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Clinical Psychology Review xx (2005) xxx–xxx

CLINICAL PSYCHOLOGY REVIEW

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

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Received 27 April 2005; received in revised form 4 October 2005; accepted 4 October 2005

## 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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doi:10.1016/j.cpr.2005.10.002

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

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[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.'

(white blood cells, red blood cells and platelets) in the bone marrow (NCIRCC, 2002). The most common form of leukemia among children is Acute Lymphoblastic Leukemia. Brain and spinal tumors are sometimes referred to as central nervous system tumors (CNS-tumors) as they reflect a rapid growth of cells in the brain or nervous system. These cells form a mass (tumor) which interrupts and damages normal brain functioning. The most common type of brain tumor in childhood is astrocytoma.

### *2.3. Diagnostic procedures and treatments for childhood cancer*

There are a number of diagnostic procedures and treatments available for children with cancer including scans, biopsy, lumbar puncture, surgery, radiotherapy, chemotherapy and bone marrow transplantation. The selection and termination of these procedures and treatments are dependent on a number of factors such as the child's age and general health, site of cancer, histology, malignancy and severity of side effects.

#### *2.3.1. Diagnostic procedures*

Perhaps the most common diagnostic procedures are CT (computerized tomography) or MRI (magnetic resonance imaging) scans which attempt to determine the presence and exact position of the cancer. These procedures can take up to one-and-a-half hours to complete and can involve the injection of a dye into the child's vein as well as on occasions sedation or general anesthetic if the child is very young or finds the procedure distressing. A biopsy is preformed in order to determine the histology and malignancy of the cancerous cells. This procedure involves surgical incision and extraction of a small amount of cancerous tissue. In some cases (usually for brain and spinal tumors) a lumbar puncture is completed in order to examine the cerebro-spinal fluid (CSF). This procedure requires a large needle to be inserted into the lower back which is uncomfortable and sometimes requires sedation.

#### *2.3.2. Treatments*

Surgical excision is usually performed if the child has a solid cancer (e.g., brain tumor) in order to remove as much of the cancerous tissue as possible. However, this may not be possible if the site or histology is contra-indicative for surgery (e.g., blood-forming cells, vulnerable location in brain). Such treatment involves general anesthetic and hospitalization. Radiotherapy is usually recommended after surgery in order to destroy any remaining cancerous cells. Radiotherapy is painless and involves the use of high-energy rays (similar to X-rays) from cobalt or radioactive iodine. Children undergoing radiotherapy usually require treatment on a daily basis, five days a week for five to eight weeks and are therefore treated as inpatients. Chemotherapy involves the use of strong drugs called 'cytotoxics' (meaning cell poisons). These drugs can be administered intravenously, by mouth in tablet form, through an injection or applied onto the child's skin. The length of chemotherapy treatment ranges from three to twelve months. For children with blood-forming cancerous cells (e.g., leukemia) a bone marrow transplant is often performed which involves the replacement of the patient's bone marrow with the healthy bone marrow of a donor.

### *2.4. Short- and long-term physical effects of treatments*

The short-term side effects related directly to chemotherapy include susceptibility to infection, nausea and vomiting, loss of appetite and taste, cold symptoms, headaches, lethargy, hair loss, pain and burning at injection site. Those associated with radiotherapy can involve constipation, mouth soreness and ulcers as well as skin damage. Less frequent and non-specific side effects have been reported to include anemia, allergic reactions, and shortness of breath, jaundice, blood in urine and lack of co-ordination (NCIRCC, 2002). Long-term physical late effects include of radiotherapy have been associated with organ damage, decreased growth and infertility (Oberfield & Sklar, 2002) as well as scars and cardiac problems being associated with bone marrow transplantations (Phipps, 1994). Moreover, while neurocognitive deficits (Steinlin et al., 2003) have been associated with an array of cancer treatments, childhood survivors of acute lymphocytic leukemia and brain tumors have been reported to be at greatest risk (Moore, 2005). Furthermore, childhood cancer survivors are found to report lower levels of physical functioning, physical role performance and general physical health compared to the normal population (Eiser et al., 1997).

### 2.5. Psychosocial impact of childhood cancer

Literature pertaining to the deleterious psychosocial impact of cancer onset, diagnosis and treatment on childhood survivors and their families is vast. Many of these children (and their families) report that the lengthy and frequent aversive diagnostic procedures and therapies are more distressing than the cancer itself (Armstrong & Horn, 1995). Indeed, research has found that these children and their families are at increased risk of heightened psychological distress (Greenberg, Pyszczynski, Solomon, Simon, & Breus, 1994; Kangas et al., 2002; Kornblith et al., 1992), disturbances in self-concept, self-esteem, body image and identity (Alter et al., 1996; Kornblith et al., 1992) as well as PTSD and PTSS (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Brown et al., 2003; Goldenberg Libov et al., 2002; Hobbie et al., 2000; Pelcovitz et al., 1998). Accordingly, such physical and psychological sequelae have been demonstrated to negatively impact upon and interact with social functioning. Childhood cancer survivors report reduced social relationships (Boman & Bodegard, 2004), peer relationship difficulties (La Greca, 1990), problems at school (Hays et al., 1992), concern about the future relationships (Stevens & Dunsmore, 1996) and are less likely to marry as well as have fewer intimate relationships in adulthood (Eiser, 1998).

## 3. Posttraumatic stress disorder

### 3.1. Prevalence of PTSD in the general population

Estimates of lifetime prevalence of PTSD in the general adult population have been reported to range from 1% to 14% (APA, 1994). The Epidemiologic Catchment Area (ECA) studies revealed lifetime prevalence of PTSD to be 1% in the general adult US population (Helzer, Robins, & McEvoy, 1987). Davidson, Hughes, Blazer, and George, (1991) found a lifetime prevalence of 1.3% in a large adult community sample. The National Comorbidity Survey reported a lifetime prevalence of 7.8% (Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995) in the general population and 20.4% in females and 8.1% in males following exposure to at least one traumatic event.

Although epidemiological studies of PTSD in children and adolescents appear relatively scarce, lifetime prevalence rates of 1.6% (Essau, Conradt, & Petermann, 1999) in a German study, 3.5% (Cuffe et al., 1998) in a US survey and 5.6% (Frans, 2003) in a Swedish study have been documented.

### 3.2. Diagnostic criteria for PTSD

The DSM-IV (APA, 1994) defines PTSD as a serious mental condition following “an individual experiencing, witnessing, or being confronted with a traumatic event/s that involved actual death or threatened death or serious injury; or a threat to the physical integrity of himself or herself or others” (p. 427). Since 1987, DSM diagnostic conceptualizations of PTSD recognized the differential reactions and symptomatic expressions of children and adults following a traumatic event and revised its definitions accordingly. While no discrete diagnostic taxonomy exists for children, differences in symptom manifestation are outlined within the six primary criteria for PTSD diagnosis.

The event must elicit “reactions of intense fear, helplessness or horror” (p. 428) in the individual (Criterion A). However, in children this reaction may manifest as disorganized or agitated behavior. To meet the criteria for a diagnosis of PTSD such reactions must subsequently mobilize three specific symptom clusters. The first cluster (Criterion B) is characterized by reexperiencing symptoms of the traumatic event (i.e., intrusive memories, nightmares, a sense of reliving of the traumatic event, as well as psychological or physiological distress at reminders of the trauma). However, for younger children this may manifest as generalized nightmares with or without recognizable content. The individual must experience one (or more) of these symptoms. The second cluster (Criterion C) is characterized by persistent avoidance of stimuli associated with the trauma and numbing in general responsiveness (i.e., effortful avoidance of thoughts, feelings and reminders of the trauma, inability to recall certain aspects of the trauma, withdrawal from others and normal activities, emotional numbing, and a sense of foreshortened future). The individual must experience three (or more) of these symptoms. Such subjective reactions in children may be less defined, presenting potential difficulties for the child in the detection and reporting of such phenomena (Salmon & Bryant, 2002). The third cluster (Criterion D) is characterized by persistent arousal (i.e., insomnia, irritability, concentration difficulties, hypervigilance, as well as exaggerated startle response). The individual must experience two (or more) of these. Children may also 'exhibit various physical symptoms, such as stomach-aches and headaches' (APA, 1994, p. 426). PTSD symptoms must persist for at least one month following exposure to the traumatic event (Criterion E) and significantly impair the individual's day-to-day functioning (Criterion F).

### *3.3. Factors associated with the risk of PTSD in children and adults*

There are a number of factors which are considered to increase the risk of PTSD and PTSS following exposure to a traumatic event. In adults these include sociodemographic variables such as lower levels of intelligence (McNally & Shin, 1995; Vasterling et al., 2002), younger age (van der Kolk, Greenberg, & Boyd, 1985), female gender (Breslau, Davis, Andreski, & Peterson, 1991), social economic status (King, King, Foy, Keane, & Fairbank, 1999) and social support (Brewin, Andrews, & Valentine, 2000), as well as personality and cognitive features such as neuroticism (McFarlane, 1989), catastrophic appraisals of trauma (Ehlers & Clark, 2000), external locus of control (Joseph, Williams, & Yule, 1995) and avoidant coping (Bryant, Marosszeky, Crooks, Baguley, & Gurka, 2000).

Similarly, in children and adolescents risk factors for PTSD and PTSS include female gender (Cauffman, Feldman, Waterman, & Steiner, 1998; Giaconia et al., 1995; Hoven et al., 2005), younger age (Hoven et al., 2005; Shannon, Lonigan, Finch, & Taylor, 1994; Vernberg, La Greca, Silverman, & Prinstein, 1996) as well as separation from parents before the age of 10 (Davidson, 1993), family history of psychological problems (Davidson, Swartz, Storck, Krishnan, & Hammett, 1985), poor parental coping (Pfefferbaum, 1997), parental exposure to the trauma (Hoven et al., 2005), maternal preoccupation with trauma (McFarlane, 1987), maternal PTSD (De-Vries, Soetekouw, Van Der Meer, & Bleihenberg, 1999; Famularo, Fenton, Kinscherff, Ayoub, & Barnum, 1994) and recency of trauma (Cohen, 1998; Fletcher, 1996). It should be noted that it remains unclear (due to their correlational nature) whether these "risk" factors reflect a vulnerability to, or a result of, PTSD, or both.

## 4. Application of PTSD and PTSS to childhood cancer

Recognition and utilization of the concepts of PTSD and PTSS in childhood cancer survivors and their parents clearly bestows a number of advantages. Firstly, children and parents who exhibit such symptomatic profiles may be able to understand these responses as recognizable and treatable reactions to traumatic experiences. Use of diagnostic taxonomies such as PTSD also enables rapid and succinct communication of potentially very complex problems. Furthermore, they assist clinicians in the selection and implementation of psychotherapeutic interventions that are specifically designed and tested for the amelioration of such symptomatic profiles. Nevertheless, conceptualization of cancer within the PTSD nosological framework is not without its difficulties and remains under continuous debate (Kangas et al., 2002). Similarly, the appropriateness of applying PTSD criteria to child and adolescent reactions to traumatic stress also warrants exploration. Accordingly, the current diagnostic features and constructs thought to underlie PTSD will be examined in terms of their application to children and adolescents as well as cancer more generally.

### *4.1. DSM-IV criteria applied to children and adolescents*

While the DSM-IV (APA, 1994) acknowledges that PTSD can be manifested differently in children and adults, there still remains some controversy surrounding its measurement and symptomatological expression in children and to a lesser degree adolescents. As well as those outlined by the DSM-IV (APA, 1994), further symptomatic divergences include low self-esteem, separation anxiety, generalized anxiety (Fletcher, 1996), bedwetting and sleep walking (Davis & Siegel, 2000). The degree of symptomatic divergence is most notable in preschool children who have been found to exhibit fewer cognitive features and little avoidance (Salmon & Bryant, 2002). It appears that although the American Academy of Child and Adolescent Psychiatry (AACAP, 1998) highlight that there are developmental stage specific diagnostic criteria (i.e., distinct symptomatic clusters) for PTSD, little research evidence in this area actually exists (Salmon & Bryant, 2002). Furthermore, the AACAP (1998) warn that children appear to experience long alternating periods of reexperiencing and avoidance, which may subsequently lead to under diagnosis.

Consequently, validity of assessment instruments for assessing PTSD in children (most of which are adapted from adult versions) is questionable (Davis & Siegel, 2000). In addition, many of the features of PTSD require verbal descriptions of internal affective states and memories which younger children are often unable to provide (Salmon & Bryant, 2002). Furthermore, the meaning of the traumatic event will differ according to developmental stage. Indeed, younger children may be more distressed by concrete aspects of the stressor (e.g., noise, pain) while older children may focus more on existential aspects (e.g., life threat, moral integrity). Accordingly, both recognition and subsequent diagnosis of PTSD in children is dependent on a number of factors including the meaning of the stressor, developmental stages and themes (i.e., emotional regulation, knowledge, memory, linguistic abilities) as well as symptomatic expression (Salmon & Bryant, 2002).

### *4.2. DSM-IV criteria applied to cancer specific traumata*

The DSM-IV requires a number of criteria to be met in order that a diagnosis of PTSD can be made (APA, 1994, pp. 426–429). However, many of the features which compose each criterion appear problematic when applied to cancer. First, unlike many traumatic stressors such as war and violence, natural disasters and rape, as well as other health-related events (e.g., traumatic brain injury, corrective surgery, burn accidents, etc.) identifying a discrete precipitating stressor in cancer is complicated given the protracted and multifaceted nature of the illness. Cancer is characterized by multiple and chronic stressors including; diagnosis, severity of disease, prognosis, invasive treatments, disfigurations, treatment side effects, late medical and psychosocial effects as well as risk of recurrence. Furthermore, the cancer stressor represents two distinct forms of diagnostic trauma type: life threat (i.e., diagnosis) and threat to physical integrity (i.e., subsequent treatment protocols). This cancer specific trauma profile also encompasses both type I (single event) and type II (repeated stressors) traumas, respectively (Terr, 1991).

With respect to the tripartite symptomatic signature of PTSD, re-experiencing symptoms (Criteria B) defined in terms of intrusive thoughts about past events, appear to be superseded or eclipsed by future orientated intrusions involving fears about one's health and the real possibility of potential relapse in many cancer patients (Kangas et al., 2002). Furthermore, meeting Criteria C (i.e., persistent avoidance of stimuli associated with the trauma) may be impossible given that many cancer patients and their families are unable to avoid stressors due to the internal locus of the stressor which necessitates ongoing treatments and follow-up appointments. Finally, Criteria D (i.e., persistent symptoms of increased arousal), which includes the presence of disturbed sleep, concentration and irritability, is heavily compounded by the side effects commonly associated with cancer treatment (Bernhard, Phil, & Ganz, 1991). Indeed, many of the disturbed psychological processes indicative of PTSD such as heightened, enduring and erroneous recall, incomplete and disorganized encoding and storage, dissociative amnesia, as well as automatic and strategic attentional biases (reviewed by Brewin & Holmes, 2003), are also found to result from cancer and its treatment, specifically for CNS/brain tumors (Fuemmeler et al., 2002). Disentangling the relative effects of subsequent cancer treatment and PTSD following a diagnosis of cancer remains a daunting yet necessary task.

It would seem that there are a number of difficulties applying the concept of PTSD (as delineated by DSM-IV [APA, 1994]) to the experience of cancer. Perhaps the most pertinent of these is that a number of these individuals may feel that they are still experiencing the trauma despite the fact that they are no longer diagnosed and treated for cancer. Accordingly, their responses may be more appropriately conceived of as traumatic, rather than posttraumatic, stress reactions. Furthermore, it is arguable that such reactions might also be conceived of as normative, as opposed to, pathological responses. Indeed, while PTSD was once considered a normative reaction to abnormal events, Yehuda and McFarlane (1995) contradicted this notion by highlighting that the development of PTSD following exposure to traumatic events tends to be the 'exception rather than the rule' and that individuals with PTSD demonstrate high rates of psychiatric comorbidity. They argue that these findings may suggest that PTSD is associated with an underlying predisposition to pathological states, rather than reflecting an isolated and normal response to stress. Similarly, even if the experience of childhood cancer was conceived of as an ongoing traumatic stressor, rates of PTSD would be the rule rather than the exception if it was a truly normative reaction.

In summary, given the present debate surrounding the appropriateness and applicability of PTSD to the experience of cancer, this review shall adopt the term 'cancer-related PTSD' and 'cancer-related PTSS' (in accordance with terms delineated by Kangas et al., 2002) in order to respect current conceptual and taxonomic dialectics.

## 5. Systematic review of cancer-related PTSD and PTSS literature

Recently, two excellent reviews of PTSD and PTSS in adults directly affected by cancer (Kangas et al., 2002) and general medical illnesses (Tedstone & Tarrier, 2003) have been published. Kangas et al. (2002) highlighted a number of issues pertinent to the assessment and treatment of cancer-related PTSD as well as advocating the need for a stronger empirical base to guide clinical management of PTSD in cancer patients. Tedstone and Tarrier (2003) documented that, irrespective of medical illness, prevalence rates of PTSS were more common than PTSD caseness. They also argued that the presence of PTSD influences the patients' healthcare utilization and medical outcome. However, to date, no study has reviewed PTSD and PTSS in childhood survivors of cancer and/or their parents and it is to this cohort that this review will restrict its examination. Furthermore, a synthesis of current findings within this field will provide healthcare professionals with a single reference source in order to better facilitate clinical decision-making and appropriate family support.

Within the last decade, a total of 24 studies (published between 1994 and 2004) were found to specifically address PTSD and PTSS in childhood cancer survivors and/or their parents. These have been reviewed in order to answer the following questions: (i) what are the methodological characteristics of studies exploring PTSD and PTSS in childhood cancer survivors and/or their parents? (ii) What is the prevalence of PTSD and PTSS in this clinical population? (iii) What are the risk factors that precipitate PTSD and PTSS in this clinical population?

### 5.1. Methodological characteristics of studies

Table 1 outlines the 24 published studies that recorded the incidence of PTSD and/or PTSS in childhood cancer survivors and/or their parents. Studies focused either exclusively on childhood survivors (Butler, Rizzi, & Handwerger, 1996; Erickson & Steiner, 2001; Hobbie et al., 2000; Langeveld, Groorenhuis, Voute, & de Haan, 2004; Meeske, Ruccione, Globe, & Stuber, 2001; Pelcovitz et al., 1998; Stuber, Meeske, Gonzalez, Houskamp, & Pynoos, 1994), the parents of childhood cancer survivors (Best, Streisand, Catania, & Kazak, 2001; Fuemmeler, Mullins, & Marx, 2001; Goldenberg Libov et al., 2002; Kazak et al., 1998; Manne, Du Hamel, Gallelli, Sorgen, & Redd, 1998, 2002, 2000; Pelcovitz et al., 1996) or both (Barakat et al., 2000, 1997; Brown et al., 2003; Kazak, Barakat, Meeske, & Christakis, 1997, 2001, 2004; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003; Stuber, Christakis, Houskamp, & Kazak, 1996, 1997). Only two studies were conducted outside the US (Landolt et al., 2003; Switzerland; Langeveld et al., 2004; Amsterdam).

While the majority of studies used heterogeneous cancer samples a number used either exclusively leukemia (Best et al., 2001; Kazak et al., 1997; Manne et al., 1998, 2002; Stuber et al., 1996) or brain tumor/CNS-cancer (Fuemmeler et al., 2001) populations. Sample sizes ranged considerably from 28 (Fuemmeler et al., 2001) to 618 (Barakat et al., 1997) participants. The grand mean at which these studies assessed participants was eight years post treatment, ranging from three days (Manne et al., 2002) to 33 years since completion (Langeveld et al., 2004). Ages of childhood cancer survivor participants ranged from six (Landolt et al., 2003) to 49 (Langeveld et al., 2004) years old.

On the whole, studies employed cross-sectional designs to detect PTSD and PTSS in childhood survivors and/or their parents, five of which employed a control/comparison groups (Brown et al., 2003; Kazak et al., 1997; Landolt et al., 2003; Pelcovitz et al., 1996, 1998). Only two cross-sectional studies included children currently in treatment (Butler et al., 1996) or mothers of children currently in treatment (Pelcovitz et al., 1996). Three studies used longitudinal designs which followed participants up at three months and six months (Manne et al., 2002), after three years (Barakat et al., 2000) and four years (Best et al., 2001) following their original participation. A total of five studies assessed only the prevalence of PTSD (Butler et al., 1996; Goldenberg Libov et al., 2002; Meeske et al., 2001; Pelcovitz et al., 1996, 1998) using the Structured Clinical Interview for DSM-IV (SCID-PTSD). Ten studies assessed the prevalence of PTSS employing self-report measures alone. These were the Posttraumatic Stress Disorder Reaction Index (PTSD-RI) (Brown et al., 2003; Kazak et al., 1997, 1998; Stuber et al., 1994, 1996, 1997), Posttraumatic Symptom Disorder Checklist-Civilian Version (PCL-C) (Manne et al., 2000), Posttraumatic Diagnostic Scale (PDS) (Fuemmeler et al., 2001) and the Impact of Events Scale (IES/-R) (Best et al., 2001; Langeveld et al., 2004). Finally, while eight studies used a combination of assessment measures (Barakat et al., 1997; Erickson and Steiner, 2001; Hobbie et al., 2000; Kazak et al., 2001, 2004; Landolt et al., 2003; Manne et al., 1998, 2002) to determine both PTSD and PTSS levels, only one of these (Kazak et al., 2001) used the Impact of Traumatic Stressors Interview Schedule

Table 1
Summary of PTSD and PTSS in childhood cancer survivors and/or their parents

| Study | Design | Sample | Assessment | Time off treatment: mean (range) | Incidence of PTSD/PTSS | Factors associated with PTSD/PTSS | Factors not associated with PTSD/PTSS |
|---|---|---|---|---|---|---|---|
| Barakat et al. (1997) | Cross-sectional interview questionnaires time one | $N=309$ childhood survivors of heterogeneous cancer<br>$N=309$ parents | PTSD-RI IES ALTTIQ | 40 months off treatment | On average child PTSS were in the normal range, with some indicating severe distress; mothers scores significantly higher | Perception of life threat<br>Perception of treatment intensity | Time off treatment |
| Barakat et al. (2000) | Longitudinal follow-up study (Barakat et al., 1997)<br>Interview postal questionnaires time two | $N=56$ childhood survivors of heterogeneous cancer<br>$N=65$ mothers | LES LExS BSI | 8.6 months off treatment | n/a | PTSS predicted general adjustment 18 months later | Lifetime stressful events |
| Best et al. (2001) | Longitudinal follow-up study (Kazak, Stuber, Barakat, & Meeske, 1996) | $N=113$ parents of children treated for leukemia | LSC PPQ STAI SNRDAT IES-R PTGI PAAS CHOP-SES | 3 years 7 months off treatment (7 months–8.6 years) | Not reported | Anxiety<br>Self-efficacy<br>Parental avoidance<br>Beliefs about cancer and duration of treatment<br>Recent treatment | Distress before treatment |
| Brown et al. (2003) | Cross-sectional interviews<br>Questionnaires healthy control | $N=52$ childhood survivors of heterogeneous cancer<br>$N=52$ of their mothers (not brain tumors) | MCSDS PTSD-RI PSS-Fa/Fr PSS-Fr A-FILE FILE FES | 5 years 9 months off treatment (1 year–14 years, 4 months) | 25% mothers exhibited symptoms indicative of cancer-related PTSD<br>Cancer survivors did not significantly differ from healthy control | Family functioning<br>Perceived emotional support<br>Family conflict<br>Life stress<br>Medical late ffects (for survivor only) | Current age<br>Age at diagnosis<br>Months off treatment<br>Disease severity |
| Butler et al. (1996) | Cross-sectional interviews | $N=72$ childhood patients and survivors | SCID-PTSD PIC-R CBCL | 41.7% on treatment<br>58.3% off treatment | 21% current cancer-related PTSD | Presently on treatment<br>Not receiving cranial irradiation | n/a |
| Erickson and Steiner (2001) | Cross-sectional interview questionnaires | $N=40$ childhood survivors of heterogeneous cancer | SCID-PTSD GAF IES WAI REMY-71 | Time since diagnosis 10 years (minimum 5 years off treatment) | 10% current cancer-related PTSD<br>88% currently met at least one trauma symptom | Personality characteristics | n/a |

|  |  |  |  |  |  |  |  |
|---|---|---|---|---|---|---|---|
| Fuemmeler et al. (2001) | Cross-sectional questionnaires | $N=18$ mothers<br>$N=10$ fathers of childhood survivors of brain tumors | PDS BSI WOC PPUS | Time since diagnosis 6 years (11 months–19 years) | 44% of mothers exhibited symptoms ndicative of cancer-related PTSD<br>40% of fathers exhibited symptoms indicative of cancer-related PTSD | Illness uncertainty | Emotion-focused coping style |
| Goldenberg Libov et al. (2002) | Cross-sectional interviews telephone | $N=49$ mothers of childhood cancer survivors | SCID-PTSD PSEI | Child's age at diagnosis 13 years (1–27 years) | 27% lifetime cancer-related PTSD<br>20% current cancer-related PTSD | Low magnitude stressors<br>Current perceptions of cancer threat family income | Time off treatment<br>Mother's education |
| Hobbie et al. (2000) | Cross-sectional interview questionnaires | $N=78$ adult survivors of heterogeneous childhood cancer | IES PTSD-RI STAI SCID-PTSD ALTTIQ BSI | 11 years off treatment (minimum 18 months of treatment) | 20.5% lifetime cancer-related PTSD<br>7.7% Severe range of PTSS | Current perceptions of life threat<br>Perceived treatment intensity | n/a |
| Kazak et al. (1997) | Cross-sectional interview questionnaires comparison group | $N=130$ childhood leukemia<br>$N=130$ mothers<br>$N=96$ fathers | PTSD-RI<br>FACE-III | 5.8 years post-treatment (n/a) | 1.4% children severe; 12.6% moderate PTSS<br>10.2% mothers severe; 30% moderate PTSS<br>9.8% fathers severe; 21.4% moderate PTSS | Avoidance in children<br>High levels of parent social support | Current age of child<br>Age at diagnosis<br>Months off treatment |
| Kazak et al. (1998) | Cross-sectional questionnaires | $N=320$ mothers<br>$N=224$ fathers of childhood survivors of heterogeneous cancer | PTSD-RI ALTTIQ FACE-III STAI | 5.7 years off treatment (1–18 years) | n/a | Trait anxiety<br>Parent appraisal of life threat<br>Family functioning<br>Child's age | Months off treatment |
| Kazak et al. (2001) | Cross-sectional interviews questionnaires | $N=66$ childhood survivors of heterogeneous cancer<br>$N=64$ mothers | IES PTSD-RI ALTTIQ YSR SCID-PTSD BSIITSIS | 4.9 years off treatment | Child: 4.3% current cancer-related PTSD;<br>Mother: 10.9% current cancer-related PTSD | n/a | n/a |
| Kazak et al. (2004) | Cross-sectional interviews questionnaires | $N=150$ adolescent survivors of heterogeneous cancer<br>$N=146$ mothers<br>$N=103$ fathers | IES-R SCID-PTSD PTSD-RI | 5.3 years off treatment (5 months–16 years) | Child: 4.7% current 8% life time cancer-related PTSD<br>Mother: 13.7% current 29.5% life time cancer-related PTSD<br>Father: 9.6% current 11.5% life time cancer-related PTSD | n/a | n/a |

(*continued on next page*)

Table 1 (*continued*)

| Study | Design | Sample | Assessment | Time off treatment: mean (range) | Incidence of PTSD/PTSS | Factors associated with PTSD/PTSS | Factors not associated with PTSD/PTSS |
|---|---|---|---|---|---|---|---|
| Landolt et al. (2003) | Cross-sectional child interview parent postal questionnaires comparison group | $N=30$ childhood survivors of heterogeneous cancer and their mothers and fathers | PTSD-RI PDS | 5–6 weeks post-diagnosis | Child: 10% symptoms indicative of cancer-related PTSD; mother: 44%; father: 44% symptoms indicative of cancer-related PTSD | Socio-economic status<br>Family situation<br>Preceding life events<br>Number of days child is in hospital<br>Functional status | Age of child<br>Gender of child |
| Langeveld et al. (2004) | Cross-sectional Questionnaires | $N=500$ adolescent and adult survivors of heterogeneous childhood cancer | IES | 15 years off treatment (5 years–33 years) | 12% severe range of PTSS<br>28% moderate range of PTSS | Female sex<br>Lower education<br>Increased number of late effects | Marital status<br>Age at follow up<br>Time off treatment<br>Diagnosis |
| Manne et al. (1998) | Cross-section Interview questionnaires | $N=65$ mothers of children undergoing bone marrow (BMT) and hematopoietic stem-cell transplantation (HST) | SCID-PTSD PCL-C | 3.2 years off treatment (4 months–7 years) | 6.2% current cancer-related PTSD<br>20% subclinical levels of PTSD | Depression<br>Anxiety | n/a |
| Manne et al. (2000) | Cross-sectional interview questionnaires | $N=72$ mothers of heterogeneous childhood cancer survivors (not brain tumors) | PCL-C ISEL MBSS LEC | 2.5 years off treatment (4 months–7 years) | 12.5% symptoms indicative of cancer-related PTSD | Perceived social constraints<br>Perceived lack of belonging | Monitoring coping style<br>Lifetime of traumatic events |
| Manne et al. (2002) | Longitudinal interview questionnaires | $N=82$ mothers of children undergoing BMT and HST | SCID-PTSD PCL-C BAI CSI | Time 1 = 3 days<br>Time 2 = 3 months<br>Time 3 = 6 months | 17.5% current cancer-related PTSD | Emotional distress<br>BMT-fears<br>Negative responses of families/friends | n/a |
| Meeske et al. (2001) | Cross-sectional interview questionnaires | $N=51$ adult survivors of heterogeneous childhood cancer | SCID-PTSD BSI | 11 years off treatment (2.8–26.7 years) | 20% current cancer related PTSD | Psychological distress | n/a |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| Pelcovitz et al. (1996) | Cross-sectional interview questionnaires control group | $N=24$ mother of heterogeneous cancer survivors (not brain tumors) | SCID-PTSD PSEI SCL-90-R | Currently in treatment | 54% lifetime cancer-related PTSD<br>25% current cancer-related PTSD | More prediagnosis high magnitude life events | Illness severity factors<br>Family and extrafamilial support |
| Pelcovitz et al. (1998) | Cross-sectional interview questionnaires control groups | $N=23$ adolescent survivors of heterogeneous cancer (not brain tumors) | SCID-PTSD PBI FACES III SCL-90-R | 3.3 years off treatment (0–11 years) | 35% lifetime cancer-related PTSD<br>17% current cancer-related PTSD | Mothers diagnosed with lifetime PTSD<br>Perceived chaotic family situation | Mothers global levels of psychological distress |
| Stuber et al. (1994) | Cross-sectional postal survey questionnaires | $N=30$ childhood survivors of heterogeneous cancer (not brain tumors) | PTSD-RI ALTTIQ | 61 months off treatment (22–128 months) | 17% symptoms indicative of cancer-related PTSD<br>30% reported mild levels of PTSS | Appraisal of treatment intensity<br>Child's age at diagnosis | Time off treatment<br>Appraisal of life threat |
| Stuber et al. (1996) | Cross-sectional postal survey questionnaires | $N=64$ childhood leukemia survivors<br>$N=63$ mothers<br>$N=42$ fathers | PTSD-RI | 6.7 years off treatment n/a | Child: 12.5%<br>Mothers: 39.7%<br>Fathers: 33.3% symptoms indicative of cancer-related PTSD | Age of child<br>Distressing medical procedures | n/a |
| Stuber et al. (1997) | Cross-sectional postal questionnaires | $N=168$ childhood survivors of heterogeneous cancer<br>$N=168$ mothers (not brain tumors) | PTSD-RI RCMAS SSRS ALTTIQ | 5.5 years off treatment (1–18 years) | n/a | Female sex<br>Stressful life events<br>Child anxiety<br>Mother and child's perception of treatment<br>Social support | Time off treatment |

A-FILE = Adolescent Inventory of Life Events and Changes; ALTTIQ = The Assessment of Life Threat and Treatment Intensity Questionnaire; BAI = Beck Depression Anxiety; BSI = Brief-Symptom Check List; CSI = Cancer Support Inventory; CHOP-SES = Children's Hospital of Philadelphia Self-Efficacy Scale; FACE-III = Family Adaptability and Cohesion Evaluation Scale; FES = Family Environment Scale; FILE = Family Inventory of Life Events and Changes; GAF = Global Assessment of Functioning; IES = Impact of Events Scale; ISEL = Interpersonal Support Evaluation List; ITSIS = Impact of Traumatic Stressors Interview Schedule; LSC = Langner Symptom Checklist; LES = Life Events Scale; LExS = The Life Experiences Scale; MBSS = Miller Behavioral Style Scale; MCSDS = The Marlowe–Crowne Social Desirability Scale; M-DIS, PTSD Module = Modified-Diagnostic Interview Schedule, PTSD Module; PAAS = Pediatric Anxiety and Avoidance Scale PBI = Parental Bonding Instrument; PCL-C = Posttraumatic Symptom Disorder Checklist-Civilian Version; PDS = Posttraumatic Diagnostic Scale; PIC-R = Personality Inventory for Children-Revised; PPQ = Perceptions of Procedures Questionnaire; PPUS = Parent's Perception Uncertainty in Illness Scale; PSEI = Potential Stressful Events Interview; PTGI = Post Traumatic Growth Inventory; PTSD-RI = Posttraumatic Stress Disorder Reaction Index; PSS-Fa = The Perceived Social Support-Family; PSS-Fr = The Perceived Social Support-Friend; REMY-71 = Response Evaluation Measure; RCMAS = Revised Children's Manifest Anxiety Scale; SNRDAT = Social Network Reciprocity and Dimensionality Assessment Tool; STAI = State-Trait Anxiety Index; SCID-PTSD = Structured Interview for DSM for PTSD; SCL-90-R = Symptom Checklist-90-Revised; SSRC = Social Support Rating Scale; WAI = Weinberger Adjustment Inventory; WOC = Ways of Coping Scale; YSR = Youth Self-Report.

(ITSIS) designed (and validated) solely for the use of assessing cancer-related PTSD in childhood cancer survivors and their parents.

### 5.2. Prevalence of PTSD and PTSS

#### 5.2.1. Prevalence of PTSD

Studies using the SCID-PTSD reported incidences of current cancer-related PTSD ranging from 4.7% (Kazak et al., 2004) to 21% (Butler et al., 1996) in childhood cancer survivors and 6.2% (Manne et al., 1998) to 25% (Pelcovitz et al., 1996) in their parents. Lifetime prevalence of cancer-related PTSD ranged from 20.5% (Hobbie et al., 2000) to 35% (Pelcovitz et al., 1996) in childhood cancer survivors and 27% (Goldenberg Libov et al., 2002) to 54% (Pelcovitz et al., 1996) in their parents.

#### 5.2.2. Prevalence of PTSS

Studies using the PTSD-RI, PDS, PCL-R, or IES documented PTSS in childhood cancer survivors to range from no abnormal symptomatology (Barakat et al., 1997) to 12.5% endorsing clinically severe levels of symptoms indicative of PTSD caseness (Stuber et al., 1996). For parents of childhood cancer survivors rates ranged from 9.8% (Kazak et al., 1997) to 44% (Fuemmeler et al., 2001) exhibiting clinically severe levels of PTSS indicative of PTSD caseness. The latter prevalence was found in a sample of parents of childhood brain tumor survivors. Overall, mothers appeared to demonstrate higher level of PTSS symptoms than fathers of childhood cancer survivors.

### 5.3. Predictors of PTSD and PTSS in childhood cancer survivors and their parents

There are a number of variables, documented throughout the 24 published studies that have been found to constitute potential risk and/or resilience factors in the development and maintenance of cancer-related PTSD and PTSS in childhood cancer survivors and their parents. These can be categorized as (i) static (fixed and unchangeable) predictors; (ii) dynamic (fluid and changeable) predictors; and (iii) relational predictors (parent–child factors) (see Fig. 1).

#### 5.3.1. Static predictors of cancer-related PTSD and PTSS

For taxonomic purposes this review considered the following variables as static in nature: parent sex, age of child, socioeconomic status, parental education, cancer type, treatment severity, time off treatment, physical late effects, number of prior stressful life events and personality style. Of those studies that examined cancer-related trauma in

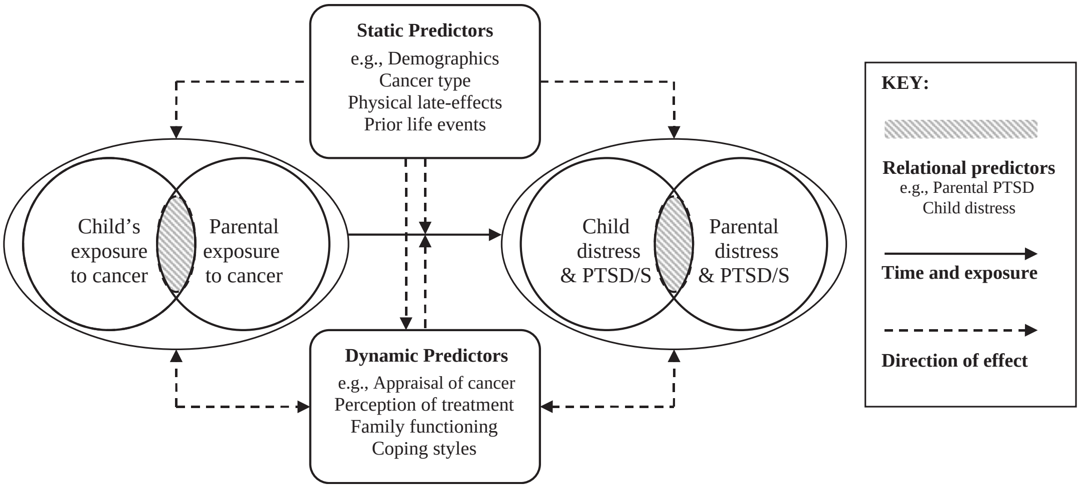

Fig. 1. Predictors of cancer-related PTSD and PTSS in children and their parents.

both parents all showed that mothers of childhood cancer survivors exhibited higher rates of cancer-related PTSS than fathers (Fuemmeler et al., 2001; Kazak et al., 1997; Landolt et al., 2003; Stuber et al., 1996). With respect to childhood cancer survivors, females were found to be at greater risk of cancer-related PTSS (Langeveld et al., 2004; Stuber et al., 1997). While Hobbie et al. (2000) found that older children diagnosed with cancer tended to exhibit higher rates of PTSD and PTSS than younger children, similar studies failed to support such age differences (Goldenberg Libov et al., 2002; Kazak et al., 1997; Landolt et al., 2003). Additionally, while some findings support the relationship between lower socioeconomic status and PTSS (Landolt et al., 2003) others find the opposite with high family incomes being positively correlated with elevated rates of PTSS (Goldenberg Libov et al., 2002). Furthermore, there appears to be no support for an association between low levels of parental education and elevated rates of PTSS (Goldenberg Libov et al., 2002).

Unfortunately, associations between cancer type and rates of PTSD and PTSS were not reported in any studies. However, it would appear that parents of childhood survivors of brain tumors were found to exhibit higher rates of PTSS (Fuemmeler et al., 2001) than those of leukemia survivors (Stuber et al., 1996) following treatment. Interestingly, objective medical data regarding treatment and/or illness severity (i.e., treatment modality and subsequent cancer related complications) repeatedly failed to predict PTSS in childhood cancer survivors (Brown et al., 2003) and PTSD in their parents (Hobbie et al., 2000; Pelcovitz et al., 1996). Furthermore, the vast majority of studies reported no correlation between time off treatment and rates of PTSD and PTSS (Barakat et al., 1997; Brown et al., 2003; Erickson & Steiner, 2001; Goldenberg Libov et al., 2002; Kazak et al., 1997, 1998; Landolt et al., 2003; Langeveld et al., 2004; Stuber et al., 1997). Only one study found time off treatment to be a significant individual predictor (final $\beta = -.36$, $p < .05$) of variance in mothers PTSS (Best et al., 2001).

Landolt et al. (2003) found a significant association between elevated levels of PTSS and physical late effects (i.e., functional outcome) for childhood cancer survivors and their parents. Furthermore, Brown et al. (2003) discovered a significant correlation between number of physical late effects (such as growth failure, cardiac impairment, sterility, and skeletal malformations obtained from patient notes by the researchers) and increased rates of PTSS in childhood cancer survivors but not their mothers. Conversely, a number of studies showed no significant associations between number and severity of physical late effects such as mild hearing loss, delayed sexual maturation and restrictions of daily activity (documented in the child's medical file) and PTSD in childhood cancer survivors (Hobbie et al., 2000; Pelcovitz et al., 1996).

Unsurprisingly, both quantity and quality of prior stressful life events were shown to be associated with increased risk of developing cancer-related PTSD and PTSS. Brown et al. (2003) found, for both childhood cancer survivors and their mothers, higher rates of PTSS was associated with higher incidences of past and recent (within the last 12 months) stressful life events. This association was strongest for those stressful life events that occurred over 12 months prior to the cancer experience. This finding supports those found in previous studies (Barakat et al., 1997; Stuber et al., 1997; Pelcovitz et al., 1996). However, a number of recent studies failed to demonstrate an association between stressful life events and PTSS in either childhood cancer survivors or their mothers (Barakat et al., 2000; Manne et al., 2000). Interestingly, although Goldenberg Libov et al. (2002) found no association between high magnitude stressors (i.e., natural disaster and abuse) experienced in the past year and rates of cancer-related PTSS, the correlation was significant for low magnitude stressors (i.e., marital distress and economic hardship).

Finally, Erickson and Steiner (2001) found that childhood cancer survivors that were PTSD-negative or met partial criteria reported higher levels of restraint and defensiveness (i.e., heightened impulse control, denial of distress and consideration for others) than those who were PTSD-positive. These authors contend that such personality characteristics reflect a relatively entrenched "repressive adaptive style" found to be more prevalent in childhood cancer populations than in normative samples. They argue that such personality characteristics may well reflect a lack of psychological awareness and subsequent reporting bias exhibited by survivors rather than true absence of trauma-related symptomatology.

### *5.3.2. Dynamic predictors and cancer-related PTSD and PTSS*

The following variables were considered dynamic in nature: perception of cancer and treatment factors, family functioning, social support and coping style. While little evidence supports the role of objective cancer and treatment factors, individual perception and appraisal of these was repeatedly shown to predict cancer-related PTSD and PTSS (Barakat et al., 2000; Best et al., 2001; Hobbie et al., 2000; Kazak et al., 1998; Stuber et al., 1997). Furthermore, current perceptions of cancer threat (Goldenberg Libov et al., 2002) and life threat today (Barakat et al., 1997;

Goldenberg Libov et al., 2002; Kazak et al., 1998) were shown to be associated with cancer-related PTSD and PTSS, as was perception of illness uncertainty (Fuemmeler et al., 2001).

Family functioning was also found to significantly contribute to the variance of cancer-related PTSS reported by mothers (Brown et al., 2003; Kazak et al., 1997). Specifically, greater family support was associated with fewer PTSS while high levels of conflict were associated with elevated levels (Brown et al., 2003). Pelcovitz et al. (1998) discovered that adolescent cancer survivors that met criteria for lifetime PTSD perceived their families as more chaotic than those without PTSD. Furthermore, increased family satisfaction and communication were consistently associated with fewer PTSS (Kazak et al., 1997). Negative responses of family and friends assessed at the time of bone marrow transplant (BMT) were also associated with PTSD in mothers (Manne et al., 2002). Kazak et al. (1998) found high levels of social support for mothers of childhood cancer survivors to be associated with fewer PTSS. However, Pelcovitz et al. (1996) found no association between family and extrafamilial support and PTSS. Interestingly, although Manne et al. (2000) found that perceived social constraint and lack of social network were associated with PTSS, other types of social support, such as tangible (instrumental aid) and appraisal (availability of someone to talk to) were not associated. Fuemmeler et al. (2001) documented that emotion-focused coping (i.e., avoidance, distancing oneself from and/or reframing the situation and controlling ones emotions) was correlated with PTSS in parents of childhood survivors of brain tumors. Manne et al. (2000) investigated that role of monitoring attentional coping styles (i.e., scanning and attending to health-related information and magnifying threatening cues). However, they found no association between monitoring and PTSS in mothers of childhood cancer survivors.

#### *5.3.3. Parent–child predictors of cancer-related PTSD and PTSS*

Studies suggest that parents (primarily mothers) of childhood cancer survivors play a fundamental role in mediating their child's PTSS (Stuber et al., 1994). Pelcovitz et al. (1996, 1998) found that adolescent cancer survivors were seven times more likely to develop PTSD if their mother had a current PTSD diagnosis. Similarly, a number of other studies found significant associations between levels of parent and child cancer-related PTSD and/or PTSS (Barakat et al., 1997; Kazak et al., 1997; Stuber et al., 1996). Furthermore, these symptoms were found to remain active years after it was clear that the child no longer faced an immediate risk to their health (Pelcovitz et al. 1998). Moreover, while maternal PTSD status correlated with adolescent PTSD status, maternal scores measuring overall adjustment (SCL-90-R) were not associated with PTSD in their children. Moreover, Pelcovitz et al. (1998) also found that although parental bonding was not associated with PTSD status in adolescent cancer survivors, perceptions of family cohesiveness and flexibility were negatively correlated.

Conversely, other studies reviewed failed to support a relationship between parent and child cancer-related PTSD and/or PTSS (Kazak et al., 2004; Landolt et al., 2003; Stuber et al., 1996). Although Landolt et al. (2003) found that levels of PTSS in mothers and fathers of pediatric patients were significantly correlated, they failed to find an association between parent and child PTSS. More recently, Kazak et al. (2004) examined rates of concordance of PTSD and PTSS in adolescent childhood cancer survivors and their parents and found no significant correlation existed between either parent (i.e., mother or father) and adolescent on rates of current and lifetime cancer-related PTSD. However, they did find that concordance on reexperiencing, avoidance and arousal symptoms between one parent and adolescent survivor all exceeded that expected by chance.

### *5.4. Summary of findings in relation to general PTSD predictors*

Overall, it would appear that rates of cancer-related PTSD and PTSS in childhood survivors and their parents are significantly higher than those found in the general child and adult population. Parents (particularly mothers) appear to be at greater risk, exhibiting higher rates of cancer-related PTSD and PTSS than childhood survivors. Furthermore, these prevalence rates found in parents exceed those documented in adult cancer survivors (Kangas et al., 2002). This relatively consistent profile may suggest that the experience of parenting a child with cancer may be inherently more traumatic than actual cancer survivorship (Smith et al., 1999).

Consistent with the general trauma literature, rates of cancer-related PTSD and PTSS were found to correlate with female gender (i.e., female cancer survivors and mothers), reduced social support and family functioning, as well as number of prior stressful life events. However, inconsistent with the general trauma literature was the relatively consistent finding that objective trauma features (e.g., treatment modality and intensity as well as life threat) failed to predict cancer-related PTSD or PTSS. Furthermore, while in the majority of cases, PTSS (examined in the general population) gradually disappears in the ensuing months following the trauma (Ehlers & Clark, 2000; Kessler et al., 1995; Perrin, Smith, & Yule, 2000), time since trauma exposure (i.e., cancer diagnosis and/or treatment cessation) failed to reliably correlate with cancer-related PTSS in childhood cancer survivors and their parents. Moreover, mixed support was found for the correlation between lower socioeconomic status and PTSS. Finally, although the general trauma literature has documented maternal PTSD to be correlated with child PTSD, support for this relationship remains inconclusive across the studies reviewed.

### *5.5. Methodological critique*

In light of the above findings it would appear that rates of cancer-related PTSD and PTSS as well as support for associated risk and resilience factors varies widely. Consequently, drawing reliable conclusions from the current evidence base remains difficult. It is therefore useful to explore a number of methodological issues which may account for some of the inconsistencies and variations observed in the current literature. These will include: (i) sampling issues; (ii) study design; (iii) assessment of cancer-related PTSD and PTSS; (iv) developmental factors; and (v) absence of theoretical foundation.

### *5.6. Sampling issues*

The extent of heterogeneity in the cancer samples was striking. Firstly, sample sizes varied considerably, ranging from 28 (Fuemmeler et al., 2001) to 618 (Barakat et al., 1997) participants. Accordingly, significant findings derived from smaller samples may be more vulnerable to type I error, thus compromising their reliability. However, reliability can be compromised in the opposite direction with studies trading off specificity and homogeneity for large (often very heterogeneous) sample sizes. Indeed, these larger samples often merged various cancer populations (Barakat et al., 1997; Kazak et al., 1998; Langeveld et al., 2004, Stuber et al., 1997), thus often overlooking their respective differences in prognosis, illness chronicity, treatment modality, number of recurrences, length of hospitalization and functional outcome. This is concerning in the light of findings which suggest that childhood brain tumor survivors and their parents, as opposed to other pediatric cancers, represent a population at increased risk of developing PTSD and PTSS (Fuemmeler et al., 2001, 2002). Indeed, Eiser, Hill, and Vance (2000) have also argued that it is inappropriate to include survivors of stage I Hodgkin's disease (who are likely to have experienced relatively brief non-invasive treatment) with survivors treated for brain/CNS tumors (which often involves complex neurosurgery and risk of neurocognitive sequelae). Furthermore, many studies used postal surveys to obtain their data (Barakat et al., 2000; Landolt et al., 2003; Stuber et al., 1994, 1996, 1997), a method known to secure poor response rates. Accordingly, it is unlikely that this self-selecting cohort is truly representative of the target population.

There was also extensive variability in time since diagnosis and/or off treatment both within and between studies. Assessment windows (time of participation) since treatment termination ranged from specific time points (3 days, 3 months and 6 months; Manne et al., 2002) to several decades (5–33 years; Langeveld et al., 2004). Moreover, a number of studies included children and/or their parents who had received a diagnosis within the past two to three weeks (Landolt et al., 2003) as well as those who were currently in treatment (Butler et al., 1996; Manne et al., 1998, 2000; Pelcovitz et al., 1996). There was also a large variability in the ages of childhood cancer survivors both within and between studies making it difficult to draw cross-study comparisons and derive reliable conclusions. Finally, a number of studies failed to provide important data such as time off treatment (Butler et al., 1996; Fuemmeler et al., 2001; Goldenberg Libov et al., 2002) and disease status of childhood survivors. Such information is critical for distinguishing direct illness and treatment effects from subsequent emotional sequelae.

### *5.7. Study design*

All but three studies (Barakat et al., 2000; Best et al., 2001; Manne et al., 2002) employed cross-sectional designs. These designs afford numerous benefits including measurements of prevalence rates in a given population, initial explorations of hypotheses (e.g., estimates of potential risk factors) and reduced attrition rates as well as being relatively inexpensive and time effective. However, distinct disadvantages are that the direction of causality is difficult to ascertain when explored within a single time point. Of course, longitudinal designs afford the distinct benefit of charting changes in adjustment and functioning which unfold over time (Eiser et al., 2000) and thus provide a more reliable and sophisticated method of understanding cancer-related PTSD and PTSS. However, very few studies utilized longitudinal designs. This dearth of longitudinal investigations may well reflect the inherent methodological difficulties in following up childhood cancer survivors whose prognosis is often uncertain and variable, hence directly affecting inclusion and exclusion criteria.

### 5.7.1. Assessment of cancer-related PTSD and PTSS

The instruments and procedures used throughout studies to measure PTSD and PTSS in participants also varied considerably. Specifically, while some used diagnostic interviews others implemented single and multiple informant self-report questionnaires. Consequently, it is important that researchers distinguish (and therefore not draw direct comparisons) between rates of PTSD diagnosis (measured by a clinician or researcher using the SCID-PTSD) and rates of PTSS (reported by participants using self-report questionnaire/s) indicative of PTSD caseness. A number of studies erroneously made such false comparisons. Furthermore, many self-report measures have not been validated on patients with chronic and life-threatening illnesses – particularly cancer – resulting in potential confounds on a number of items (e.g., sense of foreshortened future, agitation, poor concentration) (Tedstone & Tarrier, 2003). Concerns also relate to the reliability of current assessment tools used to index PTSD symptoms in children and adolescents more generally (Davis & Siegel, 2000).

A number of studies used single informants (usually mothers) to obtain measures of PTSS in parents and their children. Notably, those studies which used parents to rate their child's levels of distress yielded relational correlations in PTSS (Barakat et al., 1997; Pelcovitz et al., 1998) while those which used children as independent informants did not (Kazak et al., 2004; Landolt et al., 2003; Stuber et al., 1996). Such methodological inconsistencies may in part explain some of the variations in findings which look at concordance rates of PTSS in childhood survivors and their parents (Landolt et al., 2003). Additionally, those studies which utilized children as independent informants may have subsequently excluded those children with compromised functional outcomes following cancer, thus potentially constituting a different clinical population than those studies which used single informants to rate both parent and child symptoms. Finally, correlations between mothers' and fathers' self-reports of PTSS which have been reported in a number of studies (Fuemmeler et al., 2001; Landolt et al., 2003; Stuber et al., 1996) may in part reflect the fact that parents are likely to have completed measures together at home (Landolt et al., 2003).

### 5.7.2. Developmental factors

As previously discussed in relation to trauma in children generally, research suggests that while children and adults reactions to traumatic events are comparable, this is not evidence that child and adult PTSD are identical conditions, particularly in the case of younger children (Salmon & Bryant, 2002). Furthermore, while the validity of current instruments for assessing PTSD and PTSS in children remains questionable, the use of these measures within pediatric populations raises further uncertainty. Indeed, only one of the 24 studies reviewed attempted to design, validate and utilize an assessment specifically designed for child cancer survivors (Kazak et al., 2001). This instrument is argued to be sensitive to both developmental and illness features thought to be pertinent in cancer-related PTSD in children. A number of the studies included childhood survivors who had been diagnosed before their first birthday (Langeveld et al., 2004) and completed treatment as early as three-years-old (Brown et al., 2003). Clearly, encoding and appraisal of the traumatic experience, as well as later symptom manifestation and development is likely to be greatly influenced by the samples developmental stage and hence reported levels of PTSD and PTSS.

### 5.7.3. Absence of theoretical foundation

Although this review demonstrates that increasing attention is being focused on identifying possible risk and resilience factors in the development and maintenance of cancer-related PTSD and PTSS, many studies have failed to incorporate a conceptually driven rationale for their choice of predictor variables. Empirical research should always strive to emanate from sound theoretical frameworks in order to make sense of its experimental data. Only two studies (Brown et al., 2003; Erickson & Steiner, 2001) enlisted established conceptual models through which to derive their research questions. Although the majority of studies supplied hypotheses about why specific findings were observed, few wove these into a broader theoretical framework. Tedstone and Tarrier (2003) also argue that at present, physical health literature is not adequately assimilated into current theory and models of PTSD. Indeed, the majority of studies failed to bridge the gap between the theoretical literature on chronic illness and conceptual aspects of PTSD in general. Consequently, both cancer-related and dyadic (i.e., parent–child) models of PTSD and/or PTSS are scarce, limiting the emergence of an explanatory theoretical foundation from which to effectively guide future research questions and clinical interventions for both cancer populations and general PTSD sufferers.

## 6. Theories of PTSD applied to childhood cancer survivors and their parents

A large number of theories have attempted to elaborate the mechanisms thought to underlie the etiology and maintenance of PTSD. While each has offered important contributions to the field of posttraumatic stress this review has selected four theories through which to assimilate the current findings of cancer-related PTSD and PTSS in childhood cancer survivors and their parents: (i) stress response model; (ii) fear network model of emotional processing; (iii) dual processing theory; (iv) cognitive model of maintenance; and (v) relational models. These theories shall be explored with particular reference to their utility in conceptualizing the features and findings pertinent to the experience of childhood cancer.

### *6.1. Stress response model*

Although not exclusively intended for the specific conceptualization of PTSD, Horowitz's (1973, 1976, 1986, 1997) central ideas pertaining to individuals responses to trauma are readily applicable to the disorder. Essentially, he argues that psychological processing of trauma-related information is driven by the 'completion tendency.' This term refers to an individual's need to match and assimilate new information with prior knowledge held within existing inner models (Horowitz, 1986) or internal self-schemas (Dalgleish, 2004). This process of schematic assimilation is disrupted if thoughts, memories and images of the trauma cannot be organized within existing inner models of meaning, resulting in the failure to complete. Consequently, a number of psychological defense mechanisms are mobilized, such as numbing, repression, denial and avoidance, in order to prevent overwhelming distress and anxiety associated with the trauma (Horowitz, 1997). This is thought to generate two oppositional and oscillating processes: one to defend the individual by suppression of trauma related information (e.g., avoidance, denial and numbing) and the other to achieve 'completion' by working through the traumatic material (e.g., intrusions and flashbacks) in an ineffective effort to achieve completion or schematic assimilation (Brewin & Holmes, 2003).

Accordingly, it follows that receiving a diagnosis of childhood cancer (for both the child and their parent) may indeed constitute information which would challenge existing inner models and ideals about the self, others and the world. The repeated traumatic stressors inherent in the cancer experience (e.g., medical investigations, diagnosis, multiple treatments and follow-up appointments) may further exacerbate the process of schematic assimilation, resulting in a more chronic and persistent symptomatological presentation. Furthermore, the defensive response profile outlined by Horowitz (1986) is resonant of the repressive adaptive style found to be prevalent in childhood cancer patients (Erickson & Steiner, 2001) which is also characterized by repression, denial and avoidance. However, this profile was found to be negatively correlated with self-reports of PTSS.

### *6.2. Fear network model of emotional processing*

The fear network model of PTSD (Foa, Steketee, & Rothbaum, 1989) is based on "information-processing" theories which focus on the unique way in which the traumatic event is processed and represented in memory, rather than its impact on wider personal and social self-schemata. This fear network is represented as an associative system in long-term memory which comprises of three groups of elements: (i) information about the feared object/s; (ii) data about cognitive, behavioral and physiological reactions to feared object/s; and (iii) information which links the stimulus (traumata) and response elements together (Dalgleish, 2004). PTSD represents a pathological fear network, in which activation of any of these elements mobilizes a "fear program" resulting in unrealistic and excessive fear and distress. More recently, Foa and Rothbaum (1998) elaborated this model further by suggesting that the confirmatory or contradictory nature of the relationship between the traumatic experience and knowledge held prior to the trauma, during the trauma and after the trauma also contributes to the development of PTSD (Brewin & Holmes, 2003). In other words, individuals with rigid pre-trauma views about the self as being extremely incompetent or competent and the world as extremely unsafe or safe are at increased risk of developing PTSD. Finally, Foa and Rothbaum (1998) also discuss the role of exposure therapy in the habituation of fear, increasing the individual's sense of safety, mastery and courage, as well as disconfirmation of negative evaluations which are inconsistent with the evidence.

This model provides a comprehensive account of the various representational networks and pre-trauma schemas which underlie and perpetuate a fear program resonant of PTSD. It is likely that the protracted and multifaceted experience of childhood cancer may give rise to a complex and extensive fear network. Furthermore, it is understandable that children or parents who have rigid positive views about themselves as being extremely competent and the world as being very safe may well find the cancer experience dramatically incompatible with re-trauma schemas about one's (child's) safety and well-being. Use of exposure therapy for children and parents in habituating the fear associated with certain traumatic memories as well as assisting them access evidence of competency during distressing cancer events may indeed be successful in increasing the individual's sense of safety and well-being.

### 6.3. Dual representation theory

The central premise of dual representation theory (Brewin, Dalgleish, & Joseph, 1996) is that trauma memories are stored and represented in a fundamentally distinct way which underpins many of the symptomatic features associated with PTSD. It is argued that two parallel memory systems exist: verbally accessible memories (VAMs) which are characterized by their ability to be deliberately retrieved and modified as well as being congruent with the individual's autobiographical memory; and situationally accessible memories (SAMs) which refer to material which is not consciously accessible but dissociated, making them unavailable for editing and assimilation into autobiographical memory. Although these systems may operate concurrently, one may take precedence over the other at different times (Brewin & Holmes, 2003). The various features believed to highlight the nature of SAMs have included their relatively unconscious (Mack & Rock, 1998), lower level (Brewin et al., 1996) and perceptually based (Johnson & Multhaup, 1992; Pillemer, 1998; Tulving & Schacter, 1990) properties.

This theory offers a reasonably sophisticated explanation of PTSD, specifically in elaborating the mechanisms thought to underlie the two types of recall (i.e., flashbacks and reliving vs. verbally accessible narratives) characteristic of trauma memories. However, the theory does not explicitly include more abstracted knowledge structures such as schemas. Thus, it fails to address the transformation in meaning following traumatic events as well as the role of many pre-trauma risk factors (Dalgleish, 2004). Indeed, the role of prior life events and psychiatric history found to be prevalent in both general and cancer-related PTSD literature is not adequately accounted for within this model. Furthermore, as with the emotional processing model, developmental aspects of memory and emotion are disregarded by this model questioning its applicability to childhood PTSD. Childhood cancer survivors (particularly of brain tumors) are also at increased risk of neurocognitive sequelae thus further compounding the utility of models heavily rooted in memory representations.

### 6.4. Cognitive model of maintenance

Ehlers and Clark (2000) developed a cognitive model which focuses on the maintenance of PTSD. It is proposed that PTSD becomes persistent when the individual processes the traumatic event in a way that leads to a sense of serious current and future threat. It is proposed that this sense of threat arises from two principal sources: excessively negative appraisals of the trauma and/or its sequelae and a disturbance of autobiographical memory. It is believed that the individual's maladaptive behavioral and cognitive strategies prevent the otherwise healthy adaptation and restoration of these appraisal and memory systems (Ehlers & Clark, 2000).

This model, in addition to delineating associated disturbances in autobiographical memory, successfully elaborates and underscores the important role of cognitions and appraisal-driven emotions in the maintenance of PTSD. There is, however, one caveat in Ehlers and Clark's (2000) model when applied to the experience of childhood cancer. The authors place a great deal of emphasis on the remediation of dysfunctional cognitive strategies thought to produce a sense of current and future threat, thereby reinforcing and exacerbating PTSD symptomatology. However, a distinct feature of the cancer experience is the fact that the sense of threat is often realistically located in the future (i.e., risk of mortality, cancer recurrence, late effects, infertility and additional treatments). Such features of the cancer experience may underlie the observation that cancer-related PTSD and PTSS fails to reduce over time (due to the reality of ongoing traumata and threats). Furthermore, it may impede the success of cognitive interventions aimed at reappraising and modifying the sense of current or future threat in an effort to "place the trauma behind them."

### *6.5. Relational models*

Employing the metaphor of "contagion," Pfefferbaum and Pfefferbaum (1998) argue that PTSD can be conceived as "infectious" and hence directly and indirectly "transmitted" (Yehuda, Halligan, & Bierer, 2001) to others over time. They argue that while direct transmission involves first-hand exposure to the trauma, indirect transmission refers to secondary exposure through involvement and observations of family members or close associates. Perry, Pollard, Blakley, Baker, and Vigilante (1995) has argued that such a process could maintain symptoms that may have otherwise remitted in the absence of mutually reinforcing responses. Similarly, Scheeringa and Zeanah (2001) have proposed a compound effect model of PTSD which refers to the way the child's symptoms are moderated by the parent's distress and compromised responsiveness to him or her. These authors postulate a number of "relational PTSD patterns" which are believed to underpin the strength of this compound effect such as withdrawn, unresponsive or unavailable patterns, overprotective, or constricting styles and re-enacting, endangering or frightening interactions.

Relational PTSD models offer a preliminary framework through which to better understand the interactive nature of PTSD and PTSS in children and their parents. The utility of such models becomes further evident in the light of findings which suggest that cancer-related PTSD and PTSS proliferate throughout the entire family system. Parents of childhood cancer survivors may well become overprotective, constrictive and/or frightening as both a direct result of their child's illness and a secondary effect of their own distress thus potentially exacerbating survivor traumatization. In turn, the child's symptomatic response may further perpetuate parental traumatization. Such theoretical conjectures may possibly elucidate the observation that PTSS in childhood cancer survivors and their parents fails to decrease over time (i.e., time since treatment). However, no current relational model adequately explains the consistent finding that parents (predominately mothers) of childhood cancer survivors exhibit significantly higher rates of PTSD and PTSS than their children. Moreover, while these relational models offer good heuristic value for the conceptualization of PTSD and PTSD exhibited by family members, they fail to provide adequate empirical support for such theoretical conjectures. For example, it remains unclear what specific psychological mechanisms underlie the nature and function of contagion in distress.

### *6.6. Summary of current models*

It would appear that many of the findings (e.g., presenting features and risk factors) documented in the cancer-related PTSD and PTSS research are congruent with those reported in the general traumatological literature. However, there are also a number of features and findings which are not readily applicable to current conceptualizations and treatments interventions. Perhaps the most significant of these pertains to the nature of cancer which is distinct from other traumatic stressors in terms of its internal and future orientated realistic threat. This distinction is particularly problematic in light of current models of PTSD maintenance (Ehlers & Clark, 2000) which place the notion of negative appraisals (i.e., those relating to current and future threats) as central dysfunctional cognitions which require disconfirmation and modification. Furthermore, many theories do not adequately address the role of developmental factors (which are directly applicable to memory, emotion and appraisal processes) in the development and expression of PTSD in children. Accordingly, it may be advantageous for current models to elaborate the discussion of PTSD to encompass a developmental perspective. Such developmentally orientated research would pave the way to establishing intervention strategies that are sensitive to both the child's developmental stage and the roles and responses of parents over the course of the illness.

## **7. Directions for future research**

What is clear from the current literature on PTSD and PTSS in childhood cancer survivors and their parents is that findings are inconsistent. This prevents establishment of a coherent body of knowledge from which to inform and guide clinical assessments and interventions. Future research needs to identify specific mechanisms which both precipitate and maintain PTSD and PTSS in this clinical population. This review has highlighted a number of areas that warrant further investigation: (i) assessment of discrete cancer populations; (ii) coping styles and life-threatening illness; (iii) parent–child interactions; and (iv) the course and profile of trauma-related symptoms over time.

### 7.1. Assessment of discrete cancer populations

Only six studies used discrete cancer populations which consisted of leukemia (Best et al., 2001; Kazak et al., 1997; Manne et al., 1998, 2002; Stuber et al., 1996) and brain tumor samples (Fuemmeler et al., 2001). It is noteworthy that parents of childhood brain tumor survivors appeared to exhibit among the highest rates of PTSS and symptom chronicity. Indeed, this clinical population often endures invasive neurosurgery, frequently resulting in lengthy periods of hospitalization, temporary or permanent disfigurement and compromised cognitive and functional integrity. At present no study has explored PTSD and PTSS in childhood survivors of exclusively brain tumors. This is concerning in light of the emerging literature which suggests this subgroup of survivors are at a potentially higher risk, than other pediatric oncology populations, of psychological sequelae (Patenaude & Kupst, 2005). Indeed, two recent reviews of psychosocial outcomes in childhood brain tumor survivors (Fuemmeler et al., 2002) and PTSD in heterogeneous childhood cancer survivors (Stuber et al., 2003) have also called for future investigation into this clinical population.

### 7.2. Coping styles and life-threatening illness

Whereas role of illness appraisal has been extensively studied in the cancer-related PTSD and PTSS literature, the function of coping styles has been relatively overlooked. Given the increasing rate of available cancer treatments and consequential survival periods, research pertaining to coping strategies utilized by children and their parents and how these may impact on both responses to illness and adjustment to survivorship remains limited (Patenaude & Kupst, 2005). Brown et al. (2003) have stated that coping strategies may represent important mediating or moderating variables from which to better understand both the individual and family adaptation to the cancer experience which have not yet been explored.

### 7.3. Parent–child interactions

The relational nature of cancer-related PTSD and PTSD is far from established. Indeed, the few studies which have considered the role parent–child interactions have called for further studies to elucidate this neglected but important area. Specifically, Yule (1999) and Landolt et al. (2003) urge future research to consider how the reactions and adjustments of parents may moderate the effects of traumatic events on their children. Furthermore, Kazak et al. (2004) appealed for a more detailed examination of the mechanisms by which parent–child interactions may interact and associate with PTSS in childhood cancer survivors and their parents.

### 7.4. Course and profile of trauma-related symptoms over time

The course and profile of trauma-related symptomatology is inconsistent and poorly articulated in the current cancer-related PTSD and PTSS literature. However, a relatively consistent and reliable finding is that time off treatment appears to be unrelated to rates of cancer-related PTSD and PTSS (Brown et al., 2003; Goldenberg Libov et al., 2002; Kazak et al., 1997, 1998; Langeveld et al., 2004; Stuber et al., 1994). Smith et al. (1999) concluded that such findings may reflect a dynamic quality in symptom expression, some of which “wax and wane” in intensity, while others disappear entirely or are substituted by new symptoms. Furthermore, the process of contagion (Pfefferbaum & Pfefferbaum, 1998) may be a useful concept in understanding the symptomatic course and profile of symptoms over time. Indeed, Perry et al. (1995) suggests that such a process may maintain symptoms that might have otherwise remitted in the absence of mutually reinforcing responses. Future research needs to highlight the specific factors which may play a role in the course and profile of cancer-related PTSD symptomatology over time.

Overall, longitudinal studies are needed to effectively delineate and disentangle specific causal pathways, with respect to copings styles and parent–child interactions, in the development and expression of cancer-related PTSD and PTSS over time.

## 8. Summary

The experience of childhood cancer is a highly distressing and chronic life event which extends beyond the survivor to the entire family system. Children must endure a number of lengthy and aversive diagnostic procedures and treatments, frequently accompanied by short and long-term side effects. Accordingly, the construct of posttraumatic stress has proved a useful framework for the conceptualization of the associated psychological sequelae in childhood cancer survivors and their parents. However, its application is not without its diagnostic and conceptual difficulties. Over and above the contentions surrounding the reliability of PTSD diagnoses in children, the experience of childhood cancer represents a distinct traumatic stressor with respect to its protracted and multifaceted nature. Furthermore, a number of traumatological symptoms are confounded by the direct effects of cancer, its subsequent treatment and late effects.

Despite these shortcomings, a number of studies have documented clinically significant levels of cancer-related PTSD and PTSS in a substantial subset of childhood cancer survivors and their parents. A number of risk factors has also been delineated which 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. Many of these predictors are consistent with those highlighted in the general trauma literature. Overall, studies of cancer-related PTSD and PTSS differ considerably with respect to their methodology which may reflect the variability found in both rates of PTSD, PTSS and support for various risk factors. While a number of psychological models of PTSD appear to account for many of the findings and features of cancer-related PTSD and PTSS, there are other distinct characteristics which are not adequately explained within these paradigms. It is concluded that future studies should further explore the role of discrete cancer populations, coping styles, parent–child interactions and the profile of relational PTSD and PTSS over time.

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