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A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents

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Abstract

Recent years have witnessed a rapid acceleration in the recognition and documentation of posttraumatic stress disorder (PTSD) and posttraumatic stress symptomatology (PTSS) in childhood cancer survivors and their parents. However, applicability of PTSD both diagnostically and conceptually to cancer-related traumatic responses remains poorly articulated within the current literature. Following an outline of childhood cancer and PTSD, this paper critically examines the applicability of such a diagnosis to this clinical population. It then systematically reviews the current evidence base (24 studies) on PTSD and PTSS in childhood cancer survivors and their parents. Prevalence of PTSD and PTSS, as well as associated predictors, in this clinical population varies widely. Findings are considered in the light of a number of contemporary theories of PTSD. Limitations within current conceptualizations of PTSD are highlighted with respect to the nature of cancer as a traumatic event and the specific features of traumatic stress manifestations in childhood cancer survivors and their parents. Finally, a number of pertinent research areas are elucidated which are argued to warrant further investigation.

Keywords: Childhood cancer survivors; Parents; Posttraumatic stress disorder (PTSD); Posttraumatic stress symptoms

1. Introduction

No longer is childhood cancer considered a fatal illness. Advances in treatment technologies have ensured ever-increasing periods of disease-free survival (Brown, Madan-Swain, & Lambert, 2003; Moore, 2005). However, an equally rapid growth of research suggests that the deleterious effects of cancer and subsequent "cure" extend beyond physical sequelae. Childhood cancer survivors have repeatedly been found to be at increased risk of developing internalizing and externalizing difficulties as well as social problems (Fuemmeler, Elkin, & Mullins, 2002). In recent years a growing body of literature has highlighted presence of trauma-related symptomatology, such as avoidant behaviors, intrusive thoughts and heightened arousability in cancer survivors (see Kangas, Henry, & Bryant, 2002; Smith, Redd, Peyser, & Vogal, 1999 for reviews). Furthermore, the parents of these children have been found to report comparatively higher rates of trauma-related symptomatology (Goldenberg Libov, Nevid, Pelcovitz, & Carmony, 2002; Manne, DuHamel, & Redd, 2000, Manne et al., 2002; Pelcovitz, Goldenberg,

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Kaplan, & Weinblatt, 1996). The profile and severity of these symptoms are comparable to those exhibited by individuals diagnosed with posttraumatic stress disorder (PTSD) (Smith et al., 1999).

Accordingly, the Diagnostic Statistical Manual of Mental Disorders, 4th edition (DSM-IV; American Psychological Association [APA], 1994) modified and broadened its taxonomy of PTSD. This resulted in the inclusion of both the traumatic event itself and the experience of the person involved in the event. Specifically, being 'diagnosed with a life-threatening illness' or 'learning that one's child' (APA, 1994, p. 426) has such an illness became a qualifying stressful event. Henceforth, increasing attention has focused on the applicability and nature of cancer specific factors in the development and maintenance of both PTSD and PTSS. Correspondingly, growing recognition and documentation of PTSD in cancer patients by psycho-oncology researchers and clinicians has ensued (Kangas et al., 2002). Furthermore, increasing attention has focused upon assessing posttraumatic stress symptoms (PTSS), which provides a continuous measure of posttraumatic stress reactions and risk of PTSD diagnosis.

As an extensive and ever-expanding body of literature exists in relation to PTSD as well as the neurocognitive and psychosocial sequelae of cancer, this review aims to restrict its examination to the documentation of PTSD and PTSS in childhood cancer survivors[1] and their parents. Specifically, the following issues will be reviewed: (i) the prevalence and nature of childhood cancer as well as the associated physical and psychosocial sequelae; (ii) the prevalence and diagnostic features of PTSD in the general population including associated risk factors; (iii) the applicability of PTSD diagnosis to childhood cancer; (iv) the current empirical research base on PTSD and PTSS in childhood cancer survivors and their parents; and (v) the extent to which the experience of childhood cancer can be conceptualized within current theories of PTSD. Finally, several recommendations for future research studies are delineated.

2. Childhood cancer

2.1. Prevalence of childhood cancer

In the UK, approximately 1400 cases of cancer were diagnosed in children (0–14 years) and 1600 in adolescents and young adults (15–24) in 2001 (Office for National Statistics, Cancer Statistics registrations, 2004). In the US, the American Cancer Society estimated that 9100 new cases of children cancer (0–14 years) were diagnosed in 2002 (Cancer Facts & Figures, 2002). The risk of an individual child in the UK being diagnosed with cancer before the age of 15 is approximately 1 in 500, with a slightly higher incidence in boys than girls (Forman et al., 2003; Quinn, Babb, Kirby & Brock, 2000).

2.2. Childhood cancer

Cancer is characterized by the uncontrollable and unregulated growth of cells which invade, erode, and destroy surrounding normal tissue. Occasionally, they can metastasize throughout the body. Childhood cancers develop more rapidly than adult cancers as the cancerous cells grow together with the fast-growing tissues of the child (National Cancer Institute Research on Childhood Cancers [NCIRCC], 2002). Cancers develop because of a complicated interaction between our genes, our environment and chance. They can be distinguished in terms of their histology (i.e., tissue type), site (i.e., specific location in the body), malignancy (i.e., rate of cell growth) and symptomatic expression. Although there are over 200 different types of childhood cancer, the most common forms are leukemia (accounting for 1/3 of all cancer diagnoses) and brain/spinal tumors (constituting 1/4). Other childhood cancers include soft tissue sarcomas, neuroblastoma, non-Hodgkin's lymphoma, Wilms' tumor, Hodgkin's disease, germ cell tumors, retinoblastoma, osteosarcoma, and Ewing's sarcoma (NCIRCC, 2002).

Leukemia is characterized by the rapid growth of abnormal, immature white blood-forming cells which invade other tissues and organs. Over time their mass begins to outnumber and reduce the production of normal blood cells

[1] The term 'childhood cancer survivors' is a broad term used by many authors to refer to children and adult survivors of childhood cancer and will be adopted throughout this review. This wording will be used as an umbrella term and encompass idioms utilized in other studies such as 'child survivors,' 'pediatric cancer survivors,' 'survivors of childhood cancer,' or 'young adult cancer survivors.'