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# The Impact of Pediatric Cancer on the Family

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**Case Vignette**

"I didn't hear anything after the doctor told us Jason had cancer. My mind went blank. We were terrified." During an initial consult with their psychosocial provider, Jennifer and Tom described the moment they found out their 5-year-old son, Jason, had acute lymphoblastic leukemia (ALL), and they shared their concerns about what the next few years of treatment would mean for their family. Although the oncologist explained that Jason had a good chance of cure, they worried about his future and felt overwhelmed by all the medical information they were given. Managing intense treatment demands while continuing to work and care for Jason's sisters seemed impossible. The psychosocial provider first reassured Jennifer and Tom that their worries were very normal and then helped them to problem solve these early challenges. Rallying support to assist with immediate needs was an important, practical step. The psychosocial provider also assessed their understanding of Jason's situation and discussed how to appropriately share this information with him and his 8- and 13-year-old sisters. These strategies relieved some of Jennifer and Tom's anxiety in the first days after diagnosis and allowed the family to find a routine that now included cancer, but worked effectively for them.

Even under the best circumstances, when the likelihood of cure is good, families experience considerable stress and disruption when a child is diagnosed with cancer. In addition to adjusting to the initial shock of the diagnosis and making difficult treatment decisions, families must cope with the demands of treatment, changes in family routines, financial costs, chal-

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lenging conversations with healthcare providers and other family members, and the lingering possibility of relapse or death (Rodriguez et al. 2012). Disruption in normative activities, such as school and extracurricular functions, is common for patients and siblings during treatment (Katz and Madan-Swain 2006; Alderfer et al. 2010). In survivorship, a significant proportion of families must also deal with the child's late effects and ongoing healthcare needs. When treatment is unsuccessful, parents and siblings are faced with the overwhelming task of managing end-of-life decisions, their personal grief, and adjusting to life without the child. Thus, the diagnosis of cancer in childhood has significant and enduring implications for the psychosocial well-being of the entire family.

We begin this chapter by highlighting theoretical models that guide research and supportive care of families of children with cancer. Research on the psychosocial outcomes of parents and siblings, including aspects of family functioning, is summarized across the continuum during diagnosis and treatment, survivorship, and/or end of life. A particular focus is on innovative work that illustrates the transaction of family factors and processes that contribute to outcomes for individual family members. Although limited research has evaluated clinical trials to improve psychosocial outcomes for these families, we highlight this work when possible. Attention is focused on implications for the psychosocial assessment and ongoing care of the family. Finally, directions for future research are summarized.

## Theoretical Perspectives

*Family systems and socioecological models* emphasize that the stress of childhood cancer affects all members of the family, as individuals make adjustments to accommodate the illness and treatment in the family system (Alderfer and Kazak 2006). Bronfenbrenner (1977) proposed that an individual is nested centrally within an expanding set of rings or systems that reflect more proximal (e.g., family, school/work) to distal spheres of influence (e.g., society, culture; see Fig. 9.1). These systems have reciprocal effects on each other and the individual. Thus, a family system model considers a child's diagnosis of cancer within the context of a family that has preexisting patterns of relationships and interactions. This climate, or the common values, rules, and beliefs within the family, provides a framework for how parents and children respond to one another with respect to the challenges presented throughout treatment and afterward. For example, family environment influences how openly the family talks about the diagnosis, shares emotion and affect, and collaborates in decision making. Family members are interdependent, such that an individual's adjustment is influenced not only by intrinsic characteristics but also by the significant others in his or her life. In other words, family functioning may set the stage for how individual family members will manage cancer-related stress as a system.

Because the needs of families of children with cancer are ongoing and complex, research and clinical care is optimized when also considered within a life-span developmental perspective. As a growing number of childhood cancer survivors mature into adults, we have gained a better understanding of the evolving and lasting influence of cancer on the developing individual and family. This approach requires sensitivity to the dynamic nature of the child and family's illness experience over time (Wong et al. 2010; Kazak 2001). Transitions between developmental periods are important, as major changes in social roles and contexts can alter the course of physical and psychosocial well-being for both children and adults. For example, a child's age or the timing of diagnosis and treatment are important as they can imply different risks for psychosocial problems and provision of appropriate supportive care. Young children with cancer may have young parents who are less financially stable or new to the demands of caring for multiple, small children in the home, further compounding the strain of the cancer experience. Other parents may have different challenges, such as the cost of college tuition for older children or managing the care of elderly parents, in addition to the ill child's

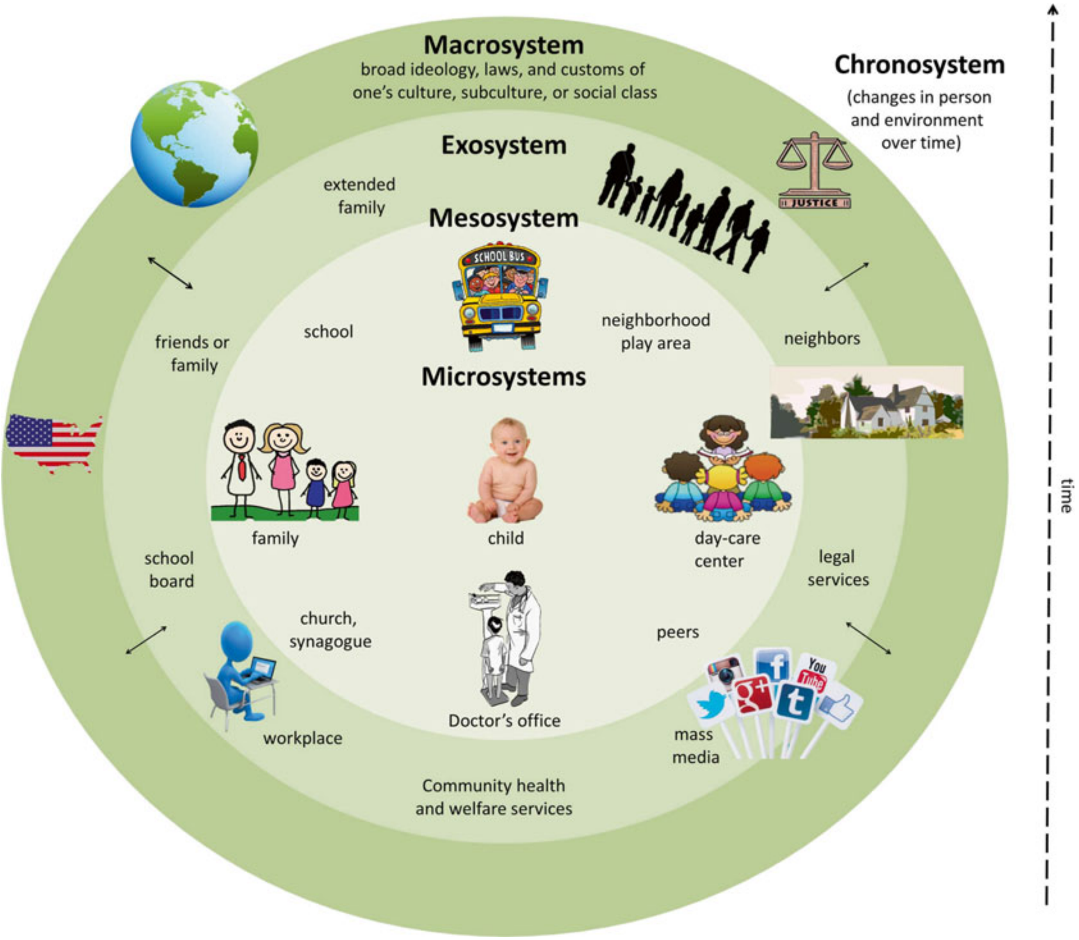

**Fig. 9.1** Ecological systems theory

care. There is also evidence that childhood cancer can affect the patient's transition between developmental periods after diagnosis, including the attainment of socially valued milestones (e.g., graduation, employment) (Stam et al. 2006). Thus, a delay or failure to achieve these milestones can have lasting implications for the family system based on the child's ultimate level of independence.

*Disability/stress models* suggest that a variety of risk and protective factors contribute to the development of psychopathology or negative outcomes in response to adversity (Wallander and Varni 1992; Lazarus and Folkman 1984). For example, medical or disease factors, intrapersonal traits, and socioecological and environmental factors are proposed to interact over time to influence an individual's trajectory of adjustment. Many families of children with cancer exhibit resilience after initial treatment and have few lasting negative effects. However, some families or individuals struggle to adapt to a child's diagnosis and treatment for cancer and may have long-term difficulties even after treatment is completed. Researchers continue to examine the interplay of factors that contribute to variation in outcomes for families over time. The Pediatric Psychosocial Preventative Health Model (PPPHM) may provide practical guidance on how to triage services based on a family's risk profile (Kazak 2006). Please see Chap. 4 on assessment for details. This model proposes a three-tiered approach to matching the level of psychosocial intervention (i.e., universal, clinical, or targeted) with the level of family need or distress as identified through the use of screening tools or clinical assessment. With these theoretical perspectives in mind, relevant literature is reviewed and recommendations for supportive care are highlighted below.

## Psychosocial Functioning of Parents

**Case Vignette**

In subsequent meetings with Jason's mom, the psychosocial provider learned that Jennifer has a history of anxiety and had been prescribed medication in the past. She felt the medication had been helpful, but she had not renewed her prescription since Jason's diagnosis. Jennifer hadn't been sleeping well, especially in the hospital, and she was finding it hard to concentrate. She had lost track of some of Jason's medications and confided that she felt guilty and stressed by the day-to-day demands of care. The nurses reported that her anxiety during Jason's mediport access often made it difficult to keep him calm. "I just feel terrible that he has to go through this. It breaks my heart. I worry about everything." Near the end of the session, Jennifer also shared that she had befriended another family on the unit whose child relapsed a few days earlier. Witnessing this family's pain was a stark reminder of the precarious situation that her family faced, despite her best attempts to reassure herself that Jason would be fine. The psychosocial provider discussed the importance of self-care and helped coordinate Jennifer's treatment with her primary care provider. They discussed cognitive–behavioral strategies to manage her worries and to establish better sleep hygiene. The psychosocial provider also taught Jennifer how to distract Jason and coordinated sessions with the medical team and child life professionals to facilitate her involvement in his procedures. Finally, they discussed how to problem solve with Tom, who was busy working and caring for Jason's sisters at home. Jennifer and Tom were able to devise a workable plan to alternate time with Jason and his sisters during hospital stays so each had time to rest at home.

Interestingly, parents of children treated for cancer are at greater risk for adverse psychological outcomes than the children themselves. A meta-analysis found that parents of children receiving treatment for cancer, particularly mothers, have greater distress than comparison samples (Pai et al. 2007). While many parents do not report clinical levels of distress, a subgroup of parents may be at risk for difficulties, particularly internalizing symptoms. Parents who considered themselves a lone parent when caring for their ill child had significantly lower incomes and greater distress (i.e., were more likely to score at or above clinical or "case" cutoffs on the Brief Symptom Inventory) than those who considered themselves to be married or partnered (Wiener et al. 2013). Other work suggests single mothers, and those with fewer socioeconomic resources, may be at the highest risk for internalizing symptoms and benefit the most from clinical assistance (Dolgin et al. 2007). Parent distress tends to be higher near diagnosis and during treatment but usually declines over time. However, the end of treatment may be a period of psychosocial risk, as fears of recurrence can surface for parents (Wakefield et al. 2011). Oftentimes, long-term adjustment is conceptualized in terms of posttraumatic responses to the stress of the child's cancer diagnosis, painful procedures, and threat to life. Elevations in posttraumatic stress symptoms have been reported for up to 54 % of parents at some time during or after their child's cancer treatment (Bruce 2006; Kazak et al. 2005). Concurrent stressors due to the child's limitations in functioning and resultant caregiver strain can also be a potent or proximal predictor of distress for parents of survivors.

Little research has focused on the experience of parents near the end of their child's life. Caring for a seriously ill child can have deleterious effects on parental quality of life, mood, sleep, and fatigue, with fear of the child's death and physical symptoms as frequent concerns (Klassen et al. 2008; Theunissen et al. 2007). As a child approaches the end of life, these stressors can be magnified. About half of parents of children with advanced cancer have been found to have high rates of distress (Rosenberg et al. 2013). These outcomes may be worse for parents of children with poorer health status, more intense treatment, less time since diagnosis, and more economic hardship (Klassen et al. 2008; Rosenberg et al. 2013). In fact, parents whose children have a "difficult death" or unrelieved pain, anxiety, and sleep disruption may report more internalizing symptoms and poorer quality of life 4–9 years after the death (Kreicbergs et al. 2005; Jalmsell et al. 2010). A systematic review indicates that bereaved parents are at risk for depression, anxiety, prolonged grief, and poor quality of life (Rosenberg et al. 2012). They routinely score worse on most scales of adjustment, especially internalizing problems, relative to norms and controls. Compared to other types of loss, parental grief is also more severe with a greater risk for complicated or prolonged grief reactions, particularly among mothers (Lannen et al. 2008; Lichtenthal et al. in press). However, over time, some parents can also recognize personal growth and positive outcomes, such as greater compassion and closer relationships, in response to a child's illness and/or death (Gilmer et al. 2012).

## Psychosocial Functioning of Siblings

**Case Vignette**

Following reports from Jennifer and Tom, the psychosocial provider met with their family to address concerns about behavioral issues and declining school performance for Jason's oldest sister, Janet. Janet reluctantly disclosed that she felt bad for Jason, but she also wanted to be a normal teenager and hang out with her friends. Since Jason was diagnosed, she had received two Ds on her report card and had taken on more chores at home, often caring for her younger sister in the mornings and evenings when her dad was at work. "I don't really get to see my friends that much. Jason's at the hospital a lot, and I don't really know what's going on. Mom used to take me shopping and come to my things at school, but now she's always tired or dealing with other stuff. Everything's just different now." The psychosocial provider discovered that Jason's sisters didn't visit him when he was in the hospital, and their parents hadn't talked much about his illness since the initial diagnosis. Janet had gotten bits of information while overhearing her parents on the phone, but she was afraid to ask questions because she didn't want to upset them. The psychosocial provider worked with the family to improve communication and to address Janet's academic and social concerns with the school counselor. Jennifer and Tom updated the girls on Jason's treatment and reassured them that it was okay to ask questions. They also made plans to reinstate family movie night on Friday evenings, even when Jason was in the hospital, and scheduled occasional one-on-one time with the girls to regain a sense of normalcy.

Nearly 80 % of U.S. children grow up with a brother or sister in the home (U.S. Census Bureau 2008), underscoring the importance of sibling dynamics as part of the family system. In fact, U.S. children are now more likely to grow up with a sibling than with a father (U.S. Census Bureau 2008). Siblings share many experiences, resulting in a unique and powerful bond that is often lifelong (McHale et al. 2006). They are attachment figures that can serve as teachers, friends, comforters, protectors, competitors, and antagonists. Siblings are role models for behavior and can exert both positive (e.g., social competence, academic engagement) and negative influences (e.g., substance use, delinquency) on one another. Furthermore, managing sibling relationships, particularly conflict, is one of the top child-rearing challenges for parents (Feinberg et al. 2012). Thus, sibling relationships are a key component of family functioning and child development. When cancer disrupts this relationship and the home environment, it may have significant implications for sibling well-being.

Much of the research on siblings of children with cancer is qualitative in nature (Vermaes et al. 2012). As parents are involved in the care of the ill child, siblings may experience additional demands at home (von Essen and Enskar 2003). Because they often do not want to further burden parents, they may be left to manage their worries and fears alone. Perception of parental differential treatment (PDT) is a family dynamic that occurs naturally in families (Feinberg et al. 2012), but may be exacerbated in the case of childhood cancer. Comparison with the ill child is common, and siblings may feel jealous, resentful, or neglected at times (Wilkins and Woodgate 2005). In many cases, there are several years of treatment during which much of the family's attention and resources are directed toward the patient. Older children may be caregivers for both healthy and ill siblings and can assume other adult roles in the home (Gaab et al. 2014). Challenges to maintaining normalcy and to engaging in typical developmental activities have been reported. Siblings report that they would like to visit the hospital more often and be involved in conversations about the ill child. However, there may be challenges to providing information about the ill child and to communicating openly about the impact of the illness on siblings (Patterson et al. 2011; von Essen and Enskar 2003). These unique stressors, coupled with parents who are less available or distressed due to the child's illness, leave siblings of children with cancer at risk for acute and long-term psychosocial difficulties.

A meta-analysis found siblings of children with chronic illness are at risk for multiple difficulties (Vermaes et al. 2012). Recent reviews focused specifically on siblings of children with cancer suggest a subset experience symptoms of anxiety, depression, posttraumatic stress, reduced quality of life and lower healthcare utilization, and disruption to academic and social functioning (Alderfer et al. 2010; Wilkins and Woodgate 2005). Several factors, such as age, gender, premorbid distress, coping, and family functioning, may be associated with sibling outcomes (Houtzager et al. 2004; Long et al. 2013). Furthermore, parents report that psychosocial support for siblings is inadequate (Ballard 2004; Patterson et al. 2011). In a large-scale survey of professionals from three pediatric oncology organizations, only 25 % reported providing psychosocial services to siblings (Wiener et al. 2012).

Most difficulties for siblings dissipate over the first year after diagnosis, but there is evidence that they may resurface or worsen in response to declines in the ill child's health or death. In the few studies using standardized measures, bereaved siblings have been noted to have lower social competence and more internalizing and externalizing problems relative to norms or controls within 2 years of the death (McCown and Davies 1995; Rosenberg et al. 2015). Self-concept may decline (Eilegard et al. 2013), and bereaved siblings who are younger or male can also exhibit difficulties in peer relationships relative to classmates (Gerhardt et al. 2012). Grief symptoms, such as sadness, sleep disruption, and inattention, can resurface years later as children mature and reflect on the loss from a different perspective (Sveen et al. 2014). However, bereaved siblings can also demonstrate positive growth, such as having a better outlook on life, being kinder, and more tolerant of others (Foster et al. 2012).

## Couple and Marital Relationships

**Case Vignette**

As Jason's treatment progressed, Jennifer and Tom reported that they felt like they were living parallel lives, often passing each other during the changing of shifts while caring for the children. Although they had been happily married for 15 years, they admitted to having more arguments lately. Some of this had spilled over to irritability toward the children as well. “We’ve always had a good relationship, but it’s hard to find time to really talk. Jennifer used to be the one I’d go to when things were bothering me, but she’s got enough on her plate. We both do!” The psychosocial provider helped the couple find ways to reconnect and find private time so they could share each other’s fears and hopes during Jason’s treatment. They discussed other outlets for stress and sources of support. Both realized the importance of resolving their conflicts without involving the children when possible. A focus on Jason’s transition to maintenance therapy, which would be less demanding, allowed them to see some relief on the horizon.

Parents of children with cancer may perceive increased marital distress and strain, especially soon after diagnosis (Long and Marsland 2011; Grootenhuis and Last 1997). A meta-analysis found significantly higher marital distress in parents of children with cancer at diagnosis compared to parents of healthy children, but not after 1-year postdiagnosis (Pai et al. 2007). Newer studies corroborate earlier research (Wijnberg-Williams et al. 2015). Effects on marital satisfaction vary and may follow one of three patterns, reflecting increasing, decreasing, or stable satisfaction over the course of treatment. Strengthened marital relationships are most likely to be found among parents long after childhood cancer treatment. Hence, time since diagnosis, as well as the strength of the relationship before cancer onset, may impact marital satisfaction. Although cancer can strain marital or couple relationships, parents of children with cancer do not appear more likely to divorce over the long term, even in the case of bereaved couples (Schwab 1998; Syse et al. 2009).

Parents often feel that their marriage is put on hold as they devote time to their sick children while juggling other daily life tasks (e.g., household chores, work, or caring for other children) (Long and Marsland 2011). As a result, parents feel communication, shared decision making, and closeness decrease, while loneliness increases (Bjork et al. 2005). The greatest source for conflict may be differences in the way each parent copes with the child’s disease. Holding back emotions in order to protect the other seems most detrimental and contributes to a loss of intimacy. Although partner’s behaviors can be a source of stress and conflict, parents can also serve as a great source of support for each other. However, the type of support can vary between practical support (e.g. household tasks, taking care of other children) and emotional support. Recent work has shown interesting patterns of coping among couples of children with cancer, such that mothers’ use of secondary control strategies involving cognitive reappraisal, positive thinking, acceptance, and distraction may have a compensatory effect against fathers’ use of disengagement coping (e.g., avoidance, wishful thinking) in predicting both mother and father distress (Compas et al. 2015).

## Family Environment and Parent–Child Relationships

While many individual and family factors can contribute to the development of psychopathology more generally, often proximal factors (e.g., parental depression, family conflict) are the most common contributors to a child’s risk in the context of cancer (Robinson et al. 2007; Drotar 1997). This mirrors the developmental literature indicating the two primary factors that buffer the impact of stress on children are often intelligence and having a warm and consistent caregiver (Masten 2001). For example, both parental depression and anxiety have been associated with greater distress in children (Garber and Cole 2010), and similar patterns have been identified in families of children with cancer.

Transmission of distress between family members may be accounted for or modified by family environment. For example, Varni and colleagues (1996) found that in families of children newly diagnosed with cancer, cohesion and expressiveness were associated with fewer child internalizing problems. In general, children in families high in conflict are more prone to difficulties, while children in a positive family environment are more likely to adjust well to the stress of a chronic illness or cancer (Drotar 1997; Long and Marsland 2011). There is some evidence that mothers of children with cancer report more family conflict relative to control mothers (Pai et al. 2007), but there is variability across families, and other aspects of family functioning may be preserved (Long and Marsland 2011).

With respect to parenting, there are mixed reports with some evidence that parenting stress is elevated during treatment and among mothers of brain tumor survivors (Long and Marsland 2011), but others find no group differences. Parenting stress has been related to greater emotional, behavioral, and social difficulties among children with cancer, while perceived vulnerability may contribute to emotional difficulties (Colletti et al. 2008). Parents may be more concerned, overindulgent, and lenient than parents of children without cancer (Long et al. 2014), but it is important to note that most studies focus on the ill child as opposed to siblings. In a seminal article on sibling adjustment within 2 years of a child's cancer diagnosis (Long et al. 2013), more family functioning problems, higher parent psychological control, and lower parent acceptance were associated with sibling distress. Family functioning contributed the most variance to sibling distress, but support was also found for a cumulative risk model with a higher overall risk score also contributing to distress.

Families also undergo significant change after a child's death. One study reported higher family cohesion among bereaved families than controls (Davies 1988), but others suggest less cohesion and increased parental strain (Martinson et al. 1994; West et al. 1991). Parents may be consumed by grief and "overlook" surviving children, or they may be closer and overprotective (Lehman et al. 1989; Gilmer et al. 2012). Bereaved parents have reported more parenting stress than controls (Lehman et al. 1989), and bereaved siblings have reported less communication, availability, and support from their parents (Foster et al. 2012).

## Recommendations for Supportive Care

Providing supportive care that is sensitive to the context of the family system is important throughout cancer treatment, survivorship, and/or end of life. Comprehensive standards for psychosocial care in pediatric psycho-oncology are currently under development and are family focused, including recommendations for the care of ill children, parents, and siblings (Wiener et al. 2015). Multidisciplinary psychosocial services that include family access to chaplains, child life specialists, school intervention, social work, psychologists, and psychiatrists are ideal. However, resources are limited, and the availability of clinical services varies both between and within centers. Recommendations for multidisciplinary care of families of children with cancer include assistance with the practical and financial burdens of treatment; communication and shared decision making between the family and healthcare providers; routine screening for family risk and protective factors that may contribute to overall adjustment; and cognitive–behavioral strategies to facilitate adaptation (Wiener et al. 2015). However, flexibility in location and modality of care is important, as contact with family members may be restricted due to hospital visitation policies or for practical reasons. This is especially true after a child's death. Obtaining parent proxy report or telephone contact with parents or siblings may be necessary. Referrals to existing resources within the community or online also may be helpful.

Regular screening for family psychosocial challenges and the assessment of strengths and available resources can more accurately inform the allocation of services depending on family risk and needs. Referrals should be made for evidence-based treatments to reduce psychological problems when warranted (Pai et al. 2006;

Kazak 2006). Novel studies have shown promise in reducing parent distress, such as Problem-Solving Skills Training (PSST) in mothers of children near diagnosis (Sahler et al. 2005, 2013) and cognitive–behavioral strategies to reduce PTSS in fathers of survivors (Kazak et al. 2004). Interventions to address sibling needs and difficulties vary, but most often sibling support groups or camps have been described in the literature (Carpenter et al. 1990; Houtzager et al. 2001; Sidhu et al. 2006). A recent cognitive–behavioral intervention has shown success at reducing distress in children with cancer by targeting maternal distress near diagnosis (Fedele et al. 2013). Overall, there is a relative lack of randomized controlled trials targeting parents and siblings relative to children with cancer, necessitating a reliance on evidence-based strategies derived from work with other populations.

Communication is an ongoing issue in the supportive care of families. Parents may struggle with how and what to share with children throughout the illness and treatment. Children should be provided with information in a developmentally appropriate manner throughout the course of the illness and end of life if applicable. In some cases, siblings are called upon to serve as a donor for stem cell transplant. These siblings represent a special circumstance in which communication, informed consent, and potential for distress should be evaluated and addressed (Macleod et al. 2003; Packman et al. 2004; Wiener et al. 2008). Siblings should receive education about tests and procedures as well as information about the potential for success and/or failure of the transplant. See Chap. 13 on Stem Cell Transplant for additional details.

Psychosocial providers should also assess the long-term needs and concerns of families during survivorship. This is an important time for preparing a diagnosis and treatment summary and providing education to the family regarding the need for follow-up. This includes determining the ongoing role of family members in the survivor's care, screening for distress (e.g., PTSS, depression, risk behaviors), and facilitating transitions to adult providers. Natural transitions in life roles and developmental contexts (e.g., child moving away from home, parent returning to work) will likely affect the family's financial stability, health insurance coverage, and access to care. The ability to provide ongoing support to survivors and their families, such as educational accommodations or vocational rehabilitation, may help optimize the family's success with long-term adaptation to the child's diagnosis and potential late effects.

Supportive care is also critically important at end of life. Although siblings report a desire to be involved and informed when their brother or sister is dying (Nolbris and Helstrom 2005; Steele et al. 2013), parents may not feel fully informed or have an accurate understanding of the child's prognosis (Wolfe et al. 2000; Kohler et al. 2011). Attention should focus on these difficult conversations; assessing family beliefs about death and previous losses; helping parents talk about death with the ill child and siblings; giving the child a chance to ask questions and express themselves through developmentally appropriate means (e.g., journal, artwork); allowing the family to share feelings for one another; and preparing them to say goodbye. Some children may wish to give gifts or will belongings to loved ones, participate in funeral planning, and make special requests for after their death (Foster et al. 2009). These discussions, while difficult, have the potential to promote healing, provide closure, and minimize guilt and regrets for family members after the death.

Research suggests that bereaved individuals underutilize services, and support groups may be seen as stigmatizing or unhelpful (Levy and Derby 1992; Cherlin et al. 2007; Lichtenthal et al. 2015). Grief is often described as an intensely personal experience, so interventions tailored to individual or family needs may be more acceptable and effective. The family's reluctance to return to the hospital after a child's death and limitations in the availability of bereavement services are often a challenge for providing continuity of care. Thus, community-based referrals or telemedicine approaches may be more feasible for bereaved families. Several meta-analyses of grief interventions have come to variable conclusions about efficacy, with the largest improvements found for individuals with more severe or complicated courses (Larson and

Hoyt 2007; Jordan and Neimeyer 2003; Neimeyer 2000; Currier et al. 2007; Rosner et al. 2010; Allumbaugh and Hoyt 1999). Thus, current recommendations suggest services focus on those bereaved individuals who experience the highest levels of symptoms.

## Directions for Future Research

While we are gaining more knowledge about the impact of cancer and its treatment on families, there is more to learn. A growing body of research has focused on outcomes of children with cancer and parents. However, less attention has focused specifically on siblings. Much of our knowledge of psychosocial outcomes in families comes from research during survivorship. Few studies have followed a large cohort of families prospectively from diagnosis into long-term survivorship to gain an in-depth assessment of predictors and processes related to psychosocial outcomes. Researchers must understand the explanatory factors that account for variation in outcomes over time as well as how development differs from typical families who have not experienced cancer.

Other methodological points for research include the need for multiple informants and mixed method approaches that move beyond paper and pencil measures. Assessments such as lab-based tasks, “real-world” observations, qualitative interviews, and biological measures (e.g., actigraphy, psychoneuroimmunology) will enhance the quality of our science. Most importantly, research that can inform the development and evaluation of interventions to prevent difficulties and promote psychosocial resilience is paramount. These interventions will be most effective if they can capitalize on innovative technologies or approaches that allow for wider dissemination and easy access to underserved populations.

## Summary

We now expect that most children diagnosed with cancer will live long and full, happy lives. Thus, considering the long-term implications of the cancer experience within the family system will help ensure the provision of appropriate supportive care and optimize outcomes for the entire family. Targeting services to subgroups at risk for distress, such as mothers near diagnosis or bereaved families, is recommended. Ongoing research that is methodologically rigorous will advance our understanding of issues relevant to families of children with cancer and inform evidence-based care. With these goals in mind, we can ensure that families affected by childhood cancer are provided with the best care to promote resilience throughout the illness, treatment, and long term.

**Clinical Pearls**

- Cancer has a widespread impact on the entire family system. Ongoing assessment and triaging of services for parents and siblings are important.
- The impact of cancer on family interactions and relationships can evolve as the demands of the illness and treatment change. These family factors play a critical role in the well-being of children and are important targets for intervention.
- Consideration of child development is paramount to understanding the influence of cancer on the family and providing appropriate supportive care.
- Interventions that incorporate evidence-based techniques to improve individual coping strategies and family interactions are recommended for families identified to be at risk for difficulties.

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