

Volume 1

**Psychosocial adjustment in
adolescent survivors of childhood
brain tumours**

Monika Juskiewicz

**D.Clin.Psy 2002
University College London**

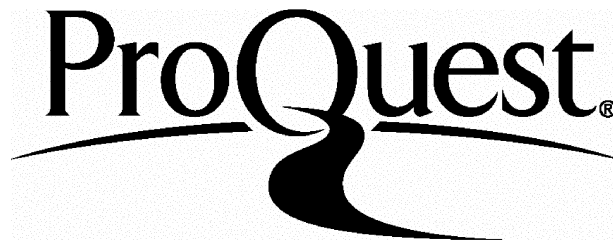
ProQuest Number: U643566

All rights reserved

INFORMATION TO ALL USERS

The quality of this reproduction is dependent upon the quality of the copy submitted.

In the unlikely event that the author did not send a complete manuscript and there are missing pages, these will be noted. Also, if material had to be removed, a note will indicate the deletion.



ProQuest U643566

Published by ProQuest LLC(2016). Copyright of the Dissertation is held by the Author.

All rights reserved.

This work is protected against unauthorized copying under Title 17, United States Code.
Microform Edition © ProQuest LLC.

ProQuest LLC
789 East Eisenhower Parkway
P.O. Box 1346
Ann Arbor, MI 48106-1346

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	1
ABSTRACT	2
CHAPTER ONE: Introduction	4-49
Overview	4
Central Nervous System (CNS) tumours – prevalence and treatment	5
Effects of Cancer and Its Treatment	6
A model of of psychosocial adjustment	15
Peer perception of children with cancer	22
The impact of physical appearance on peer relationships	23
Neuropsychological Effects of cancer and their impact on peer relationships	26
Educational Implications and the impact on psychosocial functioning	28
Psychosocial functioning – a summary of the evidence	29
Effects of childhood cancer on siblings	30
Theories of social functioning and friendship	32
Study Aims	43
Research Hypotheses	48
CHAPTER TWO: Method	50-62
Overview	50

Participants	50
Ethical considerations	54
Procedure	54
Measures	56
CHAPTER THREE: Results	63-90
Overview	63
Testing the hypotheses	64
Between group differences	66
Summary of between-group findings	72
Testing the model	74
Themes emerging form responses to the TAT	79
Open-ended questions: Subjective accounts of the impact of cancer	86
CHAPTER FOUR: Discussion	91-121
Overview	91
Summary of findings: differences between groups	92
Testing the conceptual model	101
Themes emergent from qualitative analysis	109
Methodological issues	110
Future directions for research	112
Clinical implications of the findings	115

APPENDICES

Appendix One: Letters of ethical approval	122
Appendix Two: Patient information forms	125
Appendix Three: Participant consent forms	134
Appendix Four: SDQ	137
Appendix Five: MESSY	142
Appendix Six: CFI	151
Appendix Seven: PIE	153
Appendix Eight: TAT instructions	158

REFERENCES

160

List of Tables

Table 2.1:	52
Demographic and Illness Characteristics, Clinical group participants and non-participants	
Table 2.2:	53
Demographic characteristics of clinical and sibling groups	
Table 3.1:	65
MESSY and SDQ scores for patient and parent respondents	
Table 3.2:	68
SDQ score for the clinical and sibling groups and population norms	
Table 3.3:	69
Frequency and percentage of each group scoring within abnormal ranges on the SDQ	
Table 3.4:	71
CFI subscale scores for clinical, sibling and comparison groups	
Table 3.5:	73
Themes of isolation, difference and negative perceptions of peer relationships in TAT responses for clinical and sibling groups	

Table 3.6: 76

Correlations between SDQ scores and ‘difference from norm’ for CFI subscales

Table 3.7: 78

Correlations between illness cognitions and psychosocial functioning

Table 3.8: 82

Themes categories emergent from TAT responses of the Clinical and Sibling groups

List of Figures

Figure 1.1: 16

Wallander & Varni's conceptual model of child adjustment to paediatric chronic illness.

Figure 1.2: 46

A conceptual model of the role of social and illness cognitions in the psychosocial adjustment of adolescent survivors of CNS cancer.

ACKNOWLEDGEMENTS

My sincere thanks to my supervisors, who have helped me shape and develop my thoughts and writings over this long two years researching. To Angela Griffin, whose creativity and energy helped this study be born, and provided insight and support during its life. To Cathy Creswell, who saw draft after draft (even propping tired eyes open as she emailed comments from faraway airports) and kept me on track. Thanks to Chris Barker, who as an oasis of calm and reason, has been skilled in reducing my stress levels to manageable proportions.

My gratitude to Helen Spoudeas, who was instrumental in the recruitment of families to the study, and with endless enthusiasm offered ideas and questions for me to ponder.

I am indebted to the children and families with who offered to share their knowledge and experience with me, and without whom I would have written nothing.

I would like to say thank you to Tristan, who has been patient with my grumblings, and who has provided food, musical interludes and laughter vital to my wellbeing.

Finally, I wish to thank Mama and Tata, who are always only a phone call away, and always on standby with love, advice and chicken soup.

ABSTRACT

Survival rates amongst children with brain tumours are improving. The increase in successful treatment has been accompanied by a shift in emphasis in psychological research and intervention. Now that cure is an increasingly realistic prospect, the focus of psychology is correspondingly moving towards quality of life in long-term survivors of cancer.

A growing body of evidence suggests that cancer survivors are at increased risk of internalising and externalising symptomatology and social problems. There is evidence indicating that survivors of brain tumours are at particular risk, and yet data on psychosocial difficulties in this population are scant.

The present study evaluated the extent of psychosocial difficulties in adolescent survivors of brain tumours, and carried out a preliminary investigation of factors associated with outcome on the basis of an a priori conceptual model. In particular, social skills deficits, negative appraisals about the impact of cancer, and social cognitions including expectations of friendship and sense of self as 'different' were hypothesised to be associated with psychosocial difficulties.

This study compared the functioning of 21 adolescent cancer survivors, aged 11 to 16 years, to population norms and siblings. All survivors had been treated for brain tumours in the posterior fossa region of the brain at least three years prior to participation in the study, and in this respect can be thought of as a relatively

homogeneous group. Psychosocial difficulties, social skills, and cognitions about friendship and illness were evaluated using standardised measures.

These included the Strengths and Difficulties Questionnaire, the Matson Evaluation of Social Skills with Youngsters, the Children's Friendship Inventory and the Perceived Illness Experience Scale. In addition, the Thematic Apperception Test (TAT) was used to elicit qualitative information about social relationships for cancer survivors and their siblings.

According to both self and parent report, cancer survivors had significantly more psychosocial difficulties than population norms. A significant subgroup had psychosocial difficulties in the clinically significant range. Adolescents surviving cancer did not differ in terms of social skills or expectations of friendship compared to healthy peers. In their responses to the TAT, cancer survivors did not differ from their siblings on perceptions of isolation or social difference. However, they demonstrated more negative perceptions of peer relationships than siblings, and expressed themes of group identity less.

Factors associated with poorer psychological outcome included greater levels of social skills deficits and negative appraisals of the ongoing impact of cancer on school and on peer problems. In addition, adolescents who had friendship expectations characteristic of casual, rather than close, friendships were more likely to have higher levels of psychosocial difficulties.

Screening for psychosocial difficulties and the perceived impact of cancer should form part of the long-term follow-up of survivors of childhood brain tumours.

CHAPTER ONE

INTRODUCTION

Overview

Children diagnosed with cancer are now living longer. Significant improvements in treatments mean that long-term adaptation of the survivors of childhood cancer is now of central importance in research (e.g., Varni, Katz, Colegrove, and Dolgin, 1995).

Whilst studies documenting the initial impact of a cancer diagnosis and the effects of treatment abound, there is a relative paucity of data regarding psychosocial functioning in children in long-term remission from cancer.

Tumours of the central nervous system (CNS) are of particular interest given the deficits in cognitive and neuro-endocrine function, which are common sequelae of the illness and its treatment. These difficulties may have an impact on the psychosocial adaptation of survivors of CNS cancers in addition to that of the illness and treatment.

This chapter will firstly review the impact of stressors associated with childhood cancer and its treatment. Physical, neurological and educational functioning of cancer survivors will be considered. In particular, the impact of cancer on social relationships will be a focus. A brief overview of the impact on siblings of cancer survivors will be presented. Theories of friendships offer an understanding of the importance of social relationships in childhood and adolescence and will be discussed in the light of the impact of cancer survival.

Central Nervous System (CNS) tumours - prevalence and treatment

CNS tumours are the second most prevalent of childhood cancers after leukaemia, accounting for 17% of all malignancies (Gurney, Smith & Bunin, 1999). They occur most frequently in children between the ages of 5 and 10 years (National Children's Cancer Foundation, 1997).

Brain tumours are a heterogeneous group of malignancies. Most tumours are named after the cells from which they develop. Tumours called astrocytomas, for example, grow from astrocyte cells. Diagnosis may also be based on the area of the brain affected, so that diagnostic labels may refer to both histology and site, for example, cerebellar astrocytoma (Fuemmeler, Elkin & Mullins, 2002). The simplest categorisation of tumours according to site refers to supratentorial and infratentorial tumours. Supratentorial tumours are those occurring in the upper part of the brain, above the tentorium. Infratentorial tumours, also called posterior fossa tumours, are located below the tentorium, for example in the cerebellum or brainstem (Fuemmeler et al., 2002).

Treatment of CNS tumours ideally involves complete surgical excision of the growth. Some tumours may not be removed completely by surgical methods, either due to their precarious location or their invasion of surrounding tissue. In such cases, chemotherapy and cranial irradiation may be part of the treatment package (Granowetter 1994). Increased survival has become possible with the advent of more powerful and aggressive methods of treatment.

Cancers progress at varying rates and respond with varying degrees to treatment. Treatment is often successful in eradicating the cancer. The child is then

described as being in remission and may, in effect, be cured. Risk of relapse depends on a number of variables, including tumour type and the degree to which tumour excision is possible. This means that families can never be assured the cancer will not return and live with a level of uncertainty about the future (Katz, Dolgin & Varni, 1990).

The study of the impact of childhood brain tumours is complicated by the fact that they represent a heterogeneous group of CNS malignancies and treatment modalities. Illness and treatment variables are likely to influence outcome, but due to the small sample sizes typical of research in this area, it is not often possible for their influence to be adequately investigated (Fuemmeler et al., 2002).

Effects of Cancer and Its Treatment

Physical and Medical

As a potentially fatal condition, it is imperative that children are treated with any means known to be effective. Unfortunately, the cure itself can also be costly. Numerous physical and medical conditions may arise as a result of cancer and its treatment. The effects of chemotherapy, radiation therapy and surgery depend on the methods employed, the aggressiveness of the treatment and the age of the child at the time of treatment. Children who undergo irradiation therapy may experience cognitive deficits, thyroid dysfunction, growth delay, problems with sexual maturation and fertility, cardiac problems and cataract development (Phipps, 1994). Weight gain or loss, hair loss, scars (due to surgical removal of tumours), immature development of organs, loss of hearing and sight are

additional complications (Kazak, 1994; Mulhern, Wasserman, Friedman, and Fairclough, 1989).

Survivors of childhood cancer are at higher risk of developing another cancer later in life. Continued medical follow up for life is generally recommended for all survivors, and fears about recurrence may therefore persist into adulthood (Katz et al., 1990).

Children who survive tumours of the CNS are at increased risk of significant neuro-endocrine and cognitive morbidity as a result of the tumour and the surgical and radiotherapeutic techniques used (Gaze, 1998). Although this damage is incurred at the time of treatment, its effects evolve over time because of the nature of the radiobiological insult, the slow division of nerve cells and the continuous process of the child's education and development (Hoppe-Hirsch, Renier, Lellouch-Tubiana, Sainte-Rose, Pierre-Kahn & Hirsch, 1990).

This study will examine adolescent survivors of CNS tumours located in the posterior fossa, or infratentorial, region of the brain. There is evidence that tumour location is associated with disability. Tumours of the posterior fossa are associated with a relatively lesser incidence and severity of physical and neurological abnormalities than supratentorial tumours (Jannoun & Bloom, 1990). For example, tumours involving the midbrain are associated with long-term effects of obesity and blindness, whilst survivors of cerebral tumours tend to have a greater risk of epilepsy. Psychosocial adjustment problems have been reported as significantly correlated with such disabilities and the associated impairments in functional status (Wallander & Thompson, 1995).

Long-term effects on cognitive and neuro-endocrine functioning may be associated with social adaptation. This will be explored further in the following section.

Psychosocial functioning

The expression “psychological adjustment” is a broad term often used by investigators to describe some form of psychological outcome related to the stress of a life-threatening or chronic illness. The wording of this term can differ slightly across studies, with “psychological” and “psychosocial” used as equivalent to each other, and “adjustment”, “functioning” and “difficulties” also used interchangeably. There are a wide range of symptoms and difficulties falling under the umbrella term of psychological adjustment, including internalising problems such as anxiety, depression and post-traumatic stress (e.g. Kazak, Christakis, Alderfer & Coiro, 1994; Varni, Katz, Colegrove & Dolgin, 1993), externalising problems such as aggression and hyperactivity, and social problems (e.g. Fuemmeler, Elkin & Mullins, 2002). In general, psychological adjustment tends to be operationally defined in accordance with the outcome measure used.

In this chapter, I will use the terms “psychosocial functioning”, or “psychosocial difficulties” unless a study refers to a specific definition of outcome.

“Psychosocial adjustment” reflects social difficulties as well as internalising and externalising symptomatology and therefore more accurately describes the types

of difficulties described in the research than the term “psychological adjustment”.

A large proportion of the chronic illness literature on psychosocial functioning in children encompasses CNS cancer and has many parallels with the childhood cancer literature. The theoretical base for the chronic illness research is relatively comprehensive and provides a helpful framework for understanding research into psychosocial adjustment to childhood cancer. This discussion of psychosocial adjustment will therefore begin with a review of the more general chronic illness literature and the associated theoretical models, followed by a consideration of the cancer literature, which is more specific to the present study.

It should be noted that although internalising and externalising symptomatology of children with chronic conditions has been the subject of many studies, less attention has been paid specifically to the social functioning of these children (La Greca, 1990, 1992; Spirito, DeLawyer & Stark, 1991). Within the broad area of social functioning, social interaction with peers is of particular interest with regards to the child's social development, because such relations provide the opportunity to learn appropriate social rules and social behaviours (Parker & Asher, 1989). While it is acknowledged that this is an important area for investigation (La Greca, 1990; Spirito et al., 1991), on the whole, the study of children's peer relationships has been subsumed within broader studies of social competence (McMaugh & Debus, 1999).

Chronic Illness and psychosocial functioning

Eiser (1990) defines chronic illness as including conditions affecting children for an extended period of time that, though medically manageable, are not curable.

Other authors (e.g. Hobbs & Perrin, 1985) suggest that for a condition to be classified as a chronic illness it must have symptoms or sequelae that exist for a substantial period. Overall there is a lack of agreed terminology, and a wide range of conditions, including cancers of all types, have been included in chronic illness research.

A number of population-based studies report that risk for social adjustment problems and internalising and externalising behavioural problems is about twofold for children who have suffered a chronic illness, as compared with the risk for healthy children (Gortmaker, Perrin, Weitzman, Homer et al., 1993).

These findings are supported by results found in clinical studies (e.g. Kashani, Barbero, Wiley, Morris, and Shepperd, 1988; Thompson, Hodges, & Hamlett, 1990; Timko, Stovel, Moos, & Miller, 1992; Wallander & Varni, 1989).

However, not all studies support these findings, and some found no differences between children with chronic illness and healthy controls (e.g. Harris, Newcomb, & Gewanter, 1991; Nelms, 1989). Possible explanations for differences in findings may be due to methodological variability. Samples tend to be heterogeneous, including children of different ages and with a variety of illnesses. Measures used differ across studies, making comparisons difficult.

Approaches tend to be descriptive rather than being guided by an explicit theoretical framework. This provides a somewhat piecemeal picture of the experiences of children and their families, without a robust theoretical

underpinning to enable an understanding of how the findings may be seen relative to each other (Bradford, 1997).

It seems that while children with chronic illnesses are at increased risk of emotional and behavioural problems than their healthy peers, not all children experience adjustment problems (Bradford, 1990). Varni *et al* (1997) suggest that the variability exhibited in the various empirical findings represent considerable individual differences. An important question is therefore how can we identify those families and children who are likely to experience problems. Models of psychosocial adjustment can be useful in providing a framework for understanding individual differences. Following a review of the research on psychosocial adjustment of childhood cancer survivors, Wallander *et al*'s (1989) stress and coping model will be discussed in the light of research from the chronic illness field.

Psychosocial functioning – a review of the cancer literature

As found in the chronic illness literature, while some studies suggest that survivors of cancer are at increased risk for psychosocial difficulties (Katz *et al.*, 1988; Mulhern *et al.*, 1989), others have found adjustment in line with that of control groups and standardised norms (e.g. Kaplan, Busner, Weinold & Lenon, 1987).

A possible reason for the diversity of research findings is the relatively small samples used, potentially precluding significant findings (Eiser & Havermans, 1994). Study populations are often comprised of children with different types of

cancer, decreasing the extent to which findings can be generalised across cancer groups. In the chronic illness literature, heterogeneous samples are also typical. A justification of this is provided by Pless & Perrin (1985), who comment that children across a range of illnesses face common challenges and propose that the nature of illness is relatively unimportant in predicting adjustment to illness. However, Davis' (1993) review suggests children with disorders impacting on brain dysfunction or disability are at higher risk of psychosocial difficulties than those with other types of chronic illness and merit investigation as a separate group. Despite reports that survivors of CNS cancers are at higher risk of experiencing difficulties, they are often excluded from mixed cancer studies due to "compromised CNS functioning, which may in itself contribute to the course of social development" (Eiser & Havermans, 1994, p66). As such, this is a high-risk group of survivors about whom relatively little information exists on psychosocial adjustment (Fuemmeler et al., 2002; Noll, Bukowski, Rogosch, LeRoy & Kulkarni, 1990).

Additionally, Varni & Katz (1997) note that it is not uncommon for cancer studies to include children recently diagnosed, those on treatment for several years and long-term survivors who are no longer being treated. Methods of assessment vary widely, with some studies using unstructured interviews or projective tests while others utilise standardised measures. Clearly such heterogeneity clouds the findings and may explain to a certain extent the inconsistencies in the research literature.

Methodological criticisms notwithstanding, in a review of the childhood cancer literature, Kazak (1994) asserts; "the data are clear in stating that most childhood

cancer survivors do not have clinically significant psychological difficulties and most function well. However, a troubling subset of survivors do have significant difficulties, which we do not presently understand very well” (p. 179).

The significant difficulties identified by Kazak have been reported as manifesting in a variety of ways including internalising problems, such as anxiety and panic (Kazak et al, 1997); inhibited and withdrawn behaviour, fear of trying new things, low emotional expressiveness (Stehbens, Kisker, & Wilson, 1983); somatic complaints (Mulhern *et al.*, 1989) and post-traumatic stress disorder (PTSD) (Fuemmeler, Mullins & Marx, 2001), externalising problems (Carpentieri, Mulhern, Douglas, Hanna, & Fairclough, 1993) and social problems, including peer relationship difficulties (La Greca, 1990); loss of independence (especially during adolescence); concern about ability to attract the opposite sex; and worries about the future in relation to relationships (Stevens & Dunsmore, 1996).

In her comprehensive review, Eiser (1999) cites research indicating that, relative to the general population, cancer survivors are less likely to marry and have fewer intimate relationships in adulthood (e.g. Lansky, List & Ritter-Sterr, 1986). The reasons for this have not been empirically investigated (Byrne, 1999; Schover, 1999). Concerns about infertility, tumour relapse and a shortened life expectancy, low self-esteem, cognitive disabilities, limited earning ability and compromised physical attractiveness are cited as possible contributory factors.

Similarly, Mackie (2000) writes that childhood acute lymphoblastic leukaemia and Wilms' tumour have long-term effects on adult survivors' ability to function

and cope with interpersonal relationships. Her findings indicated that the survivors functioned less well than the healthy comparison group in love/sex relationships and friendships, as well as in day-to-day coping. In this group, poor coping was associated with lower intellectual abilities.

Varni, Katz, Colegrove and Dolgin (1994) offer a reason for psychosocial difficulties in this population; stating that:

“the chronic strains of childhood cancer, such as treatment-related pain; nausea and vomiting; visible side effects such as hair loss, weight gain or loss, and physical disfigurement; and repeated absences from school and peers, interact to negatively impact social and psychological adjustment”(p.20).

Furthermore, they suggest that long periods of hospitalisation may leave the child feeling different to his or her peers, used to communicating with adults rather than peers and out of touch with the school experience and way of life.

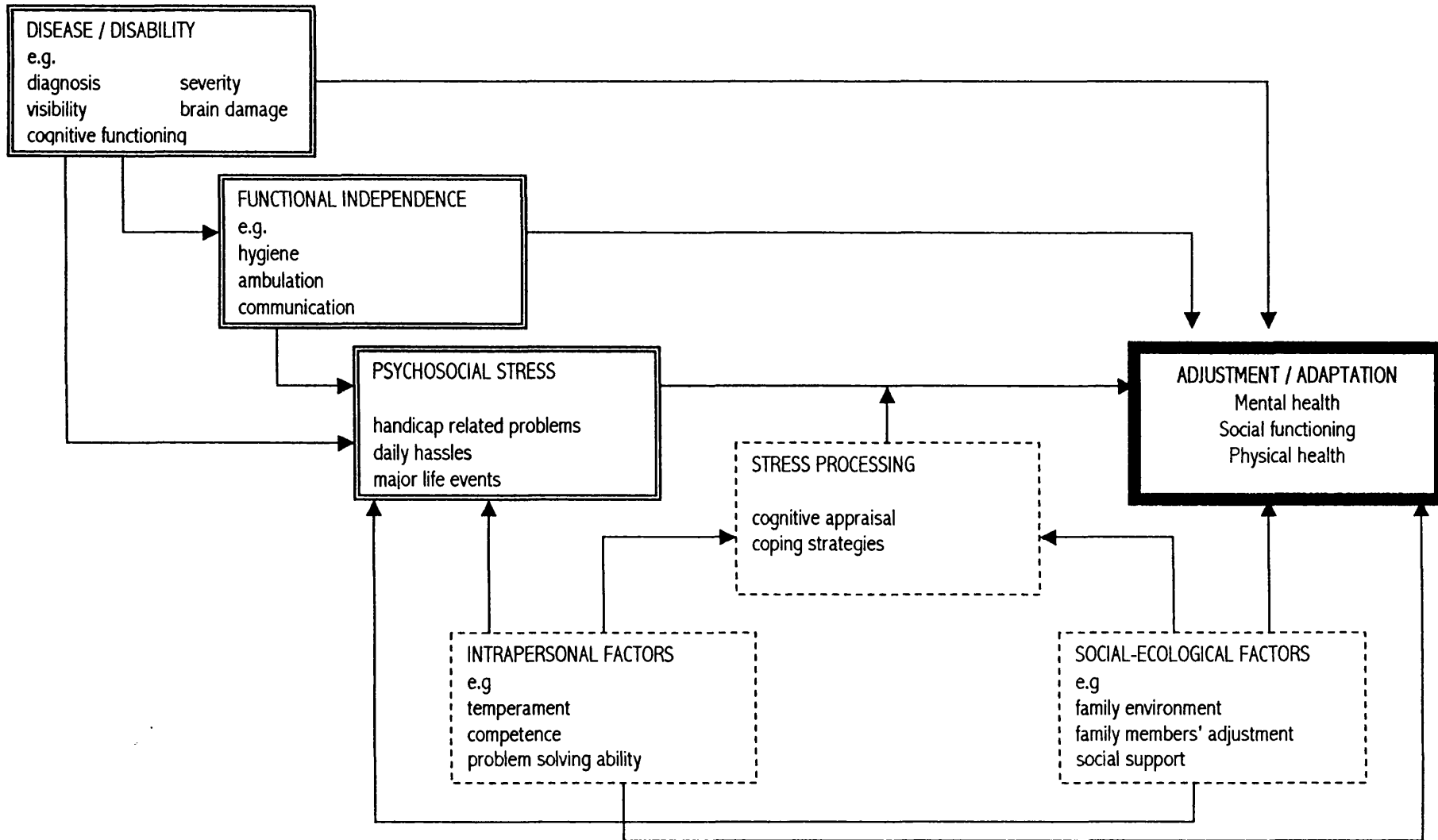
In summary, evidence indicates that childhood survivors of cancer are at increased risk of experiencing psychosocial difficulties both in the short and long term. There is some suggestion that survivors of CNS cancers are more vulnerable to psychosocial difficulties than survivors of other cancer types, and merit investigation as a separate group (Hays et al, 1992). However, there is little understanding of the predictors of outcome for this population, and little explanation for the finding that a large proportion of cancer survivors adjust well to life after treatment. There is some suggestion that individual differences

account for variable outcome. Findings in the cancer literature largely mirror those in chronic illness research. In the absence of a model for understanding the psychosocial outcome in children with CNS cancer, the application of a model developed in the chronic illness field may be relevant to the cancer population. Wallander *et al.*'s stress and coping model, described in more detail below, provides a framework for understanding individual differences in outcome in childhood illness.

A model of psychosocial adjustment

Wallander and colleagues (Wallander, Varni, Babani, Banis & Wilcox, 1988; Wallander, Feldman & Varni, 1989a; Wallander, Varni, Babani, Banis & Wilcox, 1989b, 1989c) attempted to identify the individual differences related to adjustment. A central tenet of their theoretical framework (see Figure 1.1) is that adaptation to illness is affected by the relationship between modifiable 'risk' and 'resistance' factors. Risk factors are identified as including disease and disability variables, the child's level of functional independence and psychosocial stressors. Resistance factors are identified as intrapersonal variables (such as temperament and problem-solving skills), social-ecological factors (family environment, social support) and stress processing abilities (coping strategies and cognitive appraisals). Wallander *et al.* argue that adaptation to illness can be predicted by evaluating these variables and the manner in which they balance each other. Additionally, by identifying and building on resistance factors, clinicians using the model may be able to prevent or reduce adjustment problems. Due to the comprehensive nature of the model, Varni and Wallander's approach has been to progressively test its components. This study will use the model as a guideline for understanding the roles of what Varni and Wallander

Figure 1.1 Wallander & Varni's conceptual model of child adjustment to paediatric chronic illness. Boxes with a double border indicate risk factors, boxes with a dashed border indicate resistance factors. Taken from Wallander & Varni, (1998).



call 'social-ecological' resistance and 'psychosocial' risk factors (Varni & Wallander, 1998).

'Social-ecological' resistance factors in childhood survivors of cancer

Perceived social support appears to be an important resistance factor. It is described by Varni and Katz as "the cognitive appraisal by individuals that they are cared for and valued, that significant others are available to them if needed, and that they are satisfied with their relationships" (Varni & Katz, 1997; p269). Varni, Katz, Colegrove and Dolgin (1993) found perceived social support from classmates to be the most significant predictor of depressive symptoms, trait anxiety and general self esteem in childhood survivors of cancer. They suggest that it is not the presence of a social network per se that is protective, but the perception of this network that influences its protective function. Appraisals of friendship as satisfactory therefore appear to be an important factor in psychosocial adjustment of childhood survivors of cancer. Children's expectations of their friendships may be an important part of their appraisals of friendships as satisfactory, and will be discussed in more detail later.

Varni and his colleagues used the idea of perceived social support in the development of social skills training as an intervention with survivors of cancer. They cite Cohen, Sherwood and Clark (1986), who found that higher levels of social skills predicted the levels of perceived social support and friendship formation in undergraduate college students. By using this finding as a rationale for teaching social skills to childhood cancer survivors, Varni et al presumed that undergraduate students are a comparable group to cancer survivors, which may be a questionable assumption.

Varni et al's (1993) social skills training involves "teaching the child a set of social skills that are particularly relevant to cancer and its treatment", such as methods for dealing with bullying and questions about the cancer (Varni, Katz, Colegrove, & Dolgin, 1993, p. 753). The authors reported higher perceived classmate and teacher support and an improvement on one of four scales of social competence at a 9-month follow up in comparison to pre-treatment levels for newly diagnosed children with cancer. The authors advise that the findings should be viewed as heuristic, given that a sample size needed to avoid Type II error was not achieved.

Varni et al's (1993) study is typical of others investigating social adjustment in children with chronic illness in that it uses a general measure of functioning to assess social competence (Thompson and Gustafson, 1995). In their study, Varni et al use the Child Behaviour Checklist [CBCL] (Achenbach & Edelbrock, 1984), which contains a small subscale of items pertaining to social competence. McMaugh and Debus (1999) point out that the CBCL may not adequately conceptualise or represent social adjustment due to the small subscale of items and the focus on social activities rather than competence. This emphasis on social activities may be inappropriate for use with children who have disabilities. Items include activities that are affected by illness characteristics rather than social competence (for example, school attendance and participation in physical activities). Furthermore, it is important to bear in mind that the aim of the skills training was to equip children with skills necessary for dealing with questions and teasing on their return to school after treatment, and may not be necessary or relevant to the peer relationships of long term survivors.

The study does not consider the role of 'pro-social' skills (such as being able to initiate conversations with others, or being caring and thoughtful towards others) in the formation and maintenance of friendship and the role this may play in perceived social support. This is an important omission in light of findings identifying that successful peer interactions tend to be characterised by pro-social, cooperative behaviours (McMaugh, 2001). More information is needed on the nature and likely role of social skills in children who survive cancer.

Varni and Katz's (1997) definition of perceived social support also encompasses satisfaction with peer relationships. This is a factor that is not explored further in their research and that implies appraisals of friendships may be important.

La Gaipa and Wood (1981) suggest that the effects of social support in mediating the influence of stress depend on the reciprocity of a relationship, and that for individuals lacking the social skills necessary to maintain reciprocal relationships, this support may not be available. Olson, Boyle, Evans and Zug (1993) found that although cancer survivors did not report deficits in social skills, teachers and parents rated them as having poorer social competence than healthy peers. Noll, Bukowski, Rogosch, LeRoy *et al.* (1990) reported that teacher ratings of childhood survivors of cancer revealed them to be less sociable and more withdrawn and isolated than their healthy peers. There is some evidence that children who are not integrated into their peer group are more likely to have difficulties in social relationships by misinterpreting social cues and having negatively biased perceptions of the outcome of a social event than

their popular counterparts (Crick and Dodge, 1994). It is difficult to determine whether being socially isolated leads to social skill deficits or vice versa.

Spirito, Starck, Cobiella, Drigan *et al* (1990) found no deficits in social skills in children successfully treated for cancer. However, their conclusions were drawn using non-standardised measures of social skills based on teacher assessment of classroom sociability. Furthermore, children included in this study were aged between 5 and 12 years, representing a younger sample than the other studies and making comparisons of findings difficult.

To summarise, friendships that are appraised as supportive and satisfactory are considered to be a resistance factor in the psychosocial adjustment of children with chronic illness and it is likely that this conclusion can be extended to cancer survivors. Children who are less socially competent than their peers may find it more difficult to access and make use of this social support, and may have negatively biased perceptions of social relationships. There is some evidence that survivors of cancer have lower levels of social competence, or at least are perceived as being more isolated by teachers and parents. The social skills literature is limited as it focuses on the ability of children to cope with negative social interactions rather than on pro-social skills. This is an important omission given that successful peer interactions tend to be characterised by pro-social, cooperative behaviours (McMaugh, 2001). There is a lack of research looking at whether differences in pro-social skills exist in children who have survived cancer compared to healthy peers. Levels of social skills and appraisals of potentially supportive relationships, i.e. friendships, are areas that warrant further research.

Psychosocial risk factors in childhood survivors of cancer

Poor peer relationships are conceptualised as a potential risk factor in the framework of Wallander *et al*'s (1989) model. Varni *et al* (1993) suggest that cancer survivors are at risk of 'social vulnerability', whereupon they are likely to be exposed to name-calling, intrusive questions and teasing as a result of their illness. McMaugh and Debus (1999) in their study of peer relationships in children with chronic illness, report, "teasing, harassment and questions are almost a routine feature of growing up with a disability" (p15). It is arguable that for long-term survivors of cancer, teasing and bullying could be categorised as psychosocial stressors within the tenets of Wallander *et al*'s model.

Sharp and Thompson (1992) found school avoidance, sleep disturbance, somatic complaints, and impaired concentration in (healthy) children who are bullied. Long-term problems that can arise from exposure to bullying include: low self esteem, depressive disorders and difficulties in establishing and maintaining relationships with the opposite sex (Olweus, 1997).

Arguably, 'social vulnerability' to bullying and teasing is related to healthy peers' perceptions of children with cancer. There is some evidence to suggest that if peers are knowledgeable and informed about the disease, they seem to be more likely to accept and interact with children with cancer (Treiber, Schramm & Mabe, 1986). An understanding of peer perception of children with cancer may provide clues to the nature of the social environment of cancer survivors.

Peer perception of children with cancer

Relative to a comparison group of non-chronically ill children, Vannatta *et al* (1998) found that children who had been diagnosed with brain tumours received fewer friendship nominations from classmates and were described by peer, teacher, and self-report as more socially isolated. Although they were no longer undergoing treatment, peers perceived brain tumour survivors as being sick, more fatigued, and often absent from school.

Noll *et al* (1991) found that although children with cancer had a social reputation for being significantly more socially isolated, no differences were found for their popularity, number of mutual friends, loneliness, or self-worth. A follow up study two years later (Noll *et al* 1993) indicated that adolescents with cancer continued to have a social reputation for being more socially isolated, but no significant differences were identified on multiple measures of social acceptance or their self-reported feelings.

It is plausible that a child who feels isolated at school and does not enjoy attending may prefer to avoid school and this may cause further difficulties in reintegrating at a later point. Children with newly diagnosed cancer who do not feel accepted by their peers are more likely to be at greater risk for long-term social difficulties than those who integrate well into school (Varni *et al.*, 1994; Ladd, 1990).

La Gaipa (1982) comments that peers interacting with disabled adolescents may lack the social skills to cope with demands placed on them in these interactions. They may make attempts to avoid issues that are of concern to the disabled

adolescent and in doing so may communicate to that individual that his or her thoughts and feelings are unimportant. This may be true of adolescent survivors of cancer if their peers feel unsure about how to approach the topic of illness and its meaning. La Gaipa writes that one way to handle the tension of such interactions is to rely on superficial conversation that does not threaten to involve personal and possibly aversive topics. An effect of this is that it is more difficult for the relationship to become intimate and meaningful.

The impact of physical appearance on peer relationships

Children with chronic illnesses who experience changes in appearance as a result of disease or treatment are at greater risk for peer relationship problems (Spirito *et al.*, 1991; Varni *et al.*, 1997) and “must be prepared to handle teasing, questions, and comments from peers, in addition to allaying their own concerns about feeling different and unattractive” (LaGreca, 1990; p287). Ross (1984) underlines this with her finding that children with leukaemia rated the teasing at school as a result of treatment-related changes in appearance as being more stressful than physical pain from treatment itself.

If, as suggested by Varni *et al* (1993), perceived social support is associated with good outcome, and we hypothesise that physical appearance is associated with perceptions of social support, it is plausible that children who perceive themselves to have altered appearance as a result of their illness may also feel less socially supported and consequently have greater difficulties psychosocially. In this sense, cognitive appraisals of physical appearance may mediate perceptions of social support. A second possible explanation is that children lack the necessary social competence to cope with social stressors related to their

illness, such as teasing about appearance (Katz & Varni, 1993) and as a consequence are socially isolated.

Physical attractiveness in western society has been shown to impact on interpersonal interactions and perceptions about an individual's ability and has been found across all age ranges (Jones & Adams, 1982). Studies involving healthy participants have demonstrated the impact of appearance on relationships. Lerner *et al.* (1991) reported a statistically significant relationship between adolescents' perceived physical appearance and negative peer relations as assessed by a measure completed by subjects' classmates. This effect was found even in a preschool group.

Additionally, subjective perceptions of one's own appearance is important, with a poor body image being associated with self-rankings of academic and social impairment, low self-esteem, and symptoms of depression (Noles, Cash, & Winstead, 1985; Silberstein, Striegel-Moore, Timko, & Rodin, 1988).

Results from a study of 21 cancer survivors ages 11-21 conducted by Pendley, Dahlquist, and Dreyer (1997) demonstrated the impact of physical appearance on psychosocial functioning in children with cancer. The findings showed that the more the subject perceived that his or her appearance was negatively affected by cancer, the worse he or she tended to rate social adjustment, which included feelings of loneliness and social anxiety.

A study by Varni, Katz, Colegrove, and Dolgin (1995) of 30 children aged 8-13 with varying types of cancer showed that a more positive perception of one's

physical appearance was significantly correlated with fewer depressive symptoms, less social anxiety, and a higher self-esteem as well as being correlated with perceived classmate social support.

The majority of research into the effects of physical appearance has focused on children with newly diagnosed cancer, due to the extreme physical effects of treatment at this early stage. However, long-term survivors of cancer may experience lasting effects of treatment on their appearance. In some children, irradiation results in hormonal imbalances, which result in weight gain or delayed or reduced bone growth so that children are of a shorter stature than their peers (Gaze, 1998). Hair which grows after treatment may be of a different quality and texture to hair pre-treatment, and scars resulting from excision of brain tumours are not uncommon sequelae, meaning that long term survivors may also be vulnerable to perceptions of unattractiveness and the associated social difficulties, particularly during adolescence (Kellerman & Katz, 1977).

Research into the impact of beliefs about changes in physical appearance due to illness represents a partial investigation into the role of cognitive appraisals of illness factors. Beliefs about other illness factors, such as interference of the illness with activity, or the impact of illness on peer rejection, may be of interest (Eiser, 1995). Subjective appraisals of the impact of illness may be an important factor in understanding disease characteristics and psychosocial adjustment.

Previous studies have relied on objective measurements of severity or functional dependence rather than on subjective beliefs about illness characteristics.

Perrin, Stein & Drotar (1991) recommend the use of subjective measures and an increased emphasis on appraisals of the impact of illness in order to achieve a

more valid picture of the relationship between illness characteristics and adjustment. It is feasible that a subjective appraisal of the impact of illness as severe is related to self-reports of poorer psychosocial adjustment (Wallander & Thompson, 1995).

Neuropsychological Effects of cancer and their impact on peer relationships

The neuropsychology literature covering this population investigates the nature of cognitive deficits following treatment of cancer. Irradiation in particular has been shown to have detrimental effects on cognitive functioning, with some studies describing drops in Full Scale IQ scores of up to 20 points on the WAIS-R (Mulhern, 1994). Age at diagnosis and intensity of treatment are correlated with cognitive deficits post treatment, with children treated at under 6 years of age being at greater risk for neuropsychological sequelae (Chapman, Waber, Bernstein, Pomeroy, LaVally, Sallan & Tarbell, 1995). There is some evidence that intellectual deterioration in survivors of posterior fossa tumours is progressive (Hoppe-Hirsch *et al*, 1990). In particular, cumulative deficits in non-verbal skills and information processing have been documented (Anderson, Godber, Smibert, Weiskop & Ekert, 2000). Evidence is equivocal regarding the extent to which the tumour itself has effects on cognitive function. Some studies report findings indicating that radiotherapy is the main risk factor, and that children treated with irradiation for non-CNS cancers have the same risk of brain injury as those treated for CNS malignancies (Chapman *et al*. 1995). Others argue that children with brain tumours have a higher probability of learning difficulties than children with other types of cancer over and above treatment effects (Ellenberg, McComb, Siegel & Stowe, 1987).

Anderson, Smibert, Ekert & Godber, (1994) suggest that the occurrence of null results in studies of intellectual deficits in the CNS cancer population may be due to the relatively mild nature of intellectual deficits. In their study, Anderson et al (1994) found that mean intelligence quotients for the cancer survivor group, although lower than that of the control group, were within the average range.

To summarise, there is evidence that cranial irradiation and tumour location, are related to cognitive deficits in survivors of childhood cancers. Equivocal results may reflect the relatively mild neurological impairments these children have. The impact of cognitive deficits on schooling and specifically, on peer relationships is of interest for the purpose of this study.

Neurological deficits may have a direct impact on a child's ability to interpret social cues and learn social rules (Nassau & Drotar, 1997), resulting in lower social competency in children surviving brain tumours. There may also be an indirect impact of cognitive deficits on psychosocial adjustment. An individual's awareness of academic difficulties arising as a consequence of illness and treatment may impact on peer relationships by affecting self-esteem. Repeated absences from school and difficulties in learning and memory can result in the child being continually behind his or her peers academically, leading to feelings of inadequacy and despair, particularly if he or she is aware of being more able prior to illness (Cairns, Klopovich, Hearne & Lansky, 1982). In a study involving children surviving a range of cancers, Varni *et al.* (1997) report that subjective perceptions of academic competence predict general self-esteem and are interrelated with the effects of perceived physical appearance on self-esteem.

The authors do not comment directly on the likely effects on survivors of brain tumours, for whom deficits in academic competence are more common than in other cancers.

Educational Implications and the impact on psychosocial functioning

Adjustment issues in school can be the result of direct effects of the illness or its treatment, or a function of indirect consequences of the illness such as fatigue, absenteeism, or distress (Thompson & Gustafson, 1996).

Katz et al. (1992) posit that the child who is not able to maintain as normal a social life and school attendance as possible is, in effect, being denied an opportunity to interact with others in “age-appropriate goal-oriented behaviour” (p69). They postulate that such disruption of normal activities may lead to feelings of hopelessness and despair, which in turn interfere with the child’s ability to cope with the demands of the illness and treatment.

Children may not return to school as early as is possible due to a number of possible factors (Katz et al, 1992). If a child has concerns about his or her appearance, he or she may not feel confident in returning to school. Teachers and school staff may be uninformed about the management of cancer and may be hesitant about accepting the child back into the classroom (Katz et al., 1990). Absences due to ongoing medical appointments may be an additional burden to the teacher. In addition, parents may be unsure about when their child is able to return to school and feel anxious about the demands that attending lessons will have on their child. Katz et al. (1990) warn that some children may use illness as an opportunity to avoid situations that they did not enjoy prior to illness.

Kazak et al. (1994) report that 25% of their sample of long-term cancer survivors received special school services related to learning problems. The need for the availability of special education for this population becomes clear when one considers that almost 30% of adult cancer survivors report having academic difficulties (Lansky, List, & Ritter-Sterr, 1986).

Contributing to the learning problems which many students with cancer face is the high rate of absenteeism that may result from hospitalisations, treatments, and treatment side effects (Deasy-Spinetta, 1981; Mulhern et al., 1989).

Psychosocial functioning - a summary of the evidence

Research findings across all areas of adjustment for childhood survivors of cancer appear to concur that the majority of children function well after treatment and do not have significant difficulties. As highlighted by La Greca (1990), it is more remarkable that so many children are positively adjusted than that some are not. A sub-group of children do however have significant difficulties, which include cognitive deficits, emotional and behavioural problems, and social difficulties.

Models of adjustment such as that of Wallander et al (1989) are useful in understanding individual differences in outcome. Perceptions of social support and physical appearance are two factors that have been identified as relating to psychosocial adjustment in the chronic illness and cancer literature.

Effects of childhood cancer on siblings

Murray (1998) suggests that siblings are particularly vulnerable to adjustment difficulties (depression, anger, anxiety, feelings of guilt and social isolation), and they experience similar stress to the ill child. He identifies siblings as the most emotionally neglected and unhappy of all family members during serious childhood illnesses. There is a growing awareness that the psychosocial needs of siblings of children with cancer are less adequately met than those of other family members. Evidence indicates that they can be 'overshadowed' by the sibling with cancer in terms of parental attention, and in addition, are subject to the stressors associated with dealing with the cancer experience for themselves (Walker, 1988). The idea of parental attention being an important factor is compatible with Taylor, Fuggle and Charman's (2001) finding that better sibling adjustment was associated with higher maternal awareness of their attitudes and perceptions.

Siblings have been identified as having adjustment problems including emotional and behavioural difficulties, and being socially isolated (Carpenter and Sahler, 1991). Interestingly, Glaser *et al* (1997) in their study of survivors of CNS cancers, found that although siblings had few reported school difficulties, they were perceived as reluctant to express concern for others. The authors hypothesise that this could arise as a reaction against not having needs met whilst the sibling with cancer was the focus for overwhelming concern from family and friends.

However, it is clear that not all siblings perceive the cancer experience negatively, with the literature suggesting a range of positive responses to illness

in a sibling. Murray (1998) described increased empathy for others, personal growth and the desire to help others as possible consequences of the healthy sibling's experience. Ferrari (1984, 1987) reported that siblings of children with diabetes and developmental disorders were more emotionally and socially mature than a control group.

There are salient difficulties in comparison of the findings owing to variations in design, heterogeneity of the groups of siblings, diversity in sample size, and differences in conceptualisations of adjustment and coping. The lack of longitudinal studies, the precarious definitions and confounding of coping and adaptation, and the marginal role of siblings' coping efforts have been identified as the most striking deficiencies in current research (Houtzager & Grootenhuis, 1999).

Siblings share the same family environment and consequently can be thought of as having similar opportunities and advantages. As a result, siblings are a popular comparison group in studies of adjustment to chronic illness (e.g. Lansky et al., 1986; Hays et al, 1992). However, Eiser (1989) suggests that, because of the complexity of sibling relationships, they may not be a suitable comparison group. There are both advantages and disadvantages of including a sibling comparison group in research assessing the impact of cancer. Regardless of these methodological ambiguities, they are a vulnerable group and of interest in their own right.

Theories of social functioning and friendship

Theories of social functioning and relationships with friends in healthy children and adolescents can be useful in identifying and understanding the impact of cancer on psychosocial functioning. Firstly, I will outline developmental tasks faced by young people and discuss how these are related to social functioning, and how the experience of cancer may impact upon them. It is important to think about friendship in a developmental context as there is evidence that social relationships change during childhood and adolescence. Many studies of social functioning do not consider developmental issues and include young people who may be at developmentally diverse levels, meaning that findings may be difficult to interpret (McMaugh, 2001). Secondly, I will describe theories of friendship and explore how these may inform thinking about the impact of cancer on survivors' relationships and social functioning.

Social functioning and developmental tasks in childhood and adolescence

The nature and structure of friendships vary for individuals depending on the developmental tasks the individual faces (Bigelow and La Gaipa, 1975; Dickens and Perlman, 1981). Erikson (1964) postulated that the central task of adolescence is to resolve the crisis of 'identity vs. diffusion'. He thought that following the development of identity it is possible to share oneself with another in the formation of intimate relationships, including, but not limited to, sexual relationships. Before the formation of identity, however, an individual is not able to share and commit a self, which is not fully differentiated, and not fully understood. Other theorists disagree, arguing that it is through the development of intimate relationships that an individual forms a sense of self-identity

(Sullivan, 1953; cited in Slee, 1996). Sullivan thought that the experience of intimacy and acceptance with a close, same-sex 'chum' during preadolescence provided a 'consensual validation' critical for individuals' developing a sense of personal worth. There are a number of aspects of the friendship process that can contribute to an individual's sense of self-esteem, including the recognition that one's friend knows, accepts and likes your 'real self'; perceives the world the same way you do (Duck, 1973); and supports your view of yourself (Bailey, Finney and Helm, 1975). These theories posit that all children, whether healthy or ill, face the task of identity development through social interaction during childhood and adolescence.

Katz *et al* (1990) argue that a diagnosis of cancer interferes with developmental tasks in adolescence such as the attainment of a positive self-concept and body image, autonomy and future orientation. Illness potentially creates obstacles to the achievement of these tasks by altering a child's interaction with his or her environment as well as acting directly on physical health. Fielding (1985) highlights that children with chronic illnesses are confronted with 'illness tasks', which include dealing with symptoms such as pain, fatigue, nausea and changes in appearance. These may prevent activities which the individual could carry out when well, such as school and play, which have implications for the achievement of adolescent tasks such as the development of identity and group belonging (Fielding, 1985).

Assessment and treatment have further demands, as they may be frightening, invasive and disruptive to a normal routine. Both symptoms and interventions may increase the child's dependency on parents at a time when normally a child

may be gaining independence and confidence in self-efficacy. On the other hand, being faced with issues such as mortality and suffering may pose challenges to the ill child, which the healthy child need not consider until adulthood. Fielding (1985) suggests that independence may be more of a struggle for children with chronic illness, reminding us that these children need to achieve independence from health care staff as well as parents in the transition to adolescence and adulthood.

Adolescence may be an important time for the 'developmental tasks' of identity formation, group belongingness and the growth of independence (Erikson, 1964; Fielding, 1985; Sullivan, 1953). Theories of social-cognitive development emphasise the importance of intimacy and loyalty in adolescent friendships, and note an increase in peer pressure to conform with group norms in adolescence (Berk, 1994). It appears that intimacy, loyalty and conformity are characteristic of the close relationships in which the development of self-identity and 'belongingness' can occur. Conceivably, a child who does not have intimate and loyal friendships, and does not or is not seen to conform to peer norms, may have difficulties in tackling the 'tasks' of adolescence. Children with cancer who are at risk of social isolation (Vannatta et al., 1998) and have been identified as having social skills difficulties (Noll, Bukowski, Rogosch, LeRoy *et al.*, 1990; Olson, Boyle, Evans and Zug, 1993) may have difficulties in achieving central adolescent tasks.

Developmental theories of social functioning would indicate that the participants in the present study are all at a similar developmental stage in the establishment of friendships. In line with the theories, we would expect young people over 11

years of age to be developing a sense of self-identity and becoming involved in increasingly intimate relationships, with an increasing emphasis on expectations of self disclosure and empathy rather than the mutual activities which are thought to characterise earlier and more casual friendships. Relatively few changes are hypothesised to occur in expectations of friendship over the course of adolescence (La Gaipa & Wood, 1985), which means that we would not expect differences in expectations of friendship to be related to age within the study sample.

Theories of Friendship and Social development

The term 'friendship' connotes a wide variety of human relationships, of varied duration, intensity and closeness. In Western society, friendship has been identified as the least formal of all relationships (Suttles, 1970), with no explicit rules about the nature of interactions and roles in friendship. Unlike marriage, in friendship there is no declaration of commitment to the relationship and no associated legal bonds or rights. Individuals tend to negotiate the nature and structure of friendships implicitly and informally. Voluntary interdependence is a characteristic of friendship noted in almost all theoretical accounts (Reisman & Shorr, 1979). Hays (1988) postulates that the main goal of interdependence in friendship is social-emotional, whereupon friends obtain pleasure from the interaction itself, rather than engaging in friendship in order to fulfil material or functional needs. A second important characteristic appearing consistently throughout the friendship literature is that forming a foundation for friendship interactions is some degree of a positive affective bond (Davis and Todd, 1982; Kurth, 1970; LaGaipa, 1977; Reisman, 1981).

A number of factors contribute to the development and maintenance of friendships. Environmental factors create the opportunity for friends to spend time together. Physical proximity has repeatedly been shown to contribute to friendship formation (Berscheid & Walster, 1978; Nahemov & Walster, 1975) as it increases the likelihood two individuals will meet as well as the frequency with which they interact. Children being treated for cancer may be absent from school for long periods of time and, depending on the hospital environment, may not interact with peers of a similar age while they are hospitalised.

Friends tend to be more similar to one another than non friends in a number of dimensions, including age, sex, marital status, race, religion, attitudes, interests, personality traits, and intelligence (Verbrugge, 1983; Huston and Levinger, 1978). Similarity in behavioural preferences is also highly predictive of friendship. A perception of self as 'different' may be associated with difficulties in forming friendships. McMaugh (2001) suggests that while we know relatively little about social comparison processes of children with disabilities, we should assume that these children engage in social comparison in a similar way to healthy children. It is arguable that given the visible physical differences, disabilities and deficits in educational functioning that are not uncommon in this group, an appraisal of self as "different" from others may be a factor in psychosocial functioning for cancer survivors. The evidence to date implies that healthy peers see cancer survivors as different from themselves, particularly in perceptions of social isolation (Vannatta et al, 1998).

Social comparison is thought to be central to the task of identity formation.

Friends can be 'sounding boards', providing feedback and support when an individual is trying out new roles and developing a sense of him or herself (Hess, 1972; Weiss & Lowenthal, 1975). This is particularly important during periods of role transition such as adolescence, young adulthood, retirement (Dickens and Perlman, 1981), and arguably, recovery from cancer. If an individual feels sufficiently different to his or her peers that he or she feels unable to use them as a point of comparison, this aspect of friendship may be less fulfilled. This may be relevant to adolescent survivors of cancer if they perceive themselves to be unlike their peer group.

The experience of being similar to one's peers and having shared adolescent experiences may be connected to a sense of perceived social support. Kon and Losenkov (1978) found that adolescents regarded their best friends as individuals who they confided in and by whom they felt most understood. However, for advice on complicated life situations, both boys and girls reported they would turn to their parents first. It may be that individuals talk to their friends about situations in which shared experiences and perceptions are important, but for problems, which may be outside the realm of shared adolescent experience, parents are a more important source of support. The implications of this for adolescents who have survived cancer is that they may be more likely to talk to their parents or to people who have an understanding of the cancer experience than to their peers with regards to their illness.

In addition, if these young people perceive themselves to be different to their peers as a result of their illness, it is possible that they will not feel they have

shared experiences, which their peers may understand and accept. McMaugh & Debus (1999) write that children with chronic illness may choose to conceal aspects of their illness or disability in order to protect themselves from teasing or because they do not want to be seen as “different”. Conversely, they also found that some children with chronic illness chose to disclose, seeing self-disclosure as a means of self-representation and an indication of their openness to others (Derlega and Chaikin, 1979). Children who did not self disclose were more likely to feel rejected by peers, a finding consistent with theories of friendship, which hold that self-disclosure is an important part of friendship development.

McMaugh and Debus (1999) suggest that for children with chronic illness, self-disclosure is not always voluntary and may occur in the context of intrusive and rude questions from peers. In such cases, self-disclosure loses its potential to act as a meaningful form of self-expression or self-representation and therefore does not fulfil the function of increasing intimacy, as is described in theories of friendship. Rather, the authors argue that disclosure acts as a self-protective mechanism, with the greatest motivating factor in deciding to disclose appearing to be the possibility that peers may get the 'wrong' impression. They conclude “for *some* students, school is a difficult place to disclose illness and as such may also be a difficult place to develop a sense of self that incorporates this aspect of identity”(italics in original, McMaugh & Debus, 1999, p16).

Both Argyle and Henderson (1984) and Davis and Todd (1982) have found that an expectation of intimacy underlies the friendship bond. Miell and Duck (1986) found that self-disclosure is often offered and elicited as a means of gathering information about a potential friend or strategically channelling the flow of communication to intensify or restrict the growth of a friendship. Reciprocal

disclosure of private thoughts and feelings is thought to be a primary characteristic of close friendships, and leads to friends knowing each other's "real selves". As a result, a friend's positive regard conveys a sense of acceptance (LaGaipa, 1977; Rose, 1985) that contributes to feelings of trust within the friendship. If, as the literature suggests, self-disclosure is an important part of growing friendships, reluctance to talk about illness may contribute to a general reticence in sharing intimate information for individuals who have survived cancer, and subsequently, a perceived sense of not being accepted.

Personal characteristics such as social skills (Cook, 1977) and friendship schemas (Young, 1986) have an impact on an individual's ability to successfully make friends. As we have already seen, there is some suggestion that children who have survived cancer are perceived as having deficits in the social skills needed to maintain friendships (e.g. Olson, Boyle, Evans and Zug, 1993; Noll, Bukowski, Rogosch, LeRoy *et al.*, 1990). Friendship schemas, or the beliefs that individuals have about friendships, have not been investigated in the chronic illness or cancer literature, hence it is not known whether beliefs about friendships are different for survivors of cancer compared to healthy peers. An aim of this study is to look at a facet of beliefs about friendships, namely, expectations of friendship, and whether these differ for survivors of posterior fossa tumours, their siblings and healthy peers. An understanding of differences in expectations of friendships may therefore be useful in thinking about the development and maintenance of these children's friendships.

Expectations of friendship

The expectations individuals have of a friendship are crucial determinants of attraction and success for any friendship. Expectations tend to be different for close and casual friends. For example, casual friendships are more likely to be characterised by mutual activities rather than empathy and understanding, whilst the opposite will be true for close friendships. Likewise, expectations of a friendship will vary with the developmental stage of the friend relationship. LaGaipa (1977) reported that authenticity (openness and honesty; 'genuine-ness' and spontaneity) was perceived to be important at all levels of friendship, whereas helping and self-disclosure were considered less important until the development of close friendship.

An individual's expectations and needs from a friendship are thought to fluctuate according to developmental tasks and the demands of life changes (Bigelow and LaGaipa, 1975; Dickens and Perlman, 1981). Friendships which once were satisfactory in terms of an individual's needs and expectations may become obsolete as an individual becomes older and if he or she experiences life changes which are different to that of his or her peers. It is plausible that young people who have experienced the diagnosis, treatment and survival of cancer return to friendships with altered expectations and needs. If this were the case, the friendship literature would predict that previous friendships would no longer fulfil an individual's needs and therefore may dissolve. La Gaipa and Wood (1981), in a discussion of disturbed adolescents' friendships, posits that the 'normal' child focuses on the abilities and competencies of the disturbed adolescent, while the 'disturbed' child is focusing on the authenticity of the other. Asymmetric expectations in a friendship may create tension and conflict,

and resolution of these difficulties is likely to be difficult if the individuals involved have different needs and priorities within the relationship.

An underlying assumption of La Gaipa's Children's Friendship Inventory (CFI) is that individuals with interpersonal problems have atypical views of friendship, and that friendship expectations could be used to classify children in terms of their ability to form friendships. "Withdrawn" girls were found to place less importance on empathy and more on loyalty than "popular girls" in a study using the CFI by La Gaipa and Wood (1985). The authors suggested that children who place a low value on empathy in a friendship tend to be more isolated, a finding in agreement with social skills work, which suggests that popularity is related to skills in interpersonal understanding and empathy (Adams, 1983). La Gaipa and Wood's findings should be taken heuristically, however, given the methodological limitations of the study. The sample consisted of 90 middle-class schoolgirls and as such may not be representative of children in the wider population. Furthermore, children were assessed as "withdrawn" or "popular" by their teachers and within the context of the classroom. The classroom context may not be representative of wider social behaviour and may not provide an adequate sampling of peer behaviour.

In summary, little is known about the expectations of friendship in children with chronic illness or cancer. There is some suggestion that expectations of friendship may be different for children who have experienced life changes that are not common with their peers, as is the case for survivors of cancer in a mainstream school environment. Additionally, an implication of La Gaipa and Wood's (1985) work is that friendship expectations are different for children

who have interpersonal difficulties, although whether expectations influence peer interactions or vice versa is unclear.

Theories of social development and peer relationships are useful in illuminating the possible impact of cancer on friendships and social functioning. Adolescence is an important time for the development of identity and group belonging, both of which are thought to be sculpted within the context of peer relationships.

Children who have difficulties in peer relationships may therefore have difficulties in the development of self-identity and 'belongingness'. The experience of illness is thought to impede the attainment of developmental tasks by interfering with peer activities and the development of peer relationships.

Interpersonal and intrapersonal factors such as proximity and similarity to others, social skills and friendship schemas are thought to be important in the continued growth of friendships. The cancer experience can impact on all these factors and may therefore interfere with the development and maintenance of friendships.

One aspect of peer relationships, which has received little attention in the literature, is that of friendship expectations. There is some indication that children who have interpersonal difficulties and those who have experienced life events different to those of their peers may have different expectations of friendship. It is plausible that children who have survived cancer have different expectations of friendship than their peers, and this may affect the extent to which they invest in peer relationships. Given the likelihood that friendship plays a part in social 'resistance' factors as outlined by Wallander and Varni (1998), building an understanding about children's expectations of friendship may add to existing knowledge about individual differences in outcome for children surviving cancer.

Study Aims

This study aims to take a closer look at the psychosocial adjustment of survivors of childhood CNS cancer, and in particular at peer relationships, or friendships, of these young people.

To date, CNS cancers have attracted more research on neurological and educational outcome than on psychosocial functioning (e.g. Jannoun & Bloom, 1990; Moore, Ater & Copeland, 1992). There is very little information about social skills and peer relationships in this group.

Of the studies investigating psychosocial functioning in children surviving cancer, several areas of interest have been highlighted but are as yet not well understood. Methodological factors are implicated in the lack of clarity of research findings. Previous studies have included heterogeneous samples and have not attempted to control for the effects of illness and treatment variables such as cancer type, treatment modality, age at treatment and time since treatment. In their review of research into psychosocial difficulties following treatment for brain tumours, Fuemmeler et al (2002) report that relatively few studies employ comparison groups. Another major limitation noted by these authors is the lack of conceptually driven basis for analysis, without attention to heuristic models that could guide research into adjustment problems in children surviving brain tumours.

In the study of social competence in chronic illness and cancer, multi-scale diagnostic tools such as the CBCL, rather than specific measures of social functioning, dominate the method of assessment (Thompson and Gustafson,

1996). Few studies have used multiple informants or multiple methods and the minority utilise child or peer reports. The main method of assessment has relied upon parental ratings, usually from mothers, and sometimes teacher ratings (McMaugh, 2001), hence little is understood about the child's perspective of his or her functioning. In studies of social competence, the emphasis has been on behavioural functioning and on social skills needed for dealing with negative social interactions such as teasing, while general skills in these children are under-investigated. Children's social cognitions have been relatively neglected in both the cancer and chronic illness research.

Eiser (1994) highlights the lack of projective and qualitative techniques used in research in this field. The Thematic Apperception Test (TAT) is a projective test used both clinically and in research fields. La Gaipa & Wood (1985) used it to look at psychosocial aspects of peer relationships including group identity and isolation. The authors commented that the fantasy productions evoked by the TAT test were useful in supplementing standardised measures and tapped into feelings and cognitions about peer relationships.

Methodologically, the present study builds on recommendations from existing work. The study includes children who are long-term survivors of CNS cancers in the posterior fossa region of the brain, and in these respects can be thought of as a relatively homogeneous group. As treatment-related deficits in learning may not be immediately apparent, rather tending to peak and level out after a period of two or more years (Copeland, Fletcher, Pfefferbaum-Levine, Jaffe, Reid & Maor, 1985), the sample in this study consists of children who are at least three

years post treatment and are therefore thought to be relatively stable in terms of cognitive function.

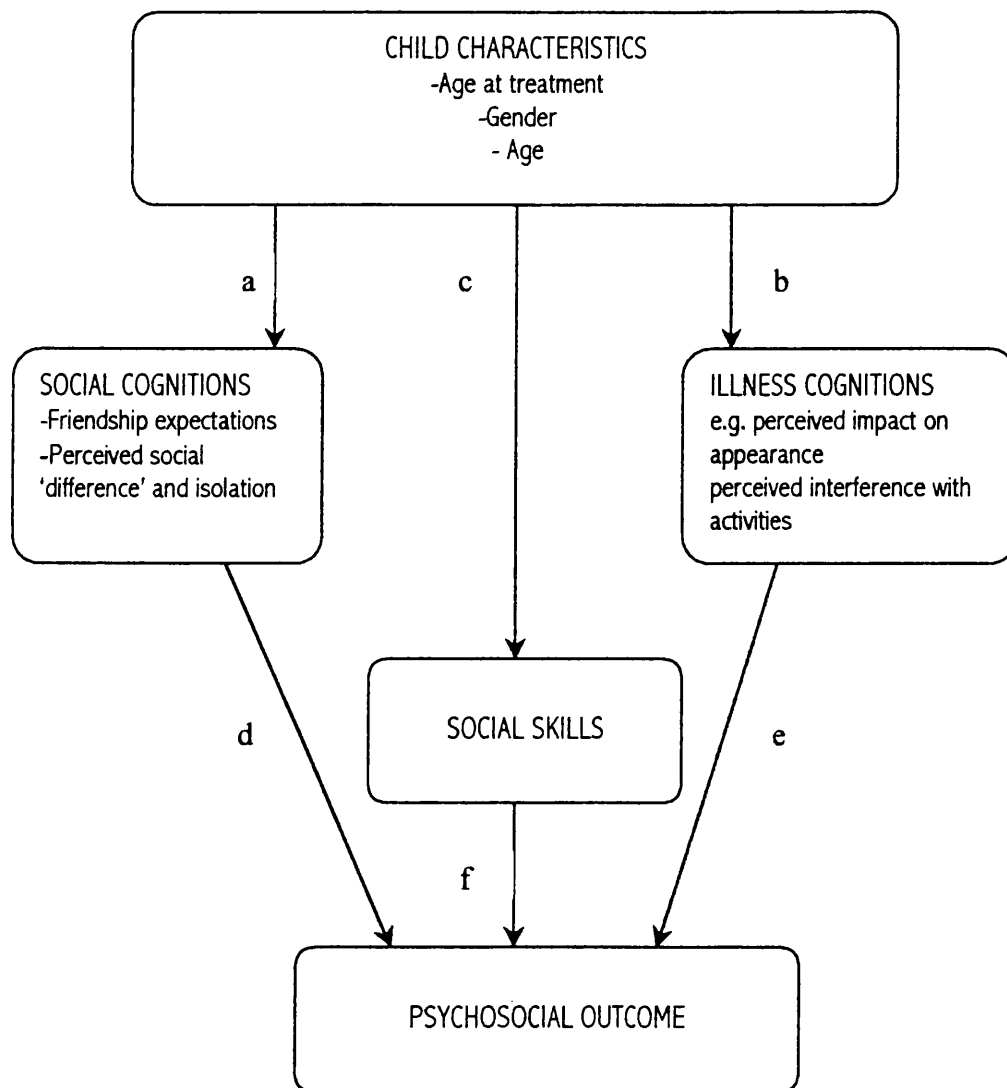
Drawing on themes and questions emerging from the existing chronic illness and cancer literature, I have devised a conceptual model outlining the possible relationships between social and illness cognitions, social skills, person and illness characteristics and psychosocial difficulties (see figure 1.2). The model is not intended to represent a comprehensive account of psychosocial adjustment in childhood cancer survivors. Rather, it aims to provide a framework for thinking about the specific area of social functioning and forms the basis for the research hypotheses.

Psychosocial difficulties are defined in this study as including internalising symptoms, externalising symptoms and peer problems. This broad definition captures most of the types of difficulties described in previous studies of children with chronic illness and cancer. A standardised screening tool covering all of these aspects (the Strengths and Difficulties questionnaire) is used to assess psychosocial difficulties in the sample.

A specific area of interest in this study are children's' friendship expectations, and social perceptions of self as isolated or 'different'. The Thematic Apperception Test is a projective instrument used in this study to elicit qualitative information about social relationships. A standardised measure, the Children's Friendship Inventory (CFI), is used to investigate whether cancer survivors differ from their peers in their expectations of friendship, and whether such differences impact on psychosocial difficulties.

Figure 1.2

A conceptual model of the role of social and illness cognitions in the psychosocial adjustment of adolescent survivors of CNS cancer



Letters a-f correspond to relationships tested

An aim of this study is to look in detail at social skills, including both positive and negative social attitudes and behaviours, as perceived by the children themselves, their parents and teachers. It is hypothesised that social skills act as a 'resistance factor' and are associated with fewer psychosocial difficulties.

It is hypothesised that children's subjective appraisals regarding illness factors may be a factor in the impact of the illness on psychosocial functioning. Using a measure designed specifically for use with children who have chronic illnesses, an aim of this study is to investigate cognitions about various illness factors, including self and parent perceptions of the impact of illness.

This study utilises teacher, parent and children's reports on measures of social skills and general psychosocial functioning. Parent report and self-report are used in a specific measure of illness beliefs.

Siblings of children with chronic illnesses have been identified in the literature as an under-investigated group who may have psychosocial difficulties. For this reason, siblings will be involved in this study, both as a comparison group to control for familial differences in the sample, and as a group of interest in their own right. Given the limitations of using a sibling comparison group alone (Eiser, 1989), population norms will also be utilised in analysis of the findings.

Having a more accurate understanding of psychosocial functioning in children who have survived cancer will be useful in informing intervention with survivors and their siblings. Knowledge of children's cognitions about friendship and

about the impact of their illness could be applied to cognitive therapies with cancer survivors.

Research Hypotheses

Taking an exploratory qualitative approach together with structured self-report and other-report measures, this study intends to test several hypotheses:

(letters in brackets relate to associations indicated in the model, Figure 1.2)

- In comparison to their siblings and healthy peers, adolescents who have survived childhood CNS cancer will:
 - i) have an increased rate of psychosocial difficulties,
 - ii) have social skills deficits,
 - iii) have different expectations of friendship.

- Psychosocial difficulties in cancer survivors will be associated with:
 - i) friendship expectations deviating from peer 'norms' (d);
 - ii) social cognitions including sensitivity to social isolation, a sense of social "difference" and a bias towards negative perceptions of social relationships (d);
 - iii) illness cognitions related to appearance, interference with activities and perceptions of peer rejection (e).

- Social cognitions (a), illness cognitions (b) and social competence (c) will be associated with child characteristics, including age, gender and age at treatment.

- Greater social competence will be associated with better psychosocial functioning (f)

CHAPTER TWO

METHOD

Overview

The clinical sample comprised 21 participants who were adolescent survivors of childhood central nervous system cancers (henceforth known as the clinical group). Of these children, 17 had siblings aged between 11 and 16, who formed a comparison group for this subset. All participants completed one standardised assessment consisting of questionnaires, a projective test and a structured interview. Population norms from the literature were used as a comparison for all measures other than the Childrens' Friendship Inventory (CFI), for which no data were available. For this measure, comparison data were obtained from a group of 181 participants attending two mainstream schools.

Participants

The inclusion criteria for all groups were that participants were aged between 11 and 16 years of age and spoke English as their first language. The age range of 11-16 was used in order to maximise homogeneity; all were attending secondary schools and were likely to have 'adolescent issues' in common. The participants were not (currently or in the past) involved in psychological interventions for psychosocial problems. A sample size of 30 participants per group was aimed for, a figure comparable to that of previous research. This being a single-site study with a restricted number of possible participants, it was not possible to recruit 30 participants without reducing the homogeneity of the group. The

homogeneity of the sample was maintained with the consequence that the sample size was smaller than was intended.

Clinical group

21 participants were recruited from the neuro-endocrine follow up clinic at a Central London teaching hospital.

Inclusion criteria for this group were: participants had previously been treated at this centre for a brain tumour of the posterior fossa. All participants underwent cranial irradiation as part of treatment. The restriction of tumour site and treatment modality aimed to increase the homogeneity of the group. All participants were diagnosed with cancer 3 or more years ago. As the cognitive deficits associated with CNS cancer treatment tend to reach the greatest level of influence at two or three years post-treatment and level off thereafter, participants less than three years post diagnosis were not included. Therefore participants in the study were more likely to have reached a stable level of cognitive functioning.

Participants were in remission at the study time as it is likely that present illness would have a negative impact on social functioning.

Demographic characteristics and illness characteristics of the clinical sample are summarised in Table 2.1. The clinical group completed treatment when they were an average age of 6.8 years old (range: 1 to 13 yrs), and had been off treatment for a mean of 7.47 years (range: 3 to 15 years).

Table 2.1

Demographic and Illness Characteristics, Clinical group participants and non-participants

	Non participants (n=13)	Participants (n=21)	Statistic	p-value
Gender				
N (%) female	5 (38.4)	7 (33.3)	$\chi^2(1)=.092$	p=.76
Mean age at				
assessment(years)	13.8	14.3	t(32), =.80,	p=.43
(SD, range)	(1.81, 11-16)	(1.65, 11-16)		
Mean age at				
treatment (years)	6.38	6.85	t(32), =.39	p=.69
(SD, range)	(3.12, 2-11)	(3.5, 1-13)		

Table 2.2*Demographic characteristics of clinical and sibling groups.*

	CNS Cancer	Siblings
	(n=17)	(n=17)
Gender	6 (35.3)	6 (35.3)
N (%) female		
Mean age (years)	14.0	13.9
(SD, range)	(1.65,11-16)	1.95(11-16)

Sibling group

17 participants who were siblings of the cancer survivors were invited to participate in the study. The nearest age sibling of the cancer survivor was invited to participate. Demographic characteristics of this group are summarised in Table 2.2.

Healthy comparison group

181 participants formed a healthy comparison group for the CFI measure. Participants were recruited from two mixed mainstream comprehensive secondary schools. One class from each school year was invited to participate in the research to ensure representation of a range of ages between 11 and 16 years. The mean age of the sample was 13.9yrs (range 11-16yrs). There were 91 males and 90 females (49.7% females) in the sample. Children of a range of academic

abilities attended the two schools, which were equivalent in size and attainment levels. One school was located in an urban area while the second school was rurally located, in order to obtain a sample representative of the wider population. Preliminary analyses did not reveal a difference between participants from the two schools in age ($t(179)=-1.32, p=.19$) or sex ($\chi^2(1)=3.17, p=.08$). Consequently, participants from the two schools were combined into one sample.

Ethical considerations

This proposal was reviewed by the Joint UCL/UCLH Committees on the Ethics of Human Research. Copies of the letters of approval are given in Appendix One.

Procedure

Recruitment of clinical and sibling groups involved letters being sent to all families suitable for inclusion in the study, informing them about the study and asking for their participation. Within 2 weeks, they were phoned to discuss the study, and if they were willing to participate, to arrange a time for the interview. All interviews were carried out in the participants' homes.

34 families were invited by letter to participate in the study. Copies of letters are provided in Appendix Two. Five families had changed address or telephone number and could not be contacted. Of the 29 followed up by telephone, 21 agreed to participate. Eight families declined to participate, representing a 27% refusal rate. Of these, two gave no reason, two did not have time to participate and four explained that they felt participation would “dredge up” potentially

painful issues. As illustrated in tables 2.1, there were no significant differences between participants and non-participants on demographic or illness characteristics. It is therefore reasonable to assume that on these measures our sample is representative of the wider clinical population.

Informed written consent to participate was given from both parents and participants. The families of the clinical and sibling groups provided details of the schools and identified teachers they thought knew the individual children best, and could be invited to participate in the study.

Participants in the clinical and sibling groups each took part in one assessment with a researcher present. The assessment lasted between forty-five minutes and an hour. All participants were offered the opportunity for breaks during the procedure. Information was collected regarding the participants' age and gender. Additional information regarding the clinical group, such as age at treatment, was ascertained from medical records.

The measures were administered in a standard order, as indicated in the 'Measures' section below. Participants in the clinical group completed an additional questionnaire (the Perceived Illness Experience scale, PIE), which was administered prior to the projective test (the Thematic Apperception Test, TAT).

Participants in the healthy comparison group completed the Childrens' Friendship Inventory (CFI) only. Information letters and consent forms outlining the research were given out to children at school to take home to parents. Those

who consented to participate completed the questionnaire individually in class time allocated for this purpose. A research assistant collected the forms when participants indicated that they were completed.

Measures

Strengths and Difficulties Questionnaire (SDQ: Goodman, 1997)

The SDQ is a well-standardised and widely clinically used tool, which was used here to provide a baseline of psychological functioning. It is a 30-item measure, completed by children, parents and teachers. The internal reliabilities of parent-completed SDQ scales were investigated in a British general population sample (N=10438) with Cronbach's alpha being .82 for total score, and ranging from .63 to .85 for the subscales. Cronbach's alpha for self completed scales was .80 for total score and ranged from .81 to .41 for the subscales (Goodman, 2001).

Normative data for the SDQ were available for 11-16 year olds for both self-rated (N=4228) and parent rated (N=4443) versions of the measure. A copy of the SDQ is in Appendix Four.

The Matson Evaluation of Social Skills with Youngsters (MESSY: Matson, 1994)

The MESSY was used as an overt measure of social skills. It consists of both other and self-rating versions, and refers to observable behaviours rather than personality traits. Additionally, none of the items on the MESSY refer to social behaviours that a child with illness or disability would not be able to do because of physical restrictions, for example, taking part in sports. There are 62 items on the self-rating scale and 64 items on the teachers'/ parents' scale. The MESSY provides scales for both appropriate and inappropriate social skills. Examples of

appropriate skills are “I share what I have with others” and “I walk up to people and start a conversation”. Examples of items on the ‘inappropriate’ scale are “I speak (break in) when someone else is speaking” and “I want to get even with someone who hurts me”. A low score on the MESSY indicates that the child has good social skills, with higher scores indicating poorer social competence. The MESSY has good reliability: the internal reliability on the proxy-rating version is .93 and .80 for the self-rating measure (Matson, Heinze, Helsel, Kapperman & Rotatori 1986). Normative data were based on 388 boys and 356 girls aged 4-18yrs (Matson, Rotatori & Helsel 1983). A copy of the MESSY is provided in Appendix Five.

Children's Friendship Inventory (CFI: LaGaipa & Wood 1986)

The CFI was used as an overt measure of the quality of friendship expectations. It is a self-rated measure consisting of 28 items. Respondents are asked to rate each item in terms of its importance as an expectation of a best friend. An example of a CFI item is “I could trust and depend on them”. The CFI has been used in research looking at aspects of friendships in children, and is subdivided into four categories: ‘strength of character’, ‘mutual activities’, ‘loyalty and commitment’ and ‘empathy and understanding’. It allows an investigation of whether the value placed on these aspects of friendship differs between the study groups. The CFI does not require participants to rate existing friendships and is therefore useful with children who may not have close friendships. The internal reliability of the scale is satisfactory, with Cronbach’s alpha being .74 for the ‘conventional morality’ subscale, .63 for ‘mutual activities’, .70 for the

‘empathic understanding’ and .70 for the ‘loyalty and commitment’ subscale (LaGaipa & Wood, 1976). A copy of the CFI is provided in Appendix Six.

Qualitative Component – Thematic Apperception Test (TAT: Murray, 1943) and open-ended question

The Thematic Apperception Test (TAT) was used as a structured interview tool to elicit responses from which social/friendship themes were identified and scored. In order to keep the research workload as manageable as possible (both for the participants and researchers), 5 TAT cards, which are identified in the TAT manual to be particularly oriented to social or friendship issues, were used (cards 1, 9BM, 9GF, 11, and 13B). TAT cards and instructions are in Appendix Eight.

Participants were given the standard TAT administration in which they were asked for stories describing what was happening in the picture, what led up to it, the outcome, and what the characters were thinking or feeling. The interviewer prompted the child when responses were unclear, as in standard clinical administration, to minimise biases of productivity or motivation and to elicit adequate information for scoring.

In addition the participants were asked: “Are there any ways in which being ill affected your (or your brother/sister’s) friendships or social life?” to allow the expression of themes which were not covered in the questionnaires.

Themes elicited by the TAT stimuli and open-ended questions were identified and scored in a two-stage process using a content analysis approach. Firstly,

content analysis procedures derived from Johnson and LaMontagne (1993) were used to analyse the TAT stories and open-ended questions. The analysis involved the following steps:

1. Responses were transcribed verbatim.
2. They were read in order for coders to become familiar with the range of responses, and central themes were noted.
3. The responses were read a second time. Themes within the broad categories of a) *interpersonal relationships* and b) *emotional responses to interpersonal relationships* were identified and recorded.
4. Themes referring to the same ideas were combined.
5. Inter-coder reliability was established using Cohen's Kappa.
6. Themes and ideas of the participants were summarized and comparisons made between themes emerging in the clinical and sibling groups.

Responses can contain more than a single thematic category. For instance, in the story below there are several themes (identified in square brackets):

“He’s got no friends, he’s sitting down on his own [loneliness/isolation]. There’s just been an earthquake. He’s really poor; they live on sand [hardship]... His dad is really ill. They call an ambulance but the Dad dies [death].”

The second stage of analysis involved TAT responses being re-read and rated on 3 dimensions: a) perceptions of social ‘difference’; b) descriptions of isolation; and c) negative perceptions of social interactions. These dimensions have been

identified in the literature as being of possible importance in the interpersonal relationships of cancer survivors. Each TAT story was given a 0 or 1 rating, where a rating of '1' indicates that the theme is explicitly expressed within the response and '0' indicates that the theme is absent.

For example, a story in which a child is described as "sitting all alone, no one around him" (*social isolation*), "all the other kids bully him and call him names" (*negative social interaction*) would achieve a rating of '1' on dimensions of isolation and negative perceptions of social interaction. For the dimension of social difference a '0' rating would be given, as there is no explicit description of the boy as being different from his peers.

Participants receive a 0 or 1 'score' for each of the three dimensions. The score represents whether a dimension is present or absent within the response, rather than a frequency count indicating the number of times the dimension was mentioned. This approach is taken to offset the effect of differences in length of responses. Comparisons between the clinical and sibling group on these dimensions can be made.

Inter-coder reliability

The author rated all responses. A second independent coder rated a random sample comprising 30% of responses. Both coders were blind to the age, sex, and group of the child. Coders were a trainee clinical psychologist and a clinical psychologist. Reliability was computed using Cohen's Kappa, a measure of reliability corrected for chance occurrence (Landis & Koch, 1977). For

exploratory qualitative research, following the guidelines of Landis and Koch, a kappa of .61 or more is thought of as indicating good agreement between coders, while a kappa between .41 and .60 is thought of as indicating moderate agreement. The reliability coefficients for TAT themes ranged between .54 and 1.0, indicating moderate to good agreement.

Perceived Illness Experience Scale - PIE - (Eiser, 1995)

The PIE was used as an overt measure of the child's experience of different aspects of their illness. It consists of 40 items relating to the child's perception of their illness experience, on sub-scales including physical appearance, interference with activity, disclosure, school, peer rejection, parental behaviour, manipulation, preoccupation with illness, food and treatment. The form uses a 5-point scale indicating agreement to statements about the illness experience. An example of an item in the 'physical appearance' subscale is "I feel my illness has made me look different".

This measure is informative with regards to the child's perception of the impact of the illness. We are able to see whether particular types of illness experience are more or less predictive of psychosocial difficulties. Both self and parent-rated forms were used. The internal reliability coefficient for the total score was good; Cronbach's alpha = .84 for the parent-rated version and .85 for the self-rated version (Eiser, 1995). A copy of the measure is provided in Appendix Seven.

Parent and Teacher rated scales

The main caregiver for each child was asked to complete two questionnaires (the MESSY and the SDQ) to give an observer's perspective of social functioning. Additionally, parents completed a PIE for the clinical group. Questionnaires (SDQ and MESSY) were completed by the named teachers for the clinical and sibling groups. Due to the low sample size (N=10), teacher responses will be excluded from statistical analysis.

CHAPTER THREE

RESULTS

Overview

Results are presented in three sections. Firstly, comparisons between clinical, sibling and comparison groups will be made. Secondly, correlations aimed at testing the hypotheses illustrated in Figure 1.2 (p46), concerning the influences of social and illness cognitions and social skills on psychological functioning, will be presented. Finally, responses of the clinical and sibling group to the TAT and open-ended questions will be delineated. This final section represents an exploratory approach to understanding participants' ideas about interpersonal relationships and the impact of cancer.

Interval data were tested for normality. Variables that met these assumptions were analysed using parametric statistics. The CFI strength of character subscale variable demonstrated positive skewness and did not appear to have a normal distribution. Non-parametric tests were used in the analysis of this variable.

Responses of the clinical group were compared to population norms using z-tests. Z-tests were used rather than independent samples t-tests as both the mean and standard deviations were known for the population norms, and due to the large sample sizes used to calculate the normative data. Paired t-tests were used for the comparison of sibling and clinical groups. Chi-square tests or binomial tests were applied to categorical variables. Bivariate and partial correlations were used to test for associations between variables.

Given the large number of comparisons made, caution needs to be taken with regard to Type 1 errors. In order to control for Type 1 error, a $p < .01$ level of significance was used, except where an important trend was reported at the $p < .05$ level.

Testing the Hypotheses

At the outset, differences in psychosocial difficulties, social skills and friendship expectations between the cancer survivor group, sibling group and population norms were examined.

Measures of psychosocial functioning included self and parent reports. Parent and child reports were not correlated, other than for SDQ total scores in the clinical group ($r(21) = .589, p = .006$). Given that self-rating responses of social skills and psychosocial functioning largely did not correlate with parent responses, both self and parent reports, as opposed to composite scores, will be used in the analyses.

Table 3.1*MESSY and SDQ scores for patient and parent respondents*

	Mean (sd)	Correlation with parent rating
<u>SDQ total score</u>		
Clinical group		
Self rating	13.6 (6.6)	r(21)= .589**
Parent rating	12.8 (7.1)	
Sibling group		
Self rating	11.6 (4.3)	r(16)= -.258
Parent rating	9.1 (4.3)	
<u>MESSY total score</u>		
Clinical group		
Self rating	127.5(22.4)	r(19)=.276
Parent rating	133.1(29.5)	
Sibling group		
Self rating	125.5(22.9)	r(16)= .272
Parent rating	137.5(27.5)	
<u>MESSY positive social skills</u>		
Clinical group		
Self rating	87.4(14.4)	r(19)=.351
Parent rating	77.4 (14.5)	
Sibling group		
Self rating	91.7(12.1)	r(16)= .388
Parent rating	81.1 (10.9)	

**Correlation is significant at the 0.01 level

note: A higher MESSY total score indicates poorer overall social skills. A higher positive social score indicates better positive social skills.

Between-group differences

1) Hypothesis: There will be an increased rate of psychosocial difficulties in the clinical group compared to population norms.

As a preliminary analysis, SDQ scores were compared for the sample broken down by child characteristics to identify confounding variables. Gender and age at treatment were not associated with SDQ scores. There was an association between age and total SDQ score, indicative of higher total SDQ scores in younger children ($r(21) = -.504, p = .02$). Partial correlations were used with further analysis to account for the role of age in psychosocial difficulties.

Parent SDQ scores did not correlate with any child characteristics.

As illustrated in Table 3.2, SDQ total scores indicated that the clinical group had an increased rate of psychological difficulties compared to population norms, for both self and parental ratings (self rated SDQ; $z = 2.41, p = 0.008$, parental rated SDQ; $z = 2.45, p = 0.007$).

The clinical group had higher scores on internalising problems, as indicated by scores on the SDQ subscale of emotional symptoms ($z = 2.59, p = .005$), and on peer problems ($z = 4.57, p = .0001$) compared to population norms, a finding consistent across self and parental reports (parent rated emotional symptoms; $z = 2.74, p = .003$, parent rated peer problems; $z = 3.19, p = .0007$). The clinical group and population norms demonstrated equivalent levels of externalising problems, as indicated by the SDQ conduct problems and hyperactivity subscales.

Table 3.3 shows the distribution of SDQ total difficulties scores according to normal or borderline and abnormal range categories employed by Goodman (1997), recalculated from the recent representative British sample of over 4000

children (Meltzer, Gatward, Goodman & Ford, 2000). 19% of the clinical group had self-reported total difficulties scores that fell in the abnormal (clinically significant) range, a proportion larger than in the total population (5.9%, $z=2.86$, $p = .004$). Parents' ratings indicated that 25% of the clinical group had difficulties in the abnormal range, significantly more than in the total population (9.7%, $z = 2.45$, $p = .01$). The majority of cancer survivors, on both self and parent rated measures, had total SDQ scores falling into the normal and borderline range.

The percentage of children within the clinically significant range on the self-rated SDQ emotional symptoms / internalising subscale (23.8% of the clinical group) were greater than the expected 5.1% found in the population norms ($z = 3.89$, $p < .0001$). More children in the clinical group scored in the abnormal range on the subscale of peer problems, compared to the population norms (clinical group; 45%, population norms; 12.2%, $z = 4.82$, $p < .0001$). On self-rated measures of externalising problems, equivalent proportions of the clinical group and population norms scored within abnormal ranges. Parents' ratings of SDQ subscales showed a similar pattern, indicating that children surviving cancer have higher rates of internalising problems ($z = 5.38$, $p < .0001$) and peer problems ($z = 5.22$, $p < .0001$) in the clinically significant range compared to population norms. On subscales measuring externalising problems, the clinical group were equivalent to population norms according to both self and parent ratings.

There was a correlation between emotional symptoms and peer problems, indicating that the same children tend to report both internalising problems and peer problems ($r(21) = .597$, $p = .004$). Similarly, there was a correlation between scores in the abnormal range for emotional and peer problems subscales,

signifying that children with scores in the abnormal range for internalising problems also tend to have peer problems in the abnormal range ($r(21) = .730$, $p < .001$).

In order to minimise the number of correlations and the likelihood of Type 1 error, analyses carried out to test the conceptual model will be conducted with total SDQ difficulties scores and not for all SDQ subscales.

Table 3.2

	Mean score (Standard deviation)					
	Clinical group		Sibling group		Population norms	
	Self rating	Parent	Self rating	Parent	Self rating	Parent
SDQ Total	14.1 (7.2)*	11.7 (6.6)*	11.6 (4.3)	9.1 (4.3)	10.3(5.2)	8.2 (5.8)
Hyperactivity/ Inattention	3.8 (2.3)	3.8 (2.8)	4.2 (2.0)	3.3(1.3)	3.8 (2.2)	3.2 (2.6)
Emotional symptoms	4.2 (2.5)*	3.8 (3.1)*	2.7 (2.1)	2.3 (2.4)	2.8 (2.1)	1.9 (2.0)
Conduct problems	2.4 (2.1)	1.7 (1.5)	2.8 (2.4)	1.9 (1.9)	2.2 (1.7)	1.5(1.7)
Peer problems	3.2 (1.7)**	3.0 (2.1)**	1.9 (1.5)	1.5 (1.6)	1.5 (1.4)	1.5 (1.7)

SDQ scores for the clinical and sibling groups and population norms

* $p < .01$, clinical group vs. population norms

** $p < .001$, clinical group vs. population norms

Table 3.3

Frequency and percentage of each group scoring within abnormal ranges on the SDQ

SDQ scale	Clinical Group n (%)		Sibling Group n (%)		Population norms (%)	
	Self rating	Parent	Self rating	Parent	Self rating	Parent
Total SDQ	4(19)*	5 (25)*	1(5.9)	0(0)	(5.2)	(9.7)
Emotional symptoms	5 (23.8)**	10(45)**	2 (11.8)	4(23.5)	(5.1)	(12.2)
Hyperactivity	2 (9.5)	3(14.3)	3 (17.6)	0(0)	(11.5)	(12.8)
Conduct problems	3 (14.3)	4(19)	4(23.5)	2(11.8)	(10.6)	(12.2)
Peer problems	3 (14.3)**	10(45)**	0 (0)	2(11.8)	(1.5)	(12.7)

* p< .01, clinical group vs. population norms

**p< .001, clinical group vs. population norms

2)Hypothesis: Siblings will have greater psychosocial difficulties than their peers and fewer difficulties than their siblings who have survived cancer.

Initial analysis indicated that sibling SDQ scores did not correlate with age or gender. SDQ total scores indicated that siblings had non-significantly lower levels of psychological difficulties than the clinical group, and equivalent levels to that of population norms(see Table 3.2).

5.9% of healthy siblings' SDQ total difficulties scores fell into the abnormal range, a proportion equivalent to the 5.2% evident in population norms. Fewer siblings than cancer survivors scored in the abnormal range on total SDQ difficulties ($\chi^2(1)= 6.71, p=.009$).

Both self and parent ratings indicated that children in the sibling group had equivalent levels of difficulties on all SDQ subscales compared to the population norms.

3) Hypothesis: Children who have survived cancer will have social skills deficits compared to their siblings and healthy peers.

Both a total social skills score and a subscale score of 'appropriate' or pro-social behaviour can be derived from the MESSY. This means that it is possible to ascertain whether low social skills scores reflect high levels of inappropriate behaviours or a lack of pro-social behaviours. This is a useful distinction, given that the friendship literature suggests that positive social skills are important in the formation and maintenance of peer relationships. A lower total MESSY score indicates better social skills, while a low score on pro-social skills is indicative of poor pro-social skills.

On both total social skills and pro-social skills, the clinical group achieved scores equivalent to population norms (total social skills: $z = .171$, $p = .43$; pro-social skills: $z = .177$, $p = .42$). The correlation between positive social skills and inappropriate social skills was not significant, indicating that having poor pro-social skills was not necessarily associated with high levels of inappropriate social behaviour.

Normative data for parent rating MESSY are not available. However, an examination of the means shows that parents scored the clinical group as having slightly poorer total and pro-social skills than indicated by self-ratings (see Table 3.1).

The sibling group achieved social skills scores in line with population norms and equivalent to those of the clinical group.

4) Exploratory research question: Do children who have survived cancer have different friendship expectations from their siblings and healthy peers?

Table 3.4 shows the clinical group and comparison group's scores on CFI subscales. Friendship expectations of the clinical, sibling and comparison groups were equivalent.

Table 3.4

CFI subscale scores for clinical, sibling and comparison groups

CFI subscale	Clinical group mean(sd)	Sibling group mean(sd)	Comparison group mean(sd)
Mutual activities	17.1(4.5)	17.0(4.6)	16.5(5.2)
Strength of character	13.0(5.4)	11.3(2.3)	12.8(4.4)
Empathy and understanding	13.0(4.3)	10.9(3.5)	12.1(3.9)
Loyalty and commitment	15.4(4.6)	14.8(4.6)	14.7(4.5)

5) Hypothesis: Children who have survived cancer will:

i) be sensitive to social isolation,

ii) have a sense of social "difference",

iii) will demonstrate a bias towards negative perceptions of social relationships.

As illustrated in Table 3.5, there was no difference between the clinical and sibling groups on TAT themes of difference and isolation. More of the clinical group included themes of negative perceptions of peer relationships than siblings in responses to the TAT ($\chi^2(1) = 31.61, p < .0001$).

Summary of between-group findings

In summary, when compared to their peers, children who survive cancer had significantly more psychosocial difficulties. Children surviving cancer had higher rates of internalising problems and peer problems in the clinically significant range compared to population norms.

However, the majority of the clinical group were within the normal and borderline ranges for psychosocial functioning, with equivalent levels of externalising problems to population norms. They had equivalent social skills and similar friendship expectations to their peers. Their parents saw them as having greater psychosocial difficulties and slightly (not significantly) poorer social competence than their peers.

Siblings of cancer survivors rated themselves as having equivalent overall psychosocial functioning, social competence and friendships expectations to their peers. However, they saw themselves as having higher levels of clinically significant conduct problems than the population norms. Parents of siblings saw them as having fewer psychosocial difficulties than the clinical group and healthy peers. There were no differences between siblings and cancer survivors on themes of difference or loneliness and isolation in interpersonal relationships. Cancer survivors perceived negative peer relationships more than their siblings.

Table 3.5

Themes of isolation, difference and negative perceptions of peer relationships in TAT responses for clinical and sibling groups

TAT theme	Clinical group	Sibling group
Sense of difference		
Present (n, %)	7 (33)	5 (29.4)
Absent (n, %)	14 (66.7)	12 (70.6)
Isolation		
Present (n, %)	16(76.2)	11(64.7)
Absent (n, %)	5(23.8)	6(35.3)
Negative perception of peer relationships		
Present (n, %)	21(100)	12 (70.6)
Absent (n, %)	0	5 (29.4)

Testing the model

The first level of analysis was to ascertain the effect of child characteristics on illness cognitions, social cognitions, social skills and psychosocial functioning. As indicated in the model, child characteristics include age, gender and age at treatment. Significant associations are described below. Following this, the main predictions of the model, (hypothesis six to eight) will be tested.

Participants' age at treatment correlated with the TAT theme of 'difference'. The theme of 'difference' emerged less frequently in the TAT responses of children treated at older ages ($r(21) = .584, p = .007$).

The CFI subscales of mutual activities and empathy and understanding were correlated with child characteristics. There was a difference between males and females on the empathy and understanding subscale, demonstrating that females attached more importance to this expectation of friendship than males ($t(19) = 2.26, p = .03$).

Age at treatment was correlated with mutual activities and empathy and understanding subscales (mutual activities, $r(21) = .488, p = .03$; empathy and understanding, $r(21) = -.464, p = .03$). Children treated at a younger age placed a lesser emphasis on the expectation of mutual activities in friendship and more emphasis on empathy and understanding than children treated at an older age.

A younger age at treatment was associated with greater difficulties at school, as measured by the PIE school subscale ($r(21) = -.429, p = .05$).

6) Hypothesis: Greater social competence will be associated with better psychological functioning.

Both parent and child-rated MESSY total scores were correlated with self-rated SDQ total difficulties, indicating that children with poorer social skills have greater psychosocial difficulties (self rated MESSY, $r(21) = .554$, $p = .007$; parent-rated MESSY, $r(21) = .457$, $p = .02$). While self-ratings of pro-social skills did not correlate with SDQ scores, children who were rated by their parents as having better pro-social skills had fewer psychosocial difficulties ($r(21) = -.411$, $p = .04$).

Children perceived as having better pro-social skills and better social skills overall were seen as having fewer psychosocial problems by their parents (MESSY total; $r(21) = .572$, $p = .008$, MESSY positive social skills; $r(21) = -.481$, $p = .03$). Children who rated themselves as being socially skilled were perceived by their parents as having fewer psychosocial difficulties ($r(21) = .474$, $p = .04$), although the correlation between self-ratings of pro-social skills and parent ratings of SDQ was not significant.

7) Hypothesis: Deviation from the 'norm' of friendship expectations is associated with increased psychosocial difficulties.

In order to ascertain the extent to which deviance from the 'norm' of friendship expectations correlates with psychosocial difficulties, 'difference from norm' scores were calculated for participants in the clinical group. 'Difference from norm' scores were calculated for each CFI subscale, by working out the modulus of the difference between a participant's subscale score and the mean score for the subscale derived from the comparison group.

Table 3.6 illustrates the relationship between psychosocial functioning and ‘difference from the norm’ on the four CFI subscales. Difference from the comparison group on the ‘mutual activities’ subscale of the CFI was correlated with SDQ scores ($r(18) = -.522, p = .02$). Children who rate the expectation of mutual activities in a friendship as more important than their peers have poorer psychosocial outcome, whereas rating mutual activities as less important than the peer average is associated with better psychosocial outcome.

Parental ratings of psychosocial functioning were not correlated with expectations of friendship.

Table 3.6

Correlations between SDQ scores and ‘difference from norm’ for CFI subscales

CFI Scale	Correlation with SDQ total	Correlation with parent SDQ total
Mutual Activities	$r(20) = -.522^*$	$r(20) = -.369$
Strength of character	$r(20) = .237$	$r(20) = .152$
Empathy and understanding	$r(20) = -.041$	$r(20) = .115$
Loyalty and commitment	$r(20) = -.391$	$r(20) = -.044$

*Correlation is significant at the 0.05 level

8) Hypothesis: Illness cognitions related to appearance, interference with activities, school, and perceptions of peer rejection will be associated with psychosocial difficulties.

As illustrated in Table 3.7, there was an association between self-rated total SDQ and scores on the PIE subscales of school and peer rejection (PIE school, $r(18) = .606, p = .002$; PIE peer rejection, $r(18) = .554, p = .006$) Children who

perceived cancer to have a greater effect on school and on peer rejection had greater psychosocial difficulties than cancer survivors who perceived cancer to have a lesser impact on these areas. Beliefs about the impact of illness on appearance and on interference with activities were not associated with psychosocial outcome.

Children who perceived cancer as interfering with activities and as having an impact on school and peer rejection were rated by their parents as having greater psychosocial difficulties (PIE interference with activities, $r(18) = .581$, $p = .007$; PIE school, $r(18) = .646$, $p = .002$; PIE peer rejection, $r(18) = .554$, $p = .006$).

Beliefs about the impact of cancer on physical appearance were not correlated with parental SDQ scores.

There was a correlation between total PIE score and total SDQ scores for both parent and self-rated versions, indicating that children who rate cancer as having a greater impact on their lives overall have greater psychosocial difficulties (self rating, $r(18) = .532$, $p = .008$; parent-rating, $r(20) = .533$, $p = .02$).

Table 3.7*Correlations between illness cognitions and psychosocial functioning*

PIE scale	Correlation with SDQ total	Correlation with parent SDQ total
Total PIE score	$r(18) = .532^{**}$	$r(20) = .533^*$
Interference with activities	$r(18) = .3146$	$r(18) = .581^{**}$
Physical appearance	$r(18) = .259$	$r(18) = .244$
School	$r(18) = .606^{**}$	$r(18) = .646^{**}$
Peer rejection	$r(18) = .554^{**}$	$r(18) = .724^{**}$

*Correlation is significant at the 0.05 level

**Correlation is significant at the 0.01 level

Testing the model: Summary of the findings

Findings were applied to the conceptual model described in Figure 1.2, p46.

Results confirmed that age at treatment was associated with illness and social cognitions. Children treated for cancer at younger ages placed less emphasis on the importance of mutual activities in friendship and more on empathy and understanding. They were more sensitive to feeling ‘different’ in social relationships and reported that cancer had a greater impact on their school life than children treated at older ages.

Gender was also associated with social cognitions. Female cancer survivors placed more emphasis on empathy and understanding in their friendships than male survivors, a difference also evident in the comparison group. Age was correlated with psychosocial difficulties in this sample, with younger children having more difficulties. None of the child characteristics were associated with social skills.

There was some evidence to support the hypothesis that social cognitions are associated with psychosocial functioning. Children who placed a lesser emphasis on mutual activities than their peers had fewer psychosocial difficulties. No other differences in friendship expectations were associated with poor psychosocial outcome. Having a sense of 'difference', isolation, or negative perception of peer relationships was not associated with psychosocial difficulties in this sample.

The model predicts that illness cognitions will be associated with psychosocial outcome. There is some evidence to support this. Children who rated cancer as having a greater impact on school and peer rejection had poorer psychosocial functioning. Children, for whom parents perceived cancer as having an impact on interference with activities, school and peer rejection, had greater psychosocial difficulties. Psychosocial difficulties were greater if cancer was perceived by the child or parent to have a greater impact on life overall.

Being socially competent was associated with fewer psychosocial difficulties.

Pro-social skills alone did not appear to be related to psychosocial outcome when rated by the children. However, children who rated themselves as having greater psychosocial difficulties were seen by their parents as having poorer pro-social skills.

Themes emerging from responses to the TAT

The themes that emerged in participants' responses to the five TAT stimulus cards are presented in Table 3.8. Each child gave a response to five cards. Rather

than reporting the responses to each card separately, all five stories for each individual are considered together.

In the section below, I will describe themes occurring in the stories of more than 30% of participants in either group. In addition, where a theme is described significantly more by one group than the other, an account of the stories will be given. Participants' code numbers are in brackets after each quotation. A code number with the prefix 'c' denotes the clinical group, while 's' denotes the sibling group.

Positive themes

Positive themes were more common in the stories of the sibling group than the clinical group, with the difference between groups being significant on themes of group identity/comradeship and close friendship.

Group identity or comradeship was a theme emergent from stories of 82% of the sibling group and 43% of the clinical group, which represents a significant difference between groups ($\chi^2(1)=32.4, p<.001$). Stories falling into this category included ideas about shared activities or similarities, for example

“they are dressed in the same way, maybe they know each other from work, they come out together after work” (s01).

Close friendship was a thematic element present in more of the sibling group's stories ($\chi^2(1)=6.49, p=.01$). It dealt with dyadic, same sex friendships characterized by proximity, for example:

“they are resting on each other so are pretty close” (s08)

or enjoyment of activities, for instance:

“Looks like they’re having fun. They were deciding who would chase, who would hide. They’re mates....they look excited” (c20).

Negative themes

The most prevalent negative themes dealt with loneliness/isolation (present in 76% of the clinical group and 70% of the sibling group), death (in 71% of the clinical group and 35% of the sibling group’s responses) and threat (in 57% of the clinical group and 65% of the sibling group’s responses). The theme of death was more common in stories of the clinical group ($\chi^2(1)=26.01, p<.001$). It is characterised by three main stories. The first focuses on the death of family members, and the sense of helplessness, and sometimes anger, associated with this. An example from the clinical group is:

“who could he ask for help to play? his dad used to play the violin but now he’s dead, why did this happen to my parents? Who killed my dad? He might take revenge.” (c17)

A second element in this theme centred on the destruction of a safe place, for example, from the sibling group:

“A waterfall, ... jungly and tropical ...it is safe. It might get, the animals might get killed and the trees cut down, so it will be a wasteland.” (s08)

Table 3.8

Themes categories emergent from TAT responses of the Clinical and Sibling groups

Thematic categories	Clinical group		Sibling group		χ^2	p value
	n=21		n=17			
	Frequency	(%)	Frequency	(%)		
<u>Positive themes</u>						
Group identity / comradeship	9	(43)	14	(82)	$\chi^2(1) = 32.4$	<.0001
Safety/protection	4	(19)	5	(29)	$\chi^2(1) = 2.74$.09
Close friendship	4	(19)	6	(35)	$\chi^2(1) = 6.49$.01
<u>Negative themes</u>						
Loneliness / isolation	16	(76)	11	(70)	$\chi^2(1) = 2.4$.121
Punishment	8	(38)	7	(41)	$\chi^2(1) = 0.18$.66
Victimisation/bullying	4	(19)	3	(18)	$\chi^2(1) = 0.03$.86
Betrayal / disloyalty	5	(24)	5	(29)	$\chi^2(1) = 0.64$.42
Hardship	8	(38)	3	(18)	$\chi^2(1) = 9.92$.002
Negative outcome of interaction	6	(29)	4	(24)	$\chi^2(1) = 0.64$.42
Death	15	(71)	6	(35)	$\chi^2(1) = 26.1$	<.0001
Self as different	7	(33)	5	(29)	$\chi^2(1) = 0.39$.53
Threat	12	(57)	11	(65)	$\chi^2(1) = 1.34$.25

Note: Several responses contained more than one thematic category.

The third type of story in this theme was characterised by ‘a fight for life’, usually between groups of animals or people. An example of this from a sibling is:

“That’s a dragon and they’re lions, running away from the dragon. All the lions are running, the lions are fighting against it... it kills 3 of the lions” (s12).

A characteristic running through all stories containing this theme, for both the clinical and sibling groups, was that death and loss are unpredictable and sudden.

The theme of threat contains similar elements to the theme of death, the main difference being that death may be threatened but does not occur in the story.

The most prevalent threat described refers either to an unspecified danger or to injury or damage, for example,

“The bridge is unstable so they run over it ... they keep on going, ... there is lots of danger on the way” (s03)

“Enemies might be coming at any moment ... they might win or lose” (c07).

This theme was equally prevalent in the responses of the sibling group (65%) and that of the clinical group (57%). Interestingly, the theme of protection and safety always appeared alongside a theme of threat (although a theme of threat was not always accompanied by a theme of protection and safety). It relates to being successfully saved from danger, either by a ‘rescuer’ or through one’s own actions. All four of the responses of the clinical group relating to safety and protection were concerned with protection coming from an outside agency, for example:

“a woman finds him and takes care of him and tells him to go home”
(c11).

Only one of the five sibling responses related to a ‘rescuer’, with sibling responses being more commonly focused on self-protection. An example of a response from the sibling group is:

“the dragon is trying to scare the hunters away, trying to protect his home from hunters who will tear down the forest. He can do it and they go away.” (s07)

The theme of isolation and loneliness contained three main elements, and was evident in similar proportions in the clinical and sibling groups (76% and 70% respectively). The first, most common, element, dealt with geographical, or physical descriptions of isolation, such as:

“He lives in the middle of nowhere, there are not many people nearby”,
“there is a mountain, it is very cold, it is empty” (c08)

“it is a deserted area in a faraway country, no one goes there”(s10).

A second element is concerned with a lack of people, for example:

“He’s sad and lonely, not many friends around (c03)”.

The third element involves the protagonist in the story not being able or willing to participate in activities or interactions with other characters. Examples of this include:

“He’s all on his own, he sees the other people playing footie” (s05)

“the little kid has run away, they’ve been ignoring him. No one won’t play with him, he’s feeling sad” (c08).

The proportion of participants giving responses containing a theme of punishment was approximately equivalent for the clinical and sibling groups. In both groups, the most prevalent element of this theme dealt with parental discipline, followed by punishment meted out by teachers or employers. Most often, punishment was presented as a consequence of misbehaviour, with fewer stories depicting unwarranted punishment.

Fewer of the sibling than clinical group gave responses in which there was a theme of ‘hardship’. One element of this theme is poverty, for example:

“he’s got no shoes on, can’t afford it. He’s having some bread; they can’t afford to feed him well. The house looks very dirty. He feels hungry” (c18)

“they don’t have much things. Only ten pieces of wood, grass. Really poor” (c05).

A second, less common, element of this theme was one of struggle in difficult conditions, for example:

“a big mountain. There is a man trying to climb up it, probably loads of bricks falling, he’s crawling in the sun” (c03).

Equivalent proportions of the two groups expressed the theme of difference in their responses. Stories characterised by this theme focused primarily on self-evaluation and difference to others, for example:

“he’s evaluating what he’s got, comparing himself to others, thinking why”(s16)

“she’s thinking, what am I doing wrong? She feels sad, like she’s different, doesn’t fit in”(c10).

A second element of this theme was expressed in stories where there is a focus on the behaviour of a group towards a ‘different’ central character:

“they might let him in for a while to see what he’s like, to test him. Depends if he’s got the same stuff in common” (s15).

Open-ended questions: Subjective accounts of the impact of cancer

“Getting on with it”

A theme central to the responses of three families (14% of the sample) focused on “getting on with it”. This theme was characterised by ideas about cancer being in the past and about having an identity in which cancer is not a central component:

“The most important thing has been to get on with it, there is a choice between being different- a kid with cancer, or being just a kid. He wanted to be just a kid, so that is how we think about it, it is not a big part of life.” (c20)

For one family, of central importance was the ability to recognise that psychosocial difficulties may be a normal part of adolescence, rather than being connected to the experience of cancer:

“At school he is doing fine, we get on with it. The doctor asked at an appointment how school was going, and he said he didn’t like school. He’s a teenager! Of course he’d say that, it doesn’t mean there is a problem.” (c14)

Academic and physical abilities

Six families (29% of the sample) talked about the impact of cancer on abilities, both academic and physical. A common element of this theme was a sense that cancer and its treatment had a negative impact on previously existing abilities, for example,

“At school I used to be top of my class but not now” (c16)

“He realises that he can’t do things anymore and this upsets him.” (c16)

Sense of difference

Five children in the clinical group (24% of the sample) described a sense of themselves as different to their peers. For one participant, this related to being unable to join in with group activities:

“I wasn’t allowed to play sport. I felt different... and I did mind it, I felt ostracised” (c01)

Another element in this theme was a sense of rejection by peers, for example:

“I do have friends but sometimes (...) they say they are busy and they go without me.” (c05)

For two children, feeling different had additional negative effects, for example;

“I feel jealous, left out, I get angry and into fights.” (c11)

Bullying

52% of the families reported that bullying, which they felt was related to cancer, caused difficulties for the cancer survivor. For eight children, bullying was perceived as directly related to physical signs of cancer and its treatment. Scars, height, weight and hair condition were the most commonly cited reasons for bullying. Attempts to cope with bullying were a common element of this theme. Older siblings in particular described their attempts to give advice and the frustration associated with not being able to help:

“She is picked on and she doesn’t know how to deal with it. I try to tell her but she can’t do it so she gets bullied a lot. I get angry cos she’s my sister but I think she’s stupid to let it happen” (c05)

“At school I know that people take the mickey but she doesn’t tell anyone. I don’t know what to do about it.” (c06)

Need for predictability

Four children in the clinical group (19% of the sample) were described as having difficulties with changes in routine and unpredictability, for example:

“He likes everything to be planned and predictable and gets scared if there are changes, so it is hard to be spontaneous ” (c03)

“He likes his routines, he’s staid in his ways. He likes things to be very structured, and if there is any uncertainty in something he won’t do it.” (c08)

Impact on friendships

Siblings described seven children in the clinical group (33% of the sample) as having social difficulties as a result of cancer and its treatment. These

difficulties were attributed to a lack of confidence, and an increased need for trust in relationships, for example:

“He doesn’t trust people easily and takes a long time to get to know someone”(c19)

and “her confidence has gone down, especially when she is in a new place or with new people” (c18)

Physical impact of cancer and treatment

Four children in the clinical group (19% of the sample) described the direct impact of physical changes on their mood and relationships with others. An example is:

“I feel down a lot these days due to my appearance and my ability due to my tumor (*sic*) and radiotherapy (*sic*).” (c16)

It should be noted that all families in the present study were given the option of referral to an adolescent psychology service. Eight families (38% of the sample) requested referral for either cognitive assessment or help with psychosocial difficulties. This was not formally assessed due to the large number of variables that may be involved in the decision to request referral.

Emergent themes: a summary of participants’ responses

Children with cancer have a lesser tendency to perceive positive aspects of interpersonal relationships, such as group identity and close friendship, than their siblings. They are more sensitive to death and loss and less likely to see themselves as self-efficacious in dealing with threat than their siblings. The

clinical group have a greater tendency to perceive hardship and struggle in interpersonal relationships than their siblings.

Several families report that cancer has an ongoing impact on their child's life.

Bullying, a sense of difference, need for predictability, negative impact on abilities, impact on friendships, and the physical impact of cancer on mood and relationships were named by families as ongoing concerns. For some families, however, cancer was not conceptualised as having an impact on life. These families described 'getting on with it' and 'leaving cancer in the past' as being central to the family philosophy.

CHAPTER FOUR

DISCUSSION

Overview

This study investigated the impact of cancer on psychosocial functioning in adolescent survivors. The main aim of the work was to compare psychosocial difficulties between the clinical group and healthy peers. A sibling group was recruited to provide additional information and as a group of interest in its own right.

The results of the present study confirm previous findings, and add new information to our understanding of the adjustment of adolescent cancer survivors. In addition, the findings provide partial support for the a priori conceptual model. This model, illustrated in Figure 1.2 (p46) elaborates on the roles of social and illness factors in psychosocial adjustment. It is not intended to represent a comprehensive model of psychosocial adjustment, such as that presented by Varni and Wallander (1998) (Figure 1.1, p16).

The model proposes that child and illness characteristics are associated with: 1) cognitions about social interactions, 2) cognitions about the impact of cancer and 3) social skills. It is hypothesised that negative social and illness cognitions are risk factors associated with poorer psychosocial outcome. Good social skills are conceptualised as a resistance factor, and are hypothesised to be associated with better psychosocial outcome.

This discussion examines the findings in the light of the study aims and the methods used. Firstly, comparisons between groups will be presented in view of the study hypotheses. Next, the results will be discussed with regards to the conceptual model. Themes emerging from responses to the TAT and open-ended questions will be discussed alongside quantitative findings where appropriate, to provide a richer account of participants' strengths and difficulties.

The limitations and strengths of the study will then be considered. This will be followed by a discussion of the wider theoretical context, and possible directions for future research. Finally, clinical implications of the findings are explored.

Summary of findings: Differences between groups

1) There will be an increased rate of psychosocial difficulties in the clinical group compared to population norms.

This hypothesis was supported by the findings of the study. Psychosocial difficulties were elevated in the clinical sample compared to population norms. A significantly greater proportion of the clinical group had scores within the abnormal range on the SDQ emotional symptoms and peer problems subscales than in the general population. Levels of externalising problems (hyperactivity and conduct problems) were equivalent to population norms in this sample.

Although the present study examined psychosocial functioning for children with a specific malignancy and within a relatively narrow age range, the findings are largely consistent with other follow-up studies of cancer survivors. In common with other research, the present study found that, as a group, adolescent cancer

survivors have significantly more psychosocial difficulties compared to population norms, and a significant subgroup have psychosocial difficulties in the clinically significant (abnormal) range (Greenberg *et al.*, 1989; Katz *et al.*, 1988; Mulhern *et al.*, 1989, Kazak *et al.*, 1997). However, as found in previous research, the majority of cancer survivors function within the normal range on measures of psychosocial adjustment (Fritz *et al.*, 1988; Koocher & O'Malley, 1981; Lansky, List & Ritter-Sterr, 1986; Wasserman, Thompson, Williams & Fairclough, 1987).

Adolescents surviving cancer have significantly higher rates of emotional symptoms and peer problems in the clinically significant range compared to population norms. This finding complements work in the field of brain tumour research, which has found childhood cancer survivors to have high levels of internalising problems compared to a population of healthy children (Hirsch *et al.*, 1979; Hoppe-Hirsch *et al.*, 1990; Danoff *et al.*, 1982; Glaser *et al.*, 1997).

Some studies have found, however, that children surviving brain tumours have equivalent levels of internalising problems to healthy peers, and fewer internalising problems than children with non-CNS cancers. (Carpentieri *et al.*, 1993; Radcliffe *et al.*, 1996). A possible explanation for the discrepancy in findings relates to the use of single sources of information about adjustment. Fuemmeler *et al.* (2002) argue that the degree of internalising problems appears to depend on whether a parent or child reports on difficulties, with parents tending to report greater difficulties than children. Results of the aforementioned studies may reflect the discrepant views of respondents rather than being

indicative of differences in levels of internalising problems. An advantage of the present study is the availability of both parent and child reports. Although there is a discrepancy between parent and child ratings of internalising problems, with parents reporting greater levels of difficulties than children, both respondents described a similar pattern of difficulties. Both parents and children indicated that more of the clinical group had internalising problems within the abnormal range compared to population norms.

The clinical group have equivalent levels of externalising problems (hyperactivity and conduct problems) to population norms, a finding that complements previous research (Mulhern et al., 1993; Carpentieri et al., 1993). Fuemmeler et al. (2002) suggest that an explanation for the relatively low levels of externalising problems in survivors of cancer lies in the experience of cancer acting as a “protective influence” in relation to these types of difficulties. Fuemmeler et al. argue that effects of cancer and treatment, such as fatigue, lengthy hospitalisation and increased parental involvement could potentially limit externalising types of behaviours such as risk-taking or aggression.

It appeared that the same children tended to report both peer problems and internalising problems. It may be that children who have emotional symptoms are less able to function effectively with their peers, or that conversely; children who have peer relationship difficulties have greater emotional symptoms as a consequence (Parker and Asher, 1987)

Overall levels of psychosocial functioning were equivalent for males and females in the present study. The pattern of difficulties appeared subtly different, with relatively greater levels of internalising symptomatology in females. Whilst there is extensive evidence to suggest that the impact of stress may be different for young males and females (Rutter, 1980), some authors suggest that this finding reflects greater externalising symptomatology in boys and is therefore a measurement artefact (Emery, 1982). The results of this study are consistent with this suggestion, although this warrants replication.

2) Siblings will have greater psychosocial difficulties than their peers and fewer difficulties than their siblings who have survived cancer.

This hypothesis was not supported by the study findings, with siblings rating themselves as having psychosocial difficulties equivalent to population norms, and clinically significant psychopathology being very much in the minority.

Previous research has reported mixed findings with regards to psychosocial adjustment of siblings, and methodological difficulties have limited the generalisability of findings.

None of the siblings in the present sample expressed concerns about having less parental attention than the sibling with cancer, as might be predicted by previous research (Spinetta & Deasy-Spinetta, 1981b; Glaser et al., 1997). Parents, on the other hand, did mention their concerns that the sibling's needs had suffered as a consequence of their brother or sister having cancer, for example:

“it was harder for his sister than for him, she got shipped around to friends and neighbours... she was just starting school when the treatment began, and she had to deal with that on her own” (20).

All siblings who reported that cancer had a negative impact on them related this to their feelings of responsibility towards the ill sibling. Several of the siblings talked about being responsible for helping their sibling to cope with bullying. An effect of this was that siblings were frustrated because they felt unable to manage the situation, for example, “that makes me angry and hurt when I see that, I want to go and sort it out but I can’t” (03).

It may be that the quantitative measures in the present study were not sufficiently sensitive to capture the nature and extent of siblings’ difficulties. The qualitative component of the research indicated that siblings have concerns about their role in relation to the child surviving cancer, and that parents are aware of siblings’ needs being subsumed to some extent. It is worth keeping in mind that families are likely to have perceived the present study as focusing on the cancer survivor rather than being an opportunity for siblings to express their concerns, meaning that a full picture of the siblings’ experience of cancer may not have been evoked.

3) Children who have survived cancer will have social skills deficits compared to their healthy peers.

This hypothesis was not supported, with no evidence of social skills deficits in the clinical group compared to population norms. This finding is consistent with

that of Spirito et al. (1990), who found no differences between cancer survivors and controls on the social competence scale of the CBCL and on a global measure of social functioning.

However, the results of the present study are at odds with the majority of published research in this domain, which has found children with CNS cancers to be at heightened risk for deficits in social competence (Bamford et al, 1976; Kun & Mulhern, 1983; Carpentieri et al, 1993 and Noll et al, 1992). A possible explanation for this discrepancy is that researchers may not publish null findings, (those indicating that children surviving cancer do not have social skills difficulties). A second explanation is that previous studies have included patients undergoing treatment. The restricted activities associated with this may have been a potential confound which lowered the scores of the cancer patients. A third possible explanation for the discrepancy in findings is the inclusion of a wide range of social functioning measures under the umbrella of social competence. Previous studies have included measures of peer acceptance, social isolation, adaptive behaviour and social skills in the assessment of social competence. The present study focuses in detail on the social skills aspect of social competence. It may be that in previous findings children are seen as less socially competent, not due to deficits in social skills, but due limitations in other aspects of social functioning. Carpentieri et al. (1993), for example, found that children with brain tumours had significantly lower scores on the 'Activities' and 'School Performance' subscales of the CBCL, both of which may be indicative of cognitive deficits and physical limitations occurring as a result of the cancer rather than social competence per se. Social isolation may be a domain in which

cancer survivors have difficulties, as suggested by Noll et al. (1992) and Vannatta et al (1998), who found that survivors of cancer were seen as more socially isolated, but not less popular, than their peers. These studies do not specifically investigate social skills in cancer survivors. It can be argued that these findings reflect the behaviour and attitudes of peers, rather than deficits in social skills in the cancer survivors. This notion is compatible with LaGaipa's (1982) suggestion that healthy peers may find it difficult to interact with disabled adolescents.

Interestingly, Noll et al. (1991) found that survivors of cancer did not differ in popularity from their peers. It may be that the constructs of popularity and social skills are related (Merrel, 1999), with good social skills leading to greater popularity. It is also possible that proficiency in social skills results from being a popular member of a peer group. Noll et al.'s study suggests that isolation and popularity are not related, indicating that an individual may be thought of well by his or her peers, but can still be separate from them. This corresponds with TAT themes expressed by the clinical and sibling groups in the present study. The clinical group included themes of group identity and close friendship significantly less in their TAT responses than their siblings. This may reflect feelings of 'separateness' to peers, or may represent a lesser involvement in groups of friends or close friendships.

It appears, then, that the existing research into social competency taps into a number of domains that are not as yet clearly delineated. The present study indicates that cancer survivors do not have deficits in social skills compared to

their siblings and population norms. The present study did not set out to compare cancer survivors to healthy peers on other aspects of social competence such as isolation or popularity. It is possible that cancer survivors have difficulties in these areas compared to their peers. There is some indication from participants' responses to the TAT that cancer survivors place a lesser emphasis on group identity and close friendship than their siblings, which may be related to aspects of social competence. This would benefit from further investigation.

4) Do children who have survived cancer have different friendship expectations from their healthy peers?

No differences in friendship expectations were found between the clinical, sibling and comparison groups. The experience of being diagnosed with and treated for cancer does not necessarily change an individual's expectations of friendship. This finding does not correspond with the notion that children who experience different life events to peers have different friendship expectations to their peers. It is possible that the present study did not directly investigate aspects of friendship that may have been affected by cancer, for example, self-disclosure. As outlined in Chapter One, existing research looking at friendships of children with chronic illness has found that children's beliefs about self-disclosure are related to difficulties with peer relationships (McMaugh & Debus, 1999).

Although the clinical group overall did not have different friendship expectations to peers, it may be that children who do have different friendship expectations to their peers have greater psychosocial difficulties than individuals who have

similar notions about friendship to their peers. This question will be related to the present sample in greater detail later.

5) Children who have survived cancer will:

i) be sensitive to social isolation,

ii) have a sense of social “difference”,

iii) will demonstrate a bias towards negative perceptions of social relationships.

This hypothesis was partially supported by the data.

Themes of social isolation and difference were expressed to a comparable degree in the clinical and sibling groups. It seems that although previous studies have found that healthy peers perceive cancer survivors as different from themselves (Vannatta et al., 1998), cancer survivors may not share this perception.

All of the participants in the clinical group gave accounts of negative peer relationships in response to TAT stimuli, significantly more so than the sibling group. This may be connected to the lesser emphasis of the clinical group on themes of ‘group identity’ and ‘close friendship’. It is possible that negative perceptions of peer relationships reflect the clinical group’s ‘separateness’ from peers. This may indicate that cancer survivors are more cautious in their approaches to peer relationships and invest less in group activities and close friendships. Clearly, this is a speculative hypothesis and would warrant further investigation.

Testing the conceptual model

A conceptual model outlining the possible relationships between social and illness cognitions, social skills, person and illness characteristics and psychosocial outcome was delineated in Chapter One (see figure 1.2). The model aims to provide a framework for thinking about the specific area of social functioning and formed the basis for the remaining research hypotheses.

Child characteristics are thought to be associated with social and illness cognitions and social skills, which in turn are hypothesised to be predictive of psychosocial difficulties. A number of relationships were not investigated in this study in order to minimise the number of correlations and so to reduce the likelihood of Type I error. For example, illness characteristics such as cognitive and endocrine deficits were not included in the analysis. Additionally, the relationship between illness cognitions and social cognitions was not tested.

Initially, the roles of child characteristics including age, gender and age at treatment were investigated. Results confirmed that age at treatment is associated with illness and social cognitions. Children treated for cancer at younger ages place less emphasis on the importance of mutual activities in friendship and more on empathy and understanding. Theories of friendship expectations would suggest that a pattern of expectations where greater emphasis is placed on empathy and understanding, and a lesser emphasis is placed on mutual activities, is consistent with close friendships (LaGaipa & Wood, 1985). In terms of the theory, then, the findings suggest that children treated at younger ages go on to be more invested in close relationships than children treated at older ages.

Children treated at younger ages may not remember receiving the diagnosis of cancer and subsequent treatment, both of which have been reported as traumatic experiences for the child and family (Fuemmeler et al., 2001; Katz et al., 1990). It is possible that children who recall their treatment may be more aware of their mortality and sense of foreshortened future, both of which have been suggested to preclude investment in intimate relationships (Byrne et al., 1999; Schover et al., 1999).

Younger age at treatment is associated with a greater sense of 'self as different' in social relationships. In addition, children treated at younger ages report that cancer has a greater impact on their school life than children treated at older ages. This finding may be understood in the light of neuropsychology literature, which identifies children treated at younger ages as being at greater risk for cognitive deficits (Chapman et al., 1995). A possible explanation is that children who struggle academically at school, and who perceive these difficulties to be a consequence of cancer and its treatment, report cancer to have a greater impact on school life and see themselves as different to their peers.

It is interesting that children treated at younger ages, in spite of seeing themselves as 'different' more than children treated at older ages, tend to have friendship expectations consistent with close friendships. This would suggest that feeling 'different' does not rule out the development of close friendships in this group. A possibility is that these children value empathy and understanding rather than mutual activities precisely because they feel different. A child who

feels different to his or her peers may have different interests, and therefore not value shared activities in friendship. Equally, it may be important to someone who feels different that his or friends can understand and empathise with these differences. Further study of the nature of friendship in this group is necessary to provide a clearer picture of friendship in cancer survivors. In particular, an investigation of how expectations of friendship relate to both the nature of and satisfaction with friendship is warranted.

Female cancer survivors place more of an emphasis on empathy and understanding in their friendships than male survivors, indicating that they assign greater importance to close rather than casual friendships. This difference is also evident in the comparison group, and is consistent with the friendship literature, which has consistently found males to invest in more casual relationships than females, with a lesser value placed on self-disclosure and intimacy (Hays, 1988).

6) Greater social competence will be associated with better psychological functioning.

This hypothesis was supported by the research findings, which indicated that being socially skilled is associated with fewer psychosocial difficulties.

It may be that children who are less socially competent may find it difficult to access peer support and accordingly have negative experiences of peer relationships (Crick & Dodge, 1994), leading to greater psychosocial difficulties.

A higher total SDQ score is associated with poorer parent-rated (but not self-rated) pro-social skills. Parents rated children as having poorer pro-social skills than the children rated themselves, perhaps reflecting a tendency for adolescents to provide a “socially desirable” positive response on the measure. The finding that pro-social skills are related to psychosocial outcome is consistent with the suggestion that pro-social skills characterise successful social interactions (McMaugh, 2001).

Social skills may mediate and be mediated by cognitions about the impact of illness and social cognitions about friendship and social “belongingness”. For example, a lack of social skills may lead to perceptions of social difference and isolation or vice versa. It was not possible to assess this relationship in the present study due to the small sample size and further research on the role of social skills is warranted.

7) Deviation from the ‘norm’ of friendship expectations is associated with increased psychosocial difficulties.

There is some evidence to support this hypothesis. Children who place a lesser emphasis on mutual activities than their peers have fewer psychosocial difficulties. In other words, individual who place a lesser emphasis on casual friendships have fewer psychosocial difficulties. This implies that having expectations consistent with close friendships is associated with better psychosocial functioning. It is important to consider that a deviation from the norm was only associated with psychosocial difficulties on one of the subscales of friendship expectations. This may be a spurious finding, and given the

likelihood of Type 1 error in this data set, should be considered with caution.

Without a measure of friendship quality, it is not possible to state whether having similar friendship expectations to peers is associated with more satisfying or closer friendships. Theoretically, closer friendships are purported to provide a greater opportunity for the successful negotiation of adolescent tasks associated with the development of identity and group belonging (Sullivan, 1953, Fielding, 1985), and in doing so may be associated with positive psychosocial functioning.

No other differences in friendship expectations are associated with poor psychosocial outcome. Having a sense of 'difference', isolation, or negative perception of peer relationships is not associated with psychosocial difficulties in this sample. This finding is at odds with the concept that a sense of difference or isolation may be associated with difficulties forming friendships (McMaugh, 2001), although again, without a measure of friendship quality it has not been possible to assess this directly.

8) Illness cognitions related to appearance, interference with activities, school, and perceptions of peer rejection will be associated with psychosocial difficulties.

The model predicts that illness cognitions will be associated with psychosocial outcome. There is some evidence to support this premise.

It is important to note, before discussing the meaning of these findings, that although there is evidence for a relationship between illness cognitions and psychosocial functioning, the direction of the relationship is unclear. It may be that having fewer psychosocial difficulties leads to a more positive perception of

the impact of cancer. On the other hand, perceiving cancer as having a greater impact on life may result in greater psychosocial difficulties.

Adolescents for whom self and parent ratings indicate that cancer has a greater impact on school have poorer psychosocial functioning. Items relating to the school subscale relate to both academic and social aspects of schooling. This finding is consistent with the chronic illness and friendship literatures, which suggest that satisfaction with school is associated with good peer relationships, the development of self-identity and self esteem (McMaugh & Debus, 1999; Varni et al., 1997).

The perceived impact of cancer on peer rejection (for both self and parent ratings) was associated with poorer psychosocial functioning. This finding is in accordance with suggestions that children who feel rejected by peers have greater difficulties (Ladd, 1990; Varni et al., 1994). Responses to the TAT themes provide information that may clarify the nature of peer rejection for this group. As previously delineated, in their responses to the TAT cards, cancer survivors did not express feelings of difference or isolation to a greater extent than their siblings. However, they expressed themes relating to group identity and close friendship significantly less than their siblings. This may indicate that although cancer survivors do not feel that they are different from their peers, they may feel less accepted by them or close to them. Existing research suggests that, rather than the children surviving cancer, it is the healthy peers who perceive a difference between themselves and cancer survivors (LaGaipa, 1982). La Gaipa suggests that healthy peers may lack the ability to communicate with children

who have disabilities and as a consequence, find it difficult to make friendships with them. A consequence of this for cancer survivors is that they may feel rejected, which in turn is associated with psychosocial difficulties. Clearly, peer relationships require the participation of at least two parties, and an understanding of healthy peers' attitudes and thoughts about interactions with cancer survivors will be important in building on existing knowledge.

The extent to which cancer is self-rated as interfering with activities is not associated with psychosocial difficulties. However, adolescents whose parents see cancer as interfering with activities have greater psychosocial difficulties. It may be that the majority of children in this sample, who are at least three years post-treatment, do not perceive cancer to affect daily activities to the same extent as during and immediately after treatment, when symptoms associated with rehabilitation may have had a larger impact on participation in activities. Their parents, however, appear to be more sensitive to the impact of cancer on activities, and parents ratings of interference with activities is correlated with psychosocial functioning. It is unclear from the extant literature why a discrepancy between parent and child reports of interference of cancer in activities exists. A possible explanation is that parents in general tend to report greater difficulties than their children (Fuemmeler et al. ,2002). Further investigation of the differences in parents' and child reports of illness appraisals would be valuable.

Perceived impact of cancer on physical appearance was not correlated with psychosocial difficulties, a finding inconsistent with previous research (Pendley

et al., 1997; Varni et al., 1995). However, these studies demonstrated the impact of physical appearance on psychosocial functioning in children with newly diagnosed cancer, and findings of the present study may reflect the lesser impact of physical appearance with time. It is clear from participants' comments that a proportion of the cancer survivors in the present study were aware of changes in their physical appearance due to cancer, particularly affecting hair quality, weight gain and growth delay, and it is equally clear that a number of adolescents felt that they were bullied as a consequence of these physical changes. However, as one of the participants explains, "it (bullying) happens less now, I am more certain of myself". It may be that as time since treatment increases, adolescents become less troubled by others' reactions to their physical appearance, and it has a lesser impact on their psychosocial wellbeing.

Additionally, a higher self or parent-rated total PIE score (indicating greater perceived impact of cancer on life overall) is associated with poorer psychosocial outcome. It is perhaps not surprising that in families where cancer is seen as having an ongoing impact on life, the cancer survivor rates him or herself, and is rated by parents, as having greater difficulties. Several families commented that cancer has an ongoing impact on their child's life. Bullying, a sense of difference, need for predictability, negative impact on abilities, impact on friendships, and the physical impact of cancer on mood and relationships were named by families as ongoing concerns. For other families, however, cancer was not conceptualised as having an impact on life. These families described 'getting on with it' and 'leaving cancer in the past' as being central to the family philosophy. It is possible that familial coping strategies are important in

determining the extent to which cancer is perceived as having an impact on life.

A valuable question for future research would be to examine whether families with a 'getting on with it' strategy have a more favourable outcome.

Themes emergent from qualitative analysis

Responses to TAT cards suggest that adolescent survivors of cancer are more sensitive to death and loss and hardship and struggle than their siblings, a finding that is compatible with the idea that facing cancer raises challenges about mortality and struggle for the ill child (Fielding, 1985). It is possible that siblings, having experienced cancer in a family member, are also aware of death and loss to a greater extent than peers. Without a comparison group of healthy peers for the TAT responses, it is not possible to ascertain this.

The clinical group were less likely to see themselves as self-efficacious in dealing with threat, and more likely to emphasise the role of a 'protector' or 'rescuer' in their TAT responses. It has been suggested that undergoing the diagnosis and treatment of cancer, and coping with the associated symptoms and interventions may increase an adolescent's dependence on his or her parents at a time when normally he or she may be gaining independence and confidence in self-efficacy (Fielding, 1985). Of course, not all of the clinical group were adolescent at the time of treatment, and it will be interesting for future research to see whether age at treatment is associated with standardised measures of self-efficacy. It is also possible that regardless of age of treatment, all children in the clinical group have greater difficulties with independence and self-efficacy due

to the experience of dependence on parents and medical teams during treatment and the ongoing dependence on follow up care.

Methodological issues

The present study has some methodological advantages over previous studies. Firstly, a conceptual model based on existing theory and research directed the study hypotheses. Secondly, the sample is relatively homogeneous. The age range of participants was relatively small, and all were attending secondary school at the time of the study. The clinical group consisted of participants at least three years post-treatment for tumours in the same brain area. This means that differences in psychosocial difficulties within the group are less likely to be reflective of tumour or treatment effects. Thirdly, parent and child ratings of social skills, illness impact and psychosocial difficulties were collected. The MESSY and PIE are both measures specifically designed for children with disabilities or illness.

However, the study does have a number of limitations. It is important to consider these before discussing implications of the findings.

Findings are reported for 21 adolescent survivors of cancer. Whilst this reflects increased homogeneity of the sample compared to other studies, due to the small sample size, tests of the model can only be regarded as preliminary. Prospective longitudinal designs are needed to disentangle the issue of statistical prediction and causality.

The small sample size reflects the difficulty of single-centre studies investigating survivors of CNS tumours (Glaser, 1997). The low incidence of brain tumours, approximately 250 per year in the UK, and the high mortality rates within two years of diagnosis requires multi-centre studies for adequate numbers to be recruited and to ultimately determine the types of adjustment difficulties these children may be facing, as well as the factors associated with positive outcomes. Previous studies have obtained larger samples by recruiting heterogeneous groups, and possibly losing sight of differences between cancer types. There is evidence that cancer site and histology is related to type and degree of difficulty (Fuemmeler et al., 2002), hence in CNS cancer research it does appear that homogeneous samples are warranted.

Due to the number of correlations carried out on the data, some findings may be a result of Type 1 error, and should be interpreted with caution. The greatest caution needs to be had for those p values significant at the .05 level. However, the great majority of results were significant at the $p < .01$ and $p < .001$ level, and represent a more prudent estimate of significance. In addition, it is noteworthy that the majority of findings are compatible with previous research and in keeping with predictions arising from existing theoretical frameworks.

Measures of the quality of social interaction in friendships or satisfaction with friendships were not included in this research. The reason for this is that few measures of friendship quality exist, and those which are well standardised rely on observation or on teacher ratings and were beyond the time limits of this study. Consequently, it was difficult to know whether friendship expectations

were in fact associated with friendship quality or satisfaction. As a result, the friendship expectation questionnaire was of limited value in this study. It may be that the CFI does not include friendship expectations that are relevant to this population. The present study has looked at one area of children's cognitions about friendships; other aspects of friendship such as satisfaction or quality are yet to be investigated in this population.

Future directions for research

The use of a conceptual model provides a guideline for research. A shared model of psychosocial adjustment in cancer would enable findings to be pooled and understood coherently. Furthermore, if researchers in the field were consistent in their use of measures, findings across research studies could be more easily compared.

Multi-site research is essential for the recruitment of larger homogeneous samples in the research of psychosocial adjustment of CNS cancer survivors. A larger sample size would allow more detailed investigation of the nature and pattern of psychosocial difficulties in this group. Further work needs to be done identifying the predictors of outcome for this population. Larger samples allowing for the use of multivariate statistical techniques and the use of prospective longitudinal designs will be important in ascertaining the predictors of outcome in survivors of cancer.

Illness characteristics such as the histology (type) of tumour, nature of treatment, medical sequelae and cognitive deficit have been identified in the literature as

possible correlates of outcome and are worthy of investigation. A greater understanding of the relationship between illness characteristics and outcome would mean that certain groups of children could be identified as being at higher risk of psychosocial difficulties. A psychologist could routinely assess these children at follow up appointments, and offer early intervention if difficulties arise. Further research may signpost possible preventative interventions with 'high risk' groups of children.

The present study found different levels of internalising symptomatology between males and females, which may indicate gender related responses to stress. Previous research suggests that males and females respond differently to stressful life events, and replication of this finding in children surviving CNS cancer is warranted.

Further investigation of the psychosocial functioning of siblings of cancer survivors would be valuable. Although on standardised measures of adjustment and functioning, siblings appeared to have equivalent strengths and difficulties to the population norms, siblings' responses to the TAT and open-ended questions revealed concerns specific to the impact of cancer. Plausibly, standardised measures are not able to detect subtle difficulties experienced by siblings of cancer survivors. Alternatively, the measures may not tap into the types of difficulties that siblings experience. For example, from siblings' TAT responses, it appeared that a sense of responsibility towards the ill sibling created difficulties for some individuals. Qualitative research and the use of projective tests would be useful in more clearly identifying the nature of siblings' concerns.

Existing research into social competency taps into a number of domains that are not as yet clearly delineated. The present study suggests that cancer survivors do not have deficits in social skills compared to their siblings and population norms. A task for future research is to define more clearly the aspects of social competency that is being investigated, rather than using broad terms, which include various aspects of social functioning. Future research could look at aspects of social competency in this group such as subjective perceptions of cancer survivors' social isolation, social difference and peer rejection. Previous studies have reported findings related to peer perceptions of isolation rather than self-perceptions. Additionally, it would be useful to clarify the relationship between closely related aspects of social functioning, such as popularity, difference and isolation, and levels of involvement in peer groups as well as with individuals. Additionally, it is important that healthy peers' beliefs and behaviours towards children surviving cancer are included in the research.

Connected to this, the nature of friendships is a fertile area for investigation with this population. There is preliminary evidence that cancer survivors may place a lesser emphasis on group identity and close friendship, and have a negative bias towards peer interactions compared to their siblings. Whether this difference exists between cancer survivors and healthy peers, and how their appraisals of peer relationships relate to their satisfaction with friendships is still to be ascertained. The TAT was an invaluable tool in providing rich information about children's appraisals of social interactions. Using a projective test alongside a standardised measure of friendship cognition and a measure of friendship quality

would enrich understanding of these children's friendships. Sophisticated measures of friendship quality and such as role-plays and peer nominations are available, and would be a valuable addition to future research.

Clinical Implications of the findings

Firstly, children who are long-term survivors of brain tumours are at greater risk of psychosocial difficulties than the general population. An implication for clinical psychology is that these children should be regularly assessed for psychosocial difficulties after 'cure', perhaps in conjunction with long-term medical follow up. Assessment measures should be sensitive to internalising problems and peer problems, which the present study has found to be most prevalent in this group. Both parent and child reports can provide different information and therefore eliciting both is likely to be useful. Siblings may have subtle difficulties that do not show up on standardised measures of psychosocial difficulties. For both cancer survivors and their siblings, interviews may be useful in eliciting information about areas of difficulty. If regular assessment by a psychologist is not possible, pen and paper measures could be given to families to complete at medical follow up. The SDQ provides an indication of scores within clinically significant ranges and could be used as a screening tool for psychosocial difficulties in cancer survivors. It has parent and child rated versions, giving multiple perspectives, and is relatively short. Gathering information by questionnaire could take place before clinic visits to or even in the waiting room. Paediatricians might consider routinely offering families the option of referral to psychological services over the period of long-term follow up. All families in the present study were given the option of referral to an

adolescent psychology service. Eight families (38% of the sample) requested referral. It may be that families do not request referral to psychology at medical follow-up as they are not aware of the potential benefits of psychological assessment or intervention, or do not know that they are eligible to access it. An active outreach approach may enable early intervention or even prevention of difficulties with this population.

Findings of the present study identify several possible correlates of psychosocial difficulties in survivors of CNS cancer. Without further research it is difficult to know whether these occur as a result of psychosocial difficulties and as such are markers of them, or whether they are causative factors that can be targeted in preventative interventions. For clinicians, an awareness of the multiplicity of factors related to psychosocial adjustment needs to be recognised.

Children treated at a younger age are at greater risk of difficulties at school, and more likely to have a sense of themselves as different to peers. There is evidence that younger age at treatment is associated with cognitive deficits and greater likelihood of problems with growth and pubertal development (Mulhern et al., 1992). These difficulties may be linked with academic difficulties and associated feelings of difference at school, although this relationships needs to be assessed formally. Given that cognitive deficits are thought to be cumulative, regular cognitive assessment carried out until cognitive function stabilises would be an important part of follow up care with cancer survivors. Accurate and up to date assessments of cognitive strengths and difficulties would be important in the provision of appropriate educational support. In addition, a focus of

psychological therapy with cancer survivors could be to consider the impact of, and adaptation to, changing abilities that may be associated with cancer and its treatment.

Whilst as a group, children surviving cancer do not differ in levels of social skills deficits compared to their peers, children who do have social skills deficits are more likely to have psychosocial difficulties. Children who are unskilled in positive social behaviours, who for example have difficulties in initiating conversations or having eye contact with peers, may have psychosocial difficulties. Additionally, children who demonstrate high levels of inappropriate behaviours, such as being unpleasant to peers, also are more likely to have psychosocial difficulties. Social skills training interventions have been used in the past in order to enable children with cancer to cope with difficult peer interactions on their return to school after diagnosis and initial treatment. The findings of the present study suggest that in children three or more years post treatment, more general social skills are important in psychosocial functioning. Social skills training aimed at social skills of 'everyday' peer interaction is a possible intervention for survivors of cancer. It is not possible, on the basis of these findings, to make a judgement about when such intervention might be most useful. Possibly, the existing social skills training approaches could be expanded to incorporate positive social skills in peer interaction. The aim of this would be to build on individuals' abilities to develop and maintain good peer relationships, alongside the existing focus on helping children cope with difficult peer relationships on their re-integration to school.

A possible focus for intervention could be with the peers of cancer survivors. A finding of this study was that survivors who perceive the cancer to cause peer rejection have greater psychosocial difficulties. There is an indication in the literature that healthy peers have difficulties in interacting with children who are ill or disabled (LaGaipa, 1982), and that a consequence of this is to preclude development of friendships, perhaps leading to appraisals of peer rejection by the child with cancer. School re-integration packages for children with cancer document the importance of educating peers about the nature of the illness (Goodell, 1984; Katz, 1985; Nessim & Katz, 1995), on the basis that peers who are knowledgeable and informed about the disease will be more likely to accept and interact with children with cancer (Mabe, Riley, & Treiber, 1987). While providing information about the effects and nature of cancer is important, a social skills training approach, which enables peers to try out ways of asking about cancer or death, might facilitate 'normal' peer interactions between healthy peers and cancer survivors.

There is some evidence to suggest that children who place less of an emphasis on expectations associated with close friendships have greater levels of psychosocial difficulties. Individuals treated at older ages are more likely to demonstrate such a pattern of friendship cognitions. If friendship expectations are associated with friendship type and quality, we would expect children treated at older ages to have less close friendships and perhaps to consequently feel less socially supported. Exploration of the meaning of children's expectations of their social relationships may be an important factor in clinical intervention. For cancer survivors treated at older ages, diagnosis and treatment may be associated with

traumatic memories and appraisals of threat to a greater extent than survivors treated at younger ages. Previous research suggests that cognitions related to the ongoing threat of cancer may preclude the development of intimate relationships (Byrne et al., 1999; Schover et al., 1999). If friendship expectations are linked to appraisals of threat and concerns about mortality or foreshortened future, cognitive psychological interventions may be useful in helping cancer survivors to find more helpful, alternative ways of understanding the place of cancer in their lives and to facilitate investment in more intimate relationships. Clearly at this point further research is required to test these tentative hypotheses about friendship expectancies and the experience of cancer.

Appraisals of the impact of illness appear to be associated with psychosocial functioning. Clinical psychologists working with cancer survivors should be aware of the ongoing effect of illness cognitions on functioning, or conversely, the effect of psychosocial difficulties on cognitions about illness. This study did not investigate in depth the nature of these cognitions and was not able to ascertain whether negative illness cognitions were a cause or consequence of psychosocial difficulties. However, this may be something a clinical psychologist could explore with an individual in therapy. It may be that children surviving cancer have a bias towards negative appraisals of the impact of illness and psychosocial difficulties are an effect of this. If this appeared to be the case, cognitive behavioural techniques could be useful in challenging unhelpful beliefs about the ongoing effect of cancer. On the other hand, it may be that cancer continues to have an effect on life. For example, adolescents may continue to be teased because of their changed physical appearance. Psychological intervention

may be useful in helping an individual to build on their coping skills in dealing with these difficulties.

The PIE could be a useful measure to use clinically in order to assess cognitions about illness. It gives a clear idea of illness-related areas of difficulty from the perspective of both the parent and child. The PIE is relatively short and straightforward and would therefore be practical as a screening tool.

The clinical group were less likely than siblings, in responses to the TAT, to see themselves as self-efficacious in dealing with threat. In their TAT responses, cancer survivors' descriptions of threat tended to be accompanied by ideas about being saved by an external 'protector' or 'rescuer', whilst siblings expressed ideas about characters being able to save themselves. This may have implications for clinicians working with cancer survivors, who may be positioned in the role of 'rescuer' or 'protector' when these children are facing difficulties. A possible focus of psychological interventions, therefore, may be the development of self-efficacy or internal locus of control.

In summary, present findings indicate that adolescent survivors of childhood CNS cancer are at increased risk of psychosocial difficulties compared to healthy peers, although the majority of survivors do not have adjustment problems.

There is evidence that cancer survivors have more negative perceptions of peer relationships and place less of an emphasis on group identity and close friendship than their peers. Cancer treatment at a young age is associated with difficulties at school and a sense of self as different. Risk factors for psychosocial difficulties include deficits in social skills, negative cognitions about the ongoing

impact of cancer, and expectations of friendship that are inconsistent with the development of close relationships. Further research is essential in order to fully account for differences in psychosocial outcome amongst survivors of cancer. For cancer cure to be a total cure, long-term follow up must extend to an awareness of and provision for psychosocial difficulties in adolescent survivors of CNS cancer.

Appendix One

Letter of ethical approval



The University College London Hospitals
The Joint UCL/UCLH Committees on the Ethics of Human Research

Committee A Co-Chairmen:
Mr M Harrison and Dr R MacAllister

Please address all correspondence to:
Iwona Nowicka
Research & Development Directorate
UCLH NHS Trust
1st floor, Vezey Strong Wing
112 Hampstead Road, LONDON NW1 2LT
Tel. 020 7380 9579 Fax 020 7380 9937
e-mail: iwona.nowicka@uclh.org

Ms Monika Juskiewicz
Trainee Clinical Psychologist
Department of Clinical Health Psychology
UCL
Gower Street

July 10, 2001

Dear Ms Juskiewicz

Study No: 01/0089 *(Please quote in any correspondence)*
Title: Psychosocial effects of childhood central nervous system cancer in adolescent survivors

Many thanks for your letter of the 3rd July addressing the points raised by the Committee. There are no further objections and the study may proceed from the point of view of ethics. Please ensure that you have obtained final approval from the Trust (via the R&D office) before proceeding with your research.

Please note that it is important that you notify the Committee of any adverse events or changes (name of investigator etc) relating to this project. You should also notify the Committee on completion of the project, or indeed if the project is abandoned. **Please remember to quote the above number in any correspondence.**

Yours sincerely


Dr R MacAllister
Co-Chairman



The University College London Hospitals
Research and Development Directorate

Dr Nick McNally - Manager
 Dr Azeem Majeed - Snr Lecturer
 Dr Rumana Omar - Snr Lecturer
 Dr Sonia Saxena - Lecturer
 Mr Graham Petty - Finance Manager (R&D)
 Ms Caoimhe O Sullivan - Statistician
 Mr Joseph Eliahoo - Statistician
 Ms Beverly Warburton - R&D Training

Professor Allyson Pollock
Director of R&D

Professor Alan Thompson
Research Director - NHNN

Dr Paul Batchelor - Snr Lecturer (EDH)
 Dr Bernadette Purcell - SpR
 Ms Susan Kerrison - Snr Research Officer
 Ms Iwona Nowicka - Ethics Admin.
 Mr Philip Diamond - Admin.
 Ms Becky Wellburn - Admin.
 Ms Doreen Sharpe - Admin.

18th June 2001

Dr Creswell
 Sub Dept of Clinical Health Psychology
 UCL

Dear Dr Creswell,

Study No: 01/0089 (*Please quote in all correspondence*)
Title: **Psychosocial effects of childhood central nervous system cancer in adolescent survivors**

Thank you for registering the above study with the R&D Directorate. I am pleased to give Trust approval for the study. Please ensure you have addressed any outstanding issues raised by the ethics committee before you start your project.

With best wishes.

Yours sincerely

Professor Allyson Pollock
 Director of R&D

Appendix Two

Letters to participants

- a) letter to parents
- b) letter to clinical group
- c) letter to sibling group
- d) letter to schools for CFI norms

**The University College London Hospitals
CANCER, CHILDREN'S & ADOLESCENT SERVICES**

NEURO-ENDOCRINE & LATE EFFECTS SERVICE

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study Title: The Psychosocial impact of childhood CNS cancer in adolescent survivors

Information Sheet for Parents

Dear Mr and Mrs «surname»

I am writing to invite you to take part of a study being carried out at The Middlesex Hospital and University College London. As the parent of a child who has been treated for cancer, your views are very important to us.

What is the purpose of this study?

Many children are now being treated for cancer and go on to return to live a full life. However, we are not clear about the effect that cancer and its treatment have on social aspects of life. By understanding more about the social lives of children who have survived cancer we hope to learn how best to help children in the future.

How are we going to do this?

We would like to ask «name», «hisher» teacher and you to fill out questionnaires focusing on different aspects of psychosocial functioning.

We will ask «name» to fill out some questionnaires that have been used by other researchers with young people. We will also be showing «himher» some pictures and asking «himher» to tell us stories about these. We will not be asking «name» to talk to us about «hisher» experiences of hospital, or anything that «heshe» does not want to talk about.

How long will this take?

We would need to spend about an hour with «name». The questionnaires we would like you to fill in should take between 30 and 45 minutes to complete.

Where will this take place?

We would either arrange to meet you before your next appointment at the Late Effects Clinic, or, if this is not possible, come to your home to talk to «name». The questionnaires for you will be sent to you by post and can be filled out in your own time.

What are the potential benefits?

If «name» decides during the course of the study that «heshe» would like to see a psychologist, we will be able to help you contact the Psychology Department at the Middlesex to discuss this.

Secondly, it should help us develop the service for children who are being treated for cancer now and in the future. It will inform us how to best help life get back to normal for these children.

And finally, we hope that this will be an interesting experience for you.

Are there any risks?

There is no reason to believe that being part of this study would be in any way harmful.

All proposals for research using human subjects are reviewed by an ethics committee before they can proceed. This proposal was reviewed by the Joint UCL / UCLH Committees on the Ethics of Human Research.

However, if you did have concerns we would hope these could be discussed with us. You can contact Dr Angela Griffin or Dr Cathy Creswell at the addresses given below to register any concerns, and they would deal with these as appropriate.

What happens next?

A researcher will contact you by telephone within the next week to find out if you would like to take part in the study, and to arrange a time to meet «name». We will also be asking for permission to contact «name»'s class tutor.

Attached to this letter is a letter for «name». If you would like to take part in this study, we would be grateful if you could go through the letters and discuss them with your child.

You do not have to take part in this study if you do not want to. If you decide to take part you may withdraw at any time without having to give a reason. Please feel free to contact Monika Juskiewicz if you have any questions about this research.

We will write to you with findings of the study when the work has been completed. All information given to us will be confidential and anonymous.

We look forward to talking to you. Thank you for taking time to read this letter.
Yours sincerely,

Dr Helen Spoudeas

Consultant in Neuroendocrine & Late Effects of Childhood Malignancies
UCLH & GOSH Hospitals
Honorary Senior Lecturer in Paediatric Endocrinology, UCL & ICH

Dr Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juskiewicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

**The University College London Hospitals¹²⁸
CANCER, CHILDREN'S & ADOLESCENT SERVICES**

**NEURO-ENDOCRINE & LATE EFFECTS
SERVICE**

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study title: The Psychosocial impact of childhood CNS cancer in
adolescent survivors

Information Sheet for Patients

Dear «name»

I am writing to invite you to take part of a study being carried out at The Middlesex Hospital and University College London. As someone who has been treated for cancer, your views are very important to us.

Why are we doing this study?

Many children are now being treated for cancer and go on to return to a full life. However, we are not clear about the effect that cancer and its treatment have on your social life. A better understanding of the ways in which you think about friendship and other parts of your life may help us help other children in the future.

How are we going to do this?

We would like to invite you to be part of this work. This would mean spending about one hour with a researcher. This person would either see you at the Middlesex Hospital when you come to the Late Effects clinic, or come to visit you at home.

During this time you would fill out four questionnaires and would spend some time talking to the researcher. You will not have to talk about anything that you do not want to.

We would also ask your parents and teacher to fill out the same types of questionnaires you do, so that we get an idea of what different people think. We would also like your brother or sister to take part so that we can see if things are different for someone who has not had cancer.

What are the potential benefits?

First of all we hope that this will be an interesting experience for you.

Secondly, it should help us make the service better for children who are being treated for cancer now and in the future. It will let us know how to best help life get back to normal for these children.

Thirdly, if you feel you would like to see if you would like to talk to someone about the things that are worrying you, there is a Psychology Department at the Middlesex that we would be able to put you in touch with

Are there any risks?

There is no reason to believe that being part of this study would be in any way harmful. You will not be asked to do anything you do not want to do.

However, if you were not happy with anything you could tell us. You can contact Dr Angela Griffin or Dr Cathy Creswell at the addresses given below to talk about any worries.

What happens next?

A researcher will contact you by phone within the next week to see if you would like to take part. If you do, we will arrange a time for you and your brother or sister to meet with her. We will ask for permission to contact your class tutor. We will also send some questionnaires to one of your parents to fill out.

You do not have to take part in this study if you do not want to. If you decide to take part and then change your mind, you can leave the study at any time. If you don't take part, your medical treatment will not be affected in any way.

When the project is finished, we will let you know what our findings are. The information you give us will be kept private, and anonymous.

We look forward to talking to you. Thank you for taking time to read this letter.

Yours sincerely,

Dr Helen Spoudeas

Consultant in Neuroendocrine & Late Effects of Childhood Malignancies
UCLH & GOSH Hospitals
Honorary Senior Lecturer in Paediatric Endocrinology, UCL & ICH

Dr Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juskiewicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

**The University College London Hospitals¹³⁰
CANCER, CHILDREN'S & ADOLESCENT SERVICES**

**NEURO-ENDOCRINE & LATE EFFECTS
SERVICE**

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study Title: The Psychosocial impact of childhood CNS cancer in adolescent survivors

Information Sheet for siblings

Dear «sibtitle»

I am writing to invite you to take part of a study being carried out at The Middlesex Hospital and University College London. As the «identifiedsib» of a person who has been treated for cancer, your views are very important to us.

Why are we doing this study?

Many children are now being treated for cancer and go on to return to a full life. However, we are not clear about the effect that cancer and its treatment have on children's social life. A better understanding of the ways in which you think about friendship and other parts of your life may help us help other children in the future.

How are we going to do this?

We would like to invite you to be part of this work. This would mean spending about one hour with a researcher. This person would see you at same time as seeing «name» at the Middlesex Hospital Late Effects clinic, or come to visit you at home.

During this time you would fill out four questionnaires and would spend some time talking to the researcher.

We will be asking your teacher and your parents to fill out the same types of questionnaires you do, so that we get an idea of what different people think. «name» will be taking part in the study too, as it is important for us to understand if things are different for him or her.

What are the potential benefits?

First of all we hope that this will be an interesting experience for you.

Secondly, it should help us develop the service for children who are being treated for cancer now and in the future. It will let us know how to best help life get back to normal for these children.

Are there any risks?

There is no reason to believe that being part of this study would be in any way harmful. You will not be asked to do anything you do not want to do.

However, if you were not happy with anything you could tell us. You can contact Dr Angela Griffin or Dr Cathy Creswell at the addresses given below to talk about any worries.

What happens next?

We will contact you by telephone within the next week to find out whether you would like to take part in the study, and to decide on a time that we can meet. We will also be asking for permission to contact your class tutor.

You do not have to take part in this study if you do not want to. If you decide to take part and then change your mind, you can leave the study at any time.

When the project is finished, we will let you know what our findings are. The information you give us will be kept private, and anonymous.

We look forward to talking to you. Thank you for taking time to read this letter.
Yours sincerely,

Dr Helen Spoudeas

Consultant in Neuroendocrine & Late Effects of Childhood Malignancies
UCLH & GOSH Hospitals
Honorary Senior Lecturer in Paediatric Endocrinology, UCL & ICH

Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juskiewicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

**The University College London Hospitals¹³²
CANCER, CHILDREN'S & ADOLESCENT SERVICES**

**NEURO-ENDOCRINE & LATE EFFECTS
SERVICE**

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study Title: The Psychosocial impact of childhood CNS cancer in adolescent survivors

Dear Parent(s)

Your child's school is cooperating with some research about the effects of childhood cancer on children's social life and friendships, which is being carried out at The Middlesex Hospital and University College London. It is important for us to know how children who have not had cancer think about friendships, and this is why we would like to invite your child to take part in this research.

Why are we doing this study?

Many children are now being treated for cancer and go on to return to a full life. However, we are not clear about the effect that cancer and its treatment have on children's social life. A better understanding of the ways in which children think about friendship may help us help other children in the future.

How are we going to do this?

Your child will be asked to complete some questionnaires during a lesson. We will be using a questionnaire that has been used in research with children before. The completed questionnaire will be used for research purposes only, and names will be removed from it to keep answers confidential.

Why my child?

All the children in your child's class are being asked to take part.

What are the potential benefits?

First of all we hope that this will be an interesting experience for your child. Secondly, it should help us develop the service for children who are being treated for cancer now and in the future. It will let us know how to best help life get back to normal for these children.

Are there any risks?

There is no reason to believe that being part of this study would be in any way harmful.

All proposals for research in which people take part are reviewed by an ethics committee before they can begin. This proposal was reviewed by the joint UCL/UCLH committees on the Ethics of Human Research.

However, if you were not happy with anything you could tell us. You can contact Dr Angela Griffin or Dr Cathy Creswell at the addresses given below to talk about any worries.

What happens next?

If you would like your child to participate in this research, please return the reply slip below straight away.

Your child does not have to take part in this study if you do not want them to. You may withdraw your child at any time without having to give a reason.

Thank you very much for your time.

Yours sincerely,

Dr Helen Spoudeas

Consultant in Neuroendocrine & Late Effects of Childhood Malignancies
UCLH & GOSH Hospitals
Honorary Senior Lecturer in Paediatric Endocrinology, UCL & ICH

Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juszkievicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

Please complete and return to your child's teacher if you are happy for your child to participate in the research study.

I **do/ do not** give permission for my child to be invited to participate in this research

Name of child: _____

Name of parent: _____

Address: _____

Appendix Three

Consent forms

- a) parent consent forms**
- b) child consent forms**

135

The University College London Hospitals
CANCER, CHILDREN'S & ADOLESCENT SERVICES

NEURO-ENDOCRINE & LATE EFFECTS SERVICE

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study Title: The Psychosocial impact of childhood CNS cancer in adolescent survivors

Consent form

Have you read the information sheet about this study? YES / NO

Have you had a chance to ask questions about and discuss this study? YES / NO

Have you had satisfactory answers to your questions? YES / NO

Have you had enough information about this study? YES / NO

Which Clinician have you spoken to about this study? _____

Do you understand that you are free to withdraw from this study...

At any time? YES / NO

Without giving a reason for withdrawing? YES / NO

without affecting your future medical treatment? YES / NO

Do you agree to take part in this study? YES / NO

Signature of clinician: _____

Signature of participant: _____

Signature of parent / guardian: _____

Dr Helen Spoudeas

Consultant in
Neuroendocrine & Late
Effects of Childhood
Malignancies
UCLH & GOSH

Honorary Senior Lecturer in
Paediatric Endocrinology
UCL and ICH

Dr Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent
Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health
Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juskiewicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health
Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

**The University College London Hospitals¹³⁶
CANCER, CHILDREN'S & ADOLESCENT SERVICES**

NEURO-ENDOCRINE & LATE EFFECTS SERVICE

Dr Helen Spoudeas

3rd Floor Dorville House
The Middlesex Hospital, Mortimer Street London W1N 8AA
Tel: 020 7380 9950 (sec) Fax: 020 7636 2144 Email: tracey.smith@uclh.org

CONFIDENTIAL

Study Title: The Psychosocial impact of childhood CNS cancer in adolescent survivors

Consent form

Have you read the information sheet about this study? YES / NO

Have you had a chance to ask questions about and discuss this study? YES / NO

Have you had satisfactory answers to your questions? YES / NO

Have you had enough information about this study? YES / NO

Which Clinician have you spoken to about this study? _____

Do you understand that you are free to withdraw from this study...

At any time? YES / NO

Without giving a reason for withdrawing? YES / NO

without affecting your future medical treatment? YES / NO

Do you agree to take part in this study? YES / NO

Signature of clinician: _____

Signature of participant: _____

Dr Helen Spoudeas

Consultant in
Neuroendocrine & Late
Effects of Childhood
Malignancies
UCLH & GOSH

Honorary Senior Lecturer in
Paediatric Endocrinology
UCL and ICH

Dr Angela Griffin

Clinical Psychologist
Dept of Child & Adolescent
Psychology
Middlesex Hospital
London W1N 8AA

Tel: 020 7380 9086

Dr Cathy Creswell

Clinical Research Fellow
Sub-dept of Clinical Health
Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 020 7679 5936

Monika Juskiewicz

Trainee Clinical Psychologist
Sub-dept of Clinical Health
Psychology
University College London
Gower Street London
WC1E 6BT

Tel: 07970 00 78 78

Appendix Four

Strengths and difficulties questionnaire (SDQ)

Strengths and Difficulties Questionnaire

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

Your Name

Male/Female

Date of Birth

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

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that you have difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your Signature

Today's Date

Thank you very much for your help

Strengths and Difficulties Questionnaire

140

P4-16

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

Child's Name

Male/Female

Date of Birth

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

Do you have any other comments or concerns?

Please turn over - there are a few more questions on the other side

Overall, do you think that your child has difficulties in one or more of the following areas: emotions, concentration, behaviour or being able to get on with other people?

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

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

• How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties interfere with your child's everyday life in the following areas?

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
FRIENDSHIPS	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
CLASSROOM LEARNING	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
LEISURE ACTIVITIES	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

• Do the difficulties put a burden on you or the family as a whole?

Not at all	Only a little	Quite a lot	A great deal
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Signature Date

Mother/Father/Other (please specify:)

Thank you very much for your help

Appendix Five

Matson's Evaluation of Social Skills with Youngsters (MESSY)

Matson's Evaluation of Social Skills with Youngsters

Self Rating Form

Date: _____	Child's name: _____
-------------	---------------------

This survey is a measure of human behaviour. Please read the statements below and rate either HOW OFTEN YOU DO THESE BEHAVIOURS or HOW MUCH YOU AGREE WITH THE STATEMENTS.

Please rate what you actually DO or BELIEVE rather than what you think the 'right' answer would be.

Rating scale

1	2	3	4	5
Not at all	A little	Sometimes	mostly	Very much

	1	2	3	4	5
1. I make other people laugh (tell jokes, funny stories)					
2. I threaten people or act like a bully					
3. I become angry easily					
4. I am bossy (tells people what to do)					
5. I gripe or complain often					
6. I speak (break in) when someone else is speaking					
7. I take or use things that are not mine without permission					
8. I brag about myself					
9. I look at people when I am talking to them					
10. I have many friends					
11. I slap or hit when I am angry					
12. I help a friend who is sad					
13. I cheer up a friend who is hurt					

1	2	3	4	5	144
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
14. I give other children dirty looks					
15. I feel angry or jealous when someone else does well					
16. I feel happy when someone else does well					
17. I pick out other peoples' faults or mistakes					
18. I always want to be first					
19. I break promises					
20. I tell people they look nice					
21. I lie to get something I want					
22. I pick on people to make them angry					
23. I walk up to people and start a conversation					
24. I say 'thank you' and am happy when someone does something for me					
25. I like to be alone					
26. I am afraid to speak to others					
27. I keep secrets well					
28. I know how to make friends					
29. I hurt other people's feelings on purpose (I try to make people sad)					
30. I make fun of others					
31. I stick up for my friends					
32. I look at people when they are speaking					
33. I think I know it all					
34. I share what I have with others					
35. I am stubborn					

1	2	3	4	5	145
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
36. I act as if I am better than other people					
37. I show my feelings					
38. I think people are picking on me when they are not					
39. I make sounds that bother others (e.g. burping / sniffing)					
40. I take care of others' property as if it were my own					
41. I speak too loudly					
42. I call people by their names					
43. I ask if I can be of help					
44. I feel good if help someone					
45. I try to be better than everyone else					
46. I ask questions when talking with others					
47. I see my friends often					
48. I play alone					
49. I feel lonely					
50. I feel sorry when I hurt someone					
51. I like to be the leader					
52. I join in games with other children					
53. I get into fights a lot					
54. I am jealous of other people					
55. I do nice things for people who are nice to me					
56. I ask others how they are, what they are doing etc.					
57. I stay with others too long (wear out my welcome)					

1	2	3	4	5	146
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
58. I explain things more than necessary					
59. I laugh at other people					
60. I think that winning is everything					
61. I hurt others' feelings when teasing them					
62. I want to get even with someone who hurts me					

© copyright 1990 DS Publishing Corporation

Matson's Evaluation of Social Skills with Youngsters

Parent / Teacher Rating Form

Date: _____ Child's name: _____

This survey is a measure of human behaviour. Please read the statements below and rate HOW OFTEN THE CHILD DEMONSTRATES THE BEHAVIOURS.

Please rate how often each behaviour actually occurs rather than what you think the 'right' answer would be.

Rating scale

1	2	3	4	5
Not at all	A little	Sometimes	mostly	Very much

	1	2	3	4	5
1. makes other people laugh (tells jokes, funny stories)					
2. threatens people or acts like a bully					
3. becomes angry easily					
4. is bossy (tells people what to do instead of asking)					
5. gripes or complains often					
6. speaks (breaks in) when someone else is speaking					
7. takes or uses things that are not his/hers without permission					
8. brags about him/herself					
9. slaps or hits when he /she is angry					
10. helps a friend who is hurt					
11. gives other children dirty looks					
12. feels angry or jealous when someone else does well					
13. picks out other children's faults and mistakes					
14. always wants to be first					

1	2	3	4	5	148
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
15. breaks promises					
16. lies to get what he/she wants					
17. picks on people to make them angry					
18. walks up to people and starts a conversation					
19. says 'thank you' and is happy when someone does something for him/her					
20. is afraid to speak to others					
21. hurts other people's feelings on purpose (tries to make people sad)					
22. is a sore loser					
23. makes fun of others					
24. blames others for his/her own problems					
25. sticks up for friends					
26. looks at people when they are speaking					
27. thinks he / she knows it all					
28. smiles at people he / she knows					
29. is stubborn					
30. acts as if he /she is better than others					
31. shows feelings					
32. thinks people are picking on him/her when they are not					
33. thinks good things are going to happen					
34. works well on a team					
35. makes sounds that bother others (e.g. burping / sniffing)					

1	2	3	4	5	149
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
36. brags too much when he/she wins					
37. takes care of others' property as if it were his/her own					
38. speaks too loudly					
39. calls people by their names					
40. asks if he/she can be of help					
41. feels good if he/she helps others					
42. defends self					
43. always thinks something bad is going to happen					
44. tries to be better than everyone else					
45. asks questions when talking with others					
46. feels lonely					
47. feels sorry when he/she hurts someone					
48. gets upset when he/she has to wait for things					
49. likes to be the leader					
50. joins in games with other children					
51. plays by the rules of a game					
52. gets into fights a lot					
53. is jealous of other people					
54. does nice things for people who are nice to him/her					
55. tries to get others to do what he/she wants					
56. asks others how they are, what they are doing etc.					

1	2	3	4	5	150
Not at all	A little	Sometimes	mostly	Very much	

	1	2	3	4	5
57. stays with others too long (wears out his/her welcome)					
58. explains things more than necessary					
59. is friendly to new people he/she meets					
60. hurts others to get what he / she wants					
61. talks about problems or worries					
62. thinks that winning is everything					
63. hurts others' feelings when teasing them					
64. wants to get even with someone who hurts him/her					

Appendix Six

Childrens' Friendship Inventory (CFI)

Appendix Seven

Perceived Illness Experience Scale (PIE)

Appendix Eight

Thematic Apperception Test Instructions

Thematic Apperception Test (TAT) - Instructions

I am going to show you some cards with pictures on them.

When I show you a card I would like you to make up a story about what is happening in the picture, what might have happened before and after the picture, and what the people in the pictures are thinking or feeling.

There is no 'right' or 'wrong', just say what ever comes in to your head.

Does that sound OK?

Prompts:

What is happening here?

What might have happened leading up to this / before this?

What might happen next?

What do you think the people are thinking or feeling?

(derived from the TAT manual - Murray, 1943)

REFERENCES

Adams, G.R. (1983). Social competence during adolescence: Social sensitivity, locus of control, empathy and peer popularity. *Journal of Youth and Adolescence*. 12, 203-211

Allan, G. (1979). *A sociology of friendship and kinship*. London: George, Allen and Unwin.

American Brain Tumor Association. (2001). *A Primer of Brain Tumors: A Patient's Reference Manual*. (7th Edition) <http://www.abta.org>

Anderson, V.A., Smibert, E., Ekert, H. & Godber, T. (1994). Intellectual, educational and behavioural sequelae after cranial irradiation and chemotherapy. *Arch Dis Childhood*. 70, 476-483

Anderson, V.A., Godber, T., Smibert, E., Weiskop, S. & Ekert, H. (2000). Cognitive and academic outcome following cranial irradiation and chemotherapy in children: a longitudinal study. *British Journal of Cancer*, 82(2), 255-62

Argyle, M. (1984). The nature of social relationships. *Jyvaeskylae Studies in Education, Psychology and Social Research*, 54, 93-106

Armstrong, F.D. (1992). Psychosocial intervention in pediatric cancer: A strategy for prevention of long-term problems. In T.M. Field, P.M. McCabe, & N. Schneiderman, (Eds). *Stress and coping in infancy and childhood* (p. 197-218).

Armstrong, F.D., & Horn, M. (1995). Educational issues in childhood cancer. *School Psychology Quarterly*, 10, 292-304.

Banis, H.T., Varni, J.W., Wallander, J.L., Korsch, B.M., et al. (1988). Psychological and social adjustment of obese children and their families. *Child: Care, Health & Development*. 14(3), 157-173.

Bailey, R.C., Finney, P. & Helm, B. (1975). Self-concept support and friendship duration. *Journal of Social Psychology*. 96(2), 237-243.

Battista, E.M. (1986). Educational needs of the adolescent with cancer and his family. *Seminars in Oncology Nursing*, 2, 123-125.

Berk, L.E. (1994). *Child Development* (3rd Ed). Needham Heights, Allyn & Bacon

Berndt, T.J & Ladd, G.W (1989). *Peer relationships in child development*. New York, Wiley

Berscheid, E., & Walster, E. (1978). Issues in studying close relationships: conceptualizing and measuring closeness. In C. Hendrick (Ed.), *Close relationships*:

Review of personality and social psychology (Vol. 10, pp. 63-91). Newbury Park, CA: Sage.

Bigelow, B.J. (1977). Children's friendship expectations: A cognitive-developmental study. *Child Development*, 48, 246-253.

Bigelow, B.J., & LaGaipa, J.J. (1975). Children's written descriptions of friendship: A multidimensional analysis. *Developmental Psychology*, 11, 857-858.

Bigelow, B.J., & LaGaipa, J.J. (1980). The development of children's friendships. In H.C. Foot, A.J. Chapman & J.R. Smith. *Friendship and Social Relations in Children* (pp. 45-64). New York: John Wiley and Sons.

Boulton, M.I. & Smith, P.K. (1994). Bully/victim problems among middle school children: stability, self-perceived competence, and peer acceptance. *British Journal of Developmental Psychology*, 12, 315-29.

Bradford, R. (1990a). Parents experiences of the care provided by medical services whilst looking after a chronically ill child. *Early Child Development and Care*, 59, 43-51

Bradford, R (1990b). Short communication: The importance of psychosocial factors in understanding child distress during routine x-ray procedures. *Journal of Child Psychology and Psychiatry*, 31(6), 973-982

Bradford, R. (1997). *Children, Families and Chronic Disease: Psychological models and methods of care*. London : Routledge

Brown,R.T., Kaslow, N.J, Hazzard, A.P., Madan-Swain,A., et-al. (1992). Psychiatric and family functioning in children with leukemia and their parents. *Journal of the American Academy of Child and Adolescent Psychiatry*, 31(3), 495-502

Brown, R.T., Sawyer, M.B., Antoniou, G., Toogood, I., Rice, M., Thompson, N., & Madan-Swain, A. (1996). A 3-year follow-up of the intellectual and academic functioning of children receiving central nervous system prophylactic chemotherapy for leukemia. *Developmental and Behavioral Pediatrics*, 17, 392-398.

Byrne, J. (1999). Infertility and Premature Menopause in Childhood Cancer Survivors. *Medical and Pediatric oncology*, 33(1), 24

Cadman, D., Boyle, N., Szatmari, P. & Offord, D. (1987). Chronic Illness, Disability, and mental and social wellbeing: findings of the Ontario Child Health Study. *Paediatrics*, 5, 60-64

Cairns, N.U., Klopovich, P., Hearne, E. & Lansky, S. (1982). School attendance of children with cancer. *Journal of School Health*, 52(3), 152-155.

Carpenter, P.J. & Sahler, O.J.Z. (1991). Sibling perception and adaptation to childhood cancer: Conceptual and methodological considerations In: J.H. Johnson & S.B Johnson

(Eds). *Advances in child health psychology* (p193-208) Gainesville: University of Florida Press.

Carpentieri, S.C., Mulhern, R.K., Douglas, S., Hanna, S., & Fairclough, D. (1993). Behavioral resiliency among children surviving brain tumors: A longitudinal study. *Journal of Clinical Child Psychology*, 22, 236-246.

Chapman, C.A., Waber, D.P., Bernstein, J.H., Pomeroy, S.L., La Vally, B., Sallan, S.E. & Tarbell, N. (1995) Neurobehavioural and nerologic outcome in long-term survivors of posterior fossa brain tumours. *Journal of Child Neurology*, 10, 209-212

Chekryn, J., Deegan, M., & Reid, J. (1986). Normalizing the return to school of the child with cancer. *Journal of the Association of Pediatric Oncology Nurses*, 3, 20-24.

Copeland, D. R., Fletcher, J. M., Pfefferbaum-Levine, B., Jaffe, M., Reid, H., & Maor, M. (1985). Neuropsychological sequellae of childhood cancer in long-term survivors. *Pediatrics*, 75, 745-753.

Cook, K.S. (1977). Exchange and power in networks of interorganizational relations. *Sociological Quarterly*, 18, 62-82.

Craft, M.J. & Craft, J.L. (1989). Perceived changes in siblings of hospitalised children: Comparison of sibling and parent reports. *Children's Health Care*, 18, 42-48

Crick, N.R. & Dodge, K.A. (1994). A review and reformulation of social information-processing mechanisms in children's social adjustment. *Psychological Bulletin*. 115(1), 74-101.

Czikszentmihalyi, M. & Graef, R (1975) Socialisation into sleep: exploratory findings. *Merrill Palmer Quarterly* 21, 3-18

Davis, H (1993). *Counselling parents of children with chronic illness or disability*. Leicester, England: British Psychological Society.

Davis, K.E. & Todd, M.J. (1982) 'Friendship and Love Relationships', in K.E. Davis & T.O. Mitchell (eds) *Advances in Descriptive Psychology*, pp. 79-122. Greenwich, JAI Press.

Deasy-Spinetta, P. (1981). The school and the child with cancer. In J. Spinetta & P. Deasy-Spinetta (Eds.), *Living with childhood cancer*, (pp. 153-168).

Derlega, V.J. & Chaikin, A.L. (1979). Intimacy and self-disclosure in interpersonal relationships. *Przegląd Psychologiczny*. 1979; Vol 22(2): 257-271.

Dickens W.J. & Perlman D. (1981) Friendship over the life-cycle. Chapter 4 in S. Duck & R. Gilmour (Eds). *Personal relationships 2: Developing personal relationships*. London: Academic Press.

Dolgin, M.J., & Jay, S.M. (1989). Childhood cancer. In T.H. Ollendick & M. Hersen (Eds.), *Handbook of child psychopathology* (2nd ed, pp. 327-340).

Duck, S.W. (1973). *Personal relationships and personal constructs: A study of friendship formation*. New York, NY, John Wiley and Sons.

Duffner, P.K., Cohen, M.E., & Freeman, A.A. (1985). Paediatric brain tumours: An overview. *Cancer Journal for Clinicians*, 35, 287-301.

Eiser, C. (1989). Coping with chronic childhood diseases: Implications for counselling children and adolescents. *Counselling Psychology Quarterly*. 2(3), 323-336.

Eiser, C. (1990). Psychological aspects of physical illness. *Journal of Child Psychology and Psychiatry* 31: 85-98.

Eiser, C. (1993). *Growing up with a chronic disease: the impact on children and their families*. London: Jessica Kingsley Publishers Ltd.

Eiser, C. (1995) Children's understanding of the cancer experience. *International Journal of Pediatric Hematology/Oncology* 357-367.

Eiser, C., Havermans, T. & Eiser, J.R. (1995). Parents' attributions about childhood cancer: Implications for relationships with medical staff. *Child Care, Health and Development*. 21(1), 31-42.

Eiser, C., Jill, J.J. & Vance, Y.H. (2000). Examining the psychological consequences of surviving childhood cancer: Systematic review as a research method in Pediatric psychology. *Journal of Pediatric Psychology*, 25(6), 449-460.

Eiser,C., Kopel,S., Cool,P. & Grimer,R (1999). The Perceived Illness Experience Scale (PIE): Reliability and validity revisited. *Child Care, Health and Development*, 25(3), 179-190

Ellenberg, L., McComb, J. G., Siegel, S. E., & Stowe, S. (1987). Factors affecting intellectual outcome in pediatric brain tumor patients. *Neurosurgery*, 21, 638–644.

Emery, R.E. (1982). Marital discord and child behavior problems. *Dissertation Abstracts International*. 43(2-B), 521.

Erikson, E.H. (1964, reprinted 1993). *Childhood and society*. New York, W. W. Norton and Co, Inc.

Ferrari, M. (1984). Chronic illness: Psychosocial effects on siblings: I. Chronically ill boys. *Journal of Child Psychology and Psychiatry and Allied Disciplines*. 25(3), 459-476.

Ferrari, M. (1987). The diabetic child and well sibling: Risks to the well child's self-concept. *Children's Health Care*, 15(3), 141-148.

Fielding, D. (1987). Working with children and young people. In J.S. Marzillier, & J. Hall,(Eds). *What is clinical psychology?* Oxford medical publications. (pp. 85-115). Oxford University Press.

Fryer, L.L., Finch, A.J., Saylor, C.F., & Smith, K.E. (1989). Helping the child with cancer: What school personnel want to know. *Psychological Reports*, 65, 563-566.

Fuemmeler, B.F., Mullins, L.L. & Marx, B.P. (2001). Posttraumatic stress and general distress among parents of children surviving a brain tumour. *Children's Health Care*, 30(3), 162-182

Fuemmeler, B.F., Elkin, T.D. & Mullins, L.L (2002). Survivors of brain tumors: Behavioral, emotional, and social adjustment. *Clinical Psychology Review*, 22, 547-585

Gaze, M.N (1998) Radiotherapy. In P.A Voute, C. Kalifa & A. Barrett (Eds) *Cancer in Children: Clinical management* (pp60-70) Oxford University Press, Oxford

Glaser, A. W., Nik Abdul Rashid, N. F., Walker, U. C. L., & Walker, D. A. (1997). School behavior and health status after central nervous system tumors in childhood. *British Journal of Cancer*, 76, 643–650

Glazer, J.P. (1991). Psychiatric aspects of cancer in childhood and adolescence. In M. Lewis, *Child and adolescent psychiatry: A comprehensive textbook* (pp. 964-977).

Goodell, A. (1984). Peer education in schools for children with cancer. *Issues in Comprehensive Pediatric Nursing*, 7, 101-106.

Goodman, R. (1997) The SDQ: a research note. *J child Psychology Psychiatry*, 38, 581-586

Gortmaker, S.L, Perrin, J.W., Weitzman, M., Homer, C.J. et al. (1993). An unexpected success story: Transition to adulthood in youth with chronic physical health conditions. *Journal of Research on Adolescence*. 3(3), 317-336

Granowetter, L. (1994). Pediatric oncology: A medical overview. In D.J. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp. 9-34).

Greenburg, H. S., Kazak, A. E., & Meadows, A. T. (1989). Psychological functioning in 8-to 16-year-old cancer survivors and their parents. *Journal of Pediatrics*, 114, 488-493.

Gurney, J.G., Smith, M.A. & Bunin, G.R. (1999). CNS and miscellaneous intracranial and intraspinal neoplasms. In L.A.G. Ries, M.A. Smith, J.G. Gurney, M. Linet, T. Tamara, J.L Young & G.R. Bunin (Eds), *Cancer incidence and survival among children and adolescents: United States SEER program 1975-1999* (pp51-64).

Bethesda, MD: SEER Program, National Cancer Institute (NIH publication No. 99-4649)

Harris, J.A., Newcomb, A.F. & Gewanter, H.L. (1991). Psychosocial effects of juvenile rheumatic disease: The family and peer systems as a context for coping. *Arthritis Care and Research*, 4(3), 123-130

Havermans, T. & Eiser, C. (1994). Siblings of a child with cancer. *Child Care, Health and Development*, 20(5), 309-322.

Hays (1988) Friendship. In S. Duck, (Ed) *Handbook of Interpersonal Relationships*. London: Wiley & Sons.

Hays, D. M., Landsverk, J., Sallan, S. E., Hewett, K. D., Patenaude, A. F., Schoonover, D., Zilber, S. L., Ruccione, K., & Siegal, S. E. (1992). Educational, occupational, and insurance status of childhood cancer survivors in their fourth and fifth decades of life. *Journal of Clinical Oncology*, 10, 1397-1406

Henning, J., & Fritz, G.K. (1983). School re-entry in childhood cancer. *Psychosomatics*, 24, 261-269.

Hirsch, J. F., Renier, D., Czernichow, P., Benveniste, L., & Pierre-Kahn, A. (1979). Medulloblastoma in childhood: Survival and functional results. *Acta Neurochirurgica*, 48, 1-15

Hobbs, N. & Perrin, J.M (Eds) (1985) *Issues in the care of children with chronic illness: A sourcebook on problems, services, and policies*. Jossey-Bass health series and Jossey-Bass social and behavioral science series. Jossey-Bass Inc, Publishers.

Hoppe-Hirsch, E., Renier, D., Lellouch-Tubiana, A., Sainte-Rose, C., Pierre-Kahn, A. & Hirsch, JF (1990) Medulloblastoma in childhood: progressive intellectual deterioration. *Child Nerv Syst* 6(2), 60-65

Horowitz, M.J. & Kazak, A.E. (1990). Family adaptation to childhood cancer: Sibling and family system variables. *Journal of Clinical Child Psychology*, 19, 221-228

Houtzager, B.A. & Grootenhuis, M.A. (1999) Adjustment of siblings to childhood cancer: a literature review. *Support & Care in Cancer*, 7(5)

Huston, T.L. & Levinger, G. (1978). Interpersonal attraction and relationships. *Annual Review of Psychology*, 29:,115-156.

Jannoun, L. & Bloom, H.J.G (1990). Long term psychological effects in children treated for Intracranial tumours. *International Journal of Radiation Oncology*, 18, 747-753

Johnson, L.J and LaMontagne, M.J (1993). Using content analysis to examine the verbal or written communication of stakeholders within early intervention. *Journal of Early Intervention*, 17(1), 73-79.

Jones, R.M. & Adams, G.R. (1982). Assessing the importance of physical attractiveness across the life-span. *Journal of Social Psychology*. 118(1), 131-132.

Kaplan, S.L., Busner, J., Weinhold, C. & Lenon, P. (1987). Depressive symptoms in children and adolescents with cancer: A longitudinal study. *Journal of the American Academy of Child and Adolescent Psychiatry*. 26(5), 782-787.

Kashani, J.H., Barbero, G.J., Wilfley, D.E., Morris, D.A., et al (1988). Psychological concomitants of cystic fibrosis in children and adolescents. *Adolescence*. 23(92), 873-880.

Katz, E.R. (1980). Illness impact and social reintegration. In J. Kellerman (Ed.), *Psychological aspects of childhood cancer*. Springfield, IL: Charles C. Thomas.

Katz, E.R & Jay, S.M. (1984). Psychological aspects of cancer in children, adolescents, and their families. *Clinical Psychology Review*, 4(5), 525-542.

Katz, E.R., Rubinstein, C.L., Hubert, N.C., & Blew, A. (1988). School and social reintegration of children with cancer. *Journal of Psychosocial Oncology*, 6, 123-140.

Katz, E.R., Dolgin, M.J., & Varni, J.W. (1990). Cancer in children and adolescents. In A.M. Gross & R.S. Drabman (Eds.), *Handbook of clinical behavioral pediatrics: Applied clinical psychology*. (pp129-146).

Katz, E.R., Varni, J.W., Rubenstein, C.L., Blew, A., & Hubert, N. (1992). Teacher, parent, and child evaluative ratings of a school reintegration intervention for children with newly diagnosed with cancer. *Children's Health Care*, 21, 69-75.

Kazak, A.E. (1994). Implications of survival: Pediatric oncology patients and their families. In D.J. Bearison & R.K. Mulhern (Eds.), *Pediatric psychooncology: Psychological perspectives on children with cancer* (pp 171-193).

Kazak, A.E., Christakis, D., Alderfer, M., & Coiro, M.J. (1994). Young adolescent cancer survivors and their parents: Adjustment, learning problems, and gender. *Journal of Family Psychology*, 8, 74-84.

Kazak, A.E., & Christakis, D.A. (1996). The intense stress of childhood cancer: A systems perspective. In C.R. Pfeffer (Ed.), *Severe stress and mental disturbance in children*, (p. 277-305).

Kazak, A. E., Barakat, L. P., Meeske, K., Christakis, D., Meadows, A. T., Penati, B., & Stuber, M. L. (1997). Posttraumatic stress, family functioning, and social support in survivors of childhood leukemia and their mothers and fathers. *Journal of Consulting and Clinical Psychology*, 65, 120–129.

Kellerman, J. & Katz, E.R. (1977). The adolescent with cancer: Theoretical, clinical and research issues. *Journal of Pediatric Psychology*, 2(3), 127-131.

Kon, I.S. & Losenkov, V.A. (1978). Friendship in adolescence: Values and behavior. *Journal of Marriage and the Family*, 40(1), 143-155.

Kun, L. E., & Mulhern, R. K. (1983). Neuropsychologic function in children with brain tumors: II. Serial studies of intellect and time after treatment. *American Journal of Clinical Oncology*, 6, 651–656.

LaGaipa, J.J (1977). Testing a multidimensional approach to friendship. In Duck, S.W (Ed.), *Theory and practice in interpersonal attraction* (pp. 249-270). London: Academic Press.

La Gaipa, J.J. (1979). A developmental study of the meaning of friendship in adolescence. *Journal of Adolescence*, 2,201-213.

La Gaipa, J.J. & Wood, H.D (1981). Friendship in disturbed adolescents. In S.W.Duck & R.Gilmour (Eds). *Personal Relationships 3: Personal relationships in disorder*. (pp169-188) New York: Academic Press.

La Gaipa, J.J. & Wood, H.D (1985). An Eriksonian approach to conceptions of friendship of aggressive and withdrawn preadolescent girls. *Journal of Early Adolescence*. 5(3), 357-369.

La Gaipa, J.J (1987) Friendship Expectations. In : R.Burnett & P.McGhee (Eds). *Accounting for relationships: Explanation, representation and knowledge* (pp. 134-157) New York, Methuen

Ladd, G.W. (1990). Having friends, keeping friends, making friends, and being liked by peers in the classroom: Predictors of children's early school adjustment? *Child Development*, 61, 1081-1100.

LaGreca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigation and intervention. *Journal of Pediatric Psychology*, 15, 285-307.

LaGreca, A.M. (1992). Peer influences in pediatric chronic illness: An update. *Journal of Pediatric Psychology*, 17(6), 775-784.

Landis, J. R., and G. G. Koch. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 36,159-174.

Lansky, S.B., Cairns, N.U., & Zwartjes, W. (1983). School attendance among children with cancer: A report from two centers. *Journal of Psychosocial Oncology*, 1, 75-82.

Lansky, S.B., List, M.A., & Ritter-Sterr, C. (1986). Psychological consequences of cure. *Cancer*, 58, 529-533.

Lerner, R.M., Lerner, J.V., Hess, L.E., Schwab, J., et-al. (1991). Physical attractiveness and psychosocial functioning among early adolescents. *Journal of Early Adolescence*, 11(3), 300-320.

Mackie, E. (2000). Adult psychosocial outcomes in long-term survivors of acute lymphoblastic leukaemia and Wilms' tumour: a controlled study. *Lancet*, 355,1310-14

Madan-Swain, A., Fredrick, L.D., Wallander, J.L.(1999). Returning to school after a serious illness or injury. In R.T. Brown (Ed). (1999). *Cognitive aspects of chronic illness in children*. (pp. 312-332). New York, NY, US: The Guilford Press.

Matson, J.L. (1994) *Matson Evaluation of Social Skills with Youngsters: Manual* (2nd Ed) Orland Park, IL: International Diagnostic Systems

McCubbin, H.I, Joy, C.B, Corneau, J.K., Patterson, J.M & Meedle, R.H. (1980). Family Stress and Coping: a decade review. *Journal of Marriage and the Family*, 42, 855-871

McCubbin, H.I. & Patterson, J.M. (1983). The family stress process: the double ABCX model of adjustment and adaption. In H.I. McCubbin, M.B. Sussman & J.M. Patterson (Eds). *Social stress and the family*. (pp.7-37) New York: A.A.Worth

McDougal, S. (1997). Children With Cancer; Effects and Educational Implications.

Retrieved January 21st, 2001, from the World Wide Web:

<http://www.acor.org/diseases/ped-onc/cfissues/backtoschool/cwc.html>

McMaugh, A. and Debus, R. (1999, December). "Just make friends, that's the most important thing!" School transition and making friends. The concerns and worries of children with illness and disability. Paper presented at the annual meeting of the Australian Association for Research in Education. Melbourne.

McMaugh, A. (2001, July). Assessing Social Adjustment among children with chronic illness: The utility of social self-efficacy and social self-concept in differentiating student outcomes. Paper presented at the AHDA Conference, Brisbane.

Meadows, A., & Silber, J. (1985). Delayed consequences of therapy for childhood cancer. *Cancer Journal for Clinicians*, 35, 271-286.

Meijer, S.A., Sinnema, G., Bijstra, J.O., Mellenbergh, G.O. & Wolters, W.H. (2000). Social Functioning in Children with a Chronic Illness. *Journal of Child Psychology and Psychiatry*, 41(3), 300-317.

Merrel, K. W. (1999). *Behavioral, social, and emotional assessment of children and adolescents*. Lawrence Erlbaum Associates.

Miell, D., Duck, S. & La Gaipa, J. (1979). Interactive effects of sex and timing in self-disclosure. *British Journal of Social and Clinical Psychology*, 18(4), 355-362.

Moore, B.D., Ater, J.L. & Copeland, D.R. (1992). Improved neuropsychological outcome in children with brain tumors diagnosed during infancy and treated without cranial irradiation. *Journal of Child Neurology*, 7(3), 281-290.

Mulhern, R., Wasserman, A., Friedman, A., & Fairclough, D. (1989). Social competence and behavioral adjustment of children who are long-term survivors of cancer. *Pediatrics*, 83, 18-25.

- Mulhern, R.K. (1994). Neuropsychological late effects. In D.J. Bearison & R.K. Mulhern (Eds.), *Paediatric psychooncology: Psychological perspectives on children with cancer* (p. 99-121).
- Murray, H.A (1943) *Thematic Apperception test: Manual* Cambridge, NA: Harvard University Press
- Murray, J.S. (1998). The lived experience of childhood cancer: one sibling's perspective. *Issues in Comprehensive Paediatric Nursing*, 21(4), 217-27
- Murray, J.S (1999). Siblings of children with cancer: a review of the literature. *Journal of Pediatric Oncology Nursing*, 16(1), 25-34
- National Children's Cancer Foundation. (1997). Facts about Childhood Cancer. Retrieved March 3rd, 2002, from the World Wide Web:
<http://www.nccf.org.childhoodcancer/facts.asp>
- Nassau, J. H., & Drotar, D. (1997). Social competence among children with central nervous system-related chronic health conditions: a review. *Journal of Pediatric Psychology*, 22, 771-793.
- Nelms, B.C. (1989). Emotional Behaviours in Chronically Ill Children. *Journal of Abnormal Child Psychology*, 17(6), 657-668

Noles, S.W., Cash, T.F., & Winstead, B.A. (1985). Body image, physical attractiveness, and depression. *Journal of Consulting and Clinical Psychology*, 53, 88-94.

Noll R.B., Bukowski W.M., Rogosch, F.A., LeRoy, S. and Kulkarni (1990). Social interactions between children with cancer and their peers: Teacher ratings. *Journal of Pediatric Psychology*, 15(1), 43-56

Noll, R.B., LeRoy, S., Bukowski, W.M., Rogosch, F.A., Kulkarni, R. (1991). Peer relationships and adjustment in children with cancer. *Journal of Pediatric Psychology*, 16(3), 307-26

Noll, R.B., Bukowski, W.M., Davies, W.H., Koontz, K., Kulkarni, R. (1993). Adjustment in the peer system of adolescents with cancer: a two-year study. *Journal of Pediatric Psychology*, 18(3), 351-64

Olson, A., Boyle, W.E., Evans, M.W. & Zug, L.A (1993). Overall function in rural childhood cancer survivors: the role of social competence and emotional health. *Clinical Pediatrics*, 32(6), 334-342

Olweus, D. (1997). Bully/victim problems in school: Facts and intervention. *European Journal of Psychology of Education*, 12(4), 495-510.

Parker, J.G. & Asher, S.R (1987). Peer relationships and later personal adjustment: are low-accepted children at risk? *Psychological Bulletin* 102, 357-389

- Parker, J.G. & Asher, S.R (1993). Friendship and friendship quality in middle childhood: Links with peer group acceptance and feelings of loneliness and social dissatisfaction. *Developmental Psychology*, 29(4), 611-621
- Peckham, V.C. (1993). Children with cancer in the classroom. *Teaching Exceptional Children*, 26, 26-32.
- Pendley, J.S., Dahlquist, L.M., & Dreyer, Z. (1997). Body image and psychosocial adjustment in adolescent cancer survivors. *Journal of Pediatric Psychology*, 22, 29-43.
- Perrin, E. C., Stein, R. E. K., & Drotar, D. (1991). Cautions in using the Child Behavior Checklist: observations based on research about children with chronic illness. *Journal of Pediatric Psychology*, 16, 411-421.
- Phipps, S (1994). Bone marrow transplantation. In D.J. Bearson & R.K Raymond (Eds) *Pediatric psychooncology: Psychological perspectives on children with cancer*. (pp. 143-170). New York, NY, US: Oxford University Press
- Pless, I.B & Perrin, J.M (1985). Issues common to a variety of illnesses. In N. Hobbs & J.M. Perrin (Eds). *Issues in the care of children with chronic illness: A sourcebook on problems, services, and policies*. (pp. 41-60). Jossey-Bass Inc, Publishers.
- Reisman, J.M., & Shorr, S.I. (1978). Friendship claims and expectations among children and adults *Child Development*, 49,913-916.

Rolland, J.S (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 26, 203-211

Rose, S.M. (1985). Same- and cross-sex friendships and the psychology of homosociality. *Sex Roles*. 12(1-2), 63-74.

Ross, J.W. (1984). Resolving nonmedical obstacles to successful school reentry for children with cancer. *Journal of School Health*. 54(2), 84-86.

Rutter, M. (1980). *Changing youth in a changing society: Patterns of adolescent development and disorder*. Cambridge, Mass.: Harvard University Press.

Schover, L.R. (1999). Psychosocial Aspects of Infertility and Decisions About Reproduction in Young Cancer Survivors: A Review. *Medical and Pediatric oncology*, 33(1), 53

Sergeant, J.R., Sahler, O.J.Z., Roghmann, K.J., Mulhern, R.K., Barbarian, O.A., Carpenter, P.J., Copeland, D.R, Dolgin, M.J & Zelter, L.K. (1995). Sibling adaptation to childhood cancer: Sibling perceptions of the cancer experience. *Journal of Pediatric Psychology*, 20, 151-164

Sexson, S.B., & Madan-Swain, A. (1993). School reentry for the child with chronic illness. *Journal of Learning Disabilities*, 26, 115-125.

Sharp, S. & Thompson, D. (1992). Sources of stress: A contrast between pupil perspective and pastoral teachers' perceptions. *School Psychology International*, 13(3), 229-242.

Siblerstein, L.R., Striegel-Moore, R.H., Timko, C. & Rodin, J. (1988). Behavioral and psychological implications of body dissatisfaction: Do men and women differ? *Sex Roles*, 19(3-4), 219-232.

Slee, P.T., (1996). *Child, Adolescent and Family Development*, Marrickville: Harcourt Brace.

Sloper, P. & White, D. (1996). Risk factors in the adjustment of siblings of children with cancer. *Journal of Child Psychology and Psychiatry*, 37, 597-607

Spirito, A., Stark, L.J., Cobiella, C., Drigan, R. et al. (1990). Social adjustment of children successfully treated for cancer. *Journal of Pediatric Psychology*, 15(3), 359-371

Spirito, A., DeLawyer, D.D. & Stark, L.J. (1992). Peer relations and social adjustment of chronically ill children and adolescents. *Clinical Psychology Review*, 11(5), 539-564

Stallard, P., Mastroiannopoulou, K., Lewis, M & Lenton, S. (1997). The sibs of children with life-threatening conditions. *Child Psychology and Psychiatry Review*, 2, 26-33

Stehbens, J.A., Kisker, C.T., & Wilson, B.K. (1983). School behavior and attendance during the first year of treatment for childhood cancer. *Psychology in the Schools*, 20, 223-228.

Stevens, M.M., & Dunsmore, J.C. (1996). Adolescents who are living with a life-threatening illness. In C.A. Corr & D.E. Balk (Eds.), *Handbook of adolescent death and bereavement* (p. 107-135).

Suttles, G. 1970. *The Social Construction of Communities*. Chicago, IL: University of Press.

Taylor, V., Fuggle, P. & Charman, T. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *Journal of Child Psychology and Psychiatry*, 42(7), 953-962

Thompson, R.J. & Gustafson, K.E. (1996). *Adaptation to chronic childhood illness*. American Psychological Association.

Thompson, R.J., Hodges, K. & Hamlett, K.W. (1990) A matched comparison of adjustment in children with cystic fibrosis and psychiatrically referred and nonreferred children. *Journal of Pediatric Psychology*, 15(6), 745-759.

Timko, C., Stovel, K.W., Moos, R.H. & Miller, J.J. (1992). A longitudinal study of risk and resistance factors among children with juvenile rheumatic disease. *Journal of Clinical Child Psychology*, 21(2), 132-142.

Treiber, F., Schramm, L. & Mabe, P.A. (1986). Children's knowledge and concerns towards a peer with cancer: A workshop intervention approach. *Child Psychiatry and Human Development*. 16(4), 249-260.

Vannatta, K., Gartstein, M.A., Short, A. & Noll, R.B. (1998). A controlled study of peer relationships of children surviving brain tumors: teacher, peer, and self ratings. *Journal of Pediatric Psychology*, 23(5), 279-87

VanDongen-Melman, J.E., Pruyn, J.F., De Groot, A., Koot, H.M., Hahlen, K., & Verhulst, F.C. (1995). Late psychosocial consequences for parents of children who survived cancer. *Journal of Pediatric Psychology*, 20, 567-586.

Varni, J.W., Katz, E.R., Colegrove, R., & Dolgin, M. (1993). The impact of social skills training on the adjustment of children with newly diagnosed cancer. *Journal of Pediatric Psychology*, 18, 751-767.

Varni, J.W., Katz, E.R., Colegrove, R., & Dolgin, M. (1994). Perceived social support and adjustment of children with newly diagnosed cancer. *Developmental and Behavioral Pediatrics*, 15, 20-26.

Varni, J.W., Katz, E.R., Colegrove, R., & Dolgin, M. (1995). Perceived physical appearance and adjustment of children with newly diagnosed cancer: A path analytic model. *Journal of Behavioral Medicine*, 18, 261-278.

Varni, J.W. & Katz, E.R. (1997) Stress, Social Support and negative affectivity in children with newly diagnosed cancer: A prospective transactional analysis. *Psycho-oncology*, 6, 267-278.

Verbrugge, L.M. (1983). A research note on adult friendship contact: A dyadic perspective. *Social Forces*. 62(1), 78-83.

Walker, C.L. (1988). Stress and coping in siblings of childhood cancer patients. *Nursing Research*, 37(4), 208-212.

Wallace, W.H.B., Blacklay, A., Eiser, C., Davies, H., Hawkins, M., Levitt, G.A. & Jenney, M.E.M. (2001). Developing strategies for long term follow up of survivors of childhood cancer. *BMJ*, 323, 271-274.

Wallander, J.L., Feldman, W.S. & Varni, J.W. (1989). Physical status and psychosocial adjustment in children with spina bifida. *Journal of Pediatric Psychology*, 14(1), 89-102.

Wallander, J.L. & Hubert, N.C. (1987). Peer social dysfunction in children with developmental disabilities: Empirical basis and a conceptual model. *Clinical Psychology Review*, 7(2), 205-221.

Wallander, J.L. & Thompson, R.J. (1995). Psychosocial adjustment of children with chronic physical conditions. In M.C. Roberts, (Ed). *Handbook of pediatric psychology* (2nd ed.). (pp. 124-141). The Guilford Press.

Wallander, J.L. & Varni, J.W. (1989). Social support and adjustment in chronically ill and handicapped children. *American Journal of Community Psychology*, 17(2), 185-201.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T., et-al. (1989). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology*, 14(3), 371-387.

Wallander, J.L. (1992). Theory-driven research in pediatric psychology: A little bit on why and how. *Journal of Pediatric Psychology*, 17(5), 521-535.

Wallander, J.L. & Varni, J.W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a disability-stress-coping model. In A.M. La Greca & L.J. Siegel,(Eds) *Stress and coping in child health: Advances in pediatric psychology*. (pp. 279-298). New York, NY, US: The Guilford Press

Wallander, J.L. & Thompson, R.J. (1995). Psychosocial adjustment of children with chronic physical conditions. In M.C. Roberts (Ed) *Handbook of pediatric psychology* (2nd ed.). (pp. 124-141). New York, NY, US: The Guilford Press.

Wallander J.L. & Varni J.W. (1998). Effects of pediatric chronic physical disorders on child and family adjustment. *Journal of Child Psychology & Psychiatry & Allied Disciplines*, 39(1),29-46.

Wallander, J.L. & Robinson, S.L. (1999). Chronic medical illness. In R.T. Ammerman & M. Hersen (Eds.) *Handbook of prescriptive treatments for children and adolescents* (2nd ed.) (pp. 364-380). Needham Heights, MA, US: Allyn & Bacon, Inc

Weiss, L. & Lowenthal, M.F. (1975). Life course perspectives on friendship. In M. F.Lowenthal, M. Thurner, D. Chiriboga et al. (Eds). *Four Stages of Life*. San Francisco: Jossey-Bass.

Westen, D., Kelpser, J., Ruffins, S.A., Silverman, M., Lifton, N. & Boekamp, J. (1991). Object relations in Childhood and Adolescence: The development of Working Representations. *Journal of Consulting and Clinical Psychology*, 59 (3), 400-409.

Young, J. E. (1979). Loneliness in college students: A cognitive approach. *Dissertation Abstracts International*, 40(3-B), 1392.