
Psychosocial Issues in Children with Cancer: The Role of Patient Advocacy and Its Impact on Care

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18.1 Introduction

“Your child has cancer.” To a family, these four words are excruciating and life altering. Yet, 15,700 families in the United States hear these words each year [1]. Regardless of who you are, no matter what your professional, educational, and cultural backgrounds are, when your child is diagnosed with cancer, it “is not just about the medicine” [2]. The common factors that unite all children and families are the psychological and social concerns, fears, and day-to-day management of the disease. Once parents are told, “your child has cancer,” the whole family is affected and forever changed [3–7]. Childhood cancer is as much a psychological disease as it is a physical one in which children and families need help managing the day-to-day isolation, pain, treatment challenges, and the consequences on their daily life. Childhood cancer threatens every aspect of the family’s life and the possibility of a future.

This chapter describes psychosocial care, illustrates its critical role in the care of the child with cancer, discusses the importance of a therapeutic alliance with the health-care team, and reviews psychosocial interventions from the time of diagnosis through survivorship, relapse, or end-of-life care. The importance of patient advocacy and its impact on medical care is highlighted, and challenges to achieving optimal

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psychosocial care are discussed. Finally, the collaboration between parent advocates and leading health-care providers that is currently underway to develop and implement national psychosocial standards of care for childhood cancer is described.

It is important to note that the authors of this chapter consist of two parent advocates who lost their only child, Mattie, to osteosarcoma as well as two practicing pediatric psycho-oncologists. Our life circumstances may have brought us together, but it is our great admiration and respect for each other that keep us working together. Throughout the chapter, the unique set of challenges, stressors, and concerns children living with a sarcoma and their families face are illustrated through the experience of Mattie and his parents. Mattie's parents give voice to Mattie's courageous journey.

18.2 Who Was Mattie?

Mattie was born on April 4, 2002, by cesarean section with an Apgar score of 9. Mattie was a precocious child who demonstrated many strengths, such as a sense of humor, observational skills, ability to understand how things worked (at the tender age of 2, he was disassembling and reassembling his Hot Wheel cars with a screwdriver), empathy beyond his years, and a vivacious and veracious need to have fun and convince others to participate in his antics. In July of 2008, when Mattie was 6 years old and attending a tennis camp, he complained of pain in his right arm. When his symptoms got worse, his pediatrician ordered an X-ray, which revealed a mass suggestive of osteosarcoma in Mattie's right humerus. CT, MRI, PET scans and a biopsy confirmed four primary tumor sites: (1) right humerus, (2) left humerus, (3) right femur, and (4) left radius. Mattie's parents were informed that their only child had multifocal synchronous osteosarcoma.

Sixteen days after diagnosis, Mattie began 14 months of treatment including high-dose combination chemotherapy with doxorubicin, cisplatin, methotrexate, ifosfamide, and etoposide. He underwent limb-salvaging resections in two-staged surgical procedures, with custom endoprosthetic reconstruction and autogenous bone grafting. His tumors demonstrated a discordant response to chemotherapy, based on percentage of necrosis: 60% in the right humerus, 80% in the left humerus, 100% in the left radius, and 2% in the right femur. Eleven months after his initial diagnosis, Mattie had another major surgery, a sternotomy, to remove nine metastatic tumors that developed in his lungs. Mifamurtide (L-MTP-PE) was also added to Mattie's treatment.

This only lists the medical procedures Mattie courageously endured. What Mattie's parents and family members observed was his struggle to learn how to cope with the profound functional impact of his surgeries and the change in his daily life thanks to his treatments. He could no longer walk, run, dress, or toilet himself. Within months of his second surgery, Mattie began working with a child psychiatrist who diagnosed him with clinical depression, anxiety, and medical posttraumatic stress disorder. He was started on Celexa and Klonopin to reduce his significant sadness and anxiety.

In August of 2009, only 6 weeks off of chemotherapy, scan results revealed that Mattie's cancer had spread to his lungs and liver. Conversations with Mattie's medical team turned from curative intent to end-of-life care. Mattie's family had to face a parent's worst fear: the reality that their child was dying and the stressful and frightening medical decisions associated with this reality.

18.3 Communicating with Children: History

Given the critical role of psychosocial care in cancer, it is surprising that the subspecialty of psycho-oncology is fairly new. However, prior to the mid-1970s, tremendous stigma surrounded a cancer diagnosis, which was usually fatal. Often, children were not informed of their cancer diagnoses. Over time, as the stigma began to diminish, more open conversations about the name and type of disease, potential side effects, and outcomes were possible. These conversations allowed physicians and other health-care professionals to more fully explore the child's psychosocial well-being and, later, to study children's psychological responses [8].

Important research findings helped change practice as well. Studies found that children who were not provided information about their illness or prognosis understood much more than was originally thought, even when false reassurances were given about their situation [9–11]. Concurrent clinical observations supported the fact that children's anxiety lessened as they found comfort in being able to talk about their own health concerns in a developmentally appropriate manner. The outcome of studies from the 1970s changed the overall practice of pediatric care, emphasizing open communication about cancer between children and their health-care professionals and encouraging parents to dialogue with their children about the disease. The findings illustrated the "enormous strength of children in facing even the most dire news if they can be assured that those around them will answer their questions honestly and not abandon them" [12] (p. 133). Furthermore, this change fueled the inclusion of mental health professionals on childhood cancer treatment teams [9–11].

18.4 What Is Psychosocial Care and Who Provides It?

Psychosocial care can be defined as services and interventions that enable patients, their families, and health-care providers to optimize biomedical health care and to manage the psychological, behavioral, and social aspects of illness and its consequences to promote better health [13]. Specifically, the goal of psychosocial care is to address the effects that cancer and its treatment have on the mental health and emotional well-being of patients, their family members, and their professional caregivers. In addition, provision of psychosocial care has been shown to yield better management of common disease-related symptoms and adverse effects of treatment such as pain and fatigue [14–17]. Research also indicates that distressed emotional states can generate somatic problems, such as sleep difficulties, fatigue, and pain

[18, 19], which can confound the diagnosis and treatment of physical symptoms. Moreover, depression and other psychosocial concerns can affect adherence to treatment regimens by impairing cognition, weakening motivation, and decreasing coping abilities [13].

The American Academy of Pediatrics created guidelines [20] for state-of-the-art care for children and adolescents with cancer. These guidelines delineated the importance of multidisciplinary care in treatment outcomes and recommended that pediatric oncology social workers, pediatric psychologists, and child life specialists work alongside medical staff. Recommendations have been made for families impacted by childhood cancer to also have access to support groups [20, 21]. Other critical disciplines include psychiatry, neuropsychology, nursing, educational specialists, creative arts, chaplaincy, and career and vocational counseling [22]. Though these professional groups are well trained and ethically competent to manage psychosocial issues and concerns, ideally attention to psychosocial issues should not be the sole responsibility or role of just these professionals but rather all providers caring for the child with cancer.

Another critically important component of psychosocial care is palliative care. For many centers, palliative care has been viewed as being synonymous with “end-of-life care,” with involvement by subspecialty palliative care teams only when death was imminent [23]. Fortunately, this is changing. Palliative care is now much more holistic, typically comprised of an interdisciplinary approach that includes physicians, nurses, psychosocial clinicians, and others [24] who aim to improve the child’s quality of life by alleviating physical, psychosocial, and spiritual suffering of the child and family regardless of disease status [25, 26]. A sarcoma diagnosis is rare in children, and it inherently carries with it medical uncertainty, as well as physical and psychosocial suffering. Therefore, it is appropriate to introduce and include comprehensive palliative care from the time of diagnosis onward [23]. If end-of-life care is needed, the palliative care team will already be in place, with focus transitioning to the child’s comfort and family support.

In 2008, psychosocial care received increased attention in the oncology world following the publication by the Institute of Medicine (IOM) entitled *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. The report translated research findings about psychosocial care into practical applications for the purpose of improving the quality of cancer care. Evidence was reported for several effective interventions, including counseling and psychotherapy, pharmacologic support, illness self-management and self-care programs, family and caregiver education, and health promotion interventions [14]. Importantly, the IOM emphasized that optimal care includes the provision of appropriate psychosocial health services [13].

Providing optimal care requires a paradigm shift and an acknowledgment that every patient-health-care professional interaction provides an opportunity to assess the stressors and concerns the patient and their family members are facing, particularly when designing treatment plans. While this should be done for everyone who has cancer and their family, it is especially critical for children. Children who are distressed remember certain procedures with greater negativity, which in turn predicts higher distress with subsequent events [22]. When sufficient information about

the child's psychological and social strengths, stressors, and preferences are obtained from the child and the parents, health-care professionals can tailor their specialty services more precisely to the child's needs, thereby averting possible negative or traumatic reactions. Moreover, a therapeutic alliance between the health-care professional and the patient/parent can be formed, which is vital toward pooling resources together toward a common goal [27]. When a therapeutic alliance is established, children and their parents are more likely to feel a part of the treatment team. This is critically important for parents who feel vulnerable and powerless over their child's disease [28]. The following examples illustrate how incorporating psychosocial care into each patient interaction can allow trust to be developed and care to be delivered in a manner that allows children to use their resources to cope more effectively.

During the diagnostic phase of his cancer journey, Mattie underwent countless IV sticks, physical exams, MRI, and CT scans. The pace of these assessments was overwhelming for Mattie, and with each new test, his awareness and knowledge grew that something was very wrong. While at first he handled the tests well, with repeated exams his frustration grew, his tolerance began to decline, and his anxiety rose to the point where even sitting for a brief consultation was impossible. At one point, when entering the CT scanning room, Mattie hid under the scanner in tears. He was absolutely hysterical, refusing to come out from his hiding place. Coaxing by multiple staff members was ineffective. The scheduling window to get his scan done passed, which of course had consequences on the timing of all his other assessments that day. Mattie's response was a sign of fear and trauma. The compounded traumas that Mattie experienced during his first weeks of being diagnosed set the stage for larger issues later in his treatment.

Mattie's parents encouraged his oncologist and treatment team to consider sedating Mattie for all scans, but they were consistently told that PET and CT scans were short and noninvasive and, for safety reasons, it would be better for Mattie to manage without sedation. The team believed that, with staff and family reassurance and some distractions, Mattie could manage the scans without sedation. His parents tried to explain that Mattie had sensory integration issues prior to his cancer diagnosis and that he was highly sensitive to sound, tight spaces, and being confined in any way. They were aware that these neurodevelopmental issues would be key factors in his ability to stay still for the scans. It was not until the head nurse of pediatric sedation and the child life specialist observed the terror Mattie experienced when attempting a CT scan that a new scanning strategy was implemented. If psychosocial information about his sensory issues and coping abilities had been obtained upfront, the additional anxiety, stress, fear, and trauma from having to stay still in the scanner could have potentially been avoided. Unfortunately, this stress carried over into all treatments he perceived as invasive.

The second example occurred while Mattie was undergoing treatment. During morning rounds on the inpatient unit, the attending oncologist found Mattie upset, tired, and feeling ill. When he did not feel well, he tended to emotionally shut down, refusing to cooperate with medical demands, especially when they came from medical personnel he was not familiar with.

The attending oncologist could have left his room and returned when it was a better time. This would have been understandable, as calming Mattie down and reasoning with him was a time-consuming process. Instead, she spent the time figuring out how to relate to Mattie. While in the room, her pager went off. This caught Mattie's attention. He wanted to know more about the pager. The oncologist pulled out her pager, showed it to Mattie, and allowed him to play with it, and they sent messages around the hospital together. A connection was made.

What did this connection accomplish? From a medical standpoint, the oncologist was able to examine Mattie and obtain the medical information she needed in a positive and non-stressful manner. Perhaps more importantly, the beginning of a strong rapport and a trusting therapeutic alliance was formed. Taking the time to understand her patient's fears, behavior, and interests enabled the oncologist to effectively provide Mattie with care. Toward the end of Mattie's life, it was this physician he confided in about his pain. He knew she would take him seriously. If children trust you, they will reveal more to you and also comply more with your medical directions [29].

18.5 Time Points During the Cancer Trajectory for Psychosocial Intervention: Providers' Perspectives

As noted, learning that one's child has cancer is a time of significant distress and family upheaval. Families find themselves confronted with a world where new medical information is being thrust upon them while decisions need to be made about potentially lifesaving treatment options, each of which poses risks for long-term health consequences. The child undergoes many transitions throughout the cancer trajectory from diagnosis to first treatment, intra-treatment transitions (e.g., chemotherapy to surgery, surgery to chemotherapy, radiation to chemotherapy, etc.), resulting in the end of treatment to survivorship, survivorship to relapse, relapse to survivorship, or survivorship to end-of-life care. The following section reviews psychosocial stresses that occur from the point of diagnosis on, with attention provided to the unique needs of youth living with a pediatric solid tumor.

18.5.1 Diagnosis Period

This is a time of tremendous uncertainty. Symptoms that had appeared benign (such as leg pain, a fracture) are worked up to rule out a malignancy. An MRI, CT, or PET scan may be scheduled and blood work obtained while families anxiously await the results. As described in the case with Mattie, children who undergo extensive testing with little psychological preparation can be traumatized by the experience. They can perceive the tests as an assault on their body and feel confused as to why their parents are not protecting them from harm.

When the diagnosis of a sarcoma is given, further testing is required to determine specific histology and to rule out metastatic disease. Parents frantic about their child

being diagnosed with cancer may find themselves relieved when the disease appears to be limited to the primary site or even more overwhelmed by news of a less favorable prognosis. While waiting for final results, children perceive their parents' distress, adolescents fear what cancer means in terms of their life expectancy and day-to-day life, and together with the medical team, treatment options are explored. Oncologists should be aware of these dynamics and the enormous stress families are under. This is an important time to engage the help of a mental health professional who can assess the child's understanding, concerns, and ability to adapt to change and the family's strengths and vulnerabilities. When available, the child life specialist can help the child obtain mastery (and therefore be less traumatized) of needle sticks and other invasive and noninvasive tests through medical play, while other professionals, such as a social worker or psychologist, can foster the child's expression of new events and begin to help the family adapt to the changes that will follow. If a line placement is being considered, psychosocial support can be very helpful in introducing the concept of line placement, access, and regular care of dressing changes plus flushing of lines.

Parents also struggle to find the right words to explain cancer and cancer treatments to their child. Mattie's parents worked with his art therapists to find images he would be able to relate to. Since Mattie loved bugs, they created "bone bugs" made out of clay. His disease was conceptualized using a clay bone bug. He visualized the clay bug crawling inside his bones, and when given the option, he grabbed the clay bone bug and smashed it on the floor with his foot to kill it, representing what chemotherapy would be doing inside his body. Other children find it helpful to think of chemotherapy as Pac-Man going through their body, destroying all the cancer cells.

18.5.2 Treatment Considerations

While treatment decisions are being made, the child and family are introduced to new medical and support personnel. The information presented can be quite overwhelming, and the role that each new staff person will have in the child's care can seem similar and be confusing. Providing families written information on the names and roles of the professionals within the team, including psychosocial providers (pictures taken from your institution's website can help enormously) and how they can be contacted begins the process of establishing trust, enhancing a sense of control, and promoting open communication.

The consent process can also be particularly stressful for families. In childhood cancer, families must assimilate a vast amount of information and make decisions in a short period of time. If not all caregivers can be present, audio recording the session allows others to hear the information at a later time. It is important that the patient is included in the consent process along with his or her caregivers and that information is provided using developmentally appropriate language. Families generally have little experience with the difference between standard treatment and clinical trials. In childhood cancer, parents often do not retain the information about

the research nature of the protocol, but primarily focus on the specifics of the treatment as well as potential prognosis [30]. They benefit from explanations about experimental questions being asked as part of the recommended therapy. The consent process extends beyond the signing of a document and ideally takes place slowly with multiple opportunities to assess their understanding and answer questions as they occur [31].

18.5.3 Treatment Initiation

The onset of treatment is a particularly stressful time for families. In sarcomas, aggressive surgical options may be considered, especially when the intent is for cure. This includes limb salvage surgeries and, less frequently, amputation. Families benefit from extensive preparation for such surgeries, including opportunities to discuss the multiple consequences of the procedure (expected outcome, functional expectations, pain, disability, deformity, and changes in appearance). Time is needed for the child and family to psychologically prepare for surgery [32].

When available and interested, some children and adolescents can benefit from discussion with other patients who have received similar procedures. As limb salvage surgery does not guarantee postsurgical function at the same level that the child had prior to surgery, expectations need to be clearly spelled out. These include the possibility of surgical complications and the need for future revisions, postsurgical wound healing complicated by adjuvant chemotherapy, and time provided to process the information, ask questions, and obtain support. Staff members who are trained to provide guidance and support at this time are physical and occupational therapists, social workers, child psychologists, and child life specialists [33]. Following surgery, the medical team and psychosocial providers should assess for emotional adjustment, anxiety, depression, family adaptation, and posttraumatic stress-like reactions. The outcome of this assessment can set into place the most appropriate interventions for the child and family.

When a limb-sparing procedure is not possible, amputation can be a very difficult option to accept. Similar to limb sparing, it might be helpful for children and adolescents to discuss the surgery and life after surgery with another amputee, though keep in mind that not all youth are comfortable seeing another person's stump prior to their own surgery. There are books and movies that youth and their parents have found helpful prior to surgery (Table 18.1). Social work, psychology, or recreation therapy may be helpful in preparing for surgery and providing support following amputation. Postsurgery, important concerns and questions pertaining to sexual function, activity, intimacy, and occupational concerns must be addressed and a follow-up plan developed and documented.

Phantom pain can be an issue for which multidisciplinary assistance is needed, including, as noted earlier, the involvement of a palliative care team. In addition to medication (tricyclic antidepressants, anticonvulsants), noninvasive therapies such as acupuncture and biofeedback [34, 35] are often utilized. More invasive options include steroid injection, spinal cord stimulation, or implanted devices. Surgery is

done only as a last resort. Physical therapists can be instrumental in providing tools such as mirror therapy and nerve stimulation (TENS), and psychologists have had some success with guided imagery, relaxation techniques, and hypnosis [36–38]. The effectiveness of cognitive behavioral therapy in pediatric pain has been well documented [39, 40], and neuropathic pain syndromes have been reported in a number of case studies [41]. Interestingly, studies have shown little to no difference in quality of life in those who underwent limb salvage as compared to those who

Table 18.1 Psychosocial resources for children and their families with sarcomas

Topic/area	Resources
Books for children	1. <i>Annie Loses Her Leg but Finds Her Way</i> by Sandra J. Philipson and Robert Takatch. Chagrin River Publishing Company, 1999 Annie and her brother Max experience the illness and recovery of their 9-year-old English Springer Spaniel who loses her leg to cancer
	2. <i>What's Up With Lyndon?</i> by Dr. Kim Chilman-Blair and John Taddeo. American Cancer Society, 2011. [available in Spanish] Childhood osteosarcoma is explained in an informative story that makes the science behind cancer accessible to young readers
	3. <i>Every Child Needs an Angel</i> by Cosmo Lorusso. iUniverse This story narrates Nicole's battle with cancer, her reliance on faith, and her mission to help others and to make a difference. It recounts the unwavering support from friends, neighbors, coworkers, medical staff, and coaches – those who became angels to Nicole in her time of need
Books for teens	4. <i>Just Don't Fall: A Hilariously True Story of Cancer, Childhood, Amputation, Romantic Yearning, Truth and Olympic Greatness</i> by Josh Sundquist. Penguin Group USA, 2010 At 9 years old, Josh Sundquist was diagnosed with Ewing's sarcoma that eventually claimed his left leg. <i>Just Don't Fall</i> is the story of the boy Josh and of the young man he became – an utterly heroic struggle through numerous hospitalizations and worse to become an award-winning skier in the Paralympics and renowned motivational speaker
	5. <i>A Special Kind of Courage</i> by Geraldo Rivera. Simon and Schuster, 1976 True stories of 11 modern youths who have faced various crises, including death, with exemplary courage
	6. <i>Teenagers: Face to Face with Cancer</i> by Karen Gravelle and Bertram John. Julian Messner, 1986 Young people, ranging roughly in age from 13 to 21, speak candidly, recalling the initial shock of their diagnoses, their treatments, and pressures at school. They address how relationships with family, friends, and romantic interests change, reflect on their futures, and discuss how they deal with the possibility of death
	7. <i>What It Takes: Fighting For My Life and My Love of the Game</i> by Tom Coughin and Mark Herzlich. ePub, 2013 Mark Herzlich, a starting linebacker for the New York Giants, was diagnosed with Ewing's sarcoma during his junior year of college. This story is about his fight against the odds to get through treatment and into the NFL
	8. <i>Just Don't Fall: A Hilariously True Story of Cancer, Childhood, Amputation, Romantic Yearning, Truth and Olympic Greatness</i> by Josh Sundquist. Penguin Group USA, 2010 At 9 years old, Josh Sundquist was diagnosed with Ewing's sarcoma that eventually claimed his left leg. <i>Just Don't Fall</i> is the story of the boy Josh and of the young man he became – an utterly heroic struggle through numerous hospitalizations and worse to become an award-winning skier in the Paralympics and renowned motivational speaker

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Table 18.1 (continued)

Topic/area	Resources
Books for parents/adults	1. <i>All the Kings Horses, All the Kings Men</i> by Donna Purves. iUniverse
	<i>All the Kings Horses, All the Kings Men</i> is a moving account of the life of the author's son, previous to and following the discovery of the presence of osteogenic sarcoma
	2. <i>Childhood Cancer: A Parent's Guide to Solid Tumor Cancers</i> , 2nd Edition, by Honna Janes-Hodder & Nancy Keene. O'Reilly & Associates, 1999
	Detailed medical information about solid tumor childhood cancers, including neuroblastoma, Wilms tumor, liver tumors, soft tissue sarcomas, and bone sarcomas
	3. <i>Children with Cancer: A Comprehensive Reference Guide for Parents</i> by Jeanne Munn Bracken. Oxford University Press, 1986
	A comprehensive road map for families of children diagnosed with various malignancies
	4. <i>Fighting Chance: Journeys Through Childhood Cancer</i> by Harry Connolly, Tom Clancy, & Curt I. Civin. Woodholm House Pub, 1998
This book follows patients, families, and caregivers battling cancer in and out of the hospital. Photographed over the course of 3 years, it includes contributions from best-selling author Tom Clancy and Dr. Curt Civin, director of Johns Hopkins Hospital's Pediatric Oncology Unit. Other insights come from nurses, parents, siblings, and the children themselves	
5. <i>Fly with a Miracle</i> by Sheila Belshaw. London: Denor Press. 2001	
<i>Fly with a Miracle</i> describes the details surrounding the pioneering and successful medical treatment in the United Kingdom for bone cancer, through the eyes of a mother and her son (the patient) who is determined to become an airline pilot	
6. <i>Soul Gifts</i> by Barbara Gill (2006)	
The author speaks of how we are all connected – “The Human Chain” – and how this connection can be used for peace and prosperity, not by organizing for “the cause” but by living it, one at a time	
7. <i>What Doctors Cannot Tell You: Clarity, Confidence and Uncertainty in Medicine</i> by Kevin B. Jones	
<i>What Doctors Cannot Tell You</i> explores the uncertainty that pervades medicine. The patients' stories empower readers to ask questions of their physicians, with a firm belief that healing and hope begin from honesty in those critical conversations	
Siblings	1. <i>Hey, What about Me?: A Personal Journal for Teens Whose Brother or Sister Has Cancer</i> by Pam Ganz. SuperSibs!, 2003
	2. <i>When Your Brother Or Sister Gets Cancer</i> by K. Ballard. Produced in association with Birmingham Children's Hospital Sibling Group and UKCCSG Sibling Project Group, 2004
Survivorship	1. <i>At Face Value: My Triumph Over A Disfiguring Cancer</i> by Terry Healey. Cabeat Press, 2006
	The story of Terry Healy who was diagnosed with cancer at age 20 and how he learned to cope with the scars that were left behind
	2. <i>Very Much Better: A Cancer Memoir of a Boy Who Lived</i> by Jason Paul Greer. American Cancer Society, LLC, 2011
The story of Jason, a Ewing's sarcoma cancer survivor	

Table 18.1 (continued)

Topic/area	Resources
Grief and loss	1. <i>Love, Jason</i> by Doug Anderson. Deep River Books
	The story of a couple's experience during their son's 5-year battle with Ewing's sarcoma and eventual loss
	2. <i>When The Bough Breaks: Forever After the Death of a Son or Daughter</i> by Judith R. Bernstein. Andrews McMeel Publishing, 1998
	This book addresses mourning, documenting the process of evolution from initial grief to an altered outlook on life. Excerpts from interviews with 50 parents who lost a child from ages 5 to 45 trace the road from utter devastation to a revised view of life, resulting in a work that is a tribute to resilience and the indomitable human spirit
Helpful websites/ resources	1. <i>Cancer.net</i>
	Website: http://www.cancer.net/cancer-types/sarcoma
	This website provides basic information, videos, and links to other resources
	2. <i>LMSarcoma Direct Research Foundation</i>
	Phone: 1-888-266-1104
	Website: http://www.lmsdr.org ; this website provides specific information and resources for leiomyosarcoma
	3. <i>Sarcoma Alliance for Research Through Collaboration</i>
	Phone: 734-930-7600
	Website: http://www.sarctrials.org/
	4. <i>Sarcoma Foundation of America</i>
The website offers patients information and support, informational links, clinical trials, and a public forum	
Website: http://www.curesarcoma.org	
E-mail: info@curesarcoma.org	
Phone: 301.253.8687 Fax: 301.253.8690	
5. <i>SarcomaHelp.org – The Liddy Shriver Sarcoma Initiative</i> Phone: 914-762-3251	
Website: http://sarcomahelp.org/	
6. <i>The Life Raft Group</i> (supporting the gastrointestinal stromal tumors community)	
Phone: 973-837-9092	
Website: http://www.liferaftgroup.org	
Support groups	1. <i>Synovial Sarcoma Support Group</i>
	Website: http://www.synovialsarcomasurvivors.org
	2. <i>The Sarcoma Alliance</i> (web page has groups for most states in the United States)
	Website: http://sarcomaalliance.org/support-groups/

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Table 18.1 (continued)

Topic/area	Resources
Financial Services	1. <i>Aid to Families with Dependent Children (AFDC)</i>
	A joint federal and state-funded program that offers monthly checks for the care of dependent children who are in financial need because their parent(s) cannot provide them with needed financial support
	Website: http://www.acf.hhs.gov/programs/ofa
	2. <i>Andre Sobel River of Life Foundation</i>
	Helps with urgent expenses, allowing single parents to stay at their child's bedside during catastrophic illness. The organization works directly with affiliated children's hospitals
	Website: http://www.andreriveroflife.org
	3. <i>American Childhood Cancer Organization (formerly Candlelighters)</i>
	Formed by parents of young cancer patients, has an ombudsman program to assist families and survivors with problems in education, employment, insurance, welfare, or military enlistment. Provides information, local support groups, and specialized information to families and caregivers of children with cancer
Phone: 855.858.2226	
Website: http://www.acco.org/	
4. <i>Cancer Care</i>	
Provides financial assistance to help with some types of costs, including transportation, home care, childcare, and pain medication	
Website: http://www.cancercare.org	
5. <i>First Hand Foundation</i>	
Helps children with health-related needs when insurance and other financial resources have been exhausted	
Website: www.firsthandfoundation.org	
E-mail: Firsthandfoundation@cerner.com	
6. <i>Foundation for Children with Cancer</i>	
Assists families of children with cancer by providing tangible and direct financial support, such as mortgage payments, insurance premiums, utility bills, or funeral expenses	
Phone: 414.716.6250	
Website: http://www.childrenwithcancer.org	
7. <i>Insure Kids Now</i>	
A national campaign to link the nation's uninsured children (0–18) to free and low-cost health insurance	
Phone: 877.Kids.Now (877.543.7669)	
Website: www.insurekidsnow.gov	
8. <i>Local Department of Human Resources and Social Services</i>	
Each county's Department of Human Resources (DHR)/Social Services (DSS) has an office or individual to handle requests for emergency assistance. DHR or DSS can assist with rent or monthly payments, moving expenses, utility bills, and financial help toward prescriptions and medical supplies. The phone number of DHR/DSS is in the county government section of one's local telephone directory	

Table 18.1 (continued)

Topic/area	Resources
	<p>9. <i>National Children's Cancer Society (NCCS)</i></p> <p>Financial and fundraising assistance related to medical treatment, such as lodging and travel. Provides advocacy support, interceding on behalf of children with bills, home care needs, insurance companies, hospitals, and other agencies to negotiate reasonable solutions</p> <p>Phone: 314.241.1600</p> <p>Website: https://www.thenccs.org/#</p>
	<p>10. <i>Ruritan Club</i></p> <p>Local clubs help families pay for medical equipment and supplies, prescription medications, and medical transportation. Listing for local clubs can be found in the business section of a local white pages directory or the national Ruritan office</p> <p>Phone: 877.787.8727</p> <p>Website: http://www.ruritan.org</p>
	<p>11. <i>State and Local General Assistance Programs</i></p> <p>Designed to provide small amounts of cash assistance to individuals who are not eligible for AFDC or SSI or who are awaiting enrollment in another income subsidy program. Check the county's DHR/DSS to determine if the state or county has a General Assistance Program and where to call or how to apply</p>
Scholarships	<p>1. <i>Kyle Lee Foundation</i></p> <p>Awards scholarships to college-bound students who have survived cancer, especially Ewing's sarcoma</p> <p>Website: www.kylelee28.com/Kyle</p> <p>2. <i>National Amputation Foundation</i></p> <p>Awards limited to entering freshmen who have had a major limb amputation and are full-time college or university students</p> <p>Phone: 516.887.3600</p> <p>Website: http://nationalamputation.org/scholar1.html</p>

underwent amputation, with good adjustment and overall acceptance to amputation by adolescents [42]. In adult populations, limb salvage appears to be more socially acceptable, with lower reported rates of social isolation than in those who had undergone amputation [43, 44]. Clinicians should be astute in asking about perceived social isolation postsurgery and during the child's survivorship phase. Ongoing screening and follow-up are needed to address delayed or previously unidentified psychosocial difficulties.

Chemotherapy is almost always utilized in the treatment of bone sarcomas and many soft tissue sarcomas. Patients are often very concerned about nausea and vomiting as well as hair loss. Consultation with a wig maker prior to all hair loss is preferable as it allows selection of a wig that matches the child's current appearance. Some children are able to donate their own hair prior to it falling out. Others prefer not to wear a wig but opt for hats, scarves, or baldness. Preparation for how the hair starts to fall out is useful as some will choose to avoid the gradual loss by

cutting or shaving their hair very short in advance. In addition, following myelosuppressive chemotherapy, patients are encouraged to avoid crowds. This can be most difficult for teens who do not wish to limit social interactions. Furthermore, for adolescent and young adult patients, fertility conversations are necessary prior to induction treatment. Males may delay start of therapy for sperm banking. Some trials exist for ovarian tissue harvest, but for many, chemotherapy cannot be delayed for the necessary hormone treatments.

Radiation is often used at some point during treatment for a sarcoma. Child life specialists, psychologists, or social workers can prepare children for radiation therapy, including what the machines look like and the time required for simulation. Distraction and cognitive behavioral tools can be very effective in reducing anxiety [45, 46]. For those who will require radiation to the brain, neuropsychiatric testing and follow-up assessments should be considered due to the known CNS toxicities. For adolescent males for whom radiation is planned for the testes, sperm banking should be offered and ovarian transposition for ovarian protection considered when radiation is planned for the abdominal/pelvic region [47].

Throughout treatment, physical discomforts and psychosocial stresses persist. Pain, mouth sores, nutritional concerns, diarrhea, or constipation often occurs. As most children are not in the habit of discussing such bodily habits, guidance and support to encourage open disclosure about these important topics can be useful. Psychosocial stresses can persist as well. Poor adherence to medically required care is often a sign of patient or family distress. Routine adherence assessment and monitoring are encouraged. When problems are identified (e.g., doses are missed), a patient or family meeting is needed to understand barriers to compliance and to set clear guidelines and expectations for care. Some centers have found increased monitoring, obtaining the support of additional family members, adjusting medication dose (to address side effects), creating reminder cues, and developing a contract with the adolescent patient that identifies critical elements of care useful.

Other signs of psychosocial stress include increased anxiety, persistent sadness, withdrawal from friends, and difficulty learning to live with reduced physical mobility. Each of these should be a trigger for a consultation with a mental health professional knowledgeable about living with cancer.

18.5.4 Survivorship

Overall, survivors of childhood cancer have been reported to have a high rate of medically significant chronic conditions, particularly those who were treated for a bone sarcoma [48–50]. Chemotherapy and radiation therapy are stressful for youth to undergo, and surgery is often part of the treatment received. Tumor-induced changes in body image, school reentry [51, 52], loss of fertility, and impact on future independence can be especially challenging in the adolescent and young adult population where sarcomas can have their peak occurrence [53, 54]. The Children's Oncology Group [55] has developed comprehensive guidelines for monitoring pediatric cancer survivors. Excellent resources addressing the long-term

psychosocial impact of pediatric cancer survivorship are also available. Due to the high rate of obesity in pediatric cancer survivors, physicians actively promoting healthy lifestyles are of utmost importance.

18.5.5 End of Therapy

As exciting as the last cycle of chemotherapy can be, the shift from regular hospital visits, frequent labs, and physical exams to more independence can be anxiety provoking. Parents and children benefit from being prepared for the anxiety that often accompanies scan visits. The psychologist or social worker can introduce the children and family to cognitive and emotionally based behavioral tools that can help reduce anxiety and cope better in the days preceding the scan visits.

Families also benefit greatly from having a transition and survivorship care plan developed by their primary team so that anticipatory guidance can be given. Helping teens learn how to maintain their medical care and advocate for themselves helps make the transition from the pediatric setting to adult oncology care smoother and can lead to better health-care compliance. Many centers now provide patients in their survivorship clinics with survivorship care plans [55, 56] that document the treatments they have had, potential or existing late effects, and a timetable for continued surveillance.

18.5.6 When Cure Is No Longer Possible

The course of sarcoma treatment for some children is characterized by a series of treatment responses and relapses leading to a time when curative options are exhausted. Health-care providers need to respect each family's decisions to stop treatment or to participate in phase I clinical trials, delicately balancing quality of life issues with those related to palliative care, grief, death, and loss. Conversation about the child's and family's goals for care is fundamental to all decisions made. Children, 14 years and older, have been identified as the age group that needs to be routinely included in advance care planning and end-of-life decision-making [57]. Allowing them to be included helps maintain their autonomy in an uncontrollable situation [58]. *Voicing My CHOICES*, a new adolescent advance care planning guide, can provide the teen with a communication tool to express their opinions about their care and how they wish to be remembered in the future [59–61].

Open discussions that address painful decisions, including home versus hospital care for the dying child, advance directives, autopsy [62], and funeral arrangements, are best held once it is understood that cure is no longer possible. However, the care team needs to respect that families approach a child's pending death differently and therefore the need for access to information about funeral arrangements, autopsies, and other legacy building strategies and materials may vary based on many factors, including the timing of the child's death. Parents appreciate understanding that hope still exists and the important role they play in instilling it

within themselves and for their child during the dying process. Hope can be redefined for parents by redirecting their energies toward managing pain and maintaining the highest quality of life possible for their child while striving for a humane and dignified death (the absence of anxiety and pain and the presence of loved ones by their child's side) [31].

It is important to address the emotional needs of parents, siblings, and extended family in the context of families' expectations, unfulfilled dreams, values, and beliefs. As death approaches, families often need assurance that they have done all they could for their child. The health-care team's availability, participation, and investment in caring for the dying child are crucial to and appreciated by all families, even those who appear to be coping well on their own. Spiritual care professionals can be of enormous support for some families during this time.

18.5.7 Bereavement Support

The child's primary medical team (physicians, nurses, social workers, child life specialists, psychologists, and pastoral and other health-care providers who have often developed relationships with the family over a period of months or years) can be an important source of support for bereaved parents and other family members [24]. An abrupt end of contact soon after the child's death can be experienced as abandonment. Although many medical, nursing, and psychosocial providers make an effort to support the bereaved family, there are no existing guidelines and a limited evidence base suggesting timeframes for when staff members should contact the family after the child's death. Clinical practice clearly indicates that hospitals have an obligation to provide some level of bereavement follow-up to the child's family [63–67]. There is also sufficient descriptive evidence to recommend that follow-up calls to assess how the family is managing after a child's death by a member of the medical team who helped care for the child with cancer are helpful and appreciated by the parents [68]. A bereavement assessment is considered essential to the appropriate management of grief-induced emotional distress [69].

Importantly, no qualitative or quantitative data has been found to suggest that a phone call, contact, or conversation can be harmful. In fact, there is data that parents who are not contacted by a member of the team who cared for their child are both "noticed" and "regretted" [70]. Moreover, a minimum period of 13 months of bereavement support is the National Hospice and Palliative Care Association Standard [71]. These facts suggest that the standard of care should consist of at least one meaningful contact between psychosocial staff members and bereaved parents following the death of a child to cancer. The purpose of this call to the child's family is to assess how the family is coping; to let them know they have not been forgotten; to identify families who are at risk for negative physical, psychological, and social sequelae; and to provide resources for community bereavement support [68, 72].

The psychosocial needs and care of patients with pediatric solid tumors and their family members can be particularly challenging at any point along the disease

trajectory. Successful treatment requires a comprehensive approach that builds trust and a therapeutic alliance among health-care providers, the patients, and their families. Once this is established, psychosocial support can assist in the treatment-related challenges in a manner that respects the autonomy of the individual and encourages patients to be active participants in their care [56, 73]. While patients can be active participants, to optimize their care, they need and benefit greatly from the advocacy efforts of their families.

18.6 Patient Advocacy and Its Impact on Care

Patient advocacy can be a complex arena to navigate for families whose child has been diagnosed with cancer. Who is the patient's advocate? Does the child have just one advocate? Within the hospital setting, children and their families are introduced to many advocates, most commonly the "patient advocate" or "patient representative." According to the American Hospital Association, "patient advocates are essentially problem solvers. They bridge gaps, ease communication, guide people through bureaucratic mazes, act as liaisons and interpreters and help keep everyone in the system focused on the consumer" [74] (p. 7). These advocates are employed by the hospital, and their goal is to ensure patient satisfaction and the delivery of quality care [75–77]. In addition to advocates within the hospital, families may also have advocates within the community, such as other family members, friends, foundations, and professional organizations who provide essential support for childhood cancer treatment and research and empower the community to join in this fight against cancer.

If you ask parents and family members who the number one advocate for their child with cancer is, the most likely response will be themselves. After all, no one knows the child better, cares, loves, or is as invested in the child as the family. Patient advocacy is defined as "parents speaking and acting on behalf of their child, as an intercessor and champion, to ensure that their child's needs are met" [28]. However, to parents and other family members, hospitals can be intimidating places that have their own culture, use their own language, and have their own hierarchy. Adjusting to all these environmental changes initially can make it difficult for parents and family members to effectively advocate for their child with cancer. Nonetheless, parents and families rise to the occasion under the most dire and stressful circumstances to make complex, life-altering, medical decisions for their children throughout the cancer journey [78, 79].

Parents and families want to be involved in their children's medical care, and this form of advocacy is consistent with family-centered care. The concept of family-centered care arose in the United States in the 1980s as part of the conference of the Surgeon General that was focused on children with special health-care needs [80]. Family-centered care received a legislative mandate in 1986 with passage of US Public Law 99-457 that requires that the whole family be treated as the recipient of services for children with special needs, and with family members deciding ways they want to be involved in decision-making about health and education services for their child [28, 81, 82].

Positive outcomes for both children and their parents have been found when parents play an active role in the health-care process [28, 81, 82]. In fact, parents of children with chronic illness have reported less stress and better emotional well-being when care was rated as more family centered [83]. Specifically, with cancer, parents have been included as coaches and co-therapists in interventions to reduce pain, anxiety, and distress during cancer-related medical procedures such as venipuncture, lumbar puncture, bone marrow aspiration, intramuscular and intravenous injections, and accessing ports. Studies of the efficacy of these interventions indicate that they are successful in reducing child pain, anxiety, and distress [28, 84–88]. The parent advocate influences medical care, and therefore parents must be taken seriously as a valuable member of the medical care team. In fact, parent involvement in medical rounds has been shown to affect medical decision-making in 90% of cases [89]. Therefore, the inclusion of parents in the treatment process is not only beneficial to the child and the family but impacts the overall effectiveness of medical care.

In 2003, Holm et al. conducted a groundbreaking study to explore the ways in which parents participated in their child's medical care [28]. Forty-five parents whose children had completed cancer treatment at least 1 year prior to the study participated. The results found that parents identify themselves as performing the role of an advocate for their child particularly during the diagnosis and treatment phases. However, the disconnect between parents' intimate knowledge of their children and limited knowledge of medical terms and procedures made it difficult for some parents to advocate for their children. Furthermore, given the high regard for medical professionals in our culture, some parents said they did not know whether it was okay to press the medical team, particularly the physicians, when they had questions or concerns because they did not want to be disrespectful. Other parents talked about being intimidated by the environment or by the physicians. Given that parents and family members play a significant role in the treatment team, it is important for physicians to be aware of the fears, insecurities, and other factors that could potentially prevent open communication with these individuals. Ultimately it is the responsibility of parents and family members to ask questions about their child's care, but it is also the responsibility of medical professionals to set the appropriate tone and safe environment to receive such questions.

During the diagnostic phase, parents expressed two main strategies of advocacy such as seeking a medical explanation for their child's symptoms and persisting until a diagnosis is obtained [28]. The research illustrated that parents are keen observers of their children and can identify subtle, yet key, observations that may otherwise be overlooked by the medical community. These observations can impact the timeliness of a cancer diagnosis. When parents bring their children to their pediatrician seeking answers, in most cases the children present with symptoms that are not especially unusual. However, because parents know the nuances of their own child's behavior, they can advocate for their child by insisting that the pediatrician evaluate the symptoms as something beyond the ordinary illness. In some cases, however, families need to be persistent in order to obtain the correct diagnosis. Pediatricians need to respect the role parents play in their child's medical care as

well as understand their concerns as it relates to the changes they are observing in their child's health and overall wellness.

During the treatment phase, parents express four main strategies of advocacy [28]. The first strategy is informing. Once children are diagnosed with cancer, most parents develop a voracious appetite to learn everything about their child's cancer. Parents find their own ways of doing this, whether by paper, electronically, or through contacts with friends and family members. The second strategy is deciding upon the course of action for their child's medical treatment. This includes which medical facility to use for treatment, choosing medical team members, deciding on treatment options, whether to participate in clinical trials, and determining when to report changes in symptoms in order to necessitate additional medical care. The third strategy is limiting medical procedures for their child. Examples of a limiting strategy would be when parents refuse to have blood pressure checks taken when the child is sleeping or refusing bedside procedural scans at convenient times for radiology technicians. The final strategy is affirming the child's medical professionals. Relationships often extend throughout treatments and sometimes continue once treatment is over. It is important for health-care professionals to be aware of the strategies associated with patient advocacy, because understanding that such strategies exist will enable professionals to assist families in successfully negotiating through them.

Holm et al.'s advocacy strategies [28] were well operationalized in Mattie's case, particularly the skill of "persisting" as a form of advocacy. When Mattie was 13 months into treatment, his parents persistently advocated to obtain answers as to his constant pain and inability to eat. He was 6 weeks off of chemotherapy, still receiving MTP-PE, an experimental immunotherapy, twice a week. Mattie was weak and participating in an aggressive physical therapy schedule in the hopes of regaining strength and the ability to walk in preparation for returning to school in the fall. However, Mattie refused all food and would not consume even water. He lived on IV fluids only. He kept insisting that he was in pain and that he needed pain medication to manage his symptoms. Mattie's parents received many consults, and the advice ranged from this being a side effect of the chemotherapy, that he was manipulating them for control, or that he was not eating because he was addicted to pain medication. When the symptoms persisted, his parents requested that Mattie undergo new scans, despite only being 6 weeks from completing a very aggressive course of chemotherapy. The team agreed and CT results confirmed that Mattie's cancer had metastasized to his liver and lungs. This scenario illustrates that childhood cancer does not always follow any set scientific pathway or checklist and therefore it is vital to listen to the insights from the patient. There should also be some caution used about assigning blame to parents regarding their child's behavior (in this case with regard to the manipulation of food and pain medication) before ruling out other medical explanations for symptoms. Such pronouncements to parents can have devastating and long-lasting consequences.

Another advocacy strategy that parents find helpful is the "informing strategy." This can be implemented by maintaining a webpage, updating Facebook or a Caring Bridge page, or, as in the case of Mattie's parents, creating a blog. Mattie's

mother (Victoria Sardi-Brown) still maintains the blog today though the focus of her writing has shifted from helping Mattie battle osteosarcoma to the aftermath of losing an only child. Though “informing” is typically thought of as acquiring as much information about cancer as possible, health-care professionals should be aware of the positive benefits families may receive from informing friends, family, and their care communities about their child’s cancer journey and their experiences.

The second form of advocacy during the treatment phase [28] is the “deciding strategy.” Following a cancer diagnosis, most parents know very little about childhood cancer. They express shock and feel overwhelmed when presented with a variety of treatment options for their child. Many of the options may entail care at a center that is geographically distanced from the family’s home. Mattie’s parents were presented with a treatment option at one major comprehensive cancer center that involved high-dose chemotherapy and limb-salvaging surgery with Repiphysis technology. They found the whole notion of surgery daunting and felt the need to consult with another major cancer institution for a second opinion before consenting to surgery. To their dismay, they found that these cancer institutions recommended two very different treatment plans. In fact, the recommendation presented to Mattie’s parents at the second cancer institution was to move directly to end-of-life care, since they felt Mattie had no chance of survival.

Parents consult medical professionals for help making decisions regarding their child’s cancer care. They are under tremendous stress when asked to understand medical facts, clinical research, and what seems to be a whole new set of language skills. Contrary recommendations are not only confusing, but induce feelings of confusion and helplessness. Health-care professionals need to be aware of these stressors on families and provide the necessary support to make decisions during such critical times. The Mattie Miracle Cancer Foundation [2] points out that childhood cancer care “is not just about the medicine,” a point illustrated by how the two institutions looked at Mattie’s case differently. One focused on the sheer medical probability of successfully surviving cancer, whereas the second was willing to fight his cancer aggressively so that he could have as much time with his family as possible. These are subtle differences that have an enormous and empowering impact on the family. Parents respond best to having options presented that take into account evidence-based data along with parental priorities, the child’s psychosocial needs and abilities, and short- and long-term consequences. Treatment choices should always be within the hands of the parents as they are the ones who have to live with the long-term consequences of these decisions. Once a decision is made, the team should support the parents’ choice. What may appear to be an innocent comment by a health-care professional may not be perceived that way by a parent. Furthermore, such comments may be remembered many years later by parents. Similarly, health-care professionals should acknowledge that the patient/family/physician fit is crucial for effective cancer care. While rare, physicians and their pediatric families should confront a poor fit head on, and when resolution attempts are not effective, changes to care team members should be recommended in order to impact optimal care.

The last advocacy strategy Holm et al. highlighted in the treatment phase was “affirming” [28]. The relationships that parents establish with medical professionals extend throughout treatment and sometimes continue after treatment is over. The treatment protocol that Mattie and his parents endured was extremely grueling, resulting in Mattie spending most of the 14 months of treatment within a hospital setting, with very few days at home. Mattie even elected to die at the hospital. He selected that option because, by that point, the hospital was his second home. Other than Mattie’s parents, he had no other family geographically close by; effectively, hospital personnel had become his extended family. On the day that Mattie died, hospital personnel who were part of Mattie’s care team came to visit him and his parents to pay their respects and say their final farewell. In essence there was an impromptu memorial service in Mattie’s room with 20 people sitting around him in a circle, sharing stories, reflections, and supporting Mattie’s parents and each other through this loss. Mattie’s parents remain close to several members of Mattie’s care team, and it is through these continued connections and relationships that they feel they are further able to keep Mattie’s presence and memory alive. The lesson learned for optimal care is that there is a great deal clinicians can gain from the lived experiences of patients and their families who have received your medical and psychosocial services. Families are usually eager to share their insights and feedback with health-care professionals and are most grateful for the care provided to their child.

Advocating for one’s child is part of the expected role of being a parent. What sets parents of children with cancer apart from those with normal developmental issues is that they face life and death situations, make difficult decisions, and observe their child endure painful and frightening treatments. The very nature of cancer and its uncertain prognosis contributes to a chronic sense of vulnerability and powerlessness. Actively advocating for their child’s needs appears to be one important way parents are able to restore a sense of control and protect their child as well as cope with their own grief and uncertainty [28]. Parents want the medical team to ask them about their child, above and beyond their medical needs. Parents bring the expertise of being vigilant, knowing their child best, and noticing and responding to subtle changes in their child that are important from the time of diagnosis and throughout treatment. Developing a therapeutic alliance, based on active collaboration and mutual respect, is a fundamental key to childhood cancer care.

18.7 The Need for National Psychosocial Standards of Care

Given the growing recognition that psychosocial care is an important component of comprehensive care for people diagnosed with cancer [13], there is a demand for accountability and outcome-driven, cost-effective models for this care. Psychosocial clinicians are being challenged to standardize their approach and evaluate the efficacy of their clinical efforts [90, 91]. There are potential barriers that can prevent high-quality care from being provided consistently across sites. Table 18.2 identifies specific problems that can become barriers to care and suggests interventional strategies for programs to consider in order to reduce obstacles to care.

Table 18.2 Barriers and recommendations to achieve optimal psychosocial care

Problem	Barrier	Recommendation
Financial and system constraints	Pediatric cancer centers have varying amounts of resources and funding which can limit the depth and breadth of psychosocial services	<ul style="list-style-type: none"> • Provide psychosocial staff with opportunities to network with staff at comprehensive centers; attend relevant meetings
		<ul style="list-style-type: none"> • Efforts to obtain funding for positions from local foundations
Access to psychosocial services	Billing structures and mental health carve-outs limit who can be seen in many centers	<ul style="list-style-type: none"> • Administration efforts to include staff in panels
		<ul style="list-style-type: none"> • Educate staff to advocate with insurance companies
		<ul style="list-style-type: none"> • Letters of medical necessity
		<ul style="list-style-type: none"> • Obtain local funding to cover uninsured costs
Access to resources	Health-care team lacks information about existing resources and how to access them	<ul style="list-style-type: none"> • Designate knowledgeable psychosocial staff to present information, algorithms to access information
Conflict and confusion in medical situations	Differing goals of medical team and family	<ul style="list-style-type: none"> • Early meetings with team and family to discuss goals
		<ul style="list-style-type: none"> • Continued check-in with family through treatment
Problems in communication	Lack of time, differing schedules, avoidance, lack of understanding of the skill sets of interdisciplinary team members	<ul style="list-style-type: none"> • Regular care conferences • Psychosocial staff can facilitate communication in meetings with medical team
Problems in staff expertise in pediatric psychosocial issues	Lack of training and experience in understanding family dynamics and belief systems as well as coping with the stresses of diagnosis, treatment, and end of life	<ul style="list-style-type: none"> • Ensure hiring of appropriate staff
		<ul style="list-style-type: none"> • Provide opportunities for relevant training through coursework, conferences, in-services

In 2012, adult psychosocial researchers formulated standards addressing the psychosocial component of adult cancer care and issued clinical practice guidelines [92]. They also developed and implemented measurable indicators for the quality of psychosocial care in oncology settings. Recent standards for the psychosocial care of children with cancer and their family members have been published [93]. Though the methods utilized in the development of standards of psychosocial care for adult cancer patients may be useful to the process of developing childhood cancer standards, the specific elements are most likely to differ significantly [91, 93].

18.8 The Impetus Behind the Development of National Childhood Cancer Psychosocial Standards of Care

The devastation of losing a child to cancer is both unimaginable and indescribable for parents. Such a death symbolizes a reversal of the natural order of life, and it erases the dreams and hopes that parents have for their child and for themselves [94]. Parents may continue to grieve long after the death of their child [95, 96]. Such chronic grief has been associated with many psychological (e.g., depression, anxiety) and somatic symptoms (e.g., loss of appetite, sleep disturbances, fatigue), including increased mortality risk [94, 96–98].

After the death of a child, many parents are left with a changed attitude about their employment. They may find that work is no longer rewarding and that their priorities in life are quite different. Instead, they are compelled to be involved in more meaningful activities that will build a legacy for their deceased child [94], such as the creation of a cancer foundation. Many nonprofit childhood cancer foundations across the United States have been started as the direct result of a child's cancer diagnosis or death. Foundation work is a heartfelt, passionate labor of love in which parents dedicate their time and energy to memorialize their child, to help other children and families battle cancer, and to find a way to reengage back into a world which no longer includes their child.

In November of 2009, 2 months after the Browns lost Mattie, they created the Mattie Miracle Cancer Foundation, a 501(c)(3) tax-exempt public charity. Mattie Miracle, based in Washington DC, is dedicated to addressing the psychosocial needs of children and families living with childhood cancer as well as educating health-care providers on the impact of such a diagnosis on children and their families. The Foundation enhances awareness, advocacy, and access to psychosocial support on both the local and national level. Locally, Mattie Miracle funds a child life specialist position and offers a pediatric nursing support group and free snack carts to inpatient pediatric families at hospitals in Washington DC and Baltimore, MD.

The Browns' cancer experience has inspired them to voice a vision for pediatric psychosocial standards of care, in which every child and family should have access to an optimal level of critical psychosocial services, regardless of where a child is treated. After Mattie's death, they began advocating on Capitol Hill. Though staffers were supportive of the concerns addressed, the number one question posed at each visit was "what are the evidenced-based practices for psychosocial care and treatment for children with cancer and their families?" Mattie Miracle did not have answers to this question, but felt compelled and motivated to find them. In 2011, Mattie Miracle had the opportunity to connect with Brett Thompson, a lobbyist and now partner at Banner Public Affairs. Brett worked with the Foundation on a pro bono basis and convinced the cofounders that they should take a risk and hold the first ever Childhood Cancer Psychosocial Symposium at the Capitol Hill Visitor's Center. The goal of this event was to provide the community and lawmakers with access to cutting-edge psychosocial research and clinical practice delivered by a panel of psychosocial oncology experts (Anne Kazak, PhD, Scientific Chair of the

Symposium; Robert B. Noll, PhD; Andrea Farkas Patenaude, PhD; Ken Tercyak, PhD; and Lori Wiener, PhD), along with insights from parents whose children battled cancer. The Symposium was filled to capacity with registrants representing 12 different states from across the country. Attendees included nurses, social workers, professional counselors, child life specialists, art therapists, occupational therapists, psychologists, medical doctors, congressional staffers, and childhood cancer advocates. Mattie Miracle wanted to capitalize on the momentum from the Symposium on Capitol Hill and consulted with Dr. Lori Wiener and Dr. Anne Kazak on next steps. They encouraged Mattie Miracle to think more broadly and to sponsor a psychosocial think tank where leaders in the field could brainstorm the creation of Standards of Care for Childhood Cancer. The American Psychosocial Oncology Society, a national organization dedicated to psychosocial aspects of cancer care, invited Mattie Miracle to host the think tank at their 2013 annual conference in Huntington Beach, CA. It was at this think tank that the Psychosocial Standards of Care Project for Childhood Cancer was born.

18.9 The Psychosocial Standards of Care Project for Childhood Cancer

Extensive preparation work by the Mattie Miracle psychosocial core team of experts was done to launch the first think tank, whose long-term goal was the development of evidence- and consensus-based, comprehensive, implementable twenty-first-century pediatric psycho-oncology standards of care. The first step was a synthesis of existing attempts to standardize the clinical practice in pediatric psycho-oncology. Wiener et al. [91] reviewed literature from 1980 to 2013 to identify existing guidelines, consensus-based reports, and standards for psychosocial care of children with cancer and their families. Twenty-seven publications about psychosocial care met the inclusion criteria, consisting of (1) articles describing standards, guidelines, or consensus-driven reports in the field of pediatric psycho-oncology with an explicit focus on pediatric or adolescent oncology patients published in a peer-reviewed journal in English between 1980 and 2013 or (2) psychosocial cancer care standards which did not exclude pediatric oncology patients. Despite persistent calls by a number of international childhood cancer oncology and psycho-oncology professional organizations about the urgency to address the psychosocial needs of children with cancer, none of these articles were sufficiently up-to-date, comprehensive, specific enough, or evidence or consensus based to serve as a current standard for psychosocial care of children with cancer and their families.

In addition to the literature review, think tank participants and their colleagues completed an online survey exploring the perceived needs of children with cancer and their families in all settings where a child with cancer could be treated. This data was qualitatively analyzed and presented at the think tank. A major goal of the think tank was to obtain consensus on what the “essential” elements for psychosocial care should be. An “essential” element, as developed by Livestrong [99], is defined as having a positive impact on morbidity, mortality, and/or quality of life, can be implemented across a variety of care settings, is supported by an evidence

base, and has been agreed upon through consensus of the provider community. Recognizing varying resources and data to support the provision of each recommended standard, elements were identified as “essential” (to be provided to all children with cancer), a “high need element” (all settings should provide direct access or referral to this element of care when possible), or a “strive element” (all settings should strive to provide direct access or referral to this element of care).

During the think tank, participants reached consensus on essential elements for the care of children with cancer, and, as a result, four working groups (Screening and Assessment, Child and Family Psychotherapeutic Interventions, Staff and Documentation, School Issues (social and neurocognitive)) were formed. The working groups consisted of 22 psychologists, three psychiatrists, five social workers, one nurse, two oncologists, and five parents from the United States, Canada, and the Netherlands. The working groups were represented by several professional groups: American Psychosocial Oncology Society (APOS); International Psychosocial Oncology Society (IPOS); Society of Pediatric Oncology (SIOP); Children’s Oncology Group (COG); National Association of Pediatric Social Work (APOSW); American Psychological Association, Division 54 (APA); Oncology Nursing (APHON); and American Association of Child Psychiatry (AACAP).

Following this groundbreaking think tank, working groups held monthly conference calls, led by a core think tank group leader. Each group reviewed the clinical literature to ensure, when possible, that standards generated were evidence based. A consensus-based approach was used to determine whether enough evidence was available for the element to remain essential. To systematically guide the process among the work groups, the Appraisal Guidelines for Research and Evaluation [100] was followed. The groups conducted further evaluations of their work by sending supporting data and a rating form to pediatric oncologists, pediatric psycho-oncologists, or other applicable health-care providers (such as child life specialists, educational specialists, oncology nurses, etc.) for feedback.

A second psychosocial think tank was sponsored by the Mattie Miracle Cancer Foundation and held at the 2014 American Psychosocial Oncology Society Conference in Tampa, FL. Small working groups reviewed the created standards, evidence summaries, and rating forms and conducted additional reviews of specific portions of the standards generated by a different working group. In addition to achieving consensus on the recommendations, think tank participants were asked to rate whether each recommendation should continue to be considered an essential element, a high need element, or a strive element.

The standards were consolidated and further revision, literature appraisal, and GRADE [101] analysis for each standard element by working group members were performed. The standards were evaluated for quality and rigor and vetting from outside organizations and individuals. As a result, 15 evidence-based “Psychosocial Standards of Care for Children with Cancer and Their Families” were published in a special supplemental issue of *Pediatric Blood & Cancer* [93]. This 3-year-long, international project involved 85 health-care professionals from 44 institutions across the United States, Canada, and the Netherlands. The project resulted in the largest and most comprehensive compilation of psychosocial standards to date in which 1217 journal articles were reviewed and appraised for rigor. These historic evidence-based standards define

what children with cancer and their families must receive to effectively support their psychosocial needs from the time of diagnosis, through survivorship or end-of-life and bereavement care. The standards have been endorsed by 14 professional organizations: (1) American Academy of Child and Adolescent Psychiatry (AACAP), (2) American Childhood Cancer Organization (ACCO), (3) American Psychosocial Oncology Society (APOS), (4) Association of Pediatric Hematology/Oncology Educational Specialists (APHOES), (5) Association of Pediatric Hematology/Oncology Nurses (APHON), (6) Association of Pediatric Oncology Social Workers (APOSW), (7) American Society of Pediatric Hematology/Oncology (ASPHO), (8) B+ Foundation, (9) Canadian Association of Psychosocial Oncology (CAPO), (10) Cancer Support Community (CSC), (11) Children's Cause for Cancer Advocacy (CCCA), (12) Children's Oncology Group (COG), (13) National Children's Cancer Society (NCCS), and (14) Society of Pediatric Psychology (SPP; Division 54 of the American Psychological Association). The standards' authors and the Mattie Miracle Cancer Foundation are committed to creating, disseminating, and implementing a twenty-first-century, widely applicable blueprint to support universally available psychosocial services [91, 93].

Conclusion

This chapter reviewed the trajectory of sarcoma care from a psychosocial perspective. The importance of strengthening the alliance among the provider, patient, and the family was emphasized as the key to improving both the cancer experience and the outcomes of a childhood cancer diagnosis. Examples were provided to illustrate how a comprehensive alliance of professionals, patients, and families is needed in order for psychosocial care to be effective and meaningful. All health-care practitioners, regardless of their profession, need to be aware that psychosocial elements are just as important as the medical care and service that they deliver. Finally, psychosocial care must be a standard part of all cancer care. With the development and implementation of Childhood Cancer Psychosocial Standards of Care, the health-care industry will help lessen the potentially devastating psychological, social, and emotional impact that such a diagnosis can have on children and their families and help improve coping and adaptation for the entire family system.

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