

Psychosocial Issues in Pediatric Oncology

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ABSTRACT

Psychosocial oncology, a relatively new discipline, is a multidisciplinary application of the behavioral and social sciences, and pediatric psychosocial oncology is an emerging subspecialty within the domain of psychosocial oncology. This review presents a brief overview of some of the major clinical issues surrounding pediatric psychosocial oncology.

INTRODUCTION

The impact of pediatric oncology is psychosocially and physically profound.¹ Children have problems coping with the stresses of treatment, surgery, chemotherapy, and radiation.² Parents and siblings also have needs. This article addresses the specific issues of pediatric oncology and palliative care in terms of their immense psychosocial impact on the patient and caregivers.

PSYCHOSOCIAL FUNCTION

Children with cancer have multiple psychosocial issues and require a unique approach to conceptualize and operationalize the issues they confront.²⁻⁶ Psychosocial effects can manifest as increased levels of depression, anxiety, and concerns about mortality.^{2,4,6-8} Delineating psychosocial functioning into domains is useful to help patients and families conceptualize and operationally define the psychosocial impact of cancer. Patients can often learn to

prioritize the need for psychosocial and behavioral interventions, thereby directing the focus of this aspect of their treatment. For simplicity's sake, this discussion is limited to the physical, emotional, cognitive, and familial domains. These domains are not discrete but overlap. One analogy that helps patients understand the concept of domains is the image of the Olympic icon. Each domain is represented by an overlapping circle. Within each domain are several subsets of psychosocial impact. Such subsets can involve the severity and etiology of the disease, the level of psychosocial distress, or the existential meaning of the disease and treatment to the patient and the family.

For a pediatric patient, the overlapping spheres are necessarily condensed within the context of developmental growth. Within the overlapping context of the developmental stage, each individual sphere will have its own significance. The impact of the cancer experience on psychosocial functioning can be conceptualized by the size of the circle and the amount of overlap on the neighboring circle(s) (Figure).

When using the concept of domains with patients, practitioners should be flexible enough to add, emphasize, or delete domains as the clinical situation requires. For example, for a pediatric oncology patient who does not completely understand the physiologic reality of the disease and treatment, the social context of friends, home, and school may be central.

Generally, the primary concern is the physical domain because of the extent the disease determines the patient's level of functioning. For instance, a childhood hematological disorder has a much different physical impact than an osteosarcoma requiring amputation. Each disease carries its own meaning, fears, and treatment sequelae that patients interpret according to their developmental level. Children so affected also face developmental and educational issues.⁹

A child's cognitive development determines the extent to which the young person can process the diagnosis. Toddlers and preschoolers will understand that they are ill, perhaps having felt bad from a cold or earache at some point. However, they may be unable to understand that the tumor or treatment is making them feel bad. They most certainly will not understand

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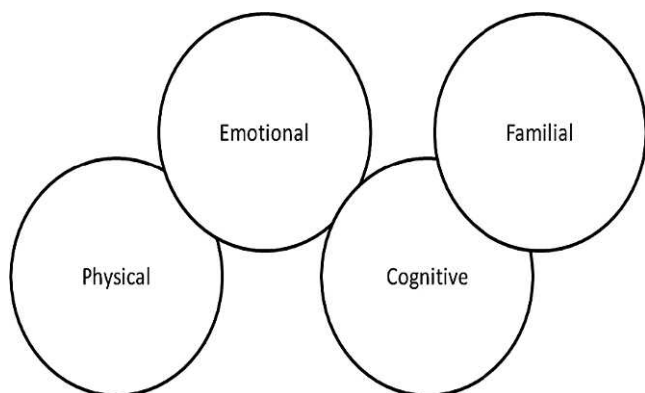


Figure. Representation of some of the many domains that may impact psychosocial functioning in pediatric oncology.

the reasons for the multiple needle sticks and procedures causing them pain. An older child in grade school will have a concrete understanding that he or she is sick and needs medicine or treatment, and a patient in high school will be able to find information—reliable and otherwise—about the disease and treatment from a myriad of websites and to ask the healthcare team appropriate questions. Despite their developmental level, high schoolers still may not be able to fully grasp the meaning and impact of their diagnosis. They may also have difficulty accepting disfiguring or debilitating treatments because they place great importance on their social domains.

Additionally, children have different coping strategies at different developmental stages.¹⁰ Parents and families also have difficulties coping when children are diagnosed with cancer, often demonstrating increased anxiety and decreased coping skills. Not surprisingly, parents of children who relapse show higher levels of distress than parents of children who remain cancer free after treatment.¹¹ In a Swedish study, a notable percentage of parents of children who relapsed had symptoms similar to those of posttraumatic stress disorder.¹² The need to assist parents as they deal with the diagnosis and treatment of their children is well known, and some successful programs are available.¹³

As a group, parents of children with cancer are relatively resilient.¹⁴ Generally, families alter their roles, responsibilities, and family functions to accommodate the child with cancer.¹⁵ Such changes can put a significant stress on the family, however, and coping with the stress is often most difficult for the child's mother.¹⁶ Comprehensive assessment and treatment of familial psychosocial issues is key because a parent's depression is the most significant factor associated with impairment in family functioning.⁹

Siblings also have a unique set of needs. In a multinational study of families with a child diagnosed with cancer,¹⁰ children reported more impairment in family functioning than parents, but the difference was not significant.

Quality of life has become an important endpoint measure when dealing with childhood cancer.^{7,11} However, standardized measures and endpoints in this regard are lacking.^{17,18} The most critical clinical point is that quality of life is what the child says it is, as exemplified by the mission of the Make-A-Wish Foundation.

The need to incorporate a dedicated family systems approach to the needs of children with cancer and their families is self-evident. Several programs developed in a summer-camp setting are extant, and they provide multiple services and activities but do not meet the challenges of providing comprehensive psychosocial care.¹²⁻¹⁴ Although not readily or universally available for pediatric oncology patients, play therapy has been shown to be a useful modality in helping children discuss the impact of cancer.¹⁹

FACTORS THAT AFFECT PSYCHOSOCIAL FUNCTIONING

A host of variables will influence the level of psychosocial functioning in pediatric psychosocial oncology. From solely a teaching point of view, it is frequently beneficial to organize the issues into discrete areas. Although by no means comprehensive, the following domains demonstrate areas that can be used to teach patients and families about the disease, treatment, and prognosis.

Disease Site

Psychosocial oncology research has shown that the level and intensity of cancer's impact depend on a variety of factors, but the primary factor is the disease site.²⁰ In turn, the role that the part of the body affected by disease plays in an individual's sense of self and body integrity depends largely on how the individual has developed his or her sense of self and place in the family and in society in general. Healthcare professionals must fully understand the value the patient attributes to the affected body part to assist the patient in his or her psychosocial recovery. The cancer may negatively impact most of the critical domains of the patient's life. Moreover, because the child is in the midst of the developmental process, cancer can disrupt the formation of identity and have a psychological impact on self-esteem. Physiological dysfunction with or without disfigurement poses obstacles to meaningful therapeutic communication and may also have implications for individual and

group psychotherapy. Psychological recovery may become more difficult because of the transformed sense of body, resulting in profound psychological trauma.^{15,16}

Brain tumors can present challenging medical, logistical, and psychiatric problems. Seizures, fatigue, and cognitive dysfunction can complicate the treatment of patients with primary or metastatic brain tumors. Active multidisciplinary implementation of effective medical and psychosocial management can result in decreased morbidity and mortality and improved quality of life for affected patients^{21,22} and their family members. Once the diagnosis of malignant brain neoplasm is confirmed, health-related quality of life for the patient and family becomes a significant issue.^{17,18} Additionally, survivors of childhood brain cancer frequently suffer severe persistent deficits in a wide range of neuropsychological functional domains. Nonetheless, brain tumor survivors and their families do not report impaired quality of life.²³

Age

Within the arena of pediatric psychosocial oncology, a new age group is being defined. The adolescent/young adult (AYA) population is garnering clinical and research attention. This age group is sadly underrepresented in the literature because the age group—the National Comprehensive Cancer Network guidelines define the AYA population as those 15-39 years old at the age of diagnosis—does not fit standard definitions or demographics. Among 20- to 39-year-olds, cancer causes more deaths than any other disease except depression that culminates in suicide.²⁴ Looking at the continuum of the lifespan, the AYA population deserves special attention. Not only are the physiological issues unique in terms of pathology and response to treatment,²⁵ but patients in this population and their families must also be viewed in a phenomenological and developmental context.

Assessing the impact or level of distress on the adolescent is a primary task for anyone working with the AYA population. Unfortunately, although medical staff are proficient at identifying and predicting distress from physiological treatment, they are not as skilled at identifying psychological problems in the same population.²⁶ Consequently, these patients continue to have unmet needs that may extend up to 5 years after the conclusion of treatment.²⁷ Young people may present with issues that are more intense than those of any other cancer population. This state of affairs arises from the physiological issues of treatment and the unique developmental challenges of autonomy and independence, peer development,

education, graduation, social development, sexual maturation, intimacy, marriage, reproduction, fertility, employment, parenting, and insurability.²⁵

Significant strides have been made in reaching this unique population through the advent of social media platforms. An example is PlanetCancer, a “community of young adults with cancer that provides a critical community of peer support and advocacy for young adults with cancer.”²⁸

Although adolescence is generally considered to be a difficult transitional time for families, many teens diagnosed with cancer adapt well if they have strong social and familial support. Families with higher levels of support report lower levels of distress.¹⁹

Palliative Cancer Care

Another factor that affects psychosocial functioning is receiving palliative care to ameliorate symptoms and improve quality of life. As the discipline of psychosocial oncology has developed and expanded,^{20,29} the nature and implementation of the continuum of oncology services and ultimately palliative services have changed. The psychosocial state of patients with advanced disease varies depending on symptom burden, medication effectiveness, familial response (or lack of response), and a myriad of other factors. Unfortunately, deficits still exist in the palliation of pediatric oncology patients.³⁰

Pediatric palliation is quite complex and multifactorial. For example, the needs of families with children who have terminal brain tumors present specific challenges that are quite different from those of families with a child who has a treatable disorder.³¹ Research has shown that parents whose terminally ill children experienced sleep disturbances, pain, and anxiety were more likely to have an increased risk of long-term psychological morbidity.³²

Another issue is that the child or adolescent will have a different understanding of a noncurable, life-limiting diagnosis or of the end of life based on developmental state. Such understanding will also be colored by the child’s phenomenological worldview. How the child transitions out of life may be eased or burdened depending on the family’s level of distress or comfort. Finally, one must ask whether the patient’s disease and treatment process have been approached with courage, honesty, and obvious medical integrity and what messages were conveyed by the staff and medical personnel. All of these variables will impact a child or adolescent’s final days and hours.

CONCLUSIONS

Previously, the hope of long-term survival for children diagnosed with cancer was remote. Advances in pediatric oncology have demonstrated the need for

comprehensive psychosocial treatment programs for children with cancer and their families.³³ Children and adolescents with cancer diagnoses face issues similar to those of their adult counterparts, but with significant and clinically relevant differences, and these challenges become magnified within the developmental context. The clinician must be sensitive to and knowledgeable of the transition process from childhood to adolescence and young adulthood. As that transition occurs, the importance of any one of the general domains noted in the figure will shift, grow, or diminish depending on the child's and family's acceptance of the disease, the impact of the treatment, and the level of development. For instance, a child or adolescent trying to discuss a cancer diagnosis may be overwhelmed with emotions, fears, and hopes. Play therapy³⁴ and games²³ are both feasible and effective in helping a child understand and communicate his or her understanding of the disease and treatment. Helping the parent, child, and relevant others to assign meaning³⁵ to the process of the cancer experience must be accomplished with sensitivity, honesty, and courage.

Similarities exist between children with chronic illnesses and those with oncologic diseases. Each disease process has unique manifestations in the child and family. Drawing inferences from this generality will drive the intervention. For example, the impact of the diagnosis on the child, adolescent, or young adult will depend on the intellectual acumen of the individual. The amount of reliance on family versus social support will vary greatly, once again depending on the individual's development. However, the cultural stigma and fear surrounding the word cancer cannot be underestimated.

Global data indicate that healthcare for children with cancer should include psychological services to prevent long-term emotional and behavioral problems, but more comprehensive psychosocial programs for children with cancer are needed. These services must be delivered in an age-appropriate, developmentally appropriate, and time-sensitive fashion.

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