Communication About Dying, Death, and Bereavement: A Systematic Review of Children's Literature

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Abstract

Background: 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.

Objectives: This study examines the content of children's literature relevant to the topic of dying and death and identifies books providers can share with children and their families.

Design: A search of children's literature was conducted using four electronic databases and one additional search engine using the word "Death" or "Dying." Storybooks about dying, death, and bereavement published in English, French, or Spanish between 1995 and 2015 were included.

Measurements: Each book underwent content analysis by at least two independent reviewers. Strict PRISMA standard was followed. Full protocol is available as PROSPERO #CRD42016042129.

Results: Two hundred ten books met inclusion criteria. The dying subject was primarily a grandparent ($n=78$) or pet ($n=44$). Books on the experience of a child dying were scarce ($n=5$). The word death or dying was used in 75% of the books ($n=158$), while others utilized euphemisms. The majority of books featured animals ($n=40$) or Caucasian subjects ($n=122$) and included spiritual elements such as heaven ($n=122$). Less than one-quarter of the books included tools for readers to address the topic of death.

Conclusions: 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.

Keywords: children's literature; bibliotherapy; death; dying; grief

Introduction

READING IS AN INTEGRAL PART OF CHILDHOOD. Along with being central to a child's development and use of imagination, reading enhances parent-child bonding and provides a way to learn about complex aspects of life and relationships. When children identify with literary characters and emotional experiences and situations that emerge from the story's message, books can be a starting point for discussion, provide greater understanding of circumstances, and can allow challenging issues to be confronted in a safe space.^{1,2}

The term bibliotherapy, which traces back to Sigmund and Anna Freud, refers to the therapeutic process that occurs when learning from reading material for therapeutic

benefit.³ For children, the process includes using books that help children think about, understand, and work through practical, emotional, spiritual, and social concerns. There are examples of bibliotherapy being used to help children communicate; obtain greater insight into personal problems⁴; and provide coping strategies for issues such as bullying, adoption, parental alcoholism, disabilities, domestic violence, self-esteem, behavior problems, eating disorders, divorce, and death. Through the creation of a safe distance, these books can facilitate a child's understanding and bring the child indirectly to the edge of sensitive issues that may be perceived as threatening.^{5,6} Such specialized topic books help children realize they are not alone^{7,8} or their experiences are unique.

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Books are helpful for families as well. Parents often struggle with how to raise difficult topics with their child and may err on the side of silence due to concern for making a mistake.⁶ Books can provide both the language parents may need to explain a topic and an opportunity while considering their child's understanding and feelings, while considering the child's cognitive and emotional development and understanding of their world. The ability to adapt to loss, cope with death, and express grief is critical for healthy childhood development.⁹

Children living with a life-limiting illness who receive open communication about their diagnosis and prognosis experience significantly less anxiety and depression.¹⁰ Yet, providers and parents both indicate difficulties in finding the right language and approach in addressing this topic with a seriously ill child.¹¹ In a prior narrative review of 65 storybooks, no books included children considering their own death or sharing their own end-of-life preparatory process.⁹ The purpose of this systematic review was to learn what books are available in the children's literature to help children cope with the topic of death and dying and to assess the content of the material presented. Our goal was to provide information that will serve as a novel resource for providers to help families facilitate honest and compassionate conversations.

Methods

An expert reference librarian designed and conducted the electronic search strategy with input from pediatric specialists (oncologist, psychologist, social worker, child life specialist). To identify eligible books, a systematic search included the Library of Congress Online Catalog, Children's Literature Comprehensive Collection, Databases of Award-Winning Children's Literature, WorldCat, and Amazon in June 2015. Search terms were "Juvenile Literature" and "Death" or "Dying" with the date of publication and target age used as limits. The study team also reviewed books suggested by experts in children literature, including one best-selling children's author, two medical librarians, a child life specialist, and a pediatric psychosocial specialist. Inclusion criteria were books published between 1995 and 2015 or considered classics; on the topic death or dying; targeted an audience between 6 and 12 years of age; and published in storybook format. We choose the age range of 6–12 years of age based on developmental theory and from our own pediatric practice experience. Children in this age range are developmentally transitioning away from concrete thinking and are entering into abstract reasoning. Yet, this was the very age range that lacked books about death. This is a vulnerable age during which personal identity, family communication approach, and understanding of loss are forming a future longitudinal identity, and yet, this age range lacks book resources. Age >13+ years started to have chapter books on death available (as noted from the review of young adult and juvenile adult literature). Books were excluded if the discussion of illness was outside of the context of death and if translation was not available in English, Spanish, or French.

Eligibility screening was performed at summary level with attentiveness to the inclusion and exclusion criteria. Each book eligible for full-text review underwent qualitative content analysis that assessed the language, format, illustrations, wording or symbolism used for death communication,

spiritual elements, child's emotions, coping strategies, and extra resources offered for healthy bereavement. Themes were defined based on team discussion and the final coding system was applied to all books' content.

Three reviewers independently analyzed all eligible books in full text. Each coder extracted data in different color font to allow for clear tracking of differences in perspective (inter-rater reliability consistently >80% in all coding domains). Discrepancies were discussed face-to-face between reviewers. Differences in perspective were then reconciled through review of the coded material by a fourth neutral coder with discussion to then reach consensus (utilized in 14 books).

The PRISMA statement for reporting systematic reviews and meta-analysis was followed¹² (Supplementary Table S1; Supplementary Data are available online at www.liebertpub.com/jpm) with the protocol made publicly available at PROSPERO (ID# CRD42016042129).

Results

A total of 210 books were included in data analysis, as shown in the PRISMA flow diagram (Fig. 1).

Summary of included books

The majority of the books were published in English ($n=194$, 92.4%) from 1995 to 2005 ($n=130$, 61.9%). Many stories were written from the perspective of a third party ($n=103$, 49%) or a child ($n=88$, 41.9%). Less than 22% of the books ($n=45$) included tools to support readers in discussing the topic of death, such as a parent guide, coping activities for the child, or a glossary of terms (Table 1).

Character demographics

Close to 90% of the books had youngsters as main characters as either animals or children ($n=184$), with only four books picturing an adult in a main role. Age was not specified in 10.5% of the books ($n=22$), both due to nonhuman subjects and due to speech focused on human experience (Table 2).

The majority of books featured Caucasian subjects ($n=122$, 58.1%) with a noted under-representation of black ($n=17$, 8.1%), Hispanic ($n=13$, 6.2%), Asian ($n=6$, 2.9%), and Native American ($n=3$, 1.4%) populations (Table 2). A list of the books representative of ethnic diversity is available in Table 3.

The dying subject was primarily a grandparent ($n=78$, 37.1%) or pet ($n=44$, 21%). The loss of friends, parents, and other family members or the experience of one's own death was less frequently described (Table 2). Books on the experience of a child dying were notably scarce ($n=5$, 2.4%, Table 4).

Communication about death

The word death or dying was used in 75% of books ($n=158$), while others utilized the idea of being gone, being out of sight, or departing for a journey. Symbols were also utilized in 69% of the storybooks ($n=145$), namely sleep and natural elements such as the sea, mountains, and flowers.

The storybooks described communication within a family or friendship context with professional counseling occurring only twice. Almost half of the books ($n=93$) explicitly valued

FIG. 1. PRISMA flow. Source: Moher D, Liberati A, Tetzlaff J, Altman DG; The PRISMA Group Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLoS Med* 2009;6:e1000097. DOI:10.1371/journal.pmed1000097. For more information, visit www.prisma-statement.org

the benefits of establishing open communication about death with children. Unique communication strategies included offering a safe space for questions ($n=11$, 5.2%) and introducing death as part of a life cycle ($n=12$, 5.7%). A few books portrayed parental figures avoiding the child's participation in the context of death, either by using confusing messages ($n=9$, 4.3%) or lack of direct communication ($n=5$, 2.4%). Other books highlighted situations in which the child avoided talking about death and adults or peers played an important role to initiate conversations ($n=6$, 2.9%).

Almost 60% of the storybooks included one or more spiritual elements ($n=122$), such as introducing the con-

cept of heaven, a divine being, or a specific religious practice. The concept of heaven was associated with doctrinal beliefs in some books, while other stories represented heaven as a more universal place. Some focused on reassuring the child that the deceased is in a better place after death, with no illness or disabilities. Although different sacred beings were cited (God, Lord, Jesus, and Allah), few books explored the mourning rituals of major world religions or cultures in depth.

Knowledge about death

Approximately 95% of the books introduced death as irreversible ($n=199$), sometimes along with the concept of universality ($n=11$, 5.2%) and nonfunctionality ($n=12$, 5.7%). Death was introduced as a natural part of the life cycle of all living beings, focusing only on the universality concept ($n=11$, 5.2%). Some books highlighted the child's learning process on irreversibility of death, questioning the possibility that the deceased would come back or mentioning behaviors of looking for the deceased. Some books focused on causality ($n=27$, 12.8%) with death described as a result of an illness, aging, or an accident. Another strategy used was to emphasize the sense of permanency ($n=8$, 3.8%), either with the deceased continuing to take care of his loved ones or maintaining a sense of connection with the deceased, in terms of everlasting love and spiritual presence.

TABLE 1. CHARACTERISTICS OF INCLUDED BOOKS

Characteristics	Specifics	n (%)
Year of publication	Before 1995	12 (5.71)
	1995–2000	74 (35.24)
	2001–2005	56 (26.67)
	2006–2010	36 (17.14)
	2011–2015	32 (15.24)
Language	English	194 (92.38)
	Spanish	13 (6.19)
	Bilingual	2 (0.95)
	French	1 (0.48)
Other resources provided	Yes	45 (21.43)
	No	165 (78.57)

TABLE 2. CHARACTER DEMOGRAPHICS

<i>Characteristics</i>	<i>Specifics</i>	<i>n (%)</i>
Age of main character	Child	184 (87.6)
	Humans	165 (78.6)
	Animals	15 (7.1)
	Nonhuman	4 (1.9)
	Adult	4 (1.9)
	Humans	2 (0.95)
	Animals	2 (0.95)
	Nonspecified	22 (10.5)
	Humans	2 (0.95)
	Animals	14 (6.7)
	Nonhuman	6 (2.85)
Race	Caucasian	122 (58.1)
	Animals or nonhuman subjects	40 (19)
	Black	17 (8.1)
	Hispanic	13 (6.2)
	Asian	6 (2.9)
	Native American	3 (1.4)
	n/a	9 (4.3)
Dying subject	Grandparents	78 (37.1)
	Pet	44 (21)
	Friend	23 (11)
	Parents	17 (8.1)
	Self	13 (6.2)
	Sibling	10 (4.8)
	Other family member	11 (5.2)
	Not specific	7 (3.3)
	Others	4 (1.9)
	Multiple dying persons	3 (1.4)

Impact of death

The majority of books described the emotional impact of death on children ($n = 130$, 60%), followed by the impact on family dynamics ($n = 45$, 21.4%) and parents ($n = 29$, 13.8%). Sadness was the emotion expressed most commonly by the child ($n = 167$, 79.5%), followed by anger ($n = 41$, 19.5%) and fear ($n = 28$, 13.3%). In addition to these feelings, 23 storybooks (11%) described somatic symptoms associated with grief, including loss of appetite, nausea, headache, insomnia, fatigue, and chest pain.

Coping strategies

Remembrance and sharing memories were the most frequent coping strategy addressed ($n = 94$, 44.8%). Receiving emotional support from others ($n = 49$, 23.3%), talking about death ($n = 28$, 13.3%), and saying goodbye ($n = 24$, 11.4%) were also mentioned. Interestingly, some storybooks portray children in the role of caretaker for the dying person ($n = 9$, 4.3%) or offering support to others ($n = 5$, 2.4%).

Discussion

Our findings indicate that while the majority of children's books did include the word death or dying, euphemisms or avoidance of conversations regarding death were used in a quarter of the storybooks and were sometimes perceived as confusing by children. Limited character racial/ethnic diversity as well as a paucity of literature for children processing their own deaths was found.

Part of healthy child development includes the task of learning about death, processing the natural end of life, adapting to grief experiences, and considering ways to support the bereaved.^{13,14} Introduced and used appropriately (Box 1), storybooks have the potential to mitigate both silence and fear surrounding the topic of death with children. Table 5 lists sample books summarized for common losses or situations experienced by children. These books offer resources on how to initiate conversations about death with children, including emotional expression, challenging themes, and coping strategies.

A troubling finding was the lack of books with a child character preparing for death. Such a book could help a child with a life-limiting illness prepare for his or her own death both in a biomedical and psychosocial perspective. This gap in the current children's literature, paired with the limited availability of parent guides, speaks to the vital need to develop developmentally and age-appropriate resources for dying children to receive information and explore feelings.

Recommendations

Developmental awareness of death. Knowledge of child development enables palliative care teams to help parents consider age-appropriate reading material and timing of introduction. While some parents may wish to shield children from the topic of death, death is informally observed early and often in a young child's world. Children are inevitably exposed to death concepts through bearing witness (noticing an elderly neighbor no longer sits on the front porch across the street); chance encounters (seeing a dead bird at the local park); and media (watching a sleeping cartoon character bounce back after a seemingly fatal fall). By age seven years, most children understand death as irreversible, inevitable, and universal.¹⁵ The recognition that all bodily functions cease after death (nonfunctionality) is generally obtained by age 10.¹⁶ A child's spiritual progression to the concept of afterlife or heaven is believed to start as early as preschool years.^{16,17} An honest compassionate approach to the inevitable topic of death enables the typical developmental search for meaning.¹⁸

Word choice. Euphemisms for death abound in children's stories, as evidenced by use in 52 books (24.8%). While these gentler words in vernacular language are likely intended to comfort a child, the use of word choice depicting sleep, travel, or absence instead of actual use of the word death resulted in the child subject feeling confusion on the topic of death rather than clarity in description or comfort in content (*My grandfather's house*). Phrases such as falling asleep can instill fear at bedtime as children can wonder whether they will wake up. Similarly, death language regarding going on a journey may instill fantasies of loss when a parent is traveling. Palliative care providers are uniquely positioned to model use of the word death when discussing natural end of life with parents.

Portrayal of diversity. A key component of effective bibliotherapy is the ability for the reader to identify with or relate to the character,^{7,19-21} and yet, due to the lack of literary diversity, not all families will find written or pictorial materials with characters representative of their ethnicity or race. In addition to personal identification, storybooks carry a socializing

TABLE 3. BOOKS THAT EXEMPLIFY ETHNIC DIVERSITY

Authors	Title	Year of publication	Language	Ethnicity represented
Beake, L; Littlewood, K	<i>Home now</i>	2006	English	African
Burrowes, A	<i>Grandma's purple flowers</i>	2000	English	African American
Carter, D; Stevenson, H	<i>Bye, Mis' Lela</i>	1998	English	African American
Loedec-Jorg, C	<i>Falikou</i>	2012	French	African
Clifton, L; Grifalconi, A	<i>Everett Anderson's Goodbye</i>	1998	English	African American
Cooke, T; Wilson, S	<i>The Grandad Tree</i>	2000	English	African American
Cosby, B; Honeywood, V	<i>The Day I saw my Father Cry</i>	2000	English	African American
Ferguson, S; Cunliffe, I	<i>Olivia Says Goodbye to Grandpa</i>	2011	English	African American
Everson, I	<i>Serafina's Silver Web: A Project to Benefit Noah's Children</i>	1999	English	African American
Fox, M; Robinson, A	<i>Sophie</i>	1995	English	African American
Fraustino, L; Andrews, B	<i>The Hickory Chair</i>	2001	English	African American
Monk, I; Porter, J	<i>Blackberry Stew</i>	2005	English	African American
Partridge, E; Castillo, L	<i>Big Cat Pepper</i>	2009	English	African American
Rappaport, D; Lewis, E	<i>The New King</i>	1995	English	African
Smith, P; Boyd, A	<i>Janna and the Kings</i>	2003	English	African American
Woodson, J; Cooper, F	<i>Sweet, Sweet, Memories</i>	2000	English	African American
Zolotow, C; Ransome, J	<i>The Old Dog</i>	1995	English	African American
Czech, J; Aitken, S	<i>The Garden Angel: A Young Child Discovers a Grandparent's Love Grows Even After Death</i>	2000	English	Asian
Edwards, M	<i>Stinky Stern Forever</i>	2005	English	Asian
Manushkin, F; Lyon, T	<i>Goodbye to Goldie</i>	2010	English	Asian
Oliviero, J; Kelly, J	<i>Som See and the Magic Elephant</i>	1995	English	Asian
Thong, R; McLeannan, C	<i>The Wishing Tree</i>	2004	English	Asian
Williams, La; Bochak, G	<i>The Long Silk Strand</i>	2000	English	Asian
Armas, T; Howard, P; Ventura, G	<i>Remembering Grandma</i>	2003	English/Spanish	Hispanic
Chaves Castaneda, R; Carrasco Ingles, A	<i>Salvavidas</i>	2006	Spanish	Hispanic
Fontaine, A; Obadinah	<i>Ocho Loved Flowers</i>	2007	Spanish	Hispanic
Goldman, J; Moreno, R	<i>Uncle Monarch and the Day of the Death</i>	2008	English	Hispanic
Hooft, M; Heuninck, R; Llado, A	<i>Adios, Abuela</i>	2014	Spanish	Hispanic
Joose, B; Potter, G	<i>Ghost Wings</i>	2002	English	Hispanic
Langer Ramirez, L	<i>Mi Abuela ya no Esta: un Cuento del Dia de los Muertos</i>	2002	Spanish	Hispanic
Luenn, N; Chapman, R	<i>A Gift for Abuelita: Celebrating the Day of Dead</i>	1998	English/Spanish	Hispanic
Maddern, E; Hess, P; Frutos Velasco, A	<i>El Senor Muerte en una Avellana</i>	2007	Spanish	Hispanic
Muller, B	<i>Felipa and the Day of the Dead</i>	2005	Spanish	Hispanic
Rius, R; Peris, C	<i>Maria no se Olvidara</i>	2005	Spanish	Hispanic
Rosen, M; Ransome, J	<i>Bonesy and Isabel</i>	1995	English	Hispanic
Ventura, A; Delicado, F	<i>El Tren</i>	2000	Spanish	Hispanic
Boyden, L; Cordova, A	<i>The Blue Roses</i>	2002	English	Native American
Carr, D; Branzei, A	<i>Micco</i>	2007	English	Native American
Devine, M; Dwyer, M	<i>Kayak Girl</i>	2012	English	Native Alaskan

role.²² Providers should strive to introduce families to literature that prioritizes respectful global inclusion as this will add to the richness of a child's character exposure and interpretation of content. For example, how a child is involved in funerals and memory rituals varies across cultures as does duration of mourning and community explanations of death (*When Dinosaurs Die: A Guide to Understanding Death* and *Pearl's Marigolds for Grandpa*).

Portrayal of family. Parental portrayals in the books varied from skillfully preparing the child for a loved one's

death to overlooking or misreading the needs of the child. Some character parents share grief with their child, while others did not.⁶ Whether in the imagery of a father turned away to hide his tears from a child (*Sammy in the Sky* and *Waiting to Sing*) or a mother pretending to be fine after a death in front of her grieving daughter (*The Garden Angel*), emotional isolation was portrayed. Some children's books gave examples of honest communication in an anticipatory manner, such as explanations of burials or graves before a child's attendance at the funeral. Other books depict silence and intention of protecting the child through exclusion from

TABLE 4. BOOKS ON A CHILD'S DYING EXPERIENCE

<i>Authors</i>	<i>Title</i>	<i>Year of publication</i>	<i>Language</i>	<i>Reading level</i>	<i>General summary</i>
Al-Chokhachy, E; Graf, U	<i>The Angel With the Golden Glow</i>	1999	English	Primary school	An angel is chosen to be born as a special child to give his family healing in the brief time he is with them.
Loedec-Jorg, C	<i>Falikou</i>	2012	French	Juvenile	A young boy finds a road in his village and begins to inquire about departures and life journeys; his parents answer his questions to help him take the road in peace.
Everson, I	<i>Serafina's Silver Web: A Project to Benefit Noah's Children</i>	1999	English	Primary school	With the help of a very special spider, a terminally ill boy learns to overcome his fear of endings and accept death as a journey.
Meunier, P; Egan, S	<i>Islands in Heaven</i>	2001	English	Juvenile	A young girl dies and goes to heaven, but finds herself concerned about the sadness of her family and friends left behind on Earth; she is granted permission to return to her island for one day to check on her loved ones.
Wesson, V; Michaels, M	<i>Painting Sunsets With the Angels</i>	1996	English	Primary school	With the help of an angel, young David finds a way to bring comfort and peace to his older sister so that she can be happy again after his death.

funeral participation (*Fireflies, Peach Pies, & Lullabies*) or hospital visits (*Wild Girl and Gran*). Grandparents were depicted as talking to their grandchildren about the natural result of age to be death, as they prepared their grandchildren for their own upcoming death in a compassionate way (*Thank you, Grandpa*).

Along with grandparents,²³ siblings are also too oft-forgotten grievers.²⁴ Sibling grief represents a substantial and profound loss experience for bereaved brothers and sisters.

Sibling loss often occurs after months or years of a sibling's extended illness or even sibling absence due to frequent hospitalizations. Sometimes siblings cope by obtaining a perfect child persona or by acting out or by bottling up feelings, by carrying family feelings, or by not processing feelings.²⁵⁻²⁹ Storybooks offer an opportunity for siblings to give voice to this loss and to safely process the complex heavy feelings associated with the death of a beloved brother or sister.

BOX 1. PRACTICAL BIBLIOTHERAPY IDEAS FOR PEDIATRICIANS TO SHARE WITH PARENTS

- Preread the books before sharing with your children to gauge your own comfort with the content, character development, and word choice
- Try to select books that fit your child's life experiences, interests, learning style, or visual preferences
- Pick a comfortable, cozy private place for reading together
- Before reading the book together, consider sharing an introductory statement such as "This is a special book I picked out for us to read together. Some of what happens in this book is sad or hard. We can think about and talk about these feelings together."
- Provide opportunity for your child to turn the pages if developmentally appropriate (sense of physical control with pace of book)
- If your child interrupts with a question or comment during the reading, listen patiently and explore feelings
- Gently gauge the level of specificity sought by your child
- Respond to questions without false reassurance or platitudes
- Ask gentle questions to help your child make connection between his or her own life experiences and book characters
- Intend to allow time for questions from your child during and after the reading: it is not uncommon for your child to wait many hours or even many days to readdress the topic
- Consider sharing cultural narrative and personal testimony of loss (death of own pet, death of friend or coworker or neighbor, etc.); include feelings and factual information
- Be present for grief processing and provide loving presence with active listening
- Receive information on additional social support and professional resources for both your child and yourself
- Recognize that children's literature and the art in these books can be therapeutic and meaningful for the adult reader too!

The items included in the box are the authors' original ideas based on their clinical work.

TABLE 5. SAMPLE BOOK LIST

<i>Authors</i>	<i>Title</i>	<i>Year of publication</i>	<i>Dying subject</i>	<i>General summary</i>	<i>Strengths</i>
Grimes, N; Colón, R	<i>What is Goodbye?</i>	2004	Sibling (brother)	Alternating poems by a brother and sister conveying their feelings about the death of their older brother and the impact it had on their family.	Acknowledges the challenges of talking about feelings and processing family emotions surrounding a sibling's death.
Old, W; Friedman, J	<i>Stacy Had a Little Sister</i>	1995	Sibling (sister)	Stacy has mixed feelings about her newborn sister. When the baby dies of Sudden Infant Death Syndrome, Stacy is sad and asks questions about her death.	Includes information about Sudden Infant Death Syndrome.
Parkinson, S	<i>All Shining in the Spring: The Story of a Baby Who Died</i>	1995	Sibling (infant)	Matthew is looking forward to his new little brother or sister, but the doctor says the baby is not growing properly and will not be able to live after it is born.	Highlights sibling's experience surrounding death of an infant in the family.
Reagan, J; Pollema-Cahill, P	<i>Always my Brother</i>	2009	Sibling (brother)	Becky and her big brother shared interests and experiences. After his death, she slowly returns to the activities they enjoyed together and learns that he is still part of the family.	Recognizes the challenges involved in siblings resuming social interaction and activities after a sibling's death.
Rothman, J; Gish, L	<i>A Birthday Present for Daniel: A Child's Story of Loss</i>	1996	Sibling (brother)	A young girl whose brother has died describes how she feels and tells about some of the things her family does to help them accept his death.	Includes ranges of emotions and different coping strategies.
Ycomans, E; DeRosa, D	<i>Lost and Found: Remembering a Sister</i>	2000	Sibling (sister)	A girl recounts her confusing thoughts and feelings after the death of her sister and the number of ways she continues to feel her sister's love.	Discusses challenges of communication about death.
Beake, L; Littlewood, K	<i>Home Now</i>	2006	Parent (parents)	After the death of her parents, a young girl goes to live with her aunt. She is sad and lonely until she meets a young elephant who has also lost his family.	Addresses the challenges faced by a child adapting to a new culture/setting after the parents' death.
Clifton, L; Grifalconi, A	<i>Everett Anderson's Goodbye</i>	1998	Parent (father)	A little boy tries to come to grips with his father's death. He struggles with conflicting emotions and goes through the different stages of grief.	Offers a portrayal of different stages of grief experienced by the boy after his father's death.
Harvey, J; Crossett, W	<i>The Sound of the Sea</i>	2006; 2005	Parent (mother)	A young boy expresses a range of feelings after his mother's death. With the help of his grandparents, he finds a way to remember her.	Portrays child's feelings of abandonment, betrayal, and guilt after his mother's death.

(continued)

TABLE 5. (CONTINUED)

<i>Authors</i>	<i>Title</i>	<i>Year of publication</i>	<i>Dying subject</i>	<i>General summary</i>	<i>Strengths</i>
Kaplan, H; Blondon, H	<i>Waiting to Sing</i>	2000	Parent (mother)	A family that loves music is devastated by the death of the mother. The beautiful music that remains helps them to find comfort.	Discusses change in family dynamics and roles after the death of a mother.
Moundic, C; Tallec O	<i>The Scar</i>	2011	Parent (mother)	When his mother dies, a little boy is angry at his loss, but does everything he can to hold onto her memory and to help his father and grandmother cope.	Addresses child's attempts to keep memories from fading and to care for the adults around him, offering a portrayal of uninhibited emotions.
Napoli, D; Felstead, C	<i>Flamingo Dream</i>	2002	Parent (father)	A young boy learns that his father has cancer and is dying. The family lived and loved together even though the father was preparing for death, making wonderful memories at the end of life.	Offers anticipatory guidance throughout cancer treatment and father's dying process.
Hemery, K; Teis, K	<i>The Healing Tree</i>	2001	Great-grandmother	A grandmother recounts how a tree helped her heal after the death of her mother when she was just a young girl.	Shares a strong intergenerational component and models healing across generations.
Kroll, V; Cote, N	<i>Fireflies, Peach Pies, & Lullabies</i>	1995	Great-grandmother	When Francie's great-grandmother dies of Alzheimer's disease, Francie finds a way to help people remember the person she was before dementia's progression.	Discusses losses throughout great-grandmother's disease process and how it impacts memory making.
Norman, L; Young, N	<i>Grandpa</i>	1998	Grandfather	A boy is coming to terms with the death of his grandfather by remembering some good things about him.	Recognizes relationship challenges after death and highlights shared healing process for both parents and children.
Wild, M; Brooks, R	<i>Old Pig</i>	2009; 1999; 1998	Grandmother	When a grandmother's time to die is near, she puts her affairs in order and takes a slow walk with granddaughter to savor beauty and impart wisdom.	Reviews how granddaughter takes care of grandmother throughout her dying process.
Yolen, J; Mathis, M	<i>Grandad Bill's Song</i>	1998; 1994	Grandfather	A boy asks others how they felt when his grandfather died and then shares his own feelings.	Emphasizes how different people cope and feel when facing the loss of a loved one.
Zalben, J	<i>Pearl's Marigolds for Grandpa</i>	1997	Grandfather	A young girl copes with the death of her grandfather by remembering all the things she loved about him.	Emphasizes child's grief process and memory making. This book offers a summary of world religions' interpretation of death.

(continued)

TABLE 5. (CONTINUED)

<i>Authors</i>	<i>Title</i>	<i>Year of publication</i>	<i>Dying subject</i>	<i>General summary</i>	<i>Strengths</i>
Bley, A	<i>And What Comes After a Thousand?</i>	2007	Friend	A little girl and her old friend share many interests. After his death, she learns to deal with her pain and comes to understand that memories remain.	Includes the experience of child's presence close to the dying person.
Bunting, E; Moser, B	<i>On Call Back Mountain</i>	1997	Friend	Two brothers encounter a lone wolf on the spot where each summer night before they had signaled their friend up on the mountain tower.	Highlights child's insight about death and illustrates siblings comforting one another.
Mills, J; Cary P	<i>Gentle Willow: A Story for Children About Dying</i>	2004; 1993	Friend (tree)	When Amanda and Little Tree discover that their friend Gentle Willow is not feeling very well and cannot be cured, they comfort her in her final days.	Emphasizes presence and silence as strategies for support; discusses limitations of medicine in terms of cure.
Penn, A; Gibson, B	<i>Chester Raccoon and the Acorn Full of Memories</i>	2010	Friend (animal)	Chester Raccoon's friend had an accident and died. Mrs. Raccoon suggests that Chester and his friends create memories to celebrate their friend's life.	Highlights common questions regarding death and burial rituals.
Stickney, D; Nordstrom, R	<i>Water Bugs and Dragonflies: Explaining Death to Young Children</i>	1997	Friend (animal)	A small colony of water bugs live below the surface of a quiet pond. Every so often, one of them climbs up a lily stalk and disappears from sight to become a new creature.	Offers resources for parents on how to introduce communication about death, using a religious tone (e.g., prayer, bible content).
Varley, S	<i>Badger's Parting Gifts</i>	1992	Friend	Badger's friends are overwhelmed when he dies. By sharing their memories of his gifts, they find the strength to face the future with hope.	Reflects on the animal's dying process and saying goodbye to his friends.
Cohen, M; Himler, R	<i>Jim's dog, Muffins</i>	2008; 1984	Pet (dog)	Jim's friends feel sad when they hear that his dog has been killed. They try to help him feel better, but Jim will not talk to anyone. He only thinks about his dog.	Emphasizes different peer support strategies.
Harris, R; Ormerod, J	<i>Goodbye, Mouse</i>	2004; 2001	Pet (mouse)	One morning, a boy finds that his pet will not wake up. Talking about his pet, burying him in a special box, and saying goodbye helps this boy feel better.	Addresses different emotions when a pet dies; recognizes time needed to grieve and waiting to get a new pet.

(continued)

TABLE 5. (CONTINUED)

<i>Authors</i>	<i>Title</i>	<i>Year of publication</i>	<i>Dying subject</i>	<i>General summary</i>	<i>Strengths</i>
Hughes, S	<i>Alfie and the birthday surprise</i>	2007; 1997	Pet (cat)	The death of Bob's cat prompts his friends and family to give him a surprise birthday party and a very special present.	Emphasizes the permanency of an old cat's memories even in the setting of a new kitten's arrival.
Viorst, J	<i>The Tenth Good Thing about Barney</i>	1971	Pet (cat)	After a boy's beloved cat died, his mother asks him to think of 10 good things about the pet to tell at his funeral.	Focuses on the positives of remembering a life.
Wallace-Brodeur, R; Mitter, K	<i>Goodbye, Mitch</i>	1995	Pet (cat)	A young boy describes how he feels throughout his cat dying process. Remembering his pet helps the boy to feel better after his death.	Emphasizes parent support and enabling child presence after pet death (child holding cat after death).
Wilhelm, H	<i>I'll Always Love You</i>	1998; 1985	Pet (dog)	A child's sadness at the death of a beloved dog is tempered by the remembrance of saying to it every night, "I'll always love you."	Illustrates experiences shared by a boy and his pet throughout life. Family talks about pet's illness and holds memorial burial.
Brown, L; Brown, M	<i>When Dinosaurs Die: A Guide to Understanding Death</i>	1998	General	The book answers different questions about death and explores feelings regarding the death of a loved one, as well as ways to honor their memories.	Offers examples on how to help others when someone they love dies. Includes death by suicide, war, poverty, prejudice, and drug abuse.
Buscaglia, L	<i>The Fall of Freddie the Leaf: A Story of Life for All Ages</i>	1982	General	A story about a leaf experiencing the changes of seasons with his companions leaves, finally falling to the ground when winter comes.	Discusses natural life cycle and transformation.
Mellonie, B; Ingpen, R	<i>Lifetimes: The beautiful way to explain death to children</i>	1983	General	All living beings have their own special lifetimes, with beginnings and endings. Dying is as much a part of living as being born.	Discusses natural life cycles of all living beings, such as plants, animals, and insects.

Cause of death. Old age and illness were the most common cited cause of death. While certain diagnoses (primarily cancer) were referenced as cause of death, there was a notable absence of biological explanation to help the young reader process causation through scientific insight. The animal characters seemed to provide more frank conversations regarding biology. For example, a grandpa elephant explains the physical decomposition from flesh to skeleton to dust before his death (*Farewell, Grandpa Elephant*) and woodland creatures learn that death means the “heart quit beating and body doesn’t work anymore” (*Chester Raccoon and the Acorn Full of Memories*). Human characters’ explanations of biology varied from metaphor such as heart had gone to sleep (*Janna and the Kings*) to confusion as a grandson worries whether he could soon have a heart attack (*Poppy’s Combine*). Palliative care providers may have the opportunity to help parents phrase biological explanations for death in understandable clear language. Only a few books included more raw topics such as suicide, drug overdose, and combat death situations (*When Dinosaurs Die* and *Once a Shepherd*) and yet children do realistically face these losses.

Location of death. Location of death has been previously recognized as an under-reported reality in children’s literature.⁹ This was a similar finding in our study, although location is an increasingly important conversational topic as families consider care transitions from hospitalizations (or long-term care facilities for grandparents) to and from home settings.

Children living with a life-limiting illness. Bereaved parents who discussed death with their child generally preferred narrative conversation format,³⁰ and yet, only five books provided insight into a child preparing for his or her own death (Table 4). This surprising shortage of children’s literature leaves parents with few developmentally informed, gently illustrated storybook resources to facilitate important meaningful conversations. The idea of introducing children with life-limiting illness to the topic of death may seem anxiety provoking and overwhelming for parents. In reality, children with life-limiting illnesses often experience psychological, spiritual, social, or even physical distress secondary to silence surrounding end-of-life topics.^{31,32} There is a recognized relational price to this silence in families.³³ These conversations would be better facilitated by a wider array of children’s literature resources with relatable characters for children with life-limiting illnesses.

Limitations and strengths

Although the literature search included an extended list of children’s books published in the last 20 years, we may have missed books recommended by bibliotherapy lists that did not match our search and inclusion criteria. For example, publishers that were not part of mainline databases or Amazon and books with no indexing category of death or dying could have been missed. This could contribute to bias, that is, overestimating the types of books identified. Our inclusion was limited to three languages, and we may have failed to identify certain demographics due to linguistic restriction.

Conclusion

Palliative care teams carry an essential role to advocate for honest, compassionate family conversations and to support parents in discussions about death by highlighting children’s communication needs and facilitating culturally informed and developmentally appropriate discussions. Provider-initiated cues to action (a shared book list, a listening conversation, or a book gift) have potential to empower and encourage families. Our findings welcome bibliotherapy partnership with stakeholders across a child’s care continuum: palliative care providers, family members, primary pediatricians, teachers, religious leaders, and school counselors in fostering these compassionate, brave storybook conversations with children in a supportive community approach. This analysis of children’s literature relevant to illness, death, dying, and bereavement can inform the development of future psychosocial tools and communication resources.

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