Psychosocial Support of the Pediatric Cancer Patient: Lessons Learned Over the Past 50 Years

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Advances in pediatric cancer treatment over the past 50 years have dramatically improved survival rates. Once considered almost uniformly fatal, pediatric cancer's overall survival rates now approach 85%. Formerly, little psychosocial support existed for the child with cancer other than that provided by nurses and family. The prospect for long-term survival was so remote that plans for the future (eg, school, social relationships, late effects of treatment, and emotional adjustment) were abandoned. As the survival rate for children with cancer improved, so did the need for and quality of psychosocial care, largely because of hope for a cure. Today children with cancer benefit from comprehensive behavioral pediatric psychosocial support programs in psychiatry, psychology, neuropsychology, child life, education (school), creative arts, chaplaincy, social work, and career and vocational counseling. Pediatric psycho-oncology research has provided insights into clinical care and the psychosocial adaptation of children and families to cancer treatment and survivorship.

Introduction

Fifty years ago, the overall 5-year survival rate of children diagnosed with cancer was estimated to be between 10% and 20% [1]. Achieving remission was rare, and was usually followed by recurrence and death. With such a dismal outcome, psychosocial support issues were much different than today. A child diagnosed with leukemia today has about a 90% chance of long-term survival (> 5 years), and the overall cure rate for children and adolescents with cancer in the United States is now approximately 85% [2]. Central nervous system (CNS) prophylaxis and multidrug regimens are largely responsible for this success. Delayed intensification of chemotherapy and the use of maintenance intrathecal methotrexate have contributed to the dramatic improvement in survival rate [3].

As cure rates began to improve, Jan van Eys emerged as one of the earliest and most eloquent researchers to understand the concept of the fully cured child with cancer. He conceptualized cancer as another normal childhood illness—a major stumbling block, but one that could become just a chapter in a child's life [4]. Moreover, a truly cured child would be similar to same-aged peers in development, maturation, achievement, and personal outlook for the future. As van Eys observed, a truly cured child is one who has achieved biological, psychological, and psychosocial success over their disease.

Psychosocial support of children with cancer and their families has been integrated into pediatric care with increasing sophistication and specialization during the past five decades. Pediatric behavioral health care teams work with children and their families to promote a positive psychosocial adjustment during the difficult and challenging time from diagnosis, through cancer treatment, and into survivorship. Today's oncology behavioral pediatrics teams work alongside medical staff and may include the disciplines of psychiatry, psychology, neuropsychology, child life, education (school), creative arts, chaplaincy, social work, and career and vocational counseling. Psychological studies have shaped our understanding of the family's psychosocial adaptation to cancer management and interventions to facilitate the best possible health-related quality of life. Finally, community-based organizations have garnered significant public awareness of cancer and promoted both private and public fund-raising to aid patient programs and research.

Challenges for Children With Cancer and Their Families

Children, teens, and young adults undergoing cancer treatment face multiple challenges. The physical challenges of cancer and treatment are well known. Pediatric patients must learn to cope with these and with changes in daily routines. Socially, time spent with usual activities and friends must now compete with clinic visits, hospitalizations, and periods of recovery. Most types of cancer treatment require children to miss community school for extended periods (6 months to 3 years) in order to manage frequent medical appointments and cycles of immunosuppression that accompany chemotherapy. Absenteeism can interfere with academic development and decrease usual opportunities for socialization with same-age peers. When children are hospitalized, separation from siblings and other family members can be difficult. Concerns about body image are common in children with alopecia and changes in physical appearance. Significant changes in well-being and daily routines may underlie a sense of loss of control for children and teens, which can adversely affect psychological adjustment.

The diagnosis and treatment of childhood cancer naturally constitute stressful experiences for parents [5,6]. Perhaps the greatest stress is cancer's inherent threat to life. Although today's survival rates are encouraging, they are not guaranteed, and parents uniformly express an awareness of the seriousness of childhood cancer and concerns regarding the child's prognosis. The many logistical, family, and financial issues associated with care can also be of concern for parents and caregivers, who must organize the family's resources and daily activities to accommodate frequent clinic visits, hospitalizations, and recovery periods for the child undergoing treatment [7,8•]. Other stresses typically include the need to assimilate new medical information quickly so that treatment decisions can be made, learning new treatment routines, and helping their children cope with distressing procedures. Although parents posses considerable emotional resilience, some are at risk for developing anxiety and depression, especially during the months following diagnosis [9•]. Importantly, parental emotional well-being is closely associated with the child's adjustment to treatment [8•]. These medical and social considerations form the environmental context in which behavioral pediatrics health care teams conceptualize individual and family psychological adjustment. The numerous challenges involved in pediatric cancer care provide multiple opportunities for intervention to facilitate a positive psychosocial adjustment.

Behavioral Pediatrics Disciplines: Roles, Contributions, and History

Modern psychosocial support teams, whether named "behavioral pediatrics" or "behavioral medicine," are multidisciplinary groups of professionals who facilitate positive adjustment and coping of patients and their families in the pediatric cancer setting. Copeland and Askins [10] describe in detail interdisciplinary behavioral medicine programs.

Psychiatry, psychology, and neuropsychology

The discipline of pediatric psycho-oncology began approximately three decades ago [11••]. Psychiatry, psychology, and neuropsychology (reviewed in subsequent sections) not only contribute specialized clinical interventions to aid children and their families, but also help define important areas of psychosocial and developmental focus through carefully designed empirical studies. Psychiatrists and psychologists provide individual and family psychotherapy to help patients cope with the emotional effects of cancer and the rigors of treatment. Psychologists can perform standardized assessment of neurocognitive and psychological functioning. Psychiatrists routinely evaluate the potential benefits of pharmacological intervention to assist the patient in managing clinical depression, anxiety, sleep disturbances, and changes in appetite. Both may assist pediatric patients with preexisting psychiatric diagnoses or conditions that may become exaggerated with the new cancer diagnosis and complicate medical treatment.

Child life

Although child life specialists were sometimes referred to as "play ladies" in the past, their role today is much more involved and integral to pediatric care. As early as the 1920s, health care providers began to appreciate the need for and unique role of these specialists in improving the experiences of hospitalized infants, children, and adolescents. Children who engage in "medical play" and are given the opportunity to exert some control in their medical environment experience decreased fear and anxiety. Confident children are more active participants in their treatment and require less anesthesia, pain medication, and sedation. In the past, families, especially siblings, were not always welcome visitors to the hospital ward. Hospitals were not physically oriented to young patients and many medical staff preferred to deal with only the children, whom they regarded as small adults, and not with the family. Child life specialists recognized the importance of maintaining family ties for the hospitalized patient and paved the way for family-centered care.

In the 1970s and 1980s, child life as a discipline established professional certification and grew in scope and sophistication. Child life specialists now play a vital role in emotional preparation for and support during medical tests and surgeries, using medical play and procedural education with special dolls and medical equipment. Their activities promote normal growth and development in a novel situation. They also provide support to the patient's siblings and parents. And, if the outcome is not good, they often provide bereavement support.

Education (school)

Developing psychoeducational programs that enhance cognitive functioning and promote academic development for children with cancer is essential to ensuring positive psychosocial outcomes. Comprehensive hospital school programs employ teachers, counselor-liaisons or school-reentry specialists, and directors. In addition to providing instruction in the core curriculum, programs may offer educational enrichment such as music, art, and physical education. Hospitals can choose to collaborate with local school districts or establish private schools within the hospital. Although necessary absenteeism from community school threatens to interrupt academic development, well-organized homebound and hospital school programs can help ensure that children remain on track academically, thereby contributing to positive social transitions and success into survivorship.

Creative arts

Artistic expression, long recognized as aiding the healing process, became a distinct profession in the 1940s. Children's artistic expression reflects their emotional state as well as their developmental, emotional, and cognitive growth. Art therapy is used as an adjunct to traditional psychotherapy in psychiatric settings, but is also used in medical settings for children with chronic illnesses such as cancer. Art therapists use the creative process to help children identify issues of concern and increase insight to facilitate positive coping. Likewise, music therapy provides an avenue of psychosocial support for pediatric oncology patients [12]. Music has been recognized for its soothing and healing influence for decades, even centuries. Music therapy was recognized as a professional entity in the 1940s, and formal music therapy associations were formed in the 1990s. The art therapy and music therapy professions offer professional credentialing based on education and experience. Creative writing and journaling provide yet another outlet for emotional expression that can be powerful and validating for children with cancer.

Chaplaincy

Fifty years ago, the role of chaplaincy in pediatric oncology was primarily in counseling grieving family members or providing spiritual support for terminal patients. Chaplains usually were not hospital based, but were clergy from the patient's own faith community who visited to provide support on an individual basis. Now, with greater likelihood of survival, the chaplain's role has evolved to providing spiritual support for patients and family during a period when their faith may be tested. As many as 82% of Americans believe that prayer has healing powers [13]. Moreover, spirituality research has demonstrated better outcomes in several diseases and injuries, including immune functioning [13,14]. Many medical schools now teach the basics of spiritual faith and its relationship with medicine [15]. For children, spiritual development follows Piagetian cognitive development from simple beliefs that a superior being will protect them, to a more complex level of abstract concepts [13], emphasizing the importance of developmentally appropriate support.

Social work

Social work programs in hospitals started in the early 1900s. From their inception, social work departments have taken a multidisciplinary team approach to patient care, working closely with physicians and nurses. Their mission has always been to help make life more comfortable and manageable for patients and their families. Social workers assess psychosocial adjustment to cancer treatment and provide constructive interventions to help patients and families cope well and maximize health. In addition, social workers conduct research, facilitate support groups, and connect families with resources.

Career and vocational counseling

Vocational services in the hospital and clinic setting are gaining more attention with the new focus on adolescent and young adult development and pediatric cancer survivorship. These programs offer counseling to those who are interested in entering college, technical school, and/or the work force. The process of career counseling involves assessing the individual's interests, work values, personality, and aptitudes, and using the information to develop a meaningful career path. Services offered by vocational counseling programs include assistance with SAT preparation, college applications, grants and scholarships, job placement, and cognitive remediation. In addition, efforts are made to help college students maintain enrollment and scholarship opportunities when they are newly diagnosed with cancer.

Psychological and Neuropsychological Research in Pediatric Oncology

The field of pediatric psycho-oncology has emerged in the last 30 years, and follows a scientist-practitioner model of providing clinical care, psychological assessment, and research to advance knowledge surrounding the psychosocial adaptation of children and families to cancer treatment and survivorship. Patenaude and Kupst [11••] provide an excellent review of the field of psycho-oncology, emphasizing the reciprocal relationship between the presence of behavioral health care experts on pediatric cancer services and the enhanced awareness of the emotional-behavioral challenges faced by children with cancer. In the 1960s, studies focused on bereavement; in the 1970s and 1980s, researchers expanded into the areas of helping children with distress related to medical procedures, the psychosocial impact of cancer treatment on the entire family, and the impact of CNS treatment on children's neurocognitive functioning. During the 1990s, studies elucidated how modifications to prior clinical trials involving CNS treatment served to improve quality of life for childhood cancer survivors. In addition, the issue of consent and assent in clinical trials gained more importance. Studies of the current decade have examined cognitive-behavioral and psychopharmacological interventions with greater depth and sophistication, introduced the importance of quality of life during survivorship, and seen the emergence of behavioral e-health technologies. The next decade holds promise for studies that will explore the contribution of individual genetic variation to cognitive and behavioral outcomes for pediatric cancer survivors.

Social and behavioral studies

Coping and adjustment of children and families

One of the first and most enduring areas of pediatric psycho-oncology research has been how to help children cope with procedure-related distress for invasive medical procedures. Predicated on the assertion that inadequate information about the hospital setting is a major cause of psychological distress during pediatric hospitalization and medical procedures, research regarding children and procedural distress first emerged in the late 1970s and early 1980s [16,17,18••]. This topic continues to be significant because of the importance of minimizing pain, anxiety, and trauma for children undergoing treatment for chronic illnesses. In a seminal study, Katz et al. [18••] demonstrated that younger children with cancer exhibit consistently higher levels of distress than older children and display a greater variety of anxious responses over a longer time span, necessitating clinical intervention to reduce the procedure-related distress. Traditionally, three categories of intervention have been studied: providing information (to enhance predictability and correct misconceptions), altering the environment (eg, by using distraction), and offering coping skills training.

Recently, memory-based intervention approaches have received attention [19,20]. Chen et al. [19] found that children's recall of procedures such as lumbar punctures, both with and without midazolam, is very accurate for event details and emotional response. However, when children are highly distressed, they remember the events with greater negativity, which in turn predicts higher distress during subsequent lumbar punctures. Thus, the authors postulate that interventions aimed at improving understanding and accurate memory of procedures will contribute to reductions in distress [20]. Informational interventions may be combined with more traditional interventions to promote better outcomes. Moreover, Dahlquist and Pendley [21] note the importance of parents' coping and behavior during procedures and their impact on child coping.

In addition to treatment procedures, major stressors for children with cancer include loss of control, the hospital environment, relapses, fear of dying, body image issues, low self-esteem, and issues related to reintegration into real-world situations (eg, school) [22]. These issues may best be addressed with honest and empathic listening, information sharing, and appropriate problem-solving.

When a child is diagnosed with cancer, siblings' lives are significantly impacted. In the 1990s it was theorized that the needs of healthy siblings were often overlooked because the parents had less energy and time to devote to these children [23]. Adjustment difficulties were related to the degree of disruption of family life caused by the illness, the resources available to the family to cope with the effects of cancer treatment, and siblings' perceptions of negative interpersonal effects of the illness on their lives [24••]. As a result of this seminal work, interventions for siblings have received increased attention. According to Barrera et al. [25], siblings who reported more social support also had fewer symptoms of depression and anxiety and fewer behavior problems than those with less support. Expert attention and sibling camps have been endorsed by parents as positive social supports for their children [26].

Cognitive-behavioral therapy interventions have been shown to improve the psychosocial adjustment of parents of children with cancer [27••,28••]. The Problem-Solving Skills Training (PSST) program developed by Sahler et al. [28••] has been established as an effective intervention for enhancing problem-solving skills and decreasing negative affectivity (ie, depression and anxiety) in mothers of children with newly diagnosed cancer. PSST has been shown to be especially beneficial for Spanish-speaking Hispanic mothers [29]. Computer-based technologies increasingly are being used in the delivery of behavioral health care, and recently were incorporated into a study of PSST for mothers of children with newly diagnosed cancer by Askins et al. [30], where findings were favorable and comparable to traditional PSST.

Communication among physicians, pediatric patients, and their caregivers

Remarkable changes in attitude have occurred over the past five decades in communication among physicians, parents, and children about their disease and treatment [11••]. Early studies demonstrated that children were not fooled by the avoidance of discussion of cancer or by false reassurances about their prognoses. Children understood more than was originally thought—they usually knew the seriousness of their condition and its name [11••]. The risk of adults not speaking to children about cancer and its treatment is that children may feel isolated and afraid—intuiting the information, but lacking a way to ask questions or process it emotionally with their caregivers. In addition, without honest reassurance, children may wrongly assume the worst situation, leading to unnecessary worry and anxiety. Therefore, today it is common practice for physicians, nurses, and parents to talk openly with children about cancer diagnoses and treatment. The timing of discussions and amount of detail recommended is tailored to the child's age and developmental level. Family-centered care, a relatively new movement from the 1990s, recognizes that in partnership with health care providers, patients and parents can serve as excellent resources in helping to improve hospital programs, policies, and the quality of pediatric cancer care.

Survivorship

About 80% to 85% of children and adolescents who are diagnosed with cancer now survive their illnesses [2,31]. In the United States, there are approximately 270,000 survivors of pediatric cancer, which includes 1 of every 640 adults between the ages of 20 and 39 years [32]. These survivors are expected to live normal life spans.

Quality of life during survivorship has become an important focus of research. The Childhood Cancer Survivor Study (CCSS) is a multi-institutional collaboration supported by a grant from the National Cancer Institute of the National Institutes of Health. Since 1994, CCSS has successfully established and followed 14,370 5-year survivors of childhood and adolescent cancer diagnosed between 1970 and 1986 and a sample of 3737 sibling controls, collecting detailed information on cancer diagnosis, treatment, health, and quality of life. Results from these data have shown that young adult survivors of childhood leukemia, Hodgkin's disease, and non-Hodgkin's lymphoma had significantly more risk of depression and somatic distress and that intensive chemotherapy added to this risk [33]. In a similar study of long-term survivors of childhood brain cancer, researchers concluded that cancer treatment does not appear to contribute directly to increased psychological distress, but rather distress is associated with diminished social functioning that may be related to cancer type or treatment, and merits supportive interventions that enhance survivors' social and vocational skills [34].

Adolescents and young adults with cancer

Recognizing that the developmental needs of adolescents and young adults (AYA) are unique from those of children and older adults, a growing body of research is defining developmental and psychosocial considerations necessary for providing optimal care to AYA patients. A greater number of AYAs are diagnosed with cancer than children, and the number has increased dramatically in the past 25 years. The AYA group faces different challenges not only for themselves, but also for the medical staff treating them. Adherence to therapy is not as good for this age group as it is for younger children, who are more dependent on their parents for important decision making. In addition, many fewer AYA patients than children are entered into clinical trials [2,35]. Psychosocial research examining the impact of cancer on the AYA group has focused on family, psychological/emotional impact, and social effects [36•]. Some of the special psychosocial challenges faced by AYA cancer survivors are stress, depression, poor outlook on their future, and neurocognitive deficits, including attention deficit hyperactivity disorder. In addition, these cancer survivors encounter more long-term issues including sexual functioning, family planning, limitations in career opportunities, and anxiety over the possibility of a second cancer either because of genetic predisposition or the toxicity of earlier treatments [37].

Palliative and supportive care

Traditionally, palliative care has referred to providing supportive care for children and their families during the time surrounding the end of life, where pain management and comfort are the primary goals. However, because parents have sometimes construed palliative care negatively as an independent process at the end of their children's lives, pediatric palliative care teams have begun to intervene earlier in the cancer treatment trajectory. This initiative has included providing services as an adjunct to phase 1 clinical trials [38]. As recently as 2000, Wolfe et al. [39] reported that children who die of cancer receive aggressive treatment at the end of life and therefore experience substantial suffering in the last month of life. Oftentimes, parents recognize considerably later than the physician that their child has no realistic chance for cure; however, when parent and physician both recognize the prognosis, treatment directed at lessening suffering has been emphasized more strongly, with greater integration of palliative care [40]. Supportive care is a growing discipline that will contribute significantly to the quality of life of children with cancer.

Neuropsychological studies

Survivors of pediatric cancers are at risk for neurocognitive decline and diminished educational and occupational attainment [41•]. As they grow older, they face new psychosocial challenges, possibly in part from these neurocognitive deficits [34]. During the 1980s, as response rates improved, significant neurocognitive sequelae were noted, leading to interest in long-term neurocognitive outcome. In the early stages, neurocognitive studies documented or cataloged the types of deficits and their change over time [42,43]. Today, studies emphasize comparing the neurocognitive superiority of two equally effective therapies.

The types of neurocognitive deficits include IQ, factual knowledge, and verbal and nonverbal abstract thinking [44]. Other areas of deficit include poor performance on tests of attention and memory, visual construction ability, and computational arithmetic skills [45]. Cross-sectional studies have shown progressive neurocognitive declines over time [44], but these declines are probably related more to a failure to learn and acquire new information, rather than a loss of previously acquired knowledge, as in dementia [46]. Young age during treatment has been strongly implicated in poor neurocognitive outcomes, emphasizing the importance of early interventions and maintenance of school progress [44,47,48]. Results of neurocognitive studies have highlighted the need for interventions and prevention strategies [49].

Interventions to improve neurocognitive functioning

Clearly, survivors of cancer that involved the CNS are at risk for neurocognitive sequelae [17,49]. Research is now redirected from simply documenting late effects to developing an effective means to prevent or remediate the impairments. Butler and Copeland [50] pioneered these efforts by developing a cognitive remediation program that has been shown to significantly improve survivors' academic achievement, development of metacognitive learning strategies, and parent reports of enhanced attention functioning [51••]. We are currently conducting a study to examine the potential benefit of intervening with cognitive training during treatment to determine whether the early application of cognitive training may help prevent or attenuate the academic declines observed in children and adolescents undergoing CNS treatment. Psychopharmacological interventions also hold promise for improving attention and cognitive functioning [52].

Community Involvement

The community supports the needs of individuals with cancer in a variety of innovative ways. The Candlelighters Childhood Cancer Foundation National Office was founded in 1970 by concerned parents of children with cancer; their membership today has grown to more than 100,000. Their mission is to provide information and awareness for children and adolescents with cancer and their families, to advocate for their needs, and to support research so every child survives and leads a long and healthy life. They also serve as a clearinghouse for information about childhood cancer including clinical trials, cancer education, patient and family support groups, travel assistance, cancer awareness, and much more. Numerous other organizations exist whose mission is to aid in the fight against cancer, such as the Lance Armstrong Foundation and the CureSearch National Childhood Foundation. These organizations not only provide essential support for pediatric cancer treatment and research, but also empower the community to join the fight against cancer.

Conclusions

Progress in pediatric cancer treatment has been extraordinary in the past five decades. On the horizon are genetics studies that will help us better understand individual differences in medical and neurocognitive response to cancer treatment, and ultimately allow the tailoring of treatment and interventions to specific individuals. The psychosocial support of pediatric cancer patients and their families is an essential component of pediatric oncology care because of the numerous challenges associated with cancer diagnosis, treatment, and survivorship. Pediatric behavioral health care teams provide specialized support to pediatric patients and their families as they meet the challenges of cancer treatment. The field of pediatric psycho-oncology has contributed important scientific theory and research that has guided our understanding of the dynamics of child and family coping, communication surrounding medical care and clinical trials, survivorship, palliative/supportive care, and interventions to improve quality of life and psychosocial adjustment.

One of the most important lessons learned is the value of open and honest communication with children regarding their illness. Another important lesson is that adolescents and young adults with cancer have developmental and psychosocial needs that are distinct from children or older adults and thus merit special consideration. We have also learned the importance of caring for the entire family. Neuropsychological studies have been key in defining neurotoxicities associated with CNS treatment and targets for cognitive remediation. As a result of the neurocognitive research findings, medical treatments have been modified when possible to minimize cognitive late effects. The current high level of community involvement promotes cancer awareness, advocacy, and research. Specialized, integrated psychosocial support contributes significantly to the positive experience of children and their families during cancer treatment and into survivorship.

Disclosures

No potential conflicts of interest relevant to this article were reported.

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have been highlighted as:

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