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Updates in Pediatric Psycho-Oncology

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Abstract

Childhood cancer accounts for less than 2% of all cancers diagnosed each year. About 12–14,000 children will be diagnosed in a given year with any type of cancer. Over the past fifty years, treatments and cure rates have improved from 10–20% five year survival rates to between 80–85% five year survival rates. Psychosocial support of children with cancer and their families has grown and has been more fully integrated into pediatric care over the past five decades. Increasing acceptance of the importance of addressing mental health has led to oncologists referring patients to specific resources and services. This paper provides updated information on psychosocial issues for those who treat children and adolescents with cancer and focuses on unique challenges for the pediatric psycho-oncologist.

Keywords

pediatrics; oncology; psychosocial care; family; siblings; cancer; psycho-oncology; psychosocial issues; depression; anxiety; survivorship; and end of life

Introduction

Childhood cancer accounts for less than 2% of all cancers diagnosed each year. About 12–14,000 children will be diagnosed in a given year with any type of cancer (Kurtz 2010, Cancer Statistics 2010). Over the past fifty years, treatments and cure rates have improved from 10–20% to between 80–85% five year survival rates currently (Askins 2008). There are approximately 2000 deaths each year from cancer, making it the leading cause of death from disease in children under 18 years old (Cancer Statistics 2010). The most common pediatric malignancies are leukemia (28%), specifically acute lymphoblastic leukemia (ALL) (21%), and Central Nervous System (CNS) tumors (18%). Other tumor types include germ cell tumors (7%), Hodgkin lymphoma (7%), non-Hodgkin lymphoma (6%), neuroblastoma (5%), acute myeloid leukemia (5%), Wilms tumor (4%), osteosarcoma (3%), rhabdomyosarcoma (3%), thyroid carcinoma (3%), melanoma (3%), retinoblastoma (2%), and Ewing sarcoma (1%) (Kurtz 2010). CNS prophylaxis treatment and multidrug regimens

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are considered to be responsible for the remarkable improved success rate in treatments of childhood cancer.

Psychosocial support is defined as an intervention to help patients cope with stressors at home, during treatment, or in the community. It can also be defined as the attentiveness to the social, psychological, and emotional health of the patient while attending to life-threatening medical symptoms and therefore covers a broad range of psychological services (Abrams 2008). Psychosocial support of children with cancer and their families has grown and has been more fully integrated into pediatric care over the past several decades. Increasing acceptance of the importance of addressing mental health has led to oncologists referring patients to pediatric psycho-oncologists and child life specialists. There is a risk of mental health disorders in cancer patients, exposed by anxieties of diagnosis, therapy, and disruption of activities of daily living, but most patients do not meet full Diagnostic and Statistical Manual criteria for psychiatric disorders. The stress of caring for a child with cancer can lead to increased risk of mild to severe psychological symptoms in parents and siblings as well. The side effects of cancer treatment itself (chemotherapy, surgery, radiation) can lead to difficulties in cognition, poor coping skills, and disordered behavior. These stressors and difficulties do not end with the completion of treatment, but follow children through growing up, going to school, and surviving longer (Pao 2007, Stuber 2012).

Unlike in adults, diagnosis and treatment for children with cancer occurs during a period of great physical, cognitive, behavioral and social development (Stuber 2012). Interference in any of these areas of development can impact both acute and long-term outcomes of a child's development. Working within a spectrum of developmental variability is one of the major ways that pediatric psycho-oncology differs from its adult counterpart. Another difference in pediatric psycho-oncology is the need for the providers to work with families, not just the patient (Kurtz 2010, Stuber 2012, Izraeli 2012). The whole family must adjust to the taxing situation of long-lasting uncertainty and fear of death (Patenaude 2005). The sick child is dependent upon their parents for transportation, adherence to treatment, and for support of their emotional and physical well-being. Children rely on their parents to take them to their appointments and to provide them with their medications, whereas many adults are able to manage getting to treatment and taking their medications on their own (Kurtz 2010, Stuber 2012, Izraeli 2012).

Developmental Issues

As with other life threatening stressors, the way a child is affected by cancer and their psychological response varies with their developmental age at diagnosis. Childhood cancer is associated with multiple physical, psychosocial, and behavioral symptoms that can be attributed to the disease itself, its treatments, reactions to medical procedures, and living with uncertain prognoses. Treatment can interfere with a child's normal development, activities, and social interactions through disfigurement, repeated school absences, losing contact with friends due to medical isolation from infections and other disruptions of daily activities (Ruland 2009). Looking at the developmental stages of preschool, school age and adolescence, there are important differences in the way that children respond to stress and information as compared to adults.

Infants and Toddlers

Infants and toddlers (under age 3 years old) respond mostly to whether they feel safe and comfortable or not. They are unable to understand explanations, but making procedures and treatment as painless as possible may be less traumatic for them. Allowing the child the ability to maintain a secure attachment to their primary caregiver while in the hospital going through treatment is a priority; hence, caregiver “rooming in” has been a vast improvement in hospital care allowing them to continue to develop as normally as possible (Dunn 2010).

Preschool Age

Preschool aged children (3–6 years old) are egocentric, meaning they believe they are at the center of everything. They also use associative logic, believing that two unrelated things that occur at the same time are understood as one causing the other. This can lead to magical thinking which Piaget described as pre-operational thinking, or the combination of reality and fantasy. Magical thinking often leads kids to believe that their cancer is a punishment for being bad and that the treatments and procedures are additional punishments. Preschoolers are just starting to develop the concept of time, so they may only understand what affects him/her in the moment. Family is still the core social interaction for children this age, so prolonged separations from family members can cause anxiety and be very difficult for the patient and the treatment team. Transitional objects may help, but having a parent nearby is the best way to address separation anxiety (Abrams 2008).

School Age

School aged children (6–13 years old) become more logical and can start to appreciate others’ viewpoints. They can understand simple functional explanations of their cancer and learn the names of their medications and procedures. At this age, rules become very important, so having a diagnosis of cancer is disruptive and frustrating. Many children question why they have gotten cancer and can become confused or distressed because there are no identifiable causes of most childhood cancers. Missing school and disrupted friendships are common and upsetting since school and friends play such an important role for social development in this age group (Abrams 2008).

Adolescence

The developmental issues facing teens include finding their identity, establishing independence, and seeking intimacy with peers which can be extremely difficult while having to endure cancer treatments. Many adolescents start to think abstractly and can understand the complexity of their illness, but are not prepared to manage the changes in their lifestyles that treatment requires. Cancer takes them out of their social world with friends and makes them dependent on their parents again. Another important concern for teens is physical attractiveness; losing hair, losing/gaining weight, and having scars can negatively impact a teenager’s self-esteem. They may be reluctant to have friends visit or may isolate themselves at a time when friends and peer groups are extremely important for social development. Adolescents also start to think about the significance of potential side effects from their treatment such as infertility, risk of recurrence, or second malignancies. Since their sense of identity is still evolving, adolescents may be reluctant to see cancer as

part of their identity; this may lead them to isolate themselves from friends or to decline from participating in support groups in the hospital which could negatively impact their social development (Stuber 2012, Abrams 2007).

Assessment/Treatment

The majority of pediatric cancer patients and their families are resilient and do not demonstrate psychiatric difficulties during and after their treatment. There are some patients who have severe enough symptoms, functional impairment or psychiatric disorders that need to be recognized and treated by a mental health professional (Stuber 2012). Many psychiatric symptoms and disorders such as anxiety and depression are underdiagnosed and undertreated (Ruland 2009). Patients who are depressed may have difficulty coping with their illness and treatment which can then lead to worsening depressive symptoms and create a downward spiral (Patenaude 2005). Children with brain tumors and CNS disease are likely to experience more psychological distress which is thought to be largely due to the neurocognitive effects of their disease. Children who have significant and severe late side effects also tend to be more depressed and have a poorer self-esteem (Weiner 2003).

Psychosocial care, including early cognitive and emotional assessments and continuing psychological care concurrent with medical treatment that utilizes a variety of therapeutic interventions for the individual child as well as for the family as a whole, should begin at the time of the diagnosis and be provided throughout the course of treatment. Cognitive assessments include standardized IQ testing and evaluation of verbal and nonverbal learning. Emotional assessments use a diagnostic interview to determine levels of anxiety and depression and coping difficulties for the patient and family (Wiener 2012, Abrams 2008). Pediatric psycho-oncologists help ensure that medical information is understood by the patient and family, help assess each family member's coping style, and make sure that they are best able to assist the family during such a critical time.

The pediatric psycho-oncologist has a variety of techniques that may be employed to facilitate coping for children of all ages. Storytelling, fantasy play, and games can help the pre-school age child process what is happening to them, while medical play and behavioral interventions might help the school age child be appropriately distracted during procedures and help them find age-appropriate words for what they are experiencing. Positive reinforcement can help pre-school and school age children be more cooperative with procedures and treatments. Encouraging adolescents to participate in medical decision-making and working with the family and the oncology team to ensure that these happen can be important jobs of the pediatric psycho-oncologist (Wiener 2012).

Depression

As with adults, it can be challenging to determine if a child with cancer has a major depression because alterations in concentration, sleep, appetite and level of energy occur in medical illness as well as with depression. Depression can affect quality of life and treatment adherence in patients with childhood cancer (Izraeli 2012, Kersun 2009). Many physicians believe that feelings of depression and anxiety are normal responses during cancer treatment and therefore may overlook significant impairing symptoms (Kersun 2009).

A study by Shemesh et al. (2005) demonstrated that a lower cut-off score on the Children's Depression Inventory (CDI) of 11 and above, instead of 13 to 15, the cut-off score used in the general population, correctly identified 80% of children with depression out of 125 medically ill children, with a specificity of 70%. The CDI has been evaluated in medically ill children and found to be diagnostically accurate in several settings including childhood cancer (Kersun 2009), but Shemesh's study suggests clinicians should have a low threshold for diagnosing and treating depression in young cancer patients.

No large randomized controlled studies have been conducted in children with cancer and depression using selective serotonin reuptake inhibitors (SSRIs), the current antidepressant treatment of choice in children and adolescents. In the US, only fluoxetine, sertraline and escitalopram have pediatric Food and Drug Administration (FDA) indications (FDA resources page 2013). Investigators have found that antidepressant medications and psychological therapies play an important role in the treatment of anxiety and depression in the childhood cancer population (Pao 2006, Kurtz 2010). Researchers at Children's Medical Center in Dallas noted that the prevalence of antidepressant use in pediatric oncology patients was 10.2% at their institution which was higher than reported rates of depression (4–8%) and antidepressant treatment (1%) in the general population (Portteus 2006). In a small retrospective study at the National Institutes of Health, 7% of children involved in cancer research trials were prescribed antidepressant medications (Pao 2006). Kersun et al. (2007) reported that 50% of pediatric oncologists at Children's Hospital of Philadelphia prescribed SSRIs for their patients. Phipps et al. (2012) followed with a large multi-institutional survey that showed 107 out of 151 oncologists (71%) reported prescribing SSRIs to their pediatric patients. Although there were significant differences between sites (range 38% to 100% ($p < 0.001$)), more than half of the oncologists reported the 2004 black box warning for SSRIs in children and teens did not change their prescribing practices. Most concerning was that fewer than 10% of the oncologists reported specifically assessing for suicidal ideation. This study highlights the need for involvement of a child psychiatrist in the pediatric oncology medical team particularly when prescribing psychotropic medications to youth (Phipps 2012).

Kersun et al. (2009) utilized the Beck Youth Inventory (BYI) for depression and anxiety as well as an oncologist rating form to determine rates of depression and anxiety in children undergoing cancer treatment and to see if their oncologists were able to detect signs and symptoms of depression and anxiety. The data showed that, based on the BYI scales, the frequency of clinically significant depression (4.9%) and anxiety (7.3%) were low and similar to rates seen in the general adolescent population. However, there was a lack of concordance between patient and oncologist reports of distress, with oncologists reporting many more of their patients as having psychological distress than the patient scales measured. Finally, although the oncologists identified distress, they were unable to identify accurately specific symptoms of depression or anxiety (Kersun 2009).

Social Support

In Varni et al. (1996), teens were assessed for perceived social support and self-esteem at the time of their cancer diagnosis and then again nine months later. Greater perceived support

predicted significantly lower psychological distress and higher self-esteem. Classmate support was the most consistent predictor of successful adaptation to cancer. Older age was correlated with increased depressive symptoms. Males had significantly more externalizing behavioral issues than females, and females received greater parental and peer support (Varni 1996, Ruland 2009).

Anxiety

Anxiety is one of the most common symptoms seen during the course of cancer treatment in children, especially anticipatory anxiety. Similar to the classical conditioning that adults develop, children and teens may develop a conditioned response to a painful procedure and then develop anticipatory anxiety, nausea, or pain in response to the smell, room, or even the knowledge that they are going to the doctor's office (Stuber 2012, Kurtz 2010). Anticipatory anxiety can be treated with behavioral interventions, as well as education, because identifying the cause of the anxiety helps some children and teens in managing it. Anxiety that involves physical symptoms such as nausea or vomiting may require pharmacologic interventions, especially when symptoms occur before even coming to the oncology clinic. In mild cases, behavioral techniques such as relaxation, hypnosis, or distraction can help, but in more severe cases, using antiemetics such as ondansetron, corticosteroids, and benzodiazepines can be effective (Tyc 1997, Kurtz 2010). Video games, movies, and computers have also been shown to decrease anticipatory anxiety before procedures and chemotherapy (Stuber 2012, Kurtz 2010).

In pre-school and school age children, separation anxiety is very common but may be exacerbated during medical treatments particularly in children who have never been away from home. They become fearful of new people, have resistance to being separated from their parents, or develop nightmares about being separated from their families. Bringing in objects from home, like a quilt or stuffed animal, to make their room less frightening may help with separation anxiety. Also, having photos of family members can be beneficial for anxious children who cannot see their parents or siblings often. Occasionally children even develop intrusive thoughts about a parent being injured or hurt in some way when they are away, which can be reduced with either cognitive behavioral therapy (CBT) or talk therapy. Distraction to alleviate anxiety is also helpful and easy in this age group (Kurtz 2010).

Delirium

Delirium literature in children is limited but does suggest that, although delirium is less common than in adults, it still requires recognition and treatment. Many symptoms are similar in children and adults, such as impaired consciousness, anxiety, disorientation, hallucinations, and apathy. Sleep wake disturbances, impaired attention, agitation, irritability, affective lability, and fluctuation of symptoms are more common in children, while impaired memory, depressed mood, speech disturbances, delusions, and paranoia are more often seen in adults (Turkel 2006). Diagnosing delirium in children is difficult but the Pediatric Anesthesia Emergence Delirium Scale (PAED) seems to have promise in recent studies. A study of 184 patients in the pediatric intensive care unit (PICU), ages 1–17, monitored over three and a half years, found the tool was successful and had a sensitivity of 91% and specificity of 98% compared to clinical interview (Janssen 2011). A recent study

validated the use of the Pediatric Confusion Assessment Method in the ICU (pCAM-ICU) to diagnosis delirium in pediatric patients who are critically ill (Smith 2011). In addition, other studies have validated the use of the Delirium Rating Scale (DRS) in critically ill pediatric patients who are delirious (Janssen 2011). Symptom-targeted medication interventions have been helpful in managing acute sleep difficulties, extreme irritability, and mood lability. Small doses of atypical antipsychotics during the acute delirium exacerbation are usually sufficient to manage the psychiatric sequelae while the underlying etiology (fever, infection, electrolyte imbalance, etc.) is determined (Turkel 2006). A recent retrospective study on the use of atypical antipsychotics in pediatric delirium (n=110, ages 1–18 years) found that olanzapine, quetiapine and risperidone were tolerated and all reduced symptoms based on the DRS, but efficacy and safety of the antipsychotics were not formally tested (Turkel 2012).

Family Issues

The initial family meeting with the psychosocial team should occur as soon as possible after a diagnosis is reached in order to initiate a trusting doctor-patient-family relationship. Immediately after receiving a life threatening and life altering diagnosis, nearly all caregivers report anxiety, as lives are disrupted, responsibilities and roles of the family members may be altered in order for the family to continue to meet basic needs of all members, and highly technical medical information has to be understood. The pediatric psycho-oncologist is equipped to help facilitate these adjustments across the family and for the patient in a developmentally appropriate manner (Wiener 2012). The child with cancer may become the center of the family, which may be an unfamiliar role, and can influence the rest of the family members dramatically (Alderfer 2009). Competent psychosocial care encourages development of effective coping strategies, integration back to school as quickly as is feasible, and provides support to the family for maximal functioning of all the members and as a group (Wiener 2012).

Family Functioning and Stress

Parents and siblings of pediatric cancer patients provide a central role of support during and after the period of active treatment. Parental psychological distress can affect the well-being of both the child with cancer and the siblings. Parents have to witness the suffering of their child, contend with the threat to their life, and deal with the challenges of day-to-day life as well (Rosenberg 2013). Few studies have been completed among parents of children with cancer and how the parent's distress affected the children. Rosenberg et al. (2013) sampled 86 parents of children with cancer and found that more than half of the parents reported high levels of psychological distress and approximately 1 in 7 experienced severe psychological distress as rated by the Kessler-6 Psychological Distress Scale. Parents of children with progressive cancer were 4 times more likely to develop severe psychological distress than parents of well children and 2 times more likely of developing severe psychological distress than adults with cancer. Parents with a history of mental illness or psychological distress were also more likely to report psychological symptoms in their children (Rosenberg 2013). Others have described a relationship between child emotional distress and parent distress, although no causality has been proven (Robinson 2009, Rosenberg 2013).

A consistent finding is that if family functioning is preserved in cohesive, expressive families, they tend to be better able to support their children and can access increased social support from others in times of acute stress. Mothers, in particular, as well as peers in adolescence, play a significant role in providing emotional and social support throughout a child's development in both healthy and sick children (Abrams 2007). Families who demonstrate positive modeling for adaptive coping despite stress can reduce symptomatic behaviors in children with illnesses. Parents with poor social support are more likely to experience more distress and be less able to manage their child's illness. A study completed in the United Arab Emirates by Eapen et al. (2008) showed that parental hope ($p=0.001$) and communication for sharing emotions ($p=0.005$) were the most important factors that contributed to better coping in children with leukemia. Poor social support for the parents has been shown to be predictive of posttraumatic stress disorder in the parents, whereas increased social support may be protective against stress-related problems (Kurtz 2010). In another study, over half of the 129 mothers and 40% of the 72 fathers of 138 newly diagnosed pediatric oncology patients met Diagnostic and Statistical Manual: Fourth Edition (DSM-IV) criteria for acute stress disorder (Patino-Fernandez 2008). In a Swedish study, at one week post diagnosis, 33% of parents reported symptoms consistent with acute stress disorder, decreasing to 28% at two months post diagnosis, and 22% at four months (Poder 2008). Family factors, such as poor cohesiveness as a family unit or having difficulty expressing feelings and emotions, may predict posttraumatic stress reactions in adolescent survivors of cancer as well (Poder 2008). There are occasions when the pediatric psycho-oncologist identifies that a parent must receive treatment for their anxiety or depression in order to help their child.

Sibling Issues

Siblings need to be considered during the course of treatment of a child with cancer (Robinson 2007). Siblings often feel as though their needs are less important than those of their sick brother or sister, but they experience the same emotions in reaction to the diagnosis of cancer (shock, helplessness, sadness) plus jealousy because they do not have all of the doctors and staff worrying about their needs. Wiener and Pao (2012) note that the healthy sibling may feel isolated if parents spend a lot of time in the hospital, or the sibling has to spend time with friends or extended family throughout treatment. Disruptions in the sibling's normal life and routines can lead to problems in school, behavior issues, anger, or withdrawal. Hospital programs that include siblings in their programs and those that have specific programs for siblings are increasingly being developed. SuperSibs!, a national organization, provides support for those children who have brothers and sisters with cancer and enables them to deal with the changes that occur in their own lives during their siblings' cancer treatment (Wiener 2012). Although it is beneficial to work with the whole family, it is not always feasible because not every family member can attend all of the appointments. The pediatric psycho-oncologist may focus on the parent to help the affected sibling or on the member of the family who is having difficulty.

Survivorship Issues

As the treatment of childhood cancer has improved, there has been increasing interest and research in the survivorship population and greater recognition of long-term issues that survivors are now facing. Some of the sequelae of childhood cancer are secondary malignancies (due to radiation and chemotherapy), neurocognitive effects, infertility, and psychological late effects, such as post-traumatic stress disorder (PTSD), increased risk of suicidal ideation, anxiety about recurrence, depression, and somatization (Kurtz 2010). Two thirds of childhood cancer survivors have at least one of the “late effects” and one fourth of the complications will be severe or life threatening. Predictors of late effects include age at diagnosis and treatment and the type of treatment received.

The Childhood Cancer Survivors Study (CSSS) is a longitudinal cohort study that tracks the health status of survivors of childhood cancer diagnosed between 1970 and 1986 across the United States and Canada. This study, funded by the National Cancer Institute (NCI), has greatly aided in understanding the long-term survival issues following childhood cancer (Zeltzer 2009). Pediatric psycho-oncologists and other mental health providers play important roles in evaluating and treating psychosocial issues, cognitive, and psychiatric needs in the survivor population. The CSSS looked at 20,276 patients and 3500 siblings and found significant psychosocial problems in this population. Survivors tended to have higher levels of emotional distress, depression, somatization, engage in risky health related behaviors like smoking and drinking, especially those with lower socioeconomic status, when compared to their siblings (Zeltzer 2009). Hudson et al. (2009) found moderate to severe impairment existed with significantly higher levels of cancer-related anxiety in patients with Hodgkin disease, sarcomas, and bone tumors in particular. Brain tumor survivors showed increased distress and depression when compared to their siblings. Survivors of leukemia, lymphoma, neuroblastoma, and bone tumors were also found to have increased depression, somatization, and distress when compared to their siblings (Weiner 2003). Some adolescents described being emotionally exhausted and having significant uncertainty about being able to relax and enjoy life after completing treatment. They also felt as though other people did not understand that the cancer experience continued even though treatment was completed (Wakefield 2010).

Radiation and Chemotherapy Effects

Irradiation is a treatment associated with significant psychological distress. Solid tumor survivors who received radiation reported more distress and fatigue according to the CSSS. CNS irradiation is linked to impairment in physical health when compared to non-CNS irradiated survivors (Zeltzer 2009). Impairment includes poor general health, poor physical functioning, increased functional impairment, and activity limitations. Chemotherapy, especially alkylating agents and anthracyclines, are associated with an increase in physical impairment and anxiety (Zeltzer 2009). Overall, most childhood cancer survivors are relatively healthy, physically and emotionally, but there are subsets of patients who have significant difficulties. Based on CSSS data, survivors are 80% more likely than their siblings to report impairment in their mental health quality of life and five times more likely to report functional impairment (Hudson 2009).

Neurocognitive Effects

Significant neurocognitive concerns are seen in up to 40% of childhood cancer survivors in one or more domains (processing speed, attention, memory) (Zeltzer 2009). Impairment in any of these domains can impede the ability to learn new information and maintain previously learned information and can lead to declines in global intellect. This is similar to what is seen in adult survivors, but in children this results in poor academic and vocational success, low self-esteem, and behavioral/emotional disorders (Zeltzer 2009). Attention problems are significant and very common following both chemotherapy and radiation, especially intracranial radiation. One study compared 2989 survivors and 649 siblings aged 12–17 years old. They found that survivors were more likely to demonstrate attention difficulties by parent report (RR 1.4; 95% CI, 1.1 to 1.9). They had elevated rates of attention problems compared to siblings in leukemia survivors (RR1.5, 95% CI 1.2 to 2.0) and CNS tumors (RR 1.8; 95% CI 1.2 to 2.5), particularly in patients who received CNS radiation or CNS radiation combined with intrathecal methotrexate (Zeltzer 2009). Ris et al. (2008) found that CNS survivors are at significant risk of developing adverse neurological conditions such as significantly lower intelligence quotients, fewer adaptive behaviors, and poor achievement scores. CNS cancer survival is associated with lower educational outcomes and decreased incidence of employment (Kazak 2010).

Protective Factors in Survivors

Returning to school early during treatment and at the completion of treatment has been shown to be protective for children. Children and adolescents are self-conscious about their physical changes and frequent absences from school and fear being ridiculed by their peers; however, explaining their illness and treatments to their class has generally been well-received, making the transition back to school smoother. Having open communication with the school and teachers throughout the treatment process makes reintegration easier when treatment is completed (Rivero-Vergne 2011). Returning to school also provides a sense of “normalcy” for children, which can help them adapt following the completion of their cancer treatment. In one study, more than half of the 51 survivors described their return to school experiences as “good” (Wakefield 2009).

Survivorship in Adolescents and Young Adults

Adolescents and young adults (AYA), a subgroup of patients that is beginning to be more closely studied, have shown considerable difficulties post-treatment. The CSSS shows that only 35% of survivors recognize that they could have serious health problems and more than 50% do not receive cancer-related follow up care (Zeltzer 2009). AYAs engage in riskier health behaviors and are less likely to utilize health care than other age groups. As noted before, cancer-related disruptions in autonomy, relationship development, and cognitive maturation may cause increased psychological distress in adulthood. Late effects increase in adolescence and young adulthood. Survivors diagnosed in adolescence had more total PTSD symptoms than those diagnosed at school age. They also had lower health related quality of life (HRQOL) and lower health perceptions and cognitive competence than those diagnosed earlier (Kazak 2010). Kazak et al. (2010) also determined that those patients with the most

intense treatments had more anxiety and avoidance and less overall health competence, worse health perceptions and cognitive competence than those with less intense treatment.

Fertility

Another important area of study is infertility in pediatric cancer survivors. In the past 10 years, interrupted child-bearing has been a source of long-term distress for survivors who were treated before starting or even thinking about having a family. Distress over infertility can affect overall mood and cause symptoms of PTSD years after cancer treatment in young adults (Schover 2009). The exact risk of sterility or infertility from chemotherapy or radiation is unknown and not well studied in the pediatric population. Although it is assumed that everyone who is treated with chemotherapy becomes infertile, that is not always the case. In 2008, the American Academy of Pediatrics developed guidelines suggesting that information about fertility preservation should be provided to children and adolescents and referrals should be made to specialists when appropriate (Knapp 2011). Zebrack et al. (2004) found that 59% of 32 young adolescent cancer survivors reported being unsure about their fertility status and had trouble remembering if their oncologist had discussed these issues. Oosterhuis et al. (2008) surveyed 37 pediatric cancer survivors over age 14 years and 97 parents and found that both patients and their parents were concerned about fertility while undergoing treatment. It is clear that information about fertility preservation is not as readily available or easy to understand as patients and parents would like. More educational materials and decision aids should be made available to patients and their families before treatment begins. Schover (2009) recommends that both the patient and the parent should be presented with information regarding infertility and fertility preservation together to prevent any confusion.

Ethical Concerns

In general, it is accepted that parents are the legal decision makers for children and adolescents with cancer until age 18. Most health care providers advocate that adolescents should be provided all pertinent information about their treatment and diagnosis and be part of the decision making process, while the final decision is left to the parents or legal guardians. Parents may misjudge their child's ability to understand and process information, which can prevent them from enrolling or including their child in research studies when the adolescent would be willing to participate. Parents may refuse to participate because of distrust of the studies and doctors, not understanding the risks and/or benefits, having a high level of anxiety, or inconvenience to the family (Knapp 2011). Ethical concerns may arise when parents and adolescents are in conflict regarding treatment decisions.

Adolescent Decision Making

There is conflicting evidence as to whether adolescents have the capacity to make health-related decisions (Halpern-Felsher 2009). There are no standard definitions of 'children', 'minors', 'adolescents', and 'young adults'. The National Cancer Institute (NCI) defines children as ages 0–14 and adolescents as 15–19; whereas the World Health Organization (WHO) defines adolescents as ages 10–19. The Center for Disease Control and Prevention (CDC) defines adolescents as 12–19 years old (Quinn 2011). The term AYA has recently

been used to describe patients who are 15–39 years of age. This has implications for cancer registries and data collection for national studies. In the United States, minors are generally considered to be anyone under the age of 18 years when a person can vote or serve in the military; however recent studies and certainly health care providers' experiences have demonstrated that many adolescents have the ability and desire to participate in their own medical decisions. Some studies of adolescent brain development suggest that judgment and responsibility do not develop fully until even the mid-20's, implying that younger adolescents maybe less competent decision makers (Quinn 2011, Giedd 2008).

A small qualitative study by Palmer et al. (2007) showed six oncology patients ranging from 14–21 years old all wished to participate in their healthcare decisions and did not feel included in the process. They also felt as though they did not receive adequate information about their treatment or side effects. Bates et al. (2009) studied 25 cancer patients and survivors ages 8–17 via an online focus group and found the majority wanted to have information on their disease and survival rates. Results were varied on whether the adolescents wanted their parents involved in making decisions (Bates 2009). It is common for adolescent patients to want to be informed regardless if they are the primary decision maker or not. As such, many hospitals and pediatric oncology practices have started to utilize parental consent and adolescent assent in their decision making regarding their treatments (Quinn 2011).

End of Life and Advanced Care Planning

Despite many medical advances in pediatric cancer care, cancer remains the leading cause of death in teenagers. Many oncology services utilize mental health providers, such as the pediatric psycho-oncologist, to help the child and family with challenges faced at the end of life (Kurtz 2010). Advanced care planning (ACP) helps parents make informed decisions, alleviates distress, avoids decisional regret, and helps the patient maintain dignity and respect (Wiener 2012). ACP is an important discussion to have with the patient and family early on in the diagnosis and treatment to pave the way for more difficult discussions later and so that if the patient is no longer able to participate in decision making, the family is knowledgeable about their wishes. Frequently, parents do not know what their children would have wanted (Walter 2013). Conversations about dying and end of life care are known to be difficult for the oncologist, the patient, and the family and are often avoided because they are too scary or depressing. Evidence supports having open conversations about end of life care early on in the process of cancer treatment making it easier and less frightening to have subsequent conversations later on when the adolescent's medical status changes (Walter 2013). Parents may feel resentful and fearful when conversations about death are avoided and for AYA a sense of isolation and fear, as well as anxiety, can develop (Wiener 2012).

Wiener et al. (2008) published a study evaluating Five Wishes®, an adult advance care document that has been successful in facilitating AYA end of life conversations. Five Wishes® includes the topics of comfort, future planning, spirituality, how to choose a power of attorney and discusses specific life support decisions. Using study feedback where adolescents clearly identified that when contemplating the end of life, they are concerned

about their lack of achievements and whether they will be remembered, an AYA specific advance care planning guide was developed with the final document being titled Voicing My Choices™ (Wiener 2012).

Lyon et al. (2013) further demonstrated that adolescents who received information regarding end of life choices, including the Lyon Family-Centered ACP Survey, the Respecting Choices interview, and Five Wishes®, were better informed than those who just received basic information. They were more likely to let their families decide what was best and more likely to agree on limiting treatment. By utilizing these ACP documents and by having frank conversations about end of life decisions with AYA, families are provided with input and opinions of the patient, so that they know what their loved ones wanted. Having specific documents as noted above can help adolescents communicate how to say goodbye (Walter 2013). It is also a way to address any misconceptions and/or unrealistic expectations before major medical events occur (Wiener 2012).

Conclusions

The field of pediatric psycho-oncology has expanded in the last 20 years (Patenaude 2010) and has contributed greatly to understanding the dynamics of child and family coping, communication around medical care, neurocognitive late effects, survivorship, psychiatric management, palliative and end of life decisions, and how to improve quality of life and psychosocial adjustment specifically for those diagnosed with childhood cancers.

This review highlights how the pediatric psycho-oncologist can aide both a child diagnosed with cancer and the family in handling the psychosocial and psychiatric issues that arise during treatment and beyond. Overall, children with cancer are resilient, but they face many challenges related to their illness including having treatment related effects for the rest of their lives, the potential of long term side effects and, for some, making end of life decisions. It is important to learn and to utilize developmental guidelines to understand the best way to talk to and to help a child through their illness and treatment which adds layers of complexity and differs from how adult psycho-oncologists and oncologists work with their patients.

Research about the long term side effects and neurocognitive changes associated with chemotherapy and intracranial irradiation has helped guide remediation and treatments during the survivorship phase. This research has also helped oncologists develop new protocols to modify chemotherapy and radiation regimens given to children to try minimize some of the late cognitive effects that affect overall quality of life. Recent research is focused on the AYA age group and understanding the impact of late effects into adulthood. As survival from pediatric cancer is projected to improve, continued research in the field of pediatric psycho-oncology is important as mental health clinicians, such as child psychiatrists and pediatric psychologists, play an important role in providing assessment, support, and treatment for children and adolescents diagnosed with childhood cancer.

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