The long-term psychological adjustment of an Australian sample of childhood cancer survivors, parents and siblings

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THE LONG-TERM PSYCHOLOGICAL ADJUSTMENT OF AN AUSTRALIAN SAMPLE OF CHILDHOOD CANCER SURVIVORS, PARENTS AND SIBLINGS: AN INVESTIGATION OF LONG-TERM PTSD, PTSS, PSYCHOLOGICAL DISTRESS, AND POSTTRAUMATIC GROWTH, AND A TEST OF THE APPLICABILITY OF A COGNITIVE MODEL OF PTSD TO CHILDHOOD CANCER SURVIVORSHIP

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ABSTRACT

This research program investigated PTSD, PTSS, psychological distress, and posttraumatic growth in Australian long-term childhood cancer survivors, their parents, and their siblings (Part 1), and examines the applicability of the Ehlers & Clark (2000) cognitive model of PTSD to childhood cancer survivorship (Part 2). Results show a small but important proportion of survivors and parents develop PTSD after cancer, and although few met current criteria, full symptom recovery was rare. Across all family groups, a higher prevalence of persistent and life impacting PTSS was reported relative to the general population. Current comorbid psychological distress was reported in up to half of participants meeting PTSD since diagnosis, and survivors reported higher levels of depression relative to normative data.

Posttraumatic growth following the cancer experience was reported by the overwhelming majority of participants, with growth sharing a moderate-strong positive relationship with PTSD and PTSS. Of interest are data suggesting that some growth categories share a negative association with PTSS, providing a possible explanation for the current equivocal evidence-base.

When comparing across groups, the prevalence of PTSD, PTSS, and posttraumatic growth was highest for mothers, and lowest for siblings. Findings show that within families, PTSS and posttraumatic growth are likely to be shared. Survivor PTSS is positively related to parental PTSS, but no symptom relationship was revealed between survivors and siblings. Conversely, a positive relationship exists between survivors and all family groups on posttraumatic growth. Findings suggest screening and intervention is necessary for all family members, particularly mothers, with some support for a family systems approach, however symptom-symptom concordance data was relatively low with the exception of intrusive symptoms and a greater appreciation of life.

Finally, Part 2 supports the generalisability of the Ehlers and Clark (2000) cognitive model of PTSD to childhood cancer survivorship, indicating that within this context, the model provides a comprehensive cognitive framework for persistent PTSD and PTSS risk assessment and intervention. In an extension of the literature, an exploratory application of this model to posttraumatic growth revealed cognitive pathways overlap between the two trauma outcomes (stress and growth). The theoretical and practical implications of these findings are discussed.

LIST OF ABBREVIATIONS

Abbreviation	Description
CCCBD	The Centre for Children's Cancer and Blood Disorders, Sydney Children's Hospital, Randwick, Australia
DASS-21	Depression, Anxiety and Stress Scale-Short Version (assessing current levels of the core symptoms of depression, anxiety, and stress).
IES-R	Impact of Event Scale-Revised (assessing current posttraumatic stress symptoms)
Partial PTSD:	One or more current symptoms of PTSD
PTGI	Posttraumatic Growth Inventory (assessing the belief of personal change following trauma)
PTSD	Posttraumatic Stress Disorder as assessed by the SCID
PTSS	Posttraumatic Stress Symptoms as assessed by the SCID or the IES-R
SCID	Structured Clinical Interview of DSM-IV: PTSD Module (assessing diagnosis of PTSD and the symptom clusters)

LIST OF TERMINOLOGY

Term	Definition
Current PTSD	A diagnosis of PTSD at the time of data collection.
Life-time PTSD	A diagnosis of PTSD at any point in a person's life.
Part Remission	A history of a diagnosis of PTSD, but at the time of data collection only one or two symptom clusters are present.
Full Remission	A history of a diagnosis of PTSD, but at the time of data collection no symptom clusters are present.
Lost to Follow-up	No current contact details on record
Outcomes	When termed with posttraumatic stress refers to either PTSD or PTSS. Similarly, when termed with posttraumatic growth, outcomes refer to both specific and/or general growth.

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PREAMBLE

Significant advances in the medical treatment of childhood cancers have resulted in a marked increase in survival rates with almost 80% of all children diagnosed with a cancer surviving beyond 5 years post treatment (Altekruse et al., 2010). This corresponds to approximately 1 in every 450 adolescents and adults purported to be a survivor of childhood cancer (Monteleone & Meadows, 2009).

Treatments for childhood cancer, whilst potentially curative, can be aggressive, painful and invasive, and associated with long-term and often latent medical effects (e.g. toxicity of drugs and radiation therapy potentially affecting different organ and body systems), as well as psychosocial consequences (e.g., depression and anxiety disorders, and behavioural, social, educational and vocational problems) (Dreyer et al., 2002; Hudson et al., 2003). The family impact can also be profound, with childhood cancer regarded as one of the most severe stressors faced by a parent (Kazak et al., 1998). Reflecting this and the life-threatening nature of the disease itself, the long-term psychosocial adjustment of childhood cancer survivors and their parents has been investigated against a posttraumatic stress paradigm. Prevalence studies indicate that a significant proportion of survivors and their parent's exhibit persistent and life impacting posttraumatic stress symptoms. Long-term psychosocial adjustment in siblings has been largely ignored, however one study has reported symptoms of PTSD to also be prevalent in this population group (Alderfer et al., 2003). Whilst informative, this research currently lacks a solid theoretical orientation where symptom onset, maintenance, and treatment can be adequately evaluated in prospective trials. Applying an existing theoretical treatment model already developed and tested within the non-cancer trauma literature may help to address this void.

Posttraumatic growth is also a recognized response to highly stressful events. While there is evidence for growth outcomes after childhood cancer, research has generally focused on 'stress-deficit' paradigms with little quantitative research on the 'positive' aspects of survival, or how posttrauma stress and growth may relate to each other (Barakat et al., 2006; Zebrack et al., 2008). There is currently no data on what factors may lead to such growth outcomes in this population. However evidence arising from the non-cancer literature indicates a cognitive role (Park & Helgeson, 2006). Further research is necessary to explore the posttrauma stress and growth relationship and move psychosocial interventions beyond the stress-deficit approach.

Additionally, no research has been conducted in the Australian healthcare context. Evidence to date has predominantly been derived from patient samples in the U.S., with only one European-based (Langeveld et al., 2004), and one Japanese based study (Ozono et al., 2007). While these findings seem consistent with other US-based studies, there has been no research into these outcomes from an Australian healthcare perspective. While many psychosocial aspects of childhood cancer may be universal (i.e., appraisal of life threat), some cultural differences may be relevant to long-term adjustment - notably, ethnic diversities, access to ongoing health care and insurance, and educational and vocational

opportunities. Australian data is clearly necessary to ensure appropriate ongoing care for Australian survivors and families, and to improve advocacy to relevant stakeholders such as health and life insurance providers.

BROAD OBJECTIVES, SIGNIFICANCE OF RESEARCH, AND DISSERTATION OUTLINE

There are two broad objectives of this research: (1) to evaluate long-term posttraumatic stress and posttraumatic growth outcomes in an Australian sample of childhood cancer survivors, their parents, and siblings; and (2) to evaluate the applicability of a cognitive theoretical and treatment model of posttraumatic stress disorder to the childhood cancer context.

The findings of this project will extend knowledge by contributing Australian prevalence data on posttraumatic stress, psychological distress, and posttraumatic growth outcomes in survivors, and their families. The recruitment of adult siblings in this project will provide much needed data on the long-term adjustment of this group of family members. This project will also provide invaluable information on whether the cognitive processes found to be important to the onset and maintenance of PTSD in other non-cancer trauma contexts are generalisable to childhood cancer survivorship. Results will provide data attesting to similarities or differences in the factors contributing to persistent PTSD due to trauma context (illness versus non-illness). Additionally, by investigating how cognitive processes may lead to diverse trauma outcomes (stress and growth), a greater understanding of which factors may lead to, or predict, PTSD and posttraumatic growth outcomes in a childhood cancer context will be generated. This is imperative if the traditional stress-deficit approach is to be extended in research and development of clinical interventions.

Corresponding to the two broad objectives, this dissertation will be separated into two key parts:

Part 1: Childhood Cancer and Trauma Responses: Prevalence and Relationships

Part 2: A Test of the Ehlers and Clark Cognitive Model of Posttraumatic Stress Disorder to Childhood Cancer.

Part 1

Childhood Cancer and Trauma Responses: Prevalence, family group comparisons, and outcome relationships

SCIENTIFIC PUBLICATIONS AND PRESENTATIONS RELATING TO PART 1

The sections of Chapter 1 relating to PTSD and childhood cancer survival and Table 1.1 are included in a theoretical paper currently undergoing the review for publication in the journal 'Psycho-Oncology'.

Preliminary findings relating to Part 1, Studies 1A and 2 of this research have been presented at numerous national and international scientific meetings to date:

(1) 10th International Conference on Long-Term Complications of Treatment of Children and Adolescents for Cancer, Ontario, Canada, 6-7 June, 2008.

(2) 39th Congress of the International Society of Paediatric Oncology, SIOP, Mumbai, India, 31 October – 4 November, 2007.

(3) Australian and New Zealand Children's Haematology & Oncology Group (ANZCHOG) Annual Scientific Meeting, 24-27 May, 2007.

(4) 29th National AACBT Conference, Sydney, 18-23 October, 2006.

(5) TOW Research Prize: Prince of Wales Hospital, Sydney, 27 October, 2006.

(6) 12th Annual conference: Australasian Society of Traumatic Stress Studies, Perth, 15-17 September, 2005.

(7) 36th Congress of the International Society of Paediatric Oncology, SIOP, Oslo, Norway, 16-19 September, 2004.

(8) 34th European Association for Behavioural & Cognitive Therapies, Manchester, UK, 8-11 September, 2004.

(9) 7th World Congress of Psycho Oncology: Copenhagen, Denmark, 23-28 August, 2004.

CHAPTER 1
INTRODUCTION

1.1 An Overview of Childhood Cancer and Childhood Cancer Survival.

Cancer is an umbrella term for a variety of diseases identified by the rapid uncontrolled growth and replication of abnormal cells. Cancers in childhood take many different forms, each with disease and treatment factors unique to their type and stage of cancer progression. The most common of these include leukaemias, followed by tumours of the central nervous system, lymphomas, sarcomas, and embryonal tumours (Family Handbook, 2009; American Cancer Society, 2000). Appendix 1A summarises these cancers in terms of known aetiology and epidemiology, symptomatology, treatment, and prognosis.

It is estimated that, each year, 1 in every 5,000 Australian children, will receive a cancer diagnosis (Australian Paediatric Cancer Registry Report, 2000). Once considered a terminal disease, today, almost 80% of these children are expected to be alive and disease free at 5-years following treatment cessation, with the majority of these expected to survive well into adulthood (Altekruse et al., 2010). A childhood cancer 'survivor' is defined at this 5-year disease free and post treatment mark. At this point, treatment changes focus from surveillance for relapse, to surveillance for late effects of treatment (Bhatia et al., 2006). Significant advances in medical treatments are largely credited for the extensive increase in survival rates, although the physical impact of these therapies may leave survivors with long-term and often latent medical side-effects (Bhatia et al., 2006; Oeffinger et al., 2006). Indeed, up to 75% of survivors may have medical sequelae as a direct consequence of the cancer or treatment, where, for 25% to 36% of survivors, the sequelae are considered to be serious or life-threatening (Bhatia et al., 2006; Oeffinger et al.202006). Some may emerge almost immediately following treatment, especially those arising from surgical procedures (e.g., amputation), however, most are not apparent until years later with the onset of growth, maturation and general ageing (Bhatia et al., 2006). This latency is often due to toxic chemotherapeutic drugs and radiation therapy to young body systems, organs, or tissues, which may delay, stunt, or impair normal somatic developmental progression (Dreyer et al., 2002). Appendix 1B lists the more common long-term effects experienced by childhood cancer survivors and the type of treatments associated.

Ongoing medical research has increased awareness and understanding of many of these physical long-term effects and has resulted in safer treatment protocols and risk management strategies (Dreyer et al., 2002). However, comparably less is known about ongoing psychosocial sequelae. Much of the psychosocial research concludes that the majority of survivors are psychosocially well adjusted, although there is evidence that a small but significant group suffer psychological and social problems (Patenaude & Kupst, 2005; Zeltzer et al., 2009). The family impact can also be profound with considerable long-term distress reported by parents and siblings (Alderfer et al., 2003, 2009; Kazak et

al., 1994; Ozono et al., 2007; Patenaude & Kupst, 2005). Over the past two decades, research into the long-term adjustment of survivors and their families has increasingly adopted a trauma focus with outcomes investigated within a posttraumatic stress framework.

1.2 Trauma and Childhood Cancer

The literature investigating childhood cancer from a trauma perspective has grown from early reports that some children being treated for cancer, survivors, and parents display symptoms consistent with a posttraumatic stress response (Nir, 1985; Pelcovitz & Kaplan, 1992; Pot-Mees, 1989; Stuber et al., 1991, 1994) and reflect the extreme nature of stressors faced by patients and their families. These include the potential life-threat associated with a cancer diagnosis, the often painful and invasive treatments faced, the sudden and ongoing life disruption, and the continued long-term effects and future uncertainty. This dissertation will now turn to reviewing the relevant trauma literature.

1.2.1 Posttraumatic Stress Disorder

According to the text revision of the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV-TR; American Psychiatric Association, 2000), Posttraumatic Stress Disorder (PTSD) is an anxiety disorder resulting from a severe psychological reaction to a traumatic event in which a distinctive symptom profile compromises day-to-day functioning. In order for a PTSD diagnosis to be substantiated, six diagnostic criteria must be met. While these are listed in more detail in Appendix 1C, PTSD is generally characterised by three psychological symptom clusters: Intrusion (criterion B), Avoidance (criterion C), and Hyper-arousal (criterion D). For diagnosis, symptoms must persist for at least one month (criterion E) and result in considerable impairment to daily functioning (criterion F). Patients typically report alternating between avoidance and re-experience of trauma-related stimuli via intrusive thoughts, flashbacks, or nightmares. Avoidance may be cognitive or behavioural and includes potentially protective responses such as emotional numbing, amnesia, or denial. High levels of psychological and physiological arousal typically accompany intrusion symptomatology, e.g. extreme startle, edginess, hypervigilance, and negative states such as anger, guilt or sadness. Symptoms of PTSD typically arise within the first three months following trauma, however delayed onset may occur six months or more after trauma. In half of cases, spontaneous complete recovery will occur within three months following symptom onset, although for others, symptoms may persist for a year or beyond and seriously threaten long-term psychosocial well-being.

PTSD is associated with a range of other psychosocial difficulties, including depressive, anxiety, and substance related disorders, dissociative symptoms, somatic complaints, social withdrawal, relationship difficulties, self-destructive and impulsive behaviour, and feelings of intense guilt (particularly survival guilt), despair, or hopelessness. For those with chronic PTSD, more than half are reported to have at least one other comorbid disorder (Yehuda & McFarlane, 1995).

The DSM-IV-TR (APA, 2000) reports that up to 8% of the general U.S. population will meet life-time criteria for PTSD. This is consistent with prevalence research indicating that between 1% and 9.2% of U.S. community samples will meet criteria for PTSD at some life point (see review by Yule, 2001). The general population incidence of *current* PTSD has been reported to be much lower within the community at any one time. While comparative U.S. data is lacking, a Canadian community survey reported that 2.0% of 1,002 participants met DSM-IV criteria for current PTSD (Stein et al., 1997), while 1.5% of 10,641 Australians who participated in the National Survey of Mental Health and Wellbeing met the same criteria within the past 12 months (Rosenman, 2002). Incidence of current PTSD, however, is most usually investigated specifically within trauma-exposed groups. Among these groups it has been estimated that as many as 25% will go on to develop PTSD following a traumatic experience (Green, 1994; Johnson et al., 2009).

1.2.2 Posttraumatic Stress Disorder: Controversy Surrounding the DSM-IV Inclusion of Life-Threatening Illness as a Trauma Inducing Event

As reviewed in Appendix 1D, the DSM-IV was the first edition to acknowledge the importance of *perception* of trauma in its criterion A, emphasising the role of subjective experience. In line with this, the DSM-IV was also the first edition to include a diagnosis of a life-threatening illness in the self or in one's child as potential trauma inducing events (APA, 1994). These inclusions recognised for the first time that serious illness in the self or a loved one has the potential to psychologically overwhelm adaptive capabilities in a way resembling other traumatic experiences.

Illness, such as cancer, is undeniably associated with a considerable threat to life and physical integrity, and can evoke feelings of overwhelming fear, horror or helplessness. Nonetheless, its inclusion as a PTSD potential stressor has generated some controversy among trauma theorists. Notably illnesses like cancer differ from other non-illness trauma (e.g. accident, assault) because the threat generally arises from the internal not external environment. Within-body trauma precludes distancing from the stressor after onset, resulting in prolonged trauma exposure (Green et al., 1997). A second related key factor is the often ambiguous and multifaceted nature of illness, thereby making it difficult to discern a precise trauma-inducing event, or indeed an end-point to trauma exposure. Illnesses such as cancer are better conceptualised as a process comprising multiple repeated traumatic threats (Kangas, et al, 2002). These traumatic threats may arise at diagnosis, persist throughout treatment, and continue after cure due to long-term latent effects of treatment including increased risk for second malignancy (see Appendix 1B).

As a prolonged and multiple stressor, cancer shares features with other trauma such as repeated sexual and physical assault (Yehuda et al., 2001), torture (Wenzel et al, 2000) and political imprisonment (Kanninen et al., 2002). Ongoing, repetitive, or multiple stressors may increase PTSD risk relative to single discrete trauma by compounding existing or residual posttraumatic stress reactions (Jurberg et al.,

2009; Kangas et al., 2002). Such events are also potentially more likely to evoke psychological defence strategies such as dissociation, denial, numbing, or repression, and these strategies have been found to increase the severity of PTSD as well as impede a natural time-course of recovery (Foa & Street, 2001). Such findings suggest that a PTSD paradigm may be both valid and applicable to a cancer context in both adults and children. Since publication of the DSM-IV, a substantial literature base has evolved evaluating PTSD, its symptoms, and comorbid distress in childhood cancer survivors and their parents, with some evidence to suggest siblings may also be at risk. This literature will now be reviewed.

1.2.3 Posttraumatic Stress Disorder, Posttraumatic Stress Symptoms and Childhood Cancer

Following the DSM-IV publication, a literature search[1] revealed 25 studies as having reported posttraumatic stress disorder and/or posttraumatic stress symptoms in childhood cancer survivors, 22 studies in one or both parents, and 1 study in siblings. Listed in Table 1.1, these studies were carried out in the United States except for one Dutch (Langeveld et al., 2004) and one Japanese (Ozono et al., 2007) report, and show equivocal results. Reports indicate between 3 to 35% of survivors meet life-time criteria (Alderfer et al., 2009; Gerhardt et al., 2007; Kazak et al., 2004a; Meeske et al., 2001; Pelcovitz et al., 1998; Rourke et al., 2007), and between 5 to 22% meet current criteria for the disorder (Erickson & Steiner, 2000; Kazak et al., 2004a; Meekse et al., 2001; Pelcovitz et al., 1998; Rourke et al., 2007; Weiner et al., 2006)[2]. While the discrepancies in findings may partly reflect methodological inconsistencies - ranging from choice of outcome measures, to sample based parameters (e.g. size, selection techniques, age cohorts, survivor definition, or cancer diagnoses; Bruce, 2006; Taieb et al., 2003), the prevalence of PTSD among childhood cancer survivors is higher than that found in the general population - for both life-time (1 to 9.2%: APA, 2000; Yule, 2001), and current PTSD (1.5 to 2%: Rosenman, 2002; Stein et al., 1997) – and within life-time prevalence rates reported in other trauma exposed groups (approximately 25%: Green, 1994; Johnson et al., 2009).

Investigations of parental PTSD prevalence have consistently shown rates to be greater than found amongst survivors with between 27 to 54% of mothers meeting life-time criteria, and between 6 to 25% meeting current criteria (Goldenberg Libov et al., 2002; Kazak et al., 1994; Manne et al., 1998; Pelcovitz et al., 1996). While fewer studies have included fathers, two have indicated that around 10% qualify for a current diagnosis (Alderfer et al., 2005; Kazak et al., 2004a), which in the only comparative study was twice the rate of survivors (Kazak et al., 2004a).

Far more prevalent in these populations are subclinical posttraumatic stress symptoms (PTSS). When evaluated separately, prevalence of PTSS are reported to be substantially higher than the disorder

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[1] PsychInfo and Medline databases were searched for reports since 1994 in English language using keywords ‘childhood cancer survivors’, ‘PTSD’ and variations (e.g., ‘paediatric cancer’, ‘posttraumatic stress’). Publications were also reviewed for relevant cited references.

[2] According to DSM-III-R and DSM-IV diagnostic criteria.

itself (see Table 1.1). For example, Kazak and colleagues (2004a) report that 73% of survivors, 97% of mothers, and 87% of fathers surveyed met the DSM-IV B-symptom cluster criteria for intrusive re-experiencing, 16%, 34%, and 16% respectively met the C-symptom cluster of avoidance, and 41%, 64%, and 44% met the D-symptom cluster hyper-arousal, despite only 5%, 14%, and 10% reporting current PTSD. These findings are consistent across studies (Erickson & Steiner, 2000; Goldenberg Libov et al., 2002; Kazak et al., 2001; Manne et al., 1998, 2002; Rourke et al., 2007), and accord with those reported for non-cancer trauma populations (Favaro et al., 2006). However, most studies do not determine whether symptom presence impairs functioning, or at what severity impairment occurs.

As reflected in Table 1.1, siblings of childhood cancer survivors are a neglected group in childhood cancer research, with only one published study investigating posttraumatic stress in this population. Although no clinical diagnostic tool was used, it was found that almost half of siblings (49%) endorsed mild symptoms of PTSD with 32% reporting moderate to severe levels (Alderfer et al., 2003). These levels were significantly greater than that reported by a control group with no family history of serious illness. Of the symptom clusters, 39% of siblings reported symptoms consistent with the DSM-IV's B-symptom cluster (intrusive re-experiencing), 21% for the C-symptom cluster (avoidance), and 23% for the D-symptom cluster (hyper-arousal; Alderfer et al., 2003).

The evidence base reviewed above shows that childhood cancer impacts on all family members with survivors, parents and siblings documented as at risk for posttraumatic stress responses following a childhood cancer experience. However, sibling data has been derived from one study only, with relatively few studies including fathers. No studies to date have recruited members from all immediate family groups limiting comparative data and the potential to evaluate the role of family factors. Similarly, no studies have been conducted from an Australian healthcare perspective. This lack of information has restricted the investigation of PTSD outcomes against factors specific to Australian patients and families (e.g., ethnic diversities, health care access, education, and employment opportunities).

1.2.4 Posttraumatic Stress and Childhood Cancer: Psychosocial Comorbidity

Comorbidities associated with PTSD have been well documented (APA, 2000) with evidence indicating that PTSS are also associated with various psychopathologies, such as depression and anxiety related disorders (Favaro et al., 2006; Gurevich et al., 2002; Norman et al., 2007; Stein et al., 1997). These findings have been replicated in the childhood cancer survivor literature (see Table 1.1). For example, in contrast to normative levels reported by a non-PTSD survivor group, survivors with PTSD reported clinically significant levels of psychological distress (Meeske et al., 2001). Furthermore, 25% of mothers with PTSD reported comorbid major depressive and generalised anxiety disorders (Manne et al., 1998). Of particular note is that these comorbidities have been reported as having secondary onset to symptoms of PTSD (Barakat et al., 2000; Manne et al., 2002), indicating that both the disorder and the

individual symptom clusters may be precursors to significant long-term psychological, social, and behavioural problems. This suggests that a posttraumatic stress model may be valuable for not only understanding traumatic stress responses following childhood cancer, but also in understanding a range of long-term psychosocial adjustment outcomes. Further research is necessary to improve understanding of the relationship between posttraumatic stress and psychological distress in all family members, especially in sibling populations.

1.2.5 Posttraumatic Growth

Posttraumatic growth, also known as 'thriving' or 'benefit finding' refers to perceptions of positive change following a highly stressful or traumatic experience whereby an individual seems to psychologically develop and grow beyond previous baseline levels of functioning, and in a way that positively enhances life value (Chelser, 2000; O'Leary, 1998; Tedeschi & Calhoun, 1996). In this sense, the evolution of posttraumatic growth is dependent on the occurrence of a highly stressful or traumatic life event, and differs from the concept of resilience which refers to an individual's ability to manage adversity well and to continue life posttrauma in a similar unchanged pre-trauma manner (Tedeschi & Calhoun, 2004b). Posttraumatic growth has been reported in many different trauma contexts (e.g., cancer, physical and sexual abuse, bereavement, combat, heart attack, rheumatoid arthritis, HIV infection; Tedeschi & Calhoun, 2004b), however, while symptoms of PTSD and psychological distress are well documented psychological responses to trauma, applications of the predominant 'stress-deficit' paradigms generally ignore reports of posttrauma growth. This not only skews prevalence data but also prevents the development of a knowledge base surrounding factors contributing to growth outcomes and how these outcomes may relate to or mediate distress.

Recent findings show posttraumatic growth to be a developmental process of self-motivated engagement in areas such as life, purpose, autonomy and mastery, indicating that posttraumatic growth is more than just perceived well-being (Durkin & Joseph, 2009). However, others suggest self-reported posttraumatic growth is more likely to represent coping efforts to deal with distress (Schroevers & Teo, 2008), or perceived, rather than actual growth (Frazier et al., 2009). While there is some indication that interventions do increase psychosocial growth post cancer (Antoni et al., 2001), evidence is nonetheless in its infancy – this is especially true with regard to how growth may impact on psychological distress. Tedeschi and Calhoun (2004a) suggest that posttrauma growth is frequently reported in trauma samples alongside psychological distress, although the positive aspects most often go undocumented. This may indicate that posttrauma growth and psychological distress may not be bipolar experiences, but instead co-exist. Research to date is equivocal on this point. For example, Alisic and colleagues (2008) found both trauma outcomes to be strongly related in children from a general population sample, while

Salsman and colleagues (2009) found PTSD and posttraumatic growth to be un-related in colorectal cancer survivors. Further, while Currier and colleagues (2009) show children report both positive and negative aspects following a serious illness, their perceptions of benefit and burden are not related. Notwithstanding these findings, reports indicate that high levels of trauma specific distress is a precursor to both PTSD and posttraumatic growth, thereby indicating that a relationship between the two trauma outcomes is likely (Park et al., 2008). In reconciling these difference, it is probable that a complex interplay between posttraumatic stress and posttraumatic growth exists. For example, some aspects of growth may be positively related to PTSD symptoms, while others may be negatively related. However it is difficult to compare a psychological disorder such as PTSD, which has clinically and empirically derived symptomatology and degree of impairment of function, to that of posttraumatic growth. Posttraumatic growth has no current agreed definition of outcome (e.g., whether unidimensional or multidimensional; Park & Helgeson, 2006), no clearly defined benchmarks as to what constitutes high or low posttraumatic growth, or indeed whether posttraumatic growth, as it is currently being measured, reflects actual beneficial change (Frazier et al., 2009). While this restricts meaningful direct comparisons, posttraumatic growth is a well reported phenomenon that is associated with positive health outcomes (Tedeschi & Calhoun, 2004b), and increased quality of life (Alisic et al., 2008). Research must begin to accommodate both trauma outcomes to further this stress-growth knowledge base (Park & Helgeson, 2006).

1.2.6 Posttraumatic Growth and Childhood Cancer

There have been a number of reports of posttraumatic growth following childhood cancer. For example, results suggest that survivors report feeling more mature than peers, having closer family relationships, being more socially aware and empathic to others, being less afraid of minor illnesses and death, having a greater sense of personal control, purpose in life, life satisfaction, and coping ability and being more in touch with existential and religious beliefs (Cella & Tross, 1986; Chesler & Zebrack, 1997; Stuber et al., 1998, 2006). This is consistent with findings in the general, and mostly adult, life-threatening illness literature (Hefferon et al., 2009). Following an investigation by Barakat et al (2006) it was concluded that 80% or more of survivors and parents report at least one positive aspect following childhood cancer survival. For parents, this is in line with parental growth reported in other childhood-illness contexts such as Down Syndrome (King & Patterson, 2000).

With regard to the stress-growth relationship there have been two quantitative investigations which have provided conflicting results. Barakat et al. (2006) reports a positive relationship between posttraumatic stress and posttraumatic growth for survivors, although this was not supported for parents. In contrast, in their study of parents of leukaemia survivors, Best et al. (2001) reports a positive association between posttraumatic growth and the PTSD symptom avoidance. No research to date has

looked at this relationship in siblings, although reports have indicated that siblings of children on treatment are likely to report high levels of social competence, maturity, independence, self-esteem, and empathy (Horowitz & Kazak, 1990). This suggests that for siblings, positive aspects are also experienced.

In order to move research and clinical treatment beyond the stress-deficit approach, further work is necessary from a symptom level, to determine how these seemingly diverse trauma outcomes may relate to each other, and whether the relationship is consistent across all family members.

1.3 Summary and Aims of Part 1 of the Program of Research

In summary, the preceding review establishes that a posttraumatic stress paradigm is valid for the investigation of psychological distress reported in childhood cancer survivors, their parents, and their siblings. Posttraumatic growth responses are also recognised, albeit understudied, following the trauma of childhood cancer. While evidence suggests that both trauma outcomes (stress and growth) may exist in the same person at the same time, evidence is mixed concerning how the two trauma outcomes may be related.

The primary aim of Part 1 of this program of research will be to provide Australian prevalence data on PTSD, PTSS, psychological distress, and posttraumatic growth in childhood cancer survivors, and their mothers, fathers, and siblings. Via the recruitment of all four family groups this project will provide much needed comparative data from a family perspective, thereby providing the first Australian data on trauma-related outcomes in long-term survivors and family members.

Table 1.1. Studies investigating PTSD and PTSS, and psychosocial comorbidity in childhood cancer survivors, parents, and siblings published since fourth edition of DSM (1994). Listed in chronological order.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Stuber et al. (1994a,b) United States	Survivors Mothers Fathers	Cross-sectional self-report 30 survivors[a] • Age 8-19y (*M*=13.8, *SD*=3.4) • Off TX: 1.8-10.7y (*M*=5.1, *SD*=2.6) 30 Mothers 30 Fathers	• PTSD-RI	• Severe range: 7% mothers • Moderate range: 17% survivors 27% mothers 24% fathers • Correlation between mother and father symptom severity • No correlation between parental symptoms and survivors	STAI *(parent completed)*	• Parental PTSD symptoms positively correlated with trait anxiety
Butler et al. (1996) United States	Survivors	Cross-sectional self-report, and parent proxy 42 parents (95% mothers) • Survivor age 3-16 yrs (*M*=8.8, *SD*=4.0) • Off TX: range unspecified (*M*=3.0, *SD*=2.8)	• PTSD Symptom Scale *(parent completed)*	• 7% survivors exhibited full symptom spectrum.	• Personality Inventory for Children-Revised. • CBCL	• PTSD Symptom severity positively associated with social incompetence, depression, anxiety, social problems, withdrawal, and attentional problems.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Pelcovitz et al. (1996) United States	Mothers	Cross-sectional self-report, interview with control 24 mothers of survivors[a] • Survivor age 14-23 yrs (*M*=16.3, *SD*=not specified) • Off TX: 0-11 (*M*=3.3, *SD*=not specified) 25 control mothers • Child age not specified	• SCID • DIS-PTSD (Modified version)	• 54% survivor mothers met life-time criteria, 25% met current criteria. • Significantly more mothers of survivors had a lifetime diagnosis and current and life-time symptoms than control mothers. • Diagnosis for survivor mothers resulted directly from the childhood cancer experience.	• PSEI • SCL-90-R • Global Social Support Interview *(developed for current study)*	• Greater number of high-magnitude stressors associated with current PTSD. • Social support and global functioning not associated with PTSD severity.
Stuber et al. (1996) United States	Survivors Mothers Fathers	Cross-sectional self-report 64 leukaemia survivors • Age: 7-19y (*M*=14.0, *SD*=3.2) • Off TX: 2yrs+ (range unspecified) (*M*=6.7, *SD*=2.8) 63 Mothers 42 Fathers	• PTSD-RI	• Severe range: 12.5% survivors 39.7% mothers 33.3% fathers • Correlations between mother and father symptom severity, and mother and survivor symptom severity • No correlation between father and survivor symptoms	N/a	N/a

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Barakat et al. (1997, 2000) United States	Survivors Mothers Fathers	Longitudinal self-report with control Time 1: 309 survivors[a] • Age 8-20 y (*M*=13.5, *SD*=3.4) • Off TX: 1.5y+ (range unspecified) (*M*=5.9, *SD*=3.5) 309 Mothers 213 Fathers 219 controls • Age 8-20y (*M*=12.3, S*D*=2.7) 211 Mothers 114 Fathers Time 2: 56 survivors[a] • Age 8-20 y (*M*=12.8, *SD*=3.7) • Off TX: (range unspecified) (*M*=4.9, *SD*=3.5) 65 Mothers 219 controls • Age 8-20y (*M*=12.3, S*D*=2.7) 211 Mothers 114 Fathers	Time 1 measures: • PTSD-RI • IES	• Severe range: 2.6% survivors 10.1% mothers 7.1% fathers • Moderate range: 12.1% survivors 27.0% mothers 28.3% fathers • Parent and survivor symptoms significantly associated • Parents of survivors reported significantly higher PTSD symptoms than controls • No significant differences between survivors and control	Time 1 measures: *Survivor completed:* • RCMAS • TSC *Parent completed:* • STAI • FACES-IIIA • SNRDAT Time 2 measures: *Survivor completed:* • LES *Parent completed:* • Life Experiences Survey • CBCL-Parent report on survivor functioning • BSI-Global Severity Index	• PTSD associated with poorer social support for mothers, and poorer family satisfaction for both mothers and fathers. • PTSD symptoms at time 1 predicted poorer general adjustment at time 2 for survivors and mothers

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al. (1997) United States	Survivors Mothers Fathers	Cross-sectional self-report with control 130 leukaemia survivors • Age 8-19y (*M*=13.5, *SD*=3.4) • Off TX: 1y+ (range not specified) (*M*=5.8, *SD*=3.1) 130 Mothers 96 Fathers 155 controls • Age: 8-20y (*M*=12.3, *SD*=2.7) 148 Mothers 80 Fathers	• PTSD-RI • IES	• Severe range: 1.6% survivors 10.2% mothers 9.8% fathers • Moderate range: 12.6% survivors 30.0% mothers 21.4% fathers • No significant differences between survivors and control • Mothers and fathers of survivors reported significantly greater symptoms than parental controls	*Child completed:* • RCMASS • TSC *Parent completed:* • FACES -IIIA • SNRDAT	• PTSD severity associated with anxiety and poor family functioning for survivors and parents. • Perceived social support associated with PTSD symptom severity for parents. • No significant differences between survivor groups, and control groups on Family functioning and social support

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al. (1997) United States	Mothers Fathers	Longitudinal self-report 29 mothers and fathers of leukaemia survivors Time 1 (in treatment/ remission) • Child age (range unspecified) (*M*=7.6, *SD*=3.5) Time 2 (off treatment) • Child survivor age (range unspecified) (*M*=9.8, *SD*=3.2) • Off TX: 0.5y+ (range, mean unspecified)	Time 2 measure: • PTSD-RI	• Mean scores significantly greater for mothers and fathers than normative data (no prevalence data provided).	Time 1 measures: • PSI-Short Form • POQOLS Time 2 measures: • STAI • RCMAS *(child survivor completed)*	• Mother and father rated parental distress, mother rated child quality of life, and father rated parenting stress at Time 1 associated with PTSD symptoms at Time 2.
Stuber et al. (1997) United States	Survivors	Cross-sectional self-report 186 survivors[a] • Age: 8-20y (*M*=13.4, *SD*=3.3) • Off TX: 1.1-18.3y (*M*=5.5, *SD*=3.6)	• PTSD-RI	• Up to 60% endorsed symptoms as present • Up to 22% endorsed frequent symptoms	• RCMASS • Social Support Rating Scale • Stress History *(developed for current study)*	• Greater anxiety, upset with family/social support, and greater stressful life events predicted persistent PTSD symptoms

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al. (1998) United States	Mothers Fathers	Cross-sectional self-report 320 mothers, 224 fathers of survivors[a] • Survivor age 6-20 yrs (*M*=13.3, *SD*=3.6) • Off TX: 1-18y (*M*=5.7, *SD*=3.4)	• PTSD-RI	*Prevalence data not reported*	• STAI • FACES-IIIA • SNRDAT	• Trait anxiety and social support associated with PTSD symptoms
Manne et al. (1998) United States	Mothers	Cross-sectional self-report, interview 65 mothers of survivors[a] • Survivor age 6-25 yrs (*M*=14.5, *SD*=5.2) • Off TX: 0.3-7y (*M*=3.2, *SD*=3.0)	• SCID • PCL-C	• 6.2% met current PTSD criteria • 20% met partial PTSD criteria • 51% met B-symptom cluster criteria (re-experiencing) • 13.8% met C-symptom cluster criteria (avoidance) • 29.2% met D-symptoms cluster criteria (arousal)	• SCID-Major Depressive Episode Module • SCID-Generalised Anxiety Module	• 25% mothers with current PTSD had comorbid major depressive and generalised anxiety disorders.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Pelcovitz et al. (1998) United States	Survivors	Cross-sectional self-report, interview with control 23 survivors[a] • Age: 15-19y (*M*=17.6, *SD*=3.1) • Off TX: 0-11 (*M*=3.3) 27 physically abused adolescents • Age: 14-16y (*M*=15.1, *SD*=1.7) 23 controls • Age at study: 15-17y (*M*=16.1, *SD*=1.9)	• SCID	• 35% survivors reported lifetime PTSD, compared to 7% abused adolescents, and 4% controls • 17% survivors reported current PTSD, compared to 11.1% abused adolescents, and 0% controls.	• FACES-IIIA • Parental Bonding Instrument. • SCL-90-R Global Severity Index *(survivor mothers completed)*	• Survivors reported Parents as more protective/caring than control but unrelated to PTSD diagnosis.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Erickson & Steiner (2000, 2001) United States	Survivors	Cross-sectional self-report, interview 40 survivors • Age 12-35y (*M*=20.4, *SD*=7.8) • Off TX: 5y+ (range/time unspecified)	• SCID • IES-Revised • SI-PTSD	• 10% met full PTSD criteria • 78% met partial PTSD criteria	• Clinical interview for Global Assessment of Functioning • SCL–90-R (Somatization scale) • Weinberger Adjustment Inventory • Response Evaluation Measure	• PTSD/PTSD symptoms associated with poorer general functioning, higher distress, and greater somatic symptoms, repressive adaptive style, denial, and repressive defensiveness. • Associations with distress and restraint strongest for Avoidance than Intrusion or Hyper-arousal.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Hobbie et al. (2000) United States	Survivors	Cross-sectional self-report, interview 78 survivors • Age 18-40y (*M*=25, *SD*=4.4) • Off TX: 1.5y+ (range unspecified) (*M*=11, *SD*=5.5)	• SCID • PTSD-RI • IES	• 20.5% met full PTSD criteria • 7.7% reported severe symptoms, 24.4% reported moderate • 9% reported Intrusion symptoms, 17.7% reported Avoidance symptoms in clinically significant range	• STAI • BSI	• Survivors with PTSD had higher levels of somatization, obsessive compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, and phobic anxiety. • Trait anxiety positively associated with intrusion and avoidance.
Manne et al. (2000) United States	Mothers	Cross-sectional self-report 72 mothers of survivors • Survivor age 5-23 yrs (*M*=13.6, *SD*=5.1) • Off TX: 0.3-7y (*M*=2.5, *SD*=2.2)	• PCL-C	• 12.5% met PTSD symptom criteria	• Perceived Social Constraint scale • Desire to Talk and Talking • Interpersonal Support Evaluation List – modified version • Miller Behavioral Style Scale	• More perceived social constraints, less perceived belonging support associated with PTSD.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Best et al. (2001) United States	Mothers Fathers	Longitudinal self-report 66 mothers and 47 fathers of leukaemia survivors Time 1 (in treatment) • Child age (range unspecified) (*M*=7.3, *SD*=4.6) Time 2 (off treatment) • Child survivor age (7-24y) (*M*=9.8, *SD*=3.2) • Off TX: 0.6–8.6y (*M*=3.7, *SD*=unspecified)	Time 2 measure: • IES-R	• N/a	Time 1 measures: • Langner Symptom Checklist • Perception of Procedures Questionnaire Time 2 measures: • STAI • SRNDAT • PTGI • Pediatric Anxiety and Avoidance Scale • Children's Hospital of Philadelphia Self-Efficacy Scale	• Anxiety at time 1 predicts PTSD symptoms at time 2 for mothers, not fathers. • Anxiety, self-efficacy, posttraumatic growth associated with avoidance.
Fuemmeler et al. (2001) United States	Mothers Fathers	Cross-sectional self-report 18 mothers and 10 fathers of brain tumour survivors • Survivor age 9-24 yrs (*M*=14.0, *SD*=unspecified) • Time since DX: 0.9-19.3y (*M*=6.8, *SD*=unspecified)	• PDS	• 44% mothers, 40% fathers met symptom criteria for PTSD.	• BSI • Ways of Coping Questionnaire • Parents Perception of Uncertainty in Illness Scale	• 56% parents reported significant levels of general distress, but no relationship data to PTSD provided. • Emotion-focussed coping and perceived uncertainty positively related to PTSD symptom severity

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al. (2001) United States	Survivors Mothers	Cross-sectional self-report, interview (validation study) 130 young adult survivors • Age 18-36y (*M*=25, *SD*=4.0) • Off TX: 3-29y (*M*=13, *SD*=5.4) 66 child/adolescent survivors • Age 6-19y (*M*=12.74, *SD*=3.7) • Off TX: 1y+ (range unspecified) (*M*=4.9, *SD*=3.3) 64 mothers	• Impact of Traumatic Stressors Interview • SCID (*mothers and young adult survivors only)* • DIS for Children-PTSD (*mothers and child/adolescent survivors only)* • IES • PTSD-RI	Full PTSD: • 6.2% young adult • 4.5% child/adoles • 10.9% mothers B-symptom cluster (re-experiencing): • 63.3% young adult • 50.0% child/adoles • 95.3% mothers C-symptom cluster criteria (avoidance): • 14.7% young adult • 16.7% child/adoles • 29.7% mothers D-cluster criteria (arousal): • 31.0% young adult • 28.8% child/adoles • 53.1% mothers	• BSI (*mothers, young adult survivors completed*) • Youth Self Report (*child/adolescent survivors completed*)	• Factors reflecting PTSD symptoms associated with depression, anxiety, interpersonal sensitivity, and general emotional distress (mothers, young adult), somatization (young adult), and internalising behaviour problems (child/adolescent) .

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Meeske et al. (2001) United States	Survivors	Cross-sectional self-report, interview 51 survivors[a] • Age: 18-37y (*M*=24.1, *SD*=4.3) • Off TX: 2.8-26.7y (*M*=11, *SD*=6.0)	• SCID	• 22% met PTSD criteria	• RAND Short Form • BSI	• PTSD group reported clinical levels of somatisation, obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, and psychoticism (non-PTSD group in nomal range) • Quality of Life scores lower for PTSD group.
Goldenberg Libov et al. (2002) United States	Mothers	Cross-sectional interview 49 mothers of childhood cancer survivors • Child age: 1-27yrs (*M*=13.6, *SD*=6.3) • Off TX: unspecified	• SCID	• 20% met current PTSD • 27% met lifetime PTSD • 90% met B-symptom cluster (re-experiencing) • 33% met C-symptom cluster (avoidance) • 39% met D-symptom cluster (arousal)	• PSEI • Perceptions of Threat Interview *(developed for current study)*	• Number of low-magnitude stressors over past year, perceived present cancer threat to child associated with PTSD severity.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Manne et al. (2002) United States	Mothers	Longitudinal self-report, interview 90 mothers of BMT recipients Time 1 (at treatment) • Child age: 0.8-20.0yrs (*M*=8.8, *SD*=5.5) • Time since DX: 0.1-10.8yrs (Mean, SD unspecified Time 2 (3 months following BMT) Time 3 (6 months following BMT)	Time 3 measures: • SCID *(40 mothers completed)* • PCL-C	• 17.5% met current PTSD • 15% met partial PTSD • 39.3% met B-symptom cluster (re-experiencing) • 37.0% met C-symptom cluster (avoidance) • 29.6% met D-symptom cluster (arousal)	Time 1, 2 and 3 measures: • Beck Anxiety Inventory • Beck Depression Inventory • Fear Network *(measure developed for this study)* • Cancer Support Inventory *(adapted)*	• Emotional distress (anxiety, depression), BMT fears, negative family/friend responses at time 1 predicted PTSD symptoms at time 3 • At time 3, emotional distress associated with PTSD severity.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Posttraumatic Stress Findings	Psychosocial comorbidity Assessment	Psychosocial comorbidity Findings
Alderfer et al. (2003) United States	Siblings	Cross-sectional self-report with control 78 siblings of childhood cancer survivors • Survivor age: unspecified • Sibling age: (range unspecified) (*M*=14.2, *SD*=2.2) • Off TX: 0.9-19.3y (*M*=5.3, *SD*=3.3) 134 controls • Age: (range unspecified) (*M*=13.2, *SD*=2.2)	• IES-R • PTSD-RI	• 49.3% reported mild symptoms • 32.0% reported moderate to severe symptoms • 38.7% reported symptoms consistent with the B-symptom cluster (re-experiencing), 21.3% C-symptom cluster (avoidance), 22.7% D-symptom cluster (arousal) • Siblings of survivors reported more symptoms than control group	• RCMAS • ALTTIQ	• Anxiety modestly associated with arousal symptoms but not found to be in clinical range. • PTSD symptoms associated with perceptions of life threat and treatment intensity.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Brown et al. (2003) United States	Survivors Mothers	Cross-sectional self-report, with control 52 survivors[a] • Age 12-23y (*M*=17, *SD*=3.4) • Off TX: 1-14y (*M*=5.7y, *SD*=3.3) 52 mothers 42 controls • Age 12-23y (*M*=16.7y, *SD*=3.4) 42 mothers	• PTSD-RI	• No survivors met PTSD criteria • 36% survivors reported mild subthreshold symptoms, significantly greater than controls • 25% mothers met PTSD criteria, significantly greater than controls	*Survivors and controls:* • Marlow-Crowne Social Desirability Scale • Adolescent Inventory of Life Events and Changes • PSS-Family • PSS-Friend *Mothers of survivors and controls:* • Family Inventory of Life Events and Changes *All participants:* • Family Environment Scale	• Survivor PTSD associated with fewer reports of social desirability. • Survivors endorsed more stressful life events than controls but not related to PTSD severity. • Maternal PTSD associated with poorer Family Functioning (increased conflict, decreased support)

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al. (2004a) United States	Survivors Mothers Fathers	Cross-sectional self-report, interview 150 survivors • Age 11.1-19.3y (*M*=14.7, *SD*=2.4) • Off TX: 1-10y (*M*=5.3, *SD*=2.9) 146 mothers 103 fathers	• IES-Revised • PTSD-RI • SCID	Moderate to severe symptoms: • 17.6% survivors • 43.7% mothers • 35.3% fathers. Current PTSD: • 4.7% survivors • 13.7% mothers • 9.6% fathers PTSD since diagnosis: • 8.0% survivors • 29.5% mothers • 11.5% fathers B-symptom cluster (re-experiencing): • 73.3% survivors • 97.3% mothers • 86.5% fathers C-symptom cluster criteria (avoidance): • 16.1% survivors • 34.2% mothers • 16.3% fathers D-cluster criteria (arousal): • 41.3% survivors • 63.7% mothers • 44.2% fathers Low rates of concordance of PTSD across family members (0-5%)	N/a	N/a

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Langeveld et al. (2004) The Netherlands	Survivors	Cross-sectional self-report 500 survivors • Age 16-49y (*M*=24, *SD*=5.1) • Off TX: 5-33y (*M*=15, *SD*=5.8)	• IES	• 12% reported severe stress symptoms	N/a	N/a
Alderfer et al. (2005) United States	Mothers Fathers	Cross-sectional self-report, interview 98 mothers and fathers of survivors • Survivor age 11-19 yrs (*M*=14.6, *SD*=2.4) • Time since DX: 1-12y (*M*=5.3, *SD*=2.9)	• IES-R • SCID	• 13% mothers, 10% fathers met current PTSD	• Family Life Scales-Family Coherence subscale	• Greater paternal PTSD severity associated with low family coherence

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Fuemmeler et al. (2005) United States	Mothers Fathers	Cross-sectional self-report with control 38 mothers, 9 fathers survivors • Survivor age (range not specified) (*M*=13.8, *SD*=4.8) • Off TX: (range not specified) (*M*=6.1, *SD*=3.4) 23 mothers, 8 fathers of Type 1 Diabetes patients • Child age (range not specified) (*M*=13.4, *SD*=3.8)	• PDS	• 32% parents of childhood cancer survivors met PTSD symptom criteria compared to 10% parents of diabetes patients. • Parents of cancer survivors reported higher levels of PTSS than parents of diabetes patients.	• BSI • Parents Perception of Uncertainty in Illness Scale • SNRDAT • Ways of Coping Questionnaire	• 49% parents of childhood cancer survivors and 29% parents of diabetes patients reported clinically significant psychological distress, although groups did not differ significantly. Association with PTSD symptoms not specified. • Greater perceived uncertainty, lower levels of emotion-focused coping associated with PTSS severity.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Phipps et al. (2005) United States	Survivors Mothers Fathers	Cross-sectional self-report with historical control 41 young adult survivors • Age: 18+ (*M*=22.5, *SD*=3.6) • Off TX: 2y+ (*M, SD* not specified). No parents recruited 41 child survivors • Age: 7-18 (*M*=14.3, *SD*=2.6) • Off TX: 2y+ (*M, SD* not specified). 41 parents (30 mothers, 10 fathers) 42 child patients • Child Age: 7-18 (*M*=12.2, *SD*=3.1) • 18-30m since diagnosis 42 parents (34 mothers, 8 fathers) 39 child patients • Child Age: 7-18 (*M*=12.6, *SD*=2.9) • 2-6m since diagnosis 39 parents (35 mothers, 4 fathers) Control data from earlier work (see Barakat et al., 1997; Kazak et al., 1997)[3]	• PTSDI (patient/survivor self report with parent proxy) • IES-R (patient/survivor and parent self-report)	*Prevalence data not reported.* Survivors: • PTSS significantly lower than on-treatment groups and controls. • No difference between young adult and child survivors on PTSS. Parents of child survivors: • PTSS significantly lower than on-treatment groups. • No difference between mothers and controls. Parent and child survivor PTSS significantly correlated.	N/a	N/a

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Santacroce & Lee (2006) United States	Survivors	Cross-sectional self-report 45 survivors • Age 22-40y (*M*=24.5, *SD*=5.5) • Off TX: 3y+ (*M*=14.2, *SD*=6.1)	• PTSDI	• 13.3% reported symptoms in clinically significant range	• Mishel Uncertainty in Illness Scale-Community Form • Health Promoting Life-style Profile II	• Uncertainty mediates relationship between PTSD symptoms and health promotion behaviour
Schwartz & Drotar (2006) United States	Survivors	Cross-sectional self-report, with control 57 survivors • Age 18-28y (*M*=21.7, *SD*=2.6) • Off TX: 1.8-18.8yrs (*M*=1.2, *SD*=0.9) 83 controls • Age 18-28y (*M*=22.2, *SD*=3.0)	• PCL-C	• 17.5% survivors met PTSD criteria • 3.6% controls met PTSD criteria	• Short Form Health Status Questionnaire • Brief Mood Rating Scale. • Centre for Epidemiological Studies Depression Scale • Satisfaction with Life Scale • Perceived Impact of Cancer on Developmental Tasks.	• PTSD group reported worse physical and psychosocial health related quality of life, more depressive symptoms, more negative affect, less positive affect, and perceived cancer having greater impact on developmental tasks, -than non-PTSD group.

[3] Control group responded to the IES rather than the IES-R. Comparisons are made with Intrusion and Avoidance symptoms only.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Stoppelbein et al. (2006) United States	Survivors	Cross-sectional self-report with comparison 39 survivors • Age (*M*=12.8, *SD*=2.8) (range unspecified) • Off TX: 0.5y+ (range unspecified) (*M*=2.6, *SD*=2.1) 39 Parental bereaved children • Age (*M*=13.0, *SD*=2.7) (range unspecified) • Time since loss: (range unspecified) (*M*=3.1, *SD*=2.8)	• Child PTSD-RI	• 10% survivors and 41% bereaved reported severe symptoms • 54% survivors, 77% bereaved reported ≥ 1 B-symptom (re-experiencing)	• RCMAS • Children's Depression Inventory • Perceived Future Threat Scale	• Depression and anxiety within normal range for survivors and bereaved children – no between group differences. • Bereaved children reported greater perceived future threat than survivors. • Perceived future threat associated with PTSD symptom severity.
Wiener et al. (2006) United States	Survivors	Cross-sectional self-report, interview 34 sarcoma survivors • Age: 17-54y (*M*=34) • Off TX: (range unspecified) (*M*=17.4y)	• SCID • IES	• 12% met criteria for PTSD	• BSI • Demographic/psychosocial questionnaire	• 77% of whole sample in clinically significant range for psychosocial distress • Psychological distress correlated with Intrusion and Avoidance symptoms

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Gerhardt et al. (2007) United States	Survivors	Cross-sectional self-report, interview with control. 56 survivors[a] • Age: (*M*=18.6, *SD*=0.8) (range unspecified) • Off TX: 3.6-12.3y (*M*=7.3y, *SD*=2.2) 56 parent proxy 60 control peers • Age (*M*=18.6, *SD*=0.7) (range unspecified) 60 parent proxy	• Kiddie-Schedule for Affective Disorders and Schizophrenia-Epidemiologic Version-5 (K-SADS-E-5)	No difference between survivors and controls: • 3% survivors met past or current PTSD criteria (not cancer related) • 6% controls met past or current PTSD criteria • 20% survivors, 13% controls met at least one past PTSS • 7% survivors, 8% controls met at least one current PTSS	• Adolescent Dissociative Experiences Scale-II (ADES)	• Survivors report fewer dissociative experiences than Controls. • Late effects of cancer associated with more past PTSS, but not current PTSS.
Ozono et al. (2007) Japan	Survivors Mothers Fathers	Cross-sectional self-report 88 survivors[a] • Age: 11-19y (*M*=16.2, *SD*=2.3) • Off TX: at least 1y (range and mean not specified) 87 mothers 72 fathers	• IES-R (Japanese version)	Severe PTSS: • 10.9% survivors • 20.7% mothers • 22.2% fathers. Mother and survivor PTSS, mother and father PTSS significantly correlated.	Japanese versions of: • STAI • FAD • Holmes-Rahe measure of social adjustment	PTSS related to: • Survivors: trait anxiety and medical sequelae. • Mothers: trait anxiety, family role functioning, and less than 10 years from diagnosis. • Fathers: trait anxiety.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Lee & Santacroce (2007) United States	Survivors	Cross-sectional self-report 45 survivors • Age: 22-47y (*M*=27.4, *SD*=5.5) • Off TX: 4-31y (*M*=14.2, *SD*=6.1)	• PTSDI	• 13.3% met symptoms in clinically significant range • 40.0% reported symptoms consistent with the B-symptom cluster (re-experiencing), 24.4% C-symptom cluster (avoidance), 55.5% D-symptom cluster (arousal)	N/a	N/a
Rourke et al. (2007) United States	Survivors	Cross-sectional self-report, interview 182 survivors • Age: 18-37y (*M*=24.8, *SD*=4.5) • Off TX: 3-29y (*M*=13.6, *SD*=5.8)	• SCID • IES • PTSD-RI	• 15.9% met criteria since cancer treatment • 14.3% met current criteria • 21.9% reported moderate to severe symptoms • 75.3% met B-symptom cluster (re-experiencing) • 25.8% met C-symptom cluster (avoidance) • 47.3% met D-symptom cluster (arousal)	• RAND-36 • BSI • STAI • LES • Achievement of Developmental Goals	• Greater psychological distress, anxiety, life events, negative effects of life events, and poorer quality of life, progress on life goals associated with PTSD diagnosis.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Alderfer et al. (2009) United States	Survivors Mothers Fathers	Cross-sectional self-report, interview 144 survivors • Age: 11-19y (*M*=14.6, *SD*=2.4) • Off TX: 1-12y (*M*=5.3, *SD*=2.9) 144 mothers 104 fathers	• SCID (*survivors only*)	• 8.3% of survivors met PTSD criteria since diagnosis	• FAD	• 47% survivors, 25% mothers, 30% fathers reported poor family functioning. • Families with survivor PTSD had poorer family functioning than families without survivor PTSD.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Jurbergs et al. (2009) United States	Mothers Fathers	Cross-sectional self-report with control[4] 128 parents of cancer patients Off TX (66 mothers, 62 fathers): • Child Age: 7-18 (*M*=13.0, *SD*=3.2) • Off TX: "currently off TX" (range, *M*, *SD* not specified). 71 parents of cancer patients on active treatment at least 1 month post diagnosis (29 mothers, 42 fathers): • Child Age: 7-18 (*M*=11.2, *SD*=3.5) 108 controls (64 mothers, 44 fathers): • Child Age: *M*=12.4, *SD*=3.0 (range not specified).	• IES-R	*Prevalence data not reported.* • PTSS significantly lower in survivor parents than on-treatment parents and controls.	N/a	N/a

[4] Jurbergs et al. (2009) study provide demographic and treatment details for on cancer treatment group, and off cancer treatment group only despite analyses being carried out for 4 groups: Group 1 = 1 to 6 months post diagnosis; Group 2 = 6 to 18 months post diagnosis; Group 3 = 18 months to 5 years post diagnosis; Group 4 = Survivor group 5 years post diagnosis.

Authors, study origin	Participants	Design/Sample	Posttraumatic Stress Assessment	Findings	Psychosocial comorbidity Assessment	Findings
Kazak et al., (2010) United States	Survivors	Cross-sectional self-report with control. 167 survivors[a] • Age: 16-30y (*M*=20.2, *SD*=3.2) • Off TX: 5y+ (range unspecified) 170 control peers • Age (*M*=21.8, *SD*=3.2) (range unspecified. Recruitment matched to survivor group)	• PCL-C	*Prevalence data not reported* • No difference between survivors and controls (mean scores). • Relative to younger treatment groups, survivors treated at adolescence show greater overall PTSS, intrusions.	• BSI • Short Form Health Status Questionnaire • Health Competence Beliefs Inventory • Heath Knowledge Inventory	• Relative to younger groups, survivors treated at adolescence show greater PTSS, distress, fewer positive health beliefs • Greater treatment intensity related to avoidance, anxiety, fewer positive health beliefs • No difference between survivors and controls on distress, health related quality of life. • Survivors had less competent health beliefs, more satisfied with health care than controls.

• Legend: [a]=Brain tumour group excluded, M=mean, N/a=not applicable, OffTX=Off treatment, SD=standard deviation.

Measures: BSI=Brief Symptom Inventory, CBCL=Child Behavior Checklist, DIS-PTSD=Diagnostic Interview Schedule-PTSD, FACES-IIIA= Family Adaptability and Cohesion Evaluation Scale-VerIIIA, FAD=Family Assessment Device, IES= Impact of Event Scale, LES= Life Events Scale, PCL-C=PTSD Checklist-Civilian Version, PDS=Posttraumatic Stress Diagnostic Scale, POQOLS=Pediatric Oncology Quality of Life Scale, PSEI= Potential Stressful Events Interview, PSI=Parenting Stress Index, PSS= Perceived Social Support, PTGI= Posttraumatic Growth Inventory, PTSDI=PTSD Index, PTSD-RI= PTSD-Reaction Index, RAND-36= RAND 36-item Health Survey, RCMAS=Revised Children's Manifest Anxiety Scale, SCID= Structured Clinical Interview for DSM-PTSD, SCL-90-R-Symptom Checklist-90-Revised, SI-PTSD= Structure Interview for PTSD, SNRDAT=Social Network Reciprocity and Dimensionality Assessment Tool, STAI=State-Trait Anxiety Inventory, TSC= Trauma Symptom Checklist.

CHAPTER 2
DESIGN, METHODOLOGY, AND PARTICIPANT CHARACTERISTICS

2.0 Overview

Part 1 of the program of research addresses two key goals: (1) to provide Australian prevalence data of PTSD, PTSS, psychological distress (depression, anxiety, stress), and posttraumatic growth in childhood cancer survivors and their parents and siblings; and (2) to investigate the relationships between these outcomes. Studies 1 and 2 will focus of each of these goals respectively. The aim of Chapter 2 is to summarise the design, methodology and the participant characteristics relevant to these studies.

In addressing the aims of Part 1, a self-report questionnaire design was primarily employed to provide indicative scores of symptom severity in the assessment of the three outcomes: posttraumatic stress, psychological distress, and posttraumatic growth. This was followed by a structured clinical interview to provide diagnostic PTSD data. The self-report questionnaire design was decided upon as the method of choice to enable greatest participation in light of the geographical spread of eligible participants (located throughout Australia, and some in remote areas). Outcome measures were selected based on their sound psychometric properties, their succinctness, and their applicability to all participant groups. Techniques were followed to promote maximum response rates[5] (De Vaus, 2002; Edwards et al., 2008).

2.1 Method

2.1.1 Design

Part 1 was a cross-sectional descriptive study involving four subject groups (survivors, siblings, mothers, and fathers), and comprising two parts (a questionnaire and a structured clinical interview). All groups completed the same outcome measures with reference to their childhood cancer experience, either as a patient, a parent, or a sibling. All participants were self-selected for this study.

As shown in Table 1.1, the self-report design is the method of choice by the majority of researchers investigating posttraumatic stress in childhood cancer survivors and family members: Of the 38 studies reviewed, 22 of the studies cited used this method exclusively, with a further 9 also employing a structured clinical interview to assess diagnosis of PTSD. Only 6 studies relied solely on a clinical interview for PTSD data collection. In the assessment of psychosocial comorbidity, 28

[5] The mail-out included a personalised cover letter, a reply paid envelope, and a non-committal incentive (pen). Follow-up techniques for non-responders included up to three follow-up phone calls, and a mail-out of a reminder letter attached to a second copy of the questionnaire and consent forms.

of the 32 studies cited relied solely on self-report measures to assess outcome (2 relied solely on interviews, 2 employed both designs). Of the two studies investigating associated posttraumatic growth, both used this method exclusively (Barakat et al., 2006; Best et al., 2001). While self-report questionnaires are not diagnostic tools, and therefore limited in the conclusions drawn, most studies have relied upon measures with sound psychometric properties including concurrent validity, diagnostic sensitivity, and discriminant validity between clinical and non-clinical populations (e.g., the Posttraumatic Stress Disorder Reaction Index: PTSD-RI, the Impact of Event Scale/-Revised: IES/-R; Creamer et al., 2003; Pynoos et al., 1993). Consequently these measures are regarded as reliable screening instruments.

2.1.2 Participant Recruitment

A. Childhood Cancer Survivors

The Centre for Children's Cancer and Blood Disorders (CCCBD) is a specialist paediatric haematology and oncology department within the Sydney Children's Hospital, Randwick, NSW, Australia. Receiving approximately 100 new paediatric cancer diagnoses each year from local, remote and rural locations, the CCCBD treats close to 50% of all cases in Eastern Australia. In 1999 the CCCBD's long-term follow-up clinic was formally established to provide ongoing specialist care for patients following curative cancer treatment. Specifically, this clinic provides ongoing assessment of, and treatment for the long-term effects of childhood cancer treatment. To be eligible for this clinic a patient must be at least 5 years from diagnosis and 3 years post treatment[6]. There is no upper age limit, or time post treatment limit applied, however at the time of participant recruitment, the longest time post treatment for survivors registered with the CCCBD is 36 years. This time frame reflects the fact that prior to the early 1970's, very few children survived cancer (Armstrong et al., 2009). To be eligible for this project, the following additional inclusion criteria were applied (other than "not meeting" the inclusion criteria, no exclusion criteria were applied):

- Currently aged 16 years or over
- Diagnosed with a malignancy when aged 18 years or younger
- Possesses basic literacy skills to understand and comprehend English
- Received care from the CCCBD during the cancer treatment period.

Eligible participants were identified from the CCCBD's long-term follow-up register and recruited via the delivery of Questionnaire Booklet (Part 1) (see section 2.1.3: Procedure). Due to

[6] One survivor was recruited into the study at 2.7 years post treatment due to limited availability for follow up visits. In this case, the participant resides a great distance from Sydney, making only annual visits.

some registered patients classified as 'lost to follow-up'[7], contact details were checked against alternative hospital records, the residential directory assistance website (whitepages.com.au), and continuing clinic visits. Names were also cross-checked against publically accessible marriage and death registries. Ethical approval to conduct the study was granted by the Human Research Ethics Committees of the South Eastern Sydney Area Health Service – Eastern Section, and the University of New South Wales.

B. Parents and Siblings of Childhood Cancer Survivors

In accordance with ethical guidelines, the recruitment of a survivor's parent or sibling followed the receipt of the signed *consent to contact parents and siblings form* from participating survivors (included in Questionnaire Pack 1; Appendix 2A). Recruitment involved the delivery of the parent and sibling versions of Questionnaire Booklet (Part 1) described in section 2.1.3 below and included in Appendix 2A. The following inclusion criteria were applied: must be a parent or sibling of a participating childhood cancer survivor, must have survivor consent to contact, and must have basic literacy skills to understand and comprehend English. Siblings must be aged 16 years and over at the time of study recruitment, and not treated for cancer themselves.

2.1.3 Procedure

Eligible participants were either handed Questionnaire Pack 1 during a scheduled long-term follow up clinic visit, or the pack was mailed to them following address verification. Questionnaire Pack 1, as shown in Appendix 2A, included: an *Introductory Letter*, a *Project Information Statement*, a *Project Consent Form*, and *Questionnaire Booklet (Part 1)*. For childhood cancer survivors, a *Consent to Contact Parents and Sibling(s)* form was also included. Parents and siblings were handed or mailed the questionnaire pack only after the signed consent to contact parents and sibling(s) form was received. A survivor's cancer and treatment information was retrieved from hospital records only after receipt of the signed project consent form.

Non-responders were followed up by phone calls (up to 3 follow-up phone calls were made at monthly intervals), by mail-out (a reminder pack containing a reminder letter attached to a second copy of the information statement, consent forms, and Questionnaire Booklet (Part 1)), and face-to-face meetings during scheduled long-term follow-up clinic visits.

Following receipt of the completed Questionnaire Booklet (Part 1), participants were eligible to take part in the clinical interview to assess PTSD diagnosis according to the DSM-IV's diagnostic criteria. Participants were contacted by phone to schedule an interview time. The interviews were

[7] Lost to follow-up refers to no current contact details on record.

optional, scheduled at the participant's convenience and via their preferred modality (face-to-face, or over the telephone). The interviewer has been trained in psychological assessment procedures at both an Honours and Masters level. Mean time between completion of Questionnaire Booklet (Part 1) and the interview was 20.5 months (range = 0 to 33.6 months, *SD* = 9.7)[8].

2.1.4 Measures

A. Questionnaire Booklet (Part 1)

Questionnaire Booklet (Part 1) included 3 self-report measures assessing psychological functioning:

- *Impact of Event Scale-Revised (IES-R)* (Weiss & Marmar, 1997): A 22-item scale assessing current posttraumatic stress symptoms in three subscales reflecting the DSM-IV's symptom criteria for PTSD: Intrusive thoughts (8-items), avoidance (8-items), and hyper-arousal (6-items). Respondents were asked to complete the scale with reference to thoughts and feelings about their cancer experience during the past 7 days. Responses were rated on a 5-point scale (0=*"Not at all"*, 1=*"A little bit"*, 2=*"Moderately*, 3=*"Quite a bit"*, 4=*"Extremely"*), and totals were calculated for the full-scale and each of the subscales.

  While the IES-R is not intended to make a clinical diagnosis, it has been applied as a screening measure across a diverse range of trauma exposed groups including childhood cancer (Alderfer et al., 2003, 2005; Best et al.,2001; Kazak et al., 2004a), and cut-off scores have been suggested for optimal clinical sensitivity. Shapiro (1996) suggests total scores between 9 to 25 be interpreted as mild, 26-43 as moderate, and over 43 as severe, with a score of 26 or higher (moderate and severe) regarded as clinically significant. The IES-R has been shown to have sound psychometric properties (Creamer et al., 2003; Rash et al., 2008).

  In this Australian study, internal consistency across the groups ranged from .85 to .94 for the subscales, and .93 to .96 for the IES-R full-scale. Correlations between the IES-R (using a score of 26 or higher to depict clinical significance) and current PTSD diagnosis (assessed by the SCID-PTSD described in section 2.1.4B below), was found to be conservative but significant (Spearman's $r = 0.25$, $p < .001$). When assessed against current

[8] The time delay between the completion of Questionnaire Booklet (Part 1) and the interview was due to the extensive work required in the development of Questionnaire Booklet (Part 2) (reviewed in Part 2, Chapter 7). Questionnaire Booklet (Part 2) was required to be completed by the participants before the interview was administered. This time lag may account for the conservative correlation between the IES-R and the SCID (see section 2.1.4A), although a mean time off treatment of more than 15 years suggests that current PTSD and PTSS is relatively persistent without treatment (Ehlers & Clark, 2000).

PTSD severity (categorised as 'mild', 'moderate', or 'severe' according to the SCID-PTSD), strong concordance between the measures was found (Spearman's $r = 0.50$, $p < .001$).

- *Depression Anxiety and Stress Scale-Short Version (DASS-21)* (Lovibond & Lovibond, 1995). A 21-item scale assessing current symptom levels of depression, anxiety and stress in three 7-item scales. Respondents were asked to complete the scale with reference to 'your feelings in general over the past week [and]... not specific to your cancer experience". Responses were rated on a 4-point scale (0=*"Did not apply"*, 1=*"To some degree/Some of the time"*, 2=*"Considerable degree/Good part of the time"*, 3="*Very much/Most of the Time"*), and totals were calculated for the full-scale and each of the subscales.

  The DASS-21 is intended as a screening instrument to measure the severity of the core symptoms that discriminate between the psychological states of depression, anxiety, and stress as well as capturing a broad dimension of general psychological distress or negative affectivity (Henry & Crawford, 2005). Recommended cut-off scores are provided by the scale's authors and categorise respondents as falling within normal, mild, moderate, severe, or extremely severe symptom levels. As the DASS-21 was developed against a dimensional rather than categorical model of disorder as depicted in the DSM-IV-TR (APA, 2000), this study categorised participants scoring in the moderate to extremely severe range as psychologically distressed. This categorisation is also in keeping with the similar distinction used for depicting clinically significant scores on the IES-R.

  The DASS-21 has been shown to have sound psychometric properties including convergent and discriminant validity (Henry & Crawford, 2002; Lovibond & Lovibond, 1995; Gloster et al., 2008), and has been used to assess depression and anxiety outcomes in many populations including adult cancer patients (Green et al., 2002), and bereaved parents of children with cancer (Goodenough et al., 2004). In the current study, internal consistency across the groups ranged from .77 to .93 for the subscales, and .92 to .96 for the DASS-21 full-scale.

- *Posttraumatic Growth Inventory (PTGI)* (Tedeschi & Calhoun, 1996): A 21-item questionnaire assessing five domains of personal growth following trauma or adversity: Relating to others (7-items), new possibilities (5-items), personal strength (4-items), spiritual change (2-items), and appreciation of life (3-items). Respondents were asked to complete the scale with respect to how much they believed their life to have changed as a result of their cancer experience. Responses were rated on a 4-point scale (0=*"Did not experience"*,

1=*"Small degree"*, 2=*"Moderate degree"*, 3=*"Great degree"*)[9], and totals were calculated for each of the sub-scale and the full-scale scores. For categorical interpretation of scale scores, response scale anchor points were used to categorise each respondent's mean subscale and full-scale score as low (less than 2), or 'moderate to great' (2 or greater). In the absence of empirically derived data, the cut-off score of 2 or higher used to depict 'high growth' is an arbitrary one, but one consistent with cut-off scores used by the IES-R and DASS-21.

The PTGI has been used to assess growth following a diverse array of traumatic experiences including childhood cancer (Barakat et al., 2005; Best et al., 2001; Helgeson et al., 2006). The measure has shown satisfactory psychometric properties (Tedeschi & Calhoun, 1996), and has been shown to be a good measure of positive posttrauma change (Shakespeare-Finch & Enders, 2008). In the current study, internal consistency across the groups, ranged from .79 to .92 across the subscales, and .89 to .90 for the PTGI full-scale.

Demographic information was collected in the areas of relationship status, education level, employment, income, and cultural identity. For survivors and siblings, information on living status (i.e., living with parents), and whether assistance was obtained in completing the questionnaire was also obtained. Date of birth was collected for parents and siblings.

B. Structured Clinical Interview

- *Structured Clinical Interview for DSM-IV: PTSD Module (SCID)* (First et al., 1995). A semi-structured clinical interview to assess current and life-time PTSD diagnosis according to DSM-IV symptom criteria (see Appendix 1C). The respondent is asked to describe "*what were the most frightening, upsetting, or life-threatening aspects of the cancer experience for you"* (Criterion 1A; if more than 1 event is recited, the respondent is asked *"which of these do you think affected you the most?"*[10]), and if the respondents reactions at the time of the event(s) involved feelings of fear, horror, or helplessness (Criterion 1B). Throughout the interview, the most distressing event(s) or experiences are regularly referred to in order to anchor the respondent's answers to the most distressing cancer specific traumatic event(s).

[9] The response scale of the PTGI was changed from a 6-point format to a 4-point format to maintain consistency within Questionnaire Pack 1.

[10] While this helped to focus the traumatic event(s) referred to throughout the interview, often respondents were unable to say that one event only caused the most distress, often two or three events were cited as equally 'most distressing'.

The assessment of B-Symptom criteria (intrusive re-experiencing) included 5 symptom related questions: recurrent and distressing recollections; recurrent distressing dreams; acting or feeling as if the trauma was recurring/reliving; intense psychological distress at internal or external cues; physiological reactivity on exposure to internal or external cues. In line with the DSM-IV (see Appendix 1C), in order to meet the B-Symptom criteria, at least one of these symptoms must be present.

C-Symptom criteria (cognitive and behavioural avoidance) included 7 symptom related questions assessing: efforts to avoid thoughts, feelings or conversations of the trauma related event(s); efforts to avoid activities, places or people that arouse recollections ; an inability to recall an important aspect of the cancer experience; markedly diminished interest or participation in significant activities; feelings of detachment or estrangement from others; restricted range of affect; sense of foreshortened future. In order to meet the C-Symptom criteria, at least 3 of these symptoms must be present (see Appendix 1C).

D-Symptom criteria (hyper-arousal) included 5 symptom related questions assessing: difficulty falling or staying asleep; irritability or outbursts of anger; difficulty concentrating; hypervigilance; exaggerated startle response. In order to meet the D-Symptom criteria, at least 2 of these symptoms must be present (see Appendix 1C).

The individual symptoms, the symptom clusters, and the disorder were confirmed as either current (experienced within the past month), or experienced since cancer diagnosis. In order to determine clinical relevance of PTSS, the interview included additional questions for each symptom confirmed as experienced in order to determine whether the symptom persisted for at least 1 month (the 'E' criteria), whether the symptom caused impairment of functioning ('F' criteria), and whether the symptom was current (within the last month) or history (greater than one month). Only symptoms meeting the E and F criteria's were classified as a symptom of PTSD. Data was categorically coded to reflect whether a person met symptom criteria (B, C, or D) and full disorder criteria (all criteria A to F are met). The SCID is a well established diagnostic interview shown to have sound psychometric properties (First et al., 1997).

2.2 Results: Participant Characteristics

2.2.1 Questionnaire Booklet (Part 1)

A. Childhood Cancer Survivors

A total of 831 childhood cancer survivors were identified on the clinic database. Of these, 22 were deceased, and 12 deemed ineligible for recruitment (6 known cognitive impairment, 1 living

overseas, 1 poor English language skills, 2 older than 18 at the time of diagnosis, and 2 at risk: emotionally unstable/suicidal). Contact details were confirmed for 445 eligible survivors, with 182 survivors returning completed questionnaire booklets and consent forms (69 male, 113 female) – a response rate of 41% (37 declined, 8 returned to sender, 5 questionnaires lost in return mail, and 213 non-responders). Of the 37 survivors who declined research participation, 27 volunteered the following reasons: 8 did not want to relive their cancer experience as they regarded it as too distressing, 7 did not consider the questions relevant to their experience (they were too young at time/or they received minimal treatment), 7 were uninterested, 3 were too busy, and 2 reported other reasons.

As shown in Table 2.1, the mean age of survivors was 24.9 years, and the mean time since end of treatment was 15.4 years. A range of cancer diagnoses were represented, the most common being leukaemia (48%), followed by solid tumours (34%), lymphomas (11%), and tumours of the central nervous system (CNS) (3%). Using Chi Square Goodness of Fit, the diagnostic distribution was compared with the adolescent and adult survivor distribution of all cases registered with long-term follow-up clinics of the CCCBD and The Children's Hospital, Westmead, NSW[11] (leukaemia = 38.8%, solid tumour = 29.7%, lymphoma = 11.1%, CNS = 10.1%, other = 10.3%; male = 55%, female = 45%; Goodenough et al., 2008). Results showed the sample distribution differed significantly from the NSW representative sample in diagnosis ($X^2(4) = 20.67$, $p < .001$) and gender ($X^2(1) = 21.72$, $p < .001$) – specifically, compared to the NSW representative sample, the sample distribution has greater representation of leukaemia and solid tumour diagnoses, a lower representation of tumours of the CNS, and a greater representation of female participants.

B. Parents of Childhood Cancer Survivors

Survivor consent was received to contact 152 mothers, and 116 fathers. This resulted in data from 109 mothers aged 34 to 77 years (M=52.7) (response rate = 72%;) Of the 43 mothers who did not participate: 36 did not respond, 1 was deceased at the time of contact, 3 questionnaires were lost in the return mail, 1 was a Step-mother to the childhood cancer survivor[12], and 2 declined. Reasons cited for declining research participation included not wanting to relive the cancer experience as it was regarded as too distressing (n=1), and felt it was too long ago (n=1).

73 fathers aged 43 to 87 years (M=56.5) agreed to participate in the research (response rate = 63%). Of the 43 non-participants: 31 did not respond, 2 questionnaires were lost in the return mail, 1

[11] The Children's Hospital at Westmead is NSW's busiest childhood cancer referral centre treating around 150 new cancer patients each year. The data represent the majority of cases in NSW, aged 16 years or over, and eligible for long-term follow-up (five years post diagnosis, and three years post treatment).

[12] Married into family after cancer treatment finished

was cognitively impaired, and 9 declined. Of those who declined, 3 of the 9 fathers provided reasons. These were not wanting to relive the experience as it was regarded as too distressing (n=2), and too busy (n=1).

Table 2.1 outlines diagnostic, treatment and demographic variables for participating parents.

C. Siblings of Childhood Cancer Survivors

Survivor consent was received to contact 179 siblings, resulting in 80 sibling participants (aged 16 to 44 years, *M*=26.8; *SD*=6.9; 23 male, 58 female) – a response rate of 45%. Of the 99 non-participants 75 did not respond, 2 were overseas at the time of contact, 3 questionnaires were lost in the return mail, 3 did not provide current contact details, and 16 declined. Of the 16 siblings declining participation 9 volunteered reasons. These were: too busy (n=5), deemed the questions irrelevant as were born after the cancer treatment period (n=2), did not want to relive the experience as it was regarded as too distressing (n=1), and was too young at the time/no recollection (n=1).

Of the 80 participants, 18 siblings had at least one other brother or sister participating. In order to exclude potential family bias only one sibling per survivor was retained for analyses. In these instances, the sibling who had completed the greatest proportion of the measures was selected to minimise missing data. Where two or more siblings completed the same number of measures (n=5), the oldest was selected. The oldest sibling criterion was used as they were presumed to have better memories surrounding the events. Following selection procedures, a total of 62 sibling participants, aged 16 to 44 years (*M*=27.4) were retained for analyses. Table 2.1 outlines the demographic and treatment details for this group.

2.2.2 Group Comparisons

Independent samples t-tests and chi-square analyses were used to test for differences between survivors and siblings, and mothers and fathers on treatment and demographic variables. Relative to survivors, siblings were more likely to be older at time of diagnosis ($t(83.4) = -2.35$, $p = .021$), and at time of questionnaire completion ($t(240) = -2.52$, $p = .013$). Fathers also were significantly older at both time points compared with mothers ($t(176) = -3.46$, $p = .001$; $t(179) = -3.40$, $p = .001$ respectively). Survivors, compared to the sibling group, were more likely to be living with parents ($X^2(1, N = 244) = 13.70$, $p < .001$), single ($X^2(3, N = 243) = 13.14$, $p = .004$), have a lower level of educational attainment ($X^2(4, N = 244) = 18.15$, $p = .001$), and earn a lower personal income ($X^2(4, N = 209) = 16.26$, $p = .003$). No significant group differences were recorded for gender, employment status, household income, or cultural identity.

Compared to fathers, mothers were less likely to have completed high school ($X^2(4, N = 180) = 16.41, p = .003$), less likely to be working in a paid position ($X^2(2, N = 182) = 19.34, p < .001$), and more likely to have a lower personal income ($X^2(4, N = 162) = 28.58, p < .001$). No significant group differences between mothers and fathers were observed for marital status, household income, or cultural identity.

All four groups were compared on diagnostic and treatment variables using Kruskal-Wallis tests for categorical data, and one-way analysis of variance for parametric data. No group differences were found for cancer type ($X^2(3) = 1.20, p = .754$), treatment received ($X^2(3)$range = 0.26 to 3.21, $p > .400$), years since treatment cessation ($F(3,388) = 0.48, p = .700$), or whether there was a disease relapse or second malignancy ($X^2(3) = 2.13, p = .545$). These findings indicate that these variables were reported similarly across groups.

2.2.3 Structured Clinical Interview

Of the responders to Questionnaire Booklet (Part 1), 155 survivors (57 male, 98 female; aged 16.2 to 48.5 years; response rate = 85%); 92 mothers (aged 36.5 to 75.0 years; response rate = 84%), 58 fathers (aged 44.7 to 68.7 years; response rate = 79%), and 48 siblings (aged 17.2 to 45.2 years; 14 male, 34 female; response rate = 77%) also consented to take part in the clinical interview. Reasons for non-participation included: not interested/too busy (survivors n=4; mothers n=1; fathers n=1; siblings n=1); living/visiting overseas (survivors n=4; mothers n=2; siblings n=3); too distressing (survivors n=3; mothers n=2); unable to find suitable time (survivors n=1; mothers n=2); since deceased (survivors n=1); child survivor since deceased (mothers n=1; fathers n=1); declined with no reason volunteered (survivors n=1; mothers n=3; fathers n=2; siblings n=1); and unable to be contacted (wrong number/no answer; survivors n=14; mothers n=9; fathers n=12; siblings n=9). There were some additional participants who agreed to take part in the interview, although no data was obtained from Questionnaire Booklet (Part 1). This was due to Questionnaire Booklet (Part 1) being lost in the return mail (survivors n=1; mothers n=3; fathers n=1). Table 2.1 outlines the demographic and treatment details for the interview groups. Using Chi Square Goodness of Fit for categorical data, and Paired Samples t-tests for parametric data, age at study participation, and years off treatment were significantly greater for the structured clinical interview, than for Questionnaire Booklet (Part 1) for each group[13]. This reflects the order and time lag between points of data collection. No other differences on any of the other demographic and treatment variables were found

[13] Age at study participation: Survivors: t(152) = 33.76; Mothers: t(87) = 14.35; Fathers: t(56) = 13.74; Siblings: t(47) = 11.71; all significant at p < .001. Years off treatment: Survivors: t(143) = 13.91; Mothers: t(83) = 13.63; Fathers: t(52) = 12.75; Siblings: t(43) = 12.06; all significant at p < .001.

indicating similar group characteristics for participants at both data collection points (questionnaire and interview) despite non-random self-selection.

Table 2.1: Questionnaire Booklet (Part 1) and structured clinical interview: Demographic and treatment details for survivors, mothers, fathers, and siblings

	Survivors		Mothers		Fathers		Siblings	
Variable	Q. Bk 1 (n=182) Mean, *SD*	Interview (n=155) Mean, *SD*	Q. Bk 1 (n=109) Mean, *SD*	Interview (n=92) Mean, *SD*	Q. Bk 1 (n=73) Mean, *SD*	Interview (n=58) Mean, *SD*	Q. Bk 1 (n=62) Mean, *SD*	Interview (n=48) Mean, *SD*
Age at participation (years):								
Mean, *SD*	24.9, *6.6*	26.8, *6.9***	52.7, *7.1*	54.1, *6.7***	56.5, *7.8*	56.8, *6.4***	27.4, *7.0*	29.4, *7.2***
Range	16.0 to 47.4	16.2 to 48.5	34.2 to 77.0	36.5 to 75.0	43.0 to 87.3	44.7 to 68.7	16.7 to 44.5	17.2 to 45.2
Age at diagnosis (years):								
Mean, *SD*	6.8, *4.5*	6.9, *4.4*	34.9, *6.5*	34.4, *6.3*	38.4, *7.1*	38.1, *6.7*	8.9, *6.0*	8.9, *6.2*
Range	0 to 18.0	0 to 16.9	18.6 to 50.7	19.0 to 50.6	24.2 to 61.0	24.2 to 56.3	-1.2 to 28.2	-0.9 to 28.2
Yrs off treatment:								
Mean, *SD*	15.4, *6.9*	17.5, *7.2***	15.7, *6.9*	17.1, *7.1***	15.5, *6.9*	16.5, *7.0***	16.6, *7.3*	18.5, *7.2***
Range	2.7 to 35.7	4.6 to 36.8	3.0 to 31.9	3.9 to 31.9	3.0 to 31.9	4.9 to 33.3	5.2 to 31.4	7.3 to 32.8
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Gender:								
Male	69 (37.9)	57 (36.8)	-	-	73 (100.0)	58 (100.0)	17 (27.4)	14 (29.2)
Female	113 (62.1)	98 (63.2)	109 (100.0)	92 (100.0)	-	-	45 (72.6)	34 (70.8)
Diagnosis:								
Leukaemia	87 (47.8)	74 (47.7)	53 (48.6)	43 (46.7)	37 (50.7)	28 (48.3)	40.3 (25)	21 (43.8)
Solid Tumour	62 (34.1)	53 (34.2)	36 (33.0)	32 (34.8)	22 (30.1)	20 (34.5)	40.3 (25)	17 (35.4)
Lymphoma	20 (11.0)	17 (11.0)	11 (10.1)	10 (10.9)	6 (8.2)	5 (8.6)	11.3 (7)	6 (12.5)
CNS Tumour	6 (3.3)	4 (2.6)	6 (5.5)	3 (3.3)	5 (6.8)	2 (3.4)	3.2 (2)	1 (2.1)
Other	7 (3.8)	7 (4.5)	3 (2.8)	3 (3.3)	3 (4.1)	3 (5.2)	4.8 (3)	3 (6.3)
Treatment:								
Chemotherapy	168 (92.3)	146 (94.2)	102 (93.6)	86 (93.5)	70 (95.9)	56 (96.6)	61 (98.4)	47 (97.9)
Radiation	121 (66.5)	106 (68.4)	72 (66.1)	58 (63.0)	50 (68.5)	39 (67.2)	36 (58.1)	29 (60.4)
Cranial	*72 (39.6)*	*62 (40.0)*	*46 (42.2)*	*34 (37.0)*	*34 (46.6)*	*23 (39.7)*	*20 (32.3)*	*16 (33.3)*
Total body	*11 (6.5)*	*8 (5.2)*	*8 (7.3)*	*7 (7.6)*	*4 (5.5)*	*4 (6.9)*	*4 (6.5)*	*4 (8.3)*
Surgical resection	74 (40.7)	66 (42.6)	44 (40.4)	39 (42.4)	31 (42.5)	26 (44.8)	30 (48.4)	20 (41.7)
Transplant (Bone-marrow/cord blood)	22 (12.1)	16 (10.3)	11 (10.1)	9 (9.8)	7 (9.6)	6 (10.3)	6 (9.7)	4 (8.3)
Relapse/2nd malignancy	31 (17.0)	23 (14.8)	17 (15.6)	15 (16.3)	10 (13.7)	8 (13.8)	6 (9.7)	5 (10.4)
Living with parents	111 (61.0)	95 (61.3)	-	-	-	-	21 (33.9)	16 (33.3)

Table 2.1: Continued.

Variable	Survivors Q. Bk 1 (n=182) n (%)	Survivors Interview (n=155) n (%)	Mothers Q. Bk 1 (n=109) n (%)	Mothers Interview (n=92) n (%)	Fathers Q. Bk 1 (n=73) n (%)	Fathers Interview (n=58) n (%)	Siblings Q. Bk 1 (n=62) n (%)	Siblings Interview (n=48) n (%)
Relationship status:								
Single	109 (59.9)	93 (60.0)	3 (2.8)	3 (3.3)	1 (1.4)	-	21 (33.9)	18 (37.5)
Partner not defacto	28 (15.4)	24 (15.5)	2 (1.8)	1 (1.1)	-	-	15 (24.2)	9 (18.8)
Married/ defacto	43 (23.6)	36 (23.2)	91 (83.5)	75 (81.5)	69 (94.5)	54 (93.1)	25 (40.3)	21 (43.8)
Divorced/separated	1 (0.5)	-	9 (8.3)	6 (6.5)	3 (4.1)	3 (5.2)	1 (1.6)	-
Widowed	-	-	4 (3.7)	4 (4.3)	-	-	-	-
Level of education:								
Not completed high school	52 (28.6)	44 (28.4)	43 (39.4)	36 (39.1)	9 (12.3)	5.2 (3)	16.1 (10)	14.6 (7)
Completed high school	42 (23.1)	38 (24.5)	12 (11.0)	8 (8.7)	9 (12.3)	12.1 (7)	17.7 (11)	18.8 (9)
Apprenticeship/TAFE	50 (27.5)	39 (25.2)	25 (22.9)	21 (22.8)	27 (37.0)	43.1 (25)	17.7 (11)	14.6 (7)
University graduate	31 (17.0)	26 (16.8)	16 (14.7)	12 (13.0)	17 (23.3)	20.7 (12)	41.9 (26)	43.8 (21)
University postgraduate	7 (3.8)	7 (4.5)	12 (11.0)	11 (12.0)	10 (13.7)	15.5 (9)	6.5 (4)	8.3 (4)
Level of current employment:								
Full-time	71 (39.0)	59 (38.1)	31 (28.4)	26 (28.3)	42 (57.5)	58.6 (34)	53.2 (33)	58.3 (28)
Part-time/casual	62 (34.1)	55 (35.5)	43 (39.4)	36 (39.1)	10 (13.7)	10.3 (6)	32.3 (20)	31.3 (15)
Household income per annum:								
Up to $20,000	14 (7.7)	13 (8.4)	10 (9.2)	7 (7.6)	4 (5.5)	3.4 (2)	6.5 (4)	4.2 (2)
$20,001 to $40,000	26 (14.3)	19 (12.3)	19 (17.4)	14 (15.2)	7 (9.6)	6.9 (4)	8.1 (5)	6.3 (3)
$40,001 to $70,000	40 (22.0)	38 (24.5)	27 (24.8)	21 (22.8)	14 (19.2)	20.7 (12)	27.4 (17)	27.1 (13)
$70,001 to $100,000	29 (15.9)	25 (16.1)	17 (15.6)	15 (16.3)	16 (21.9)	24.1 (14)	25.8 (16)	29.2 (14)
$100,001 plus	35 (19.2)	28 (18.1)	25 (22.9)	23 (25.0)	26 (35.6)	36.2 (21)	29.0 (18)	31.3 (15)
Personal income per annum:								
Up to $20,000	82 (45.0)	74 (4.7)	36 (33.0)	25 (27.2)	10 (13.7)	6 (10.3)	16 (25.8)	12 (25.0)
$20,001 to $40,000	33 (18.1)	30 (19.4)	31 (24.8)	27 (29.3)	11 (15.1)	8 (13.8)	20 (32.3)	13 (27.1)
$40,001 to $70,000	22 (12.1)	17 (11.0)	19 (17.4)	17 (18.5)	21 (28.8)	17 (29.3)	19 (30.6)	18 (37.5)
$70,001 to $100,000	8 (4.4)	4 (2.6)	3 (2.8)	2 (2.2)	13 (17.8)	12 (20.7)	3 (4.8)	3 (6.3)
$100,001 plus	5 (2.7)	4 (2.6)	6 (5.5)	6 (6.5)	12 (16.4)	10 (17.2)	1 (1.6)	1 (2.1)

Table 2.1: Continued

Variable	Survivors		Mothers		Fathers		Siblings	
	Q. Bk 1 (n=182) n (%)	Interview (n=155) n (%)	Q. Bk 1 (n=109) n (%)	Interview (n=92) n (%)	Q. Bk 1 (n=73) n (%)	Interview (n=58) n (%)	Q. Bk 1 (n=62) n (%)	Interview (n=48) n (%)
Cultural identity								
Australian	154 (84.6)	132 (85.2)	98 (89.9)	82 (89.1)	70 (95.9)	55 (94.8)	59 (95.2)	46 (95.8)
Aboriginal/Islander	1 (0.5)	1 (0.6)	1 (0.9)	-	-	-	-	-
European	8 (4.4)	8 (5.2)	2 (1.8)	2 (2.2)	-	-	2 (3.2)	2 (4.2)
Asian	2 (1.1)	-	3 (2.8)	3 (3.3)	1 (1.4)	1 (1.7)	-	-
North American	1 (0.5)	1 (0.6)	-	-	-	-	-	-
Central/South American	1 (0.5)	-	-	-	-	-	-	-
Middle Eastern	3 (1.6)	3 (1.9)	2 (1.8)	-	-	-	-	-
Other	1 (0.5)	1 (0.6)	1 (0.9)	1 (1.1)	1 (1.4)	1 (1.7)	-	-

**p < .001; Note: Valid percentages used for frequency data

CHAPTER 3
STUDY 1

PREVALENCE AND FAMILY GROUP COMPARISONS OF POSTTRAUMATIC STRESS, PSYCHOLOGICAL DISTRESS AND POSTTRAUMATIC GROWTH

3.0 Overview

Study 1 aims to document prevalence and compare family groups (survivors, mothers, fathers, siblings) on cancer-related posttraumatic stress and posttraumatic growth, and non-cancer related psychological distress (depression, anxiety and stress) in an Australian sample of childhood cancer survivors, their parents, and their siblings. Using the self-report questionnaires and the clinical interview reviewed in Chapter 2, Study 1 will address the dearth of Australian data, while also providing further information on the long-term psychosocial impact of siblings who, from a family perspective, have traditionally been a forgotten group. As an additional area of investigation, group differences on the two trauma outcomes will be investigated for full participating family units, and symptom/growth relationships between family members and rates of family concordance will be explored.

In light of the above, Study 1 will take three parts - Study 1A (prevalence), Study 1B (family group comparisons), and Study 1C (family group comparisons for full family units).

3.1. Study 1A
Prevalence of PTSD, PTSS Psychological Distress and Posttraumatic Growth

3.1.0 Overview

The primary objective of Study 1A is descriptive with no specific predictions made with regard to expected prevalence rates of these three outcomes. Instead, Study 1A will document the first Australian prevalence data for posttraumatic stress, psychological distress, and posttraumatic growth in childhood cancer survivors, parents and siblings. Study 1A will also document demographic and treatment correlates of these outcomes.

3.1.1 Method

3.1.1.1 Participants

Following the methods described in Chapter 2, self-report measures were completed by 182 survivors, 109 mothers, 73 fathers, and 62 siblings. The numbers of participants completing the interview were 155 survivors, 92 mothers, 58 fathers and 48 siblings

3.1.1.2 Measures

Described in Chapter 2, the following measures were administered to participant groups (survivors, mothers, fathers, siblings):

- *Structured Clinical Interview for DSM-IV: PTSD Module* (*SCID*; First et al., 1995).
- *Impact of Event Scale-Revised* (*IES-R*; Weiss & Marmar, 1997).
- *Depression Anxiety and Stress Scale-Short Version* (*DASS-21*; Lovibond & Lovibond, 1995).
- *Posttraumatic Growth Inventory* (*PTGI*; Tedeschi & Calhoun, 1996).

3.1.1.3 Statistical Analyses[14]

Using SPSS for windows, version 15, relationships between the self-report measures (IES-R, DASS-21, PTGI) and the demographic and treatment variables were assessed by Pearson's bivariate correlational analysis[15]. The alpha level of $p \leq .05$ was applied to depict statistical significance.

3.1.2 Results

Note: Table 3.1 shows a full summary of the percentage of respondents meeting SCID-PTSD criteria by group. Table 3.2 summarises the full-scale mean scores for each group and the percentages of respondents meeting moderate or above criteria for the IES-R, DASS-21, and PTGI. Tables 3.4 to 3.6 show bivariate correlates of the self-report measures and the demographic and treatment variables. As these tables also relate to Study 1B, these tables will be presented at the end of Study 1B.

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[14] Assumption testing: The assumption of Linearity was confirmed, however violations of normality were found for the self-report IES-R and DASS-21 measures (IES-R skew = 1.75, kurtosis = 2.98; DASS-21 skew = 2.09, kurtosis = 5.17). Transformation of variables was investigated using both naturalistic logarithmic (NL) and square root (SQRT) calculations. Square root transformations revealed greatest statistical correction for the measures (IES-R skew = 0.79, kurtosis = -0.08; DASS-21 skew = 0.80, kurtosis = 0.12). However transformed data were not considered superior to real data following inspection of histograms which continued to show normality violations, minimal change to statistical results, and consideration of problems associated with interpretation (Tabachnick & Fidell, 2001).

[15] Some categorical demographic variables pose difficulty in coding as a continuous variable (Relationship Status, Education Level, Employment Status). In these cases one-way ANOVA's were also conducted but will be reported only if differing from the correlational results.

3.1.2.1: Posttraumatic Stress Disorder (SCID)

Childhood cancer constituted a traumatic event, in accordance with DSM-IV criterion A, for 46.5% of survivors, 82.6% of mothers, 82.8% of fathers, and 37.5% of siblings. Since cancer diagnosis, full PTSD criteria[16] were met by 9.7% of survivors, 18.5% of mothers, and 10.3% of fathers, and criteria for the current disorder were met by 3.9% of survivors, 4.3% of mothers, and 1.7% of fathers[17]. The percentage of respondents meeting part-remission[18] for the disorder suggest that an additional 5.8% of survivors, 13.0% of mothers, and 8.6% of fathers who had once met full criteria, still met partial symptomatology. One mother met full-remission[19] following a PTSD diagnosis. No siblings met criteria for PTSD at any time point since cancer diagnosis.

3.1.2.2: Posttraumatic Stress Symptoms (SCID and IES-R)

Comparative to the disorder, a substantially higher number of participants met criteria for the individual symptom clusters according to the SCID. Since cancer diagnosis, 62.6% of survivors, 85.9% of mothers, 72.4% of fathers, and 58.3% of siblings qualified for the B-symptom cluster of intrusive re-experiencing. Current criteria were met by fewer respondents: survivors=34.2%, mothers=50.0%, fathers=44.8%, siblings=20.8%. The frequency of participants meeting criteria for the remaining symptom clusters was lower, although still higher than those meeting full PTSD (see Table 3.1). Mothers reported the highest prevalence of most symptoms (since diagnosis and current) with the exception of current C-symptomatology where survivors reported the highest rates. Siblings reported the lowest symptom prevalence across all categories.

According to the self-report IES-R, and as shown in Table 3.2, all groups show moderate to severe levels of clinically significant PTSS (survivors=16.3%, mother=19.1%, fathers=15.3%, siblings=8.2%). Consistent with SCID results, mothers report highest scores for *Intrusion* (M = 7.05, SD = 6.67), *Hyper-arousal* (M = 2.52, SD = 4.45), and *Full-scale IES-R* (M = 14.35, SD = 16.44), while survivors endorsed highest *Avoidance* (M = 5.50, SD = 6.50) scores.

Table 3.4 shows correlational relationships between the IES-R and the demographic and treatment variables. For survivors, higher IES-R scores were significantly associated with a relapse

[16] Full PTSD criteria refers to respondents meeting all DSM-IV-PTSD criteria according to the SCID (A to F; see Appendix 1C)

[17] An additional survivor met all PTSD criteria except criterion A. In this instance, although severe current symptomatology was evident, his response throughout his experience was one of spiritual acceptance, rather than fear, horror or helplessness.

[18] Part remission refers to respondents who have a history of meeting full PTSD criteria since diagnosis, but who currently meet only 1 or more symptom cluster (B, C, or D) criteria. Note that current symptom criteria is only recorded as present if it also has been found to impair functioning (criterion F).

[19] Full remission refers to respondents who have a history of meeting full PTSD criteria since diagnosis, but who currently do not experience any of the symptom clusters (B, C, or D).

or second malignancy, currently living with a parent, not in a current relationship, and not in current full-time employment[20]. Mother's were significantly more likely to have higher IES-R scores if their cultural identity was other than Australian, their child was diagnosed with a solid tumour, or their child's treatment included a surgical resection, but were more likely to have lower IES-R scores if their child was diagnosed with a leukaemia. Father's were significantly more likely to have higher IES-R scores if their child was diagnosed with a malignancy of the Central Nervous System (CNS), and were likely to have lower IES-R scores with more years off treatment. Sibling's were more likely to have higher IES-R scores if their brother or sister was diagnosed with a leukaemia ($p < .05$; small to moderate correlations found).

3.1.2.3: Psychological Distress (DASS-21)

As shown in Table 3.2, survivors scored highest on *Depression* (*M* = 7.39) and *Anxiety* (*M* = 4.73), and siblings scored highest for *Stress* (*M* = 11.21). Fathers scored lowest on *Anxiety* (*M* = 2.66) and *Stress* (*M* = 7.40), while siblings scored lowest on *Depression* (*M* = 4.46). Across all scales, prevalence of moderate to severe psychological distress was greatest for survivors (*Depression* = 23.5%; *Anxiety* = 15.6%; *Stress* = 19.0%), followed by mothers (11.9%, 10.1%, and 11.9% respectively). Prevalence of *Stress* was lowest for fathers (9.6%), *Depression* was lowest for siblings (6.6%), and *Stress* was lowest for both fathers and siblings (8.2%).

Table 3.5 shows relationships between the DASS-21 and the demographic and treatment variables. As shown, survivors who reported themselves as currently living with a parent, or not in a current relationship were significantly more likely to score higher on the DASS-21[21]. For mothers, higher scores were significantly associated with a younger mothers current age and a younger mothers age at the time of their child's diagnosis, as well as a 'solid tumour' diagnosis in their child. For fathers, higher DASS-21 scores were significantly associated with a CNS malignancy in their child, and for siblings higher scores were associated with an older age at diagnosis ($p < .05$; small correlations found)[22].

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[20] One-way ANOVA revealed Survivor IES-R scores did not significantly differ according to Employment Status: not employed (*M* = 17.0, *SD*=16.1), part-time (*M* = 12.7, *SD*=14.7), full-time (*M* = 10.4, *SD*=14.5). *F(2,175)* = 2.92, *p* = .057.

[21] One-way ANOVA revealed Survivor DASS-21 scores differed significantly according to Education Level: not completed high school (M = 24.2, SD = 21.4), completed high school (M = 16.6, SD = 20.3), apprenticeship/TAFE (M = 27.6, SD = 25.8), university graduate (M = 15.5, SD = 17.8), university postgraduate (M = 33.4, SD = 28.3). F(4,174) = 2.66, p = .0.34.

[22] One-way ANOVA revealed Sibling DASS-21 scores differed significantly according to Education Level: not completed high school (M = 35.3, SD = 33.2), completed high school (M = 14.2, SD = 6.7), apprenticeship/TAFE (M = 15.1, SD = 7.7), university graduate (M = 16.4, SD = 13.9), university postgraduate (M = 18.0, SD = 19.8). F(4,56) = 2.08, p = .0.34.

3.1.2.4: Posttraumatic Growth (PTGI)

The large majority of participants endorsed at least 1 growth item at the moderate to great level (survivors = 90.6%, mothers = 97.2%, fathers = 95.9%, siblings = 74.2%). As shown in Table 3.2, mothers scored highest across all subscales (*M* full-scale PTGI = 35.82), and siblings lowest (*M* full-scale PTGI = 19.16). *Appreciation of Life* showed highest prevalence for moderate to great growth across all groups (survivors=50.8%, mothers=72.2%, fathers=52.1%, siblings=32.3%), while *New Possibilities* showed lowest prevalence for mothers (24.1%), fathers (19.2%), and siblings (9.7%), and *Spiritual Change* showed lowest prevalence for survivors (22.2%).

Table 3.6 shows relationships between the PTGI and the demographic and treatment variables. As shown, survivors who were older at diagnosis or not currently working full-time[23] were significantly more likely to score higher on the PTGI. A lower educational level[24] and lower household income was significantly associated with higher PTGI scores for mothers. Fathers were significantly more likely to have higher PTGI scores if their child was diagnosed with a lymphoma or their child's treatment included a surgical resection, but were more likely to have lower PTGI scores the longer the years off treatment or if their child's diagnosis included a leukaemia. Sibling's were significantly more likely to have higher PTGI scores if they were older at diagnosis, their brother or sister had a relapse or a second malignancy, or their brother's or sister's treatment included a surgical resection, but were likely to have lower PTGI scores the more years their brother or sister were off treatment, or if their brother or sister was diagnosed with a leukaemia ($p < .05$; small to moderate correlations found).

3.1.3 Discussion

Study 1A provides the first Australian data on the long-term psychosocial adjustment of a sample of childhood cancer survivors, parents and siblings. Using self-report measures and clinical interview, results show relatively high levels of 'moderate to great' growth in this sample of respondents, although clinically significant levels of posttraumatic stress and psychological distress are also reported across all family members.

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[23] One-way ANOVA revealed Survivor PTGI scores did not significantly differ according to Employment Status: not employed (*M* = 31.7, *SD* = 16.5), part-time (*M* = 27.9, *SD* = 18.6), full-time (*M* = 24.7, *SD* = 16.6). *F(2,179)* = 2.37, *p* = .096.

[24] One-way ANOVA revealed Mothers PTGI scores did not significantly differ according to Education Level: not completed high school (*M* = 38.7, *SD* = 13.5), completed high school (*M* = 37.2, *SD* = 14.8), apprenticeship/TAFE (*M* = 33.6, *SD* = 16.2), university graduate (*M* = 38.1, *SD* = 13.0), university postgraduate (*M* = 26.7, *SD* = 16.2). *F(4,102)* = 1.87, *p* = .122.

Since cancer diagnosis, PTSD in this sample was reported by 19 percent of mothers, and 10 percent of survivors and fathers, while no siblings met full diagnostic criteria. For survivors and fathers, these rates are within the range reported by other non-Australian studies (e.g., Kazak et al., 2004a), and slightly higher than the estimated 8% general population prevalence (APA, 2000). For mothers, rates were lower than previously reported in other studies (see Table 1.1, Chapter 1), however considerably greater than general population estimates (APA, 2000), and in line with rates reported in other trauma exposed groups (Green, 1994). Current PTSD was found to be substantially lower with only 4% of survivors and mothers, and only 1.7% of fathers meeting current criteria. It is noteworthy however, that nearly all participants who have qualified for the disorder at some time point since cancer diagnosis still experience at least partial PTSD, indicating that even if current criteria are not fully met, complete symptom recovery is rare even many years following the end of cancer treatment. In line with this, self-reported severity ratings suggest higher levels of distress than are perhaps reflected by the categorical diagnostic distinctions of the DSM-IV. For example, current levels of clinically significant posttraumatic stress (as measured by the IES-R) were reported by 16% of survivors, 19% of mothers, 15% of fathers, and 8% of siblings.

In comparison to the disorder, substantially higher rates of the symptom-clusters were evident across all family members. The highest prevalence was found for the B-symptom cluster of intrusive re-experiencing, where 63% of survivors, 86% of mothers, 72% of fathers, and 58% of siblings have met symptom criteria since diagnosis, and 34%, 50%, 45% and 21% respectively still experience current symptomatology. The D-symptom cluster of hyper-arousal was next most endorsed, with fewest participants meeting the C-symptom cluster of avoidance - however prevalence rates were still higher for this symptom relative to the disorder for all groups. While these findings generally accord with reports from other childhood cancer populations, the Study 1's relatively lower prevalence of the symptom clusters than reported by other studies (e.g., Goldenberg Libov et al., 2002; Kazak et al., 2001, 2004a; see Table 1.1), is most likely due to each symptom being screened as causing impairment to daily functioning (see Section 2.1.4B). Consequently, the prevalence rates reported by Study 1 show the proportion of participants with symptoms persisting for at least one month and causing distress and disruption to life.

Compared to posttraumatic stress, psychological distress showed quite a different profile of responses. Survivors consistently reported higher severity and prevalence than parents. This was also mostly the case for siblings although data indicates that on average siblings report higher severity of stress than survivors. This however was not maintained for prevalence data with prevalence of moderate to severe stress being higher for survivors than siblings, although siblings report higher severity of stress than parents, and greater prevalence of moderate to severe stress than

fathers. Survivors reported mean scores greater than the normative sample provided by Lovibond and Lovibond (1995) for Depression (normative sample: *M* = 6.34, *SD* = 6.97), while siblings reported higher scores for stress (normative sample: Stress: *M* = 10.11, *SD* = 7.91). Parents reported lower scores across all scales of the DASS-21. Nearly one quarter of survivors reported moderate to severe levels of depression, 16% anxiety, and 19% stress, in contrast to the 10 to 12% reported by mothers, 8 to 11% reported by fathers, and 7 to 12% reported by siblings. While the rates concur with previous survivor data (e.g., Goodenough et al., 2008; Hudson et al., 2003; Koocher & O'Malley, 1981; Recklitis et al., 2003), the results digress from posttrauma responses where mothers are mostly found to report greater levels. In explanation, the current findings may reflect stressors unique to the survivor group, which may occur regardless of whether or not the cancer experience evoked a traumatic response. For example, interruptions to education and peer interactions, as well as changes in physical appearance and other long-term effects may impact on body image, self-esteem, educational and vocational attainment, and relationships (Marsland et al., 2006). These adjustment problems are often associated with ongoing psychological distress (Patenaude & Kupst, 2005). As shown in Table 2.1 (Chapter 2), survivors were more likely than siblings to have a lower level of education and personal income, less likely to be in an exclusive intimate relationship, and more likely to be living with their parents. While this may be confounded by age (the survivor group was significantly younger than the sibling group at the time of diagnosis and study participation), the finding that not being in a relationship and still living at home with a parent were significantly related to increased psychological distress in survivors suggests that survivors may be particularly vulnerable to social adjustment problems and consequently psychological distress.

Relative to posttraumatic stress, posttraumatic growth showed high current prevalence across groups with nearly all participants reporting at least one positive aspect. The findings of high posttrauma growth relative to stress as a result of a past childhood cancer experience are in line with those reported in other studies of childhood cancer survival (Barakat et al., 2006; Chesler, 2000; Chesler & Zebrack, 1997, Zebrack & Chesler, 2002), and are consistent with findings from other trauma groups (Tedeschi & Calhoun, 2004a, 2004b). The most highly endorsed growth category at the moderate to great level was a greater appreciation of life, where more than 70% of mothers, more than half of survivors and fathers, and almost one third of siblings reported moderate to great levels. This contrasts with spiritual change and finding new possibilities from the cancer experience which were the two least endorsed categories. While no past studies of childhood cancer survivors have investigated the domains of posttraumatic growth, findings concur with non-illness trauma. Relative to other growth categories, a greater appreciation of life is often highly endorsed by trauma survivors (Hefferon et al., 2009; Morris et al., 2005; Schroevers & Teo, 2008; Shakespeare-Finch & Enders,

2008), with spiritual change likely to be endorsed at lower levels (Morris et al., 2005; Shakespeare-Finch & Elders, 2008).

In summary, the findings of Study 1A show few cases of current PTSD, while prevalence of self-reported posttraumatic growth was high. While this indicates that most family members may function well psychosocially, prevalence of partial PTSD, and indeed clinical levels of both PTSS and psychological distress, implies a psychosocial burden may be carried by a considerable subset across all family members - including siblings - for many years after a childhood cancer 'cure'. This is particularly true for mothers, who seem to be the most vulnerable family group to develop traumatic stress responses following a childhood cancer experience, and for survivors where nearly one quarter reported moderate to severe levels of depression. Study 1B will now investigate whether the differences shown between family groups are statistically important.

3.2. Study 1B

Family Group Comparisons of PTSD, PTSS, Psychological Distress and Posttraumatic Growth

3.2.0 Overview

Study 1B aims to provide family group comparisons on prevalence and severity of PTSD, PTSS, psychological distress, and posttraumatic growth. As reviewed above, parents consistently report higher prevalence and severity of PTSD and PTSS than survivors (see sections 1.2.3), and evidence of comorbidity suggests psychological distress will share a similar pattern (reviewed in section 1.2.4). Similarly, there is evidence that indicates posttraumatic growth and posttraumatic stress also share a positive relationship (Cadell et al., 2003; Helgeson et al., 2006). Consistent with this view, mothers are reported to endorse higher numbers of posttraumatic growth items than survivors and fathers (Barakat et al., 2006).

With the inclusion of fathers and siblings to the investigation, Study 1B will both contribute to and expand current knowledge on the long-term family impact of childhood cancer. As no studies have compared long-term adjustment in siblings to other family members, hypotheses will be based on the assumption that siblings may be protected to some extent from some of the worst aspects of the cancer experience. For example, siblings do not endure painful and invasive treatments themselves, and are less likely to be involved in the bedside care and decision making process (Alderfer et al., 2003). Based on this assumption and the evidence to date, Study 1B will test the following set of hypotheses:

- *Hypothesis 1: Parents versus Survivors and Siblings:*
  Compared to survivors and siblings, more parents will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Psychological Distress, and Posttraumatic Growth.

- *Hypothesis 2: Mothers versus Fathers:*
  Compared to fathers, more mothers will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Psychological Distress and Posttraumatic Growth.

- *Hypothesis 3: Survivors versus Siblings:*
  Compared to siblings, more survivors will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Psychological Distress and Posttraumatic Growth.

3.2.1 Method

3.2.1.1 Statistical Analyses[25]

Using SPSS for windows, version 15, differences between groups (survivors, mothers, fathers and siblings) on subscale and full-scale scores were compared via standard applications of univariate analysis of variance techniques (ANOVA) with cohort type treated as a between groups variable with 4 levels (mother, father, survivor, sibling). For hypothesis testing there were 3apriori planned contrasts (contrast 1: *'parents'* versus *'survivors and siblings'*; contrast 2: *'mothers'* versus *'fathers'*; contrast 3: *'survivors'* versus *'siblings'*). Chi-square analyses were used to test for differences in non-parametric data including PTSD diagnosis and symptomatology as assessed by the SCID, and the categorical classification of 'high' and 'low' scorers on the self-report measures. Due to comparisons requiring multiple analyses, the conservative alpha level of $p \leq .01$ was applied.

3.2.2 Results

Note: Table 3.1 provides a full summary of the percentage of respondents meeting SCID-PTSD criteria by group. Table 3.2 summarises the full-scale and sub-scale mean scores for each group and statistical results of the ANOVA comparisons. Table 3.2 also summarises the percentages of respondents meeting moderate or above criteria for the IES-R, DASS-21 and PTGI. Table 3.3 summarises the results of the non-parametric Chi-square comparisons between groups for all four measures.

3.2.2.1 Hypothesis 1: Parents versus Survivors and Siblings:

"Compared to survivors and siblings, more parents will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Psychological Distress and Posttraumatic Growth."

Posttraumatic Stress (SCID): Parent and Survivor Comparisons: As expected, criterion A (defining a "traumatic event") was met by significantly more mothers and fathers than survivors ($p < .001$). Also as expected, significantly more mothers than survivors met B and D-symptom criteria since diagnosis ($p \leq .001$). Contrary to expectations, parents and survivors did not differ significantly on any other SCID diagnostic category either since diagnosis or current ($p > .01$; see Tables 3.1 and 3.3).

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[25] Assumption testing: Homogeneity of variance showed some violations for between group comparisons. In such cases, non-parametric statistical tests were also conducted, but will be reported only if differing from standard parametric treatments of the data.

Posttraumatic Stress (SCID): Parent and Sibling Comparisons: As expected, criterion A was met by significantly more mothers and fathers than siblings ($p < .001$). Also as expected, significantly more mothers than siblings met full DSM-IV criteria for PTSD and the 3 symptom clusters since diagnosis ($p = .001$), as well as current B ($p = .001$) and D-symptom criteria ($p = .010$). Similarly, significantly more fathers than siblings met criteria for current B-symptomatology ($p = .009$). Contrary to expectations, parents and siblings did not differ significantly on any other SCID diagnostic category either since diagnosis or current ($p > .01$; see Tables 3.1 and 3.3).

Posttraumatic Stress (IES-R): As expected, ANOVA confirmed significant main effects between groups for scores on the *Intrusion* scale, however contrary to expectations, no difference was revealed for the other IES-R scales. Planned contrasts further confirmed this finding: parents endorsed significantly higher scores on *Intrusion* than survivors and siblings ($p = .002$), but no differences were found for *Avoidance* ($p = .870$), *Hyper-arousal* ($p = .064$), or *full-scale IES-R* ($p = .063$)[26] (see Table 3.2). Also contrary to expectations was the finding of no significant difference between parents and survivors, or parents and siblings on prevalence of moderate to severe PTSS ($p > .01$, see Tables 3.2 and 3.3).

Psychological Distress (DASS-21): Contrary to expectations, ANOVA showed no significant main effects between groups on scores for any of the DASS-21 scales (see Table 3.2). Similarly, planned contrasts revealed no significant difference between parents and survivors/siblings for *Depression* ($p = .514$), *Anxiety* ($p = .283$), *Stress* ($p = .022$), or *full-scale DASS-21* ($p = .085$)[27]. Also contrary to expectations, prevalence of moderate to severe *Depression*, *Anxiety*, or *Stress* did not differ significantly between survivors and mothers or fathers, nor did they differ significantly between siblings and mothers or fathers ($p > .01$, see Tables 3.2 and 3.3)

Posttraumatic Growth: As expected ANOVA revealed significant main effects on all scale scores of the PTGI. Planned contrasts revealed that parents scored significantly higher than survivors and siblings on most PTGI scales ($p < .001$), except *New Possibilities,* where contrary to expectations, no significant difference was found despite a trend in the expected direction ($p = .035$; see Table 3.2). Similarly, as expected, prevalence of moderate to great posttraumatic growth showed significantly higher rates for mothers than survivors and siblings for *Relating to Others*, *Personal Strength*, *Spiritual Change*, and *Appreciation of Life* ($p \leq .002$). More mothers than siblings also met

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[26] Mann-Whitney U tests revealed that Sibling scores ranked significantly lower than Mothers scores for Intrusion ($z = 2100.00$, $p < .001$); Hyper-arousal ($z = 2247.50$, $p < .001$), and full-scale IES-R ($z = 2378.00$, $p = .006$).

[27] The Mann-Whitney U tests revealed that Survivors scores ranked significantly higher than Mothers and Fathers scores on the Anxiety subscale ($z = 7752.50$, $p = .002$; $z = 5033.00$, $p = .003$); and Siblings scores ranked significantly higher than Mothers and Fathers scores on the Stress subscale ($z = 2466.00$, $p = .005$; $z = 1482.50$, $p = .001$).

moderate to great prevalence for *full-scale PTGI* ($p < .001$). Contrary to expectations, prevalence rates did not differ between mothers and survivors, and mothers and siblings for *New Possibilities*, and between fathers and survivors, or fathers and siblings on any PTGI category ($p > .01$; see Tables 3.2 and 3.3).

3.2.2.2 Hypothesis 2: Mothers versus Fathers:

"Compared to fathers, more mothers will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Posttraumatic Growth, and Psychological Distress."

Posttraumatic Stress (SCID): Contrary to expectations, prevalence rates on criterion A did not significantly differ between mothers and fathers ($p = .947$). Similarly, prevalence rates between mothers and fathers did not significantly differ for any of the PTSD or PTSS diagnostic categories ($p > .01$; see Tables 3.1 and 3.3).

Posttraumatic Stress (IES-R): Contrary to expectations, planned contrasts revealed no significant difference between scores for mothers and fathers on any of the IES-R scales: *Intrusion* ($p = .319$), *Avoidance* ($p = .875$), *Hyper-arousal* ($p = .479$), and *full-scale IES-R* ($p = .506$) (see Table 3.2). Also contrary to expectations was the finding of no significant difference between mothers and fathers on prevalence of moderate to severe PTSS ($p = .517$, see Table 3.3).

Psychological Distress (DASS-21): Contrary to expectations, planned contrasts revealed that mothers and fathers did not differ on scores for any of the DASS-21 scales: *Depression* ($p = .918$), *Anxiety* ($p = .348$), *Stress* ($p = .323$), and *full-scale DASS-21* ($p = .463$), nor did they differ on prevalence of moderate to severe psychological distress ($p > .01$; see Tables 3.2 and 3.3).

Posttraumatic Growth: As expected, planned contrasts confirmed mothers scored significantly higher than fathers on *Personal Strength* ($p < .001$) and *Spiritual Change* ($p = .002$). Mothers, compared to fathers, also scored higher on full-scale PTGI, although just outside of the .01 significance level ($p = .012$). Contrary to expectations, scores did not significantly differ on the other PTGI scales: *Relating to Others* ($p = .235$), *New Possibilities* ($p = .211$), and *Appreciation of Life* ($p = .045$). As expected prevalence of moderate to great posttraumatic growth was significantly higher for mothers than fathers for *Personal Strength*, *Appreciation of Life*, and *full-scale PTGI* ($p \leq .006$), however contrary to expectations, prevalence did not differ between mothers and fathers for *Relating to Others*, *New Possibilities*, and *Spiritual Change* ($p > .01$; see Tables 3.2 and 3.3).

3.2.2.3 Hypothesis 3: Survivors versus Siblings:

"Compared to siblings, more survivors will have responded to the childhood cancer experience as traumatic, and will show higher severity and greater prevalence of PTSD, PTSS, Posttraumatic Growth and Psychological Distress."

Posttraumatic Stress (SCID): Contrary to expectations, prevalence rates on criterion A did not significantly differ between survivors and siblings ($p = .434$). Similarly, prevalence rates between survivors and siblings did not significantly differ for any of the PTSD or PTSS diagnostic categories ($p > .01$; see Tables 3.1 and 3.3).

Posttraumatic Stress (IES-R): Contrary to expectations, planned contrasts revealed no significant difference between scores for survivors and siblings on any of the IES-R scales: *Intrusion* ($p = .041$), *Avoidance* ($p = .047$), *Hyper-arousal* ($p = .078$)[28], and *full-scale IES-R* ($p = .039$) (see Table 3.2). Also contrary to expectations was the finding of no significant difference between survivors and siblings on prevalence of moderate to severe PTSS according to the IES-R ($p = .118$; see Tables 3.2 and 3.3).

Psychological Distress (DASS-21): Contrary to expectations, planned contrasts revealed that survivors and siblings did not differ on scores for any of the DASS-21 scales: *Depression* ($p = .022$), *Anxiety* ($p = .070$), *Stress* ($p = .376$), and *full-scale DASS-21* ($p = .268$) (see Table 3.2). As expected, prevalence of moderate to severe *Depression* was significantly greater for survivors than siblings ($p = .004$), although contrary to expectations, no significant difference was found for *Anxiety* or *Stress* ($p > .01$; see Tables 3.2 and 3.3).

Posttraumatic Growth: As expected, planned contrasts confirmed that survivors scored significantly higher than siblings on most PTGI scales ($p \leq .005$), with the exception of *Spiritual Change*, where no significant difference was found ($p = .032$) (see Table 3.2). Also as expected, prevalence rates for moderate to great posttraumatic growth were significantly higher for survivors than siblings for *New Possibilities* ($p = .005$). Contrary to expectations prevalence rates did not differ for any other PTGI scale ($p > .01$; see Tables 3.2 and 3.3).

3.2.3 Discussion

Study 1B provides comparative data between survivors, mothers, fathers and siblings on each of the outcome measures (PTSD, PTSS, psychological distress, posttraumatic growth), and is the first study to include all four family groups in comparative analyses. Findings indicate that

[28] The Mann-Whitney U test revealed that Survivors scores ranked significantly higher than Siblings scores for the Hyper-arousal subscale ($z = 4127.00$, $p = .001$).

parents, particularly mothers, were more likely to report a traumatic response (stress or growth) at some time-point following a childhood cancer experience relative to survivors and siblings. This is in contrast to psychological distress where few differences between the groups were confirmed.

In line with hypotheses, both mothers and fathers were more likely than survivors or siblings to respond to the childhood cancer experience as traumatic (DSM-IV PTSD criterion A). Correspondingly, results show that since diagnosis, mothers are more likely to report greater prevalence of PTSD and the symptom clusters than siblings, while for survivors this was confirmed for the B and D-symptoms only. These findings accord with earlier data indicating that parents, particularly mothers, have higher rates of PTSD and PTSS than survivors (see Table 1.1). However, contrary to predictions and earlier findings (e.g., Kazak et al., 2004a, Ozono et al., 2007), prevalence of PTSD or PTSS since diagnosis did not differ between fathers and survivors, nor was any difference confirmed between fathers and siblings. For current symptomatology, only rates of the B-symptom cluster, and the corresponding self-reported intrusion symptoms (as measured by the IES-R) generally revealed any parent and survivor/sibling distinction.

Furthermore and contrary to predictions, analyses did not confirm any differences between mothers and fathers, and between survivors and siblings on severity or prevalence of PTSD and PTSS. This was despite data showing a consistent trend for mothers to report higher severity and prevalence rates than fathers, and survivors to report higher severity and prevalence rates than siblings. The low severity and prevalence of PTSD and PTSS reported by this Australian study relative to past research (see Table 1.1) may account for these results and may show that these differences in statistical terms are likely to be small and difficult to confirm, at least by smaller single institutional studies.

The current PTSD and PTSS data also alludes to some interesting trends that break from the consistent findings shown in Table 1.1. Although not statistically significant, data does indicate a tendency for current avoidance symptoms (as measured by the SCID and the IES-R) to be met by more survivors than parents. There is also an indication that fathers report lower current PTSD and the C and D symptom clusters than survivors. As survivor and family cohorts begin to age and move further away from the treatment period, psychological risk profiles may begin to alter thereby having potential clinical significance. Further investigation with longer survivor cohorts is warranted.

Little differences were confirmed between groups with regard to psychological distress despite data showing survivors consistently report higher severity and prevalence than parents and siblings. Comparisons did however confirm that more survivors meet moderate to severe levels of depression relative to siblings. With this being the only exception, the results are not congruent with predictions despite the data trend showing that, as discussed in Study 1A, psychological distress

shows a different pattern of distribution between family groups than the trauma outcomes, and this likely reflects the unique stressors faced by the survivor group (Marsland et al., 2006; Patenaude & Kupst, 2005).

Findings confirmed predictions that parents report greater strength of posttraumatic growth following a childhood cancer experience relative to survivors and siblings, and mothers report greater prevalence of moderate to great levels of growth than survivors and siblings. This was true for all categories of growth except for gaining new possibilities following a childhood cancer experience suggesting that this element of growth is reported at similar levels. Against predictions however, no differences were confirmed between fathers and survivors or siblings on prevalence rates of posttrauma growth. These findings show similarities with PTSD and PTSS since diagnosis (rather than current posttraumatic stress symptomatology), and lend support to the argument that following the experience of trauma, posttraumatic growth takes time to emerge (Tedeschi & Calhoun, 1995). In contrast, PTSD often dissipates with increasing time since trauma (Jurbergs et al., 2009; Yule, 2001). For families of childhood cancer survivors, this is in line with a reduction in associated stressors such as a declining chance of relapse, and, particularly for parents, survivors who are old enough to assume greater responsibility for their own health care needs (Goodenough et al., 2008).

Contrary to PTSD and PTSS findings, posttraumatic growth comparisons between mothers and fathers, and survivors and siblings generally supported data trends and expectations. While no differences were confirmed for PTSD and PTSS comparisons, mothers report greater strength and greater prevalence of posttraumatic growth relative to fathers, and survivors generally report greater strength of growth than siblings. Specifically mothers are more likely to report greater personal strength, spiritual change and appreciation of life than fathers following their childhood cancer experience, while survivors report greater strength of growth in all areas except spiritual change where little difference was confirmed.

In summary, the findings of Study 1B show that relative to survivors and siblings more parents report a traumatic response following a childhood cancer experience. Specifically, it is mothers who report a higher prevalence of PTSD and PTSS since diagnosis than survivors and siblings and in line with this, a higher prevalence and severity of posttrauma growth. Psychological distress shows a different profile of responses to the trauma outcomes with survivors reporting higher severity and prevalence relative to other family groups, however these differences were generally not confirmed at a statistical level, perhaps highlighting problems associated with smaller single institutional studies.

Although few differences were confirmed between mother and father, and survivor and sibling severity and prevalence of PTSD and PTSS, there does seem to be a consistent pattern indicating that mothers are most at risk, and siblings least at risk for developing a traumatic response (stress and growth) to the childhood cancer experience. This lends support to the argument that siblings are more likely to be protected from the worst aspects of the experience in comparisons to survivors and parents (Alderfer et al., 2003). Nonetheless, a subgroup do report clinically significant levels of posttraumatic stress and moderate to great levels of posttraumatic growth providing further evidence that siblings are not immune to a certain calibre of post-trauma responses (Alderfer et al., 2003). Study 1C will now investigate whether these trauma responses are likely to run in families.

Table 3.1. Percentage of participants meeting DSM-IV diagnostic criteria for PTSD and PTSS (since diagnosis, current, and partial)

	Survivors	**Mothers**	**Fathers**	**Siblings**
	(N = 155)	**(N = 92)**	**(N = 58)**	**(N = 48)**
SCID	**n (%)**	**n (%)**	**n (%)**	**n (%)**
A-Criterion[a,b,d,e]	72 (46.5)	76 (82.6)	48 (82.8)	18 (37.5)
Since Diagnosis				
PTSD[d]	15 (9.7)	17 (18.5)	6 (10.3)	0 (0.0)
B-Symptom Cluster[a,d]	97 (62.6)	79 (85.9)	42 (72.4)	28 (58.3)
C-Symptom Cluster[d]	25 (16.1)	23 (25.0)	10 (17.2)	1 (2.1)
D-Symptom Cluster[a,d]	42 (27.1)	45 (48.9)	17 (29.3)	6 (12.5)
Current				
PTSD	6 (3.9)	4 (4.3)	1 (1.7)	0 (0.0)
B-Symptom Cluster[d,e]	53 (34.2)	46 (50.0)	26 (44.8)	10 (20.8)
C-Symptom Cluster	14 (9.0)	6 (6.5)	3 (5.2)	(0.0)
D-Symptom Cluster	25 (16.1)	22 (23.9)	5 (8.6)	3 (6.3)
Part-Remission	9 (5.8)	12 (13.0)	5 (8.6)	0 (0.0)
Full-Remission	0 (0.0)	1 (1.1)	0 (0.0)	0 (0.0)

Note: A-Criterion =Traumatic event, B-Symptom Cluster =Intrusive Re-experiencing; C-Symptom Cluster =Avoidance; D-Symptom Cluster =Hyper-arousal.

[a] X^2 Survivors and Mothers ($p < .01$)
[b] X^2 Survivors and Fathers ($p < .01$)
[c] X^2 Survivors and Siblings ($p < .01$)
[d] X^2 Siblings and Mothers ($p < .01$)
[e] X^2 Siblings and Fathers ($p < .01$)
[f] X^2 Mothers and Fathers ($p < .01$)

Table 3.2. PTSS, posttraumatic growth, and psychological distress in childhood cancer survivors, parents, and siblings

Measure	**Survivors (N = 182)**	**Mothers (N = 109)**	**Fathers (N = 73)**	**Siblings (N = 62)**	***F (418-411)***
	M *(SD)*	**M (*SD)***	**M *(SD)***	**M *(SD)***	
IES-R					
Intrusion[a]	5.41 (6.00)	7.05 (6.67)	6.11 (6.74)	3.66 (4.68)	4.2*
Avoidance	5.50 (6.50)	4.76 (6.22)	4.61 (6.13)	3.66 (5.61)	1.4
Hyper-arousal	2.05 (3.99)	2.52 (4.45)	2.10 (4.65)	0.97 (2.98	1.9
Full-scale	12.91 (14.55)	14.35 (16.44)	12.82 (16.35)	8.28 (12.00)	2.2
DASS-21					
Depression	7.39 (9.02)	5.39 (9.04)	5.26 (8.17)	4.46 (6.81)	2.6
Anxiety	4.73 (6.78)	3.58 (7.41)	2.66 (4.91)	2.98 (5.29)	2.3
Stress	10.06 (9.46)	8.72 (8.80)	7.40 (7.84)	11.21 (7.88)	2.7
Full-scale	22.17 (22.55)	17.69 (23.14)	15.32 (18.49)	18.66 (17.31)	2.1
PTGI					
Relating to others[a,c]	9.77 (6.15)	12.53 (5.78)	11.45 (5.42)	7.31 (6.34)	11.6*
New possibilities[c]	5.79 (4.66)	5.84 (4.12)	5.03 (4.08)	3.16 (3.71)	6.6*
Personal Strength[a,b,c]	5.51 (3.91)	8.07 (3.25)	5.56 (3.41)	3.90 (3.91)	19.6*
Spiritual Change[a,b]	1.81 (2.00)	2.87 (2.19)	1.90 (2.19)	1.16 (1.80)	10.8*
Appreciation of Life[a,c]	5.10 (2.89)	6.54 (2.43)	5.70 (2.50)	3.63 (3.13)	15.7*
Full-scale[a,c]	27.66 (17.40)	35.82 (14.72)	29.64 (14.70)	19.16 (16.75)	14.4*
Measure	**n (%)**	**n (%)**	**n (%)**	**n (%)**	
IES-R (Moderate-Severe)	29 (16.3)	20 (19.0)	11 (15.3)	5 (8.2)	
DASS-21 (Moderate-Severe)					
Depression[f]	42 (23.5)	13 (11.9)	8 (11.0)	4 (6.6)	
Anxiety	28 (15.6)	11 (10.1)	6 (8.2)	5 (8.2)	
Stress	34 (19.0)	13 (11.9)	7 (9.6)	7 (11.5)	

Table 3.2. Continued

Measure	**Survivors (N = 182)**	**Mothers (N = 109)**	**Fathers (N = 73)**	**Siblings (N = 62)**	***F (418-411)***
	n (%)	**n (%)**	**n (%)**	**n (%)**	
PTGI (Moderate-Great)					
Relating to Others[d,g]	57 (31.7)	55 (50.9)	25 (34.2)	11 (17.7)	
New Possibilities[f]	48 (26.8)	26 (24.1)	14 (19.2)	6 (9.7)	
Personal Strength[d,g,i]	67 (37.2)	68 (63.0)	21 (28.8)	14 (22.6)	
Spiritual Change[d,g]	40 (22.2)	42 (39.3)	21 (28.8)	9 (14.5)	
Appreciation of Life[d,g,i]	92 (50.8)	78 (72.2)	38 (52.1)	20 (32.3)	
Full-scale[g,i]	51 (28.0)	45 (41.7)	15 (20.5)	8 (12.9)	

Note: Valid percentages used for frequency data. *$p < .01$

[a] planned contrasts: Parents and Survivors/Siblings ($p < .01$)
[b] planned contrasts: Mothers and Fathers ($p < .01$)
[c] planned contrasts: Survivors and Siblings ($p < .01$)
[d] X^2 Survivors and Mothers ($p < .01$)
[e] X^2 Survivors and Fathers ($p < .01$)
[f] X^2 Survivors and Siblings ($p < .01$)
[g] X^2 Siblings and Mothers ($p < .01$)
[h] X^2 Siblings and Fathers ($p < .01$)
[i] X^2 Mothers and Fathers ($p < .01$)

Table 3.3. Summary of Chi-Square comparisons for categorical PTSD, PTSS, psychological distress, and posttraumatic growth

Measure	Survivors and Mothers X^2 (p)	Survivors and Fathers X^2 (p)	Siblings and Mothers X^2 (p)	Siblings and Fathers X^2 (p)	Mothers and Fathers X^2 (p)	Survivors and Siblings X^2 (p)
SCID	*df = 247*	*df = 213*	*df = 140*	*df = 106*	*df = 150*	*df = 203*
A-Criterion	31.54 (.000)*	22.68 (.000)*	29.09(.000)*	22.90 (.000)*	0.00 (.981)	1.58 (.453)
Since diagnosis:						
PTSD	3.97 (.046)	0.02 (.884)	10.10 (.001)*	5.26 (.022)	1.81 (.178)	5.02 (.025)
B-Symptom Cluster	15.28 (.000)	1.80 (.180)	13.28 (.000)*	2.32 (.128)	4.13 (.042)	0.28 (.597)
C-Symptom Cluster	2.90 (.088)	0.04 (.845)	11.66 (.001)*	6.49 (.011)	1.25 (.264)	6.48 (.011)
D-Symptom Cluster	12.04 (.001)*	0.10 (.748)	18.06 (.000)*	4.37 (.037)	5.64 (.018)	4.33 (.038)
Current:						
PTSD	0.03 (.854)	0.61 (.434)	2.15 (.143)	0.84 (.361)	0.76 (.383)	1.95 (.166)
B-Symptom Cluster	5.82 (.016)	1.95 (.162)	11.18 (.001)*	6.74 (.009)*	0.38 (.537)	3.15 (.076)
C-Symptom Cluster	4.89 (.484)	0.86 (.355)	3.27 (.071)	2.26 (.110)	0.12 (.735)	4.66 (.031)
D-Symptom Cluster	2.27 (.132)	1.97 (.161)	6.71 (.010)	0.21 (.646)	5.64 (.018)	3.01 (.083)
IES-R (Moderate-Severe)	*df = 283*	*df = 250*	*df = 166*	*df = 133*	*df = 177*	*df = 239*
Full-scale	0.35 (.554)	0.04 (.843)	3.55 (.059)	1.57 (.211)	0.42 (.517)	2.44 (.118)
DASS-21 (Moderate-Severe)	*df = 288*	*df = 252*	*df = 170*	*df = 134*	*df = 182*	*df = 240*
Depression	5.84 (.016)	5.10 (.024)	1.25 (.263)	0.79 (.372)	0.04 (.841)	8.39 (.004)*
Anxiety	1.78 (.182)	2.45 (.118)	0.17 (.685)	0.00 (.996)	0.18 (.670)	2.13 (.145)
Stress	2.48 (.115)	3.37 (.067)	0.01 (.930)	0.13 (.722)	0.24 (.621)	1.82 (.178)
PTGI (Moderate-Great)	*df = 288*	*df = 253*	*df = 170*	*df = 135*	*df = 181*	*df = 241*
Relating to others	10.54 (.001)*	0.16 (.691)	18.26 (.000)*	4.67 (.031)	4.91 (.027)	4.43 (.035)
New possibilities	0.27 (.607)	1.63 (.202)	5.34 (.021)	2.40 (.121)	0.61 (.436)	7.78 (.005)*
Personal Strength	17.96 (.000)*	1.64 (.201)	25.76 (.000)*	0.67 (.414)	20.38 (.000)*	4.44 (.035)
Spiritual Change	9.54 (.002)*	1.22 (.270)	11.40 (.001)*	3.94 (.047)	2.10 (.148)	1.70 (.193)
Appreciation of Life	12.78 (.000)*	0.03 (.860)	25.77 (.000)*	5.36 (.021)	7.70 (.006)*	6.41 (.011)
Full-scale	5.70 (.017)	1.52 (.218)	15.19 (.000)*	1.39 (.239)	8.77 (.003)*	5.77 (.016)

Note: A-Criterion = Traumatic event, B-Symptom Cluster = Intrusive Re-experiencing; C-Symptom Cluster = Avoidance; D-Symptom Cluster = Hyper-arousal.
*$p < .01$; df=degrees of freedom

Table 3.4. Pearson bivariate correlation coefficients between the full-scale IES-R and demographic and treatment variables

	Survivors (n=178)	**Mothers (n=105)**	**Fathers (n=72)**	**Siblings (n=61)**
Gender	0.03	-	-	-0.11
Age at participation	-0.10	-0.12	-0.02	0.13
Age at diagnosis	0.03	-0.08	0.11	0.21
Years off Treatment	-0.13	-0.05	-0.34**	-0.03
Relapse/2nd Malignancy	0.25**	0.08	0.03	0.20
Diagnosis				
Leukaemia	-0.07	-0.24*	-0.19	-0.33**
Solid Tumour	0.04	0.21*	-0.15	0.25
Lymphoma	0.04	-0.01	0.22	0.12
CNS Tumour	0.10	0.19	0.39**	0.10
Treatment				
Chemotherapy	-0.06	-0.09	-0.05	0.08
Radiotherapy	-0.06	0.10	-0.01	-0.08
Cranial	0.01	-0.02	0.06	-0.13
Total body	0.01	-0.02	0.03	-0.12
Surgical resection	0.04	0.25**	0.16	0.14
Transplant	0.07	-0.04	-0.06	-0.03
Living with parent	0.18*	-	-	-0.13
Relationship status	-0.21**	0.12	0.08	0.13
Education level	-0.10	-0.15	0.01	-0.12
Employment Status	-0.18*	-0.02	0.00	-0.11
Household income	-0.16	0.02	0.04	-0.21
Personal Income	-0.13	0.12	-0.07	-0.07
Cultural Identity	-0.01	0.26**	0.20	-0.11

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2
**p < .05, ** p < .01*

Table 3.5. Pearson bivariate correlation coefficients between the full-scale DASS-21 and demographic and treatment variables

	Survivors (n=179)	**Mothers (n=109)**	**Fathers (n=73)**	**Siblings (n=61)**
Gender	0.14	-	-	-0.09
Age at participation	-0.08	-0.31**	0.01	0.37**
Age at diagnosis	-0.11	-0.25*	0.13	0.17
Years off Treatment	0.00	-0.06	-0.21	0.21
Relapse/2nd Malignancy	0.04	-0.09	-0.09	0.21
Diagnosis				
Leukaemia	-0.00	-0.14	-0.09	-0.13
Solid Tumour	0.04	0.20*	-0.12	0.20
Lymphoma	-0.05	-0.04	0.14	-0.07
CNS Tumour	0.09	-0.03	0.28*	0.03
Treatment				
Chemotherapy	0.06	0.05	0.01	0.14
Radiotherapy	-0.06	0.00	-0.01	0.04
Cranial	0.06	-0.07	0.00	-0.06
Total body	0.01	-0.08	0.07	-0.05
Surgical resection	0.06	0.18	0.13	0.25
Transplant	0.00	-0.06	-0.01	-0.09
Living with parent	0.25**	-	-	-0.15
Relationship status	-0.19*	-0.12	-0.07	0.17
Education level	-0.00	-0.15	-0.21	-0.25
Employment Status	-0.04	-0.07	-0.11	0.07
Household income	-0.07	-0.09	0.01	-0.24
Personal Income	-0.10	-0.08	-0.17	-0.01
Cultural Identity	0.03	0.09	0.09	-0.16

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2
**p < .05, ** p < .01*

Table 3.6. Pearson bivariate correlation coefficients between the full-scale PTGI and demographic and treatment variables

	Survivors (n=182)	**Mothers (n=108)**	**Fathers (n=73)**	**Siblings (n=62)**
Gender	0.03	-	-	0.14
Age at participation	-0.02	0.07	-0.15	0.07
Age at diagnosis	0.25**	0.03	0.02	0.49**
Years off Treatment	-.013	-0.02	-0.27*	-0.30*
Relapse/2nd Malignancy	-0.02	-0.01	-0.10	0.34**
Diagnosis				
Leukaemia	-0.04	-0.17	-0.28*	-0.27*
Solid Tumour	-0.01	0.14	-0.06	0.17
Lymphoma	0.06	-0.04	0.31**	0.16
CNS Tumour	0.07	0.06	0.21	0.12
Treatment				
Chemotherapy	0.01	0.04	0.00	-0.02
Radiotherapy	0.02	0.10	-0.22	-0.19
Cranial	0.07	0.04	-0.23	-0.18
Total body	0.04	0.05	-0.08	-0.12
Surgical resection	0.05	0.13	0.26*	0.34**
Transplant	0.08	0.07	-0.05	-0.02
Living with parent	0.01	-	-	-0.21
Relationship status	-0.00	0.07	0.10	0.02
Education level	-0.01	-0.20*	-0.21	-0.13
Employment Status	-0.16*	-0.08	0.13	-0.08
Household income	-0.08	-0.22*	-0.07	-0.20
Personal Income	-0.07	-0.07	-0.12	-0.09
Cultural Identity	0.02	-0.03	0.03	-0.12

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2
**p < .05, ** p < .01*

3.3. Study 1C

Post-Hoc Investigation: Family Relationships and Concordance on the Trauma Outcomes (PTSD, PTSS, and Posttraumatic Growth) in Full Family Units.

3.3.0 Overview

Study 1C aims to further the family understanding of the traumatic impact of childhood cancer by investigating full participating family groups on prevalence, relationships, and concordance of PTSD, PTSS, and posttraumatic growth.

To date, most investigations of posttraumatic stress and posttraumatic growth in family members have been derived from an individual group, rather than a family systems level. While there is some indication that parental symptoms are positively related (Ozono et al., 2007; Stuber et al., 1994b; 1996), and an association exists between survivors and at least one parent (Barakat et al., 1997; Ozono et al., 2007; Phipps et al., 2005; Stuber et al., 1996), little is known as to whether rates of posttraumatic stress and posttraumatic growth cluster within families – i.e., if PTSD, PTSS or posttraumatic growth is evident in one family member, what is the likelihood of another family members also qualifying for the same disorder, symptom or growth outcome? One investigation has looked at this directly with regard to posttraumatic stress (Kazak et al., 2004a). Although siblings were not included in that study, there was little evidence to support family concordance on rates of the disorder, but some evidence to indicate concordance may occur at a symptom level. No investigation has examined whether posttraumatic growth clusters within families.

As recruitment criteria for Study 1 were not contingent upon full family participation, no planned family-unit related hypotheses are articulated and relevant analyses are presented as post-hoc exploration.

3.3.1 Method

3.3.1.1 Participants

In order to investigate relationships between family PTSS and posttraumatic growth, the issue of family concordance, and to include siblings in the family unit assessment, the data from the IES-R, SCID, and PTGI were investigated in analyses admitting only families who had a representative from each of the four groups. 31 full families units completed the IES-R, 30 completed the PTGI, and 20 completed the SCID. Demographic and treatment details are presented in Table 3.7. As no data was collected on whether the full family units currently live together, this was not a selection criterion.

3.3.1.2 Statistical Analyses[29]

Using SPSS for windows, version 15, relationships between family IES-R and PTGI scale scores, and relationships between the self-report measures (IES-R, PTGI) and the demographic and treatment variables[30] were investigated using Pearson Bivariate correlation. Hierarchical Multiple Regression Analyses were also conducted to further test the question of symptom/outcome relationships between family members. However, due to the current inadequate sample size required for these analyses (Tabachnick & Fiddel, 2001), these analyses are regarded as exploratory. Accordingly, there were four models for each family member for the IES-R scales (Intrusion, Avoidance, Hyper-arousal, full-scale IES-R), and six models for each family member for the PTGI scales (Relating to Others, New Possibilities, Personal Strength, Spiritual Change, Appreciation of Life, full-scale PTGI). 2 Steps were included for each model: At Step 1, the demographic and treatment variables found to correlate significantly with IES-R and PTGI full-scale scores were entered. These are outlined in Tables 3.11 and 3.13 respectively[31]. At Step 2, the corresponding scale score for the three remaining family members were entered. The alpha level of $p \leq .05$ was applied for these analyses.

The alpha level of $p \leq .05$ was applied for these analyses.

As very little is known about expected levels of family concordance on the trauma outcomes, this assessment remained descriptive.

3.3.2 Results

3.3.2.1 Relationships between Family PTSS and Posttraumatic Growth

A. Pearson Bivariate Correlational Analyses

Results of the correlational analyses are summarised in Table 3.10. As shown, all correlations were in the positive direction.

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[29] Group comparisons between survivors and siblings, and mothers and fathers on the demographic variables were conducted in the same manner as that described in Chapter 2. Survivors relative to siblings were more likely to be living with parents, not in a meaningful relationship, and receive help in completing Questionnaire Booklet (Part 1). Fathers, relative to mothers were more likely to be in full-time employment and to earn a higher personal income. Group comparisons were also conducted on the outcome measures in the same manner as that described in Chapter 3, Study 1B. In general results showed similarities to those from the larger cohort reported in Study 1B. For example, few differences were revealed between the groups on the SCID, and the IES-R, although on the PTGI parents report higher levels than survivors and siblings. Appendix 3A summarises these findings.

[30] Some categorical demographic variables pose difficulty in coding as a continuous variable (Relationship Status, Education Level, Employment Status). In these cases one-way ANOVA's were also conducted but will be reported only if differing from the correlational results.

[31] One-way ANOVA revealed Survivor IES-R and PTG scores significantly differed according to Employment Status: not employed (M = 18.8, SD = 17.2; M = 35.5, SD = 14.8), part-time (M = 4.6, SD = 5.1; M = 18.7, SD = 12.2), full-time (M = 10.1, SD =8.8; M = 27.6, SD = 11.5). $F(2,28)$ = 4.06, p = .028, $F(2,28)$ = 4.16, p = .026 respectively.

Posttraumatic Stress (IES-R): Survivor and father IES-R scores were most strongly correlated showing significant positive relationships across all scales (r = 0.54 to 0.79, p < .01). Survivor and mother scores were significantly correlated for *Hyper-arousal* (r = 0.61, p = <.001) and *full-scale IES-R* (r = 0.39, p = .034) only.

Correlations between mothers and siblings IES-R scores were also strong and consistent across all scales (r = 0.37 to 0.55, p < .05), although correlations between fathers and siblings were significant for *Avoidance* (r = 0.41, p = .026), and *full-scale IES-R* (r = 0.39, p = .033) only.

Mothers and fathers IES-R scores were significantly correlated for *Intrusion* (r = 0.43, p = .019), *Hyper-arousal* (r = 0.75, p < .001), and *full-scale IES-R* (r = 0.50, p = .005). No significant relationships were revealed between survivors and siblings.

Posttraumatic Growth (PTGI): Survivor and mother PTGI scores shared significant correlations across most scales with the exception of *Personal Strength* and *Spiritual Change* which were non-significant (r = 0.31, p = .091; r = 0.33, p = .071 respectively). Similarly, survivor and father scores share significant correlations for all but *New Possibilities* and *Appreciation of Life* (r = 0.31, p = .091; r = 0.33, p = .071 respectively).

Correlations between siblings and parents showed that across all PTGI scales, siblings and fathers scale scores were most strongly correlated (r = 0.40 to 0.65, p < .05) relative to siblings and mothers where only *Personal Strength* showed a significant relationship (r = 0.44, p = .015).

Mothers and fathers PTGI scores were significantly correlated for *Relating to Others* (r = 0.41, p = .023), and *Spiritual Change* (r = 0.38, p = .041) only, while survivors scores were most strongly correlated with the corresponding siblings score for most PTGI scales. The exception to this was *New Possibilities* and *Appreciation of Life* where this relationship was non-significant (r = 0.35, p = .104; r = 0.35, p = .061 respectively).

B. Exploratory Hierarchical Multiple Regression Analyses:

Results of the hierarchical regression analyses are summarised in Table 3.12 for posttraumatic stress and 3.14 for posttraumatic growth.

Posttraumatic Stress (IES-R): With the exception of the *Avoidance* models for mothers and siblings, the full models were significant explaining between 17 to 71% of the variance of PTSS severity. The corresponding family scores entered at Step 2 collectively predicted PTSS severity at a significant level over and above that of the demographic and treatment variables entered at Step 1 for all but three of the prediction models. With the exception of the *Intrusion* model for survivors (*F*

change = 2.43, R^2 *change* = 0.20, *p* = .095), and the *Avoidance* models for mothers (*F change* = 1.31, R^2 *change* = 0.13, *p* = .294), and siblings (*F* = 2.80, R^2 = 0.16, *p* = .060), Step 2 collectively and significantly explained between 17 to 47% of the variance.

Survivors: The full models reveal that survivors with a low household income are more likely to report higher severity of *Intrusion, Avoidance, Hyper-arousal* and *full-scale IES-R* symptoms. Survivors who also have both a mother and father with a high corresponding IES-R scale score are more likely to report higher *Avoidance* and *full-scale IES-R* severity.

Mothers: The full models reveal that mothers with a child diagnosed with a CNS tumour, and a non-diagnosed child (sibling) with a high corresponding IES-R scale score are more likely to report higher *Hyper-arousal* and *full-scale IES-R* severity. Mothers with a non-diagnosed child (sibling) with a high corresponding IES-R *Intrusion* scale score are more likely to report higher *Intrusion* severity.

Fathers: The full models reveal that fathers with a child diagnosed with a CNS tumour and a survivor with a high corresponding scale score are more likely to report higher severity of *Intrusion, Avoidance, Hyper-arousal* and *full-scale IES-R* symptoms.

Siblings: The full models reveal the siblings with a mother with a high corresponding IES-R scale score are more likely to report higher *Intrusion, Hyper-arousal,* and *full-scale IES-R* severity

Posttraumatic Growth (PTGI): For survivors the full *Personal Strength* model was able to explain 38% of the variance in the PTGI scales score, with the corresponding family scores entered collectively at Step 2 accounting for 34% of this variance. No other survivor model was significant. For mothers, the full *New Possibilities* and *Appreciation of Life* models were able to significantly explain 23 and 21% of the variance in the respective PTGI scale score, although collectively the corresponding family scores entered at Step 2 did not significantly contribute to the prediction models (*F change* = 1.52, R^2 *change* = 0.12, *p* = .234; *F change* = 0.94, R^2 *change* = 0.08, *p* = .437 respectively). No other mother model showed significance.

For fathers and siblings, each of the full models were significant explaining between 23 to 60% of the variance of PTGI strength, however Step 2 contributed at a significant level for only half of these prediction models. For fathers, these were the *New Possibilities* model (*F change* = 3.04, R^2 *change* = 0.24, *p* = .050), the *Spiritual Change* model (*F change* = 3.46, R^2 *change* = 0.27, *p* = .033), and the *full-scale PTGI* model (*F change* = 4.47, R^2 *change* = 0.27, *p* = .014). For sibling, these were the *Personal Strength* model (*F change* = 4.72, R^2 *change* = 0.22, *p* = .011), the *Appreciation of Life* model (*F change* = 3.38, R^2 *change* = 0.18, *p* = .036), and the *full-scale PTGI* model (*F change* = 4.43, R^2 *change* = 0.19, *p* = .014).

Survivors: The full models reveal that survivors with a higher personal income are more likely to score higher on the PTGI scale of *New Possibilities.* No other model had individual variables contribute at a significant level.

Mothers: The full models reveal that mothers whose child's diagnosis did not include leukaemia are more likely to score higher on the PTGI scales of *New Possibilities, Appreciation of Life,* and *full-scale PTGI.* Mothers who also have a survivors with a high corresponding PTGI scale score are also more likely to score higher on *New Possibilities.* No other model (*Relating to Others, Personal Strength, Spiritual Change)* had individual variables contribute at a significant level.

Fathers: The full models reveal that fathers who have a non-diagnosed child (sibling) with a high corresponding PTGI scale score are more likely to score higher on *New Possibilities, Appreciation of Life, ,* and *full-scale PTGI.* No other model (*Relating to Others, Personal Strength, Spiritual Change)* had individual variables contribute at a significant level.

Siblings: The full models reveal that siblings who have a brother or sister who have had a relapse or second malignancy, or their brother or sisters treatment involved a surgical resection are more likely to score higher on all PTGI scales with the exception of *Spiritual Change.* Siblings who also have a father with a high corresponding PTGI scale score are also more likely to score higher on the PTGI scales of *New Possibilities, Appreciation of Life,* and *full-scale PTGI.* The full model for *Spiritual Change* reveals that siblings whose brother or sisters treatment involved a surgical resection, and have a survivor brother or sister with a high score on the corresponding PTGI scale are more likely to score higher on the PTGI scale.

3.3.2.2 Family Concordance

Table 3.15 lists the rates of concordance between family members meeting PTSD, its symptom clusters, and the DSM-IV's A-criterion according to the SCID, as well as rates of concordance between family members meeting moderate to severe PTSS according to the IES-R, and moderate to great posttraumatic growth according to the PTGI.

Posttraumatic Stress (SCID): No families had two or more members meet full PTSD criteria at any time point since diagnosis. The A-criterion was met by all members in 10% of families. Parental concordance was at 60%, followed by at least one parent and the survivor at 50%, then at least one parent and sibling at 25%, and least concordance between survivor and sibling at 15%.

From a symptom viewpoint, highest intra-family concordance was found for the B-symptom cluster of intrusive re-experiencing where 20% of families surveyed had all family members meet symptom criteria since diagnosis, and 10% of families share current criteria. Parental concordance

since diagnosis was at 65% (current concordance = 40%), followed by 50% concordance between at least one parent and the survivor (current concordance = 15%), 50% between at least one parent and a sibling (25% current concordance), and 35% between survivor and sibling (15% current concordance). Concordance, both since diagnosis and current, on the C and D-symptom clusters were much lower or non-existent (range = 0 to 15%).

Posttraumatic Stress (IES-R): No families surveyed had all members meet moderate to severe levels of PTSS. However parental concordance was reported at 6.5 %, with the same rate of concordance by at least one parent and the survivor. Only 3.2% of families had both a parent and sibling meet the moderate to severe category, with no families reporting concordance between survivor and sibling.

Posttraumatic Growth (Family Concordance): Appreciation of Life had the highest concordance rates, being met by all members in 17% of families. Parental concordance was at 50%, followed by at least one parent and the survivor at 43%, at least one parent and a sibling at 27%, and survivor and sibling at 20%.

Having both parents in a family meet moderate to great posttraumatic growth was most common: *Relating to Others* (23%), *Spiritual Change* (20%), *Appreciation of Life* (50%), and *full-scale PTGI* (17%), however family concordance was highest for at least one parent and the survivor for *New Possibilities* (13%) and *Personal Strength* (30%). Relatively low concordance rates were found across most family categories for *Relating to Others* (3 to 23%), *New Possibilities* (3 to 13%), *Spiritual Change* (0 to 20%), and *full-scale PTGI* (3.3 to 17%).

3.3.3 Discussion

Study 1C investigated participating full family units on the relationship and concordance of posttraumatic stress symptoms and posttraumatic growth outcomes. Results show that these symptoms and outcomes do share positive relationships between family members. Family concordance of posttraumatic stress shows that 60% of families had both parents respond to the childhood cancer experience as traumatic, and half of the families had a parent and a survivor meet this criterion, however concordance rates were generally low with the exception of intrusive symptomatology. Family concordance of posttraumatic growth was highest for a greater appreciation of life and personal strength following the childhood cancer experience. Findings contribute to a family systems understanding of the traumatic impact of childhood cancer.

Relationship analyses revealed that an association exists between family members on PTSS severity. The strongest of these was between survivors and fathers, while no PTSS relationship was confirmed between survivors and siblings. The exploratory regression models supported these

relationships. Results show that, in line with earlier findings (Barakat et al., 1997; Stuber et al., 1996), survivor PTSS is predicted most strongly by both mother and father PTSS. This indicates that survivors are more likely to present with increased PTSS if their mother and father also have increased PTSS. In line with this, father PTSS is predicted by survivor symptom severity. The relationship between parental and survivor PTSS was further supported by concordance data, where comparisons between family members show that 50% of families had a survivor and at least one parent respond to the childhood cancer experience as traumatic and up to 50% of families had a survivor and at least one parent meet B-symptom criteria at some time point since diagnosis (up to 15% with current symptom concordance).

Mother and sibling PTSS showed a strong and consistent relationship which was further supported by the exploratory regression models. These models revealed a reciprocal relationship whereby increased symptom severity in one, predicts increased symptom severity in the other. Family concordance rates show that one quarter of all families investigated had a sibling and at least one parent respond to the childhood cancer experience as traumatic, with up to 35% meeting the B-Symptom criteria since diagnosis (25% with current symptom concordance).

Parental PTSS is also shown to be positively related, although this was less clear in the regression analyses. Nonetheless, this relationship is supported by the high proportion of concordance reported between mothers and fathers. Results show the highest concordance rates between mothers and fathers with up to 65% of families having both parents meeting B-symptomatology, and 60% having both parents respond to the cancer experience as traumatic. Survivor and sibling comparisons show no relationship, and data show relatively low concordance between family members. Nonetheless, concordance data still shows that up to 35% of families had both survivors and siblings meet B-symptom criteria since diagnosis (15% meeting current criteria), with 15% having both responded to the cancer experience as traumatic.

Posttraumatic growth outcomes also showed some relationship between family members, although family posttraumatic growth was shown to have little predictive influence on individual outcomes in the exploratory analysis. While the strongest relationship was between fathers and siblings, in line with posttraumatic stress, concordance data shows that growth is shared at highest rates between mothers and fathers, and lowest rates between survivors and siblings. Concordance between family members was highest for the perception of a greater appreciation of life (between 17 to 50%), and greater personal strength following the cancer experience (between 13 to 30%). For parents, spiritual change also showed relatively high concordance (20%), although this was not the case between other family members. The findings may reflect the often cited reports of closer family relationships that have stemmed from the cancer experience (Chesler & Zebrack, 1997; Zebrack &

Chesler, 2002), perhaps resulting in a degree of shared perceived psychosocial benefits or growth for some families.

Notably, results show PTSS in mothers is associated with PTSS in all other family members (survivors, fathers and siblings), supporting findings that maternal distress following childhood cancer has the most wide reaching impact on family functioning (Brown et al., 2003). This finding, along with the strong relationships between father and survivor PTSS, and high concordance rates between mothers and fathers does suggest that posttraumatic stress following childhood cancer, is shared between some families, having clinical importance with regard to screening and intervention. Evidence suggests that family functioning is associated with PTSD (Alderfer et al., 2009), and conversely PTSD is likely to affect family functioning. This further underscores the need for a family systems approach to both research and treatment. For example, it may be that reducing maternal PTSS will lead to a corresponding reduction in family distress.

With regard to posttraumatic growth, findings show that some areas of growth are shared between members in up to a half of all families. Findings may indicate that as with posttraumatic stress, a greater family benefit may be achieved by promoting growth in one family member (Antoni et al., 2001).

In summary, the findings indicate that both trauma outcomes run in families, although some symptoms or areas of growth are more likely to be shared than others. Family concordance on PTSD and PTSS is generally low with the exception of intrusive re-experiencing, according with previous findings (Kazak et al., 2004a). However, the low concordance rates may be a reflection of the low levels of PTSD and PTSS reported. Few participants qualified for a PTSD diagnosis, particularly current PTSD. Further, comparing symptom to symptom PTSS, and outcome to outcome posttraumatic growth, may be limiting. Within families, distress or growth may manifest differently between family members. With this in mind, results pertaining to full PTSS (full-scale IES-R) and posttraumatic growth (full-scale PTGI), rather than paired symptom and growth outcomes may be more informative (Phipps et al., 2005). Part 1 will now turn to investigate whether the two trauma outcomes (stress and growth) are related.

Table 3.7. Comparisons on PTSD, PTSS posttraumatic growth for full family units

Measure, M *(SD)*	**Survivors**	**Mothers**	**Fathers**	**Siblings**	***F*(87 -90)**
IES-R (n=31)					
Intrusion	5.42 (5.10)	5.26 (4.48)	6.58 (7.53)	3.33 (4.54)	2.99
Avoidance	3.42 (4.65)	3.51 (5.32)	5.13 (5.89)	2.90 (3.73)	1.36
Hyper-arousal	1.58 (3.50)	1.48 (2.91)	1.97 (5.01)	0.57 (2.22)	1.25
Full-scale	10.39 (11.71)	10.26 (11.84)	13.68 (17.28)	6.80 (9.19)	2.76
PTGI (n=30)					
Relating to Others[a]	9.07 (5.06)	12.43 (5.45)	12.13 (4.94)	6.60 (6.19)	12.26**
New Possibilities	5.00 (3.85)	5.43 (3.94)	5.43 (3.94)	3.00 (3.72)	3.41
Personal Strength[a]	5.17 (3.37)	7.80 (3.09)	5.73 (3.18)	3.50 (4.12)	14.00**
Spiritual Change[a]	1.40 (2.04)	2.97 (2.09)	2.46 (2.34)	1.07 (1.76)	8.84**
Appreciation of Life[a,c]	5.55 (2.39)	6.50 (2.03)	5.83 (2.70)	3.43 (3.13)	11.81**
Full-scale[a,c]	26.16 (14.02)	35.00 (14.23)	31.60 (13.78)	17.60 (17.04)	13.71**
Measure, % (n)					
SCID (n=20)					
A-Criterion[g,h]	55.0 (11)	75.0 (15)	75.0 (15)	30.0 (6)	
Since Diagnosis					
PTSD	5.0 (1)	20.0 (4)	20.0 (4)	0 (0)	
B-Symptom Cluster	50.0 (10)	75.0 (15)	75.0 (15)	60.0 (12)	
C-Symptom Cluster[g,h]	10.0 (2)	30.0 (6)	30.0 (6)	0 (0)	
D-Symptom Cluster[i]	25.0 (5)	35.0 (7)	25.0 (5)	15.0 (3)	
Current					
PTSD	5.0 (1)	0 (0)	0 (0)	0 (0)	
B-Symptom Cluster[d]	15.0 (3)	45.0 (9)	50.0 (10)	25.0 (5)	
C-Symptom Cluster	5.0 (1)	0 (0)	0 (0)	0 (0)	
D-Symptom Cluster	15.0 (3)	20.0 (4)	0 (0)	15.0 (3)	
IES-R (Moderate to Severe) (n=31)					
Full-scale	12.9 (4)	9.7 (3)	12.9 (4)	3.3 (1)	

Table 3.7. Continued

Measure, % *(n)*	**Survivors**	**Mothers**	**Fathers**	**Siblings**	***F*(87 -90)**
PTGI (Moderate-Great) (n=30)					
Relating to Others[g]	16.7 (5)	43.3 (13)	36.7 (11)	10.0 (3)	
New Possibilities	16.7 (5)	30.0 (9)	23.3 (7)	10.0 (3)	
Personal Strength	30.0 (9)	53.3 (16)	30.0 (9)	23.3 (7)	
Spiritual Change[g]	13.3 (4)	40.0 (12)	36.7 (11)	10.0 (3)	
Appreciation of Life[g]	53.3 (16)	73.3 (22)	56.7 (17)	26.7 (8)	
Full-scale[g]	13.3 4)	40.0 (12)	20.0 (6)	10.0 (3)	

Note: A-Criterion = Traumatic event, B-Symptom Cluster = Intrusive Re-experiencing; C-Symptom Cluster = Avoidance; D-Symptom Cluster = Hyper-arousal.

[a] planned contrasts: Parents and Survivors/Siblings ($p < .01$).
[b] planned contrasts: Mothers and Fathers ($p < .01$).
[c] planned contrasts: Survivors and Siblings ($p < .01$).
[d] X^2 Survivors and Mothers ($p < .01$)
[e] X^2 Survivors and Fathers ($p < .01$)
[f] X^2 Survivors and Siblings ($p < .01$)
[g] X^2 Siblings and Mothers ($p < .01$)
[h] X^2 Siblings and Fathers ($p < .01$)
[i] X^2 Mothers and Fathers ($p < .01$)

*$p < .05$, ** $p < .01$ Valid percentages used for frequency data

Table 3.8. Summary of ANOVA planned contrasts on PTSS and posttraumatic growth for full family units

	Parents and Survivors/Siblings	**Mothers and Fathers**	**Survivors and Siblings**
Measure	***F* (*p*)**	***F* (*p*)**	***F* (*p*)**
IES-R (n=31)	*df = 1,30*	*df =1,30*	*df = 1,30*
Intrusion	4.63 (.040)	1.08 (.308)	4.11 (.052)
Avoidance	3.56 (.069)	1.83 (.186)	0.43 (.517)
Hyper-arousal	2.78 (.106)	0.52 (.476)	2.02 (.165)
Full-scale	5.73 (.023)	1.43 (.045)	2.47 (.127)
PTGI (n=30)	*df = 1,29*	*df = 1,29*	*df = 1,29*
Relating to others	28.78 (.000)*	0.09 (.773)	4.70 (.039)
New possibilities	3.41 (.024)	0.53 (.892)	5.98 (.021)
Personal Strength	26.44 (.000)*	8.73 (.231)	6.74 (.015)
Spiritual Change	20.75 (.000)*	1.21 (.280)	0.92 (.334)
Appreciation of Life	20.09 (.000)*	1.68 (.206)	12.85 (.001)*
Full-scale	32.52 (.000)*	1.28 (.268)	9.02 (.005)*

*$p < .01$; df=degrees of freedom

Table 3.9. Summary of chi-square comparisons for categorical PTSD and posttraumatic growth for full family units

Measure	Survivors and Mothers X^2 (*p*)	Survivors and Fathers X^2 (*p*)	Siblings and Mothers X^2 (*p*)	Siblings and Fathers X^2 (*p*)	Mothers and Fathers X^2 (*p*)	Survivors and Siblings X^2 (*p*)
SCID (n=20)	*df = 40*	*df = 40*	*df = 40*	*df = 40*	*df = 40*	*df = 40*
A-Criterion	1.76 (.185)	1.76 (.185)	8.12 (.004)*	8.12 (.004)*	0.00 (1.00)	2.56 (.110)
Since diagnosis:						
PTSD	2.06 (.151)	2.06 (.151)	4.44 (.035)	4.44 (.035)	0.00 (1.00)	1.03 (.311)
B-Symptom Cluster	2.67 (.102)	2.67 (.102)	1.03 (.311)	1.03 (.311)	0.00 (1.00)	0.40 (.525)
C-Symptom Cluster	2.50 (.114)	2.50 (.114)	7.06 (.008)*	7.06 (.008)*	0.00 (1.00)	2.11 (.147)
D-Symptom Cluster	0.48 (.490)	0.00 (1.00)	2.13 (.144)	0.63 (.429)	0.48 (.490)	0.63 (.429)
Current:						
PTSD	1.03 (.311)	1.03 (.311)	[a]	[a]	[a]	1.03 (.311)
B-Symptom Cluster	2.29 (.004)*	5.58 (.018)	1.76 (.185)	2.67 (.102)	0.10 (.752)	0.63 (.429)
C-Symptom Cluster	1.03 (.311)	1.03 (.311)	[a]	[a]	[a]	1.03 (.311)
D-Symptom Cluster	0.17 (.677)	3.24 (.072)	0.17 (.677)	3.24 (.072)	4.44 (.035)	0.00 (1.00)
IES-R (Moderate-Severe) (n=31)	*df = 61*	*df = 61*	*df = 61*	*df = 61*	*df = 61*	*df = 61*
Full-scale	0.16 (.688)	0.00 (1.00)	1.00 (.317)	1.86 (.173)	0.16 (.688)	1.86 (.173)
PTGI (Moderate-Great) (n=30)	*df = 60*	*df = 60*	*df = 60*	*df = 60*	*df = 60*	*df = 60*
Relating to others	5.08 (.024)	3.07 (.080)	8.52 (.004)*	5.96 (.015)	0.28 (.598	0.58 (.448)
New possibilities	1.49 (.222)	0.42 (.519)	3.75 (.053)	1.92 (.166)	0.34 (.559)	0.58 (.448)
Personal Strength	3.36 (.067)	0.00 (1.00)	5.71 (.017)	3.47 (.559)	3.36 (.067)	0.34 (.559)
Spiritual Change	5.46 (.020)	4.36 (.037)	7.20 (.007)*	5.96 (.015)	0.07 (.791)	0.16 (.688)
Appreciation of Life	2.58 (.108)	0.07 (.795)	13.07 (.000)*	5.55 (.018)	1.83 (.176)	4.44 (.035)
Full-scale	5.46 (.020)	0.48 (.488)	7.20 (.007)*	1.18 (.278)	2.86 (.091)	0.16 (.688)

Note: A-Criterion = Traumatic event, B-Symptom Cluster = Intrusive Re-experiencing; C-Symptom Cluster = Avoidance; D-Symptom Cluster = Hyper-arousal.
*$p < .01$; df=degrees of freedom
[a]cell size = 0 for both groups – comparisons cannot be computed.

Table 3.10. Pearson bivariate correlation coefficients for family members from full participating family units on PTSS and PTG

Measure	Survivors and Mothers	Survivors and Fathers	Siblings and Mothers	Siblings and Fathers	Mothers and Fathers	Survivors and Siblings
IES-R (n=31)						
Intrusion	0.32	0.56**	0.48**	0.23	0.43*	0.23
Avoidance	0.27	0.54**	0.37*	0.41*	0.33	0.23
Hyper-arousal	0.61**	0.79**	0.52**	0.31	0.75**	0.11
Full-scale	0.39*	0.69**	0.55**	0.39*	0.50**	0.18
PTGI (n=30)						
Relating to Others	0.39*	0.34*	0.22	0.48**	0.41*	0.40*
New Possibilities	0.40*	0.21	0.10	0.57**	0.19	0.30
Personal Strength	0.31	0.52**	0.44**	0.51**	0.25	0.58**
Spiritual Change	0.33	0.49**	0.13	0.40*	0.38*	0.51**
Appreciation of Life	0.38*	0.17	0.27	0.56**	0.32	0.35
Full-scale	0.42*	0.42*	0.27	0.65**	0.31	0.51**

* $p < .05$, ** $p < .01$

Table 3.11. Pearson bivariate correlation coefficients between the full-scale IES-R and demographic and treatment variables for full family units

	Survivors (n=31)	**Mothers (n=31)**	**Fathers (n=31)**	**Siblings (n=31)**
Gender	0.05	-	-	-0.33
Age at participation	-0.18	-0.09	-0.18	-0.21
Age at diagnosis	-0.04	0.09	0.04	0.05
Years off Treatment	0.21	-0.14	-0.34	-0.25
Relapse/2nd Malignancy	0.18	0.08	0.15	0.01
Diagnosis				
Leukaemia	-0.30	-0.24	-0.24	-0.35
Solid Tumour	0.15	-0.08	-0.21	0.06
Lymphoma	-0.05	0.25	0.35	0.29
CNS Tumour	0.37*	0.39*	0.47**	0.24
Treatment				
Chemotherapy#	-	-	-	-
Radiotherapy	-0.19	-0.07	-0.16	-0.28
Cranial	-0.13	-0.12	-0.10	-0.23
Total body	-0.17	0.12	-0.06	-0.11
Surgical resection	0.30	0.15	0.08	0.12
Transplant	-0.26	-0.01	-0.17	-0.17
Living with parent	0.12	-	-	-0.02
Relationship status	0.02	0.12	0.09	0.14
Education level	-0.09	-0.00	0.19	-0.03
Employment Status	-0.25	0.23	-0.09	-0.15
Household income	-0.51**	0.26	0.18	-0.02
Personal Income	-0.09	0.28	-0.07	-0.04
Cultural Identity##	0.09	-0.11	0.11	-

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2

All survivors underwent chemotherapy treatment; ## All siblings identified as Australian.

**p < .05, ** p < .01*

Table 3.12. Summary of hierarchical multiple regression analyses for corresponding survivor, mother, father and sibling Scores on the IES-R as predictors of PTSS (Beta standardised regression coefficients)

		Dependent Variable (IES-R)			
		Intrusion	Avoidance	Hyper-arousal	Full-scale
Survivors (n = 25)					
Step 1	CNS Tumour Diagnosis	0.29	0.20	0.36*	0.31
	Household Income	-0.40*	- 0.43*	-0.43*	- 0.47**
	F(2,23)	***4.22****	***3.70****	***6.20*****	***6.20*****
	Adjusted R^2	***0.21***	***0.18***	***0.29***	***0.29***
Step 2	Mothers Scores	0.23	0.36*	0.40	0.33*
	Fathers Scores	0.39	0.43**	0.30	0.48**
	Siblings Scores	0.20	0.01	0.26	0.07
	F change(5,20)	***2.43***	***5.66*****	***10.97*****	***6.75*****
	R^2 change	***0.20***	***0.35***	***0.40***	***0.33***
	F	***3.46****	***5.78*****	***12.29*****	***8.39*****
	Adjusted R^2	**0.33**	**0.49**	**0.69**	**0.60**
Mothers (n = 29)					
Step 1	CNS Tumour Diagnosis	0.35	0.26	0.56**	0.39*
	F(1,28)	***4.02***	***2.00***	***12.77*****	***4.86****
	Adjusted R^2	***0.09***	***0.03***	***0.29***	***0.12***
Step 2	Survivors Scores	0.04	0.12	0.20	0.15
	Fathers Scores	0.24	0.13	0.29	0.16
	Siblings Scores	0.39*	0.26	0.41**	0.43*
	F change(4,25)	***3.16****	***1.31***	***12.92*****	***4.16****
	R^2 change	***0.24***	***0.13***	***0.42***	***0.28***
	F	***3.61****	***1.50***	***16.95*****	***4.74*****
	Adjusted R^2	**0.27**	**0.06**	**0.69**	**0.34**
Fathers (n =29)					
Step 1	CNS Tumour Diagnosis	0.42*	0.38*	0.53**	0.47**
	F(1,28)	***6.03****	***4.64****	***11.12*****	***7.80*****
	Adjusted R^2	***0.15***	***0.11***	***0.26***	***0.19***
Step 2	Survivors Scores	0.42*	0.42*	0.55**	0.55**
	Mothers Scores	0.22	0.10	0.27	0.11
	Siblings Scores	-0.01	0.21	0.12	0.19
	F change(4,25)	***3.36****	***3.64****	***15.79*****	***7.56*****
	R^2 change	***0.24***	***0.26***	***0.47***	***0.37***
	F	***4.41*****	***4.22*****	***19.03*****	***8.99*****
	Adjusted R^2	**0.32**	**0.31**	**0.71**	**0.52**
Siblings (n =29)					
Step 2	Survivors Scores	0.00	-0.06	-0.39	-0.23
	Mothers Scores	0.46*	0.26	0.49*	0.44*
	Fathers Scores	0.11	0.38	0.31	0.37
	F(3,26)	***3.03****	***2.80***	***3.54****	***4.44****
	Adjusted R^2	**0.17**	**0.16**	**0.21**	**0.26**

*p < .05, ** p < .01

Table 3.13. Pearson bivariate correlation coefficients between the full-scale PTGI and demographic and treatment variables for full family units

	Survivors (n=30)	**Mothers (n=30)**	**Fathers (n=30)**	**Siblings (n=30)**
Gender	0.28	-	-	0.16
Age at participation	-0.09	0.16	-0.26	0.14
Age at diagnosis	0.10	0.23	0.05	0.37*
Years off Treatment	-.016	0.04	-0.42*	-0.28
Relapse/2nd Malignancy	-0.03	-0.18	0.21	0.45*
Diagnosis				
Leukaemia	-0.19	-0.40*	-0.33	-0.17
Solid Tumour	-0.04	0.29	0.05	-0.06
Lymphoma	0.21	0.14	0.40*	0.26
CNS Tumour	0.02	0.00	0.08	0.16
Treatment				
Chemotherapy	-	-	-	-
Radiotherapy	0.17	-0.20	-0.32	-0.17
Cranial	-0.26	-0.20	-0.35	-0.12
Total body	0.02	-0.15	-0.12	-0.19
Surgical resection	0.26	0.21	0.29	0.43*
Transplant	0.07	-0.19	-0.14	-0.20
Living with parent	-0.04	-	-	-0.19
Relationship status	0.13	0.23	0.26	0.25
Education level	0.01	-0.13	-0.11	0.13
Employment Status	-0.21	0.03	0.32	0.04
Household income	0.16	0.04	0.14	-0.04
Personal Income	0.38*	-0.12	0.10	-0.01
Cultural Identity	0.15	-0.19	0.03	-

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2

[#] All survivors underwent chemotherapy treatment; [##] All siblings identified as Australian.

**p < .05, ** p < .01*

Table 3.14. Summary of hierarchical multiple regression analyses for corresponding survivor, mother, father and sibling scores on the PTGI as predictors of posttraumatic growth (Beta standardised regression coefficients)

		Dependent Variable (PTGI)					
		Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life	Full-scale
Survivors (n = 26)							
Step 1	Personal Income	0.26	0.41*	0.37	0.21	0.27	0.38
	F(1,25)	***1.80***	***5.11****	***4.07***	***1.12***	***2.00***	***4.22***
	Adjusted R^2	***0.03***	***0.14***	***0.22***	***0.01***	***0.04***	***0.11***
Step 2	Mothers Scores	0.21	0.21	0.11	0.12	0.31	0.19
	Fathers Scores	0.14	0.05	0.28	0.32	-0.03	0.16
	Siblings Scores	0.16	0.18	0.32	0.27	0.19	0.24
	F change(4,22)	***1.32***	***0.81***	***4.69****	***2.46***	***1.39***	***2.11***
	R^2 change	***0.14***	***0.08***	***0.34***	***0.24***	***0.15***	***0.19***
	F	***1.45***	***1.85***	***4.99*** **	***2.17***	***1.56***	***2.78***
	Adjusted R^2	**0.07**	**0.12**	**0.38**	**0.15**	**0.08**	**0 .22**
Mothers (n = 29)							
Step 1	Leukaemia Diagnosis	-0.29	-0.46**	-0.12	-0.34	-0.49**	-0.40*
	F(1,28)	***2.64***	***7.66*** **	***0.44***	***3.69***	***8.79*** **	***5.45****
	Adjusted R^2	***0.05***	***0.19***	***-0.02***	***0.09***	***0.21***	***0.13***
Step 2	Survivors Scores	0.28	0.36*	0.10	0.18	0.23	0.32
	Fathers Scores	0.30	0.03	0.01	0.29	0.14	0.06
	Siblings Scores	-0.05	-0.07	0.37	-0.11	0.03	0.02
	F change(4,25)	***2.12***	***1.52***	***1.93***	***1.38***	***0.94***	***1.42***
	R^2 change	***0.19***	***0.12***	***0.19***	***0.13***	***0.08***	***0.12***
	F	***2.32***	***3.16****	***1.57***	***2.00***	***2.89****	***4.49***
	Adjusted R^2	**0.15**	**0.23**	**0.07**	**0.12**	**0.21**	**0.17**

Table 3.14. (Continued)

		Dependent Variable (PTGI)					
		Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life	Full-scale
Fathers (n =28)							
Step 1	Years off Treatment	-0.31	-0.27	-0.29	-0.22	-0.21	-0.34
	Lymphoma Diagnosis	0.24	0.22	0.22	0.25	0.25	0.29
	F(2,26)	***3.18***	***2.39***	***2.72***	***2.12***	***2.09***	***4.53****
	Adjusted R^2	***0.14***	***0.09***	***0.11***	***0.07***	***0.07***	***0.20***
Step 2	Survivors Scores	0.01	-0.02	0.31	0.12	-0.10	0.02
	Mothers Scores	0.32	0.16	0.06	0.36	0.18	0.15
	Siblings Scores	0.29	0.48*	0.20	0.36	0.48*	0.48**
	F change(5,23)	***2.86***	***3.04****	***2.73***	***3.46****	***2.78***	***4.47****
	R^2 change	***0.22***	***0.24***	***0.22***	***0.27***	***0.23***	***0.27***
	F	***3.26****	***3.00****	***2.94****	***3.17****	***2.67****	***5.22*****
	Adjusted R^2	**0.29**	**0.26**	**0.26**	**0.28**	**0.23**	**0.43**
Siblings (n =28)							
Step 1	Age at Diagnosis	0.14	0.10	0.29	0.18	0.25	0.21
	Relapse/2nd Malignancy	0.36*	0.47**	0.39*	0.21	0.34*	0.41**
	Surgical Resection	0.44*	0.42*	0.34*	0.47**	0.43**	0.46**
	F(3,25)	***5.16*****	***6.37*****	***6.45*****	***4.18****	***6.26*****	***8.04*****
	Adjusted R^2	***0.31***	***0.37***	***0.37***	***0.25***	***0.36***	***0.43***
Step 2	Survivors Scores	0.23	0.13	0.29	0.45*	0.08	0.26
	Mothers Scores	0.05	0.02	0.25	-0.03	0.12	0.06
	Fathers Scores	0.22	0.38*	0.18	0.09	0.37*	0.31*
	F change(6,22)	***1.68***	***2.61***	***4.72****	***2.17***	***3.38****	***4.43****
	R^2 change	***0.12***	***0.15***	***0.22****	***0.15***	***0.18***	***0.19***
	F	***3.63****	***5.10*****	***7.03****	***3.47****	***5.72*****	***7.89*****
	Adjusted R^2	**0.36**	**0.47**	**0.56**	**0.35**	**0.50**	**0.60**

*p < .05, ** p < .01

Table 3.15. Percent of family concordance on rates of PTSD, PTSS, and posttraumatic growth

Measure	All family members n (%)	Survivor and One Parent n (%)	Survivor and Sibling n (%)	Sibling and One Parent n (%)	Mother and Father n (%)
SCID (n=20)					
A-Criterion	2 (10.0)	10 (50.0)	3 (15.0)	5 (25.0)	60.0 (12)
Since diagnosis:					
PTSD	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0)
B-Symptom Cluster	4 (20.0)	10 (50)	7 (35.0)	10 (50.0)	65.0 (13)
C-Symptom Cluster	0 (0.0)	1 (5.0)	0 (0.0)	0 (0.0)	10.0 (2)
D-Symptom Cluster	0 (0.0)	3 (15.0)	1 (5.0)	2 (10.0)	5.0 (1)
Current:					
PTSD[a]	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0)
B-Symptom Cluster	2 (10.0)	3 (15.0)	3 (15.0)	5 (25.0)	40.0 (8)
C-Symptom Cluster[a]	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0)
D-Symptom Cluster	0 (0.0)	3 (15.0)	0 (0.0)	1 (5.0)	0 (0)
IES-R moderate-severe (n=31)					
Full-scale	0 (0.0)	2 (6.5)	0 (0.0)	1 (3.2)	6.5 (2)
PTGI moderate-great (n=30)					
Relating to Others	1 (3.3)	4 (13.3)	1 (3.3)	2 (6.7)	23.3 (7)
New Possibilities	1 (3.3)	4 (13.3)	2 (6.7)	1 (3.3)	10.0 (3)
Personal Strength	4 (13.3)	9 (30.0)	5 (16.7)	7 (23.3)	20.0 (6)
Spiritual Change	1 (3.3)	2 (6.7)	0 (0.0)	1 (3.3)	20.0 (6)
Appreciation of Life	5 (16.7)	13 (43.3)	6 (20.0)	8 (26.7)	50.0 (15)
Full-scale	1 (3.3)	3 (10.0)	1 (3.3)	2 (6.7)	16.7 (5)

Note: A-Criterion = Traumatic event, B-Symptom Cluster = Intrusive Re-experiencing; C-Symptom Cluster = Avoidance; D-Symptom Cluster = Hyper-arousal.
[a] cell size > 0 for one group only – concordance cannot be investigated

CHAPTER 4
STUDY 2

POSTTRAUMATIC STRESS, PSYCHOLOGICAL DISTRESS AND POSTTRAUMATIC GROWTH: RELATIONSHIPS, CO-EXISTENCE, AND COMORBIDITY:

4.0 Overview

Comorbidities associated with PTSD and PTSS have been well documented (outlined in section 1.2.4). In line with this, survivor research shows PTSD and PTSS to share a positive relationship with psychological distress (see Table 1.1). Further, psychological distress has been shown to predict PTSS severity in survivors (Stuber et al., 1997) and parents (Best et al., 2001; Manne et al., 2002). While few studies have included siblings, the robust findings of PTSD comorbidity as reported by other trauma groups suggest this will be a consistent finding across all family groups (survivors, mothers, fathers and siblings).

There is evidence to indicate that posttraumatic stress and posttraumatic growth are not mutually exclusive constructs but instead co-exist to varying degrees within the same individual (Cadell et al., 2003; Tedeschi & Calhoun, 2004a). However, posttrauma growth research is still very much in its infancy (Park & Helgeson, 2006; as reviewed in section 1.2.5). Only two studies to date have investigated the stress-growth relationship from a childhood cancer perspective, and these have reported inconsistent results (Barakat et al., 2006; Best et al., 2001; as reviewed in section 1.2.6). No research to date has included siblings. Further work is necessary from a symptom level, to determine how these seemingly diverse trauma outcomes may relate to, predict, or co-exist with each other.

In light of the above, Study 2 aims to assess the relationship and comorbidity of posttraumatic stress and psychological distress (depression, anxiety and stress), and the relationship and co-existence of posttraumatic stress and posttraumatic growth in childhood cancer survivors, parents, and siblings. With regard to the latter, in light of past inconsistent findings, Study 2 will assume that a positive relationship exists for the purpose of hypothesis testing. Based on these objectives, the following set of hypotheses will be tested:

Hypothesis Set 1: PTSS, PTSD and Psychological Distress

A. *PTSS will be significantly positively related to Psychological Distress for all groups (survivors, parents, siblings)*

B. *Psychological Distress will significantly predict PTSS severity over and above the demographic and treatment variables.*
C. *Mean scores on Psychological Distress will be significantly higher for the PTSD group than the non-PTSD group.*
D. *The PTSD group will be significantly more likely to meet moderate to severe levels of Psychological Distress than the non-PTSD group.*

Hypothesis Set 2: PTSS, PTSD and Posttraumatic Growth

A. *Hypothesis 2: PTSS will be significantly positively related to Posttraumatic Growth for all groups (survivors, parents, siblings).*
B. *Posttraumatic Growth will significantly predict PTSS severity over and above the demographic and treatment variables.*
C. *Mean scores on Posttraumatic Growth will be significantly higher for the PTSD group than the non-PTSD group.*
D. *The PTSD group will be significantly more likely to meet moderate to great levels of Posttraumatic Growth than the non-PTSD group.*

4.1 Method

4.1.1 Participants

As a continuation of Study 1 (Chapter 3), Study 2 includes the same sample of participants: self-report measures were completed by 182 survivors, 109 mothers, 73 fathers, and 62 siblings. Methods of recruitment and participant characteristics are described in Chapter 2.

4.1.2 Measures

Study 2 refers to the following set of self-report measures, each fully described in Chapter 2:

- *Impact of Event Scale-Revised* (*IES-R;* Weiss & Marmar, 1997).
- *Depression Anxiety and Stress Scale-Short Version* (*DASS-21*; Lovibond & Lovibond, 1995).
- *Posttraumatic Growth Inventory* (*PTGI*; Tedeschi & Calhoun, 1996).

4.1.3 Statistical Analyses

Using SPSS for windows, version 15, relationships between scores on self-report measures (IES-R, DASS-21, PTGI) were assessed by Pearson's bivariate correlational analyses, and hierarchical multiple regression models were used to test the prediction hypotheses. For each of the

regression models, variables were entered in two steps in order to control for demographic and treatment variables. Step 1 included demographic and treatment variables found to be significantly correlated with the IES-R scales for each group (see Table 3.4). Step 2 included the DASS-21 subscales of *Depression, Anxiety,* and *Stress* (Hypotheses 1B), or the PTGI scales of *Relating to Others, New Possibilities, Personal Strength, Spiritual Change,* and *Appreciation of Life* (Hypothesis 2B). The same model was tested in the prediction of each of the dependent variables (*Intrusion, Avoidance* and *Hyper-arousal*). In reporting explained variance, the more conservative adjusted R^2 is used due to the small sample size of some analyses relative to the number of independent variables[32].

For comorbidity investigations, participants meeting PTSD at some time point since diagnosis were categorised and compared with those not meeting the full PTSD criteria since diagnosis (PTSD versus non-PTSD groups)[33]. As no siblings have met PTSD criteria, siblings were excluded from these analyses. One-way Analyses of Variance (ANOVA), and Chi-squared analyses were used to test for differences between PTSD and non-PTSD groups on DASS-21 scores.

4.2 Results

4.2.1 Hypothesis Set 1: PTSS, PTSD and Psychological Distress

4.2.1a Hypothesis 1A: PTSS will be significantly positively related to Psychological Distress for all groups (survivors, mothers, fathers, siblings).

Results of correlational analyses between PTSS and Psychological distress are presented in Table 4.1. As expected, all scales of the IES-R and the DASS-21 showed significant positive relationships across all groups (moderate to strong correlations; $r = 0.37$ to 0.71, $p < .01$). The IES-R *Hyper-arousal* scale correlated most strongly across all DASS-21 scales ($r = 0.48$ to 0.71, $p < .01$) with the exception of the DASS-21 *Stress* scale for siblings which correlated most strongly with IES-R *Intrusion* ($r = 0.44$, $p < .001$).

4.2.1b Hypothesis 1B: Psychological Distress will significantly predict PTSS severity over and above the demographic and treatment variables.

As predicted, and as shown in Table 4.2 hierarchical regression analyses showed Psychological Distress significantly predicted PTSS severity over and above the demographic and

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[32] Based on the following rules of thumb: Minimum cases to IV ratio for testing the multiple correlation: $N \geq 50 + 8m$; Minimum cases to IV ratio for testing individual predictors: $N \geq 104 + m$ (Tabachnick & Fidell, 2001)

[33] PTSD since diagnosis was used to categorise respondents into PTSD and non-PTSD groups as few participants currently meet full PTSD criteria. As shown in Study 1A, nearly all participants who have met PTSD since diagnosis still exhibit partial PTSD.

treatment variables. Across all groups, each of the full models were significant explaining between 25 to 56% of the variance of PTSS severity. The DASS-21 scales entered at Step 2 collectively predicted PTSS severity at a significant level over and above that of the demographic and treatment variables entered at Step 1– Step 2 accounting for between 20 to 47% of the variance ($p < .01$).

At Step 2, *Anxiety* and *Stress* were revealed to be significant individual contributors to the prediction of *Intrusion* severity for survivors ($\beta = 0.22$, $p = .032$; $\beta = 0.23$, $p = .027$), *Depression* and *Stress* for *Avoidance* severity ($\beta = 0.19$, $p = .042$; $\beta = 0.30$, $p = .004$), and *Depression, Anxiety* and *Stress* for both *Hyper-arousal* ($\beta = 0.20$, $p = .018$; $\beta = 0.26$, $p = .005$; $\beta = 0.24$, $p = .009$) and *full-scale IES-R* severity ($\beta = 0.17$, $p = .039$; $\beta = 0.22$, $p = .016$; $\beta = 0.29$, $p = .002$). For mothers, *Anxiety* contributed significantly to the prediction of PTSS severity across all IES-R scales at an individual level (*Intrusion* $\beta = 0.39$, $p = .009$; *Avoidance* $\beta = 0.50$, $p = .001$; *Hyper-arousal* $\beta = 0.46$, $p < .001$; *full-scale IES-R* $\beta = 0.50$, $p = .001$). Father models show *Stress* to significantly contribute to the prediction of *Intrusion*, *Avoidance*, and *full-scale IES-R* severity ($\beta = 0.39$, $p = .026$; $\beta = 0.39$, $p = .039$; $\beta = 0.34$, $p = .040$), and *Anxiety* to *Hyper-arousal* severity ($\beta = 0.50$, $p < .001$). For siblings *Anxiety* was a significant individual predictor of *Avoidance* severity ($\beta = 0.36$, $p = .036$), and *Depression* and *Anxiety* for *Hyper-arousal* severity ($\beta = 0.48$, $p = .001$; $\beta = 0.32$, $p = .029$). No DASS-21 scale was a significant individual contributor to the prediction of *Intrusion* or *full-scale IES-R* severity for siblings.

Consistent with correlational findings, across all groups Step 2 collectively accounted for the highest proportion of variance in the *Hyper-arousal* models (full models: *Adjusted* $R^2 = 0.33$ to 0.56; Step 2: R^2*change* = 0.30 to 0.44).

4.2.1c Hypothesis 1C: Mean scores on Psychological Distress will be significantly higher for the PTSD group than the non-PTSD group.

Table 4.3 compares mean DASS-21 scores for survivors, mothers and fathers meeting full PTSD criteria at some point since diagnosis as measured by the SCID (PTSD groups), and those who have not (non-PTSD groups). As predicted, mean scores on the DASS-21 were significantly greater for the PTSD groups than the non-PTSD groups across all scales for survivors, mothers, and fathers ($p < .05$).

4.2.1d Hypothesis 1D: The PTSD group will be significantly more likely to meet moderate to severe levels of Psychological Distress than the non-PTSD group.

Table 4.4 shows that 43% of survivors, 19% of mothers, and 33% of fathers with PTSD since diagnosis also meet moderate to severe depression and anxiety, and 36%, 31%, and 50%

respectively also meet moderate to severe levels of stress. Survivors meeting PTSD at some time point since diagnosis were significantly more likely to score in the moderate to severe category for *Depression* (X^2 = 3.99, p = .046) and *Anxiety* (X^2 = 9.12, p = .003) than survivors in the non-PTSD group. Relative to the non-PTSD groups, mothers in the PTSD group were significantly more likely to score in the moderate to severe category for *Stress* (X^2 = 9.59, p = .002), and fathers in the PTSD group were significantly more likely to score in the moderate to severe category for *Anxiety* (X^2 = 5.06, p = .025) and *Stress* (X^2 = 11.09, p = .001).

4.2.2 Hypothesis Set 2: PTSS, PTSD and Posttraumatic Growth

4.2.2a Hypothesis 2A: PTSS will be significantly positively related to Posttraumatic Growth for all groups (survivors, parents, siblings).

Results of correlational analyses between the IES-R and the PTGI are presented in Table 4.5. As expected, all scales of the IES-R and the PTGI showed significant positive correlations for survivors and fathers (small to strong correlations; r = 0.18 to 0.51, p < .05). This was also true for siblings (small to moderate correlations; r = 0.26 to 0.49, p < .05) although contrary to expectations, no significant relationship was found between *Avoidance* and *Spiritual Change* (r = 0.22, p = .089), *Hyper-arousal* and *Personal Strength* (r = 0.22, p = .092), and *Hyper-arousal* and *Appreciation of Life* (r = 0.18, p = .168). For mothers, a significant positive relationship was revealed for all IES-R scales and *New Possibilities* (small to moderate correlations; r = 0.27 to 0.30, p < .01; see Table 4.5) however contrary to expectations, no significant relationships were revealed with any of the other PTGI scales.

4.2.2b Hypothesis 2B: Posttraumatic Growth will significantly predict PTSS severity over and above the demographic and treatment variables.

As shown in Table 4.6, each of the full models were significant for survivors, mothers and fathers explaining between 9 to 39% of the variance of PTSS severity. For siblings, this was true for the *Intrusion* and *full-scale* models only (22 and 17% of variance respectively).

In line with the hypothesis, hierarchical regression analyses confirm Posttraumatic Growth to significantly predict PTSS severity over and above the demographic and treatment variables, however this was confirmed for only10 of the 16 models tested. For survivors, the PTGI scales entered at Step 2 significantly accounted for between 7 to 26% of the variance of symptom severity across the four models tested: *Intrusion* (p < .001), *Avoidance* (p = .002), *Hyper-arousal* (p = .013), *full-scale IES-R; p* < .001). For mothers, Step 2 was significant for the *Avoidance* (12% of variance; p = .019) and *full-scale IES-R* models only (11% of variance; p = .039); for fathers Step 2 was

significant for the *Intrusion* (15% of variance; $p = .024$), *Avoidance* (15% of variance; $p = .031$), and *full-scale IES-R* (15% of variance; $p = .021$) models only; and for siblings Step 2 was significant for the *Intrusion* (17% of variance; $p = .037$) model only.

At Step 2, there were few significant individual predictors. For Survivors, *Spiritual Change* significantly predicted *Intrusion* severity ($\beta = 0.24$, $p = .002$). For mothers, consistent with correlational analyses *New Possibilities* significantly predicted PTSS severity across all IES-R scales (*Intrusion* $\beta = 0.33$, $p = .013$; *Avoidance* $\beta = 0.32$, $p = .012$; *Hyper-arousal* $\beta = 0.33$, $p = .014$), and *Personal Strength* significantly but negatively predicted *Avoidance* severity ($\beta = -0.25$, $p = .042$). For fathers, *New Possibilities* significantly predicted *Avoidance* severity ($\beta = 0.51$, $p = .012$). No PTGI scale was a significant individual contributor to the prediction of PTSS severity for siblings.

4.2.2c Hypothesis 2C: Mean scores on Posttraumatic Growth will be significantly higher for the PTSD group than the non-PTSD group.

Table 4.7 compares mean PTGI scores for survivors, mothers and fathers meeting full PTSD criteria at some point since diagnosis as measured by the SCID (PTSD groups), and those who have not (non-PTSD groups). As shown, mean scores on the *Relating to Others,* and *Spiritual Change* scales were significantly greater for survivors in the PTSD group than the non-PTSD group ($p < .05$), however contrary to predictions, mean scores did not significantly differ for any other PTGI scale, and no differences were confirmed for mothers and fathers across any PTGI scale.

4.2.2d Hypothesis 2D: The PTSD group will be significantly more likely to meet moderate to great levels of Posttraumatic Growth than the non-PTSD group.

Table 4.8 shows that between 20 to 73% of survivors, 25 to 81% of mothers, and 33 to 67% of fathers with PTSD since diagnosis also meet moderate to great levels of posttraumatic growth. Relative to the non-PTSD group, survivors meeting PTSD at some time point since diagnosis were significantly more likely to score in the moderate to great category for *Relating to Others* ($X^2 = 5.28$, $p = .022$) and *Spiritual Change* ($X^2 = 12.29$, $p < .001$). Fathers in the PTSD group were significantly more likely to score in the moderate to great category for *New Possibilities* ($X^2 = 4.88$, $p = .027$) than fathers in the non-PTSD group. Contrary to predictions, no further differences were confirmed.

4.3 Discussion

Study 2 has shown that, as predicted, psychological distress relates to, predicts, and co-exists with posttraumatic stress. Posttraumatic growth was also revealed to relate to and predict

posttraumatic stress, suggesting the two outcomes do co-exist. However, multivariate analyses revealed family group differences at the symptom/growth domain level.

In line with the hypotheses, current PTSS severity was found to share strong positive associations with psychological distress for all groups, and psychological distress was found to be a strong predictor of current PTSS severity even after the influence of the demographic and treatment variables were accounted for. Further, PTSD and psychological distress were shown to co-exist at higher rates for those with a history of PTSD compared to those with no history of PTSD. Those with a history of PTSD since diagnosis scored higher and were more likely to meet moderate to severe levels of psychological distress relative to those with no history of PTSD, concurring with data indicating that a PTSD diagnosis may be a risk factor for psychological distress (Barakat et al., 1997, 2000). Indeed, results show up to one half of survivors, mothers, and fathers meeting PTSD since diagnosis also report current levels of moderate to severe psychological distress. While the findings of Study 2 are in line with others reporting similar associations between posttraumatic stress and psychological distress (Barakat et al., 1997, 2000; Kazak et al., 1998; Manne et al., 1998; Meeske et al., 2001), and results show this relationship is maintained for survivors, mothers, fathers, and siblings, at a symptom level differences were seen to exist. For example, PTSS severity was revealed to be most strongly related to anxiety for mothers across all four prediction models, and stress for fathers across three of the four prediction models. These findings are in contrast to survivors and siblings where the relative predictive importance of depression anxiety and stress varied depending on the symptom of PTSD investigated.

A positive relationship was generally confirmed between posttraumatic stress and posttraumatic growth for all groups, suggesting that these responses do co-exist (Cadell et al., 2003; Morris et al., 2005). Across these groups, posttraumatic growth shared the strongest relationship with the PTSD symptom of intrusion. The strength of the relationship between posttraumatic growth and intrusive symptoms is in line with the often cited reports in the general trauma literature (Helgeson et al., 2006). However, while upheld in the correlational analyses, an exception to this finding is in the prediction models for mothers. In line with past findings in parents of leukaemia survivors (Best et al., 2001), posttraumatic growth was the strongest predictor of avoidance symptomatology. This finding is important as it indicates that family group differences not only exist in the reporting of posttraumatic growth (Study 1B), but also in its relationship with posttraumatic stress. Consistent with this, posttraumatic growth was shown to predict PTSS for survivors, but less so for siblings, and survivors with a history of PTSD since diagnosis scored higher and were more likely to meet moderate to great levels of posttraumatic growth relative to those with no history of PTSD. Specifically, survivors meeting PTSD criteria since cancer diagnosis

feel better able to relate to others and have gained greater personal strength and spirituality relative to survivors with no history of cancer related PTSD. This contrasts with parental findings where PTSS, particularly mothers PTSS, shared the strongest relationship with the posttraumatic growth domain of new possibilities. However, for mothers, no differences were revealed between the PTSD and no-PTSD history groups on the strength or prevalence of any one domain of posttraumatic growth. This was also true for fathers with the only exception being the prevalence of the growth category of new possibilities, underlining the strong relationship of this growth category and parental PTSS (more fathers with a history of PTSD since diagnosis endorsed finding new possibilities following their childhood cancer experience than those with no PTSD history). The limited differences revealed between the PTSD and no-PTSD groups for parents indicates that, particularly for mothers, a PTSD history is not necessarily a determinant for higher levels (prevalence and severity) of posttraumatic growth following childhood cancer.

Of particular interest are findings showing some categories of posttraumatic growth may share an inverse relationship with PTSS. For example, the posttraumatic growth categories of *Relating to Others* and *Personal Strength* show a consistent negative relationship in the prediction of PTSS for mothers. *Personal Strength* was also a negative predictor of PTSS for fathers, for survivors *Relating to Others* was a negative predictor of avoidance symptomatology, and for siblings *Appreciation of Life* was a negative predictor of hyper-arousal symptomatology. These findings show that not all domains of growth will share a positive relationship with posttraumatic stress, possibly explaining the differing reports in the literature (Park & Helgeson, 2006). It may be that the domain(s) of growth assessed, the measure of growth used, and/or the population surveyed will determine whether the stress-growth relationship is positive, negative or unrelated.

The differences revealed between groups (survivor, mother, father, sibling) at both the symptom (PTSS, Psychological Distress), or growth category level suggest that ongoing PTSS following a childhood cancer experience may manifest in subtly different ways depending on family membership. This membership is likely to reflect the context from which the trauma is experienced (e.g., victim versus witness, child versus adult, sibling versus parent) and implies that the relationships between PTSS and psychological distress, and PTSS and posttraumatic growth within families are more complex than revealed by earlier studies (Best et al., 2001; Barakat et al., 2000, 2006; Manne et al., 1998; Meeske et al., 2001). In understanding these complexities, a posttraumatic stress model that emphasises subjective experience and interpretation may be valuable for not only understanding traumatic stress responses following childhood cancer, but also in understanding a range of long-term psychosocial adjustment outcomes including psychological distress and posttraumatic growth. For example, sustained levels of intrusion, avoidance, or hyper-

arousal symptomatology following childhood cancer may be indicative of psychopathology such as depression, anxiety, or stress, as well as posttraumatic growth. Following Chapter 5's summation of Part 1 findings, this research will turn to Part 2 whereby the applicability of a theoretical and treatment model of PTSD to childhood cancer survivorship will be investigated.

Table 4.1. pearson bivariate correlation coefficients between PTSS and psychological distress

	DASS-21			
IES-R	Depression	Anxiety	Stress	Full-scale
Survivors (n=176)				
Intrusion	0.42**	0.48**	0.44**	0.50**
Avoidance	0.47**	0.47**	0.49**	0.54**
Hyper-arousal	0.56**	0.60**	0.56**	0.64**
Full-scale	0.53**	0.57**	0.55**	0.61**
Mothers (n=105)				
Intrusion	0.43**	0.54**	0.46**	0.51**
Avoidance	0.38**	0.53**	0.42**	0.47**
Hyper-arousal	0.50**	0.65**	0.49**	0.59**
Full-scale	0.45**	0.59**	0.48**	0.54**
Fathers (n=72)				
Intrusion	0.43**	0.56**	0.61**	0.60**
Avoidance	0.37**	0.50**	0.54**	0.53**
Hyper-arousal	0.48**	0.71**	0.62**	0.66**
Full-scale	0.45**	0.62**	0.63**	0.63**
Siblings (n=60)				
Intrusion	0.43**	0.42**	0.44**	0.50**
Avoidance	0.41**	0.51**	0.38**	0.49**
Hyper-arousal	0.63**	0.60**	0.39**	0.61**
Full-scale	0.52**	0.55**	0.44**	0.57**

*p < .05, ** p < .01

Table 4.2. Summary of hierarchical multiple regression analyses for psychological distress as a predictor of PTSS (Beta standardised regression coefficients)

		Dependent Variable			
		IES-R Intrusion	IES-R Avoidance	IES-R Hyper-arousal	IES-R Full-scale
Survivors (n = 173)					
Step 1	Relapse/2nd Malignancy	0.19**	0.23**	0.19*	0.24**
	Living with parent	-0.00	0.10	0.16	0.10
	Relationship Status	-0.15	0.02	-0.11	-0.08
	Employment Status	-0.11	-0.13	-0.06	-0.12
	F(4,169)	***4.04*** **	***4.06*** **	***5.62*** **	***5.45*** **
	Adjusted R^2	***0.07***	***0.07***	***0.10***	***0.09***
Step 2	DASS-21 Depression	0.11	0.19*	0.20*	0.17*
	DASS-21 Anxiety	0.22*	0.12	0.26**	0.22*
	DASS-21 Stress	0.23*	0.30**	0.24**	0.29**
	F change(7,166)	***19.64*** **	***24.20*** **	***37.76*** **	***36.77*** **
	R^2 change	***0.24***	***0.28***	***0.36***	***0.35***
	F	***11.49*** **	***13.64*** **	***21.49*** **	***20.84*** **
	Adjusted R^2	**0.30**	**0.34**	**0.45**	**0.44**
Mothers (n = 100)					
Step 1	Leukaemia/Solid Tumour Dx	-0.04	-0.01	0.01	-0.02
	Surgical Resection	0.17	0.20*	0.15	0.19
	Cultural Identity	0.22*	0.24*	0.19	0.23*
	F(3,97)	***3.27****	***4.25*** **	***2.31***	***3.77****
	Adjusted R^2	***0.06***	***0.09***	***0.04***	***0.08***
Step 2	DASS-21 Depression	-0.01	-0.13	0.02	-0.05
	DASS-21 Anxiety	0.39**	0.50**	0.46**	0.50**
	DASS-21 Stress	0.10	0.06	-0.01	0.06
	F change(6,94)	***8.86*** **	***8.90*** **	***15.07*** **	***11.89*** **
	R^2 change	***0.20***	***0.20***	***0.30***	***0.25***
	F	***6.46*** **	***7.10*** **	***9.19*** **	***8.46*** **
	Adjusted R^2	**0.25**	**0.27**	**0.33**	**0.31**
Fathers (n = 66)					
Step 1	Years off Treatment	-0.26*	-0.25*	-0.26*	-0.28*
	CNS Tumour	0.33**	0.30*	0.38**	0.35**
	F(2,64)	***8.26*** **	***6.81*** **	***10.43*** **	***9.75*** **
	Adjusted R^2	***0.18***	***0.15***	***0.22***	***0.21***
Step 2	DASS-21 Depression	0.02	-0.01	0.08	0.03
	DASS-21 Anxiety	0.20	0.13	0.50**	0.27
	DASS-21 Stress	0.39*	0.39*	0.12	0.34*
	F change(5,61)	***10.33*** **	***6.80*** **	***17.20*** **	***12.63*** **
	R^2 change	***0.27***	***0.21***	***0.35***	***0.29***
	F	***10.95*** **	***7.55*** **	***17.65*** **	***13.61*** **
	Adjusted R^2	**0.43**	**0.33**	**0.56**	**0.49**
Siblings (n =59)					
Step 2	Leukaemia	-0.36**	-0.27*	-0.24	-0.33*
	F(1,58)	***8.78*** **	***4.57****	***3.62***	***6.98****
	Adjusted R^2	***0.12***	***0.06***	***0.04***	***0.09***
Step 2	DASS-21 Depression	0.24	0.14	0.48**	0.28
	DASS-21 Anxiety	0.09	0.36*	0.32*	0.28
	DASS-21 Stress	0.20	0.04	-0.12	0.07
	F change(4,55)	***5.88*** **	***6.36*** **	***15.98*** **	***9.75*** **
	R^2 change	***0.21***	***0.24***	***0.44***	***0.31***
	F	***7.16*** **	***6.23*** **	***13.59*** **	***9.85*** **
	Adjusted R^2	**0.30**	**0.26**	**0.46**	**0.38**

*p < .05, ** p < .01

Table 4.3. Comparisons of PTSD-history and no PTSD-history groups on psychological distress in childhood cancer survivors, mothers and fathers

	No-PTSD History		PTSD History		
	M	**(SD)**	**M**	**(SD)**	***F***
Survivors	*n=137*		*n=14*		
Depression	6.58	(8.35)	11.57	(11.02)	4.25*
Anxiety	3.93	(5.49)	10.57	(9.16)	16.12**
Stress	9.17	(8.56)	16.00	(10.38)	7.77**
Full-scale	19.68	(19.55)	38.14	(27.04)	10.49**
Mothers	*n=73*		*n=16*		
Depression	3.84	(4.99)	8.75	(13.74)	5.97*
Anxiety	2.25	(4.00)	7.13	(11.82)	8.37**
Stress	7.48	(7.04)	12.75	(12.06)	5.52*
Full-scale	13.56	(13.12)	28.63	(36.61)	7.97**
Fathers	*n=51*		*n=6*		
Depression	4.35	(6.41)	14.33	(14.94)	9.28**
Anxiety	2.12	(3.47)	9.00	(11.78)	10.78**
Stress	6.24	(6.38)	19.67	(12.68)	18.75**
Full-scale	12.71	(13.37)	43.00	(36.46)	17.38**

**Note: Siblings are excluded from analyses as no siblings have meet PTSD criteria at any time point since diagnosis.*
**p* < .05 ***p* < *.01*

Table 4.4. Percentage of survivors, mothers and fathers with and without a history of PTSD meeting moderate to severe psychological distress

	no PTSD History + Psychological Distress **n (%)**	PTSD History + Psychological Distress **n (%)**	X^2
Survivors	*n=137*	*n=14*	
Depression	27 (19.7)	6 (42.9)	3.99*
Anxiety	17 (12.4)	6 (42.9)	9.12**
Stress	23 (16.8)	5 (35.7)	3.01
Mothers	*n=73*	*n=16*	
Depression	6 (8.2)	3 (18.8)	1.60
Anxiety	5 (6.8)	3 (18.8)	2.27
Stress	4 (5.5)	5 (31.3)	9.59**
Fathers	*n=51*	*n=6*	
Depression	4 (7.8)	2 (33.3)	3.70
Anxiety	3 (5.9)	2 (33.3)	5.06*
Stress	3 (5.9)	3 (50.0)	11.09**

**Note: Siblings are excluded from analyses as no siblings have meet PTSD criteria at any time point since diagnosis.*
**p* < .05 ***p* < *.01*

Table 4.5. Pearson bivariate correlation coefficients between PTSS and posttraumatic growth

	PTGI					
IES-R	Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation of Life	Full-scale
Survivors (n=175)						
Intrusion	0.47**	0.42**	0.35**	0.42**	0.40**	0.46**
Avoidance	0.25**	0.29**	0.27**	0.23**	0.27**	0.29**
Hyper-arousal	0.24**	0.19*	0.22**	0.21**	0.18*	0.24**
Full-scale	0.37**	0.35**	0.32**	0.33**	0.34**	0.39**
Mothers (n=104)						
Intrusion	0.09	0.30**	0.05	0.16	0.16	0.18
Avoidance	0.03	0.28**	0.02	0.16	0.19	0.15
Hyper-arousal	0.03	0.27**	0.03	0.18	0.12	0.14
Full-scale	0.05	0.30**	0.04	0.17	0.17	0.17
Fathers (n=72)						
Intrusion	0.40**	0.51**	0.38**	0.40**	0.37**	0.48**
Avoidance	0.36**	0.48**	0.32**	0.25*	0.28*	0.42**
Hyper-arousal	0.37**	0.45**	0.40**	0.37**	0.30*	0.46**
Full-scale	0.41**	0.49**	0.39**	0.36**	0.34**	0.49**
Siblings (n=61)						
Intrusion	0.49**	0.38**	0.40**	0.37**	0.40**	0.48**
Avoidance	0.38**	0.36**	0.34**	0.22	0.34**	0.39**
Hyper-arousal	0.31*	0.26*	0.22	0.33**	0.18	0.30*
Full-scale	0.44**	0.38*	0.37**	0.33**	0.36**	0.44**

*p < .05, ** p < .01

Table 4.6. Summary of hierarchical multiple regression analyses for posttraumatic growth as a predictor of posttraumatic stress (Beta standardised regression coefficients)

		Dependent Variable			
		IES-R Intrusion	IES-R Avoidance	IES-R Hyper-arousal	IES-R Full-scale
Survivors (n = 172)					
Step 1	Relapse/2nd Malignancy	0.20*	0.23**	0.19*	0.23**
	Living with parent	-0.00	0.11	0.17	0.09
	Relationship Status	-0.15	0.02	-0.11	-0.08
	Employment Status	-0.11	-0.13	-0.06	-0.12
	F(4,168)	***4.03***	***3.82***	***5.60***	***5.26***
	Adjusted R^2	***0.07***	***0.06***	***0.10***	***0.09***
Step 2	PTGI Relating to Others	0.22	-0.17	0.11	0.05
	PTGI New Possibilities	0.07	0.11	-0.11	0.05
	PTGI Personal Strength	-0.09	0.14	0.17	0.07
	PTGI Spiritual Change	0.24**	0.13	0.13	0.19*
	PTGI Appreciation of Life	0.15	0 16	0.02	0.14
	F change (9,163)	***12.75***	***4.10***	***2.99****	***7.50***
	R^2 change	***0.26***	***0.10***	***0.07***	***0.17***
	F	***9.50***	***4.13***	***4.30***	***6.95***
	Adjusted R^2	**0.31**	**0.14**	**0.15**	**0.24**
Mothers (n = 99)					
Step 1	Leukaemia/Solid Tumour	-0.03	-0.01	0.02	-0.01
	Surgical Resection	0.17	0.20*	0.16	0.19
	Cultural Identity	0.21*	0.24*	0.19	0.23*
	F(3,96)	***3.27****	***4.21***	***2.36***	***3.77****
	Adjusted R^2	***0.06***	***0.09***	***0.04***	***0.08***
Step 2	PTGI Relating to Others	-0.14	-0.25	-0.24	-0.22
	PTGI New Possibilities	0.33*	0.32*	0.33*	0.35**
	PTGI Personal Strength	-0.15	-0.25*	-0.17	-0.21
	PTGI Spiritual Change	0.01	0.05	0.12	0.06
	PTGI Appreciation of Life	0.13	0.26	0.08	0.17
	F change(8,91)	***1.94***	***2.87****	***1.95***	***2.46****
	R^2 change	***0.09***	***0.12***	***0.09***	***0.11***
	F	***2.50****	***3.52***	***2.14****	***3.06***
	Adjusted R^2	**0.11**	**0.17**	**0.09**	**0.14**
Fathers (n = 66)					
Step 1	Years off Treatment	-0.26*	-0.25*	-0.26*	-0.28*
	CNS Tumour	0.33**	0.30*	0.38**	0.35**
	F(2,64)	***8.26***	***6.81***	***10.43***	***9.75***
	Adjusted R^2	***0.18***	***0.15***	***0.22***	***0.21***
Step 2	PTGI Relating to Others	0.05	0.17	0.04	0.10
	PTGI New Possibilities	0.26	0.51*	0.30	0.38*
	PTGI Personal Strength	-0.16	-0.23	0.02	-0.15
	PTGI Spiritual Change	0.23	0.06	0.17	0.17
	PTGI Appreciation of Life	0.13	-0.12	-0.09	-0.02
	F change(7,59)	***2.82****	***2.66****	***2.31***	***2.91***
	R^2 change	***0.15***	***0.15***	***0.12***	***0.15***
	F	***4.71***	***4.10***	***4.93***	***5.28***
	Adjusted R^2	**0.28**	**0.25**	**0.29**	**0.39**
Siblings (n =60)					
Step 1	Leukaemia	-0.37**	-0.28*	-0.24	-0.33**
	F(1,59)	***9.16***	***4.87****	***3.64***	***7.30***
	Adjusted R^2	***0.12***	***0.06***	***0.04***	***0.10***
Step 2	PTGI Relating to Others	0.24	0.22	0.20	0.24
	PTGI New Possibilities	0.01	0.22	0.22	0.16
	PTGI Personal Strength	0.06	0.04	-0.05	0.03
	PTGI Spiritual Change	0.09	-0.11	0.17	0.03
	PTGI Appreciation of Life	0.09	-0.02	-0.22	-0.03
	F change (6,54)	***2.58****	***1.65***	***1.38***	***2.08***
	R^2 change	***0.17***	***0.12***	***0.11***	***0.14***
	F	***3.88***	***2.23***	***1.77***	***3.06****
	Adjusted R^2	**0.22**	**0.11**	**0.07**	**0.17**

*p < .05, ** p < .01

Table 4.7. Comparisons of PTSD-history and no PTSD-history groups on posttraumatic growth in childhood cancer survivors, mothers and fathers

	No-PTSD History		PTSD History		
	M	**(SD)**	**M**	**(SD)**	***F***
Survivors	*n=138*		*n=14*		
Relating to Others	9.33	(6.04)	13.86	(4.75)	7.39**
New Possibilities	5.67	(4.74)	6.93	(4.10)	0.91
Personal Strength	5.36	(3.92)	7.50	(3.32)	3.88
Spiritual Change	1.73	(1.97)	3.33	(2.06)	8.87**
Appreciation of Life	4.96	(2.94)	6.40	(2.32)	3.43
Full-scale	26.90	(17.57)	36.13	(14.85)	3.84
Mothers	*n=73*		*n=15*		
Relating to Others	12.22	(6.02)	12.27	(4.59)	0.00
New Possibilities	5.70	(3.84)	6.13	(4.31)	0.44
Personal Strength	8.01	(3.32)	7.60	(3.33)	0.19
Spiritual Change	2.57	(2.15)	3.53	(1.92)	2.58
Appreciation of Life	6.30	(2.49)	7.00	(2.30)	1.01
Full-scale	34.47	(14.95)	36.53	(13.45)	0.25
Fathers	*n=51*		*n=6*		
Relating to Others	11.24	(5.67)	11.00	(4.47)	0.01
New Possibilities	4.45	(3.94)	7.67	(3.93)	3.58
Personal Strength	5.59	(3.30)	5.33	(3.01)	0.03
Spiritual Change	1.69	(2.02)	3.00	(3.29)	1.97
Appreciation of Life	5.65	(2.49)	6.67	(1.97)	0.93
Full-scale	28.61	(14.83)	33.67	(13.52)	0.63

**Note: Siblings are excluded from analyses as no siblings have meet PTSD criteria at any time point since diagnosis.*

*$p < .05$ **$p < .01$

Table 4.8. Percentage of survivors, mothers and fathers with and without a history of PTSD meeting moderate to great posttraumatic growth

	no PTSD History + Posttraumatic Growth **n (%)**	PTSD History + Posttraumatic Growth **n (%)**	X^2
Survivors	*n=138*	*n=15*	
Relating to Others	38 (27.5)	8 (53.3)	5.28*
New Possibilities	39 (28.3)	3 (20.0)	0.30
Personal Strength	51 (37.0)	9 (60.0)	4.06*
Spiritual Change	27 (19.6)	9 (60.0)	12.29**
Appreciation of Life	67 (48.6)	11 (73.3)	3.33
Mothers	*n=73*	*n=16*	
Relating to Others	36 (49.3)	7 (43.8)	0.04
New Possibilities	16 (21.9)	4 (25.0)	0.16
Personal Strength	45 (61.6)	9 (56.3)	0.01
Spiritual Change	25 (34.2)	6 (37.5)	0.15
Appreciation of Life	51 (70.0)	13 (81.3)	1.77
Fathers	*n=51*	*n=6*	
Relating to Others	17 (33.3)	2 (33.3)	0.00
New Possibilities	7 (13.7)	3 (50.0)	4.88*
Personal Strength	13 (25.5)	2 (33.3)	0.17
Spiritual Change	12 (23.5)	3 (50.0)	1.94
Appreciation of Life	26 (51.0)	4 (66.7)	0.53

**Note: Siblings are excluded from analyses as no siblings have meet PTSD criteria at any time point since diagnosis.*
*$p < .05$ **$p < .01$

CHAPTER 5
GENERAL DISCUSSION (PART 1)

5.0 Overview

The broad objective of Part 1 of this program of research was to evaluate the long-term psychosocial adjustment of an Australian sample of childhood cancer survivors, their parents, and their siblings. In line with current evidence (see Section 1.2.3 and Table 1.1), this adjustment was evaluated from a trauma perspective. Part 1 investigated the prevalence and severity of PTSD, PTSS, and psychological distress as well as the prevalence and strength of posttraumatic growth following childhood cancer. Part 1 provided family group comparisons of these outcomes both from a group (survivors, mothers, fathers, siblings) and family systems (full family units) approach, and investigated the relationships of PTSD and PTSS with posttraumatic growth and psychological distress. From these investigations, Part 1 of this program of research has provided novel contributions to the childhood cancer survivor literature contributing considerably to the existing knowledge-base. Specifically, this research has provided the first Australian data on trauma related outcomes in long-term survivors of childhood cancer and family members. Further, via the inclusion of adult siblings, Part 1 has not only contributed to the dearth of data on the long-term adjustment of this family group, but has also provided the first family based investigation to compare all four family groups (survivors, mothers, fathers, siblings) on the long-term adjustment of the measured outcomes. Part 1 has also provided valuable data that contributes to the small existing evidence base pertaining to the relationships and concordance of PTSD and PTSS within full family units – including siblings for the first time, and provides the first investigation (including both illness and non-illness trauma) into the family concordance of posttraumatic growth. Finally, investigations into the relationships between outcome measures (PTSD, PTSS and psychological distress, PTSD, PTSS and posttraumatic growth), has provided a novel contribution in its analyses of posttraumatic stress comorbidity and co-occurrence at the symptom and growth domain level. This discussion now turns to summarising the main findings, acknowledging methodological limitations, discusses future directions for this field of research, and outlines the implications of the findings.

5.1 Summary of the Findings of Part 1

5.1.1 PTSD, PTSS and Psychological Distress

The findings of Part 1 show that the majority of survivors, parents and siblings do not develop clinical levels of psychopathology following a childhood cancer experience, however a sub-group experience clinically significant levels of distress at some time point since diagnosis. Using

self-report measures and clinical interview, prevalence results (Study 1A) show survivors and parents in this Australian study report rates of PTSD since diagnosis to be similar to that reported by Kazak et al. (2004a), and within the broad range reported in other non-Australian childhood cancer survivor studies (see Table 1.1), as well as non-illness trauma (Green, 1994; Johnson et al., 2009). However, the few cases of current PTSD reported by survivors and parents, and no reported cases for siblings (either since diagnosis or current), contrasts with much of the existing research (e.g., see Table 1.1). The low prevalence of current PTSD also contrasts with the relatively high current prevalence rates of clinically significant PTSS, psychological distress, and the rarity of a complete PTSD symptom recovery. These findings indicate that although full current PTSD is unlikely for this long-term survivor and family cohort, a considerable subgroup of survivors, mothers, fathers and siblings will experience clinically significant levels of distress sometimes many years following cancer treatment.

Study 2 reveals a strong and predictive relationship between PTSS and psychological distress. Indeed, Studies 1A and 2 revealed a history of PTSD since diagnosis was the best indicator of current distress. Study 1A showed that almost all of respondents with a history of PTSD since diagnosis met at least one DSM-IV PTSD symptom cluster at the time of study participation, and Study 2 revealed that half of these respondents also met moderate to severe levels of psychological distress. Importantly however, while a history of PTSD since diagnosis does red-flag risk for ongoing distress, it was not a defining prerequisite as shown by the relatively higher prevalence rates of current PTSS (both the PTSD symptom clusters, and clinically significant levels of PTSS) and moderate to severe levels of current psychological distress.

Study 1B, in its comparisons of family groups on the severity and prevalence of PTSD, PTSS and psychological distress, confirmed that both parents, relative to survivors and siblings, were more likely to respond to the childhood cancer experience as traumatic. Relative to survivors and siblings, mothers were revealed to be most at risk of developing trauma related symptoms. However, few differences were confirmed between mothers and fathers, survivors and siblings, and between fathers and survivors and siblings. This was despite a consistent pattern in the data indicating mothers to be most at risk relative to all other family groups and siblings to be least at risk for developing these symptoms. Similarly, few differences were confirmed for psychological distress, although the data did indicate a different pattern of distribution to that of the trauma responses (both stress and growth). For example, although differences were not confirmed at a significant level, the data shows survivors to report greater severity and prevalence of moderate to great depression, anxiety and stress relative to other family groups. This is consistent with earlier reports suggesting survivors experience a range of ongoing stressors unique to their experience (Hudson et al., 2003;

Koocher & O'Malley, 1981; Recklitis et al., 2003). Of interest is the finding that siblings report relatively higher levels of stress than parents, and similar levels of anxiety to that reported by fathers. While this differs from reports of PTSS, these findings may reflect the sibling experience whereby they are often witness to intense distress in their parents, suffering in their brother or sister, family disruption, shifting family responsibilities, and parental absence (Alderfer et al., 2003, 2009).

The findings of Study 2 show that family group differences extend to the relationships between PTSS and psychological distress. This was particularly apparent for parents. Mother's PTSS was most likely to be associated with anxiety, while for fathers, intrusion and avoidance symptoms were most associated with stress and hyper-arousal symptoms were most strongly associated with anxiety. As shown in Table 1.1, survivor PTSS has been associated with a range of psychosocial adjustment problems, and these are reflected in Study 2 results with depression, anxiety, and stress all significant predictors of PTSS. In contrast, for parents, anxiety (both trait anxiety and generalized anxiety) is most often investigated and consistently reported alongside PTSS for both mothers and fathers. However in a study by Best et al., (2001), and in line with Study 2 findings, anxiety was a predictor of PTSS for mothers but not for fathers. Correlational analyses for survivors and siblings (Table 3.5) or comparison analyses between mothers and fathers (Table 3.2) revealed no gender differences on the measure of psychological distress (DASS-21). Therefore, the findings of Study 2 suggest that although a subgroup of all family members may respond to the childhood cancer experience as traumatic, and experience traumatic stress symptoms, this distress may manifest differently depending on family group membership.

5.1.2 Posttraumatic Growth

The investigation of posttraumatic growth enhances the limited and conflicting results from the childhood cancer survivor literature (Barakat et al., 2001; Best et al., 2001). Study 1A shows prevalence of moderate to great posttraumatic growth is reported at higher rates than the stress-deficit responses (PTSD, PTSS, psychological distress) especially the reports of a greater *Appreciation of Life*. While it is difficult to compare an outcome such as posttraumatic growth with a clinical disorder (see section 1.2.5), the overwhelming majority of childhood cancer survivors, their parents, and to a lesser extent their siblings do report at least moderate levels of posttraumatic growth from their cancer experience, and these positives are reported alongside stress deficit responses such as PTSS.

Study 1B compared family groups on the strength and prevalence of posttraumatic growth. Mothers were revealed to report most growth and siblings least growth following the childhood cancer experience indicating similarities in the familial distribution of the two trauma responses

(stress and growth). Findings confirmed that parents collectively report greater strength of posttraumatic growth than survivors and siblings, although prevalence findings revealed no difference exists between fathers and survivors or fathers and siblings. The lack of difference reported between fathers and survivors and siblings is consistent between both stress and growth trauma responses (although fathers were significantly more likely to respond to the childhood cancer experience as traumatic; DSM-IV Criterion A). An important finding in the data, although not statistically significant, indicates fathers actually report lower levels of current PTSD, PTSS and posttraumatic growth than survivors. For fathers, both PTSS (Table 3.4), and posttraumatic growth (Table 3.6) was associated with less time since treatment indicating that fathers may recover from the traumatic experience at a faster rate than other family groups, particularly mothers. A possible explanation may be that compared to mothers, fathers may be less involved in the decision making process and hospital-based care of their child during the treatment process, as well as in their follow-up care, especially as survivors transition into adulthood and begin to assume greater responsibility for their own health care needs (Alderfer et al., 2003; Goodenough et al., 2008).

Study 2 shows posttraumatic stress (PTSD, PTSS) and posttraumatic growth share a positive predictive relationship across family groups indicating that these two trauma responses do co-exist. Although a causal link was not determined, findings are in line with the theoretical premise that stress is required to induce growth (Tedeschi & Calhoun, 2004b). In line with past reports (Helgeson et al., 2006) this relationship was strongest between posttraumatic growth and the PTSD symptom of intrusion, although for mothers, posttraumatic growth was a stronger predictor of avoidance symptomatology. Further differences between family groups existed. For parents, *New Possibilities* shared the strongest relationship with posttraumatic stress. This contrasts with survivors and siblings where few posttraumatic growth categories were significant individual predictors of PTSS, although survivors with a PTSD history since diagnosis, relative to those with no PTSD history, reported higher levels and prevalence of moderate to great *Relating to Others*, *Personal Strength* and *Spiritual Change*.

Of particular importance to the understanding of the relationship between posttraumatic growth and PTSS is the indication that some categories of posttraumatic growth share a negative relationship with PTSS. This may indicate that growth experienced in some domains, may either reduce distress, or may evolve because of a lesser degree of distress experienced. This was most apparent for parents, where *Personal Strength* was shown to be a consistent negative predictor of PTSS, and for mothers this also included the growth category of *Relating to Others*. The data also indicates that *Relating to Others* is a negative predictor of *Avoidance* in survivors. *Relating to Others* may partially reflect indices of social support, social or family functioning, social

incompetence or social constraints. Poorer levels of these social indicators are associated with increased PTSS (see Table 1.1). Higher reported *Relating to Others* may indicate better functioning in social and family domains, particularly for mothers. In a different sense, *Personal Strength*, which has at its essence a sense of greater ability to deal well with future adversity (Tedeschi & Calhoun, 2004b), may be associated with a decrease in PTSS due to it reducing persistent anxiety often associated with childhood cancer survivorship (e.g., fear of relapse). Persistent anxiety or current threat perception is a core factor in persistent PTSD and PTSS (Ehlers & Clark, 2000).

5.1.3 Full Family Unit Investigations: Relationships and Concordance on PTSD, PTSS, and Posttraumatic Growth

Study 1C revealed moderate positive relationships between most family members on PTSS and posttraumatic growth. However, while family concordance rates for both trauma responses (stress, growth) are generally low, the DSM-IV PTSD B-Symptom cluster (since diagnosis), and the posttraumatic growth domain of a greater appreciation of life was shared by at least two family members in at least half of the families investigated. Concordance rates are highest between parents, and between survivors and at least one parent. Lowest concordance rates were reported between survivors and siblings. Exploratory regression analyses suggest that PTSS relationships are strongest between survivors and fathers (although mothers were also a significant predictor of survivor PTSS), and between siblings and mothers. Maternal PTSS was shown to be an indicator for increased PTSS among all other family members. This differs for posttraumatic growth, where analyses reveal the strongest relationship to be between fathers and siblings. Importantly, although concordance rates are generally low, the findings show that some trauma responses are shared at relatively high rates within the family system suggesting that a family systems approach in future research and treatment of childhood cancer survivors and their families may be warranted.

5.2 Methodological Considerations and Future Directions

In interpreting the findings of Part 1, there are a number of methodological considerations that must be taken into account. Most notably, this research was within a single institution resulting in small sample sizes, thereby limiting the generalisability of findings.

The small sample size was particularly concerning for the father and sibling groups, where for example, post-hoc analyses revealed only a 30% power to detect a small-moderate effect at the conservative .01 alpha level (as used in these comparisons; see Table 3.3). This is relative to a 71% power achieved for survivor and mother comparisons. When the significance level was increased to the more conventional alpha of.05, and effect size was increased to medium, power increased to 87%

for the father and sibling analyses, and 99.7% for survivor and mother comparisons. This is likely to explain the few findings of statistically significant difference, despite data trends indicating a consistent difference between groups.

The small sample size resulted in heterogeneity regarding cancer diagnosis and treatment intensity, with an over-representation of leukaemia and solid tumour diagnoses, and an under-representation of CNS tumours relative to cases registered with NSW long-term follow-up clinics (see section 2.2.1). Results of correlational analyses suggest that differences in psychological outcomes exist according to cancer diagnosis, treatment received, or occurrence of relapse, although these varied relative to family group membership (survivor, mother, father, sibling; see Tables 3.4 to 3.6). While there have been equivocal findings throughout the literature on the relative importance of these objective variables, findings from the Childhood Cancer Survivor Study[34], indicate that cancer and treatment related variables are important risk factors for distress (Zeltzer et al., 2009). While this may be the case, evidence suggests that it is the subjective interpretation of the experience that is most important for determining outcome (Taieb et al., 2003).

The cross-sectional design employed by Part 1, whilst providing a snap-shot of outcome and relationships, does not establish causality or the direction of the relationship. For example, Study 2 shows a relationship exists between PTSS and psychological distress, although it was not determined whether psychological distress follows PTSS onset as was shown by Barakat et al., (1997, 2000) in their longitudinal investigation. This is also the case with regard to the relationship between PTSS and posttraumatic growth. Furthermore, the cross-sectional design relies on retrospective accounts of symptoms, sometimes experienced many years ago and is therefore subject to recall biases. This was particularly the case for PTSD and PTSS history. Also with regard to PTSD and PTSS, although the questionnaire (IES-R) and the interview (SCID) requested respondents to answer questions in relation to the most traumatic aspects of the cancer experience, past and intervening trauma outside of the cancer experience was not assessed. Consequently it is difficult to rule out that other non-cancer related traumatic events may have influenced symptom responses. With regard to posttraumatic growth, there is currently no theoretical or empirical evidence that provides clinically meaningful cut-off scores as is available for the measures of PTSD, PTSS and psychological distress. Consequently, the cut-off scores used to depict “no-low” and “moderate-great” growth in this body of research is an arbitrary one and should be interpreted as such.

It was beyond the scope of this program to include non-illness trauma exposed controls for each family group. While this is a limitation, findings are comparable to previous studies,

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[34] The Childhood Cancer Survivor Study (CCSS) is a large multi-centre study collaborating with 26 treatment centres across the United States and Canada (www.ccss.stjude.org).

particularly with regard to family distribution of outcome. Past comparison research including a non-illness control group generally supports the findings that mothers of survivors report higher PTSD and PTSS than mothers of control groups, while comparisons with survivors generally show no difference (Barakat et al., 1997; Gerhardt et al., 2007; Kazak et al., 1997, 2010; Phipps et al., 2005). In interpreting these survivor results, an important consideration is the control group. For example, 3 of the 5 studies (Barakat et al., 1997; Kazak et al., 1997; Phipps et al., 2005) use the same control population. In line with large scale prevalence investigations (e.g., Rosenman, 2002), the majority of these control participants have experienced a moderate to severe stressor, and refer to this stressor when completing the PTSS measure. However, prevalence information was not provided on the type of trauma experienced, the number of traumatic experiences, and the time since trauma, all of which can influence onset and severity of PTSD and PTSS (Rosenman, 2002). In the remaining two investigations (Gerhardt et. al.,2007; Kazak et al., 2010), no information on trauma exposure was provided, although in this investigation, survivor PTSD is only marginally above general population prevalence (Rosenman, 2002; Stein et al., 1997) indicating a low trauma survivor group. An important note however, is that PTSD and PTSS, as reported by Part 1, is a real consequence of the cancer experience, and in some cases this requires clinical attention.

In order to address the above mentioned limitations, future large cohort studies are necessary, particularly within the Australian context. Larger cohorts may help to verify the low reported levels of current PTSD relative to other non-Australian studies, and findings pertaining to posttraumatic growth, particularly with regard to its relationship with PTSS, and whether, as indicated in Study 2, some categories of posttraumatic growth are associated with less distress. Furthermore, larger Australian studies may allow for the investigation of long-term adjustment of survivors and their families who live in rural or remote regions compared to their city counterparts. At the CCCBD, nearly 60% of families with a child being treated for cancer come from rural or remote regions of Australia, as well as the South Pacific region (Goodenough et al., 2008). Given the extensive differences on a range of important variables (e.g., access to health care and potential educational and occupational discriminations), future large-scale investigations within the Australian context are important (Cohn et al., 2003). Finally, demographic and treatment variables are generally not found to be reliable predictors of PTSD or PTSS for survivors of childhood cancer or their parents (Taieb et al., 2003). In line with this, the current research revealed inconsistencies in correlates and predictors between the larger study (Study 1A, Study 2) and the smaller full-family unit investigation (Study 1C). As current and previous data is mostly derived from single institutional studies, large scale multi-centre studies will help to verify whether the demographic and

treatment variables reported as risk factors or correlates by this research are upheld, helping to better understand and profile risk for PTSS, PTSD and posttraumatic growth.

In addition to larger cohort research, longitudinal investigations that track psychosocial adjustment from diagnosis to survivorship will also help to address the limitations, map psychological risk profiles throughout the cancer trajectory (diagnosis, treatment, survivorship), help to determine specific periods of risk, and shed further light on family system outcomes. Longitudinal investigations may also further understanding of the stress-growth relationship, particularly with regard to causality. For example, whether higher reported growth in one area, will result in lower PTSS, or whether lower PTSS will result in higher growth. Importantly, longitudinal investigations may also help to red-flag participants who are most likely to become lost to follow-up.

A further consideration is the help received by survivors in completing the self-report questionnaire. A proportion of survivors and siblings received assistance with completing Questionnaire Booklet (Part 1). This mostly came from parents, although for a few respondents help was received by a sibling, spouse or other family member. This help was mostly obtained in answering or remembering demographic and treatment details (51 survivors, 9 siblings). 16 survivors and 1 sibling also reported difficulty in understanding questions. Unfortunately, these questions were not specified, and therefore relevance to this dissertation was unable to be ascertained (Questionnaire Booklet – Part 1 included additional questionnaires used in other studies conducted by the CCCBD). 5 survivors received help for other reasons (emotional support, parents offered), and 4 survivors indicated that they received help from a parent in completing all of the questions. However, again, information is lacking as to whether the parent completed the questionnaire in the absence of the survivor, or if the parent acted as a scribe only. This question is important as it would determine the implications of the parental help with regard to interpreting results (parent proxy or parental influence/bias). The question of help received is one not often asked in survivor research but is one that has particular relevance not only in interpretation of findings, but also in understanding the functioning of the survivor cohort. Some cancers, and cancer treatments are known to cause cognitive deficits (see Appendix 1B), and anecdotal reports from the CCCBD indicate that some adult survivors of childhood cancers continue to have a high dependency on their parents in a number of areas of everyday functioning. Future research is needed to determine the level and implications of this dependency.

Methodological differences between Part 1 and previous studies may explain the low current PTSD prevalence rates. While a strength of this program of research is the investigation of long-term survivor cohorts, this does contrast with earlier research (see Table 1.1). Part 1 has recruited a substantially older survivor cohort (at least 16 years, M=26.8, SD=6.9 at time of interview), with a

corresponding greater length of time since cancer treatment for all family groups (M's=16.5 to 18.5 years). Most previous studies have a mean time since treatment of around 3 to 5 years, and younger aged cohorts (e.g., Alderfer et al., 2005; Kazak et al., 2004a; Manne et al., 1998; 2002; Pelcovitz et al., 1996, 1998). It is well documented that PTSD dissipates with increasing time since trauma exposure (Jurbergs et al., 2009; Yule, 2001), however it is also likely that as time goes on, more survivors and their family members will become lost to follow-up. Indeed, more than 40% of childhood cancer survivors identified from the CCCBD's clinic database meeting participation criteria for Part 1 had no verifiable contact details[35]. It is likely that a considerable proportion of survivors in this group exhibit high levels of distress, actively avoiding reminders of their cancer experience and therefore being less likely to return to treatment centers' for long-term follow-up care (Kazak et al., 2004a). Importantly however, a more recent US study of an adult long-term survivor cohort (*M* off treatment = 13.6 years; *M* age = 24.8 year) still reports current prevalence of PTSD and the symptom clusters to be substantially higher than reported by this Australian investigation (Rourke et al., 2007). While further studies are needed with long-term survivor and family groups to verify these findings, findings suggest that the relatively low levels of current PTSD are due to something more than age and years since treatment. A likely consideration is the potential confounding of reports of distress with reports of growth, as individuals reporting posttraumatic growth may be more likely to deny negative consequences (Tedeschi & Calhoun, 2004b). A final consideration may be the healthcare context. As this is the first investigation of Australian childhood cancer survivors and families, it may be likely that associated stressors such as access to healthcare, insurance, and financial implications are likely to be different to that in other comparable countries, such as the US.

5.3 Implications of Part 1 of the Program of Research

The findings of Part 1 have several implications with respect to screening and intervention. Most importantly, Part 1 has shown that, although the majority of long-term childhood cancer survivors, parents and siblings show no evidence of clinical psychopathology as a consequence of the cancer experience, a sub-group experience ongoing distress sometimes many years following the end of treatment. These findings underscore the need for screening of PTSD, PTSS, and psychological distress, and where evidence of impaired psychosocial functioning exists, clinical intervention is imperative. The finding of high PTSS prevalence, particularly for intrusive symptomatology, supports the necessity of symptom screening. The symptom clusters reported are

[35] As survivor consent was required prior to contacting parents and siblings, this may have also restricted potential recruitment of family groups (See section 2.1.3).

severe enough to impair functioning[36] and the symptoms, as well as the disorder, are associated with psychological comorbidity. Furthermore, early PTSS screening will likely be useful in identifying survivors and family members high in avoidance symptomatology, allowing for early intervention and education that will potentially reduce long-term distress.

Secondly, screening and intervention must be inclusive of all family members, and ideally this should begin at diagnosis to identify individuals most at need for clinical intervention, and to reduce the negative impact of childhood cancer on the full family unit. The identification and treatment of vulnerable individuals and their families early on in the treatment and survivorship periods will have long-term benefits not only to the affected individuals, but also to the health care system as a whole. Mothers, who are at highest risk, are in greatest need for intervention, especially considering that their functioning may have the strongest impact on the family. Although siblings are less likely to experience a traumatic response, an important minority are at risk, most particularly for the PTSS symptoms of intrusive re-experiencing and general levels of stress. Siblings are likely to have specialized needs, some of which may be important to address separately to other family members (e.g., possible feelings of guilt, or resentment towards other family members).

Finally, posttraumatic growth is reported by all family groups, and is an important adjustment consideration particularly as posttraumatic growth is reported to be associated with greater well-being and quality of life (Alisic et al., 2008; Tedeschi & Calhoun, 2004b), as well as greater distress (Cadell et al., 2003; Tedeschi & Calhoun, 2004a). Of clinical importance is the understanding of what categories of growth are indicative of positive or negative adjustment. While the findings of Part 1 are in need of verification and further investigation, indices of posttraumatic growth may highlight areas of functioning that are in need of intervention. For example, parents, with low levels of self-reported *Personal Strength* may red-flag interventions to promote self-efficacy in the management of cancer related long-term risk-factors. Low reports of *Relating to Others* may suggest necessary intervention in the domains of social and family functioning. Similarly, high reports of *New Possibilities* may be an indication of greater disruption to life causing greater life change and therefore a risk-factor for greater distress. Of particular interest is the finding that for survivors, *Relating to Others* may be associated with less avoidance symptomatology, possibly having clinical relevance in the prevention of survivors and family members becoming lost to follow-up.

In summary, evidence from Part 1 suggests that for some survivors and family members, distress may persist for many years without adequate intervention, and this may be an important

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[36] Impairment of functioning and period of symptom experiencing of at least 1 month was a determinant for symptom presence (see Section 2.1.4B)

consideration in providing evidence based justification for the allocation of additional resources in the already stretched public health system. This dissertation will now turn to investigate the applicability of a theoretical and treatment model of PTSD to childhood cancer survivorship in order to further understand risk-factor profiles and to provide an evidence-based theoretical treatment framework.

Part 2

A Test of the Ehlers and Clark (2000) Cognitive Model of PTSD Applied to Childhood Cancer Survivorship

SCIENTIFIC PUBLICATIONS AND PRESENTATIONS RELATING TO PART 2

Sections 6.1 and 6.2 are included in a theoretical paper currently undergoing the review for publication in the journal 'Psycho-Oncology'.

The theoretical application of the Ehlers and Clark (2000) Cognitive Model of PTSD has been presented at numerous national and international scientific meetings to date:

(1) 29th National AACBT Conference, Sydney, 18-23 October, 2006.

(2) TOW Research Prize: Prince of Wales Hospital, Sydney, 27 October, 2006.

(3) 12th Annual conference: Australasian Society of Traumatic Stress Studies, Perth, 15-17 September, 2005.

(4) 36th Congress of the International Society of Paediatric Oncology, SIOP, Oslo, Norway, 16-19 September, 2004.

(5) 34th European Association for Behavioural & Cognitive Therapies, Manchester, UK, 8-11 September, 2004.

(6) 7th World Congress of Psycho Oncology: Copenhagen, Denmark, 23-28 August, 2004.

CHAPTER 6: INTRODUCTION

6.1 Childhood Cancer and PTSD: The Need for a Theoretical and Treatment Model

As shown in Section 1, a posttraumatic stress framework may be valuable for not only understanding posttraumatic stress following childhood cancer, but also in understanding a range of long-term psychosocial adjustment outcomes such as depression and anxiety. However, the predominant focus within the literature to date has been on the prevalence of PTSD symptomatology rather than evaluating symptom onset or maintenance against any particular theoretical model. This theoretical gap has two important consequences. Firstly, it restricts the application of knowledge gained from other trauma areas to childhood cancer, and secondly, scientifically validated intervention and treatment strategies for this population continue to be sparse and devoid of guidance from testable theory.

An exception to this is the work carried out by Kazak and colleagues (Kazak et al., 1999, 2004b, 2006) who have developed a context specific intervention model of pediatric medical traumatic stress. Providing a developmentally sensitive framework within a family context Kazak et al's model provides a holistic account of traumatic stress responses within a paediatric medical setting. However, while subjective interpretation of the experience is an important aspect of the model, it lacks specificity with regard to cognitive processes known to underlie PTSD and its symptoms. Indeed, of the many different theoretical accounts for the onset, and treatment of PTSD (e.g. cognitive, behavioural, social, biological), cognitive based frameworks have received the most empirical support (Tarrier et al., 2006).

Cognition is fundamental to PTSD via the *perception* of serious threat criterion, and many symptoms having a cognitive basis (flashbacks, memory distortions, fear responses). Cognitive theories of PTSD include the *Fear Network Model* (Foa et al., 1989), and the *Dual Representation Theory* (Brewin et al., 1996). However it is the Ehlers and Clark (2000) *Cognitive Model of PTSD* that is perhaps regarded as the most comprehensive account of the aetiology, persistence, and treatment of PTSD (Brewin & Holmes, 2003), with the cognitive factors proposed by the model reported to be better predictors of outcome than the predominantly non-cognitive factors reported elsewhere (Ehring et al., 2006).

While a strength of the Ehlers and Clark cognitive model is the incorporation and expansion of empirically derived evidence to date (Brewin & Holmes, 2003), it is the model's central proposition that may prove most pertinent to cancer populations. In addressing an apparent temporal contradiction arising from the DSM-IV classification of PTSD as an anxiety disorder, Ehlers and Clark propose PTSD results from perception of *present threat* of a *past* event. For childhood cancer

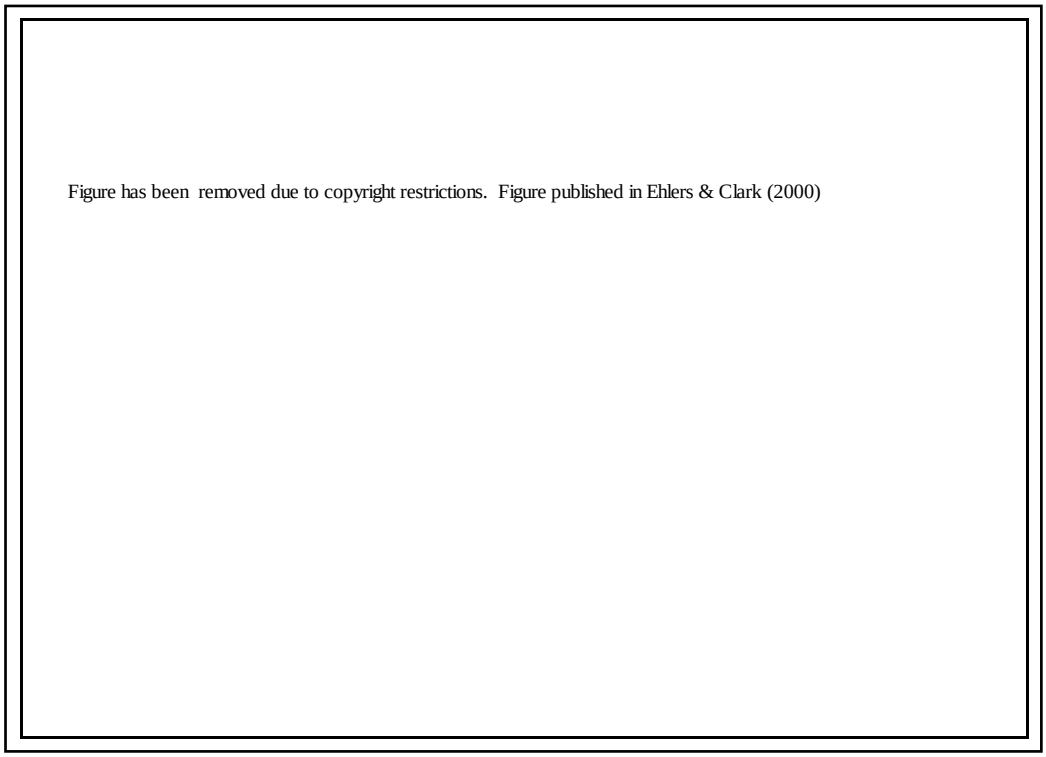
survivors, some aspects surrounding cancer-related PTSD may not necessarily be anchored in memory. For example, in addition to past events (e.g. repeated medical procedures), there are future threats (e.g. relapse, latent treatment effects) which may perpetuate PTSD symptoms (e.g., fear of relapse maintaining intrusive thoughts or hyper-vigilance), and this needs to be accommodated both theoretically and clinically in a treatment model.

Providing a testable framework for how specific *symptoms* of PTSD may arise, Ehlers and Clark draw upon an evidence-base from trauma groups as diverse as assault (Halligan et al., 2003; Kleim et al., 2007), imprisonment (Ehlers et al., 2000), accident (Ehring et al., 2006), and trauma witness (Laposa & Alden, 2003). The model indicates developmental relevance, having been applied to child survivors of road traffic accidents (Ehlers et al., 2006; Stallard, 2003), injury (McKinnon et al., 2008), young refugees (Vickers 2005), and traumatic injury (McKinnon et al., 2008). Hence while developed and tested outside the context of chronic life-threatening childhood illness, it is argued that the concepts proposed by Ehlers and Clark are generalisable to the childhood cancer experience and survivorship (Suneson et al., 2004). Indeed, this potential applicability of the model has been briefly suggested elsewhere (Bruce, 2006), with some general aspects already applied to survivors diagnosed with adult cancers (Black & White, 2005), and stroke (Field et al., 2008). The model will now be overviewed with respect to evidence supporting its application to childhood cancer.

6.2 The Ehlers and Clark Cognitive Model of PTSD

Ehlers and Clark propose PTSD onset and maintenance reflects three predominant sets of interacting processes: (1) cognitive appraisals which are excessive and negative, (2) dysfunctional cognitive and behavioural strategies for controlling threat perception and stress symptoms, and (3) trauma memory deficits. Figure 6.1 shows a diagrammatic account of the Ehlers and Clark Cognitive Model of PTSD which summarises how these processes are proposed to fit within the model. These will be outlined in turn followed by a brief commentary on the cognitive phenomenon *mental defeat* which is also incorporated within the model.

Figure 6.1. The Ehlers and Clark (2000) Cognitive Model of PTSD.



6.2.1. Cognitive Appraisals

The DSM-IV criterion for defining an event as traumatic embraces the idiosyncratic meaning assigned to a traumatic experience which may lead to feelings of "intense fear, horror, or helplessness" and peritraumatic appraisal (e.g. "I am going to die"). Individuals developing PTSD often present with beliefs more negative in nature than those held by individuals who do not develop PTSD - even after exposure to similar trauma (Ali et al., 2002). The Ehlers and Clark (2000) model considers these cognitive appraisals in three categories: those about the event (e.g., "I could have been killed"), those addressing peri-trauma behaviour/feelings (e.g., "I made things worse by my actions"), and those concerned with post-trauma sequelae (e.g., "my life is ruined"). If cognitive appraisals in any of these three areas are exceptionally negative, difficulty may arise with maintaining a sense of trauma 'in the past', hence fostering perceptions of serious, current threat. The postulated mechanism is that excessive negative appraisals maintain symptoms of heightened arousal - taking the form of strong emotional and cognitive responses, including intense fear, guilt, anger, depression, or shame, and encourage the use of dysfunctional coping strategies (see section 6.2.2) to control threat perception. These symptom appraisals may subsequently shape other

unhelpful thoughts (e.g., “I’m going mad”, “I’ve changed for the worse”), potentially reinforcing existing appraisals and generating further negative beliefs (Ehlers & Clark, 2000).

There is wide support for the importance of appraisals in the onset and persistence of PTSD, with evidence suggesting that appraisals better predict outcome than more objective event-related measures (Ali et al., 2002; Ehlers et al., 1998), and with tests of the model showing appraisals to correlate with PTSD severity, and symptom persistence (Dunmore et al., 2001; Halligan et al., 2003). This includes appraisals not event-specific but which surround or stem from the trauma, such as self-blame (e.g., own behaviours/emotions caused or exacerbated trauma) (Laposa & Alden, 2003), perception of others’ reactions (e.g., others apportion blame or treat differently following trauma) (Ehlers et al., 2000), overgeneralisation from trauma to other life situations (e.g., negative beliefs about self and world) (Dunmore et al., 2001), and interpretation of trauma sequelae including stress-related symptoms (e.g., flashbacks as evidence of losing sanity) (Dunmore et al., 2001; Ehlers et al., 2000).

6.2.1.1 Appraisals and Childhood Cancer

Appraisals of the type highlighted by Ehlers and Clark have been documented in the childhood cancer literature. Beliefs about cancer-related life threat and treatment intensity are one of the few cognitive factors formally investigated as a predictor of long-term psychosocial adjustment in survivors. Consistent with non-illness trauma, these appraisals have been found to be more important in predicting PTSD outcomes than objective parameters indexing curative cancer treatment and prognosis (Taieb et al., 2003). In addition, future-related fears after cure (fear of relapse, second malignancies, poor long-term health) have been associated with long-term adjustment problems, including PTSD (Stoppelbein et al., 2006), and often cited as predominant concerns for survivors (Mattsson et al., 2007; Weiner et al., 2006; Zebrack & Chesler, 2001).

Appraisals in domains other than perceived treatment intensity, life threat and future related fears have received much less, if any attention. This is despite reports from young adult survivors cognitively evaluating themselves as ‘different from my peers’. While some of these self-beliefs may be positive (e.g., feel more mature, greater life purpose), others are negative and include relatively poorer self-image, lower self-worth and gloomier outlook (Seitzman et al., 2004; Zebrack & Chesler, 2001), as well as a belief in having changed for the worse (relative to imagined pre-cancer baseline potential). The latter includes beliefs that cancer and treatment are directly responsible for a reduced capacity to learn and poorer employment opportunities (Mattsson et al., 2007). Compounding the impact of these appraisals is the ongoing nature of the cancer experience,

with routine consults with long-term follow-up clinics becoming perpetual reminders of cancer as a cause of existing concerns and lifelong threat.

Therefore, in line with Ehlers and Clark's model, many of the events following cancer diagnosis in childhood, while ultimately leading to a medically defined cure, may strengthen existing negative beliefs in certain individuals, and in turn create or perpetuate new appraisals which may be excessive and negative.

6.2.2. Cognitive/Behavioural Strategies

As efforts to manage distressing PTSD symptoms, various cognitive and behavioural strategies may be spontaneously employed. These often have maladaptive outcomes, by serving to ameliorate distress in the short-term but actually maintaining PTSD in the long-term. This may be due to "here and now" strategies preserving a trauma focus and preventing more adaptive cognitive integration of trauma memory within past experience (see Section 6.2.3, Trauma Memory Deficits).

Cognitive strategies include thought suppression (e.g., to control intrusive thoughts), rumination (e.g., perseverant thinking without effort to alleviate concomitant distress), and dissociation (e.g., disconnecting self from conscious awareness and event impact). Behavioural strategies can include direct avoidance of trauma cues (e.g., persons, places), assumed safety behaviours (e.g., to minimise likelihood of feared events occurring), and 'escape' (e.g. substance abuse, gambling). Studies indicate that PTSD symptom severity correlates strongly with reported use of these cognitive and behavioural avoidance strategies (Clohessy & Ehlers, 1999; Dunmore et al., 2001; Ehring et al., 2008; Kleim et al., 2007; Steil & Ehlers, 2000), which is perhaps unsurprising given that avoidance is a DSM-IV criterion symptom cluster. Nonetheless, both cognitive and behavioural avoidance have been found to have detrimental effects on appropriate trauma memory formation and remission of PTSD symptoms (Steil & Ehlers, 2000).

6.2.2.1. Cognitive/Behavioural Strategies and Childhood Cancer

Some reminders of past treatment experiences are difficult for survivors to avoid (Kangas et al., 2002). For example, in addition to the physical reminders of treatment and medical late effects, there are many internal and external cues. Many patients are aware of anniversaries such as the date of their diagnosis or treatment cessation, in addition to locations (e.g., hospitals), people (e.g., doctors), and sensory stimuli (e.g., hospital smells). There is also exposure to news bulletins (e.g. celebrity cancer diagnosis/death), and cancer diagnoses in significant others. All of these cues can potentially elicit intrusive re-experiencing and hyper-arousal symptoms in some patients (Cella & Tross, 1986).

While cancer-related stimuli are potentially omnipresent, Stuber and colleagues (1997) reported more than 20 percent of survivors sought to avoid reminders. Some strategies were behavioural (e.g., avoiding hospitals, conversations), and others cognitive (e.g., thought suppression). Reluctance to revisit a cancer experience was cited by nearly half of families declining to participate in research (Kazak et al., 2004a). This suggests avoidance is a prominent coping strategy which may underestimate the prevalence of PTSD-related problems with the most distressed families opting out of studies.

Compared with overt behavioural strategies, research with childhood cancer survivors is sparse concerning the use of specific cognitive coping elements proposed by the model, in particular rumination and dissociation. However, the current authors speculate that rumination may be partially reflected in self-reported cancer-related worries and fear of cancer recurrence, which are reported as important contributors to psychosocial adjustment problems (Zebrack & Chesler, 2001). Additionally, some survivors report feeling numb or emotionally void when thinking about their cancer (Stuber et al., 1996), possibly indicating dissociation is a learned adaptive response style. It is clear that further research into such cognitive strategies is warranted, with the model providing a useful framework.

6.2.3. Trauma Memory Deficits

PTSD is often associated with memory disturbance, such as poor intentional recall, enhanced unintentional recall (intrusive thoughts, flashbacks), robust trauma memories and triggers (memories resistant to change even when known to be incorrect), and the continued perception of current threat to past trauma (absence of a time context). In accounting for these memory disturbances, Ehlers and Clark suggest that under extreme stress (e.g., time of trauma), data-driven processing (e.g. of sights, sounds, physiological states) is enhanced as attentional resources focus on novel sensory detail. Commensurate with limited attentional capacity models (Brewin et al., 1996), higher-order conceptual processing during trauma (elaboration and contextualisation of the event in time, place and theme) will be limited as proportionally more cognitive resources are allocated to data-driven processing.

Ehlers and Clark propose that many symptoms of PTSD-related memory disturbance are explained via this dual encoding hypothesis (enhanced data-driven sensory processing versus impaired higher-order conceptual processing). For example, difficulties in subsequent intentional memory recall are presumed to reflect limited higher order processing capabilities, specifically poor autobiographical memory integration accounting for memory disorganisation, poor temporal order and a lack of time context, and missing information. The increase in unintentional recall (intrusive

thoughts) is explained by increased data-driven sensory processing, with correspondingly poor anchoring of trauma memory autobiographically. Similar mechanisms are evoked to account for the robust nature of traumatic memories. Weak autobiographical links to other information prevent access to, and modification of traumatic memories, while the absence of the time context helps to maintain a continued perception of serious, current threat. Supporting these memory aspects of the model, evidence of memory deficits and incomplete cognitive processing during trauma have been positively related to PTSD severity (Cavenett & Nixon, 2006; Dunmore et al., 2001; Ehlers et al., 2000; McKinnon et al., 2008).

6.2.3.1. Trauma Memory Deficits and Childhood Cancer

Of the processes postulated in the Ehlers and Clark model as contributing to persistent PTSD, cognitive processing and memory formation at the time of a child's cancer diagnosis and treatment are the least investigated. This is a significant knowledge gap, especially for predicting long-term PTSD outcomes. Even so, from the limited studies available, the precision of recall of painful cancer treatments seems inversely related to the level of reported distress from those procedures, i.e. poorer recall associated with greater current distress (Chen et al., 2000). This suggests that some cancer treatments may evoke extreme distress with subsequent attentional capacity deficits consistent with those proposed by the model

For children diagnosed with cancer, many events may be highly distressing leading to potential deficits in higher order memory processing and enhanced data-driven sensory focus. These include being informed of a cancer diagnosis, enduring repetitive invasive painful medical procedures (Chen et al., 2000; Green et al., 1997), psychosocial trauma from hospital admissions (Hedstrom et al., 2003), or being physically restrained by a parent for a medical procedure – reported as more stressful than the procedure itself (Steward et al., 2004). The model provides a conceptual and empirical framework to forward research in the memory processing domain.

6.2.4 Mental Defeat and Childhood Cancer

In addition to the three sets of processes described above (i.e. appraisals, dysfunctional strategies, trauma memory deficits), Ehlers and Clark outline another cognitive factor proposed to influence the onset and maintenance of PTSD, and which may have particular relevance to childhood cancer: the phenomenon of mental defeat. Mental defeat is a descriptor for perceived loss of psychological autonomy, and feelings of 'not being human'. The model proposes that mental defeat seriously challenges perceptions of self-worth and self-efficacy, leading to excessive negative appraisals such as a belief of inability to act effectively in the face of danger (Brewin & Holmes,

2003; Ehlers & Clark, 2000). Children treated for cancer may be at particular risk for mental defeat styles of thinking, due to being minors with little perceived control or consent over treatment (particularly if subjected to physical restraint or sedation during procedures).

6.2.5 Summary and Limitations of the Literature

The above discussion proposes that many of the cognitive processes outlined by Ehlers and Clark (2000) as leading to the onset and persistence of PTSD have been and can be observed in the childhood cancer survivor population, although the vast majority of these processes are yet to be formally investigated. Being a broad scoped model, Ehlers and Clark have incorporated and expanded upon many of the cognitive aspects known to precipitate or maintain PTSD, however to date no studies have applied the three predominant processes of model to the life-threatening illness context - specifically childhood cancer. This is necessary for the development of evidence-based prospective clinical interventions for the subgroup with long-term clinical as well as subclinical presentations of PTSD.

6.3 The Ehlers and Clark Cognitive Model and Posttraumatic Growth

As shown in Study 2 (Chapter 4), posttraumatic stress and posttraumatic growth share a positive relationship. Both are known to arise following a highly stressful or traumatic experience, and both are widely viewed as having a cognitive underpinning (Ehlers & Clark, 2000; Park & Helgeson, 2006). However, do the same factors proposed to account for the onset and maintenance of PTSD also apply to posttraumatic growth? While existing theories have adopted many of the concepts developed from understanding posttraumatic stress outcomes, none have investigated these outcomes from the same posttrauma theoretical framework. It is argued that in doing so, the relationship between these two outcomes may be further elucidated.

Of the proposed theories of posttraumatic growth, a vast majority emphasise the role of cognitive processing (Park & Helgeson, 2006; Park et al, 2008a; Tedeschi & Calhoun, 2004b). For example, growth in the aftermath of trauma is thought to arise from cognitive processes such as rumination, meaning generation, and positive re-appraisal (Tedeschi & Calhoun, 2004b). Rumination, initially an automatic process, becomes more effortful as traumatised individuals search for meaning or re-appraise their changed life circumstances in an attempt to rebuild assumptions or belief systems violated by the traumatic experience and construct new post-trauma schemas (Janoff-Bulman, 2004; Joseph & Linley, 2006; Park et al, 2008b; Tedeschi & Calhoun, 2004b). These accounts of growth generation are closely based on those proposed by cognitive theorists in the explanation of PTSD (e.g., Horowitz, 1986; Janoff-Bulman, 1992), although the re-appraisal process

may be in opposite directions. For example, negative appraisals developed following trauma may lead to and maintain PTSD (Ehlers & Clark, 2000), while it is the positive appraisals that are associated with posttraumatic growth (Park et al., 2008a; Schroevers & Teo, 2008).

While positive re-appraisal or meaning generation may lead to posttraumatic growth, these processes help the traumatised individual to make sense of the trauma allowing previously incongruent information to be incorporated into existing cognitive structures (Horowitz, 1986; Lepore et al., 2000). This cognitive incorporation of the traumatic experience is a key treatment goal for the reduction of PTSD symptoms (Ehlers & Clark, 2000). In taking this premise, it seems likely that if some symptoms of posttraumatic stress arise from a shattering of basic beliefs, and posttraumatic growth arises from re-appraising these in a positive light, then posttraumatic growth, via the mechanisms of positive re-appraisal and meaning generation, will have the effect of reducing excessive negative appraisals, thereby reducing symptoms of posttraumatic stress. Yet the positive relationship found between stress and growth suggests otherwise. This indicates that the apparent relationship between PTSD and posttraumatic growth is complex. While both are reactions to trauma and seem to have underlying cognitive processes at their core, investigations into the relative role of these same processes are likely to show distinct differences. By applying the processes proposed by Ehlers and Clark (2000) to both stress and growth outcomes, it is likely that a greater understanding of this relationship will be provided.

6.4 Summary and Aims of Part 2 of the Program of Research

In summary, although developed and tested outside of the life-threatening illness context, the Ehlers and Clark (2000) Cognitive Model of Posttraumatic Stress Disorder is proposed as providing an appropriate theoretical and treatment model to further investigate such responses in the childhood cancer context. The apparent role of meaning making and re-appraisal suggests the processes underlying posttraumatic growth outcomes are also likely to be cognitive.

The primary aims of Part 2 of this program of research are two-fold: Firstly, to test the applicability of the Ehlers and Clark (2000) Cognitive Model of Posttraumatic Stress Disorder to the childhood cancer context; and secondly, to test whether this same model is able to account for posttraumatic growth outcomes. In its application to the childhood cancer context, this project will provide the first data attesting to the predictive utility of the Ehlers and Clark cognitive model to life-threatening illness. By investigating how cognitive processes may lead to diverse trauma outcomes, this project continues to extend the traditional stress-deficit approach, providing a greater understanding of which factors may lead to, or predict PTSD and Posttraumatic Growth outcomes in a childhood cancer context.

CHAPTER 7
QUESTIONNAIRE BOOKLET (PART 2): COGNITIVE MEASURE DEVELOPMENT AND PILOT STUDY.

7.0 Overview

As reviewed above, the Ehlers and Clark (2000) Cognitive Model of PTSD has been tested in many different trauma contexts although it is yet to be applied to illnesses such as cancer. In line with this, the measures designed and used for model testing have been developed outside of the illness context. In addressing the aims of Part 2, a battery of self-report questionnaires are required which are specific to the cancer context. Chapter 7 summarises the development and the pilot study of these measures which has lead to the development of Questionnaire Booklet (Part 2), and ultimately the measures used in Studies 3 (Chapter 9) and 4 (Chapter 10) in testing the applicability of the Ehlers and Clark (2000) cognitive model of PTSD to childhood cancer survival.

7.1 Method

7.1.1 Measure Development

An existing battery of self-report measures have been developed and used by Ehlers and colleagues in testing the constructs of the model (Dunmore et al., 1999, 2001; Foa et al., 1999; Halligan et al., 2002, 2003; Murray et al., 2002). These measures, outlined below, come under three broad domains: Peritraumatic cognitive processing (assessing trauma memory deficits), cognitive appraisals of trauma and trauma sequelae, and dysfunctional cognitive and behavioural strategies.

7.1.1.1 Existing Self-Report Measures:

A. Negative Appraisals of Trauma and Trauma Sequelae

Six measures assessing appraisals surrounding the trauma and trauma sequelae. Responses are rated on a 7-point scale (1=*"Totally Disagree"*, 2=*"Disagree Very Much"*, 3=*"Disagree Slightly*, 4="*Neutral"*, 5="*Agree Slightly"*, 6="*Agree Very Much"*, 7="*Totally Agree"*). These scales have shown high internal consistency, and been shown to correlate with PTSD severity, and to discriminate between groups with and without PTSD, as well as recovered versus persistent PTSD groups (Dunmore et al., 1999, 2001; Foa et al., 1999; Ehring et al., 2006).

- *The Post Traumatic Cognitions Inventory* (PTCI: Foa et al., 1999). A 37-item scale assessing cognitions following a traumatic experience in three subscales: Negative Thoughts about the Self (e.g., *"There is something wrong with me as a person*"), Negative Thoughts about the World (e.g., *"The world is a dangerous place"*), and Self-Blame (e.g., *"The event happened to me because of the sort of person I am"*). Respondents are instructed to complete the scale with reference to *"the way that you thought, in the last month, in regard to the traumatic event that you have experienced"*.

- *Perceived Permanent Change Scale* (Dunmore et al., 1999, 2001). A 10-item scale assessing the belief that the traumatic assault has had a permanent and negative life impact (e.g., *"My life has been destroyed by the assault"*). Respondents are instructed to complete the scale with reference to *"the way that you thought, in the last month, in regard to the traumatic event that you have experienced"*.

- *Interpretation of PTSD Symptoms Scale – Revised Version* (Dunmore et al., 1999, 2001). An 11-item scale assessing the degree to which respondents appraise their stress responses in the aftermath of the traumatic experience. These reactions include intrusions (e.g., *"Something terrible will happen if I do not try to control my thoughts about the event"*), avoidance (e.g., *"If I avoid things after the event it means I am a coward"*), emotional numbing (i.e., *"If I feel numb it means I will never be able to be in touch with the world again"*), anger (e.g., *"Anger will make me go off the rails)*, and general reactions (e.g., *My reactions since the event show I must be losing my mind*). Respondents are instructed to complete the scale with reference to *"the way that you thought, in the last month, in regard to the traumatic event that you have experienced"*.

- *Perceptions of Others Responses Questionnaire* (Dunmore et al., 1999, 2001). A 20-item scale assessing the perceived reactions of others following the traumatic experience. The scale consists of 13-items assessing perceived negative reactions (e.g., *"People have rejected me because of what has happened"*), and 7-items assessing perceived positive reactions (e.g., *"I am completely able to ask other people for any support I need"*). Respondents are instructed to complete the scale with reference to *"how much you would have agreed or disagreed with each one in the four weeks following the assault"*.

- *Negative Appraisal of Action Scale* (Dunmore et al., 1999, 2001). 6-item scale assessing the perception that ones own actions were to blame for an assault (e.g., *"It is my fault that the assault happened because I could have prevented it and I didn't"*), or exacerbated an assault (e.g., *"I blame myself because my actions made the situation worse"*).

- *Negative Appraisal of Emotions Scale* (Dunmore et al., 1999, 2001). Respondents are asked to describe emotions experienced during the assault, followed by a 7-item scale assessing the interpretation of those emotions as experienced in the month following the trauma (e.g., "*If I can react like that, I must have been totally out of control*").

B. Dysfunctional Cognitive and Behavioural Strategies

Three scales assessing dysfunctional cognitive and behavioural strategies employed to cope with reactions in the aftermath of the trauma. Responses are rated on a 4-point scale (*"Never"*, *"Sometimes"*, *"Often"*, and *"Always"*).

- *Memories of Accident Scale* (Private correspondence, Ehlers, 2003). 18-item scale assessing the dysfunctional strategies used to deal with intrusive memories of the accident. These include thought suppression (e.g., *"I try to push them out of my mind"*), rumination (e.g., *"I dwell on how the event could have been prevented"*), and numbing techniques (e.g., *"I drift off into a world of my own"*). Respondents are asked to complete the scale with reference to *"what you do when memories of the accident pop into your mind?"* with a time frame of *"during the past week"*. Developed over a series of studies (Clohessy & Ehlers, 1999; Dunmore et al., 1999; 2001; Ehlers et al., 1998; Halligan et al., 2002; Murray et al., 2002; Steil & Ehlers, 2000), this scale and earlier versions have shown high internal consistency, and been shown to correlate with and predict PTSD severity (Ehring et al., 2006).

- *Behaviour after Assault* (Dunmore et al., 1999, 2001). 26-item scale assessing the extent to which the respondent engages in dysfunctional behaviours following an assault. These include behavioural avoidance (e.g., "*Avoid going to the area where the assault occurred")*, cognitive avoidance (e.g., *"Try to push thoughts about the assault to the back of your mind"*), and safety-behaviours (e.g., *"Make sure that you are not alone"*). Respondents are asked to complete the scale with reference to *"which best describes how often you do the following (please indicate how often you try to engage in each behaviour even if you were unable to succeed)"*. No time frame is specified. This scale has been shown to have high internal consistency, and been

shown to predict PTSD severity, and to discriminate between groups with and without PTSD, as well as recovered versus persistent PTSD groups (Dunmore et al., 1999, 2001).

- *State Dissociation Questionnaire - Persistent* (Halligan et al., 2002, 2003; Murray et al., 2002). A 9-item scale assessing the degree of *current* dissociative experiences. This scale is described below (see Peritraumatic Cognitive Processing, Section 7.1.1C below), however respondents were asked to rate items with regard to how often the statements applied *"over the past week"*. When applied as a measure of persistent dissociation, this scale has been shown to have high internal consistency, and been shown to correlate with PTSD severity (Ehring et al., 2006).

C. Peritraumatic Cognitive Processing (assessing Trauma Memory Deficits)

Four measures assessing memory processing at the time of the trauma. Respondents are asked to complete the scale retrospectively with regard to *"what went through your mind during the traumatic event"*. Responses are rated on a 5-point scale (0="*Not at all/Never*", 1="*A Little*", 2="*Moderately*", 3="*Strongly*", 4="*Very strongly*"). These measures have each shown good reliability and validity, and to be associated with intrusive memories and PTSD (Ehring et al., 2006; Halligan et al., 2002, 2003; Murray et al., 2002).

- *Data Driven Processing Scale* (Halligan et al.,2002, 2003). An 8-item scale assessing the degree of surface level, sensory processing at the time of the event or experience (e.g., *"I was overwhelmed by sensations and couldn't put everything together"* and *"My mind was fully occupied with what I saw, heard, smelled, and felt"*).

- *Lack of Self-Referent Processing Scale* (Halligan et al., 2003). An 8-item scale assessing the degree to which the event or experience was processed with respect to the self, and within the context of other autobiographical self representations at the time of the event or experience (e.g., *"I felt as if the event was happening to someone else"* and *"I felt there was no way back to my normal life after this"*).

- *State Dissociation Questionnaire* (Halligan et al., 2002, 2003; Murray et al., 2002). A 9-item scale assessing the degree of dissociative experiences at the time of the event or experience (e.g., *"My body felt as if it was not really mine"* and *"I felt as if I was living in a dream or a film, rather than in real life"*).

- *The Mental Defeat Scale* (Dunmore et al., 1999, 2001). An 11-item scale assessing the degree to which the respondent felt a perceived loss of psychological autonomy at the time of the event or experience (e.g., *"I no longer felt like a human being'* and *'I felt completely humiliated and lost any sense of inner dignity"*).

7.1.1.2 Cancer Specific Measure Development:

Items for each scale were individually evaluated before selection, and relevant wording changes were made so as to apply to the cancer context. Items were peer reviewed by a panel including a paediatric oncologist, a clinical nurse consultant, a psychologist, and a long-term survivor of childhood cancer (also a psychology under-graduate student).

Following review, item content was retained for the measures assessing peritraumatic cognitive processing, however measures of cognitive appraisals, and dysfunctional cognitive and behavioural strategies underwent considerable changes to wording and item content so as to be specific to the experience of cancer survival (an exception to this was the *State Dissociation Questionnaire – Persistent* where existing item content was retained, although instructions were altered to refer specifically to cancer rather than assault or accident). Cognitive appraisal measures underwent additional item development to allow for the assessment of 'positive' as well as 'negative' appraisals. For every 'negative' appraisal item (e.g.: *"I feel as though my life has been destroyed by my cancer"*), a corresponding 'positive' item was included (e.g. *"I feel as though my life has been enhanced by my cancer"*). The rationale behind this dual item inclusion is that, as shown by the coexistence of posttrauma stress and growth, both negative and positive appraisals of the same item may be true for some respondents. As suggested by Posttraumatic Growth research, positive reappraisals may be important as predictors of this outcome (Joseph & Linley, 2006) - the roles of negative appraisals to growth outcomes are yet to be investigated. Additionally, instructions for all appraisal measures direct respondents to rate items in the current context. This deviates from the existing *Perceptions of Others Responses Questionnaire*, and the *Negative Appraisal of Emotions Scale* (Dunmore et al., 1999, 2001) which both request respondents to retrospectively appraise their thoughts or emotions as they applied in the month following the trauma (see Section 7.1.1.1A above). As the population of interest (childhood cancer survivors) are at least 3 years post cancer treatment (mean time off treatment = 15 years), current appraisals are regarded as more relevant in the investigation of persistent PTSD for this group (Private correspondence, Ehlers, 2003).

Table 7.1 lists the items developed, and the pre-existing scale the items were based on (see Section 7.1.1.1 above). These items underwent pilot testing for face validity, readability and relevance to the cancer experience.

7.2 Pilot Study: Assessing the Readability and Relevance of Measures to the Cancer Context

7.2.1 Pilot Study Participants

Participants were identified from relevant databases from the Prince of Wales Hospital's departments of Oncology, Radiation Oncology, and Haematology. Eligibility criteria included: current age between 18 and 60 years, diagnosed with a malignancy and currently off treatment, basic literacy skills to understand and comprehend English, and having been cared for by the Prince of Wales Hospital. A total of 328 eligible participants were identified and mailed a questionnaire pack. Of the 328, 32 were returned to sender, 12 were since found to be deceased, 2 declined to participate, and there were 243 non-responders. This resulted in data from a total of 85 participants – a response rate of 26%.

Adult cancer survivors were chosen so as not to inadvertently exclude potential childhood cancer survivors from participation in the main project[37]. At the time of research participation, the 85 respondents were aged between 18 to 58 years (M = 42.1, SD = 9.0; 23 male, 62 female), and off treatment between 1.5 to 10.8 years. This was represented as: 'less than 1 year' (n=2); '1 to 2 years' (n=11); '2 to 5 years' (n=40); 'more than 5 years' (n=32). The majority of participants were survivors of breast cancer (n=36), followed by Hodgkins lymphoma (n=8), tumours of the CNS (n=8); non-Hodgkins lymphoma (n=6), leukaemia (n=5), prostate/testicular (n=4), and other (n=18). The majority of participants were either married or living as defacto (76%; single = 19%; divorced = 4%; widowed= 1%), had a university degree or higher (37%; apprenticeship/TAFE qualification = 33%; year 12 high school = 7%; less than year 12 high school =23%), and were full-time employed (46%; part-time = 25%; student = 4%; stay home parent = 18%; retired = 6%; unemployed = 2%).

7.2.2 Pilot Study Procedure

Eligible patients were mailed a pilot study pack consisting of an Information Statement, Project Consent Form, Questionnaire Booklet, and a reply paid envelope (see Appendix 7A). The Questionnaire Booklet contained the newly developed measures of cognitive appraisals, and dysfunctional cognitive and behavioural strategies. Following completion of the measures, respondents were asked for their feedback on readability, ease of comprehension and measure completion, relevance to the cancer experience, and questionnaire design. Following receipt of the signed project consent form, cancer and treatment information was retrieved from hospital records.

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[37] There is future potential to expand the Childhood Cancer Survival Study to include survivors from other Australian and New Zealand childhood cancer treatment centres.

7.2.3 Pilot Study Questionnaire Booklet Design and Measures

A. Questionnaire Booklet (Pilot Study) Design

The Questionnaire Booklet (Pilot Study) was separated into two sections. The first contained four measures assessing negative and positive appraisals, and two measures assessing dysfunctional cognitive and behavioural strategies. These are each described below. For each of the appraisal measures, the corresponding negative and positive appraisal items were listed as parts 'A' (negative item) and 'B' (positive item) for each item number[38] (see Table 7.1). The second section requested feedback on the questionnaire and items contained within, as well as demographic information.

Prior to completing the six measures, respondents were given the following instructions: *"Questionnaires 3 to 8 are particularly interested in how you feel that yourself or others behaved or responded to your cancer experience. For many of these items there are two opposing statements. Your response to these item pairs can seem the direct reverse of each other, but often they are not – in some cases both may be true. Please read each of these and rate how true each statement is for you."*[39]

B. Section 1: Measures

(i) Appraisal Measures:

Most scales and subscales were based on the appraisal measures outlined in Section 7.1.1.1A above, with the exception of two subscales developed specifically for childhood cancer survivors: *Unfairness* of getting cancer, and *Consequences of Cancer*. All four appraisal measures were rated on a 5-point response scale (1="*Totally Disagree"*, 2="*Disagree*, 3="*Neither Agree nor Disagree*, 4="*Agree"*, 5="*Totally Agree"*).

- *Post Cancer Appraisals Scale:* Included 34-negative items and 34-positive items assessing Thoughts of the Self (e.g., "*I feel there is something wrong with me as a person" / "I feel there is nothing wrong with me as a person"*), Perceived Permanent Change (e.g., *"I feel as though my life has been destroyed by my cancer" / "I feel as though my life has been enhanced by my*

[38] It was decided to list positive and negative items together as parts 'A' and 'B' of the same item number as this would lessen the likelihood of respondents interpreting these dual items as deception or a 'trap' within the questionnaire.

[39] Questionnaires 1 and 2 were the Impact of Event Scale-Revised (Weiss & Marmar, 1997), and the Posttraumatic Growth Inventory (Tedeschi & Calhoun, 1996). As these measures are not relevant to measure development, and results pertaining to these measures are not relevant to this section of the dissertation, they are not included in this discussion.

cancer"), Interpretations of PTSD Symptoms *(*e.g., *"My reactions since having cancer show that I am losing my mind" / "My reactions since having cancer show that I am in control of my mind"*), Self-Blame/Actions During Cancer Treatment (e.g., *"I made my illness worse by the way I acted" / "I made my illness better by the way I acted"*), and Unfairness (e.g., *"It was unfair that I got cancer" / "I was lucky to have had cancer"*). Respondents were instructed to complete the scale with reference to "*the way that you thought during the last month with regard to your experience with cancer"*.

- *Appraisals of Other's Responses Following Cancer Scale:* Included 11-negative items and 11-positive items assessing perceptions of other's responses following a cancer experience (e.g., *"People have rejected me because I have had cancer" / "People have embraced me because I have had cancer"*). Respondents were instructed to complete the scale with reference to *"how you believe other people respond to you when they know about your past cancer experience"*

- *Consequences of Cancer Scale:* Included 6-negative and 6-positive items assessing perceived changes to physical (e.g., *"My physical health is much worse now" / "My physical health is much better now"*, social (e.g., *"I will never be able to have a close and intimate relationship" / "I am better able to have a close and intimate relationship"*), and vocational life domains (e.g., *"My employment opportunities are now limited" / "My employment opportunities have increased"*). Respondents were instructed to complete the scale with reference to *"how cancer has impacted on your life"*.

- *Emotions During Cancer Scale:* Respondents were asked to describe emotions experienced during the highly distressing cancer related event described earlier (see section B(ii): Dysfunctional Cognitive and Behavioural Strategies below)[40]. This was followed by an 8-item scale (4-negative and 4-positive items) assessing appraisals of those emotions (e.g., *"My emotions were completely out of control" / My emotions were completely in control"*). Respondents were instructed to complete the scale with reference to *"the emotions you have just described above"*.

[40] The Emotions During Cancer Scale refers to a highly distressing cancer related event already described by the respondent when completing measures assessing Dysfunctional Cognitive and Behavioural Strategies. Consequently The Emotions During Cancer Scale was positioned after these measures.

(ii) Dysfunctional Cognitive and Behavioural Strategies:

The dysfunctional cognitive and behavioural strategies scales were based on those outlined in Section 7.1.1.1B above. Prior to completing the measures, respondents were asked to describe *"which event/experience causes you the most feelings of distress when you remember it or think back on it today (e.g., initial diagnosis, surgery, needles, being isolated from family/friends, going back to work for the first time, etc)"*. Items were then completed with reference to the event described. Responses were rated on a 4-point scale (0=*"Never,* 1=*"Sometimes*, 2=*"Often*, 3=*"Always"*).

- *Memories of Cancer Scale:* An 18-item scale assessing dysfunctional cognitive strategies used to deal with intrusive memories of the cancer experience. Strategies include thought suppression (e.g., *"I try to push them out of my mind"*), rumination (e.g., *"I dwell on how my cancer could have been prevented"*), and numbing techniques (e.g., *"I drink alcohol, take medication or use drugs"*). Respondents were instructed to complete the scale with reference to *"what you do when memories of the experience you have just outlined above pop into your mind. Please circle the answer that best applies to you during the past two weeks.*

- *Behaviour After Cancer Scale:* A 14-item scale assessing dysfunctional cognitive and behavioural strategies following cancer. Strategies include cognitive avoidance (e.g., *"I avoid telling people about it"*), behavioural avoidance (e.g., *"I avoid going to the hospital where my treatment occurred),* and safety behaviours (e.g., *"I overprotect those close to me*"). Respondents were instructed to complete the scale with reference to *"how often you do the following with regard to the experience you have just described (please indicate how often you try to engage in each behaviour even if you were unable to succeed).*

C. <u>Section 2: Comments, Feedback and Demographics</u>

Following completion of the measures, respondents were then asked for their comments and feedback on the questionnaires and items contained within: *"In this section we would like to know your comments and feedback on this questionnaire – whether you found it easy to read and understand, whether some items were more difficult for you to answer than others, or any other comments you may have"*. Specific questions followed: *"Did you find the questionnaire easy to read and understand?", "Were some items/scales more difficult to complete than others",* and *"Please write down any additional comments or feedback that you may have on the design or wording of this questionnaire, or whether you feel the questions were relevant to your experience"*.

Each question requested the respondent to *"... specify the questionnaire/question number you are referring to"*.

Demographic information was requested on current relationship status, highest level of education attained, and current employment status.

7.2.4 Pilot Study Results and Design of Questionnaire Booklet (Part 2)

Feedback provided by pilot study participants is presented in Table 7.2. Of note, comments indicated a tendency for item repetition (e.g., comments 2.21, 4.6), confusion from slight context or time-frame changes between instructions (e.g., comments 1.10, 2.7), item wording confusing or double-barrelled (e.g., comments 1.2, 1.14), more specific references to earlier pages required (e.g., comment 1.3), and the questionnaire as a whole in need of condensing (e.g., comments 3.8, 4.3, 4.4, 4.21). Changes were made following these comments, as well as recommendations by the review panel (see Section 7.1.1.2 above) in a final review of items. These changes are outlined below as they relate to item selection and design of Questionnaire Booklet (Part 2).

7.2.4.1 Item Selection and Design: Questionnaire Booklet (Part 2) (Childhood Cancer Survivor Study):

A. Questionnaire Booklet (Part 2) Design: Changes Made From Pilot Study

For Questionnaire Booklet (Part 2), the measures were separated into sections with section specific instructions to more clearly reflect the context in which the responses be made. These were:

- Section 1 (not cancer specific): *"Questionnaire 1 comprises a list of statements that may potentially describe how you currently think or feel about yourself. Please read each statement and rate how true each is for you"*.

- Section 2 (cancer specific): *"Questionnaires 2 to 5 comprise lists of statements that potentially describe how either yourself or others behaved or responded to your cancer experience. Please read each statement and rate how true each is for you"*.

- Section 3 (event specific and memory dependent): *"The third part of this survey is interested in your thoughts and feelings surrounding a specific cancer related event. Only complete this section if you remember aspect(s) of your cancer diagnosis and/or treatment. This may include*

a "vague" recollection of a specific event, even if you do not remember much else around this time. If you have no memory at all of this period, please go straight to page 11"[41].

Questionnaires contained under Sections 1 and 2 instructed respondents to answer with regard to thoughts, feelings, or behaviours over the "*last month*". As Section 3 refers to memories of thoughts, feelings, or behaviours at the time of a cancer specific event, these questionnaires required retrospective accounts and therefore no time frame was specified.

B. Changes to Items:

Note: Table 7.3 summarises the item changes to each sub-scale following the pilot study and suggestions from the review panel, and Appendix 7B shows the resulting item content and layout in Questionnaire Booklet (Part 2).

(i) Changes to Appraisal Measures:

1. Items assessing negative/positive *Thoughts of the Self* were removed from the *Post Cancer Appraisals Scale* to be completed as a scale on its own. *Thoughts of the Self* are general appraisals of the self and not cancer specific. The resulting *Thoughts of the Self After Cancer Scale* was included under Section 1 of Questionnaire Booklet (Part 2). Instructions included: *"Listed below are different thoughts and feelings that people can have after a stressful experience such as cancer. We are interested in how well these statements describe how you have thought or felt during the last month..."* and items were preceded by the statement: *"I believe/feel that..."*.

2. The *Post Cancer Appraisals Scale* retained items assessing *Perceived Permanent Change, Interpretations of PTSD Symptoms, Self-Blame/Actions During Cancer Treatment,* and *Unfairness,* but was changed to include items assessing *Appraisals of Others Responses Following Cancer,* and *Consequences of Cancer*. This resulted in one scale for cancer specific appraisals and was included under Section 2 of Questionnaire Booklet (Part 2). Instructions included: *"Listed below are different thoughts and feelings that people can have after a stressful experience such as cancer. We are interested in how well these statements describe how you have thought or felt during the last month with regard to your past experience with*

[41] Page 11 thanks the participant for their time and allows space for any additional comments they may like to make with regard to the survey, the project, or their experience of cancer in general.

cancer...". Items were preceded by the statement: *"Because of my cancer experience, I believe/feel that...".*

3. The *Emotions During Cancer Scale* was included under Section 3 of Questionnaire Booklet (Part 2) as it referred to a specific event. A new negative and positive item was included based on the existing *Negative Appraisals of Emotions Scale* (Dunmore et al., 1999, 2001) and following suggestions by the review panel (Item 5.5: *"My emotions were completely abnormal given the circumstances"/"My emotions were completely normal given the circumstances"*).

4. The positive and negative item pair format ("A" and "B") was discarded and negative and positive items were randomly distributed throughout the questionnaires. This was in response to comments reflecting frustration in completing the questionnaire or dislike of the format (e.g., comments 1.11, 1.17, 2.2, 2.8, Table 7.2). Instructions for each of the appraisal measures was changed to include *"Some of these statements may seem the direct reverse of another in the list, however please respond to each separately as your ratings may not be the opposite of an earlier one (e.g., in some cases both statements may be true)".*

(ii) Changes to Dysfunctional Cognitive and Behavioural Strategies Measures

Following Pilot Study feedback (e.g., see comment 2.21, Table 7.2), and comments made during the Interview Stage of Part 1[42], the instructions for these questionnaires were changed from answering with regard to a specific event or experience that caused "*the most feelings of distress*" to answering with regard to the cancer experience in general. These measures were included under Section 2 of Questionnaire Booklet (Part 2). Instructions were changed to reflect this: Memories of Cancer Scale: *"After an experience with cancer, people often have memories which come to mind at unexpected times. We are interested in what you do when unwanted memories of your cancer experience pop into your mind..."*; and Behaviour After Cancer Scale: *"Listed below are behaviours and actions which people may engage in following an experience with cancer. Please circle the word which best describes how often you do the following with regard to your cancer experience. (Please indicate how often you try to engage in each behaviour during the past month, even if you were unable to succeed)..."*

[42] During the interview stage of Part 1 (see Chapter 2), the majority of respondents had difficulty referring to one 'distressing' cancer related event when prompted. Most recalled two or more events, and referred to these interchangeably when answering questions on the Structured Clinical Interview for DSM-IV – PTSD Module (SCID).

There were few comments suggesting item changes for these measures, although a slight change in the wording of item 9.9 was made following review panel suggestions (see Table 7.3).

7.3 Questionnaire Booklet (Part 2): Final Measures and Design

The final measures contained in Questionnaire Booklet (Part 2) included those developed and tested via the Pilot Study, as well as those that were not (contained under "*Section 3 – Event Specific*")[43]. The measures and layout of Questionnaire Booklet (Part 2) are outlined below. Appendix 7B contains a full copy of this booklet:

Section 1 (not cancer specific):

Questionnaire 1:

Thoughts of the Self After Cancer Scale: A 26-item measure assessing both negative (13-items) and positive (13-items) thoughts about the self (e.g., *"I do/don't know who I am", "I can/cant' rely on myself",* and *"I feel/don't feel as though I am crazy"*). Respondents were instructed to complete the measure as follows: *"Listed below are different thoughts and feelings that people can have after a stressful experience such as cancer. We are interested in how well these statements describe how you have thought or felt during the last month. Some of these statements may seem the direct reverse of another in the list, however please respond to each separately as your ratings may not be the opposite of an earlier one (e.g., in some cases both statements may be true). Please read each statement carefully and rate how much you AGREE or DISAGREE with the statement. There are no right or wrong answers. Please be sure to rate each statement""*. Responses were rated on a 5-point scale (1:*"Totally Disagree",* 2:*"Disagree",* 3:*"Neither Agree nor Disagree",* 4:*"Agree,* 5:*"Totally Agree"*).

Section 2 (cancer specific):

Questionnaire 2:

Post Cancer Appraisals Scale: A 60-item measure assessing negative (30-items) and positive (30-items) appraisals of cancer and cancer sequelae. Appraisals include those surrounding interpretations of emotional responses (e.g., *"My reactions when I think about it show that I am losing/am in control of my mind"*), other peoples reactions or responses (e.g., *"Other people have*

[43] As these measures did not undergo item change (see Sections 7.1.1.1B: *State Dissociation Questionnaire-Persistent*, and 7.1.1.1C: *all Peritraumatic Cognitive Measures*) they were not included in the Pilot Study Questionnaire.

rejected/embraced me because of it"), consequences of cancer[44] (e.g., *"My physical appearance has changed for the worse/better"*), self-blame/behaviour (e.g., *"It is my fault that I got cancer" / "I got cancer through no fault of my own"*, and *"I made my illness worse/better by the way I acted"*), and fairness or unfairness of cancer (e.g., *"It was unfair that I got cancer" / "I was not unfair that I got cancer as it could have happened to anyone"*). Instructions for completing this measure was the same as given for Questionnaire 1, however respondents were instructed to complete the measure *"with regard to your past experience with cancer*". Responses were rated on the same 5-point scale described above for Questionnaire 1.

Questionnaire 3:

State Dissociation Questionnaire – Persistent (Halligan et al., 2002, 2003; Murray et al., 2002): A 9-item scale assessing the degree of current dissociated experiences (e.g., *"My body feels as if it is not really mine"*, and *"I feel as if I am living in a dream or a film, rather than in real life"*). Respondents were instructed to complete the questionnaire as follows: *"Below are a number of statements describing thoughts and feelings people may experience after a stressful experience such as cancer. For each statement, please rate how often each of these have applied to you during the last month when you think about, or are reminded of your cancer experience. There are no right or wrong answers. Please be sure to rate each statement"*. Responses were rated on a 5-point scale (0:*"Not at all/Never"*, 1:*"Very Little"*, 2:*"Moderately"*, 3:*"Strongly"*, 4:*"Very Strongly"*).

Questionnaire 4:

Memories of Cancer Scale: An 18-item scale assessing the dysfunctional strategies used to deal with intrusive memories surrounding the cancer experience. These include thought suppression (e.g., *"I try to push them out of my mind"*), rumination (e.g., *"I dwell on how my cancer could have been prevented"*), and numbing techniques (e.g., *"I drift off into a world of my own"*). Respondents were instructed to complete the measure as follows: *"After an experience with cancer, people often have memories which come to mind at unexpected times. We are interested in what you do when unwanted memories of your cancer experience pop into your mind. Please rate the answer that applies best to you during the past month. There are no right or wrong answers to these statements. Please be sure to rate each statement"*. Responses were rated on a 4-point scale (0:*"Never"*, 1:*"Sometimes"*, 2:*"Often"*, 3:*"Always"*).

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[44] The Consequences of Cancer and the Perceived Permanent Change subscales were combined to form one "Consequences of Cancer Scale".

Questionnaire 5:

Behaviour After Cancer Scale: A 14-item scale assessing the extent to which the respondent engages in dysfunctional behaviours following cancer. These include behavioural avoidance (e.g., *"I avoid going to the hospital where my treatment occurred"*), cognitive avoidance (e.g., *"I allow myself to remain numb"*), and safety behaviours (e.g., *"I overprotect those close to me"*). Respondents were instructed to complete the measure as follows: *"Listed below are behaviours and actions which people may engage in following an experience with cancer. Please rate how often you do each of the following with regard to your cancer experience. (Please indicate how often you try to engage in each behaviour during the past month, even if you were unable to succeed)". There are no right or wrong answers. Please be sure to rate each statement"*. Responses were rated on the same 4-point scale described above for Questionnaire 4.

Section 3 (event specific):

Questionnaire 6:

Event Description: This questionnaire requires the respondent to describe the cancer related event that was most distressing. Respondents were instructed as follows: *"Think back on your experience of having cancer and cancer treatment. Please describe in the space below which event/experience caused you the most feelings of distress at the time (for example, "being told I had cancer", "having a bone marrow transplant", "having needles", "being told I had relapsed", "other people's reactions to me"). This event or experience may include a specific memory even though you might not remember much else around this time"*.

Questionnaire 7:

Cognitive Processing During Trauma: This 36 item questionnaire contains 4 measures assessing memory processing at the time of the most distressing cancer related event. These measures, described above (see section 6.1.1A), are *The Mental Defeat Scale* (Dunmore et al., 1999, 2001), *The Data-Driven Processing Scale* (Halligan et al., 2002,2003), the *Lack of Self-Referent Processing Scale* (Halligan et al., 2003), and *The State Dissociation Questionnaire* (Halligan et al., 2002, 2003; Murray et al., 2002). Respondents were instructed to complete the questionnaires as follows: *"Below are a number of statements describing thoughts and feelings people may experience during a stressful event. For each statement, please rate the extent to which it applied to you during your experience you described in questionnaire 6. There are no right or wrong answers. Please try to remember how you felt and thought at the time of the experience, not what you thought*

afterwards with the benefit of hindsight. Please be sure to rate each statement". Responses were rated on the same 5-point scale described above for Questionnaire 3.

Questionnaire 8:

Description of Emotions: This questionnaire requires the respondent to describe the emotions experienced at the time of the cancer related event that was most distressing to them personally. Respondents were instructed as follows: *"People experience a range of different emotions during an experience with cancer. Please describe in the space below the emotions you had at the time of your experience outlined in questionnaire 6 (e.g., scared, frightened, angry, happy, relaxed, numb, etc)"*.

Questionnaire 9:

Emotions During Cancer Scale: A 10-item scale assessing negative (5-items) and positive (5-items) appraisals of emotions experienced during a distressing cancer related event(s) (e.g., *"My emotions made things so much worse/better than they would otherwise have been"*). Respondents were instructed to complete the measure as follows: *"With regard to the emotions you have just described above, please rate how much you agree or disagree with each statement below by circling the best response. Some of these items may seem the direct reverse of another, however please rate each separately as your response may not always be the opposite on an earlier one (in some cases both may be true). There are no right or wrong answers to these statements. Please be sure to rate each statement"*. Responses were rated on the same 5-point scale described above for Questionnaire 1.

7.4 Statistical Evaluation of the Cognitive Appraisal and Dysfunctional Cognitive and Behavioural Measures with the Childhood Cancer Survivor Group

Following receipt of Questionnaire Booklet (Part 2) from the 122 childhood cancer survivors (see chapter 8), the newly developed measures assessing Cognitive Appraisals of Cancer and Cancer Sequelae and Dysfunctional Cognitive and Behavioural Strategies were further evaluated for internal consistency. Where internal consistency was shown to be low, or that it may be improved, component structure was also evaluated. Following these evaluations, changes were made to two scales: the *Post Cancer Appraisals Scale* and the *Emotions During Cancer Scale.* These are outlined below.

- *Post Cancer Appraisals Scale:* Four items assessing *Actions During Cancer Treatment* were removed from this scale[45] (Negative items: Item 2.18: *"I made my illness worse by the way I acted"*, Item 2.58: *"I recovered more slowly, or was more sick than anyone else with the same cancer"*; Positive items: Item 2.10: *"I made my illness better by the way I acted"*, Item 2.22: *"I recovered more quickly, or was less sick than anyone else with the same cancer"*). These items were combined with the *Emotions During Cancer Scale* to form the *Appraisals of Cancer Reactions Scale* (outlined below). The remaining 56-item measure, assessed negative (28-items) and positive (28-items) appraisals of cancer and cancer sequelae including interpretations of emotional responses, other peoples reactions or responses, consequences of cancer, self-blame and unfairness. Internal consistency was shown to be high (Streiner & Norman, 2003) for the 28-item negative scale ($\alpha = 0.89$) and the 28-item positive scale ($\alpha = 0.76$).

- *Emotions During Cancer Scale:* The measure of internal consistency was moderate for the 5-item negative scale ($\alpha = 0.58$), and low for the 5-item positive scale ($\alpha = 0.20$). In an effort to enhance scale integrity, four items assessing appraisals of actions during cancer treatment (2 negative items and 2 positive items) were combined with this scale to form the *Appraisals of Cancer Reactions Scale.* Cronbach's alpha was improved to 0.62 for the negative scale, and 0.42 for the positive scale. Principal Components Analysis was further applied to assess component structure and item loadings. These analyses confirmed a 4-item solution provided greatest integrity for the negative scale (one item assessing appraisals of actions during cancer: Item 2.18: *"I made my illness worse by the way I acted"*, and three items assessing appraisals of emotions during cancer: Item 9.4: *"My emotions made things so much worse than they would otherwise have been"*, Item 9.6: *"I was completely unable to control my emotions"*, Item 9.8: *"I cannot accept the emotions which I had*"); and a 2-item solution provided greatest integrity for the positive scale (one item assessing appraisals of actions: Item 2.10: *"I made my illness better by the way I acted"*, and one item assessing appraisals of emotions: Item 9.9: *"My emotions made things so much better than they would otherwise have been"*). Internal

[45] Cronbach's alpha showed little change with these items included in this scale (30-item positive scale: $\alpha = 0.77$; 30-item negative scale: $\alpha = 0.90$). These items were removed solely for the purpose of enhancing the *Appraisals of Cancer Reactions Scale*.

consistency was shown to be moderate for both the negative and positive scales ($\alpha = 0.61$, $\alpha = 0.57$)[46].

The final measures and their items as applied to Studies 3 and 4 (Chapters 9 and 10) are listed in Table 7.4.

[46] The low internal consistency scores as measured by Cronbach's alpha may reflect the small number of items per scale. Principal Component Analyses showed component loadings for the retained scale items to have a high degree of overlapping variance (Tabachnick & Fidell, 2001).

Table 7.1. Item development: Cancer specific items included in pilot study

Appraisal Measures	
Negative Scale	**Positive Scale**
1. Thoughts of the Self[a]	
1. I can't deal with things that upset me	I can deal with things that upset me
2. I feel as though I am crazy	I don't feel as though I am crazy
3. I feel there is something wrong with me as a person	I feel there is nothing wrong with me as a person
4. I am not able to feel normal emotions	I am able to feel normal emotions
5. I feel like an object, not like a person	I feel like a person, not like an object
6. I feel dead inside	I feel alive inside
7. I can't rely on myself	I can rely on myself
8. I feel inadequate as a person	I feel adequate as a person
9. I can't trust that I will do the right thing	I can trust that I will do the right thing
10. I am a weak person	I am a strong person
11. I feel like I don't know who I am	I feel like I do know who I am
12. I feel on edge all of the time	I don't feel on edge all of the time
13. I can't stop bad things from happening to me	I can stop bad things from happening to me
14. I feel isolated and set apart from my family	I feel close to my family
15. I feel isolated and set apart from my friends	I feel close to my friends
2. Perceived Permanent Change[b]	
1. I will never be able to bring myself to accept my cancer	I am able to accept my cancer
2. I have permanently changed for the worse	I have permanently changed for the better
3. My relationships with others has permanently changed for the worse	My relationships with others has permanently changed for the better
4. I feel that I have not been able to move on with my life	I feel that I have been able to move on with my life
5. I feel as if nothing good can happen to me anymore	I feel as if lots of good can still happen to me
6. I feel as though my life has been destroyed by my cancer	I feel as though my life has been enhanced by my cancer
7. I have no future to look forward to	I do have a future to look forward to
3. Interpretations of PTSD Symptoms[c]	
1. My reactions since having cancer mean that I am losing my mind	My reactions since having cancer mean that I am in control of my mind
2. If I think about my cancer, I feel out of control	If I think about my cancer, I feel in control
3. If I avoid things that remind me of my cancer experience it means I am a coward	If I avoid things that remind me of my cancer experience it does not mean that I am a coward
4. If I cannot control my thoughts and feelings about my cancer experience, something terrible will happen	If I cannot control my thoughts and feelings about my cancer experience, nothing terrible will happen
5. My reactions since my cancer show that I am a poor coper	My reaction since my cancer show that I am a good coper
6. If I cannot control my thoughts and feelings about my cancer experience, then I will go crazy	If I cannot control my thoughts and feelings about my cancer experience, then I will not go crazy
4. Appraisals of Others Responses Following Cancer[d]	
1. People don't believe me when I tell them about my cancer experience	People do believe me when I tell them about my cancer experience
2. People blame me for my cancer	People do not blame me for my cancer
3. Other people think that I don't deserve support	Other people think that I do deserve support
4. Other people expect I should be completely recovered by now	Other people do not expect that I should be completely recovered by now
5. People have rejected me because I have had cancer	People have embraced me because I have had cancer

Table 7.1. (Continued).

Appraisal Measures	
Negative Scale	**Positive Scale**
6. People who I thought would stand by me have let me down	People who I thought would stand by me have not let me down
7. Other people are embarrassed of me now	Other people are proud of me now
8. People don't know how to deal with knowing that I had cancer	People deal well with knowing that I had cancer
9. People don't seem to listen when I talk to them about my experience with cancer	People seem to listen when I talk to them about my experience with cancer
10. People cannot understand what I have gone through	People really seem to understand what I have gone through
11. I feel that I cannot relate well to most people	I feel that I am able to relate well to most people
5. Self-Blame/Actions During Cancer Treatment [e]	
1. It is my fault that I got cancer	I got cancer through no fault of my own
2. I could have prevented my cancer but I didn't	I could not have prevented my cancer
3. I recovered more slowly, or was more sick, than anyone else would have been with the same cancer	I recovered more quickly, or was not as sick as anyone else with the same cancer
4. I made my illness worse by the way I acted	I made my illness better by the way I acted
5. I made the whole experience worse because of my actions	I made the whole experience better because of my actions
6. Unfairness[f]	
1. It was unfair that I got cancer	I was lucky to have had cancer
7. Consequences of Cancer[f]	
1. My physical health is much worse now	My physical health is much better now
2. My physical appearance has changed for the worse	My physical appearance has changed for the better
3. My employment opportunities are now limited	My employment opportunities have increased
4. I don't have as many friends as I would like	I have plenty of friends
5. It is difficult for me to meet new people	I am better able to meet new people
6. I will never be able to have a close and intimate relationship	I am better able to have a close and intimate relationship
8. Emotions Surrounding Cancer[g]	
1. My emotions were completely out of control	My emotions were completely in control
2. If I ever had emotions like that again I would not be able to cope	If I ever had emotions like that again I would be able to cope
3. I cannot accept the emotions which I had	I can accept the emotions which I had
4. My emotions made things so much worse than they would otherwise have been	My emotions made things so much better than they would otherwise have been

Table 7.1. (Continued).

Dysfunctional Cognitive and Behavioural Strategies
9. Memories of Cancer[h]
1. I try to push them out of my mind
2. I try to erase the memory of the event
3. I try hard to control my emotions
4. I distract myself with something else
5. I work hard at keeping busy with other things
6. I think about how life would have been different if I never had cancer
7. I dwell on how my cancer could have been prevented
8. I think about why my cancer happened to me
9. I dwell on how I might have been before cancer
10. I dwell on what other people have done to me
11. I dwell on what I have done wrong
12. I go over what happened again and again
13. I worry that I, or someone in my family, might get cancer
14. I drift off into a world of my own
15. I drink alcohol, take medication or use drugs
16. I put on loud music or TV
17. I dwell on what happened without really solving or deciding anything
10. Behaviour After Cancer[i]
1. I avoid people who remind me of it
2. I avoid everyday things that remind me of it
3. I avoid going to the hospital where my treatment occurred
4. I avoid sleeping because of nightmares about it
5. I allow myself to remain numb
6. I avoid telling people about it
7. I allow myself to become detached from what is going on around me
8. I avoid looking at TV or newspaper reports about cancer or cancer treatment
9. I avoid being in situations that I cannot completely control
10. I avoid forming new relationships
11. I avoid unfamiliar places or situations
12. I put off making decisions
13. I make sure that I am not alone
14. I overprotect those close to me (e.g. children, family, friends)

[a] Based on items in the *Posttraumatic Cognitions Inventory: Negative Thoughts About the Self Scale (Foa et al., 1999).*
[b] Based on items in the *Perceived Permanent Change Scale (Dunmore et al., 1999, 2001).*
[c] Based on items in the *Interpretation of PTSD Symptoms Scale – Revised Version (Dunmore et al., 1999, 2001).*
[d] Based on items in the *Perceptions of Others Responses Questionnaire (Dunmore et al., 1999, 2001).*
[e] Based on items in the *Posttraumatic Cognitions Inventory: Self-Blame Scale (Foa et al., 1999),* and the *Negative Appraisals of Action Scale (Dunmore et al., 1999, 2001).*
[f] Items developed for this study.
[g] Based on items in the *Negative Appraisals of Emotions Scale (Dunmore et al., 1999, 2001).*
[h] Based on items in the *Memories of Accident Scale (Private correspondence, Ehlers, 2003).*
[i] Based on items in the *Behaviour After Assault Scale (Dunmore et al., 1999, 2001).*

Table 7.2. Pilot study: Participant feedback on item development

1. Readability and ease of understanding:
1. All questions easy to read but some required more thought than others, e.g. the agree/disagree Q's sounded similar but subtly different.
2. Item 3.14 strange wording that made me think about the question for too long – confusing
3. Top of page 12 refers to page 10 but not clear which part – needs to be more specific
4. The meaning of 'compared to most people' on page 7 was not that clear.
5. Very clear, well set out and easy to respond to.
6. Overall it was easy to read and understand.
7. Straightforward.
8. Found the whole questionnaire to be very good. It covered all areas in a clear appropriate way.
9. Some questions *(not specified which ones)* could have been more to the point.
10. At times I had to re-read the instructions to remember what context I was being asked in.
11. Questionnaire 3 I thought was totally stupid – after that you lost me.
12. Fairly easy to understand, initially emotionally difficult to complete.
13. Easy and understandable.
14. Items 3.9 & 3.14 – confusing – double negatives.
15. Easy to fill out – took little time.
16. I had no problems.
17. Disliked A and B questioning style.
18. I found it to be very clear.
19. Not sure if should be answering from 'most of the time' perspective as emotions swing from extremes. Some clarification would help.
20. Questions with one word answers would be better. Multiple choice answers difficult and seem to follow a trend.
21. I think some questions are asked more than once (e.g. 4.4ab, 4.8ab, 3.13ab, 5.3ab).
2. Some questionnaires/items more difficult than others:
1. Needed full concentration to answer the questions.
2. Questionnaire 3 was particularly difficult to answer – interpretation is torturous.
3. Questionnaires 6-8 were easy to focus on as they related to a specific experience.
4. Questionnaires 6&7 were difficult to answer because I had cancer so long ago (7 yrs).
5. Questionnaire 3 more difficult – it took a bit of thinking back.
6. Writing down feelings is harder (page 12) but give you a chance to address areas.
7. The different time frames (7 days, 2 weeks, 1 month) made answering much harder.
8. Questionnaires 3 to 5 with the A B answers. These were more challenging to complete and required a great deal of soul searching.
9. Some areas needed to be more specific as didn't know what it was that you were asking in the questions – a bit ambiguous.
10. Questionnaire 6 as was hard not to think about how I'd answer one question, then the next.
11. A yes/no categorisation in addition to never/sometimes/often/always would help (Questionnaires 6 & 7).
12. Item 8.2 – emotions are usually very hard to describe.
13. All about the same.
14. Some varied but all were okay to complete.
15. To choose one event (page 10) was too hard as I felt there were 3 or 4 distressing moments.
16. Questionnaire 4 made me think more especially with the questions about what you think other people think.
17. I needed to read the questions twice before answering.
18. Questionnaire 8 – it's hard to talk about emotions.

Table 7.2. (Continued)

2. Some questionnaires/items more difficult than others (Continued):
19. Questionnaires 6 to 8. I don't really have any feelings of distress on remembering my cancer experience – felt it didn't relate to me.
20. Questionnaire 4, particularly the later items were hard to answer as it's hard to generalise – different people have different reactions.
21. Questions relating to one event (questionnaire 6 to 8) were more difficult as it is hard to adhere to one situation.
22. Would be useful to include different sections depending on how long ago cancer was, esp. if they are cured and have had no relapse.
3. Relevance to experience of cancer:
1. I am surprised at how truthful my responses are – you obviously understand what people go through.
2. Questionnaire 3 seemed slightly irrelevant – perhaps applicable to someone who had got cancer through smoking.
3. I can see why you offer a counselling service as it really did make me think about some deep issues.
4. Most questions were not relevant to my experience as I was one of the lucky ones who managed to cope without too much difficulty.
5. Easy to understand and relevant to my experience.
6. Questions are very relevant.
7. Questions are certainly appropriate but left me feeling there was more needed to be said about post cancer life.
8. Questions are extremely relevant but the survey is in need of severe condensing – it is very onerous to complete.
9. I thought it was well prepared and didn't shy away from the difficult issues – I did feel it was relevant to me.
10. It could have been more relevant to me. There are so many emotions happening to you all at once. It is also upsetting to go through memories of that time especially now that I have moved on.
11. I have filled in 100's of surveys following my cancer - most haven't been written for cancer so are very irrelevant. At least this one is.
12. Need to address the relationship some people have with the treatment and after surgery, impact of it both emotionally and physically.
13. I enjoyed completing the quest're very much. Q's were relevant but didn't suggest a feeling of euphoria I felt when cancer was gone.
14. This questionnaire pretty much outlines everything that is required.
15. The questionnaire was relevant to some situations related to my condition – 40% yes, 60% no.
4. Other:
1. Made me think about all the ways you can be affected by treatment. Was like a self-assessment.
2. I wish you hadn't mentioned how long it would take to complete – I kept putting it away to do at another time.
3. Bit too long.
4. Too much paperwork.
5. Found to be absolutely draining, exhausting and confronting.
6. Some areas were almost identical which made the questionnaire repetitious.
7. Well set out, spacing's and sections well organised.
8. I had a lot of mixed feelings when answering items and I would have liked the opportunity to explain them.
7. I didn't like the time constraints.
8. I was surprised by some of my responses, especially when I had the same responses to opposing statements.
9. It came across that you thought people were physically and emotionally a mess because they had cancer. I haven't found this at all.
10. There were some things I had been saying I was going to do. This experience helped to motivate me once I recovered somewhat.
11. Writing was a cleansing experience for me.
12. Overall found the wording and design very good and questions relevant.
13. I feel questionnaires can be too generalised.

Table 7.2. (Continued)

4. Other (Continued):
14. Some very specific Q's but also open-ended ones which is good – but no room to make overall comment on experience of cancer.
15. Learnt a lot about myself, esp Q7. Never previously considered that I avoid situations/relationships that I feel I am not in control of.
16. Most quest'rs seem to relate to negatives about having had cancer – showing positive/successful approach to it may be an advantage.
17. It was interesting to think about my experience from this perspective 5 years on. Makes me realise how much this experience stays with you emotionally even at a subconscious level and makes me wonder how much it impacts my life day to day.
18. The only thing distressing is this survey – don't automatically assume people are distressed. Felt this is very much geared for females.
19. Survey was fine but brought back memories that want to leave packed away. Sometimes feel our emotions are not taken care of & feel very alone.
20. The further I got into the questionnaire the more difficult I found it to answer. I think this actual questionnaire had an impact on me. The cancer is always there in my mind but this caused a very personal, very private boil over.
21. Well designed, probably too lengthy to ensure good compliance among respondents.
22. Feel like you could have asked more questions on the experience of treatment itself.
23. The experience I had has not really affected me.
24. Difficult to separate how I felt about the cancer from how the side effects of the medication made me feel.
25. Item 3.4: how can anyone be lucky to have had cancer? Item 3.10: how can you know? Item 3.33: how on earth can your life be enhanced by cancer?
26. Many people feel I should be 100% ok now and don't expect me to have strong feelings about it. A few know it is a part of who I am and what it means to me.
27. It has been 7 yrs now since my treatment. I may have answered questions quite differently a few years ago, or immediately following.
28. All in all this survey has been very interesting.
29. I regard my cancer and its treatment as a process which has allowed me to change my life for the better today.

Table 7.3. Item development: Item changes following pilot study review

Appraisal Measures **Negative Scale**	**Positive Scale**
Thoughts of the Self After Cancer Scale:	
1. Thoughts of the Self	
1. I *cannot* deal with things that upset me	I can deal with things that upset me
2. I feel as though I am crazy	I don't feel as though I am crazy
3. *There is* something wrong with me as a person	*There is* nothing wrong with me as a person
4. I am *unable* to feel normal emotions	I am able to feel normal emotions
~~*5. I feel like an object, not like a person*~~[a]	~~*I feel like a person, not like an object*~~[a]
6. I feel dead inside	I feel alive inside
7. I can' rely on myself	I can rely on myself
8. I *am* inadequate as a person	I *am more than* adequate as a person
9. I *cannot* trust that I will do the right thing	I can trust that I will do the right thing
10. I am a weak person	I am a strong person
11. *I don't* know who I am	*I know* who I am
12. I *am* on edge all of the time	I *am not* on edge all of the time
13. I can't stop bad things from happening to me	I *am able to* stop bad things from happening to me
~~*14. I feel isolated and set apart from my family*~~[b]	~~*I feel close to my family*~~[b]
~~*15. I feel isolated and set apart from my friends*~~[b]	~~*I feel close to my friends*~~[b]
16. I am isolated and set apart from others (new item)[b]	*I am close to others (new item)*[b]
Post Cancer Appraisals Scale	
2. Perceived Permanent Change	
1. I *am unable to* bring myself to accept *that I had* cancer	I am able to accept *that I had* cancer
2. *Overall,* I have permanently changed for the worse	*Overall,* I have permanently changed for the better
3. My *relationship with my family has changed* for the worse	My *relationship with my family has changed* for the better
4. *I have* not been able to move on with my life	*I have* been able to move on with my life
~~*5. I feel as if nothing good can happen to me anymore*~~[c]	~~*I feel as if lots of good can still happen to me*~~[c]
6. *My life* has been destroyed by my cancer	*My life* has been enhanced by my cancer
~~*7. I have no future to look forward to*~~[c]	~~*I do have a future to look forward to*~~[c]
3. Interpretations of PTSD Symptoms	
1. My reactions *when I think about it show* that I am losing my mind	My reactions *when I think about it show* that I am in control of my mind
2. *When I think about it,* I feel out of control	*When I think about it,* I feel in control
3. *Avoiding things* that remind me of *it makes me a weak person*	*Avoiding things* that remind me of *it* does not *make me a weak person*
~~4. If I cannot control my thoughts and feelings about my cancer experience, something terrible will happen~~[d]	~~If I cannot control my thoughts and feelings about my cancer experience, nothing terrible will happen~~[d]
5. My reactions *when I think about it* show that I am a poor coper	My reaction *when I think about it* show that I am a good coper
~~6. If I cannot control my thoughts and feelings about my cancer experience, then I will go crazy~~[d]	~~If I cannot control my thoughts and feelings about my cancer experience, then I will not go crazy~~[d]
4. Appraisals of Others Responses Following Cancer	
1. *Other* people don't believe me when I tell them about *it*	*Other* people believe me when I tell them about *it*
2. *Other* people blame me for *it*	*Other* people do not blame me for *it*
3. Other people think *I do not deserve their* support	Other people *think I deserve their* support

Table 7.3. (Continued)

Appraisal Measures	
Negative Scale	**Positive Scale**
4. Other people expect *that emotionally* I should be completely recovered by now	Other people *understand that emotionally I may need more time to recover*
5. Other people have rejected me because *of it*	*Other* people have embraced me because *of it*
6. People *whom* I though would stand by me have let me down	People *have always continued to stand by me*
7. Other people are embarrassed of me now	Other people are proud of me now
8. *Other* people *do not deal well* with knowing *about it*	*Other* people deal well with knowing *about it*
9. People *don't listen* when I talk to them about *it*	*Other people listen* when I talk to them about *it*
10. *Other people do not* understand what I have gone through	*Other people understand* what I have gone through
11. *I cannot* relate well to most people	I *am better able* to relate well to most people
5. Self-Blame/Actions During Cancer Treatment	
1. It is my fault that I got cancer	I got cancer through no fault of my own
2. I could have prevented my cancer ~~*but I didn't*~~	*Nothing I could have done would have* prevented my cancer
3. I recovered more slowly, or was more sick, than anyone *else with* the same cancer	I recovered more quickly, or was *less* sick *than* anyone else with the same cancer
4. I made my illness worse by the way I acted	I made my illness better by the way I acted
~~5. I made the whole experience worse because of my actions~~[e]	~~I made the whole experience better because of my actions~~[e]
6. Unfairness	
1. It was unfair that I got cancer	*It was not unfair that I got cancer as it could have happened to anyone*
7. Consequences of Cancer	
1. My physical health is *now much worse than before my cancer*	My physical health is *now much better than before my cancer*
2. My physical appearance has changed for the worse	My physical appearance has changed for the better
3. My employment opportunities are now limited	My employment opportunities have increased
~~4. I don't have as many friends as I would like~~[f]	~~I have plenty of friends~~[f]
5. It is difficult for me to *make new friends*	I am better able to *make new friends*
6. I *find it difficult* to have a close and intimate relationship	I am better able to have a close and intimate relationship
<u>Emotions Surrounding Cancer Scale</u>	
8. Emotions Surrounding Cancer	
1. *I was completely unable to control my emotions*	*I was* completely in control *of my emotions*
2. If I ever had emotions like that again I *will* not be able to cope	If I ever had emotions like that again I *will* be able to cope
3. I cannot accept the emotions which I had	I can accept the emotions which I had
4. My emotions made things so much worse than they would otherwise have been	My emotions made things so much better than they would otherwise have been
5. My emotions were completely abnormal given the circumstances (new item)	*My emotions were completely normal given the circumstances (new item)*

Table 7.3. (Continued)

Dysfunctional Cognitive and Behavioural Strategies

Memories of Cancer Scale

9. Memories of Cancer[h]

1. I try to push them out of my mind
2. I try to erase the memory of the event
3. I try hard to control my emotions
4. I distract myself with something else
5. I work hard at keeping busy with other things
6. I think about how life would have been different if I never had cancer
7. I dwell on how my cancer could have been prevented
8. I think about why my cancer happened to me
9. I dwell on how I might have been *if I never had cancer*
10. I dwell on what other people have done to me
11. I dwell on what I have done wrong
12. I go over what happened again and again
13. I worry that I, or someone in my family, might get cancer
14. I drift off into a world of my own
15. I drink alcohol, take medication or use drugs
16. I put on loud music or TV
17. I dwell on what happened without really solving or deciding anything

Behaviour After Cancer Scale:

10. Behaviour After Cancer[i]

1. I avoid people who remind me of it
2. I avoid everyday things that remind me of it
3. I avoid going to the hospital where my treatment occurred
4. I avoid sleeping because of nightmares about it
5. I allow myself to remain numb
6. I avoid telling people about it
7. I allow myself to become detached from what is going on around me
8. I avoid looking at TV or newspaper reports about cancer or cancer treatment
9. I avoid being in situations that I cannot completely control
10. I avoid forming new relationships
11. I avoid unfamiliar places or situations
12. I put off making decisions
13. I made sure that I am not alone
14. I overprotect those close to me (e.g. children, family, friends)

Note: Any changes made to item wording have been italicised.
Deleted items are shown as striked-though. Reasons for item deletion:
[a]Items considered confusing. [d]Items 3.4 and 3.6 considered confusing/similar to items 3.1, and 3.2.
[b]Items 1.14 and 1.15 condensed to a single item 1.16. [e]Items 5.5 similar to items 5.3 and 5.4
[c]Items 2.5 and 2.7 similar to items 2.4 and 2.6. [f]Items 7.4 similar to items 7.5.

Table 7.4. Final cognitive measures and their items as included in Questionnaire Booklet (Part 2).

Appraisal Measures	
Negative Scale	**Positive Scale**
1. Thoughts of the Self after Cancer	
1. I cannot deal with things that upset me	I can deal with things that upset me
2. I feel as though I am crazy	I don't feel as though I am crazy
3. There is something wrong with me as a person	There is nothing wrong with me as a person
4. I am unable to feel normal emotions	I am able to feel normal emotions
5. I feel dead inside	I feel alive inside
6. I can' rely on myself	I can rely on myself
7. I am inadequate as a person	I am more than adequate as a person
8. I cannot trust that I will do the right thing	I can trust that I will do the right thing
9. I am a weak person	I am a strong person
10. I don't know who I am	I know who I am
11. I am on edge all of the time	I am not on edge all of the time
12. I can't stop bad things from happening to me	I am able to stop bad things from happening to me
13. I am isolated and set apart from others	I am close to others
2. Post Cancer Appraisals Scale	
Perceived Permanent Change	
1. I am unable to bring myself to accept that I had cancer	I am able to accept that I had cancer
2. Overall, I have permanently changed for the worse	Overall, I have permanently changed for the better
3. My relationship with my family has changed for the worse	My relationship with my family has changed for the better
4. I have not been able to move on with my life	I have been able to move on with my life
5. My life has been destroyed by my cancer	My life has been enhanced by my cancer
Interpretations of PTSD Symptoms	
6. My reactions when I think about it show that I am losing my mind	My reactions when I think about it show that I am in control of my mind
7. When I think about it, I feel out of control	When I think about it, I feel in control
8. Avoiding things that remind me of it makes me a weak person	Avoiding things that remind me of it does not make me a weak person
9. My reactions when I think about it show that I am a poor coper	My reaction when I think about it show that I am a good coper
Appraisals of Others Responses Following Cancer	
10. Other people don't believe me when I tell them about it	Other people believe me when I tell them about it
11. Other people blame me for it	Other people do not blame me for it
12. Other people think I do not deserve their support	Other people think I deserve their support
13. Other people expect that emotionally I should be completely recovered by now	Other people understand that emotionally I may need more time to recover
14. Other people have rejected me because of it	Other people have embraced me because of it
15. People whom I though would stand by me have let me down	People have always continued to stand by me
16. Other people are embarrassed of me now	Other people are proud of me now
17. Other people do not deal well with knowing about it	Other people deal well with knowing about it
18. People don't listen when I talk to them about it	Other people listen when I talk to them about it
19. Other people do not understand what I have gone through	Other people understand what I have gone through
20. I cannot relate well to most people	I am better able to relate well to most people

Table 7.4. (Continued).

Appraisal Measures **Negative Scale**	**Positive Scale**
Self-Blame/Actions During Cancer Treatment	
21. It is my fault that I got cancer	I got cancer through no fault of my own
22. I could have prevented my cancer	Nothing I could have done would have prevented my cancer
Unfairness	
23. It was unfair that I got cancer	It was not unfair that I got cancer as it could have happened to anyone
Consequences of Cancer	
24. My physical health is now much worse than before my cancer	My physical health is now much better than before my cancer
25. My physical appearance has changed for the worse	My physical appearance has changed for the better
26. My employment opportunities are now limited	My employment opportunities have increased
27. It is difficult for me to make new friends	I am better able to make new friends
28. I find it difficult to have a close and intimate relationship	I am better able to have a close and intimate relationship
3. Appraisals of Cancer Reactions Scale	
1. I was completely unable to control my emotions	
2. I cannot accept the emotions which I had	
3. My emotions made things so much worse than they would otherwise have been	My emotions made things so much better than they would otherwise have been
4. I made my illness worse by the way I acted	I made my illness better by the way I acted
Dysfunctional Cognitive and Behavioural Strategies	
4. Memories of Cancer Scale	
1. I try to push them out of my mind	
2. I try to erase the memory of the event	
3. I try hard to control my emotions	
4. I distract myself with something else	
5. I work hard at keeping busy with other things	
6. I think about how life would have been different if I never had cancer	
7. I dwell on how my cancer could have been prevented	
8. I think about why my cancer happened to me	
9. I dwell on how I might have been if I never had cancer	
10. I dwell on what other people have done to me	
11. I dwell on what I have done wrong	
12. I go over what happened again and again	
13. I worry that I, or someone in my family, might get cancer	
14. I drift off into a world of my own	
15. I drink alcohol, take medication or use drugs	
16. I put on loud music or TV	
17. I dwell on what happened without really solving or deciding anything	
5. Behaviour After Cancer Scale:	
1. I avoid people who remind me of it	
2. I avoid everyday things that remind me of it	
3. I avoid going to the hospital where my treatment occurred	
4. I avoid sleeping because of nightmares about it	

Table 7.4. (Continued).

Dysfunctional Cognitive and Behavioural Strategies

5. I allow myself to remain numb
6. I avoid telling people about it
7. I allow myself to become detached from what is going on around me
8. I avoid looking at TV or newspaper reports about cancer or cancer treatment
9. I avoid being in situations that I cannot completely control
10. I avoid forming new relationships
11. I avoid unfamiliar places or situations
12. I put off making decisions
13. I made sure that I am not alone
14. I overprotect those close to me (e.g. children, family, friends)

6. State Dissociation Questionnaire – Persistent (Halligan et al., 2002; 2003; Murray et al., 2002):
Note: This scale did not undergo pilot testing

1. I feel dazed, unable to take in what is happening
2. The world around me seems strange or unreal
3. My body feels as if it is not really mine
4. I feel emotionally numb
5. I feel as if I am separate to my body and am watching it from outside
6. I feel as if time is going faster or slower than it really is
7. I feel as if I am living in a dream or a film, rather than in real life
8. Things around me seem too big or too small, or distorted in shape
9. I feel distant from my emotions

Peritraumatic Cognitive Processing (Assessing Trauma Memory Deficits)

Note: These scale did not undergo pilot testing

7. The Mental Defeat Scale (Dunmore et al., 1999, 2001)

1. I lost any will-power
2. I didn't care what happened to me anymore
3. I felt completely defeated
4. I no longer felt like a human being
5. In my mind, I gave up
6. I felt destroyed as a person
7. I wanted to die
8. I lost any inner resistance
9. I felt like an object
10. I felt completely at the mercy of other people or the situation
11. I felt completely humiliated and lost any sense of inner dignity

8. Data Driven Processing Scale (Halligan et al., 2002; 2003)

12. I couldn't really take it all in
13. I did not fully understand what was going on
14. It was just a stream of unconnected impressions following each other
15. I could not think clearly
16. I was overwhelmed by sensations and couldn't put everything together
17. I was confused and could not fully make sense of what was happening
18. My mind was fully occupied with what I saw, heard, smelled, and felt
19. My mind was full of impressions and my reactions to them

Table 7.4. (Continued).

Peritraumatic Cognitive Processing (Continued)
9. State Dissociation Questionnaire (Halligan et al., 2002, 2003; Murray et al., 2002)
20. I felt dazed, unable to take in what was happening
21. The world around me seemed strange or unreal
22. My body felt as if it was not really mine
23. I felt emotionally numb
24. I felt as if I was separate to my body and was watching it from outside
25. I felt as if time was going faster or slower than it really was
26. I felt as if I was living in a dream or a film, rather than in real life
27. Things around me seemed too big or too small, or distorted in shape
28. I felt distant from my emotions
10. Lack of Self-Referent Processing Scale (Halligan et al., 2003)
29. I felt as if the event was happening to someone else
30. I felt like I was a different person from the person I used to be
31. I was aware that the event was happening but not so much that it was happening to me
32. I felt cut off from my past
33. I felt cut off from my future
34. I couldn't imagine anything beyond this experience
35. Things that had been important to me before did not matter any longer
36. I felt there was no way back to my normal life after this

CHAPTER 8
STUDY DESIGN, METHODOLOGY, AND PARTICIPANT CHARACTERISTICS

8.0 Overview

Part 2 of this program of research addresses two key goals: (1) to test the applicability of the Ehlers and Clark (2000) cognitive model of posttraumatic stress disorder to childhood cancer survivors; and (2) to test whether the cognitive factors proposed by the Ehlers and Clark (2000) model are also applicable to posttraumatic growth. Studies 3 and 4 will focus on each of these goals respectively. The aim of Chapter 8 is to summarise the design, methodology, and the participant characteristics relevant to these studies.

8.1 Method

8.1.1 Design

Part 2 was a cross-sectional analytic study designed to specifically test the predictive utility of the cognitive processes proposed by the Ehlers and Clark (2000) model in accounting for persistent posttrauma outcomes in childhood cancer survivors. As an extension of Part 1, Part 2 comprised the completion of self-report measures contained in Questionnaire Booklet (Part 2) (see Appendix 7B). All participants were self-selected for this study.

8.1.2 Participants

Of the 155 childhood cancer survivors who participated in the structured clinical interview (see Chapter 2, section 2.2.3) all were invited to participate in Part 2 and all subsequently agreed. Of these, 122 survivors aged between 16.3 to 48.5 years (38 males; 84 females; response rate=79%) completed and returned the self-report measures. Table 8.1 outlines the demographic and treatment details for these participants. Although regular follow-up phone calls were made to encourage participation, reasons for non-participation were not volunteered by the 33 non-responders. Responders and non-responders were compared on demographic, treatment, and outcome (IES-R, SCID, PTGI) variables. The non-respondent group were significantly more likely to be male ($X^2(1, N = 155) = 7.80, p < .01$), and identify with a culture other than Australian ($X^2(1, N = 146) = 7.66, p < .02$) than the respondent group.

8.1.3 Procedure

All childhood cancer survivors who participated in the interview stage described in Part 1 (Chapter 2, Section 2.2.3) were invited to take part in Part 2. Following consent, Questionnaire

Pack 2 was mailed to each eligible participant. Questionnaire Pack 2 included a covering letter outlining the purpose of the second section of the research, Questionnaire Booklet (Part 2), and a reply paid envelope. Follow-up phone calls were made at regular monthly intervals to encourage questionnaire completion. Mean time between interview participation and completion of Questionnaire Booklet (Part 2) was 1.2 months (range = -3.6 to 12.0 months, *SD* = 1.9).

8.1.4 Measures

8.1.4.1 Outcome Measures: PTSD and Posttraumatic Growth

Measures used to assess PTSD diagnosis, and posttraumatic growth outcomes are listed below. These have been described in detail in Part 1, Chapter 2, Section 2.1.4.

- *Structured Clinical Interview for DSM-IV: PTSD Module (SCID*) (First et al., 1995).
- *Impact of Event Scale-Revised (IES-R)* (Weiss & Marmar, 1997).
- *Posttraumatic Growth Inventory (PTGI)* (Tedeschi & Calhoun, 1996).

8.1.4.2 Cognitive Measures (Based on the Ehlers and Clark's Cognitive Model)

The cognitive measures contained in Questionnaire Booklet (Part 2) (Appendix 7B) measure the three broad processes described by the Ehlers and Clark (2000) Cognitive Model as leading to persistent PTSD: cognitive appraisals of trauma and trauma sequelae, dysfunctional cognitive and behavioural strategies, and peritraumatic cognitive processing (assessing trauma memory deficits). These measures are based on those developed by Ehlers and colleagues in the testing of the model (Dunmore et al., 1999, 2001; Ehring et al., 2006; Foa et al., 1999; Halligan et al., 2002, 2003; Murray et al., 2002). Their development is described in detail in Chapter 7, and item content is contained in Table 7.4.

A. Cognitive Appraisals of Cancer and Cancer Sequelae

- *Thoughts of the Self After Cancer Scale:* A 26-item measure assessing both negative (13-items) and positive (13-items) general thoughts about the self. Internal consistency for the current study was high for the negative ($\alpha = 0.87$) and positive scales ($\alpha = 0.83$).

- *Post Cancer Appraisals Scale:* A 56-item measure assessing negative (28-items) and positive (28-items) appraisals of cancer and cancer sequelae.. Internal consistency for the current study was high for the negative ($\alpha = 0.89$) and positive scales ($\alpha = 0.76$).

- *Appraisals of Cancer Reactions Scale:* A 6-item measure assessing negative (4-items) and positive (2-items) appraisals of actions and emotions during the cancer experience. Internal consistency for the current study was moderate for both the negative (α = 0.61) and positive scales (α = 0.57)[47].

In addition to the above appraisal measures, a measure developed and tested within the childhood cancer survival context has been included to assess perceived past life threat of cancer and treatment intensity, as well as perceived future life threat. As a measure of appraisals of cancer and cancer sequelae, this measure fits well within the model. This data was collected at the time of Study 1, and does not have a corresponding positive scale.

- *Assessment of Life Threat and Treatment Intensity Questionnaire* (Stuber et al., 1997): A 7-item measure assessing the extent to which cancer and cancer treatment are perceived to be intense and life-threatening both currently and in the past (e.g., *"I thought I would die when I had cancer", "I could still die from my cancer",* and "*Cancer treatment was hard for me"*. Responses were rated on a 5-point continuous scale (from 1: "*Disagree"* to 5: "*Agree"*). This scale showed high internal consistency (α = 0.71) for the current study[48].

B. Dysfunctional Cognitive and Behavioural Strategies.

- *Memories of Cancer Scale:* An 18-item scale assessing dysfunctional strategies used to deal with intrusive memories surrounding the cancer experience. This scale showed high internal consistency (α = 0.92) for the current study.

- *Behaviour After Cancer Scale:* A 14-item scale assessing the extent to which the respondent engages in dysfunctional behaviours following cancer. This scale showed high internal consistency (α = 0.87) for the current study.

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[47] The low internal consistency scores as measured by Cronbach's alpha (α) may reflect the small number of items per scale – component loadings for the retained scale items show a high degree of overlapping variance indicating the items measure the same construct (Tabachnick & Fidell, 2001).

[48] The measures assessing PTSS (IES-R) and posttraumatic growth (PTGI) were administered with the ALTTIQ (Questionnaire Booklet (Part 1)), while the other cognitive processing measures were administered with Questionnaire Booklet (Part 2). This may account for stronger relationship between the ALTTIQ and PTSD, PTSS, and posttraumatic growth.

- *State Dissociation Questionnaire – Persistent* (Halligan et al., 2002, 2003; Murray et al., 2002): A 9-item scale assessing the degree of current dissociated experiences. This scale showed high internal consistency (α = 0.91) for the current study.

C. Trauma Memory Deficits.

As described in Chapter 7, item content for the following measures were retained as developed by the scale authors. Scale instructions were altered to refer specifically to cancer rather than accident or assault.

- *Peritraumatic Cognitive Processing:* This questionnaire (36-items in total) contains 4 measures assessing memory processing at the time of a most distressing cancer related event. Listed below, these measures showed high internal consistency (α = 0.90 to 0.92) for the current study:
  - *The Data-Driven Processing Scale* (Halligan et al., 2002,2003). 8-items.
  - *The Lack of Self-Referent Processing Scale* (Halligan et al., 2003): 8-items..
  - *The State Dissociation Questionnaire* (Halligan et al., 2002, 2003; Murray et al., 2002): 9-items.
  - *The Mental Defeat Scale* (Dunmore et al., 1999, 2001): 11-items.

Table 8.1. Demographic and treatment details for childhood cancer survivors

Variable (n=122)	n (%)
Gender:	
Male	38 (31.1)
Female	84 (68.9)
Age at Stage 2 (years):	
Mean (SD)	27.2 (7.0)
Range	16.3 to 48.5
Age at diagnosis (years):	
Mean (SD)	6.6 (4.4)
Range	0 to 16.9
Yrs off treatment:	
Mean (SD)	16.0 (6.9)
Range	4.0 to 35.7
Diagnosis:	
Leukaemia	57 (46.7)
Solid Tumour	39 (32.0)
Lymphoma	15 (12.3)
CNS Tumour	4 (3.3)
Other	7 (5.7)
Treatment:	
Chemotherapy	115 (95.0)
Radiation	84 (70.0)
Cranial	*50 (42.4)*
Total body	*7 (6.0)*
Surgical resection	54 (44.6)
Transplant	12 (9.8)
Relapse/2nd malignancy	18 (14.8)
Living with parents	77 (63.1)
Relationship status:	
Single	77 (63.6)
Partner not defacto	19 (15.7)
Married/ defacto	25 (20.7)
Level of education:	
Not completed high school	34 (27.9)
Completed high school	33 (27.0)
Apprenticeship/TAFE	29 (23.8)
University graduate	20 (16.4)
University postgraduate	6 (4.9)
Level of current employment:	
Full-time	44 (36.1)
Part-time/casual	47 (38.5)
Household income per annum:	
Up to $20,000	9 (9.1)
$20,001 to $40,000	16 (16.2)
$40,001 to $70,000	34 (34.3)
$70,001 to $100,000	18 (18.2)
$100,001 plus	22 (22.2)
Personal income per annum:	
Up to $20,000	64 (61.0)
$20,001 to $40,000	23 (21.9)
$40,001 to $70,000	13 (12.4)
$70,001 to $100,000	2 (1.9)
$100,001 plus	3 (2.9)
Cultural identity	
Australian	108 (93.9)
European	5 (4.3)
North American	1 (0.9)
Middle Eastern	1 (0.9)

Note: Valid percentages used for frequency data.

CHAPTER 9
STUDY 3

A TEST OF THE APPLICABILITY OF THE EHLERS AND CLARK COGNITIVE MODEL OF PTSD TO CHILDHOOD CANCER SURVIVAL.

9.0 Overview

The aim of Study 3 is to assess the generalisability of the Ehlers and Clark (2000) cognitive model of posttraumatic stress disorder to childhood cancer survivorship. In doing so, Study 3 will address the existing theoretical gap in childhood cancer PTSD research by applying a cognitive model found to be valuable in understanding and treating non-illness trauma.

As outlined in Chapter 6, the model suggests three predominant and interactive cognitive processes that lead to the onset and maintenance of PTSD. These include: excessive negative appraisals of the trauma and trauma sequelae, dysfunctional cognitive and behavioural strategies, and trauma memory deficits (peritraumatic cognitive processing). Support for this model has been generated from a diverse evidence base (e.g., Halligan et al., 2003; Ehlers et al., 2000, 2006; Ehring et al., 2006; Laposa & Alden, 2003; Stallard, 2003; Vickers 2005), but it is not yet known whether these same processes can account for PTSD outcomes following childhood cancer. In order to address this theoretical gap, Study 1 will test the set of hypotheses outlined below. Specifically, Study 3 will test whether the three processes posited by Ehlers and Clark (2000) will differentiate between PTSD and non-PTSD groups and predict PTSD severity[49]. Study 3 will also test whether, as indicated by the model (see Chapter 6, section 6.2.3), peritraumatic cognitive processing can account for prevalence and severity of B-symptomatology (intrusive re-experiencing). Lastly, based on Ehlers and Clark's (2000) proposition that excessive negative appraisals, and dysfunctional cognitive and behavioural strategies are important maintaining factors in longer-term PTSD (see Chapter 6, section 6.2.1 and 6.2.2), Study 3 will test whether excessive negative appraisals, and dysfunctional cognitive and behavioural strategies are stronger predictors of PTSD severity than peritraumatic cognitive processing.

- *Hypothesis 1:* Scores on measures of Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and

[49] As no survivors qualified for 'recovered' PTSD (see Table 9.2; full-remission PTSD) hypotheses concerning PTSD maintenance could not be tested.

Behavioural Strategies will be significantly lower for the No-history PTSD group, than for the PTSD group.

- *Hypothesis 2:* Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies will each predict PTSD severity.

- *Hypothesis 3:* Scores on measures of Peritraumatic Cognitive Processing will be significantly lower for Survivors in the No-History B-symptomatology group, than for those in the Current B-Symptomatology or Recovered B-symptomatology groups. Similarly, scores on these same measures will be significantly lower for survivors in the Recovered group compared to the Current group.

- *Hypothesis 4:* Negative Appraisals of Cancer and Cancer Sequelae will predict PTSD severity over and above Peritraumatic Cognitive Processing.

- *Hypothesis 5:* Dysfunctional Cognitive and Behavioural Strategies will predict PTSD severity over and above Peritraumatic Cognitive Processing,

9.1 Method

9.1.1 Participants

Following the methods described in Chapter 8, self-report measures were completed by 122 childhood cancer survivors.

9.1.2 Measures

9.1.2.1 Outcome Measures: PTSS and PTSD

Measures used to assess PTSS and PTSD diagnosis are listed below. These have been described in detail in Part 1, Chapter 2, Section 2.1.4.

- *Impact of Event Scale-Revised (IES-R)* (Weiss & Marmar, 1997).
- *Structured Clinical Interview for DSM-IV: PTSD Module (SCID)* (First et al., 1995).

9.1.2.2 Cognitive Measures (Based on Ehlers and Clark's Cognitive Model)

The cognitive measures used to assess the three broad processes described by the Ehlers and Clark (2000) as leading to persistent PTSD are listed below. These measures and their development have been described in detail in Chapter 7.

Cognitive Appraisals of Cancer and Cancer Sequelae

- *Negative Thoughts of the Self After Cancer Scale.*
- *Negative Post Cancer Appraisals Scale.*
- *Negative Appraisals of Cancer Reactions Scale.*
- *Assessment of Life Threat and Treatment Intensity Questionnaire* (*ALTTIQ;* Stuber et al., 1997).

Dysfunctional Cognitive and Behavioural Strategies

- *Memories of Cancer Scale.*
- *Behaviour After Cancer Scale.*
- *State Dissociation Questionnaire – Persistent* (*SDQ- Persistent;* Halligan et al., 2002, 2003; Murray et al., 2002).

Peritraumatic Cognitive Processing (assessing Trauma Memory Deficits)

- *Data Driven Processing Scale* (Halligan et al., 2002; 2003).
- *Self Referent Processing Scale* (Halligan et al., 2002; 2003).
- *State Dissociation Questionnaire – Peritraumatic* (Halligan et al., 2002, 2003; Murray et al., 2002).
- *The Mental Defeat Scale* (Dunmore et al., 1999, 2001).

9.1.3 Statistical Analyses[50]

[50] Assumption testing: Violations of normality were found for the self-report outcome measure (IES-R: skew = 1.45, kurtosis = 1.84) as well as the *Peritraumatic Cognitive Processing* measures (skew range = 0.19 to 1.34; kurtosis range = -0.79 to 1.57), and the *Dysfunctional Cognitive/Behavioural Strategies* measures (skew range = 0.90 to 1.69; kurtosis range = 0.36 to 2.21). Transformation of variables was investigated using both naturalistic logarithmic (NL) and square root (SQRT) calculations. Square root transformations revealed greatest statistical correction for the measures (IES-R: skew = 0.58, kurtosis = -0.52; PTGI: skew = -0.42, kurtosis = -0.76; *Peritraumatic Cognitive Processing* measures: skew range = -0.46 to -0.51; kurtosis range = -0.51 to -0.67; *Dysfunctional Cognitive/Behavioural Strategies* measures: skew range = 0.11 to 1.05; kurtosis range = -0.60 to 0.03) - although histograms still revealed a tendency for positive skew. Because of this, the moderate extent of violations, and consideration of problems associated with interpretation (Tabachnick & Fidell, 2001), real data were used in these analyses - however analysis with transformed data were also conducted. Results with transformed data will only be reported if differing from real data results. The assumption of Linearity was confirmed.

Using SPSS for windows, version 15, differences between groups (*'No-history PTSD'* and *'PTSD'*) on the demographic and treatment variables and on the cognitive measures were assessed by Chi-Square tests of Independence (categorical data) or standard applications of the Independent Sample t-test (continuous data). Due to low sample sizes in the current-PTSD group and the partial-remission PTSD groups (see Table 9.1), these groups were combined to form a single *'PTSD group'*[51]. For t-test analyses, where unequal variances between groups were revealed, the equal variances not assumed statistic is reported.

Differences between groups meeting B-symptomatology (*No-history, Recovered, Current*) were assessed by standard applications of univariate analysis of variance techniques (ANOVA). For hypotheses testing there were 3 planned contrasts (contrast 1: *'No-history'* versus *'Recovered'*; contrast 2: *'No-history'* versus *'Current'; 'Recovered'* versus *'Current'*). Where Levene's test revealed the assumption of equality of variance to be violated, post-hoc non-parametric analyses were conducted.

Relationships between the IES-R and the demographic and treatment variables were assessed by Pearson's bivariate correlational analyses. Hierarchical multiple regression models were used for assessment of cognitive measures as predictors of PTSD severity or B-symptom severity. In reporting explained variance, the more conservative adjusted R^2 is used due to the small sample size of some analyses relative to the number of independent variables[52]. The alpha criterion of $p \leq .05$ was applied to denote statistical significance.

9.2 Results

Prevalence Data

Table 9.1 lists mean scores and prevalence data for the IES-R and the SCID. As shown, according to the IES-R, 14.8% of survivors met moderate to severe levels of clinically significant PTSS. According to the SCID, childhood cancer constituted a traumatic event, in accordance with DSM-IV criterion A for 47.5% of survivors. 10.7% met full diagnostic criteria for PTSD since diagnosis, with 5.7% still meeting full current PTSD criteria. A further 4.9% of survivors who had

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[51] The PTSD group reflects PTSD since diagnosis: The part-remission PTSD group has met full PTSD criteria since diagnosis and still currently meet at least one of the symptom cluster criteria (i.e., they have developed PTSD as a consequence of their past cancer experience, and were still experiencing some of the symptoms when assessed for this study). Between group comparisons revealed no difference in demographic and treatment variables, and no difference in most cognitive processing variables – exceptions to this were, according to Mann-Whitney U Tests: the Current-PTSD group reported significantly greater Negative Thoughts of the Self (M = 36.0, SD = 5.6) and Persistent Dissociation (M = 16.1, SD = 4.8) than the Part-remission PTSD group (M = 25.7, SD = 3.6; M = 6.5, SD = 5.6; z = -2.57, p = .008; z = -2.44, p = .014).

[52] Based on the following rules of thumb: Minimum cases to IV ratio for testing the multiple correlation: $N \geq 50 + 8m$; Minimum cases to IV ratio for testing individual predictors: $N \geq 104 + m$ (Tabachnick & Fidell, 2001).

once met full criteria for PTSD following their childhood cancer experience still met partial symptomatology (with at least one B, C, or D-symptom cluster still being met). No survivors met full-remission following a PTSD diagnosis.

Of the symptom clusters, 59.8% qualified for the B-symptom cluster of intrusive re-experiencing since cancer diagnosis with 30.6% still meeting current criteria. The frequency of participants meeting criteria for the remaining symptom clusters was lower, although still higher than those meeting full PTSD.

Relationships between Demographic and Treatment variables and PTSD:

No-History PTSD versus PTSD groups: Table 9.2 shows no differences were revealed between survivors in the No-history PTSD group and the PTSD-group.

PTSS Severity: Table 9.3 shows Pearson bivariate correlational relationships between the IES-R scale and the demographic and treatment variables. Higher IES-R scores were significantly associated with having received cranial radiation during treatment (small correlation, $r = 0.22$, $p = .017$)[53].

9.2.1: <u>Hypothesis 1</u>

" Scores on measures of Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies will be significantly lower for the No-history PTSD group, than for the PTSD group".

As predicted, and as shown in Table 9.4, the PTSD group reported significantly higher scores on most cognitive processing measures than the No-history PTSD group:

Peritraumatic Cognitive Processing: Survivors in the PTSD group, relative to the No-history PTSD group, reported significantly higher levels of *Data-Driven Processing*, *Lack of Self-Referent Processing* and *State Dissociation* at the time of experiencing a distressing cancer related event. Contrary to expectations, the PTSD group and the No-history PTSD group did not differ significantly on the measure of *Mental Defeat* ($t = -1.81$, $p = .073$).

Negative Appraisals of Cancer and Cancer Sequelae: Survivors in the PTSD group reported significantly higher *Negative Thoughts of the Self, Negative Post Cancer Appraisals*, and greater *Appraisals of Life-Threat and Treatment Intensity* than the No-history PTSD group. Contrary to

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[53] Using transformed outcome measures the correlation between IES-R and Cranial Irradiation became non-significant at the $p < .05$ level ($r=0.18$, $p=.054$).

expectations, the No-history PTSD group and the PTSD group did not differ significantly on *Appraisals of Cancer Reactions* (t = -1.12, p = .264).

Dysfunctional Cognitive and Behavioural Strategies: Survivors in the PTSD group, relative to the No-history PTSD group, reported engaging in significantly more dysfunctional strategies to control intrusive memories of their cancer experience (*Memories of Cancer*), and significantly more dysfunctional behaviours to avoid reminders of their cancer experience (*Behaviour after Cancer),* and as well as engaging in *Persistent Dissociation* on reminders of their cancer experience.

9.2.2: Hypothesis 2

"Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies will predict PTSD severity."

As shown in Table 9.5, PTSS severity as measured by the full-scale IES-R shared significant positive relationships with most cognitive variables (moderate to strong correlations; r = 0.25 to 0.55, p < .01) with the exception of Data Driven Processing (r = 0.16, p = .116) and Appraisals of Cancer Reactions (r = 0.14, p = .174). Hierarchical regression analyses were conducted to specifically test the hypotheses. Due to sample size, there were limitations in the number of independent variables included in the analysis[54]. Because of this, three regressions were run, each assessing one of the three processes proposed by the model: *Peritraumatic Cognitive Processing*, *Appraisals of Cancer/Cancer Sequelae,* and *Dysfunctional Cognitive and Behavioural Strategies.* For each analysis, variables were entered in two steps. Step 1 included the treatment variable *Cranial Radiation* which was shown to be significantly correlated with the IES-R scale (see Table 9.3). At step 2, the relative cognitive variables assessing *Peritraumatic Cognitive Processing, Appraisals of Cancer/Cancer Sequelae,* and *Dysfunctional Cognitive and Behavioural Strategies* were entered.

As predicted, and as shown in Table 9.6, all three models were significant explaining between 28 to 34% of the variance of PTSS severity, with Step 2 accounting for a significant proportion of this variance (Model 1: $R^2change$ = 0.26, p < .001 ; Model 2: $R^2change$ = 0.32, p < .001; Model 3: $R^2change$ = 0.31, p < .001). Contrary to expectations, Data-Driven Processing was found to significantly but negatively predict PTSS severity in Model 1 (β = -0.34, p = .008).

The final models revealed that: a lack of data-driven processing, and greater state dissociation (Model 1), as well as more negative post cancer cognitions, and more negative appraisal

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[54] Based on the following rules of thumb: Minimum cases to IV ratio for testing the multiple correlation: N ≤ 50 + 8m; Minimum cases to IV ratio for testing individual predictors: N ≤ 104 + m (Tabachnick & Fidell, 2001).

of life threat and treatment intensity (Model 2) each significantly contribute to the prediction of PTSS severity at an individual level. While no individual predictor contributed to Model 3 at a significant level, dysfunctional post cancer behaviours were just outside of the $p \leq .05$ criterion for individual significance ($\beta = 0.27$, $p = .051$)[55].

9.2.3: Hypothesis 3

"Scores on measures of Peritraumatic Cognitive Processing will be significantly lower for Survivors with No-History of meeting B-symptom criteria (Intrusive re-experiencing), than for those who meet current or recovered symptom criteria. Similarly, scores on these same measures will be significantly lower for survivors in the recovered group compared to the current group".

As shown in Table 9.7, significant main effects were revealed between groups meeting Intrusion symptom criteria and scores on *Mental Defeat, Data-Driven Processing, Lack of Self-Referent Processing,* and *State Dissociation.* As predicted, planned contrasts, or where Levene's test revealed the assumption of equality of variance to be violated, post-hoc non-parametric comparisons revealed that:

'No-history' and 'Current Intrusion Groups': Survivors in the No-history group scored significantly lower on all measures of Peritraumatic Cognitive Processing than those in the Current group ($p < .05$).

'No-history' and 'Recovered' Intrusion Groups: Survivors in the No-history group scored significantly lower than the Recovered group on measures of *Mental Defeat* and *Lack of Self-Referent Processing,* although contrary to expectations no difference was found on measures of *Data-Driven Processing* ($p = .586$) and *State Dissociation* ($p = .145$).

'Recovered' and 'Current' Intrusion Groups: Survivors in the Recovered group scored significantly lower on all measures of Peritraumatic Cognitive Processing than those in the Current group ($p < .05$).

9.2.4: Hypothesis 4

"Negative Appraisals of Cancer and Cancer Sequelae will predict PTSD severity over and above Peritraumatic Cognitive Processing".

[55] Model 3: When transformed data used Memories of Cancer became a significant individual predictor (*B = 0.32, p = .014).*

As shown in Table 9.8 (Model 1) the hierarchical multiple regression analysis employed to test the hypothesis adopted a 3 step model. Step 1 included the treatment variable *Cranial Radiation* which was shown to be significantly correlated with the IES-R scale (see Table 9.3). At step 2, the four measures assessing *Peritraumatic Cognitive Processing* variables were entered, followed by the four measures assessing *Negative Appraisals of Cancer and Cancer Sequelae* entered at Step 3.

As predicted, and as shown in Table 9.8 (Model 1), Step 3 was significant, with the *Negative Appraisals of Cancer and Cancer Sequelae* variables explaining an additional 13% of the variance in PTSS severity over and above the 26% explained by the Peritraumatic Cognitive Processing variables entered at Step 2 (Model 1: $R^2change = 0.13$, $p = .001$).

The final model revealed that a lack of data-driven processing, greater state dissociation, more negative post cancer appraisals, and more negative appraisals of life threat and treatment intensity each significantly contribute to the prediction of PTSS severity at an individual level.

9.2.5: Hypothesis 5

"Dysfunctional Cognitive and Behavioural Strategies will predict PTSD severity over and above Peritraumatic Cognitive Processing".

As shown in Table 9.8 (Model 2) the hierarchical multiple regression analysis employed to test the hypothesis adopted a 3 step model. Step 1 included the treatment variable *Cranial Radiation* which was shown to be significantly correlated with the IES-R scale (see Table 9.3). At step 2, the four measures assessing *Peritraumatic Cognitive Processing* variables were entered, followed by the three measures assessing *Dysfunctional Cognitive and Behavioural Strategies* entered at Step 3.

As predicted, and as shown in Table 9.8 (Model 2), Step 3 was significant, with the *Dysfunctional Cognitive and Behavioural Strategies* variables explaining an additional 13% of the variance in PTSS severity over and above the 26% explained by the Peritraumatic Cognitive Processing variables entered at Step 2 (Model 2: $R^2change = 0.13$, $p = .001$).

The final model revealed that a lack of data-driven processing, greater state dissociation, and more dysfunctional behavioural strategies each significantly contribute to the prediction of PTSS severity at an individual level.

9.3 Discussion

Study 3 has confirmed that, as predicted, the cognitive processes proposed by Ehlers and Clark as leading to persistent PTSD in trauma survivors are generalisable to the childhood cancer context, even many years following cancer treatment. With an average time off treatment of 16 years (or 18 years for those meeting current PTSD or partial-remission) findings show that, as with

other non-illness trauma (e.g., assault, accident, political imprisonment), the cognitive processes as proposed by the model do account for the onset and severity of *persistent* PTSD in this Australian group of long-term childhood cancer survivors.

Consistent with the hypotheses, survivors with current PTSD (full disorder or in partial remission) reported engaging in significantly more data-driven processing, lack of self-referent processing, and state dissociation at the time of their most distressing cancer related event relative to survivors with no history of PTSD, and the degree of peritraumatic cognitive processing collectively predicts the severity of posttraumatic stress symptoms even many years after treatment cessation. In line with the model and past findings from non-illness trauma (Dunmore et al., 2001), results show that survivors with PTSD (current or in partial remission) are more likely to engage in enhanced sensory processing and impaired conceptual processing during highly distressing or traumatic cancer related event(s).

Study 3 also confirmed that each of these *peritraumatic cognitive processes* (data-driven processing, lack of self-referent processing, state dissociation) were able to differentiate between survivors meeting current intrusive symptomatology (B-symptom criteria of the DSM-IV) and those who never met this criterion. These same processes also distinguished between survivors meeting current B-symptom criteria and those who have since recovered. These findings are in line with the model which outlines that incomplete trauma memory processing leads to poor autobiographical memory integration and heighted cue driven trauma memory retrieval, both of which lead to intrusive re-experiencing of trauma memories and the initial onset of PTSD (Ehlers & Clark, 2000).

Of note is the finding that data-driven processing is a negative predictor of PTSS severity - suggesting a lack of data-driven processing is associated with more severe PTSS. This is contradictory to results discussed above showing survivors with PTSD (current or in partial remission) to report greater use of data-driven processing than survivors with no history of PTSD. However, this result is not exclusive to Study 3. In their prediction model, Halligan et al. (2003) also report data-driven processing to be in the negative direction and show both data-driven and lack of self-referent processing to be highly intercorrelated with the construct of peritraumatic dissociation - indicating that the negative result may be an artefact of a high degree of interaction between the peritraumatic cognitive processing variables[56] (Tabachnick & Fidell, 2001). Halligan et al. (2003) argue that peritraumatic dissociation (reduced awareness, derealisation, depersonalisation, emotional numbing, and a lack of time and autobiographical context) leads to both increased data-driven processing and lack of self-referent processing. In an effort to untangle these constructs, a single

[56] A suppressor variable was ruled out as the sole cause of this result following the exclusion of each of the independent variables in the regression equations (Tabachnick & Fidell, 2001).

measure was proposed to better reflect three unique and predominant aspects of peritraumatic cognitive processing (*Self-referent processing 1*: derealisation, depersonalisation and emotional numbing; *Self-referent processing 2:* lack of time and self-referent context; *Data-driven processing:* inability to take in or comprehend the event) (Halligan et al., 2003). Whether this measure is better able to discern the predictive utility of the different peritraumatic processes has not yet been investigated.

Of further interest are the results pertaining to mental defeat. While it was suggested that mental defeat may be particularly relevant to PTSD following childhood cancer (see section 6.2.4), this was not supported. Mental defeat was not revealed to significantly differentiate between survivors with PTSD (current and partial) and those with no PTSD history, nor was it shown to be a significant individual predictor. Past research shows mental defeat to be both associated with and an early predictor of PTSD following assault or political imprisonment in adults (Dunmore et al., 1999, 2001; Ehlers et al., 2000; Kleim et al., 2007). In accounting for the current findings, it may be that the deliberate and aggressive nature of assault or political imprisonment differentiates the influence of mental defeat on PTSD from illness related trauma. For example, children with cancer, although not having control over many aspects of their disease or treatment are nonetheless often encouraged as being "strong", "brave" or "good", and usually have strong support structures in place during the traumatic experience (family, friends, hospital staff). This is in contrast to assault or political imprisonment which is most often associated with deliberate acts of aggression in an attempt to break the will of the victim (Ehlers et al., 2000). An additional consideration is that children, particularly the very young, have a less developed sense of autonomy than adults and illness may delay or inhibit autonomous development in some children (Stam et al., 2006). However, notwithstanding this difference, the finding that mental defeat does differentiate between survivors with current intrusive memories (B-Symptom criteria), relative to those with no history and those who have since recovered (as well as differentiating between the no history and the since recovered groups) indicates that mental defeat is a relevant concept in understanding childhood cancer and PTSD. Results show mental defeat to be associated with intrusive symptom onset and persistence rather than the full disorder. This is in line with the theorised mechanisms of mental defeat influencing the nature of the trauma memory (via negative appraisals), rendering it more resistant to change (Ehlers et al., 2000; Dunmore et al., 2001). As intrusive re-experiencing of the cancer experience is the symptom most often reported by survivors of childhood cancer (see Table 1.1), these findings show that mental defeat needs to be an important consideration both during the cancer treatment period, as well as in the treatment and intervention of intrusive symptomatology.

Results relating to the other Ehlers and Clark (2000) cognitive processes investigated also confirmed predictions. Survivors with current or partial PTSD reported significantly more current negative appraisals of the self, cancer and cancer sequelae, and past and current life threat and treatment intensity relative to the no-history PTSD group. The current and partial PTSD group also reported significantly greater use of *dysfunctional cognitive and behavioural strategies* to control intrusive memories of their cancer, to avoid cancer reminders, and to control threat via safety seeking behaviours. The above findings are in line with previous studies with victims of assault, political imprisonment, and road traffic accidents (Ali et al., 2002; Dunmore et al., 1999; Ehlers et al., 2000; Halligan et al., 2003; Kleim et al., 2007; Murray et al., 2002), and support the hypothesis that these same cognitive processes account for persistent PTSD in childhood cancer survivors. Prediction models also confirmed that the degree of *negative appraisals* and *dysfunctional cognitive and behavioural strategies* predict PTSS severity over and above that of the *peritraumatic cognitive processes* providing evidence that, as with non-illness trauma (e.g., Ehring et al., 2008; Halligan et al., 2003), these processes are important in provoking and maintaining PTSD following the initial peritraumatic period. Again, this is consistent with the model and further supports its applicability to a childhood cancer context (Ehlers & Clark, 2000). For the *dysfunctional cognitive and behavioural strategies,* this was particularly true for behaviours after cancer. Childhood cancer survivors often report actively avoiding reminders, particularly avoiding returning to hospitals or doctor surgeries (Kazak et al., 2004a; Stuber et al., 1997). While these findings indicate that such avoidance is a significant factor in persistent PTSD and its symptoms, it also directly impacts on the level of follow-up care and management of potential long-term health risks. Consequently, the findings of Study 3 underline that behavioural avoidance requires careful attention and management in the treatment setting in order to reduce both physical and psychological health risk.

Furthermore, contrary to predictions, appraisals surrounding behavioural or emotional reactions during cancer and cancer treatment did not differ between the no-PTSD and PTSD (partial and current) groups, nor was it significantly associated with, or a significant individual contributor to the prediction of PTSS severity. This finding may indicate that such appraisals do not contribute to PTSD onset, maintenance or severity in a childhood cancer context in the same way they would following other types of trauma. For example, in the context of sexual assault, victims may experience physiological arousal which may be interpreted by them as signs of secret enjoyment, or that the assault was secretly wanted. As this is incongruent with and threatens personal belief systems, feelings of self disgust, guilt or shame may result (Dunmore et al., 1999, 2001; Ehlers & Clark, 2000). In childhood cancer however, emotional and behavioural responses following diagnosis or painful treatments may be more likely to be considered by the survivor as justifiable in

accordance with the experience, particularly from a retrospective ‘adult’ account made many years following the actual childhood experience.

In summary, the above findings replicate many of the earlier findings from non-illness trauma (e.g., Dunmore et al., 1999, 2001; Halligan et al., 2003), providing strong evidence that the cognitive processes proposed by Ehlers and Clark (2000) as leading to the onset and maintenance of persistent PTSD are generalisable to the childhood cancer context, even many years following the end of treatment. However findings also show that the type of trauma dictates relevance of certain cognitive processes (Kleim et al., 2007). Study 3 revealed some differences between childhood cancer and other non-illness trauma, especially with regard to appraisals of reactions to cancer, and mental defeat. This understanding is imperative for the development of context specific assessment, treatment and intervention models. Study 3 has shown that the Ehlers and Clark (2000) model offers much in the design and implementation of such prediction and treatment interventions for the subset of childhood cancer survivors vulnerable to developing PTSD. In an attempt to further understand posttraumatic growth following childhood cancer, Study 4 will now explore whether the cognitive processes proposed by Ehlers and Clark (2000) may account for posttraumatic growth outcomes.

Table 9.1. PTSS and posttraumatic growth in childhood cancer survivors

Measure	**Mean (SD)**
IES-R	
Intrusion	4.93 (5.77)
Avoidance	5.17 (6.10)
Hyper-arousal	1.77 (3.36)
Full-scale	11.85 (13.24)
PTGI	
Full-scale	27.30 (17.45)
Measure	**n (%)**
IES-R (Moderate-Severe)	18 (14.8)
PTGI (Moderate-Great)	32 (26.2)
SCID:	
A-Criterion	58 (47.5)
Since Diagnosis	
PTSD	13 (10.7)
B-Symptom Cluster	73 (59.8)
C-Symptom Cluster	19 (15.6)
D-Symptom Cluster	31 (25.4)
Current	
PTSD	7 (5.7)
B-Symptom Cluster	37 (30.6)
C-Symptom Cluster	12 (9.8)
D-Symptom Cluster	20 (16.4)
Part-Remission PTSD	6 (4.9)
Full-Remission PTSD	0 (0.0)

Note: A-Criterion = Traumatic event, B-Symptom Cluster = Intrusive Re-experiencing; C-Symptom Cluster = Avoidance;
D-Symptom Cluster = Hyper-arousal.
Part-remission PTSD = Full PTSD met following cancer with at least one symptom cluster still current.
Full-remission PTSD = Full PTSD met following cancer with no symptom clusters currently met.

Table 9.2. Demographic and treatment details according to PTSD history and posttraumatic growth strength

Variable	**No history PTSD (n = 109)** **M (SD)**	**PTSD (n = 13)** **M (SD)**	***t*(,113 to 119)**	**'Low' PTG (n = 90)** **M (SD)**	**'Mod-Great' PTG (n = 32)** **M (SD)**	***t*(113 to 119)**
Age at Q2 Participation	26.8 (6.9)	30.3 (7.8)	-1.69	27.3 (7.0)	27.0 (7.2)	0.15
Age at Diagnosis	6.5 (4.3)	7.9 (4.5)	-1.09	6.4 (4.1)	7.4 (5.0)	-1.13
Years off Treatment	15.8 (6.6)	18.0 (9.1)	-0.84	16.3 (6.7)	15.3 (7.7)	0.65
Variable:	**n (%)**	**n (%)**	***X*^{2}(1 to 4)**	**n (%)**	**n (%)**	***X*^{2}(1 to 4)**
Gender			0.36†			0.19
Male	33 (30.3)	5 (38.5)		31 (34.4)	7 (21.9)	
Female	76 (69.7)	8 (61.5)		59 (65.6)	25 (78.1)	
Diagnosis			3.29†			2.39†
Leukaemia	52 (47.7)	5 (38.5)		45 (50.0)	12 (37.5)	
Solid Tumour	35 (32.1)	4 (30.8)		27 (30.0)	12 (37.5)	
Lymphoma	12 (11.0)	3 (23.1)		11 (12.2)	4 (12.5)	
CNS Tumour	3 (2.8)	1 (7.7)		2 (2.2)	2 (6.3)	
Other	7 (6.4)	-		5 (5.6)	2 (6.3)	
Treatment						
Chemotherapy	102 (94.4)	13 (100.0)	0.76†	85 (95.5)	30 (93.8)	0.15†
Radiotherapy	75 (70.1)	9 (69.2)	0.00†	60 (68.2)	24 (75.0)	0.52
Cranial	*43 (41.0)*	*7 (53.8)*	*0.79*	*37 (42.5)*	*13 (41.9)*	*0.00*
Total Body	*7 (6.7)*	-	*0.93*†	*4 (4.7)*	*3 (9.7)*	*1.02*†
Surgical Resection	48 (44.4)	6 (46.2)	0.01	38 (42.7)	16 (50.0)	0.50
Transplant	12 (11.0)	-	1.59†	8 (8.9)	5 (15.6)	1.35†
Relapse/2nd Malignancy			0.01†			0.18†
Yes	16 (14.7)	2 (15.4)		14 (15.6)	4 (12.5)	
Living with Parents			1.80†			0.01
Yes	71 (65.1)	6 (46.2)		57 (63.3)	19 (59.4)	
Relationship Status			1.59†			1.26
Single	67 (62.0)	10 (76.9)		58 (65.2)	19 (59.4)	
Partner not defacto	17 (15.7)	2 (15.4)		12 (13.3)	6 (18.8)	
Married/defacto	24 (22.2)	1 (7.7)		19 (21.1)	7 (21.9)	

Table 9.2. (Continued).

Variable	No history PTSD (n = 109) n (%)	PTSD (n = 13) n (%)	*t*(,113 to 119)	'Low' PTG (n = 90) n (%)	'Mod-Great' PTG (n = 32) n (%)	*t*(113 to 119)
Level of Education			5.85†			3.85
Not completed high school	29 (26.6)	5 (38.5)		23 (25.6)	12 (37.5)	
Completed high School	32 (29.4)	1 (7.7)		25 (27.8)	7 (21.9)	
Apprenticeship/TAFE	26 (23.9)	3 (23.1)		22 (24.4)	7 (21.9)	
University graduate	18 (16.5)	2 (15.4)		17 (18.9)	3 (9.4)	
University postgraduate	4 (3.7)	2 (15.4)		3 (3.3)	3 (9.4)	
Current employment status			4.51†			4.10
Full-time	39 (35.8)	5 (38.5)		37 (41.1)	7 (21.9)	
Part-time/casual	45 (41.3)	2 (15.4)		33 (36.7)	13 (40.6)	
Household income per annum			3.17†			2.35†
Up to $20,000	7 (7.8)	2 (22.2)		7 (9.1)	2 (9.1)	
$20,001 to $40,000	14 (15.6)	2 (22.2)		12 (15.6)	4 (18.2)	
$40,001 to $70,000	32 (35.6)	2 (22.2)		24 (31.2)	10 (45.5)	
$70,001 to $100,000	16 (17.8)	2 (22.2)		15 (19.5)	3 (13.6)	
$100,001 plus	21 (23.3)	1 (11.1)		19 (24.7)	3 (13.6)	
Personal income per annum			3.42†			2.45†
Up to $20,000	58 (61.1)	6 (60.0)		48 (59.3)	16 (66.7)	
$20,001 to $40,000	22 (23.2)	1 (10.0)		20 (24.7)	3 (12.5)	
$40,001 to $70,000	11 (11.6)	2 (20.0)		10 (12.3)	3 (12.5)	
$70,001 to $100,000	2 (2.1)	-		1 (1.2)	1 (4.2)	
$100,001 plus	2 (2.1)	1 (10.0)		2 (2.5)	1 (4.2)	
Cultural Identity			0.87†			3.49†
Australian	96 (93.2)	12 (100.0)		82 (94.3)	26 (92.9)	
European	5 (4.9)	-		4 (4.6)	1 (3.6)	
North American	1 (1.0)	-		1 (1.1)	-	
Middle Eastern	1 (1.0)	-		-	1 (3.6)	

*$p \leq .05$, ** $p \leq .01$

†Chi Square results should be interpreted with caution due to more than 20% of cell frequencies below 5.

Note: Valid percentages used for frequency data

Table 9.3 Pearson bivariate correlation coefficients between demographic and treatment variables and PTSS and posttraumatic growth

Variable	IES-R Full-scale	PTGI Full-scale
Gender	-0.02	0.04
Age at participation	-0.06	0.00
Age at diagnosis	0.04	0.23*
Years off Treatment	-0.08	-0.11
Relapse/2nd Malignancy	0.12	-0.03
Diagnosis		
Leukaemia	0.01	0.05
Solid Tumour	0.03	0.01
Lymphoma	-0.07	0.02
CNS Tumour	0.14	0.08
Other	-0.07	0.02
Treatment		
Chemotherapy	-0.10	0.04
Radiotherapy	0.02	0.02
Cranial	0.22*	0.14
Total body	-0.12	0.10
Surgical resection	-0.03	-0.01
Transplant	-0.12	-0.07
Living with parent	0.10	-0.02
Relationship status	-0.11	0.06
Education level	-0.00	-0.04
Employment Status	-0.07	-0.12
Household income	-0.13	-0.10
Personal Income	-0.05	0.02
Cultural Identity	-0.11	0.09

Note: *Gender:* male=1, female=2; *Relapse/2nd Malignancy*: no=0, yes=1; *Leukaemia:* no=0, yes=1; *Solid Tumour:* no=0, yes=1; *Lymphoma:* no=0, yes=1; *CNS Tumour:* no=0, yes=1; *Chemotherapy:* no=0, yes=1; *Radiotherapy:* no=0, yes=1; *Surgical Resection:* no=0, yes=1; *Transplant:* no=0, yes=1; *Living with Parent:* no=0, yes=1; *Relationship Status*: divorced/separated/widowed=1, single=2, partner not defacto=3, married/defacto=4; *Education Level*: not completed high school=1, completed high school=2, apprenticeship/TAFE=3, university graduate=4, university postgraduate=5; *Employment Status*: no=1, part-time=2, full-time=3, *Household and Personal Income*: 0-$20,000=1, 20,001-$40,000=2, $40,001-$70,000=3, $70,001=$100,000=4, $100,001+=5; *Cultural Identity*: Australian=1, Other=2
*$p < .05$, ** $p < .01$*

Table 9.4. Mean scores on Ehlers and Clark's cognitive processes according to PTSD group

Variable	No history PTSD M (SD)	PTSD (Current or partial remission) M (SD)	t(94 to 120)
Peritraumatic Cognitive Processing	(n = 84)	(n = 12)	
Mental Defeat	8.2 (8.6)	13.0 (7.8)	-1.81
Data-Driven Processing	12.6 (8.1)	19.8 (7.0)	-2.96**
Lack of Self-Referent Processing	6.1 (6.8)	12.3 (7.8)	-2.91**
State Dissociation	6.4 (7.2)	18.0 (8.5)	-5.13**
Cognitive Appraisals – Negative	(n = 109)	(n = 13)	
Thoughts of the Self	23.9 (7.7)	31.2 (7.0)	-3.24**
Post Cancer Appraisals	55.0 (12.9)	69.5 (12.8)	-3.83**
Appraisals of Cancer Reactions	8.5 (2.6) †	9.3 (2.0)	-1.12
Life Threat & Treatment Intensity	21.5 (5.7)	25.8 (3.9)	-2.67**
Dysfunctional Strategies	(n = 109)	(n = 13)	
Memories of Cancer	10.1 (8.3)	20.2 (8.1)	-4.12**
Behaviour after Cancer	4.4 (5.0)	10.2 (6.3)	-3.87**
Persistent Dissociation	3.0 (4.6)	11.7 (7.9)	-3.90**

*$p \leq .05$, ** $p \leq .01$
† n = 86

Table 9.5. Pearson bivariate correlation coefficients between Ehlers and Clark's cognitive processes and PTSS and posttraumatic growth

Variable	IES-R Full-scale	PTGI Full-scale
Peritraumatic Cognitive Processing	(n = 96)	(n = 96)
Mental Defeat	0.33**	0.10
Data-Driven Processing	0.16	0.06
Lack of Self-Referent Processing	0.42**	0.27**
State Dissociation	0.44**	0.26*
Cognitive Appraisals – Negative	(n = 122)	(n = 122)
Thoughts of the Self	0.25**	0.03
Post Cancer Appraisals	0.43**	0.13
Appraisals of Cancer Reactions†	0.14	- 0.17
Life Threat & Treatment Intensity	0.33**	0.44**
Dysfunctional Strategies		
Memories of Cancer	0.55**	0.42**
Behaviour after Cancer	0.55**	0.36**
Persistent Dissociation	0.50**	0.33**
Cognitive Appraisals – Positive		
Thoughts of the Self		0.08
Post Cancer Appraisals		0.27**
Appraisals of Cancer Reactions†		0.35**

*$p \leq .05$, ** $p \leq .01$
† n = 99

Table 9.6. Summary of hierarchical multiple regression analyses testing Ehlers and Clark's cogntive processes as predictors of severity of PTSS (Beta standardised regression coefficients)

		DV = Full-Scale IES-R		
		Model 1: Peritraumatic Cognitive Processing	Model 2: Negative Appraisals of Cancer/Cancer Sequelae	Model 3: Dysfunctional Cognitive /Behavioural Strategies
Step 1	Cranial Radiation	0.20	0.19	0.16
	F(1,91 to113)	***3.86***	***3.50***	***2.90***
	Adjusted R^2	***0.03***	***0.03***	***0.02***
Model 1	Mental Defeat	0.07		
Step 2	Data Driven Processing	-0.34**		
	Lack of Self-Referent Processing	0.22		
	State Dissociation	0.46**		
	F change (5,87)	***7.95*** **		
	R^2 change	***0.26***		
	F	***7.37*** **		
	Adjusted R^2	**0.28**		
Model 2	Negative Thoughts of the Self		0.12	
Step 2	Negative Post Cancer Appraisals		0.34**	
	Assess of Life Threat/Tx Intensity		0.32**	
	Negative Appraisals of Cancer Reactions		-0.05	
	F change (5,88)		***10.97*** **	
	R^2 change		***0.32***	
	F		***9.77*** **	
	Adjusted R^2		**0.33**	
Model 3	Memories of Cancer			0.19
Step 2	Behaviour after Cancer			0.27
	Persistent Dissociation			0.16
	F change (4,110)			***17.91*** **
	R^2 change			***0.31***
	F			***14.47*** **
	Adjusted R^2			**0.34**

*p < .05, ** p < .01

Table 9.7. Mean scores on peritraumatic cognitive processing according to B-symptomatology group membership

	B-Symptom Intrusion			
	No history (n = 35)	**Recovered (n = 31)**	**Current (n = 30)**	
Variable	**M (SD)**	**M (SD)**	**M (SD)**	***F*(2,93) / X^2(2)†**
Mental Defeat[a,b,c]	4.77 (6.3)	8.55 (8.4)	13.80 (9.0)	21.01**†
Data-Driven Processing[b,c]	11.3 (8.3)	12.39 (7.8)	17.17 (7.6)	4.82**
Lack of Self-Referent Processing[a,b,c]	2.8 (3.8)	7.35 (7.0)	11.13 (8.1)	23.19**†
State Dissociation[b,c]	3.8 (4.6)	6.94 (8.1)	13.40 (8.8)	23.00**†

*$p \leq .05$, ** $p \leq .01$
[a] planned contrast: *'No history'* v *'Recovered'* ($p \leq .05$).
[b] planned contrast: *'No history'* v *'Current'* ($p \leq .05$).
[c] planned contrast: *'Recovered'* v *'Current'* ($p \leq .05$).
† Levene's test was significant. Results for the Kruskal Wallis test are cited for main effects (X^2), and Mann-Whitney U tests were used to assess contrast differences

Table 9.8. Summary of hierarchical multiple regression analyses testing the predictive utility of Ehlers and Clark's proposed maintaining factors in PTSS after accounting for the variance of peritraumatic cogntive processing (Beta standardised regression coefficients)

		DV = Full-Scale IES-R	
		Model 1: Negative Appraisals of Cancer/Cancer Sequelae	Model 2: Dysfunctional Cognitive /Behavioural Strategies
Step 1	Cranial Radiation	0.20	0.20
	F(1,91)	***3.86***	***3.86***
	Adjusted R^2	***0.03***	***0.03***
Step 2	Mental Defeat	0.07	0.07
	Data Driven Processing	-0.34**	-0.34**
	Lack of Self-Referent Processing	0.22	0.22
	State Dissociation	0.46**	0.46**
	F change (5,87)	***7.95*** **	***7.95*** **
	R^2 change	***0.26***	***0.26***
	F	***7.37*** **	***7.37*** **
	Adjusted R^2	**0.26**	**0.26**
Model 1 Step 3	Negative Thoughts of the Self	0.07	
	Negative Post Cancer Appraisals	0.28*	
	Assessment of Life Threat/Tx Intensity	0.25*	
	Negative Appraisals of Cancer Reactions	0.02	
	F change (9,88)	***4.91*** **	
	R^2 change	***0.13***	
	F	***7.01*** **	
	Adjusted R^2	**0.37**	
Model 2 Step 3	Memories of Cancer		0.08
	Behaviour after Cancer		0.40*
	Persistent Dissociation		0.05
	F change (4,113)		***6.25*** **
	R^2 change		***0.13***
	F		***7.78*** **
	Adjusted R^2		**0.37**

*p < .05, ** p < .01

Note: When transformed data used, similar overall results – no change to overall step and full-model

CHAPTER 10
STUDY 4

AN EXPLORATORY INVESTIGATION INTO THE APPLICABILITY OF THE EHLERS AND CLARK COGNITIVE MODEL OF PTSD IN ACCOUNTING FOR POSTTRAUMATIC GROWTH IN CHILDHOOD CANCER SURVIVORS.

10.0 Overview

The aim of Study 4 is to explore whether the processes proposed by the Ehlers and Clark (2000) cognitive model of PTSD are able to account for posttraumatic growth in childhood cancer survivors. In doing so, Study 4 will contribute a greater understanding of the cognitive processes that may give rise to posttraumatic growth, and will determine whether these are similar to, or differ from the processes associated with the onset and maintenance of posttraumatic stress.

The cognitive processes proposed by the Ehlers and Clark Cognitive Model of PTSD have not been specifically applied to posttraumatic growth. Consequently, little is known as to how, if at all, these cognitive processes are able to account for posttraumatic growth. Despite this, it is widely acknowledged that cognition plays a central role (Park & Helgeson, 2006; Park et al., 2008a). As outlined in Chapter 6 (section 6.3), there is evidence that cognitive appraisals are important to the development of posttraumatic growth. This is mostly with regard to an association between posttraumatic growth and positive appraisals or re-appraisals of trauma or trauma sequelae (Park et al., 2008a; Schroevers & Teo, 2008). However, there is also evidence to suggest that negative appraisals may also be associated with growth. For example, Barakat and colleagues (2006) found the appraisal of life threat and treatment intensity surrounding childhood cancer to share a positive association with posttraumatic growth. As these same appraisals have traditionally been associated with PTSD outcomes, this finding suggests that some of the cognitive processes underlying PTSD and posttraumatic growth may be shared. This is not surprising considering that both are outcomes of trauma – that is both require a traumatic experience before either can occur (Park et al., 2008a).

As Study 4 is an exploratory investigation, for the purpose of hypotheses testing, a basic platform will be assumed in that the cognitive processes proposed by the Ehlers and Clark (2000) cognitive model will also be applicable to Posttraumatic Growth. Based on the evidence reviewed above, it is expected that positive appraisals will be positively associated with posttraumatic growth.

- *Hypothesis 1:* Scores on measures of Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark

(Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will be significantly lower for the No-Low PTG group, than for the Moderate-Great PTG group.

- *Hypothesis 2:* Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark (Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will each share a positive relationship with strength of Posttraumatic Growth.

- *Hypothesis 3:* Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark (Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will each predict the strength of Posttraumatic Growth

10.1 Method

10.1.1 Participants

Following the methods described in Chapter 8, self-report measures were completed by 155 childhood cancer survivors.

10.1.2 Measures

10.1.2.1 Outcome Measure: Posttraumatic Growth

Described in detail in Part 1, Chapter 2, Section 2.1.4, the measure used to assess posttraumatic growth is listed below.

- *Posttraumatic Growth Inventory (PTGI)* (Tedeschi & Calhoun, 1996).

10.1.2.2 Cognitive Measures (Based on Ehlers and Clark's Cognitive Model)

The cognitive measures used to assess the three broad processes described by Ehlers and Clark (2000) as leading to persistent PTSD are listed below. These measures and their development have been described in detail in Chapter 7.

Cognitive Appraisals of Cancer and Cancer Sequelae

- *Negative Thoughts of the Self After Cancer Scale*
- *Positive Thoughts of the Self After Cancer Scale*
- *Negative Post Cancer Appraisals Scale.*
- *Positive Post Cancer Appraisals Scale.*
- *Negative Appraisals of Cancer Reactions Scale.*
- *Positive Appraisals of Cancer Reactions Scale*
- *Assessment of Life Threat and Treatment Intensity Questionnaire* (*ALTTIQ;* Stuber et al., 1997).

Dysfunctional Cognitive and Behavioural Strategies

- *Memories of Cancer Scale.*
- *Behaviour After Cancer Scale.*
- *State Dissociation Questionnaire – Persistent* (*SDQ- Persistent;* Halligan et al., 2002, 2003; Murray et al., 2002).

Peritraumatic Cognitive Processing (assessing Trauma Memory Deficits)

- *Data Driven Processing Scale* (Halligan et al., 2002; 2003).
- *Self Referent Processing Scale* (Halligan et al., 2002; 2003).
- *State Dissociation Questionnaire – Peritraumatic* (Halligan et al., 2002, 2003; Murray et al., 2002).
- *The Mental Defeat Scale* (Dunmore et al., 1999, 2001).

10.1.3 Statistical Analyses[57]

Using SPSS for windows, version 15, differences between groups ('*No-Low PTG'* and '*Moderate-Great PTG*') on the demographic and treatment variables and on the cognitive measures

[57] Assumption testing: Violations of normality were found for the self-report outcome measure (PTGI: skew = 0.14, kurtosis = -1.16) as well as the *Peritraumatic Cognitive Processing* measures (skew range = 0.19 to 1.34; kurtosis range = -0.79 to 1.57), and the *Dysfunctional Cognitive/Behavioural Strategies* measures (skew range = 0.90 to 1.69; kurtosis range = 0.36 to 2.21). Transformation of variables was investigated using both naturalistic logarithmic (NL) and square root (SQRT) calculations. Square root transformations revealed greatest statistical correction for the measures (IES-R: skew = 0.58, kurtosis = -0.52; PTGI: skew = -0.42, kurtosis = -0.76; *Peritraumatic Cognitive Processing* measures: skew range = -0.46 to -0.51; kurtosis range = -0.51 to -0.67; *Dysfunctional Cognitive/Behavioural Strategies* measures: skew range = 0.11 to 1.05; kurtosis range = -0.60 to 0.03) - although histograms still revealed a tendency for positive skew. Because of this, the moderate extent of violations, and consideration of problems associated with interpretation (Tabachnick & Fidell, 2001), real data were used in these analyses - however analysis with transformed data were also conducted. Results with transformed data will only be reported if differing from real data results. The assumption of linearity was confirmed.

were assessed by Chi-Squared tests of Independence (categorical data) or standard applications of the Independent Samples t-test (continuous data). Where unequal variances between groups were revealed, the equal variances not assumed statistic is reported in the case of t-test analyses. Relationships between the PTGI and the demographic and treatment details were assessed by Pearson's bivariate correlational analyses. Hierarchical multiple regression models were used for assessment of cognitive measures as predictors of strength of posttraumatic growth. In reporting explained variance, the more conservative adjusted R^2 is used due to the small sample size of some analyses relative to the number of independent variables[58]. The alpha criterion of $p \leq .05$ was applied to denote statistical significance. Full-scale PTGI scores were used to strengthen multivariate analyses.

10.2 Results

Prevalence Data

Table 9.1 lists mean scores and prevalence data on the self-report measure assessing posttraumatic growth (PTGI). As shown 26.2% of survivors endorse moderate to great levels of growth.

Relationships between Demographic and Treatment Variables and PTGI:

Categorical investigations, as shown in Table 9.2, revealed no difference between the *'No-Low'* and *'Moderate-Great'* posttraumatic growth groups indicating that these two groups were comparable in demographic and treatment details, although Table 9.3 shows higher scores on the PTGI were significantly related to an older age at diagnosis ($r = 0.23$, $p = .013$).

10.2.1 Hypothesis 1:

"Scores on measures of Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark (Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will be significantly lower for the No-Low-PTG group than for the Moderate-Great PTG group".

As predicted, and as shown in Table 10.1, the Moderate-Great-PTGI group reported engaging in significantly higher levels of Dysfunctional Cognitive and Behavioural Strategies

[58] Based on the following rules of thumb: Minimum cases to IV ratio for testing the multiple correlation: $N \geq 50 + 8m$; Minimum cases to IV ratio for testing individual predictors: $N \geq 104 + m$ (Tabachnick & Fidell, 2001).

(*Memories of Cancer, Behaviour after Cancer, Persistent Dissociation*), and endorsed more *Positive Post Cancer Appraisals* than the Low-PTGI group. Contrary to the hypothesis, the groups did not differ significantly on any other cognitive measure.

10.2.2 Hypothesis 2:

"Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark (Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will each share a positive relationship with strength of Posttraumatic Growth".

As shown in Table 9.5, strength of Posttraumatic Growth, as measured by the PTGI, shared significant positive relationships with the Peritraumatic Cognitive Processes of *Lack of Self-Referent Processing* and *State Dissociation* (small correlations; $r = 0.26$, $p = .007$, $r = 0.27$, $p = .011$), the Negative Appraisal measure of *Assessment of Life Threat and Treatment Intensity* (moderate correlation; $r = 0.44$, $p < .001$), and all measures of Dysfunctional Cognitive and Behavioural Strategies: *Memories of Cancer, Behaviour after Cancer,* and *Persistent Dissociation* (moderate correlations; $r = 0.33$ to 0.42, $p < .001$). Analyses with the Positive Appraisal measures revealed that *Positive Post Cancer Appraisals* and *Positive Appraisals of Cancer Reactions* were both significantly related to PTGI (moderate correlations; $r = 0.27$ to 0.35, $p \leq .002$). No significant relationship was found between the PTGI and *Positive Thoughts of the Self* ($r = 0.08$, $p = .412$).

10.2.3 Hypothesis 3:

"Positive Appraisals of Cancer and Cancer Sequelae, as well as the Cognitive Processes proposed by Ehlers and Clark (Peritraumatic Cognitive Processing, Negative Appraisals of Cancer and Cancer Sequelae, and Dysfunctional Cognitive and Behavioural Strategies) will each predict the strength of Posttraumatic Growth".

As shown in Table 10.2, the hierarchical regression analyses employed to test the hypothesis adopted a 2 step model. Due to the sample size[59], four regression models were run, each assessing one of the four cognitive processes (*Peritraumatic Cognitive Processing, Negative Appraisals of Cancer/Cancer Sequelae, Dysfunctional Cognitive and Behavioural Strategies, Positive Appraisals of Cancer/Cancer Sequelae*). Step 1 included the demographic variable *Age at Diagnosis* which

[59] Based on the following rules of thumb: Minimum cases to IV ratio for testing the multiple correlation: $N \geq 50 + 8m$; Minimum cases to IV ratio for testing individual predictors: $N \geq 104 + m$ (Tabachnick & Fidell, 2001).

was shown to be significantly correlated with the PTGI scale (see Table 9.3). At Step 2, the relative cognitive variables assessing the four cognitive processes were entered.

As predicted, and as shown in Table 10.2, each of the four models were significant explaining between 9 to 22% of the variance of strength of posttraumatic growth. Step 2 accounted for a significant proportion of this variance (Model 1: $R^2change = 0.11$, $p = .028$; Model 2: $R^2change = 0.19$, $p < .001$; Model 3: $R^2change = 0.19$, $p < .001$; Model 4: $R^2change = 0.16$, $p = .001$).

The final models revealed that more negative appraisals of life threat and treatment intensity, less negative appraisals of cancer reactions (Model 2), and a greater attempt to control cancer related intrusive memories (Model 3), as well as more positive post cancer appraisals and more positive appraisal of cancer reactions (Model 4) each significantly contribute to the prediction of Strength of Posttraumatic Growth at an individual level. No peritraumatic cognitive processes (Model 1) significantly predicted strength of Posttraumatic Growth at individual level[60].

10.3 Discussion

Study 4's exploratory investigation of posttraumatic growth and the cognitive processes proposed by the Ehlers and Clark Cognitive model of PTSD have revealed that many of the cognitive processes shown to account for PTSD are also associated with posttraumatic growth. Most notably, posttraumatic growth in childhood cancer survivors is associated with both a past and current perception of serious cancer related threat, peritraumatic cognitive processing, particularly that reflecting disorganised trauma memory, and dysfunctional cognitive and behavioural strategies. Other processes showed no association with PTSD. These include negative appraisals surrounding or stemming from the cancer experience, and the peritraumatic cognitive processes of mental defeat and data-driven processing. As expected, posttraumatic growth is associated with positive appraisals of the cancer experience, however, general appraisals of the self, positive and negative, showed no association. This indicates that of the processes investigated, it is those that are cancer specific that show most association with posttraumatic growth.

Negative appraisals of past and current life threat and treatment intensity were positively correlated with, and predictive of posttraumatic growth. While this finding accords with that of Barakat et al (2006), it highlights that it is the perception of threat that is associated with posttraumatic growth, rather than negative peripheral appraisals of the cancer experience (e.g., reactions, other peoples responses, consequences, fairness or unfairness), or a general overall negative self-view. The finding that the perception of threat is predictive of posttraumatic growth is

[60] Model 1: When transformed data used *State Dissociation* became significant ($\beta = 0.33$, $p = .026$).

perhaps not surprising given that posttraumatic growth is a response to a traumatic experience and by definition this perception is required (APA, 2000). However, results show that posttraumatic growth is associated with a perception of *current* as well as past threat, even many years following the end of cancer treatment. This finding is in line with Ehlers and Clark's (2000) central proposition whereby a perception of serious current threat is required for the onset and maintenance of PTSD, indicating that posttraumatic growth may share similar cognitive pathways to that of PTSD

The association between posttraumatic growth and the perception of past threat suggests that cognitive processing at the time of the traumatic cancer related event(s) will reflect this threat perception. Investigations into the relationship between posttraumatic growth and the peritraumatic cognitive processes did confirm this to an extent; however where results show non-significance the consistency of findings does warrant attention. For example, a lack of self-referent processing and greater state dissociation were significantly correlated with posttraumatic growth and although non-significant at an individual level were the strongest predictors of strength of posttraumatic growth. Furthermore, although non-significant, survivors with 'moderate to great' posttraumatic growth showed a tendency to engage in these same two processes at a higher degree than those with 'no or low' posttraumatic growth. According to Ehlers and Clark (2000) these processes reflect incomplete cognitive processing at the time of trauma and lead to trauma memory disorganisation and fragmentation explaining poor intentional recall, incomplete trauma memory, and the 'here and now' quality of intrusive memories. While these findings accord with the often cited association between posttraumatic growth and the PTSD symptom of intrusive re-experiencing (Helgeson et al., 2006), they also indicate that as expected growth arises following a traumatic experience. Of note is that data-driven processing did not show the same trend results although this process is regarded as an important contributor to the onset of intrusive symptomatology (Ehlers & Clark, 2000). This may be a reflection of the measures used, with the more distinct measures proposed by Halligan et al., (2003; discussed in Study 1) possibly providing greater insight into the relative roles of these peritraumatic cognitive processes. However it may also reflect that it is the disjointed nature of the trauma memory, rather than enhanced sensory memories, that are most relevant to posttraumatic growth. Indeed, posttraumatic growth is thought to reflect cognitive efforts to rebuild the cancer memory or construct a new cancer narrative in order to make sense of the cancer experience (Joseph & Linley, 2006; Tedeschi & Calhoun, 2004b).

The peritraumatic process of mental defeat showed no association with posttraumatic growth. As mental defeat is proposed to seriously impair perceptions of self-worth following trauma (Ehlers & Clark, 2000), this finding is consistent with that showing no association between negative self appraisals and posttraumatic growth. However, this finding may also suggest that as discussed

in Chapter 9, mental defeat may be dependent on cognitive maturation and autonomy development, and is therefore limited in childhood trauma. Mental defeat may also be less relevant to trauma associated with childhood cancer than other deliberate or aggressive traumas such as assault or political imprisonment.

The strongest association between posttraumatic growth and the Ehlers and Clark (2000) cognitive processes was with the dysfunctional cognitive and behavioural strategies. Survivors endorsing 'moderate to great' levels of growth engage in significantly more cognitive efforts to control intrusive thoughts of the cancer experience, behavioural efforts to avoid cancer reminders, and dissociative episodes upon reminders of the cancer experience than survivors meeting 'no or low' levels of growth, and the degree of engagement in these strategies collectively predicts the strength of posttraumatic growth. Of these processes, it is the dysfunctional strategies used to control intrusive thoughts that were found to be most strongly associated with and predictive of posttraumatic growth. This again concurs with reports citing a strong association between posttraumatic growth and the PTSD symptom of intrusive re-experiencing (Helgeson et al., 2006), but also supports the coexistence of posttraumatic growth and PTSD symptomatology. For example, while the dysfunctional strategies used to cope with symptoms of PTSD has the paradoxical effect of maintaining these symptoms (Ehlers & Clark, 2000), they may also have the effect of maintaining posttraumatic growth. Interestingly, this suggests that the PTSD symptomatology itself, particularly intrusive re-experiencing, may be important in generating and perpetuating posttraumatic growth. In this sense, posttraumatic growth may be more indicative of PTSD coping efforts rather than actual positive change (Frazier et al., 2009).

In support of this coping hypothesis is the finding that positive appraisals are also associated with posttraumatic growth. Positive appraisals are regarded as cognitive coping efforts to reinterpret the traumatic experience in a positive light in order to assign meaning to the trauma (Park et al., 2008b). Results show that positive appraisals of the cancer and cancer sequelae, and positive appraisals of cancer reactions were both significantly correlated with, and predictive of, posttraumatic growth. Survivors who endorsed 'moderate to great' growth also report greater positive appraisals of the cancer and cancer sequelae than those in the 'no or low' growth category. Although in line with past posttraumatic growth research (Park et al., 2008a; Schroevers & Teo, 2008), of interest is that, as with the negative appraisals, a general overall positive self-view showed no association with posttrauma growth. This indicates that appraisals associated with posttraumatic growth – both positive and negative - are specific to the cancer context, offering further support that posttraumatic growth may reflect efforts to cope with cancer related distress rather than actual positive change (Frazier et al., 2009).

Whether posttraumatic growth is a coping process, or reflective of actual positive change is a topic under investigation, however it is likely that both are true (Frazier et al., 2009). For example, Frazier et al. (2009) distinguish between perceived posttraumatic growth (e.g., retrospective self reported growth following trauma, as is measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996), and actual posttraumatic growth (e.g., actual pre to posttrauma change). In their prospective study of trauma exposed university students, Frazier et al. (2009)[61] reported perceived and actual posttraumatic to be unrelated. Perceived posttraumatic growth was strongly related to coping efforts to positively reinterpret the trauma (e.g., positive appraisal), whereby actual posttraumatic growth was not. Further, perceived posttraumatic growth was associated with an increase in distress, as is consistent with other coping efforts, while actual posttraumatic growth was associated with a decrease in distress (Frazier et al., 2009). This suggests that actual and perceived posttraumatic growth are distinct constructs. Whether perceived posttraumatic growth facilitates actual posttraumatic growth over time is unknown. Studies conducted shortly after trauma show little association between perceived and actual growth (Frazier et al., 2009; Tomich & Helgeson, 2004), however evidence suggests perceived and actual growth are more strongly associated when assessed at least 2 years post trauma (Park & Helgeson, 2006). This indicates that actual posttraumatic growth may be the consequence of successful coping and positive adaptation over time. While this warrants further investigation, it may be that dysfunctional cognitive and behavioural strategies, via the maintenance of threat perception, prevent the adaptive cognitive and behavioural processes required to transition from perceived to actual posttraumatic growth, thereby having the effect of maintaining both PTSD as well as perceived posttraumatic growth. It is important to note however, that perceived posttraumatic growth, while not necessarily resulting in reduced distress has been associated with positive health outcomes (Tedeschi & Calhoun, 2004b), and increased quality of life (Alisic et al., 2008). This indicates that a clear distinction between perceived and actual posttraumatic growth is unlikely. It also indicates that perceived posttraumatic growth is not necessarily dysfunctional in the same way as the coping processes proposed by the Ehlers and Clark (2000) model. Instead, perceived posttraumatic growth may be a positive coping strategy or cognitive process evoked to deal with PTSS.

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[61] In their prospective study, Frazier et al (2009) investigated 122 psychology undergraduate students who reported experiencing a traumatic event between T1 and T2 (an eight week period).
- Perceived Posttraumatic Growth, as measured by the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) was administered at T2 only (The PTGI is a measure of how much an individual *believes* to have changed *because of* a traumatic event).
- Actual Posttraumatic Growth was assessed by a battery of existing measures chosen to reflect domains of growth (e.g., relationship quality, perception of life as meaningful, life satisfaction, gratitude, religiosity-spirituality). These measures were administered at both T1 and T2 with the change score (T2 minus T1) indicating Actual Posttraumatic Growth.

From a clinical perspective, the findings of Study 4 may have particular relevance. Perceived posttraumatic growth may be more indicative of the maintaining factors leading to an individuals persistent PTSS. The dysfunctional coping efforts, particularly behavioural and cognitive avoidance, are likely to be maintaining the perception of current and future threat preventing adaptive change (Ehlers and Clark, 2000). However, for childhood cancer survivors, current and future threat may be very real (e.g., relapse, long-term medical effects; see Appendix 1B). A challenge for treatment centres is to reduce dysfunctional coping strategies such as avoiding hospitals, medical professionals, or even talking about the cancer experience. These strategies prevent disease appropriate education, assessment, and the implementation of risk-based medical follow-up which can reduce both the perception of, and real long-term medical risk (Hudson et al., 2009). If this can be achieved, perceived posttraumatic growth may move from a coping process employed in efforts to alleviate distress, to a process that produces actual adaptive growth.

Furthermore, for a significant subgroup of childhood cancer survivors, it is evident that a considerable amount of cognitive processing has already taken place. It may be that within a clinical setting, elaboration of the already developed positive appraisals may help to modify dysfunctional beliefs (e.g., fear of relapse, perceived change for the worse) maintaining threat perception (Ehlers & Clark, 2000). Indeed, the modification of dysfunctional beliefs, and the removal of the dysfunctional cognitive and behavioural strategies are key PTSD treatment goals of the Ehlers and Clark (2000) Cognitive Model.

In summary, Study 4's exploratory investigation has shown that the Ehlers and Clark (2000) cognitive processes related to PTSD are also related to posttraumatic growth, however of these processes, it is those that are specific to the traumatic cancer related event(s) that are most relevant (e.g., life-threat from the disease and treatment, or a threat to physical integrity, rather than processes associated with peripheral threat). These findings are the first to show that the cognitive pathways to posttraumatic growth follow a traumatic stress model. However, the results of Study 4 suggest that self-reported posttraumatic growth may better reflect coping efforts to alleviate symptoms of distress, rather than actual growth following the cancer experience (Frazier et al., 2009). There is a need for future longitudinal investigations to unravel the relationships between perceived and actual posttraumatic growth, their relationships to outcomes (positive and negative), and indeed the mechanisms that may, if at all, allow perceived posttraumatic growth to transition into actual posttraumatic growth.

Table 10.1. Mean scores on Ehlers and Clarks cognitive processes and positive appraisal according to posttraumatic growth group

	PTG		
Variable	**No-low M (SD)**	**Moderate-Great M (SD)**	***t*(94 to120)**
Peritraumatic Cognitive Processing	(n = 69)	(n = 27)	
Mental Defeat	8.8 (8.9)	8.9 (8.2)	-0.05
Data-Driven Processing	13.3 (8.0)	13.9 (9.0)	-0.27
Lack of Self-Referent Processing	6.4 (6.6)	8.1 (8.7)	-1.02
State Dissociation	6.8 (6.9)	10.5 (10.7)	-1.67
Cognitive Appraisals – Negative	(n = 90)	(n = 32)	
Thoughts of the Self	24.7 (8.3)	24.8 (7.1)	-0.08
Post Cancer Appraisals	56.0 (14.3)	58.2 (11.6)	-0.77
Appraisals of Cancer Reactions	8.8 (2.5) †	8.0 (2.7)††	1.37
Life Threat & Treatment Intensity	21.5 (5.5)	23.3 (5.9)	-1.56
Dysfunctional Strategies	(n = 90)	(n = 32)	
Memories of Cancer	9.9 (8.4)	15.0 (9.0)	-2.92**
Behaviour after Cancer	4.2 (5.2)	7.2 (5.6)	-2.68**
Persistent Dissociation	3.2 (4.9)	6.0 (7.0)	-2.07*
Cognitive Appraisals – Positive	(n = 90)	(n = 32)	
Thoughts of the Self	50.4 (6.7)	51.3 (6.9)	-0.67
Post Cancer	97.5 (9.4)	102.9 (8.2)	-2.90**
Cancer Reactions	6.0 (1.6) †	6.7 (1.9) ††	-1.91

*$p \leq .05$, ** $p \leq .01$
† n = 69
†† n = 30

Table 10.2. Summary of hierarchical multiple regression analyses testing Ehlers and Clark's cogntive processes, and positive appraisals as predictors of posttraumatic growth (Beta standardised regression coefficients)

		DV = Full-Scale PTGI			
		Model 1: Peritraumatic Cognitive Processing	Model 2: Negative Appraisals of Cancer/Cancer Sequelae	Model 3: Dysfunctional Cognitive /Behavioural Strategies	Model 4: Positive Appraisals of Cancer/Cancer Sequelae
Step 1	Age at Diagnosis	0.14	0.12	0.23*	0.12
	F(1,94 to119)	***2.00***	***1.43***	***6.37****	***1.43***
	Adjusted R^2	***0.01***	***0.01***	***0.05***	***0.01***
Model 1	Mental Defeat	-0.14			
Step 2	Data Driven Processing	-0.19			
	Lack of Self-Referent Processing	0.27			
	State Dissociation	0.28			
	F change (5,90)	***2.85****			
	R^2 change	***0.11***			
	F	***2.71****			
	Adjusted R^2	**0.09**			
Model 2	Negative Thoughts of the Self		0.08		
Step 2	Negative Post Cancer Appraisals		0.13		
	Assessment of Life Threat/Treatment Intensity		0.36**		
	Negative Appraisals of Cancer Reactions		-0.23*		
	F change (5,93)		***5.68****		
	R^2 change		***0.19***		
	F		***4.88****		
	Adjusted R^2		**0.17**		
Model 3	Memories of Cancer			0.37*	
Step 2	Behaviour after Cancer			0.06	
	Persistent Dissociation			0.03	
	F change (4,116)			***9.63****	
	Adjusted R^2 change			***0.19***	
	F			***9.16****	
	Adjusted R^2			**0.22**	
Model 4	Positive Thoughts of the Self				-0.05
Step 2	Positive Post Cancer Appraisals				0.26*
	Positive Appraisals of Cancer Reactions				0.30**
	F change (4,94)				***6.19****
	R^2 change				***0.16***
	F				***5.06****
	Adjusted R^2				***0.14***

*p < .05, ** p < .01

CHAPTER 11
GENERAL DISCUSSION (PART 2)

11.0 Overview

The broad objectives of Part 2 of this program of research were to assess the generalisability of the Ehlers and Clark (2000) Cognitive Model of PTSD to childhood cancer survivorship, and to assess whether the cognitive processes proposed by the model can also account for reports of posttraumatic growth. From these investigations, Part 2 has made the following important contributions to the childhood cancer survivor literature. First, using existing measures developed within the non-illness trauma literature, a pilot study was undertaken to tailor measures to the cancer survivor population. There are few context specific assessment tools currently, and as such this work provides a valuable resource for continued research in the area. Second, Part 2 has provided the first evidence for the array of cognitive factors proposed by the Ehlers and Clark (2000) Cognitive Model as accounting for persistent PTSD and PTSS within the childhood cancer context. This model is currently regarded as one of the most comprehensive in the trauma literature, providing a model for symptom onset and maintenance as well as symptom specific intervention. Consequently, Part 2 provides a novel contribution to the cognitive risk assessment of PTSD and PTSS, particularly as many of these processes have not previously been assessed within the childhood cancer context. In line with this, Part 2 also provides a tested framework for both symptom and disorder intervention. Part 2 extends the existing childhood cancer survivor literature by documenting the existence of both trauma related stress and growth. A unique contribution to the existing knowledgebase is the application of a cognitive model of PTSD to posttraumatic growth. Data collected for this program of research provides strong evidence that both trauma outcomes share overlapping cognitive pathways.

11.1 Summary of the findings of Part 2

Study 3 shows that many of the cognitive processes proposed by Ehlers and Clark (2000) are generalisable to the childhood cancer context in accounting for and predicting persistent PTSS, as well as differentiating between PTSD and non-PTSD groups. Specifically, in relation to the cancer experience, appraisals of life threat and treatment intensity, dysfunctional cognitive and behavioural strategies, and the peritraumatic cognitive process of dissociation had the strongest predictive relationship with PTSD and PTSS. Notably, the findings that behavioural and emotional reactions during cancer, and the peritraumatic process of mental defeat were not predictive of PTSS, nor did they differentiate between PTSD and non-PTSD groups, indicates that differences exist between childhood cancer related trauma, and other non-illness trauma groups. However, mental defeat was shown to be a significant determinant of B-symptomatology (intrusive-re-experiencing).

Study 4's exploratory investigation provided evidence that many of the cognitive processes proposed by Ehlers and Clark (2000) in accounting for persistent PTSD, can also explain the onset of posttraumatic growth. These were most apparent for processes specific to the traumatic cancer related event, rather than peripheral threat appraisals (e.g., reactions, other peoples responses, consequences, fairness or unfairness). The association between posttraumatic growth and the Ehlers and Clark (2000) cognitive processes was strongest for dysfunctional cognitive and behavioural strategies, particularly the strategies used to control intrusive memories of the traumatic experience. In line with the Ehlers and Clark (2000) central proposition for PTSD, the perception of past and current threat showed relevance to the prediction of posttraumatic growth, indicating that it is an important precursor to both PTSD and posttraumatic growth. Also in line with PTSD, Study 4 indicates that the peritraumtic processes of state dissociation and a lack of self-referent processing may be important to posttraumatic growth.

11.2 Methodological Considerations and Future Directions

In interpreting the results of Part 2, a number of methodological considerations are necessary. These include some of the considerations already discussed in Part 1, Chapter 5, Section 5.2. For example, the findings of Part 2 are limited by the small sample size taken from a single institution. Related to this is the inclusion of a heterogeneous group of childhood cancer survivors. While Part 2's comparison analyses (Table 9.2 and 9.3) indicate that demographic and treatment variables are generally not related to the trauma outcomes, posttraumatic growth was related to an older age at diagnosis. While this indicates that a certain level of cognitive maturation at the time of the traumatic experience is necessary for subsequent growth to occur, past evidence suggests this is also important for the development of PTSD and PTSS (Salmon & Bryant, 2002). In line with this, preliminary results of continuing research with this Australian cohort has shown that although even very young children are able to recall aspects of their cancer experience, age at diagnosis influences the number, type, and characteristics of memories surrounding a childhood cancer experience (an older age reporting more memories of greater strength). This in turn predicts both PTSS and posttraumatic growth. Although not specifically investigated in Part 1, these preliminary findings suggest that the relative importance of the peritraumatic cognitive processes of the Ehlers and Clark (2000) model will be determined, at least to some extent, by a child's age or cognitive development. Future investigations with larger cohorts are necessary to investigate age specifically as it applies to the Ehlers and Clark (2000) cognitive model, as well as the other demographic and treatment factors. For example, survivors who have undergone CNS directed therapy may have considerable cognitive impairment potentially affecting cognitive processing ability (see Appendix 1B)[62]. The Ehlers and Clark (2000) cognitive model provides scope to incorporate background factors, such as developmental cognitive maturation factors, or cognitive damage caused by

[62] An important consideration is that The CNS group was under-represented relative to NSW long-term survivor distributions (see Chapter 2, footnote 9).

cancer or cancer treatment. These are important considerations when applying a cognitive based approach. The reliance on cross-sectional, retrospective reports of PTSD history as well as the peritraumatic cognitive processes may also limit conclusions drawn. Future research with survivor groups closer to the treatment period may help to further determine which cognitive factors are most important to the prediction of PTSD, PTSS, and posttraumatic growth.

Part 2's investigations were restricted to the survivor group due to sample size considerations, and the fact that the pilot work was carried out on a survivor population only. While it is likely that measures will generalise to parents and siblings, findings indicate that trauma is context specific (Kleim et al., 2007). As shown in Part 1, Study 2, it is likely that subtle differences will exist depending on the context from which the trauma is experienced (e.g., victim versus witness, child versus adult, sibling versus parent). However, as the Ehlers and Clark (2000) cognitive model has shown to be applicable in many trauma contexts including trauma witness (Laposa & Alden, 2003), these differences are likely to be minimal. Even so, any difference will have clinical relevance in tailoring family specific intervention programs, which are particularly necessary for mothers of childhood cancer survivors given their increased risk for PTSD and PTSS. Current work is underway with the Australian cohort of mothers, fathers, and siblings (see Part 1) in testing the applicability of the Ehlers and Clark (2000) cognitive model to these family groups.

The long-term nature of this survivor cohort suggests that PTSD and PTSS are relatively persistent without treatment (Ehlers & Clark, 2000). Nonetheless, the time-delay[63] between data collection points may result in less reliable findings. For example, the appraisal measure, ALTTIQ, was administered at the same time as the IES-R and PTGI, with results indicating that relative to the other cognitive measures assessed (based on the Ehlers and Clark model) this measure shares the strongest relationship with these two outcomes (PTSS and posttraumatic growth). Now that the cognitive measures have been developed, limited time-delays would be necessary in future studies of this nature. Future findings will help to verify the results of Studies 3 and 4.

Finally, future investigation is required to determine perceived versus actual growth. While Frazier et al. (2009) have developed a measure to investigate these two outcomes, the findings of Study 2 indicate that posttraumatic growth is complex. Given the strong association with coping strategies, it is likely that perceived posttraumatic growth does reflect coping efforts to deal with PTSS, however it is also likely that posttraumatic growth reflects other processes such as cognitive re-structuring (Park & Helgeson, 2006), as well as actual positive change (e.g., greater relating to others may reflect greater social skills; Tedeschi & Calhoun, 2004). In order to move the posttraumatic growth literature forward,

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[63] A mean time lag of 20.5 months occurred between Questionnaire Booklet (Part 1) and the clinical interview, with a further mean time lag of 1.2 months between the clinical interview and Questionnaire Booklet (Part 2). These time-delays were due to the extensive work required in the development of Questionnaire Booklet (Part 2) (see Section 2.1.3).

longitudinal investigations are necessary to determine whether perceived posttraumatic growth does transition into actual posttraumatic growth over time, while research targeting the different categories of growth and outcomes are important in the understanding of which categories of growth are indices for distress, and which are indices for well-being. This information will be of clinical value in the assessment of risk of distress, as well as in the development of interventions to reduce distress.

11.3 Implications of Part 2 of the Program of Research

The findings of Part 2 show clinical importance. Notably, the Ehlers and Clark (2000) cognitive model provides a framework for cognitive risk profiling as well as symptom specific intervention for the sub-group of childhood cancer survivors with clinically significant persistent PTSS. Although Part 2's findings are in need of future verification, and testing with survivor groups closer to the treatment period, this investigation has provided a greater insight into the cognitive factors that may lead to persistent distress in this life-threatening illness context. The measures designed in Part 2 have promise in their application to families of childhood cancer survivors, potentially leading to the development of assessment and intervention tools targeted specifically for family members, especially mothers, who, as shown in Study 2, are the most at risk group following childhood cancer to develop PTSD or PTSS. While work is necessary to develop the intervention framework, this model may have additional application in extending the work already conducted by Kazak and colleagues (1999, 2004, 2006) in treating adolescent cancer survivors. The Surviving Cancer Competently Intervention Program (SCIIP) is a family centered intervention program that already incorporates cancer specific appraisal of the cancer experience, however the findings of Part 2 have shown that a wide range of appraisals, and indeed cognitive factors generally, are involved in the development and persistence of PTSD and PTSS.

An important implication for the reduction of distress is the treatment of behavioural and cognitive avoidance. These strategies maintain PTSD, and PTSS, as well as posttraumatic growth as an avenue for coping with intrusive thoughts associated with the cancer experience. Cognitive risk profiling using the measures developed in Part 2 may help to identify survivors most at risk of developing avoidance practices, as well as those likely to become lost to follow-up. In these cases, disease appropriate education, assessment, and the implementation of risk-based medical follow-up is imperative in order to effectively manage on-going health risk (Hudson et al., 2009), and reduce excessive threat perception.

With regard to posttraumatic growth, understanding is still in its infancy, particularly with regard to how posttraumatic growth may be harnessed to reduce distress (Park & Helgeson, 2006). Because of this, implications are largely restricted to the conceptual and research level. Part 2 has shown that the development of posttraumatic growth follows similar cognitive pathways to that of PTSD. A task facing posttraumatic growth researchers is to further elucidate the cognitive factors that may lead to posttraumatic growth eliciting actual life change, and those that arise in an effort to cognitively make

sense of the cancer experience or to cope with cancer related distress. From this, a potential exists to develop the domains of growth associated with a reduction in distress or greater well-being.

In summary, Part 2 has provided valuable data on the applicability of a cognitive treatment model to childhood cancer survivorship. By investigating how the same cognitive processes may lead to diverse trauma outcomes, Part 2 has extended the traditional stress-deficit approach, and has provided a greater understanding on the cognitive factors that may lead to PTSD, PTSS, and posttraumatic growth outcomes in the Australian childhood cancer context.

CHAPTER 12
CONCLUDING COMMENTS

This program of research examined the long-term psychosocial adjustment of an Australian sample of long-term childhood cancer survivors, parents, and siblings from a trauma perspective, and applied a cognitive theoretical and treatment model of PTSD to childhood cancer survivorship. Taken together, the results support the application of a cognitive model of trauma to childhood cancer survival, and provide evidence for the utility of a cognitive theoretical and intervention framework within this context.

By investigating a long-term survivor cohort (survivor years since treatment: M = 15.4, SD = 6.9) the ongoing impact of childhood cancer can be better understood. This study demonstrated that across all family groups, PTSD is low, although clinically significant levels of PTSS persist. Among family members, mothers were most at risk for PTSS, while siblings showed lowest risk. This distress is likely to persist without appropriate psychological intervention. The Ehlers and Clark (2000) model shows promise in its application to childhood cancer survivors, and may prove clinically useful as model to develop symptom specific intervention within this context.

Results show that while psychopathology is low, reports of posttraumatic growth are highly prevalent across family groups, with posttraumatic growth co-existing with PTSD and PTSS, and sharing similar cognitive pathways in its development. However, in the explanation of the divergent relationship findings within the literature, results suggest a negative relationship exists between PTSS and some domains of growth. Future investigation into the potential differing roles of posttraumatic growth on PTSS from a domain specific level will extend the traditional stress-deficit approach to research and intervention within the childhood cancer survivor population and their families.

In conclusion, findings from this program of research shows that childhood cancer impacts on all family members, and while the psychological impact may not be life-threatening, it is life-altering in both positive and negative ways, and this can last for many years following the end of treatment.

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Appendices

APPENDIX 1A

Cancers of Childhood. An Overview of Aetiology, Epidemiology, Symptomatology, Treatment, and Prognosis

Within the umbrella term of 'childhood cancer' there are a multiple diagnoses each with disease and treatment factors unique to their type and state of cancer progression. What follows is a broad overview of the more common childhood cancer diagnoses, with a summary of current evidence of causative risk factors, population prevalence, symptomatology, treatment, and prognosis specific to each disease.

1. Leukaemia

Approximately 30 percent of all paediatric cancer is leukaemia, making it the most common form of cancer occurring in children aged 15 years and younger (American Cancer Society, 2009). Leukaemia is a disease of the white blood cells which are primarily responsible for the body's response in the fight against infection. All blood cells are produced in the bone marrow from stem cells. The very immature cells produced by these stem cells are termed blast cells, which, during maturation, differentiate into the different red and white blood cells and platelets that are be transported throughout the body via the blood stream and lymphatic system (American Cancer Society, 2009)

There are two main types of white blood cells, lymphocytes and myeloid cells. Lymphocytes make up 40 percent of white blood cells found in the healthy body, and can be further classified into T-Lymphocytes, B-Lymphocytes and natural killer (NK) cells (Kempert, 2010). The primary function of lymphocytes is to destroy non-self cells, such as viruses, bacteria or abnormal body cells, by excreting cytotoxic chemicals and by producing antibodies against the targeted cell (Kempert, 2010).

Myeloid cells, also known as granulocytes, are a key component of the innate immune system, and contain enzyme containing granules capable of destroying micro-organisms. Myeloid cells make up 50 percent of the body's white blood cells and can be further differentiated into one of three main types: neutrophils, eosinophils and basophils, of which the neutrophil is predominant. These cells move to and ingest a targeted cell or organism in a process called phagocytosis, during which the enzymes then destroy the target. On some occasions, a granulocyte will simply lyse the organism without ingestion (Kempert, 2010).

Leukemia results from a malfunction and loss of control in the stem cells responsible for white blood cell development. This malfunction causes the abnormal production of blast cells. The resultant leukemic blast cells are unable to follow the normal maturation process, replicating and spreading throughout the bone marrow. These cells compete with, and restrict the functioning of, healthy marrow cells, inhibiting the normal process of blood cell formation and development. This results in a variety of symptoms which includes a lack of energy, anaemia (too few red cells), bruising and hemorrhaging

(thrombocytopenia- too few platelets), and severely reduces the body's immune response (neutropenia – too few neutrophils), vastly increasing the risk of infection (American Cancer Society, 2009). As well as affecting the bone marrow, these leukemic cells spill over into the blood and can cause symptoms by involving many other organs in the body, contributing to the severity of the disease (Pui, 2008).

1.1 *Acute Lymphoblastic Leukaemia (ALL)*

Acute Lymphoblastic Leukaemia (ALL) accounts for approximately 75 percent of all childhood leukaemia, making it the most common paediatric leukemia (American Cancer Society, 2009; Margolin et al. 2006). It is also the most prevalent of all cancers found in children aged 15 years and younger in Australia, making up one quarter of all cancer diagnoses in this age group (AIHW, 2008). ALL originates from a mutation in a solitary lymphoid progenitor cell, the stem cells responsible for the production of B and T lymphocytes (Pui, 2008). As little as 30 years ago, ALL was considered virtually incurable, however diagnostic and treatment advances have seen the overall cure rate rise to more than 80 percent (American Cancer Society, 2009).

The incidence of ALL is highest amongst the 2 to 4 year age groups, is more common in boys than in girls, and is seen most often in industrialised countries and amongst children of European descent (American Cancer Society, 2009; Pui, 2008; Smith & Gloeckler Ries, 2002). Both genetic and environmental factors have been implicated in the aetiology. Genetic factors are thought to contribute to the disease with the occurrence of familial leukaemia, higher incidence of leukaemia in identical twins and an increased incidence associated with chromosomal abnormalities such as Down Syndrome, Neurofibromatosis, Blooms Syndrome and Fanconi's Anemia (Pui, 2008; Margolin, et al., 2006). Variations in incidences found between different races may also imply a genetic link to ALL (Smith & Gloeckler Ries, 2002).

The peak in incidence of ALL has also been found to have a geographical and historical context that corresponds to periods of industrialisation in Western countries. This suggests that ALL is susceptible to environmental leukemogens, chemicals known to cause cancer under certain circumstances. Other possible factors that have been investigated in the pathogenesis of ALL include exposure to viral infections, either in-utero or after birth, or congenital immunodeficiency diseases that cause abnormalities of the immune system (American Cancer Society, 2009). While these continue to be of interest to researchers, no definitive link has yet been found (Margolin, et al. 2006).

1.2 *Acute Myeloid Leukaemia (AML)*

Acute Myeloid Leukaemia (AML) is the second most common type of leukaemia seen in children (American Cancer Society, 2009). AML is seen most often in adults, however, it accounts for up to 20 percent of all childhood leukaemia (Golub & Arceci, 2006). The prognosis for AML is not as favourable as that for ALL with current survival rates reported at around 50 percent (O'Brien et al.,

2002). The incidence of AML remains quite stable throughout childhood, although there is a peak in diagnosis during the neonatal period and a slight increase in prevalence during adolescence (American Cancer Society, 2009).

AML develops in a similar way to ALL, however the cells affected are the immature myeloid cells. (Golub & Arceci, 2006; Lichtman & Liesveld, 2001). There is no evidence to suggest that any gender differences exist in the incidence of AML, and incidence seems to be distributed reasonably evenly amongst the races (American Cancer Society, 2009; Weinblatt, 2009).

Developmental risk factors are similar to that of ALL, with family history and inherited and non-inherited diseases affecting chromosomal structure and immune functioning. Environmental leukemogens such as chemicals and ionizing radiation, maternal cigarette smoking and alcohol consumption have all been found to influence the onset and development of AML (American Cancer Society, 2009; Golub & Arceci 2006). However, while genetic risk factors have been implicated and documented, most cases of AML do not seem to have a genetic link, suggesting that exposure to certain environmental leukemogens or diseases are the predominant predisposing factors (Lichtman & Liesveld, 2001).

1.3 *Treatment of Leukaemia*

Treatment of leukaemia is primarily based upon chemotherapy, although the many different forms of leukaemia require different regimens (Pui, 2008). Prophylactic cranial radiation was routine until the late 1980s but is only used for select high risk patients today. Bone marrow transplant is used in ALL only for very high risk patients or patients who have relapsed, but is used more frequently as front line treatment for AML. Many drugs and antibiotics are used as part of the supportive care (Weinblatt, 2009). A number of factors affect prognosis including the type of leukaemia, age, sex, race, initial white blood cell and platelet count, the presence of a mediastinal mass, and the rapidity of malignant cell reduction. (Golub & Arceci, 2006; Margolin et al., 2006).

2. Tumours of the Central Nervous System (CNS)

2.1 *Medulloblastomas and Gliomas (Ependymomas and Astrocytomas)*

After leukaemia, the second most common paediatric cancer diagnosis is a tumour of the central nervous system (CNS) (American Cancer Society, 2009). A diagnosis of a brain or spinal cord tumour makes up approximately 20 percent of all cancers found in children 15 years and younger (American Cancer Society, 2009; Smith & Gloeckler Ries, 2002). Although advancements have been made in the diagnosis and treatment of these tumours, overall brain tumours are associated with the highest death and morbidity rates of all childhood cancers (Strother et al., 2002). CNS tumours are solid tumours arising from mutations of the different cells of the CNS. The tumours often attack surrounding tissue, and in some instances metastasize, usually transported by the cerebral spinal fluid, to other areas of the

brain, only rarely spreading to other parts of the body. The two most common CNS tumours found in children are medulloblastomas and gliomas (*www.cancerbacup.org.uk)*.

Medulloblastomas are the most common malignant brain tumour found in children, and are also the most invasive (MacDonald & Packer, 2002a; Mueller, 2009). This tumour develops from the immature blast cells found in the brain's cerebellum, the structure found in the hind brain responsible for the body's co-ordination, balance, and fine muscle movement and tone. Gliomas develop from glial cells, the cells which support the nerves of the brain (neuromes), and can be further subdivided depending on the cell type from which the tumour originates. The two most common gliomal tumours found in children are astrocytomas and ependymomas (Mueller, 2009). These tumours are most often contained within the cerebrum of the frontal and temporal lobes. The cerebrum is the outer layers of the brain responsible for carrying out such tasks as intellectual and cognitive functioning, sensory processing, and motor functions. Gliomas may also be found in the brain stem, spinal column, and other parts of the brain (MacDonald & Packer, 2002b).

Tumours of the CNS can increase the intracranial pressure of the brain, obstructing and compressing the various structures of the brain. The predominant symptoms associated include headaches, nausea, fatigue, declining learning ability and personality changes (Strother et al., 2002). Other functions , such as neurological weakness or loss of neurological function such as speech, may be impaired, depending upon such variables as the location of the tumour, the type of the tumour and the size and aggressiveness (the grade; usually differentiated between low grade, or low aggressiveness, and high grade, or high aggressiveness) of the tumour.

The incidence of CNS tumours in childhood indicates that they occur most often during the first 10 years of life where boys are diagnosed slightly more often than girls (American Cancer Society, 2009).

While the cause of CNS tumours are largely unknown, evidence suggests that exposure to ionizing radiation, and some specific genetic disorders such as Cowden Syndrome, Li-Fraumeni Syndrome, and Neurofibromatosis, increase susceptibility to the development of a CNS tumour in children (Mueller, 2009). While the association with genetic disorders has been widely documented, less than 10 percent of children diagnosed with a brain tumour present with these disorders (Strother et al., 2002). Other factors such as familial inheritance, diet, and exposure to environmental chemicals have been implicated, but research has not been conclusive (Strother et al., 2002).

The overall 5-year survival rate for children with CNS tumours is reported at 75% (American Cancer Society, 2009), although these rates differ significantly depending upon factors such as type, location and grade of tumour, and the age of the child. Due to the aggressiveness of treatment, age, and the stage of development of the child, treatment for this disease often results in significant endocrinological and intellectual sequelae (MacDonald & Packer, 2002a).

Treatment of CNS tumours usually begins with surgery to remove the tumour and for low-grade tumours this may be curative (Mueller, 2009; MacDonald, 2002b). For higher grade tumours, cranial or craniospinal radiation, with or without chemotherpay is then required. Craniospinal radiotherapy has been found to cause significant long-term effects such as growth and intellectual retardation, and treatment is therefore being refined in order to reduce the negative impact. The effectiveness of chemotherapy is increasing, with research continuing in this area (MacDonald & Packer, 2002c).

3. Lymphomas

Lymphomas are malignant solid tumours (neoplasms) of the lymphatic system, and are characterised by enlargements of the lymph glands found in the neck, armpits, chest, abdomen and groin (Johnston, 2008). The lymphatic system is responsible for draining and filtering cellular waste and by-products, as well as aiding in the production and circulation of the lymphocytes responsible for fighting infection. Lymphomas negatively affect the production and circulation of healthy blood cells, leaving the patient at a greater risk for infection. Collectively, lymphomas make up around 10 percent of paediatric cancers, but are classified as either Hodgkin's disease, 3.6 percent, or as non-Hodgkin's lymphoma, 4.3 percent (Altekruse et al., 2010).

3.1 *Hodgkin's Disease (HD)*

Hodgkin's Disease (HD) is characterised and defined by the presence of malignant Hodgkin's and Reed-Sternberg (HRS) cells and lympocytic and histiocytic (L&H) cells (Horning, 2001). These cells arise and transform from the B-Lymphocyte and in the case of HD, undergo significant expansion to form giant cells (Hudson & Donaldson, 2002). The tumour may be restricted to the original lump, referred to as stage 1 HD, or there may be two or more lymph nodes that are regionally close to each other affected, (stage 2). If the disease has spread to affect both the upper and lower body it is referred to as stage 3. Stage 4 is diagnosed if it has spread to involve other organs such liver, lung or bone (Hudson & Donaldson, 2002).

Symptoms of HD include night sweats, fevers, severe weight loss, itchy irritable skin, and in some instances pain may be felt immediately after the ingestion of alcohol. HD has a bimodal age distribution, with an early peak around twenty years, and then again after the age of fifty, with few cases under 10 years (Hochberg, 2009).

A genetic predisposition for HD has been supported by findings of increased incidence in families with HD, and children from Anglo backgrounds. HD also differs geographically with industrialised countries finding a peak in the mid to late 20's while developing countries experience this peak during adolescence. Research seems to point to a viral link, with the Epstein-Barr Virus being implicated (Hochberg, 2009).

Five year survival rates for children diagnosed with HD are reported at greater than 90 percent (American Cancer Society, 2009; de Alarcon & Metzger, 2008). Treatment protocols currently include surgery to biopsy the affected lymph node, chemotherapy and radiation therapy. Currently, radiation therapy is being decreased and refined where possible in order to reduce some of the long-term negative effects associated with this treatment (de Alarcon & Metzger, 2008).

3.2 *Non-Hodgkin's Lymphoma (NHL)*

Non-Hodgkin's Lymphoma (NHL), also a tumour of the lymphatic system, is quite distinct from Hodgkin's Disease. Non-Hodgkins lymphomas do not contain the HRS cells predictive of HD, and instead often closely resemble the features of Acute Lymphoblastic Leukemia. NHL develops from a mutation in the development of B or T lymphocytes and will usually arise in the lymph nodes, but may also develop in other body organs. In NHL, the malignant lymphocytes can be highly prone to spreading, quickly infiltrating the blood, bone marrow, central nervous system, and intestine. Symptoms are similar to that of HD, however the abdomen is the most common presentation of the tumour, and gastrointestinal problems are often a feature.

Incidence of NHL increases steadily with age, is more common than HD under 10 years of age, with a male predominance, and occurs more often in children from Anglo backgrounds (Hochberg, 2009; Johnston, 2008; Magrath, 2002). Genetic links for NHL development have not been substantiated, but research suggests that viral exposure to the Epstein-Barr virus or malaria may be a predisposing factor (Hochberg, 2009; Macgrath, 2002). Furthermore, people exposed to conditions that have suppressed the immune system such as HIV, bone marrow transplants, or the successful treatment for HD, are at greater risk of developing NHL (Johnston, 2008).

There is over 85 percent survival rate for children diagnosed with NHL, however, this varies depending on the type and stage of the disease (American Cancer Society, 2009). Treatment usually involves multimodal chemotherapy and in some cases a bone marrow transplant may also be necessary. Surgery to remove the tumour may be performed, but recently has not been found to contribute to overall survival when chemotherapy treatment is also given (Patte et al., 2007). Similarly, radiation therapy has not been found to be beneficial in most cases in the treatment of NHL (Macgrath, 2002).

4. Sarcomas

Sarcomas are tumours that arise from the mesenchymal cells of the body. These cells mature and differentiate to form soft tissue such as muscle, fat and fibrous tissue, as well as bone and cartilage (Wexler et al., 2002). Collectively, sarcomas account for approximately 12 percent of childhood cancer diagnoses, (soft tissue tumours 6 percent, and bone tumours 6 percent) (Heare et al., 2009).

4.1 *Rhabdomyosarcoma*

The most common soft tissue sarcoma is rhabdomyosarcoma, a tumour that develops from muscle or fibrous tissue (American Cancer Society, 2009). As this muscle tissue is found throughout the body, a tumour of this kind may arise anywhere. The more common locations are the head and neck, often presenting as a blocked nose or sinus, or (Hayes-Jordan & Andrassy, 2009). Tumours around this area may metastasize into the brain and CNS. Other tumour origins may include the muscles of the arms, legs, chest or abdomen which present as a definable lump, or the bladder or testes causing difficulty in passing urine.

Epidemiologic research has found a link between the development of rhabdomyosarcoma and chromosomal abnormalities such as Li-Fraumeni Syndrome and Neurofibromatosis suggesting a genetic predisposition. Furthermore, children with adult relatives who have been diagnosed with early onset breast carcinoma and adrenocortical carcinoma have also been found to have an increased risk of rhabdomyosarcoma development. Other causative risk factors suggested include marijuana and cocaine use by either the mother or father shortly before conception, and use of these drugs during pregnancy by the mother (Wexler et al., 2002).

Rhabdomyosarcomas are prone to spreading. Metastasis may occur by the direct extension of the tumour into the neighbouring organs and tissue. Malignant cells may also metastasize to the lymph nodes, lungs, bone or bone marrow (Hayes-Jordan & Andrassy, 2009).

Treatment of these forms of tumours depend on factors such as the location and size of the tumour, and to what extent it has spread (Hayes-Jordan & Andrassy, 2009). Initial diagnosis requires a biopsy, x-rays, scanning and bone marrow analysis to determine the extent of spread. From this the tumour may be diagnosed as stage 1 if contained solely within the site of origin, and hence able to be completely removed by surgery, through to stage 4 when the tumour has been found to have spread to other parts of the body (Hayes-Jordan, & Andrassy, 2009; Wexler et al., 2002).

The five year survival rate for children diagnosed with rhabdomyosarcoma is reported at approximately 70 percent (Hayes-Jordan & Andrassy, 2009). However, this figure changes significantly depending upon the stage of the diagnosis. A stage 4 rhabdomyosarcoma is associated with a 40-50% percent survival (Hayes-Jordan & Andrassy, 2009), whereas a greater than 85 percent survival prognosis is associated with stage 1 (Wexler et al., 2002).

Current treatment protocols include surgery to remove the tumour if feasible, radiation therapy aimed at local control, and chemotherapy may be necessary for the primary control and prevention of metastatic disease (Wexler et al., 2002).

4.2 *Sarcomas of bone*

Depending upon the cell of origin, these tumours may be subdivided into the osteosarcoma, fibrosarcoma and chondrosarcoma. The most common of these being the osteosarcoma, which develops

from the primitive bone-forming tissue (Heare et al., 2009; Link et al., 2002). These malignant bone tumours, whilst being fairly uncommon in childhood, occur most often during adolescence (Heare et a., 2009). Osteosarcomas may develop in any bone, most often the long bones of the arms and legs, as well as the skull, jaw or pelvis (Cripe, 2008). Symptoms most often include pain in the affected bone area, as well as swelling, or restricted movement (Heare et al., 2009). These tumours only rarely spread to other parts of the body, but if this occurs, the lungs are most often affected (Cripe, 2008).

Diagnosis of oesteosarcoma occurs slightly more often in males than females, and American research suggests a slight predominance in children from African-American than Anglo backgrounds (Cripe, 2008; Link et al., 2002). While the cause of osteosarcoma is largely unknown, evidence suggests that rapid bone growth is a predisposing factor (Link et al., 2002). Genetic predisposition may arise from bone lesions or bone dysplasias, disorders marked by abnormal bone development or growth, such as Paget disease, fibrous dysplasia, enchondromatosis, and hereditary multiple exostoses. Chromosomal abnormalities arising from Li-Fraumeni syndrome and Rothmund-Thomson Syndrome are also associated with increased risk (Cripe, 2008; Heare et al., 2009; Link et al., 2002).

A hereditary predisposition is suggested by increased diagnosis found amongst family members, as well as a strong link between osteosarcoma and the genetically inherited form of retinoblastoma. The only environmental risk factor that has been associated with osteosarcoma development is ionizing radiation (Cripe, 2008; Link et al., 2002).

Currently, five-year survival rates for children diagnosed with a non-metastatic osteosarcoma is reported at just under 70 percent (Heare et al,, 2009). However, if at the time of diagnosis the tumour has spread, or if the tumour is located in an area that is unable to be removed such as the skull or vertebrae, the prognosis is less favourable (Heare et al., 2009; Link et al., 2002).

Treatment usually involves chemotherapy to reduce the tumour, followed by surgery to remove the tumour (Heare et al., 2009). Depending on the size, location, and stage of the tumour, an amputation of the limb (or part of) may be necessary, being replaced by a prosthetic limb. On some patients, limb salvage surgery may be carried out, replacing part of the affected bone with an internal endoprosthetic device (Link et al., 2002).

4.3 *Ewing's sarcoma*

Ewing's sarcoma is another form of tumour found to affect the bones, however, the soft tissue surrounding the bone may also be the site of growth. It is understood that Ewing's sarcoma develops from the neural cells, cells of the nervous tissue, although the exact cell of origin is unknown (Toretsky, 20028. The variations of this form of sarcoma all share the same chemical profile and a series of nonrandom translocations specific to this group of tumours (Ginsberg et al., 2002; Toretsky, 2008).

Like osteosarcomas, Ewing's sarcoma is predominant during adolescence, only rarely occurring in infants or adults older than 30 years (Ginsberg et al., 2002), and boys are slightly more likely to be

diagnosed with Ewing's sarcoma than girls (Heare et al., 2009; Toretsky, 2008). The longer bones of the arms and legs are most likely to be affected, but it may also develop in the hip or vertebrae (*www.cancerbacup.org.uk*). Symptoms are also similar to that of osteosarcomas.

The racial distribution of Ewing's sarcoma indicates that children from Anglo backgrounds are at least 9 times more likely to be diagnosed with this form of tumour compared with children from both African and African American descent, who are rarely affected (Heare et al., 2009). Furthermore, while these tumours have been reported in countries such as India and Japan, they are extremely uncommon in China (Ginsberg et al., 2002; Toretsky, 2008).

Familial inheritance has not been found to be a significant factor in the etiology of Ewing's sarcoma, although a small increase in incidence has been found amongst siblings (Ginsberg et al., 2008). Similarly, no definitive links have been found with congenital disorders, skeletal abnormalities, genetic or chromosomal abnormalities, nor has any environmental factor been found to increase risk (Ginsberg et al., 2002; Toretsky, 2008).

Overall five year survival rates are currently reported as over 60 percent. Those with tumours that have not metastasized to other sites have a survival rate approaching 70 percent, whereas those patients presenting with metastatic disease have a survival rate of approximately 25 percent (Heare et al., 2009; Toretsky, 2008). Treatment is similar to that of osteosarcomas, however in the case of Ewing's sarcoma, the tumour is responsive to radiation therapy, which is important for the local control of the tumour (Heare et al., 2009; Toretsky, 2008).

5. Embryonal Tumours

Embryonal tumours develop from cells responsible for embryonal tissue and organ development. Collectively, embryonal tumours make up approximately 18 percent of childhood cancers and are most common in early childhood. The most probable cause for these malignancies is a congenital mutation caused by an abnormal gestation process or chromosomal development in the growing embryo (Lacayo & Davis, 2010; Paulino & Coppes, 2009). The more common forms of these tumours are Wilms' Tumour, Neuroblastoma, Hepatoblastoma and Retinoblastoma.

5.1 *Wilms' Tumour*

Wilms' Tumour occurs in approximately 6 percent of all pediatric cancer cases (Davidoff, 2009). Wilms' tumour arises from the nephroblast cells responsible for in-utero kidney development and presents as a hard abdominal lump associated with pain or discomfort in the area, fever, or hypertension (*www.cancerbacup.org.uk)*. Wilms' Tumour is associated with congenital abnormality syndromes including genital abnormalities, hemihypertrophy (when one side of the body grows larger than the other), and aniridia (the absence of the iris in the eye). However these associations are rare with

most research suggesting a congenital genetic mutation as the most likely cause (Paulino & Coppes, 2009).

Wilms' Tumour occurs predominantly in children under 5 years of age (Davidoff, 2009), is slightly more common in females than males, and racial differences are apparent. Children from African or African American racial backgrounds are more likely to present with this form of tumour than Caucasians, and it is less common amongst children from Asian populations (Davidoff, 2009).

The survival prognosis for children diagnosed with Wilms' Tumour is greater than 90 percent (Davidoff, 2009). Multimodality treatment regimens are used involving surgery for diagnosis and treatment, with the removal of the kidney, chemotherapy and sometimes radiation therapy (Davidoff, 2009; Paulino & Coppes, 2009).

5.2 *Neuroblastoma*

Neuroblastomas, accounting for 7 percent of childhood cancers, are the most common cancer diagnosis in infants, although relatively uncommon at other stages of childhood (AIHW, 2008; Brodeur & Maris, 2006; Heck et al., 2009). These tumours develop from abnormal neuroblasts which, in the embryo, are responsible for the development of the nervous system and neural tissue (Heck et al., 2009). Neuroblastoma most often presents in the adrenal glands above the kidneys. Areas such as the spinal, thoracic, pelvic or cervical regions are also known sites of tumour growth (Lacayo & Davis, 2010). Symptoms vary depending on tumour location, but fatigue, tenderness, weight loss and constipation or breathlessness may occur (*www.cancerbacup.org.uk)*. As with other embryonal tumours, neuroblastomas seem to develop sporadically with a malfunction in embryonal development the most likely cause. Family heredity, congenital anomalies and syndromes have all been found to predispose a patient to neuroblastoma development, although these are extremely rare (Brodeur & Maris, 2006; Heck et al., 2009)

In contrast to Wilms' Tumour, males are slightly more likely than females to be diagnosed with neuroblastoma (Heck et al., 2009). Prognosis for infants is the greatest with a five-year survival rate of over 80 percent (Heck et al., 2009; Lacayo & Davis, 2010). This decreases with age with children aged 5 years and greater having a much reduced 40 percent survival rate. Other factors such as the site of the tumour, and the aggressiveness (stage) of the tumour also affect treatment outcome (Brodeur & Maris, 2006). Treatment consists of surgery, chemotherapy and radiotherapy and for advanced stages, autologous bone marrow transplant may be indicated.(Brodeur & Maris, 2006; Lacayo & Davis, 2010).

5.3 *Hepatoblastoma*

Hepatoblastomas develop from immature cells responsible for the embryonal development of the liver. Whilst hepatoblastoma is quite rare, accounting for less than 1 percent of childhood cancers, it is the most common form of liver cancer in the paediatric population (Tomlinson & Finegold, 2002;

Willert & Dahl, 2010). These tumours present with a large abdominal lump, often accompanied by pain, nausea and weight loss, and occasionally jaundice (Tomlinson & Finegold, 2002). The aetiology of hepatoblastoma is thought to be similar to that of other embryonal tumours with an abnormal developmental process occurring during liver development in the foetus (Willert & Dahl, 2010). Further to this, some associations have been found with hereditary and chromosomal syndromes, and more recently with prematurity (Tomlinson & Finegold, 2002).

Males present more often with hepatoblastoma than females, and it is most common amongst children under 3 years of age. Incidence in children in Far Eastern countries have been reported at 10 times that of Western countries, and within this statistic, children from Caucasian backgrounds in America are almost 5 times more susceptible to hepatoblastoma when compared with African American children (Tomlinson & Finegold, 2002; Willert & Dahl, 2010). Overall, five year survival rates are approaching 70 percent, although this may range between 25 to 91 percent depending on the severity and aggressiveness of the tumour (Roebuck, 2006; Willert & Dahl, 2010). Treatment predominantly includes a mixture of surgery and chemotherapy (Roebuck, 2006; Tomlinson & Fingold, 2002).

5.4 *Retinoblastoma*

Retinoblastomas are tumours of the eye arising from the immature retinoblasts responsible for the embryonic development of the retina (Hurwitz et al., 2002). Retinoblastoma accounts for less than 3 percent of childhood cancers (American Cancer Society, 2009) and in most instances is diagnosed within the first three years of life (Hurwitz et al., 2002). The tumour is predominantly diagnosed while it is still contained within the ocular area. If left untreated it may spread to other areas of the eye, brain or body (Hurwitz et al., 2002). An abnormal white pupil is often the first indication of retinoblastoma, however if there has been haemorrhage into the tumour, the pupil will appear a dark red colour (Hurwitz et al., 2002; *www.cancerbacup.org.uk*).

Retinoblastoma either be inherited , in which case a tumour most often develops in both eyes, or a sporadic occurrence, usually affecting one eye only (*www.cancerbacup.org.uk)*. The inherited form makes up two fifths of retinoblastoma diagnoses and is caused by an abnormal gene, the Rb gene, with autosomal dominant inheriatnce (Hurwitz et al., 2002). The non-inherited form has been linked to a variety of congenital abnormalities, mental retardation and increased parental age, although most children diagnosed with this form of retinoblastoma do not present with these co-occurring factors. The non-inherited retinoblastoma seems to instead occur sporadically during embryonic development (Hurwitz et al., 2002).

While retinoblastoma is thought to occur more often in the Middle East, India, Central and South America, no reliable gender or racial differences have been reported (Hurwitz et al., 2002). Overall survival rates are currently reported at over 90 percent (Schefler, 2008; Shields & Sheilds, 2002; *www.cancerbacup.org.uk)*. Treatment may vary depending on factors such as the position and size of

the tumour and whether one or both eyes are affected. Smaller tumours may be treated by cryotherapy, where the tumour is frozen and thawed; by plaque radiotherapy, whereby a small radioactive disc is attached into the outer surface of the eye; or by laser therapy. For larger tumours and metastasized tumours, chemotherapy and radiotherapy are used to control and reduce the tumour. In some instances, enucleation, the removal of the eye, is required. New treatment procedures have resulted in increased prognosis for vision retainment in most patients (Hurwitz et al., 2002; Shield & Shields, 2002; *www.cancerbacup.org.uk*).

APPENDIX 1B

A Summary of the Somatic Late Effects of Childhood Cancer Treatment

Late effects of childhood cancer treatment can cause health complications that range from the relatively mild to life-threatening, and can involve all organ and tissue systems (Bhatia et al., 2006) What follows gives a general overview of the potential late effects of childhood cancer therapy, broadly focusing on individual organ systems, the evidence relating to diagnosis, treatment, and demographic information, and the cancer-related treatments that may potentially modify these effects.

1. Mortality

Relative to the general population, survivors of childhood cancer are at a significant increased risk for mortality. In the study by Wilson et al. (in press), mortality among survivors of childhood cancer treated at the Sydney Children's Hospital between 1972 and 1999 was 7.5 times higher relative to the NSW population. Deaths were due to relapse of the primary cancer, secondary cancers, and complications of treatment such as radiation and chemotherapy. Similar results are reported in American (Mertens et al., 2001, 2009) and Scandinavian reports (Moller et al., 2001).

2. Secondary Cancers and Relapse

Second cancers are malignancies that are diagnostically distinct from the primary diagnosis and are a serious risk for childhood cancer survivors (Bhatia et al., 2006), whereas relapse is the re-occurrence of the same disease following a disease-free period (Family Handbook, 2010). Risk for relapse for survivors of childhood cancer decreases with increasing time since diagnosis, although relapse is the leading cause of death in long-term survivors of childhood cancer (54.8%), followed by death from second cancers (11.9%; Wilson et al., in press).

Relative to the general population, childhood cancer survivors are between 3 to 9 times more likely to develop a secondary cancer, depending on diagnosis and treatment received, with this risk increasing with age for most diagnoses (Meadows et al., 2009). There are a number of risk factors associated with secondary cancers. These include the primary diagnosis, where some childhood cancers are known to place the survivor at higher risk (Bhatia et al., 2006; Meadows et al., 2009). Specifically, a primary diagnosis of Leukaemia or Hodgkins disease places the survivor at increased risk for second cancers of the thyroid and skin cancers; Hodgkins disease also increases risk for malignancies of the gastro-intestinal tract and breast; whereas an original diagnosis effecting the CNS places the survivor at an increased risk for a second CNS malignancy (Meadows et a., 2009).

Further risk factors are associated with the treatment of the primary diagnosis (Bhatia et al., 2006; Meadows et al., 2009). High total dose of ionizing radiation places the survivor at increased risk across a range of diagnoses, with secondary cancers developing mostly within the field of radiation

exposure (Bhatia et al., 2006; Wakeford, 2004). Some forms of chemotherapy, particularly that including alkylating agents increase risk according to increasing dose (Bhatia et al., 2006). Other risk factors include a younger age at diagnosis, particularly less than 5 years and female gender, where risk is considerably higher for secondary breast and thyroid cancers (Bhatia et al., 2006; Monteleone et al., 2009).

2. Cognitive and Neurological Late Effects

Children diagnosed with a tumour of the central nervous system (CNS), leukemia, or those undergoing a bone marrow transplant, and hence total body irradiation, most often receive CNS directed therapy. This therapy consists of cranial irradiation, a course of chemotherapy, usually including the drug methotrexate (MTX), and sometimes surgery (Dreyer et al., 2002). While methotrexate is known to cause subtle learning problems, the modality of treatment most often associated with cognitive and neurological impairment is radiotherapy. Many studies have found that the brain and brain tissue is particularly sensitive to radiation causing vascular and biochemical abnormalities hindering the development of neurological pathways (Bhatia et al., 2006; Keene et al., 2000). Those treated with higher doses of radiation are at most risk, although the combination of methotrexate and radiotherapy may enhance possible cognitive and neurological damage (Bhatia et al., 2006; Dreyer et al., 2002; Keene et al., 2000). The tumour itself may also predetermine cognitive and neurological damage depending upon its location, the structures involved, size, and surgical procedures used in treatment (Bhatia et al., 2006).

Findings of cognitive and neurological impairment have been supported by many studies of child, adolescent and adult populations. However, as the brain undergoes a considerable amount of development during early childhood, children under 5 years of age are most at risk for cognitive and neurological damage (Bhatia et al., 2006). Furthermore, girls undergo more rapid neurological development during this period causing them to be at a higher risk from cancer treatment than boys (Bhatia et al., 2006; Dreyer et al., 2002). The most often reported effects of CNS therapy include attention and memory problems, and below average IQ. However effects such as behavioural, balance and co-ordination problems, vision and hearing deficits, changes to personality, and dementia and seizure disorders may also occur. Stunted growth, weight problems, delayed puberty, and infertility may also arise if radiation to the pituitary glands and hypothalamus occurs (Bhatia et al., 2006; Keene et al., 2000).

3. Endocrine Dysfunction

Endocrine complications are one of the most prevalent long-term sequelae observed among survivors of childhood cancer (Gleeson & Shalet, 2001). Endocrine dysfunction may result either from

the direct effects of treatment (radiation, chemotherapy and surgery) on the function of the endocrine glands (primary gland failure) or from failure of the hypothalamus and pituitary to release hormones that stimulate the endocrine end organs (central gland failure) (Castellino & Hudson 2002) or from compression or invasion by tumour.

Complications involving the endocrine system are highly prevalent among childhood cancer survivors (Gleeson & Shalet, 2001). The endocrine system is made up of a variety of hormone secreting glands which each have different functions. The glands most affected by cancer treatment are the hypothalamus, pituitary, thyroid, adrenal, and the testes and ovaries. Damage to these structures may result in growth deficiencies, puberty and fertility problems, obesity, and a range of other late effects (Bhatia et al., 2006; Keene et al., 2000).

Growth impairment is a well reported complication of cranial irradiation with damage to the hypothalamus and pituitary gland known to cause growth hormone deficiency (GHD) (Bhatia et al., 2006; Dreyer et al, 2002). Younger children and those treated with high doses of radiation, are most at risk of developing GHD, and although adequate hormone levels can be assisted by growth hormone replacement therapy, catch-up growth is not achieved (Bhatia et al., 2006). Radiotherapy to bones can damage bone growth, and when spinal irradiation is given vertebral growth is often inhibited and may result in deformities such as scoliosis (Bhatia et al., 2006). Height may also be affected by radiation to the abdomen, where the gonads, also responsible for growth, may have been damaged (Dreyer et al., 2002). Chemotherapy is also known to damage the gonads and inhibit bone growth (Noorda et al., 2001).

Gonadotrophins are hormones secreted by the pituitary gland, are regulated by the hypothalamus and have an effect on the function of the gonads (ovaries and testes). These hormones are necessary for the onset of puberty, maintenance of sex characteristics, and the production of sex hormones by the gonads (Zacharin et al., 2001). Radiation given to the brain or abdomen, ovaries or testes, can damage the production and secretion of gonadotrophins, sex hormones and germ cells, resulting in gonadal dysfunction, especially infertility (Bhatia et al., 2006). Direct damage to the gonads may also result from certain chemotherapeutic agents as well as surgery (Bhatia et al., 2006; Keene et al., 2000; Monteleone & Meadows, 2009). Infertility or reduced fertility, early or late onset of puberty, amenorrhea, poorly developed or complete absence of secondary sex characteristics, or early menopause are all associated with gonadal dysfunction. Younger children are at a substantially lower risk for gonadal dysfunction, compared with those who are pubescent or post pubescent. Boys have been found to be more susceptible to gonadal damage than prepubertal girls due to the increased sensitivity of the testes to cancer treatment. The risks of infertility relate to the age of treatment, the chemotherapy agents used and the dose of irradiation to which ovary or testi are exposed. Sex hormone replacement therapy may be required for some survivors (Bhatia et al., 2006).

The thyroid gland, whilst not sensitive to chemotherapy, is highly sensitive to radiation. It is stimulated by thyroid-stimulating hormone (TSH) produced by the pituitary gland and regulated by the hypothalamus. It is responsible for such processes as growth, metabolism and cognitive development (Keene et al., 2000). Hypothyroidism, or an underactive thyroid is a highly common late-effect most often associated with radiation to the neck (Bhatia et al., 2006). Hypothyroidism is associated with slowing childhood growth, a reduced tolerance to cold, tiredness and fatigue, constipation and weight gain (Dreyer et al., 2002; Keene et al., 2000; Zacharin et al., 2001). These symptoms can arise from between 5 to 20 years after treatment cessation and may be treated with thyroid replacement medication (Keene et al., 2000).

Hypothyroidism has been associated with weight gain, due to this disorder slowing metabolism and increasing fatigue, and the hypothalamus has also been implicated through the abnormal secretion of insulin. However, while the endocrine system seems to have an underlying role, the cause of weight gain and obesity is largely unknown (Dreyer et al., 2002; Keene al., 2000).

Cortisol depletion is another reasonably common late effect arising some time after cancer treatment. Cortisol depletion may result from damage to the pituitary gland after cranial radiation, reducing the body's ability to respond to stress. Blood pressure regulation is affected and may result in extremely low blood pressure, and possible collapse, during a stressful event. Increased tiredness, lethargy and weight loss are also associated with cortisol depletion (Zacharin et al., 2001). Additionally, decreased levels of antidiuretic hormone, responsible for the body's salt and water balance, may arise from a tumour in the pituitary gland or surgery to this area resulting in diabetes insipidus. In this situation, fluid is not retained by the kidney and is passed quickly through the body resulting in a high risk of dehydration and salt imbalance. Both cortisol and antidiuretic hormone deficiencies can be overcome by daily medication and monitoring (Zacharin et al., 2001).

4. Cardiac and Pulmonary Dysfunction

Cardiac and pulmonary toxicity are well documented with both chemotherapy and irradiation. Heart damage is most often associated with chemotherapy, and in particular with anthracyclines and high dose cyclophosphamide used in the treatment of many tumours (Bhatia et al., 2006; Ward, 2000). These drugs damage the myocytes, cells which make up the heart muscle, causing thin and stiff cardiac walls (Keene et al., 2000). As a result, heart growth is impaired and output reduced. Symptoms such as palpitations, shortness of breath, tiredness, or chest pain may indicate cardiac pathology such as cardiomyopathy (a weakness of the heart muscle), pericarditis (an inflammation of the sac surrounding the heart which accumulates fluid), or ventricular arrhythmia (irregular heart beat), all by which reduce the hearts capacity and functioning ability (Keene et al., 2000; Zacharin et al., 2001). Anthracycline-induced cardiotoxicity is a dose-dependent side effect. Cardiac dysfunction may only present years after

completion of cancer therapy, even though evaluation of the heart function is initially normal in the early years of follow-up and may be life-threatening (Bhatia et al., 2006).

Radiation therapy to the lungs or mantle regions may also result in damage to heart muscle, arteries and surrounding blood vessels. Fibrosis (a loss of elasticity and an increase of fibrous tissue) is most often associated with radiation therapy and may result in coronary artery disease, leaking valves and ventricular dysfunction (Bhatia et al., 2006). When both radiotherapy to the heart region and chemotherapy are used, the risk for cardiac dysfunction increases. Risk also increases when treatment is given to infants and toddlers as the heart is immature and growth is impaired at an early stage of development. While girls are known to be at a higher risk of treatment associated heart problems, reasons for this gender difference are not clear. The increased body fat of females may be attributable (Dreyer et al., 2002).

Cardiac dysfunction can occur a few years after treatment; however it is usually not evident until much later in life, often not until mid to late adulthood, and may be brought on by body stressors such as pregnancy or weight lifting (Bhatia et al., 2006). Due to the long latency, survivors are recommended to have regular check ups, especially during pregnancy, in order to detect the development of related heart problems and associated risk (Dreyer et al., 2002).

Similarly, cancer treatment has adverse late effects to pulmonary function. Radiation to the chest cavity, and chemotherapy can result in restricted lung diameter and airway capacity. Fibrosis of the lungs, and pneumonitis (inflammation of the lungs) are the most common late effects of radiation, while some chemotherapeutic drugs such as bleomycin, have been associated with scarring of the lungs, and surgery to remove whole or part of a lung reduces pulmonary function (Dreyer et al., 2002; Zacharin et al., 2002). Reduced lung capacity and lowered oxygen/carbon dioxide transfer result, causing symptoms such as decreased exercise tolerance, dry cough, or difficulty breathing (Keene et al., 2000). As lung development and growth occurs during childhood, treatment effects are more severe in children than adults (Monetleone & Meadows, 2009). Survivors of childhood cancer who are at risk of pulmonary dysfunction are encouraged to seek annual check ups, maintain a healthy level of cardiovascular fitness, and reduce the risk of influenza, pneumonia or other respiratory infections by maintaining general health and receiving vaccinations (Keene et al., 2000).

5. Gastrointestinal, Hepatic and Renal Damage

The gastrointestinal tract (GI) includes the oesophagus, stomach, intestines and rectum. Radiation and abdominal surgery involving the gastrointestinal area, and certain chemotherapeutic drugs are known to cause GI problems. GI symptoms are common acute problems, but some may persist or develop later. The development of Graft Versus Host Disease (GVHD), whereby the immune system attacks certain organs (Zecca et al., 2002), or an infection after treatment, has also been implicated in the development of GI dysfunction. Fibrosis and enteritis (an inflammation of the GI lining) may develop

causing abdominal pain, ulcers, diarrhoea, nausea, loss of appetite, constipation, adhesions, obstructions, lactose intolerance and/or malabsorption problems (Bhatia et al., 2006; Keene et al., 2000). Most complications will arise within 5 years after treatment cessation, although some have been reported as late as 20 years (Dreyer et al., 2002). Treatment of these symptoms may include a low fat, lactose and gluten free diet, and in extreme cases surgery may be necessary (Keene et al., 2000).

Radiotherapy is more often associated with long term hepatic effects with this form of treatment known to induce chronic fibrosis of the liver (Bhatia et al., 2006). Liver fibrosis is when the liver tissue is scarred. Symptoms include an enlarged liver or spleen, abdominal fluid build up, and nausea. If fibrosis becomes severe enough, cirrhosis can result (Keene et al., 2000). Fibrosis and cirrhosis may also result from long term chemotherapy using methotrexate (MTX), although this is a relatively uncommon late effect. Risk of hepatic damage increases when treatment is combined with radiotherapy (Bhatia et al., 2006; Dreyer et al., 2002). The risk of developing hepatitis, an inflammation of the liver causing fibrosis, cirrhosis, and reduced immune functioning, is also increased when treatment includes blood transfusions, although current blood screening practices considerably reduces this risk (Keene et al., 2000).

As liver damage is difficult to detect without a biopsy, it can often go unnoticed until it becomes severe enough to cause problems such as jaundice, fever, diarrhoea, itching, or nausea. Patients with liver damage are discouraged from drinking alcohol and using over-the-counter medications, and encouraged to have regular liver screenings and hepatitis vaccinations. In severe cases, a liver transplant may be necessary (Keene et al., 2000; Dreyer et al., 2002).

Kidneys are the main organs of the renal system vital for healthy body function. A major role of these organs are to filter waste products from the blood and body fluid, regulate blood pressure, and maintain healthy levels of salt, vitamins and minerals (Keene et al., 2000). While children diagnosed with a tumour of the kidney, such as Wilms' Tumour, most often require the effected organ to be surgically removed, normal renal functioning is maintained by the remaining healthy kidney. Kidney pathology is a relatively rare result of cancer treatment; however chronic kidney inflammation (nephritis) is associated with high dose radiation to the abdominal area and may lead to renal failure or heart damage (Bhatia et al., 2006). Other symptoms include excessive urination or the retaining of fluid, painful urination or blood in the urine, fatigue, anaemia or high blood pressure (Keene et al., 2000). Drugs such as cisplatin and ifosfamide used in chemotherapy treatment may also cause nephrotoxicity and subsequent renal failure, or renal Fanconi's syndrome resulting in an electrolyte imbalance, stunted growth or bony deformities (Dreyer et al., 2002).

Bladder and urinary tract damage is also associated with radiation and chemotherapy causing fibrosis and subsequent reduced elasticity or muscle control, and hemorrhagic cystitis. Hemorrhagic cystitis results when the vessels of the bladder are damaged causing blood to leak into the urine, painful and frequent urgent urination and poor bladder control (Bhatia et al., 2006; Keene et al., 2000).

Most effects of cancer treatment are usually short term with the renal system able to overcome resulting toxicity and damage, however long term damage and severity is associated with increased dose and duration of treatment. Renal pathology may become evident during the course of treatment, or may arise many years after treatment cessation (Dreyer et al., 2002). Survivors are encouraged to maintain kidney health by avoiding certain contact sports, drinking large amounts of water, and avoiding certain medicines known to affect renal functioning. Dialysis or a kidney transplant may be necessary for patients with progressive kidney failure, although this is extremely rare (Keene et al., 2002).

6. Visual and Hearing Problems

Tumours of the eye may result in surgery or radiotherapy impairing vision. Chemotherapy is not usually associated with optic damage, although prolonged steroid use may cause damage to the lens (Bhatia et al., 2006; Zacharin et al., 2001). In the treatment of some tumours, the complete removal of the eye may be required, while in other instances this may not be necessary with partial or complete vision retained. Radiation directly to the eye itself, cranial radiotherapy or total body irradiation may damage the eye directly, its orbit, or ophthalmic structures (Monteleone & Meadows, 2009). Problems include the development of cataracts resulting in a progressive blurring of vision, orbital hypoplasia from damage to tear ducts causing dry irritable eyes, photophobia from damaged photoreceptors causing light sensitivity, hypoplasia or reduced bone growth surrounding the eye, or a progressive loss of vision from damage to the retina or optic nerve (Bhatia et al., 2006; Keene et al., 2000; Zacharin et al., 2001). Medications and eye drops are used to continually care for dry, sensitive eyes and the use of sunglasses are recommended to protect the eye against damaging ultra-violet light. Cataracts and increased pressure associated with eye and bone growth can be removed with surgery in most instances (Bhatia et al., 2006; Keene et al., 2000).

Hearing loss, most notably to the high frequency range, is caused by drugs such as cisplatin or carboplatin, both known to damage the cochlear and auditory nerve and cause biochemical and electrophysiologic changes (Bhatia et al., 2006; Keene et al., 2000). Radiation given to the head and neck is also associated with hearing loss and auditory damage, as well as chronic ear infections caused by the thickening and drying of the external ear canal or ear drum (Keene et al., 2000; Zacharin et al., 2001). As auditory problems usually occur during treatment children regularly undergo auditory screening. Auditory damage may interfere with the acquisition and development of language skills, especially in younger patients, and while irreversible may be overcome by the use of a hearing aid. Antibiotics and ear drops are used to treat ear infections and reduce wax build up, and survivors are encouraged to seek regular auditory check ups (Bhatia et al., 2006; Keene et al., 2000).

7. Other

Cancer treatment may also affect other areas of growth, development and functioning causing long term medical consequence. Graft Versus Host Disease (GVHD) may result from bone marrow transplantation whereby the body's immune system attacks certain organs (Zecca et al., 2002). Musculoskeletal abnormalities caused by radiation to bones and tissues may result in scoliosis as well as hypoplasia and atrophy tightening soft tissue, muscles and skin preventing normal bone growth. Other musculoskeletal problems which may also result from cancer treatment include reduced bone density, leg length discrepancies, asymmetries of growth, osteoporosis, osteopenia, avascular necrosis or osteoarthritis (Dreyer et al., 2002; Keene et al., 2000). Skin may become pigmented, dry or itchy, and sometimes moles may develop in treated areas. Both short and long term hair loss, change in colour and texture and alapacia are caused by damage to hair follicles. Breast growth may be adversely affected with reduced growth, underdevelopment or breast deformity often a result of radiation to the breast tissue. Patients treated with 24Gy cranial irradiation may not be able to breast feed after delivery. (Johnston et al., 2008). An increased risk of breast cancer is also associated with treatment to this region (Keene et al., 2000). Tooth enamel may become thin, roots and buds damaged, and saliva production decreased. This reduces tooth development and growth as well as making them more prone to bacteria and decay (Zacharin et al., 2001).

8 Summary: Advances in Long-Term Treatment

Long-term medical effects of cancer treatment can vary from patient to patient depending on factors such as the cancer diagnosis, the treatment type and dosages (e.g. drugs, radiation), the length and intensity of the treatment, the sex and age of the patient, and time since treatment cessation (Bhatia et al., 2002; Monteleone & Meadows, 2009). Continued medical research has increased knowledge of these possible side effects, and where possible, treatment protocols are now refined so as to minimise potential damage for new patients. For example, cranial irradiation is discouraged as far as is possible for children younger than 3 years of age in order to protect the child from cognitive and neurological damage. Likewise, radiation may be given to both sides of the body to prevent growth asymmetries, and certain organs are now shielded from radiation treatment (Keene et al., 2000). Adjuvant therapy is continuing to develop with protective agents and IV fluids given alongside certain drugs in order to flush toxins quickly out of the body and reduce damage to organs such as the kidneys, bladder and genitals (Keene et al., 2000; Monteleone & Meadows, 2009). In addition, many oncology treatment centres keep detailed treatment histories to assist ongoing research and monitor future health risk. For example, at the CCCBD, 'risk factor' protocols have been developed to identify and monitor survivors who are at an increased risk of long-term medical effects due to past cancer treatment, thus allowing for the most effective ongoing medical care. Therefore, it is evident that a knowledge base for long-term effects in

the medical domain has been established, and is continually being refined as an evidence-based platform for the prevention or management of the long-term medical effects due to paediatric cancer treatment.

APPENDIX 1C

The Diagnostic Criteria for Posttraumatic Stress Disorder According to the American Psychiatric Association's DSM-IV-TR (APA, 2000).

A. The person has been exposed to a traumatic event in which both of the following were present:
   1. the person experienced, witnessed, or was confronted with an event or events that involved actual or threatened death or serious injury, or a threat to the physical integrity of self or others.
   2. the person's response involved intense fear, helplessness, or horror. **Note:** In children, this may be expressed instead by disorganized or agitated behaviour.

B. The traumatic event is persistently reexperienced in one (or more) of the following ways:
   1. recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. **Note:** In young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
   2. recurrent distressing dreams of the event. **Note:** In children, there may be frightening dreams without recognizable content.
   3. acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur on awakening or when intoxicated). **Note:** In young children, trauma-specific re-enactment may occur.
   4. intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
   5. physiological reactivity on exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by three (or more) of the following:
   1. efforts to avoid thoughts, feelings, or conversations associated with the trauma
   2. efforts to avoid activities, places, or people that arouse recollections of the trauma
   3. inability to recall an important aspect of the trauma
   4. markedly diminished interest or participation in significant activities
   5. feeling of detachment or estrangement from others
   6. restricted range of affect (e.g., unable to have loving feelings)
   7. sense of a foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

D. Persistent symptoms of increased arousal (not present before the trauma), as indicated by two (or more) of the following:
   1. difficulty falling or staying asleep
   2. irritability or outbursts of anger
   3. difficulty concentrating
   4. hypervigilance
   5. exaggerated startle response

E. Duration of the disturbance (symptoms in Criteria B, C, and D) is more than 1 month.

F. The disturbance causes clinically significant distress or impairment in social, occupations, or other important areas of functioning.

APPENDIX 1D

An Overview of the Inclusion of Life-Threatening Illness as a Trauma Inducing Event for PTSD.

Posttraumatic stress disorder was first recognised in the third edition of the DSM (DSM-III, APA, 1980), acknowledging for the first time the importance of the event in the evolution of traumatic stress symptoms. Prior to this, psychological trauma, labelled as traumatic neurosis, hysteria, or shell-shock, was believed to arise from individual factors such as a predisposed vulnerability to psychological disorder or secondary gain (Jones & Wessley, 2007). However, the DSM-III's Criterion A definition of what constituted a traumatic event was vague, stating the event is "*generally outside the range of usual human experience…. [and] would evoke significant symptoms of distress in most people*" (APA, 1980, p...). Experiences such as chronic illness were explicitly excluded. The revised edition of the DSM-III's (DSM-III-R, APA, 1987) Criterion A retained this chronic illness exclusion, but included examples of qualifying events such as a "*serious threat to one's life or physical integrity*" and "*serious threat or harm to one's children, spouse, or other close relatives and friends*". Additionally, while not included as a requirement within the Criterion A definition, the text stated that the event "*is usually experienced with intense fear, terror, and helplessness*", thereby leaning toward an acknowledgment of the role of subjective interpretation.

There was increasing disquiet concerning the chronic illness exclusion with a growing literature reporting incidences of posttraumatic stress symptomatology following such experiences, particularly cancer. Posttraumatic stress symptoms were reported in adult (Kaasa et al., 1993) and childhood cancer patients (Nir, 1985; Pot-Mees, 1989; Stuber et al., 1991), and cancer survivors (Cella, Pratt & Holland, 1986; Cella &Tross, 1986; Kornblith et al., 1992; Stuber et al., 1991). In response, the American Psychiatric Association conducted field trials to specifically investigate whether a life-threatening illness could result in a diagnosis of PTSD. This research, using a series of structured interviews and self-report measures, confirmed symptoms of intrusive thoughts, avoidance, and heightened arousal in adult and child cancer populations, as well as mothers of childhood cancer survivors, and at levels extreme enough to impair functioning in ways characteristic of a PTSD diagnosis (Alter, et al., 1996; Stuber et al., 1998). Subsequently, the fourth edition of the DSM (DSM-IV; APA, 1994, p.424) included diagnosis of a "*life-threatening illness*", and "*learning that one's child has a life-threatening disease*" as qualifying events for PTSD.

The DSM-IV also included another important change - namely an emphasis on the *perception* of trauma in diagnosis (Criterion A2). This marked an important theoretical shift whereby a traumatic experience was no longer defined by the event itself, as per prior editions of the DSM, but instead defined by the psychological experience of that event for the individual. These changes to Criterion A included in the DSM-IV have been retained in the most recent text revision (DSM-IV-TR, APA, 2000).

APPENDIX 2A

Questionnaire Pack 1

Due to the size of this Appendix, Questionnaire Pack 1 for each group (survivor, parent, sibling) has been saved in PDF format to the disc attached to the back cover of this dissertation. Within the file folder titled 'Appendix 2A' , the following are included:

1. Introductory Letter
2. Project Information Statement
3. Project Consent Form
4. Consent to Contact Parents and Siblings Form (survivors only)
5. Questionnaire Booklet (Part 1)

Please note that not all of the measures included in the Questionnare Booklet (Part 1) are relevant to this dissertation. Those that are relevant are contained within pages 4 to 8, and on page 12 (demographic and treatment details).

APPENDIX 3A

Group Comparisons on Trauma Outcome Measures for Full Family Units (Study 1C)

Statistical Analyses

Using SPSS for windows, version 15, group differences on IES-R and PTGI scores were tested using repeated measures ANOVA with 3 planned contrasts (contrast 1: *'parents'* versus *'survivors/siblings';* contrast 2: *'mothers'* versus *'fathers'*; contrast 3: *'survivors'* versus *'siblings'*). Between the categorical SCID classifications, chi-square tests of independence were used. Due to multiple analyses, the conservative alpha level of $p \leq .01$ was applied.

Results

Posttraumatic Stress (SCID): As shown in Tables 3.7 and 3.9, most comparisons between groups on rates of clinical PTSS and PTSD generally revealed no significant difference, however there were exceptions to this trend. Compared to survivors, more mothers met current B-symptomatology (p = .004), and compared to siblings, more mothers and more fathers responded to childhood cancer as a traumatic event (p = .004), and met C-symptom criteria since diagnosis (p = .008).

Posttraumatic Stress (IES-R): As shown in Tables 3.7 and 3.9, repeated measures ANOVA revealed no significant differences across groups for the IES-R scales ($p > .01$; see Table 3.7), and no group differences were found for any of the planned contrasts between parents and survivors/siblings, mothers and fathers, and survivors and siblings ($p > .01$; see Table 3.8). Similarly, no significant differences were revealed between groups on prevalence of moderate to severe PTSS ($p > .01$).

Posttraumatic Growth (PTGI): As shown in Table 3.8, repeated measures ANOVA revealed significant differences across groups for most scales of the PTGI ($p < .01$), except *New Possibilities* where no significant difference was found (p = .021; see Table 3.7). Planned contrasts revealed that parents scored significantly higher than survivors and siblings across most scales ($p < .001$), although *New Possibilities* was above the .01 level (p = .024). Planned contrasts between mothers and fathers revealed no significant difference for any PTGI scale ($p > .01$), however, survivors scored significantly higher than siblings on *Appreciation of Life* and *full-scale PTGI* ($p \leq .005$). No other group differences were found between survivors and siblings ($p > .01$).

Comparisons between groups on prevalence of moderate-great posttraumatic growth revealed that mothers were more likely than siblings to meet the moderate-great category for most scales: *Relating to Others*, *Spiritual Change*, *Appreciation of Life*, and *full-scale PTGI* ($p \leq .007$), while no significant difference was revealed for *Personal Strength* (p = .017) or *New Possibilities* (p = .053). No other differences across groups were revealed (see Table 3.9).

APPENDIX 7A

Pilot Pack

As with Appendix 2A, the Pilot Pack has been saved in PDF format to the disc attached to the back cover of this dissertation. Within the file folder titled 'Appendix 7A' , the following are included:

1. Project Information Statement
3. Project Consent Form
4. Questionnaire Booklet (Pilot Study)

Please note that there were three versions of the Project Information Statements and Project Consent Form to reflect the relevant treatment department. These were: Department of Medical Oncology; the Department of Radiation Oncology; and the Department of Haematology. As the department and signatory were the only change made to these forms, only one version has been included for reference information.

APPENDIX 7B

Questionnaire Pack 2

Questionnaire Pack 2 is saved in PDF format to the disc attached to the back cover of this dissertation. Within the file folder titled ‘Appendix 7B’ , the following are included:

1. Letter of Introduction
2. Questionnaire Booklet (Pilot Study)