



PSYCHOSOCIAL DISORDERS IN PAEDIATRIC CANCER PATIENTS

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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 paediatric care over the past five decades. Psychosocial oncology, a relatively new discipline, is a multidisciplinary application of the behavioural and social sciences, and paediatric 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 paediatric psychosocial oncology. Children's cancers are not always treated like adult cancers. It's important to know that this expertise exists and that there are effective treatments for many childhood cancers. Adjusting to a child's cancer diagnosis and finding ways to stay strong is challenging for everyone in a family.

Keywords: Paediatric oncology, psychosocial oncology

INTRODUCTION:

Although there have been many medical advances in the treatment for cancer patients in India, there has not been a similar attention to addressing the psychological and social (psychosocial) distress associated with the disease. Yet, the dramatic increase of cancer rates in India over the last decade has placed an enormous burden on families and society.^[1] Psychosocial distress accompanying cancer can include depression, anxiety, or other emotional distress; lack of financial resources for treatment or transportation; disruptions in work and family life; and existential issues related to meaning of life. The transition into survivorship brings its own set of challenges as families readjust to home and family life, and children re-enter school and social settings. Children may be years behind in school, and faced with the challenge of lasting attentional and memory problems, as well as hearing loss and other physical limitations. There is a constant fear of relapse which leaves families on guard—is that headache normal? We should not only consider the effects of cancer treatments on brain development but also the impact of childhood cancer as a stressful and potentially traumatic experience. The failure to assess, manage, and monitor the psychosocial distress related to cancer

diagnoses and treatments can compromise the effectiveness of health care and adversely affect the health of cancer patients. Hence, it is paramount, especially in cancer centres in low-to-middle income countries, that patient distress be routinely monitored and assessed to provide quality cancer care for every patient. Furthermore, collecting and analysing data on distress and the sources of distress among a centre's patient population will help psychosocial providers identify needs and determine how best to address gaps in services. Screening protocols that are routinely followed in clinical practice can improve access to mental health services, rather than a system that relies solely on physical referrals or patients' self-referrals. Screening for distress and understanding what could be driving the distress are critical to identifying needs of patients who are early in the cancer trajectory. To this end, psychosocial providers in India have started to implement routine distress screening as part of clinical care in their cancer centres. To determine the level of emotional distress among patients with new diagnoses of cancer and potential factors (demographic, socioeconomic, clinical characteristics) that were associated with their distress, we implemented a cross-sectional, cohort study at a comprehensive cancer institute in South India. Our specific aims were to 1) assess the level of distress and psychosocial issues related to the distress as reported by patients using a standard measure of distress (NCCN Distress Thermometer) and 2) to determine whether there were demographic factors (sex, age, socioeconomic status, religion) and clinical factors (awareness of diagnosis and prognosis, type of cancer, physical symptoms) that were significantly associated with the level of distress. The impact of paediatric oncology is psychosocially and physically profound. Children have problems coping with the stresses of treatment, surgery, chemotherapy, and radiation. Parents and siblings also have needs. This article addresses the specific issues of paediatric oncology and palliative care in terms of their immense psychosocial impact on the patient and caregivers. 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 paediatric care over the past several decades. Increasing acceptance of the importance of addressing mental health has led to oncologists referring patients to paediatric 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 behaviour. 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).

The long-term psychological effects of intensive cancer treatments in children have been a topic of study since the 1980's. As a group, childhood cancer patients cope psychologically well with the experience, but still, many report anxiety, depression, and even posttraumatic stress. Among children with cancer, research suggests that specific posttraumatic stress symptoms occur more frequently than the full spectrum of posttraumatic stress disorder (PTSD) and may affect nearly 75% of youth during or after treatment. There is substantial variability, with some studies suggesting that perceived life threat or clinically-related factors (e.g., length of hospital stays, reoccurrence, treatment intensity) are associated with more severe posttraumatic stress symptoms. Posttraumatic stress symptoms may include nightmares or flashbacks, a desire to avoid people, places, or things associated with the experience, a difficulty in feeling emotions, feeling helpless, distant, or cut off from others, and feeling anxious or easily startled. These symptoms may be experienced by children and their parents as well as siblings. Children with cancer have multiple psychosocial issues and require a unique approach to conceptualize and operationalize the issues they confront. Psychosocial effects can manifest as increased levels of depression, anxiety, and concerns about mortality. 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 behavioural 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 paediatric 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 neighbouring circle. 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 paediatric 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 haematological 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.

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 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. 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. In a Swedish study, a notable percentage of parents of children who relapsed had symptoms similar to those of posttraumatic stress disorder. 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.

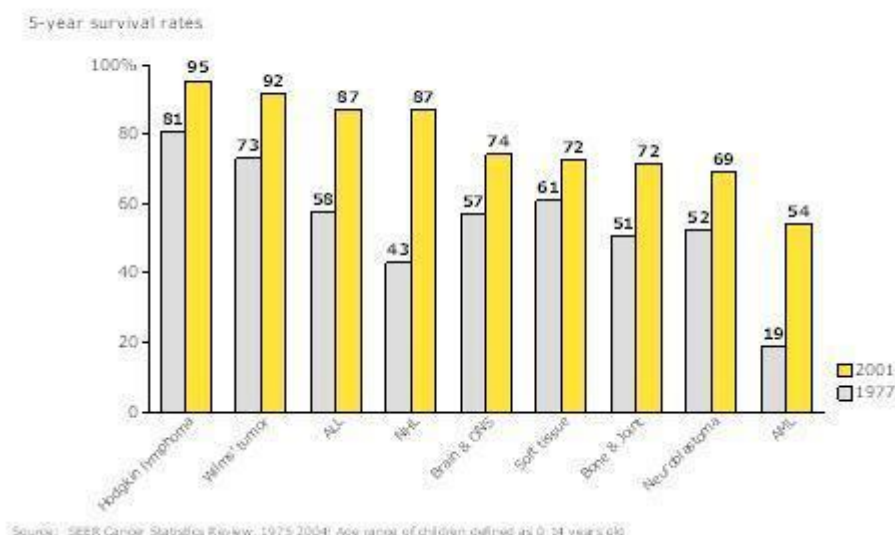
As a group, parents of children with cancer are relatively resilient. Generally, families alter their roles, responsibilities, and family functions to accommodate the child with cancer. Such changes can put a significant stress on the family, however, and coping with the stress is often most difficult for the child's mother. 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

The majority of paediatric 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). Paediatric 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 paediatric 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 behavioural 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 paediatric psycho-oncologist (Wiener 2012).

In addition, survival has not been consistent across childhood cancers



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