that address this issue.

Full text: <https://goo.gl/oLnm3X>

Talking about death with children with incurable cancer: Perspectives from parents

JOURNAL OF PEDIATRICS, 2015;167(6):1320-1326. Most parents in this study cited several reasons for not discussing death with their child. The authors findings highlight the sensitive and complex issues surrounding these conversations, indicating that there may be a role for clinicians in supporting parents. They were asked whether they had discussed the impending death with their child, whether they reflected on this discussion positively, their reasons for not discussing death with their child, and the manner in which the conversation regarding death occurred. Of the 86 parents of 56 children who participated, 55 parents (of 35 children) did not discuss the impending death with their child. The themes identified: 1) Parents' inability to discuss the impending death; 2) Parents' desire to protect their child; 3) Views regarding talking with children; 4) Parents' views of child characteristics; 5) Child's unwillingness to discuss the subject; 6) Lack of opportunity to talk; and, 7) Child's disability. The parents who did discuss death with their child generally used symbolic and/or religious narratives, or they had brief, direct conversations regarding death.

Abstract (w. link to references): <https://goo.gl/BFvPCX>

2.2 Sibling Perspectives

2018

Charity finds the needs of siblings of seriously ill children are ignored by government

U.K. (England) | *Charity Today* – 21 December 2018 – Brothers and sisters of seriously ill children risk being left with a long-term negative impact on their mental health and education unless there is more funding to support them, a report published by Rainbow Trust Children's Charity warns.¹ The report ... illustrates that demand for sibling support is increasing, and the mental health and educational attainment of brothers and sisters of seriously ill children can be affected by their situation. It calls on statutory authorities to recognise the value of sibling support and to fund it. The report includes testimonials from brothers and sisters supported by Rainbow Trust and data from children's hospices surveyed about the increasing need for sibling support. More than 70% of children's hospices, who responded to a 2018 Rainbow Trust survey of sibling support in England, said the demand for sibling support has increased over the last three years but only a third said that they can "always" meet demand.

<https://goo.gl/AEZEKN>

1. 'See us, Hear us, Notice us: The case for supporting siblings of seriously ill children,' Rainbow Trust Children's Charity, December 2018.

Download/view at: <https://goo.gl/gdmrh6>

Siblings' voices: A prospective investigation of experiences with a dying child

DEATH STUDIES, 2018;42(3):184-194. Sibling relationships reflect a unique childhood bond, thus the impact on a sibling when a child is seriously ill or dying is profound. The authors conducted a prospective, longitudinal, qualitative study over 2 years using interpretive descriptive methodology to understand siblings' perspectives when a brother or sister was dying at home or in hospital. The insights from the 10 siblings revealed complex experiences, both personal and with the ill child, their families, and peers. These experiences were paradoxically sources of strain and of support, revealing the importance of validation and normalization in assisting siblings to successfully navigate the experience.

Abstract (w. a link to references): <https://goo.gl/059E9o>

Children's perspectives on living with a sibling with a chronic illness

PEDIATRICS, 2018;142(2):e20174151. Clinical guidance emphasizes the importance of considering the whole family when caring for a child with a pediatric chronic illness. However, there is a lack of research specific to sibling experience. Parental accounts are used in studies to examine family experiences; consequently, the direct voices of siblings are neglected. The authors identified two overarching themes providing new insights: 1) "Changing relationships" (had two sub-themes: "changing family relationships" and "changing relationship to self"); 2) "Managing changes" (had three sub-themes: "coping and acceptance," "support from friends, peers, and support groups," and "negative reactions from others"). Studies were often descriptive with little explicit qualitative analysis. The findings are used to outline how changes in family relationships often result in reduced communication and a suppression of healthy siblings' needs. Siblings develop strategies to help them cope with and accept their circumstances, including finding new prosocial ways of meeting their needs in the form of skills and roles they develop.

Abstract: <https://goo.gl/u2fyhZ>

The hidden cost of cancer: The siblings' story, a mother's narrative on how three of her children journeyed through their 14-year-old sister's 9-month journey from ill health to death and beyond

ILLNESS, CRISES & LOSS | Online – 12 February 2018 – The siblings of children diagnosed with cancer can get lost in the cancer journey. Through a mother's eyes, this article examines the issues faced by three siblings when their teenage sister is diagnosed with and dies of cancer. It focuses on the impact their sister's illness has on their educational, social, emotional, and communication skills. Each sibling not only had their own unique set of needs, but this article argues that the term cancer survivor should also be extended to the siblings as they comprise an intrinsic part of the family's cancer journey. The article calls on professionals to adopt a holistic approach to reduce the impact that childhood cancer has on the siblings, and it highlights the far-reaching consequences of not properly supporting the siblings during this time.

Abstract: <https://goo.gl/qBYgKK>

2015

Supporting youth grieving the dying or death of a sibling or parent: Considerations for parents, professionals, and communities

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2015;9(1):58-63. Current research is directly engaging the voices of youth who have experienced a parent or sibling's death. Although there continues to be much evidence about the distressing effect of such deaths on children and adolescents, there is a welcome emerging tendency to distinguish between adaptive and maladaptive grief. Although the literature strongly encourages parents to take an open and honest approach to supporting youth prior to a death, many barriers remain to them doing so. The literature identifies healthcare providers as being ideally positioned to provide guidance to families around best practice in the area of preparing youth for the death of a parent or sibling. Following a death, there is now encouraging evidence regarding the efficacy of certain interventions for bereaved youth, both in the short and long term, which is an important development in the field.

Abstract: <https://goo.gl/Moetmk>

2.3 Parental Illness, Dying and Death

2018

Health and social care professionals' experiences of supporting parents and their dependent children during, and following, the death of a parent: A qualitative review and thematic synthesis

PALLIATIVE MEDICINE | Online – 29 October 2018 – Children need to be prepared for the death of a parent and supported afterwards. Parents seek support from health and social care professionals to prepare their children. Support is not always forthcoming. The search yielded 15,758 articles. Fifteen met the [authors'] inclusion criteria. A total of 13 included professionals' experiences of supporting parents and children before parental death. Two included experiences of supporting surviving parents and children afterwards. Three analytical themes identified as follows: 1) Aspiring to deliver family-focused care.; 2) Health and social care professionals' behaviors and emotion; and, 3) Improving connections with parents and children. Professionals struggle to connect empathically with parents and their children to prepare and to support children when a parent is dying and afterwards. Awareness of professionals' needs would enable provision of appropriate support for parents and children.

Abstract: <https://goo.gl/L5JWsZ>

Difficulties for a practitioner preparing a family for the death of a parent: A narrative inquiry

MORTALITY, 2018;23(3):247-260 A practitioner inquiry within an specialist palliative care context used narrative methods to explore difficulties faced by practitioners when assisting a family in the process of preparing a child for the death of a parent. In this account, the practitioners failed to facilitate advanced family preparation despite several attempts. Methods to address and overcome inherent ethical difficulties and reveal relational practice were developed. Data included naturally occurring conversations between practitioners relating to one family, systematically exploring difficulties faced and meaning constructed in depth. The data were then used to fictionalise a family account that re-presented actual challenges practitioners confronted. Reflexivity was used to unfold the layers of complex influences and ethical issues practitioners face when grappling with making meaning. Even with a clear understanding of processes and willingness to facilitate difficult conversations, practitioners face tensions between respect for a dying patient's needs, avoiding undermining the family culture and meeting children's needs. Contrary to the requirement to practise from an evidence base, some situations require the ability to work with 'not knowing'. Limitations include the subjective nature of the account and the smoothing over of complexity pertaining to lived experience.

Abstract (w. link to references): <https://goo.gl/QeRjVd>

Supporting parents and children prior to parental death in a National Health Service setting

BEREAVEMENT CARE, 2018;37(2):67-73. The Children & Families Service in Fife Specialist Palliative Care adopts a psycho-educational model of support which offers advice and information to enable parents to prepare themselves and their children for parental dying, death and bereavement. The role of the Children & Families Practitioner is to support the family as early as possible, through each stage of their journey through bereavement, as far as possible. Working closely with school staff and other services ensures that everyone concerned has the information they need from us to support the children and young people concerned.

Abstract (w. link to references): <https://goo.gl/GMdrqP>

Children's and young people's experiences of a parent's critical illness and admission to the intensive care unit: A qualitative metasynthesis

JOURNAL OF CLINICAL NURSING, 2018;27(15-16):2923-2932. Experiencing a parent's critical illness and admittance to the ICU is overwhelming. The bond between the parent and child is exposed by the separation from the ill parent. To comprehend and manage the experience, children and young people seek information depending on their individual capacities. They express a need to be close to their ill parent and to be seen and approached as close members of the family. However, children experience being overseen in their needs for support during their parent's ICU illness with the risk of being left in loneliness, sadness and lack of understanding of the parent's illness. Children and young people as relatives need to be acknowledged as close members of the family, when facing the illness trajectory of a parent, who is admitted to the ICU. They need to be seen as close family members and to be approached in their needs for support in order to promote their well-being during a family illness crisis. Early supportive interventions tailored to include children of the intensive care patient are recommended.

Abstract: <https://goo.gl/R3phwL>

2017

Troubling meanings of family and competing moral imperatives in the family lives of young people with a parent who is at the end of life

CHILDREN'S GEOGRAPHIES | Online – 12 July 2017 – This article draws on a narrative study of young people with a parent who is at the end of life (EoL) to examine how family lives are troubled by life-limiting parental illness. Young people struggled to reconcile the physical and emotional absence of family members with meanings of "family"; the extent to which young people could rely on family to "be there" in these troubling circumstances was of practical, emotional and moral significance. The authors' discussion is situated in the context of an English EoL care policy predicated on the ideal of a good death as one that takes place at home accompanied by family members. They explore how the shift away from family as a site for nurturing children towards family as a space to care for the dying is experienced by young people, and consider how these competing moral imperatives are negotiated through relational practices of care.

Abstract: <https://goo.gl/8MRM6G>

Preparing children for the loss of a loved one

UPTODATE | Online – 8 June 2017 – The terminal phase of illness is a vulnerable time in a family's life, especially when the person dying has dependent children. Concerns about the children's welfare and impulses to protect children from the pain of parental loss may create challenges to honest communication and family-focused care. One cannot underestimate how distressing the anticipated death of a parent can be, not only for the family but also for the clinical staff that are caring for the family. Clinicians should seek to understand the family structure, values, and functioning so that medical and supportive care can be provided to the family as a whole. Attention to the children's developmental stage and the family's specific needs and circumstances can guide clinicians in helping patients and family members to support children during the parent's illness and into the end of life period. In general, parents must be respected as experts on their own children, even if family functioning is complex or compromised. Their love and hopes should guide the clinical approach on how to prepare their children for one parent's impending death. This topic will address the issues surrounding the dying process and the death of a parent with dependent children, including the approach to parents, children, and the family as a unit. This topic will assume that the children are in a two-parent household with one parent having a terminal illness (the ill parent) and one being healthy. In families with a single parent, other relatives or caregivers may need to be enlisted to provide support. In addition, the authors refer to children (rather than a child) throughout this topic. They recognize that this family unit may not be applicable to all situations and discuss specific issues and approaches in other family situations wherever relevant.

Full text: <https://goo.gl/yRrQLS>

How to support teenagers who are losing a parent to cancer: Bereaved young adults' advice to healthcare professionals – A nationwide survey

PALLIATIVE & SUPPORTIVE CARE, 2017;15(3):313-319. This work derives from a Swedish nationwide survey and employs a qualitative approach with a descriptive/interpretive design to obtain answers to an open-ended question concerning advice to healthcare professionals. Of the 851 eligible young adults who had lost a parent to cancer when they were 13-16 years of age within the previous 6 to 9 years, 622 participated in our survey. Of these 622 young adults, 481 responded to the open-ended question about what advice to give healthcare professionals. Four themes emerged: 1) To be seen and acknowledged; 2) To understand and prepare for illness, treatment, and the impending death; 3) To spend time with the ill parent; and, 4) To receive support tailored to the individual teenager's needs. This nationwide study contributes hands-on suggestions to healthcare staff regarding attitudes, communication, and support from the perspective of young adults who, in their teenage years, lost a parent to cancer. Teenagers may feel better supported during a parent's illness if healthcare professionals take this manageable advice forward into practice and see each teenager as individuals; explain the disease, its treatments, and consequences; encourage teenagers to spend time with their ill parent; and recommend sources of support.

Abstract (w. list of references): <https://goo.gl/T3Mx2p>

Think adult – think child! Why should staff caring for dying adults ask what the death means for children in the family?

BRITISH MEDICAL BULLETIN, 2017;123(1):5-17. Bereaved children and young people in the U.K. are "hidden mourners." Children experience grief that varies according to the circumstance of death and their cognitive ability. Voluntary organizations can be supportive, but provision is patchy and vulnerable to austerity. Areas of concern include adult-centric denial of the importance and long-term consequences of childhood grief, and uncertainty in how best to relate to bereaved children in faiths and in schools. Growing points include increased awareness of the immediate and long-term consequences of childhood bereavement and that even young children can experience loss through death. "Think adult – think child" means that all staff caring for dying adults should take responsibility for asking what the death means for the children in the family, with schools, primary care and faith organizations having protocols and expertise available to support grieving children; recent catastrophes expose need for agencies to have management plans that focus on vulnerable children and young people.

Full text: <https://goo.gl/W8ocRs>

Supporting children facing a parent's cancer diagnosis: A systematic review of children's psychosocial needs and existing interventions

EUROPEAN JOURNAL OF CANCER CARE, 2017;26(1):e12432. This review aimed to 1) Summarise the psychosocial needs of children/adolescents (0-18 years) with a parent with cancer across the illness trajectory (diagnosis to bereavement); and, 2) Evaluate existing interventions for this population. Of 98 full text articles retrieved, 12 reported on children's psychosocial needs, and 12 intervention studies were identified. Three factors emerged as critical to consider in future intervention development: 1) Children need age-appropriate information about their parent's cancer; 2) Children require support communicating with parents, family members and health professionals; and, 3) Children need an environment where they feel comfortable sharing positive/negative emotions and can have their experiences normalised among peers. All intervention studies reported at least one positive outcome, however, only five reported significant improvements in child/family functioning based on validated quantitative measure/s. Variability in study design and quality, combined with considerable heterogeneity in intervention characteristics and outcome variables limited the conclusions, which could be drawn. Therefore, further carefully designed and scientifically evaluated interventions for children facing a parent's cancer diagnosis are clearly warranted.

Abstract: <http://goo.gl/VbnXLv>

Parents with cancer: Searching for the right balance between telling the truth and protecting children

PALLIATIVE & SUPPORTIVE CARE, 2017;15(1):88-97. Recent scientific approaches to cancer patients draw attention to the psychological aspects of the disease and the involvement of their families, who are forced to reorganize themselves in order to manage the patient's illness. Functional responses to a stressful event facilitate open communication between family members and empathy for the patient's children, who need to be involved and informed about the illness in a clear and open fashion. The goal of this study was to explore the communication styles used by cancer-stricken parents with their children and to identify a correlation with the patient's levels of anxiety and depression and their ability to cope. The authors also sought to understand whether location, severity, and time from diagnosis influenced communication, coping, anxiety, or depression. Results showed statistically significant correlations between higher levels of anxiety and depression and more closed communication styles. The coping styles "hopelessness/helplessness," "cognitive avoidance," and "anxious preoccupation" were associated with a closed communication style that is correlated with higher levels of anxiety and depression. Tumor location, time from diagnosis, and stage of disease did not show statistically significant correlations with anxiety, depression, coping mechanisms, or communication styles.

Abstract (inc. list of references): <http://goo.gl/OLKJrT>

2015

Parenting challenges in the setting of terminal illness: A family-focused perspective

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2015;9(1):52-57. The study of parental cancer has focused predominantly on the early stages of disease. Less is known about how families with minor children prepare for parental loss when the cancer is advanced. This review found evidence 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. This review also highlighted a growing evidence base affirming the importance of responsive communication prior to death.

Abstract: <https://goo.gl/ZPE6JS>

2.4 Parental Dementia

2018

“It was then that I thought ‘whaat? This is not my Dad’’: The implications of the ‘still the same person’ narrative for children and young people who have a parent with dementia

DEMENTIA, 2018;17(2):180-198. This research used auto/biographical interviews to explore the experiences of 19, 8 to 31 year olds who had a parent with dementia. Thematic analysis revealed challenges occasioned by the master narrative that people with dementia are “still” the same person they were prior to the onset of their condition. While this notion is – rightly – at the heart of person-centered care in dementia services, the “still” discourse conflicts with the experiences of young people. Their accounts suggest that the construction of their parent as the same person is not helpful and that, furthermore, expectations that they will behave and feel towards that parent as they did before are a source of distress in what is already a challenging situation. This paper highlights the need to equip young people with support that acknowledges that their parent may well be drastically different to the Mum or Dad they previously “knew.”

Abstract (inc. list of references): <https://goo.gl/xznWcB>

2017

“Every time I see him he’s the worst he’s ever been and the best he’ll ever be’’: Grief and sadness in children and young people who have a parent with dementia

MORTALITY, 2017;22(4):324-338. Research suggests that the grief experienced by the family members of persons with dementia has a distinctive nature that differentiates it from sorrow attendant on most other ill health causes. Over a variable period of time, 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: here we seek to add to the literature by re-presenting the grief-related perceptions and experiences of children and young people who have a parent with a young onset dementia. We draw on findings from a narrative auto/biographical investigation to describe what dementia grief was like for study participants and to make suggestions for resources and support for those in this position.

Abstract (inc. list of references): <https://goo.gl/cdDrrJ>

3. Post-Death

2018

Trauma-informed care and post-traumatic growth among bereaved youth: A pilot study

OMEGA – JOURNAL OF DYING & DEATH | Online – 10 October 2018 – Although a fair amount has been written about post-traumatic stress disorder among bereaved children and adolescents, less has been written about post-traumatic growth (PTG) and its predictors among this population. This study examines predictors of PTG and the impact of trauma-informed care on PTG among bereaved youth. A pre-experimental, pre-test/post-test design was applied to measure PTG among bereaved children before and after attending a healing camp that provides trauma-informed care. A regression model was applied to examine predictors of PTG. Results showed children participating in the camp increased their PTG scores to a statistically significant degree. Circumstance of death (sudden or expected) was a predictor in this study. The results are discussed in relation to limitations, implications for future research, and practice.

Abstract: <https://goo.gl/r2tExK>

2017

Prolonged grief and post-traumatic stress in bereaved children: A latent class analysis

PSYCHIATRY RESEARCH, 2017;258(12):518-524. Few studies have yet examined sub-groups among children (aged 8-18) confronted with the death of a close loved one, characterized by different profiles of symptoms of prolonged grief disorder (PGD) and symptoms of bereavement-related post-traumatic stress disorder (PTSD). This study sought to identify such sub-groups and socio-demographic and loss-related variables associated with sub-group membership. The authors used data from 332 children, most of whom were confronted with the death of a parent, mostly due to illness. Latent class analysis revealed three classes of participants: 1) A resilient class (38.6%); 2) A predominantly PGD class (35.2%); and, 3) A combined PGD/PTSD class (26.2%). Class membership was associated with self-rated levels of depression and functional impairment, and parent-rated behavioural problems. No significance between-class differences on demographics or loss-related variables were found. The current findings of distinct classes of PGD, and PGD plus PTSD attest to the construct validity of PGD as a distinct disorder, and can inform theory building and the development of diagnostic instruments relevant to children with pervasive distress following loss.

Abstract: <https://goo.gl/bGeJiN>

Embodied and sensory encounters: Death, bereavement and remembering in children's family and personal lives

CHILDRENS GEOGRAPHIES | Online – 26 October 2017 – Whilst children's "significant" death and bereavement experiences have received considerable attention as constituting a family trouble, this article examines children's rarely considered perspectives on encounters with death, bereavement and remembrance which are intrinsic to family and personal lives. Family homes are a site for younger children's previously unexplored embodied, sensory and material engagements with death, bereavement and remembrance. These engagements occur through children's treasuring and displaying of keepsakes and photographs, and through children bearing witness to dying pets and deceased bodies. Via these temporally and spatially located practices, familial and cultural values are passed on to children, family is constituted, and children are embedded in a broader kinship group. This article illuminates how children vividly recount experiences of death, bereavement and remembering, invoking "home" and other private spaces as places in which death is experienced and retold.

Abstract: <https://goo.gl/Tx86VW>

Bereavement in children and young people

OXFORD BIBLIOGRAPHIES | Online – 27 April 2017 – There is a tension in the literature between positivist approaches that try to discern universal norms – and deviations from these norms – for the process of bereavement, and constructivist approaches that maintain that understandings of bereavement vary across time and space. The field of literature on bereavement in children and young people is shaped by this tension, coupled with a parallel debate about the concept of childhood. The psychological literature undoubtedly dominates, and is largely rooted in research in Western countries, on the death of someone close, mainly a parent or sibling. The literature on bereaved children in developed countries has developed with little reference to the literature on bereaved children in developing countries, which are likely to have very different patterns of mortality, as well as different traditions of mourning and attitudes to childhood. This article explores the largely Western literature on contemporary bereavement in childhood, looking at children, young people, and adults' accounts of their experiences, before turning to theoretical approaches, and then outlining the literature on the outcomes of bereavement in this context. The article then looks at published works on the needs of children in these circumstances, guidelines for support in different contexts, and introduces debates on how to measure the effectiveness of this support. Finally, it looks at the literature on research with bereaved children and young people.

Full text: <https://goo.gl/nYATtH>

Risk of suicide, deliberate self-harm and psychiatric illness after the loss of a close relative: A nationwide cohort study

WORLD PSYCHIATRY, 2017;16(2):193-199. This nationwide study provides the first comprehensive assessment of the incidence of serious mental health conditions after the loss of a close relative. A significantly elevated risk of suicide, deliberate self-harm and psychiatric illness is shown, particularly in the first year after the loss. Loss of child or spouse resulted in higher risk, and young age, a history of mental illness and sudden losses were found to be specific risk factors. This study points to early identification of highrisk persons displaying adjustment problems in order to mitigate distress and reduce the risk of serious mental health conditions after loss of a close family member.

Full text: <https://goo.gl/FcDQzu>

Online emotion regulation in digitally mediated bereavement. Why age and kind of loss matter in grieving online

JOURNAL OF BROADCASTING & ELECTRONIC MEDIA, 2017;61(1):41-57. Research by media psychologists of emotional communication in online bereavement still leaves many questions unanswered. Previous research has identified similarities as well as differences in emotion regulation patterns of children, adolescents, and adults. The author's investigation of digitally mediated bereavement goes one step further by exploring additional types of mechanisms within the emotion regulatory processes of coping online. A total of four different bereavement platforms, used by mourners of differing ages and kinds of losses, from young children to widowers, were examined in a quantitative content analysis of online postings, generating insights into shared emotion regulation patterns and intimacy online. The findings highlight interpersonal empathy, irrespective of age of the bereaved or type of loss, but also disclose age-based differences in emotion regulatory processes. Implications for further media psychological analysis are laid out.

Abstract (w. a link to references): <https://goo.gl/RcWYw6>

N.B. The focus of this issue of the *Journal of Broadcasting & Electronic Media* is "practices of loss online." **Journal contents page:** <https://goo.gl/zjKtHu>. See also 'Death in The Digital Age: How Does Social Media Affect Children's Grief?' ('Resources,' p.74).

Best practices in children's bereavement: A qualitative analysis of needs and services

JOURNAL OF PAIN & SYMPTOM MANAGEMENT, 2016;52(6):e137. The purpose of the study is to consolidate the knowledge, resources, and recommended practices concerning children's bereavement so as to better understand what the service needs are in our community and how to best meet them. Nine bereavement experts, such as child grief counsellors and managers of children's bereavement groups, were interviewed for approximately sixty minutes each on current and best practices in children's bereavement. The interview transcripts were analyzed for major themes. Additionally, a quantitative review of 50 palliative patient medical charts was undertaken to better understand the demand for support in our community. The demand for support included areas such as children's understanding of illness and death, family functioning, and academic concerns. Services were offered to 92% of children whose parents or grandparents indicated a need for support. Most of these services offered were in the form of social work; however, 33% of patients were also offered specialized children's programs, informational resources, and books on how to speak to children about illness, death, and dying. There are consistent recommendations throughout literature and agreed upon by experts as to how children experience grief and what services should be available to them. Recommendations include: more cohesion between medical professionals and bereavement services, clear language in describing death and avoiding euphemisms, practices outside of one-on-one counselling such as bibliotherapy and play therapy, peer support from other bereaved children, increased communication and education in schools, and increased support over the summer months.

Abstract: <https://goo.gl/Nq16b6>

Supporting the grieving child and family

PEDIATRICS, 2016;138(3):e20162147. This clinical report offers practical suggestions on how to talk with grieving children to help them better understand what has happened and its implications and to address any misinformation, misinterpretations, or misconceptions. An understanding of guilt, shame, and other common reactions, as well as an appreciation of the role of secondary losses and the unique challenges facing children in communities characterized by chronic trauma and cumulative loss, will help the pediatrician to address factors that may impair grieving and children's adjustment and to identify complicated mourning and situations when professional counseling is indicated. Advice on how to support children's participation in funerals and other memorial services and to anticipate and address grief triggers and anniversary reactions is provided so that pediatricians are in a better position to advise caregivers and to offer consultation to schools, early education and child care facilities, and other child congregate care sites. Pediatricians often enter their profession out of a profound desire to minimize the suffering of children and may find it personally challenging when they find themselves in situations in which they are asked to bear witness to the distress of children who are acutely grieving.

Full text: <http://goo.gl/7NIMJE>

2015

“Help me. I am so alone.” Online emotional self-disclosure in shared coping-processes of children and adolescents on social networking platforms

COMMUNICATIONS: THE EUROPEAN JOURNAL OF COMMUNICATION RESEARCH, 2015; 40(4):403-423.

This article investigates the motives and patterns of children's and adolescents' interpersonal online communication on bereavement platforms. A qualitative content analysis of two different youth bereavement platforms illuminates how one common feature is the verbalization and illustration of missing support in the offline world. The substantial usage of social network platforms can be considered an extension of children's and adolescents' personal social environment. Furthermore, topics on bereavement platforms ultimately go beyond grief, as children and adolescents also include emotions such as hope, gratitude and cohesiveness. Communication within online bereavement communities enables a process known from off-line communication as transformation from a loss-oriented to restoration-oriented coping.

Abstract: <https://goo.gl/Kr6Ccn>

The “five stages” in coping with dying and bereavement: Strengths, weaknesses and some alternatives

MORTALITY | Online – 23 October 2018 – This article offers an analysis of one well-known psychological theory, the “five stages” in coping with dying and bereavement. Despite widespread acceptance among the general public and continued presence in some forms of professional education, it is argued that the “five stages” model is less attractive than it initially appears. Significant criticisms of the theory are set forth here, as well as notable strengths of its underlying foundations. Lessons to learn about this theory are offered in terms of both coping with dying and coping with bereavement. In addition, examples of alternative theories from the literature are presented in both spheres. Although the “five stages” model is important as a classical theory with constructive historical implications, it does not measure up to the standards of a sound theory in contemporary thinking, can actually do damage when misapplied to individuals or applied too rigidly, and should be set aside as an unreliable guide to both education and practice.

Abstract: <https://goo.gl/R8sMLF>

3.1 Death of a Sibling

2018

Psychosocial outcomes in cancer-bereaved children and adolescents: A systematic review

PSYCHO-ONCOLOGY, 2018;27(10):2327-2338. This is the first systematic review that integrates findings on psychosocial outcomes after parental or sibling cancer bereavement. Twenty-four studies, based on 13 projects, were included. Ten projects had cross-sectional designs. Only two projects used large, population-based samples and non-bereaved comparison groups. Bereaved children and adolescents showed similar levels of depression and anxiety compared with non-bereaved or norms. Severe behavioral problems were found rarely. However, in two large, population-based studies, about half of the bereaved individuals reported unresolved grief. Bereaved adolescents had a higher risk for self-injury compared with the general population in one large, population-based study. Communication with health-care professionals, family, and other people, social support, distress during illness, age, gender, and time because loss were associated with psychosocial bereavement outcomes. Results indicate a high level of adjustment in cancer-bereaved children and adolescents. A modifiable risk factor for adverse psychosocial consequences is poor communication.

Abstract: <https://goo.gl/dGkQhX>

Emotional security theory: An application to sibling bereavement

DEATH STUDIES | Online – 12 September 2018 –The present study investigated the relevance of emotional security theory in a sample of 72 young adults who experienced sibling bereavement. The authors investigated: 1) Whether perceptions of prolonged parental grief predicted key aspects of emotional security (disengagement, preoccupation, and security); and, 2) Whether emotional security mediated a relation between perceptions of prolonged parental grief and young adult emotional functioning. Results supported the potential utility of emotional security theory as a theoretical framework for understanding sibling bereavement.

Abstract: <https://goo.gl/Brzv1X>

Cancer-bereaved siblings' positive and negative memories and experiences of illness and death: A nationwide follow-up

PALLIATIVE & SUPPORTIVE CARE, 2018;16(4):406-413. In this nationwide Swedish study bereaved siblings' responses were categorized into four different themes: 1) Endurance versus vulnerability; 2) Family cohesion versus family conflicts; 3) Growth versus stagnation; and, 4) Professional support versus lack of professional support. The first theme expressed endurance as the influence that the ill siblings' strong willpower, good mood, and stamina in their difficult situation had on healthy siblings, whereas vulnerability was expressed as the feeling of emptiness and loneliness involved with having an ill and dying sibling. In the second theme, family cohesion was expressed as the bonds being strengthened between family members, whereas family conflicts often led siblings to feel invisible and unacknowledged. In the third theme, most siblings expressed the feeling that they grew as individuals in the process of their brother's or sister's illness and death, whereas others experienced stagnation because of the physical and mental distress they bore throughout this time, often feeling forgotten. In the last theme – professional support – most siblings perceived physicians and staff at the hospital as being warm, kind, and honest, while some siblings had negative experiences. The study shows that bereaved siblings can have positive memories and experiences. The significance of the positive buffering effect on bereaved siblings' own endurance, personal growth, family cohesion, and social support should be noted. This knowledge can be valuable in showing healthcare professionals the importance of supporting the siblings of children with cancer throughout the cancer trajectory and afterwards into bereavement.

Abstract (w. list of references): <https://goo.gl/F1gpWf>

Grief and growth in bereaved siblings: Interactions between different sources of social support

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):363-371. The objective of this study was to characterize the relation between different sources of school-based social support (friends, peers, and teachers) and bereaved siblings' grief and grief-related growth and to examine whether non-parental sources of social support buffer the effects of low parent support on bereaved siblings. Families were recruited from cancer registries at 3 pediatric institutions 3-12 months after a child's death. Bereaved siblings were 8-18 years old and majority female (58%) and White (74%). During home visits, siblings reported their perceptions of social support from parental and non-parental sources using the Social Support Scale for Children, as well as grief and grief-related growth using the Hogan Sibling Inventory of Bereavement. Parent, friend, and teacher support were positively correlated with grief-related growth, whereas parent and peer support were negatively correlated with grief for adolescents. Teacher and friend support significantly moderated the association between parent support and grief such that teacher and friend support accentuated the positive effects of parent support. Friend and peer support moderated associations between parent support and grief/growth for adolescents but not children. School-based social support, namely from friends, peers, and teachers, appears to facilitate the adjustment of bereaved siblings. Findings suggest that bereaved siblings may benefit from enhanced support from teachers and friends regardless of age, with middle/high school students particularly benefitting from increased support from close friends and peers.

Abstract: <https://goo.gl/rNPqx6>

The hidden cost of cancer: The siblings' story, a mother's narrative on how three of her children journeyed through their 14-year-old sister's 9-month journey from ill health to death and beyond

ILLNESS, CRISES & LOSS | Online – 12 February 2018 – The siblings of children diagnosed with cancer can get lost in the cancer journey. Through a mother's eyes, this article examines the issues faced by three siblings when their teenage sister is diagnosed with and dies of cancer. It focuses on the impact their sister's illness has on their educational, social, emotional, and communication skills. Each sibling not only had their own unique set of needs, but this article argues that the term cancer survivor should also be extended to the siblings as they comprise an intrinsic part of the family's cancer journey. The article calls on professionals to adopt a holistic approach to reduce the impact that childhood cancer has on the siblings, and it highlights the far-reaching consequences of not properly supporting the siblings during this time.

Abstract: <https://goo.gl/qBYgKK>

Care at end of life influences grief: A nationwide long-term follow-up among young adults who lost a brother or sister to childhood cancer

JOURNAL OF PALLIATIVE MEDICINE, 2018;21(2):156-162. A majority of cancer-bereaved siblings report long-term unresolved grief, thus it is important to identify factors that may contribute to resolving their grief. Several predictors for unresolved grief were identified: siblings' perception that it was not a peaceful death, limited information given to siblings the last month of life, information about the impending death communicated the day before it occurred, siblings' avoidance of the doctors, and lack of communication with family and people outside the family about death. Depressive symptoms and time since loss also predicted unresolved grief. Together, these predictors explained 54% of the variance of unresolved grief.

Abstract: <https://goo.gl/YnVGv8>

2017

Spirituality and religious coping are related to cancer-bereaved siblings' long-term grief

PALLIATIVE & SUPPORTIVE CARE | Online – 20 December 2017 – Many bereaved siblings have still not come to terms with their grief many years after the loss, but few studies have focused on what can help. The aims of this study were to identify cancer-bereaved adolescents' and young adults' ways of coping with grief after loss of a sibling, and examine whether these ways of coping were related to their experience of having worked through their grief. This nationwide survey of 174 cancer-bereaved siblings is based on one open-ended question about coping with grief ("What has helped you to cope with your grief after your sibling's death?") and one closed-ended question about siblings' long-term grief ("Do you think you have worked through your grief over your sibling's death?"). The siblings described four ways of coping: 1) Thinking of their dead brother/sister and feeling and expressing their grief; 2) Distracting or occupying themselves; 3) Engaging in spiritual and religious beliefs/activities; and, 4) Waiting for time to pass. One of these categories of coping with grief, namely, engaging in spiritual and religious beliefs and activities, was associated with siblings' experience of having worked through their grief two to nine years after the loss.

Abstract (inc. list of references): <https://goo.gl/amycc6>

Consequences of sibling death problematic, potentially predictable, and poorly managed

JAMA PEDIATRICS, 2017;171(6):519-520. The death of a loved one is a traumatic life event associated with increased mortality and poor health. Although studies have examined the association among bereavement, mental disorder outcomes, and elevated risk for mortality in spouses, parents, and offspring, sibling bereavement is less studied. Coined "forgotten grievers, bereaved siblings experience the long-term effect of bereavement on their health and social environments. This is especially true when sibling bereavement occurs during the formative childhood years. Understanding the health and mortality risks associated with sibling bereavement is an important research area and essential component in the development of interventions designed at promoting the health and well-being of individuals who have experienced the death of a sibling.

Abstract: <https://goo.gl/2Md81m>

School aged children's experiences 7 and 13 months following a sibling's death

JOURNAL OF CHILD & FAMILY STUDIES, 2017;26(4):1112-1123. This study described 6 year to 12-year-old children's responses 7 and 13 months after siblings' death. Using semi-structured interviews, at 7 months, children were asked about events around their sibling's death. At both 7 and 13 months, children were asked about their thoughts and feelings about the deceased, concerns or fears, and life changes since the death. Thirty one children (58% female), recruited from four South Florida hospitals and Florida obituaries, participated. Children's mean age was 8.4 years; 64.5% were Black, 22.5% Hispanic, 13% White. Interviews were analyzed using conventional content analysis. Resulting themes: 1) Circumstances of the death; 2) Burial events; 3) Thinking about and talking to the deceased sibling; 4) Fears; and, 5) Life changes. Most children knew their sibling's cause of death, attended funeral/memorials, thought about and talked to their deceased sibling, reported changes in family and themselves over the 13 months. Fears (something happening to themselves, parents, other siblings – death, cancer, being snatched away) decreased from 7 to 13 months especially in 7-year to 9-year-olds. Seven-year to 9-year-olds reported the greatest change in themselves from 7 to 13 months. More Black children and girls thought about the deceased and reported more changes in themselves over the 13 months. School aged children thought about and talked with their deceased sibling, reported changes in themselves and their family and their fears decreased over the first 13 months after their sibling's death.

Abstract (w. list of references): <https://goo.gl/WY2pYQ>

Sibling supporters' experiences of giving support to siblings who have a brother or a sister with cancer

JOURNAL OF PEDIATRIC ONCOLOGY NURSING, 2017;34(2):83-89. All 12 sibling supporters currently working in Sweden participated in this study from which five categories emerged, showing they supported siblings from diagnosis until possible death. They enabled siblings who were in the same situation to meet each other and arranged activities suited to their ages, as well as offering an encouraging environment. To help the siblings, the sibling supporters found it necessary to interact with both the parents and the ward staff. They felt their support was important and necessary in helping siblings promote their own health both when the sick child was alive and also after his or her death. Their experience was that they listened to the siblings' stories and met them when they were in their crisis.

Abstract: <http://goo.gl/Zt6GWL>

2016

Bereaved siblings' advice to health care professionals working with children with cancer and their families

JOURNAL OF PEDIATRIC ONCOLOGY NURSING, 2016;33(4):297-305. Siblings of children with cancer experience psychosocial distress during the illness and after bereavement, but often stand outside the spotlight of attention and care. This study explored bereaved siblings' advice to health care professionals (HCPs) working with children with cancer and their families. The most common advice, suggested by 56% of siblings, related to their own support. One third suggested giving better medical information to siblings. Some siblings wanted to be more practically involved in their brother's/sister's care and suggested that HCPs should give parents guidance on how to involve siblings. Other common advice related to psychosocial aspects, such as the siblings' wish for HCPs to mediate hope, yet also realism, and the importance of asking the ill child about what care they wanted. Information, communication, and involvement should be emphasized by HCPs to support siblings' psychosocial needs in both the health care setting and within the family.

Abstract: <https://goo.gl/P6wg4M>

Because I'm also part of the family. Children's participation in rituals after the loss of a parent or sibling: A qualitative study from the children's perspective

OMEGA – JOURNAL OF DEATH & DYING, 2016;73(2):141-158. The objective of this study was to examine how Norwegian children today are included in death-related rituals after the loss of a parent or sibling, how they experienced their own participation, and to explore the meaning the rituals had for them. The study indicates that it was very important for the children to be included in the rituals and accordingly be recognized as grievers alongside adults. Being included contributes to legitimating their status as a "full" member of the family system, with an equal status to adult grievers in an important and vulnerable phase of the family's life. The children were pleased that they through ritual performances were given the opportunity to "see for themselves," both in order to better comprehend and accept the reality of the loss and to take farewell with their loved ones.

Abstract: <https://goo.gl/P8qQPY>

2015

Bereaved parents' strategies and reactions when supporting their surviving children

WESTERN JOURNAL OF COMMUNICATION, 2015;79(5):533-554. Bereaved parent-child communication and support can significantly affect surviving children's well-being and family functioning, yet offering support may be difficult for bereaved parents amidst their own distress. The results from 11 in-depth interviews outline bereaved parents' support strategies (e.g., direct conversation, concealment, sharing space and time, enabling outside communication, commemoration) and positive and negative reactions. This study focused on support from the provider perspective, so implications for parental support and grief processes are discussed. Practical considerations for supporting surviving children are explored.

Abstract (w. link to references): <https://goo.gl/vBwYAd>

Always with me: Understanding experiences of bereaved children whose baby sibling died

DEATH STUDIES, 2015;39(4):242-251. An arts-based qualitative method was used to explore the experiences of children's bereavement after a baby sibling's death, in the context of their family and school life. Data were collected during in-depth interviews with 9 bereaved children and 5 parents from 4 Canadian families and analyzed. A central process, evolving sibling relationship over the years, and a pattern of vulnerability/resilience, ran through all four themes, which reflected ideas of connection, impact of parental grief, disenfranchisement and growth. Findings indicated that home and school are critical to children in creating safe spaces for expressing the evolving nature of infant sibling bereavement.

Abstract (w. link to references): <https://goo.gl/KFhmiK>

Supporting youth grieving the dying or death of a sibling or parent: Considerations for parents, professionals, and communities

CURRENT OPINION IN SUPPORTIVE & PALLIATIVE CARE, 2015;9(1):58-63. Current research is directly engaging the voices of youth who have experienced a parent or sibling's death. Although there continues to be much evidence about the distressing effect of such deaths on children and adolescents, there is a welcome emerging tendency to distinguish between adaptive and maladaptive grief. Although the literature strongly encourages parents to take an open and honest approach to supporting youth prior to a death, many barriers remain to them doing so. The literature identifies healthcare providers as being ideally positioned to provide guidance to families around best practice in the area of preparing youth for the death of a parent or sibling. Following a death, there is now encouraging evidence regarding the efficacy of certain interventions for bereaved youth, both in the short and long term, which is an important development in the field.

Abstract: <https://goo.gl/Moetmk>

3.2 Death of a Parent

2018

Psychosocial outcomes in cancer-bereaved children and adolescents: A systematic review

PSYCHO-ONCOLOGY, 2018;27(10):2327-2338. This is the first systematic review that integrates findings on psychosocial outcomes after parental or sibling cancer bereavement. Twenty-four studies, based on 13 projects, were included. Ten projects had cross-sectional designs. Only two projects used large, population-based samples and non-bereaved comparison groups. Bereaved children and adolescents showed similar levels of depression and anxiety compared with non-bereaved or norms. Severe behavioral problems were found rarely. However, in two large, population-based studies, about half of the bereaved individuals reported unresolved grief. Bereaved adolescents had a higher risk for self-injury compared with the general population in one large, population-based study. Communication with health-care professionals, family, and other people, social support, distress during illness, age, gender, and time because loss were associated with psychosocial bereavement outcomes. Results indicate a high level of adjustment in cancer-bereaved children and adolescents. A modifiable risk factor for adverse psychosocial consequences is poor communication.

Abstract: <https://goo.gl/dGkQhX>

Understanding grief in children who have lost a parent with cancer: How do they give meaning to this experience? Results of an interpretative phenomenological analysis

DEATH STUDIES, 2018;42(10):483-490. Though the adjustment of bereaved children is increasingly investigated through quantitative studies, their intimate representations regarding the loss of their parent remain unknown. This qualitative study aims at exploring how they give meaning to this experience. Nondirective interviews with bereaved children were conducted and submitted to an interpretative phenomenological analysis. Fourteen children (8 boys, 6 girls, mean age 8.5 years) were recruited. Seven major themes depicting their grief experience were identified. The importance of the surviving parent is critically highlighted. Findings suggest that the remaining parent could become a fundamental actor in providing grief support for the bereaved children.

Abstract (w. link to references): <https://goo.gl/soGxFi>

“Don’t bother about me.” The grief and mental health of bereaved adolescents

DEATH STUDIES, 2018;42(10):607-615. Death of a relative or friend is a potentially disruptive event in the lives of adolescents. To provide targeted help, it is crucial to understand their grief and mental health experiences. Thematic analysis of 39 semi-structured telephone interviews yielded two themes: grieving apart together, and personal growth. High self-reliance and selective sharing were common. Feelings of guilt and “why” questions seemed more pronounced among the suicide bereaved. There was strong evidence of personal growth, increased maturity and capacity to deal with personal mental health/suicidality. Despite its devastating effects, experiencing a death can be a catalyst for positive mental health.

Abstract (w. link to references): <https://goo.gl/d6bSrK>

“Death lay here on the sofa”: Reflections of young adults on their experience as caregivers of parents who died of cancer at home

QUALITY HEALTH RESEARCH | Online – 27 September 2018 – The prevalence of terminally ill patients, who die at home, is increasing. The aim of this study was to address the meaning of being young adults, who were the caregivers of their dying parents. In-depth, semi-structured interviews were conducted with 14 Israeli Jewish young adults, who had been the primary caregivers for parents who had cancer and eventually died at home. Three themes emerged: 1) “I was Chosen and was led into that situation”: modes of taking on and performing the role of a caregiver.; 2) “My life was on hold”: the experience of performing the caregiving role; and 3) “I underwent ... the real school of life”: caring for the dying parent as an imprint on self-development. Participants integrated compassionate caring into their identity, reflecting an empowering encounter of young carers with their dying parents as a process of growth in the face of harsh, stressful experiences.

Abstract: <https://goo.gl/WbpMu5>

Childhood bereavement: The role of the surviving parent and the continuing bond with the deceased

DEATH STUDIES, 2018;42(7):415-425. This study investigated the relationship between the role of the surviving parent in the child's grieving process, the continuing bond (CB) with the deceased parent and biopsychosocial functioning, and active grief in adulthood. A survey of 135 adults, parentally bereaved in childhood, indicated the surviving parent's role in facilitating the grieving process promoted a positive CB with the deceased in childhood as well as general functioning in adulthood. The CB with the deceased had a weak association with both better general functioning and relational active grief.

Abstract (w. link to references): <https://goo.gl/tm94xT>

Cause of caregiver death and surviving caregiver coping style predict thwarted belongingness in bereaved youth

ARCHIVES OF SUICIDE RESEARCH | Online – 23 May 2018 – Both *bereavement* and *thwarted belongingness* serve as risk markers for youth suicide-related behaviors. This study examined candidate predictors of thwarted belongingness among bereaved youth, including caregiver cause of death and surviving caregiver coping style. Forty-three caregiver-bereaved families (58 children aged 7-13 years old) participated in a longitudinal study investigating associations between hypothesized bereavement-related contextual factors and youth thwarted belongingness. Cause of caregiver deaths included anticipated deaths preceded by illness (37%), sudden natural deaths (25.6%), accidental deaths (20.9%), death by suicide (9.3%), and death from drug overdose). Children's thwarted belongingness was significantly higher among youth bereaved by suicide compared to youth bereaved by youth bereaved by sudden natural death, accident, and anticipated death by illness. Implications for risk screening and assessment of suicide risk among bereaved youth are discussed.

Abstract: <https://goo.gl/hsM1dw>

Meaning of the death of an elderly father: Two sisters' perspectives

OMEGA – JOURNAL OF DEATH & DYING, 2018;66(3):195-213. Multiple bereaved adult children, as siblings, have rarely been studied. The authors expand the paradigm of bereavement research to explore the ways that two sisters describe the experience and meaning of the death of their elderly father. The two sisters each participated in two separate qualitative ethnographic interviews, followed by standard qualitative analyses of the transcribed narratives. The findings yield contrasting perspectives of the sisters' disparate views of their family, of their father, and their views of each other, that provide insight into the complexity of the sharp differences in their reactions to their father's death. Their views of their father's death reflected their particular relationship with their father, their non-shared experiences over the life course, and their personal world views. Differences and contradictions in the views of multiple siblings can broaden our understanding of bereavement and of the processes central to parent-child ties at the end of life.

Abstract: <https://goo.gl/HHMvJa>

Out of the mouths of babes: Links between linguistic structure of loss narratives and psychosocial functioning in parentally bereaved children

JOURNAL OF TRAUMATIC STRESS, 2018;31(3):342-351. Participants included 44 children (54.5% male) aged 7 to 12 years who were bereaved by the death of a caregiver. Children were assessed via self and caregiver-report measures and an in-person interview regarding the loss of their caregiver. Linguistic categories included pronouns and verb tense. Drawing from linguistic and self-distancing theories, the authors hypothesized that children's use of language reflecting self-distancing (third-person pronouns and past tense) or social connectedness (first-person plural pronouns) would be negatively associated with psychological/behavioral distress and avoidant coping. Similarly, the authors expected that children's use of self-focused language (first-person singular pronouns and present tense) would be positively associated with psychological/behavioral distress and avoidant coping. As hypothesized, preliminary findings suggest that children who employed more self-distancing language and used more social connectedness words reported less avoidant coping... Also as hypothesized, children who employed more self-focused language had higher levels of self-reported post-traumatic stress symptoms ... and avoidant coping ... and higher parent-reported psychological/behavioral distress. Implications for theorybuilding, risk screening, and directions for future research with bereaved youth are discussed.

Abstract: <https://goo.gl/eqNBqk>

2017

Distrust in the end-of-life care provided to a parent and long-term negative outcomes among bereaved adolescents: A population-based survey study

JOURNAL OF CLINICAL ONCOLOGY, 2017;35(27):3136-3142. Previous research shows that the death of a parent places children at risk for a number of negative outcomes. The role of trust in health care at the end of life has been acknowledged as crucial for patients and adult family members. However, the consequences of children's distrust in the care provided to their parents remain unknown. The authors investigated the negative long-term outcomes of cancer-bereaved sons' and daughters' distrust in the care that was provided to a dying parent. In those who reported no or little trust (i.e., distrust) in the health care provided to their dying parents, we found statistically significantly higher risks of various negative outcomes at the time of survey :bitterness toward health care professionals for not having done everything that was possible and for having stopped treatment, self-destructiveness (e.g., self-injury), and psychological problems (e.g., moderate to severe depression).

Full text: <https://goo.gl/zNxmK3>

Prolonged grief and post-traumatic stress in bereaved children: A latent class analysis

PSYCHIATRY RESEARCH, 2017;258(12):518-524. Few studies have yet examined sub-groups among children (aged 8-18) confronted with the death of a close loved one, characterized by different profiles of symptoms of prolonged grief disorder (PGD) and symptoms of bereavement-related post-traumatic stress disorder (PTSD). This study sought to identify such sub-groups and socio-demographic and loss-related variables associated with sub-group membership. The authors used data from 332 children, most of whom were confronted with the death of a parent, mostly due to illness. Latent class analysis revealed three classes of participants: 1) A resilient class (38.6%); 2) A predominantly PGD class (35.2%); and, 3) A combined PGD/PTSD class (26.2%). Class membership was associated with self-rated levels of depression and functional impairment, and parent-rated behavioural problems. No significance between-class differences on demographics or loss-related variables were found. The current findings of distinct classes of PGD, and PGD plus PTSD attest to the construct validity of PGD as a distinct disorder, and can inform theory building and the development of diagnostic instruments relevant to children with pervasive distress following loss.

Abstract: <https://goo.gl/bGeJiN>

Factors underlying the relationship between parent and child grief

OMEGA – JOURNAL OF DYING & DEATH | Online – 24 August 2017 – The death of a parent in a child's life is a significant risk factor for later mental and physical health problems. While much has been written about the surviving parent's functioning and its effects on their bereaved children, little work has been done to look into factors underlying this effect such as how the parent copes. The present study recruited 38 parent-child dyads from a community-based grief support center. Parent and child, independently, completed various measures of emotional functioning, including grief symptoms and coping such as social support and locus of control. The results indicated that parental coping did have an impact on children's grief symptoms. This represents a unique view of adaptation in bereaved children: Parental coping strategies can have an impact on the child, independent of the child's coping strategies. By focusing on parent coping, we have highlighted another possible pathway through which parental functioning affects children's grief.

Abstract: <https://goo.gl/KTYSw4>

When a parent dies: A systematic review of the effects of support programs for parentally bereaved children and their caregivers

BMC PALLIATIVE CARE | Online – 10 August 2017 – The included studies were published between 1985 and 2015, with the majority published 2000 onwards. They were published within several disciplines, such as psychology, social work, medicine and psychiatry, which illustrates that support for bereaved children is relevant for different professions. The interventions were based on various forms of support: group interventions for the children, family interventions, guidance for parents and camp activities for children. In fourteen studies, the interventions were directed at both children and their remaining parents. These studies revealed that when parents are supported, they can demonstrate an enhanced capacity to support their children. In three studies, the interventions were primarily directed at the bereaved children. The results showed positive between group effects both for children and caregivers in several areas, namely large effects for children's traumatic grief and parent's feelings of being supported; medium effects for parental warmth, positive parenting, parent's mental health, grief discussions in the family, and children's health.

Full text: <https://goo.gl/Vp1HdX>

Think adult – think child! Why should staff caring for dying adults ask what the death means for children in the family?

BRITISH MEDICAL BULLETIN, 2017;123(1):5-17. Bereaved children and young people in the U.K. are "hidden mourners." Children experience grief that varies according to the circumstance of death and their cognitive ability. Voluntary organizations can be supportive, but provision is patchy and vulnerable to austerity. Areas of concern include adult-centric denial of the importance and long-term consequences of childhood grief, and uncertainty in how best to relate to bereaved children in faiths and in schools. Growing points include increased awareness of the immediate and long-term consequences of childhood bereavement and that even young children can experience loss through death. "Think adult – think child" means that all staff caring for dying adults should take responsibility for asking what the death means for the children in the family, with schools, primary care and faith organizations having protocols and expertise available to support grieving children; recent catastrophes expose need for agencies to have management plans that focus on vulnerable children and young people.

Full text: <https://goo.gl/W8ocRs>

2016

Growing from grief: Qualitative experiences of parental loss

OMEGA – JOURNAL OF DYING & DEATH, 2016;73(3):203-230. Currently, there are 2.5 million children in the U.S. who suffered the loss of a parent. Grieving children are more likely to experience symptoms of depression and anxiety compared with their non-grieving peers. Adults who experienced a loss during childhood were interviewed to assess what was most helpful and most harmful in coping through the years following the death. The qualitative descriptions were coded and analysis of common themes determined. Five theoretical constructs were found: adjustment to catastrophe, support, therapy, continuing a connection with the deceased parent, and reinvestment. The findings have clinical applications for bereaved children, their families, and clinical programs targeting this population. The unique insights provide an emotionally salient expression of their experiences and provide a framework for how best to support this group.

Abstract: <https://goo.gl/mzA49d>

Because I'm also part of the family. Children's participation in rituals after the loss of a parent or sibling: A qualitative study from the children's perspective

OMEGA – JOURNAL OF DEATH & DYING, 2016;73(2):141-158. The objective of this study was to examine how Norwegian children today are included in death-related rituals after the loss of a parent or sibling, how they experienced their own participation, and to explore the meaning the rituals had for them. The study indicates that it was very important for the children to be included in the rituals and accordingly be recognized as grievers alongside adults. Being included contributes to legitimating their status as a "full" member of the family system, with an equal status to adult grievers in an important and vulnerable phase of the family's life. The children were pleased that they through ritual performances were given the opportunity to "see for themselves," both in order to better comprehend and accept the reality of the loss and to take farewell with their loved ones.

Abstract: <https://goo.gl/P8qQPY>

The effects of the family bereavement program to reduce suicide ideation and/or attempts of parentally bereaved children six and fifteen years later

SUICIDE & LIFE THREATENING BEHAVIOR, 2016;46(S1):S32-S38. Findings concerning the long-term effects of the Family Bereavement Program (FBP) to reduce suicide ideation and/or attempts of parentally bereaved children and adolescents are presented. Parental death is a significant risk factor for suicide among offspring. This study is a long-term follow-up of 244 children and adolescents who had participated in a randomized trial of the FBP, examining the intervention effects on suicide ideation and/or attempts as assessed through multiple sources. Results indicate a significant effect of the FBP to reduce suicide ideation and/or attempts at the 6 and 15-year follow-up evaluation. The findings support the potential benefits of further research on "upstream" suicide prevention.

Abstract (w. link to literature cited): <https://goo.gl/5s6hkW>

2015

Parental divorce and parental death – An integrative systematic review of children's double bereavement

CLINICAL NURSING STUDIES, 2015;3(4):103-111. The lack of studies on double bereavement may perhaps reflect the fact that 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. This way the research and clinical practice focusing on double bereavement could contribute to dismantle the inapt barriers between the fields of bereavement and divorce and represent a valuable bridge between these fields

Full text: <https://goo.gl/fp7Qfe>

The taunting of parentally bereaved children: An exploratory study

DEATH STUDIES, 2015;39(4):219-225. This exploratory study addresses the rarely mentioned, minimally investigated topic of peer taunting of parentally bereaved children. It suggests that social support cannot be adequately conceptualized or measured on an essentially one-dimensional scale from high to low support. The data are derived from lengthy semi-structured transcribed research interviews of bereaved children. Using conservative criteria, 7 of the 35 children were found to have experienced direct, raw taunting about their loss. The varied forms of taunting experienced are described, as well as a range of victim reactions. Suggestions of foci for future research are presented.

Abstract (w. link to references): <https://goo.gl/3GWAAb>

Parentally bereaved children & adolescents: The question of peer support

OMEGA – JOURNAL OF DEATH & DYING, 2015;71(3):245-271. This study investigates peer interaction and peer support for parentally bereaved children and adolescents. Major findings included: 71.4% of the sample received support from peers, although 71.4% preferred not to have bereavement-related peer interaction. A significantly greater percentage of females versus males experienced peer support and a positive emotional response, and a significantly greater percentage of children bereaved by anticipated deaths versus sudden deaths had received bereavement-related peer interaction and support. No significant differences were found between younger and older children.

Abstract: <https://goo.gl/yVdtqu>

3.3. In the Classroom

This section includes several articles that were part of a literature search completed (October 1, 2018) for Compassionate Ottawa project entitled: Dying, Death, Loss and Grief: Building a Shared Language for School Communities. For more information, please visit Compassionate Ottawa at compassionateottawa.ca.

2018

Schools fall short when it comes to helping students in grief – here's how they can improve

THE CONVERSATION | Online – 4 January 2018 – An adolescent experiences the death of his mother after a lengthy illness. When I ask what services he would like to receive from the school, he initially says he didn't expect special treatment, would be embarrassed by counseling from the school mental health staff and wouldn't feel comfortable if many of his teachers asked to talk to him about his grief. At the same time, the student felt as though the school should somehow take his situation into account. "I don't know what the school should do," the student told me. "But I just lost the person I love most in my life and they act as if nothing happened." In my many years as a developmental-behavioral pediatrician who specializes in school crisis and child bereavement, I believe this dilemma – that is, the need to do enough but not to overwhelm the grieving student or the adults who are trying to help – represents a major challenge for America's schools. The need for recognition by trusted adults of their loss, a genuine expression of sympathy and an offer of assistance is often what students seek after a major loss – but too often don't receive.

<https://goo.gl/sdsZkJ>

Supporting bereaved students at university: Balancing institutional standards and reputation alongside individual compassion and care

DEATH STUDIES | Online – 4 October 2018 – Bereaved university students in the U.K. are an overlooked population in research, policy, and practice. The authors examine the implications of this neglect via: 1) International literature on bereavement in young people; 2) International literature on bereavement in higher education students; 3) U.K. and U.S. literature on workplace bereavement and its implications for universities in preparing the future workforce; and, 4) Findings from a scoping study of 90 U.K. universities' bereavement support, which identified no shared comprehensive strategy for student bereavement. The authors' findings show an urgent need for U.K universities to address this neglect.

Abstract: <https://goo.gl/Q7tJBK>

Kids supporting kids: A 10-week small group curriculum for grief and loss in schools

COUNSELLING & PSYCHOTHERAPY RESEARCH | Online – 27 September 2018 – Experiencing the death of a loved one can negatively affect a child's emotional, behavioural and academic functioning. However, no inschool group interventions exist to assist children in processing and grieving the loss of loved ones. To address this, 'Kids Supporting Kids,' a 10-step group counselling protocol for elementary school students, was developed to help students who have experienced loss of a loved one. The group curriculum aims to help students develop healthier coping skills to deal with grief-related distress; decrease internalising and externalising problems; and decrease problematic trauma symptoms. Students, teachers and parents [i.e., study participants] were each given pre-test measures. The group consisted of 10 weekly sessions on the topics of establishing safety, sharing their stories, creating a narrative with positive memories, identifying and expressing emotions, coping skills, social and family support, remembering loved ones and saying goodbye. Students, parents and teachers were also given mid-group checks and post-group questionnaires. Qualitative improvements towards these goals were noted by students, parents and teachers. Students reported developing healthier coping skills, which were observed and noted as behavioural and emotional improvements by parents and teachers. The study supports the hypotheses that qualitative improvements would be noted by each group and that the feasibility of this protocol would be supported.

Abstract: <https://goo.gl/iPVuU4>

Peer support for bereaved children: Setting eyes on children's views through an educational action research project

DEATH STUDIES, 2018;42(7):446-455. This article investigates children's views on providing peer support to bereaved children. The data (pre- and post interviews and written documents) come from an action research study of a teacher-researcher and her 16 children aged 10–11 years old. Analysis of the data shows children's ideas on supporting a bereaved child and how this support should be provided, taking into consideration various factors such as the relationship with the bereaved and the role of memories. The paper emphasizes that children should have structured opportunities across the whole-school curriculum to learn how loss affects people's lives to support themselves and others.

Abstract (w. link to references): <https://goo.gl/mmx4od>

Voices that want to be heard: Using bereaved Danish students suggestions to update school bereavement response plans

DEATH STUDIES, 2018;42(4):254-267. This study explored how Danish students experienced returning to school following parental bereavement. Eighteen focus group interviews were conducted with 39 participants aged 9 to 17. All participants had experienced the loss of a primary caregiver. Data collection was divided into two phases. In Phase I, 22 participants from four grief groups were interviewed 4 times over the course of a year. During Phase II, confirmatory focus groups were undertaken with the 17 participants. This article explores the findings related to ideas and suggestions made by the students about how the Danish school response could be improved to better meet their needs. The presentation of data is divided into seven themes, which are: 1) Desired school response; 2) Desired support from teachers; 3) Desired boundaries between students and teachers; 4) Desired collaboration; 5) Desired support from peers; 6) Desired rules and structure; and, 7) Desires related to gifts and rituals. Study findings indicate that most students want to be included and have a say when the school plans how to respond to their loss. Students further highlight a need for teacher support when having to reconnect with the class; a need for set rules in relation to leaving the class when feeling sad, and; a need for schools to see the loss as a life-changing event, and grief as something that does not simply disappear after a few months. The article concludes by discussing the ways in which the recommendations provided by the participants can be incorporated into a modern revision of Danish school bereavement response plans.

Abstract (w. link to references): <https://goo.gl/xigye7>

The role of school psychologists in the support of grieving children

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):361-362. School psychologists 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. Yet, there has been minimal research published on this topic in professional journals. This special section of *School Psychology Quarterly* is devoted to grief and loss with the hope of beginning to narrow this gap in the literature. The three articles in this special section add to an evolving evidence-base that grief in children is common and the impact can be profound, that school professionals can and should play a major role in supporting grieving children, and that school psychologists can play a key role in empowering classroom educators and other school professionals so that no child in the future has to grieve alone.

Abstract: <https://goo.gl/CKGgq8>

N.B. Special section of the September 2018 issue of the APA's *School Psychology Quarterly* focuses on grief and loss in children and adolescents. **Journal contents page:** <https://goo.gl/8PeUTb>

Grief and growth in bereaved siblings: Interactions between different sources of social support

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):363-371. The objective of this study was to characterize the relation between different sources of school-based social support (friends, peers, and teachers) and bereaved siblings' grief and grief-related growth and to examine whether non-parental sources of social support buffer the effects of low parent support on bereaved siblings. Families were recruited from cancer registries at 3 pediatric institutions 3-12 months after a child's death. Bereaved siblings were 8-18 years old and majority female (58%) and White (74%). During home visits, siblings reported their perceptions of social support from parental and non-parental sources using the Social Support Scale for Children, as well as grief and grief-related growth using the Hogan Sibling Inventory of Bereavement. Parent, friend, and teacher support were positively correlated with grief-related growth, whereas parent and peer support were negatively correlated with grief for adolescents. Teacher and friend support significantly moderated the association between parent support and grief such that teacher and friend support accentuated the positive effects of parent support. Friend and peer support moderated associations between parent support and grief/growth for adolescents but not children. School-based social support, namely from friends, peers, and teachers, appears to facilitate the adjustment of bereaved siblings. Findings suggest that bereaved siblings may benefit from enhanced support from teachers and friends regardless of age, with middle/high school students particularly benefitting from increased support from close friends and peers.

Abstract: <https://goo.gl/rNPqx6>

Links between bereavement due to sudden death and academic functioning: Results from a nationally representative sample of adolescents

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):372-380. Bereavement due to sudden loss may disrupt positive adjustment among youth, yet few studies have examined the age at which youth are most likely to first encounter sudden loss, the co-occurrence of sudden loss with other traumatic events, and the independent effects of sudden loss on academic functioning. Data were analyzed from the National Comorbidity Survey Adolescent Supplement. Youth reported on whether they had experienced sudden loss (along with 17 other traumatic events), the age at which they had first experienced sudden loss, and multiple indicators of academic functioning. Sudden loss was the most frequently occurring traumatic event among youth; approximately 30% of adolescents reported at least one sudden loss in their lifetime. Youth were most likely to have first experienced sudden loss during middle adolescence (15 to 16 years of age). Although sudden loss co-occurred with several other traumas, about 10% of youth reported experiencing only sudden loss. After accounting for demographic characteristics and other traumatic events, experiencing sudden loss was associated with lower academic achievement, lower ability to concentrate and learn, less enjoyment of school, lower school belongingness, and lower beliefs that teachers treat youth fairly. Sudden loss is common among adolescents and has important implications for school functioning. Schools may improve academic functioning by adopting routine screening for sudden loss and assessing potential need for bereavement-informed mental health services.

Abstract: <https://goo.gl/YEEeBk>

Relational teaching and learning after loss: Evidence from Black adolescent male students and their teachers

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):381-389. Prior research shows that many teachers feel ill-equipped to deal with students experiencing loss, and teachers of Black male adolescents, in particular, sometimes mistake grieving for misbehavior. This multi-method case study investigated the way teachers and their Black male students at a single-sex school related around encounters with loss. We examined students' and teachers' grief experiences through stories that were shared during qualitative interviews and focus group meetings and by observing everyday interactions throughout the school building. Additionally, a survey was distributed to the senior class and school staff asking respondents to report their experiences with loss, grief, and relational support. We found that both groups shared a desire to forge relationships for grief support and that both students and teachers also felt their emotional needs were unacknowledged at times. We also documented many successful moments when the strength of a personal bond between student and teacher eased the pain of a significant personal loss. In this article, we argue that specific relational strategies, as outlined within the model of relational teaching and learning, can be effective for supporting students through periods of grief and can, in turn, also positively impacts teachers' own recovery from loss. Furthermore, we propose that school psychologists can play a critical role in supporting the relationship building between students and teachers, particularly in under-resourced schools without enough mental health personnel.

Abstract: <https://goo.gl/qcmXNm>

Teacher perspectives on grief among children with intellectual disabilities

JOURNAL OF LOSS & TRAUMA, 2018;23(2):159-175. The death of a parent can have a profound impact on a child. However, little is known about how children with intellectual disabilities demonstrate grief or how teachers respond to student grief. Constructivist grounded theory methods were used to analyze data collected from five special education teachers of elementary students with intellectual disabilities. Categories related to grieving, loss, support, coping, and emotion were found. Teachers reported a range of grieving behaviors displayed by children with intellectual disabilities in the classroom and used various strategies to provide support. Grief in surviving caregivers and assistance from other school personnel were also described. The need for additional training of teachers and counselors about grief in children with intellectual disabilities is highlighted.

Abstract (w. link to references): <https://goo.gl/zcgKnj>

The Danish bereavement response in 2015: Historic development & evaluation of success

SCANDINAVIAN JOURNAL OF EDUCATIONAL RESEARCH, 2018;62(1):140-149. In the 1980s, Norwegian researchers pioneered efforts towards developing school support for bereaved children. Eighteen years later, a Danish approach was created based on these foundations. This article explores the Danish school bereavement response plans (b-plans) and investigates their ability to support both teachers and bereaved children. Today, the system has one of the highest implementation rates in the world and the majority of teachers feel equipped to deal with bereavement in school. Nevertheless, adopting a standardised approach potentially leads to the neglect of individual needs. Moreover, concerns exist over whether existing b-plans are current. This article concludes that b-plans have succeeded in becoming the primary tool used by teachers, a feat that systems in other countries often fail to achieve. However, the system seldom includes the perspectives of the students it was designed to help. This is the challenge that the next generation of b-plans must remedy.

Abstract (w. link to references): <https://goo.gl/sUYRsg>

2017

The success of a planned bereavement response: A survey on teacher use of bereavement response plans when supporting grieving children in Danish schools

PASTORAL CARE IN EDUCATION, 2017;35(1):28-38. This article investigates the strengths and weaknesses of the Danish Bereavement response plans. These are used by teachers to support grieving students and have been implemented in 96% of all Danish schools. The study is based on an Internet survey conducted with 967 teachers. Issues investigated are: "generalisation of grief," "forgetting long-term grief," "teacher distress" and "renewal of plans." Participating teachers believe that the current system works well and that the bereavement response plans have made them feel more confident when confronted with loss. However, this comes at a potential cost of generalising children's experiences of grief, so that they fit into the school support system. While the response plans are effective at ensuring initial support for bereaved children, their influence seems to diminish with time. The study found that many plans were around a decade old and that this could mean some had been forgotten or become outdated. The article concludes that while teachers find the current response plans effective, the bereavement response system could benefit from being updated. Such an update needs to focus on dealing with the issues highlighted in this article. Future response plans should also have greater emphasis on the needs voiced by bereaved students who have experienced the system.

Abstract (w. link to references): <https://goo.gl/3faamx>

2016

Voices we forget – Danish students experience of returning to school following parental bereavement

OMEGA – JOURNAL OF DEATH AND DYING | Published online – 21 November 2016 – This study explores how Danish students experience returning to school following parental bereavement. Eighteen focus group interviews with 39 participants aged 9 to 17 years were conducted. All participants had experienced the loss of a primary caregiver. Data collection was divided into two phases. In Phase I, 22 participants from four grief groups were interviewed 4 times over the course of a year. During Phase II, confirmatory focus groups were undertaken with the 17 participants. This article explores findings related to the four themes of initial school response, long-term support, challenges within the class, and academic challenges. The study found that (a) students struggle to reconnect with classmates following the return to school and often feel alone, (b) schools fail to have guidelines in place for what they are allowed to do if becoming sad the class, and (c) schools seem to forget their loss as time passes.

Abstract: <https://goo.gl/jp7YX3>

2015

Suggestions for the ideal follow-up for bereaved students as seen by school personnel

EMOTIONAL & BEHAVIOURAL DIFFICULTIES, 2015;20(3):289-301. Although the school personnel i.e., study participants obviously have high levels of empathy and commitment towards grieving students, they expressed limited knowledge about how child bereavement affects school performance, concentration, and learning, and how this restricted their own efforts to arrange for grieving children during the school day. They also signalled tensions created by the need to mediate too many tasks in the teacher's role, school staff's lack of grief knowledge, and guilt for not doing more for bereaved children at school. Despite the existence of solid theoretical and research base in the field of grief in children, opportunities for provision of evidence-validated intervention by teachers and other school personnel in response to grief, and prompt referral of bereaved children suffering more complex grief reactions, appear to be severely compromised. The school personnel pointed out the necessities for action plans and written routines, resources and clarifications of roles, and some basic help principles, key help measures, and improvements to improve the support for bereaved schoolchildren.

Abstract (w. link to references): <https://goo.gl/Jk47KX>

Teachers' perception of bereaved children's academic performance

ADVANCES IN SCHOOL MENTAL HEALTH PROMOTION, 2015;8(3):187-198. It is well documented that loss and trauma may lead to a reduction in school grades and an increase in the school dropout rate among school children. However, in order for the schools to support students in the best way after trauma and loss, it is of great importance that teachers are aware of these problems. In this study, the authors investigated the perceptions of the academic problems of bereaved students among 138 teachers and headmasters from six secondary and high schools. They administered questionnaires to the whole sample, and six focus group interviews were conducted to obtain in-depth knowledge from the same population. Teachers perceive a deterioration of school performance in grieving students. The teachers' perceptions are in accordance with what students report in studies. The teachers perceived grieving students as struggling with learning, showing reduced achievement in tests, and experiencing learning setbacks. There is a need for schools to try to remedy these problems in order for students to achieve their learning potential. The students' academic decline is not due to their lack of resources, but is a temporary setback due to the loss.

Abstract (w. link to references): <https://goo.gl/CH6397>

3.4 Bereavement Through Suicide

2018

“Why did he choose to die?”: A meaning-searching approach to parental suicide bereavement in youth

DEATH STUDIES | Online – 25 September 2018 – This article analyzes how young people talk about their experience of parental suicide in different social contexts. The results show how these young grievers are preoccupied with the question of why the parent committed suicide. Moreover, they tend primarily to interpret the suicide in line with stigmatizing discourses regarding who is to blame, which has negative impacts on their identities. In contrast, a “meaning-searching approach” seeks to answer the question of what caused the suicide and to identify a combination of internal vulnerabilities and external stressors. Professional interventions are recommended to foster the latter health promoting coping strategy.

Full text (with link to references): <https://goo.gl/HsaEJx>

2017

The perceived experience of children bereaved by parental suicide

OMEGA – JOURNAL OF DEATH & DYING, 2017;75(2):184-206. Children whose parent died by suicide are a vulnerable and underserved population. This phenomenon will be described, as well as implications for practice and research. “Double whammy,” a conceptualization of the overall experience of this marginalized group, emerged through two in-depth interviews from a phenomenological qualitative study with professionals who facilitate support groups for children bereaved by parental suicide. It was corroborated with current literature and practice experiences of the authors and their colleagues. Stigma was the largest contributor to the “Double Whammy,” and the following themes emerged as well: feeling isolated, feeling abandoned, and feeling responsible. The self-volition of suicide challenges how bereaved children make meaning and internalize feelings about the deceased parent, one’s self, and others. Developmentally appropriate education about suicide grief, depression, and normalizing the grief process is pivotal in helping children to effectively cope and manage their feelings.

Abstract: <https://goo.gl/3KiYNq>

4. Intersection of Grief, Diversity and Social Barriers

The literature on palliative and end-of-life (EoL) care for children and youth of culturally and linguistically diverse communities is extensive, but there is a paucity of published research specifically on the issue/topic of grief and bereavement. In the case of Hindus, Jews and Muslims, culture and ethnicity are considered synonymous with faith and spiritual beliefs, likewise with Indigenous and First Nations peoples. Several years ago, The Lancet published a series contrasting EoL perspectives of different faiths. The series can be accessed at: <https://goo.gl/BGQbSJ>. See also 'Bereavement Support Across Cultures' ('Resources, p.74).

4.1 Cultural & Linguistically Diverse Communities

2018

Relational teaching and learning after loss: Evidence from Black adolescent male students and their teachers

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):381-389. Prior research shows that many teachers feel ill-equipped to deal with students experiencing loss, and teachers of Black male adolescents, in particular, sometimes mistake grieving for misbehavior. This multi-method case study investigated the way teachers and their Black male students at a single-sex school related around encounters with loss. We examined students' and teachers' grief experiences through stories that were shared during qualitative interviews and focus group meetings and by observing everyday interactions throughout the school building. Additionally, a survey was distributed to the senior class and school staff asking respondents to report their experiences with loss, grief, and relational support. We found that both groups shared a desire to forge relationships for grief support and that both students and teachers also felt their emotional needs were unacknowledged at times. We also documented many successful moments when the strength of a personal bond between student and teacher eased the pain of a significant personal loss. In this article, we argue that specific relational strategies, as outlined within the model of relational teaching and learning, can be effective for supporting students through periods of grief and can, in turn, also positively impacts teachers' own recovery from loss. Furthermore, we propose that school psychologists can play a critical role in supporting the relationship building between students and teachers, particularly in under-resourced schools without enough mental health personnel.

Abstract: <https://goo.gl/qcmXNm>

2017

**Immigrants coping with transnational deaths and bereavement:
The influence of migratory loss and anticipatory grief**

FAMILY PROCESS | Online – 14 December 2017 – This study examines immigrants' experiences of bereavement and coping with the deaths of family members in a transnational context. Data were collected through in-depth personal interviews with middle-aged and older immigrants from different countries of origin, who have been living in the U.S. for a majority of their adult lives. Thematic analysis of participants' narratives showed that immigrants' geographic distance from family complicated caregiving circumstances and rituals surrounding burial, and impacted the grieving process. At the same time, this distance also served as an emotional barrier and provided protection from prolonged grief. Immigrants' U.S.-based family and work responsibilities served as buffers from prolonged grief. Over time, immigrants became Americanized in their attitudes toward coping with death and favored a fast return to productive activities. Finally, immigrants' experience of migratory loss and anticipatory grief early in immigration, along with their personal growth and resilience developed over time, impacted their bereavement experiences later in life. Considering the limitations and the exploratory nature of the present study, further research is needed to investigate the specifics of coping with loss and bereavement among immigrants.

Abstract: <https://goo.gl/kUxKLD>

**Effect of a bereavement support group on female adolescents'
psychological health: A randomised controlled trial in South Africa**

THE LANCET GLOBAL HEALTH, 2017;5(6):e604-e614. Research from South Africa underscores how culture influences children's experiences and understanding of loss, highlighting the importance of interventions that are contextually sensitive and accommodate local norms. The intervention's incorporation of principles underpinning cognitive behavioural therapy, a highly effective treatment for depression among adolescents and adults living with HIV, is another strength. Abangane emphasises coping strategies for emotions related to loss itself; however, recent theories suggest that helping participants cope with associated restoration stressors like changed responsibilities, family organisation, and financial standing could hold equal importance. These and other components of the programme were recently enhanced based on the evaluation findings, which could result in more robust treatment effects. Notably, this study represents an unusual effort to strengthen the theoretical basis for a locally derived intervention, instead of adapting a foreign intervention to ensure its cultural relevance in context.

Full text: <https://goo.gl/rqbgAi>

Communication about dying, death, and bereavement: A systematic review of children's literature

JOURNAL OF PALLIATIVE MEDICINE, 2017;20(5):548-559. Children's books have the potential to facilitate communication about death for children living with a serious illness and for children coping with the death of a loved one. Two-hundred-ten books met inclusion criteria. The dying subject was primarily a grandparent or pet. Books on the experience of a child dying were scarce. The word death or dying was used in 75% of the books, while others utilized euphemisms. The majority of books featured animals or Caucasian subjects and included spiritual elements such as heaven. Less than one-quarter of the books included tools for readers to address the topic of death. Storybooks can be a helpful tool to introduce communication about dying and death with children. Gaps exist in current children's literature to effectively enable children to reflect on their own dying process. A general summary of available books is provided to assist those caring for children and families facing end-of-life issues.

Full text: <https://goo.gl/EEbSzD>

A socio-cultural approach to children's perceptions of death and loss

OMEGA –JOURNAL OF DEATH & DYING, 2017;76(1):53-77. By employing the phenomenographic approach, the present study explored children's cognitive understanding of and emotional responses to death and bereavement. Participants included 52 Korean, 16 Chinese, and 16 Chinese American children ages 5-6. Thematic analysis of children's drawings and open-ended interviews revealed that most children associated death with negative emotions such as fear, anxiety, and sadness. The majority of children used realistic expressions to narrate death. The core themes from their drawings included causes for death, attempts to stop the dying, and situations after death. This study contributes to the literature by targeting young children who have been relatively excluded in death studies and provides evidence in the usefulness of drawings as a developmentally appropriate data collection tool. The findings also enrich our knowledge about children's understanding of death and bereavement, rooted in the inductive analysis of empirical data with children from culturally diverse backgrounds.

Abstract: <https://goo.gl/deXN3Z>

2015

British and Pakistani children's understanding of death: Cultural and developmental influences

BRITISH JOURNAL OF DEVELOPMENTAL PSYCHOLOGY, 2015;33(1):31-44. This study explored British and Pakistani 4 to 7-year-olds' understanding of death. The aim was to examine possible influences on the acquisition of the sub-components of the death concept by investigating how they are understood by children of different ages and cultural and religious backgrounds. Three groups of children were compared: White British and British Muslim living in London, and Pakistani Muslim living in rural Pakistan. In line with previous research, irreversibility of death was one of the first sub-components to be acquired, while causality was the last. The two groups of British children shared many similarities in their understanding of inevitability, applicability, irreversibility, and cessation. Pakistani Muslim children understood irreversibility earlier than did children in both British groups. In all three cultural groups, children's responses demonstrated very limited understanding of causality. The authors' findings support the view that aspects of a mature understanding of death develop between the ages of 4 and 7 years and that the process of understanding death as a biological event is, to a great extent, universal. They also suggest that aspects of children's reasoning are influenced by culturally specific experiences, particularly those arising from living in rural versus urban settings.

Abstract: <https://goo.gl/3oi6Yb>

4.2 Indigenous & First Nations Peoples

The literature on palliative and end-of-life and end-of-life care for Indigenous and First Nations peoples is extensive, but there is a paucity of published research specifically on the issues/topic of support for bereaved and grieving children and youth in these communities in Canada. See also 'Finding Our Way Through: Navigating Loss & Grief in First Nations Life,' 'Learning about Grief & Bereavement in First Nations Communities' and 'Grief & Loss' ('Resources,' p.74).

2016

Aboriginal grief and loss: A review of the literature

AUSTRALIAN INDIGENOUS HEALTH BULLETIN, 2016;16(3). This review of the literature on Aboriginal grief and loss finds a lack of well-articulated theories, models and practice specific to the cultural and historical context of grief (as distinct from trauma) for Australian Aboriginal people, whether by Aboriginal or non-Aboriginal authors. Although there is significant research on the impact of trauma in Aboriginal communities, this 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 on their social and emotional well-being.

Full text: <https://goo.gl/jv7fL2>

4.3 Lesbian, Bisexual, Gay & Transgender

The literature on palliative and end-of-life care for the LBGT communities is extensive, but there is a paucity of published research specifically on the issue/topic of support for bereaved and grieving children and youth.

2018

Palliative and end-of-life care for lesbian, gay, bisexual, and transgender cancer patients and their caregivers

SEMINARS IN ONCOLOGY NURSING, 2018;34(1):60-71. The ability to provide effective care for lesbian, gay, bisexual, and transgender (LGBT) cancer patients and caregivers depends on two essential insights: 1) LGBT patients and their caregivers have unique needs related to palliative and end-of-life (EoL) care support; and, 2) Addressing these needs in a meaningful way requires enacting not only LGBT-specific knowledge, but also invokes known best practices for these fields, including essential competencies for relationship-building and effective communication. Many of the recommendations offered here include concepts and practices that would enhance optimal outcomes with patients from all walks of life because they are fundamental to truly patient-centered care. Improving palliative and EoL care for LGBT cancer patients, therefore, is likely to have a broader benefit of enhancing effective and supportive care for all oncology patients, effectively "raising all boats." Oncology nurses are well-positioned to improve care experiences and outcomes for LGBT patients and caregivers. Understanding the unique history and challenges that members of the LGBT community face, as well as the community's strengths and capacity of resilience, is the key to providing competent and effective care.

Full text: <https://goo.gl/j15fmm>

Extract from Seminars in Oncology Nursing article

Ensure that those who are identified as family and significant others by the patient and their appointed surrogates are offered bereavement services as appropriate and desired. When possible or feasible, ask the patient and their caregiver who they would want to be sure is included, and who they see as needing these services. Bereavement and grief support services also need to be accessible and delivered in a manner that is welcoming and affirming. For example, support groups that mix LGBT and non-LGBT participants partners and spouses may not feel as welcoming or useful if LGBT participants feel the need to explain or normalize their situation for others rather than process their own grief. Knowing what will work best requires individualized assessment and options that allow participants to choose what is best for them. Because LGBT cancer patients and caregivers have unique experiences because of their minority status, they are at risk for being underserved by programs that are designed with embedded heteronormative assumptions. Also, when possible, organizations should explore multiple modes of delivery such as in-person or online support groups. Distance-accessible options may be particularly helpful for people who live in rural communities and experience social isolation, and those who may feel more comfortable in this setting.

4.4. Children with Intellectual/Developmental Disabilities

See 'Managing Grief Better: People with Intellectual Disabilities' and 'Bereavement in the Lives of People with Intellectual Disabilities' ('Resources,' p.74).

2018

Teacher perspectives on grief among children with intellectual disabilities

JOURNAL OF LOSS & TRAUMA, 2018;23(2):159-175. The death of a parent can have a profound impact on a child. However, little is known about how children with intellectual disabilities demonstrate grief or how teachers respond to student grief. Constructivist grounded theory methods were used to analyze data collected from five special education teachers of elementary students with intellectual disabilities. Categories related to grieving, loss, support, coping, and emotion were found. Teachers reported a range of grieving behaviors displayed by children with intellectual disabilities in the classroom and used various strategies to provide support. Grief in surviving caregivers and assistance from other school personnel were also described. The need for additional training of teachers and counselors about grief in children with intellectual disabilities is highlighted.

Abstract(w. link to references): <https://goo.gl/vwgfTg>

2017

Overcoming barriers to grief: Supporting bereaved people with profound intellectual and multiple disabilities

INTERNATIONAL JOURNAL OF DEVELOPMENTAL DISABILITIES, 2017;63(3):131-137. Engaging people with profound intellectual and multiple disabilities (PIMD) in relation to issues of bereavement and loss is often seen as a complex therapeutic challenge. The author examines the barriers preventing them from engaging with the grieving process in supported ways. Through the lens of Worden's Tasks of Grief model, the author provides an assessment of the social, emotional, and physical constraints that impact on the person's experience of bereavement. Although there are some similarities between people with PIMD and their more able peers, there are some additional factors which may place people with PIMD at greater risk of complicated grieving. In addition, the author identifies the socio-contextual factors that can mediate experiences of and reactions to loss in this group. Within this framework, the limitations of a purely cognitivist approach to this area are demonstrated. The author encourages therapeutic practice with people with PIMD, which partly focuses on enabling the grieving process. Suggestions and approaches for support, including multi-sensory methods, are offered.

Abstract (w. link to references): <https://goo.gl/FJwDhb>

2016

Supporting students with autism spectrum disorder through grief and loss

TEACHING EXCEPTIONAL CHILDREN, 2016;48(3):128-136. The grieving process for students without disabilities, though personal and complex, is well described in the literature. There is less research examining the grief process and the necessary supports for students with disabilities. Students with developmental or intellectual disabilities experience grief, and many students 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 may also present challenging behaviour, and disruptive behaviour during periods of grief. Unfortunately, research indicates that caregivers and school personnel typically do not recognize the increase in challenging behaviors as expressions of grief, and these responses may be minimized, misinterpreted, or attributed to the disability rather than the grief.

First page view: <https://goo.gl/Dg85bK>

4.5 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. Several years ago, The Lancet published a series contrasting EoL perspectives of different faiths. The series can be accessed at: <https://goo.gl/BGQbSJ>

2018

Children's and adults' understanding of death: Cognitive, parental, and experiential influences

JOURNAL OF EXPERIMENTAL CHILD PSYCHOLOGY, 2018;166(2):96-115. This study explored the development of understanding of death in a sample of 4- to 11-year-old British children and adults. It also investigated four sets of possible influences on this development: parents' religion and spiritual beliefs, cognitive ability, socio-economic status, and experience of illness and death. Participants were interviewed using the "death concept" interview that explores understanding of the sub-components of inevitability, universality, irreversibility, cessation, and causality of death. Children understood key aspects of death from as early as 4 or 5 years, and with age their explanations of inevitability, universality, and causality became increasingly biological. Understanding of irreversibility and the cessation of mental and physical processes also emerged during early childhood, but by 10 years many children's explanations reflected not an improved biological understanding but rather the co-existence of apparently contradictory biological and supernatural ideas – religious, spiritual, or metaphysical. Evidence for these coexistent beliefs was more prevalent in older children than in younger children and was associated with their parents' religious and spiritual beliefs. Socio-economic status was partly related to children's biological ideas, whereas cognitive ability and experience of illness and death played less important roles. There was no evidence for co-existent thinking among adults, only a clear distinction between biological explanations about death and supernatural explanations about the afterlife.

Abstract: <https://goo.gl/CsuPSU>

Spirituality for wellbeing of bereaved children in residential care: Insights for spiritually sensitive child-centred social work across country contexts

CHILD & ADOLESCENT SOCIAL WORK JOURNAL, 2018;35(2):181-195. This study examined the effect of spiritual intervention programmes. Data include pre and post-tests from 1,689 bereaved children in residential homes across 13 countries. Post-treatment scores of bereaved children were higher on outcome measures of psychological well-being, self-concept, health, happiness, resilience and academic performance. Post-treatment scores on measures such as depression and discrepancy between perceived and preferred self were markedly lower. Children from South Asian and African countries, boys and Christians scored higher on the self-concept scale, health questionnaire and resilience scale, and lower on the depression and discrepancy measures *vis-à-vis* their counterparts from European countries, the U.S. and Canada, girls and non-Christians. Children who underwent the customized spiritual intervention programme *vis-à-vis* open-ended sessions on centering and meditation and those who regularly self-practiced, were more likely report higher scores on the wellbeing measure. The results suggest that spiritual intervention programmes work for institutionalized bereaved children and further propose that they should be customized and focused, incorporate diversity, emphasize on positive thinking, futuristic attitude and self-practice.

Abstract (inc. list of references): <https://goo.gl/tZSBvf>

2017

Spirituality and religious coping are related to cancer-bereaved siblings' long-term grief

PALLIATIVE & SUPPORTIVE CARE | Online – 20 December 2017 – Many bereaved siblings have still not come to terms with their grief many years after the loss, but few studies have focused on what can help. The aims of this study were to identify cancer-bereaved adolescents' and young adults' ways of coping with grief after loss of a sibling, and examine whether these ways of coping were related to their experience of having worked through their grief. This nationwide survey of 174 cancer-bereaved siblings is based on one open-ended question about coping with grief ("What has helped you to cope with your grief after your sibling's death?") and one closed-ended question about siblings' long-term grief ("Do you think you have worked through your grief over your sibling's death?"). The siblings described four ways of coping: 1) Thinking of their dead brother/sister and feeling and expressing their grief; 2) Distracting or occupying themselves; 3) Engaging in spiritual and religious beliefs/activities; and, 4) Waiting for time to pass. One of these categories of coping with grief, namely, engaging in spiritual and religious beliefs and activities, was associated with siblings' experience of having worked through their grief two to nine years after the loss.

Abstract (inc. list of references): <https://goo.gl/amycc6>

5. Grief and Implications for Long-Term Impact

2018

Childhood bereavement: The role of the surviving parent and the continuing bond with the deceased

DEATH STUDIES, 2018;42(7):415-425. This study investigated the relationship between the role of the surviving parent in the child's grieving process, the continuing bond (CB) with the deceased parent and biopsychosocial functioning, and active grief in adulthood. A survey of 135 adults, parentally bereaved in childhood, indicated the surviving parent's role in facilitating the grieving process promoted a positive CB with the deceased in childhood as well as general functioning in adulthood. The CB with the deceased had a weak association with both better general functioning and relational active grief.

Abstract (w. link to references): <https://goo.gl/tm94xT>

2017

Spirituality and religious coping are related to cancer-bereaved siblings' long-term grief

PALLIATIVE & SUPPORTIVE CARE | Online – 20 December 2017 – Many bereaved siblings have still not come to terms with their grief many years after the loss, but few studies have focused on what can help. The aims of this study were to identify cancer-bereaved adolescents' and young adults' ways of coping with grief after loss of a sibling, and examine whether these ways of coping were related to their experience of having worked through their grief. This nationwide survey of 174 cancer-bereaved siblings is based on one open-ended question about coping with grief ("What has helped you to cope with your grief after your sibling's death?") and one closed-ended question about siblings' long-term grief ("Do you think you have worked through your grief over your sibling's death?"). The siblings described four ways of coping: 1) Thinking of their dead brother/sister and feeling and expressing their grief; 2) Distracting or occupying themselves; 3) Engaging in spiritual and religious beliefs/activities; and, 4) Waiting for time to pass. One of these categories of coping with grief, namely, engaging in spiritual and religious beliefs and activities, was associated with siblings' experience of having worked through their grief two to nine years after the loss.

Abstract (inc. list of references): <https://goo.gl/amycc6>

Consequences of sibling death problematic, potentially predictable, and poorly managed

JAMA PEDIATRICS, 2017;171(6):519-520. The death of a loved one is a traumatic life event associated with increased mortality and poor health. Although studies have examined the association among bereavement, mental disorder outcomes, and elevated risk for mortality in spouses, parents, and offspring, sibling bereavement is less studied. Coined "forgotten grievers, bereaved siblings experience the long-term effect of bereavement on their health and social environments. This is especially true when sibling bereavement occurs during the formative childhood years. Understanding the health and mortality risks associated with sibling bereavement is an important research area and essential component in the development of interventions designed at promoting the health and well-being of individuals who have experienced the death of a sibling.

Abstract: <https://goo.gl/2Md81m>

Think adult – think child! Why should staff caring for dying adults ask what the death means for children in the family?

BRITISH MEDICAL BULLETIN, 2017;123(1):5-17. Bereaved children and young people in the U.K. are "hidden mourners." Children experience grief that varies according to the circumstance of death and their cognitive ability. Voluntary organizations can be supportive, but provision is patchy and vulnerable to austerity. Areas of concern include adult-centric denial of the importance and long-term consequences of childhood grief, and uncertainty in how best to relate to bereaved children in faiths and in schools. Growing points include increased awareness of the immediate and long-term consequences of childhood bereavement and that even young children can experience loss through death. "Think adult – think child" means that all staff caring for dying adults should take responsibility for asking what the death means for the children in the family, with schools, primary care and faith organizations having protocols and expertise available to support grieving children; recent catastrophes expose need for agencies to have management plans that focus on vulnerable children and young people.

Full text: <https://goo.gl/W8ocRs>

5.1 Academic Achievement

2018

Links between bereavement due to sudden death and academic functioning: Results from a nationally representative sample of adolescents

SCHOOL PSYCHOLOGY QUARTERLY, 2018;33(3):372-380. Bereavement due to sudden loss may disrupt positive adjustment among youth, yet few studies have examined the age at which youth are most likely to first encounter sudden loss, the co-occurrence of sudden loss with other traumatic events, and the independent effects of sudden loss on academic functioning. Data were analyzed from the National Comorbidity Survey Adolescent Supplement. Youth reported on whether they had experienced sudden loss (along with 17 other traumatic events), the age at which they had first experienced sudden loss, and multiple indicators of academic functioning. Sudden loss was the most frequently occurring traumatic event among youth; approximately 30% of adolescents reported at least one sudden loss in their lifetime. Youth were most likely to have first experienced sudden loss during middle adolescence (15 to 16 years of age). Although sudden loss co-occurred with several other traumas, about 10% of youth reported experiencing only sudden loss. After accounting for demographic characteristics and other traumatic events, experiencing sudden loss was associated with lower academic achievement, lower ability to concentrate and learn, less enjoyment of school, lower school belongingness, and lower beliefs that teachers treat youth fairly. Sudden loss is common among adolescents and has important implications for school functioning. Schools may improve academic functioning by adopting routine screening for sudden loss and assessing potential need for bereavement-informed mental health services.

Abstract: <https://goo.gl/YEEeBk>

2015

Teachers' perception of bereaved children's academic performance

ADVANCES IN SCHOOL MENTAL HEALTH PROMOTION, 2015;8(3):187-198. It is well documented that loss and trauma may lead to a reduction in school grades and an increase in the school dropout rate among school children. However, in order for the schools to support students in the best way after trauma and loss, it is of great importance that teachers are aware of these problems. In this study, the authors investigated the perceptions of the academic problems of bereaved students among 138 teachers and headmasters from six secondary and high schools. They administered questionnaires to the whole sample, and six focus group interviews were conducted to obtain in-depth knowledge from the same population. Teachers perceive a deterioration of school performance in grieving students. The teachers' perceptions are in accordance with what students report in studies. The teachers perceived grieving students as struggling with learning, showing reduced achievement in tests, and experiencing learning setbacks. There is a need for schools to try to remedy these problems in order for students to achieve their learning potential. The students' academic decline is not due to their lack of resources, but is a temporary setback due to the loss.

Abstract (w. link to references): <https://goo.gl/CH6397>

5.2 Mental Health

2018

Early intervention for bereaved children: What mental health professionals think

DEATH STUDIES | Online – 17 December 2018 – People rarely specify what “early intervention” following bereavement means. The authors explored the views of experienced professionals working primarily with bereaved children. In an anonymous online survey, 84 mental health professionals answered questions about the content and timeframe of early intervention. The types of interventions varied, but conversation and support were most frequent. Most considered early intervention to mean before or during the first month following the loss. Although meta-analyses show little benefit of early intervention, professionals disagree and see the need to tailor interventions to the type of death, the situation of the family, and the intensity of reactions.

Abstract: <https://goo.gl/eEgjNy>

Psychosocial outcomes in cancer-bereaved children and adolescents: A systematic review

PSYCHO-ONCOLOGY, 2018;27(10):2327-2338. This is the first systematic review that integrates findings on psychosocial outcomes after parental or sibling cancer bereavement. Twenty-four studies, based on 13 projects, were included. Ten projects had cross-sectional designs. Only two projects used large, population-based samples and non-bereaved comparison groups. Bereaved children and adolescents showed similar levels of depression and anxiety compared with non-bereaved or norms. Severe behavioral problems were found rarely. However, in two large, population-based studies, about half of the bereaved individuals reported unresolved grief. Bereaved adolescents had a higher risk for self-injury compared with the general population in one large, population-based study. Communication with health-care professionals, family, and other people, social support, distress during illness, age, gender, and time because loss were associated with psychosocial bereavement outcomes. Results indicate a high level of adjustment in cancer-bereaved children and adolescents. A modifiable risk factor for adverse psychosocial consequences is poor communication.

Abstract: <https://goo.gl/dGkQhX>

Cause of caregiver death and surviving caregiver coping style predict thwarted belongingness in bereaved youth

ARCHIVES OF SUICIDE RESEARCH | Online – 23 May 2018 – Both bereavement and thwarted belongingness serve as risk markers for youth suicide-related behaviors. This study examined candidate predictors of thwarted belongingness among bereaved youth, including caregiver cause of death and surviving caregiver coping style. Forty-three caregiver-bereaved families (58 children aged 7-13 years old) participated in a longitudinal study investigating associations between hypothesized bereavement-related contextual factors and youth thwarted belongingness. Cause of caregiver deaths included anticipated deaths preceded by illness (37%), sudden natural deaths (25.6%), accidental deaths (20.9%), death by suicide (9.3%), and death from drug overdose). Children's thwarted belongingness was significantly higher among youth bereaved by suicide compared to youth bereaved by youth bereaved by sudden natural death, accident, and anticipated death by illness. Implications for risk screening and assessment of suicide risk among bereaved youth are discussed.

Abstract: <https://goo.gl/hsM1dw>

Interventions for young bereaved children: A systematic review and implications for school mental health providers

CHILD & YOUTH CARE FORUM, 2018;47(2):151-171. Many young children experience the death of a family member and they may be at risk for developing psychological and behavioral problems, but not much is known about how to help young children cope with such a stressful and painful experience. The purposes of this study are to identify the interventions for bereaved young children and examine the effectiveness of the interventions. A systematic review of the literature was performed to investigate the effects of interventions for preschool-age children (3-5 years) who experience the death of a family member. Seventeen studies that met the inclusion criteria for the purpose of this review were identified. All of the studies involved a small sample, and majority of the studies mixed preschool children with other older children in the sample. Play-based therapies were the most common interventions for grieving young children. Involving parents in the interventions, regardless of their therapeutic orientation, was a critical ingredient. Limited empirical evidence of positive intervention outcomes for preschool-age bereaved children was available. Surviving parents were seen as an important agent to help young children grieve and cope with the experience of loss. Implications for school mental health practice and research are provided.

Abstract (w. list of references): <https://goo.gl/Lgri1f>

Care at end of life influences grief: A nationwide long-term follow-up among young adults who lost a brother or sister to childhood cancer

JOURNAL OF PALLIATIVE MEDICINE, 2018;21(2):156-162. A majority of cancer-bereaved siblings report long-term unresolved grief, thus it is important to identify factors that may contribute to resolving their grief. Several predictors for unresolved grief were identified: siblings' perception that it was not a peaceful death, limited information given to siblings the last month of life, information about the impending death communicated the day before it occurred, siblings' avoidance of the doctors, and lack of communication with family and people outside the family about death. Depressive symptoms and time since loss also predicted unresolved grief. Together, these predictors explained 54% of the variance of unresolved grief.

Abstract: <https://goo.gl/YnVGV8>

Prolonged grief and post-traumatic stress in bereaved children: A latent class analysis

PSYCHIATRY RESEARCH, 2017;258(12):518-524. Few studies have yet examined sub-groups among children (aged 8-18) confronted with the death of a close loved one, characterized by different profiles of symptoms of prolonged grief disorder (PGD) and symptoms of bereavement-related post-traumatic stress disorder (PTSD). This study sought to identify such sub-groups and socio-demographic and loss-related variables associated with sub-group membership. The authors used data from 332 children, most of whom were confronted with the death of a parent, mostly due to illness. Latent class analysis revealed three classes of participants: 1) A resilient class (38.6%); 2) A predominantly PGD class (35.2%); and, 3) A combined PGD/PTSD class (26.2%). Class membership was associated with self-rated levels of depression and functional impairment, and parent-rated behavioural problems. No significance between-class differences on demographics or loss-related variables were found. The current findings of distinct classes of PGD, and PGD plus PTSD attest to the construct validity of PGD as a distinct disorder, and can inform theory building and the development of diagnostic instruments relevant to children with pervasive distress following loss.

Abstract: <https://goo.gl/bGeJiN>

Distrust in the end-of-life care provided to a parent and long-term negative outcomes among bereaved adolescents: A population-based survey study

JOURNAL OF CLINICAL ONCOLOGY, 2017;35(27):3136-3142. Previous research shows that the death of a parent places children at risk for a number of negative outcomes. The role of trust in health care at the end of life has been acknowledged as crucial for patients and adult family members. However, the consequences of children's distrust in the care provided to their parents remain unknown. The authors investigated the negative long-term outcomes of cancer-bereaved sons' and daughters' distrust in the care that was provided to a dying parent. In those who reported no or little trust (i.e., distrust) in the health care provided to their dying parents, we found statistically significantly higher risks of various negative outcomes at the time of survey :bitterness toward health care professionals for not having done everything that was possible and for having stopped treatment, self-destructiveness (e.g., self-injury), and psychological problems (e.g., moderate to severe depression).

Full text: <https://goo.gl/zNxmK3>

Risk of suicide, deliberate self-harm and psychiatric illness after the loss of a close relative: A nationwide cohort study

WORLD PSYCHIATRY, 2017;16(2):193-199. This nationwide study provides the first comprehensive assessment of the incidence of serious mental health conditions after the loss of a close relative. A significantly elevated risk of suicide, deliberate self-harm and psychiatric illness is shown, particularly in the first year after the loss. Loss of child or spouse resulted in higher risk, and young age, a history of mental illness and sudden losses were found to be specific risk factors. This study points to early identification of high-risk persons displaying adjustment problems in order to mitigate distress and reduce the risk of serious mental health conditions after loss of a close family member.

Full text: <https://goo.gl/FcDQzu>

2016

The effects of the family bereavement program to reduce suicide ideation and/or attempts of parentally bereaved children six and fifteen years later

SUICIDE & LIFE THREATENING BEHAVIOR, 2016;46(S1):S32-S38. Findings concerning the long-term effects of the Family Bereavement Program (FBP) to reduce suicide ideation and/or attempts of parentally bereaved children and adolescents are presented. Parental death is a significant risk factor for suicide among offspring. This study is a longterm follow-up of 244 children and adolescents who had participated in a randomized trial of the FBP, examining the intervention effects on suicide ideation and/or attempts as assessed through multiple sources. Results indicate a significant effect of the FBP to reduce suicide ideation and/or attempts at the 6 and 15year follow-up evaluation. The findings support the potential benefits of further research on "upstream" suicide prevention.

Abstract (w. link to literature cited): <https://goo.gl/5s6hkW>

5.3 Criminology

2014

The Ripples of Death: Exploring the Bereavement Experiences and Mental Health of Young Men in Custody

THE HOWARD JOURNAL OF CRIMINAL JUSTICE, 2014;53(4):pp.341-359. This study of 33 young men who were sentenced to a young offender institution revealed a higher than average experience of traumatic and/or multiple deaths as well as higher scores on the Massachusetts Youth Screening Instrument (version 2, MAYSI-2). While not a diagnostic tool, the MAYSI scores help to identify the mental health needs of participants under the age of 18 years. The findings of the study reveal that young people involved in offending have higher rates of distinct types of bereavement including parental death, multiple deaths or traumatic deaths such as homicide or suicide. While the nature of the association between bereavement and criminality is not clear nor are the results of this study of statistical significance, it is thought that young people experiencing such severe emotional stressors may lead to less resilience and more vulnerability to negative outcomes. Some research also found an association between multiple deaths and poor outcomes in areas such as depression, education, self-esteem and risk-taking behavior. The discussion offers insights into the relationship between incarceration, custody and an interruption to a healthy grieving process as well as highlighting the importance of providing a range of information and supports in community and schools in childhood prior to intersecting with the criminal justice system. Implications of prison and detention centers adopting a change in culture to assist and encourage young men to attend to their emotions and coping strategies are discussed. The findings support the potential benefits of further research in this area.

Abstract (w. link to literature cited): <https://strathprints.strath.ac.uk/47226/>

6. Programs & Interventions

2018

How grief camp reinforces the need for death education in elementary schools

CANADIAN JOURNAL FOR NEW SCHOLARS IN EDUCATION, 2018;9(2):90-99. Established to help normalize the grieving process, grief camps are traditionally for children and adolescents who have experienced a death-related loss. These camps take children and adolescents out of their daily environment, inviting them to express their grief in innovative and developmentally appropriate ways. The author is a volunteer at two grief camps in Manitoba and it is apparent that these camps not only fill a gap in the bereavement experiences of children and adolescents, but also highlight the need for more preparation in terms of dying, death, and loss. Pupils in Ontario spend almost 6,000 hours in elementary school, yet there is no curriculum that directly addresses death. As a microcosm, grief camp reinforces the need for death education on a macro level in elementary schools.

Abstract: <https://goo.gl/35yfrL>

N.B. Click on pdf icon to access full text:

Three perspectives on mental health problems of young adults and their parents at a 15-year follow-up of the family bereavement program

JOURNAL OF CONSULTING & CLINICAL PSYCHOLOGY, 2018;86(10):845-855. Effects are reported of the Family Bereavement Program (FBP) on the mental health of bereaved youth and their surviving parent 15 years following the program. At the 15-year follow-up 80% of the youth and 76% of the bereaved parents were re-interviewed. Mental health problems and service use were self-reported by young adults and their parents. Key informants reported on mental health problems of young adults. Young adults in the FBP reported significantly less use of mental health services and of psychiatric medication than controls. Key informants reported significantly lower mental health problems for young adults who were in FBP as compared with controls and for those who were younger lower internalizing and externalizing problems for those in the FBP as compared with controls. Bereaved parents reported a significantly lower rate of alcoholism and less use of support groups than controls. The results provided evidence that FBP led to lower mental health problems and less service use by bereaved young adults and their parents as compared with controls.

Abstract: <https://goo.gl/uEMohp>

Trauma-informed care and post-traumatic growth among bereaved youth: A pilot study

OMEGA – JOURNAL OF DYING & DEATH | Online – 10 October 2018 – Although a fair amount has been written about post-traumatic stress disorder among bereaved children and adolescents, less has been written about post-traumatic growth (PTG) and its predictors among this population. This study examines predictors of PTG and the impact of trauma-informed care on PTG among bereaved youth. A pre-experimental, pre-test/post-test design was applied to measure PTG among bereaved children before and after attending a healing camp that provides trauma-informed care. A regression model was applied to examine predictors of PTG. Results showed children participating in the camp increased their PTG scores to a statistically significant degree. Circumstance of death (sudden or expected) was a predictor in this study. The results are discussed in relation to limitations, implications for future research, and practice.

Abstract: <https://goo.gl/r2tExK>

Kids supporting kids: A 10-week small group curriculum for grief and loss in schools

COUNSELLING & PSYCHOTHERAPY RESEARCH | Online – 27 September 2018 – Experiencing the death of a loved one can negatively affect a child's emotional, behavioural and academic functioning. However, no in-school group interventions exist to assist children in processing and grieving the loss of loved ones. To address this, 'Kids Supporting Kids,' a 10-step group counselling protocol for elementary school students, was developed to help students who have experienced loss of a loved one. The group curriculum aims to help students develop healthier coping skills to deal with grief-related distress; decrease internalising and externalising problems; and decrease problematic trauma symptoms. Students, teachers and parents [i.e., study participants] were each given pre-test measures. The group consisted of 10 weekly sessions on the topics of establishing safety, sharing their stories, creating a narrative with positive memories, identifying and expressing emotions, coping skills, social and family support, remembering loved ones and saying goodbye. Students, parents and teachers were also given mid-group checks and post-group questionnaires. Qualitative improvements towards these goals were noted by students, parents and teachers. Students reported developing healthier coping skills, which were observed and noted as behavioural and emotional improvements by parents and teachers. The study supports the hypotheses that qualitative improvements would be noted by each group and that the feasibility of this protocol would be supported.

Abstract: <https://goo.gl/iPVuU4>

Pathfinders: Promoting healthy adjustment in bereaved children and families

DEATH STUDIES, 2018;42(3):134-142. Pathfinders is a 10-session 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. It is an accessible, grief-focused and trauma-informed family systems model that is theory-driven, research-informed, and grounded in practice-based evidence. Pathfinders incorporates principles central to narrative approaches, with a focus on restorative processes for helping children and families stay on track developmentally. This article outlines the structure, process, and content of Pathfinders, including examples of creative interventions used within the program.

Full text: <https://goo.gl/GYZGPK>

The Danish bereavement response in 2015: Historic development & evaluation of success

SCANDINAVIAN JOURNAL OF EDUCATIONAL RESEARCH, 2018;62(1):140-149. In the 1980s, Norwegian researchers pioneered efforts towards developing school support for bereaved children. Eighteen years later, a Danish approach was created based on these foundations. This article explores the Danish school bereavement response plans (b-plans) and investigates their ability to support both teachers and bereaved children. Today, the system has one of the highest implementation rates in the world and the majority of teachers feel equipped to deal with bereavement in school. Nevertheless, adopting a standardised approach potentially leads to the neglect of individual needs. Moreover, concerns exist over whether existing b-plans are current. This article concludes that b-plans have succeeded in becoming the primary tool used by teachers, a feat that systems in other countries often fail to achieve. However, the system seldom includes the perspectives of the students it was designed to help. This is the challenge that the next generation of b-plans must remedy.

Abstract (w. link to references): <https://goo.gl/sUYRsg>

"Give us a break!": Using a solution focused programme to help young people cope with loss and negative change

BEREAVEMENT CARE, 2018;37(1):17-27. This research evaluated the impact of 'Give us a break!' – a programme 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." The findings provide evidence that the programme positively impacted on young people in terms of their sense of relatedness to others, sense of mastery, social and emotional competence and optimistic thinking. Furthermore, these findings were not contingent upon the type of loss experienced (bereaved/non-bereaved). Some methodological limitations are highlighted and directions for future research considered.

Abstract (w. link to references): <https://goo.gl/XvdDMx>

2017

When a parent dies: A systematic review of the effects of support programs for parentally bereaved children and their caregivers

BMC PALLIATIVE CARE | Online – 10 August 2017 – The included studies were published between 1985 and 2015, with the majority published 2000 onwards. They were published within several disciplines, such as psychology, social work, medicine and psychiatry, which illustrates that support for bereaved children is relevant for different professions. The interventions were based on various forms of support: group interventions for the children, family interventions, guidance for parents and camp activities for children. In fourteen studies, the interventions were directed at both children and their remaining parents. These studies revealed that when parents are supported, they can demonstrate an enhanced capacity to support their children. In three studies, the interventions were primarily directed at the bereaved children. The results showed positive between group effects both for children and caregivers in several areas, namely large effects for children's traumatic grief and parent's feelings of being supported; medium effects for parental warmth, positive parenting, parent's mental health, grief discussions in the family, and children's health.

Full text: <https://goo.gl/Vp1HdX>

Coping with Christmas: A group intervention for bereaved children

BEREAVEMENT CARE, 2017;36(3):112-118. This paper outlines a day-long group intervention for children over the Christmas period who have experienced the loss of a family member. Christmas can be a painful time for children and families as intense feelings of grief may emerge and can be difficult to manage. Group interventions with bereaved children have been demonstrated to be effective and a group intervention was developed that encouraged Christmas to be seen as a time for remembrance, enjoyment and for the development of coping skills. The content and structure of the group is described. Findings from evaluations are reported and issues about the intervention are discussed.

Abstract (w. link to references): <https://goo.gl/BznsSj>

Applying a positive youth development perspective to observation of bereavement camps for children and adolescents

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2017;13(2-3):173-192. A positive youth development perspective focuses on recognizing psychosocial strengths and providing social environments that contribute to the development of these in children and adolescents. Bereavement camps can provide such an environment as they help children cope with the death of someone close. The purpose of this study was to observe 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). Observational notes were recorded by researchers during on-site visits to three different weekend bereavement camps. Results identified how each element of positive developmental settings was exemplified in either typical camp activities or bereavement-focused activities. For example, assigning campers to cabin groups based on age and gender provided opportunities to belong, and giving campers a comfort object and a big buddy provided supportive relationships. Findings were used to create a positive developmental settings observation checklist for use by bereavement camp practitioners to assess the extent to which each camp provides the requisite elements for promoting positive youth development.

Abstract (w. link to references): <https://goo.gl/ejQdr6>

The success of a planned bereavement response: A survey on teacher use of bereavement response plans when supporting grieving children in Danish schools

PASTORAL CARE IN EDUCATION, 2017;35(1):28-38. This article investigates the strengths and weaknesses of the Danish Bereavement response plans. These are used by teachers to support grieving students and have been implemented in 96% of all Danish schools. The study is based on an Internet survey conducted with 967 teachers. Issues investigated are: "generalisation of grief," "forgetting long-term grief," "teacher distress" and "renewal of plans." Participating teachers believe that the current system works well and that the bereavement response plans have made them feel more confident when confronted with loss. However, this comes at a potential cost of generalising children's experiences of grief, so that they fit into the school support system. While the response plans are effective at ensuring initial support for bereaved children, their influence seems to diminish with time. The study found that many plans were around a decade old and that this could mean some had been forgotten or become outdated. The article concludes that while teachers find the current response plans effective, the bereavement response system could benefit from being updated. Such an update needs to focus on dealing with the issues highlighted in this article. Future response plans should also have greater emphasis on the needs voiced by bereaved students who have experienced the system.

Abstract (w. link to references): <https://goo.gl/3faamx>

**The development of a hospital-wide bereavement program:
Ensuring bereavement care for all families of pediatric patients**

JOURNAL OF PEDIATRIC HEALTH CARE, 2017;31(1):88-95. Although grief is a normal response to loss, the death of a child is believed to be one of the most difficult losses a person can endure, and bereaved parents are considered to be an "at-risk" group. Even though most deaths of children in the U.S. occur in hospitals, bereavement care provided by hospitals is highly variable, and little attention has been directed to how hospitals can best support grieving parents. The authors describe the development of a hospital-wide bereavement program at Boston Children's Hospital, where they conceptualize bereavement care as a preventive model of care. The authors identify the primary constructs of the program as education, guidance, and support and outline a template for use by other hospitals. They recommend that all pediatric hospitals implement basic, coordinated bereavement programs as the standard of care to ensure that all families receive bereavement care after the death of a patient.

Abstract: <http://goo.gl/QPigz8>

**Psychosocial well-being of young people who participated
in a support group following the loss of a parent to cancer**

JOURNAL OF SOCIAL WORK IN END-OF-LIFE & PALLIATIVE CARE, 2017;13(1):44-60. Despite the evidence of unmet support needs among young people who have lost a parent to cancer, only a few support group initiatives have been reported. This observational prospective study explored the psychosocial well-being of young people who participated in support groups at a Swedish specialist palliative care setting. On three occasions, 29 participants, aged 16-28 years, answered questionnaires covering characteristics of the participants, circumstances of the losses, psychosocial well-being of the young people, and their own assessment of the support groups. The support groups attracted mostly young women who were often unprepared for the loss. The living arrangements differed between younger and older participants; however, the loss-related variables did not differ. Significant positive changes were found regarding a sense of meaning in their future life and life satisfaction. The helpfulness of the group was assessed as high/very high and the group brought a valuable fellowship with others in a similar situation. Universality and beneficial interactions were reported and strengthened psychosocial well-being developed over time. This change, according to the young people themselves, may be attributed to the group support. The findings are useful for planning interventions to support young people in bereavement in order to enhance their psychosocial well-being.

Abstract (w. a link to references): <https://goo.gl/gjCqtF>

2016

The effects of the family bereavement program to reduce suicide ideation and/or attempts of parentally bereaved children six and fifteen years later

SUICIDE & LIFE THREATENING BEHAVIOR, 2016;46(S1):S32-S38. Findings concerning the longterm effects of the Family Bereavement Program (FBP) to reduce suicide ideation and/or attempts of parentally bereaved children and adolescents are presented. Parental death is a significant risk factor for suicide among offspring. This study is a long-term follow-up of 244 children and adolescents who had participated in a randomized trial of the FBP, examining the intervention effects on suicide ideation and/or attempts as assessed through multiple sources. Results indicate a significant effect of the FBP to reduce suicide ideation and/or attempts at the 6 and 15-year follow-up evaluation. The findings support the potential benefits of further research on "upstream" suicide prevention.

Abstract (w. link to literature cited): <https://goo.gl/5s6hkW>

Analysis of lyrics from group songwriting with bereaved children and adolescents

JOURNAL OF MUSIC THERAPY, 2016;53(3):207-231. Songwriting is a group intervention that is often used to help bereaved children and adolescents express thoughts and feelings associated with grief experiences. Few studies have examined the lyrical content of songs written by bereaved children/adolescents and how thematic content may vary by age and developmental understanding of death. Thirty-three participants, ages 6-16, were grouped according to age (child, tween, or teen) and asked to write a group song. Analysis of song lyrics was based on both inductive and deductive content analysis processes. A seven-item questionnaire was also used with the tween and teen groups to gather descriptive information about the songwriting process, including participant views on benefits, enjoyment, and preferences. Analyses revealed a total of five different themes among the three age groups, with two of the five themes present across the age groups. A majority of the participants enjoyed the songwriting process, but no clear indication of preference for verbal or written contribution was determined based on age or gender.

Abstract: <https://goo.gl/edKbSp>

2015

The development of a framework to support bereaved children and young people: The Irish Childhood Bereavement Care Pyramid

BEREAVEMENT CARE, 2015;34(2):43-51. Children's bereavement poses a challenge not only for children themselves but for the families, communities, volunteers and professionals who support them. The Irish Childhood Bereavement Network set out to develop a framework to provide a comprehensive guide for children's bereavement support. The model is based on contemporary literature, existing policy and the views of professions, volunteers and parents. The process resulted in the 'Irish Childhood Bereavement Care Pyramid.' The major pillars of children's needs, support/service responses and staff competencies are described at four levels, basic up to complex. The aim of the Pyramid is to guide adults to ensure that children are provided with the information and reassurance they need around a bereavement, to promote early intervention as appropriate and to recognise those few children who need specialist support to learn to live with their bereavement. Family context and the child's changing developmental status are emphasised as core considerations.

Abstract: <https://goo.gl/b2MuxQ>

¹'The Irish Childhood Bereavement Care Pyramid: Guide to support for bereaved children and young people' (2014) Download/view at: <https://goo.gl/pJkZVH>

N.B. The Irish Childhood Bereavement Care Pyramid was noted in the 2015 literature review under 'Resources' (p.37).

Writing the "penultimate chapter": How children begin to make sense of parental terminal illness

MORTALITY, 2015;20(2):163-177. The paper proposes that during the terminal stage of parental illness, children are involved in "writing" a "penultimate chapter." This is a prospective chapter and the quality of its content is dependent on the extent to which children are included in conversations and information sharing about the illness. The "writing" of the "penultimate chapter" is important in helping children make meaning from their current lived experience and helps prepare them in the writing of their final chapter about their parent. This paper develops and extends the ideas proposed by Walter in the 1990s. Walter delineated his ideas about bereaved people maintaining a relationship with the deceased person and through this being involved in "writing a last chapter" about their lives. Part of the process of maintaining the relationship with the deceased person and finding a stable place for them is achieved through "the writing of the last chapter." The last chapter is written after the death and involves conversations with people who knew the deceased. Walter's model is developed here to incorporate the pre-bereavement period.

Abstract (w. link to references): <https://goo.gl/4EFR9w>

Interventions in the acute hospital setting to help children facing bereavement

ST. CHRISTOPHER'S END-OF-LIFE JOURNAL, 2015;5(1). An important aspect of end-of-life care (EoLC) in the acute hospital setting is caring for the whole family, including children and young people. Children and young people may be unseen and unheard by hospital staff. However, they are still affected by the forthcoming death of someone close to them. Early and proactive interventions to support children and young people facing bereavement can help them to adapt to loss. Although education can support nurses in addressing the needs of children and young people facing bereavement, a cultural shift is required so that hospital nurses recognise their responsibility to help adults prepare children for the forthcoming death. Enabling children and young people to express their needs, be part of the dying process if they so wish and create resources to help their future memories of the person who is dying or has died can foster resilience in the face of loss. This article outlines a joint project that was run by adult and children's services in an acute hospital trust and a charitable organisation, which led to the development of written information to help adults prepare and support children at this challenging and uncertain time. It discusses the barriers and concerns expressed by hospital nurses in relation to offering family-centred EoLC in an adult acute care environment.

Abstract: <https://goo.gl/wHFfEr>

7. Assessment Tools

2018

The Adolescent Grief Inventory: Development of a novel grief measurement

JOURNAL OF AFFECTIVE DISORDERS, 2018;240(11):203-211. The Adolescents Grief Inventory (AGI) includes novel items such as "anger," "self-blame" and "sense of peace," making it a comprehensive grief measure. The AGI discriminated between different participant groups, based on cause of death, kinship, having received a mental health diagnosis or treatment, or having engaged in suicidal behaviour, in the expected directions. Adolescents who had lost a first-degree family member scored higher overall than those who had lost a non-family member (e.g., a friend), or another family member, respectively. Those who had received a mental health diagnosis, a mental health treatment, who ever had suicidal ideation, engaged in deliberate self-harm or attempted suicide scored higher overall than those who had not.

Abstract: <https://goo.gl/yCfEgL>

Psychometrics of the PTSD & depression Screener for Bereaved Youth

DEATH STUDIES | Online – 30 March 2018 – Interventions for bereaved children and families range from supportive counseling, designed to promote social connectedness and expression of feelings and thoughts about the deceased, to intensive trauma/grief-specific therapy, designed to ameliorate symptoms of post-traumatic stress disorder (PTSD) and depression. That said, professionals have few brief assessment instruments to match response and functioning to appropriate interventions. This study is a psychometric evaluation of the Screener for Bereaved Youth. Data were collected from 284 bereaved children, 6-17 years of age. A factor analysis revealed distinct sub-scales for PTSD (eight items) and depression (four items). The PTSD and depression sub-scales showed both concurrent and discriminant validity. Endorsement of four items on either subscale was associated with meeting full criteria on more extensive measures of PTSD and depression. These findings are discussed with specific consideration to the multiple systems in which the measure could be used and applications to clinical services.

Abstract: <https://goo.gl/7YZWqF>

Exploring characteristics of children presenting to counseling for grief and loss

JOURNAL OF CHILD & FAMILY STUDIES, 2018;27(3):860-871. To date, researchers exploring childhood bereavement have largely relied on unstandardized assessment instruments and/or have independently evaluated specific constructs rather than factoring in the dimensionality of loss. The purpose of this study was to utilize psychometrically established instruments to examine the multivariate shared relationship between characteristics of bereaved children referred for counseling – their ages, genders, ethnicities, types of loss, and life stressors – and their behavioral manifestations as well as the relationship between these characteristics and levels of parent-child relational stress. Utilizing archival clinical files, the authors examined these characteristics from bereaved children whose parents sought counseling services from two university-based counseling clinics. Two canonical correlational analyses were conducted to examine the following: 1) Relationship between characteristics of bereaved children and their subsequent behavioral manifestations; and, 2) Relationship between characteristics of bereaved children and levels of parent-child relational stress. Correlational findings from this study provided insight into bereaved children's manifestations of loss and levels of parent-child relational stress as contingent upon these specific characteristics. Specifically, results indicated a strong relationship between age and bereaved children's behavioral manifestations. This finding reinforced the importance for clinicians to understand developmental implications when working with bereaved children. Furthermore, caregivers who reported minimal overall external stressors also reported less parent-child relational interference. This finding further emphasizes the importance for caregivers to maintain utmost stability for bereaved children.

Abstract (inc. list of references): <https://goo.gl/cCxA3o>

2017

What is measured in bereavement treatment for children and adolescents? A systematic literature review

ILLNESS, CRISIS & LOSS | Online – 22 December 2017 – Treatment studies vary largely on how the effect of the grief treatment is measured. This systematic review evaluates whether controlled bereavement intervention studies focus on symptomatology or grief as outcome measure and also summarizes the effect of grief treatment. Eight studies met the inclusion criteria and reported in total on 30 different outcome measures. Only two studies measured grief as a separate outcome and both showed promising results for the treatment of grief with bereaved children. Systematic use of validated measures of prolonged grief in treatment studies is needed. Implications of the findings and recommendations for future studies are discussed in the perspective of complicated grief becoming part of the 11th Revision of the International Classification of Diseases. Grief interventions for parentally bereaved youth is promising but lack consistent use of reliable grief measures for solid documentation of the effect. The specific role of parenting and culture for the outcome of the intervention should be investigated in more detail.

Abstract: <https://goo.gl/qNGwhh>

2016

Preliminary evaluation of a prolonged grief questionnaire for adolescents

OMEGA – JOURNAL OF DEATH & DYING, 2016;74(1):80-95. Currently, there is no established measure to assess prolonged grief in adolescents. A new measure was designed based on the Extended Grief Inventory, the Inventory of Complicated Grief – Revised for Children, and the Inventory of Prolonged Grief for Children/Adolescents. The authors investigated the psychometric properties of the Prolonged Grief Questionnaire for Adolescents in a sample of 69 14 to 18-year-old parentally bereaved adolescents living in rural Rwanda. Additionally, they obtained socio-demographic information and assessed loss experiences and depressive symptoms. A principal component analysis revealed item loadings on two factors, which the authors named separation distress and secondary emotions. Internal consistency in this first evaluation was high, and the criterion validity was satisfying. A sensitivity of 85.3% and a specificity of 85.9% were found. The small sample size is a major limitation. However, the Prolonged Grief Questionnaire for Adolescents may be a promising tool for assessing prolonged grief symptoms in adolescents.

Abstract: <https://goo.gl/x6FBjp>

2015

New checklist helps identify children, teens with bereavement disorder

MEDICALXPRESS | Online – 22 July 2015 –With 39 straight-forward questions and an easily intelligible rating system, the 'Persistent Complex Bereavement Disorder Checklist – Youth Version' is the first tool of its kind. The University of California Los Angeles-University of Texas psychological test aims not only to help identify kids and teens whose grief may have taken a wrong turn but also attempts to gauge the severity of their symptoms. Authors hope educators, mental health providers, pediatricians, hospice providers and grief support communities will use the checklist.

Full text: <https://goo.gl/SZKQDq>

8. Education/Training Initiatives

2017

A multimodal mindfulness training to address mental health symptoms in providers who care for and interact with children in relation to end-of-life care

AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE, 2017;34(9):838-843. Medical providers may face unique emotional challenges when confronted with the suffering of chronically ill, dying, and bereaved children. This study assessed the preliminary outcomes of participation in a group-based multimodal mindfulness training pilot designed to reduce symptoms of burnout and mental health symptoms in providers who interact with children in the context of end-of-life care. A total of 13 medical providers who care for children facing life-threatening illness or bereaved children participated in a 9-session multimodal mindfulness session. Mental health symptoms and burnout were assessed prior to the program, at the program midpoint, and at the conclusion of the program. Participation in the pilot was associated with significant reductions in depressive and post-traumatic stress disorder (PTSD) symptoms among providers. Mindfulness-based programs may help providers recognize and address symptoms of depression and PTSD. Additional research is needed to enhance access and uptake of programming among larger groups of participants.

Abstract: <https://goo.gl/oMNkL2>

Going straight to the source: A pilot study of bereaved parent-facilitated communication training for pediatric subspecialty fellows

PEDIATRIC BLOOD & CANCER, 2017;64(1):156-162. Medical trainees consistently report suboptimal instruction and poor self-confidence in communication skills. Despite this deficit, few established training programs provide comprehensive, pediatric-specific communication education, particularly in the provision of "bad news." To the authors' knowledge, no programs currently use bereaved parent educators to facilitate communication training for pediatric sub-specialty trainees. The authors designed and implemented a pilot communication training seminar in which bereaved parent educators and faculty facilitators led small groups in interactive, role-play scenarios. Participants reported significant improvement in overall preparedness, breaking bad news to a patient and family, and including the adolescent or young adult patient in conversations. Additionally, participants reported a significant improvement in their ability to address a patient and family's need for information, emotional suffering at the end of life (EoL), if and when a patient should be included in the conversation, and EoL care decisions.

Abstract: <http://goo.gl/KX1amY>

9. Resources

Although not within the purview of the literature review, a number of online resources “surfaced” during the search of the literature, which may be of interest, for example:

Canada

1. Lakehead University: 'Finding Our Way Through: Navigating Loss & Grief in First Nation Life.'
(Enter title to word-search Google)
2. Lakehead University: 'Learning About Grief & Bereavement in First Nations Communities.'
(Enter title to word-search Google)
3. Office of the Children's Advocate (Manitoba) : "'Don't call me resilient": What Loss and Grief Look Like for Children and Youth.' <http://cwrp.ca/publications/3365>
4. Strong Nations: 'Grief & Loss.' <https://goo.gl/PmLXZ2>

U.K.

1. Child Bereavement: 'Children with Special Needs and Their Grief.'
(Enter title to word-search Google)
2. University of Hertfordshire: 'Managing Grief Better: People with Intellectual Disabilities.'
<https://goo.gl/LxKQ48>
3. University of Hertfordshire: 'Bereavement in the Lives of People with Intellectual Disabilities.'
<https://goo.gl/rXXoNn>

U.S.A.

1. American Federation of School Administrations: 'Social Media and Grieving Children: Helpful or Harmful?' <https://goo.gl/6gXgeZ>
2. Caring Foundation: Children's Grief Awareness Day (15 November 2018):
<https://goo.gl/nuhYrN>
3. Family Lives On Foundation: 'Death in The Digital Age: How Does Social Media Affect Children's Grief?' <https://goo.gl/pHuPpE>
4. Myers-Rosa Foundation: 'Helping Autistic Children Understand Death and Dying.'
<https://goo.gl/DSw1wQ>
5. Springer Publishing: 'Clinical Handbook of Bereavement and Grief Reactions.'
<https://goo.gl/TwWQsp>

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