

Review Article

Integrative Pediatrics and Child Care Psychosocial Support for Distressed Parents of Pediatric Cancer Patients

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Abstract

Survival rates for childhood cancer diagnosed before the age of 18 years have improved due to aggressive multidisciplinary therapeutic approaches. Parents have been found to be psychologically affected by their child's diagnosis, treatment, side-effects of the treatment and child's health status. Though parental emotional difficulties, such as depression and anxiety, have been reported to decrease after cancer treatment, parents continue to experience chronic post-traumatic stress (PTS) for a long time after their child's treatment. Parents may also report persistent feelings of loss, uncertainty, and anxiety about the recurrence of the disease or the emergence of late effects in their child. Such illness-specific distress of the parents should be assessed in order to fully understand their psychosocial functioning. Sensitizing health care professionals to the identification of this factor and its associated difficulties is essential for the implementation of efficient intervention strategies. General health of parents plays an important role in continuation of care for the sick child and the treatment follow up. Parental distress and PTS are associated with the emotional and behavioral functioning of children with cancer. There is a genuine need to offer programs of psychological attention to parents of children with cancer in order to reduce their emotional and cognitive psychopathology and to help them adopt adequate coping strategies.

Keywords: Childhood cancers, Parental stress, Post-traumatic stress, Assessment tools, Coping mechanisms

Abbreviations: PTS: Post-Traumatic Stress; ASD: Acute Stress Disorder; PTSD: Posttraumatic Stress Disorder; QoL: Quality of Life; PIP: Pediatric Inventory for Parents; PAT: Psychosocial Assessment Tool ; HRQL: Health-Related Quality of Life

Introduction

Due to improvements in childhood cancer treatment, the overall survival rate of all childhood cancers combined has improved. Childhood cancer has been described as a life-changing experience for parents. Following diagnosis,

parents are expected to rapidly learn a substantial amount of cancer-related information, adopt particular care giving skills, as well as reorganize their family roles and routines. These adjustments are all aimed at transitioning their focus from parent to both parent and primary caregiver of a child with cancer, often leading to

considerable emotional strain, which may persist over time. Published data indicates that approximately 27% of parents suffered from clinical levels of psychological distress up to 5 years post-diagnosis [1].

Parental stress or distress may refer to a vast array of symptoms, such as uncertainty, anxiety, depression, traumatic stress, psychological health, etc. Parents of children diagnosed with cancer have described the impact of diagnosis and treatment as devastating and associated with feelings of shock, upset, anger and stress. Furthermore, they express sorrow, anxiety and feelings of uncertainty about their child's prognosis. Parents often want to be close to their child, doing all they can, watching over and acting on behalf of their child, comforting and supporting, and their care burden increases. It is acknowledged that people differ in their reactions to stressful events and this may depend on many factors such as their previous experiences and differences in their roles, responsibilities and coping mechanisms. Moreover, religion, culture and the nature of marital relationship between couples are very important factors affecting how parents of children with cancer respond to stress. A parent's emotional issues may disrupt the ill child's cancer treatment, impact parenting and support for the ill child and well siblings, and threaten family functioning and stability over time [2-4].

Aggravating and risk factors

The diagnosis of cancer in children imposes high levels of stress on the family and particularly parents and adversely affects their mental health status. Several factors such as young age of patient, long treatment course, invasive cancer-related treatment procedures, high cost of treatment, child's age, distance from the hospital to the place of residence, financial status of the family and the husband and wife relationship significantly affect the stress of parents following the diagnosis of cancer in their children. Other risk factors often implicated to aggravate parental stress are female gender, preexisting psychological problems, high trait anxiety, low social economic status, child behavior problems, high care-giving demands, individual coping, family conflicts, no religious affiliation, and chronic disease in a family member other than the child surviving cancer, concurrent stresses and lack of social support. Caring for a child with *advanced cancer* is likely to be even more distressing. Not only do parents witness their child's protracted physical and emotional suffering, they also must contend with the ultimate threat to their child's life, which is heightened among children with more advanced

stages of disease. Parents consistently show elevated levels of state anxiety, emotional distress, and negative affect during their children's procedures [2,5,6].

Pattern of parental stress

Psychological distress among parents of children with cancer has been shown to decrease as a function of time since the child's cancer diagnosis to the post-treatment period, generally reaching normative levels around 3 years post-diagnosis. However a subgroup of parents run (between 18% and 30%) reports a high level of psychological distress even after end of the child's treatment [3]. Parents report that the initial stages of diagnosis and treatment are the most overwhelming time because of uncertainty. After end of treatment parents have to handle the risk of relapse and report increased levels of worry and fear of recurrence. For some parents, the cancer experience causes marital strains, strains in relationships with the previously ill child and/or its siblings, as well as economical and occupational difficulties. Parents of children with cancer face several challenges, both during and after the time when the child is ill, that may contribute to development and/or maintenance of psychological distress even years after end of the child's cancer treatment. Any expressions of posttraumatic stress during this phase may indeed be accompanied by reactions to current stressors. Nevertheless, fear of a relapse, and worry about evolving negative consequences of the treatment may also be intensified during the period following the end of treatment. Accordingly, current stressors related to the child's disease may be present also after completion of the treatment [7].

The Impact on patients and families

The often unexpected and life-threatening diagnosis and the initiation of invasive medical treatment and its sequelae interfere with the entire family's normal activities and routines for a long period of time and impose stressors of varying duration, predictability, and impact. Family life is disrupted as families struggle with a 'new normal' that consists of frequent hospital visits, overwhelming medical bills, and a questionable future [5]. In these families, the parent's own needs and distress may affect parenting, child well-being, and family functioning across the illness trajectory. Importantly, parents of children with cancer also report significantly decreased health-related quality of life as compared with population norms due to increased care giving responsibilities and numerous stressors associated with

their illness. These stressors include financial burden, role strain, separations, interruptions in daily routines, poor sleep, and uncertainty regarding the child's prognosis [8].

Clinical levels of psychological distress such as PTSS, anxiety, and depression has serious consequences, not only for the individual, but also for the society. For the individual the distress is associated with low quality of life, functional disability, parenting challenges, and increased risk for somatic disorders such as coronary heart disease. For the society, the distress is associated with costs due to health care utilization, productivity loss, and sick leave. 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. Parental psychosocial functioning has been found to be positively correlated with psychosocial functioning in children. Children with cancer whose parents have severe distress and PTSS may receive insufficient emotional support and have difficulties coping with their situation [9].

Posttraumatic Stress Disorder (PTSD)

The life-threatening nature of cancer qualifies the diagnosis as a traumatic event of sufficient magnitude to potentially lead to Acute Stress Disorder (ASD) or Posttraumatic Stress Disorder (PTSD). Early studies reported a prevalence of current PTSD from 6.2% to 25%, and lifetime prevalence of 27% to 54% in parents (predominantly mothers) of children with cancer, a marked 5- to 10-fold increase relative to general population surveys. Symptoms of PTS in parents are a concern and may be an appropriate target for intervention, particularly in the period following diagnosis. Early signs and symptoms of PTS require early assessment and intervention since the disruptive symptoms may linger over time in a subset of parents. The risk factors associated PTSD include female gender, greater physical late effects, increased number of prior stressful life events, perceived severity of cancer and treatment, family conflict, poor social support, and emotion-focused coping. Provision of early, adequate support to parents who are vulnerable to PTSD will help not only the parents, but also their children with cancer. Clinically, attention should be paid to continuous parent support needs and individual variation vis-à-vis distress vulnerability should be acknowledged [10-12].

Influence of gender of parent

Although mothers and fathers worldwide today increasingly share the practical responsibilities of the family equally, the mother still appears to be the one who spends more time with the child at the hospital. As a consequence mothers may be more exposed to the stressors associated with caring for the sick child, and may also to a greater extent carry memories of traumatic experiences; thereby being prone to develop more intrusive thoughts. Mothers of children newly diagnosed, in remission, relapsed, or off-treatment report higher levels of anxiety and depressive symptoms than fathers of children with cancer. Furthermore, as is often found in the general population, mothers tend to report more and higher levels of symptoms than fathers with respect to anxiety, depression, and PTSD. These differences may well be related to the traditional distribution of care-giving tasks and responsibilities. Also, since women seem more willing to report discomfort than men, gender differences may also be due to reporting style and impact of cultural dimension to the consideration of stress perception. In particular, many researchers report that the cultural background of the parents has an effect on their stress levels when caring for a child with cancer. Moreover, in published literature, data on fathers is lacking and it is required to conduct future longitudinal studies to provide a more representative depiction of parental distress across the cancer trajectory. The question remains whether it is necessary and possible to tailor interventions to specific needs of mothers and fathers of children with cancer [13,14].

Assessment tools

Family psychosocial risk screening is an important initial step in delivering evidence-based care. Parental distress can be approached by a variety of measures including psychological symptom inventories, mixed distress scales, anxiety-depression inventories, mental quality of life subscales or traumatic stress inventories. These make it possible to evaluate subclinical distress in the form of frequency or severity of symptoms and infer the presence of clinically significant distress when levels exceed predetermined cut-points. One such tool is Pediatric Inventory for Parents which includes four domains of stressors related to caring for a child with a chronic illness, including communication, emotional functioning, medical care, and role function. The Psychosocial Assessment Tool (PAT) is a brief parent report screener based on the trilevel Pediatric Psychosocial Preventative Health Model (PPPHM; Universal, Targeted,

Clinical). The PAT provides an evidence-based screener that identifies families at three levels of risk and can provide the basis for further evaluation and treatment of children with cancer and their families. Screening is acceptable for families and important for identifying risk factors associated with poorer patient health-related quality of life (HRQL) during childhood cancer treatment. Targeted interventions addressing family resource needs as well as parent distress identified through screening may be effective in promoting patient HRQL [15,16].

Coping with stress

Parental coping is both an individual and an interpersonal process and the various forms of avoidance and disengagement are associated with greater emotional distress. The significant correlations between partners' reports of disengagement coping and their depressive symptoms suggest that some couples may be characterized by more maladaptive coping mechanisms and higher levels of distress. Certain coping strategies, such as active problem solving, seeking social support, and optimism can serve as protective factors. Specific strengths of the family should be identified and used. Self-efficacy is essential to sustaining an individual's effort to cope with stressful tasks, determining success in adversity management, and adjusting to general challenges during and after their children's treatment. Spiritual beliefs can often buffer care giving stress; however, parents' religious faith may be challenged as they watch the suffering their child endures and find it difficult to reconcile their spiritual beliefs. Parents might well benefit from a tailored intervention based on strengths and weaknesses that is targeted to their specific needs with respect to the phase of childhood cancer. To prevent the development of PTSS and PTSD, timely interventions are required to provide early adequate support to vulnerable individuals and to eliminate the occurrence of traumatic events. When persistent posttraumatic symptoms remain, however, the professional effort may have to cover a more elaborated treatment approach. This includes multimodal treatment where attention is paid to the symptoms of intrusive thoughts and re-experiencing, and avoidance, as well as to the unspecific symptoms following PTS [17-19].

Role of information

Informing parents about their child's diagnosis and treatment plan helps to relieve uncertainty. This information can also enhance parental coping, improve their ability to make informed decisions, and assist with the transition to home. To make informed decisions

about treatment, parents of children with cancer require accurate information about not only prognosis and acute effects of therapy, but also about potential late effects of treatment. Parents are more likely to experience peace of mind when their child's oncologist provides high quality information regarding the disease; however, some parents feel overwhelmed with the amount of information and exhausted by the initial teaching. Receiving information about a child's cancer diagnosis can be both beneficial and stressful to parents. Written information, verbal discussions, simple videos, and websites are all potential resources that can be used to educate parents of children newly diagnosed with cancer. Moreover, the information provided during the conversation may not be fully comprehended by the parent or the child because of the physician's misleading use of terms when disclosing the disease. Most professionals tend to support an open and honest approach to information-sharing; however, one must consider the need to maintain hope and spirit and promote an optimistic identity influenced the amount and type of information shared by parents. Professionals should maintain an open mind about information-sharing strategies families may choose, remain sensitive to parents and children's information requirements and adopt a flexible approach to information provision [20-22].

Conclusion

Parents are profoundly affected by a child's cancer diagnosis. Understanding the degree of PD and contributing factors among parents with children with advanced cancer has the potential to better enable clinicians to identify higher risk families and optimize outcomes. In addition, better insight may enable the design and implementation of parental supportive interventions. In view of the interconnectedness of parent and child mental health, family-centered psychosocial care has been long considered essential in pediatric oncology. The child and the family need to develop new coping skills, make use of outside support and resources, and receive specific interventions in order to maximize their adjustment. Continuing improvements in outcomes of cancer therapy and in psychotherapeutic treatment will reduce the psychological impact and assist in the child and family's adjustment to childhood cancer. In addition to pushing for cures for cancer, we should also advocate for psychological support as a standard of care for childhood cancer. This means having social workers, therapists, and Child Life advocates as a part of the treatment team, and with the family every step of the way.

Declaration

There is no conflict of interest.

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