



Published in final edited form as:

*Curr Pediatr Rev.* 2017 ; 13(1): 24–33. doi:10.2174/1573396313666161116094916.

## The Impact of Cancer and Its Treatment on the Growth and Development of the Pediatric Patient

Sarah Brand, PhD<sup>1,2</sup>, Joanne Wolfe, MD, MPH<sup>1,3</sup>, and Chase Samsel, MD<sup>1,2</sup>

<sup>1</sup>Department of Psychosocial Oncology and Palliative Care, Dana-Farber Cancer Institute, MA

<sup>2</sup>Department of Psychiatry, Boston Children's Hospital, MA

<sup>3</sup>Department of Medicine, Boston Children's Hospital, MA

### Introduction

While pediatric survival rates have increased over the past 40 years, it has been well established that cancer and its treatment significantly impact children and their families. For the majority of families, a child's cancer diagnosis and treatment is the most difficult life experience they will face. While most families adjust to this significant stressor, there is no doubt that coping with the treatment process is an extremely difficult experience with multiple psychosocial consequences (Liptak, Zelter, & Recklitis, 2015).

This paper highlights the emotional and psychological impacts of cancer and its treatment on children and their families at each developmental stage and highlights common issues across the cancer treatment continuum. Combined knowledge of developmental and treatment stage complexities is essential to inform providers of how best to care for these children and families.

### Developmental Considerations

Children go through four recognizable stages of development from birth to adulthood that are typically conceptualized as infant, toddler/preschool, school age, and adolescence. The impact of cancer treatment depends on the developmental stage of the child (see Table 1) as do recommendations for mitigating adverse sequelae. As children exist in the context of families, interventions to mitigate the impact of cancer treatment are described at each stage of development and recommendations are provided for the child, the parent, and the family.

#### Infants

The first year of life is a formative time in a child's emotional development, as they are developing attachment, trust, and security through their relationships with primary caregivers. Pain, exposure to unfamiliar situations and people, and the disruption of normal routines, all which occur throughout cancer treatment, can significantly impact the infant's ability to achieve these developmental tasks.

During the first year of life, infants begin to develop self-calming skills through translating their experience into information they can use to regulate their behaviors. As infants are often soothed through feeding/sucking, providing opportunities for suckling through breastfeeding, bottle feeding, or a pacifier during stressful situations can provide a sense of security for the child. In addition, interventions that help parents establish or re-establish daily routines can be very helpful, as consistent routines can maximize consistency and predictability for the child. Infants take their cues from their primary caregivers, therefore providing services to the parents to facilitate coping is recommended. Finally, it is important to provide families with information about how to continue to engage with their child in activities that encourage normal development, just as they would with a healthy infant. This includes talking and reading to their child, face-to-face interaction, and playing with toys that facilitate motor development. In addition to providing a developmental benefit, these activities can increase the family's sense of agency and control (King et al., 2007).

### **Toddlers/Preschoolers (2–5)**

Piaget characterized the period between ages 2–5 as the pre-operational stage (Piaget, 1929). Cognitive development is characterized by egocentric and magical thinking during this period, as well as associative logic. Children in this age group often contribute causality to animism (i.e. belief that an inanimate object is capable of action and has lifelike qualities), artificialism (i.e. environmental characteristics such as thunder can be attributed to human actions), and transductive reasoning (i.e. inferring a relationship between two unrelated events), which can impact how they understand their illness.

Providing simple and consistent explanations about their illness and their treatment is recommended for these children (McCabe, 1996). This should include factual information such as the name of the illness, as well as basic and concrete information about treatment and the expected impact on the child's daily routine. For example, "You have a sickness called leukemia, which is why you have been feeling so tired. You need to stay in the hospital so you can get a special medicine called chemotherapy to make the leukemia go away. When you are in the hospital mommy or daddy will be with you and your brother can visit. We will still have pizza night on Friday." It is also important to help children understand that nothing they did, said, or thought caused their illness, as they are capable of creating their own, likely egocentric, explanation about why they got sick in the absence of this information, (for example "I hit my sister and that's why I got sick.") This is an age of great curiosity (especially as children approach age 4), so it is important for parents to anticipate their child may have many questions (e.g. "But why?") and be prepared to provide simple answers, such as those listed above.

**Importance of Play**—Between the ages of 2–5, children develop a multitude of skills through play. Play is related to adaptive functioning and is a mechanism through which children develop skills related to creativity, problem solving, and coping (Piaget, 1929). Because play is such a natural part of children's lives, interventions have been developed that utilize play to help children adapt and cope with many facets of medical illness. As reviewed by Moore & Russ (2006), multiple research studies have shown that play

interventions with medically ill children can reduce hospital-related fears, prevent anxiety, and even impact objective measures of pain.

**Behavioral Impact**—Independence and the desire for control develop during this period, which can feel difficult for parents to manage in the context of the medical treatment. Providing opportunities for choices when appropriate (e.g., “Which medicine do you want to take first, the red one or the blue one?”) is a helpful way of providing control to the child. However, special care should be taken by parents and providers to offer choices only when they exist (e.g., do you want to take your medicine?). It is also important to encourage parents to establish and enforce rules and engage in limit setting, as this contributes to a sense of security for children.

Another key developmental feature of this time period is development of the ability for self-regulation. Self-regulation requires a child to be aware of incoming information and choose a response (Blair & Diamond, 2008). Below is an example of how a psychologist was able to capitalize on this facet of development within the medical setting.

**Case Example**—Steve was a three-year-old child who was being treated for neuroblastoma. Each week in clinic, the dressing for Steve’s central line had to be changed. While this was not a painful procedure, there was some discomfort associated with removing the bandage and required the area around the line to remain sterile. During the first few dressing changes, Steve screamed, kicked, and thrashed, requiring him to be physically restrained by his father Bill, which was extremely distressing for both Steve and Bill. Prior to the next dressing change, the program psychologist met with Steve’s nurse and wrote down each step involved in the dressing change process (e.g., 1) remove old bandage, 2) clean area, 3) let dry, 4) put new bandage on). The psychologist then met with Steve and his parents. During this meeting, they reviewed the steps and wrote them on a piece of paper that Steve had decorated, leaving a place for Steve to get a sticker when each step was completed. The psychologist also demonstrated the procedure on a stuffed animal, and then helped Steve do the procedure himself on the animal. Steve and his parents were sent home with the stuffed animal and the supplies, and throughout the week Steve often spontaneously would change the dressing on the animal. At the next dressing change, the psychologist was present and provided a simple narration of the procedure for Steve, putting a sticker in place each time the step was complete. The following week Steve was calm enough to chose his own sticker and place it on the chart. After three weeks, Steve began developing his own narration for the dressing change, which included self-talk (e.g., about the cleaning, “this won’t hurt, it’s just cold”) and Steve no longer required restraint.

### School Age (6–12)

**Cognitive**—Children between 5–12 are developing the capacity to think logically and to consider other points of view, including differentiating between themselves and the outside world. Piaget labeled the time between ages 4–7 as the intuitive thought sub-stage and between ages 7–11 as the concrete operational stage (Piaget 1929). Thinking patterns continue to be relatively concrete, with a focus on cause and effect and fairness. School aged children have an expanded knowledge about the world and about bad things that can happen,

so it is not uncommon to see fears develop during this period. Children may have heard the word cancer before, and therefore it is important to ask them about their understanding of what cancer is and what causes it, so any misconceptions can be addressed directly. Bares and Gelman (2008) compared the beliefs about colds and cancer in children ages 5, 7, and 10. This study illustrates the cognitive developmental progression of knowledge of illness during this period. Results showed that 5-year-old children had similar reasoning about cancer and colds; specifically that they were both contagious illnesses, caused by contact with contaminants, and similar in their length and severity. By age seven, the children began to discriminate between cancer and colds on some of the dimensions, demonstrating an appreciation that cancer is more serious than a cold and lasts longer. At age 10, the children were also able to understand that cancer would not go away on its own, and that it was not transmitted through contagion (Bares & Gelman, 2008).

It is important to clearly state to school age children that nothing they did caused them to get cancer, and that their cancer is not a punishment for something they did. Children will vary widely in their desire for information, participation in discussions about their illness, and their role in the decision-making process, so it is important to address each of these topics specifically with the child and their family.

**Social Impact**—Children are becoming aware of themselves as individuals during this period (Erikson, 1950). Social hierarchies begin to develop as children start to measure themselves against their peers and there is an increased interest in the development of friendships and a desire to belong to a group.

School plays a central role for facilitating cognitive and emotional growth, as children develop academic skills such as reading and writing, and also learn to navigate and develop social relationships through increased interactions with peers. While cancer treatment often prevents many children from attending school full time, returning to school after diagnosis can promote positive adjustment for children with cancer (Thompson et al., 2015). Recommendations regarding school reentry are provided in the treatment section of this paper.

**Behavioral Impact**—As highlighted by the case below, many children in this age group struggle with taking oral medication during treatment (Patel, Jacobsen, Jhaveri, & Bradford, 2015). It is not unusual for children of this age to have little experience swallowing a pill, and unfortunately many treatments require pills or liquid medication for symptom management. Targeted interventions can improve pill-swallowing behavior and increase treatment adherence in children (Patel et al., 2015), especially in school-age children (Garvie, Lensing, & Rai, 2007).

**Case Example**—Lilly was an eight-year-old girl who was being treated for ALL. Like many oncology patients, Lilly was required to take Bactrim three times a week. The first time Lilly was given the Bactrim pill, she put it in her mouth but did not swallow it, stating that it was “way too big.” She was asked to try again and this time gagged on the pill, which caused her to become very upset. She later stated that she had ‘choked’ on the pill and was unwilling to try taking it again. The liquid version of Bactrim was then tried but Lilly threw

up immediately following the administration, and told her parents she would “never ever ever” take the liquid version again, because of the taste. After multiple attempts to get Lilly to take either version of the medication, a psychology consult was requested. Both Lilly and her parents were open to meeting with the psychologist. During the meeting, Lilly and her parents noted that any discussion about medication quickly became heated and stressful. Lilly reported that her fears about taking the medication were that it would cause her to choke or throw up, and that if she was unable to take it her parents would be mad at her.

The intervention proposed to Lilly and her parents was a shaping protocol using mock pills (candy) of increasing larger sizes combined with parent training and relaxation strategies. During the first session, the role of each participant was discussed with regards to pill swallowing. As a group, it was decided that Lilly’s role was to try her best, her parents’ role was to provide only positive encouragement, and the psychologist’s role was to provide instructions. Lilly and her family were familiar with relaxation strategies and these were briefly reviewed and one particular strategy (5 slow counting breaths) was chosen to use prior to initiating any pill swallowing exercise.

Lilly and her parents were then shown the mock pills, which ranged from very small (sprinkles) to large (mike and ikes). The steps for taking a pill were outlined and demonstrated by the clinician: 1) sit at the table, 2) do breathing, 3) stick out tongue, 4) place pill on tongue, 5) take a drink of water, and 6) swallow the pill. At Lilly’s request, treatment started during the first session. The psychologist modeled the steps using the smallest ‘pill’ and then provided Lilly an opportunity to try. Lilly easily completed two trials of the first two ‘pills’ and was provided with positive reinforcement by the psychologist and her parents. Within two sessions, Lilly had worked her way up to the largest ‘pill’ and during the third session she successfully took her Bactrim. Over the next six months, Lilly came back for two booster sessions, which she requested when a new oral medication was introduced.

## Adolescence

**Cognitive**—The adolescent years through adulthood is described by Piaget as Formal Operations (King, Martin, Volkmar, & Lewis, 2007; McNeely, 2009). He and other developmental and cognitive scientists studied and described the vast period of 12 years and older as a period of acquired abstract thought and complex reasoning (King et al., 2007; McNeely, 2009; Piaget, 1929). Teenagers at the end of middle school and through high school can work in theoreticals and hypotheticals, reflecting in advancing mathematics and problem solving in physics and chemistry. They develop the ability to apply concepts learned in one subject to other subjects and even to themselves. Collectively, this brings about a greater ability to have moral reasoning and existential thought.

Discussions of cancer diagnosis, treatment, and prognosis for adolescents should match their intellect and respect their developing abilities. Adolescents can understand weighing of risks and benefits, future complications, and the concept of death. However, adolescent psychosocial and emotional development discernibly influences the tolerance of information and potential treatment preferences.

**Psychosocial**—The main hallmark of adolescence is the search for identity. This is exhibited in Erickson’s stage of Identity vs. Role Confusion (Erikson, 1950; King et al., 2007). Adolescents become interested in their independence, where they fit in to society, and distinguishing themselves from their parents. Essentially, the teenager asks, “Who am I?”. This question repeats itself often including re-examining assumptions about the world, parental and family norms and values, as well as peer group identity and belonging. They may try on different roles and explore new possibilities. This trying on of hats can often cause angst when adolescents struggle to find a peer group, role, or identity in society (McNeely, 2009). Explorations of role and identity are often punctuated by ongoing body changes during puberty, adding to the stress of identity exploration. The internal and external pressures to be a part of a group and assert independence are often facilitated by brash acts that counter intuitively may put ones future at risk, such as using drugs or alcohol and testing parental limits and government laws (King et al., 2007; McNeely, 2009; Morgan, Davies, Palmer, & Plaster, 2010).

Role confusion can occur when an adolescent’s search is met with failures or difficulties. This confusion can lead to significant angst, rejection of peers and family, and depression. More extreme and reckless experimentation with peer groups and lifestyle choices may occur when teens experience role confusion (Erikson, 1950; King et al., 2007; McNeely, 2009).

The two main psychosocial challenges for adolescents with cancer are the desire to continue to develop an identity apart from cancer and to be viewed as an independent individual with agency (Barlow & Ellard, 2006; Morgan et al., 2010).

Teens often report they “just want to be normal!” when frustrated by breaks in school, jobs, and peer activities (D’Agostino, Penney, & Zebrack, 2011; Morgan et al., 2010). This increasing period of independence for other teens is contrasted with further reliance on medical visits and treatment in teens with cancer. Opportunities to go to parties, sporting events, school, and even “hang out” is often prevented by infection precautions, fatigue, pain, and nausea. When healthy teens go out of their house or have other teens over to theirs, teens with cancer might avoid these encounters for fear of their appearance. Many teens searching for or trying to project their identity do not want to be thought of as the “cancer kid” or “sick kid” who is either cushinoid, cachetic, bald, taking medications, and/or carrying around a backpack of tubes (Butow et al., 2010; Morgan et al., 2010; Spear, 2000). Angst and frustration around inability to be a “normal” teen may lead to more risk-taking to assert oneself as similar to other teens without cancer or provide temporary relief of the reality of having cancer, such as medication non-adherence or violating contact precautions (Butow et al., 2010; Morgan et al., 2010; Spear, 2000).

**Case Example**—Johnny was a 15 year old male with high-risk by age Acute Lymphoblastic Leukemia in Consolidation II who has been frustrated and disengaged with oncology providers and staff during his treatment. His parents often talked for him during visits, and he tended to only speak up when treatments or side-effects would potentially interfere with his ability to hang out with friends or go on weekend trips. His parents attempted to involve him more with treatment as advised by medical staff, as they put him in



charge of taking his pills in his own pill box. Soon after this transition, Johnny had increasing cough and fatigue, and he developed a substantial pneumonia that landed him in the hospital when he had his physiologic white blood cell count nadir. Further work-up revealed an infection with *Pneumocystis pneumonia* (PCP), most likely explained by non-adherence to his three-times weekly Bactrim treatment. After a prolonged treatment course and recovery, Johnny admitted to not taking his Bactrim upon further history taking, and cried that he “just want(ed) to feel like I was a kid without cancer for a little while! I hate this cancer!” He revealed that he felt it was the least important drug and the only one he had stopped. Providers and parents engaged Johnny in further dialogue about the importance of all his treatments including Bactrim, reflecting back to him how his non-adherence was not only life-threatening, but caused him to miss significant time potentially spent with friends and family. He became more included in all aspects of his treatment going forward, grasped his illness better, received validation of his frustration by his psychosocial clinician and team, and reported feeling more understood. Johnny displayed no further risk-taking with his treatment, and his PCP did not recur.

Establishing oneself as an independent individual with agency is inherently important for all teens. This often is related to “being normal” and finding activities and groups that define an adolescent aside from cancer. Aside from feeling normal, it is also important in gaining agency about being ill and having cancer, too. Though often a naturalistic period of assertion for independence and control, cancer diagnoses and treatment can rob and halt development with adolescents’ relegation to passive roles (Morgan et al., 2010; Spear, 2000). Teenagers are often relegated to the desires and decisions of their parents and health care providers during the diagnosis of cancer and during its treatment. Information and treatment disengagement is often done with the assumption that teenagers cannot comprehend the seriousness of cancer and its decisions, whether by parents and providers overtly asking teenagers to leave the room for “adult conversations” or less consciously not thinking to include adolescents in the conversations to begin with (D’Agostino et al., 2011; Irwin, 2003; Morgan et al., 2010; Spear, 2000).

The American Academy of Pediatrics and Society of Adolescent Medicine support actively involving teenagers in their health by interviewing them apart from their parents at age 12 to both prime teens for critical thinking and foster independent ownership of their own care, especially those with complex health conditions (American Academy of et al., 2011). The usage of adolescent interview tools such as HEADSS has shown more accurate and honest reporting of symptoms and problems when engaging teenagers in their own health and encourages them to think critically about their health and future (Goldenring, 2004). As with asking about drugs, sex, and suicide during the HEADSS exam, cancer may also be thought of as something adults would like teenagers not to worry about or is too serious for them to comprehend. But just like drugs, sex, and suicide, it does affect them, and including adolescents in information receiving and decision-making is both helpful and just (Irwin, 2003; J. W. Mack & Joffe, 2014; Morgan et al., 2010; Spear, 2000). Studies show that teens feel a greater sense of efficacy, resilience, and comfort in the treatment of their cancer when included in decision-making and information-receiving as well as are more adherent to their treatment regimens (Phipps, 2007; Rosenberg, Yi-Frazier, Wharton, Gordon, & Jones, 2014; Stuber, Nader, Houskamp, & Pynoos, 1996). Corresponding parenting styles can affect their

engagement. Passive and authoritarian parenting styles can lead to delays and barriers in adolescent engagement in their own care by disempowerment and learned helplessness. Authoritative parenting, however, has been shown to lead to earlier and better independence and agency in teens own medical care, social, and school functioning (Botello-Harbaum, Nansel, Haynie, Iannotti, & Simons-Morton, 2008; Hamner, Latzman, Latzman, Elkin, & Majumdar, 2015; Steinberg, Lamborn, Dornbusch, & Darling, 1992).

Adolescents are not autonomous individuals with infallible decision-making skills despite their yearning for and progress towards independence. They need provider and parental guidance and should be given room to become part of their own care rather than sole guardians of it. Moreover when teens are trying to establish who they, the stress of cancer are can often lead to regression or growth (Arpawong, Oland, Milam, Ruccione, & Meeske, 2013; Hullmann, Fedele, Molzon, Mayes, & Mullins, 2014), putting them at greater or lesser ability to engage in their own health. For those experiencing what some call “post-traumatic growth”, teenagers may advance in some ways to Erickson’s stage of young adulthood, Intimacy vs Isolation (Arpawong et al., 2013; Hullmann et al., 2014; Stuber et al., 1996). This is a developmental phase of seeking and committing to love and relationships as a highly held goal and desire (Erikson, 1950; King et al., 2007). This behavior can be exhibited by some mid- or late-adolescents discussing wishes for and seeking a partner and child/family.

**Behavioral**—The most concerning adolescent behavior during cancer therapy is non-adherence and risk-taking (Morgan et al., 2010; Spear, 2000). A study of 403 youth aged 9–18 with chronic and life-limiting health conditions found that 1/3 of them reported missing medications doses in the last month and an incidence of risk-taking behaviors equivalent to large national samples of youth without chronic conditions (Weitzman, Ziemnik, Huang, & Levy, 2015). These behaviors are tied to identity development and bears repeating. Teens can be more focused on the immediacy of their plight in regards to their appearance, activities, and perception amongst their peers when they feel their identity development is being stymied (D’Agostino et al., 2011; Irwin, 2003). Role confusion and angst go hand in hand with feeling disempowered and without agency. It explains how a frustrated neutropenic teen may be more interested in smoking a cigarette with peers than pneumonia, another hospitalization, and potential shortened lifespan.

Empowering, empathizing with, and involving teens in their own care helps mitigate role confusion and acting out. Sometimes this is providing them with mentors closer to their age with whom they can identify, and other times it is listening to adolescents goals of care and making adjustments as able (Maslow et al., 2013; Phipps, 2007; Rosenberg et al., 2015; Rosenberg et al., 2014). A study of medically ill children including teenagers with cancer showed greater rates of vocational, educational, and health-care behaviors in teens participating in a peer positive youth development group (Maslow et al., 2013).

## Phases of Cancer Treatment

While there are many shared aspects across the cancer continuum, there are also components that are unique to the stage of pediatric cancer treatment. This section discusses



psychosocial aspects unique to the phases of diagnosis, active treatment, end-of-treatment, and end-of-life care.

## Diagnosis

The diagnostic period includes the time leading up to a child's cancer diagnosis and the diagnosis itself, is extremely stressful for the child and their parents. Compas and colleagues (Compas, Jaser, Dunn, & Rodriguez, 2012) noted that a diagnosis of cancer is often unanticipated and uncontrollable. Many children present initially with symptoms that are relatively benign (e.g., headaches, fatigue, nausea) and therefore a diagnosis of cancer is often a huge shock. It is not unusual for parents to be told that cancer is the likely diagnosis, but that more information is needed to determine the type of cancer, the expected treatment, and likely outcome. The child must undergo multiple tests and procedures to obtain the necessary information to make the final diagnosis, which can be uncomfortable and provoke further anxiety for both the child and the parents (J. Mack & Grier, 2004). Many parents report that this period of waiting is one of the most excruciating of the entire experience (Grootenhuis & Last, 1997; Palmer, Mitchell, Thompson, & Sexton, 2007; Patenaude & Kupst, 2005).

Psychosocial interviews have repeatedly shown benefits for children prospectively and retrospectively with recent expert consensus guidelines and comprehensive reviews of the literature (Anne E. Kazak et al., 2015; Steele, Mullins, Mullins, & Muriel, 2015). Consensus guidelines for pediatric psychosocial care include structured interviews, monitoring of symptoms, and integrated care with oncology teams (Patenaude, Pelletier, & Bingen, 2015; Wiener, Kazak, Noll, Patenaude, & Kupst, 2015). Having psychosocial clinicians working with oncology providers from beginning aids in normalization and acceptance of psychosocial support, greater provider satisfaction, and facilitates medical team communication (Freyer et al., 2006; Patenaude & Kupst, 2005; Patenaude et al., 2015; Steele et al., 2015; Thompson & Young-Saleme, 2015; Wiener et al., 2015).

After the required information has been obtained, a diagnosis can be made and shared with the family. Ideally this should be scheduled in advance, both so the family can arrange for important family members or friends to be present, and a multidisciplinary team including physicians, nursing, and psychosocial staff can attend. There is often the question about if the patient should be included in the initial discussion. It is a good policy is to discuss the ways in which it might make sense culturally, emotionally, and psychologically to involve adolescent patients to be part of the initial conversation. By including the adolescent patient, clinicians are sending the message that they are an important part of their care team, which can decrease non-adherence during treatment (Compas et al., 2012; Lyon, McCabe, Patel, & D'Angelo, 2004; Palmer et al., 2007). In addition, if they are not included as part of the initial conversation, they often assume that the information they have been given is not complete, and that the information is much worse than what they were told (D'Agostino et al., 2011; Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Lyon et al., 2004; J. Mack & Grier, 2004; McCabe, 1996).

The decision about including younger children is less straightforward and should be discussed with the parents prior to the Day One Talk (Mack & Grier, 2004). Some parents

prefer to hear the information first and have an opportunity to process it and ask questions before sharing the diagnosis with their children. If this is the case, it is appropriate to hold a separate conversation with the child and the parents to discuss the diagnosis and plan for treatment (J. Mack & Grier, 2004). For children of all ages, it is important that a system for open and honest information exchange with their medical providers be set forth from the beginning, but consensus guidelines support anticipatory guidance and education of illness with children (Thompson et al., 2015; Thompson & Young-Saleme, 2015).

### Active Treatment

The active treatment period can last anywhere from months to years. Treatment requires a huge amount of adaptation on the part of all family members, as everyone must contend with unexpected events, changes in the family routine, financial costs, and the possibility of the death of a child (Compas et al., 2012).

Distress associated with the cancer experience is not uncommon in children and the child's functioning during cancer treatment is often associated with parent and family functioning (Hamner et al., 2015; Pai et al., 2007). It is therefore strongly recommended that pediatric oncology centers provide access to psychosocial support and interventions for patients and families throughout the cancer trajectory and this has recently been adopted as a psychosocial standard of care for pediatric oncology (Steele et al., 2015).

The disruption of normal activities such as attending school and participating in extracurricular activities are often keenly felt by children undergoing cancer treatment and many children report feelings of isolation during cancer treatment (D'Agostino et al., 2011). However, despite the strong existing literature demonstrating the importance of peer interaction for healthy and ill children, peer support during cancer treatment is often cited as an unmet need (Christiansen et al., 2015). Social interactions with other children undergoing cancer treatment can be promoted through hospital-based activity programs or support groups, or through specialized camps such as Hole-In-The-Wall Gang ([www.holeinthewallgang.org](http://www.holeinthewallgang.org)) that have designated programs children with medical illnesses.

Cancer treatment can prevent many children from attending school full time, causing them to miss out on important academic and social learning opportunities. If attending school full time is not possible, most clinicians recommend that children stay involved with the school community, to facilitate a sense of normalcy and promote continued educational attainment. To facilitate re-entry, pediatric oncology programs should identify a team member who can coordinate communication between the patient/family, school, and the healthcare team (Christiansen et al., 2015). In addition, psychosocial clinicians can work with the school to develop a special education plan, which outlines the academic services the child will likely need while on treatment. Services requested can include home-based tutoring, shortened school days, rest breaks, the ability to wear a hat, shortened assignments, a focus on quality as opposed to quantity of work, and unlimited absences. Information for teachers and other school personnel about common side-effects of cancer treatment should also be included such as fatigue and nausea, and an individual plan symptom management within the school setting.

School visits, where members of the team go to the school and provide developmentally appropriate information to the patient's classmates about cancer, can be an additional way of facilitating reentry for the patient and for the school. School visits can be very beneficial for both the patient and for the classroom, as they provide accurate information about cancer and its treatment, and dispel rumors or misconceptions that may be circulating (Northman et al., 2015).

### End of Treatment

This is often initially a very joyous time for families and patients as their long-awaited goal and hopes are now realized. Families often celebrate along with providers and staff on their last treatment day. Often a great relief and welcome event, this can surprisingly be a hard time for children and adolescents, too. While families and patients will continue to return for screening and off-treatment visits, it occurs at increasingly less frequent intervals, and many find they miss elements of the process aside from the treatment and fear of death. The removal from strongly-formed attachments and relationships as well as the structure and routine of the cancer treatment process are the most difficult for families.

Multiple relationships with providers and caring individuals are formed through the cancer treatment process. Going through a stressful life event with consistent individuals in the cancer team naturally forges bonds that families miss despite the desire to be rid of the fears and frustration of cancer (Romaniuk & Kristjanson, 1995). For some families, this may often be the most comprehensive and caring environment they have experienced. For others with financial hardship, the lessening of free gifts, food, and activities found in well-supported pediatric cancer clinic settings is difficult. For toddlers and infants, they grow up and find many attachment-figures in clinic and can experience separation distress. For school-aged children and adolescents, idealization and role identity as a "cancer kid" may have developed, and it can be difficult to transition to no longer feeling as special or having others being unsympathetic (Barlow & Ellard, 2006; D'Agostino et al., 2011; Palmer et al., 2007). The move away from structure and schedule of cancer treatment may often be one of the most surprisingly difficult transitions for children and teens. Children may return to a less structured routine and variable caregivers in day care and school settings. They may end up seeing and being with their parents less as they return to work and find that this is unwanted change despite being glad for the absence of nausea, pain, and fatigue. Those with chaotic home lives or those teens who will now be given more responsibility and be on their own may find it difficult to adapt. Adolescents may have not been as habituated to the social pace as a full-time teen and experience frustration and unhappiness.

Cancer team providers and psychosocial staff can anticipate many of these needs and start preparing for this transition as it approaches. It is not uncommon for families to reach out during this time expressing surprise as how difficult the transition back to "normal life" has been. Validating and normalizing this experience along with providing strategizes and plans for the family to regain their independence are key.

Survivorship is a well-studied period of time that can often be filled with psychosocial stress. Many patients continue to do well at 5 and 10 years out from cancer treatment (Phipps et al., 2012). Those who do less well are more likely to have higher levels of distress

during treatment, poor social and family support, and/or late-effects of their cancer treatment that interfere with their functioning (Bitsko et al., 2016; Kwak et al., 2013; Prasad et al., 2015; Schultz et al., 2007). Regardless of risk factors, survivorship groups and treatment have been shown to be useful in coping and regaining functioning (Nathan et al., 2009). The study of school liaison programs have shown them to be highly valued and correlated with quicker and more successful returns to the school setting (Northman, Ross, Morris, & Tarquini, 2015; Thompson et al., 2015).

### End of Life

Children can understand the universality and irreversibility of death as early as the beginnings of school age years (Piaget, 1929). Even toddlers and pre-school aged children can understand that people who die no longer interact even if they cannot understand the permanence of death. Developmentally appropriate answers to children's questions about death must take into account not saying things that will mislead them and make them potentially more worried. Well-meaning or cautious phrases, known as errors of kindness (Freyer et al., 2006; Hinds et al., 2005; J. W. Mack & Joffe, 2014), such as telling children they will "go to sleep" may mislead young children into thinking they cannot wake back up or be stuck having nightmares or in a dream. Likewise, making promises that are impossible and cannot be kept, such as dying will not hurt, is another error of kindness that can end up making children more fearful when discomfort occurs at end of life. Parent guidance to utilize reassuring and comforting concrete terms while not feeling pressured to answer questions they do not have the answer is effective. Instead of stating that there will be no pain in reply to "will it hurt to die?", parents can say they will be with children to help them be comfortable and their providers will be able to make any pain better if it comes up.

Children want to know they will be safe, comfortable, taken care of, and have some control. Despite common parental worries, children can maintain hope even when discussing potentially undesired outcomes and goals of care (Kamihara, Nyborn, Olcese, Nickerson, & Mack, 2015). Often, familiar objects, activities, and closeness of loved ones are most important to them, not unlike adult desires at the end of life. Adolescents and even young children regularly want to know where their belongings will go and how they want to be remembered. Some even want to plan what happens at their funeral (Wiener et al., 2012; Zadeh, Pao, & Wiener, 2015). This meaning-making can be encouraging and comforting for many children who otherwise may be without a sense of control when they hear they are dying. Advance planning tools such as *Voicing My Choices* and *5 Wishes* are excellent facilitators of these tough discussions and meaning-making for providers and families. Studies of their use have shown highly positive regard and efficacy in describing hopes and desires (Wiener et al., 2012).

Parents universally have their own fears and discomforts about discussing their children's death. Discussing death with their children who may be or are dying is even more daunting. As difficult as it may be, the vast majority of parents do not regret discussing death/goals of care with their children (J. W. Mack & Joffe, 2014). Moreover, 27% of parents regret not addressing it in one large study (Kreicbergs et al., 2004). Studies show that many children and adolescents want to have information about their cancer and treatment, and suffer in

silence from withheld prognostic news, with their fears about dying causing significant distress and anxiety than can often be worse than reality (Sahler, Frager, Levetown, Cohn, & Lipson, 2000; Wolfe, Friebert, & Hilden, 2002). Providers can help reduce distress and harm by ideally having conversations about goals of care early and over time. Broaching the topic when first discussing treatment and prognosis with parents and patients at diagnosis develops trust, demonstrates this topic as safe to talk about, and makes continuing and developing this conversation easier over time (J. Mack & Grier, 2004). After diagnosis, opportunities to discuss goals of care can be found during hospitalizations for acute illness, decompensations, treatment complications, and disease progression. Later conversations have been shown to be associated with less desired intensive cancer-directed treatment and regret (Mack et al., 2012).

Expression of the myriad emotions children and adolescents experience at end of life warrants encouragement and responsiveness. Exploration and expression of emotion comes in mediums children are used to, ranging from painting/drawn art, video collages and testimonials, to website making and blogs, as well as music, writing/journaling, and talking. Psychosocial clinicians, child life specialists, palliative care clinicians, and other specialists can facilitate these processes with children and families (Freyer et al., 2006). Creative expression has been shown to be therapeutic not only for children but also families during and after the process (A. E. Kazak, 2005; B. Sourkes et al., 2005; B. M. Sourkes, 1995). Families often treasure the art and testimony made by their children, reflecting on it as some of their most prized possessions. Children's legacy-making is often one of the strongest anxiolytics at the end of life, providing calm and solace by recognizing love and a life of importance (Wiener et al., 2012; Zadeh et al., 2015).

## Conclusion

It is not surprising that cancer and its treatment significantly impacts children and their families, no matter their developmental stage. Providing children and families with psychoeducation, information, and anticipatory guidance about what to expect over the course of treatment, including implications for child development, is a psychosocial standard of care (Thompson et al., 2015) and can reduce uncertainty and distress over the course of treatment (Contrada, Leventhal, & Anderson, 1994; Last & Van Veldhuizen, 1996; Slavin, O'Malley, Koocher, & Foster, 1982). And while the focus of pediatric cancer treatment is on the child, decades of research have shown parents and caregivers of pediatric cancer patients are resilient but also profoundly impacted by their child's illness. Caring for the child with cancer also necessitates providing appropriate psychosocial services to parents and caregivers (Kearney, Salley, & Muriel, 2015).

The suggestions provided above are applicable to all children and families undergoing cancer treatment, but utilizing a developmental lens with regards to age and faculties of the child allows for guidance of engagement and treatment. While preschool age patients benefit from explanations about their illness that are simple and concrete, adolescent patients are able to engage in complex reasoning required to weight risks and benefits of potential treatments, and to think abstractly about potential complications. It remains of utmost importance to tailor all information given to the specific needs and preferences of the patient

and family, and clinicians can better appreciate and advocate for these needs and preferences by critically evaluating children's developmental tasks, norms, and status.

## References

- Cooley WC, Sagerman PJ. American Academy of P, American Academy of Family P, American College of P, Transitions Clinical Report Authoring G. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011; 128(1):182–200. DOI: 10.1542/peds.2011-0969 [PubMed: 21708806]
- Arpawong TE, Oland A, Milam JE, Ruccione K, Meeske KA. Post-traumatic growth among an ethnically diverse sample of adolescent and young adult cancer survivors. *Psychooncology*. 2013; 22(10):2235–2244. DOI: 10.1002/pon.3286 [PubMed: 23554227]
- Bares CB, Gelman SA. Knowledge of illness during childhood: Making distinctions between cancer and colds. *International Journal of Behavioral Development*. 2008; 32(5):443–450. DOI: 10.1177/0165025408093663
- Barlow JH, Ellard DR. The psychosocial well-being of children with chronic disease, their parents and siblings: an overview of the research evidence base. *Child Care Health Dev*. 2006; 32(1):19–31. DOI: 10.1111/j.1365-2214.2006.00591.x [PubMed: 16398788]
- Bitsko MJ, Cohen D, Dillon R, Harvey J, Krull K, Klosky JL. Psychosocial Late Effects in Pediatric Cancer Survivors: A Report From the Children's Oncology Group. *Pediatr Blood Cancer*. 2016; 63(2):337–343. DOI: 10.1002/pbc.25773 [PubMed: 26488337]
- Blair C, Diamond A. Biological processes in prevention and intervention: The promotion of self-regulation as a means of preventing school failure. *Development and psychopathology*. 2008; 20(03):899–911. [PubMed: 18606037]
- Botello-Harbaum M, Nansel T, Haynie DL, Iannotti RJ, Simons-Morton B. Responsive parenting is associated with improved type 1 diabetes-related quality of life. *Child Care Health Dev*. 2008; 34(5):675–681. DOI: 10.1111/j.1365-2214.2008.00855.x [PubMed: 18796059]
- Butow P, Palmer S, Pai A, Goodenough B, Luckett T, King M. Review of adherence-related issues in adolescents and young adults with cancer. *J Clin Oncol*. 2010; 28(32):4800–4809. DOI: 10.1200/JCO.2009.22.2802 [PubMed: 20212260]
- Christiansen HL, Bingen K, Hoag JA, Karst JS, Velazquez-Martin B, Barakat LP. Providing Children and Adolescents Opportunities for Social Interaction as a Standard of Care in Pediatric Oncology. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):S674–699. DOI: 10.1002/pbc.25774
- Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in childhood and adolescence. *Annual Review of Clinical Psychology*. 2012; 8:455.
- Contrada R, Leventhal E, Anderson J. Psychological preparation for surgery: Marshaling individual and social resources to optimize self-regulation. *International review of health psychology*. 1994; 3:219–266.
- D'Agostino NM, Penney A, Zebrack B. Providing developmentally appropriate psychosocial care to adolescent and young adult cancer survivors. *Cancer*. 2011; 117(10 Suppl):2329–2334. DOI: 10.1002/encr.26043 [PubMed: 21523754]
- Erikson, EH. *Childhood and society*. Harmondsworth: Penguin Books; 1950.
- Freyer DR, Kuperberg A, Sterken DJ, Pastyrnak SL, Hudson D, Richards T. Multidisciplinary care of the dying adolescent. *Child Adolesc Psychiatr Clin N Am*. 2006; 15(3):693–715. DOI: 10.1016/j.chc.2006.02.003 [PubMed: 16797445]
- Garvie PA, Lensing S, Rai SN. Efficacy of a pill-swallowing training intervention to improve antiretroviral medication adherence in pediatric patients with HIV/AIDS. *Pediatrics*. 2007; 119(4):e893–e899. [PubMed: 17353298]
- Goldenring JM, Rosen DS. *Getting into Adolescent Heads*. Contemporary Pediatrics. 2004
- Grootenhuis MA, Last BF. Adjustment and coping by parents of children with cancer: a review of the literature. *Support Care Cancer*. 1997; 5(6):466–484. [PubMed: 9406361]



- Hamner T, Latzman RD, Latzman NE, Elkin TD, Majumdar S. Quality of life among pediatric patients with cancer: Contributions of time since diagnosis and parental chronic stress. *Pediatr Blood Cancer*. 2015; 62(7):1232–1236. DOI: 10.1002/pbc.25468 [PubMed: 25755193]
- Hinds PS, Drew D, Oakes LL, Fouladi M, Spunt SL, Church C, Furman WL. End-of-life care preferences of pediatric patients with cancer. *J Clin Oncol*. 2005; 23(36):9146–9154. DOI: 10.1200/jco.2005.10.538 [PubMed: 16172453]
- Hullmann SE, Fedele DA, Molzon ES, Mayes S, Mullins LL. Posttraumatic growth and hope in parents of children with cancer. *J Psychosoc Oncol*. 2014; 32(6):696–707. DOI: 10.1080/07347332.2014.955241 [PubMed: 25158296]
- Irwin CE Jr. Adolescent health at the crossroads: where do we go from here? *J Adolesc Health*. 2003; 33(1):51–56. [PubMed: 12834997]
- Kamihara J, Nyborn JA, Olcese ME, Nickerson T, Mack JW. Parental hope for children with advanced cancer. *Pediatrics*. 2015; 135(5):868–874. DOI: 10.1542/peds.2014-2855 [PubMed: 25847801]
- Kazak AE. Evidence-based interventions for survivors of childhood cancer and their families. *J Pediatr Psychol*. 2005; 30(1):29–39. [PubMed: 15610982]
- Kazak AE, Abrams AN, Banks J, Christofferson J, DiDonato S, Grootenhuis MA, ... Kupst MJ. Psychosocial Assessment as a Standard of Care in Pediatric Cancer. *Pediatric Blood & Cancer*. 2015; 62(S5):S426–S459. DOI: 10.1002/pbc.25730 [PubMed: 26700916]
- Kearney JA, Salley CG, Muriel AC. Standards of Psychosocial Care for Parents of Children With Cancer. *Pediatric Blood & Cancer*. 2015; 62(S5):S632–S683. [PubMed: 26700921]
- King, R., Martin, A., Volkmar, FR., Lewis, M. *Lewis's Child and Adolescent Psychiatry: A Comprehensive Textbook*. edition, t, editor. Wolters Kluwer Health/Lippincott Williams & Wilkins; 2007.
- Kreicbergs U, Valdimarsdottir U, Onelov E, Henter JI, Steineck G. Talking about death with children who have severe malignant disease. *N Engl J Med*. 2004; 351(12):1175–1186. DOI: 10.1056/NEJMoa040366 [PubMed: 15371575]
- Kwak M, Zebrack BJ, Meeske KA, Embry L, Aguilar C, Block R, ... Cole S. Trajectories of psychological distress in adolescent and young adult patients with cancer: a 1-year longitudinal study. *J Clin Oncol*. 2013; 31(17):2160–2166. DOI: 10.1200/JCO.2012.45.9222 [PubMed: 23650425]
- Last B, Van Veldhuizen A. Information about diagnosis and prognosis related to anxiety and depression in children with cancer aged 8–16 years. *European Journal of Cancer*. 1996; 32(2):290–294.
- Liptak, C., Zelter, L., Recklitis, C. Psychosocial care of the child and family. In: Noathan, O., editor. *Hematology and Oncology of Infancy and Childhood*. 8. 2015.
- Lyon ME, McCabe MA, Patel KM, D'Angelo LJ. What do adolescents want? An exploratory study regarding end-of-life decision-making. *J Adolesc Health*. 2004; 35(6):529.e521–526. DOI: 10.1016/j.jadohealth.2004.02.009
- Mack, Cronin A, Taback N, Huskamp HA, Keating NL, Malin JL, Weeks JC. End-of-Life Care Discussions Among Patients With Advanced Cancer A Cohort Study. *Annals of Internal Medicine*. 2012; 156(3):204–210. DOI: 10.7326/0003-4819-156-3-201202070-00008 [PubMed: 22312140]
- Mack J, Grier HE. The day one talk. *Journal of clinical oncology*. 2004; 22(3):563–566. [PubMed: 14752081]
- Mack JW, Joffe S. Communicating about prognosis: ethical responsibilities of pediatricians and parents. *Pediatrics*. 2014; 133(Suppl 1):S24–30. DOI: 10.1542/peds.2013-3608E [PubMed: 24488537]
- Maslow G, Adams C, Willis M, Neukirch J, Herts K, Froehlich W, ... Rickerby M. An evaluation of a positive youth development program for adolescents with chronic illness. *J Adolesc Health*. 2013; 52(2):179–185. DOI: 10.1016/j.jadohealth.2012.06.020 [PubMed: 23332482]
- McCabe MA. Involving children and adolescents in medical decision making: developmental and clinical considerations. *J Pediatr Psychol*. 1996; 21(4):505–516. [PubMed: 8863460]
- McNeely, C. *The Teen Years Explained: A guide to Healthy Adolescent Development*. Baltimore, MD: Johns Hopkins University; 2009.

- Moore M, Russ SW. Pretend play as a resource for children: Implications for pediatricians and health professionals. *Journal of Developmental and Behavioral Pediatrics*. 2006; 27(3):237–248. DOI: 10.1097/00004703-200606000-00011 [PubMed: 16775523]
- Morgan S, Davies S, Palmer S, Plaster M. Sex, drugs, and rock ‘n’ roll: caring for adolescents and young adults with cancer. *J Clin Oncol*. 2010; 28(32):4825–4830. DOI: 10.1200/JCO.2009.22.5474 [PubMed: 20498401]
- Nathan PC, Ford JS, Henderson TO, Hudson MM, Emmons KM, Casillas JN, ... Oeffinger KC. Health behaviors, medical care, and interventions to promote healthy living in the Childhood Cancer Survivor Study cohort. *J Clin Oncol*. 2009; 27(14):2363–2373. DOI: 10.1200/JCO.2008.21.1441 [PubMed: 19255308]
- Northman L, Ross S, Morris M, Tarquini S. Supporting pediatric cancer survivors with neurocognitive late effects: a model of care. *J Pediatr Oncol Nurs*. 2015; 32(3):134–142. DOI: 10.1177/1043454214554012 [PubMed: 25416520]
- Pai AL, Greenley RN, Lewandowski A, Drotar D, Youngstrom E, Peterson CC. A meta-analytic review of the influence of pediatric cancer on parent and family functioning. *J Fam Psychol*. 2007; 21(3):407–415. DOI: 10.1037/0893-3200.21.3.407 [PubMed: 17874926]
- Palmer S, Mitchell A, Thompson K, Sexton M. Unmet needs among adolescent cancer patients: a pilot study. *Palliat Support Care*. 2007; 5(2):127–134. [PubMed: 17578063]
- Patel A, Jacobsen L, Jhaveri R, Bradford KK. Effectiveness of pediatric pill swallowing interventions: a systematic review. *Pediatrics*. 2015; 135(5):883–889. [PubMed: 25896843]
- Patenaude AF, Kupst MJ. Psychosocial functioning in pediatric cancer. *J Pediatr Psychol*. 2005; 30(1):9–27. [PubMed: 15610981]
- Patenaude AF, Pelletier W, Bingen K. Communication, Documentation, and Training Standards in Pediatric Psychosocial Oncology. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):S870–895. DOI: 10.1002/pbc.25725 [PubMed: 26700930]
- Phipps S. Adaptive style in children with cancer: implications for a positive psychology approach. *J Pediatr Psychol*. 2007; 32(9):1055–1066. DOI: 10.1093/jpepsy/jsm060 [PubMed: 17698880]
- Phipps S, Peasant C, Barrera M, Alderfer MA, Huang Q, Vannatta K. Resilience in children undergoing stem cell transplantation: results of a complementary intervention trial. *Pediatrics*. 2012; 129(3):e762–770. DOI: 10.1542/peds.2011-1816 [PubMed: 22311995]
- Piaget, J. *The Child’s Conception of the World*. 1929.
- Prasad PK, Hardy KK, Zhang N, Edelstein K, Srivastava D, Zeltzer L, ... Krull K. Psychosocial and Neurocognitive Outcomes in Adult Survivors of Adolescent and Early Young Adult Cancer: A Report From the Childhood Cancer Survivor Study. *J Clin Oncol*. 2015; 33(23):2545–2552. DOI: 10.1200/JCO.2014.57.7528 [PubMed: 26150441]
- Romaniuk DK, Kristjanson LJ. The parent-nurse relationship from the perspective of parents of children with cancer. *J Pediatr Oncol Nurs*. 1995; 12(2):80–89. discussion 90–82. [PubMed: 7612201]
- Rosenberg AR, Syrjala KL, Martin PJ, Flowers ME, Carpenter PA, Salit RB, ... Lee SJ. Resilience, health, and quality of life among long-term survivors of hematopoietic cell transplantation. *Cancer*. 2015; 121(23):4250–4257. DOI: 10.1002/ncr.29651 [PubMed: 26288023]
- Rosenberg AR, Yi-Frazier JP, Wharton C, Gordon K, Jones B. Contributors and Inhibitors of Resilience Among Adolescents and Young Adults with Cancer. *J Adolesc Young Adult Oncol*. 2014; 3(4):185–193. DOI: 10.1089/jayao.2014.0033 [PubMed: 25969794]
- Sahler OJ, Frager G, Levetown M, Cohn FG, Lipson MA. Medical education about end-of-life care in the pediatric setting: principles, challenges, and opportunities. *Pediatrics*. 2000; 105(3 Pt 1):575–584. [PubMed: 10699112]
- Schultz KA, Ness KK, Whitton J, Recklitis C, Zebrack B, Robison LL, ... Mertens AC. Behavioral and social outcomes in adolescent survivors of childhood cancer: a report from the childhood cancer survivor study. *J Clin Oncol*. 2007; 25(24):3649–3656. DOI: 10.1200/JCO.2006.09.2486 [PubMed: 17704415]
- Slavin LA, O’Malley JE, Koocher GP, Foster DJ. Communication of the cancer diagnosis to pediatric patients: Impact on long-term adjustment. *Am J Psychiatry*. 1982

- Sourkes B, Frankel L, Brown M, Contro N, Benitz W, Case C, ... Sunde C. Food, toys, and love: pediatric palliative care. *Curr Probl Pediatr Adolesc Health Care*. 2005; 35(9):350–386. DOI: 10.1016/j.cppeds.2005.09.002 [PubMed: 16301200]
- Sourkes, BM. *Armfuls of time : the psychological experience of the child with a life-threatening illness*. Pittsburgh: University of Pittsburgh Press; 1995. [1995] ©
- Spear LP. The adolescent brain and age-related behavioral manifestations. *Neurosci Biobehav Rev*. 2000; 24(4):417–463. [PubMed: 10817843]
- Steele AC, Mullins LL, Mullins AJ, Muriel AC. Psychosocial Interventions and Therapeutic Support as a Standard of Care in Pediatric Oncology. *Pediatric Blood & Cancer*. 2015; 62(S5):S585–S618. DOI: 10.1002/psc.25701 [PubMed: 26700919]
- Steinberg L, Lamborn SD, Dornbusch SM, Darling N. Impact of parenting practices on adolescent achievement: authoritative parenting, school involvement, and encouragement to succeed. *Child Dev*. 1992; 63(5):1266–1281. [PubMed: 1446552]
- Stuber ML, Nader KO, Houskamp BM, Pynoos RS. Appraisal of life threat and acute trauma responses in pediatric bone marrow transplant patients. *J Trauma Stress*. 1996; 9(4):673–686. [PubMed: 8902740]
- Thompson AL, Christiansen HL, Elam M, Hoag J, Irwin MK, Pao M, ... Kelly KP. Academic Continuity and School Reentry Support as a Standard of Care in Pediatric Oncology. *Pediatric Blood & Cancer*. 2015; 62(S5):S805–S817. DOI: 10.1002/psc.25760 [PubMed: 26700927]
- Thompson AL, Young-Saleme TK. Anticipatory Guidance and Psychoeducation as a Standard of Care in Pediatric Oncology. *Pediatric Blood & Cancer*. 2015; 62(S5):S684–S693. DOI: 10.1002/psc.25721 [PubMed: 26700925]
- Weitzman ER, Ziemnik RE, Huang Q, Levy S. Alcohol and Marijuana Use and Treatment Nonadherence Among Medically Vulnerable Youth. *Pediatrics*. 2015; doi: 10.1542/peds.2015-0722
- Wiener L, Kazak AE, Noll RB, Patenaude AF, Kupst MJ. Interdisciplinary Collaboration in Standards of Psychosocial Care. *Pediatr Blood Cancer*. 2015; 62(Suppl 5):S425.doi: 10.1002/psc.25718 [PubMed: 26700915]
- Wiener L, Zadeh S, Battles H, Baird K, Ballard E, Osherow J, Pao M. Allowing Adolescents and Young Adults to Plan Their End-of-Life Care. *Pediatrics*. 2012; 130(5):897–905. DOI: 10.1542/peds.2012-0663 [PubMed: 23045560]
- Wolfe J, Friebert S, Hilden J. Caring for children with advanced cancer integrating palliative care. *Pediatr Clin North Am*. 2002; 49(5):1043–1062. [PubMed: 12430625]
- Zadeh S, Pao M, Wiener L. Opening end-of-life discussions: how to introduce Voicing My CHOICES, an advance care planning guide for adolescents and young adults. *Palliat Support Care*. 2015; 13(3):591–599. DOI: 10.1017/S1478951514000054 [PubMed: 24622210]

**Table 1**

## Impact of Cancer Treatment Across Development

	<b>Psychosocial Challenges</b>	<b>Cognitive Challenges</b>	<b>Behavioral Result</b>
Infant/Toddlers (0–2 years)	Difficulties with regular feeding, comfort, and cares in can lead to caregiver mistrust and attachment disruptions.	Developing sensory and motor curiosities can be particularly disrupted by pain, nausea, and discomfort of treatment.	Worsening abilities to self-soothe and be soothed. Increased irritability with touch or aversion to it.
Preschool(3–5 years)	Failure to develop sense of personal control over environment and physical tasks such as toileting, feeding self, walking can lead to fearfulness, anxiety, doubt, frustration, and guilt.	Imagination and magical thinking develops. Fantasy and fears can be complex around physical and environmental difficulties of treatment. Complex abstract thought about death is still limited.	Temper tantrums and procedural resistance can develop when unable to have control, experiencing inconsistent limits/messages, and changing routines. Token economy can be helpful motivator.
School Age(6–11 years)	Disruptions in school, sports, and activities valued by family units can lead to sense of inferiority and guilt/shame.	More concrete understanding of treatment including length, number of treatments, and developing understanding of death.	Frequent aversion to medicine, nutrition, and other differences compared to family members due to sense of unfairness and disruption of normalcy.
Adolescents (12–18 years)	Inability to find acceptance in peer groups and explore different roles can lead to frustration and confusion. Profound loneliness and isolation can develop without intimate peer relationships.	Abstract reasoning and theoretical concepts of death develops. Concepts learned in one context can be applied to others. Critical thinking, planning, and agency in care are possible.	Risk-taking and non-adherence due to sense of invincibility or active denial. Behavior often for the benefit of social/peer values and activities with less influence or care about family values

Author Manuscript

Author Manuscript

Author Manuscript

Author Manuscript