Volume 1

Posttraumatic stress symptoms in childhood brain tumour survivors and their parents

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Overview

The literature review explores the relationship between the experience of childhood cancer and Posttraumatic Stress Disorder (PTSD) as well as posttraumatic stress symptoms (PTSS). Childhood cancer constitutes a life-threatening traumatic event, frequently engendering deleterious psychological sequelae throughout the entire family system. Accordingly, researchers have attempted to identify numerous predictor variables thought to underlie the development and expression of cancer-related trauma in survivors and their parents. It is concluded that very little is known about the prevalence of posttraumatic stress symptoms (PTSS) in brain tumour survivors and their parents. Furthermore, whilst parent-child interactions and coping styles have received a good deal of attention in health psychology and traumatology literature, very little is known about their moderating effects in cancer-related PTSD and PTSS. In response to these shortcomings, the empirical paper explores and tests the prevalence of PTSS in childhood brain tumour survivors and their parents including the moderating effects of parent-child interactions and attentional coping styles. It was found that approximately one in three childhood brain tumour survivors and their parents exhibited severe levels of PTSS, indicative of PTSD caseness. Mixed support was yielded for a number of the moderating factors explored. Although the critical appraisal highlights a number of methodological limitations and alternative interpretations, it is argued that the study's findings command sizable research and clinical implications.
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Part I: Literature Review

A Systematic and Conceptual Review of Posttraumatic Stress in Childhood Cancer Survivors and their Parents
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, the 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 number of correlates, varies widely in this clinical population. Findings are considered in the light of a number of contemporary theories of PTSD. Limitations within current conceptualisations 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.
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 internalising and externalising difficulties as well as social problems (Fuemmeler, Elkin, & Mullins, 2002). In recent years a growing body of literature has highlighted the presence of trauma-related symptomatology, such as avoidant behaviours, intrusive thoughts and heightened arousability in cancer survivors (see Smith, Redd, Peyser, & Vogal, 1999; Kangas, Henry, & Bryant, 2002 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, Goldberg, 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 conceptualised within current theories of PTSD. Finally, a number of recommendations for future research studies are delineated.

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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 utilised in other studies such as ‘child survivors’, ‘paediatric cancer survivors’, ‘survivors of childhood cancer’, or ‘young adult cancer survivors’.
Childhood cancer

Prevalence of childhood cancer

In the UK, approximately 1,400 cases of cancer were diagnosed in children (0-14 years) and 1,600 in adolescents and young adults (15-24) in 2001 (Office for National Statistics, Cancer Statistics registrations, 2004). 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 et al., 2000).

Childhood Cancer

Cancer is characterised by the uncontrollable and unregulated growth of cells which invade, erode and destroy surrounding normal tissue. Occasionally, they can metastasise 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 leukaemia (accounting for one-third of all cancer diagnoses) and brain/spinal tumours (constituting one-quarter). Other childhood cancers include soft tissue sarcomas, neuroblastoma, non-Hodgkin’s lymphoma, Wilms’ tumour, Hodgkin’s disease, germ cell tumours, retinoblastoma, osteosarcoma, and Ewing’s sarcoma (NCIRCC, 2002).
Leukaemia is characterised by the rapid growth of abnormal, immature white blood-forming cells which invade other tissues and organs. Over time their mass begins to out number and reduce the production of normal blood cells (white blood cells, red blood cells and platelets) in the bone marrow (NCIRCC, 2002). The most common form of Leukaemia among children is Acute Lymphoblastic Leukaemia. Brain and spinal tumours are sometimes referred to as central nervous system tumours (CNS-tumours) as they reflect a rapid growth of cells in the brain or nervous system. These cells form a mass (tumour) which interrupts and damages normal brain functioning. The most common type of brain tumour in childhood is astrocytoma.

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.

Diagnostic procedures. Perhaps the most common diagnostic procedures are CT (computerised 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 on occasions sedation or general anaesthetic is required if the child is very young or finds the procedure distressing. A biopsy is performed 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 tumours) 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.

Treatments. Surgical excision is usually performed if the child has a solid cancer (e.g., brain tumour) in order to remove as much of the cancerous tissue as possible. However, this may not be possible if the site or histology is contraindicative for surgery (e.g., blood-forming cells, vulnerable location in brain). Such treatment involves general anaesthetic and hospitalisation. 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., Leukaemia) 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.

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 include constipation, mouth soreness and ulcers as well as skin damage. Allergic reactions, shortness of breath, jaundice, blood in urine and lack of co-ordination have also been noted as reactions to treatments, but are less common (NCIRCC, 2002). Long-term physical late effects include organ damage, decreased growth and infertility (Oberfield & Sklar, 2002), scars, cardiac problems (Phipps, 1994) as well as neurocognitive deficits (Steinlin et al., 2003), with childhood survivors of acute lymphocytic leukaemia and brain tumours being 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).

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).

**Posttraumatic Stress Disorder**

*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, & George, (1991) found a lifetime prevalence of 1.3% in a large adult community UK 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.
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 conceptualisations of PTSD recognised the differential reactions and symptomatic expressions of children and adults following a traumatic event and revised its definitions accordingly. Whilst 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 disorganised or agitated behaviour. To meet the criteria for a diagnosis of PTSD such reactions must subsequently mobilise three specific symptom clusters. The first cluster (Criterion B) is characterised 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 generalised nightmares with or without recognisable content. The individual must experience one (or more) of these symptoms. The second cluster (Criterion C) is characterised 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 characterised 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 symptoms. Children may also ‘exhibit various physical symptoms, such as stomachaches 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).

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, 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 low self-esteem, female gender (Cauffman, Feldman, Waterman, & Steiner, 1998; Giaconia et al., 1995), younger age (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), maternal preoccupation with trauma (McFarlane, 1987), maternal PTSD (De Vries et al., 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.

Application of PTSD and PTSS to childhood cancer

The recognition and utilisation 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 recognisable and treatable reactions to traumatic experiences. The 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, the conceptualisation 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.
DSM-IV criteria applied to children and adolescents

Whilst the DSM-IV (APA, 1994) acknowledges that PTSD can manifest differently in children and adults, there still remains some controversy surrounding its measurement and symptomological expression in children and to a lesser degree adolescents (Lonigan et al., 2003). As well as those outlined by the DSM-IV (APA, 1994), further symptomatic divergences include low self-esteem, separation anxiety, generalised 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, the 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) whilst older children may focus more on existential aspects (e.g., life threat, functional integrity). Developmental
factors can further influence a child’s response to traumatic stressors with respect to their encoding of the event (i.e., younger children tend to encode less and more slowly resulting in less information being available for retrieval), their degree of prior knowledge (i.e., children’s understanding and appraisal of the stressor will have a direct affect on the amount and nature of information that enters memory) and linguistic abilities (e.g., traumatic events experienced prior to the development of language may become enacted behaviourally) (Salmon & Bryant, 2002). Consequently, children’s appraisals and responses to potentially traumatic stressors involve a complex interaction between the nature of the event and their cognitive development.

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. Firstly, 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 characterised by multiple and chronic stressors including: diagnosis, severity of disease, prognosis, invasive treatments, disfigurations, treatment side effects, follow-up appointments, late medical and psychosocial effects as well as risk of recurrence. Consequently, it may be that a number of individuals experiencing childhood cancer never actually reach a truly “post” traumatic position. 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 (Criterion 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 Criterion 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 the trauma due to the internal locus of the stressor which necessitates ongoing treatments and follow-up appointments. Finally, Criterion 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; Stuber et al., 2003). Indeed, many of the disturbed psychological processes indicative of PTSD such as heightened, enduring and erroneous recall, incomplete and disorganised 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 tumours (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 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, whilst 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 were conceived of as an ongoing traumatic stressor, rates of PTSD would be the rule rather than the exception if it were 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.
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 utilisation 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 facilitate clinical awareness, 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; and (iv) what are the methodological limitations of these studies?
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, Grooren, 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; Manne et al., 2002; Manne, Du Hamel, & Redd, 2000; Pelcovitz, Goldenberg Libov, Kaplan, & Weinblatt, 1996) or both (Barakat et al., 2000; Barakat et al., 1997; Brown et al., 2003; Kazak, Barakat, Meeske, & Christakis, 1997; Kazak et al., 2001, 2004; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003; Stuber, Christakis, Houskamp, & Kazak, 1996; Stuber et al., 1997). Only two studies were conducted outside the US (Landolt et al., 2003; Switzerland; Langeveld et al., 2004; Amsterdam).

Whilst the majority of studies used heterogeneous cancer samples, a number used either exclusively leukaemia (Best et al., 2001; Kazak et al., 1997; Manne et al., 1998; 2002; Stuber et al., 1996) or brain tumour/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 group (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., 2000; 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, whilst eight studies used a combination of assessment measures (Barakat et al., 1997; Erickson & 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 (ITSIS; Kazak et al., 2001) designed
(and validated) solely for the use of assessing cancer-related PTSD in childhood cancer survivors and their parents.

**Prevalence of PTSD and PTSS**

*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.

*Prevalence of PTSS.* Studies using the PTSD-RI, PCL-R, PDS, 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, Mullins, & Marx, 2001) exhibiting clinically severe levels of PTSS indicative of PTSD caseness. The latter prevalence was found in a sample of parents of childhood brain tumour survivors. Overall, mothers appeared to demonstrate higher level of PTSS symptoms than fathers of childhood cancer survivors.
<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Sample</th>
<th>Assessment</th>
<th>Time off treatment: mean (range)</th>
<th>Incidence of PTSD/PTSS</th>
<th>Factors associated with PTSD/PTSS</th>
<th>Factors not associated with PTSD/PTSS</th>
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</thead>
<tbody>
<tr>
<td>Barakat et al. (1997)</td>
<td>Cross-sectional</td>
<td>N= 309 childhood survivors of heterogeneous cancer N= 309 parents</td>
<td>PTSD-RI IES ALTTIQ</td>
<td>40 months off treatment</td>
<td>On average child PTSS were in the normal range, with some indicating severe distress. Mothers scores significantly higher</td>
<td>Perception of life threat</td>
<td>Time off treatment</td>
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<td>Interview Questionnaires</td>
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<td>Barakat et al. (2000)</td>
<td>Longitudinal follow-up study (Barakat et al. 1997)</td>
<td>N= 56 childhood survivors of heterogeneous cancer N= 65 mothers</td>
<td>LES LExS BSI</td>
<td>8.6 months off treatment</td>
<td>n/a</td>
<td>PTSS predicted lifetime stressful events</td>
<td>Lifetime stressful events</td>
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<td>Interview Postal</td>
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<tr>
<td>Best et al. (2001)</td>
<td>Longitudinal follow-up study (Kazak et al. 1996)</td>
<td>N= 113 parents of children treated for leukaemia</td>
<td>LSC PPQ STAI SNRDAT IES-R PSS-Fr PAAS CHOP-SES</td>
<td>3 years 7 months off treatment (7 months – 8.6 years)</td>
<td>Not reported</td>
<td>Anxiety Self-efficacy Parental avoidance Beliefs about cancer and duration of treatment Recent treatment</td>
<td>Distress before treatment</td>
</tr>
<tr>
<td>Brown et al. (2003)</td>
<td>Cross-sectional</td>
<td>N= 52 childhood survivors of heterogeneous cancer N= 52 of their mothers (not brain tumours)</td>
<td>MCSDS PTSD-RI PSS-Fr/PSS-Fr A-FILE FILE FES</td>
<td>5 years 9 months off treatment (1 year – 14 years, 4 months)</td>
<td>25% mothers exhibited symptoms indicative of cancer-related PTSD Cancer survivors did not sig. diff from healthy control</td>
<td>Family functioning Perceived emotional support Family conflict Life Stress Medical Late effects (for survivor only)</td>
<td>Current age Age at diagnosis Months off treatment Disease severity</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample</td>
<td>Assessment</td>
<td>Time off treatment: mean (range)</td>
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<td>Factors not associated with PTSD/PTSS</td>
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<td>Butler et al. (1996)</td>
<td>Cross-sectional Interviews</td>
<td>N= 72 childhood patients and survivors</td>
<td>SCID-PTSD PIC-R CBCL</td>
<td>41.7% on treatment 58.3% off treatment</td>
<td>21% current cancer-related PTSD</td>
<td>Presently on treatment</td>
<td>Not receiving cranial irradiation Personality characteristics</td>
</tr>
<tr>
<td>Erickson &amp; Steiner 2001</td>
<td>Cross-sectional Interview Questionnaires</td>
<td>N= 40 childhood survivors of heterogeneous cancer</td>
<td>SCID-PTSD GAF IES WAI REMY-71 PDS BSI WOC PPUS</td>
<td>Time since diagnosis 10 years (minimum 5 years off treatment)</td>
<td>10% current cancer-related PTSD</td>
<td>88% currently met at least one trauma symptom</td>
<td>44% of mothers exhibited symptoms indicative of cancer-related PTSD</td>
</tr>
<tr>
<td>Fuemmeler et al. (2001)</td>
<td>Cross-sectional Questionnaires</td>
<td>N= 18 mothers N= 10 fathers of childhood survivors of brain tumours</td>
<td>Time since diagnosis 6 years (11 months – 19 years)</td>
<td>Illness uncertainty</td>
<td>Emotion-focused coping style</td>
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<tr>
<td>Goldenberg Libov et al. (2002)</td>
<td>Cross-sectional Interviews Telephone</td>
<td>N= 49 mothers of childhood cancers survivors</td>
<td>SCID-PTSD PSEI</td>
<td>Child’s age at diagnosis 13 years (1-27 years)</td>
<td>27% lifetime cancer-related PTSD</td>
<td>Low magnitude stressors</td>
<td>Time off treatment Mothers education</td>
</tr>
<tr>
<td>Hobbie et al. (2000)</td>
<td>Cross-sectional Interview Questionnaires</td>
<td>N= 78 adult survivors of heterogeneous childhood cancer</td>
<td>IES PTSD-RI STAI SCID-PTSD ALTTIQ BSI</td>
<td>11 years off treatment (minimum 18 months of treatment)</td>
<td>20.5% lifetime cancer-related PTSD</td>
<td>Time of life threat Perceived treatment intensity</td>
<td>n/a</td>
</tr>
<tr>
<td>Kazak et al. (1997)</td>
<td>Cross-sectional Interview Questionnaires Comparison group</td>
<td>N= 130 childhood leukaemia survivors N= 130 mothers N= 96 fathers</td>
<td>PTSD-RI FACE-III</td>
<td>5.8 years post-treatment (n/a)</td>
<td>1.4% children severe; 12.6% moderate PTSS 10.2% mothers severe; 30% moderate PTSS 9.8% fathers severe; 21.4% moderate PTSS</td>
<td>Avoidance in children High levels of parent social support</td>
<td>Current age of child Age at diagnosis Months off treatment</td>
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<tr>
<td>Study</td>
<td>Design</td>
<td>Sample</td>
<td>Assessment</td>
<td>Time off treatment: mean (range)</td>
<td>Incidence of PTSD/PTSS</td>
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<td>Kazak et al. (1998)</td>
<td>Cross-sectional Questionnaires</td>
<td>N= 320 mothers N= 224 fathers of childhood survivors of heterogeneous cancer</td>
<td>PTSD-RI ALTTIQ FACE-III STAI</td>
<td>5.7 years off treatment (1-18 years)</td>
<td>n/a</td>
<td>Trait anxiety Parent appraisal of life threat Family functioning Child’s age</td>
<td>Months off treatment</td>
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<td>Kazak et al. (2001)</td>
<td>Cross-sectional Interviews Questionnaires</td>
<td>N= 66 childhood survivors of heterogeneous cancer N= 64 mothers</td>
<td>IES PTSD-RI ALTTIQ YSR YSR SCID-PTSD BSI ITSIS IES-R SCID-PTSD PTSD-RI</td>
<td>4.9 years off treatment</td>
<td>Child: 4.3% current cancer-related PTSD Mother: 10.9% current cancer-related PTSD</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Kazak et al. (2004)</td>
<td>Cross-sectional Interviews Questionnaires</td>
<td>N= 150 adolescent survivors of heterogeneous cancer N = 146 mothers N = 103 fathers</td>
<td>PTSD-RI FDS</td>
<td>5.3 years off treatment (5 months – 16 years)</td>
<td>Child: 4.7% current 8% life time cancer-related PTSD Mother: 13.7% current 29.5% life time cancer-related PTSD Father: 9.6% current 11.5% life time cancer-related PTSD</td>
<td>n/a</td>
<td>n/a</td>
</tr>
<tr>
<td>Landolt et al. (2003)</td>
<td>Cross-sectional Child Interview Parent postal Questionnaires Comparison group</td>
<td>N= 30 childhood survivors of heterogeneous cancer and their mothers and fathers</td>
<td>PTSD-RI PDS</td>
<td>5-6 weeks post-diagnosis</td>
<td>Child: 10% symptoms indicative of cancer-related PTSD Mother: 44% Father: 44% symptoms indicative of cancer-related PTSD</td>
<td>Socio-economic status Family situation Preceding life events Number of days child is in hospital Functional status</td>
<td>Age of child Gender of child</td>
</tr>
<tr>
<td>Langeveld et al. (2004)</td>
<td>Cross-sectional Questionnaires</td>
<td>N= 500 Adolescent and adult survivors of heterogeneous childhood cancer</td>
<td>IES</td>
<td>15 years off treatment (5 years – 33 years)</td>
<td>12% severe range of PTSS 28% moderate range of PTSS</td>
<td>Female sex Lower education Increased number of late effects</td>
<td>Marital status Age at follow up Time off treatment Diagnosis</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Description</td>
<td>Assessment</td>
<td>Time off treatment: mean (range)</td>
<td>Incidence of PTSD/PTSS</td>
<td>Factors associated with PTSD/PTSS</td>
<td>Factors not associated with PTSD/PTSS</td>
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<tr>
<td>Manne et al. (1998)</td>
<td>Cross-section Interview Questionnaires</td>
<td>N= 65 mothers of children undergoing bone marrow (BMT) &amp; hematopoietic stem-cell transplantation (HST)</td>
<td>SCID-PTSD PCL-C</td>
<td>3.2 years off treatment (4 months – 7 years)</td>
<td>6.2% current cancer-related PTSD 20% subclinical levels of PTSD</td>
<td>Depression Anxiety</td>
<td>n/a</td>
</tr>
<tr>
<td>Manne et al. (2000)</td>
<td>Cross-sectional Interview Questionnaires</td>
<td>N= 72 mothers of heterogeneous childhood cancer survivors (not brain tumours)</td>
<td>PCL-C ISEL MBSS LEC</td>
<td>2.5 years off treatment (4 months – 7 years)</td>
<td>12.5% symptoms indicative of cancer-related PTSD</td>
<td>Perceived social constraints Perceived lack of belonging</td>
<td>Monitoring coping style Lifetime of traumatic events</td>
</tr>
<tr>
<td>Manne et al. (2002)</td>
<td>Longitudinal Interview Questionnaires</td>
<td>N= 82 mothers of children undergoing BMT and HST</td>
<td>SCID-PTSD PCL-C BAI CSI</td>
<td>Time1 = 3 days Time2 = 3 months Time3 = 6 months</td>
<td>17.5 % current cancer-related PTSD</td>
<td>Emotional distress BMT- fears Negative responses of families / friends</td>
<td>n/a</td>
</tr>
<tr>
<td>Meeske et al. 2001</td>
<td>Cross-sectional Interview Questionnaires</td>
<td>N= 51 adult survivors of heterogeneous childhood cancer</td>
<td>SCID-PTSD BSI</td>
<td>1 year off treatment (2.8 – 26.7 years)</td>
<td>20% current cancer related PTSD</td>
<td>Psychological distress</td>
<td>n/a</td>
</tr>
<tr>
<td>Pelcovitz et al (1996)</td>
<td>Cross-sectional Interview Questionnaires Control group</td>
<td>N= 24 mothers of heterogeneous cancer survivors (not brain tumours)</td>
<td>SCID-PTSD PSEI SCL-90-R</td>
<td>Currently in treatment</td>
<td>54% lifetime cancer-related PTSD 25% current cancer-related PTSD</td>
<td>More prediagnosis high magnitude life events</td>
<td>Illness severity factors Family and extrafamilial support</td>
</tr>
<tr>
<td>Pelcovitz et al (1998)</td>
<td>Cross-sectional Interview Questionnaires Control groups</td>
<td>N= 23 adolescent survivors of heterogeneous cancer (not brain tumours)</td>
<td>SCID-PTSD PBI FACES III SCL-90-R</td>
<td>3.3 years off treatment (0-11 years)</td>
<td>35% lifetime cancer-related PTSD 17% current cancer-related PTSD</td>
<td>Mothers diagnosed with lifetime PTSD Perceived chaotic family situation</td>
<td>Mothers global levels of psychological distress</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample</td>
<td>Assessment</td>
<td>Time off treatment: mean (range)</td>
<td>Incidence of PTSD/PTSS</td>
<td>Factors associated with PTSD/PTSS</td>
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<tr>
<td>Stuber et al. (1994)</td>
<td>Cross-sectional Postal Survey Questionnaires</td>
<td>N= 30 childhood survivors of heterogeneous cancer (not brain tumours)</td>
<td>PTSD-RI ALTTIQ</td>
<td>61 months off treatment (22 – 128 months)</td>
<td>17% symptoms indicative of cancer-related PTSD 30% reported mild levels of PTSS</td>
<td>Appraisal of treatment intensity Children age at diagnosis</td>
<td>Time off treatment Appraisal of life threat</td>
</tr>
<tr>
<td>Stuber et al. (1996)</td>
<td>Cross-sectional Postal Survey Questionnaires</td>
<td>N= 64 childhood leukaemia survivors N= 63 mothers N= 42 fathers</td>
<td>PTSD-RI</td>
<td>6.7 years off treatment (n/a)</td>
<td>Child: 12.5% Mothers: 39.7% Fathers: 33.3% symptoms indicative of cancer-related PTSD</td>
<td>Age of child Distressing medical procedures</td>
<td>n/a</td>
</tr>
<tr>
<td>Stuber et al. (1997)</td>
<td>Cross-sectional Postal questionnaires</td>
<td>N= 168 childhood survivors of heterogeneous cancer N= 168 mothers (not brain tumours)</td>
<td>PTSD-RI RCMAS SSRS ALTTIQ</td>
<td>5.5 years off treatment (1 - 18 years)</td>
<td>n/a</td>
<td>Female sex</td>
<td>Time off treatment Stressful life events Child Anxiety Mother and child's perception of treatment Social support</td>
</tr>
</tbody>
</table>

A-FELE = 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; ITTIS = Impact of Traumatic Stressors Interview Schedule; LSC = Langner Symptom Checklist; LES = Life Events Scale; LExS = The Life Experiences Scale; MBSS = Miller Behavioural Style Scale; MCDS = The Marlowe-Crowne Social Desirability Scale; M-DIS, PTSD Module = Modified-Diagnostic Interview Schedule, PTSD Module; PAAS = Paediatric 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; SNRDA = 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.
Correlates 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 categorised as (i) static (fixed and unchangeable) correlates; (ii) dynamic (fluid and changeable) correlates; and (iii) relational correlates (parent-child factors) (see Figure 1).

**Figure 1.** Correlates of cancer-related PTSD and PTSS in children and their parents

**Static correlates 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 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). Whilst 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, whilst 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 brain tumour survivors were found to exhibit higher rates of PTSS (Fuemmeler et al., 2001) than those of leukaemia survivors (Stuber et al., 1996) following treatment. Interestingly, objective medical data regarding illness and/or treatment severity repeatedly failed to predict PTSS in childhood cancer survivors (Brown et al., 2003) and PTSD in 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 mother’s 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.

Dynamic correlates 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 styles. Whilst 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 whilst 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 tumours. 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.

*Parent-child correlates of cancer-related PTSD and PTSS.* Studies suggest that parents (primarily mothers) of childhood cancer survivors play a fundamental role in moderating their child's PTSS. 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, whilst maternal PTSD status correlated with adolescent PTSD status, maternal scores measuring overall adjustment (SCL-90-R; Derogatis, 1977) 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 paediatric 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.

Summary of findings in relation to general PTSD correlates
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, whilst in the majority of cases, PTSS (examined in the general population)
gradually disappears in the ensuing months following the trauma (Ehlers & Clark, 2000; Kessler, Sonnega, Bromet, Hughes, & Nelson, 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.

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.

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, thus often overlooking their respective differences in prognosis, illness chronicity, treatment modality, number of recurrences, length of hospitalisation and functional outcome. This is concerning in the light of findings which suggest that childhood brain tumour survivors and their parents represent an oncology subgroup at increased risk of developing PTSD and PTSS (Fuemmeler et al., 2001; Fuemmeler et al., 2002; Patenaude & Kupst, 2005). Indeed, Eiser, Hill and Vance (2000) have also argued that it is inappropriate to include survivors treated for stage I Hodgkin’s disease (that comprises relatively brief non-invasive treatment) with survivors treated for brain/CNS tumours (which often involves complex neurosurgery and risk of neurocognitive sequelae). Furthermore, many studies used postal surveys to obtain their data, 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 and disease status of childhood survivors. Such information is critical for distinguishing direct illness and treatment effects from subsequent emotional sequelae.

**Study Design.** The majority of the studies reviewed utilised 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, the 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 utilised 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.

**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, whilst 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
elevated rates of PTSD diagnosis (measured by a clinician or researcher using the SCID-PTSD) and elevated rates of PTSS (reported by participants using self-report questionnaire/s). 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) whilst 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 utilised 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, Mullins, & Marx, 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).

*Developmental factors.* As previously discussed in relation to trauma in children generally, research suggests that whilst 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, whilst the validity of current instruments for assessing PTSD and PTSS in children remains questionable, the use of these measures within paediatric populations raises further uncertainty. Indeed, only one of the 24 studies reviewed attempted to design, validate and utilise 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.

*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 broader theoretical frameworks. Tedstone and Tarrier (2003) also argue that at present, physical health literature is not adequately assimilated into current theories 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 relational (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.

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 aetiology and maintenance of PTSD. Whilst each has offered important contributions to the field of posttraumatic stress this review has selected five 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 conceptualising the distinct features intrinsic to the experience of childhood cancer.
Stress response model

Although not exclusively intended for the conceptualisation of PTSD, Horowitz's (1973, 1976, 1986, 1997) central ideas pertaining to individual's responses to trauma are readily applicable to this 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 organised within existing inner models of meaning, resulting in the failure to complete. Consequently, a number of psychological defence mechanisms are mobilised, 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 survivors (Erickson & Steiner, 2001) which is also characterised by repression, denial and avoidance. However, this profile was found to be negatively correlated with self-reports of PTSS.

_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 three groups of elements: (i) information about the feared object/s; (ii) data about cognitive, behavioural 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 mobilises 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 pre-trauma schemas about one’s (child’s) safety and well-being. The use of exposure therapy for children and parents in habituating the fear associated with certain traumatic memories as well as assisting them to access evidence of competency during and after distressing cancer events may indeed be successful in increasing the individual’s sense of safety and well-being.

Dual representation theory

The central premise of dual representation theory (Brewin et al., 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 (VAM’s) which are characterised by their ability to be deliberately retrieved and modified as well as being congruent with the individual’s autobiographical memory; and situationally accessible memories (SAM’s) 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 SAM's have included their relatively unconscious (Mack & Rock, 1998), lower level (Brewin, Dalgleish, & Joseph, 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) prevalent in individuals with PTSD. 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 tumours) are also at increased risk of neurocognitive sequelae thus further compounding the utility of models heavily rooted in memory representations.

*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 principle sources: excessively negative appraisals of the trauma and/or its sequelae and a disturbance in autobiographical memory. It is believed that the individual’s maladaptive behavioural 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 & 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, the cancer stressor 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”.

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Relational models

Employing the metaphor of ‘contagion’, Pfefferbaum and Pfefferbaum (1998) argue that PTSD (or distress more generally) can be conceived as ‘infectious’ and hence directly and indirectly ‘transmitted’ (Yehuda, Halligan, & Bierer, 2001) to others over time. They argue that whilst 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. For example, traumatic reactions exhibited by parents may be subsequently transmitted to their children. Perry et al. (1995) has argued that such processes 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 traumatisation. In turn, the child's symptomatic response may further perpetuate parental traumatisation. 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, whilst these relational models offer good heuristic value for the conceptualisation of PTSD and PTSS 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 distress contagion.

**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 conceptualisations and treatment 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, current models of PTSD are limited in explaining the consistent finding that childhood survivors of cancer exhibit fewer traumatic stress symptoms than their parents. This observation may well reflect the scarcity of developmentally (Salmon & Bryant, 2002) and relationally (Scheeringa & Zeanah, 2001) orientated theories of PTSD.

**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 the establishment of a coherent body of knowledge from which to inform and guide clinical assessments and interventions. Although it is evident that a significant proportion of this clinical population display cancer-related PTSD and PTSS, future research needs to identify the specific mechanisms which both precipitate and maintain this emotional disturbance. 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.

**Assessment of discrete cancer populations**

Only six studies used discrete cancer populations which consisted of leukaemia (Best et al., 2001; Kazak et al., 1997; Manne et al., 1998, 2002; Stuber et al., 1996) and brain tumour samples (Fuemmeler et al., 2001). It is noteworthy that parents of childhood
brain tumour 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 hospitalisation, 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 tumours. This is concerning in light of the emerging literature which suggests this subgroup of cancer survivors are at a potentially higher risk of psychological sequelae (Patenaude & Kupst, 2005). Indeed, two recent reviews of psychosocial outcomes in childhood brain tumour 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.

Coping styles and life-threatening illness

Whereas the 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 utilised 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.
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 specific parent-child interactions may interact and associate with PTSS in childhood cancer survivors and their parents.

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, whilst 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 coping styles and parent-child interactions, in the development and expression of cancer-related PTSD and PTSS over time.

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 conceptualisation 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 have 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 correlates 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. Whilst 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 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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Part II: Empirical Paper

Posttraumatic Stress Symptoms in Childhood Brain Tumour Survivors and their Parents
Abstract

Objectives: To investigate the prevalence of posttraumatic stress symptoms (PTSS) and general psychological adjustment difficulties in childhood survivors of brain tumours and their parents. To examine the role of hospitalisation, number of tumour recurrences, parent-child interactions and attentional coping styles on PTSS. The concordance of survivor and parent symptomatology, together with the effect of elevated PTSS on healthcare behaviour was also investigated. Method: The study employed a cross-sectional correlational design. Participants consisted of 52 childhood brain tumour survivors, aged 8–16, who completed the Parent-Child Interaction Questionnaire - Revised, Child Behavioural Style Scale, and Impact of Events Scale – 8; and 52 parents who completed the Parent-Child Interaction Questionnaire - Revised, Miller Behavioural Style Scale, Impact of Events Scale – Revised, General Health Questionnaire, and Strengths and Difficulties Questionnaire - Parent Form. Results: Over one third (35%) of childhood brain tumour survivors and 29% of their parents reported severe levels of PTSS indicative of a Posttraumatic Stress Disorder (PTSD) diagnosis. Duration of hospitalisation, parent-child conflict and high levels of monitoring and blunting attentional coping styles were associated with elevated distress in survivors. The number of tumour recurrences and parent-child conflict correlated with greater distress levels in parents. Conclusions: Childhood survivors of brain tumours appear to represent a paediatric oncology subgroup at considerable risk of developing PTSD and PTSS.
Introduction

Brain tumours command the highest mortality rate of all childhood cancers. Between 30,000 and 40,000 children worldwide have a brain tumour diagnosis (Bleyer, 1999), making it the second most prevalent type of childhood cancer (National Cancer Institute Research on Childhood Cancers, 2002) and constituting 17% of the paediatric oncology population (Fuemmeler, Elkin, & Marx, 2002). Fortunately, rapid advances in diagnostic procedures and treatment protocols for this paediatric population have ensured ever increasing periods of disease-free survival (Moore, 2005). However, research examining the psychosocial cost of survivorship in childhood brain tumour survivors, and particularly their parents, remains scarce (Fuemmeler et al., 2002). This may well reflect the fact that a great deal of paediatric psycho-oncology research has excluded childhood brain tumour survivors as they are considered atypical of the general paediatric cancer population (Patenaude & Kupst, 2005). Nonetheless, a number of recent reviews have drawn attention to this subgroup which appears to represent a cancer population at considerably higher risk of neurocognitive decline (Armstrong & Mulhem, 2000), compromised physical functioning (Moore, 2005) and psychosocial sequelae (Fuemmeler et al., 2002; Patenaude & Kupst, 2005).

In recent years, the construct of Posttraumatic Stress Disorder (PTSD) has proved a useful framework for the conceptualisation of psychological sequelae exhibited by a subset of childhood cancer survivors and their parents (Kazak et al., 2004). PTSD is characterised by a triad of symptomatic clusters: reexperiencing of the traumatic event; persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness; as well as persistent and heightened arousal. Following the inclusion of...
cancer in the Diagnostic and Statistical Manual, 4th edition (DSM-IV; American Psychological Association [APA], 1994) as a qualifying stressor for PTSD, a growing body of research is documenting this disorder, along with PTSS in childhood cancer survivors and their parents. Such recognition and utilisation of the concepts of PTSD and PTSS in this cohort bestow a number of advantages: firstly, children and parents who exhibit such symptomatic profiles may be able to understand these responses as recognisable and treatable reactions to traumatic experiences; secondly, the use of diagnostic taxonomies such as PTSD enables rapid and succinct communication of potentially very complex presenting problems; and finally they assist clinicians in the selection and implementation of timely and appropriate psychotherapeutic interventions.

In studies which have examined current cancer-related PTSD, rates of diagnosis range from 4.7% (Kazak et al., 2004) to 21% (Butler, Rizzi, & Handwerger, 1996) in childhood cancer survivors and 6.2% (Manne, DuHamel, Gallelli, Sorgen, & Redd, 1998) to 25% (Pelcovitz, Goldenberg, Kaplan, & Weinblatt, 1996) in their parents. In those studies which have examined rates of PTSS, severe levels of symptomatology (measured by self-report questionnaires) range from 1.4% (Kazak, Barakat, Meeske, & Christakis, 1997) to 17% (Stuber, Meeske, Gonzalez, Houskamp, & Pynoos, 1994) in childhood cancer survivors and 9.8% (Kazak et al., 1997) to 44% (Fuemmeler, Mullins, & Marx, 2001) in their parents. Notably, the latter figure constitutes both the highest prevalence rate found among studies as well as the only study to examine exclusively parents of childhood brain tumour survivors. Rates of cancer-related PTSD and PTSS appear to vary widely - an observation which may well in part reflect the diversity of measures and samples used in studies. Most interestingly, parents appear to report higher
levels of symptomatology than survivors (Barakat, Kazak, Gallagher, Meeske, & Stuber, 2000; Brown, Madan-Swain, Lambert, 2003; Kazak et al., 2001, 2004; Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003).

Researchers have also explored the role of various factors in the development of cancer-related PTSD and PTSS in childhood cancer survivors and their parents. Surprisingly, a number of studies have found that objective illness parameters (e.g., measures of cancer and treatment severity) repeatedly fail to significantly correlate with PTSD and PTSS in childhood cancer survivors and/or their parents (Brown, Madan-Swain, & Lambert, 2003; Langeveld, Grootenhuis, Voute, & de Haan, 2004; Pelcovitz et al., 1996). Nevertheless, two potentially distressing illness parameters, which have not yet been explored in relation to cancer-related PTSD and PTSS, are the duration of hospitalisation and number of recurrences. Furthermore, due to the multifaceted and protracted nature of the cancer stressor, it is likely that the quality of parent-survivor interactions and methods of coping will constitute further important variables in cancer-related PTSD and PTSS and general psychological adjustment in childhood cancer survivors and their parents.

The duration of hospitalisation may be particularly pertinent to the majority of childhood brain tumour survivors who often endure high-risk brain neurosurgery resulting in extended periods of hospitalisation that frequently include separation from parents. It is well documented that traumatised children and adolescents display heightened levels of separation anxiety (Fletcher, 1996; Scheeringa, Zeanah, Drell, & Larrieu, 1995; Smith, Perrin, & Yule, 1999) following exposure to traumatic events and
that separation from parents predicts later PTSD in children (Davidson, 1993; McFarlane, 1987). Furthermore, attachment systems often become activated during times of chronic and life-threatening paediatric illness (Schmidt, Strauss & Braehler, 2002). Cancer treatment may therefore potentially exacerbate separation anxiety in survivors placing them at increased risk of traumatisation as a result of hospitalisation. Indeed, Connolly, McClowry, Hayman, Mahony and Artman (2004) found that PTSS in children correlated with increased inpatient stays following cardiac surgery. In addition, children (owing to their cognitive development) have been documented to be more sensitised to, and hence distressed by, concrete aspects of the traumatic event (e.g., duration of stressful experiences, sounds, sights and physical discomfort) than adults who may become more traumatised by abstract features of the event such as degree of life threat (Salmon & Bryant, 2002). Hospitalisation may therefore present the child with a number of concrete stressors that become integral to the traumatic experience of childhood cancer.

The number of tumour recurrences may well constitute a feature of the cancer experience which has implications for both threat to the life and physical integrity of the survivor. Accordingly, one may argue that this represents a more abstract and future orientated feature of childhood cancer thereby engendering a more deleterious impact on parents than survivors. Indeed, Kazak et al. (1997) has argued that childhood cancer survivors may be less able than their parents to appreciate the implications and seriousness of their condition. The trauma literature has also suggested that a central feature of PTSD maintenance is the sense of current and future threat (Ehlers & Clark, 2000). Understandably, confirmation of such future threats (i.e., diagnosis of recurrence)
is likely to exacerbate negative appraisals of the cancer experience and reinforce an ongoing sense of fear, danger and helplessness.

Although childhood cancer has been conceptualised as a 'family disease' (Chesler & Barbarin, 1987) and argued to constitute the most stressful experience that the family system can encounter, the role of parent-child interactions in the development of PTSS and general psychological adjustment has received relatively little attention. Guided by social-ecological (Bronfenbrenner, 1979) and family systems (Haley, 1976; Minuchin, 1974) theories, a limited number of studies found that increased perceptions of family chaos (Kazak et al., 1997; Pelcovitz et al., 1998) and conflict (Brown et al., 2003) were associated with elevated PTSS in childhood cancer survivors and/or their parents. However, notably these studies explored perceptions of the family system as a whole, thus overlooking the unique contribution of parent-child interactions in the development of PTSS and general psychological adjustment. Furthermore, these authors also excluded childhood brain tumour survivors and their parents from their studies. Recently, Orbuch, Parry, Chesler, Fritz, and Repetto (2005) found that higher-quality parent-child interactions (defined by increased openness and support) predicted subsequent psychological well being in young adult survivors of childhood cancer. However, the extent to which parent-child interactions correlate with PTSS in childhood brain tumour survivors and their parents remains unexplored.

Additionally, it may be conjectured that parental distress may further increase the risk of PTSS in survivors (Kazak et al., 2004). Indeed, employing the metaphor of 'contagion', Pfefferbaum and Pfefferbaum (1998) have argued that PTSD (or distress
more generally) can be conceived as 'infectious' and hence directly and indirectly 'transmitted' to others over time (Koplewicz et al., 2002; Laor et al., 1997).

Accordingly, whilst a number of childhood cancer survivors may not develop PTSS as a direct result of the cancer experience, over time they may well be at increased risk of indirect transmission of PTSS and general psychological distress from exposure to traumatised parents. Scheeringa and Zeanah (2001) have developed a 'compound effect model' of PTSS which similarly attempts to characterise the process by which parental distress can moderate the relationship between the traumatic event and the child’s symptomatic response. Whilst a number of studies have documented concordance of PTSS and general psychological distress in paediatric populations and their parents (Barakat et al., 1997; 2000; Pelcovitz et al., 1998; Shears, Nadel, Gledhill, & Garralda, 2005), none have examined symptomatic contagion in childhood brain tumour survivors and their parents. Furthermore, no study has yet examined whether contagion in parent–survivor dyads increases over time.

The importance of parental and child coping during times of increased and protracted distress (inherent in the cancer experience) is paramount. Surprisingly, little attention has focused on the role of coping strategies in the development of PTSS and general psychological adjustment in childhood brain tumour survivors and their parents. However, there is an interesting body of research emerging from health information processing theory (Miller, Shoda, & Hurley, 1996; Miller, Mischel, O’Leary, & Mills, 1996) which suggests that individuals tend to either ‘monitor’ (i.e., actively scan, seek out and magnify threatening cues) or ‘blunt’ (i.e., distract from, avoid and minimise threatening information) as responses to health threats. These responses are considered
to constitute two equally prevalent and stable dispositional ‘attentional coping styles’ (Miller & Schnoll, 2000). In response to high-threat conditions (e.g., severe and prolonged life-threatening illnesses) monitors repeatedly demonstrate higher levels of anxiety, rumination and rehearsal of ‘bad news’ (Miller & Schnoll, 2000; Muris, de Jongh, van Zuuren, ter Horst, 1994), as well as heightened physiological tension (Bruehl, Carlson, Wilson, & Norton, 1996) compared to blunters. In addition, individuals who display higher levels of monitoring attentional coping styles have been found to report high levels of anxiety and PTSS (Schwartz, Lerman, Miller, Daly, Masny, 1995; Miller, Rodoletz, Schroeder, Mangan, & Sedlacek, 1996). This has been further observed to lead to the mobilisation of excessive denial, emotional numbing and behavioural disengagement strategies (Miller et al., 1996). This pathogenic pathway has become conceptually known as the Monitoring Process Model (MPM: Miller, Roussi, Caputo, & Kruus, 1995; Schwartz et al., 1995).

Guided by the MPM, Manne, DuHamel and Redd (2000) explored the relationship between monitoring coping styles and PTSS in mothers of childhood cancer survivors, yet found no empirical support for this model. However, they excluded childhood cancer survivors from their investigation which is unfortunate in the light of research findings which suggest that paediatric oncology survivors demonstrate significantly higher levels of blunting attentional coping compared to healthy controls (Phipps, Fairclough, & Mulhern, 1995; Phipps & Srivastava, 1997). Indeed, individuals who demonstrate a greater propensity for blunting repeatedly exhibit less psychological distress than those who endorse greater monitoring coping styles (Miller et al., 1994; Miller & Schnoll, 2000). Accordingly, the extent to which increased levels of blunting
acts as a protective factor in the development of PTSS in childhood cancer survivors and their parents remains unexplored. Furthermore, paediatric oncology survivors’ propensity for blunting may in part explain the consistent finding that parents exhibit considerably higher rates of cancer-related PTSD and PTSS than survivors.

If PTSD and PTSS increase the risk of excessive denial and behavioural disengagement, as documented in the general trauma (Foa & Riggs, 1995; Horowitz, 1986) and health psychology literature (Miller & Schnoll, 2000), the consequences of these outcomes on healthcare behaviour (e.g., outpatient appointment attendance, adherence to medical recommendations) may be potentially life-threatening. Perhaps even more troubling is the fact that such consequences in the cancer-related PTSD and PTSS literature remain unknown. In related fields, PTSS has been found to predict greater medical non-adherence in paediatric liver transplant patients (Shemesh et al., 2000) and cardiac morbidity in a longitudinal study of adult heart transplant survivors (Dew et al., 1999). Accordingly, the effect of elevated PTSS in childhood brain tumour survivors and particularly their parents (who are likely to oversee and coordinate the child’s medical care [Stuber, Shemesh, & Saxe, 2003]) on subsequent healthcare behaviour clearly warrants investigation.

Therefore, this study aims to pursue a number of original paths of enquiry, namely the relationship between specific illness parameters (i.e., duration of hospital admission and number of tumour recurrences), parent-child interactions and attentional coping styles with the development of PTSS and general psychological adjustment difficulties in childhood brain tumour survivors and their parents. Additionally, it
attempts to examine whether symptoms are ‘contagious’ over time and investigate the relationship between elevated PTSS and healthcare behaviour. A total of seven research hypotheses will be investigated:

1) survivors will endorse significantly higher levels of blunting than healthy children (i.e., compared to standardised normative data)

2) there will be a positive association between duration of hospital admission and PTSS and general psychological adjustment difficulties in survivors

3) there will be a positive association between number of recurrences and PTSS and general psychological adjustment difficulties in parents

4) higher levels of perceived quality of parent-child interactions (i.e., conflict resolution and acceptance) will be associated with lower levels of PTSS and reduced general psychological adjustment difficulties in survivors and their parents

5) high levels of monitoring attentional styles will be correlated with elevated levels of PTSS and general psychological adjustment difficulties. Conversely, high levels of blunting attentional styles will be associated with lower levels of PTSS and reduced general psychological adjustment difficulties in survivors and their parents

6) there will be a correlation between parental and survivor PTSS and general psychological adjustment difficulties which will increase as a function of time off treatment

7) there will be a negative association between PTSS and healthcare behaviour as indexed by outpatient appointment attendance.
Method

Participants

Participants. Potential participants were identified from a list of children who were diagnosed and treated for brain tumours between 1996 and 2004 at a single-site children's hospital in the U.K. Eligibility for inclusion included: (1) children aged over four-years-old at time of diagnosis; (2) children aged between 8 and 16-years-old at time of participation; (3) children had completed treatment at least 6 months and no more than 7 years prior to participation and were disease-free; and (4) the parent was involved in the child's care during diagnosis and treatment. Of the initial list of 180 parent/guardian-survivor dyads, 140 met the research criteria and were approached via two separate methods, as detailed in figure 2. A final sample of 52 childhood brain tumour survivors and 52 parents took part in the study. Parents consisted of 46 biological mothers and 6 biological fathers. The mean age of parents was 42 (ranging from 31 to 53 years). Sample parameters of childhood brain tumour survivors are reported in Table 1.
Figure 1. Recruitment flowchart

Non-participants. Statistical analyses revealed that (survivor) non-participants did not differ significantly from participants with respect to sex ($\chi^2 [1] = 1.80, p = .18$) and age at assessment ($t[119] = -.07, p = .95$).
Table 1

Sample Characteristics of Childhood Brain Tumour Survivors

<table>
<thead>
<tr>
<th>Disease and demographic information</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sex of survivor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
<td>55.8</td>
</tr>
<tr>
<td>Male</td>
<td>23</td>
<td>44.2</td>
</tr>
<tr>
<td>Ethnicity</td>
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<td></td>
</tr>
<tr>
<td>White</td>
<td>44</td>
<td>84.6</td>
</tr>
<tr>
<td>Asian</td>
<td>4</td>
<td>7.7</td>
</tr>
<tr>
<td>Mixed race</td>
<td>3</td>
<td>5.8</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Brain tumour diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Astrocytoma</td>
<td>19</td>
<td>36.5</td>
</tr>
<tr>
<td>Craniopharyngioma</td>
<td>8</td>
<td>15.4</td>
</tr>
<tr>
<td>Ependymoma</td>
<td>6</td>
<td>11.5</td>
</tr>
<tr>
<td>Medulloblastoma</td>
<td>5</td>
<td>9.6</td>
</tr>
<tr>
<td>Mixed Glioma</td>
<td>4</td>
<td>7.7</td>
</tr>
<tr>
<td>Other</td>
<td>10</td>
<td>19.2</td>
</tr>
<tr>
<td>Number of recurrences</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>38</td>
<td>73.1</td>
</tr>
<tr>
<td>1</td>
<td>7</td>
<td>13.5</td>
</tr>
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<td>2</td>
<td>5</td>
<td>9.6</td>
</tr>
<tr>
<td>3</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Treatment type</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Surgery only</td>
<td>18</td>
<td>34.6</td>
</tr>
<tr>
<td>Chemotherapy only</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>Radiotherapy only</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>Chemotherapy and radiotherapy only</td>
<td>2</td>
<td>3.8</td>
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<tr>
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<td>3.8</td>
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<tr>
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<td>22</td>
<td>42.3</td>
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<tr>
<td>Surgery, chemotherapy and radiotherapy</td>
<td>5</td>
<td>9.6</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Age/Time</th>
<th>Mean (S.D)</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age of child at diagnosis</td>
<td>8.1 (2.73)</td>
<td>4 – 13</td>
</tr>
<tr>
<td>Age of child at assessment</td>
<td>12.7 (2.70)</td>
<td>8 – 16</td>
</tr>
<tr>
<td>Duration in hospital (days)</td>
<td>22.2 (15.81)</td>
<td>2 – 67</td>
</tr>
<tr>
<td>Time off treatment (months)</td>
<td>36.1 (19.93)</td>
<td>8 – 88</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Healthcare behaviour*</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of DNA appointments</td>
<td>3.9 (4.71)</td>
<td>0 – 19</td>
</tr>
<tr>
<td>Number of cancelled appointments</td>
<td>22.07 (10.55)</td>
<td>0 – 53</td>
</tr>
</tbody>
</table>

*DNA = scheduled appointments that families did not attend; cancelled = scheduled appointments cancelled before day of meeting (figures based on percentage of DNA’s and cancellations).

Procedure

Two recruitment strategies were employed to accrue participants for the study. The first of these involved sending recruitment packs to families who did not have scheduled appointments at the hospital. The recruitment pack – designed in accordance with the
internal Research Ethics Committee and APA guidelines - consisted of a recruitment letter explaining the purpose of the study (see Appendix 1), parent/guardian and child information sheets (see Appendix 2), consent forms (see Appendix 3), parent/guardian and child questionnaire batteries (see Appendix 4) as well as a stamped-addressed return envelope. Families that did not respond within three months of initial solicitation were sent a reminder letter, an additional recruitment pack and stamped addressed return envelope.

The second recruitment strategy targeted those families that had scheduled check-up appointments at the hospital. These families were directly approached and invited to participate. Families who stated that they were willing to take part in the study were given recruitment packs with the option of completing the forms in clinic or at home. Those who agreed to complete the packs in clinic were provided with appropriate stationery and an internal mailing envelope. In addition, children under the age of 10 were assisted (following consent from their parent/s) by a researcher to complete the questionnaires. Families that opted to take the recruitment packs home were given follow-up telephone calls if their questionnaire packs were not returned within two months in order to resolve any questions or concerns regarding the measures and ensure that their forms had not been misplaced.

The percentage of respondents from postal recruitment packs was 36% (seven parents replied stating that they did not wish to participate because it was either still too distressing for them to think about or they did not wish to dwell on the experience) and the percentage of participants from outpatient clinic appointments was 74% (two parents
declined providing similar reasons to those from postal solicitation, whilst five agreed to take the packs home but did not return them) yielding a final sample size of 52 parent-survivor dyads who completed the questionnaires.

Design and analysis

Parametric (Pearson's product moment and eta correlation coefficient) statistics were used to examine bivariate associations between independent (continuous and nominal data) and dependent (continuous) variables. Hierarchical multiple regression models were tested in order to examine the relative effects of significant correlation coefficients in accounting for variance in dependent variables. In these analyses, at $\alpha = 0.05$, the current sample size afforded a power greater than .80 (80%) to find medium and large size effects.

Ethical considerations

The proposal was reviewed by the Great Ormond Street Hospital for Children NHS Trust/Institute of Child Health Research Ethics Committee. A Copy of the approval letter is shown in Appendix 5.

Measures

Disease and treatment characteristics

A patient information database was used to obtain data regarding survivor sex, ethnicity, age at diagnosis and assessment, tumour type, treatment modality, duration of hospitalisation, number of tumour recurrences, months off treatment and outpatient appointment attendance.
Parent psychological measures

Parent-child interactions. The Parent-Child Interaction Questionnaire – Revised – Parent Version (PACHIQ-R-P; Lange, Evers, Jansen, & Dolan, 2002) is a 21-item self-report scale designed to assess the quality of the parenting relationship between parent and target child. Scoring is based on a 5-point likert scale with regard to frequency or applicability of certain target behaviours, attitudes and feelings exhibited by parent and child. The measure is composed of a Conflict Resolution subscale (12 items) which reflects how the parent effectively manages parenting tasks and disagreements (e.g., ‘[child’s name] breaks our house rules almost everyday’) and an Acceptance subscale (nine items) which pertains to positive thoughts and feelings held about the target child (e.g., ‘I am very proud of [child’s name]’). The PACHIQ-R-P provides total subscale scores (Conflict Resolution: 12 – 60; Acceptance: 9 - 45) and PACHIQ-R-P Total (21 – 105). Higher total scores on individual and combined subscales indicate more positive parent-child interactions. The measure has been standardised on normal and outpatient samples (Lange et al., 2001; 2002). It demonstrates high internal reliability of total scaled scores (mothers: .86; fathers: .86) and subscale scores (Conflict Resolution: .90, .93; Acceptance: .79, .81, for mother and fathers respectively).

Attentional coping styles. The abbreviated version (Steptoe, 1989) of the Miller Behavioural Style Scale (MBSS; Miller et al., 1987) was used to assess the propensity for individuals to seek out (monitor) or avoid (blunt) threatening health related information. This measure consists of two scenarios (i.e., going to the dentist and the threat of job loss), each of which is followed by eight potential response styles. Four of
these describe monitoring attentional styles (e.g., ‘I would watch all the dentist's movements and listen for the sound of the drill’) whilst the remaining four delineate blunting approaches (e.g., ‘I would do mental puzzles in my mind’). Respondents are asked to imagine the scenarios and then endorse those responses that apply to them (i.e., dichotomous yes/no scoring). Summing the items endorsed on each subscale yields their respective scores (ranging from 0 – 8 for each subscale). The original MBSS demonstrates satisfactory internal reliability (monitoring: .79; blunting: .69) (Miller, 1987), adequate test-retest reliability (monitoring: .72; blunting: .75) and good discriminate validity (Miller, Brody, & Summerton, 1988; Ross & Maguire, 1995). Although the abbreviated version was used in the present study, significant correlations with the original version have been observed (monitoring: .90; blunting: .83) (Steptoe, 1989).

Posttraumatic stress symptoms. The Impact of Event Scale – Revised (IES-R; Weiss & Marmar, 1997) is a well standardised 22-item self-report instrument designed to measure the three symptom clusters – intrusion, avoidance and hyperarousal - associated with DSM-IV PTSD. The scoring scheme consists of a 5-point likert scale which is used to indicate the incidence and frequency of symptoms during the past seven days. The Avoidance subscale consists of eight items (e.g., ‘I stayed away from reminders of it’). The Intrusion subscale also comprises of eight items (e.g., ‘Pictures about it popped into my mind’) and the Hyperarousal subscale consists of six items (e.g., ‘I was jumpy and easily startled’). The IES-R provides symptom cluster scores (Avoidance: 0 – 34; Intrusion: 0 – 34; Hyperarousal: 0 – 24) and IES-R Total score (0 – 92). The IES-R has been used with a number of adult cancer samples (Hampton &
Frombach, 2000; Langeveld et al., 2004). The measure shows high internal reliability (IES-R Total: .96; Avoidance: .87; Intrusion: .94; Hyperarousal: .91), concurrent validity (.84) and a cut-off score of 33 was found to yield the highest diagnostic power (.88), providing a sensitivity of .91 and a specificity of .82 (Creamer, Bell, & Failla, 2003). Accordingly, whilst the IES-R is not a diagnostic tool, it may be used to screen individuals who are likely to warrant a diagnosis of PTSD as well as assessing levels of PTSS.

**General psychological adjustment difficulties.** The General Health Questionnaire - 12 (GHQ12; Goldberg, 1972) is a 12-item self-report screening measure for the detection of minor psychiatric disorder (i.e., non-psychotic psychological impairment) in community and non-psychiatric clinical settings. The measure asks respondents to rate their health over the past seven days in relation to the 12 items. The scoring scheme consists of a 4-point likert scale which yields a total score ranging from 0 – 36. Coding of items differs in terms of the presence or absence of psychological distress. The measure shows high internal (.89) and test–retest reliability (.73) as well as concurrent validity (.70) (Hardy, Shapiro, Haynes, & Rick, 1999). It is generally considered that scores of ≤12 are typical, scores of ≥15 indicate psychological distress and those of ≥20 suggest severe psychological adjustment difficulties (Goldberg, 1978). The reported sensitivity and specificity values of the GHQ12 are .85 and .79 (Mari & Williams, 1985) as well as .87 and .93 (Shamasunder et al., 1986) respectively.
Child and adolescent psychological measures

Parent-child interaction. The Parent-Child Interaction Questionnaire – Revised – Child Version (PACHIQ-R-CH; Lange et al., 2002) is a 25-item self-report scale designed to assess the quality of the parenting relationship between child and mother (PACHIQ-R-CHm) and/or father (PACHIQ-R-CHf). The nature of the instruments’ behavioural, attitudinal and affective focus, subscales (i.e., Conflict Resolution and Acceptance) and scoring scheme are identical to the PACHIQ-R-P described above. However, item content is notably different (e.g., Conflict Resolution subscale [17 items]: ‘My [mother/father] thinks I cannot do anything for myself’ and Acceptance subscale [8 items]: ‘When I have a problem I ask my [mother/father] for advice). The PACHIQ-R-CH provides total subscale scores (Conflict Resolution: 17 – 85; Acceptance: 8 - 40) and PACHIQ-R-CH Total (25 – 125). The measure shows high internal reliability of subscale scores (Conflict Resolution: .93, 95; Acceptance: .78, .80, for PACHIQ-R-CHm and PACHIQ-R-CHf respectively) and PACHIQ-R-CH Total (PACHIQ-R-CHm: .92; PACHIQ-R-CHf: .93).

Attentional coping styles. The Children’s Behavioural Style Scale (CBSS; Miller et al., 1995) was developed from the adult MBSS (Miller et al., 1987) and used to assess monitoring and blunting tendencies. Like the MBSS, the CBSS consists of four stress provoking scenarios (e.g., ‘You are in class at school. The teacher comes over to you and tells you the head teacher wants to see you at break’) and employs an identical scoring scheme (see MBSS above). Scenarios are followed by four monitoring responses (e.g., ‘think about what the head teacher did to other kids’) and four blunting responses (e.g., ‘think about other things to get your mind off the head teacher). Summing the
items endorsed on each subscale yields their respective scores (ranging from 0 – 16 for each subscale). The CBSS has been shown to yield good internal consistencies (Monitoring: .85; Blunting: .77) in a paediatric oncology sample (Phipps & Srivastava, 1997).

**Posttraumatic stress symptoms.** The Impact of Event Scale – 8 (IES-8; Dyregrov & Yule, 1995; Yule, 1998) is an 8-item self-report instrument designed to measure two of the three symptom clusters associated with DSM-IV PTSD: intrusion and avoidance. The scoring scheme consists of a 4-point likert scale used to indicate the incidence and frequency of symptoms during the past seven days. The Avoidance subscale consists of four items (e.g., ‘I tried to remove it from memory’) and the Intrusion subscale also comprises four symptom items (e.g., ‘I thought about it when I didn't mean to’, ‘Pictures about it popped into my mind’). The IES-8 provides symptom cluster scores (Avoidance: 0 – 20; Intrusion: 0 – 20) and IES-8 Total score (0- 40). The IES-8 shows adequate internal reliability (IES-8 Total .75; Avoidance: .73; Intrusion: .70) (Smith et al., 2003). Using a cut-off of 17, the IES-8 has been found to effectively discriminate PTSD cases, misclassifying only 10% (Dyregrov & Yule, 1995; Stallard, Velleman, & Baldwin, 1999). Accordingly, the IES-8 can be used to screen children and adolescents who are likely to warrant a diagnosis of PTSD as well as assessing levels of avoidant and intrusive PTSS.

**General psychological adjustment difficulties.** The Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997, 2001) is a well-standardised 25-item self-report questionnaire that measures psychological adjustment difficulties in children and
adolescents. Whilst two versions of the SDQ were administered; the SDQ-P4-16 (for parents to rate adjustment and psychopathology in their child/adolescent aged between 4 – 16 years) and the SDQ11-16 (a self-report of adjustment and psychopathology for children and adolescents aged 11-16-years-old), it was decided that only the SDQ-P4-16 would be used for data analysis. This was justified on a number of grounds: (i) paediatric cancer survivors often underreport difficulties (Stuber et al., 2003); (ii) parental reports are more predictive of psychiatric disorder than self-reports (Goodman, 2001); and (iii) the SDQ11-16, which was completed by survivors aged between 11-16 (n = 20), correlated highly (p = .002) with parent reports (SDQ-P4-16 Total Difficulties score). The SDQ-P4-16 is scored on a 3-point likert scale and composed of five scales (each of five items) which yield scores for Emotional symptoms, Conduct problems, Hyperactivity-inattention, Peer problems and Prosocial behaviour. All but the last scale are summed to generate SDQ-P4-16 Total difficulties score (0 – 40). The SDQ-P4-16 shows satisfactory internal reliability (SDQ-P4-16 Total: .80), test-retest reliability (.62) and inter-rater reliability (.34) (Goodman, 2001). Cut-off scores for identification of likely cases of psychiatric disorder on the SDQ-P4-16 are: Total difficulties 17-40; Emotional Symptoms 5-10; Conduct problems 4-10; Hyperactivity 7-10; Peer problems 4-10; and Prosocial behaviour 0-4 (Goodman, 2000, 2001).
Results

A number of preliminary analyses were conducted in order to examine and correct (where permissible) interval data with respect to normality and outliers. All continuous variables met the assumptions for parametric statistics. Eta statistics were used to examine the concordance of a number of nominal demographic and illness variables with continuous data.

The results are organised into five sections: (i) examination of psychological and outcome variables; (ii) associations between demographic and illness variables with outcome variables; (iii) concordance of survivor and parent PTSS and general psychological adjustment difficulties; (iv) associations between PTSS and healthcare behaviour; and finally (v) independent and shared effects of variables that significantly correlated with PTSS and general psychological adjustment difficulties.

Examination of psychological and outcome variables

**Parent-child interactions.** Total survivor and parent scores for parent-child interactions (see Table 2) were comparable to normative samples (i.e., child: Conflict Resolution, $M = 68$; Acceptance, $M = 32$; Total, $M = 101$; parent: Conflict Resolution, $M = 51$; Acceptance, $M = 38$; Total, $M = 90$; Lange et al., 2002). Significant positive correlations were observed between survivor and parent scores for Conflict Resolution ($r (52) = .41, p < .01$), Acceptance ($r (52) = .46, p < .01$) and Total ($r (52) = .46, p < .01$). It was also found that whilst Conflict Resolution was not significantly negatively correlated with age of survivors, Acceptance was ($r (52) = -.40, p < .01$).
Attentional coping styles. As predicted, the current sample of childhood brain tumour survivors endorsed significantly more blunting responses (see means in Table 2) than standardised normative child data (\(M = 3.9; t (51) = 5.90, p < .01\)) thus supporting the study's first hypothesis. In fact, childhood brain tumour survivors in this sample also endorsed significantly more than standardised paediatric oncology samples (\(M = 4.8; t (51) = 4.05, p < .01\)). No significant differences were found between the endorsement of monitoring coping responses in the above populations and the current sample.

Childhood brain tumour survivors reported the use of significantly more monitoring than blunting attentional coping strategies (\(t (51) = 3.68, p < .01\)) as did their parents (\(t (51) = 7.34, p < .01\)). Furthermore, a significant negative correlation was found between age of survivor at assessment and number of blunting responses endorsed (\(r (52) = -.48, p < .01\)).

Prevalence of posttraumatic stress symptoms. A total of 18 (35%) childhood brain tumour survivors reported posttraumatic stress symptoms indicative of PTSD diagnosis compared to 15 (29%) of their parents. However, only one parent compared to nine survivors reported no PTSS at all. With regard to symptom clusters scores (IES subscales), childhood brain tumour survivors reported significantly higher levels of avoidant ideation than intrusive symptomatology (\(t (51) = 3.50, p < .01\)). Conversely, parents demonstrated this symptom cluster discrepancy in the opposite direction endorsing significantly more intrusive than avoidant ideation (\(t (51) = -4.32, p < .01\)) (see Table 2 for means and standard deviations).
Prevalence of general psychological adjustment difficulties. A total of 17 (33%) parents reported psychological adjustment difficulties (as measured by the GHQ12).

Seven (14%) of these parents yielded scores indicative of severe emotional problems and distress. Parents reported total difficulties indicative of psychiatric disorder in 12 (23%) of the survivors. In addition, 19 (37%) were reported to exhibit Peer Problems, 16 (31%) Emotional Symptoms, 7 (14%) Conduct Problems and 5 (4%) Hyperactivity.

Table 2
Descriptive Statistics of Brain Tumour Survivors and Their Parents

<table>
<thead>
<tr>
<th>Psychological variables</th>
<th>Survivors (n = 52)</th>
<th>Parents (n = 52)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PACHIQ-R</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>98.8 (10.76)</td>
<td>88.1 (7.15)</td>
</tr>
<tr>
<td>Conflict Resolution</td>
<td>65.7 (8.21)</td>
<td>49.9 (5.17)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>32.8 (3.89)</td>
<td>38.1 (3.30)</td>
</tr>
<tr>
<td><strong>CBSS/MBSS</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
<td>8.7 (3.50)</td>
<td>4.1 (1.76)</td>
</tr>
<tr>
<td>Blunting</td>
<td>6.6 (3.25)</td>
<td>1.9 (1.13)</td>
</tr>
<tr>
<td><strong>IES</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>11.8 (9.37)</td>
<td>25.2 (20.75)</td>
</tr>
<tr>
<td>Avoidance</td>
<td>7.0 (6.35)</td>
<td>7.9 (7.33)</td>
</tr>
<tr>
<td>Intrusion</td>
<td>4.8 (7.73)</td>
<td>11.6 (8.55)</td>
</tr>
<tr>
<td>Hyperarousal</td>
<td></td>
<td>5.7 (6.77)</td>
</tr>
<tr>
<td><strong>SDQ-P4-16</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotional symptoms</td>
<td>3.5 (2.58)</td>
<td></td>
</tr>
<tr>
<td>Conduct problems</td>
<td>1.5 (1.50)</td>
<td></td>
</tr>
<tr>
<td>Hyperactivity</td>
<td>3.6 (2.05)</td>
<td></td>
</tr>
<tr>
<td>Peer Problems</td>
<td>2.7 (2.43)</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>11.4 (6.22)</td>
<td></td>
</tr>
<tr>
<td>Prosocial behaviour</td>
<td>8.3 (1.89)</td>
<td></td>
</tr>
<tr>
<td><strong>GHQ12</strong></td>
<td>13.1 (6.25)</td>
<td>0-36</td>
</tr>
</tbody>
</table>

IES = Impact of Events Scale (IES-8-item for children and IES-Revised 22-item for adults); PACHIQ-R = Parent-child Interaction Questionnaires – Revised (PACHIQ-R- Parent version, 21-item and PACHIQ-R- Child version, 25-item); CBSS/MBSS = Children’s Behavioural Style Scale (4-item for children)/Miller Behavioural Style Scale (2-item for parents); SDQ-P4-16 = Strengths and Difficulties Questionnaire – Parent-rated, 4-16-years-old; GHQ12 = General Health Questionnaire – 12-item version.
Associations between demographic and illness variables with outcome variables

The study's second hypothesis that duration of hospital admission would be positively correlated with PTSS and general psychological adjustment difficulties in survivors was confirmed (see Table 3). A significant positive correlation was found for greater number of days in hospital with increasing IES-8 Totals ($p = .01$) and SDQ-P4 Totals ($p = .01$). Furthermore, a significant positive correlation was also found for greater number of recurrences with increasing IES-R Totals ($p = .02$) in parents thus partially supporting the third hypothesis. No other factors significantly correlated with outcome variables.

Table 3
Associations between Demographic and Illness Variables with Posttraumatic Stress Symptoms and General Psychological Adjustment Difficulties

<table>
<thead>
<tr>
<th></th>
<th>Posttraumatic stress symptoms</th>
<th>General psychological adjustment difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survivors (n = 52)</td>
<td>Parents (n = 52)</td>
</tr>
<tr>
<td>Demographic variables</td>
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<td></td>
</tr>
<tr>
<td>Sex of survivor</td>
<td>.05</td>
<td>.12</td>
</tr>
<tr>
<td>Survivor age at diagnosis</td>
<td>-.17</td>
<td>.11</td>
</tr>
<tr>
<td>Survivors age at participation</td>
<td>-.16</td>
<td>.21</td>
</tr>
<tr>
<td>Illness variables</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tumour type</td>
<td>.24</td>
<td>.45</td>
</tr>
<tr>
<td>Treatment modality</td>
<td>.36</td>
<td>.24</td>
</tr>
<tr>
<td>Days in hospital</td>
<td>.34*</td>
<td>.21</td>
</tr>
<tr>
<td>Number of recurrences</td>
<td>.07</td>
<td>.33*</td>
</tr>
<tr>
<td>Months off treatment</td>
<td>-.14</td>
<td>.07</td>
</tr>
</tbody>
</table>

* Totals of IES-8 (Impact of Event Scale – 8-item) for survivors and IES-R (Impact of Events Scale – Revised) for parents.

** Totals of SDQ-P4 (Strengths and Difficulties Questionnaires – Parent-rates, 4-16-years-olds) for survivors and GHQ12 (General Health Questionnaire – 12-item) for parents.

* Computed using the eta ($\eta$) coefficient (it should be noted that although the coefficients appear large they do not reach statistical significance due to the greater number of nominal categories and small number of participants in each cell)

$p < .05$  ** $p < .01$
**Associations between psychological variables and outcome variables**

The study’s fourth hypothesis that greater perceived quality of parent-child interactions would be negatively correlated with PTSS (IES-8 and IES-R Total scores) and general psychological adjustment difficulties (SDQ-P4 and GHQ12), was partially supported (see Table 4). Higher levels of Conflict Resolution (i.e., perceived ability to resolve parent-child conflicts) related to fewer PTSS for both survivors ($p = .01$) and their parents ($p = .04$). However, when age of survivor was controlled for the above relationship for parents was no longer significant ($r = -.25, p = .08$). Higher levels of Conflict Resolution and PACHIQ-R-CH Total was also associated with reduced general psychological adjustment difficulties (SDQ-P4) for survivors only ($p < .01; p = .02$ respectively). No associations were observed in relation to levels of Acceptance (i.e., positive thoughts and feelings about parent-child interactions) and rates of PTSS in survivors or parents.

The fifth research hypothesis, that greater endorsement of monitoring attentional coping styles would be significantly correlated with elevated PTSS, was supported by survivors ($p < .01$) only (see Table 4). However, contrary to the study’s predictions, increased endorsement of blunting attentional coping strategies was also significantly correlated with elevated PTSS ($p = .02$) in survivors. The hypothesis was not confirmed by parents who exhibited no associations between PTSS and attentional coping styles.

Intercorrelations conducted between objective and psychological variables revealed that only duration of hospital admission was significantly correlated with higher levels of monitoring attentional coping styles ($r = .33, p = .02$) and poorer perceptions of Conflict Resolution ($r = .30, p = .03$) in survivors.
Table 4
Correlations of Psychological Variables with Posttraumatic Stress Symptoms and General Psychological Adjustment Difficulties

<table>
<thead>
<tr>
<th>Relationship quality</th>
<th>Posttraumatic stress symptoms\textsuperscript{a}</th>
<th>General psychological adjustment difficulties\textsuperscript{b}</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Survivors (n = 52)</td>
<td>Parents (n = 52)</td>
</tr>
<tr>
<td>PACHIQ-R-CH/P Total</td>
<td>-.25</td>
<td>-.15</td>
</tr>
<tr>
<td>PACHIQ-R-CH/P Conflict Resolution</td>
<td>-.34*</td>
<td>-.29*</td>
</tr>
<tr>
<td>PACHIQ-R-CH/P Acceptance</td>
<td>.08</td>
<td>.10</td>
</tr>
<tr>
<td>Attentional coping styles</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Monitoring</td>
<td>.36**</td>
<td>-.18</td>
</tr>
<tr>
<td>Blunting</td>
<td>.32*</td>
<td>-.02</td>
</tr>
</tbody>
</table>

\textsuperscript{a} Totals of IES-8 (Impact of Event Scale -8-item) for survivors and IES-R (Impact of Events Scale -Revised) for parents.

\textsuperscript{b} Totals of SDQ-P\textsuperscript{4-16} (Strengths and Difficulties Questionnaires -Parent-rates, 4-16-years-olds) for survivors and GHQ\textsuperscript{12} (General Health Questionnaire -12-item) for parents.

\textsuperscript{c} Totals and subscale totals of PACHIQ-R-CH (Parent-Child Interaction Questionnaires -Revised-Child) for survivors and PACHIQ-R-P (Parent-Child Interaction Questionnaires -Revised-Parent) for parents.

*p < .05  \ **p < .01

Concordance of survivor and parent PTSS and general psychological adjustment

The study's sixth prediction that correlations would exist between survivor and parent PTSS and general psychological adjustment difficulties was partially confirmed (see Table 5). No significant associations were found between survivor and parent IES Total or symptom cluster subscale scores. However, significant positive correlations were exhibited for both parent IES-R Total (p = .02) and IES-R Hyperarousal (p < .01) with general psychological adjustment difficulties in survivors. A significant association was also observed between survivor (SDQ-P\textsuperscript{4-16}) and parent general psychological adjustment difficulties (GHQ\textsuperscript{12}) (p = .02). Concordance of PTSS (calculated by converting survivor and parent IES Totals into percentages and obtaining the absolute
difference between the two) failed to positively correlate with time off treatment as predicted.

Table 5
Concordance between Survivors and Parents PTSS and Psychological Adjustment

<table>
<thead>
<tr>
<th>Survivor PTSS and adjustment difficulties</th>
<th>Parent PTSS and psychological adjustment difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Parent IES-R Total</td>
</tr>
<tr>
<td>Survivor IES-8 Total</td>
<td>.16</td>
</tr>
<tr>
<td>Survivor IES-8 Avoidance</td>
<td>.03</td>
</tr>
<tr>
<td>Survivor IES-8 Intrusion</td>
<td>.16</td>
</tr>
<tr>
<td>Survivor SDQ-P4-16 Total</td>
<td>.33*</td>
</tr>
</tbody>
</table>

PTSS = posttraumatic stress symptoms; IES-8 = impact of Event Scale – 8-item; IES-R = impact of Events Scale – Revised; SDQ-P4-16 = Strengths and Difficulties Questionnaire – Parent-rated, 4-16-years-old; GHQ12 = General Health Questionnaire – 12-item version.

* p < .05  ** p < .01

Associations between PTSS and healthcare behaviour

Results did not support the study’s seventh hypothesis that elevated PTSS in survivors and their parents would negatively correlate with rates of outpatient appointment attended (i.e., DNA [did not attend] and/or cancelled appointments).

Independent and shared effects of variables on PTSS and psychological adjustment

In order to identify the variance in PTSS and general psychological adjustment difficulties accounted for by illness factors (i.e., days in hospital and number of
recurrences), parent-child Conflict Resolution and attentional coping styles, three multiple regression equations were estimated. These variables were selected as they significantly correlated with outcome measures in bivariate analyses. The PACHIQ-R-CH Total was not included as its significance resulted from Conflict Resolution.

For survivors, two separate equations were performed in order to examine the contribution of predictor variables on PTSS and general psychological adjustment difficulties (see Table 6). The overall multiple regression model for predicting PTSS in survivors was significant: $F(4, 51) = 5.09, p < .01$. Number of days spent in hospital (step one: 6.60, $p = .01$) and collective psychological variables (step two: 4.17, $p = .01$) produced a significant change in the variance of PTSS at each step (see Table 6). However, no variables independently accounted for the variance in PTSS in the final model. This finding (i.e., lack of independent effects) may be explained in part due to the covariance observed between monitoring and blunting coping styles ($r = .25, p = .08$). Days in hospital accounted for 12% of the variance in PTSS. After controlling for days in hospital psychological variables collectively accounted for a further 19% of the variance. The total model accounted for 31% of the variance in PTSS in survivors.

The overall multiple regression model for predicting general psychological adjustment difficulties in survivors was also significant: $F(5, 51) = 5.61, p < .01$. Number of days spent in hospital (step one: 8.30, $p < .01$), Conflict Resolution (Step two: 4.32, $p = .04$), and collective parental distress variables (step three: 4.22, $p = .01$) produced a significant change in the variance of general psychological adjustment difficulties at each step (see Table 6). Only number of days in hospital ($\beta = .28, t(51) =$
2.23, \( p = .03 \) and parent IES-R Hyperarousal (\( \beta = .62, t(51) = 2.27, p = .03 \)) independently predicted general psychological adjustment in survivors. Days in hospital accounted for 14% of the variance in general psychological adjustment. After controlling for days in hospital, psychological variables collectively accounted for a further 7% of the variance. Finally, parental distress variables independently accounted for an additional 17%. Accordingly, the total model accounted for 38% of the variance in general psychological adjustment difficulties in survivors.

Table 6

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>( \beta )</th>
<th>( R^2 ) change</th>
<th>( R^2 ) change</th>
<th>( F ) change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>PTSS as criterion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Step 1: Illness variable</td>
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</tr>
<tr>
<td>Days in hospital</td>
<td>.12</td>
<td>.12</td>
<td>6.60**</td>
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<tr>
<td>Step 2: Psychological variables</td>
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<tr>
<td>PACHIQ-R-CH Conflict Resolution</td>
<td>-.25</td>
<td>-.19</td>
<td>4.17**</td>
<td></td>
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<tr>
<td>Monitoring</td>
<td>.23</td>
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<td></td>
</tr>
<tr>
<td>Blunting</td>
<td>.23</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>SDQ-P4-16 as criterion</strong></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Step 1: Illness variable</td>
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<td></td>
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</tr>
<tr>
<td>Days in hospital</td>
<td>.14</td>
<td>.14</td>
<td>8.30**</td>
<td></td>
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<tr>
<td>Step 2: Psychological variables</td>
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<td></td>
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</tr>
<tr>
<td>PACHIQ-R-CH Conflict Resolution</td>
<td>-.16</td>
<td>-.17</td>
<td>4.22*</td>
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<tr>
<td>Step 3: Parental distress variables</td>
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<tr>
<td>Parent IES-R Total</td>
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<td></td>
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</tr>
<tr>
<td>Parent IES-R Hyperarousal</td>
<td>.62*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent GHQ12 Total</td>
<td>.20</td>
<td></td>
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</tr>
</tbody>
</table>

PTSS = posttraumatic stress symptoms; SDQ-P4-16 = Strengths and Difficulties Questionnaire – Parent-rated, 4-16-years-old; IES-R = Impact of Events Scale – Revised; GHQ12 = General Health Questionnaire – 12-item version; PACHIQ-R-CH = Parent-Child Interaction Questionnaire – Revised – Child.

* \( p < .05 \)    ** \( p < .01 \)
A single multiple regression equation was computed for predicting PTSS in parents (see Table 7) as only one variable was found to be significantly correlated with general psychological adjustment. The overall hierarchical multiple regression model for predicting PTSS in parents was significant: $F(2, 51) = 4.98, p = .01$. Only number of tumour recurrences (step one: $5.93, p = .02$) produced a significant change in the variance of PTSS. Number of tumour recurrences continued to independently predict the variance in PTSS at a significant level ($\beta = .30$, $t(51) = 2.27, p = .03$) following the addition of Conflict Resolution into the model. Number of recurrences accounted for 11% of the variance in PTSS. After controlling for number of recurrences, Conflict Resolution (step two) accounted for a further 6% of the variance. The total model accounted for 17% of the variance in PTSS in parents of childhood brain tumour survivors.

Table 7

<table>
<thead>
<tr>
<th>Predictor variables</th>
<th>$\beta$</th>
<th>$R^2$</th>
<th>$R^2$ change</th>
<th>$F$ change</th>
</tr>
</thead>
<tbody>
<tr>
<td>PTSS as criterion</td>
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</tr>
<tr>
<td>Step 1: Illness factor</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Number of recurrences</td>
<td>.30*</td>
<td>.11</td>
<td>.11</td>
<td>5.93*</td>
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<tr>
<td>Step 2: Psychological variable</td>
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</tr>
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<td>PACHIQ-R-P Conflict Resolution</td>
<td>-.25</td>
<td>.17</td>
<td>.06</td>
<td>3.71</td>
</tr>
</tbody>
</table>

*PTSS = posttraumatic stress symptoms; PACHIQ-R-P = Parent-Child Interaction Questionnaire—Revised—Parent.  
*p < .05
Discussion

The aim of this study was to investigate the prevalence of posttraumatic stress symptoms and general psychological adjustment difficulties in children who had survived brain tumours and their parents. The relationship between specific illness parameters (i.e., duration of hospital admission and number of tumour recurrences), parent-child interactions and attentional coping styles and PTSS and general psychological adjustment difficulties was also examined. In addition, the concordance of survivor and parent symptomotology, together with the effect of elevated PTSS on healthcare behaviour was also investigated.

Over one third (35%) of childhood brain tumour survivors reported severe levels of PTSS indicative of a PTSD diagnosis compared to 29% of their parents. These rates of PTSS in parents are somewhat lower than those reported by Fuemmeler et al. (2001) (40% in fathers and 44% in mothers assessed using the Posttraumatic Stress Diagnostic Scale; Foa, 1996). Conversely, rates of severe PTSS in childhood brain tumour survivors appear to be considerably greater than those documented in previous studies of childhood cancer survivors (1.4% - 17%; Hobbie et al., 2000; Kazak et al., 1997; Landolt et al., 2003; Langeveld et al., 2004; Stuber, Christakis, Houskamp, & Kazak, 1996; Stuber et al., 1994). Overall, these findings are inconsistent with previous studies which have reported higher levels of PTSS in parents compared to childhood cancer survivors (Barakat et al., 1997; 2000; Brown et al., 2003; Kazak et al., 1997; 2001; 2004; Landolt et al., 2003; Stuber et al., 1996). Furthermore, the number of childhood brain tumour survivors that meet criteria for PTSD did not only exceed the rates of current PTSD documented in child community samples (1.6% - 5.6%; Essau et al., 1999;
Cuffe et al., 1998; Frans, 2003) and paediatric cancer populations (4.7% - 21%: Butler et al., 1996; Erickson & Steiner, 2001; Kazak et al., 2004; Meeske et al., 2001; Pelcovitz et al., 1998) but also those found by many studies of children following natural disasters (5%: Shannon, Lonigan, Finch, & Taylor, 1994), warfare (33%: Arroyo & Eth, 1985; 27%: Saigh, 1991), violent crime (27%: Schwarz & Kowalski; 29%: Berton & Stabb, 1996), kidnapping (33%: Terr, 1983) and sexual abuse (21%: Atkins, Ralphe, & Foa, 1989). Whilst selection bias and small sample size may confound the current study's estimates, these results confirm speculations that childhood brain tumour survivors are at potentially higher risk of developing PTSD and PTSS than other paediatric oncology populations (Fuemmeler et al., 2001; Manne et al., 1998). They additionally support the notion that PTSD is not a uniform or normative reaction to traumatic events, but develops (with deleterious effects) in only a subset of those individuals exposed (Yehuda & McFarlane, 1995). Furthermore, survivor and parent general psychological adjustment was also compromised. One third of parents (33%) reported general psychological adjustment difficulties, with 14% of these scores indicating severe emotional problems and psychological distress (Goldberg, 1978). General psychological adjustment difficulties indicative of psychiatric disorder were reported in almost one quarter (23%) of childhood brain tumour survivors. Approximately one third of the total survivor sample exhibited clinically significant peer (37%) and emotional (31%) difficulties.

Consistent with previous findings, survivor sex (Landolt et al., 2003), age at diagnosis (Goldenberg Libov, Nevid, Pelcovitz, & Carmony, 2002; Kazak et al., 1997; Landolt et al., 2003) and participation (Brown et al., 2003; Langeveld et al., 2004) as
well as time off treatment (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) failed to significantly associate with PTSS in childhood brain tumour survivors or their parents. Presumably, the latter finding reflects the protracted and multifaceted nature of the cancer experience which extends well beyond treatment termination (e.g., follow-up appointments, ongoing risk of recurrence and late effects).

In accordance with the study's predictions, whilst greater duration of hospitalisation was found to be significantly correlated with elevated general psychological adjustment difficulties in survivors increased number of tumour recurrences significantly correlated with elevated parental PTSS (but not general psychological adjustment difficulties). These findings may suggest that the trauma related to tumour recurrence may manifest itself in a form independent and distinct from more general forms of emotional distress in parents of childhood brain tumour survivors. Alternatively, for survivors, days in hospital did not appear to exert an independent effect on the variance in PTSS. This findings may therefore reflect the high degree of covariance between monitoring, blunting and days in hospital present among childhood brain tumour survivors. Nonetheless, these findings lend empirical support to the supposition that children (owing to their cognitive development) may become distressed by more concrete aspects of the cancer experience (i.e., separation from parents, hospital bed confinement, painful procedures, etc), while parents may be at greater risk of being distressed by more abstract, future orientated features (i.e., threats to child’s life or physical integrity implicated by tumour recurrence) (Salmon & Bryant, 2002). Although
it may be argued that duration of hospitalisation is likely to be compounded by other
disease parameters, treatment modality and tumour type failed to significantly correlate
with duration of hospitalisation or survivor distress. However, treatment complications
and physical sequelae were not explored in this present study and thus their influence
remains unknown.

Interestingly, it was also found that duration of hospitalisation correlated
significantly with survivors’ endorsement of monitoring coping styles and perceptions of
conflict with their parents. This suggests that experience of hospitalisation (together with
the associated distress) may both increase survivors propensity to scan, seek out and
magnify threatening cues (i.e., monitor) and also have a deleterious impact on the
quality of parent-child interaction (i.e., conflict resolution). Indeed, the medical
requirements, procedural demands, periods of separation as well as frightening sights
and sounds associated with hospitalisation may well have a large impact on the
survivors’ response to health threat information and perceptions of their parent/s.
Furthermore, number of tumour recurrences also covaried (although not significantly)
with parents perception of conflict with their child.

In relation to parent-child interactions, partial support was generated for
perception of relational quality and PTSS and general psychological adjustment in
childhood brain tumour survivors and their parents. Greater positive thoughts and
feelings about parent-child interactions (i.e., Acceptance subscale) held by both
survivors and their parents did not appear to significantly correlate with PTSS or general
psychological adjustment difficulties. However, perceptions of parents’ ability to
effectively conduct parenting tasks and resolve disagreements (i.e., Conflict Resolution subscale) reported by survivors and their parents did appear to act as a protective factor. Indeed, it may be conjectured that conflictual survivor-parent dyads may lack the support and understanding required to successfully negotiate and resolve the trauma associated with the cancer experience. Such results extend empirical support for the role of family conflict in predicting PTSS (Brown et al., 2003; Kazak et al., 1997; Orbuch et al., 2005; Pelcovitz et al., 1998) as well as further underscoring the importance of using family system models in conceptualising survivor and parents’ adjustment to trauma. The fact that this relationship fell just below statistical significance in independently predicting variance in PTSS (for both survivors and parents), and even more so for survivor general psychological adjustment difficulties, is likely to reflect the covariance between hospitalisation and parent-child conflict in accounting for distress.

The compound effect model (Sheeringa & Zeanah, 2001) was also partially supported (i.e., parental traumatisation and distress moderates the child’s symptomatic response to the trauma). Overall levels of parental distress collectively accounted for a significant proportion of the variance in survivors’ general psychological adjustment difficulties. This was particularly pronounced for parental hyperarousal which independently predicted a significant proportion of general adjustment difficulties in survivors. One interpretation of these findings could be that parents who exhibited heightened levels of insomnia, irritability, anger and nervousness (characteristic of hyperarousal) had a deleterious influence on the psychological well-being of survivors. Such findings are consistent with those of McFarlane (1987) who found that parental irritability at eight months following a traumatic event (bushfire) predicted child distress.
26 months later. Interestingly, although parent and survivor PTSS were not associated, it was found that of those parents who reported symptoms indicative of a PTSD diagnosis 46% of their children also met PTSD caseness whilst 27% reported no symptoms at all. These findings may suggest that although some parents may struggle to effectively contain and ameliorate distress (thereby increasing the risk of contagion) others appear capable of ‘holding’ symptoms for the dyad (Kazak et al., 2004). The mechanisms which underlie such dynamics clearly require further investigation.

The association between parent and survivor PTSS did not increase as a function of time off treatment, thereby contributing little support to the hypothesis that PTSS can be conceived of as contagious and thereby transmitted to others over a period of time (Koplewicz et al., 2002; Laor et al., 1997). It may be argued that time off treatment may well be confounded by survivor age. Indeed, the trauma literature suggests that younger children depend on the reactions and responses of their parents in order to make sense of the traumatic experience (Landolt et al., 2003; Laor et al., 1996; Scheeringa, Zeanah, Drell, & Larrieu, 1995). Accordingly, survivor age and developmental stage may well constitute important determinants in the concordance of survivor and parent PTSS. However, this alternative explanation is not supported by the present sample which yielded no significant correlation between time off treatment and survivor age.

Consistent with the study’s hypothesis, childhood brain tumour survivors endorsed significantly higher levels of blunting attentional coping styles than healthy standardised controls as well as generic paediatric cancer samples (Phipps & Srivastava, 1997). These current findings lend support to the notion that childhood cancer survivors
may employ a greater number of blunting attentional coping styles in an attempt to deal
with the stresses of the cancer experience (Phipps et al., 1995; Phipps & Srivastava,
1997). However, whilst higher levels of monitoring endorsed by brain tumour survivors
was associated with elevated rates of PTSS in bivariate analyses, it did not
independently account for the variance in survivor symptoms in the regression model.
This most likely reflects the covariance found between blunting and monitoring coping
styles. These findings lend mixed support to the theoretical and clinical utility of
monitoring and blunting coping dispositions as delineated by Miller and Schnoll (2000).
Although greater endorsement of monitoring attentional coping strategies was correlated
with PTSS, they were also found to be dynamic and fluid (i.e., they covaried with
duration of hospitalisation). This may imply that attentional coping styles are mediated
by contextual factors rather than intrinsic personality dispositions. Furthermore,
attentional coping styles were not found to be correlated with increased PTSS in parents.
Such results are consistent with those reported by Manne et al. (2000) who found that
mothers of paediatric cancer survivors with high monitoring coping styles did not report
elevated PTSS. They argued that such findings may reflect the nature of the health threat
which is not related to the parent’s personal health risk (a defining characteristic of a
monitoring attentional coping style) but their child’s. It may be argued that this
explanation was partially confirmed in this present study: a correlation existed for
childhood brain tumour survivors (in bivariate analyses).

No correlation was found between elevated endorsement of PTSS and increased
rates of appointment cancellations and/or DNA’s for childhood brain tumour survivors
or their parents. These findings suggest that although a substantial proportion of
survivors and their parents exhibit severe levels of PTSS it does not appear to have a deleterious impact on healthcare behaviour (i.e., outpatient appointment attendance). In fact, elevated level of PTSS may actually increase appointment attendance (Kazak et al., 2004). Alternatively, the findings may simply reflect a sample of participants who were symptomatic but also proactive (hence willing to engage in the study). Indeed, individuals that exhibited reduced healthcare adherence may have been unlikely to participate in the present study.

The empirical validity and clinical utility of the present findings should be considered in the light of several methodological limitations. The appropriateness and applicability of PTSD and PTSS to childhood cancer remains unclear. Indeed, the applicability of “post” traumatic stress conceptualisations is questionable in light of cancer representing a potentially ongoing traumatic stressor. Furthermore, this study can only speculate that PTSS and general psychological adjustment difficulties were consequential of the cancer experience. The use of cross-sectional correlational studies precludes the establishment of causal directionality and premorbid psychological functioning. For example, it could be speculated that parent-survivor conflict may actually be a symptomatic expression of the deleterious and far reaching effects of PTSS and general psychological adjustment difficulties. Similarly, associations between survivor and parental distress could be interpreted in a number of alternative ways other than that of contagion. Future studies will need to employ prospective longitudinal designs in order to effectively delineate and disentangle causal pathways as well as examine the trajectory of symptomatic profiles within parent-survivor dyads over time.
Regrettably, compared to similar research the present study’s recruitment rate was low (37%), thus questioning the representativeness of these findings to the target population of brain tumour survivors and their parents. This may reflect the inherent difficulty in recruiting families of paediatric oncology patients and survivors who are frequently solicited to participate in clinical research trials. Such factors may have also compromised sample size, thus limiting statistical power. Accordingly, the study may have lacked the sensitivity (i.e., increasingly the likelihood of type II error) required to expose statistically significant correlates and predictors. Conversely, the present study may also have compromised specificity by examining a large number of associations (i.e., increasingly the chances of type I error).

Although the study employed a relatively conservative age range (8 – 16-year-olds) with respect to the limited pool of potential participants, survivors’ cognitive development (as well as neurocognitive status following tumour growth and subsequent treatment) may well have compounded a number of associations. However, whilst first-order correlations remained significant when survivor age was controlled for, demographic (and neurocognitive outcome) variables may well have exerted a moderate influential effect on the current variables under investigation. Notably, an important, yet unexamined, factor which warrants further investigation is the role of functional outcome (i.e., medical late effects and neurocognitive sequelae) in the moderation of PTSS and general psychological adjustment. Indeed, compromised functional outcome, highly prevalent in brain tumour survivors (Fuemmeler et al., 2002), is likely to have a deleterious impact on the psychological adjustment of parent-survivor dyads.
Finally, a number of measures used in the current study were derived from the psychopathology literature and are therefore not immune to the confounds inherent in chronic and life-threatening illness (e.g., comorbid symptomatology). In addition, using exclusively parental reports of survivor’s general psychological adjustment may well have compromised data reliability (Smith et al., 2001). Future studies should therefore seriously consider the use of measures sensitive to the potential confounding factors inherent in chronic and life-threatening illness and related medical treatments, as well as those which examine the specific issues pertinent to families who have survived cancer.

**Conclusion**

The current findings indicate that for a substantial proportion of brain tumour survivors and their parents the process of survivorship is a considerably disturbing and traumatising experience. It was discovered that these survivors report symptoms of posttraumatic stress disorder of a magnitude that exceeds that found in many individuals exposed to natural disasters, violent crime, warfare, kidnapping and sexual abuse. Duration of hospital admission constitutes a significant independent predictor of distress for survivors and additionally appears to correlated with both perceptions of parent-child conflict and monitoring attentional coping styles. The number of tumour recurrences appeared to independently predict degree of traumatisation in parents. Additionally, whilst the capacity to resolve conflicts within the parent-survivor dyad may increase the partnership’s resilience to the traumatising effects of cancer, traumatisation is also likely to have a deleterious impact on the quality of their interactions. Increased endorsement of attentional coping styles (monitoring and blunting) in survivors correlated with traumatisation. This finding may reflect the survivors’ need to summon additional
coping strategies in the face of increasing stressors (such as hospitalisation). Parental psychological distress appears to be associated with general psychological adjustment difficulties in survivors and thus suggest that parents may moderate the development and maintenance of psychological symptoms in children. Encouragingly, elevated psychological distress in parents and survivors has no significant effect on healthcare adherence.
References


Part III: Critical Appraisal

Posttraumatic Stress in Childhood Brain Survivors and their Parents: Methodological Limitations, Research and Clinical Implications
Introduction

The experience of childhood cancer represents a frightening and aversive life event, engendering deleterious psychological sequelae throughout the entire family system. In recent years, the construct of posttraumatic stress has provided a useful framework for the conceptualisation and treatment of traumatic stress reactions associated with childhood cancer. However, very little attention has focused upon the prevalence of posttraumatic stress symptoms (PTSS) in brain tumour survivors and their parents. Indeed, many studies have excluded such children as they are considered atypical of paediatric oncology survivors (Patenaude & Kupst, 2005). This is unfortunate in the light of a growing body of literature which suggests that children with brain tumours are at greater risk of psychological sequelae than other paediatric oncology populations (Fuemmeler, Elkin, & Marx, 2002).

The present study therefore endeavoured to principally investigate the prevalence of PTSS in childhood brain tumour survivors and their parents. It was found that approximately one-third of childhood brain tumour survivors and their parents exhibited severe levels of PTSS, indicative of Posttraumatic Stress Disorder (PTSD). These levels were found to equal and (in many cases) exceed those documented in previous studies of childhood cancer survivors and their parents. Furthermore, the length of hospital admission, number of tumour recurrences, conflictual parent-child interactions and increased number of attentional coping styles were discovered to correlate with PTSS and general psychological adjustment in brain tumour survivors and/or their parents. Although the research and clinical implications of these findings are sizable and extensive, it is important to examine the study's methodological limitations in order to
evaluate the reliability and validity of the current data. Accordingly, this critical
evaluation first considers a number of limitations within the present study, together with
alternative interpretations of the data. Secondly, in light of the cancer-related PTSS and
PTSD evidence base, together with the current findings, a number of theoretical
implications are explored and elaborated. Finally, this review attempts to synthesise a
number of clinical implications into a three-tiered intervention model.

Limitations and alternative interpretations
Although in the present sample, no significant differences in survivor age and sex
existed between participants and non-participants, the majority of families that declined
participation related their decision to the fear and distress associated with revisiting the
cancer experience. A number of authors have speculated that high levels of PTSS
(specifically avoidance) are likely to cause symptomatic individuals to actively avoid
participation (Erickson & Steiner, 2001; Kazak et al., 2004; Streisand, Rourke, Katz,
Stein, & Kazak, 1999). Accordingly, prevalence rates of cancer-related PTSD and PTSS
may well be underestimated (Erickson & Steiner, 2001; Kazak et al., 2004), thereby
reducing the generalisability of the current findings to the target population. Such issues
of generalisability are also pertinent to the parents that took part in the present study who
were composed of predominantly mothers.

The reliability of drawing comparisons between rates of cancer-related PTSD
and PTSS both between and within samples is questionable given the variability of
measures used in studies to index traumatic stress reactions. Furthermore, the use of
cut-off scores on continuous PTSS measures for deriving PTSD caseness can also be
potentially misleading. Indeed, instruments for indexing PTSS are not diagnostic but rather methods of cataloguing subjective phenomenon commonly associated with PTSD. The present study employed different but related measures of PTSS for childhood brain tumour survivors (IES-8; Dyregrov & Yule, 1995) and their parents (IES-R; Weiss & Marmar, 1997). Whilst each measure suggests cut-off scores for establishing an approximation of individuals who are likely to meet PTSD diagnosis, these have been informed from different demographic cohorts. Therefore, rates of approximated PTSD may reflect differences in the measures' specificity and sensitivity rather than diagnostic caseness, thus questioning the validity of the current findings (i.e., that rates of PTSD were approximately equal in survivors and their parents).

Self-report measures used in studies of paediatric cancer survivors should also be critically examined with respect to issues of reliability. Childhood cancer survivors have been found to report lower levels of distress (depression and anxiety), higher rates of social desirability, avoidance and repressive adaptation (denial of emotional states) compared to healthy controls (Canning, Canning, & Boyce, 1992; Erickson & Steiner, 2001; Phipps & Srivastava, 1997; Worchel, 1989). Therefore, accuracy in the recognition and/or reporting of distress in childhood cancer survivors is questionable. In an attempt to reduce such confounds a number of researchers have utilised parental informants of survivor symptoms. However, this method is also not without its own confounds; it is conceivable that a parent’s assessment of their child’s symptoms is likely to be biased by their own mental health problems (Landolt, Vollrath, Ribi, Gnehm, & Sennhauser, 2003; Smith, Perrin, & Yule, 2001). Indeed, in the present study the only association found between parent and child distress was yielded from measures
completed exclusively by parents (i.e., SDQ-P4\textsuperscript{16} with GHQ\textsuperscript{12}). However, in another recent study, which employed the identical parental measures (SDQ-P4\textsuperscript{16} and GHQ\textsuperscript{12}), no significant correlations were found between parents and children following meningococcal disease despite mothers displaying psychological adjustment difficulties (Shears, Nadel, Gledhill, & Garralda, 2005).

Whilst the present study employed a relatively conservative survivor age range (8 – 16 year-olds) compared with previous cancer-related PTSS and PTSD research, it still presents a significant factor in assessing the reliability of the current findings. Cognitive and psychosocial development is likely to influence what the survivor finds distressing (Salmon & Bryant, 2002) about the cancer experience. Additionally, parent-child interactions and attentional coping styles may also be confounded by developmental factors. However, it should be stressed that the present study found no significant associations between survivor age and parent-child conflict resolution. Neurocognitive sequelae (common in survivors of brain tumours) are also likely to impact on the child’s cognitive and psychosocial development, thus presenting a further confounding factor which was not controlled for in the present study. A significant difficulty inherent to all childhood cancer research is discriminating those symptoms which are directly related to the illness process from those which are mediated by traumatisation. For example, a number of traumatic stress symptoms (e.g., irritability, agitation, concentration difficulties, stomach aches and/or headaches [American Psychiatric Association, 1994]) are very difficult to distinguish from the secondary residual effects of cancer and its treatment (Stuber, Shemesh, & Saxe, 2003). Whilst the present study specifically selected a measure of PTSS which excludes hyperarousal
symptoms (IES-8) in order to reduce such confounds and increase the validity of data, the questionnaire for general psychological adjustment (SDQ-P^4-16) was not immune to such contamination.

Perhaps the largest limitation of cross-sectional correlational designs is their inability to establish directional causality. Consequently, correlational data lend themselves only to theoretical speculation about causal pathways. The finding of the current study, that higher levels of perceived conflict resolution within the parent-survivor dyad associated with lower rates of PTSS and reduced general psychological adjustment difficulties (for survivors only), lends itself to a number of alternative interpretations. For example, it may be conjectured that the deleterious effects of traumatisation may lead to conflictual parent-child interactions. Scheeringa and Zeanah (2001) described how parental and child traumatisation can result in a number of symptomatic relational patterns (e.g., unresponsive, overprotective and constrictive styles). Such patterns are likely to have a deleterious impact on the parent’s ability to effectively manage parenting tasks and resolve disagreements. Indeed, the current study found that length of hospitalisation correlated with quality of parent-child interactions. The present study also aimed to find preliminary support for the contagion theory of distress (Pfefferbaum & Pfefferbaum, 1998). The common method of indexing contagion has been derived from assessing concordance of parent and child symptoms. However, concordance may reflect a number of alternative dynamics. For example, the independent traumatisation of survivor and parent may result in the manifestation of associated but autogenic symptomatic expression. Furthermore, the theoretical premise that high levels of monitoring attentional coping styles actually place individuals at
greater risk of developing PTSS and PTSD (Miller & Schnoll, 2000) is also questionable. Indeed, it seems reasonable to surmise that individuals who exhibit high levels of intrusion and/or hyper-arousal symptoms are likely to consequently show increased levels of monitoring attentional coping styles (i.e., scanning and magnifying health threats). In contrast, those who report high levels of avoidant ideation are likely to subsequently endorse greater levels of blunting (avoidance of health related information). Clearly, the present data can furnish a number of theoretical suppositions, all of which are equally plausible in the absence of more sophisticated and prospective longitudinal analyses.

Theoretical implications

A relatively consistent finding documented throughout much of the cancer-related PTSD and PTSS literature is the durability of symptomatic expression over time. However, these findings appear inconsistent with the general traumatological literature which suggests that a sizeable proportion of individuals who exhibit PTSS following a trauma recover in the ensuing months (Ehlers & Clark, 2000; Kessler, Sonnega, Bromet, Hughes, & Nelson, 1995; Perrin, Smith, & Yule, 2000). There are a number of theoretical implications which may account for this profile exhibited in childhood cancer survivors and their parents. The first involves the specific nature of childhood cancer that is characterised by protracted and multifaceted stressors which are likely to extend throughout the course of survivorship. These children and their parents may therefore be precluded from reaching a strictly post traumatic position. Accordingly, survivorship within families may reflect an ongoing traumatic experience that consequently maintains levels of PTSS in survivors and parents. Similarly, the persistence of symptoms may
further reflect the delayed onset of PTSS in childhood cancer survivors. Indeed, some individuals diagnosed with PTSD report that their symptoms did not appear until months, even years, following the traumatic event (Ehlers & Clark, 2000). This is often thought to be the result of attributing new meaning (consciously or unconsciously) to past traumatic event/s (Davey, 1989). Correspondingly, as a child progresses through survivorship they may come to understand and transpose new meanings to aspects of the cancer experience. For example, the threat to life imposed by the cancer may only become traumatising when a child becomes aware of the seriousness and implications of their condition. Moreover, issues of infertility may not be fully realised until the survivor reaches adulthood. Such developmental considerations in the course of cancer-related PTSD and PTSS are at present poorly articulated and deserve further investigation.

Although little support was harnessed for the concordance of survivor and parent PTSS in the present study, an interesting profile emerged with respect to PTSD caseness. It was found that of those parents who reported symptoms indicative of a PTSD diagnosis 46% of their children also met PTSD caseness whilst 27% were asymptomatic. These findings suggest that there may be a number of dynamic factors which mediate contagion in stress. Indeed, the direct and indirect transmission of distress following the experience of cancer appears dependent on a number of factors, including individual susceptibility and resilience (e.g., sex, age, prior life events and comorbidity), dyadic, family, social and cultural variables (Pfefferbaum & Pfefferbaum, 1998). In elaborating the role of parent-child interactions more fully, it may be conjectured that, just as Sheeringa and Zeanah (2001) delineated specific pathogenic relational patterns, protective interactional styles which engender immunity in survivors may also be
prevalent. Such protective patterns may translate into a parent's capacity (be it consciously or unconsciously) to "hold" symptoms for the dyad (Kazak et al., 2004). Such theoretical conjectures require empirical support from sophisticated longitudinal studies in order to fully understand the underlying mechanisms and dynamic nature of cancer-related PTSD and PTSS within families.

There also appears to be an emerging and increasingly consistent PTSS cluster profile exhibited by childhood cancer survivors and their parents. Whilst survivors report a considerably greater number of avoidant compared to intrusive (reexperiencing) ideational symptoms, their parents exhibit the reverse profile (Kazak, et al., 2001, 2004; Hobbie et al., 2000; Erickson & Steiner, 2001). Such profiles found in childhood survivors and their parents are incongruent with the stress response theory of PTSD (Horowitz, 1997) which postulates that intrusive and avoidant ideation are oscillating features of a disturbed and rather unconscious completion tendency. It may be more appropriate to understand these symptoms as pathogenically independent – avoidant ideation reflecting a conscious effort to avert automatic intrusive thoughts which stem directly from the traumatic experience (Joseph, William, & Yule, 1995). This explanation dovetails with the findings that survivors mobilise a greater number of blunting coping strategies in an attempt to cope with childhood cancer (Phipps et al., 1995; Phipps and Strivastava, 1997). Alternatively, one may surmise that these mutually prevalent oscillating tendencies manifest at an interpersonal, rather than intrapersonal, level in parent-child dyads exposed to the same traumatic experience. In other words, dyads may distribute the symptomatic load, whereby survivors tend to suppress trauma related information while parents reexperience it for the pair. Further research is needed
in order to elucidate this profile of symptoms exhibited in parent-survivor dyads.

The current finding that length of hospitalisation during treatment for a brain tumour correlates with quality of parent-child interactions with respect to conflict resolution has considerable research implications. Indeed, there are a number of mechanisms which may underlie such observations. Research suggests that children may be more inclined to perceive pain as punishment, thus concluding they may have misbehaved (Rennick, Johnston, Dougherty, Platt, & Ritchie, 2002). Accordingly, they may feel frustrated and angry with parents and healthcare providers involved in the administration of painful and/or frightening treatments and consequently increase perceptions of parent-child conflict. Furthermore, parents of children with chronic and life-threatening illness often find it difficult to impose and sustain boundaries and discipline. This is generally a consequence of physical factors inherent in the medical setting as well as the guilt and responsibility often experienced by parents (Rosman, 1988; Young, Dixon-Woods, Findlay, & Heney, 2002). In addition, the regressive pull and activation of attachment systems frequently observed during periods of disease (Feeney, 2000; Schmidt & Strauss, 2002) may compound and exacerbate the normative developmental tasks of adolescence, thereby increasing parent-survivor discord.

Arguably, the duration of hospitalisation may also constitute an umbrella term encompassing numerous illness related factors. However, length of hospitalisation was not found to correlate significantly with cancer type, treatment modality or number of tumour recurrences. Thus, clearly more research is needed to tease out the specific features of hospitalisation which moderate parent-survivor conflict.
The study's finding that monitoring attentional coping styles in survivors significantly correlated with duration of hospitalisation extends support for the reconceptualisation of monitoring and blunting as being moderated by contextual rather than intrinsic dispositional factors (Miller & Schnoll, 2000) in childhood cancer survivors. Indeed, Phipps et al. (1995) found that endorsement of blunting increased as a function of time since diagnosis. They concluded that survivors may recruit additional avoidant coping strategies in the face of the numerous contextual stresses associated with the cancer experience. Similarly, the current study found that endorsement of monitoring attentional coping strategies increased as a function of time in hospital. Considered together, these findings lend support to the transactional stress and coping model of chronic childhood illness (Thompson et al., 1998). Acknowledging that illnesses differ appreciably with respect to distress and demands presented to the survivor and parents (e.g., illness visibility, life-threat, intrusiveness of care routines), Thompson et al. (1998) argue that these parameters, together with their interaction with demographic and psychosocial factors, impact on the individuals coping modes over the course of adjustment. The current sample of brain tumour survivors endorsed significantly more blunting attentional coping strategies than generic oncology norms (Phipps et al., 1995). Whether this finding reflects the need for brain tumour survivors to summon greater coping strategies than generic oncology populations (e.g., due to the former's increased exposure to aversive treatments and/or life threat) remains unknown.

The concepts of monitoring and blunting can also be examined with respect to their underlying theoretical constructs. As these concepts have been described throughout the health psychology literature under the banner of a number of idioms...
(e.g., ‘dispositional attentional styles’, ‘stable coping modes’, ‘cognitive-affective processing styles’, ‘processing patterns’, and ‘coping styles’) their conceptual specificity remains questionable, specifically in relation to current models of PTSD. For example, conceived as distinctive information processing or encoding styles they are theoretically consistent with what Ehlers and Clark (2000) describe as data-driven processing (which focuses on sensory impressions) versus conceptual processing (that focuses on placing and organising the information into a meaningful context). They argue that data-driven processing constitutes an important peri-traumatic determinant in the development of PTSD. Indeed, although not supported in the present study, individuals who engage in high levels of monitoring have been found to exhibit elevated levels of intrusive and avoidant ideation characteristic of PTSD (Schwartz et al., 1995; Miller et al., 1996).

**Clinical implications**

It is clear from the current empirical base that a substantial subset of childhood cancer survivors and their parents suffer severe and persistent traumatic stress reactions. In accordance with the Medical Traumatic Stress Working Group (MTSWG, 2005) this review proposes a three-tiered clinical intervention model which aims to synthesise empirically informed clinical implications for the management and care of families negotiating the experience of childhood cancer. Focusing predominately on the findings of the present study, the model also draws from findings derived from previous cancer-related PTSD and PTSS research (see Figure 1).
All families entering hospital could be viewed as entering a Tier One level of assessment and intervention. In light of the growing catalogue of cancer-related PTSD and PTSS predictor variables it may be advantageous at this level to conduct brief family consultations for the purposes of risk assessment and general information provision. Brief screening measures for the family (i.e., acute stress reactions and PTSD risk factors), specifically around the time of diagnosis (often a particularly distressing
period [Kazak et al., 2003]) could be completed. Indeed, Winston, Kassam-Adams, Garcia-Espana, Ittenbach, and Cnaan (2003) have developed the Screening Tool for Early Predictors of PTSD (STEPP) which is a 12-item screening measure for children and their parents at risk of developing PTSD. It may also be important (specifically for families of children diagnosed with a brain tumour) to consider the number of coping strategies utilised by children (as this may reflect underlying distress levels).

Furthermore, gaining an understanding of the quality of parent-child interactions may also provide information about a family’s potential risk of further distress.

Significantly, it is important that survivors and their parents are assessed separately because significant associations in PTSS may not exist (Kazak et al., 2004; Landolt et al., 2003; Stuber et al., 1996). Moreover, it is recommended that healthcare providers are alert to the symptomatic confounds inherent in the detection of PTSS in childhood cancer survivors (Stuber et al., 2003) as well as the tendency for this clinical population to underreport distress symptoms (Erickson & Steiner, 2001; Kazak et al., 2004). Further goals of the initial consultation could include the distribution of information leaflets to raise awareness and recognition of common distress reactions as well as the identification and promotion of family strengths (e.g., open communication, warmth, flexibility) and resources (e.g., support networks, social activities) (Orbuch et al., 2005). However, it should be noted that in accordance with the National Institute for Clinical Excellence (NICE; 2005) guidelines on early interventions for PTSD, it is not advised that these initial consultations take the form of systematic, single-session interventions focusing on the emotional impact of the traumatic incident. Instead, it is recommended that these Tier One consultations offer support and guidance with respect
to reassurance about immediate distress and information about the likely course of symptoms (NICE, 2005).

Interventions at a Tier Two level may be suitable for families who report increased levels of distress and/or a number of PTSD risk factors. Strategies at this level could involve the provision of increased support, tailored care planning and ongoing monitoring. It may be useful at this level to elicit parent and child appraisals and perceptions of cancer severity (significant correlates of PTSD and PTSS; Barakat et al., 2000; Best et al., 2001; Hobbie et al., 2000; Kazak et al., 1998; Stuber et al., 1997) and where necessary modify these (Ehlers & Clark, 2000) and provide realistic hope in accordance with the available evidence. However, such strategies may be difficult to implement in families experiencing childhood brain tumours due to the very real and serious threat to life. It may be useful to consider tailored care planning for parents and children who are symptomatic or at increased risk of traumatic stress reactions. For example, children who are likely to require lengthy hospitalisation (e.g., children with brain tumours) should be given extra attention. Indeed, as evidence suggests that increased duration of admission is likely to impact on survivors coping efforts and the quality of parent-child interactions, it is recommended that parents are encouraged to spend as much time with their child during hospitalisation. It may also be useful to spend time enquiring about the specific fears and worries held by children and parents. Provision of simple and succinct information about hospitalisation and treatment procedures may further help to reduce the sense of fear and helplessness (MTSWG, 2005). Ongoing monitoring could be operationalised in the form of named healthcare
providers who act as "advocates" for families requiring Tier Two clinical provisions.

The role of the advocate could involve addressing the family’s specific psychosocial concerns, difficulties and dilemmas, function as the family voice in medical team meetings and co-ordinate specialist individual and/or family therapy interventions.

Tier Three areas of assessment and intervention could target survivors and/or family members who exhibit persistent and clinically significant levels of distress, or are at considerably high risk of developing PTSD. It may be useful to reassess traumatic stress reactions in order to obtain a clearer picture of the individuals’ current symptomatic profile. Such an assessment instrument might include the Impact of Traumatic Events Interview Schedule (ITSIS; Kazak et al., 2001) designed to measure cancer specific PTSS in child and young adult survivors and their mothers following treatment. It is also recommended that individuals who meet criteria for Tier Three be referred for specialist psychological treatment following the family’s consent. It may be beneficial for advocates to spend time with the family discussing this referral and address any concerns or questions they may have about specialist interventions as many individuals with PTSD and PTSS fear that discussing their experiences will induce further trauma (Ehlers & Clark, 2000). Whilst there are a number of cognitive behavioural treatment programs for adults suffering from PTSD, very little empirical evidence currently exists for the use of such interventions with children, and less still for families traumatised by childhood cancer. However, Kazak et al. (1999) has developed the Surviving Cancer Competently Intervention Program (SCCIP) for survivors and their families and derived preliminary empirical support (Kazak et al., 2004). The SCIPP combines cognitive behavioural principles within a family systems approach for the
treatment of cancer-related PTSD and PTSS. This programme aims to assist individuals identify cancer-related adversaries (traumatic reminders and excessive avoidance), examine and challenge associated beliefs and appraisals, develop coping behaviours, mobilise social networks and utilises an interpersonal systems framework to identify current and likely future impact of cancer on the family (Kazak, 2005). Furthermore, Kazak et al. (in press) has revised and piloted a programme for parents of children at the time of diagnosis. Such an intervention may prove valuable for immunising those parents at high risk of developing cancer-related PTSD.

Conclusion

Despite the various methodological limitations delineated in this review (many of which reflect inherent characteristics of the clinical population and weaknesses in correlational research designs) the present findings command sizable research and clinical implications. The course and profile of PTSS in childhood cancer survivors and their parents appears incongruent with those found in the general trauma literature, presumably reflecting the distinctive traumatic nature of the cancer experience. In addition, the concept of contagion in distress may be a potentially valuable framework for understanding and treating the deleterious effects of childhood cancer which proliferate throughout the family system. The precise mechanisms that underlie the impact of hospitalisation on attentional coping styles and parent-child interactions clearly warrant further investigation. This critical appraisal proposed a preliminary clinical intervention model which includes the coordination of information resources, routine psychological screening and intervention packages for families negotiating the
experience of childhood cancer. However, many more clinical initiatives and
innovations supported by empirical derived research findings are needed in order to
effectively meet the psychological needs of childhood cancer survivors and their parents.
References


Kazak, A. E., Alderfer, M., Streisand, R., Simms, S., Rourke, M. T., Barakat, L., et al.,


Appendices
Appendix 1:

Recruitment letters
Dear .............

Project Title: How children and their parents cope with the experience of childhood brain tumours

My colleagues and I are conducting a study which attempts to explore the different ways children diagnosed and treated for brain tumours and their parents cope with this experience. In particular, we are keen to discover how coping styles and child-parent relationships affect adjustment to such experiences.

As you and your child are "experts" in this area we are very interested to hear about your experiences. In sharing these individual experiences with us, we hope that we will then be able to better assist the emotional adjustment of other families who are facing similar situations.

We have enclosed an information sheet for you and your child, which outlines the study in more detail. If you agree to take part then we would be very grateful if you and your child could complete the enclosed questionnaires and sign the consent forms and return the following in the stamped addressed envelope provided:

a) The completed "Parent/Guardian Questionnaire Pack"
b) The completed "Child Questionnaire Pack"
c) Signed child and parent consent forms

Whilst participation in this study does not require a meeting, if you would like one of us to assist you and/or your child completing the packs or would like the opportunity to discuss your experiences further then we would be happy to meet with you. This can either take place at Great Ormond Street Hospital or in your home. We would be happy to visit you during the working day, in the evening or at the weekend; whichever is best for you.

We would like you to know that these questionnaires are invaluable for helping us support other parents and children who may face similar experiences in the future.
one of us on the numbers below and we will be happy to talk to you.

Many thanks and best wishes,

Matt Bruce
Trainee Clinical Psychologist
Tel: 

Louise Isham
Trainee Clinical Psychologist
Tel: 

Kim Phipps
Neuro-oncology Research Nurse Specialist
Tel: 
Email: 

Dianne Gumley
Consultant Clinical Psychologist
Tel: 
Email: 

NB:
You do not have to take part in this study if you do not want to. If you do decide to take part you may withdraw at any time without having to give a reason.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Institute of Child Health Research Committee.

Delete as appropriate

YES, I / my child would like some assistance in completing the forms.

YES, I / we would like an opportunity to discuss our experiences with a researcher

I would like to meet at: Home (tick if applicable) □
Hospital (tick if applicable) □

I / we can be contacted on the following telephone number/s:
Home (if applicable): ..............................................
Mobile (if applicable): ..............................................
Great Ormond Street Hospital for Children
NHS Trust

Reminder letter

Address

Date

Dear ............

Project Title: How children and their parents cope with the experience of childhood brain tumours

You may recall receiving a letter from us in ...(month)... asking whether you would be willing to take part in a study looking at different ways children diagnosed and treated for brain tumours and their parents cope with this experience.

Understanding your experience, and your child's, will provide enormous help in assisting and supporting other families who are facing similar situations.

You are "experts" in this area and we would still be very interested to hear about you and your child's experiences and thus are writing to invite you to participate.

If you do have time to take part then we would be very grateful if you and your child could complete the questionnaires and return the following in the stamped addressed envelope provided in the original pack by the 31st of March 2005:

a) The completed "Parent/Guardian Questionnaire Pack"
b) The completed "Child Questionnaire Pack"
c) Signed child and parent consent forms

Whilst participation in this study does not require a meeting, if you would like one of us to assist you and/or your child completing the packs or would like the opportunity to discuss your experiences further then we would be happy to meet with you. This can either take place at Great Ormond Street Hospital or in your home. We would be happy to visit you during the working day, in the evening or at the weekend; whichever is best for you.

We would like you to know that these questionnaires are invaluable for helping us support other parents and children who may face similar experiences in the future.

In Partnership with the Institute of Child Health, UCL
Patron: Her Majesty The Queen
Chairman: Sir Cyril Chantler MA MD FRCP FRCPath FMedSci
If you wish to find out more about the study before deciding to take part please contact one of us on the numbers below and we will be happy to talk to you.

Many thanks and best wishes,

Matt Bruce  
Trainee Clinical Psychologist  
Tel: 

Louise Isham  
Trainee Clinical Psychologist  
Tel: 

Kim Phipps  
Neuro-oncology Research Nurse Specialist  
Tel: 

Dianne Gumley  
Consultant Clinical Psychologist  
Tel: 

NB: You do not have to take part in this study if you do not want to. If you do decide to take part you may withdraw at any time without having to give a reason.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Institute of Child Health Research Committee.

Delete as appropriate

YES, I / my child would like some assistance in completing the forms.

YES, I / we would like an opportunity to discuss our experiences with a researcher

I would like to meet at: Home (tick if applicable) □
Hospital (tick if applicable) □

I / we can be contacted on the following telephone number/s:

Home (if applicable): ........................................
Mobile (if applicable): ........................................
Appendix 2:

Information sheets
PARENT / GUARDIAN INFORMATION SHEET

How children and their parents experience the diagnosis and treatment of childhood brain tumours

The aim of the project
To explore how children and their parents cope with the experience of childhood brain tumours.

Why is the project being done?
Research has suggested that diagnosis and treatment of childhood brain tumours can be very stressful for patients and their families. Such levels of stress can have a negative impact on individuals' emotional functioning. This project attempts to investigate whether certain coping styles and parent-child interactions decrease the levels of stress experienced by individuals following treatment of childhood brain tumours. We may then be able to advise patients and families about specific coping styles (or strategies) and ways of interacting with each other that help reduce stress levels and promote healthy emotional adjustment following diagnosis and treatment.

How is this project to be done?
This study hopes to gain the views of a sample of children and their parents about their experience of childhood brain tumours. You and your child will each be asked to fill in some short questionnaires. These may be completed at the hospital or at home. If you or your child would like some assistance in completing these questionnaires we would be happy to arrange a convenient time to meet, either at the hospital or at your home.

What are the risks and discomforts?
There will be no physical risks or discomforts from taking part. Some of the questions might ask about experiences related to the diagnosis or treatment that may be uncomfortable or upsetting for you and your child to think about. If completing the questionnaire makes you or your child upset you are free to stop at any point and withdraw from the study. In addition, we can also arrange for you or our child to see a psychologist here at the hospital if you feel that such support would be helpful (but we will advise you about such facilities in more detail should you find the questionnaires distressing).

What are the potential benefits?
It is hoped that this study will be able to highlight certain coping styles and ways of interacting with each other, which increase the likelihood of patients and their families adjusting well emotionally following diagnosis and treatment of brain tumours. This information may therefore be used to advise families about specific ways (or strategies) of coping and interacting during the course of the illness which promotes optimum emotional adjustment. There may not be any direct benefits to you and your child from taking part. However, if this project gives us any information that might help your doctors and other healthcare professionals to take care of you and your child, we can pass this information back to them if you are happy for us to do so.

Please turn over
Who will have access to the case/research records?
Only the researchers and a representative of the Research Ethics Committee will have access to the data collected during this study. The use of some types of personal information is safeguarded by the Data Protection Act 1998 (DPA). The DPA places an obligation on those who record or use personal information, but also gives rights to people about whom information is held. If you have any questions about data protection, contact the Data Protection officer via the switchboard on 020 7405 9200 extension 5217.

What are the arrangements for compensation?
This project has been approved by an independent research ethics committee who believe that it is of minimal risk to you. However, research can carry unforeseen risks and we want you to be informed of your rights in the unlikely event that any harm should occur as a result of taking part in this study. No special compensation arrangements have been made for this project but you have the right to claim damages in a court of law. This would require you to prove fault on the part of the Hospital and/or any manufacturer involved.

Do I have to take part in this study?
If you decide, now or at a later stage, that you do not wish to participate in this research project, that is entirely your right and will not in anyway prejudice any present or future treatment.

Who do I speak to if problems arise?
If you have any complaints about the way in which this research project has been, or is being conducted, please, in the first instance, discuss them with the researcher. If the problems are not resolved, or you wish to comment in any other way, please contact the Chairman of the Research Ethics Committee, by post via the Research and Development Office, Institute of Child Health, 30 Guilford Street, London, WC1N 1EH, or if urgent, by telephone on 020 7905 2620, and the Committee administration will put you in contact with him.

If you have any queries you can telephone or email any of us and we will be happy to answer your questions.

Matt Bruce
Trainee Clinical Psychologist
Matt.bruce@excite.com  Tel:  

Louise Isham
Trainee Clinical Psychologist
Louise.isham@hotmail.com  Tel:  

Dianne Gumley
Consultant Clinical Psychologist
Gumled@gosh.nhs.uk  Tel:  

Kim Phipps
Neuro-oncology Research Nurse Specialist
Phippk@gosh.nhs.uk  Tel:  

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CHILD INFORMATION SHEET (Ages 8 - 12)

How children and their parents experience the diagnosis and treatment of childhood brain tumours

You are invited to take part in a project about children and their families who have experienced childhood brain tumours. Please read this information sheet because it tells you why we are doing this project and what we will ask you to do if you want to take part.

Why are we doing the project?
Lots of children have to come to hospital to be treated for their illnesses. Because of this we want to find out what it like for them as well as their families. We hope that what you tell us will help us understand how to look after children who find the experience of going to hospital frightening or stressful. We are interested to hear what every child and their parent has to say.

Why have I been chosen?
We are inviting all children between the ages of 8 - 16 who have experienced having a brain tumour and have had to go to hospital for treatment.

Do I have to do it?
You do not have to take part in the project if you do not want to. If you take part and then want to change your mind then that's OK and you won't have to tell us why you wanted to stop. If you decide not to take part it will not change anything that happens to you in hospital. If you do take part then we would like you to sign a form stating that you are willing to be involved in the project.

What will I have to do?
If you decide to take part in the project we would like you to fill in some short questionnaires. But don't worry, if you find them a bit tricky one of us can help you fill them in.

Are there any risks?
We don't think there are any risks, but there might be a small chance that some children will get a bit upset when thinking about what happened to them. If this happens, we will tell you about somewhere that you could go to talk to someone who can help.

Why will it be good to take part?
The things that you and other children (and parents) tell us will be very useful and will help us find out how to help other children who have might also have the same illness in their childhood.
What will happen to the questionnaires?
Whatever you tell us will be kept confidential; that means that no one will see the questionnaires except for the people doing the project (the names below). Also they will not tell anyone else what you said.

What if something goes wrong?
We do not expect anything to go wrong, but if it does we will talk to your mum or dad about what they can do.

What happens to the results of the project?
We hope to write a report for other people to see so that they can help other children who have had an illness like yours. Your name will not be on the report.

Matt Bruce
Trainee Clinical Psychologist
Matt.bruce@excite.com   Tel:

Louise Isham
Trainee Clinical Psychologist
Louise.isham@hotmail.com   Tel:

Dianne Gumley
Consultant Clinical Psychologist
Gumled@gosh.nhs.uk   Tel:

Kim Phipps
Neuro-oncology Research Nurse Specialist
Phippk@gosh.nhs.uk   Tel:
How children and their parents experience the diagnosis and treatment of childhood brain tumours

You are invited to take part in a project about adolescents and their families who have experienced childhood brain tumours. Please read this information sheet because it tells you why we are doing this project and what we will ask you to do if you want to take part.

Why is the project being done?
Research has suggested that diagnosis and treatment of brain tumours can be very stressful for young people as well as their families. This study attempts to investigate whether certain coping styles and family communication styles decrease the levels of stress experienced by the family following treatment of brain tumours.

Why have I been chosen?
We are inviting all young people between the ages of 8 - 16 who have experienced having a brain tumour and have had to go to hospital for treatment.

Do I have to do it?
You do not have to take part in the project if you do not want to. If you take part and then want to change your mind then that's OK and you won't have to tell us why you wanted to stop. If you decide not to take part it will not change anything that happens to you in hospital. If you do take part then we would like you to sign a form stating that you are willing to be involved in the project.

What will I have to do?
If you decide to take part in the project we would like you to fill in some short questionnaires. If you need help doing this we will be pleased to help you.

Are there any risks?
There will be no physical risks or discomforts from taking part. Some of the questions might ask you about experiences related to the diagnosis or treatment you received which may be uncomfortable or upsetting for you to think about. If completing the questionnaire makes you upset you are free to stop and withdraw from the project.

What are the possible benefits?
The things that you and other young people tell us about having an illness and going to hospital, including the way they coped with these experiences, will be very useful. It will help us find out how to help other young people cope if they ever have the illness in their lifetimes.

Please turn over
What will happen to the questionnaires?
Whatever you tell us will be kept confidential and no one will see the questionnaires except for the people doing the project (the names below) and that they will not tell anyone else what you said.

What if something goes wrong?
We do not expect anything to go wrong, but if it does we will talk to your mum or dad about what they can do.

What happens to the results of the project?
We hope to write a report for other health care professionals so that they can help other young people have experienced an illness like you did. Your name will not be on the report.

If you have any queries you can telephone or email any of us and we will be happy to answer your questions.

Matt Bruce
Trainee Clinical Psychologist
Matt.bruce@excite.com  Tel:

Louise Isham
Trainee Clinical Psychologist
Louise.isham@hotmail.com

Dianne Gumley
Consultant Clinical Psychologist
Gumled@gosh.nhs.uk

Kim Phipps
Research Sister
Phippk@gosh.nhs.uk  Tel:
Appendix 3:

Consent forms
PARENT CONSENT FORM

Title of project:
How children and their parents experience the diagnosis and treatment of childhood brain tumours

Name of Principal investigator:
Dianne Gumley

1. I confirm that I have read and understood the information sheet for the above project and have had the opportunity to ask questions.

2. I confirm that I have had time to consider whether or not want to be included in the project.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. I understand that responsible individuals from GOSH may look at sections of my child's medical notes. I give permission for these individuals to have access to my child's records.

5. I agree to take part in the above project.

Name of participant Date Signature

Matt Bruce
Researcher (to be contacted if there are any problems) Email/phone number
**CHILD CONSENT FORM**

**Title of project:**
How children and their parents experience the diagnosis and treatment of childhood brain tumours

**Name of Principal investigator:**
Dianne Gumley

---

1. I have read and understood the information sheet have asked any questions that I wanted to.

2. I have had enough time to decide if I want to take part in the project.

3. I understand that I only need to take part if I want to and that I am free to stop doing the project at any time, without giving any reason.

4. I understand that the people doing the research project may look at my hospital notes if they need to. This is OK if my parent lets them.

5. I agree to take part in this project.

---

**Name of participant**  
**Date**  
**Signature**

---

_Matt Bruce_  
Researcher (to be contacted if there are any problems)
Appendix 4:

Parent/guardian and child questionnaire packs
Parent / Guardian Questionnaire Pack

There are a number of short questionnaires we would like you to complete. Below is a brief explanation of what each questionnaire is about.

1. **PACHIQ-R-P**: This questionnaire asks about the way you get on with your child

2. **Impact of Events Scale**: This asks about how the experience of having a child with a brain tumour has affected you

3. **Miller Behavioural Style Scale**: This questionnaire asks about the way you generally cope with stressful situations

4. **General Health Questionnaire**: This asks about your current general health and day-to-day functioning

5. **Strengths and Difficulties Questionnaire**: This asks about the strengths and difficulties you think your child has following his/her brain tumour

Just before you begin, please remember:

- There are no "right" answers to any of these questions. They are simply a quick way of getting an understanding your experiences and views which are very valuable to us.

- If at any point during the completion of these questionnaires you wish to discontinue you are free to do so without giving a reason.

- If there is anything that you would like to ask or if you have any worries or queries about any of the questions please contact any one of us about them (our contact details are on the information sheets).
This questionnaire consists of two parts. Both parts contain statements about how you are getting on with one of your children (who experienced having a brain tumour). During the completion of this questionnaire we would like you to take this child in mind.
PART ONE OF THIS QUESTIONNAIRE

On this page you will find 8 statements. For each of these statements we would like you to indicate how much the statement does apply to your relationship with the child, whose name you have written on the previous page. We would like you to give your immediate response to the questions; you should avoid reflecting too long upon your answer.

Here is an example: "I find it important that "Jack" sticks to our agreement."

For the dots you should read the name of your child whose name you have written on the previous page. The statement is followed by five possible answers. You should TICK the one that you feel most applies to your relationship with your child. For example, if you felt that it was very important for your child to stick to your agreement you would place a tick in the "does exactly apply to us" box as shown below.

<table>
<thead>
<tr>
<th>I find it important that ... sticks to our agreement</th>
<th>Does not apply to us at all</th>
<th>Does only slightly apply to us</th>
<th>Does more or less apply to us</th>
<th>Does mostly apply to us</th>
<th>Does exactly apply to us</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Using the statements below, place a TICK in the box that most describes your relationship with your child

<table>
<thead>
<tr>
<th></th>
<th>Does not apply to us at all</th>
<th>Does only slightly apply to us</th>
<th>Does more or less apply to us</th>
<th>Does mostly apply to us</th>
<th>Does exactly apply to us</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 If ... doesn't feel like tidying his/her room, that's ok with me</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 ... breaks our house rules everyday</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3 I find it difficult to say something kind to ...</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 There are many conflicts between us which we cannot solve</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5 I don't accept criticism from ...</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6 I am often dissatisfied with ...</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 ... really trusts me</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 I take time to listen to ...</td>
<td>☐☐☐☐☐</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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PART TWO OF THIS QUESTIONNAIRE

On this page you will find some more statements. For each statement we would like you to indicate how often each situation occurs in your case.

The following is an example of such a statement:

"I encourage "Jill" to do his/her best at school"

The statements are followed by 5 possible answers. After you have read the statement, please TICK the answer you have chosen. For example, if you almost never encourage .... to do his/her best at school, then you would tick the *almost never* as shown below.

<table>
<thead>
<tr>
<th>I encourage .... to do his/her best at school</th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Almost always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Using the statements below, place a TICK in the box that most describes your relationship with your child</th>
<th>Never</th>
<th>Almost never</th>
<th>Sometimes</th>
<th>Almost always</th>
<th>Always</th>
</tr>
</thead>
<tbody>
<tr>
<td>9 I show my appreciation clearly when ... does something for me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 If we spend the whole day together s/he gets on my nerves</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11 I like to listen to ...’s stories</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 It seems like ... thinks s/he is the boss of the house</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13 I enjoy physical contact with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14 I decide which friend ... can invite around to our house</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15 I don’t feel like listening to what ... has been doing</td>
<td></td>
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<tr>
<td>16 When .... And I differ in our opinions, I shout at him/her</td>
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<tr>
<td>17 If ... doesn’t do what I say, I usually don’t bother about it</td>
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<tr>
<td>18 ... listens when I explain something</td>
<td></td>
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<tr>
<td>19 I am very proud of ...</td>
<td></td>
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<tr>
<td>20 I compliment ...</td>
<td></td>
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<td></td>
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<tr>
<td>21 When ... is upset it is unclear to me what is going on</td>
<td></td>
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</tbody>
</table>
**IMPACT OF EVENT SCALE - REVISED**

*Instructions:* Below is a list of difficulties people sometimes have after stressful life events. Please read each item, and then indicate (BY TICKING) how distressing each difficulty has been for you *during the past 7 days* with respect to the experience of your child being diagnosed and treated for a brain tumour. How much were you distressed or bothered by these difficulties?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>A little bit</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Any reminder brought back feelings about it.</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>2</td>
<td>I had trouble staying asleep.</td>
<td></td>
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<tr>
<td>3</td>
<td>Other things kept making me think about it.</td>
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<tr>
<td>4</td>
<td>I felt irritable and angry.</td>
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<tr>
<td>5</td>
<td>I avoided letting myself get upset when I thought about it or was reminded of it.</td>
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<tr>
<td>6</td>
<td>I thought about it when I didn’t mean to.</td>
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<tr>
<td>7</td>
<td>I felt as if it hadn't happened or wasn't real.</td>
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<tr>
<td>8</td>
<td>I stayed away from reminders about it.</td>
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<td></td>
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<tr>
<td>9</td>
<td>Pictures about it popped into my mind.</td>
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<tr>
<td>10</td>
<td>I was jumpy and easily startled.</td>
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<tr>
<td>11</td>
<td>I tried not to think about it.</td>
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<tr>
<td>12</td>
<td>I was aware that I still had a lot of feelings about it, but I didn’t deal with them.</td>
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<tr>
<td>13</td>
<td>My feelings about it were kind of numb.</td>
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<tr>
<td></td>
<td></td>
<td>Not at all</td>
<td>A little bit</td>
<td>Moderately</td>
<td>Quite a bit</td>
</tr>
<tr>
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<tr>
<td>14</td>
<td>I found myself acting or feeling like I was back at that time.</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>15</td>
<td>I had trouble falling asleep.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>I had waves of strong feelings about it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17</td>
<td>I tried to remove it from my memory.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>I had trouble concentrating.</td>
<td></td>
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<tr>
<td>19</td>
<td>Reminders of it caused me to have physical reactions, such as sweating, trouble breathing, nausea, or a pounding heart.</td>
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<tr>
<td>20</td>
<td>I had dreams about it.</td>
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<tr>
<td>21</td>
<td>I felt watchful and on guard.</td>
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<td></td>
</tr>
<tr>
<td>22</td>
<td>I tried not to talk about it.</td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
Miller Behavioural Style Scale

1. Vividly imagine that you are afraid of the dentist and have to get some dental work done. Which of the following would you do?

Tick all of the statements that might apply to you.

☐ I would ask the dentist exactly what work was going to be done.
☐ I would take a tranquiliser or have a drink before going.
☐ I would try to think about pleasant memories.
☐ I would want the dentist to tell me when I would feel pain.
☐ I would try to sleep.
☐ I would watch the dentist's movements and listen for the sound of the drill.
☐ I would watch the flow of water from my mouth to see if it contained blood.
☐ I would do mental puzzles in my mind.

2. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about lay-offs has been made and will be announced in several days.

Tick all of the statements that might apply to you.

☐ I would talk to my fellow workers to see if they knew anything about what the supervisor evaluation of me said.
☐ I would review the list of duties for my present job and try to figure out if I had fulfilled them all.
☐ I would go to the movies to take my mind off things.
☐ I would try to remember any arguments or disagreements I might have had that would have resulted in the supervisor having a lower opinion of me.
☐ I would push all thoughts of being laid off out of my mind.
☐ I would tell my spouse that I'd rather not discuss my chances of being fired
☐ I would try to think which employees in my department the supervisor might have thought had done the worst job.
☐ I would continue doing my work as if nothing special was happening.
General Health Questionnaire

We want to know how your health has been in general over the last few weeks. Please read the questions below and each of the four possible answers. Tick the box under the response that best applies to you.

Have you recently:

1. Been able to concentrate on what you’re doing?
   better than usual  same as usual  less than usual  much less than usual
   □  □  □  □

2. Lost much sleep over worry?
   not at all  no more than usual  rather more than usual  much more than usual
   □  □  □  □

3. Felt that you are playing a useful part in things?
   not at all  no more than usual  rather more than usual  much more than usual
   □  □  □  □

4. Felt capable of making decisions about things?
   more so than usual  same as usual  rather less than usual  much less than usual
   □  □  □  □

5. Felt constantly under strain?
   not at all  no more than usual  rather more than usual  much more than usual
   □  □  □  □

6. Felt you couldn’t overcome your difficulties?
   not at all  no more than usual  rather more than usual  much more than usual
   □  □  □  □

7. Been able to enjoy your normal day to day activities?
   more so than usual  same as usual  rather less than usual  much less than usual
   □  □  □  □
8. Been able to face up to your problems?
more so than usual  same as usual  rather less than usual  much less than usual
□ □ □ □

9. Been feeling unhappy or depressed?
not at all  no more than usual  rather more than usual  much more than usual
□ □ □ □

10. Been losing confidence in yourself?
not at all  no more than usual  rather more than usual  much more than usual
□ □ □ □

11. Been thinking of yourself as a worthless person?
not at all  no more than usual  rather more than usual  much more than usual
□ □ □ □

12. Been feeling reasonably happy, all things considered?
more so than usual  same as usual  rather less than usual  much less than usual
□ □ □ □
**Strengths and Difficulties Questionnaire**

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of the child's behaviour over the last six months.

Child's Name .................................................................................................................. Male/Female

Date of Birth ..................................................................................................................

<table>
<thead>
<tr>
<th></th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>Considerate of other people's feelings</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Restless, overactive, cannot stay still for long</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Often complains of headaches, stomach-aches or sickness</td>
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<tr>
<td>Shares readily with other children (treats, toys, pencils etc.)</td>
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<tr>
<td>Often has temper tantrums or hot tempers</td>
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<tr>
<td>Rather solitary, tends to play alone</td>
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<tr>
<td>Generally obedient, usually does what adults request</td>
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<tr>
<td>Many worries, often seems worried</td>
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<tr>
<td>Helpful if someone is hurt, upset or feeling ill</td>
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<tr>
<td>Constantly fidgeting or squirming</td>
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<tr>
<td>Has at least one good friend</td>
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<tr>
<td>Often fights with other children or bullies them</td>
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<tr>
<td>Often unhappy, down-hearted or tearful</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Generally liked by other children</td>
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<tr>
<td>Easily distracted, concentration wanders</td>
<td></td>
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<tr>
<td>Nervous or clingy in new situations, easily loses confidence</td>
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<tr>
<td>Kind to younger children</td>
<td></td>
<td></td>
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<tr>
<td>Often lies or cheats</td>
<td></td>
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<tr>
<td>Picked on or bullied by other children</td>
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<tr>
<td>Often volunteers to help others (parents, teachers, other children)</td>
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<tr>
<td>Thinks things out before acting</td>
<td></td>
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<tr>
<td>Steals from home, school or elsewhere</td>
<td></td>
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<td></td>
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<tr>
<td>Gets on better with adults than with other children</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Many fears, easily scared</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Sees tasks through to the end, good attention span</td>
<td></td>
<td></td>
<td></td>
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</tbody>
</table>

Do you have any other comments or concerns?

*Please turn over - there are a few more questions on the other side*
Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?
  - Less than a month
  - 1-5 months
  - 6-12 months
  - Over a year

- Do the difficulties upset or distress your child?
  - Not at all
  - Only a little
  - Quite a lot
  - A great deal

- Do the difficulties interfere with your child's everyday life in the following areas?
  - HOME LIFE
  - FRIENDSHIPS
  - CLASSROOM LEARNING
  - LEISURE ACTIVITIES

- Do the difficulties put a burden on you or the family as a whole?
  - Not at all
  - Only a little
  - Quite a lot
  - A great deal

Signature .............................................................................................. Date ..................................

Mother/Father/Other (please specify:)

Thank you very much for your help
Child Questionnaire Pack

There are a number of short questionnaires we would like you to fill in. Below is a list of the questionnaires in the pack.

6. **PACHIQ-R-P**: This questionnaire asks about the way you get on with your mum, dad or guardian

7. **Impact of Events Scale**: This questionnaire asks about whether you still think about the time you had a brain tumour

8. **Child Coping Style Scale**: This questionnaire asks about the way you deal with difficult situations

9. **Strengths and Difficulties Questionnaire**: This asks about the strengths and difficulties you think you have following your brain tumour

Before you begin, try to remember:

- There are no “right” answers to any of these questions.

- If you want to stop filling in the questionnaires you can. You don’t have to tell us why you wanted to stop either.

---

2 *Included in questionnaire packs for children aged 11-16 years*
Participant ID  ..... (participant number) ..... 

Age .....................................

Date .....................................

This questionnaire consists of descriptions about how children and teenagers get on with their parents. We would like to know how you are getting on with your Mum OR Dad OR Guardian. We would like you to think about ONLY ONE parent when completing this questionnaire.
Before you start please circle the parent you have chosen to think about:

...Mum...  ...Dad...  ...Guardian...

Please read the descriptions below. Place a tick in the box that most describes the way you get on ONLY with the parent you have circled above. You can fill in which parent you have decided to think about on the dotted lines. Remember that all the questions are about the parent you circled above.

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>Doesn't apply to me at all</th>
<th>Does not apply to me</th>
<th>In between</th>
<th>Applies to me</th>
<th>Definitely applies to me</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>My .......... doesn't understand me very well</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2</td>
<td>I find my .......... a bore</td>
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<tr>
<td>3</td>
<td>I often have a laugh with my ..........</td>
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<tr>
<td>4</td>
<td>My .......... thinks that I cannot do anything for myself</td>
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<tr>
<td>5</td>
<td>My .......... and I have problems which we cannot work out</td>
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<tr>
<td>6</td>
<td>When my .......... tells me not to do something, I do it anyway</td>
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<tr>
<td>7</td>
<td>My .......... mostly talks to me in a friendly voice</td>
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<tr>
<td>8</td>
<td>Most of the time I do what my .......... asks</td>
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<tr>
<td>9</td>
<td>I like it if my .......... explains things to me</td>
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<tr>
<td>10</td>
<td>My .......... asks me to do things all the time</td>
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<tr>
<td>11</td>
<td>I think that my .......... knows a lot</td>
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<tr>
<td>12</td>
<td>When my .......... and I disagree we can talk about it</td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>13</td>
<td>My .......... does not think about my wishes enough</td>
<td></td>
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<td></td>
</tr>
<tr>
<td>14</td>
<td>My .......... and I get on well</td>
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<td></td>
<td></td>
<td>Never</td>
<td>Almost never</td>
<td>Sometimes</td>
<td>Almost always</td>
<td>Always</td>
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<tr>
<td>15</td>
<td>My .......... listens to me when I want to talk to her</td>
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<tr>
<td>16</td>
<td>When I have a problem I ask my .......... for advice</td>
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<tr>
<td>17</td>
<td>No matter what my .......... says, I still do what I want</td>
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<tr>
<td>18</td>
<td>Whenever I have an idea my .......... does not think much of it</td>
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</tr>
<tr>
<td>19</td>
<td>When my .......... tells me not to do something I don't do it</td>
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<tr>
<td>20</td>
<td>I call my .......... names</td>
<td></td>
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</tr>
<tr>
<td>21</td>
<td>If I am sad about something my .......... comforts me</td>
<td></td>
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</tr>
<tr>
<td>22</td>
<td>My .......... often does things that I find stupid</td>
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</tr>
<tr>
<td>23</td>
<td>When I do something for my .........., she is pleased about it</td>
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</tr>
<tr>
<td>24</td>
<td>My .......... is proud of me</td>
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<tr>
<td>25</td>
<td>When my .......... disallows something I understand why</td>
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</tr>
</tbody>
</table>
Impact of Events Scale (IES-8)

Think about the time when you had a brain tumour and received treatment.

Below is a list of things some people say after frightening events. Please read each one carefully and put a tick in the box, showing how much it was true for you DURING THE PAST SEVEN DAYS. If it was not true during that time, please tick the "not at all" column.

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Not very often</th>
<th>Sometimes</th>
<th>Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I thought about it when I didn't mean to.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>2. I tried to remove it from memory.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. I had waves of strong feelings about it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. I stayed away from reminders of it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. I tried not to talk about it.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>6. Pictures about it popped into my mind.</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>7. Other things kept making me think about it.</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>8. I tried not to think about it.</td>
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</tbody>
</table>
CBSS - Child Version (Revised)

Imagine that:

I. Your parent takes you to the doctor's because you are sick. You are sitting in the waiting room waiting for the doctor. Would you:

Circle “yes” or “no”

1) Play with toys or a game in the waiting room     yes  no
2) Talk to your parent about how sick you feel     yes  no
3) Play with other children in the waiting room     yes  no
4) Think about what the doctor might do to you     yes  no
5) Look at a book, either by yourself or with your parent     yes  no
6) Close your eyes and think about where in your body you feel sick     yes  no
7) Think about something else to get your mind off being sick     yes  no
8) Think about what the doctor did to you the last time you were sick     yes  no

II. You’re playing in the living room with a friend and you accidentally break a lamp. Your parent will be home soon. While you are waiting with your friend for your parent to come home, would you:

9) Keep looking at the pieces and think about what happened     yes  no
10) Go outside and play until your parent gets home     yes  no
11) Think about what will happen when your parent gets home     yes  no
12) Just play at home and forget the lamp     yes  no
13) Talk about it with your brother or sister or your friend     yes  no
14) Go and watch TV     yes  no
15) Think about the look on your parent’s face     yes  no
16) Get your mind off what happened by thinking about other things     yes  no
III. You are in class at school. Your teacher comes over and tells you the head teacher wants to see you at break. While you are waiting for break, would you:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>17</td>
<td>Think about other things to get your mind off the head teacher</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18</td>
<td>Think about what you did to make the head teacher want to see you</td>
<td></td>
<td></td>
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<tr>
<td>19</td>
<td>Think about what the head teacher might say or do</td>
<td></td>
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<tr>
<td>20</td>
<td>Continue with your class pretending you don’t know</td>
<td></td>
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<tr>
<td>21</td>
<td>Think about what the head teacher did to other kids</td>
<td></td>
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<tr>
<td>22</td>
<td>Try to keep your mind on your school work</td>
<td></td>
<td></td>
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<tr>
<td>23</td>
<td>Pretend the head teacher will say something good to you</td>
<td></td>
<td></td>
</tr>
<tr>
<td>24</td>
<td>Watch the faces of your teacher and the other children to see what they might think about it</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

IV. You are sitting in the dentist’s chair. The dentist has gone out of the room to get something, but soon will come back and start working on your teeth. You feel worried about what the dentist will do. While you are waiting, would you:

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>yes</th>
<th>no</th>
</tr>
</thead>
<tbody>
<tr>
<td>25</td>
<td>Look around to see what tools the dentist will use</td>
<td></td>
<td></td>
</tr>
<tr>
<td>26</td>
<td>Think about what the dentist did when you were there before</td>
<td></td>
<td></td>
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<tr>
<td>27</td>
<td>Think about what you don’t want the dentist to do</td>
<td></td>
<td></td>
</tr>
<tr>
<td>28</td>
<td>Keep looking at the pictures on the wall</td>
<td></td>
<td></td>
</tr>
<tr>
<td>29</td>
<td>Think about other things to get your mind off the dentist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>30</td>
<td>Close your eyes and pretend you are someplace else</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31</td>
<td>Think of things you want to ask the dentist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>32</td>
<td>Think about being with friends or your parent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Strengths and Difficulties Questionnaire

For each item, please mark the box for Not True, Somewhat True or Certainly True. It would help us if you answered all items as best you can even if you are not absolutely certain or the item seems daft! Please give your answers on the basis of how things have been for you over the last six months.

Your Name ........................................................................................................... Male/Female

Date of Birth ...................................................................

<table>
<thead>
<tr>
<th></th>
<th>Not True</th>
<th>Somewhat True</th>
<th>Certainly True</th>
</tr>
</thead>
<tbody>
<tr>
<td>I try to be nice to other people. I care about their feelings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am restless, I cannot stay still for long</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get a lot of headaches, stomach-aches or sickness</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I usually share with others (food, games, pens etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I get very angry and often lose my temper</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am usually on my own. I generally play alone or keep to myself</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I usually do as I am told</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I worry a lot</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I am helpful if someone is hurt, upset or feeling ill</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am constantly fidgeting or squirming</td>
<td></td>
<td></td>
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<tr>
<td>I have one good friend or more</td>
<td></td>
<td></td>
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<tr>
<td>I fight a lot. I can make other people do what I want</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I am often unhappy, down-hearted or tearful</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other people my age generally like me</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am easily distracted, I find it difficult to concentrate</td>
<td></td>
<td></td>
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<tr>
<td>I am nervous in new situations. I easily lose confidence</td>
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<td></td>
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<tr>
<td>I am kind to younger children</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am often accused of lying or cheating</td>
<td></td>
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<td></td>
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<tr>
<td>Other children or young people pick on me or bully me</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I often volunteer to help others (parents, teachers, children)</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I think before I do things</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I take things that are not mine from home, school or elsewhere</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I get on better with adults than with people my own age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I have many fears, I am easily scared</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>I finish the work I'm doing. My attention is good</td>
<td></td>
<td></td>
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</tbody>
</table>

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side
Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

<table>
<thead>
<tr>
<th>Yes - minor difficulties</th>
<th>Yes - definite difficulties</th>
<th>Yes - severe difficulties</th>
</tr>
</thead>
<tbody>
<tr>
<td>No</td>
<td></td>
<td></td>
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</tbody>
</table>

If you have answered "Yes", please answer the following questions about these difficulties:

- How long have these difficulties been present?

<table>
<thead>
<tr>
<th>Less than a month</th>
<th>1-5 months</th>
<th>6-12 months</th>
<th>Over a year</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
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</tbody>
</table>

- Do the difficulties upset or distress you?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Only a little</th>
<th>Quite a lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

- Do the difficulties interfere with your everyday life in the following areas?

<table>
<thead>
<tr>
<th>HOME LIFE</th>
<th>FRIENDSHIPS</th>
<th>CLASSROOM LEARNING</th>
<th>LEISURE ACTIVITIES</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

- Do the difficulties make it harder for those around you (family, friends, teachers, etc.)?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>Only a little</th>
<th>Quite a lot</th>
<th>A great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tr>
</tbody>
</table>

Your Signature

Today's Date

Thank you very much for your help
Appendix 5:

Letter of ethical approval
30th April 2004

Ms D Gumley
Department of Psychological Medicine
GOSH

Dear Ms Gumley,

*Full title of study: Post-traumatic stress symptoms in childhood survivors of brain tumours and their parents: Moderating effects of coping styles and parent-child interactions*

Thank you for your letter of 20th April 2004, responding to the Committee’s request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chairman.

**Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

The favourable opinion applies to the following research site:

**Site: Great Ormond Street Hospital for Children NHS Trust/The Institute of Child Health**

Principal Investigator: *Ms D Gumley, Consultant Clinical Psychologist*
Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

Statement of Compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

Yours sincerely,

Laura Howe
Research Ethics Coordinator

Enclosures: Standard approval conditions