

Pediatric Oncology

Series Editors: Gregory H. Reaman · Franklin O. Smith

Joanne Wolfe

Barbara L. Jones

Ulrika Kreicbergs

Momcilo Jankovic *Editors*

# Palliative Care in Pediatric Oncology

 Springer

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Editors

# Palliative Care in Pediatric Oncology

 Springer

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## Introduction

*Palliative Care in Pediatric Oncology* is a novel textbook intended for all clinicians caring for children with advanced cancer. Several concepts are important to understanding this text, beginning with the definition of palliative care. According to the World Health Organization, palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Optimal care of children with cancer involves the individualized blending of care directed at the underlying illness and the physical, emotional, social, and spiritual needs of the child and family with continuous reevaluation and adjustment.

Importantly, palliative care is *not* a phase of care and the term “palliative” should not be used to imply that a child’s cancer is incurable. Misuse of the term “palliative” to imply a phase of care creates barriers to integrating a palliative approach into the care of all children with advanced cancer. Indeed, as editors, we would favor eliminating the use of the terms “curative intent” and “palliative intent” to describe cancer-directed therapies. Experience and research suggest that however cancer treatments are labeled; families continue to hope for cure, life extension, and even a miracle, up until their child’s very last breath. Using these labels often serves to convey prognosis in a rather “short-hand” manner, rather than using optimal communication strategies as described in Chap. 4. Cancer-directed therapy labels should reflect family goals of care which typically fall into one of three approaches to helping the child to (1) live as long as possible, (2) live as long as possible and as well as possible, or (3) live as comfortably as possible. Needless to say, these goals evolve over time, depending on the child’s illness outcome.

Notably, this textbook was written by oncology clinicians in collaboration with palliative care clinicians and this approach models how these subspecialists can effectively work together. Importantly, pediatric oncology clinicians all need to know basic, “primary” palliative care. Palliative care specialists should be invited into the care of children and families with more complex suffering to provide an added layer of support.

*Palliative Care in Pediatric Oncology* comprehensively covers the epidemiology of suffering in childhood cancer and the impact of distress on the child, families, the community, and the clinicians who serve them. The text emphasizes the critical role of the primary interdisciplinary oncology team

and collaboration with a palliative care team, when indicated. Communication is a fundamental procedure in palliative care, an intervention that when optimally employed can facilitate easing suffering and enhancing well-being. The text also discusses the integration of cancer-directed therapy in pediatric advanced cancer as well as palliative care in stem cell transplantation. Individual chapters also focus on the various domains of distress including physical, psychological, spiritual, and social. Some children with advanced cancer do face end of life, and thus the text also focuses on this critical period of care as well as support for families in their bereavement. The text ends with a focus on caring for ourselves as clinicians as we care for children with advanced cancer and considerations about needed innovations to better support children with advanced cancer and their families.

It is our hope that this text provides an added layer of support to clinicians working with children with advanced cancer and their families. It has been a privilege working with such a talented group of authors in service to enhancing the well-being of children with advanced cancer and their families.



Alisha Kassam, Kimberley Widger,  
and Franca Benini

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## 1.1 Epidemiology of Advanced Cancer in Children

Survival rates for childhood cancer in developed countries have steadily improved over the last few decades from 58% in the mid-1970s to over 80% today (Fig. 1.1). These increased survival rates are due to high participation rates in large international collaborative clinical trials together with improvements in cancer-directed therapies and supportive care (Hudson et al. 2014).

Despite the tremendous progress in treating pediatric malignancies, 20% of children with cancer will still die from their disease. As such, death from cancer remains the leading cause of

non-accidental death in children (ages 1–14 years) (Fig. 1.2). Figure 1.3 shows the distribution of childhood cancer deaths by cancer type. Leukemia accounts for a third of all cancer-related deaths, followed by central nervous tumors and neuroblastoma (Pizzo et al. 2011; Pizzo et al. 2016).

Pediatric cancer is a family illness (Patterson et al. 2004). Apart from the physical impact of the disease and its treatments on the ill child, there is also an emotional, social, and spiritual impact on the child, parents, and siblings (see Case 1). Particularly when a child dies, the experience may impact on the health of family members for many years to come. Much of the research to date are retrospective accounts primarily from parents as opposed to hearing from the ill child or siblings directly. As well, much of the research is more qualitative in nature or involves small sample sizes making it a challenge to determine the prevalence of distress and suffering in family members.

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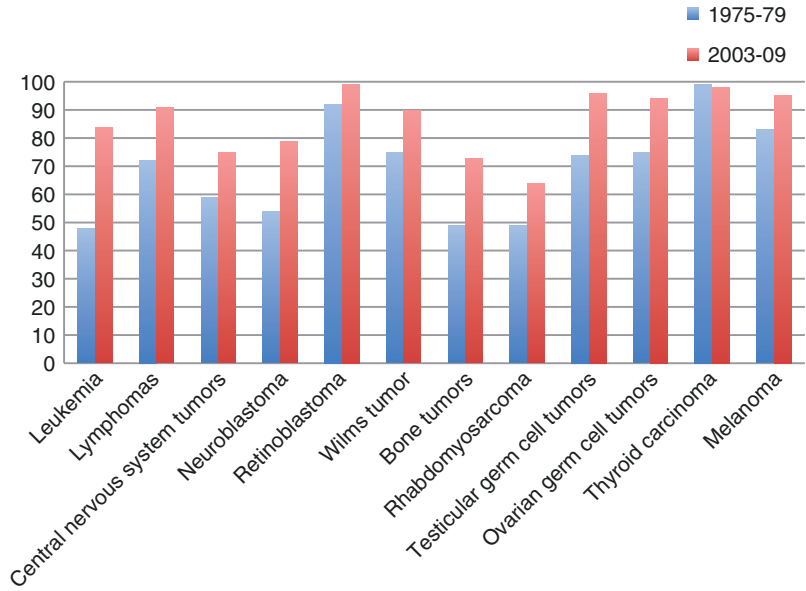
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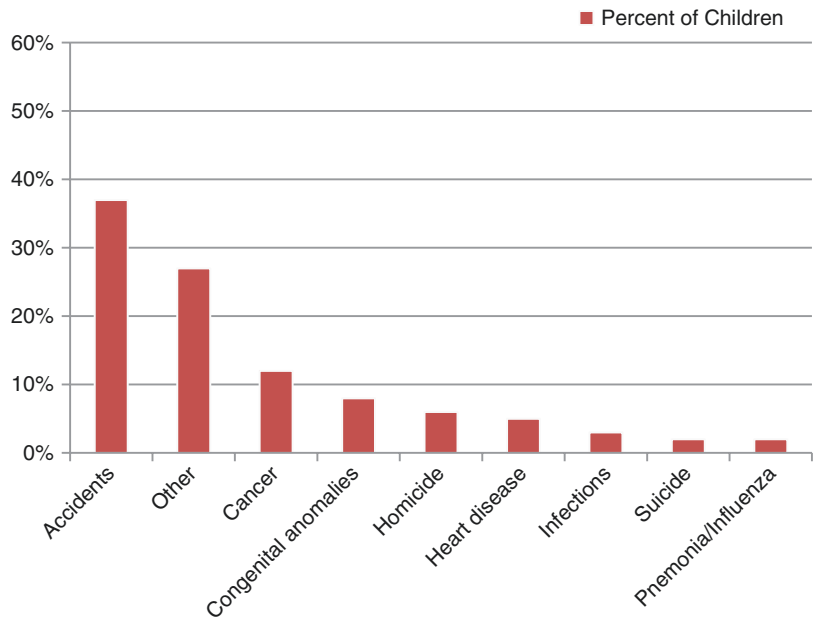
## 1.2 Prevalence and Patterns of Suffering in Children with Cancer

Children with cancer experience physical, emotional, social, and spiritual suffering as a result of the disease process, treatments for the disease, and treatment-related side effects. Not surprisingly, compared with children who have survived

**Fig. 1.1** Pediatric cancer 5-year survival rates from birth to 19 years old for two time periods. Adapted from the American Cancer Society. Special Section: Cancer in Children and Adolescents (2014) <https://www.cancer.org/content/dam/cancer-org/research/cancer-facts-and-statistics/annual-cancer-facts-and-figures/2014/special-section-cancer-in-children-and-adolescents-cancer-facts-and-figures-2014.pdf>



**Fig. 1.2** Causes of childhood death in the USA, 2006. Causes of death among children 1–14 years of age

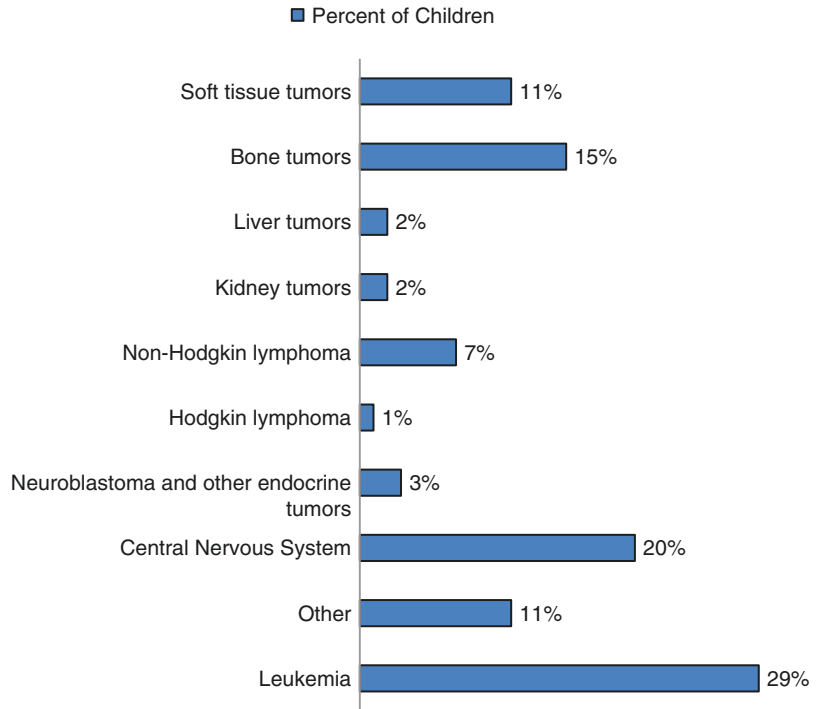


childhood cancer, children receiving cancer-related treatments have significantly higher mean scores for depression (49.0 vs. 45.9), anxiety (49.5 vs. 46.2), pain interference (50.2 vs. 44.7), and fatigue (52.9 vs. 43.8) and significantly lower scores for peer relationships (45.4 vs. 52.1) (Hinds et al. 2013). When there is disease progression, prospective parent-proxy reports of

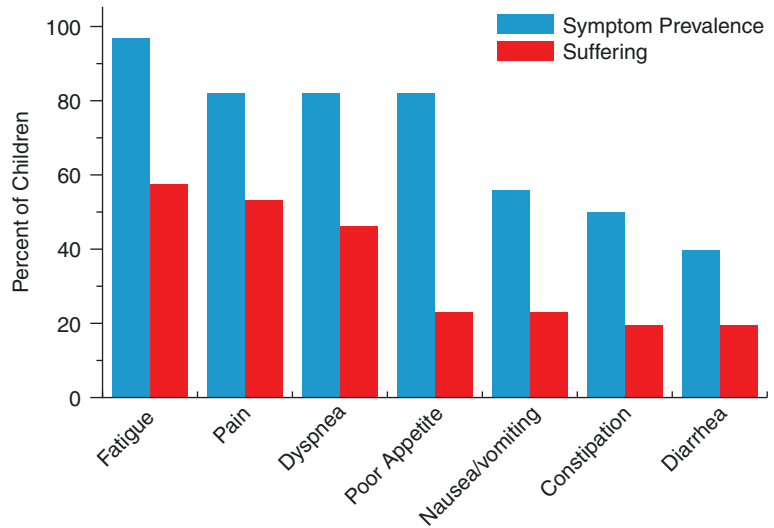
quality of life indicate in the last 6 months of life children had significantly worse physical health, more pain, and more fatigue compared to those who survived more than 6 months, while there were no significant differences in emotional or social functioning (Tomlinson et al. 2011).

Wolfe et al. (2000a) were the first to report a high symptom burden and substantial suffering

**Fig. 1.3** Childhood cancer deaths by cancer type in children and adolescents 0–19 years of age, 2006



**Fig. 1.4** The degree of suffering from common symptoms in the last month of life. The percentage of children who, according to parental report, had a specific symptom during the last month of life and who had “a lot” or “a great deal” of suffering as a result. Adapted from Wolfe J, Grier HE, Klar N, Levin SB, Ellenbogen JM, Salem-Schatz S, et al. Symptoms and suffering at the end of life in children with cancer. *N Engl J Med.* 2000; 342(5):326–33



in children who died of cancer. The proportion of children who, according to their parents, had a specific symptom during the last month of life and the proportion who suffered from the symptom are shown in Fig. 1.4. The most commonly reported symptoms were fatigue, pain, and dyspnea. Other prevalent symptoms included poor

appetite, nausea and vomiting, constipation, and diarrhea. Worryingly, 89% of children experienced at least one symptom from which, based on parental report, they suffered “a lot” or a “great deal.”

The finding of a high prevalence of symptoms in children with advanced cancer has been

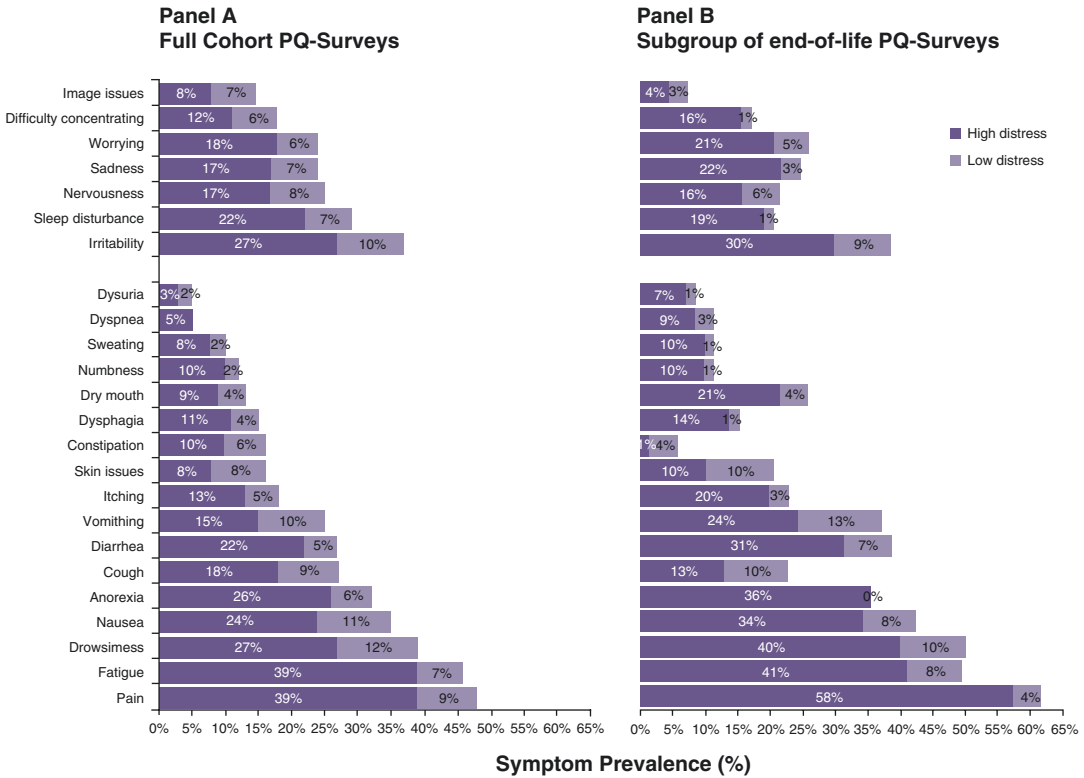
replicated over the last decade in studies across the world (Heath et al. 2010; Jalmsell et al. 2006). Heath et al. (2010) examined the symptoms and level of suffering among Australian children with cancer at the end of life. They found that 84% of parents reported their child had suffered from at least one symptom in their last month of life. Pain, fatigue, and poor appetite were the most common. Similarly, Jalmsell et al. (2006) found a high prevalence of symptoms reported by parents of Swedish children with advanced cancer including fatigue (86%), reduced mobility (76%), pain (73%), and decreased appetite (71%). Symptoms like depression (48%) and anxiety (38%) were reported to a lesser degree (Jalmsell et al. 2006), while a study in the USA found higher prevalence of depression (65%) and anxiety (48.3%), along with fear (49.2%) and sleep disturbance (60%) during the last month of life from the perspective of bereaved parents (Friedrichsdorf et al. 2015). In Germany, bereaved parents indicated that 65% of children with cancer experienced severe suffering from pain and 63.6% from nausea during the last month of life; however, the majority (72.3%) of parents felt that their child was happy, in a good mood, and peaceful during the same time period (von Lützau et al. 2012).

The above studies evaluated symptoms in children with any cancer diagnosis; however, the underlying malignancy can influence the symptom profile. In addition to the common symptoms of pain, fatigue, and dyspnea, children with hematologic malignancies may also experience bleeding, coagulopathies, and symptoms of anemia. Children with central nervous system tumors are at risk of seizures and symptoms related to increased intracranial pressure. Children with solid tumors may experience symptoms related to compression of vital structures by the tumor such as bowel obstruction or spinal cord compression. The oncology team must be familiar with the symptoms of the underlying malignancy in order to provide anticipatory guidance to families. Preparing children and families for what symptoms to expect as the child's disease progresses, and educating them on how they will be promptly managed, can mitigate much of the suffering and distress.

In order to accurately understand the symptom experience of children with cancer, it is vital to also hear the perspective of the child when developmentally appropriate. Unfortunately, the majority of available literature about the symptom experience of children is based on clinician and parent observations (Hinds et al. 2007). A review article published in 2007 found that less than 17% of the published data about the end of life in pediatric oncology patients included actual patient reported outcomes (Hinds et al. 2007). The largest study to prospectively describe patient reported symptom distress in children with advanced cancer was published in 2015 (Wolfe et al. 2015). Symptom prevalence and distress observed in these children are shown in Fig. 1.5. Common physical symptoms reported by children with advanced cancer were pain (48%), fatigue (46%), and drowsiness (39%), while the most common psychological symptoms were irritability (37%), sleep disturbances (29%), nervousness (25%), sadness (24%), and worrying (24%). Pain was the most common highly distressing symptom. Similar to previous studies that have relied on parent report, symptom prevalence and distress were worse in the last 12 weeks of life. Children who experienced a recent disease progression or received moderate or high-intensity cancer therapy reported worse symptom scores.

While prevalence cannot be determined, some of the most poignant accounts of the suffering associated with having cancer come through qualitative research that include interviews with children and adolescents (Hurwitz et al. 2004; Weaver et al. 2016) or analysis of diaries or websites created by children living with or who have died from cancer (Suzuki and Beale 2006; Flavelle 2011). Table 1.1 includes a selection of quotes from these studies that highlight the experience in terms of symptoms, the desire to protect friends and family from the experience, and the thoughts about the future.

The research to date both from the child's perspective and through parent-proxy reports strengthens our understanding that children with advanced cancer experience distressing symptoms throughout their disease course and especially at



**Fig. 1.5** Symptom prevalence and distress observed in 104 children with advanced cancer who completed 920 PQ surveys during 9 months of follow-up (a) and in the subgroup of 25 children who died and had completed 73 PQ surveys in the last 12 weeks of life (b). Adapted from

Wolfe J, Orellana L, Ullrich C, Cook EF, Kang TI, Rosenberg A, Geyer JR, Feudtner C, Dussel V. Symptoms and Distress in Children with Advanced Cancer: Prospective Patient-Reported Outcomes from the PediQUEST Study. *J Clin Oncol.* 2015; 33(10):1928–35

**Table 1.1** Quotes from children and adolescents about the cancer experience

Symptoms
“They ask you, ‘you feeling any pain.’ You know? Some people like to be macho...like, at the beginning I was kind of like that but I know it’s...I have to tell them what’s going on so they can help me more” (Weaver et al. 2016, p 4)
“Today was the worst out of all of them, my bone marrow biopsy. It feels like getting a tooth drilled without any pain meds except in your hip instead of your mouth. And afterward it feels like you fell down the stairs and landed on your ass really hard” (Suzuki and Beale 2006, p 157)
“Don’t know if I want Emmie here. Sure, I love hanging out with her and just chillin’ but I don’t want her to see me like this either. I don’t wanna get really mad at her cause I’m in pain or don’t wanna sleep the whole time she visits” (Flavelle 2011, p 31)
“I think my spirits are getting low. I know they’re getting low but I think I may be getting to a point where I’m getting depressed. It sucks” Flavelle 2011, p 29)
Protecting others
“I’ve had a lot of people compliment me on the way that I’ve been handling this ... Well, I’m a good actor. This is the truth. I am scared, angry, and sad. All this positive (sic) stuff is mainly for my family and friends ... What kind of messed up thing did I have to do to have God slap me in the face like this” (Suzuki and Beale 2006, p 157)
“That hard time is a seeing that my friends and family want to stress more. I am often trying to take things from them such as take the stress from them. So, that’s personally what I try to do, to take away other people’s stress and worries” (Weaver et al. 2016, p 4)
“I mean, I understand like being upset and not wanting to talk...but you just got to be like you were before, happy and respectful” (Weaver et al. 2016, p 5)

(continued)

**Table 1.1** (continued)*Thoughts about the future*

“Because your cancer, not all cancers, but it can take you away and you never know when you’re going to get taken away” (Weaver et al. 2016, p 5)

“I understood very strongly that in order to die, you must first melt away physically. I had seen it happen to many other children. Kids who ate did not die. Therefore I ate; no matter how much my throat hurt or my gums bled. I would eat and throw it up, and then I would eat again” (Suzuki and Beale 2006, p 157)

“They had 3 different options, so I went with number 2. I do think they could have explained it better... the first time I heard it, it was pretty much, “You’re going to die, and we can prolong your life, but you’re going to die.”... but then it was explained over and over again, and I know it is not the truth. I might die, there’s a very big chance of that, and I’m scared of that, but there are people who make it, and I’m hoping I’m one of them” (Hurwitz et al. 2004, p 2144)

“I think the tumor is growing REALLY fast or the swelling has gotten worse ... Maybe I just need more drugs. I don’t really want to be on more drugs. Each time I go up a drug or get a new one makes me wonder who’s winning. All I can do is get chemo and radiation and hope for the best. I pray every night for some strength and the strength to get through this” Flavelle 2011, p 31)

the end of life. This research highlights the need for comprehensive assessment of symptoms and a good understanding of typical worries and experiences in order to intervene appropriately to both prevent and address suffering in children and adolescents with cancer.

### 1.3 Prevalence and Patterns of Suffering in Parents of Children with Cancer

Regardless of disease outcome, the diagnosis and subsequent treatment of childhood cancer have a significant emotional impact on parents, which may result in poor psychosocial outcomes that may in turn impact on the well-being of the entire family (Patterson et al. 2004; Rosenberg et al. 2014). Posttraumatic stress disorder is evident across both bereaved and non-bereaved parents after childhood cancer; however, the prevalence is quite different with non-bereaved mothers’ rates at 20% versus fathers’ at 13%, while bereaved mothers’ and fathers’ rates were 53% and 33%, respectively (Norberg et al. 2011). For parents of children with advanced cancer, 50% experience high levels of psychological distress (Rosenberg et al. 2013). Distress levels were higher when parents felt that the ill child also had significant emotional suffering or the family was experiencing financial hardships. Levels of distress were lower when parents reported goals of

care that aligned with their understanding of the child’s prognosis (Rosenberg et al. 2013).

In a systematic review of quantitative research with parents of children who died from cancer, higher rates of anxiety and depression were evident compared with population norms or non-bereaved parent samples across three studies (Rosenberg et al. 2012). Other included research identified prolonged grief, poor physical and psychological health, and lower quality of life in bereaved parents. Factors associated with poor outcomes included the length of time the child received cancer treatment, with less than 6 months or more than 18 months being more difficult, the child having received a stem cell transplant, death in the hospital, little preparation for death, economic difficulties, and the child’s quality of life (Rosenberg et al. 2012). The length of follow-up varied widely across the included studies from 1 month to 9 years after the child’s death. One study with longer follow-up indicated that outcomes were worse 4–6 years after the death but then improved between 7 and 9 years after the death (Kreicbergs et al. 2004).

Despite the negative outcomes highlighted, some research also identifies positive outcomes for parents following the death of a child particularly in the areas of relationships, increased appreciation for life, greater empathy for others, and enhanced spirituality (Gilmer et al. 2012; Lichtenthal et al. 2013). The impact of a child’s death on parents is clearly linked to relation-

ships with health professionals and aspects of care that are provided both before and after the death (Kreicbergs et al. 2005; Snaman et al. 2016a, b), highlighting opportunities for health professionals to support parents and foster more positive outcomes. The responsibility of institutions that cared for children prior to death to continue to provide care to the family after the death has recently received greater attention in the research literature (Snaman et al. 2016b). The importance of this ongoing connection is highlighted in Case 2 through the comments of bereaved parents.

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#### 1.4 Prevalence and Patterns of Suffering in Siblings of Children with Cancer

Cancer and its treatment are generally unpredictable. Parents report living day by day and not making plans more than a day or two in advance. Sudden changes in the child's condition impact parents' ability to attend special events in their own lives or in the lives of the siblings. The ill child's needs must take priority leaving siblings feeling jealous, anxious, and insecure (Sidhu et al. 2005). In a systematic review of research about the psychosocial adjustment of siblings throughout child's cancer treatments, 65 papers were identified. Overall, findings indicated that siblings struggled particularly in the first 3 months after diagnosis with increased levels of fear, sadness, helplessness, worry, anger, and guilt as well as some evidence of posttraumatic stress symptoms (Alderfer et al. 2010). Findings from most studies indicated that siblings did not demonstrate psychiatric symptoms such as anxiety or depression. However, quality of life scores were lower than normal limits for at least the first year after diagnosis but returned to normal levels at 2 years (Alderfer et al. 2010). In some of the included studies, gender and age played a role in the degree and type of distress with females showing more difficulties overall, school-age children having more challenges with physical quality of life, and adolescents having more anxiety and overall lower scores for quality of life

(Alderfer et al. 2010). More recent research also highlights the influence of the child's age and developmental stage on the prevalence and patterns of distress with younger bereaved siblings tending to express grief through temper tantrums and irritability, while adolescents tended to have more difficulty in school and engage in risk-taking behaviors (Barrera et al. 2013).

In a study of bereaved siblings an average of 12 years after a child's death from cancer, only about a quarter reported ongoing psychological distress (Rosenberg et al. 2015). For the majority of these siblings, anxiety, depression, and the use of alcohol or illicit substances increased in the first year after the death but over time returned to what it was prior to the child's diagnosis (Rosenberg et al. 2015). Similarly, Eilegard et al. (2013) found little differences in the prevalence of anxiety and depression when comparing bereaved siblings and age-matched non-bereaved siblings, 2–9 years after the death. The areas where there were differences between the two groups included sleep, maturity, and self-esteem with bereaved sibling reporting more difficulties with sleep and lower levels of maturity and self-esteem.

In a study, of 39 siblings, 44% felt they had experienced changes in their personality following a child's death from cancer, while 61% and 54% of their mothers and fathers reported personality changes in the sibling. The changes were both positive and negative with some becoming more compassionate and mature, while others reported being more withdrawn, fearful, sad, or angry. Interestingly, siblings tended to report more of the positive changes in themselves, while the parents tended to report more of the negative changes (Foster et al. 2012).

In one study, one third of 39 participating siblings indicated that their experience impacted on their relationships with friends. Some found it difficult to relate to their friends as they could not understand what the experience was like. Others found new groups of friends, sometimes becoming close to the deceased child's peers (Foster et al. 2012). In another study with 58 siblings, a majority (82%) reported that their relationships with others were not negatively impacted by the illness with median scores for