Parental mental health, parenting behaviours and the quality of life of children with cancer

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Abstract

Two central themes were assessed in this thesis involving children with cancer. First, the relationship between the child's medical functioning and their overall quality of life (QOL). Second, how the child's illness and subsequent QOL related to parental mental health and parenting behaviours. These themes were explored using the Risk and Resilience model developed by Wallander et al. (1989b).

Study one involved children diagnosed with acute lymphoblastic leukaemia (ALL), the most common form of childhood cancer. Results showed that the child's medical functioning (e.g., time since diagnosis) did not relate to the child's QOL, but did relate to parental mental health. Furthermore, child QOL was significantly related to both parental mental health (depression) and parenting behaviours (endorsement of force).

In an attempt to explore these themes in greater detail, Study two involved two groups of cancer survivors, those with ALL or tumours of the central nervous system (CNS). Medically, these groups have different prognoses, treatments, and long-term consequences. Results showed that those with poorer medical functioning, i.e., CNS tumours, had poorer QOL than both the ALL group and population norms, confirming the relationship between the child's medical and psychological adaptation. Furthermore, the child's adaptation was strongly related to both parental mental health and parenting behaviours, again providing evidence for the relationship between child and parent functioning.

The results of both studies in this thesis go some way to demonstrate the wide-ranging effects that cancer can have on both the child and family. The child's QOL can be compromised by the illness. Moreover, cancer has a detrimental effect on the family life, from pervasive feelings of depression and worry, to long-term concerns about child-rearing. This thesis has shown that those children with CNS involvement, and their families, are particularly at-risk. To conclude, a section outlining clinical interventions which can help reduced the impact of childhood cancer on the family are discussed.

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Glossary

Term	*Description / Explanation*
ALL	Acute Lymphoblastic Leukaemia
Adjuvant chemotherapy*	Chemotherapy given after surgical removal of, or radiotherapy to, a primary tumour.
Alopecia*	Absence of hair from where it normally grows
BMT	Bone marrow transplant
Bone marrow aspirations	A procedure to remove fluid and small pieces of bone marrow from the inside of bone for diagnostic purposes.
CNS	Central Nervous System
Chemotherapy*	Drugs that are toxic to cancer cells. Literally meaning 'chemical therapy'.
Immuno-suppressed*	Suppression of the immune response, usually by disease (e.g., AIDS) or drugs (e.g., steroids).
Intramuscular injection	Injections deep into the muscle mass where the drug is absorbed into the system.
Intravenous injections	Injections given into a vein.
Lumbar puncture	An invasive diagnostic test, in which cerebro-spinal fluids is extracted for examination and pressure of the spinal column is measured.
Neoadjuvant chemotherapy*	Chemotherapy given before the treatment of a primary tumour.
Oncology*	The science of the study of cancer
On-treatment	During the active phase of treatment. For example, 2-3 years in the treatment of ALL.
Off-treatment	Once active treatment has been completed.
Prognosis	The likely outcome of an illness.
Radiotherapy*	Use of X-rays to kill cancer cells

Term	*Description / Explanation*
Survivor	Generally taken to mean 5-years from diagnosis, disease-free and/or 2 years from the completion of treatment disease-free.
Venipuncture	The puncture of a vein with a hollow needle in order to obtain a blood specimen.

* *Source: Oxford Concise Medical Dictionary (1998)*

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Declaration

The author is employed as a research assistant, funded by the Cancer Research Campaign. This PhD was researched and written up as only one part of the studies discussed in this thesis – there were many other threads of research being conducted concurrently. This can be seen by the number of other publications which have emerged from this work during the past four years (please see the reference section). There were a number of researchers working alongside the author, who also collected some of the data contained within this thesis, primarily Professor Christine Eiser. However, while some of the data was not collected by the author (although approximately 75% of it was), all of the data was entered and analysed by the author.

CHAPTER ONE.

MEDICAL OVERVIEW OF CHILDHOOD CANCER

Summary

Cancer treatment is physically demanding and painful and takes its toll on both the child and family. It is suggested in this thesis that the diagnosis of cancer, a medical condition, relates to the child's psychological adaptation, and furthermore, the parent's mental health and parenting behaviours. However, before these pathways are explored empirically, it is important to understand the child's medical experience both during and after treatment. The current chapter gives a medical overview of childhood cancer. Subsequent chapters review literature illustrating how this medical condition affects both the child's and parent's psychological adaptation.

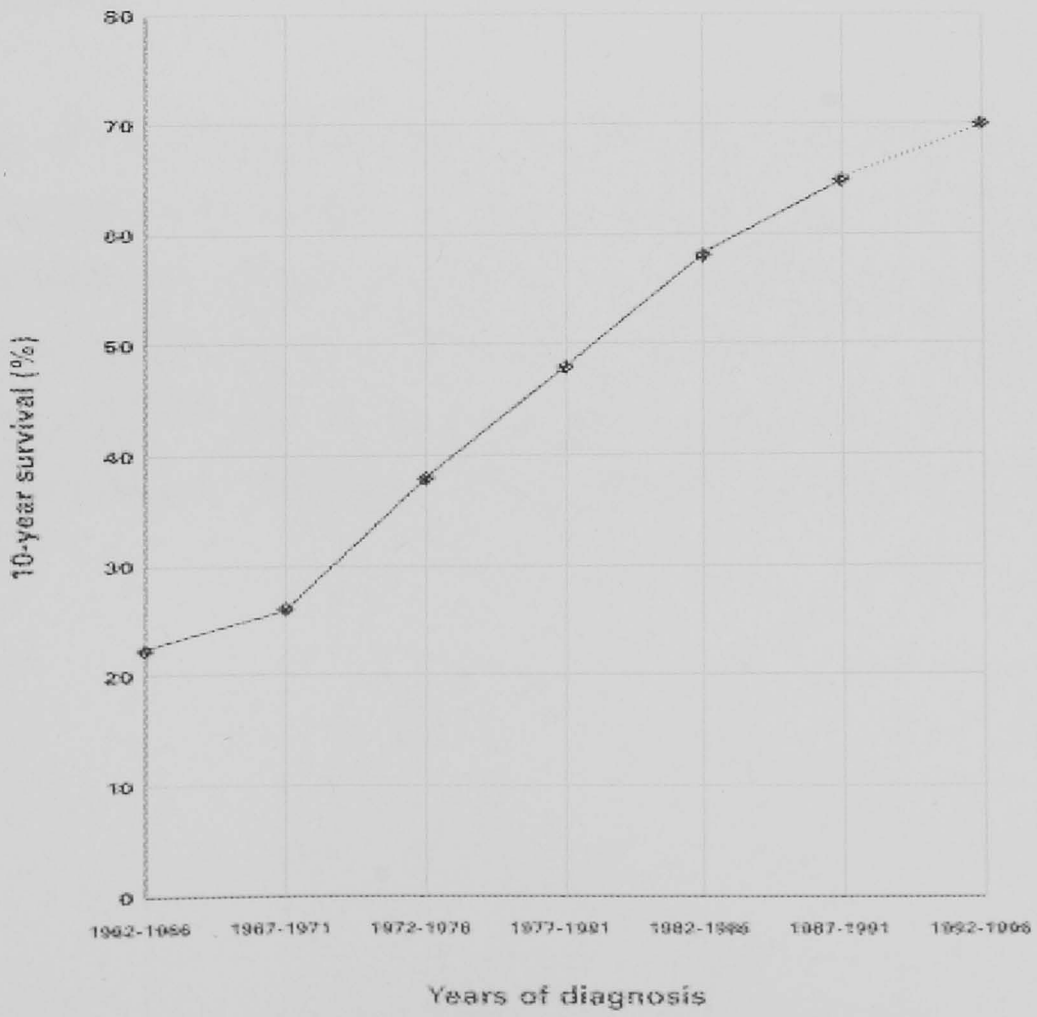
Over the past 30 years, significant advances have been made in the treatment of childhood cancers, resulting in improved survival rates for certain malignancies. These advances include improved chemotherapy regimens and the increased ability to treat children once they have relapsed. However, cancer survival comes at a cost. Each of the three cancer treatments, chemotherapy, radiotherapy and surgery, is associated with short- and long-term physical consequences. In the short term, chemotherapy causes weight change, alopecia and nausea; radiotherapy causes loss of appetite and irritation at the site where radiation was received. Post-operative nausea and pain are common short-term side-effects of surgery. In the long term, children experience an increased chance of developing a second cancer, organ dysfunction, fertility problems, growth problems and skeletal abnormalities. These consequences are discussed in relation to the child's diagnosis and type of treatment given.

1.1 Prevalence and types

Paediatric cancers are rare, with an annual prevalence being estimated at one in 581 children under 15 years of age in the UK (Stiller, Allen, & Eatock, 1995). Despite the rarity of this disease, paediatric malignancies are the second commonest cause of non-accidental death in children (Pinkerton, Cushing, & Sepion, 1994).

Over the past 40 years, significant advances have been made in the treatment of childhood cancers, resulting in improved survival rates (Davies, 1993). Please see Figure 1.1 for details of how mean 10-year survival rates have changed since 1962. This is particularly the case for those diagnosed with acute lymphoblastic leukaemia (ALL), the most common childhood cancer (Stiller & Bunch, 1990). In 1960, 1% of children with ALL survived to five years post-diagnosis, compared with 55% in 1976 (Stehbens, 1988). This rate increased to 81% during the 1990-1994 period in the UK (Stiller & Eatock, 1999).

Figure 1.1 Changes in 10-year survival rates for childhood cancers from 1962 - 1996 (source: Cancerbacup &UKCCSG)



The term *'survivor'* is used to apply to children who are still alive and disease-free five years from diagnosis or two years after completion of treatment (MacLean, Foley, Ruccione, & Sklar, 1996). In contrast, those children who are still undergoing active treatment are referred to as being *'on-treatment'*. These terms will be used throughout this thesis (see Glossary, p. vii).

Much of the increase in survival rate can be attributed to a combination of improvements to chemotherapy regimens, the identification of specific leukaemia cells requiring different treatment regimes, improvements in maintaining remission and recovery from relapse, and the ability to treat infections in the immuno-suppressed child (Powers, Vannatta, Noll, Cool, & Stehbens, 1995). Table 1.1 shows the annual incidence of common childhood cancers in the UK, and their respective survival rates. The most common childhood cancers are leukaemias (cancers of the blood and bone marrow, including ALL), central nervous system (CNS) tumours (cancers of the brain and spinal cord, including medulloblastomas), and lymphomas (cancers of the lymph glands, including Hodgkin's disease). CNS tumours are the most common solid tumours in childhood.

Age of onset varies according to the malignancy (Granowetter, 1994). Cancers occurring more frequently in children under five years old include leukaemias, neuroblastoma (cancer of nerve tissue), retinoblastoma (cancer of the eye) and Wilms' tumour (cancer of the kidney). Cancers such as Hodgkin's lymphoma, bone and CNS tumours tend to occur in children over five years old. Across cancers, boys are likely to be affected 1.2 times more frequently than girls.

Table 1.1 *Annual incidence of common childhood cancers in the UK*

Diagnosis	**Annual rates per million***	**5-year Survival rates (1983-85) %****
Leukaemias		
Acute Lymphoblastic Leukaemia	29.7	81% in period 1991-94***
Acute Myeloid Leukaemia	6.0	26
Lymphomas		
Hodgkin's	4.1	88
Non-Hodgkin's	6.1	70
Brain and Spinal cord		
Astrocytoma	8.9	72
Medulloblastoma	5.0	42
Bone tumours		
Osteosarcoma	2.4	54
Ewing's sarcoma	1.7	42
Soft tissue sarcomas		
Rhadbomyosarcoma (muscle)	4.2	61
Fibrosarcoma (connective tissues)	0.8	63
Others		
Wilm's tumour (kidney)	7.2	79
Retinoblastoma (eye)	3.5	91

*Pinkerton et al. (1994) **Stiller & Bunch (1990) ***Stiller & Eatock (1999)

1.2 Treatments

Current treatments for childhood cancer are chemotherapy, radiotherapy and surgery.

Chemotherapy may be taken by mouth, intravenously or intrathecally (directly into the spinal column). It involves the use of cytotoxic agents (i.e. drugs toxic to cells) to destroy the cancerous cells. However, chemotherapy drugs also attack healthy as well as cancerous cells. Chemotherapy drugs work by circulating throughout the body and so is the best form of treatment for a disease that arises in different parts of the body simultaneously, such as leukaemia (UKCCSG, 1996). It is also an effective means of treating and curing some cancerous tumours. Some of the drugs used in chemotherapy work at particular phases of the cell cycle (phase-specific drugs) and some work at non-specific phases (non-specific drugs). In practice, a cocktail, or combination, of drugs is used in order to fight cells at various stages of their division process, and in various parts of the body.

Improvements in chemotherapy combinations have largely been due to the advent of clinical trials. These are nationally and internationally established treatment regimens set by the Medical Research Council in the UK, Societé Internationale D'Oncologie Pediatrique in Europe, and the Children's Oncology Group in the USA (Stiller & Eatock, 1999). Trials usually compare a standard, established 'arm' of treatment, with a new experimental arm of treatment. During the period 1990 to 1994, 82% of newly diagnosed children were entered into a trial compared with 59% between 1980 and 1984 (Stiller & Eatock, 1999). Intensive clinical trials began in the UK in 1980, and since then new trials (approximately every four-to-five years) are based upon the best arm of the previous trial which is used as the standard arm of the next one (Stiller et al., 1995).

Radiotherapy is the use of radiation to treat cancerous cells. It is necessary when surgery and chemotherapy cannot completely destroy a tumour, when complete removal of a tumour is associated with relapse, or when the tumour has been removed, but residual cells have been identified pathologically (Granowetter,

1994). Radiation is usually given in the form of an external beam to the body. Radiation is either localised to certain parts of the body, e.g. cranial-spinal in the case of CNS tumours, or directed over the entire body (known as total body irradiation) as in the case of those receiving bone marrow transplants (discussed below).

Surgery can be used for diagnostic purposes (biopsies), or to completely remove a tumour (resection). In some cases chemotherapy and radiotherapy are administered before surgery in order to shrink or control the tumour and facilitate the procedure (Granowetter, 1994). Afterwards, adjuvant chemotherapy (i.e., drug therapy given *after* the initial surgical procedure) is administered when the risk of recurrence in secondary sites is known to be high. New surgical techniques are increasingly subtle and precise, thereby minimising the child's physical disability and improving their psychological well-being after treatment. With regard to bone tumours, for example, a metal prosthesis can be inserted in place of the diseased bone as opposed to a complete limb amputation.

Duration of treatment and treatment course

Girls with ALL usually have two years of treatment. Boys are now being enrolled on clinical trials which are three years in duration, owing to the increased risk of relapse in young males. An extra year of treatment is expected to reduce this relapse rate. Nowadays, children diagnosed with standard-risk[1] ALL are treated with chemotherapy only. Radiotherapy is mostly only necessary for children who relapse or fail to respond to chemotherapy (i.e. high-risk ALL). For children who fail to go into remission, or who relapse, a bone marrow transplant (BMT) is a treatment option. BMTs involve whole body radiation, which destroys the child's bone marrow, after which the patient is given a bone marrow transplant from an available donor. In certain cases where the marrow has been extracted prior to transfusion (e.g., when the child was in remission, but was considered at a high-risk of relapsing), patients can be their own donors. This is called an autologous BMT. Marrow used from a family member or unrelated person is known as an allogenic BMT (Powers et al., 1995).

Children diagnosed with solid tumours are usually treated with surgery, with a combination of chemotherapy and/or radiotherapy to eliminate remaining traces of cancerous cells. For those who require surgery only, duration of treatment is short. However, for those children who require adjuvant chemotherapy in addition to their surgery, the likely duration of this treatment is approximately six to nine months.

1.3 Physical problems associated with cancer treatment

1.3.1 Short term physical consequences

Each treatment has its associated physical consequences. During chemotherapy, children routinely experience nausea and vomiting, alopecia (absence of hair), a tendency to bleeding and anaemia, mouth sores, and a reduction in appetite (Van Dongen-Melman & Sanders-Woudstra, 1986). Radiation therapy, although

[1] Risk is determined by the stage of cancer at diagnosis, age and gender of child (depending on cancer).

painless, does have residual side-effects. These include reddening and irritation of the skin where radiation was received, loss of appetite, and general malaise (Granowetter, 1994). Specific side-effects relate to the site of the tumour. For example, abdominal radiation may result in diarrhoea, whereas cranial irradiation may result in headaches. Short-term, physical problems associated with surgery include post-operative nausea, pain at the wound site, and for a child with a bone tumour, for example, relearning to walk on a newly inserted prosthetic limb, or becoming accustomed to an artificial limb.

1.3.2 Long term physical consequences

Survivors of childhood cancer have an increased chance of developing a second cancer in later life (Stehbens, 1988). The number of children developing second cancers within 25 years of diagnosis has been reported as approximately 4%, which corresponds to approximately 5-6 times the risk in the general population (Hawkins, Draper, & Kingston, 1987). Radiation increases the risk of tumours within skin, bone and soft tissue; these comprise the majority of secondary cancers (Davies, 1993).

Radiation therapy is especially associated with longer-term damage. The nature of reported side-effects are both neuropsychological and neurological. These include learning difficulties (Eiser, 1991), skeletal abnormalities, major organ dysfunction (Stehbens, 1988), compromised fertility (Granowetter, 1994; Nicholson & Byrne, 1993), and stunted growth and endocrine problems (Ogilvy-Stuart et al., 1992).

Of course, the side-effects caused by radiotherapy somewhat depends on the type, dose, duration and frequency with which it is given, but generally it carries severe consequences. The age at which radiation is received is a strong predictor of later side-effects, with children younger than three years old being especially vulnerable. In fact, where cranial-spinal radiation is the norm (e.g., to treat CNS tumours), radiotherapy is rarely given to children younger than two years old, and if possible, is delayed until the child is at least three.

Surgery can also cause long-term physical problems. Apart from the risks involved with undergoing surgery itself, a vast array of problems can result from surgical procedures. These problems are very particular to the exact cancer diagnosis. For example, for children with CNS tumours, surgery can cause damage to healthy brain tissue and can result in major scarring where the brain surgery took place.

1.4 Summary

The following points were made in this chapter:

- Survival prospects have improved for many cancer diagnoses over the past 30 years, particularly for ALL, the most common form of childhood cancer;
- This change can be attributed to improvements in treatments (including improved chemotherapy combinations and a better ability to treat infections) and the worldwide involvement of clinical trials;
- The current treatments for childhood cancer are chemotherapy (use of toxic drugs), radiotherapy (use of radiation) and surgery (for either diagnostic or resection purposes);
- All treatments have been associated with a number of both short- and long-term physical side-effects.

In the next chapter, literature is reviewed that examines how the child psychologically adapts to cancer, both at diagnosis and after treatment has ended. This demonstrates the association between the child's medical functioning and their psychological adaptation. In addition, the concept of Quality of Life (QOL) is introduced, which is the key child assessment tool used in the empirical work in this thesis.

CHAPTER TWO.

THE CHILD'S PSYCHOLOGICAL ADAPTATION TO CANCER

Summary

The empirical work in this thesis is concerned with the child's adaptation to cancer and their Quality of Life (QOL). The literature in this chapter serves to illustrate one of the key themes in this thesis, namely the association between the child's medical functioning (reviewed in Chapter 1) and their psychological adaptation. Until now, the child's psychological adaptation has routinely been assessed using isolated measures. However, current dissatisfaction with these unidimensional measures has led to the study of QOL, a multidimensional assessment of the child's overall well-being. To begin, however, this unidimensional literature will be reviewed in two sections (mental health and social functioning), before the topic of QOL is introduced.

Regardless of treatment status (on- vs. off-treatment), children with cancer appear to have comparable levels of mental health as controls and norms, and in some instances appear to function *better*. School absenteeism is a problem for most children, particularly during treatment, but in some cases, after treatment ends. The literature is mixed with regard to behavioural and social problems: while children appear to have no more behaviour problems than peers, they are rated as being more socially isolated, but have a similar number of mutual friends and are not more lonely. Children who have undergone more severe treatments, however, tend to have more problems at school. In terms of body image, many adolescent survivors have considerable physical appearance concerns, some of which continue into adulthood.

The final section of this chapter introduces QOL, discusses its measurement and introduces the debate over whether to obtain child or proxy ratings. Finally, the way in which QOL is assessed in this thesis is outlined.

2.1 The child's adaptation to cancer: theoretical perspectives

Within this thesis, the risk and resistance model developed by Wallander and colleagues (e.g., Wallander, Varni, Babani, & Wilcox, 1989b; Varni & Wallander, 1988) was used as a base to explore the relationship between the child's medical functioning, their QOL and parental functioning. This model (Figure 2.1) is an amalgamation of key concepts drawn from earlier influential medical and psychosocial models resulting in a single conceptual model of adaptation to chronic illness and handicap (Bradford, 1997).

If the risk factors within Wallander et al.'s (1989b) model are reviewed, the overlap with the World Health Organisation's (WHO, 1980) International Classification of Impairments, Disability and Handicap (ICIDH) is clear. The WHO model attempts to explain the consequences of disease, by proposing a sequence from impairment to disability to handicap, or directly from impairment to handicap (Johnston & Pollard, 2001; see Figure 2.2). The term **impairment** represents the loss or abnormality of structure or function at a level below that of the individual (e.g., at the organ level). **Disability** refers to an inability to perform activities at the individual level, while **handicap** refers to disadvantage and role limitation for the individual within a social setting. Therefore, the WHO model can be seen as a sequence from an organic medical level to that of the psychosocial aspects of disease (Johnson & Pollard, 2001).This sequence is mirrored within Wallander et al.'s model. According to Figure 2.1, there is a sequence from disease / disability parameters (which is similar to the level of *impairment*) to functional independence (*disability)* to psychosocial stresses (*handicap)*. There is also a hypothesised pathway from disease / disability directly to psychosocial stresses, similar to the impairment to handicap pathway in the WHO model.

Figure 2.1 *Model of risk and resistance (Wallander et al., 1989b)*

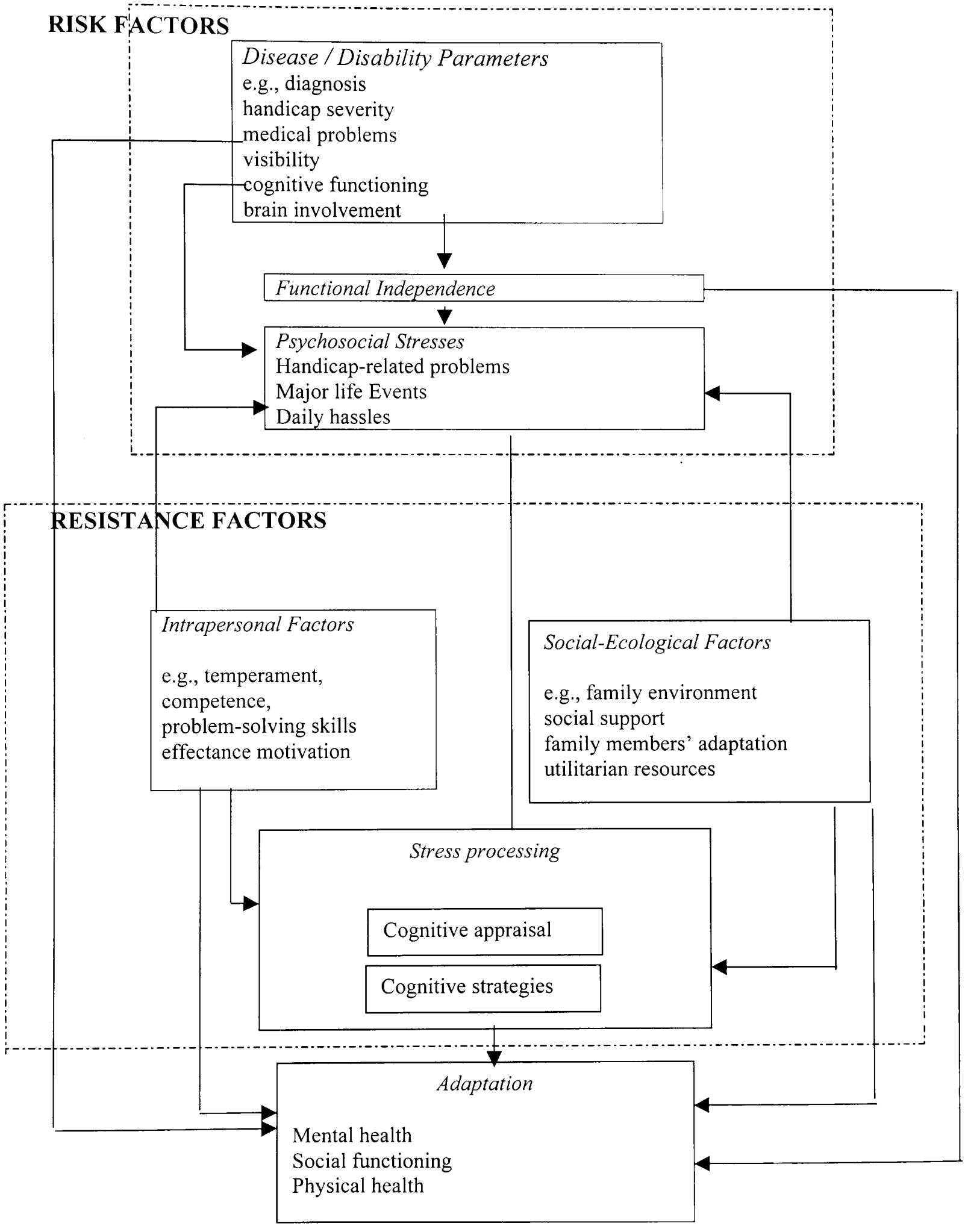
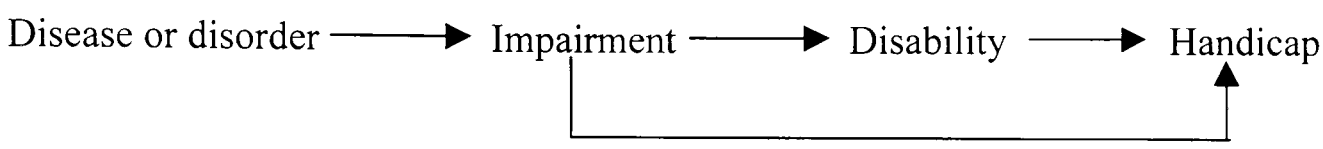


Figure 2.2 International Classification of Impairments, Disability and Handicap (WHO, 1980)



One limitation of the WHO model is that no attention is given to the effects of buffering, or resistance factors, in relation to child adaptation to illness and handicap. In contrast, Wallander et al.'s (1989b) model does attempt to organize these factors within their model, with key concepts being derived from influential psychosocial literature. For example, sections of the model mirror work by Lazarus and Folkman (1984), Lipowski (1970) and Pless and Pinkerton (1975), the latter two considered to be among the first influential models used within paediatric literature.

To illustrate, Lazarus and Folkman (1984) explored the pathways between different coping strategies (including problem- and emotion-focused coping) and adaptation, which can be seen within the stress processing to child adaptation link in Wallander et al.'s (1989b) model. Key aspects from Lipowski's (1970) and Pless and Pinkerton's (1975) models have also been integrated within Wallander et al.'s model, for example, Lipowski (1970) summarised three category of variables which influence the way children learn to cope with their illness: interpersonal factors (e.g. child's age, intelligence and social background), disease related factors (e.g., type of disease, location) and environmental factors (e.g., attitudes of parents and significant others). Pless and Pinkerton's (1975) model involved similar factors, but they also incorporated a feedback loop dimension which attempted to capture changes in functioning over time. These factors are all subsumed within Wallander et al.'s model.

There are some concerns with Wallander et al.'s (1989b) model however. The progression from disease / disability to functional independence to psychosocial stress (risk factors), appears overly simplistic. In fact, the WHO (1980) model, which shares this simplicity, has recently been criticised for its lack of empirical

validity. For example, Johnston and Pollard (2001) have shown that in a number of different patient groups, the sequence between the three variables does not emerge clearly within statistical analysis. Others have shown some weak support for the model (e.g., Fuhrer, Rintala, Hart, Clearman, & Young, 1992), but much of this evidence is based on cross-sectional designs. Additionally, from a measurement stance, there is a difficulty in obtaining accurate measures of each of these three concepts (Johnston & Pollard, 2001).

A second criticism concerns the lack of precise definition of certain terms, not least the key concepts of "risk" and "resistance". While these terms have been discussed previously by others (e.g., Rutter, 1985), they have not been clearly defined by Wallander and colleagues (Bradford, 1997). Furthermore, within the model, there is some confusion regarding what the authors have meant *exactly* by other terms (e.g., effectance motivation). This confusion is not helped by having a few examples, and not a definitive list of which variables should be tested within each category. This could be seen as a positive or negative attribute of the model: positive in that the authors are not stating exactly what variables should be assessed, in order that others may explore *their* representation of the model, allowing new and exciting relationships to be tested and confirmed. The authors, you may say, have given a degree of freedom within their model. Negatively, however, it can be said that the model is too bland and not specific enough, thereby leaving the scope too broad. This potentially could result in a large number of studies purporting to be testing the same model, but each with different ideas of what the concepts mean. This is especially interesting in the light of a quote from Wallander (1992) who stated that "*Meaningful communication is unthinkable in the absence of agreement regarding the meaning of the words used by the communicators*" (p. 527, emphasis added). Within the same article, he went on to state what he thought was adequate criteria for good definitions. Citing Pedhazur and Schmelkin (1991), Wallander stated that *"(a) a definition must not be too broad or too narrow; (b) a definition should not contain vague, ambiguous, obscure, or figurative language; (c) a definition should not be circular; and (d) a definition should state the essential of the things named."* (p. 527, emphasis added). Therefore, when applied to their own model, it seems as if Wallander and

colleagues (1989b) have tried not to be too narrow, but have perhaps left the scope a little too broad, and can be criticized for being ambiguous.

Notwithstanding these criticisms, the model by Wallander et al. (1989b) provides an adequate model within which researchers can accommodate and test key concepts. To date, this model is the most sophisticated and theoretically driven model for use within the paediatric literature, and the one used within this thesis.

Wallander et al. (1989b) have argued that it is not possible to test their model in its entirety, due to the complexity and number of variables, but rather separate sections must be tested to see if they operate in the hypothesised direction and whether the key variables interact as predicted. Keeping this in mind, within this thesis, Wallander et al.'s model will be used to test the relationship between *child adaptation: disease / disability parameters* (risk factors) and *social-ecological factors* (resistance factors) in two empirical studies (Chapters 6-10). Before moving on to review literature pertinent to this thesis, the current empirical evidence for and against Wallander et al.'s model will be summarised.

What evidence have Wallander and colleagues provided in support of their model?

Disease / disability factors

While Wallander et al. (1989b) have so far failed to find any strong evidence for the direct association between disease / disability factors and child adaptation. For example, Wallander et al. (1989c) reported no relationship between disease severity, the presence of a learning difficulty, nor the child's functional independence and child behaviour in their sample of children with cerebral palsy or spina bifida. Similarly, Wallander, Feldman and Varni (1989a) found no relationship between factors such as bladder control, number of operations, location of spinal cord lesions and ambulatory status and child adaptation in their sample of children with spina bifida. Using a sample of children with physical disability, Wallander, Pitts and Mellins (1990) found no association between functional impairment (also seen as a disease / disability factor) and child adaptation.

These findings led Wallander and colleagues to put forward a *non-categorical* approach to studying chronic childhood illnesses. This means that there are greater similarities between diseases than there are differences. Supporters of this approach argue that there is no need to study disease groups uniformly, such as children with diabetes separate from spina bifida, since the commonalities between the groups are larger than the discrepancies (Jessop & Stein, 1983). However, as Wallander and Varni (1998) stated, there exists a need for future research to assess this approach.

"they.....suggest that different physical disorders may share (for example) nature of onset and course, life threat potential, intrusiveness / pain of treatment, secondary functional and cognitive disability, and visibility / social stigma. Furthermore, the burden of daily care almost always falls on the family. They suggest further that it is the variation within each of these psychological dimensions that would have implications for adjustment rather than different medical diagnoses. A broader, non-categorical conceptual approach- one that is not specific to each disorder, but focuses on these psychosocial commonalities in the class of chronic physical disorder – could enhance our understanding of the impact on the psychological adjustment of children and their families, and could improve care. This long-standing, but empirically under-studied notion warrants

further evaluation. " (p. 29).

It is one of the aims of this thesis to show that disease / disability factors *do* in fact relate to child adaptation by providing evidence from existing cancer literature and demonstrating this empirically in this thesis (Chapters 6 and 9).

Social-ecological resistance factors

Wallander et al. (1989d) assessed the relationship between the socio-ecological environment and adaptation in *mothers* of physically handicapped children (i.e., the aim was not to see if the socio-ecological environment effected the child's adaptation, but the mother's). Maternal adaptation was assessed using the Malaise Inventory (Rutter, Tizard, & Whitmore, 1970) and a measure of social functioning constructed for this study. They assessed four separate socio-ecological environment dimensions: utilitarian resources (e.g., family income, mother's education, family size), the handicapped child's adaptation, psychosocial family resources (e.g., family support, marital satisfaction and social support), and the availability and use of services. Using multiple regression analyses, 34% of the variance in maternal adaptation was explained by psychosocial family resources. Neither the handicapped child's adaptation nor utilitarian resources were associated with maternal adaptation.

In a second study, Wallander et al. (1989b) again tested the family environment and utilitarian resources in relation to *child* adaptation, using a sample of children with one of five chronic disorders (diabetes, juvenile rheumatoid arthritis, chronic obesity, spina bifida or cerebral palsy). Their results showed that child adaptation was correlated with a number of family environment factors, specifically family conflict, poor family cohesion and poor parental control.

Within this thesis we aim to add to this research by assessing the relationship between the socio-ecological environment and the child's adaptation in two ways. First, we aim to extend Wallander et al.'s (1989d) findings by assessing parental mental health, using in-depth measures of mental health, in relation to the child's adaptation. Second, in an attempt to extend the family environment findings in the Wallander et al. (1989b) paper, we will assess parenting behaviours in relation to

child adaptation.

Child adaptation

Within Wallander et al.'s (1989b) model, child adaptation was defined as representing the child's mental health, social functioning and physical health. In their empirical work, Wallander and colleagues (1988; 1989a-d) assessed this concept using the Child Behavior Checklist (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983) or the Vineland Adaptive Behavior scales (Sparrow, Balla, & Cicchetti, 1984; used by Wallander et al., 1990).

Within the present chapter, literature which addresses the child's mental health will be discussed, in addition to more social aspects of adaptation, such as attending school, behaviour problems, social relations and perception of body image. The child's physical health, as affected by cancer, was addressed in Chapter 1. Within this thesis, the concept of child adaptation will be captured by an assessment of the child's quality of life (QOL). This concept will be explored in the latter half of this chapter.

The general limitations of this research are addressed in Chapter 3 (Parental mental health), since both chapters review cancer literature and therefore have similar methodological flaws.

2.2 The child's adaptation to cancer

Children and adolescents are faced with important developmental tasks as they mature. When a child or adolescent is diagnosed with cancer, these normal developmental changes may be hindered or arrested. For all children, physical appearance is affected, through alopecia, weight loss or gain, scars through invasive procedures, and in some instances, permanent body alterations. For younger children, frequent hospitalisation impedes the learning of new school material or developing closer peer relationships. Adolescents have to contend with other difficulties. At a time when they are usually attaining independence from the family, while strengthening their peer relations, sitting school exams, and thinking about career pathways, they are forced to rely heavily on their parents, cannot take

part in normal social activities, and may have to take much time off school. For these reasons, children and adolescents with cancer have been identified as a group at risk for psychosocial adjustment difficulties (Sanger, Copeland, & Davidson, 1991).

Wherever possible, the research presented in this chapter will be presented in terms of treatment status, i.e., whether children are on- or off-treatment. Where the research is not clear, studies will be grouped together according to developmental status, e.g., the body image literature. The studies cited within this chapter are summarised in Table 2.1.

2.2.1 The child's mental health

On-treatment

In one of the earliest empirical papers assessing child adaptation following the diagnosis of cancer, Kashani and Hakami (1982) identified a 17% incidence of major depressive episodes using DSM-III diagnostic criteria (identified through interview techniques). However, compared with healthy controls and published norms on questionnaire assessments, children with cancer have been reported as being no more anxious or depressed (Allen, Newman, & Souhami, 1997; Mulhern, Fairclough, Douglas, & Smith, 1994). In contrast, there have been reports that children with cancer are actually *less* depressed and anxious than normal controls (Canning, Canning, & Boyce, 1992; Kaplan, Busner, Weinhold, & Lenon, 1987; Phipps & Srivastava, 1997; Worchel et al., 1988). In these studies, the scores obtained from control samples are usually typical, whereas the cancer group are well below expected values (Phipps & Srivastava, 1997).

These inconsistent results have been explained in a number of ways. First, from a methodological point of view, the way mental health has been measured has been questioned. Second, from a more theoretical perspective, different coping theories have been suggested in response to the results.

Methodologically, paper-and-pencil measures have been criticised for not being sensitive enough to tap these youngsters' concerns, compared with more in-depth

techniques (Kazak & Nachman, 1991). For example, Kashani and Hakami (1982) reported a high level of depression using interview reports, where children can talk freely about their concerns, and later questionnaire studies (e.g., Allen et al., 1997).

From a more theoretical perspective, it may be that children with cancer develop certain coping strategies to help them adjust to their illness. Two types of coping strategies have been proposed: the use of **repression** (e.g., Canning et al., 1992) or the use of **denial** (e.g., Worchel et al., 1988). The difference between these two strategies is that Canning et al. (1992) suggest that repression (defined by elevated levels of defensiveness) is part of an underlying personality style, with there being either an absence or attenuated awareness of emotional distress, compared with Worchel et al.'s (1988) account which suggests that children refuse to acknowledge their feelings in certain situations.

For example, Canning et al. (1992) reported that adolescents with cancer had lower levels of self-reported depression than a healthy control group. The authors assessed their coping strategies and concluded there was a higher proportion of repressors in the cancer population than in the control group, which may help explain these results. This style of adaptation may help begin to explain why some children with cancer report comparatively lower levels of depression than controls (Canning et al., 1992). Similar results have been found by Phipps and Srivastava (1997) who reported that children with cancer were less depressed and anxious than healthy controls, but showed greater defensiveness when asked about their illness.

An alternative explanation concerning why children show fewer mental health symptoms than controls was discussed by Worchel et al. (1988). They proposed that children were denying the serious implications of their illness, explaining the apparent absence of depressive and anxious symptoms. In this case, the authors discussed that denial may actually be an appropriate coping mechanism in response to the diagnosis of cancer. In their sample, children were seen as falling very quickly into a new routine of hospital visits and medical treatments. Although negative feelings were evident these were most commonly expressed in

situations where the child was in an individual counselling session, or in a support group. Therefore, it seems that children have learned very quickly where and with whom to share their negative feelings (Worchel et al., 1988).

Survivor studies

This section draws on a literature review of survivors of childhood cancer by Eiser, Hill and Vance (2000). In line with the results of work conducted with children on-treatment, most studies with survivors report similar levels of mental health problems in comparison with controls, in terms of anxiety, self-esteem (Sloper, Larcombe, & Charlton, 1994) and general psychological functioning (Gray et al., 1992a & b; Noll, Bukowski, Davies, Koontz, & Kulkarni, 1993). In comparison with norms, survivors report similar levels of self-concept (Anholt, Fritz, & Keener, 1993) and depression (Noll et al., 1993). In contrast, Radcliffe, Bennett, Kazak, Foley and Phillips (1996) reported that survivors of CNS tumours were *less* anxious and depressed than published norms, but had comparable self-perception.

The only study to report *poorer* functioning in comparison with norms was that by Eiser et al. (1997) who recruited a sample of bone tumour survivors. In this study, all survivors had had limb-salvage surgery (replacement of the diseased bone with a metal endoprosthetic limb). Using the SF-36 (Jenkinson, Coulter, & Wright, 1993), survivors had significantly poorer physical functioning, role performance, general health and social functioning, and increased levels of pain, than UK published norms.

It would appear that children with cancer demonstrate good psychological functioning, despite their diagnosis. Generally, children show similar levels of functioning to healthy control children and in some studies function even better. Attempts have been made to explain these counter-intuitive results. Methodologically, paper-and-pencil measures of psychopathology have been criticised for not being sensitive to the illness-specific issues these children may have (e.g., Kashani & Hakami, 1982). Theoretically, it has been suggested that children have different coping mechanisms that help explain their psychological functioning, e.g., they may either repress their feelings or deny the seriousness of the illness (e.g., Canning et al., 1992; Worchel et al., 1988).

2.2.2 Social functioning: School attendance, behaviour, social relationships and body image

In addition to research which has examined the child's mental health, there has also been a considerable amount of research dedicated to the assessment of more 'everyday' aspects of functioning, such as how the child feels about school and friends, their body, and how they feel their illness has impacted on these issues.

Considering the amount of classroom time children miss due to having treatment or not feeling well, it is not surprising that school re-entry has been noted as a particularly difficult time for those with cancer (Sanger et al., 1991). Drawing on a review by Vance and Eiser (in press), a great number of studies have assessed issues such as absenteeism (Charlton et al., 1991; Lansky, Cairns, & Zwartjes, 1983; Rynard, Chambers, Klinck, & Gray, 1998), behaviour problems (Anderson, Smibert, Ekert, & Godber, 1994; Gartstein, Short, Vannatta, & Noll, 1999; Madan-Swain, Brown, Sexson, & Baldwin, 1994; Noll et al., 1999), and social relations (Noll, Bukowski, Rogosch, LeRoy, & Kulkarni, 1990; Noll, LeRoy, Bukowski, Rogosch, & Kulkarni, 1991; Noll, Ris, Davies, Bukowski, & Koontz, 1992).

Attendance

Absenteeism is highest among children the year following diagnosis (Rynard et

al., 1998), and is higher than reported levels for healthy peers and children with other chronic or orthopaedic conditions (Charlton et al., 1991; Stehbens, Kisker, & Wilson, 1983). Although absenteeism decreases over the years following diagnosis, children with cancer attend school less frequently than peers (Katz, Rubinstein, Hubert, & Blew, 1988; Lansky et al., 1983). Furthermore, this difference between peers and children with cancer is most pronounced for those with CNS tumours (Lansky et al., 1983), providing evidence for the association between brain involvement as a disease / disability risk factor and child adaptation (Wallander et al., 1989b).

Behavioural problems

Behaviour within this context generally refers to externalising or internalising problems, compared with problems in social relations, in particular peer interactions, which are discussed in the next section.

Considering the invasiveness and duration of treatment, and the amount of school time missed, some researchers have hypothesised that children with cancer may develop behavioural problems. However, compared with healthy controls, children with cancer do not appear to have significantly more behavioural problems, as measured by the CBCL (Achenbach, 1991; Achenbach & Edelbrock, 1983), regardless of treatment status (*on-treatment:* Gartstein et al., 1999; *off-treatment:* Anderson et al., 1994; Madan-Swain et al., 1994; Noll et al., 1999). Teachers and parents also tend to rate the children's behaviour within normal ranges (*on-treatment:* Rynard et al., 1998; *off-treatment:* Noll et al., 1997). One study also recruited siblings of survivors of CNS tumours, showing that neither the survivors nor their siblings had worse school behaviour than controls (Glaser, Rashid, U, & Walker, 1997).

Some problems have been noted with children on-treatment however, including having less energy and changeable moods (Adamoli et al., 1997; Deasy-Spinetta & Spinetta, 1980; Mancini et al., 1989), which is not surprising given their treatment demands. More positively, Deasy-Spinetta and Spinetta (1980) reported that children with cancer were no different from peers in their willingness to

attend school, being teased or the extent to which they demonstrated age inappropriate dependent behaviours. Furthermore, children who had completed treatment were seen as more willing to attend school, less argumentative and apprehensive, were not teased and were rated as being no more clingy or dependent upon adults than healthy classmates (Glaser et al., 1997; Spirito et al., 1990).

However, caution must be exercised here. Many studies are based on the Deasy-Spinetta Behaviour Questionnaire (DSBQ; Deasy-Spinetta & Spinetta, 1980; e.g., Adamoli et al., 1997; Mancini et al., 1989) or the CBCL (Achenbach 1991; e.g., Gartstein et al., 1999; Madan-Swain et al., 1994). The DSBQ has recently come under some criticism as findings appear to be sensitive to the exact way in which instructions are given (van Dongen-Melman, De-Groot, Hahlen, & Verhulst, 1996). The CBCL has also been criticized for work with chronically sick children (Perrin, Stein, & Drotar, 1991; see Chapter 3 for a more detailed discussion). Therefore, although it appears as if children generally have few behavioural difficulties, it is worth considering the quality of the measurements used in these studies.

Social relationships

Most of the studies researching the child's social relationships have been conducted by Noll and his colleagues. They have recruited children who are on-treatment (Noll et al., 1999), off-treatment (Noll et al., 1993), or mixed on-off-treatment status (Noll et al., 1990, 1991). In their 1992 account, Noll et al. recruited a sample of children with malignancies not involving the brain who were still on-treatment, a sample of CNS survivors and a sample of children with sickle cell disease (SCD).

Their methodology involves comparison of children with cancer with healthy controls or other chronically ill children using the Revised Class Play assessment (RCP; Masten, Morrison, & Pellegrini, 1985). In this activity, individuals are requested to imagine that they are a director of a school play and to choose children in their class for one of three roles: sociability-leadership, aggressive-

disruptive and sensitive-isolated. In different studies by Noll and colleagues, children, teachers, or both, have completed the measure. The fact that it is teacher-completed has been a source of concern. Considering that it was developed for child completion, its reliability has not yet been determined for use by teachers (Vance & Eiser, in press).

Children with cancer (both on- and off-treatment) were perceived by teachers as being more socially withdrawn, isolated and shy than matched peers (Noll et al., 1990). However, when Noll et al. (1991) studied classmate reports, they found few social problems. Although peers reported children with cancer as more socially-isolated, no significant differences were found for their popularity, number of mutual friends, loneliness, or self-worth. Similar results were reported by Noll et al. (1993).

In their most recent paper, Noll et al. (1999) reported data from both children and teachers. Teachers chose children with cancer more often than their classmates for sociability-leadership roles. Children with cancer were selected less often for aggressive-disruptive roles by both their classmates and teachers.

A number of studies have recruited children who have undergone more aggressive treatments or who have had cancers with poorer prognoses. For example, Noll et al. (1992) reported that survivors of CNS tumours were more often nominated by teachers for sensitive-isolated roles compared with peers, children with malignancies not involving the CNS and children with SCD. Similarly, Vannatta, Gartstein, Short and Noll (1998b) reported that survivors of CNS tumours were more likely to be assigned sensitive-isolation roles according to teacher, child and classmate reports. Survivors were less likely to be nominated as a "best friend" by healthy peers.

Finally, Vannatta, Zeller, Noll and Koontz (1998a) also used the RCP (Masten et al., 1985) to compare social functioning in children following a bone marrow transplant (BMT) with matched peers. Although peers chose BMT survivors for roles involving social isolation and withdrawal, survivors themselves did not

favour these roles. BMT survivors were chosen by peers significantly less often as a 'best friend' and were less likely to have their best friend choices reciprocated. Again, these studies demonstrate the importance of brain involvement (disease / disability risk factor; Wallander et al., 1989b) in child adaptation.

There are a number of concerns with these studies. First, obtaining teacher reports is limited. While they may be excellent sources of information about the child, since they are less emotionally involved than parents, they can only base their reports on how the child acts in the classroom, i.e. they cannot give a complete picture of the child's behaviour. Second, there may be a selection bias in that parents who know their child has behaviour problems in school may be unlikely to give permission for the teacher to participate in such studies (Eiser & Vance, in press). Third, the current research is dominated by one group of researchers who have repeated their methodology with a number of difference cancer samples (e.g., ALL, CNS, BMT). To date, we have a fairly limited view of the child's social relationships beyond data produced from the RCP (Masten et al., 1985).

Body Image

Cancer can have a number of effects on the developing individual, including changing how the child feels about their appearance and how others perceive them, thereby influencing their body image (La Greca, 1990). It might be expected that the child's developmental stage rather than their treatment status (on- vs. off-treatment) would be a more important predictor of body image, i.e., we might predict that adolescents with cancer would suffer from greater body image problems than younger children with cancer. Adolescence is a period in which body image becomes extremely important, as puberty results in much more attention being placed on physical appearance (Pendley, Dahlquist, & Dreyer, 1997). Physical appearance seems crucial at this stage in interpersonal relations (Coleman & Hendry, 1990). Previous work has shown that adolescents with cancer have been reported as feeling more negatively about their bodies compared with younger children with cancer (Price, 1992).

Fritz and Williams (1988) reported that body concerns were problematic for more than half of their sample of 41 adolescent survivors, and that they were

particularly worried about their sexuality, sexual attractiveness, and reproductive capacity - issues that are especially pertinent at this developmental stage (Coleman & Hendry, 1990). Similar findings were reported by Madan-Swain et al. (1994), Stern, Norman and Zevon (1993), and Puukko et al. (1997). Interestingly, the latter study recruited a sample of women (mean age = 20.1 years) who had survived childhood leukaemia, reporting that even years after treatment these women had major sexual identity problems including feeling less feminine and more infantile.

There have also been links between time since treatment ended and adolescent body image. For example, although Pendley et al. (1997) reported no differences between adolescent cancer survivors and healthy controls on measures of body image, they did report that within the cancer group, those who were further from treatment had more negative body image perceptions. Furthermore, the authors obtained independent ratings of actual appearance in order to investigate whether any negative body perceptions the adolescent survivors had could be labelled as accurate assessments or misperceptions of actual appearances. Their results showed that the adolescent survivors were not rated as being less attractive by independent observers (taking into account time since treatment had ended). Therefore, it appears as if their negative body image is not shared by others. To explain these findings, the authors reported that as the initial euphoria of surviving their illness diminishes, the adolescents increasingly feel more and more different from their peers, leading to a decline in body image. Although the authors employed a number of body image questionnaires, covering many aspects of body image and self-perception, caution must be exercised when interpreting these results considering the small sample of adolescent survivors (N=21).

It might be expected that children who are obviously disfigured as a result of their treatment, such as those who have had limb amputation or brain surgery, would have poorer body image than children who have no such disfigurement. Surprisingly, this has not been studied with paediatric oncology samples. In fact, many researchers have excluded these particular children from studies of body image (cf: Pendley et al., 1997).

Absenteeism is a problem for all children regardless of treatment status, but behaviourally children appear similar to controls and norms. Socially children with poorer prognoses appear to be more isolated than peers or children with cancers not involving the brain. Adolescents with cancer have greater body image concerns than younger children with cancer, and these problems can last into adulthood.

There is the concern, however, that we are only achieving 'glimpses' into the child's adaptation, by having many studies each addressing different aspects of adaptation. One way to overcome this problem is to pull together all of these aspects of adaptation and create a single measure of 'quality of life' (QOL). In the latter half of this chapter, QOL will be addressed with the view of including this as the main child adaptation measure in this thesis.

2.3 Quality of life (QOL)

The definition and measurement of QOL has been the subject of considerable debate (Guyatt, Feeny, & Patrick 1993; Patrick & Bergner, 1990). These debates have often focused around whether QOL should be an objective or subjective account of the impact of illness on someone's life. Early efforts at measuring QOL centred around functional indicators, such as the ability to walk or run, or medical indicators, such as blood pressure or being overweight. However, it became clear that this objective standpoint was not enough to assess QOL and that it must also encompass more subjective ratings (Eiser & Morse, 2001). For example, although two children may not be able to run (same objective rating), one may have overcome their disability and have developed a keen interest in passive activities, whereas the other may be quite depressed at their inability to take part in active exercise (different subjective rating).

2.3.1 Definition of QOL

Most QOL measures have evolved from the World Health Organization (WHO) definition of health as "a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity" (WHO, 1948). QOL

can encompass all aspects of existence beyond purely medical issues, including one's life, housing, environment, work and school (Seid, Varni, & Jacobs, 2000). "Health-related QOL" refers specifically to the subjective and objective impact of dysfunction linked with an illness, injury, or medical treatment (Spieth & Harris, 1996). The consensus within this approach is that a patient's health-related QOL includes, at the minimum, the physical, psychological, and social domains outlined by the WHO, as well as disease-specific and treatment-related symptoms (Seid et al., 2000).

More specific to the field of paediatric oncology, the American Cancer Society Workshop held a meeting in January 1995 with the aim of discussing research methods and barriers in defining and measuring QOL (Bradlyn, et al., 1996). The participants present at that meeting agreed upon the following definition of QOL:

"Quality of life (QOL) in pediatric oncology is multidimensional. It includes, but is not limited to, the social, physical, and emotional functioning of the child and adolescent, and when indicated, his/her family. Measurement of QOL must be from the perspective of the child, adolescent, and family, and it must be sensitive to the changes that occur throughout development."

(Bradlyn et al., 1996, pp.1333-1334)

The following issues would have been key in developing this definition of QOL:

- QOL is a multidimensional construct, and therefore cannot be measured through unidimensional measures;
- Considering the key role the family plays in the child's illness, family functioning is an important issue to consider when assessing a child's QOL;
- The child is in a position whereby they cannot consent to medical procedures, and is dependent upon his/her family. Parents play a central role in any chronic illness that a child may have and, as a direct result, researchers must also take into account the parents functioning;
- If at all possible, QOL should be measured from the child's and family perspective;
- Since children are developing as individuals, what is important to the child's QOL will change over time as they move in and out of different

developmental stages. Measures of QOL must take into this into account.

In defining QOL, we draw on the work of Bradlyn et al. (1996). QOL is a multidimensional concept, with consideration of the impact of the family in the child's illness, and it must take into account the perspective of the child and their parents.

2.3.2 Measurement of QOL

The assessment of QOL has generally taken one of two forms, (1) where researchers use a battery approach, utilising multiple measures of functioning thought to be representative of QOL (for example, physical functioning, health status, mental health, body image and school functioning), and (2) where researchers have attempted to develop comprehensive QOL measures. The latter is preferable for many reasons; for example asking a child or parent to complete numerous measures is time consuming, creates concentration burdens and may not be possible in a hospital or clinic setting. Repetition of items is also a problem in battery approaches. For example some measures may have overlapping elements, which means that more items are completed than necessary. Additionally, by creating a comprehensive QOL measure, psychologists can attempt to produce a well validated and reliable measure which is succinct and can be used in future medical situations for clinical purposes.

There is also the question of whether QOL measures should be generic or disease-specific. Both formats are available and there are benefits and drawbacks to each (Eiser & Morse, 2001). For example, generic measures allow an assessment of how far the QOL of children with chronic illnesses is different from a control group or established norms, whereas disease-specific measures do not allow such comparisons. Alternatively, disease-specific measures allow a more detailed examination of how different illnesses affect the child's functioning, for example how worried children are about having lumbar punctures or chemotherapy, issues particular to children undergoing cancer treatment. Therefore, when deciding upon QOL measures, it is important that the study aims are matched with the measure used. If a standard between-group comparison is required, a generic

measure may be required, whereas if a measure is to be used to determine the efficacy of different treatments, a disease-specific measure may be more useful.

2.3.3 Proxy or self-ratings?

For children, assessment of QOL has traditionally been based on parents', most often mothers', reports. Mothers' ratings are especially useful where the child is too ill or handicapped to provide information directly, or simply too young to read and respond reliably and accurately to measures. Reliance on mothers' ratings is often unavoidable in some circumstances. For example, the majority of children with ALL are diagnosed between one- and four-years of age (Stiller et al., 1995).

However, it is increasingly argued that self-ratings need to be made by children whenever possible. This is a response to changes in legislation which emphasise the need to obtain the child's point of view wherever possible (Department of Health, 2000), recognition that considerable differences can exist between child and parent ratings (Eiser & Morse, 2001) and follows from the subjective nature of QOL.

Several methodological problems arise when obtaining child self-reported data, however. These include the tendency to choose the first answer given to them (so-called 'position bias'; Pantell & Lewis, 1987), acquiescence response bias (agreeing with the investigator) and a limited understanding of negatively phrased items (Pantell & Lewis, 1987). For example, Pantell and Lewis (1987) showed that children under the age of 12 had difficulty disagreeing with items that would reflect good functioning.

2.4 QOL and this thesis

Current dissatisfaction with research assessing single facets of the child's mental health or social functioning has turned our attention to the assessment of how cancer impacts upon their overall functioning. As such, QOL is becoming an increasingly popular way of assessing how cancer affects the child's, and family's, overall well-being. As QOL is a fairly recently developed concept, most published QOL papers are concerned with definition issues or the initial development of appropriate measures.

In this thesis QOL will be chosen as the main assessment of the child's adaptation for the following reasons. First, we are dealing with young children who cannot complete lengthy batteries of questionnaires, so it is preferable to assess QOL in one single, succinct measure. Second, QOL gives an overall idea of how the child is functioning, not just snapshots of information. Third, it concurs with the key concepts of mental health, social functioning and physical health outlined in Wallander et al.'s (1989b) model as representing child adaptation.

As discussed previously, one of the key themes in this thesis is to assess the relationship between child adaptation and parental mental health in families of children with cancer. Therefore, in order to understand this relationship further, the next chapter reviews existing literature that has assessed (1) parental mental health at-diagnosis, and (2) how this relates to child adaptation.

Table 2.1 The child's Psychological adaptation to cancer – summary table

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Adamoli et al. (1997)	Italy	Leukaemia	6-16	Teachers of 291 children; on-treatment	291 matched healthy controls	Cases attend school less regularly than controls. Cases differed from controls on sub-scales measuring learning, socialisation and emotionality. Cranial irradiation and young age at diagnosis were associated with poorer behaviour functioning.
Allen et al. (1997)	UK	Mixed cancers	M = 15.4	43 adolescents and their parents; on-treatment	173 matched controls	Adolescents were no more depressed or anxious compared to controls. Girls with cancer were more depressed and anxious than boys with cancer.
Anderson et al. (1994)	Aust-ralia	Mixed cancers	Gp 1: 12.1 Gp 2: 11.7	Gp 1: N=100 survivors who had chemotherapy & cranial irradiation and their parents; Gp 2: N=50 survivors treated with chemotherapy and a parent	100 matched healthy controls (not for the behaviour measure)	No significant between cancer-group differences on behaviour. There were differences on the school scores, with group 1 recording poorer performances.
Anholt et al. (1993)	USA	Mixed cancers	7-18	120 Survivors	120 healthy children; norms	Self-concept was similar to population norms. Survivors rated their school status, behaviour, overall happiness and satisfaction more positively than controls.
Canning et al. (1992)	USA	Mixed cancers	12-18	31 children newly diagnosed and their parents.	83 healthy children	Children with cancer are less depressed and anxious than healthy controls. Repression has been suggested as a positive coping style in children with cancer.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Charlton et al. (1991)	UK	Mixed cancers	4-16	29 children on-treatment	20 chronically ill children; 23 children with orthopaedic conditions.	Cancer patients missed 35% of school time, higher than those with other chronic diseases and orthopaedic patients.
Deasy-Spinetta et al. (1980)	USA	Mixed cancers	5-17	Teachers of 42 children; on-treatment	42 matched controls	Problems included attendance, completion of school work, concentration and a lack of energy. Cases attended school willingly, were accepted in school; no school phobia.
Eiser et al. (1997)	UK	Bone tumours	8-28	41 children; survivors	Norms	Scores below population norms on measures of physical functioning, physical role performance, pain, general health, and social functioning.
Fritz & Williams (1988)	USA	Mixed cancers	M=17.3	41 adolescent; survivors	Norms	Over half the sample had body image problems, especially surrounding issues such as sexuality, attractiveness to the opposite sex, and reproductive capacity. Over 26% were hyprochondriacal.
Gartstein et al. (1999)	USA	Mixed cancers	8-15	64 children and their parents; on-treatment	49 children with sickle cell disease; 21 with haemophilia; 35 with juvenile rheumatoid arthritis, and matched healthy controls for all chronically ill children, and parents.	Mothers and fathers did not report cases having more behaviour problems than controls. Cases self-reported similar depression levels as controls.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Glaser et al. (1997)	UK	Brain or spinal cord tumours	6-17 (M=10.8)	27 children (off-treatment); 27 parents; 27 teachers; 21 siblings.	25 matched controls; 20 sibling controls.	Neither cases nor siblings had worse school behaviour compared with controls. Cases were less likely to participate in formal sports, had impaired play scores and worried more than controls. Teachers reported cases as having more pain and mobility problems and poorer self-esteem.
Gray et al. (1992 a & b)	Canada	Mixed cancers	18-37	62 adult survivors of childhood cancer; off-treatment.	Norms; peers (selected by survivors)	No significant differences between survivors and peers on standardised inventories, story-telling or physical symptoms. Compared with peers, survivors were less satisfied with social relationships; showed greater concern about infertility; expressed more perceived control and more satisfaction with their degree of autonomy; were more likely to prefer interacting with others.
Kaplan et al. (1987)	USA	Mixed cancers	7-18	21 children; 17 adolescents with cancer; mixed on-off treatment.	Norms	Children with cancer were significantly less depressed than norms. Adolescents with cancer had mean depression levels no different from population norms.
Kashani & Hakami (1982)	USA	Mixed cancers	6-17	35 children; (ranged from one month to 10 years post-diagnosis) and their parents	NONE	17% of the group reached criteria for a major depressive disorder. Children were interviewed, with a number of key themes running throughout including nonchalance (especially younger children) and anger (especially older children).

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Katz et al. (1988)	USA	Mixed cancers	Gp 1: 5-17 (M=9.76) Gp 2: 5-17 (M=10.48)	Gp 1: Intervention: N=49 children, their parent, primary physician and main teacher. Gp 2: Standard care: N=36 children with cancer, their parent, primary physician and main teacher. On-treatment	NONE	Attendance was poorest during the year following diagnosis and only moderately improved during the next year. Children receiving standard care showed poorer school and social adjustment than cases in the intervention group. The intervention group showed significant improvements post-programme.
Lanksy et al. (1983)	USA	Mixed cancers	Mixed	239 children; mixed on-off treatment	NONE	Attendance was poorest the year of diagnosis, increasing in subsequent years. Three years post-diagnosis, the number of days absent was still more than pre-diagnosis reports. Three years post-diagnosis, children with CNS tumours missed more school than healthy children.
Madan-Swain et al. (1994)	USA	Mixed cancers	12-18 (M=15.6)	25 adolescents and parents; survivors	16 matched control families.	Cases reported less body comfort than controls. Mothers of cases reported being less flexible and more rigid than control mothers.
Mancini et al. (1989)	Italy	Mixed cancers	6.6-15.1	Teachers of 91 children; On-treatment	91 matched controls.	Cases had poor attendance according to teachers. However, they attended school willingly, had no school phobia, worked hard, and kept up with school work when absent from school. They were less energetic, had changeable moods, and difficulty in remembering.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Mulhern et al. (1994)	USA	Leukaemia or solid tumours	8-16.8	99 children and their parents; mixed on-off treatment, mainly on-treatment (median = 0.7 years post-diagnosis)	Norms	Fewer than 10% of children scored above threshold indicative of mild depression.
Noll et al. (1990)	USA	Mixed cancers	8-18 (M=12.3)	Teachers of 24 children; Mixed on-off treatment	24 matched controls	Cases missed on average 25.6 days compared with 6.5 days for controls. Cases were selected significantly less often for sociability-leadership roles, and more often for sensitive-isolation roles. The prototypical pattern for cases was low-positive, low average-disruptive, and high-isolated scores.
Noll et al. (1991)	USA	Mixed cancers	8-18	24 children; mixed on-off treatment	24 matched controls	No differences were found between groups on the best friend, liking scale or the loneliness measure. Peers nominated cases more for sensitivity and social isolation roles, but equally for sociability-leadership and aggressive-disruptive roles.
Noll et al. (1992)	USA	Mixed cancers	8-18	Teachers of: Gp 1: children with brain tumours (N=15; survivors); Gp 2: children with other cancers (N=26; on-treatment)	Teachers of: Gp 3: 33 children with sickle cell disease and matched controls for all children.	Cases scored significantly higher on the sociability-leadership dimension and lower on the disruptive-aggressive dimension compared with controls. Children with CNS tumours were significantly higher on the sensitive-isolation dimension compared with controls.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Noll et al. (1993)	USA	Mixed cancers	11-18	19 children and their teachers; off-treatment	19 matched controls	No differences were found between groups on the measures of best friends, liking scales, loneliness, depression or self-concept. For cases there were no changes over time on measures of social reputation, best friends, and liking scales.
Noll et al. (1999)	USA	Mixed diagnoses	8-15 (M=11.5)	70 children 70 teachers 64-67 mothers 49-55 fathers; on-treatment	70 matched controls	Cases had missed an average of 31.29 days, compared with 6.17 for controls. Cases were functioning better socially than controls, similarly emotionally to controls and had lower athletic self-concept.
Pendley et al. (1997)	USA	Mixed cancers	11-21	Survivors	Healthy children recruited from local advertisements	Healthy controls and survivors did not differ on measures of body image, attractiveness, loneliness, social anxiety and school absenteeism. Within the adolescent cancer group, body image had a negative relation with time since treatment ended.
Phipps & Srivastava (1997)	USA	Mixed cancers	7-16	107 children; mixed on-off treatment	442 controls	Children with cancer scored significantly lower levels of depression and anxiety than controls. Assessment of coping styles indicated that children with cancer were more defensive than controls.
Puukko et al. (1997)	Finland	ALL	M=20.1 years	30 adult survivors of childhood ALL	Matched controls	Adult women continued to have sexual identity issues, including having more restrictive images of sex, feeling less feminine and more often indifferent or infantile than controls.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Radcliffe et al. (1996)	USA	CNS tumours	6-18	38 children, their mothers and teachers; survivors	Norms	Compared with norms, children rated themselves as less anxious, depressed and athletically competent, but similar in terms of self-perception. Mothers rated their children as less competent than children's self-report.
Rynard et al. (1998)	Canada	Mixed cancers	5-19	Teachers of 67 children; Parents of 55 children. 36 children; on-treatment	NONE	*Psychological adjustment:* Children on-treatment miss one-third of school days. Parents rated their children as more aggressive, depressed and hyperactive than teachers. *Programme evaluation:* Teachers rated discussion and dialogue between the school and hospital staff as the most helpful part of the programme. Parents report a need for communication between hospital and school.
Sloper et al. (1994)	UK	Mixed cancers	9-18 (M=12.32)	31 children, their parents and teachers; survivors	Matched peers (only 15 families completed all measures)	No differences were found on measures of anxiety and self-esteem. Survivors were rated by teachers at-risk for behavioural adjustment problems.
Spirito et al. (1990)	USA	Mixed cancers	5-12 M = Gp 1: 9.0 Gp 2: 9.3	Gp 1: N=11 from one centre; Gp 2: N=45 from second centre, their parents and teachers; Survivors	52 matched healthy controls	Children were rated by teachers as being more willing to attend school and having better attendance than controls. They were rated lower on items measuring apprehension in school, restlessness, getting teased and arguing. Neither teachers nor parents reported group differences on the measure of problem behaviours.
Stehbens et al. (1983)	USA	Mixed cancers	<5 yrs, 6 mths.	Teachers of 36 children; On-treatment	Teachers of 26 children with haemophilia	Both cancer groups were absent more than those with haemophilia. Teachers did not rate behaviour differences for any of the children, nor was there any pre-post- diagnosis behaviour changes.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Stern et al. (1993)	USA	Mixed cancers	14-23	48 adolescent; survivors	40 healthy adolescents	Survivors were relatively well-adjusted, but had a less positive self-image in terms of their social and sexual selves.
Vannatta et al (1998a)	USA	BMT survivors	8-16 (M=11.7)	48 children and their teachers; survivors	48 matched controls	Cases missed on average 13.63 days compared with 5.21 days for controls. Peers selected BMT survivors more frequently for passive-anxious and active-isolation roles. Teachers nominated BMT survivors less often for aggressive-disruptive roles. BMT survivors were chosen by peers less often as a best friend and were less likely to have their best friend reciprocated.
Vannatta et al. (1998b)	USA	Brain tumours	8-18	28 children and their teachers; survivors	28 matched controls	Cases missed on average 10.54 days compared with 5.4 days for controls. Teachers, self and peer reports showed that children with brain tumours were seen as more sensitive-isolated and were selected less often as a best friend. Liking ratings did not differ between groups.
Worchel et al. (1988)	USA	Leukaemias and solid tumours	7-18	76 children; mixed on-off treatment	42 psychiatric patients; 304 healthy controls.	Children with cancer reported less depression than psychiatric patients and healthy controls. Denial was suggested as a possible coping style used by children to cope with their cancer.

CHAPTER THREE.

PARENTAL MENTAL HEALTH: RELATIONSHIP WITH THE CHILD'S ADAPTATION TO CANCER.

Summary

This chapter provides a review of literature that is central to both empirical studies presented in this thesis, namely parental mental health following their child's cancer diagnosis, both during treatment and once treatment has been completed. Additionally, the literature illustrates the second key theme underlying this thesis, namely the association between the child's medical and psychological functioning (reviewed in Chapters 1 and 2) and parental mental health.

Although most parents display a complex mixture of emotions at diagnosis and during treatment, the majority do not have at-risk levels of mental health. However, there are a significant proportion of parents who do report elevated levels of depression and anxiety throughout treatment. These findings have also been reported for parent of survivors: while most do not show signs of clinical levels of mental health, many parents express deep feelings of loss and uncertainty; some even suffer from post-traumatic stress disorder, even years after their child's diagnosis.

Research assessing the association between parental mental health and child adaptation both during and after treatment has shown that poor maternal mental health is related to poorer child depression, behaviour problems and overall adaptation.

This chapter concludes with a discussion of methodological limitations, which have been observed both in the parent mental health (current chapter) and child adaptation (chapter 2) literatures.

3.1 Introduction

As discussed in Chapter 2, parental mental health, parenting behaviours and their relationship with child adaptation, are central concepts that will be studied in this thesis. Both of these *social-ecological factors* (Wallander et al., 1989b) are resistance factors, predicted to protect the child from poor adaptation. Wallander et al. discussed the direct effect that these factors can have on the child's adaptation.

These pathways have been examined in other areas of research. First, parental (particularly maternal) mental health has been repeatedly studied in relation to child outcomes in both chronic illness and mainstream developmental psychology literatures (see Cummings & Davies, 1994; Downey & Coyne, 1990, for reviews). This research highlighted the negative implications of the parent's poor mental health on the child's development. Second, much research has considered the family environment by examining the relationship between parenting behaviours and child outcomes (Maccoby & Martin, 1983). While this research is commonplace within mainstream developmental psychology, its application has not yet become routine within child chronic illness work, although it does appear to fit within Wallander et al.'s (1989b) conception of family environment. Within this chapter, the parent's mental health following their child's diagnosis will be reviewed. Parenting behaviours are discussed in chapters 4 and 5. Literature presented in this chapter is summarised in Table 3.1.1 (on-treatment) and 3.1.2 (survivor).

3.2 Parental mental health: at diagnosis and on-treatment.

On diagnosis, parents must come to terms with the myriad implications and consequences of their child having a life-threatening illness. They must learn the language of the treatment (e.g., bone marrow aspirations, lumbar punctures etc.) and master the intricacies of those treatments they will be required to perform (e.g., administering chemotherapy drugs at home). In the midst of these new stressors and responsibilities, parents must make important decisions, including whether or not their child should participate in a clinical trial (see Chapter 1, section 1.2).

3.2.1 Do parents exhibit severe mental health problems at diagnosis?

Given the stress and the uncertain course of cancer, parents commonly experience a range of emotions; shock, grief, depression, anxiety, anger and hostility are common reactions among parents of newly diagnosed children (Allen et al., 1997; Fife, Norton, & Groom, 1987; Hoekstra-Weebers, Jaspers, Kamps, & Klip, 2001; Sloper, 2000). Although these emotions typically diminish over time as the child settles into their treatment regime, some parents remain distressed long after diagnosis (Brown et al., 1992; Sloper, 2000).

These emotional changes over time have been documented in a number of studies. In their ten-year longitudinal study (the longest prospective design to date), involving 64 families of children with ALL, Kupst et al. (1982) reported that in the year following diagnosis, anxiety, sadness, and information seeking were common behaviours shown by parents, but there were no indications of severe grief reactions. Approximately one-third of mothers were anxious at this time. Although parents appeared to react well to the illness and treatment, they exhibited variations in their moods and behaviours.

At two years post-diagnosis, Kupst et al. (1984) contacted 60 families (93.7%) of the initial sample to examine coping over time. Although coping took many different forms (e.g., denial, anger), most of the families were coping well and scored within normal ranges on standardised measures (mean was below the 'at-risk' band). Correlates of good coping included lack of concurrent stress, adaptive maternal coping and outside support. At the six-year follow-up, 43 (67%) of the original sample were included in the study (Kupst & Schulman, 1988). The authors reported that between the two- and six-years post-diagnosis, there had been a significant increase in positive parental coping behaviours. Overall, it would appear that from diagnosis through to six years post-diagnosis, parents *do not* show severe mental health problems, and in fact, adjust very well to their child's diagnosis. However, it is worth bearing in mind that these families were predominantly middle-to-upper class and the children were treated in a paediatric hospital which provided a great amount of support (including child life therapists, marriage counsellors and pastoral counsellors).

In a similar study, Brown et al. (1992) compared 55 families at different stages of the illness experience (N=23 families at diagnosis, N=22 one year post-diagnosis, and N=10 one year after the completion of chemotherapy). While there were minimal maternal mental health problems in the three groups, there were between group differences. Specifically, mothers of children who had completed treatment (Group three) reported more family cohesiveness, marital satisfaction, and less depression than mothers of children at-diagnosis or one year post-diagnosis. While it seems that maternal functioning does improve over the course of the illness, it is worth remembering that they are not the same participants studied longitudinally, and the number of participants in group three was small (N=10). Additionally, mental health levels were low in all three groups, so although functioning improved across "time", it is worth questioning what this means in real terms. However, it would appear that these results are consistent with Kupst et al. (1982, 1984, 1988): parents do not exhibit severe mental health problems at diagnosis, and what levels of distress there are, declines over time.

Interpreting these parental mental health scores is difficult since they have not been compared with either control groups or population norms. Therefore, although parents do not appear to have severe problems and any problems they do exhibit decline over time, we do not know how different they are from 'normal'. Sawyer, Antoniou, Toogood and Rice (1997) have gone some way to overcome this problem by including a healthy control group in their study of parents of children with cancer. In their longitudinal study, they recruited a sample of children with different cancers (excluding children with CNS tumours). They compared the mental health of parents of healthy children with that of parents of children with cancer at diagnosis, one- and two-years later, using the General Health Questionnaire-28 (GHQ-28; Goldberg, 1978). At diagnosis both mothers and fathers of children with cancer had significantly poorer overall mental health, and in particular higher levels of anxiety and insomnia, compared to the mothers and fathers of healthy children. This difference was not evident at one- and two-years post-diagnosis.

A concern with these studies is that only mean levels of parental mental health are reported. No attention has been given to the number, if any, of parents who fall in

"at-risk" categories of psychopathology. This leaves the reader unable to gauge exactly how varied parents mental health is.

There are some studies that do provide such a standard (Fife et al., 1987; Manne et al., 1995, 1996; Dahlquist, Czyzewski, & Jones, 1996; Hoekstra-Weebers et al., 2001). These studies have shown the benefits of *intra-group analysis*: reporting the percentage of parents falling in different mental health severity categories (e.g., moderate-to-severe; at-risk). While mean levels of parental depression in these studies were in the mild range at diagnosis, a substantial number of parents scored within moderate-to-severe ranges and continued to do so over time. For example, within a month of diagnosis, three- and six-months post-diagnosis, Manne et al. (1995) reported that 25%, 20% and 20%, respectively, of parents scored in the moderate-to-severe range using the Beck Depression Inventory (BDI; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Furthermore, at six months post-diagnosis, the incidence of severe depression was significantly higher than that reported for a healthy adult community sample (Oliver & Simmons, 1984; cited in Manne et al., 1996). Similarly, Fife et al. (1987) showed that 33% of mothers were clinically depressed three-months post-diagnosis, falling to 19% one-year post-diagnosis. Comparable findings have been reported by Dahlquist et al. (1996) and Hoekstra-Weebers et al. (2001). These studies indicate that although mean scores on standardised measures during the early phases of treatment may indicate that many parents do not have significant mental health problems, a substantial number of parents present with elevated symptoms, both at diagnosis and further into treatment.

These minority parents can easily be lost in the calculation of group means. For instance, if we think back to Sawyer et al. (1997), they reported that at-diagnosis, while parents of children with cancer (both mothers and father) were more distressed than control parents, they were not statistically different at the one- and two-year follow-ups. However, it is conceivable that a number of parents *did* display elevated levels of distress at one- and two-year post-diagnosis but these scores were masked by the group means.

One way of assessing individual differences more closely is to use qualitative

methodologies. This has the benefit of highlighting those specific issues that parents feel are important in affecting their well-being or mental health. One such study was conducted by Sloper (1996) who interviewed 98 parents six months post-diagnosis. According to the interview data, more distress was reported where parents had also experienced concurrent stressors - including difficulties at work, financial strain and a lack of social support. In this sample, parents discussed the disruption to family life caused by the child's constant hospitalisation and clinic visits - 50% of mothers and 37% of fathers talked about how they were forced to either reduce their work-load or give up work completely, thereby increasing their financial concerns. Fourteen percent of respondents felt they had no one to talk to during their child's illness. Uncertainty over the child's future was a concern for 27% of parents. This data shows that apart from the distress caused by a child's diagnosis, parents also worry about more practical issues as the child settles into the treatment regime. These practical concerns have rarely been studied in paediatric cancer literature.

This section has considered the extent to which parents self-report mental health problems at diagnosis and during treatment. The effect these problems may have on their child's adaptation will now be reviewed.

3.2.2 Does parental functioning have a direct relationship with child adaptation?

While the relationship between parental mental health and child adaptation is the main focus of this section, a number of subsidiary findings will be reported, such as the relationship between child adaptation and family functioning or social support.

Brown et al. (1993) reported that mothers of children with ALL who were diagnosed with a psychiatric disorder rated their children as being depressed and having internalising behaviour problems. Of their sample (N=61), 34% met criteria for diagnosis of a psychiatric disorder (including major depressive disorder (21.3%), generalised anxiety disorder (18%), dysthymic disorder (8.2%) and panic disorder (8.2%)). Although this study shows the relationship between mother's mental health and her perception of the child's functioning, the fact that

the mother is the sole respondent raises questions about whether the mother's psychiatric disorder is biasing her accounts of her child. Would these children appear depressed or have more behaviour problems if rated by someone other than their mother? If we cannot obtain child self-report, is there a way to eliminate this maternal bias?

Manne et al. (1995, 1996) attempted to control for this bias. They showed that after controlling for initial mental health problems, parental mental health remained strongly related to child behaviour problems. Specifically, they proposed a relationship between illness variables (e.g., treatment severity, number of days hospitalised), family variables (e.g., family functioning, routines), parental depressive symptoms and child behaviour problems at diagnosis, three- and six-months post-diagnosis. In this study of 59 parents, child behaviour problems significantly predicted parental depression at three-months post-diagnosis, even when parental depression at diagnosis was controlled for. Therefore, in comparison to Brown et al.'s (1993) cross-sectional study, Manne et al. have shown that even after partialling out the effect of 'depressive bias' (Manne et al., 1995), child behaviour problems *do* contribute to parental depression. Neither illness nor family variables had a strong relationship with parental depression once child behaviour problems were controlled for. This is an important study, showing the strength of maternal mental health in predicting child behaviour.

Sawyer, Streiner, Antoniou, Toogood and Rice (1998) conducted a similar study to that above, but in contrast, they assessed both mothers *and* fathers mental health over time and investigated the difference, if any, in their relationship with child adaptation. Sawyer et al. reported that poorer maternal mental health (GHQ-28; Goldberg, 1978) immediately after the child's diagnosis, was significantly associated with poorer child adaptation two years later (CBCL; Achenbach, 1991; Achenbach & Edelbrock, 1983). In contrast, paternal mental health and family functioning had a limited effect on the child's later behavioural adaptation. These results demonstrate that maternal, more than paternal, mental health, affects child adaptation. Importantly, the follow-up period in this study (two years) was much longer than in Manne et al.'s (1995, 1996) study (six months). This points to the pervasive effect that the mother's mental health at diagnosis can have on the

child's later adaptation. Although the study assessed the relationship between mother-child functioning at diagnosis and two years later, it would have been more informative if Sawyer et al. had assessed the mother's two-year functioning in relationship to the child's two-year adaptation, controlling for the mother's functioning at diagnosis. This would have resolved any concerns about 'depressive bias'.

Varni, Katz, Colegrove and Dolgin (1996) also studied family functioning in relation to child adaptation. This is also one of the few childhood cancer studies to empirically design their research around Wallander et al.'s (1989b) risk and resiliency model (see Figure 2.1). The pathway between social-ecological resistance factors and child behaviour was tested in this longitudinal study (one-, six-, and nine-months post-diagnosis). Results showed that higher family functioning (cohesion and expressiveness) significantly predicted lower psychological distress and higher social competence in the child (CBCL; Achenbach, 1991, Achenbach & Edelbrock, 1983). Behaviours that promoted child adaptation included commitment, help, support and open expression in the family. The same authors found that nonfamilial social support significantly predicts the adjustment of newly diagnosed children (Varni, Katz, Colegrove, & Dolgin, 1994). Therefore, these two studies together suggest that both familial and nonfamilial social environments are important in the adjustment of children with cancer.

The two studies that addressed family functioning, Varni et al. (1996) and Sawyer et al. (1998), reported different patterns in relation to the child's distress or adjustment (scales on the CBCL). While Varni et al. showed the significance of family functioning in reducing child distress, Sawyer et al. reported a limited relationship between family functioning and child adjustment. One difference between the two studies is that Sawyer et al. also assessed maternal mental health (Varni et al. did not), which may have been a stronger variable in predicting child behaviour than family functioning (both variables are considered to be social-ecological factors; Wallander et al., 1989b). This was shown at the bivariate level, where Sawyer et al. reported a positive correlation between child adjustment and family functioning. However multivariate analysis showed that family functioning

no longer remained a significant predictor of child adjustment, over and above the influence of maternal mental health. Of course, it is impossible to say whether family functioning would have remained such a significant predictor of child distress in Varni et al.'s study if maternal mental health had been assessed, but it may explain the discrepancy between the results of these two studies.

It must be taken into account when considering these studies that the mother gave self-reports of her own mental health and perception of her child's behaviour in all cases. While Manne et al. (1995, 1996) were able to account for influence of 'depressive bias', this was the only study to attempt to control for prior functioning. Therefore, it is clear that further work is needed in order to take account of the 'depressive bias' effect. Additionally, to increase our understanding of the mother-child relationship, it seems natural to move toward an assessment of how children feel their functioning is affected by their mother's mental health.

In an attempt to overcome this single respondent design limitation, Mulhern Fairclough, Smith and Douglas (1992) studied the relationship between maternal and child mental health (as well as social support, child social competence, demographic and medical variables) using both mother *and* child self-report. Importantly, increased maternal depression was associated with increased child depression, as reported by the child. This is a key finding since it is one of the few studies to link the mother's mental health with the child's self-reported depression. Furthermore, the authors reported that low social support and increased length of hospitalisation predicted maternal depression, whereas increased time since diagnosis was related to increased child depression (self-report). This finding has also been reported by Worchel et al. (1988).

A second study to report child self-reported data was conducted by Carlson-Green, Morris and Krawiecki (1995). This is the only study to assess parent and child variables as predictors of child behaviour in a sample of children with CNS tumours. In this study, children self-completed an IQ test and a test of achievement (a measure that assesses single word recognition, decoding, written spelling to dictation and arithmetic). Parents completed measures of coping, life events (family stressors over the past twelve months), family functioning and

child behaviour. Results showed that children from dual-parent homes with fewer negative life events had significantly fewer behaviour problems than children from single-parent homes, experiencing many negative life events. An absence of negative life events has previously been related to parental coping (Kupst & Schulman, 1988; Sloper, 1996). This study extends these findings by showing that it can also affect the child's behaviour. Predictors of poorer child IQ included severe treatments and a longer time since diagnosis, whereas high SES and dual-parentage were related to better IQ. Predictors of poorer child achievement included severe treatments, longer time since diagnosis, younger age at diagnosis and lower SES. This study demonstrated the importance of disease / disability factors in predicting child IQ and achievement, whereas the child's behaviour was influenced by social-ecological factors (Wallander et al., 1989b).

Parental mental health can have a direct relationship with child adaptation: poor parental adjustment was associated with child depression (Brown et al., 1993; Mulhern et al., 1992), behaviour and adjustment problems (Manne et al., 1995, 1996; Sawyer et al., 1998), and distress (Varni et al., 1996). Negative family life events were associated with behaviour problems (Carlson-Green et al., 1995).

3.3 Parental functioning: Off-treatment or 'survivor' studies

Apart from the risk of long-term physical consequences (see Chapter 1), completion of treatment is a difficult time for families as many see the treatment as what is keeping their child alive (Eiser, 1998). Once the child finishes active treatment, the parent can display a mixture of emotions, including relief that treatment has finished, concerns about long-term health consequences, and anxiety over possible relapse (Chesler & Barbarin, 1987; Kazak, 1994; Koocher & O'Malley, 1981). Therefore, considering these findings, it is important that research is conducted which assesses the long-term functioning of children and their families.

3.3.1 Do parents exhibit elevated mental health problems after their child completes treatment?

When parents discuss their thoughts and feelings about survival, many talk about positive relationship changes (Kvist, Rajantie, Kvist, & Siimes, 1991), adopting new values and attitudes, improved marital relationships, and feeling grateful for their child's survival. Others discuss feelings of lowered anxiety, greater appreciation of life, increased altruism and improved value systems (Kupst & Schulman, 1988; Kupst et al., 1995). Negative comments include health worries and feelings of anger and guilt (Greenberg & Meadows, 1991). Even years after treatment, parents still report feelings of concern about their child's future health complications, their social development, and the possibility of relapse (Leventhal-Belfer, Bakker, & Russo, 1993).

Van Dongen-Melman, Van Zuuren and Verhulst (1998) conducted one of the few in-depth qualitative analyses with parents of survivors. Parents discussed feelings of overwhelming loss – loss in their outlook on life, their marital relationship, and a loss of the image of their healthy child. Concerning the latter, parents felt that despite their child surviving, s/he was not the child they had prior to the illness, and felt they had lost part of their child in the treatment process. However, positive changes were noted by some parents, including having a stronger marriage and doing more things together as a family. It appears that despite their child completing treatment, parents are left feeling as if they have suffered a loss. This may be in the form of losing their perception of their once healthy child or losing their outlook on life which once may have been carefree and free of anxiety. The illness experience appears to have changed the way parents view life. But do these concerns negatively affect their mental health?

3.3.1.1 Incidence of psychological distress

In comparison with the number of studies of parental distress during treatment, studies of the long-term consequences for parents of survivors are much rarer (Van Dongen-Melman et al., 1995). The results have been conflicting: many papers report no continuing psychological distress after treatment (Brown et al., 1992; Greenberg, Kazak, & Meadows, 1989; Kazak & Meadows, 1989; Noll et al., 1995;

Speechley & Noh, 1992), whereas others point to heightened distress (Greenberg & Meadows, 1991; Kazak, Christakis, Alderfer, & Coiro, 1994).

In comparison with controls, parents of survivors were no different in levels of depression and anxiety (Speechley & Noh, 1992), general symptoms (Greenberg et al., 1989; Noll et al., 1995), or family functioning (Kazak & Meadows, 1989). However, within group analysis indicated that parents of children with cancer who reported low levels of social support were more depressed and anxious than control parents (Speechley & Noh, 1992).

Longitudinal studies have reported parallel findings to these cross-sectional accounts. For example, in their final ten-year post-diagnosis report, Kupst et al. (1995) recruited 44% of their initial group (see section 3.2.1 for earlier follow-ups). As had been found in their earlier reports, most parents were coping well and none had severe mental health problems.

However, caution must be taken when interpreting these results. For example, although group means were no different between parents of cancer survivors and published norms on measures of parental distress and family functioning, Kazak et al. (1994) reported that approximately 10% of parents fell within the psychologically distressed range, and between 20% and 30% scored within the range predictive of seeking help. This raises an issue highlighted earlier in this chapter: there is an over-reliance on the assessment of group means, with a failure to identify the number of parents who fall in 'at-risk' categories. While Kazak et al. (1994) did conduct an intra-class analysis, most studies to not provide this information. In order to further out understanding of parents of survivors, it would be clinically useful to attempt to identify and predict those individuals who continue to function poorly. Echoing this need for individual research, Kupst (1994) recently discussed the need to move from the assessment of global group differences, to focusing on those families who do not adjust well and to determine why this is.

One way of assessing specific issues of concern to these families is to use assessments that tap into more general aspects of functioning and worries, rather than generic assessments of mental health or psychiatric symptoms. One such

study was conducted by Van Dongen-Melman et al. (1995) who devised a disease-specific measure to assess problems experienced by parents of children with cancer. This measure included sub-scales to assess mental health, uncertainty, fear, loss of control and negativity. Using this measure, they reported that the incidence of anxiety, depression, disease-related fear and sleep disturbance was low in their sample of 133 parents. However, the majority of parents reported continued feelings of uncertainty (90%) and loneliness (84%).

This study shows that by using cancer-specific measures, we may be more able to identify concerns of parents of survivors. This within-subject analysis may be one way of identifying those families who are not adjusting well, a methodology recommended by Kupst (1994) in preference to assessing group means in comparison to control families. However, this study by Van Dongen-Melman et al. (1995) is the only study to have assessed families at such a specific level, leaving much scope for future research.

3.3.1.2 Posttraumatic Stress Disorder (PTSD)

Since having a child diagnosed with a life-threatening disease was added to the DSM-IV (American Psychiatric Association, 1994) as an inclusion category for PTSD, the study of PTSD among parents of children with cancer has become more popular.

The Post-traumatic Reaction Index (Frederick, 1985), has been commonly used in childhood cancer PTSD work. This 20-item self-report questionnaire has been used in studies of adult response to a range of traumatic events, including natural disasters, suicide and family violence (Frederick, Pynoos, & Nader, 1992). Using this measure, estimates of severe PTSD in mothers of survivors has ranged from 7% (Stuber et al., 1994) to 39.7% (Stuber, Christakis, Houskamp, & Kazak, 1996), with moderate levels reported in approximately 27% of mothers (Stuber et al., 1994; Barakat et al., 1997). Fathers also appear to suffer from PTSD, with severe symptoms noted in between 7.1% (Barakat et al., 1997) and 33.3% (Stuber et al., 1996). Moderate symptoms were found in approximately 25% of fathers (Barakat et al., 1997; Stuber et al., 1994). Using clinical interviews rather than questionnaire methods, Pelcovitz et al. (1996) reported that 54% of their sample of 24 mothers of

children with cancer met criteria for lifetime PTSD (i.e. symptoms lasting for more than six months) compared with 4% of control mothers.

These ranges vary widely. For example, Stuber et al. (1994) reported that 7% of mothers had severe PTSD, which translated to only two out of 30 mothers. Eight mothers had moderate PTSD, translating into 27% of their sample. In their 1994 paper, Stuber et al. reported that 39.7% of mothers had severe PTSD, which corresponds to 25 mothers (out of 63). Reporting percentages based on such small samples can be rather misleading. Another reason for the varying range of PTSD symptoms could be the range in time off treatment. Mean time off treatment range from 3.28 years (Pelcovitz et al., 1996) to 6.7 years (Stuber et al., 1996). Parent's symptoms may decline with time since diagnosis. However, it is clear that a large number of mothers exhibit moderate levels, a result which warrants further consideration.

Research on parental mental health following completion of treatment is scarce, but shows parallel findings to the on-treatment literature. While many studies report no group differences on mental health measures compared with controls or norms, others report continued distress. Parents feel that both positive and negative life changes emerged from the illness, including relationship improvements and worry over relapse. However, it can be concluded that despite the child having completed treatment, many parents feel uncertain and lonely (Van Dongen-Melman et al., 1995) or exhibit symptoms of PTSD (Stuber et al., 1994, 1996).

3.3.2 Parental functioning: relationship with survivor adaptation

The following studies demonstrate that, even after the completion of treatment, parental functioning still significantly relates to child adaptation. For example, parents of adolescent survivors receiving special educational needs rated themselves as functioning poorly, as less adaptable, and rated their adolescent as having poor social competence (Kazak & Meadows, 1989). Similarly, in their study of 42 survivors, Newby, Brown, Pawletko, Gold and Whitt (2000) reported that greater academic difficulties were associated with a greater frequency of behaviour problems (parent rated). Parental coping has been related to parent-rated child behaviour (Sloper et al., 1994). Specifically, increased use of *wishful thinking* and decreased use of *direct action* were related to more child behaviour problems. Mother's functioning had a stronger relationship with their child's functioning than father's functioning in Sloper et al.'s (1994) study (rs = 0.65 and 0.42 respectively), echoing previous work by Sawyer et al. (1998). The child's self-reported adjustment and self-concept ratings have also been associated with family functioning (Overholser & Fritz, 1990). These results show that while research in this area is scarce, there is a need to follow-up these research findings.

The only study which is known to have assessed the child's QOL during treatment and relate this to off-treatment parent and child functioning was conducted by Kazak and Barakat (1997). Importantly, their results showed that the child's QOL (parent-rated) during treatment was significantly related to maternal PTSD symptoms and state anxiety after treatment. Furthermore, emotional distress (a sub-scale of the QOL measure) was significantly correlated with maternal PTSD and state anxiety, and child anxiety after treatment. Parenting stress during treatment was strongly correlated with state anxiety for both mothers and fathers after treatment. Although these results cannot be considered conclusive since the sample size was small (N=29), it is important in showing the links between functioning during treatment and later adjustment. It is also the only study to have employed a named measure of QOL, albeit parent reported.

Within the survivor literature, relationships have been demonstrated between academic needs, parental functioning (Kazak & Meadows, 1989) and child behaviour (Newby et al., 2000), parental coping and child behaviour (Overholser & Fritz, 1990; Sloper et al., 1994) and child QOL during treatment and later parent and child adjustment (Kazak & Barakat, 1997).

3.4 Methodological Limitations of the child adaptation and parental adjustment literature (Chapters 2 and 3)

The strength of these conclusions which researchers make depends upon the rigour of the methodology employed. These methodological concerns which have been present in this and the previous chapter are summarised below.

3.4.1 Samples

Lack of homogeneity of groups

Small numbers, mixed diagnoses, and recruiting children across wide age-ranges, are common methodological concerns. There is a negative correlation between sample size and sample homogeneity: the obvious way to increase sample size is to relax the inclusion criteria and recruit children from wider age-ranges, and with mixed diagnoses.

To give an example, both Sloper (1996) and Dahlquist et al. (1996) recruited children with a number of different cancer diagnoses, including those with CNS tumours. However, others studies exclude children with CNS tumours due to 'potential behavioral effects' (Manne et al., 1995; p. 194). Considering the rarity of childhood cancers, it is understandable that researchers choose to combine children with differing diagnoses into one cancer group. However, as outlined in Chapter 1, different cancers have different prognoses, treatments and associated long-term consequences. Grouping different cancers together severely limits the representativeness of any results. Although a diagnosis of cancer will affect all parents and children, regardless of the actual diagnosis, it is not unreasonable to predict that children with more 'severe' cancers and their parents might be the ones to continue to adjust poorly.

Again, considering the rarity of childhood cancer, it is not surprising that children are recruited across a wide age range. For example, Dahlquist's sample ranged in age from 22-months to 18-years, Brown et al.'s. (1992) from 2- to 17-years, and Manne et al. (1995; 1996) included children from 3- to 18-years. Depending on the age of the child, however, the diagnosis of cancer will affect different developmental milestones. For example, issues of attachment or delayed school start may be more important to the toddler or pre-schooler, whereas teenagers may be more concerned with gaining independence from parents, school exam attainments, and peer and sexual relations (Willis, Elliot, & Jay, 1982; Chapter 2 Section 2.2). Again, it is not unreasonable to predict that parents will respond to cancer differently according to the difficulties they see their child experiencing. Therefore, while the research discussed above gives us some indication of the effect cancer has on the child and parents, work with homogeneous samples is needed to understand the unique effects of diagnosis and age on child and parent adaptation.

Selection of control groups / norms

Control groups have advantages and are particularly useful when the measures used are not standardised, or have been normed on samples that are largely different from the ones being studied (Kazak & Nachman, 1991). However, control groups can also compromise findings if they are poorly matched. In situations such as these, important phenomena may be masked (Kazak & Nachman, 1991). Concerning published norms, although a large amount of psychometric data may exist, these data may not be appropriate for all subject groups within the US, and certainly not for other cultures.

3.4.2 Measures

Failure to report extreme scores and over-usage of measures

Reporting mean values on standardised measures masks those individuals with at-risk scores (see Section 3.2.1). Additionally, while generic measures may be useful for comparing parents of children with cancer with controls or norms, they have been criticised for not being sensitive to the problems unique to this group.

There has also been an over-reliance on certain measures. For example, the CBCL (Achenbach, 1991; Achenbach & Edelbrock, 1983) was used as an outcome measure in most of the studies reported in this and the previous chapter. This measure has been criticised for use with chronically ill children for many reasons (Perrin et al., 1991). First, the measure was designed to identify psychopathology, not problems considered within the 'normal' range. Therefore, it is questionable whether it should be used with physically ill children at all. Second, different versions are used for different age-groups, thereby prohibiting across age comparisons. This is pertinent because the cancer literature typically uses heterogeneous samples with respect to age. Also, in a longitudinal study, children may complete different versions of the CBCL at each time point, hindering the assessment of within sample change (Perrin et al., 1991). Third, the assessment of 'physical symptoms' (e.g., assessment of physical problems and limitations) within the Somatic Symptoms sub-scale is problematic, since chronically ill children will undoubtedly score higher than healthy children, thereby artificially inflating their scores. Finally, another sub-scale, the Social Competence sub-scale has been criticised for not being sensitive to physically ill children. This sub-scale assesses the child's participation in social events (including sports and games), but does not question children's reasons for non-participation or what children do as an alternative. Therefore, children with cancer who may be unable to participate in sports and games because of treatment restrictions may compensate for this by helping to coach or participate in some non-contact way. These children do not have social inadequacies, they are simply physically unable to take part. However they show great social competence by continuing to be involved in some other way.

As a case in point, Manne et al. (1996) reported a positive relationship between child behaviour problems and maternal depression. However these children may not have had behaviour problems in the traditional sense (e.g., aggression, acting out), it may be that they have inflated scores on the somatic symptoms or social competence scales as a direct result of their illness.

Respondents: child vs. proxy reports

Very few studies involved the child directly in their studies (cf Mulhern et al., 1992 for an exception). Obtaining child reported data can be difficult. Children can be very ill and unable to give their own data, and they must be able to understand what is being asked of them in order to give truthful, accurate responses. Practically, considering their limited attention and cognitive load, measures must be short, yet reliable. At present, there is a lack of available measures fitting this criteria.

Equally, there are reasons why child reported data must be obtained wherever possible. Parents cannot be with their child in every instance (e.g., school or nursery), and they cannot accurately rate how their child feels at all times. It is suggested that in order to further our understanding of the experience of childhood cancer, both child and parent reports should be obtained if at all possible.

3.5 Conclusions

Studies were reviewed that examined the effects of diagnosis and treatment, and subsequent survival of the child on the parent's mental health. Several conclusions can be drawn from this research. While group means indicate that mental health scores are within normal ranges on standardised measures, intraclass analyses reveal that a substantial minority of parents *do* score at-risk levels of clinical distress both at diagnosis (e.g., Manne et al., 1995, 1996; Dahlquist et al., 1996) and once the child has completed treatment (e.g., Kazak et al., 1994). These intraclass analyses are only possible with measures that provide guidelines concerning different levels of at-risk functioning.

Therefore, while some researchers may give the impression that parents are functioning well (reporting group means), others may stress the number of at-risk parents, each giving a different impression of parental mental health. Both accounts are correct however: some parents adjust well, others do not. As a result, there has been a move towards identifying those parents who do not function well and identifying why this is the case (Kupst, 1994).

Despite their limitations, studies reviewed indicate that parental mental health significantly relates to child behaviour problems, both during and after the completion of treatment. Additionally, although research is scarce, maternal mental health appears to have stronger links with child behaviour than paternal mental health.

Finally, as discussed previously, one of the key themes in this thesis is to assess the relationship between the child's adaptation, parental mental health and parenting behaviours. Therefore, as this chapter was concerned with parental mental health, the next step is to review research that has examined parenting behaviours in relation to child adaptation. This in conducted in two stages; Chapter 4 reviews literature concerning parenting a *healthy* child, and Chapter 5 reviews literature focused on parenting a child with *cancer*. These reviews complete the theoretical portion of the thesis.

Table 3.1.1 Parental mental health: on-treatment studies

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Allen et al. (1997)	UK	Mixed cancers	M=15.4	43 adolescents and their parents	173 matched controls	Mothers were the most anxious member of the family and were more anxious than fathers. Maternal anxiety scores were higher than published norms.
Brown et al. (1992)	USA	ALL	2-17	55 children; 23 families at diagnosis; 22 families one year pd; 10 families one year post-treatment	Norms	Mothers in the 1-year post-diagnosis group were extremely anxious, and fathers were depressed. Families one year post-treatment demonstrated more adaptive family functioning traits.
Brown et al. (1993)	USA	ALL	2-17	61 mother-child pairs;	Norms	34% of mothers met criteria for at least one psychiatric disorder. Children with mothers with a psychiatric disorder self-reported greater anxiety and were rated by their mothers as being more depressed.
Carlson-Green et al. (1995)	USA	CNS tumours	2-16 (M=7)	Parents of 63 children Family data obtained at diagnosis; Child data obtained 24mths pd	Norms	Child behaviour problems were best predicted by family and demographic variables. Child cognitive functioning was best predicted by family and illness variables.
Dahlquist et al. (1996)	USA	Mixed cancers	22mnths – 18 yrs (M = 7.92)	42 mothers & fathers	Norms	Mothers generally showed a decrease in anxiety over time. No change was noted for fathers anxiety levels over time. 13% of mothers and 8% of fathers reported moderate-to-severe levels of depression.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Fife et al. (1987)	USA	ALL	22 mths – 16 years	33 mothers 27 fathers 31 siblings 13 patients	NONE	33% of mothers are moderately depressed at 3-months post-diagnosis, falling to 19% at 1-year post-diagnosis Fathers depression rose from 21% to 29% during this time.
Hoekstra -Weebers et al. (2001)	Holland	Mixed cancers	0-16	62 fathers; 66 mothers	Norms	At one-year post-diagnosis, 35% of fathers and 38% of mothers reported at-risk levels of psychopathology.
Kupst et al. (1982)	USA	ALL	0- 11+	64 families (both mothers and fathers) medical staff children	Norms	Majority of families were coping well. On-third of mothers were anxious.
Kupst et al. (1984)	USA	ALL	M= 8 yrs, 3 months	60 families	Norms	Coping with the child's illness took many forms, from minimising the severity of the illness to showing feelings openly (e.g., crying, anger). Correlates of coping at 2 years include quality of the marriage and family relationship, previous coping and adequacy of support system.
Kupst et al. (1988)	USA	ALL	M=12 yrs, 9 months	43 families	NONE	Families showed significant improvements in coping from 2-years post-diagnosis to this point.
Kupst et al. (1995)	USA	ALL	M = 19.1	28 families	Norms	Long-term survivors and their parents continued to be well-adjusted and cope well.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Manne et al. (1995)	USA	Mixed cancers	3-18 (M=11.6)	55 mothers, 5 fathers	Norms	One quarter of parents experience moderate-to-severe depression during the 3-month period post-diagnosis. Child behaviour problems were associated with parent depression.
Manne et al. (1996)	USA	Mixed cancers	3-18	55 mothers and 4 fathers	Norms	The majority of parent show a decrease in depression over time. Less spousal support was associated with depression. Disease parameters did not correlate with parent depression.
Mulhern et al. (1992)	USA	leukaemia & solid tumours;	8-16	99 children; 99 mothers	Norms	Increased maternal depression was predicted by low perceived social support and hospitalisation of the child, which was associated with higher child depression.
Noll et al. (1991)	USA	Mixed cancers	8-15	42 families	Matched families	48% of mothers of children with cancer and 26% of control mothers showed clinical levels of distress (sig). 51% of fathers of children with cancer and 45% of control fathers demonstrated clinical levels of distress (nsig).
Sawyer et al. (1993)	Australia	Mixed cancers	4-16 (M=9.0)	22 families (both mothers and father)	21 matched families	At diagnosis, mothers of children with cancer were more anxious, had more somatic symptoms and were more socially dysfunctional than control mothers. At 1-year pd, test mothers were more depressed and reported more social dysfunction than control mothers. Fathers showed a similar pattern, but were generally less depressed than mothers.

Study	Study origin	Child's diagnosis	Child's age	Cancer Samples	Comparison groups	Results
Sawyer et al. (1997)	Australia	Mixed cancers	2-5	38 families (both mothers and father) On-treatment	39 matched families	At diagnosis, mothers and fathers in the test group were significantly more anxious and had more insomnia than controls. This declined with time, with no differences being found between groups at later assessments.
Sawyer et al. (1998)	Australia	Mixed cancers	2-5	38 families (both mothers and fathers)	NONE	Maternal adjustment at diagnosis predicted the child's psychological adjustment 2 years post-diagnosis. Paternal adjustment and family functioning had a negligible effect on the child's adjustment.
Sloper (1996)	UK	Mixed cancers	<18 years	98 families (including one sibling if aged between 8-16 years)	NONE	Negative effects on parental employment, finance and family relationships and lack of emotional support were related to increased distress.
Sloper (2000)	UK	Mixed cancers	9 mths – 18 yrs (M = 9.3)	T1: 63 mothers & 48 fathers; T 2: 67 mothers & 56 fathers On-treatment	Norms	High levels of distress were seen in 51% of mothers and 40% of fathers at 6- and 18-months pd. Distress did not change significantly over time, despite 18 months passing since diagnosis.
Varni et al. (1996)	USA	Mixed cancers	5-13 (M=8.02)	62 parents	Norms	Family cohesiveness and expressiveness predicted the child's psychological and social functioning

Table 3.1.2 Parental Mental Health: Survivor studies

Study	Study Origin	Child's diagnosis	Child's age	Cancer samples	Comparison groups	Results
Barakat et al. (1997)	USA	Mixed cancers	8-20 Mean ToffT[1]: 5.86 years.	309 mothers, 213 fathers; 309 children	211 control mothers 114 fathers 219 children	10.1% of mothers and 7.1% of fathers reported severe PTSD symptoms (compared with 3% and 0% of controls respectively). 27% of mothers and 28.3% of fathers scored within moderate ranges (compared with 18.2% and 17.3% respectively). PTSD symptoms in parents were associated with many variables including mother- and father-rated family satisfaction.
Green-berg & Meadows (1991)	USA	Mixed cancers	8-16 Tsd: 5-16 years	120 parents; 118 children	NONE	Positive thoughts concerning survival included having new values and attitudes and good social support. Negative thoughts include feelings of anger and guilt and marital problems.
Kazak & Meadows (1989)	USA	ALL; AML; NHL[2]	10-15 ToffT at least 5 years	35 parents and children	13 control parents and children Norms	Relative to norms and the control group, families of survivors similar levels of distress, family functioning and child behaviour. Parents of children with educational difficulties (N=16) reported less family adaptation and more distress than parents of the 19 survivors with no educational difficulties.
Kazak, et al. (1994)	USA	ALL; AML; NHL	10-15	59 parents and children	Norms	Parent variables found to be near normative levels (e.g. family functioning, social support, parental distress, anxiety, hopelessness).

[1] ToffT: time off treatment
[2] NHL: Non-Hodgkin's Lymphoma

Study	Study Origin	Child's diagnosis	Child's age	Cancer samples	Comparison groups	Results
Kazak & Barakat (1997)	USA	90% ALL; 10% AML	T1: 7.64 years (on-treatment) T2: 9.79 years (off-treatment)	29 parents and children	None Norms	Parents who reported high stress at time 1 (on-treatment) were more likely to report high anxiety at time 2 (off-treatment). Parent rated child QOL was correlated with mothers' off-treatment PTSD symptoms.
Kazak et al. (1997)	USA	84% ALL 16% AML	8-19 Mean ToffT = 5.79 years	130 parents and children	155 control parents and children	The two groups did not differ in terms of family functioning or social support. Age at diagnosis, age of child at present, and time since completion of therapy were not associated with outcomes.
Kvist et al (1991)	Finland	N=48 ALL; N=5 NHL	M age: 12.8 years at completion of treatment	53 parents and children	NONE	Parents perceived life changes during the illness period positively. Parent had more complaints about therapy than patients overall, except for induction therapy (patients had more complaints).
Leven-thal-Belfer et al (1993)	USA	Mixed cancers	Median tsd = 11 years.	24 mothers and 13 fathers	NONE	Parents reported many concerns, including child's future health complications, and social development. Parents reported communicating freely with one another.
Newby et al. (2000)	USA	Mixed cancers	6-18 M ToffT = 6.8 years	42 parents, teachers and children	Norms	Time off treatment and academic difficulties correlated with child behaviour problems.
Noll et al. (1995)	USA	Mixed cancers	8-18 M tsd = 52.4 months	25 parents	25 control families	Mothers and fathers of survivors were not significantly different from control mothers and fathers on measures of general symptoms.
Over-holser & Fritz (1990)	USA	Mixed cancers	M=10.3 2-7 years after treatment	44 parents and children	NONE	Three areas were isolated as causing the most distress in parents: personal distress, marital discord, and financial burden.

Study	Study Origin	Child's diagnosis	Child's age	Cancer samples	Comparison groups	Results
Pelcovitz et al (1996)	USA	Mixed diagnoses	M=: 16.13. Mean ToffT = 3.28 years.	24 mothers	25 control mothers	Mothers of study group had higher levels of PTSD than control mothers. Types of problems reported by mothers include intrusive thoughts and impaired sleep.
Speech-ley & Noh (1992)	USA	Mixed diagnoses	3-18 Mean ToffT = 5.6 years	63 mothers, 49 fathers	64 control mothers, 62 fathers	No differences in depression or anxiety. Mothers of children with cancer experienced low levels of social support and were more depressed and anxious than control mothers.
Stuber et al (1994)	USA	Leukaemia or solid tumours	8-19; Mean ToffT = 61.53 months	30 mothers 17 fathers 30 children	NONE	25% of fathers and 27% of mothers scored within the moderate level of PTSD symptoms. 7% of mothers reported severe symptoms.
Stuber et al (1996)	USA	N=58 ALL; N=7 AML	7-19 Mean ToffT = 6.7 years	63 mothers 42 fathers 65 children	None	39.7% of mothers and 33.3% of fathers scored within the severe PTSD symptoms level. Examples of problems include: re-experiencing disturbing scenes, being afraid when thinking about what happened, fearing recurrence and having memory difficulties.
Van Dongen-Melman, et al (1995)	Holland	Leukaemia & lymphomas	8-12 years ToffT 6 mnths - 8 yrs	133 parents	None	Incidence of psychological distress was low (e.g. depression, anxiety), but more subtle disturbances were noted, e.g. problems with loneliness, and uncertainty.
Van Dongen-Melman et al (1996)	Holland	ALL	8-12 years. ToffT: 6 mnths - 7 yrs, 9 months.	8 mothers and fathers	None	An overall perseveration of problems and feelings of uncertainty existed.

CHAPTER FOUR.

PARENTING BEHAVIOURS AND THE CHILD'S DEVELOPMENT

Summary

Literature presented in this chapter concerns parenting behaviours (a socio-ecological resistance variable) and their relationship with the child's psychological development in healthy samples. This chapter is particularly relevant to the empirical work presented in this thesis as it introduces some key theoretical frameworks which are later applied to parenting a child with cancer.

Early theorists classified parents according to a 2-D model of 'control-warmth', with four parenting styles emerging: authoritative, authoritarian, permissive (indulgent and neglectful) (Baumrind, 1971; Maccoby & Martin, 1983). Authoritative parenting, more than any other style of parenting, has been associated with optimal child outcomes. However, there have been concerns with global categorisation of parents, hence there has been a move towards teasing apart these global parenting styles into more specific aspects.

Steinberg and colleagues have been key in teasing apart these parenting styles. First, they dichotomised *control* (from the 2D 'control-warmth' model; Maccoby & Martin, 1983) into psychological and behavioural aspects. Empirical work has shown that each of the three parenting styles, warmth, psychological and behavioural control, relate to different adolescent outcomes. Second, Steinberg assessed parenting **styles** as distinct entities from **practices**, representing the parent's attitudes versus their actual behaviours (Darling & Steinberg, 1993). These aspects of parenting are discussed in relation to adolescent outcomes.

4.1 Parenting: setting the scene

The term 'parenting' is a broad umbrella term, about which much is written (Collins, Maccoby, Steinberg, Hetherington, & Bornstein, 2000; Stevenson-Hinde, 1998). This is evident in the sheer number of journals and book chapters dedicated to the subject (for example the four lengthy volumes of the 'Handbook of Parenting' edited by Mark Bornstein, 1995a-d). During the past 30 years, research has built a remarkably consistent picture of the type of parenting conducive to the successful socialisation of children (Darling & Steinberg, 1993). This chapter reviews the main findings from this body of literature. Considering the size of the field, a detailed account is impractical. Therefore, a theoretical overview is the most efficient means of surveying this research.

How do we apply this body of research to parenting a child with cancer? In the words of Collins et al. (2000), parents are seen to "mediate the association between broader social, cultural, economic, and historical contexts and children's behaviour and personality" (p. 228). In other words, these broader contexts affect the parent's behaviour, which then affects the child. For instance, Collins et al. gave the example of poverty influencing parents, who in turn become stressed and punitive with their children. It seems that parenting research is most appropriately seen as situation specific: specific within a particular culture, at a particular point in time. Therefore, putting this into context, one of the aims of this thesis is to investigate how parents 'parent' their child given the context of cancer. It is our intention to show that key elements of these models can be borrowed from developmental psychology and applied to the specific context of parenting a child with cancer. Specifically, we will empirically assess the importance of the family environment (parent behaviours) in affecting the child's adaptation to cancer (Wallander et al., 1989b).

4.2 Authoritative, Authoritarian and Permissive parenting

Parental warmth, inductive reasoning, low power assertion and consistency in parenting behaviours are associated with positive child developmental outcomes (Steinberg, Lamborn, Darling, Mounts, & Dornbusch, 1994). Since Baumrind's seminal work in the 1970s, this collection of behaviours has been known as 'authoritative' parenting. This cluster of traits has been identified with a number

of positive child outcomes, including positive self-perceptions, social development, mental health and competence (for a summary of these results see Maccoby & Martin, 1983). Baumrind (1971) also discussed two other parenting types, both of which have been linked with less optimal child outcomes (Maccoby & Martin, 1983):

- *Authoritarian* - parents who display low warmth and insist on their child's obedience (Holden, 1997).
- *Permissive* - parents who display a combination of low control and inconsistent discipline practices, but high affection.

Maccoby and Martin (1983) proposed that Baumrind's typology could be enhanced if parenting was viewed as two dimensional, varying along the two independent constructs of control and warmth. Authoritative parents, representing approximately 19% of a normal population of parents, are high in both control and warmth (Holden, 1997). This contrasts with authoritarian parents who are high in control, but low in warmth (approx. 20% of parents in a normal population). One major difference put forth by Maccoby and Martin (1983) was separating 'permissive' parenting into two: indulgent (low in control and high in warmth; approx. 30% of parents) and neglectful (low warmth and low control; approx. 8% of parents). Permissive-neglectful parenting is not routinely included within parenting questionnaires since it is so rare and socially difficult to discuss. Within this thesis, this type of parenting is not assessed quantitatively, but if present, could be picked up in the interview assessments. However, it is not expected that parents who agree to take part in clinical research aimed at improving care for their children would be neglectful. This, of course, is a bias existing in much research. Permissive-neglectful families are frequently studied in abuse and/or neglect literature (Trickett & Susman, 1988). For these reasons, Table 4.1 presents an overview of the three central parenting types: authoritative, authoritarian and permissive-indulgent (Baumrind, 1971; Maccoby & Martin, 1983).

Table 4.1. Overview of authoritative, authoritarian and permissive-indulgent parenting types.[4]

- **AUTHORITATIVE (High in control, high in warmth)**
- Favour inductive, non-coercive discipline; foster a democratic style of family decision-making in which children participate and are allowed to question parental viewpoints.
- Encourage the child's independence and individuality.
- Expect mature behaviour from child; encourage rules and standards, using commands, and sanctions when necessary.
- Open communication between parents and children, with parents listening to children's point of view, as well as expressing their own; encouragement of verbal give and take.
- Recognition of rights of both parents and children.

- **AUTHORITARIAN (High in control, low in warmth)**
- Use power assertion (verbal and physical) to control child.
- Attempt to shape and control the behaviour and attitudes of their children in accordance with an absolute set of standards.
- Expect high level of maturity; valuing obedience, respect for authority, work, tradition, and preservation of order.
- Discourage verbal give and take between parent and child.

- **PERMISSIVE-INDULGENT (Low in control, high in warmth)**
- Use little punishment, and avoid if possible, asserting authority or imposing controls.
- Take a tolerant, accepting attitude toward the child's impulses.
- Make few maturity demands, allowing children to regulate their own behaviour and make their own decisions when at all possible.
- Are inconsistent in their parenting behaviours.

[4] Source Maccoby & Martin (1983)

Categorising parents according to these traits and assessing these in relation to child outcomes, is one of the best-known approaches to studying parenting (Holden, 1997). Although much parenting research continues to derive from this parenting model, the model itself has its problems.

One criticism of this theory is the failure to classify all parents as being either authoritarian, authoritative or permissive (indulgent or neglectful). Approximately 20% of parents remain unclassified. The reason for this is almost certainly that parents display a range of characteristics from each of the parenting types (Holden, 1997). For example, parents may advocate open communication with their child (authoritative), but they may be permissive in their behavioural control.

A second criticism is that the theory does not address changes in parenting behaviours over time or across situations. Parenting behaviours *do* change over time, as a result of changes in the parents, their child, or their situation (Holden, 1997). For example strict behavioural control may be a common behaviour shown by parents of toddlers, but it might not be such a common behaviour shown by parents of 18-year olds. The theory does not give any guidelines or predictions as to how parents may change.

Third, the research emphasising the benefits of authoritative parenting over authoritative or permissive-indulgent has generally been based upon data collected from US, healthy, white middle-class families. However, these findings change somewhat when the samples are drawn from other ethnic and social class groups (Deater-Deckard, Dodge, Bates, & Pettit, 1996). There is now evidence to suggest that authoritarian parenting is not associated with negative child outcomes in Bermudan families (Deater-Deckard & Scarr, 1994) or African-American families (Deater-Deckard et al., 1996). According to Kelly, Power and Wimbush (1992), "a common problem with research on minority families is that models of child rearing developed on majorities have often been used as standards in evaluating minority parenting practices. When this has been done, the differences have often been interpreted as deficits." (p. 573).

Fourth, a question has been raised concerning the unidirectionality of this theory (Holden, 1997). The majority of research has assessed how the parent's behaviour affects the child, ignoring the reciprocal affect of the child's behaviour on the parent.

4.3 Breaking down parenting types into definable components

Although the authoritative parenting style has been shown to be the optimal way of parenting a child (albeit in white-middle classes) (e.g., Steinberg, Lamborn, Dornbusch, & Darling, 1992), it is still not clear exactly *why* this type of parenting positively influences the child. Similarly, it is not clear why authoritarian or permissive-indulgent parenting styles do not relate to optimal child outcomes.

For example, if we compare the authoritative and authoritarian styles, it would appear that the defining feature affecting children is the difference in warmth; authoritative parents are warm, authoritarian parents are not, whereas both are highly controlling. However, the evidence does not seem to point to this. If we refer back to Table 4.1, authoritative control is achieved using non-coercive means, whereas authoritarian control is achieved using power assertive means. It would appear that classifying parents as 'controlling' does not capture the subtle, but important differences between types of control.

4.3.1 Re-definition of warmth and control (Maccoby & Martin, 1983) into three dimensions: warmth, behavioural control, and psychological control.

In an attempt to breakdown the concept of control, Steinberg and colleagues (Steinberg, Elmen, & Mounts, 1989; Steinberg et al., 1992) dichotomised control into *behavioural control,* which refers to parental monitoring and limit setting; and *psychological autonomy,* which refers to encouraging the child to express opinions, using non-coercive discipline and reasoning (the reverse of psychological control). They retained the original concept of *warmth,* which refers to the extent to which parents are loving, responsive, and involved (Steinberg et al., 1992). To further simplify matters, instead of using the authoritarian, authoritative and permissive terminology, they began to view parenting as running along a continuum from high-to-low authoritativeness on the three aspects of style: warmth, behavioural control and psychological autonomy.

Splitting 'control' into psychological and behavioural components is not new (cf: Schaefer, 1965; Barber, Olsen, & Shagle, 1994), but little empirical work has tested this distinction. Gray and Steinberg (1999) reported evidence suggesting that studying '*control*' as a single dimension can lead to confusing and inconsistent results.

Steinberg and his colleagues first empirically tested this distinction in a follow-up report of a study started in 1987 in which parenting was assessed in relation to adolescent grade success (Dornbusch, Ritter, Liederman, Roberts, & Fraleigh, 1987). In the 1987 study, authoritativeness (assessed in a questionnaire format developed to mirror Baumrind's view of parenting) was positively associated with grade success, whereas permissive and authoritarian parenting were negatively associated with grade success. In their 1989 follow-up of the same sample, Steinberg et al. (1989) split control into behavioural and psychological control because "it is impossible to tell whether all, or only certain, features of authoritative parenting contribute to academic success. Authoritativeness is multifaceted." (Steinberg et al., 1989). In this study, they assessed the two individual control dimensions and found that each made an independent contribution to school achievement. Additionally, they reported that the impact of authoritative style (warmth, psychological and behavioural control) on school achievement was mediated, in part, through the effects of authoritativeness on the development of a healthy sense of adolescent autonomy (i.e., authoritativeness → autonomy → school achievement).

Three years after this publication, Steinberg et al. (1992) again tested this trinity of authoritative styles, warmth, psychological and behavioural control, in a study involving more than 6,000 US students. School performance was the adolescent outcome measure. However, in addition to assessing these *styles* of parenting, they included two variables representing parenting *practices*. Before reporting their results, the definition of styles and practices will be further elaborated.

4.3.2 Parenting styles and practices

According to Darling and Steinberg (1993), parenting style is "a constellation of attitudes toward the child that are communicated to the child and create an emotional climate in which the parent's behaviors are expressed" (p.493). Parenting styles are not goal directed or defined. By contrast, parenting practices are "behaviors defined by specific content and socialization goals" (p. 492), i.e. they can be conceived of as actions. For example, attending school concerts and smacking a child are both examples of practices. Parenting style conveys the parent's attitude toward the child, whereas practices are the actual behaviours, ways of disciplining etc. Therefore, two parents can both smack their child (same practice), but one is warm and affectionate and discusses the reason for the punishment with the child, whereas the other is cold and unaffectionate (different style).

The types of discipline used by parents are examples of parenting practices. Therefore, when considering parenting style as a separate entity from parenting practices, we can refer back to the typology outlined by Baumrind (1971) and Maccoby and Martin (1983) (see Table 4.1). The discipline practices used by parents as ways of dealing with childhood disputes are an integral part of parenting. For example, *authoritarian* parents use coercive discipline practices (e.g., spanking) to control their children, whereas *permissive* parents have been shown to be inconsistent, sometimes ignoring their child's behaviours and sometimes giving in, which routinely results in reinforcing their misbehaviours. In contrast, *authoritative* parents advocate induction, which is the use of explanations, logic or reasoning by parents. They appeal to the child's pride or desire to be grown-up, and to their concern for others (Maccoby & Martin, 1983). Therefore, when thinking about the distinction between practices and style, for example, one can think of *authoritarian* parents using coercive discipline practices in a demanding, yet cold style, *permissive* parents using inconsistent lax discipline practices, in a warm style, and *authoritative* parents using inductive discipline practices in a demanding and warm style.

To return to their study, Steinberg et al. (1992) included a measure of parental involvement in school activities as representing parenting practices and a measure of warmth, psychological and behavioural control as representing high-low

authoritative style. Results showed that increased authoritativeness led to better adolescent school performance and stronger school engagement than non-authoritativeness. Furthermore, this effect was mediated by parenting practices, i.e. authoritative style → parental involvement (practices) → school performance. When discussing these results, the authors defined authoritativeness as a style of parenting that has concrete behavioural manifestations, and it is through these concrete behaviours that the parent's style influences the adolescent's behaviour - "this is the mediational process." (Steinberg et al., 1992). To put this another way, involvement in the adolescent's school activities is more effective given the context of an authoritative style. How parents express their involvement may be as important as whether and to what extent they do (Steinberg et al., 1992).

In their most recent empirical paper, Gray and Steinberg (1999) conducted a study with 8,700 students between 14- and 18-years old in US high schools in order to identify precisely which aspects of authoritativeness (warmth, psychological and behavioural control) have the strongest effect on adolescent development. They did not employ a measure of parenting practices.

Gray and Steinberg (1999) utilised a battery of measures that assessed adolescent behaviour problems (antisocial behaviour, school deviance, drug and alcohol use, and peer conformity), psychosocial development (work orientation, self-reliance, and self-esteem), internal distress (somatic and psychological problems) and academic competence (academic self-competence and grade point average). They reported a highly significant negative relationship between behavioural control and behaviour problems. There was also a small negative effect of warmth on behaviour problems. Both psychological autonomy granting and warmth positively predicted adolescent psychosocial development, each showing unique predictive power in a multiple regression analysis. Behavioural control had a negligible effect on psychosocial development. Psychological autonomy, and to a lesser extent, warmth, had a significantly negative relationship with internal distress. Behavioural control had no effect on internal distress. Interestingly, there was an interaction between psychological autonomy and warmth so that each variable exerted its greatest effect when the other was at its lowest. Therefore, it seems that low warmth can be overcome by the parent showing high

psychological autonomy and vice versa. Academic competence was positively correlated with all three parenting variables. Further analysis showed that behavioural control had the strongest effect at moderate, not high, levels.

Analysing low-medium-high levels of each parenting characteristic in relation to each adolescent outcome is a useful way to examine whether the relationship is linear or nonlinear and overcomes problems with studying continuous variables. This was demonstrated in that medium behavioural control was more beneficial to academic competence than high levels. Overall, this study reflects the usefulness of breaking down the overarching parenting types into definable, measurable concepts, as each component has a different relationship with different facets of the adolescent outcomes.

Using this model, the same team of researchers have shown that parental warmth, behavioural control, and psychological autonomy are associated with a healthy self-concept, work orientation, and self-reliance (Steinberg et al., 1994). Additionally, in a study of 3,781 US high-school students (Brown, Mounts, Lamborn, & Steinberg, 1993), it was reported that warmth, psychological autonomy, and behavioural control directly influenced adolescent behaviours (academic achievement, drug use, self-reliance), which in turn influenced peer group membership (sporting peers, 'druggies', 'normals', brains, or populars). Specifically, high warmth was related to membership in normal, sporting, or popular groups, whereas high behavioural control and psychological autonomy were related to membership in the 'brain' groups and negatively associated with membership in 'druggie' groups.

4.4 Conclusions

Steinberg and his colleagues have been key in redefining and extending existing parenting theories. After breaking down the 2D warmth-control model (Maccoby & Martin, 1983) into warmth, psychological and behavioural control, they have showed that each different style influenced adolescent outcomes in its own, unique way.

They have also made the distinction between style (the 'how' of parenting) and

practices (the 'what' of parenting). While they tested this distinction in their 1992 paper (practices: involvement in the adolescents schooling; Steinberg et al., 1992), it does not appear to have been applied since then. In reality, the distinction between styles and practices can be a difficult one, and the borders between the two can become quite muddied. While issues such as attending concerts or school functions can easily be seen as practices, what are setting rules about when the child has to do their homework? Would this come under the heading of 'practice' (it is an actual behaviour, setting rules which the child must obey) or would it be a style of behavioural control (setting limits is a key factor of behavioural control; Steinberg et al., 1992). Therefore, while the distinction *can* be applied in certain circumstances, for example discipline practices, the two can begin to overlap also. Discipline practices will be assessed in relation to child QOL in Study One.

A second criticism of Steinberg and colleagues' work is that the model has only been used with adolescent, US, healthy samples, in relation to academic and behavioural outcomes. Although these studies must be commended for their size, the model has still to be tested on other ethnic groups or children in different developmental stages. As discussed above, parenting theories developed for the majority may not apply to the minority (Kelly et al., 1992).

While this work is extremely important in parenting research, there remain large gaps in our knowledge. For example, there exists a need to assess how individual parenting characteristics, not global types, relate to different aspects of child outcomes and how parenting changes according to developmental and situational changes. Furthermore, and more central to this thesis, we still lack an understanding of how parenting behaviours are different in samples other than healthy US groups.

In the next and final review chapter in this thesis, literature concerned with parenting a child with cancer is presented. This literature is central to understanding the relationship between child adaptation and parenting behaviours, a key theme running throughout this thesis.

CHAPTER FIVE.

PARENTING A CHILD WITH CANCER – A SYSTEMATIC REVIEW

Summary

A systematic review of parenting a child with cancer is reported. This literature is particularly important in the current thesis as one of the central aims is to assess the association between the child's medical and psychological functioning (reviewed in Chapters 1 and 2) and how parents rear a child with cancer.

Of the seventeen American papers reviewed, observational techniques were the most frequently cited research design, followed by questionnaire and qualitative designs. There were a mixture of outcome assessments, with the child's fear, anxiety and distress being the most commonly studied. Other illness-focused assessments included treatment adherence, play performance and pain. Two studies assessed the child's behaviour. No study assessed the parenting in relation to the child's general well-being, such as their overall mental health, social functioning or body image.

Results showed that parents who use harsher discipline practices have more fearful and anxious children prior to chemotherapy. Parental distraction has generally been observed to be associated with a reduction of the child's fear and distress during medical procedures. Other positive parenting behaviours include commanding the child to engage in coping, coaching and positive reinforcement. Parental supportiveness has a positive influence on the child's treatment adherence. There have been no suggestions to date concerning how parents help their child's general adjustment outwith their illness. Finally, there have been no systematic studies of parenting a child who has completed treatment.

5.1 Introduction

Parents have the tremendous task of rearing their child to become a successful, responsible adult. The diagnosis of cancer complicates this child-rearing process (Chesler & Barbarin, 1987). At diagnosis, parents are encouraged by medical staff to behave as normally as possible with their ill child. Parents are faced with many challenges: they must attempt to balance the demands of everyday life, administer treatment at home, cope with a continuously sick child, travel back and forth to the hospital, answer the child's questions about the illness, yet continue to encourage the child to retain a level of normality. In practice, this can be difficult (Dolgin, Phipps, Harow, & Zeltzer, 1990).

Despite these challenges, very little work has focused on the actual practice of parenting a child with cancer. As Dolgin et al. (1990) remarked, "Specific studies of parental management of the chronically ill child and the determinants and outcomes of different parenting strategies, have not been reported to date." (p. 734). Since this was written a decade ago few advances have been made.

Since there are currently few published articles on parenting a child with cancer, a systematic review of current literature was conducted. The aims were to examine what has been reported to date, assess what types of studies have been reported, to examine their methodology in great detail and to investigate recommendations for future advances in this area.

5.2 Systematic reviews

Systematic reviews are increasingly recommended, especially in health sciences work, where they "locate, appraise and synthesise evidence from scientific studies in order to provide informative empirical answers to scientific research questions" (NHS centre for reviews and dissemination, 1996). Systematic reviews "differ from other types of review in that they adhere to strict scientific design in order to make them more comprehensive, minimise the chance of bias and so ensure their reliability. Rather than reflecting the bias of the authors or being based only on a selection of the published literature, they contain a comprehensive summary of the evidence." (Cook, Sackett, & Spitzer, 1995).

A number of guidelines for conducting systematic reviews have been described (Oxman, 1994). It is generally recommended that a systematic review is completed in nine stages (see Table 5.1).

Table 5.1 *The nine stages involved in conducting a systematic review*

Stage	*Purpose*
0	Assess the need for a review, i.e., demonstrate that no one else is doing one on a similar topic.
1	Plan the review, include thoughts about the length of the review and the research questions being asked.
2	Conduct literature searches.
3	Select key references. Clear inclusion and exclusions criteria will be applied to each captured reference.
4	Key data is extracted from selected references.
5	Results of selected references are brought together and organised.
6	Write report.
7*	Report is assessed by a panel of experts who discuss the relevance of this work.
8	Recommendations are made for future work.

*Considering that this review has not been commissioned and therefore we do not have a panel of experts, stage 7 will be difficult to achieve in a traditional manner. However, the aim is to submit this chapter for publication which we believe will meet the requirement of having the report assessed by a panel of reviewers.

The purpose of this paper is to report the results of a systematic review concerned with parenting a child with cancer.

5.3 Method

5.3.1 Stage 0 and 1

A literature review of the Cochrane database of systematic reviews revealed that no other review on the current topic had been published (stage 0). In planning the review (stage 1), the expected length was thought to be small-to-moderate in size

since this is an under-researched area. The specific questions to be addressed were:

1. *What research designs are used to study parenting a child with cancer?*
2. *What child outcome measures are used in these studies?*
3. *Do parents of children with cancer 'parent' their children differently from parents of healthy children?*
4. *What parenting behaviours are related to negative or positive child outcomes during and after treatment?*

These questions were chosen by the author as they were intended to cover the aspects of parenting a child with cancer which were most appropriate given the content of this thesis.

5.3.2 Stages 2 and 3

The inclusion and exclusion criteria adopted for the following review were as follows.

Inclusion criteria:

- Parents of children with cancer during any phase of their treatment;
- Written in English (due to the financial burden of translation costs);

Exclusion criteria:

- Review papers;
- Case studies;
- Studies of children of parents with cancer;
- Healthy children's understanding of cancer;
- Epidemiological or medical articles.

5.3.2.1 Search procedure

Searches were conducted using the following keywords and combination of keywords:

#1 *cancer (797006 records)*

#2 *parenting (10878 records)*

#3 *parenting style (506 records)*

#4 *parenting strategies (70 records)*

#5 *child-rearing (2580 records)*

#6 *#2 or #3 or #4 or #5 (12957 records)*

#7 *#1 and #6 (103 records)*

The keyword '*parenting'* (*#2)* was entered as previous searches by the author had shown that issues such as parental coping, adjustment and mental health were being captured when *'parent'* was used, resulting in thousands of irrelevant references. Therefore, although limited in scope, the choice of '*parenting'* was believed to capture the topic under consideration.

The following databases were searched from 1981 to July 2001 on the WebSPRIS database.

- MEDLINE
- EMBASE
- PsycLIT (formerly known as PsychLIT)
- RCN Journals Database (1985-1996)

From the final 103 articles retrieved, 19 were marked. Of these 19, ten were excluded for the following reasons: two discussed adult cancer, three discussed parental mental health (these are included in Chapter 3: Kazak & Barakat, 1997; Radcliffe et al., 1996; Van Dongen-Melman et al., 1995) and five were not applicable. Of the remaining nine papers, seven were retrieved. The two articles that could not be retrieved were dissertation abstracts and neither author had published from their dissertations. Therefore these references were excluded (see Table 5.2 for the twelve excluded articles).

5.3.2.2 Additional searching strategies

The lead authors of each of the seven papers were electronically searched in the databases for other relevant references. This resulted in a further seven papers being retrieved. All 14 papers were hand searched for additional references. This resulted in a further three papers being found, totalling 17 articles.

Key authors were also contacted for information on additional unpublished, in preparation, or in press publications. This did not yield any new references. Therefore, 17 papers were included in the present review.

5.4 Results (Stages 4-6)

Seventeen papers were identified and key data extracted. This information is summarised alphabetically in Table 5.3. **For simplicity, articles will be referred to by their study number in square brackets, for example [1] is Blount, Corbin, Sturges, Wolfe, Prater and James (1989).**

All seventeen papers were published in the US between 1987 and 1999. Twelve papers [4, 6-16] included children with mixed diagnoses, five included children with a diagnosis of leukaemia [1-3, 5, 17]. Sample sizes ranged from four [17] to 77 children [14]. Number of parents ranged from four [17] to 95 [4]. In some papers both parents are included, although few discussed exact numbers of mothers and fathers.

The largest age range, from 2- to 17-years, was observed in two articles [5, 9]. The majority of papers recruited children from approximately 3- to 13-years. Time since diagnosis ranged from within a month [16] to nine years [9]. One study recruited children at all stages of their illness [4], with the majority reporting mean time since diagnosis of approximately 2-3 years post-diagnosis.

In general, the papers included in this review are similar in source (US) and sample characteristics (mixed diagnoses, modest sample size, large age-range) as other studies (for example, those reviewed in Chapter 3) published in the paediatric oncology field.

1. What research designs are used to study parenting a child with cancer?

Although some studies used more than one method, ten studies used observational designs to assess parent-child relations [1-3, 5, 10, 12-15, 17], eight used questionnaires [5-9, 11, 14, 16] and two reported qualitative data [4, 11].

Observational methods

Ten studies used observational methods to assess parent-child interactions during bone marrow aspirations and/or lumbar punctures [1-3, 5], venipunctures [10, 12-15], or intravenous and intramuscular injections [17] (see Glossary, p. vii). Five articles [1-3, 13, 17] used the Child-Adult Medical Procedures Interaction Scale (CAMPIS; Blount, Corbin, & Wolfe, 1987; Blount, Sturges, & Powers, 1990), an observation tool which assesses child and parent vocalisations. The remaining observational studies [5, 10, 12-15] used similar tools: the Observational Scale of Behavioral Distress (Jay, Ozolins, Elliott, & Caldwell, 1983) [5], the modified edition of the Procedure Behavior Rating Scale (Katz, Kellerman, & Siegel, 1980) [10, 12, 15] and the Procedure Behavior Rating Scale – Venipuncture Version (Jacobsen et al., 1990) [13, who also used the CAMPIS, see above].

Essentially, these observational programmes are similar in nature, each assessing parent-child interactions using specific coding schemes. The parent-child interactions are usually audiotaped and a transcript made of the verbal interchange. The transcripts and audiotapes are then coded using the particular coding programme, which allows categorisation of the subject, speaker, phases of the medical procedure and adult or child vocalisations [1]. Table 5.4 gives examples of the CAMPIS content codes.

Table 5.4 CAMPIS content codes

ADULT TO ADULT	Humour directed to adults Nonprocedure-related talk to adults Procedure-related talk to adults Child's general condition related talk
ADULT TO CHILD	Humour directed to child Nonprocedure-related talk to child Command to use coping strategy Command to engage in procedural activity Praise Criticism Notice of procedure to come Reassuring comment Giving control to child Apology Behavioural commands to the child Checking child's status Empathy
CHILD VOCALISATIONS	Crying Screaming Verbal resistance Emotional support Verbal fear Verbal pain Verbal emotion Information seeking Child informs about status Request relief from nonprocedural discomfort Making coping statements Nonprocedural-related talk by the child Assertive procedural verbalisations Audible deep breathing Humour by the child

Questionnaire methods

Eight studies used generic measures of parenting [5-9, 11, 14, 16]. Three used the Parenting Dimensions Inventory (Power, 1992; Slater & Power, 1987) [5, 14, 16], two used the Child-Rearing Practices Report (Block, 1965; 1980) [6, 9] and two used the Child Development Questionnaire (CDQ; Zabin & Melamed, 1970) [7-8], or an amended version of the CDQ [11].

The PDI (Power, 1992; Slater & Power, 1987) is an 84-item questionnaire assessing three main constructs: support (nurturance, responsiveness and nonrestrictive attitude), control (amount of control, type of control and maturity demands) and structure (consistency and organisation of the household).

The CRPR (Block, 1965; 1980) is a 91-item generic parenting Q-sort which parents sort according to those that are most descriptive of the parents' behaviour toward the child (7), to those that are least descriptive (1). Examples of the statements are: '*I often feel angry with my child', 'I tend to spoil my child'* and *'I think it is best if the mother, rather than the father, is the one with the most authority over the children'*. This measure was administered once in its original Q-sort format [9], and again as a questionnaire [6].

The CDQ (Zabin & Melamed, 1970) was designed to assess the discipline practices used by parents in response to the child's avoidance of fearful situations (for example, going to the dentist, having injections). Jelalian et al. [11] revised the measure to assess everyday childhood disputes (for example, the child dawdling in the morning before school, arguing about rules). In both the CDQ [7-8] and the revised-CDQ [11], parents are requested to choose the parenting practice they would most likely resort to given that situation. The parenting discipline practices used in both the CDQ and revised-CDQ are: positive reinforcement, modelling / reassurance (or '*logic and rationalisation'* [11]), force, reinforcement of dependency, (or '*giving in'* [11]) and punishment.

To summarise, eight of the seventeen articles used generic questionnaire assessments of parenting. Three groups used the PDI (Power, 1992; Slater &

Power, 1987), two used the CRPR (Block, 1965; 1980), and three used the CDQ (Zabin & Melamed, 1970), or an amended version of the CDQ [11].

Qualitative methods

Two studies [4, 11] reported parental interview data. Chesler and Barbarin [4] conducted in-depth interviews concerning discipline, illness communication with their child, helping their child respond and manage their illness, and preparing the child for death. Using semi-structured interviews, Jelalian, Stark and Miller [11] focused on mother's reported conflict during discipline situations.

To summarise, observational methods were the most often cited methodology used to study parent-child relations (N=10). These methods were used to assess parent-child interactions during painful medical procedures, such as lumbar punctures or venipunctures. Eight used generic parenting measures, and two reported parental interview data.

2 What child outcome measures are used in these studies?

Ten articles assessed the child's level of fear and distress during medical procedures [1-3, 5, 10, 12-15, 17]. Of these, four included an assessment of the child's self-reported pain [5] or parental ratings of their child's fear and pain [10, 12, 17]. One study examined the child's hospital fears [8], and two studies assessed the child's treatment adherence [14, 16]. Dolgin et al. assessed the child's self-reported anxiety [7,8] and two assessed the child's play performance [14, 16]. Three studies [4, 6, 9] did not include any child outcome measures. Only two studies [11,16] assessed the child's behaviour, a non-illness related outcome.

To summarise, of the 17, only two studies assessed non-illness specific outcomes: the child's general behaviour [11,16]. The majority assessed the child's fear, anxiety, pain and distress during medical procedures. Other illness-related assessments included treatment adherence and play performance. Three studies did not include any assessments of the child. Very little assessment of parenting in relation to general child outcomes is reported.

3 Do parents of children with cancer 'parent' their children differently from parents of healthy children?

Four studies [6, 8-9, 11] compared parents of children with cancer with parents of healthy children. Dolgin et al. [8] included a third group: parents of children with non-life threatening chronic conditions (recruited from allergy/immunology and neurology clinics).

Comparison with parents of healthy children

Few differences between parents of children with cancer and parents of healthy children were reported using the CRPR (Block, 1965; 1980) [6,9]. Davies, Noll, DeStefano, Bukowski and Kulkarni [6] reported that their two parent groups differed on only two of the 91 items (2%). Parents of children with cancer were more overprotective and worried about their child's health than control parents. Hillman [9] reported differences between parents of children with cancer and control parents on eleven of the 91 statements (12%) covering issues such as parental expectations, discipline and overprotectiveness. When time since diagnosis was taken into account, parents of children who had been diagnosed for less than one year differed on more items (17%) than parents of children diagnosed for longer than one year (9%). Parents of newly diagnosed children reported spoiling their child more and setting fewer rules than parents of children longer from diagnosis.

Results using the CDQ (Zabin & Melamed, 1970) [8] and the revised-CDQ [11] showed no between-group differences in choice of parenting discipline practice [8,11]. However, mothers of children with cancer reported more conflict about discipline and felt less in control in situations requiring discipline than control mothers based on interview reports [11].

Comparison with parents of healthy children and non-life threatening chronically ill children

Dolgin et al. [8] reported that, regardless of the child's diagnosis (whether in the cancer or non-life threatening chronically ill group), parents of more medically vulnerable children (according to physician ratings) used less punitive discipline practices and fostered more dependency.

To summarise, using questionnaire methods, two studies [6, 9] reported minor between-group differences, while two [8, 11] reported none. Dolgin et al. [8] reported that level of medical vulnerability, rather than actual diagnosis, was important in choice of discipline practices. Based on interview data, mothers of children with cancer report more discipline conflict than mothers of healthy children. These results appear to demonstrate few differences between parents of children with cancer and control parents, using questionnaire assessments. However, using qualitative methodologies, it appears that mothers do report some difficulties. This raises questions regarding whether generic parenting measures can detect those specific issues of concern to parents. However, since Jelalian et al. [11] only interviewed mothers about their discipline conflict, we do not yet know whether there are other areas of parenting difficulty.

4. What parenting behaviours are related to negative or positive child outcomes during and after treatment?

Twelve papers [1-3, 5, 7, 10, 12-17] discussed parenting behaviours in relation to negative or positive child outcomes.

Negative parenting practices during medical procedures

Anticipatory Nausea and Vomiting (ANV) was higher where parents relied more heavily on threat of punishment in managing their child's fear than among children whose parents used modelling / reasoning [7].

Dahlquist, Power, Cox and Fernbach [5] reported that parents of young children (aged 2-7 years) who reported setting fewer rules and used less consistent, less organised and more permissive discipline practices, perceived their child as more anxious before medical procedures. Younger children of parents who were less

responsive and less nurturant demonstrated higher levels of behavioural distress during the anticipatory phase of the procedure.

Positive parenting practices during medical procedures

Distracting the child during the procedures resulted in decreased distress [1-3, 12-13, 15, 17]. However, Jacobsen et al. [10] found that distraction was not related to decreased child distress. This study was conducted during a venipuncture, a procedure which the child can see at all times. This is in contrast to the other studies which distracted the child during lumbar punctures and bone marrow aspirations, procedures which are conducted behind the child's back. Jacobsen et al. [10] believed that distraction did not work during venipuncture owing to the high number of visual cues available at all times.

Other parenting behaviours resulting in decreased child distress during medical procedures include commanding the child to engage in coping behaviours [1-2], parental coaching (i.e., the parent engaging in positive behaviours of encouragement) and positive reinforcement [12]. However, coaching was not helpful to 3-4 year old children, who showed *increased* stress levels during their procedures [15]. Manne et al. [15] believed that children of this age are too young for vigorous parental coaching.

Supportive parenting relates to increased treatment adherence

Two studies [14, 16] assessed the relationship between parenting and the child's treatment adherence. Results showed that supportive parents (those who were nurturant, responsive and had a nonrestrictive attitude) had fewer adherence problems with their children, reported reactions to the treatment more rapidly, cancelled and delayed fewer appointments than non-authoritative parents [14], had less difficulty in obtaining co-operation with tasks and less refusals to complete treatment tasks [16]. In contrast, parents who were inclined to let a child's misbehaviour go without some sort of reprimand were more likely to have difficulties obtaining co-operation with oral care, central access care, other hygienic care and physical examinations [14].

To summarise, parents who use harsher discipline practices have children with increased levels of ANV [7] and anxiety [5]. Parental distraction has generally been observed to be associated with a reduction of the child's fear and distress during medical procedures [1-3, 12-13, 15, 17], although one study did not find this effect [10]. Other positive parenting behaviours include commanding the child to engage in coping [1-2], coaching and positive reinforcement [12]. Finally, parental supportiveness has been reported as a positive influence on the child's treatment adherence [14, 16].

5.5 Discussion

Many of the methodological limitations considered in Chapter 3 can be seen in these papers, including the use of heterogeneous samples and recruiting children across wide age-ranges. Again, this is to be expected given the substantial difficulties inherent in conducting psychosocial work with this population. Given these reservations, limitations in the seventeen articles will be addressed.

First, small sample sizes do raise important questions regarding the representativeness of the findings. The smallest study involved four children, with the majority recruiting 20-40 subjects (see Table 5.3). While the rarity of childhood cancer prohibits the recruitment of large numbers of children and parents, concerns are raised over the power of these small samples. Despite this, however, there is value in assessing small studies, such as the one reported by Powers et al. [17], since they can give valuable insights into very rare groups of children (e.g., in terms of diagnosis or treatment options) or very detailed information regarding intervention programmes.

Second, generic assessments may not examine issues of difficulty to these parents. For example, Hillman [9] and Davies et al. [6] hypothesised that parenting must change after their child's diagnosis, and then concluded that in practice it does not change significantly. However, the problem is that parents may face problems that are not addressed in generic parenting measures, therefore they *appear* to be similar to controls. For example, issues such as caring for well siblings, worries over giving the child their medication, and continually monitoring the child for signs of relapse, are not assessed in generic assessments of parenting.

Third, only four of the 17 articles [5, 7-8, 12] included child self-reported questionnaire data. This is a common limitation within the paediatric literature (see Chapter 3). Furthermore, all the assessments were treatment focused, with no assessment made of the child's general adaptation or QOL (for example their peer relationships, physical activities or body image).

Fourth, no paper assessed the parent-child relationship *after* the child had completed treatment. No article assessed lingering difficulties and concerns which arise after the initial treatment has been successful. Chesler and Barbarin [4] did recruit children from all stages of their illness, but even so, much of their chapter was dedicated to post-diagnosis communication, discussions about how their child reacted to their illness, and preparing the child for death. No article had quantitatively assessed the child's functioning post-treatment. Considering the increase in survival rates in childhood cancer, this is surprising.

5.6 Conclusions

There is a bias towards (1) work published in the USA, and (2) articles reporting observational data during medical procedures. Given that children are not anaesthetised in the US during procedures such as lumbar punctures or bone marrow aspirations, there is a clinical need for this research in the US. However, since children in the UK *are* anaesthetised there is perhaps less demand for research into coping with painful medical procedures in the UK. This may go some way to explain the lack of non-US articles. Notwithstanding this, children in the UK *do* still undergo medical procedures, such as having blood taken, thumb pricks and being given chemotherapy. Children do get distressed during these procedures and it would be helpful to determine how parents support their children in UK clinics. Therefore, these articles may still have important consequences for cancer work in this country.

In some respects, although the articles that employed a generic measure of parenting made references to authoritarian, authoritative or permissive parenting, no paper explicitly discussed testing a model of parenting. Despite this, results are broadly in line with what might be predicted from Chapter 4. Harsher discipline

(authoritarian parenting) is related to child fear and distress [8], lax discipline (permissive parenting) to treatment adherence problems [14, 16] and parents who demonstrate distraction, commanding their child to engage in coping behaviours and coaching their child (authoritative type parenting), help their child's distress decrease [1-3, 12-13, 15]. Parents of children with cancer report more conflict in discipline situations than parents of healthy children [11] and report concerns about discipline, overprotectiveness [6, 9] and spoiling [4]. However, there remains a gap in our knowledge about (1) how parents of children 'parent' their children on an everyday basis, (2) how parenting is affected once treatment is completed, and (3) how this affects the child's general functioning, their QOL.

Table 5.2. Studies excluded from the systematic review

Study	Reason excluded
Brief report: Parenting stress and quality of life during treatment for childhood leukaemia predicts child and parent adjustment after treatment ends Kazak-AE; Barakat-LP (1997)	Parent adjustment (Chapter 3)
Experiences of parents of childhood cancer survivors: A qualitative analysis Van-Dongen-Melman-JEWM; Van-Zuuren-FJ; Verhulst-FC (1998)	Parent adjustment (Chapter 3
Adjustment in childhood brain tumor survival: Child, mother, and teacher report. Radcliffe-J; Bennett-D; Kazak-AE; Foley-B; Phillips-PC (1996)	Parent adjustment (Chapter 3)
Child-rearing concerns of parents with cancer. Hymovich-DP (1993)	Adult cancer
The family's functioning with newly diagnosed breast cancer in the mother: the development of an explanatory model. Lewis-FM; Hammond-MA; Woods-NF (1993)	Adult cancer
Gender differences in parenting a child with cancer. Brown-KAE; Barbarin-OA (1996)	Sex-role division; not parent-child interaction
The Perception of Procedures Questionnaire: Psychometric properties of a brief parent report measure of procedural distress Kazak-AE; Penati-B; Waibel-MK; Blackall-GF (1996)	Development of a measure
"We're at the breaking point": Family distress and competence in serious childhood illness. Kazak,-Anne-E (2001)	Therapy case study
Parent-child interactions with pediatric bone marrow transplant patients. Lee-ML; Cohen-SE; Stuber-ML; Nade-K (1994)	Pilot study / too basic at this stage
Parental reports of changes and challenges that result from parenting a child with cancer. Enskar-K; Carlsson-M; Golsater-M; Hamrin-E; Kreuger-A (1997)	Parent's discussing their feelings about their child's illness
Correlates of child distress during lumbar punctures: Parent behavior and parenting characteristics. Morrow - CE (1993)	Dissertation abstract – author had not published from thesis
Parenting style and parent-child coping during a painful medical procedure. Gorfinkle - KS(1992)	Dissertation abstract – author had not published from thesis

Table 5.3 Articles included in systematic review of parenting a child with cancer.

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
1	Blount et al. (1989)	23 children undergoing a BMA[1] (N=11) or both a BMA and LP[2] (N=12) and their parents.	5-13 (M=9.75)	Children Parents	NONE	ALL[3] Tsd: 40mths	*Children & Parents Observational Measures* CAMPIS	• During the procedure, parents' reassuring comments, apologies to the child, giving the child control, and criticisms of the child, were associated with child distress. • Commanding the child to engage in coping behaviours, nonprocedural talk to the child (distraction), and humour, resulted in child coping.
2	Blount et al. (1990)	22 children undergoing a BMA and LP procedure, and their parents.	5-13 (M = 9.75)	Children Parents	NONE	ALL Tsd: 4 months	*Children & Parents Observational Measures* CAMPIS CAMPIS-R	• Parents were responsive to their child's needs prior to and during the procedure. • Use of distraction and talk prior to the procedure increased child coping. • During the most painful part of the procedure, parents used commands for the child to cope (e.g., promoting deep breathing).
3	Blount et al. (1991)	22 children undergoing a BMA and LP and their parents	5-13 (M = 9.58)	Children Parents	NONE	ALL No tsd info given	*Children & Parents Observational Measures* CAMPIS CAMPIS-R Children were categorised high- or low-'copers'	• Parents of high-coping children engaged in more coping-promoting behaviours than parents with low-coping children. • Both high- and low-coping children were more likely to respond by coping to coping prompts than distress-promoting prompts or neutral prompts. • Distraction by parents lead to child coping.

[1] BMA = bone marrow aspiration
[2] LP = lumbar puncture
[3] ALL = acute lymphoblastic leukaemia

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
4	Chesler & Barbarin (1987)	26 children 23 siblings 95 parents (from 55 families)	>6 years	Children Parents Siblings	NONE	Mixed diagnoses Mixed tsd	*Interview covering the following issues:* Discipline and household chores, communicating with the child, helping the child respond to the illness, and preparing the child for death.	• Many parents find it difficult to continue rearing their child in a normal manner; this extends to discipline and asking the child to take part in household chores. Spoiling is a problem. • Parents find it difficult to communicate about the illness to the child.
5	Dahlquist et al. (1994)	66 children undergoing a BMA / LP and their parents	2 groups: 2-7 (M=5.74) 8-17 (M=12.08)	Children Parents	NONE	96% leukaemia; M tsd (months) = 30.4	*Children* OSBD >8 yrs – visual analogue pain scale (Dahlquist et al., 1985). *Parents* PDI STAI	• Anxious parents of 2-7 year olds were less consistent, less organised, less nurturant, and used more punitive discipline strategies than parents of older children (8-17). • Young children of less responsive and nurturant parents were observed as showing more behavioural distress.
6	Davies et al. (1991)	24 children and both parents	8-18 (M = 12.68)	Parents Physi-cians	24 mothers of healthy children.	Mixed diagnoses; Tsd M=52.44 mths.	*Parents:* CRPR *Physicians* CRPR (Physicians rated items they thought would differentiate the cancer group from controls.)	• Parents in the cancer group differed from control mothers on 2 of 91 items. • Physicians predicted differences in the areas of overinvolvement, discipline, worry about the child, nutritional concerns, and use of supernatural explanations. These were not echoed by the mothers in the cancer group.

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
7	Dolgin & Katz (1988)	10 children with ANV and their parents.	5-18 (M= 11.0)	Children Parents	10 children without ANV and their parents.	Mixed diagnoses; On-treatment	*Children:* STAI-C *Parents:* CDQ	• Children with ANV were more likely to have parents who used threat of punishment in managing their child's fear. • Parents of children with ANV endorsed modelling and reassurance less often than parents of children with no ANV.
8	Dolgin et al. (1990)	31 children and mothers	5-13 (M=8.7)	Children Parents Physi-cians	30 children with chronic non-life threaten-ing conditions; 28 healthy children; and their mothers.	65% had leukaemia; 35% had solid tumours. Under active treatment (no data given)	*Children* HFRS STAIC *Parents* CDQ STAI *Physicians* PPR	• There were no between-group differences on the CDQ. • Within the cancer group, parents of more vulnerable children (according to PPR) used less punitive strategies and fostered more dependency. • More anxious mothers used more force and less modelling and reassurance than less anxious mothers.
9	Hillman (1997)	58 children and one of their parents.	2-17 (M= 35.9 months)	Parents	58 parents of healthy children.	Mixed diagnoses; Tsd range: 1month – 9 years (with 36.2% diagnosed within a year).	*Parents* CRPR	• 11 of 91 item differences were found between the groups of parents in the areas of parental expectations, discipline, expression of emotion, parental concern, and overprotectiveness. • Assessing tsd[4], parents of children who were closer to diagnosis set fewer rules and spoiled their child more than parents of children who had been diagnosed over 1 year ago.

[4] Tsd: time since diagnosis

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
10	Jacobsen et al. (1990)	70 children undergoing VP[5] and their parents.	3-10 (M = 6.1 yrs)	Children Parents	NONE	Mixed diagnosis Tsd: 2-83 months (M=32)	*Children & Parents Observational measures* PBRS-Modified *Parents Pre-venipuncture assessment* STAI; 10-cm VAS assessing (1) their own anxiety about the procedure, (2) the child's level of fear, and (3) the child's fear.	• Parents with increased situational anxiety, who rated their children as more fearful and less cooperative prior to the VP, had children who were more distressed. • Parental explanations had a soothing effect on children who were distressed prior to the procedure, but had the opposite effect on those calm prior to the procedure. • Non-procedural talk (distraction) was not related to differences in child distress.
11	Jelalian et al. (1997)	22 children and mothers	3-10 (M=6 yrs, 7 mths)	Mothers	22 mothers of healthy children	Mixed diagnoses; Tsd: 22 on-treatment; 2 recently off-treatment.	*Mothers* DSQ ECBI Parent discipline interview.	• No between-group parenting differences reported using the DSQ, or behaviour differences using the ECBI. • Interview data highlighted less sense of control in discipline situations and less consistency in implementing discipline strategies in the cancer group than in controls.

[5] VP = venipuncture

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
12	Manne et al. (1990)	23 children undergoing a VP and their parents; Baseline and intervention study. Gp 1: *Behavioural intervention* (parent coaching, attentional distraction, and positive reinforcement) (N=13)	4-9 (M=4.7)	Children Parents Nurse	No healthy controls; Cancer Gp 2: *Attention control* (N=10); parents given no active interventio n.	Mixed diagnoses Tsd: 25 months (0-79)	*Children* *Observational scale* PBRS-Modified FACES *Parents* VAS of child's pain and own anxiety; *Nurse* 5-point Likert scale of difficulty inserting needle, child's distress and own distress.	• Use of parent coaching, attentional distraction, and positive reinforcement produced a significant reduction in children's observed distress, parents' anxiety and parent's ratings of child pain. • The intervention did not influence child self-reported pain, or nurses anxiety levels.
13	Manne et al. (1992)	43 children undergoing 3-phases of VP (preparation; needle insertion; completion) and their parents	3 – 9.33 (M = 5.38)	Children Parents	NONE	Mixed diagnoses Tsd: 28.7 mths (1-95)	*Children & Parents* *Observational measures* PBRS-VP CAMPIS	• Parents who used distraction tactics during all three phases of the VP had children who coped better, and evidenced reduced distress and crying. • For children who were upset prior to VP, parental directives resulted in *less* distress. However, if the child was calm prior to VP, parental directives *increased* child distress. The authors interpreted this as children needing different levels of parental responsiveness: distressed children may be calmed by explanations, calm children may view the parent's efforts as intrusive.

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
14	Manne et al. (1993)	77 children; 63 mothers; 13 fathers; 1 grandmother	3-10 (M=5.5 yrs)	Children Parents Nurse	NONE	Mixed diagnoses; M tsd = 27.2 months (range = 1-112)	*Children* OSCD-VP *Parents* LPPS PDI (only completed by a subset of 32 parents) *Nurse* Adherence measure (developed by authors)	• Younger children had more frequent adherence problems than older children. • More supportive parents cancelled and delayed fewer appointments, were on time more frequently for appointment, and reported reactions to treatment with less delay than less supportive parents.
15	Manne et al. (1994)	35 children undergoing VP and their parents. Baseline and intervention study. Group 1 (N=18): *Parents* coached children directly using distraction methods.	3- 8.9 (M=5.25)	Children Parents	No healthy controls; Group 2 (N=17): *Nurses* coached parents to help child using distraction methods.	Mixed diagnosis Tsd: 24 months (1-95)	*Children & Parents Observational measures* PBRS-VP CAMPIS	• There were no differences in the two groups, showing that professional encouragement to coach children was as effective as parents coaching their child directly. • Parental coaching was effective in getting the child to use distraction techniques (use of a party blower). This technique resulted in less crying. • For 3-4 year old children, parental coaching was related to increased distress, which the authors attributed to vigorous coaching at this young age resulting in increased child stress levels.

ID	Study	Cancer sample	Partici-pant's age (years)	Report Source	Controls	Illness variables	Measures (references in list at end of table)	Results
16	Manne et al. (1999)	54 children and one caregiver	3-13 (M= 8.33)	Parents; Nurse	NONE	Mixed diagnoses (exc. CNS tumours) Tsd: within one month.	*Parents* LLPS CBCL PDI CRCT *Nurse* CRCT	• More consistent parents, as measured by the PDI, had fewer difficulties obtaining cooperation with tasks and less refusals to complete tasks. • General child behaviour problems were associated with parental ratings of treatment cooperation.
17	Powers et al. (1993)	4 children having injections and their parents. Baseline and intervention study. Children taught distraction techniques; parents taught distraction, coaching and counting techniques.	3 yrs 0 mths – 5 yrs 0 months.	Children Parents Nurse	NONE	ALL Tsd: within 6 months	*Children & Parent Observational measures* CAMPIS-R OSBD *Parents* 10-cm VAS assessing, the child's fear (1) prior to, and (2) following the procedure. *Nurse* 10-cm VAS assessing, (1) distress, and (2) cooperation, of the child following the procedure.	• Children's distress decreased after training. • Parents rated children as becoming less afraid prior to the procedure and experiencing less pain during the procedure after training.

Measures used in Table 5.3

Abbrev.	Full name and reference
CAMPIS	Child-Adult Medical Procedure Interaction Scale (Blount, Corbin, & Wolfe, 1987)
CAMPIS-R	CAMPIS-revised (Blount et al., 1990)
CBCL	Child Behavior Checklist (Achenbach, 1991; Achenbach & Edelbrock, 1983)
CDQ	Child Development Questionnaire (Zabin & Melamed, 1980)
CRCT	Caregivers Ratings of Cooperation with tasks (developed by Manne et al., 1999)
CRPR	Child-rearing practices Report (Block, 1965; 1980)
DSQ	Discipline Strategies Questionnaire (developed by Jelalian et al., 1997)
ECBI	Eyberg Childhood Behavior Inventory (Robinson, Eyberg, & Ross, 1980)
FACES	FACES scale (LeBaron & Zeltzer, 1984)
HFRS	Hospital Fears Rating Scale (Melamed & Siegel, 1975)
LLPS	Lansky Play Performance Scale (Lansky et al., 1985)
OSBD	Observational Scale of Behavioral Distress (Jay et al., 1983)
OSCD-VP	Observational Scale of Child Distress During Venipuncture (Katz et al., 1980)
PBRS-M	Modified version of the Procedure Behavior Rating Scale (Katz et al., 1980)
PBRS-VP	PBRS Venipuncture Version (Jacobsen et al., 1990)
PDI	Parenting Dimensions Inventory (Power, 1992; Slater & Power, 1987)
PPR	Primary Physician Ratings (developed by Dolgin et al., 1990)
STAI	State-Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1976)
STAI-C	State-Trait Anxiety Inventory for Children (Spielberger, 1973)

CHAPTER SIX.

STUDY ONE. THE RELATIONSHIP BETWEEN PARENTING PRACTICES, PARENTAL MENTAL HEALTH, AND THE CHILD'S QUALITY OF LIFE – AN EMPIRICAL STUDY.

Summary

The central aim of study one was to assess a section of Wallander et al.'s (1989b) model outlined in Chapter 2, namely the relationship between the child's medical functioning (disability / disease factors), psychological adaptation (using a comprehensive measure of QOL), parental mental health and parenting behaviours (two social-ecological factors). Literature pertaining to these variables was reviewed in Chapters 1-5. A secondary aim was to improve upon past methodological limitations by setting strict inclusion criteria regarding the child's age-range and diagnosis and obtaining both parent and child reported data.

With a sample of 36 children with ALL and their parents, both parental mental health and parenting behaviours related to child self-reported QOL. Specifically, parental depression and endorsement of force together predicted poorer child QOL. Disease / disability factors had a negligible effect on child QOL, but did effect parental mental health.

This chapter concluded with a discussion of the results, methodological limitations, and suggestions for future work, some of which were attempted in study two of this thesis.

6.1 *Introduction*

The aim of this first empirical study was to test the pathways between child adaptation, disability / disease factors and social-ecological factors, the chosen variables based on Wallander et al.'s (1989b) model outlined in Chapter 2. A sample of 36 children with ALL and their parents were recruited to test these pathways. Please see Figure 6.1 for a diagrammatic view of the pathways being assessed.

Figure 6.1 Pathways based on Wallander et al.'s (1989b) model assessed in Study One

6.1.1 Child adaptation / QOL

As discussed in Chapter 2, the child's adaptation to cancer has most commonly

been assessed using unidimensional measures of mental health (e.g., depression, anxiety), school functioning or behaviour. However, as previously noted, there are a number of concerns with obtaining these detached 'glimpses' into different aspects of child functioning, as well as concerns with the actual measures used. For example, the CBCL (Achenbach, 1991; Achenbach & Edelbroch, 1983), a parent or teacher reported measure, is one of the most commonly used measures in the paediatric oncology field, despite the large number of criticisms which have been directed towards it (see the limitations section of Chapter 3 for a critique of the CBCL). As a result, there has been a move toward assessing the child's QOL, purported to be a global assessment of the child's overall functioning, using more suitable measures for chronically ill children.

Following this movement, child adaptation was operationalised as QOL within study one. Following the definitions of QOL discussed by both the WHO (1948) and Bradlyn et al. (1996) in section 2.3.1, QOL measures should be multidimensional (assessing aspects such as social, physical and emotional functioning), take into account the child's perspective and be sensitive to age-changes. The chosen QOL measure in the current study fulfilled these criteria, by assessing the child's physical, psychological, social, cognitive, and disease and treatment aspects functioning, from both the child and, if required, proxy perspective. Additionally, child (8-12 years) and teen (+13 years) formats were available to enable across-age comparisons, although in the current study only the former version was needed.

6.1.2 Disease / Disability Factors

While Wallander and colleagues (e.g., 1989a-c) failed to find evidence for any strong links between disease / disability factors and child adaptation, which led them to put forward a non-categorical approach to studying chronic childhood illnesses (see Chapter 2), one of the main aims of this thesis was to show that these factors do indeed relate to child adaptation. In fact, a number of cancer specific studies have already demonstrated a link between these variables. For example, previous research has supported the relationship between brain involvement and child adaptation (cf: Lansky et al., 1983; Noll et al., 1992;

Vannatta et al., 1998a; see Chapter 2), and treatment status and child QOL (Varni et al., 1998). To expand on the latter, as part of their QOL measure development, Varni et al. reported that children with cancer who were currently on active treatment had significantly poorer QOL than children who had completed treatment (demonstrating discriminant or clinical validity). Therefore, in the current study the hypothesis was tested that children still receiving active treatment ('on-treatment') would report poorer QOL than children who had completed treatment ('off-treatment'), using the same QOL measure as Varni et al. In addition, a more fine-grained indicator of treatment status, namely number of days since diagnosis, was tested in relation to the child's QOL, with the hypothesis being that QOL would improve as time increases.

While not strictly a disease / disability factor according to Wallander et al.'s (1989b) model, the child's chronological age was assessed in relation to QOL. While no specific hypotheses were set at this stage, an assessment of age changes was considered important in light of the developmental literature discussed in Chapter 2. This literature highlighted the impact cancer can have on different developmental stages, such as effect on schooling and peer relationships.

An additional hypothesis was explored at this stage, namely that *parental* mental health problems would decrease with time since diagnosis, following literature reviewed in section 3.2.1 of Chapter 3 (cf: Kupst et al., 1982, 1984, 1988). Specifically, it is expected that as the child settles into their treatment routine and goes into remission, the parent's mental health levels would improve. If supported, this would provide evidence for a pathway between disease / disability variables (time since diagnosis) and family members' adaptation (parental mental health), a link not previously included within Wallander et al.'s (1989b) model (see Figure 6.1, dashed arrow line).

6.1.3 Social-ecological factors

As discussed in Chapter 2, Wallander et al.'s (1989b) model included reference to the *family environment* as a resistance factor. Within their empirical work, Wallander et al. conceptualised this variable as representing family conflict,

cohesion and control. With a sample of children with one of five chronic illnesses (not cancer) they reported that poor child adaptation was correlated with poor family cohesion, parental control and increased family conflict. This appears to be the only reference to the family environment in Wallander et al.'s work to date.

Within this thesis, however, much attention has been given to the family environment, in both healthy (Chapter 4) and paediatric oncology (Chapter 5) samples. This research has shown that there is much more to parenting than what was studied by Wallander et al. (1989b). One particularly important area of research reviewed within both of these chapters concerns the use of discipline practices, or more generally, parenting practices, i.e. *"behaviors defined by specific content and socialisation goals"* (Darling & Steinberg, 1993, p. 492). With regard to parenting healthy children, this literature demonstrated the links between negative or restrictive discipline usage and poor child outcomes, while strategies such as reasoning with the child during conflicts were related to positive child outcomes. With respect to parenting a child with cancer, Dolgin and Katz (1988) and Dolgin et al. (1990) showed that use of negative discipline strategies, such as punishment, related to increased child fear during medical procedures. Additionally, mothers of children with cancer reported feeling less in control and less consistent during discipline situations than mothers of healthy children (Jelalian et al., 1997), although it was not clear what types of situations this referred to. Therefore, while it seems that disciplining children is a challenging issue, there has been no research assessing how parents discipline children with cancer during normal, everyday childhood misdemeanours, such as throwing tantrums and not going to bed when told, and the effect this has on the child's QOL.

Building on the research reviewed in chapters 4 and 5, the family environment in this study was operationalised as representing parenting discipline practices in response to normal, everyday misdemeanours. This led to the prediction that restrictive parenting practices, such as force and punishment, would relate to poorer child QOL, whereas optimal practices, such as logic and reasoning and positive reinforcement, would relate to better child QOL.

The second social-ecological variable to be assessed in relation to the child's QOL was the *family members' adaptation* (Wallander et al., 1989b). Previously, Wallander et al. (1989d) used a measure of general maternal malaise to represent this concept (see Chapter 2), while others in the paediatric oncology literature have assessed aspects of adaptation ranging from depression and anxiety to PTSD (see Chapter 3). This research has consistently demonstrated the strong relationship between poorer parental adaptation and poorer child outcomes (usually child behaviour as measured on the CBCL, Achenbach, 1991; Achenbach & Edelbrock, 1983) (cf: Manne et al., 1995, 1996; Sawyer et al., 1998; see Chapter 3). Drawing on the strengths of this past research, within this study, the family members' adaptation was operationalised as the parent's mental health (depression, anxiety and insomnia, somatic symptoms and social dysfunction), parental worry and stress (illness-specific and parenting), and perception of the child's vulnerability to health-related problems.

Drawing from the literature reported in Chapter 3, it was hypothesised that increased incidence of parental mental health problems would be related to poorer child QOL. Additionally, given that parents continue to worry and stress about their child's health, even years after diagnosis (Chesler & Barbarin, 1987), it was predicted that parents of children with poorer QOL, would report increased levels of worry and stress than parents of children with greater QOL. It was also predicted that medically vulnerable children (parent reported) would have poorer QOL.

To summarise, Chapter 6 is the first empirical study within this thesis, bringing together the strands of research reviewed in the first 5 chapters, being ordered within the constraints of Wallander et al.'s (1989b) model.

6.2 Methodology

6.2.1 Sample

The sample included 36 children (19 boys), aged 6-12 years (M= 8.78 years) and one of their parents (M=34 years). All children had been diagnosed with ALL. As

would be expected for this age-group, 36% were still on active treatment, while the remainder were seen purely for follow-up. Of the complete sample, 14% (N=5) had suffered a relapse (one girl had relapsed and was currently on-treatment; two boys and two girls had had a relapse, but had completed treatment). Parents were relatively well educated (age for compulsory school completion is 16 years). Reflecting the geographical area in which we recruited this group, the sample was primarily Caucasian. Sample characteristics are presented in Table 6.1. The age-range was chosen in this study as the principal aim was to develop a computer aided-QOL measure for 6-12 year-olds *not* reported within this thesis (please see Eiser, Vance, & Seamark, 2000, for details of this measure).

Table 6.1. Sample characteristics – children and parents

Child N=36					
		Mean	SD	Median	Range
Age, years		8.78	2.04	8.5	6-12
Age at diagnosis, years		4.87	2.68	4.0	1-12
Time since diagnosis, years		3.85	2.61	3.51	0.04-8.02
% male	53				
% on-treatment	36				
% suffered a relapse	14				
Parent[1] N=36					
		Mean	SD	Median	Range
Age, years		34.06	6.42	34.0	26-46
Age finished education, years		17.30	2.80	16.0	15-28
% Caucasian	94				
% Married	73				
% in employment	47				

[1] Seven fathers and 29 mothers accompanied their child to clinic in this study. This will be known as the 'parent' group. No mother-father differences were found on any of the measures used in this study, although this must be interpreted with caution considering the skewed numbers in each group.

6.2.2 Measures

All measures used in Study One can be seen in Appendix 1 and 2.

Parent completed

Parenting Practices: Discipline Strategies Questionnaire (DSQ: Jelalian et al., 1997)

This 11-item questionnaire, first introduced in Chapter 5, assesses parental management of common situations, for example the child throwing a tantrum, nagging while parent is speaking on the phone, and not going to bed when told. The original version of this measure, the Child Development Questionnaire (CDQ: Zabin & Melamed, 1980) has been used in previous cancer studies by Dolgin and colleagues (Dolgin & Katz, 1988; Dolgin et al., 1990; see Chapter 5). While the original version assessed parenting during situations that children may find avoidant or fearful (e.g., going to the doctors, learning to ride a bike, during thunder and lightening), the DSQ assesses more everyday childhood misdemeanours. While both versions are short and easy to complete, the latter was chosen for study one since it was felt that parents would be more able to draw upon personal experience when completing the DSQ. Using this measure, Jelalian et al. (1997) reported that mothers of children with cancer disciplined their child no differently from mothers of healthy children. However, this study does not inform as to how different discipline strategies can effect the child's QOL.

Parents are requested to select from a choice of five discipline practices which one they would be most likely to use in the given situation: *force, punishment, positive reinforcement, logic and rationalisation, and reinforcement of dependency*. See Table 6.2 for a summary of each of these discipline practices. The measure has demonstrated face validity and test-retest reliability (Jelalian et al., 1997). It is not possible to determine an estimate of internal consistency due to the interdependency of the scoring system. Scores are not given on a linear scale. For example, in this eleven-item measure, if a parent chooses ten force responses, only one other discipline practice can possibly be chosen. Although it is not fully acceptable to lack validity estimates, the decision to retain this measure was taken due to the paucity of other available parenting practices measures. The measure

fulfilled all other criteria, including item content, ease of completion, length, and suitability for children in the age-range in this study. Therefore, while acknowledging its limitations, the measure was included in the present study.

One of the original items, *sassing other adults,* was removed as the word 'sassing' is quite American and may confuse some parents. It was not considered necessary to Anglicise other items. Therefore, ten items were used in the current study.

Table 6.2. Description of each discipline strategy used in the Discipline Strategies Questionnaire (Jelalian et al., 1997).

Discipline practice	*Description*
Force	Actions in which the parent forces the child unwillingly to engage in the appropriate behaviour. For example, take child's hand and make him do the chore.
Punishment	Parent instructs the child that if he engages in an inappropriate action, an undesirable or unpleasant consequence will occur. For example, taking away a child's privileges.
Positive reinforcement	Parent instructs the child that if he engages in an appropriate behaviour, a consequence will occur that would be pleasing or favourable. For example, give child a compliment if he obeyed the rules.
Reinforcement of dependency	Parent concedes to his child's wish and the child is able to continue in the behaviour in an undesired situation. For example, giving the child what he wants to stop him having a tantrum.
Logic and rationalisation	Parent encourages the child to engage in the appropriate behaviour by trying to alleviate or minimise the child's resistance. For example, explaining the importance of a regular bedtime and getting enough sleep when child refuses to go to bed.

Parental mental health

The General Health Questionnaire-28 (GHQ-28: Goldberg, 1978)

This widely used 28-item questionnaire yields a total mental health score and four seven-item sub-scales assessing anxiety and insomnia, social dysfunction, somatic symptoms and depression. Scores range from 0 to 21 on each sub-scale, with a possible overall score of 84. Higher scores indicate poorer mental health. Recommended threshold cut-offs for at-risk levels have been cited at 23/24, i.e. 'normals' score 23 or below, 'cases' score at 24 or above (Goldberg et al., 1997). Being able to categorise parents as cases or not allows *intra-group analyses* to be conducted, a particularly strong statistical technique not routinely used in published work to date (for discussion concerning reporting of means vs. extreme scores, please see section 3.2.1). Split-half reliability was computed on a sample of 853 questionnaires and reported as 0.95 (Goldberg, 1978). Since its development the measure has repeatedly shown to be valid and reliable (e.g., Goldberg et al., 1997). This scale has been previously used with parents of cancer patients (e.g., Sawyer et al., 1993, 1997, 1998; see Chapter 3).

The Child Vulnerability Scale (CVS: Forsyth, Horwitz, Leventhal, Burger, & Leaf, 1996).

This scale assesses parental perceptions of their child's vulnerability to health problems. It includes eight statements concerning parent's behaviour towards their child in relation to health concerns (e.g., being worried that their child gets more colds than other children, checking on the child during the night). Ratings are made on a series of five point Likert scales (where 1 = strongly agree to 5 = strongly disagree). Unweighted scores are summed across the eight items yielding a range of perceived vulnerability from eight (high vulnerability or perceived poor health) to 40 (low vulnerability or good health). Internal consistency estimates published by Forsyth et al. (1996) were acceptable ($\alpha = .74$).

Illness stressors (adapted from Chesler & Barbarin, 1987)

This 15-item scale was newly-developed and measured parental stress levels associated with the child's illness. Items were taken from a qualitative study conducted by Chesler and Barbarin (1987; see Chapter 5). In this study, they

identified five areas of illness stress: practical burden of care, learning how to give treatment, worries about other family members, emotional stress and existential stress (worry about unjustness of the situation). To give a few examples, 57% of parents reported that they were 'strongly' worried about the child's reaction to treatment, 52% were 'strongly' worried about relapse, 38% 'moderately-to-strongly' worried about spoiling the child, and 52% were 'strongly-to-moderately' worried about their other children getting sick.

In an attempt to create a cancer-specific stress scale, the primary issues discussed by parents (as can be seen in Chesler & Barbarin, 1987) were constructed as a quantitative instrument. Scores range from 15 (no stress) to 60 (extremely high stress). Therefore, results should be treated with caution as this is the first time the measure was used and needs further validation work.

Maternal worry scale (DeVet & Ireys, 1998)

This 11-item scale measures mothers' future worry about their chronically ill child. The scale was developed with 140 mothers of chronically ill children, and demonstrated good internal consistency (α= .94) and test-retest reliability (r = .84). Scores range from 11 (low worry) to 44 (high worry). Examples of the items include worries about future reliance on medication, getting worse in the future and being different from others. One item ("will always need medication or stronger medication") was removed due to its overlap with another item ("will always need to take medication"), i.e. leaving 10 items. Therefore, in the present study possible scores ranged from 10 to 40.

This scale has been shown to have one single factor, and previously correlated with parental mental health (depression, anxiety) and reports of child behaviour (externalising and internalising problems) in a mixed sample of children with chronic illnesses (DeVet & Ireys, 1998).

Parental Stress Scale (Berry & Jones, 1995)

This 18-item parent scale was developed in the US for parents of healthy children. It was validated by Berry and Jones (1995) against the Parenting Stress Index

(Abidin, 1986), the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983), measures of emotions (e.g., guilt, anxiety) and role satisfaction (e.g., job and marital satisfaction). The Parental Stress Scale was found to be highly reliable, both internally (α = .83) and over time (test-retest = six weeks). Additionally, the scale discriminated between mothers of children with emotional and behavioural problems versus control mothers, demonstrating its discriminant validity. Factor analysis yields four sub-scales: parental rewards, parental stressors, lack of control and parental satisfaction. Total scores range from 18 (low stress) to 72 (high stress).

Child completed (outcome variable)

Pediatric Quality of Life Inventory - 32 (PCQL-32; Varni et al., 1998)

This cancer specific measure includes 32 items organised around five domains: physical functioning (5 items), disease and treatment related symptoms (9 items), psychological functioning (6 items), social functioning (5 items) and cognitive functioning (7 items). Ratings are made on a series of four-point Likert scales (where 0 = never a problem to 3 = always a problem) and respondents are asked to think back over a 1 month period. Scores range from 0 (excellent QOL) to 96 (very poor QOL). The PCQL-32 includes a child form for 8-12 year olds and an adolescent form for 13-18 year olds. There are identical forms for parent self-report. High internal consistency levels have been reported by Varni et al. (1998) (α = 0.91 and 0.92 for patient and parent report respectively). The scale has also demonstrated clinical validity (disease, physical functioning and total scores distinguish between children on- and off-treatment), and construct validity (sub-scales correlated with measures of emotional distress). (This scale was also completed by parents in the study and data are reported in Vance, Morse, Jenney, & Eiser, 2001).

6.2.3 Procedure

Study procedures were reviewed and approved by the relevant ethics board.

Parents and children attend the clinic during all stages of the child's illness. Close to diagnosis, parents and children may attend weekly or bi-weekly, for treatment

(e.g., chemotherapy) or medical procedures (e.g., lumbar punctures). Every attempt was made to recruit the parent and child before their visit with the doctor, before they received treatment or had a medical procedure. Children who were admitted onto the ward, i.e. were very close to diagnosis, very ill or had relapsed, were not recruited.

All parents whose child was within the appropriate age range (6-12 years) were approached when attending a routine clinic appointment, informed of the study and asked if they would like to take part. Both child and parent gave their written consent. If they agreed, parents were asked to complete the battery of questionnaires in clinic, while the child and researcher worked in a separate office. Both parent and child were told that they could withdraw at any time and that the study results were anonymous. They were encouraged to be as open and honest as possible with their responses, and asked if they wished to talk about any of the questions and discuss anything which they felt was confusing or upsetting.

The PCQL-32 was completed by children over 8-years of age. A separate QOL measure was completed by all children and is described in Vance et al. (2001).

Refusal Rates

Forty-five parents were approached, two of whom refused. Seven parents were unable to complete the questionnaires at the clinic because of time constraints and did not return them later by post (data from these children were not used). Thirty-six complete parent data sets were retained. Of the 36 children, only 27 completed the PCQL-32 due to age and/or time constraints.

Outliers

Following discussion with a statistician, exploration of the data revealed a small number of outliers. Three individuals were outlying on the GHQ-28 (Goldberg, 1978), but were all parents of newly diagnosed children. Since it was understandable that they had high GHQ-28 scores, their data were retained. Two additional parents had extremely low mental health scores, but their children were six and ten years from diagnosis, therefore this also seemed a normal response.

However, one highly depressed individual was removed from further analysis involving the mental health measure as sample characteristics showed that this child had been diagnosed over five years ago, was off-treatment, had not suffered a relapse, and the child self-reported a good QOL. Therefore, it was believed that this parent may have been adding 'noise' to the data, and was not a valid member of the sample for this measure only. Two further subjects were removed from analyses involving parental discipline practices (Jelalian et al., 1997) as they had a significant amount (33%) of missing data (Bryman & Cramer, 1999). Therefore, 35 data sets were retained for the mental health measure (N=36-1), and 34 for the parental discipline practices (N=36-2).

Treatment of results and statistical analysis

First, each measure was explored and their descriptive statistics reported. Secondly, correlations were conducted between the variables and medical / demographic variables. Where data appeared skewed, nonparametric correlation coefficients (Spearman rank order) or Mann-Whitney U-tests were conducted. Thirdly, a series of simple and multiple regression analyses were conducted in order to assess predictors of child QOL. Regression analyses do not assume that variables are normally distributed, though they do assume the residuals (measured - predicted values) are normally distributed, around a mean of zero. This assumption cannot be checked before the analysis, but post-hoc. This can be done by examining (a) a histogram of the residuals or (b) a normal probability plot in which the series of points of a normal distribution fall on a straight line.

Descriptive data will be referred to throughout and can be seen in Appendix 3.

6.3 Results

6.3.1 Descriptive and Preliminary statistics

This section summarises descriptive statistics of the measures, intercorrelations among sub-scales, and relationships with medical and demographic factors.

Internal consistency: Cronbach's alpha estimates

Cronbach's alpha is a measure of internal consistency and assesses the correlations between the items in a scale. The higher the correlations between the items, the greater the internal consistency. In other words, the reliability of a test is related to the homogeneity of the items with each other (Breakwell, Hammond, & Fife-Schaw, 1995). It is important to assess Cronbach's alpha for a number of reasons. First, estimates for one sample cannot be assumed to hold true for other samples. Therefore, Cronbach's alpha must be examined for each measure used in the present study. If the reliability estimates are poor, the measures should not be used. Second, the majority of measures used in this study are American and therefore it is essential that we assess their utility in other populations. See Table 6.3 for internal consistency estimates (Cronbach's alpha) for the measures used in the current sample.

Table 6.3 Internal consistency estimates (Cronbach's alpha) for the measures used in the current sample.

Measure	*Number of items*	*Cronbach's Alpha*
Child Vulnerability Scale	8	0.85
Maternal Worry Scale	10	0.68
Illness stress	15	0.64
Parental Stress scale	18	0.80
GHQ: subscale A	7	0.88
GHQ: subscale B	7	0.91
GHQ: subscale C	7	0.77
GHQ: subscale D	7	0.90
GHQ: total scale	28	0.94
PCQL: physical functioning	5	0.40
PCQL: psychological functioning	6	0.61
PCQL: social functioning	5	0.69
PCQL: cognitive functioning	7	0.57
PCQL: disease functioning	9	0.68
PCQL: total scale	32	0.86

An internal consistency of 0.70 has been recommended for measures to detect between-group differences in clinical trials, and above 0.90 for interpreting individual scores (Nunnally, 1978). However, in practice, values of 0.50 and above may be considered acceptable (Cronbach, 1951). As can be seen from Table 6.2, alpha levels were generally very good, with the exception of 'physical functioning' ($\alpha = 0.40$).

As discussed earlier, due to the type of scoring used with the DSQ (Jelalian et al., 1997), internal consistency data cannot be determined. In absence of an internal reliability estimate, a research assistant coded each of the five parenting discipline choices for each of the 10 questions, deciding if each statement was an example of force, punishment, logic and rationalisation, reinforcement of dependency, or positive reinforcement. She coded all statements accurately.

Discipline Strategies Questionnaire (Jelalian et al., 1997)

As can be seen in Table 6.4, logic and rationalisation is the most frequently endorsed discipline practice, followed by positive reinforcement, force, punishment, and reinforcement of dependency.

Table 6.4 Means, SD, medians and ranges for each discipline practice

Discipline practice	*Mean*	*SD*	*Median*	*Range*
Force	1.16	1.07	1	0-4
Punishment	1.10	1.08	1	0-4
Logic and rationalisation	4.84	1.57	5	2-8
Reinforcement of dependency	0.81	1.11	0	0-4
Positive reinforcement	1.87	1.20	2	0-4

Logic and rationalisation was the most popular choice for all of the situations, except for the items *when the child throws a tantrum* (force was the most popular choice) and *when the child nags the parent* (punishment is equally as popular as logic).

Skewness data showed that reinforcement of dependency and punishment were

significantly different from normal, with the others not being significantly non-normal (see Appendix 3). In other words, the number of people endorsing these strategies was low-to-medium. However, because of the skewness, nonparametric analyses were chosen (Dancey & Reidy, 1999).

Spearman rank correlations between the five discipline categories showed that force was negatively correlated with logic and rationalisation ($\rho = -0.50$, $p<0.01$). Punishment was negatively correlated with positive reinforcement ($\rho = -0.44$, $p<0.05$), and logic and rationalisation ($\rho = -0.47$, $p<0.01$).

Relationship with demographic and medical factors

Time since diagnosis (tsd) and *treatment status* are similar variables, with *tsd* being more specific, being measured as number of days since diagnosis. *Treatment status* refers to whether the child is on- or off-active treatment.

No correlations were found between the child's chronological age, age at diagnosis or tsd and the five discipline practices. The older parents were when they left education, the more they endorsed logic and rationalisation practices ($\rho = 0.47$, $p<0.05$).

Using Mann-Whitney U-tests, neither gender nor treatment status emerged as a determinant of parental self-reported use of discipline.

GHQ-28 (Goldberg, 1978)

Means, standard deviations, medians and ranges for parental mental health are presented in Table 6.5.

Table 6.5 Means, SD, medians and ranges for parent mental health

Mental health sub-scale	*Mean*	*SD*	*Median*	*Range*
Subscale A: Somatic symptoms	6.63	4.51	6	1-18
Subscale B: Anxiety and insomnia	7.43	4.85	6	2-21
Subscale C: Social dysfunction	7.47	2.72	7	2-14
Subscale D: Depression	2.38	3.16	0.5	0-11
GHQ total	23.9	13.16	20	7-59

Individual item means were reviewed in order to gauge which statements parents endorsed most. Of the 28 items, the statements parents most agreed with were: feeling well and in good health, been getting edgy and bad-tempered and been able to enjoy everyday events. The least endorsed statement was: thinking of the possibility of doing away with oneself (depression sub-scale).

As with the discipline practices, the distribution of the mental health parameters was positively skewed. This means that most parents generally scored in the low range (better functioning) of this scale. Skewness data showed that the variable distributions were acceptable, except for depression which was significantly deviant (see Appendix 3). Therefore, nonparametric analyses were used.

Spearman correlations revealed that each sub-scale correlated highly and significantly with all other sub-scales (ρ's ranged from .36 to .88), indicating that good functioning in one aspect of mental health was strongly associated with good functioning in other areas.

Relationship with demographic and medical variables

Parents of children further from diagnosis (i.e., increased tsd) were less anxious and suffered from less insomnia than parents of children closer to diagnosis (ρ = -0.45, $p<0.05$). Parents of children who were on-treatment were significantly more anxious than parents of children off-treatment (Z = -2.37, $p<0.05$). Tendencies were shown in the same direction for the depression sub-scale (Z= -1.91, p = 0.08) and the overall GHQ-28 total score (Z = -1.84, p = 0.06).

Older age at diagnosis was correlated with increased parental anxiety and insomnia (ρ = 0.55, $p<0.01$), somatic symptoms (ρ= 0.40, $p<0.05$), and overall poorer general mental health (ρ= 0.43, $p<0.05$). This trend was also shown in the depression sub-scale (ρ = 0.32, p = 0.08). No effect was found for gender.

At-risk levels of psychopathology

Goldberg et al. (1997) recommended a threshold of 23/24 with the GHQ-28. Categorising parents in this way, 13 parents were classified as cases, with the remaining 22 scoring in the 'normal' range. Importantly the mean score for the GHQ-28 was barely over the cut-off score of 23 (M=23.90), indicating that parents in this sample had relatively high levels of mental health problems. While it makes more sense to view people as lying on a continuum from healthy to undoubted psychiatric illness, cut-off scores give some indication of how many individuals score proportionately at-risk levels.

Results indicated that comparison of cases vs. 'normals' could not be explained by time since diagnosis (t = 1.51, p = 0.14) or treatment status (χ = 2.17, p = 0.14). No demographic variable (child's age, age at diagnosis, gender, marital status) differed between the groups, i.e., we were unable to discriminate cases from normals.

Perception of child vulnerability, maternal worries, illness and parenting stress

Table 6.6 shows the means, standard deviations, medians and ranges for the child vulnerability scale, maternal worries, illness and parenting stress. Skewness data for each measure was normal (see Appendix 3).

Table 6.6 Means, SD, medians and ranges for perception of child vulnerability, maternal worries, illness and parental stress.

Measure	*Mean*	*SD*	*Median*	*Range*
Child vulnerability scale	26.83	6.33	27	13-40
Maternal worry scale	17.16	3.68	17	11-26
Illness stress scale	28.18	6.87	27.25	18-42
Parental stress scale	36.99	7.79	36	22-55

Mean item responses on the child vulnerability scale were greatest on the following: child getting more colds than other children, having to keep their child indoors, and their child seeming less healthy than other children. Parents were most worried about their child getting sick or ill again, having side-effects from the treatments and growing up too fast because of the illness. Most illness stress was due to fears of their child relapsing, getting worse again, being overprotective and spoiling their child. In terms of parenting stress, parents endorsed the following items most: worrying whether they are doing enough for their child, their child being a major source of stress in their life, and caring sometimes taking more energy than they have to give.

Intercorrelations

Pearson correlations show that increased parental worry was associated with increased illness stress ($r = 0.41$, $p<0.05$), and greater perception of vulnerability ($r = -0.52$, $p<0.01$). Higher illness stress was correlated with higher parenting stress ($r = 0.42$, $p<0.05$).

Relationship with demographic and medical variables

Using independent t-tests or Pearson correlations, no medical or demographic variable related to these measures.

Child reported PCQL-32 (Varni et al., 1998)

Means, standard deviations, medians and ranges of the PCQL-32 measure of QOL are shown in Table 6.7.

Table 6.7 Means, SD, medians and ranges of the PCQL-32

Sub-scale	*Mean*	*SD*	*Median*	*Range*
Physical	3.00	2.49	3	0-9
Psychological	4.53	3.03	4	0-12
Social	4.44	3.19	4	1-15
Cognitive	4.44	3.09	4	0-10
Disease & medical	6.21	3.85	4	0-17
Overall QOL	21.64	11.65	20	3-50

According to the individual item means, children reported arguing or fighting with others, worrying about the future, and not getting their own way as their most problematic issues. Walking or moving around and becoming sick when thinking about medical treatments were the least problematic.

Distributional analysis indicated that the data were positively, but not non-normally skewed, i.e. the children generally self-reported good functioning and a good overall QOL. Therefore, parametric analysis were used.

Intercorrelations

Correlations between the sub-scales ranged from r= 0.14 to r= 0.85. Not all correlations were significant, however. The cognitive sub-scale did not correlate with the child's psychological, social or disease functioning. Physical functioning did not correlate with social functioning. This highlights a difference between those sub-scales which assess internal aspects of functioning, *psychological, social*, and *disease functioning* (which correlate highly with each other: rs from 0.65 to 0.73), and more external functioning sub-scales, *cognitive* and *physical* (which also correlate well with each other: r = 0.53). All sub-scales correlate with the total score (rs from 0.53 to 0.85). The *internal* functioning sub-scales tap into

feelings and emotions, e.g., how scared the child feels going to the hospital for check-ups or feeling scared or sad, whereas the *external* functioning scales include statements about actual behaviours, such as being able to run or walk.

Relationship with demographic and medical variables

Older children reported better physical functioning than younger children ($r = -0.50$, $p<0.01$). Time since diagnosis, parents age, and age parent left education did not correlate with the child's self-reported QOL.

Using independent samples t-tests, sub-scale scores were not affected by treatment status, gender, or the parent's employment status.

Range of PCQL-32 measurement

Table 6.8 presents the percentages of floor and ceiling effects as reported on the PCQL-32. Ceiling effects are the percentage of parents and children who endorse the highest anchor point for each item for each subscale. Similarly, floor effects are the number of endorsements made at the lowest anchor point. To give an example, 18.5% of children self-reported ceiling levels on the physical functioning sub-scale, i.e., they report 'never' having physical problems on all items in that subscale. In contrast, no child self-reported 'always' having physical problems.

Table. 6.8. Percentage of ceiling and floor effects on the PCQL-32

Domain	*% ceiling*	*% floor*
Physical	18.5	0
Psychological	3.70	0
Social	0	3.70
Cognitive	11.11	0
Disease & treatment	11.11	0

6.3.2 Spearman correlations between parent predictor variables:

Parental discipline practices, parental mental health and perception child vulnerability, maternal worries, illness and parenting stress.

Due to the non-normal distribution of some variables, non-parametric analyses were conducted.

Increased illness stress was significantly correlated with increased depression (ρ= 0.36, $p<0.05$). Parents who perceived their child as being vulnerable showed a tendency towards being more depressed (ρ = -0.38, p=0.06). Finally, no significant correlations were found between parenting discipline practices and perception of child vulnerability, maternal worries, illness and parenting stress.

6.3.3 Predictive value of Parental influence on child QOL

To test the hypotheses that child QOL will be predicted by (1) parental discipline practices, (2) parental mental health, and (3) child vulnerability, maternal worries, illness and parenting stress, three separate regression analyses were conducted. A final regression was conducted including all significant variables from the first three analysis. Only significant results will be presented for simplicity.

Preliminary analysis showed that medical and demographic variables did not predict the child's QOL. Therefore they will not be included in further analyses.

To summarise:

Regression 1:

Parenting discipline practices as predictors of child QOL

Regression 2:

Parental mental health as predictors of child QOL

Regression 3:

Child vulnerability, maternal worries, illness and parent stress as predictors of child QOL

Final regression: Using stepwise regression, the significant variables which

emerged during steps 1-3 were entered to assess their combined predictive power in explaining child QOL.

Regression 1: Parenting discipline practices

Four of the five discipline practices were entered into a stepwise regression: force, logic and rationalisation, punishment and positive reinforcement. The choice was taken to exclude *reinforcement of dependency* from this analysis due to its low endorsement by parents and extremely skewed distribution. Due to the scoring of this measure, a stepwise regression model must be used. Parents were scored out of ten, with the scores for each practice being interdependent (i.e., if someone had chosen four logic and rationalisation responses, they could only have a maximum of six force responses).

Table 6.9 shows that force emerged as the only significant predictor of the child's QOL.

Table 6.9 Stepwise regression of child QOL on discipline practices

	B	SE B	*t*	*p*
Constant	13.21	3130	4.22	.001
Force	**6.97**	**2.07**	**3.38**	**.003**

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	1	1129.35	1129.35	11.39	.0025
Residual	24	2378.94	106.42		

Multiple R	.57
R square	.32
Adjusted R square	.29
Standard error	9.96

Table 6.9 shows that force significantly adds to the equation: F (1,24) =11.39, p = 0.025. For every endorsement of force, the child's QOL score increases, on average, by 6.97 points, i.e. a *poorer* QOL.

Regression Two: Parental mental health.

The four mental health sub-scales, somatic symptoms, social dysfunction, depression, and anxiety and insomnia, from the GHQ-28 were added into a standard regression.

Depression was the only significant predictor of child QOL. The model summary (Table 6.10) shows an effect with the inclusion of the mental health variable, depression (F (4,21)= 5.33, $p<0.01$). This test is an overall indication that depression significantly predicts the dependent variable, child QOL.

Table 6.10 Regression of child QOL on parental mental health

	B	SE B	*t*	*p*
Constant	31.08	6.84	4.55	.000
Depression	**3.42**	**0.78**	**4.36**	**.001**
Anxiety & Insomnia	-0.45	0.69	-0.64	.53
Social dysfunction	-1.52	1.32	-1.36	.19
Somatic symptoms	-0.40	0.76	-0.54	.60

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	4	1767.47	441.87	5.33	.006
Residual	21	1740.82	82.90		

Multiple R	.71
R square	.50
Adjusted R square	.41
Standard error	9.10

Table 6.10 shows that parental depression predicts child self-reported QOL ($p<0.05$). For every one point increase in depression, the child's QOL scores increases on average of 3.42, which corresponds to a *poorer* QOL. This model explains 50% of the variance (41% R^2 adj).

Regression three: Child vulnerability, maternal worry scale, illness stress, and parenting stress. None of these variables significantly predicted child QOL, therefore no result tables are shown.

Final regression:

A final regression analysis was carried out with the two relevant variables that predicted child QOL in regressions one and two: *force* and *depression*. This model was run in order to see if the two variables covaried and explained the same variance (see Table 6.11).

Table 6.11 *A stepwise regression of child QOL on endorsement of force and parental depression.*

	B	SE B	*t*	*p*
Constant	8.99	2.87	3.14	.005
Force	**6.29**	**1.72**	**3.62**	**.002**
Depression	**2.06**	**0.60**	**3.46**	**.002**

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	2	1944.14	972.07	14.29	.001
Residual	23	1564.15	68.01		

Multiple R	.74
R square	.55
Adjusted R square	.52
Standard error	8.25

This model was significant overall ($F(2, 23) = 14.29$, $p < 0.001$) and demonstrated that parental depression and endorsement of force together predict 55% of the variance in child QOL (52% R^2 adj). When added together, the individual variables were not weakened substantially. This shows that these two variables are not overlapping in the variance they are predicting.

Cook's D

In addition to running the regression analysis at each stage, Cook's D diagnostic statistic was obtained. This test identifies those outliers arising from a

combination of different variables. The distance investigates outliers in the dependent variables, whereas leverage identifies those outlying on the independent variables. The combination of the distance and leverage is what Cook's D measures - this is known as influence. When conducting regression analysis, Cook's D identifies outliers, and in this case, the analysis should be re-run without the outlying variable(s). This was done after both depression and force were added together. According to Tabachnick and Fidell (1989, p. 130), outliers are subjects that have an influence of more than 1.00. In this case, no case was identified above this level, showing that all analyses were stable.

All post-hoc probability plots were acceptable.

6.4 Discussion

Contrary to predictions, children who were on-treatment and therefore had a shorter time since diagnosis did not rate their QOL as significantly poorer than those who were off-treatment or longer from diagnosis. As discussed earlier in the chapter, Varni et al. (1998) reported differences in QOL reports according to treatment status when developing the PCQL-32 measure. This was not replicated in the present study, which may be partly attributed to the small number of children on-treatment in this study (N=13). In contrast, Varni et al. recruited 291 children, 108 of whom were newly diagnosed.

One possibility for this finding is that the children in this study were mainly passed the intensive phase of their illness. Intensive therapy is given over most of the first year of treatment, requiring many hospitalisations, thereafter the child is on maintenance therapy, which involves home-based chemotherapy, regular clinic appointments, and fewer admissions. In this study, children who were in-patients did not participate, leaving only those who were attending as out-patients. Therefore, children may have been feeling much better by the time they were tested in this study. This is reflected in the mean time since diagnosis being close to four years post-diagnosis (M=3.85, SD = 2.61 years). In study two, a sample of long-term survivors will be assessed, testing the prediction that QOL reports generally do not change considerably after the initial acute periods of treatment.

Alternatively, the result may be attributed to a cultural difference in medical care. In the US, children are not anaesthetised during painful medical procedures such as lumbar punctures or bone marrow aspirations (hence the number of studies dedicated to helping the child cope with pain; see Chapter 5). In contrast, children in the UK *are* anaesthetised. Therefore, one might expect that children in the UK do not rate the cancer experience as frightening and detrimental to their QOL as US children. As far as we are aware, there have been no cross-cultural studies assessing changes in QOL as a function of medical care differences.

The child's chronological age did not correlate with the child's QOL with one exception: older children reported better physical functioning. As discussed in Chapter 2, the diagnosis of cancer has different effects depending upon the child's age and developmental status. The lack of clear QOL patterns in relation to age may simply be attributed to the small age-range of the children in this study. In study two, children will be recruited across a much larger age-range, with both linear and non-linear effects of age being studied in relation to QOL.

Parents of children closer to diagnosis and still on-treatment were not functioning significantly worse than parents of children further from diagnosis, with one exception: parents of children who were closer to treatment and still on-treatment reported more anxiety and insomnia. Mental health had been expected to improve with time but, with this one exception, this was not found. Perhaps the sample was too small to detect these changes, which is suggested by the strong statistical tendencies towards increased depression and poorer overall mental health in parents of children on-treatment. Future work is needed to test this hypothesis with a larger sample.

Parents of children who were older at diagnosis reported significantly more anxiety, somatic symptoms, and poorer overall mental health. Suggestions for this may be that parents are more aware of the effect cancer will have on the school career, body image and peer relationships of older children (Willis et al., 1982; see Chapter 2). Clinically, survival statistics are known to decrease with

increasing age at diagnosis. For example, for children diagnosed with ALL between one- and four-years of age, five-year survival rates are 81% compared with 74% for those diagnosed between five- and nine-years old, and 61% for those diagnosed between ten- and 14-years of age (Stiller & Eatock, 1999). Therefore, it may be that parents of children older at diagnosis were concerned about both the child's psychological and physical health future.

In the past, both disease / disability factors have been studied in relation to child and parent functioning, with inconclusive results. For example, while Manne et al. (1995) reported that functional impairment, treatment severity and number of days hospitalised had a weak relationship with parental depression, their effects disappeared once psychological variables were accounted for. In contrast, both Mulhern et al. (1992) and Worchel et al. (1988) reported that increased time since diagnosis was related to increased child depression (self-reported). Mulhern et al. (1992) also reported that increased length of hospitalisation was predictive of increased maternal depression. In the present study, the child's self-reported QOL was not effected by disease / disability factors. However, better parental mental health was associated with two of these factors, off-treatment status and younger age at diagnosis. Therefore, considering Wallander et al.'s (1989b) model, an association was not demonstrated between disease / disability factors and *child* adaptation, but *parental* mental health (a social-ecological factor), providing evidence for a new pathway in the risk / resilience model outlined in Figure 6.1. This is a finding that deserves further study.

6.4.1 Predicting child QOL

Regression analyses were conducted in order to assess the most powerful predictors of child QOL. These regression models showed that increased endorsement of force and increased parental depression were significant predictors of poorer child QOL, supporting our initial hypotheses that restrictive parenting practices and poorer mental health would relate to poorer child QOL. This also provides evidence for the pathway between social-ecological factors and child adaptation (Wallander et al., 1989b). The use of optimal parenting practices,

such as logic and reasoning and positive reinforcement, did not emerge in our analyses, rejecting our initial hypothesis.

Child vulnerability, worries, illness and parenting stress did not significantly predict child QOL, thereby rejecting another hypothesis. A note of caution must be added here. As the regression analyses were based on a modest sample size, the results at this stage must be viewed as explorative, with replication being necessary in future work (NB. Power calculations follow in the limitations section). However, the explained variance amounted to 52% (R^2 adjusted), which does indicate that this is a promising result worth following-up.

The component of Darling and Steinberg's (1993) framework linking parent discipline practices with child outcomes was tested in this study (see Chapter 4). In this case increased use of force negatively related to the child's QOL. This concurs with previous cancer research which has demonstrated the negative effect that *force,* as an authoritarian discipline practice, has on the child reactions to medical procedures (Dolgin & Katz, 1988; Dolgin et al.,1990; see Chapter 5). More generally, force has been associated with poorer child outcomes in healthy samples (see Chapter 4). This study has added to previous work by assessing the relationship between parents and children using a theoretically driven parenting model, and by assessing the effect of authoritarian control on the child's QOL. Of course, the type of discipline used by a parent gives only a glimpse of the child-rearing process. Other aspects of parenting will be assessed in study two.

The present study also highlighted the relationship between poorer child QOL and parental mental health problems. These results concur with previous research outlined in Chapter 3. However, one limitation of much of the cancer work reviewed in this chapter is the reliance upon single-respondent designs, thereby increasing the risk of 'depressive bias', i.e. the single-responder's mental health may in some way cloud their judgements of the child's problem behaviour (Manne et al., 1995, 1996). A second limitation with the cancer literature concerns the overreliance of the CBCL (Achenbach, 1991; Achenbach & Edelbrock, 1983) as a child outcome measure in relation to parental mental health. This measure has

been criticised for use with chronically ill samples (Perrin et al., 1991; see Chapter 3 for full discussion of this measure). This study has added to the existing literature by (1) obtaining both parent and child self-reported data, and (2) using a comprehensive measure of the child's QOL in relation to parental mental health.

6.4.2 General discussion

The most frequently endorsed discipline practice was logic and rationalisation, defined by Jelalian et al. (1997) as *"those actions in which the parent encourages the child to engage in the appropriate behavior by trying to alleviate or minimize the child's resistance. The parent can achieve this through the following means: telling the child why the behavior is not good to do"* (E. Jelalian, personal communication). The least popular discipline practice was reinforcement of dependency, defined as *"those actions in which the parent concedes to his/her child's wish and the child is able to continue in the behavior in an undesired situation (e.g., 'ask the adults to excuse my child for his behavior')"* (E. Jelalian, personal communication). Recall from Chapter 4 that logic and rationalisation is a characteristic of authoritative parenting, whereas reinforcement of dependency is typically seen in permissive parents.

These results contrast sharply with those found by Jelalian et al. (1997). Punishment was the most frequently endorsed discipline practice in their sample of 22 mothers of children with cancer, followed by force, logic and rationalisation, positive reinforcement then reinforcement of dependency. This middle-to-upper class sample was drawn from a large paediatric haematology-oncology clinic in the USA. No ethnicity information was given.

The difference between the two studies lies in the endorsement of authoritarian controls - punishment and force. Whereas these were highly endorsed strategies in the US sample, in the UK sample, punishment and force were much less favoured (after logic and rationalisation and positive reinforcement). The identical questionnaires were administered in similar ways, so the difference could be partly explained by cultural differences: British parents may have been more reluctant to advocate more controlling practices, due to social desirability issues.

Alternatively, it may be that British and American parents genuinely use very different discipline choices as a way to deal with common child misdemeanours.

Discipline practices were not associated with the child's age or gender, suggesting that this measure can be used equally for boys and girls and for all ages in the recommended range (3-12 years). Additionally, there were no treatment status (on- vs. off-treatment) or time since diagnosis effects illustrating that the child's cancer status itself did not emerge as a determinant of parental self-reported use of discipline. These results are both similar and different from reports by Dolgin et al. (1990). Similarly, both studies demonstrated the lack of an association between the child's objective medical status and parental discipline practices, but differently, Dolgin et al. (1990) reported that physician subjective ratings of the child's vulnerability did relate to discipline practices. In the present study, parental subjective reports of the child's vulnerability did not influence their choice of discipline practice.

Parental mental health reports were comparable to those reported by Sawyer et al. (1997, discussed in Chapter 3), who also used the GHQ-28. They administered the GHQ-28 at three time points: at diagnosis, one and two years later. Mean scores in the present study were comparable with those recorded by Sawyer et al. (1997) when they assessed parents at diagnosis. When we assessed threshold scores in the current study, 13 parents scored as cases. In fact, the group mean score (M=23.90) was above the recommended threshold of 23, albeit narrowly (as was Sawyer et al's, maternal functioning at-diagnosis score, M=23.5, fathers were slightly below this, M=22.0). This intra-class analysis demonstrates the importance of assessing cases and non-cases as otherwise we would not have given much thought to what a mean score of 23.90 actually represents. This was discussed in Chapter 3 as a common failing in paediatric oncology research. According to recommendations, those scoring above 23 points ought to be viewed as at-risk of having mental health problems. Unfortunately, whether parents scored as cases or not could not be predicted from the current data set. There were no differences in terms of time since diagnosis, treatment status, or any other demographic or medical variable. One reason for this could be due to the small

samples recruited in this study (N = 13 cases vs. 22 normals). Therefore, a future avenue of research would be to explore this finding and identify those variables that do predict poor functioning. In line with this, in study two, the impact that cancers involving the central nervous system (CNS), a disease / disability factor, have on the at-risk levels of maternal depression is assessed.

Parents of children on-treatment perceived their child as being more vulnerable than those off-treatment. Mean scores in the present study were similar to levels of vulnerability in a group of mothers of children with asthma, but higher than healthy controls (Eiser, Vance, & Seamark, 2000). It may be that had we recruited children with a poorer prognosis, vulnerability scores would have been higher. As it is, children with ALL have a relatively good prognosis. With regard to the maternal worries and illness stress scales, the majority of parents scored in the middle range on both scales. It could be argued that since children with ALL tend not to have obvious physical problems (compared to, for example, children with CNS tumours), parents are not likely to endorse issues pertaining to looking different from peers or having difficulty finding a partner - items in the maternal worries scale. They may be more likely to endorse questions regarding continuing medication or relapse, real threats to parents of all cancers. Similarly, the illness scale contains items about other siblings becoming ill etc., issues which may be more applicable to cancers that have genetic links (e.g., retinoblastoma, a cancer of the eye). In fact, when individual items were reviewed on both these measures parents were more likely to endorse questions surrounding aspects of future relapse, the child becoming ill again and the child growing up too quickly. Parents were also worried about overprotecting and spoiling the child, but not especially concerned about the child getting married, looking different or finding a partner. These may not be not issues parents of 6-12 year olds with ALL are particularly concerned about.

6.4.3 Methodological limitations

In earlier chapters methodological problems found in the cancer literature were discussed. These criticisms reflected both poor methodology and practical

considerations. While planning this study these considerations were acknowledged. However, as with all studies, various compromises were made.

First, the sample size was smaller than desired. The ALL cohort for this clinic was 76, consisting of children both on- and off-treatment. Some children attended the clinic regularly, others annually (according to their medical status). Therefore, on occasions when research visits were not possible, a child who attended annually may be missed and the chance of recruiting them in the future was slim, whereas if the child was newly diagnosed the chance of recruiting this child again in the future was high. Failure of families to turn up to their scheduled appointment also limited numbers.

Accordingly, based on Cohen (1992), the sample size needed to conduct adequately powerful analyses was calculated. Setting alpha at $p<0.05$ and power at .80 and a medium effect size, a sample size of 64 is needed for mean differences to be detected. In this study, we obtained a sample size which was adequate to detect large effect sizes (N=26 according to Cohen, 1992). Considering correlations designs, a sample of 85 would be required for medium effects at a power of 0.80. Again, in this study, we obtained a sample large enough to detect large effect sizes (N=28 according to Cohen, 1992). Questions about parent-child relationship will ultimately depend on recruitment of larger samples and involve multi-site collaboration.

Second, mothers usually accompany their child to clinic. However, in this case seven fathers attended. Ideally only mothers or fathers would be recruited as gender differences have been reported elsewhere (Sawyer et al., 1997). However, due to the modest sample size both mother and father data were collapsed into one group. No differences were found between mothers and fathers in this study on all measures, but this must be interpreted with caution considering the small number of fathers involved. Ideally, in future work mothers and fathers should be studied separately.

Third, the GHQ-28 (Goldberg, 1978), although used many times with both healthy and clinical populations, had a limited scope in the present study. Data was positively skewed in all sub-scales. Therefore, for study two the decision was taken to search for an alternative mental health measure, one which has demonstrated more normative data distribution patterns. This will be discussed in the next chapter.

Finally, the directionality of the parent-child regression must be addressed. The child's QOL was chosen as the dependent, or outcome variable, based on much work in the developmental literature that has examined parent-to-child influences (Holden, 1997). Although it is understood that parents do exert a large influence over children, it is equally feasible that children influence their parents. It is probable that the child who is not functioning well after diagnosis will influence their parent to the extent that s/he may become depressed or anxious. Therefore, although this chapter has been written with a parent-to-child focus, it is certainly not intended as the sole direction of influence. Without longitudinal data, these associations cannot be determined causally.

Notwithstanding these shortcomings, the present study showed many strengths. For example the sample was relatively homogeneous, with a small age range and uniformity in diagnosis. The small age range hindered our recruitment chances, but developmentally was a much more important choice. This study gives us a clear insight into the effects of childhood cancer on children with ALL in middle childhood.

6.5 Conclusions

Links between social-ecological factors (parental depression and use of force) and child adaptation (QOL) have been demonstrated, providing evidence for Wallander et al.'s (1989b) model. Together, these factors explained a high proportion of the variance, although these analyses warrant replication due to the small sample size. While a link between disease / disability factors and child adaptation did not emerge, the presence of a new pathway between disease /

disability factors and parental mental health (a social-ecological factor) did. This pathway is a new addition to Wallander et al.'s (1989b) model.

Clearly there is a need for a more thorough assessment of these pathways in larger samples and with other cancer groups. Therefore, the decision was taken to conduct a second study, assessing disease / disability factors, and both social-ecological variables (the family environment and family members' adaptation) in a more rigorous manner using two groups of cancer survivors, those with ALL or tumour of the central nervous system (CNS). Furthermore, in order to examine the differences between self- and proxy-rated child adaptation, both child- and mother-rated QOL reports were obtained (recall only child self-reports were obtained in Study One). However, prior to reporting Study Two, pilot work was undertaken to develop a suitable measure of parenting for use with parents of these survivors. This work is reported in Chapter 7, Study Two is detailed in Chapters 8-10.

CHAPTER SEVEN.

THE DEVELOPMENT OF A GENERIC MEASURE OF PARENTING.

7.1 Development of a generic parenting measure

A large number of parenting questionnaires exist, assessing a wide range of issues from attitudes towards pregnancy, the child, control of children, family problems and expectations of parenting (see Holden & Edwards, 1989, for a review of 83 parenting measures). These measures have generally been criticised for their vagueness, lack of psychometric properties and lack of replication work (Holden & Edwards, 1989). The aim of this chapter was to report the development of a generic measure of parenting suitable for use with parents of children with cancer. The aim was to produce a measure to be used in study two of this thesis (Chapters 8-10).

Holden and Edwards (1989) recommended that researchers develop new valid, reliable measures, focused in their study of parenting, theoretically derived, and acceptable to parents. In response to this, Robinson et al. (1995) developed a measure based on Block's (1965) Child-Rearing Practices Report (CRPR), with its theoretical impetus coming from Baumrind's tripartite typology (see Chapter 4).

Block's (1965) CRPR has been one of the few measures that has been used repeatedly in developmental work (see Chapter 5 where it has been used in cancer research by Davies et al., 1991 and Hillman, 1997). Although it has been popular, mainly due to its extensive coverage of a wide range of parenting issues, various problems exist. These include its (1) length (91-items), (2) design as a Q-sort (which can be confusing to some parents), (3) large number of factors (28 to 33) with low to moderate reliabilities, and (4) outdated items (Robinson et al., 1995).

Based on a sample of 1251 US parents (534 fathers and 717 mothers), Robinson et al. (1995) developed *The Parenting Styles and Dimensions Questionnaire* for use with pre- and school-aged children. Starting with the CRPR, they reduced the scale to 50 items representing three factors, representing Baumrind's tripartite theory: authoritative, authoritarian, and permissive (indulgent, not neglectful) parenting. Items were retained in the analyses if they (1) had a loading near .30 (according to established statistical criterion), (2) they loaded for both mothers

and fathers, and (3) loaded for both parents of pre-school and school-aged children. The resultant sub-scales were:

- *authoritative* (21 items, warmth and support, reasoning / induction, democratic participation, and responsiveness; alpha = 0.89);
- *authoritarian* (17 items, non-reasoning / punitive strategies, corporal punishment, directiveness, and verbal hostility; alpha = 0.84);
- *permissiveness* (12 items, lacking follow-through, ignoring misbehaviour, and lacking self-confidence; alpha = 0.73).

Although this measure was tested widely, demonstrating good psychometric properties with US, Russian and Chinese samples (Hart, Nelson, Robinson, Olsen, & McNeilly-Choque, 1998; Hart et al., in press), there were problems that restricted its usage in this thesis. First, since families taking part in this research were interviewed and completed many additional questionnaires, the measure was considered too long (N=50). Second, although the authoritative and permissive scales were acceptable, a number of items in the authoritarian scale were considered too harsh and punitive for use with a UK sample (e.g., *slaps child when disobedient, grabs child when disobedient, guides child by punishment more than by reason*).

In response to this, an authoritarian scale was extracted from Dekovic et al.'s (1991) questionnaire (also based on the original CRPR; Block, 1965) and used instead of Robinson et al.'s (1995) twelve item authoritarian scale. The three sub-scales making up the scale, *control by guilt, control by anxiety* and *authoritarian control* (total of 11 items), have demonstrated adequate validity and reliability (Dekovic et al., 1991). While the sub-scales do not refer to coercive discipline, they do assess other key authoritarian issues such as being cold, controlling and demanding. Therefore, the final questionnaire consisted of 44 items assessing authoritative (N=21), permissive (N=12) (Robinson et al., 1995), and authoritarian (N=11)(Dekovic et al., 1991) parenting.

However, there are concerns with changing Robinson et al.'s (1995) original scale. First, removing questions regarding physical punishment is removing an important aspect of authoritarianism. However, it was felt that we could not ask parents about their use of physical punishment. Second, by replacing the authoritarian scale, we have interfered with the psychometric properties of the measure. Thus, a pilot study was conducted to check the acceptance and psychometric properties of the scale with a sample of UK parents of healthy school children.

7.2 Pilot Study One: The Parenting Styles and Dimensions Questionnaire: Version 2.

7.2.1 Methodology

7.2.1.1 Procedure

Two local junior schools in the South-West region of England were contacted and asked whether they would be happy for their students to take a questionnaire home for their parents, which they would return directly to the researchers in a free-post envelope. Responses were positive and both agreed to take part.

7.2.1.2 Sample

The questionnaire was sent to 600 mothers of 4-8 year old children. Of these, 123 parents responded (21% response rate; Mean age=6.45 years, SD = 1.08; 55% boys). Parents were given a consent form and a letter explaining that the researchers were developing a questionnaire to assess what it is like to rear a young child. Parents were asked to complete the questionnaire, adding any comments on the questions, and encouraged to highlight any wording they felt was old-fashioned or clumsy.

The items were rated on a 5-point Likert-scale from one (never) to five (almost always), representing how much the parents agreed with each statement.

7.2.2 Results

Three mean scores were derived for each parent: authoritarian, authoritative and permissive.

7.2.2.1 Internal consistency

Cronbach's alpha levels were computed for each scale: authoritative ($\alpha = 0.89$), authoritarian ($\alpha = 0.62$), and permissive ($\alpha = 0.75$).

7.2.2.2 Changes made as a result of the pilot study

(1) Four items were removed since they demonstrated poor item-total reliability or displayed a restricted range of responses.

- 'I believe that a child should be seen and not heard' *(authoritarian scale)*;
- 'I do not allow my child to question my decisions' *(authoritarian scale)*;
- 'I encourage my child to freely express himself even when disagreeing with me' *(authoritative scale);*
- 'I carry out discipline after my child misbehaves' *(permissive scale,* negative scoring)

(2) Four items were changed since the original wording was inappropriate. Even after changes, the items were still considered indicative of the original parenting style.

- 'I believe that scolding and criticism makes a child improve' to 'I believe that criticism makes a child improve' *(authoritarian scale)*;
- 'I teach my child that in one way or another, punishment will find him when he is bad' to ' I teach my child that bad behaviour will always be found out' *(authoritarian scale)*;
- 'I control my child by warning him about the bad things that can happen to him' to 'I control my child by warning that some situations are very dangerous' *(authoritarian scale)*;
- 'I express affection by hugging, kissing and holding my child' to 'I treat my child like a friend' *(authoritative scale)*.

7.2.3 Discussion

Robinson et al.'s (1995) parenting measure was selected, alterations made to the authoritarian scale, and piloted in a postal study of 123 mothers of 4-8 year old children. Although the Cronbach's alpha levels were acceptable, the scale needed additional alterations. Four items were removed since they demonstrated a poor item-total reliability or a restricted range of responses. Four items were reworded due to inappropriate language. The resulting scale included 40 items (20-item authoritative scale; 11-item permissive scale; 9-item authoritarian scale).

Since additional amendments had been made to the scale, the decision was taken to conduct a second pilot study in order to check the psychometric properties and acceptability of the amended version.

7.3 Pilot study two: The Parenting Styles and Dimensions Questionnaire: Version 3.

7.3.1 Methodology

7.3.1.1 Procedure

Considering four items had been changed and four items removed, the measure was sent out to a further 200 parents of 4-12 year olds, in the same schools as used in Pilot Study One, to check the internal validity of the new scale (Version 3).

7.3.1.2 Sample

Of the 200 parents, 55 responded (28% response rate). Mean age of the children was 6.98 years (SD = 2.54), and 53% were boys. Again, parents were given a consent form and a letter explaining the aim of the research. They were also asked to comment on any wording they felt was inappropriate or confusing.

7.3.2. Results

As before, three scores were derived for each parent: authoritarian, authoritative and permissive.

7.3.2.1 Internal consistency

This data showed comparable Cronbach's alpha estimates to the first pilot study, albeit slightly lower: authoritative (α = 0.77), authoritarian (α = 0.62), and permissive (α = 0.62).

7.3.2.2 Changes made as a result of the pilot study

No items were removed or changed in this version since no comments were given regarding confusing or inappropriate wording. Therefore, as these questions were less abrasive and yet remained moderately valid, these changes were retained and this measure used in Study Two.

7.3.3 Discussion

A generic questionnaire measure was identified, amended and piloted in two studies using parents of healthy school-children in the South-West of England. The resultant measure has moderate internally consistency estimates and appears to be appropriate for use with UK parents.

7.4 General Discussion

A questionnaire measure of parenting was developed and piloted on two samples drawn from schools in South-West England. After amendments, the scale demonstrated moderately acceptable levels of internal consistency and was deemed suitable for a British sample. While this measure was phrased in a more up-to-date manner than many other parenting questionnaires, there are still concerns with assessing parenting using such methods. For example, according to written comments, parents discussed using a number of tactics in response to their children's behaviour, or using different tactics in different situations. This subtlety in parent's behaviour is difficult to pick up in questionnaires. Secondly, issues in a generic questionnaire may not address issues of concern to mothers rearing a child

with cancer. Third, it is difficult to assess developmental subtleties using such questionnaire methods.

As a result, while the development of a suitable generic measure of parenting is important and useful for much parenting research, the intricacies involved in parenting a child with cancer remain unresearched. Therefore, in study two involving mothers of children with cancer, the decision was taken to interview mothers and ask them directly about the difficulties involved in rearing a child with cancer in addition to having them complete the newly developed questionnaire. The interview was part of a longer interview aimed at assessing overall mother and child functioning. Qualitative methods are useful in situations such as these, where they help clarify and investigate those topics ill-understood (Murphy, Dingwall, Greatbatch, Parker, & Watson, 1998). Study two is reported over the next three chapters.

Notwithstanding these concerns with the questionnaires, the resultant measure showed promise for use in parenting research. It satisfactorily tapped the three main constructs, was short and easy to administer, and therefore fulfilled our aim of producing a measure for use in Study Two (results presented in Chapter 9). It is also currently being used in a longitudinal research project involving newly diagnosed children and their parents in the Child and Family Research Unit, University of Sheffield. Data is not available at this time. It is hoped that the measure can be further validated and perhaps improved upon in this study.

CHAPTER EIGHT.

STUDY TWO. TESTING THE PATHWAYS BETWEEN DISEASE / DISABILITY FACTORS, SOCIAL-ECOLOGICAL FACTORS AND THE QUALITY OF LIFE OF CHILDREN WHO HAVE SURVIVED ALL OR CNS TUMOURS.

INTRODUCTION AND METHODOLOGY

8.1 Building on Study One

This study adds to study one (Chapter 6) by assessing:

- two groups of childhood cancer survivors: those with acute lymphoblastic leukaemia (ALL) and central nervous system (CNS) tumours;
- the child's QOL from both the child's and the mother's perspective;
- adolescent self-reported body image (BI);
- parenting behaviours using both quantitative and interview methodologies;
- maternal mental health using a specific measure of depression and one of overall well-being.

8.2 Introduction

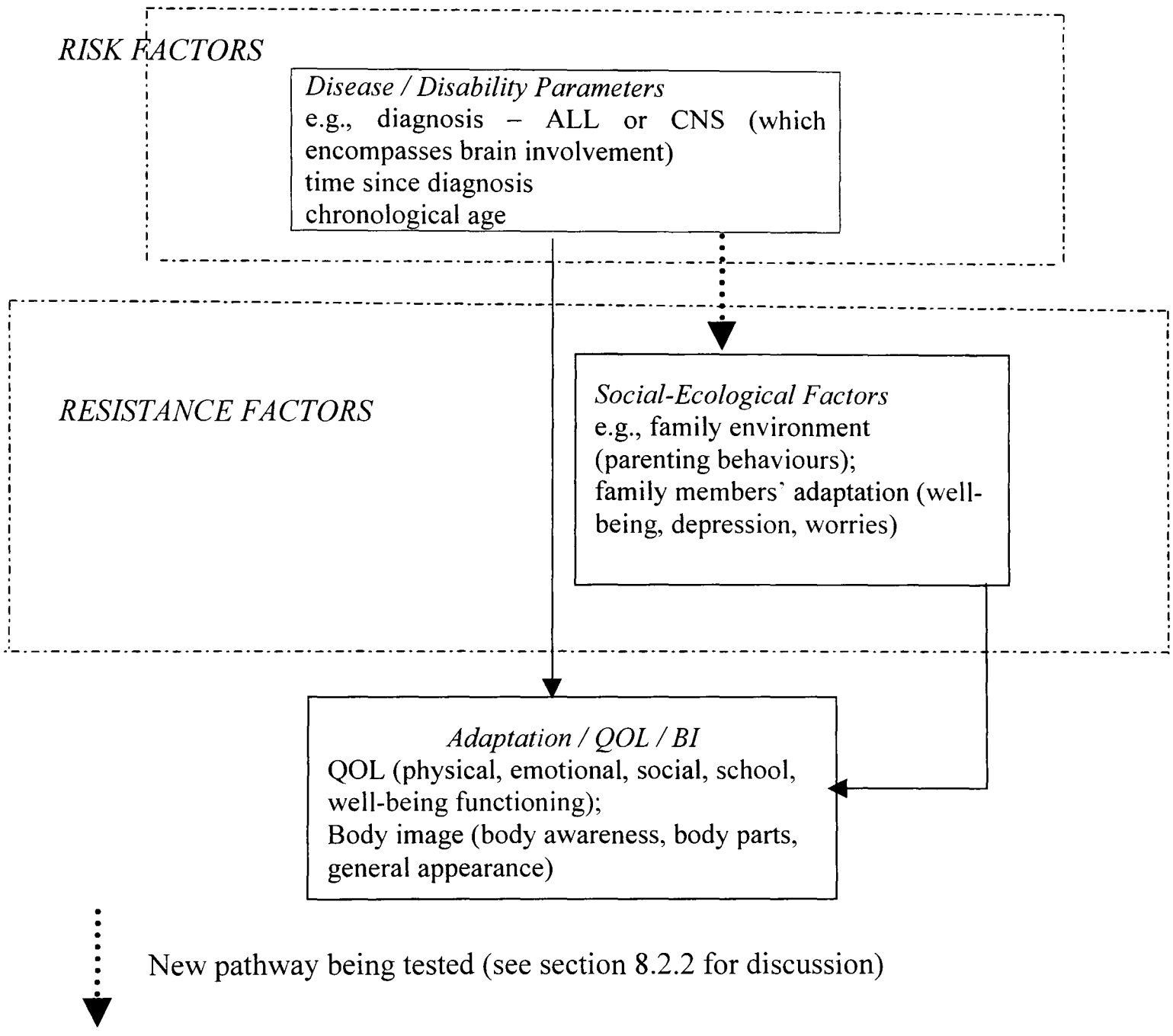
Study two explores the same pathways from Wallander et al.'s (1989b) model as study one, i.e., the relationship between disease / disability factors, social-ecological factors and the child's adaptation (see Chapter 2). Child adaptation was again operationalised as child QOL. A measure of body image (BI) was also included as an additional component of child adaptation. This will be discussed more as the chapter progresses. Please see Figure 8.1 for a diagram of the pathways assessed in the current study.

8.2.1 Disease / Disability Factors

Within study two, two groups of cancer survivors were recruited, those surviving ALL or tumours of the CNS, and their mothers. All children had completed active treatment. Epidemiological data indicate that together, these two groups account for approximately two-thirds of all childhood cancers. While they are both relatively common childhood cancers, they are very different diseases in terms of prognosis, treatment and associated long-term consequences (see Chapter 1). For example, recent statistics indicate that 81% of children survive ALL five years from diagnosis, compared with between 42% and 72% of children with CNS tumours (see Table 1.1). Children with standard risk ALL are treated with a cocktail of chemotherapy drugs, while children with CNS tumours can expect a combination of surgery, chemotherapy and radiotherapy. As a result of both the initial disease and subsequent treatment, these two groups of children can have very different long-term consequences. Due to these differences, a greater

examination of the relationship between disease / disability factors and child QOL was afforded in the current study.

Figure 8.1 Pathways based on Wallander et al.'s (1989b) model assessed in Study Two



CNS tumours are the most common solid tumours and are frequently associated with major neurological, neuroendocrine, and neurocognitive late-effects (Glaser, Kennedy, Punt, & Walker, 1999; Mulhern, 1999). In terms of their psychological functioning, children with CNS tumours are more likely to have poorer QOL (Armstrong et al., 1999), and greater social competence and emotional problems (Kun, Raymond, Mulhern, & Crisco, 1983) than children with cancers not involving the CNS. As discussed in detail in Chapter 2, in comparison with their healthy classmates, children with CNS tumours are rated as more sensitive and

isolated (Noll et al., 1992; Vannatta et al., 1998b). These findings have led to the prediction that survivors of CNS tumours would report poorer QOL than survivors of ALL. If supported this would provide evidence for the pathway between disease / disability factors and child adaptation (Wallander et al., 1989b).

Also discussed in Chapter 2 was the topic of body image. Body image (BI) is a relatively under-researched area within the paediatric oncology literature, and where it has been conducted, children with CNS tumours have routinely been excluded (cf: Pendley et al., 1997). However, due to the extensive treatment that these children would have had, it is expected that they will have considerable visual side-effects that would have a detrimental effect on their BI. For example, scarring from surgery, patchy hair growth due to radiotherapy and increased weight due to steroid usage (see Chapter 1). It is unlikely that children who have been treated for ALL would have as many residual problems. For these reasons, it was hypothesised that survivors of CNS tumours would self-report poorer BI than survivors of ALL. Due to age restrictions of the questionnaire used (see section 8.3.3.2), only adolescents (13 years and older) completed the measure. However, considering the literature presented in Chapter 2, it appears that adolescents suffer from greater BI problems than younger children with cancer. Adolescence is a period of great physical change, during a time where image and physical appearance are given a lot of attention. Therefore, while the measure used in the current study excluded younger children, current literature suggests that adolescents are more affected by BI concerns that can occur as a result of the illness.

Within this study, the decision was taken to obtain, and report, both child self-report and mother proxy-rated QOL data. As discussed earlier in Chapter 2, there has been considerable debate over who should report on a particular child's functioning, the child or a proxy (for example a parent, teacher or doctor). While working with children requires much measurement consideration in terms of cognitive load, ease of wording and appropriateness of questions, not to mention issues of consent, current movements towards obtaining child self-reports wherever possible (cf: Department of Health, 2000) led to the decision to obtain

both child and proxy data in this study. Therefore, considering the discussion provided previously concerning the differences between ALL and CNS tumours, the same hypotheses were presented with regard to proxy respondents, i.e., mothers of survivors of CNS tumours would report their child as having poorer QOL than mothers of survivors of ALL. It was further predicted that both survivor and mother proxy-rated QOL scores would be lower than published norms for healthy children. Finally, drawing on literature showing that mothers generally report that illness has more negative consequences for their child's QOL than the children themselves (Bruil, 1999; Ennett et al., 1991; Sawyer, Antoniou, Toogood, & Rice, 1999), it was hypothesised that mothers would report poorer QOL than their children self-report.

Contrary to results obtained in study one, Varni and colleagues (1998, 1999) provided evidence that QOL improves when children complete active treatment. One possible explanation given for the lack of QOL change in study one was that after children complete their acute treatment phase, QOL does not alter significantly. Therefore, using a larger sample of childhood cancer survivors in this study, it was hypothesised that QOL would **not** change as a function of time since diagnosis since all children were past the acute treatment phase.

The final disease / disability variable assessed in relation to child QOL was that of the child's chronological age. While in study one the age-range was very modest (6-12 years), in study two the range was considerably larger (8-21 years). While no specific hypotheses were set at this stage, the relationship between child's chronological age and QOL (child and proxy reported) was explored in detail by assessing both (1) ordinal effects, i.e. children (8-12 years) and adolescents (>13 years old) separately, and (2) linear effects, i.e. age as a continuous variable from 8- to 21-years old. Considering the developmental discussion provided in Chapter 2 (section 2.2), it follows that the QOL of survivors of different ages will be affected in different ways. For example, a younger child may be affected by not being present during the transition to high school, which may result in failure to meet and make new friends. Alternatively, the older adolescent, who may normally be thinking of leaving home, developing deeper relationships, and

embarking on a university career, may be forced to spend this time in hospital with family. Therefore, the effect that age may have on the various QOL sub-scales was explored in this study. The effect of age as a continuous variable was assessed in relation to BI (recall only adolescents completed this measure), with no specific hypotheses given at this stage given the paucity of research in this area, especially with survivors of CNS tumours.

8.2.2 Social-environmental factors

As in study one, the family environment (Wallander et al., 1989b) was operationalised in terms of parenting behaviours. Building on the last study, however, parenting was assessed in a much more detailed manner. Specifically, authoritative, authoritarian and permissive parenting types (Maccoby & Martin, 1983; Chapter 4) were assessed in a generic questionnaire (developed in Chapter 7), while warmth, psychological autonomy and behavioural control (Gray & Steinberg, 1999; Steinberg et al., 1989; Chapter 4) were assessed using a semi-structured interview format (to be discussed fully in section 8.3.3.1).

Based on previous literature it was expected that parents who scored highly in the optimal aspects of parenting, i.e. authoritative (questionnaire), warmth and psychological autonomy (interview) would have children with higher QOL (Gray & Steinberg, 1999; Steinberg et al., 1994) than parents who scored highly in the less optimal authoritarian or permissive scales. Please see Chapter 4 for a review of this literature.

The predictions surrounding behavioural control are more complicated however. Whereas recent developmental work has shown the benefits of **moderate** levels of behavioural control on adolescent outcomes, including academic self-image, school grades (Gray & Steinberg, 1999) and incidence of self-regulating problems (Kurdek & Fine, 1994), there is evidence to suggest that **high** levels of control are necessary in the context of chronic illness. For example, previous work has shown that in the context of diabetes, parents who are more organised have adolescent with better treatment ahderence (Shouval, Aber, Galatzer, 1982). Furthermore, Wertleib, Hauser and Jacobsen (1986) discussed that whereas a family's emphasis

upon high control, rules and limits may spark behavioural problems in non-diabetic individuals, families of children with diabetes may need to orient differently since control is needed to organise a demanding medical routine and treatment regimen. It seems that the demands of daily medication and attention to symptoms require a degree of control that may not be necessary for healthy children. Given the clinical needs of this group, behavioural control may ensure the child's safety and make them feel secure. These results led to the prediction that children who were functioning poorly, i.e., poorer QOL, therefore needing more structure and stability than "normal' healthy children, would have mothers who reported higher levels of behavioural control.

The second social-ecological factor tested in study two was that of maternal mental health, used to represent family members' adaptation (Wallander et al., 1989b). As discussed in Chapter 6, there were concerns with the GHQ-28 (Goldberg, 1978) used in study one. Many of the items discussed suicidal ideations, as opposed to general feelings of sadness, and many parents appeared uncomfortable when completing it. Therefore, in trying to improve upon the assessment of mental health, two different measures were employed in study two: one measuring depression, the second assessing general well-being. The Maternal Worry Scale (DeVet & Ireys, 1998) was used again in study two. The decision was taken not to include the vulnerability or stress scales used in study one due to time constraints placed upon the study.

While this does not appear to have been studied in previous cancer research, considering the long-term physical and psychological late-effects associated with CNS tumours, it was hypothesised that mothers of survivors of CNS tumours would self-report poorer mental health and worry more about their children than mothers of ALL survivors. Furthermore, given the presence of these late-effects, the hypothesis was tested that more mothers of children with CNS tumours would score 'at-risk' levels of depression and have poorer well-being than population norms. If these predictions are confirmed, it would provide support for an association between disease / disability factors and maternal mental health, a

pathway not previously present in Wallander et al.'s (1989b) model (see Figure 8.1), but confirmed in study one.

As discussed in Chapter 3 (section 3.3.2), even years after the completion of cancer treatment, parental functioning still significantly effects child adaptation. For example, relationships have been demonstrated between educational needs, parental functioning (Kazak & Meadows, 1989) and child behaviour (Newby et al., 2000), parental coping and child behaviour (Overholser & Fritz, 1990; Sloper et al., 1994) and child QOL during treatment and subsequent parent and child adjustment (Kazak & Barakat, 1997). Therefore, considering this literature, and the results of study one where maternal depression was a predictor of poorer child QOL, it was hypothesised that mothers with poorer mental health and increased levels of worry about their children would have children with poorer QOL (both proxy- and self-reported).

8.3 Methodology

8.3.1 Procedure

Study procedures were reviewed and approved by the relevant ethics board. Children were eligible for the study if they were between eight- and 21-years old, had an initial diagnosis of ALL or a CNS tumour, were disease-free and had completed treatment at least two years ago. The term 'survivor' is used throughout to refer to these children. This age-range was chosen as it encompassed all children still monitored in the paediatric unit who were survivors.

Mothers[1] and survivors who were eligible for the study were approached by the clinic nurse during a routine appointment, told about the study and given information sheets and consent forms. Those who agreed to participate gave their contact details, which were passed on to the research team. The family were visited at home, with the mother being interviewed first to establish rapport and gain an understanding of the child's illness knowledge. While children were

[1] Throughout, 'mothers' are referred to. Only one father completed both interview and questionnaire.

interviewed, mothers completed the questionnaire battery. Children completed their questionnaires with the researcher. Children (8-12 years) were given different questionnaires from those in their teens (+13 years; see below).

8.3.2 Sample

Two hundred and eighty four families were identified through hospital records. Of these, seven had died, eight had relapsed, 13 had severe learning disabilities, 71 were not approached or were currently being followed-up in satellite clinics so could not be recruited, and 60 had moved house and could not be located. Therefore, 159 (56%) were considered lost to the study.

Of the possible 125 families, 25 refused (reasons: *lack of time, done a similar study, wants to get on with life,* and *doesn't like talking about the illness).* The remaining 100 families accepted and were contacted by the research team.

Of the 100 families, two children relapsed between recruitment and scheduling a visit, three refused once contacted (*lack of time* or *disinterest in the study),* ten families could not be reached by telephone or letter (despite numerous attempts and revisiting the hospital records for updated records), and one family was excluded owing to their high level of distress during the visit. This left 84 families eligible for the study (67.2% of the original 'recruitable' sample of 125 families).

Missing Questionnaire data

Of the 84 families (N=53 ALL; N=31 CNS), two survivors of ALL and five survivors of CNS tumours failed to complete their questionnaire owing to major cognitive impairments. Six mothers of survivors of ALL and three mothers of survivors of CNS did not complete theirs. Although mothers were asked to complete the questionnaires in the presence of the researcher, a number requested to complete them and send them back in the post. Lack of response accounted for maternal missing data.

The final sample therefore included 77 survivors of childhood cancer and 75 mothers (see Table 8.1.1 for survivor details and 8.1.2 for mother details).

Missing Interview data

Interviews with mothers of 45 survivors of ALL and 23 survivors of CNS tumours were conducted. Interview data was not available for three mothers of survivors of ALL and four mothers of survivors of CNS tumours (faulty tapes, N=3; did not speak English, N=1; not available N=2; refused to be taped, N=1).

Table 8.1.1 Sample characteristics - Survivors

	ALL (N=51; 20 male)	***CNS (N=26; 13 male)***
	M(SD) range	M(SD) range
Child's age (yrs)	13.75 (3.19) 9-21	13.65 (3.01) 8-19
Age at diagnosis (yrs)	4.28 (2.43) 0.17- 12.76	7.61 (2.79) 3.76 – 13.30
Time since diagnosis (yrs)	9.94 (3.38) 4.15 – 17.76	6.86 (2.47) 2.85 – 12.58

Table 8.1.2 Sample characteristics - Mothers

	ALL (N=47)		***CNS (N=28)***	
	M(SD) range	% (N)	M(SD) range	%(N)
Mother's age (yrs)	42.23 (6.15) 30-58		40.19 (4.34) 32 – 50	
Age left education*				
16 or under		35 (18)		46 (12)
17 or over		32 (16)		27 (7)
Marital status**				
Cohabiting		73 (37)		77 (20)
Other (inc. single / divorced)		10 (5)		15 (4)

*13 mothers of survivors of ALL and 9 mothers of survivors of CNS tumours did not complete this question.

** 5 mothers of survivors of ALL and 4 mothers of survivors of CNS tumours did not complete this question.

8.3.3 Measures

All interview schedules and questionnaire measures used in study two can be found in Appendices 4-6.

8.3.3.1 Maternal Interviews

Interviews were semi-structured and lasted 1–2 hours. The interview followed a set of pre-designed themes, including the child's education, physical functioning, body image and family relationships. These themes were selected on the basis of clinical and research experience with survivors of childhood cancer (Eiser, 1998). Due to the semi-structured nature of the interview, mothers were given the freedom to discuss issues of importance to them, issues not necessarily on the schedule. The full maternal interview is given in Appendix 4. Each interview was taped and later transcribed by a trained secretary. These verbatim interviews served as the raw data for the interview analysis.

Mothers were asked to talk about their thoughts and feelings about the child's functioning now. The period leading up to, and following, the diagnosis was *not* discussed, as the central aim was to investigate how mothers felt *after* completion of treatment. While mothers were told that the interview was focused on the present, it was natural that discussion about the past would arise. These issues were not coded. By talking about the present and recent past, the threat of retrospective reliability is not such an issue. Regardless, although memories can be inaccurate, they can represent the interviewee's personal reality (Koocher & O'Malley, 1981).

8.3.3.2 Questionnaire Measures

Child completed (8-12 year olds)

Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999)

This 30-item generic measure assesses five domains of functioning: physical (8 items), emotional (5 items), social (5 items), school (5 items), and well-being (6 items), plus one item assessing the respondent's overall impression of their health status. All items are summed to produce an overall QOL score. After

transformation, scores range from 0-100, with higher scores representing better QOL. The PedsQL includes a child (8-12 year olds) and adolescent form (>13 years old). Internal consistency estimates for patient (child and adolescent responses combined) reports are acceptable ($\alpha = 0.83$; Varni et al., 1999).

This QOL scale was developed by the same authors as the PCQL-32 cancer-specific measure used in study one (Varni et al., 1998). The decision was taken to use this newer generic measure in the present study for two reasons. First, some items in the PCQL-32 were not completely acceptable, for example asking children how they feel about relapse. The generic measure does not ask such sensitive questions. Second, as part of the project that the author was employed on, a third group of children without cancer were recruited as a control group, hence a cancer-specific measure would not have been suitable. While this data was not intended for use in this thesis, it precluded using a cancer-specific measure.

Teen completed (>13-years old)

Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999)

This form is identical to that above, except that the word 'kids' is substituted by 'teen'.

Body Image Instrument (BII; Kopel, Eiser, Cool, Grimer, & Carter, 1998)

This 19-item revised questionnaire was developed to assess body image concerns in survivors of childhood cancer. The measure consisted of three sub-scales: general appearance (7 items), body awareness (8 items) and body parts (4 items). Published internal consistency estimates are acceptable (αs from 0.68 to 0.85). Items were scored on a 5-point Likert scale from 1 (poor BI) to 5 (good BI).

Parent completed

Pediatric Quality of Life Inventory (PedsQL; Varni et al., 1999)

A comparable version of the PedsQL measure was completed by parents in order to obtain a proxy rating. Internal consistency estimates are acceptable ($\alpha = 0.86$; Varni et al., 1999).

Parenting Styles and Dimensions Version 3. (Dekovic, Janssens, & Gerris, 1991; Robinson, Mandleco, Olsen, & Hart, 1995)

This 40-item questionnaire assessed authoritative, authoritarian and permissive parenting, and was developed for this study (see Chapter 7).

Items are scored from 1 (never) to 5 (almost always), with higher scores indicating greater endorsement of a particular parenting type. Parents derived a score for each of the three parenting types. In previous work with healthy children (Chapter 7), Cronbach's alpha estimates were acceptable (α = 0.62 to 0.77).

Maternal worry scale (DeVet & Ireys, 1998)

This scale was described and used in study one. This measure was retained in study two since it includes issues pertinent to parents of survivors of cancer as they approach adulthood, such as finding a boy / girlfriend or getting married.

The Short-form 36 (SF36; Jenkinson, Layte, Wright, & Coulter, 1996)

The SF36 is a measure of overall functional capacity and general health, or well-being. It is a well-validated tool and used extensively in psychological and medical work. This measure was included to give an overall impression of the mother's well-being, rather than focusing on one specific aspect of mental health.

The measure assesses eight aspects of functioning, covering physical function, role limitations due to physical problems, role limitations due to emotional problems, social functioning, mental health, energy/vitality, pain and general health perception. Additionally, there is one item assessing the respondents health compared to the previous year. Scores are transformed into percentages, with higher scores representing better functioning. Internal consistency estimates for each of the eight sub-scales are adequate (α = 0.70-0.90; Jenkinson et al., 1996). The scale also has demonstrated content, criterion and construct validity (Jenkinson et al., 1996).

Center for Epidemiologic Studies Depression (CES-D; Radloff, 1977))

The 20-item CES-D scale measures depressive affect, positive affect, interpersonal relations and somatomotor concerns, and has been used in many studies of adult and child cancer patients (Hann, Winter, & Jacobsen, 1999; Nelson, Miles, Reed, Davis, & Cooper, 1994). The scale has shown adequate internal consistency ($\alpha > 0.85$), test-retest reliability and construct validity (Hann et al., 1999). All items are summed to obtain a total depression score. Symptoms / feelings are presented and respondents choose how often they have felt like that in the past week, from none (less than one day) to most/all (5-7 days). Overall scores range from 0 – 60, with a cut-off score of 16 indicating at-risk levels of depressive symptomatology. Again, utilising cut-off scores enables intra-class analyses of the data.

8.3.4 Coding of maternal interviews

As this was an exploratory study, various decisions were taken about the most appropriate type of analysis. A grounded-theory, or bottom-up, approach (Strauss & Corbin, 1990), was ruled out due to the large number of mothers involved (N=68). This type of analysis would have been impossible given the time constraints placed upon the overall study. Also, considering the wealth of published parenting literature, it was considered inefficient not to utilise the strengths of that research in guiding the current work (see Chapter 4). Therefore, it was decided to analyse the interviews in a top-down manner, according to existing parenting theories. Specifically, directions were taken from a number of key sources: Baumrind (1971), Gray & Steinberg (1999), Maccoby & Martin (1983), and Steinberg et al. (1989). These sources are reviewed in Chapter 4.

Coding these interviews according to existing parenting theories was considered a positive methodological move for the following reasons:

- it allows an analysis of the range of views discussed by mothers, the ways in which they cope with their parenting stresses, and how they interact with their child in coping with their illness;
- it allows an assessment of the extent to which existing parenting theories developed for use with healthy populations capture the issues discussed by mothers of children with cancer. This will allow an assessment of the

applicability of this theory for use with minority samples (cf: the criticisms of parenting theories for use with ethnic minority groups in Chapter 4, e.g., Deater-Deckard et al., 1996), and to discuss those issues raised by mothers which are not captured by the mainstream theories;

- Following a technique developed by Pettit, Bates and Dodge (1997), the theoretically-driven excerpts identified can be quantified and weighted, with mothers receiving scores in each category. Therefore, a direct comparison of the parenting scores and the child's QOL can be made.

Applying a theoretical framework

All coding was conducted by the author. The coding of each transcript was conducted in three steps. First, based upon the empirical work of Steinberg and colleagues, excerpts that corresponded to the three parenting dimensions, warmth, psychological autonomy and behavioural control were identified. As discussed in Chapter 4, Steinberg and colleagues (Gray & Steinberg, 1999; Steinberg et al., 1984) 'unpacked' Maccoby and Martin's (1983) two-dimensional *control-acceptance* concept. Steinberg et al. changed this 2D theory by dividing *control* into two components, psychological autonomy (the reverse of psychological control) and behavioural control. While this is not a new distinction (cf: Barber, Olsen, & Shagle, 1994; Schaefer, 1965), very little empirical research has focused on the differential effects of both types of control (Gray & Steinberg, 1999). Previous research had highlighted the confusing and inconsistent findings yielded by assessing a unidimensional construct of control (Barber et al., 1994).

According to Gray and Steinberg (1999) *"the items composing these three dimensions cover a variety of topics"* (p. 578, emphasis added). Since the parenting behaviours were relatively broad and could cover an extensive range of topics, the second stage of the coding was to select individual sub-components, representing each core dimension, which would guide the interview analysis in a more focused way. In order to capture the essence of each parenting dimension, key parenting articles were reviewed (Baumrind, 1971; Gray & Steinberg, 1999; Maccoby & Martin, 1983). The three dimensions and their sub-components are discussed below.

According to Gray and Steinberg (1999) excerpts indicating that the parent is *"loving, responsive, and involved"* (p. 577, emphasis added) with the child represent parental **warmth**. These sub-components were echoed in the other key parenting articles.

Psychological autonomy refers to non-coercive discipline, allowing the child to express themselves in the family (Gray & Steinberg, 1999), and encouraging bi-directional, open communication (Baumrind, 1971; Maccoby & Martin, 1983). Therefore, excerpts which represented these sub-components were coded as representing psychological autonomy. In the present study, communication generally referred to illness-related issues, such as how often the parent and child discussed the illness, how much the child knew about their illness, and so on.

Behavioural control includes issues of parental monitoring, limit setting (Gray & Steinberg, 1999) and encouraging age-appropriate, mature behaviour from the child (Maccoby & Martin, 1983). Therefore, in the following analysis, excerpts representing setting rules and limits on the child's behaviour, encouraging the child to attain age-appropriate behavioural goals and monitoring the child's behaviours, were coded as representing behavioural control. Table 8.2 summarises both the dimensions and their sub-components.

Table 8.2 Coding framework for mother interviews derived from key parenting texts

1	**Warmth**	• Involvement • Responsiveness • Description of relationship / loving
2	**Psychological autonomy**	• Open, bi-directional communication • Encouraging expression of individuality / opinions • Induction / reasoning (noncoercive discipline)
3	**Behavioural control**	• Limit setting • Maturity demands • Monitoring

The third step of the coding process, driven by Pettit et al. (1997), involved 'weighting' each excerpt. In Pettit et al.'s study of authoritative parenting, parents were asked to describe their children's exposure to peers which were later summarised by the interviewer on a 5-point Likert scale.

In the current study, a similar weighting procedure was conducted. Instead of a 5-point scale which was considered too detailed, a 3-point Likert scale was used. An excerpt received three points if it was viewed as being a high or positive example of the parenting dimension, for example *"we are extremely close"* (Dimension *warmth:* Sub-component: *Description of relationship / loving).* Neutral or moderate excerpts were assigned two points, for example, *"we are fairly close".* Negative or low excerpts were assigned one point, for example *"our relationship has become strained and we are drifting apart".* Scores for each dimension and sub-component were calculated according to this system. Where mothers reported more than one excerpt for a parenting dimension, a total score was calculated based on the number and weighting of each excerpt. A score was intended to represent the apparent strength of the variable as indicated by the number of references made to the parenting dimension and the intensity of each reference (Weiss & Richards, 1997).

Inter-rater reliability

A random selection of 17 interviews was read by a second researcher (25%), who was familiar with the parenting theory, coding, and weighting procedure. Reliability of coding was 83%. Discrepancies were resolved through further discussion.

In Chapter 9, the results from both the interview and quantitative analyses will be presented, before being discussed in Chapter 10.

CHAPTER NINE. STUDY TWO RESULTS – INTERVIEW AND QUANTITATIVE

SECTION I. INTERVIEW ANALYSIS

9.1 Treatment of data

A paper copy of each transcript was read through a number of times until it was familiar. Excerpts which represented the parenting dimensions were pencilled in the margin, with the sub-component also noted (e.g., warmth; loving). After this, using a word document version of the transcript, each excerpt was 'copied and pasted' into a separate table (See Appendix 7). At this stage, each excerpt within the table was read and weighted (given a score of 1, 2, or 3). These data were then entered into SPSS and means calculated for each dimension and sub-component.

The second section of the interview analysis results presents (1) the breadth and range of maternal excerpts and (2) the extent to which this normal parenting framework captured the essence of parenting a child with cancer.

9.2 Results: Discussion of Parenting dimensions

In order to display the breadth and range of coded maternal responses it was decided to present an example of each of the weightings (high, medium, low) for each sub-component within each of the three dimensions (please refer to Table 8.2). After each example the child's identification number is given in parenthesis in addition to the weighting (high, medium or low) assigned to each quote.

9.2.1 Warmth

Most of the mother-child relationships were at least moderately warm. This lack of variance is not surprising given the self-selecting bias involved in work such as this. It may be expected that mothers who had a poor relationship with their child would be less willing to participate in a study aimed at improving childhood cancer care. Alternatively, mothers may not present themselves in a way other than warm, even if this is different from their 'real' behaviour. However, despite the restricted range, interesting themes did emerge.

Involvement

Many mothers discussed their involvement with the child's schooling, especially where the child was not performing well academically. For example, they discussed their determination in getting the child official help (either in the form of statementing, extra help or moving to a special school). Many talked emphatically about how important it was to get their child adequate help, sometimes having to fight against the school system.

But I will battle away to make sure that I get him some help. And there's already a woman in the school who does help with reading and things like that, who's got an excellent reputation and R responds very well to her. So I'm hoping that I'll be able to get her to help.....I worked to send her [sister] to private school, so the plan is that he will then get that opportunity to go to a smaller school with smaller classes .... and get more individual attention (RS 76, ***high****)*

After leaving school, many mothers were involved with the child's future educational plans, attending college open days, requesting college prospectuses, or even organising work directly for the child.

I like to encourage her to work. She used to work in the bingo hall at Selby Bridge, but that was evenings, which I didn't think was good for her, because she wanted to stay in bed because she was bored all through the day. So I had a word with them ....I asked the manager there if anything came up for days would they consider giving H the job ....so we got her a job.(HM69, ***high****)*

He was interested in radio and I got him in Bradford BCB [radio station], *and he went there and they thought he was smashing. (SC38,* ***high****)*

Activities in which the mother and child were involved in together were also discussed. These included, for example, shopping, going to dance classes together, joining a gym or attending sport matches together.

I enjoy her company, she's very perceptive. We share a lot of interests in English literature, reading, drama, theatre, cinema, this sort of thing, and we enjoy those things together, sharing them. (KA44, ***high****)*

I would say sometimes he throws himself into more things than the other children on the street with a similar age. But I think that's probably the way me and his

dad are as well, because we'll go out and we'll play with him at football and what-have-you. (DJ18, ***moderate****)*

Except for one father (he appeared during the interview now and again, but the mother was the main respondent), no one scored as having low involvement with their child. (This excerpt was not coded since the mother was the main respondent, but it serves to illustrate the low involvement.) This one father was asked if he was an involved father.

It depends what you call involved. I'm not a hands-on father, I'm not a go-out-and-play-tennis-with-the-kids sort of father, I'm not a digging sandcastles and ..... I'm not that sort of father. (RJ79, ***low****)*

Responsiveness

Many mothers also talked about the need to boost their child's self-confidence, or be responsive to their child's low points, or frailties. For example, many discussed the lengths they would go to increase their child's self-esteem.

She has whatever she wants done to her hair, we go and peruse the make-up in town and buy things that flatter her, try and advise her. 'But that's not fashionable'. 'Yes, but we can make it if we put it with so and so, and you wear this with it'. (SK60, ***high****)*

If he started doing some exercises to tighten his stomach up he might be more inclined to do it. But we got him some dumb bells, didn't we, and he has a go with dumb bells. He's got some muscles now. (SC38, ***moderate****)*

An issue discussed by many mothers was the need for their child to get counselling or psychologist. This responsiveness to their child's needs was apparent in a number of scripts.

I'd been in school yet again at another meeting with the teachers because of J's behaviour and I said about the counselling side, that J needed counselling, and they said, 'shall we arrange for a visit to psychiatrist?' So I said, yes, please....J definitely needed counselling.(JB51, ***high****)*

There were other, negative ways that parents responded to their child's difficulties, representing the *low* codings. For example, one mother teased her

child for having no friends as a result of the illness. Another mother resorted to name-calling in response to her child's weight gain.

there was a phase when he didn't have any mates and we used to tease him and call him 'Billy-no-mates'! (DI49, ***low)***

I call him chunk...And he'll mess about with his stomach - shuffle, shuffle. Sometimes I'll say, 'get upstairs, chunk,'...It depends what mood he's in. You've seen his fat face anyway. But it doesn't bother him at times, but sometimes it does. (LC106, ***low)***

Description of relationship / loving

A number of parents described how close they were to their children, some feeling that the illness had brought them closer together, it had made them more aware of how precious their child is.

I loved her, I've always loved her. Every mother loves her children, but with F.... We were very close, that's what I'm saying, and it just made me closer to her. It made me realise how much I love her and how thankful .. you should never take anything for granted in life, people you love or anything. I love her and I just think that every day, that thought is always there. To me she's extra precious. (FP25, ***high)***

I think we're fairly close (AL22, ***moderate)***

A number of parents, however, felt their relationship was becoming strained with the onset of the teenage years. Arguing was becoming more common, and the parent and child were spending less and less time together.

At this age they only want you when <u>they</u> want you, don't they, it's not when you want them. But, yes, we were closer after she was poorly, but that's dwindling now.(NB03, ***low)***

9.2.2 Psychological autonomy

Within this section, the following sub-components were coded: *communication, encouragement of the child's opinions and expressions within the family* and *induction (non-coercive) discipline* (See Table 8.2).

Communication

Due to the nature of the interview, most mothers discussed illness communication since this was more pertinent to the overall discussion. Many parents felt that it was important to be open about the illness, encouraging bi-directional communication. They discussed how their child is present at every meeting and is consulted about every treatment decision made.

We haven't not told her anything. We've told her all that we know about it. So, yes, we think it's better to tell her, rather than just say, 'oh, it's nothing, we'll tell you another time'. So everything we know we've told her. (MB96, ***high****)*

Some parents did not talk much about the illness.

Q: do you talk quite regularly about the illness?
We don't actually talk, but if it comes up in conversation we get talking and both the children have come out with leukaemia without thinking about it. (AS32, ***moderate)***

Some children due to their young age at diagnosis, had very few memories about the illness and treatment. A number of parents described how important it was to try and communicate about this time with their child, despite the emotional upset it may still cause.

Q: Have you talked about it since [child was ill]*?*
Yes, quite a lot. Because she doesn't remember it, it's like she wants to know why, where and how, because she doesn't remember it at all. I think it's difficult for her to sort it out in her own head.. (KT65, ***high****)*

Alternatively, some mothers do not want the child to be involved with treatment decisions and exclude the child from these.

I think we actually said to the doctor that we didn't want him telling him how serious it was. We actually said that. (ME64, ***low****)*

Expression of opinions

The essence of this category was encouraging the child to develop their own mind and opinions, and learning to make their own decisions. This category was one of the most varied. Many mothers talked about how they tried to encourage their child to express their opinions about education:

Q: What do you think will happen to her when she leaves school?
Well, she's no idea and I've no idea...What she wants to do is up to her really, so long as she doesn't do nothing. You can only encourage and hope, you can't plan for them. (KJ58, ***moderate****)*

about social activities :

I don't discourage him – if he wanted to do it, I would encourage him to do it. I mean, we follow rugby quite closely. we're very much involved in it and the club that I work for, they do summer schools and they have a week of rugby training and they're messing about with the players, doing daft things, and he always goes on those (MC46, ***moderate****)*

about treatment decisions:

she'd sort of said to me, 'I don't want to get any taller now, mum, I'm tall enough. Do I really need to take this [hormone replacement therapy] *anymore?' I said the only way to find out is to ask, so we sat and asked Dr B, and Dr B actually said to her, 'well, you've got to the height now, K, that we sort of predicted for you. How do you feel?' and she said, 'well, I'd like to stop it'.. So he said halve the dose for 2 weeks, then halve it again for another 2 weeks, then stop, then to come back and they'd do the tests and see how she's getting on. So that's what we did. She was quite pleased with herself. (KT65,* ***high****)*

One comment she's made to me is that even when she's older she will take herself to the hospital once a year for blood tests. Whether she sticks to that, I don't know – she could go a few years and think, oh, I'm fine now,' and not bother. But I hope to think she will go once a year, like they would want her to. But, again, that's up to her, I think (HW73, ***moderate****)*

In contrast, some mothers did not encourage their child's independence of mind. For example, one mother was asked if her child had been on an organised holiday weekend organised by the hospital:

She has, but she's never been.....In fact, I don't ask her now. We still get them and, to be honest, I don't ask her because I know she'll say no. (LP66, ***low****)*

Induction

A number of mothers discussed their use of reasoning when their child was upset, demanding or refusing to listen. Some excerpts described trying to calm the child

down and explain the value of illness treatments, whereas others involved teenage tantrums.

She gets in bad tempers and she'll have fallen out with her friends at school and things like that, and she'll come home and she'll take it out on us. It's like, 'I hate you and I hate this family,'....and we'll get slam, slam, slam, and she'll toddle off upstairs. So I just leave her....Then about half an hour later I'll go up with a cup of tea...' and then she'll sit and she'll maybe have a little cry and I'll say, 'you've got to learn to ignore it, because by retaliating it just makes it worse'. But it's very difficult. But we get on really well, me and K, we do talk and I do try and talk to her about it. (KT65, ***high)***

But she'll come home and do her homework as soon as she comes in, and there's no 'oh, I can't do it,' and getting upset about it. If she can't do it I've said to her leave it and go and see that teacher tomorrow and ask them to go through it with you. She seems to have got over that. (LW91, ***moderate)***

Some mothers scored in the low end of the spectrum, due to their threatening, non-reasoned, manner with their child.

I'll say, 'come on, you've got to get to school,' that same old story, 'you'll get sent to prison if you don't go to school' (RS76, ***low)***

Others just left their child to their own devices and did not attempt to help their child make decisions. For example, one mother's reaction to her child's poor behaviour and academic attainments in school was:

I just say please yourself and do what you want. (CM57, ***low)***

9.2.3 Behavioural control

This dimensions consisted of the following sub-components: *limit setting, maturity demands, and monitoring.* Of the three dimensions, this was the richest in variety and breadth of issues.

Limit setting

Within this section, many mothers talked about their child's eating habits. Many children become difficult eaters as a result of their past treatment. Mothers react differently to this – some prepare the child anything they want to (low control),

whereas others set limits, instructing the child that they must eat what is prepared for them (high control). Most mothers try to accommodate their child's food preferences, showing a moderate degree of limit setting.

I cook a meal for everybody and I've told her that if she doesn't like it, then she'll have to go without because there's nothing else there to eat. ...It's the only way to get around it. (NH14, ***high****)*

He doesn't like my cooking.
Q: So what do you do?
Give him whatever he wants. No, we do insist they sit down to a meal on a Sunday. (MH15, ***moderate****)*

As a result of the child's illness, many mothers have been forced to set limits on the child's sporting or physical activities. For example, one mother of a CNS survivor discussed how the child wanted to continue riding his bike, despite poor co-ordination and limited sight. Rather than refusing the child's request, the mother decided on a set of rules that the child must obey, for example, only riding on their own property, wearing a helmet, when one parent is in attendance.

That's the good thing about being here, he can shoot round the back and stuff. But he can't see behind him, so if he had to look behind him he'd have to turn his head right round.... but we won't let him go on the roads. But he does ride round up here (MH15, ***moderate****)*

Another mother was very strict in terms of sporting activities:

she was asking for roller blades....and basically I just put my put down and I said, 'no. I'm not having any roller blades, full stop, under no circumstances'. I suppose in the back of my mind there was the thought in my mind that she's been brought through hell and she's cured and she's alive, and it's like I'm damned if she's going to go on some roller blades and get run over by a car. (ES43, ***high****)*

Similarly, another mother of a CNS survivor had worries about her child's physical activities. Despite her concerns, she tried to allow the child to take part in activities that he wanted to do, but put a limit on more dangerous sports.

Like when we played cricket or if we go on a family picnic, whatever the other children are doing, well L will do it as well, I mean he won't be able to do like

they do .....I think the only things that we might discourage him, if he wanted to do rock climbing or things like that (LB93, ***moderate****)*

In the low range, some mothers discussed their lack of limit setting, for example one mother had no control over her child's routines, allowing her to stay up very late each night, resulting in her school performance slipping. Another mother allowed her 14-year-old son to ride a motorbike.

I think he just likes having fun now and that's his way of expressing his feelings, on his motorbike.
Q: Does that worry you?
No.
Q: You don't worry that he's going to hurt himself quite badly or anything?
No. (AG04, ***low****)*

Maturity demands

This was an extremely varied sub-component. Most examples were somewhat illness related, with mothers discussing how they encouraged their child to behave in a mature and age-appropriate manner.

One issue frequently discussed was that of handing over on-going medication responsibility to the child. A number of survivors of childhood cancer are on growth hormone treatment (GHT), particularly those who had radiotherapy at the hypothalamic-pituitary axes, close to the pituitary gland. The treatment involves daily injections of the growth hormone. Mothers in this study discussed how they gradually encouraged their child to take responsibility for their own medication.

I decided she needed to start using it herself again, to get used to it. And now her co-ordination's a lot better she's not stabbing herself in the finger. (LH83, ***moderate****)*

While many children were young or physically unable to take an independent role in their GHT, some mothers continued to make their child feel involved.

But he does everything else and we even let him take, I sort of say 'right, are you going take it out' [the needle]*...Try and take it out....So he does the bulk of it, it's the co-ordination bit between pressing the injection and...Yeah he can't, he can't go like that and stick and you know press the button (LB93,* ***moderate****)*

A number of mothers discussed how important it was for their child to become independent, despite their physical or psychological late-effects. For example, one mother taught her child how to wash himself again, while another taught her son to be able to cook and clean for himself.

Everyday he'd probably be a bit more independent than yesterday, he'll probably be more independent tomorrow than he is today ....I do know I've done my best and if I pop my clogs tomorrow I know that I've done my best ...I've pushed to be so independent for him, so that you know if I die tomorrow, he can go to Iceland and, and go and get a frozen meal and stick it in a microwave and, you know he won't starve....And I think he could do that, you know cos his life skills, you know we've worked on them a lot (TD71, ***high****)*

This was an important thread running through many scripts: the child being able to help around the home and learn to become independent. For example, while many children with CNS tumours have residual physical problems, including co-ordination and balance difficulties, it was important to mothers that their child at least tries to help around the home.

he's very clumsy.. He drops stuff out of the oven and stuff....You've got to let him do these things.
Q: Obviously you want him to try things, but then if he drops hot stuff on the floor how do you then deal with that?
Oh, we just clean it up.
Q: Do you ever get to the point of saying, 'I'll do it for you, rather than you be upset'?
No, he has to do it. (MH15, ***high****)*

Another parent discussed how important it was to make the child learn how to become financially independent before leaving home. This parent started handing over household responsibilities that she would have to master when living independently, for example paying bills.

I want to give her the opportunity to have her own money, her own benefits, so she can spend how she wants and learn how to look after money, which she's still not quite experienced at. Also, to have her paying some of the bills here, some of my bills – give her the money and let her pay them. I'm just trying to make sure that she's ready for anything that crops up when she does leave home. So I'm going to

have her doing that over the next 12 months, so that she's ready when she does move out. (LH83, ***high****)*

On the other hand, some mothers find it difficult that their child is growing up.

I think we shelter him more than we did the other children. We take him to and from school, and pick him up and run him about, do a lot more for him, even though he's 21 on 24 November coming, than we would do for the other children at a similar age. (SC38, ***low****)*

Monitoring

A number of children need constant attention both at school and at home. Some of these children cannot be treated as a normal child due to the late-effects they have as a result of their illness.

She's got more or less full-time support at school and they have a lunch club so she doesn't have to cope with an unstructured lunch time, she can go to a room with some other kids and they can just play.....I mean I think she's going to need a lot of supervision and mentoring, whatever she does. (RT74, ***high****)*

Some mothers discussed a number of moderately monitored activities, such as keeping an eye on the child's medication, restricting their diet, or requesting the child plays near their home.

We've got kids [here] *all the time. You see, I won't let C go to their houses.*
Q: Why's that?
Because they let her run wild.
Q: So at least if they're here you can keep an eye on what they're doing?
Yes (CM57, ***moderate****)*

now he's got his watch and we say, 'set your watch for,' and he sets his watch and he sets his alarm and I say, 'you've got your watch, use it,' you know, you've got the damn thing on your wrist, you know, that's what it's there for so use it. So he sets his alarm and he's very good actually at timekeeping (DI49, ***moderate****)*

Other parents discussed how they did not need to monitor their child.

We don't interfere much with her homework. Unless we get reports from the school that she not doing it, we assume she's doing it (CC75, ***low****)*

9.3 Extent to which normal parenting theories capture the essence of parenting a child with cancer

One of the central aims of this analysis was to assess the extent to which this parenting framework could be applied to the study of parenting a child with cancer.

Three main patterns emerged. First, themes emerged that could not be coded within the existing parenting framework. These were extracted and retained for further assessment. These were issues mothers raised spontaneously during the interviews. Second, there were a number of situations where the child led the mother-child interaction, again making the coding difficult since it was the child's behaviour, not the mother's, that was central to such discussions. Third, as children become older there is less need for mothers to exert control over their behaviours and choices. Again, coding these excerpts according to the theory was difficult.

Nonetheless, the vast majority of parental excerpts were successfully coded within the parenting framework.

9.3.1 Issues not coded within the parenting framework

Themes which could not be coded within the framework were transferred into a coding table (see Appendix 7). These issues were not weighted since they were not theoretically driven and could not be easily quantified. These excerpts could quite easily be categorised into two main sections: general thoughts on child-rearing and concerns about the illness.

9.3.1.1 General thoughts on child-rearing

Difficulties

Many mothers discussed issues of difficulty, such as spoiling their child or becoming too protective, either of the ill child or their siblings. For example, this mother discussed putting herself in debt to give the child new clothes.

I got her all new clothes, I wanted to make her feel ..... I didn't have any money, I just thought 'sod that', bank loan, buy her new clothes. I'm just too soft with them all, I know I am, but I find it difficult to deprive them. (FP25)

Spoiling was an issue for many families, especially during treatment, but sometimes this carried on afterwards.

he probably got extremely spoilt in terms that he spent a lot of time with me, he got bought a lot of presents, not just by us but by other people, and that was a way of coping with it – every time he had to have another injection, 'let's go and look in the bookshop,' or whatever (RS76)

I still pamper him. I can't change myself, I always will. If they said to me, right, he's cured, that's it, it's not going to come back, then I wouldn't, but because they can never say that I always will. (RH103)

Some mothers realised that spoiling the child can have negative consequences:

I've had to be cruel to be kind. ....I used to give in to her and I used to mollycoddle her too much. And that's gone against me, really, because now she doesn't seem to have as much confidence as she should have in herself to be able to do things for herself. (AL22)

It's my fault, she's very spoilt, but we thought we were going to lose her, so that's why. So I've made a rod for my own back really (CM57)

In contrast, many mothers discussed their determination not to allow their child to become spoilt:

I don't like spoilt children that can behave badly in public and things like that, and I don't think being poorly is any reason to do that really. I know in some cases you do tend to, but it only seems to fall back on you, because you get a spoilt child that can't behave and we realise that it's not doing them any good... (DC86)

I don't believe in wrapping them up in cotton wool, I've said that right from the beginning. Whatever would happen would happen, and both her and T [brother] *had to have a normal life as much as possible. I have heard of people who have wrapped their children up in cotton wool and are ruing the day...But where S is concerned, no, I'm fairly strict-ish with her. (SB59)*

Other mothers discussed their desire to overprotect the ill child, more so than their other (well) children:

I'm very protective of her. When she gets ill now or if I see just a little bruise and that, I just go to pieces. Or she gets a cold and I'm 'aaaah,' I'm all on edge. If D [brother] *gets a cold or anything like that it doesn't bother me, but if M* [ill sibling] *starts falling ill I go to pieces. (MB96)*

he's still my baby - even though I've got her [sister], *he's the baby. I worry about him more. It's like when he started at high school I'm worrying that he couldn't look after himself, whereas E* [sister] *just went off and went to school and I went, 'was your day okay?' and I'm saying to him, 'don't lose your lunch pack, and have you got your bag, and don't forget your pencil case,' (MC46)*

Alternatively, there were mothers who became more obsessed with the health of their other, well children, fearing they may too become ill:

B [sister]*...she went through a phase where she was coming up in bruises and that's how D* [ill sibling] *started, and I panicked with her more than I have done with D (DJ18)*

If I find myself getting panicky, say one of the boys is ill... I've sort of got mental pictures of K [ill sibling], *because they were about the same age as what she was at that time when she was diagnosed. So I had to take a step back and say, 'come on.. just be logical'. I do tend to take them to the doctor's more than what I would have done. (KL20)*

Mother's attitude towards parenting

Many mothers discussed the profound influence the child's illness had on their attitudes towards the child and their general outlook on life. Different issues became important as a result of the child's cancer.

I think we're more closer now and we don't take life for granted like we did before. Every day's precious to us now. It comes to her birthday and it's like we've got another year over. I think now we're winning. (AH12)

it's obviously affected our life and I suppose it's put things like money and stuff in perspective doesn't it..dusting the house, you know, things like that, that I might have fussed about before, it really, a bit trivial aren't they? (SR84)

9.3.1.2 Concerns about the illness

Side-effects of medication / treatment

Apart from concerns and worries about the child's future health status and long-term consequences of treatment, many mothers discussed their fears surrounding their child's schooling and future career, or even ability to get life insurance.

the thing that does bother me is that because he has had leukaemia it will always be there, sort of lurking, when he's going to be employed...I was reading an article about a boy that had had leukaemia many, many years ago and he was now in his 20s and he can't get life insurance and things like that. So I think our troubles are not over yet (MC46)

I'm not sure things like GCSEs are going to be an option for K..So I'm not sure how it's going to affect her employment-wise. Whether she actually will ever be able to manage full-time employment, or whether we're maybe going to have to look at more part-time, I don't know. (KT65)

But I do worry about her illness in the future, because it may affect her employment prospects. Being hard about it, who would take on somebody who's likely to be ill or spend a lot of time off work. From an employer's point of view, she's not a good deal. (CC75)

Relapse

The threat of relapse was a very real worry for most parents. However, mothers had very different ways of coping with this threat.

the doctor explained that it wasn't something that will come back in an instant, it will be a gradual process of being unwell. It's always at the back of my mind, but you have to think positive, otherwise you'd kill yourself, wouldn't you? But I'd like him to grow up as normally as possible. (CV97)

as they've told us, it could grow back again. It could grow back again in the brain stem. It could grow on her spine. It, it can come back anywhere... I just live one day at a time....I try not to think about it because if I do I, I can get very upset. I just take one day at a time and, and I thank God that I've got N ...I don't plan ahead any more. (NH14)

This mother's life was completely taken over by her fear of relapse:

They say it gets easier as time goes on, but it doesn't, it gets harder, because you're waiting for that 5 years I am, I'm waiting for them to say 5 years now, 90% that it's not going to come back, but it's only been 4 and there's still that year to go....Every day for 4 years I've asked him [if he has any headaches], *and I always will. I'm scared that he won't tell me if he does have a headache because he knows what he's been through. So I'm scared that he won't. ...It will never ever go away.. (RH103)*

Whereas this mother tried not to worry for both her own and her son's health:

It's getting easier now, ...I don't look for it as much now. I think it's took me quite a few years to get to that situation.. I've stopped jumping to the assumption every time he gets a sore throat. I try not to think now that way. I try to get philosophical and think I'm wasting good time just worrying and all it does is make me feel poorly. If something comes along now, then I'll wait and see, because I've done it before, jumped to that conclusion and it's been a virus or something and then you're thinking I've done all that worrying, and that has an effect on D, it worries him if I worry. So I try not to. (DK102)

9.3.2 Child-driven situations

There were certain situations in which the child led, or had control of, the mother-child interactions, for example during illness communication. Many mothers discussed how they would try talking to the child, but the child would not reciprocate. Many children bottled up their thoughts and feelings and refused to talk. Interestingly, this has been a central criticism of this trait parenting theory (Holden, 1997; Holden & Miller, 1999) in that it generally assesses mother–to–child directions, but not the reverse. When this occurred during the present study, the examples were not coded (see examples below). This was considered the most conservative approach since one would have to guess subjectively what type of parenting style the parent would have used if the child had reciprocated.

She won't talk about it and she never talks about her operation or anything, anytime being in hospital she just.....avoids that completely...She doesn't like people to mention it and she just shuts up altogether. I think like where as I prefer to talk about things she's the complete opposite, she doesn't want, want to discuss things like that. (JQ101)

With Ju [sibling] you could sit down and explain, 'well, I don't know whether that's a good idea, how about trying it this way?' and she would do it. With J [ill

child], *no, she wanted to do something, she wanted to do it there and then and you couldn't persuade her at all. (JB51)*

9.3.3 Developmental effects

Similarly, another situation that made coding complicated existed when the children did not *need* parental control. For example, when asked about their child's level of medication or homework monitoring, many mothers replied that their child did not need monitoring or limits set. This was generally because the child was getting older and parents were reducing their influence.

She's got her little routines for herself. And like with homework, as soon as she comes in it's straight to homework, nothing else, it's homework for an hour. (AH12)

This made coding difficult: is this an example of 'low' endorsement? If so, does this indicate a level of parental permissiveness? There are problems with this however. Although it may appear that the parent is being lax with the child, it may be because the child is mature enough to monitor themselves. Alternatively, the child may be acting maturely due to optimal parental efforts in the past. For these reasons, these examples were not coded.

SECTION II. QUANTITATIVE ANALYSES

9.4 Treatment of Data

First, each measure was explored and descriptive statistics presented. Data distribution data can be seen in Appendix 8. Second, each measure was assessed for its relationship with demographic and medical variables, and where possible, comparisons with published norms were made. Finally, regression analyses were conducted to assess the predictors of child self-reported QOL, mothers proxy-rated QOL and mother's mental health.

9.5 Descriptive and Preliminary statistics

Demographic / medical differences

Using independent t-tests, survivors of ALL were significantly younger than survivors of CNS tumours at diagnosis ($t = -4.97$, $df = 69$, $p<0.001$) and were significantly further from diagnosis ($t = 3.78$, $df = 70$, $p<0.01$). There were no differences between diagnostic groups on any other demographic variables (child's chronological age, mother's age, the age mothers left full-time education, marital status).

These results are consistent with population data: most children diagnosed with ALL are between one- and four-years old, whereas children with CNS tumours tend to be older, depending on their exact diagnosis (for example, medulloblastomas are most commonly diagnosed between five- and nine-years old, whereas astrocytomas are most common in the 10-14 age range; Stiller et al., 1995).

Internal consistency: Cronbach's alpha estimates

Internal consistency estimates (Cronbach's alpha) were calculated for each measure, with each found to be at an acceptable level (see Table 9.1).

Table 9.1 Internal consistency estimates (Cronbach's alpha)

Measure	***Number of items***	***Cronbach's Alpha***
Parenting questionnaire		
Authoritative	20	0.85
Permissive	11	0.76
Authoritarian	9	0.64
Maternal Worry Scale	11	0.88
CES-D total scale	20	0.95
Depressive affect	7	0.95
Somatomotor concerns	5	0.95
Positive symptoms	4	0.74
Interpersonal relations	4	0.88
SF-36	36	0.91
PedsQL Parent total score	30	0.85
PedsQL Child total score	30	0.81

Child reported PedsQL (Varni et al., 1999)

Data distribution was normal, therefore parametric statistics were used.

Intercorrelations (whole group)

Correlations between the sub-scales ranged from r = 0.27 to r = 0.63 and were significant in all cases, i.e., good functioning in one domain indicates good functioning in other domains.

Relationship with demographic and medical factors

A 5 subscale (physical, emotional, social, school, well-being) by 2 diagnosis (ALL, CNS) by 2 age (8-12; 13+) MANOVA was conducted, with results showing an overall main effect of diagnosis (F (5, 63) = 3.64, $p<0.01$), but not age (F (5, 63) = 1.34, p = 0.16). The interaction between age and diagnosis was not

significant (F (5, 63) = 0.30, p = 0.91). Univariate F-tests indicated significant diagnostic differences on the following: physical (F(1, 67) = 5.79, p<0.05), social (F(1, 67) = 7.42, p<0.01), and school functioning (F(1, 67) = 6.79, p<0.05). In all cases, survivors of CNS tumours had poorer functioning than survivors of ALL. No differences were found on emotional functioning (F(1, 67) = 0.09, p = 0.76) or well-being (F(1, 67) = 0.16, p = 0.69). Please see Table 9.3 for PedsQL descriptives for survivor self-report.

The only univariate age difference concerned the child's well-being (F(1, 67) = 0.477, p<0.05; M (child) = 83.14 vs. M (teen) = 73.35), but since the multivariate effect was non-significant, this result should be treated with caution. However, the means indicate that teenagers (+13 years) self-reported poorer well-being than younger children (8-12 years).

Table 9.2. Means (SD) and ranges for the PedsQL sub-scales for survivors of ALL and CNS tumours

	ALL		***CNS***	
Scale	***Mean(SD)***	***Range***	***Mean(SD)***	***Range***
Physical	85.28 (14.37)	35.71-100	72.24 (19.59)	25.00-100
Emotional	73.63 (17.15)	40.00-100	72.88 (16.50)	50.00-100
Social	86.54 (15.86)	45.00-100	73.08 (20.64)	20.00-100
School	74.49 (15.37)	25.00-100	63.33 (17.11)	30.00-90
Wellbeing	79.71 (17.76)	33.33-100	74.46 (17.63)	37.50-100

** p<0.05; **p<0.01*

Since QOL scores differed according to diagnostic group, further analyses either (a) assessed each group individually, or (b) where appropriate, controlled for diagnostic group.

ALL only

Using independent t-tests or Pearson correlations, results showed that neither demographic nor medical variables related to QOL scores.

CNS only

Assessing chronological age as a continuous variable (in comparison to above where age was separated into 'child' and 'teens'), younger children had better emotional functioning ($r = -0.47$, $p<0.05$), well-being ($r = -0.40$, $p<0.05$) and an overall QOL ($r = -0.40$, $p<0.05$) than older children. No other demographic or medical variables related to QOL scores.

Published norms

Varni et al. (in press) reported QOL population norms for a sample of 401 healthy children. While they retained the physical functioning sub-scale in its original format, they collapsed the emotional, school and social functioning sub-scales, re-labelling this as 'psychosocial health' (i.e., they did not include the well-being sub-scale in their calculations)[1]. The total QOL scale was calculated without the well-being scale using the current data. Therefore, when comparing these norms with the present data, the PedsQL measure was recalculated without well-being, *for these calculations only.* See Appendix 9 for the equation necessary to compute these differences and a list of published norms.

Survivors of CNS tumours had significantly poorer physical functioning ($t = 3.46$, $df = 424$ $p<0.001$), psychosocial health ($t = 4.14$, $df = 423$ $p<0.001$), and total QOL ($t = 4.20$, $df = 425$ $p<0.001$) than population norms. Survivors of ALL did not differ from the healthy norms ($ts = -0.35$, 1.78, and 1.29 respectively).

[1] Varni et al. (in press) published norms for the PedsQL version 4. Version 3 is used in the current thesis. The *only* difference between the two scales is that the well-being subscale has been removed in version 4. Varni et al (in press) talk about 'psychosocial health' as representing the social, school and emotional functioning scales.

Mother rated PedsQoL (Varni et al., 1999)

Data distribution was not significantly skewed, hence parametric analyses were conducted.

Intercorrelations

Similar to the child self-reported data, all correlations were significant and ranged in size from r = 0.48 to r = 0.66, i.e. good functioning in one sub-scale indicated good functioning in other sub-scales.

Relationship with demographic and medical factors

A 5 subscale (physical, emotional, social, school, well-being) by 2 diagnosis (ALL, CNS) by 2 age (8-12; 13+) MANOVA was conducted, with results showing an overall main effect of diagnosis (F (5, 58) = 6.27, $p<0.001$), but not age (F (5, 58) = 0.70, p = 0.62). The interaction between diagnosis and age was not significant (F (5, 58) = 0.81, p=0.55).

Univariate F-tests showed significant diagnostic differences on the following sub-scales: physical (F (1, 62) = 26.01, $p<0.001$), social (F(1, 62) = 18.91, $p<0.001$), school (F (1, 62) = 11.81, $p<0.001$) functioning, and well-being (F(1, 62) = 5.55, $p<0.05$). In all cases, CNS functioning was poorer than ALL functioning. Emotional functioning did not vary according to diagnosis (F (1, 62) = 3.20, p=0.08). Please see Table 9.2 for PedsQL descriptives for both ALL and CNS groups. Age did not have a significant univariate effect on any sub-scale.

Table 9.3 *Means (SD) and ranges for the PedsQL sub-scales for mothers of survivors of ALL and CNS tumours*

	ALL		***CNS***	
Scale	***Mean(SD)***	***Range***	***Mean(SD)***	***Range***
Physical	83.77 (20.57)	12.50-100	59.71 (21.74)	25.00-100
Emotional	69.76 (19.75)	30.00-100	60.00 (17.59)	30.00-100
Social	80.00 (21.79)	15.00-100	54.60 (20.41)	15.00-100
School	71.89(18.53)	35.00-100	53.90 (25.54)	15.00-100
Well-being	80.25 (20.57)	12.50-100	69.61 (18.87)	25.00-100

Similarly, since QOL scores differed between the ALL and CNS groups, further analyses either (a) assessed each diagnostic group individually, or (b) where appropriate, controlled for diagnostic group.

ALL only

Time since diagnosis and age at diagnosis did not correlate with PedsQL sub-scale scores or total QOL. T-tests confirmed that PedsQL scores did not differ as a function of gender, the age mothers left full-time education or marital status. Increased chronological age correlated with increased school functioning, although the correlation was moderate in size ($r = 0.31$, $p<0.05$).

CNS only

Neither chronological age (as a continuous variable), gender, the age mothers left full-time education or marital status related to PedsQL scores. Increased age at diagnosis correlated with greater physical ($r = 0.45$, $p<0.05$) and social functioning ($r = 0.47$, $p<0.05$), and increased time since diagnosis correlated with poorer social functioning ($r = -0.40$, $p=0.052$).

Published norms

Varni, Seid and Kurtin (in press) reported QOL population norms for a sample of 717 parents of healthy children. Similar to the above calculations concerning child self-reported QOL, they collapsed the emotional, school and social functioning sub-scales, re-labelling this as 'psychosocial health'. Using student t-tests, these

norms were compared with each of the diagnostic group means. Mothers of survivors of CNS tumours had significantly poorer physical functioning ($t = 8.63$, $df = 739$, $p<0.001$), psychosocial health ($t = 10.63$, $df = 739$, $p<0.001$), and total QOL ($t = 11.05$, $df = 739$ $p<0.001$) than population norms. Mothers of ALL survivors reported poorer physical ($t = 2.18$, $df = 760$, $p<0.001$), psychosocial health ($t = 6.40$, $df = 760$, $p<0.001$) and total QOL ($t = 5.76$, $df = 760$, $p<0.001$) than population norms. See Appendix 9 for the list of published norms.

Comparison of child and mother-reported QOL

In order to assess differences in QOL scores by respondent (mother-child), paired t-tests were conducted (assuming nonindependence between the two reports; Ennett et al., 1991). Please refer to Tables 9.2 and 9.3 for the QOL means and SD for each respondent. Paired t-tests were conducted between the mother and child pairs *for each diagnostic group separately*.

Survivors of ALL and their mothers only differed on reports of the child's social functioning, with children reporting higher scores than their mothers ($t = -2.06$, $df = 44$, $p<0.05$). However, survivors of CNS tumours reported better emotional ($t = -3.17$, $df = 23$, $p<0.01$), social functioning ($t = -3.60$, $df = 23$, $p<0.01$), and total QOL ($t = -2.32$, $df = 23$, $p<0.05$) than their mothers reported.

Range of PedsQL measurement

Floor and ceiling effects for the ALL and CNS groups were calculated (see Chapter 6 for a discussion of these terms). Ceiling effects were present in all but the school sub-scale for both CNS mother and survivor groups. Floor effects were not present in any sub-scale. Ceiling effects were most marked for the ALL group, i.e., a higher percentage of survivors of ALL reported excellent functioning compared with survivors of CNS tumours.

Table 9.4a. Percentage of ceiling and floor effects for the ALL group

Domain	*ALL*			
	Mother		*Child*	
	% ceiling	*% floor*	*% ceiling*	*% floor*
Physical	26.08	0	27.45	0
Emotional	13.04	0	13.73	0
Social	32.61	0	37.25	0
School	7.32	0	6.38	0
Well-being	19.57	0	23.53	0

Table 9.4b. Percentage of ceiling and floor effects for the CNS group

Domain	*CNS*			
	Mother		*Child*	
	% ceiling	*% floor*	*% ceiling*	*% floor*
Physical	3.57	0	3.85	0
Emotional	7.14	0	11.54	0
Social	7.14	0	7.69	0
School	0	0	0	0
Well-being	10.71	0	7.69	0

Teen reported Body Image Instrument (Kopel et al., 1998)

Due to measurement restrictions, only survivors aged 13 and above could complete the BI questionnaire. Therefore, 20 survivors of ALL and ten with CNS tumours were included in this analysis. Data was not significantly skewed.

A 3 subscale (body parts, general appearance, body awareness) by 2 diagnosis (ALL, CNS) MANOVA, showed that there was a main effect of diagnosis ($F(3, 26) = 5.23$, $p<0.01$). Univariate F-tests showed that this was significant for general appearance and body awareness (see Table 9.5).

Table 9.5 Means (SD) and range for the BI scale for each diagnostic group

	ALL		***CNS***		
Scale	**Mean(SD)**	**Range**	**Mean(SD)**	**Range**	**F**
Body Parts	3.68 (0.74)	2.25-5.00	3.15 (1.02)	1.00-4.25	2.71
General appearance	3.25 (0.71)	2.00-4.86	2.57 (0.92)	1.43-4.14	5.00*
Body awareness	4.00 (0.66)	2.63-5.00	3.01 (0.71)	2.13-4.13	14.37**

*p<0.05 **p<0.01

Since BI differed between diagnostic groups, further analyses (a) assessed each group individually, or (2) where appropriate, controlled for diagnostic group.

Relationship with demographic and medical factors – ALL and CNS separately

Pearson correlations or t-tests between the BI sub-scales, demographic and medical factors revealed no significant relationships.

Parenting Styles and Dimensions Questionnaire Version 3. (Dekovic et al., 1991; Robinson et al., 1995[a]; Chapter 7)

Intercorrelations

Correlations between the three dimensions were as follows: authoritative with authoritarian (r = .15, p = NS); authoritative with permissive (r = -0.27, p <0.05); and permissive with authoritarian (r = .20, p = NS).

Table 9.6 Means (SD) and ranges for parenting scales by ALL and CNS

	ALL		***CNS***		
Scale	***Mean (SD)***	***Range***	***Mean (SD)***	***Range***	***t***
Authoritative	4.25 (.37)	3.40 - 5.00	4.38 (.34)	3.67 - 4.79	-1.32
Permissive	2.24 (.50)	1.55 - 3.82	2.04 (.52)	1.00 - 3.30	0.69
Authoritarian	3.18 (.39)	2.50 - 4.29	3.28 (.95)	1.00 - 4.75	-0.50

Relationship with demographic and medical factors

The permissive sub-scale was significantly positively skewed, whereas neither the authoritative and authoritarian sub-scales were significantly skewed. Using Mann-Whitney U-tests or Spearman correlations neither medical (e.g., diagnosis, time since diagnosis) nor demographic (e.g., gender, chronological age) variables related to the parenting scores (see Table 9.6 for descriptive data).

[a] An effort to generate teen parenting data was made on a newly-developed teen-worded parallel questionnaire. However, due to the burden of the child interview, QOL and BI measurements, very few questionnaires were completed (N=10). Hence this data is not reported.

Parenting Interview dimensions (developed for study; earlier in chapter)

Intercorrelations

Spearman correlations between the three dimensions were as follows: warmth with psychological autonomy ($\rho = 0.22$, $p = 0.07$); warmth with behavioural control ($\rho = 0.02$, $p = NS$); and psychological autonomy with behavioural control ($\rho = 0.32$, $p<0.01$). The positive correlation between the two control aspects was unexpected and further explored. Between diagnostic group comparisons indicated that this correlation was only significant for those mothers of survivors of CNS tumours (CNS: $\rho = 0.50$, $p<0.01$; ALL: $\rho = 0.22$, $p = NS$).

Relationship with demographic and medical variables

Parent interview dimensions scores did not relate to demographic or medical variables, using non-parametric analysis.

Table 9.7 Means (SD) and ranges for the three parenting interview dimensions

	ALL		***CNS***		
Dimension	***Mean (SD)***	***Range***	***Mean (SD)***	***Range***	*z*
Warmth	2.39 (.40)	1.67 – 3	2.53 (.36)	2 – 3	-1.39
Psychological autonomy	2.29 (.57)	1-3	2.38 (.46)	1.5 – 3	-0.69
Behavioural control	2.16 (.44)	1.33 – 3	2.25 (.52)	1-3	-0.77

Maternal Worry Scale (DeVet & Ireys, 1998)

Relationship with demographic and medical factors

Mothers of survivors of ALL were significantly less worried than mothers of survivors of CNS tumours (see Table 9.8 for results). This data was positively skewed, hence the use of non-parametric tests.

Table 9.8 Means (SD) and ranges for the Maternal Worry Scale for mothers of survivors of ALL and CNS tumours

	ALL		***CNS***		
Scale	***Mean(SD)***	***Range***	***Mean(SD)***	***Range***	***z***
Maternal Worry	1.42 (0.36)	1.00-2.82	2.04 (0.65)	1.09-3.27	-4.59*

*p<0.001

In order to assess the 11-items individually, a series of Mann-Whitney tests were conducted. Bonferroni corrections were set at 0.005 (11/0.05). Results showed that group differences were found in 8 of the 11 items, with mothers of survivors of CNS tumours consistently worrying more than mothers of survivors of ALL. See Table 9.9 for results.

Table 9.9 Means (SD) for the 11-items from the Maternal Worry Scale for mothers of survivors of ALL and CNS tumours

	ALL	***CNS***	
Item	***Mean***	***Mean***	***Z***
Looking different	1.26	1.74	-3.61*
Finding a boy/girlfriend	1.35	2.00	-4.21*
Getting married	1.26	1.65	-3.68
Getting worse again	1.94	2.04	0.15
Not being able to do what want	1.50	2.30	-4.27*
Have a hard time getting places	1.18	2.60	-5.71*
Will always need medication	1.32	1.91	-3.63*
Worry about side-effects	2.15	2.04	-0.27
Will grow-up too fast	1.41	1.61	-1.14
Won't be able to handle things in future	1.35	2.30	-4.69*
Will need stronger medication	1.35	1.91	-3.29*

*$p<0.001$

Mann-Whitney tests indicated that gender, the mother's age at leaving full-time education and marital status did not differentiate between the groups. However, older age at diagnosis correlated significantly with increased worries ($\rho = 0.35$, $p<0.01$). Chronological age and time since diagnosis did not correlate with maternal worries.

SF- 36 (Jenkinson et al., 1996)

Traditionally, the SF36 sub-scales have been investigated individually. However, in order to assess the mother's overall well-being, a principal components factor analysis was performed on the eight scores. This yielded a single factor accounting for 65% of the variance. The scree plot for this analysis showed a clear one factor solution, therefore it was deemed possible to sum the scores and have a unique SF36 total score (see Figure 9.1). This technique has been applied to the SF36 previously (e.g., Eiser, Darlington, Stride, & Grimer, in press). Therefore, in the following analysis both the total score and the individual scores were used where appropriate.

Figure 9.1. Scree plot of SF36 well-being scale.

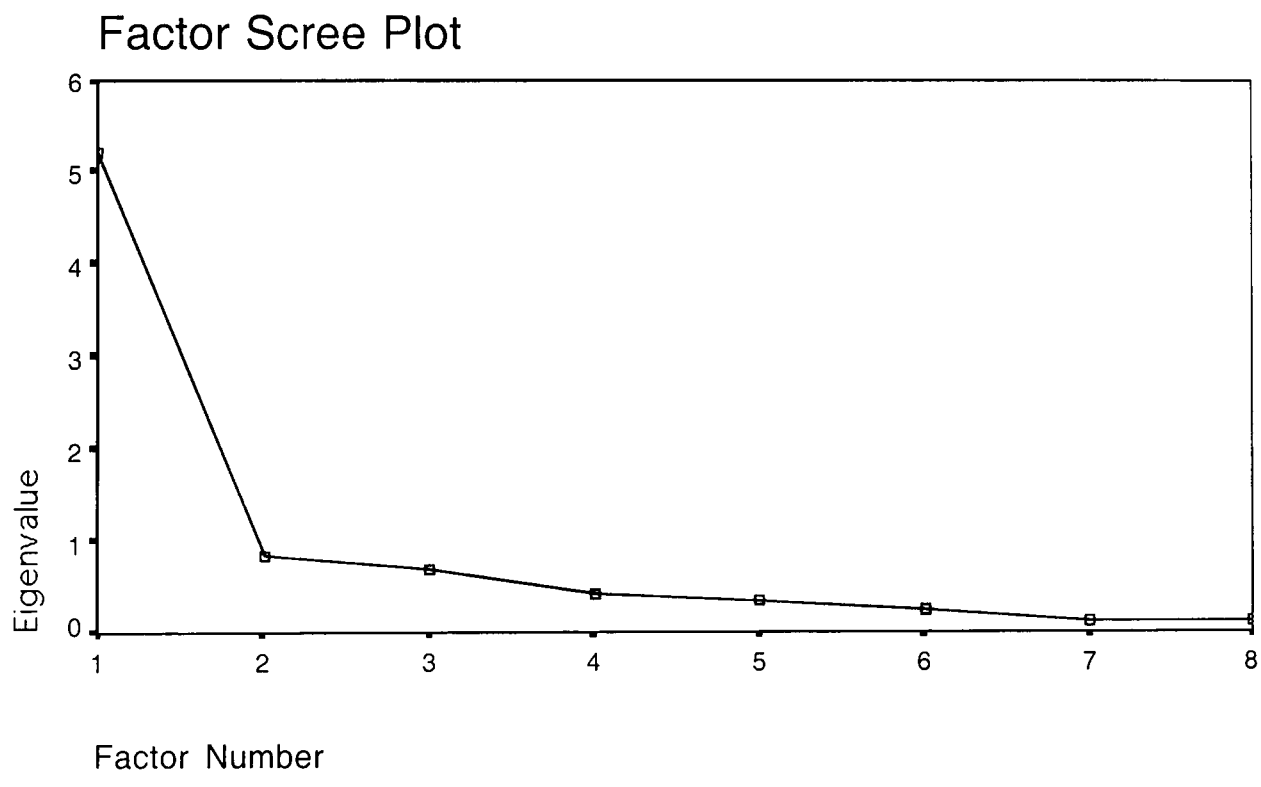


Table 9.10 Means (SD) and ranges for the SF36 sub-scales for mothers of survivors of ALL and CNS tumours

	ALL		***CNS***		
Scale	***Mean(SD)***	***Range***	***Mean(SD)***	***Range***	***F***
Energy/vitality	63.78 (20.90)	10-90	52.62 (22.34)	20-90	1.18
Mental health	71.14 (20.49)	4-96	65.52 (22.89)	16-96	0.08
General Health	73.35 (22.36)	10-100	68.81 (26.24)	0-100	0.12
Social func.	74.47 (19.75)	33-89	75.56 (21.20)	22-89	0.24
Emotion limit.	80.18 (33.76)	0-100	76.41 (33.00)	0-100	0.17
Body pain	83.18 (24.93)	11-100	82.15 (24.77)	22-100	0.01
Physical limit.	83.33 (16.11)	0-100	79.76 (32.33)	0-100	0.12
Physical func.	89.30 (16.11)	30-100	91.50 (11.93)	50-100	0.50

Intercorrelations

Since the data were slightly skewed, spearman correlations between the eight sub-scales ranged from $\rho = 0.34$ to $\rho = 80$ and were significant in all cases, indicating that good well-being in one domain is indicative of good well-being in other domains.

Relationship with demographic and medical factors

An 8 subscale (energy, mental health, general health, social functioning, emotional limitation, body pain, physical limitations, physical functioning) by 2 diagnosis (ALL, CNS) MANOVA showed that there was no main effect of diagnosis.

As a result, all data (mothers of survivors of CNS tumours and ALL) were collapsed. (Mother's were different on levels of energy at the $p<0.05$ level, but considering the number of comparisons, this result was discarded.)

Mothers of boys functioned more poorly than mothers of girls. This was significant for mental health ($Z= -2.16$, $p<0.05$; $M = 61.63$ vs. 75.62), general health ($Z = -2.07$, $p<0.05$; $M = 65.09$ vs. 77.21) and energy ($Z = -2.13$, $p<0.05$; M

= 52.04 vs. 66.45). There were no differences in SF36 scores as a function of the age mothers left full-time education or marital status.

As the child's chronological age increased, mother's functioning decreased. This was the case for physical functioning (ρ = -0.45, $p<0.001$), mental health (ρ= -0.35, $p<0.01$), general health perception (ρ= -0.34, $p<0.01$), pain (ρ = -0.33, $p<0.05$), energy (ρ = -0.43, $p<0.001$), and the total SF-36 score (ρ = -0.33, $p<0.05$).

Older age at diagnosis correlated significantly with poorer general health perception (ρ = -0.30, $p<0.05$). Increased time since diagnosis correlated with poorer role limitation due to physical problems (ρ= -0.29, $p<0.05$), energy (ρ = -0.26, $p<0.05$), and increased pain (ρ = -0.31, $p<0.05$).

Published norms

Published norms for healthy samples on the SF36 are available (Jenkinson et al., 1993). Norms were chosen for women aged between 35-54 years, as this was the most similar age-group to those mothers recruited in the present study. Student t-tests were used to compare these normative values with the mean scores obtained in the present study for mother's of survivors of CNS tumours and ALL separately. Please see Appendix 9 for norm details.

According to these calculations, mothers were *not* different from published norms. The only exception was that mothers of survivors of ALL and CNS tumours reporting significantly poorer social functioning ($t = 3.58$, $df = 1245$, $p<0.001$; $t = 2.47$, $df = 1229$, $p<0.02$ respectively) than norms.

CES-D (Radloff, 1977)

Intercorrelations

Since the data were slightly skewed, nonparametric correlations were conducted. Spearman correlations ranged from ρ = 0.37 to ρ = 0.75, with all sub-scales significantly correlating with each other.

Relationship with demographic and medical factors

A 4 subscale (interpersonal relations, somatomotor concerns, positive affect, depressive affect) by 2 diagnosis (ALL, CNS) MANOVA, indicated that depression scores did not differ between diagnostic groups (see Table 9.11).

Table 9.11 Means (SD) and ranges for CES-D scores for mothers of survivors of ALL and CNS tumours

	ALL		***CNS***		
Scale	***Mean(SD)***	***Range***	***Mean(SD)***	***Range***	***F***
Interpersonal relations	1.47 (2.50)	0-10	1.50 (2.74)	0-10	0.38
Somatomotor concerns	2.84 (3.45)	0-13	3.74 (3.84)	0-15	0.27
Positive affect	3.29 (4.94)	0-10	3.86 (3.31)	0-10	0.13
Depressive affect	3.69 (4.94)	0-19	5.24 (5.99)	0-20	0.02

Mann-Whitney tests showed a tendency towards mothers of boys reporting greater depressive affect than mothers of daughters ($Z = -1.94$, $p=0.052$; $M = 6.25$ vs. 2.55 respectively).

Single mothers were more depressed than mothers who had a partner ($Z = -1.99$, $p<0.05$; $M = 19.40$ vs. 11.66 respectively). However, caution needs to be taken considering the skewed data (most mothers were in a relationship; see Table 8.1.2). There were no group differences according to the age mothers left full-time education.

Increased child chronological age was correlated with increased depressive affect ($\rho= 0.31$, $p<0.05$), somatomotor concerns ($\rho = 0.28$, $p<0.05$), decreased positive affect ($\rho = 0.39$, $p<0.01$) and increased total depression ($\rho= 0.43$, $p<0.001$). Older age at diagnosis was correlated with increased depressive affect ($\rho = 0.32$, $p<0.05$). Time since diagnosis did not correlate with depression scores.

At-risk depression

According to guidelines set by Radloff (1977), a cut-off score of 16 (of a possible 60) represents an at-risk score of clinical depression.

Recoding the depression scores according to this cut-off (dummy variable - with '0' coded as not depressed and '1' as depressed), resulted in 15 mothers being classified 'at-risk'. According to Chi-square analysis, the child's diagnostic group did not have an association with mother's being at-risk of depression. However, mothers of daughters were less likely to be depressed than mothers of boys (χ^2 = 3.86, df = 1, $p<0.05$). Please see Table 9.12 for observed and expected frequencies for gender by depression risk.

Table 9.12 Observed and (expected) frequencies for gender by depression risk

Depression risk?	Male	Female
No	14 (17.2)	24 (20.8)
Yes	10 (6.8)	5 (8.2)

Mann-Whitney tests showed that mothers of older children were significantly more likely to be above the cut-off score than mothers of younger children (Z = -2.33, $p<0.05$; M= 13.40 vs. 15.67 years).

Published norms

Hann et al. (1999) reported CES-D data for a healthy group of women (N=62). Although this is not technically population norm data, it does give an indication of how healthy women in this age-range generally score. Using student t-tests, mothers of survivors of CNS tumours were shown to be more depressed than healthy women (t = -2.20, df = 79, $p<0.05$). There were no differences between mothers of survivors of ALL and healthy women (t = -1.76, df = 94, p between 0.05 - 0.1, according to Howell, 1992, statistical tables).

9.6 Relationship between parenting, maternal mental health and the child's QOL (mother and survivor report).

Spearman correlations were conducted between mother and survivor reported PedsQL scores and the following:

(1) Parent Styles and Dimensions Questionnaire Version 3.

(2) Parent interview dimensions

(3) Maternal mental health (worries, SF36, depression)

(1) Parent Styles and Dimensions Questionnaire Version 3 (developed in Chapter7).

No significant correlations were found between mother proxy-rated and survivor self-reported QOL scores and the parenting style and dimensions questionnaire scores.

(2) Parent interview dimensions

Mother reported child-QOL scores decreased as behavioural control increased ($r = -0.23$, $p<0.05$). No significant correlations were found for warmth or psychological autonomy. No significant correlations were found between survivor self-reported QOL scores and parenting interview dimensions.

(3) Parent mental health (worries, SF36, depression)

Table 9.13 shows the Spearman correlations between maternal mental health variables, and mother proxy-rated and survivor self-reported PedsQL scores. Specifically, QOL scores decrease as maternal mental health decreases, as reported by both mother and survivor.

Table 9.13 Correlations between maternal mental health and QOL scores (mother- and survivor-report)

	Worries	***SF36***	***Depression***
Mother rated	*Rho (p)*	*Rho (p)*	*Rho (p)*
Physical	-0.62***	0.14	-0.14
Emotional	-0.50***	0.55***	-0.51***
Social	-0.54***	0.35*	-0.44**
School	-0.51***	0.25	-0.36*
Well-being	-0.50***	0.36*	-0.34*
Total QOL	*-0.67****	*0.46****	*-0.46****
Survivor rated			
Physical	-0.34*	0.31*	-0.16
Emotional	-0.16	0.44**	-0.33*
Social	-0.42**	0.33*	-0.27
School	-0.18	0.19	-0.07
Well-being	-0.15	0.30*	-0.20
Total QOL	*-0.30***	*0.38***	*-0.27**

**p<0.05; **p<0.01; ***p<0.001*

9.7 *Predictors of survivor self-reported QOL*

A multiple regression analysis was conducted to assess which variables significantly predicted the survivors self-reported QOL scores. Only variables significant at the bivariate level were entered into the equation, i.e., diagnosis, worries, depression and the SF36 total score. At this point, the decision was taken to remove one of the two mental health variables (depression or SF36) due to the threat of multicollinearity. Multicollinearity is a threat when two variables are extremely correlated (Tabachnick & Fidell, 1996). They advise either eliminating one of the offending variables if they exceed a correlation of 0.70 at the bivariate level or amalgamating the two variables in some way (depression and SF36 correlated at $\rho = 0.82$). Since the SF36 was thought to be a more global assessment of the mother's well-being, this variable was retained and the singular measure of depression removed. Table 9.14 shows the result of this regression.

Table 9.14 Multiple regression of survivor self-reported QOL – whole group

	B	SE B	*Beta*	*t*	*p*
Constant	69.24	12.37		5.60	.000
Diagnosis[b]	**-9.02**	**3.98**	**-0.30**	**-2.26**	**.027**
Worries	-1.94	4.01	-0.07	-0.48	.630
SF36	0.16	0.11	0.18	1.46	.149

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	3	2328.05	776.02	4.32	.008
Residual	65	11663.39	179.44		

Multiple R	.41
R square	.17
Adjusted R square	.13
Standard error	13.40

Table 9.14 shows that diagnosis significantly added to the equation: F (3,65)= 4.32, p = 0.008, indicating that survivors of ALL scored on average 9.02 points higher on their QOL measure, i.e., they had a better QOL.

Since diagnosis was identified as the sole factor in predicting child QOL of those

c Diagnosis was coded as a dummy variable with 0 = ALL and 1 = CNS tumours.

included in the regression, a second set of regressions was undertaken: one assessing QOL in survivors of ALL, and a second assessing the CNS group. The remaining variables, maternal worry and well-being, were entered into the equation.

Tables 9.15 and 9.16 show the results of these regressions.

Table 9.15 Multiple regression of survivor self-reported QOL - ALL only

	B	SE B	*Beta*	*t*	*p*
Constant	52.90	15.07		3.51	.001
Worries	4.25	5.86	0.13	.73	.47
SF36	**0.27**	**0.11**	**0.41**	**2.38**	**.02**

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	2	722.36	361.18	3.05	.058
Residual	41	4851.08	118.32		

Multiple R	.36
R square	.13
Adjusted R square	.09
Standard error	10.88

This regression indicates that the QOL of survivors of ALL was predicted by mother's well-being. Specifically, the survivors QOL increased as the mother's well-being increased (F (2, 41) = 3.05, p = 0.058). The regression equation narrowly missed reaching traditional levels of significance (p=0.058), but does indicate the importance of mental health in predicting child QOL. This model explained 13% of the variance (R^2 adjusted = 9%).

Table 9.16 Multiple regression of survivor self-reported QOL - CNS only

	B	SE B	*Beta*	*t*	*p*
Constant	72.22	25.01		2.88	.01
Worries	-3.01	5.76	-0.12	-0.52	.61
SF36	0.03	0.24	0.03	0.14	.89

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	2	97.19	48.60	0.20	.82
Residual	21	5182.67	246.79		

Multiple R	.14
R square	.02
Adjusted R square	-.08
Standard error	15.71

As can be seen from Table 9.16, and contrary to what was found for the ALL group, the mother's mental health did not predict the QOL of CNS survivors.

Post hoc regression analysis indicated that in each of the three regressions, there were no outliers according to Cook's D reports, and the normal probability plots were acceptable.

9.8 Predictors of mother proxy-rated QOL

Identical analyses were conducted as in the previous section, this time predicting the mother's perception of the child's QOL. As before, only those variables significant at the bivariate level for the whole group were considered: diagnosis, behavioural control (from the parent interview dimensions), worries, depression and the SF36 total score. As with the child's self-reported analysis, due to the threat of multicollinearity, the decision was taken to omit depression from the analysis due to its high correlation with the SF36 score (ρ = -0.82). Table 9.17 shows the results of this regression.

Table 9.17 Multiple regression of mother-reported QOL – whole group

	B	SE B	*Beta*	*t*	*p*
Constant	85.11	13.08		6.51	.000
Diagnosis	**-11.80**	**4.06**	**-0.32**	**-2.91**	**.005**
Worries	**-10.30**	**3.94**	**-0.34**	**-2.61**	**.011**
SF36	**0.27**	**0.11**	**0.26**	**2.47**	**.016**
Behavioural control	**-6.49**	**3.49**	**-0.17**	**-1.86**	**.068**

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	4	11635.97	2908.99	19.22	.000
Residual	58	8777.51	151.34		

Multiple R	.76
R square	.57
Adjusted R square	.54
Standard error	12.30

Table 9.17 shows that diagnosis, worries and maternal well-being (SF36) significantly added to the equation: $F(4,58)= 19.22$, $p<0.001$. This model explained 57% of the variance (R^2 adjusted = 54%). Survivors of ALL scored approximately 12 points higher on the QOL measure *as reported by the mother.* Additionally, for every one point increase in mother's worries, QOL deteriorated by 10.30 points. Examination of the SF36 scores indicates that as mother's well-being increased by one point, QOL increased by 0.27 points.

Behavioural control also had a strong tendency towards predicting the mother's proxy-reports. Specifically, for every point increase in behavioural control, the child's QOL deteriorated by 6.49 points. This narrowly missed reaching traditional significance levels ($p = 0.068$).

Since diagnosis was a significant predictor of the mother's proxy ratings (as it was for survivor self-reports), two additional regression analyses were conducted, paralleling the survivor analyses. Results are reported in Tables 9.18 and 9.19.

Table 9.18 Multiple regression of mother-reported QOL - ALL only

	B	SE B	*Beta*	*t*	*p*
Constant	*71.45*	*21.22*		*3.37*	*.002*
Worries	**-12.73**	**6.67**	**-0.31**	**-1.91**	**.06**
SF36	**0.34**	**0.14**	**0.41**	**2.43**	**.02**
Behavioural control	-1.17	4.64	-0.03	-0.25	.80

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	3	3810.57	1270.19	9.07	.0001
Residual	35	4903.13	140.09		

Multiple R	.66
R square	.44
Adjusted R square	.39
Standard error	11.84

Table 9.18 indicates that for the ALL group, the mother's proxy-rated QOL scores were significantly predicted by the mother's own well-being (SF36). Maternal worries also emerged as a strong variable, narrowly missing significance (t = -1.91, p = 0.06). Specifically, as the mother's well-being increased and worries decreased, the mother's proxy QOL ratings increased. This model was highly significant, explaining 44% of the variance (F (3, 35) = 9.07, p<0.001).

Table 9.19 Multiple regression of mother-reported QOL - CNS only

	B	SE B	*Beta*	*t*	*p*
Constant	79.53	21.66		3.67	.002
Worries	-7.64	6.10	-.32	-1.25	.225
SF36	0.27	0.23	.30	1.16	.26
Behavioural control	**-11.93**	**6.88**	**-.38**	**-1.73**	**.098**

Analysis of Variance

	DF	Sum of squares	Mean square	*F*	*p*
Regression	3	2665.88	888.63	5.16	.008
Residual	20	3440.74	172.04		

Multiple R	.66
R square	.44
Adjusted R square	.35
Standard error	13.11

For mothers of survivors of CNS tumours, their child's QOL was strongly related to the mother's use of behavioural control, but not their mental health. The variable, behavioural control was significant at the $p<0.1$ level, i.e., there was a strong trend between poorer QOL and increased use of behavioural control.

Post hoc regression analysis indicated that in all of the regressions, there were no outliers according to Cook's D reports, and the normal probability plots were acceptable.

9.9 Predictors of maternal mental health

Since the correlations between mothers proxy-rated QOL and maternal mental health (depression, SF36 and worries) were so strong (see Table 9.13), in fact stronger than the correlations with survivor self-reported QOL, three final regressions were conducted to assess whether the mother's view of the child's QOL was a stronger predictor of mother's mental health than survivor self-reported QOL. Diagnosis and chronological age were also entered as predictors. Please see Table 9.20 for a summary table of the three separate regressions.

Table 9.20 Multiple regression of maternal mental health – whole group

	Depression		**SF36**		**Maternal worries**	
Predictor variables:	*Beta*	*t*	*Beta*	*t*	*Beta*	*t*
Diagnosis	-0.16	-1.19	0.15	1.21	0.28	3.00**
Age	0.25	2.10*	-0.17	-1.56	-0.05	-0.63
Survivor s-r[1] QOL	0.17	1.18	-0.01	-0.05	0.16	1.60
Proxy rated QOL	-0.61	-4.01***	0.48	3.46***	-0.66	-6.18***
F	6.60***		5.03**		18.99***	
R^2	0.37		0.24		0.54	

**p<0.05; **p<0.01; ***p<0.001*

[1] *self-reported*

The regressions demonstrate a number of different trends. First, the survivors self-reported QOL did not predict *any* measure of the mother's mental health. In contrast, the mother's proxy-rated QOL measure predicted *every* measure. Diagnosis only had a significant effect on maternal worries, which was reflected in the bivariate results also. Similarly, chronological age only effected mother's level of depression. Variance explained ranged from 24%-54%.

The next chapter discusses both the interview and quantitative results obtained in study two.

CHAPTER TEN.

STUDY TWO. DISCUSSION

Summary

The interview analysis allowed an examination of the intricacies involved in parenting a child with cancer, a previously under-researched topic. While the parenting framework appeared to accommodate most of this data, three major themes emerged which could not be categorised satisfactorily. These were: child-rearing difficulties, survivor led interactions, and developmental changes in parenting.

The quantitative analyses also afforded an examination of under-researched relationships in this area. For example, results showed that survivors of a CNS tumour had poorer QOL and BI than survivors of ALL. In particular, past research involving BI has routinely excluded CNS survivors, despite the obvious side-effects caused by their initial disease and subsequent treatment.

Self-reported QOL (whole group) was predicted by the child's diagnosis, with a CNS diagnosis predicting poorer QOL. Assessment of each diagnostic group showed that for survivors of ALL, increased maternal mental health (SF36) predicted increased QOL, while no significant predictors emerged in the analyses of CNS self-reported QOL.

Proxy-reported QOL (whole group) was predicted by the child's diagnosis, maternal worries, mental health and use of behavioural control. Again, assessment of each diagnostic group showed different trends. For mothers of ALL survivors, increased worries and poorer mental health predicted poorer proxy-rated QOL scores. In contrast, for mothers of survivors of CNS tumours, poorer proxy-ratings were predicted by mother's increased use of behavioural control.

The generic parenting questionnaire (Chapter 7) failed to relate to self- or proxy-reported QOL. Results from the interview analysis were used to enhance and expand on the quantitative results obtained in Study Two.

10.1 Introduction

The results of both the interview and quantitative analyses will be discussed according to the original aims set out in Chapter 8, namely to explore the relationship between (1) disease / disability factors and (2) social-ecological factors, and child adaptation (QOL / BI), following the risk and resistance model outlined by Wallander et al. (1989b) in Chapter 2.

10.2 Disease / Disability Factors and child adaptation

As predicted, survivors of CNS tumours self-reported poorer QOL and BI than survivors of ALL. Specifically, survivors of CNS tumours self-reported poorer physical, social, school functioning and total QOL than survivors of ALL. Furthermore, in comparison with published norms, survivors of CNS tumours had poorer QOL than healthy children. Survivors of ALL did not have significantly different scores from published norms. In terms of their BI, survivors of CNS tumours had poorer body awareness, general appearance and overall BI than survivors of ALL. These results are consistent with the relationship between disease / disability factors and child adaptation outlined by Wallander et al. (1989b; Chapter 2). Specifically, the child's diagnosis (brain involvement) had a direct effect on child QOL and BI.

While the BI results are intriguing, considering that studies of this kind routinely exclude children with CNS tumours (e.g., Pendley et al., 1997), caution must be exercised because of the small numbers involved. Future work should be conducted with larger samples in order to replicate these findings.

Also as predicted, mothers of survivors of CNS tumours reported poorer QOL for their children than did mothers of ALL survivors, in all sub-scales and the total QOL score. In contrast to the survivors' self-reports however, both mothers of survivors of CNS tumours and ALL reported significantly poorer QOL scores when compared with published norms.

These results agree with previous work suggesting that children with CNS tumours have poorer functioning than children with non brain-related malignancies (cf: Glaser et al., 1999; Mulhern, 1999). Armstrong et al. (1999) also showed that children with CNS tumours had poorer QOL than did children with leukaemias / lymphomas and solid tumours. While this study is to be commended for obtaining homogeneous cancer groups, they only obtained parent reported QOL scores. The present study adds to the current literature by assessing both mother *and* child self-reported QOL. Both Armstrong et al. and the present study together suggest that future research involving children with cancer must try as far as possible to obtain single diagnostic groups given the discrepancies between children with different cancers. In addition, children with cancers involving the CNS must be assessed furthermore to obtain a deeper understanding of the impact both the initial tumour and subsequent treatment has on later functioning. This study has afforded a glimpse into this groups' functioning, but there is a long way to go before the experiences of children with CNS tumours are fully understood.

The next set of predictions concerned the difference between proxy and self-reported QOL data. For survivors of ALL and their mothers, the only difference was found in their ratings of social functioning, the other sub-scales did not differ significantly. In contrast, there were marked differences in emotional, social functioning and total QOL when survivors of CNS tumours and their mothers were compared[1]. This finding has been reported in other chronic illness literature (Bruil, 1999; Ennett et al., 1991; Vance, Morse, Jenney, & Eiser, 2001).

One explanation for the high agreement between ALL survivors and their mothers is

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[1] For more information on proxy issues in this data set, please see C Eiser, Y H. Vance, B Horne, A Glaser, H Galvin (submitted). The value of the PedsQL^{TM} in assessing quality of life in survivors of childhood cancer. Journal of Child Psychology & Psychiatry.

that these survivors were of an age (M = 13.75 years) where they could verbalise their emotions more coherently to their mothers than could the younger children. Alternatively, since a high proportion of these survivors were functioning very well and scoring at ceiling levels, there was less room for disagreement between survivors and their mothers. This is supported by the fact that up to 37% of ALL survivors self-reported ceiling levels on the QOL subscales, compared with up to 32% of mothers. No floor effects were found for either mothers or survivors.

In contrast, survivors of CNS tumours and their mothers did significantly differ on many aspects of QOL. This could potentially be explained in a number of ways. First, mothers may have projected their mental health problems or worries for the survivors onto their present QOL ratings, resulting in lower scores than may otherwise have been expected. Second, the survivors may have been overly optimistic about their QOL, or generally not understood the questions, resulting in inflated scores. Third, survivors may have been less able to communicate their feelings to their mothers, therefore increasing the discrepancy between mothers' and survivors' scores. Further work needs to be done in order to resolve these issues.

As predicted, increased time since diagnosis did not correlate with the child's self-reported QOL for either diagnostic group. This replicates the finding reported in study one and again contrasts with Varni et al. (1998; 1999) who reported on- vs. off-treatment group differences. The current finding adds to the suggestion that once children have passed the acute period of treatment, or are off active-treatment, the perception of their own QOL does not change significantly. In contrast, time since diagnosis did correlate with one aspect of proxy rated QOL: mothers of survivors of CNS tumours reported poorer social functioning for those who were further from treatment. This agrees with previous research that has shown that survivors of CNS tumours have difficult peer relations, experiencing isolation and social withdrawal (Noll et al., 1992; Vannatta et al., 1998b), especially during adolescence. Time since diagnosis did not correlate with ALL proxy reports.

Considering chronological age as a continuous variable, younger survivors of CNS tumours self-reported better emotional functioning, well-being and total QOL than did older survivors of CNS tumours. Post-hoc explanations for this may be that as survivors of CNS tumours get older they are more aware of their limitations and become increasingly despondent. These problems may be exacerbated as they try to find jobs, a partner, or develop closer peer relations. Younger children may still be unaware of the future consequences of their illness. These are issues that could be followed-up in future longitudinal research. There was however no significant effect of age when child (8-12) vs. teen (13+) reports were assessed in relation to QOL, suggesting the absence of an ordinal age effect. In particular, it might be hypothesised that QOL diminishes in young adults who are approaching school leaving age, or an age where romantic relations become salient. Unfortunately, this could not be tested quantitatively as the number of survivors over 16 years old (school leaving age) was too small. However, drawing upon the interview data, mothers did discuss a number of worries they had for their children during this time. This topic is addressed in more detail during the clinical implications section (11.2) in Chapter 11. In particular, it is suggested that children and families are given more support during this difficult time, for example with respect to opportunities for school leavers. There were no age effects on QOL for children with ALL, either using continuous or dichotomous analyses. However, their mothers reported that older children had better school functioning.

Finally, there was no effect of chronological age on BI. This is perhaps not as surprising as initially thought. For example, while the BI literature discussed in Chapter 2 showed that BI worsens with age (Pendley et al., 1997), in the current study only adolescents were assessed due to the lack of a suitable measure for younger children. Perhaps if an appropriate measure had been available to assess a wider age-range, BI would be shown to diminish with age. Again, further work is needed to resolve these issues.

To summarise, the pathway between disease / disability factors and child adaptation was partially confirmed. Specifically, malignancies involving the child's brain was a significant risk factor in predicting poor QOL and BI. No other variable emerged clearly from the data.

10.3 Social-ecological factors and child adaptation

10.3.1 Family environment / parenting behaviours

Two very different approaches to assessing parenting behaviours were used in study two. First, mothers were interviewed regarding their thoughts and feelings regarding parenting a child with cancer, with the resultant transcripts being subjected to a rigorous qualitative analysis. Excerpts pertaining to parenting were categorised within a pre-existing parenting framework derived from key parenting texts (Baumrind, 1971; Gray & Steinberg, 1999; Maccoby & Martin, 1983; Steinberg et al., 1989) that was introduced in Chapter 8 and reported fully in Chapter 9. In addition to this verbatim analysis, the resulting categories (warmth, psychological control and behavioural control) were quantified and used within the quantitative section of the analysis in Chapter 9, i.e., the interview analysis produced data that could be interpreted both qualitatively and quantitatively. The second way of assessing parenting behaviours in study two involved using a generic questionnaire measure of parenting, developed especially for this thesis (Chapter 7). This questionnaire resulted in three parenting scores: authoritative, authoritarian and permissive.

Results will be considered in two sections initially: (1) the interview analysis in terms of the breadth and depth of categories, the applicability of the parenting coding framework used, and the unexpected themes that emerged from the data; and (2) the quantitative findings (from both the coded interview data and the generic measure of parenting).

As can be seen in Chapter 9, mothers discussed a wide range of topics during their interviews. The sheer breadth of issues reviewed in this chapter was far richer than anticipated. For example, mothers talked at length about ways of improving body image, communicating about the illness, encouraging autonomy, and teaching everyday skills such as paying bills. More often than not, these excerpts could comfortably be coded within the warmth, psychological and behavioural control framework outlined earlier. Therefore, it would seem that this framework, developed and used with healthy US populations, can be applied to a chronically ill sample. There had previously been criticisms that the parenting theories developed for use with white, US families did not apply to ethnic minority groups, including Bermudan (Deater-Deckard & Scarr, 1994) and African-American (Deater-Deckard et al., 1996) families, therefore there were questions about the applicability with chronically ill groups (see Chapter 4).

Three themes however, emerged from the data that could not be coded within this framework. These were (1) difficulties with child-rearing, (2) child led mother-child interactions, and (3) developmental concerns (see section 9.3). Many of the quotes within these categories were illness-specific, such as the fear of relapse affecting parenting decisions, but many were not, such as the child being stubborn and refusing to discuss issues with the mother. This suggests that while the parenting theory is suitable for use with chronically ill samples, there is a considerable amount of data that could not be accommodated within the constraints of the framework. This suggests that future parenting frameworks should expand to include some of the issues raised in this analysis. Within the remainder of this discussion, the interview results will be referred to routinely as a way of defending or elaborating the results of the quantitative results, which are reported next.

If the quantitative results are now considered, it can be seen that contrary to predictions, neither the optimal aspects of parenting (authoritative, warmth and psychological autonomy) nor the sub-optimal aspects (permissive or authoritarian)

correlated with QOL (as reported by the survivor or mother). One reason for the failure of optimal parenting behaviours to correlate with child QOL may be that only mothers who are warm and involved with their child agree to take part in research projects of this nature. By definition, they are involved with their child if they agree to help out in cancer research aimed towards improving their child's care. One concern is that, since medical staff recruited families, there may have been a conscious or unconscious recruitment bias, in which the medical staff failed to approach certain families who they felt were not appropriate for the study or were not coping well enough to participate. While the clinic staff were pressed to approach all families, there may have been a few families who were not approached. Unfortunately, this selection bias could not be controlled for since ethics committee stipulations demanded that medical staff recruit patients. Alternatively, it may be that parents who are not particularly warm or involved with their child's care may not attend clinic in the first place, leaving recruitment impossible.

However, what emerged from both the bivariate and multivariate analyses was that decreased QOL was related to increased behavioural control, as reported by the mother. When the diagnostic groups were separated, this finding only emerged for those with CNS tumours ($p < 0.1$). This appears to confirm initial predictions: those survivors requiring the greatest amount of behavioural control were those with the greatest number of problems, i.e., those with the poorest QOL. Considering the current sample, the survivors of CNS tumours were, indeed, those with the greatest need of assistance. This was also reflected time and time again in the interview analysis. For example, many children had to re-learn developmental tasks, such as walking or washing, others needed almost constant attention and monitoring, with clear boundaries on their behaviour. Many mothers talked of how their child was not a normal teenager, and could not be left alone in the house, go shopping with friends, even take responsibility for personal grooming. For example:

But we try to....you know we gave him a sponge and he put loads of like you know shower gel on and he said to him 'right go like that' and we always say to him right

you know 'Clean yourself you know, down below' and things like that but he like he can't do his hair. But if he's in the shower like, he's ok once in the shower but he's still not getting all the bubbles off him so you've got to push him back inside the cubicle again, its a 'get in there'.. He can't do things like just a normal bath routine cos the thing is cos like, he'll easily slip and he can't wash his own hair in the bath....obviously I have to do it. So I'm sorting out his PE kit for him, getting his shoes and his coat together, then go back upstairs, do his teeth cos like he needs help you know, you've got to do his teeth for him **(mother of a 12-year-old CNS tumour survivor)**

Mothers talked of how they would try and encourage their child to become more independent, while setting limits on their behaviour. These limits were not age-appropriate as they would be for normal healthy teenagers, but were essential for the child's safety and security. Therefore, the negative relationship between behavioural control and QOL makes sense: those children who have a poorer QOL, or more long-term problems, need increased behavioural control. This agrees with previous literature: children with chronic illnesses may need high behavioural control whereas medium levels are optimal for 'normal' healthy children (Gray & Steinberg, 1999; Kurdek & Fine, 1994; Wertlieb et al., 1986). This finding extends existing developmental theory by demonstrating the different trends in parental control that emerge when non-healthy samples are studied. It also demonstrates the link between specific parenting practices (a social-ecological factor) and child adaptation (Wallander et al., 1989b).

Using the theoretically driven generic questionnaire developed in Chapter 7, authoritative, authoritarian and permissive parenting did not relate to medical (e.g., diagnosis, time since diagnosis), demographic (e.g., chronological age, gender) or child QOL variables (section 9.5). Therefore, it seems advantageous to consider these results in light of the interview analysis before remarking on any specific methodological concerns there are with the measure. As mentioned earlier, three themes emerged from the analysis that could not be coded within the parenting framework. To recap these were, (1) **difficulties with child-rearing**, for example spoiling and being overprotective, worries about relapse, and changed parenting

outlooks; (2) **child led mother-child interactions**, for example where the mother may try to discuss the illness, but the child refuses to communicate; and (3) **developmental concerns**, for example where use of certain parenting behaviours seems inappropriate given the age of the child.

Do the items in the theoretically driven questionnaire overlap with those issues raised by mothers?

The first emergent theme refers to child-rearing difficulties that mothers spontaneously discussed during the interview, such as excessive spoiling and being overprotective. Within the questionnaire measure, there was only a single item assessing spoiling, "*I spoil my child*". Considering the richness of data obtained in the interview analysis concerning spoiling, it is clear that this single item could not begin to capture the essence of this construct. For example the interview analysis highlighted a range of 'spoiling' responses, from one mother who placed herself in debt due to excessive spoiling, to others who felt torn between wanting to spoil their child and feeling that it might have long-term negative behavioural consequences.

Yet while scant attention was paid to the subject of spoiling, no mention at all was made to issues of overprotectiveness in the questionnaire measure. Interestingly, in a recent review of the central parenting constructs studied in 'normal' parenting research, Holden and Miller (1999) discussed the difficulty involved in categorising certain constructs, one of them being *overprotectiveness*. In their review, however, studies that assessed clinical samples were excluded, which would include studies similar to the present. Therefore, this finding suggests that feelings of overprotectiveness are felt by many parents, not just parents of ill children, but are ignored in current parenting frameworks and measures.

During the interviews, many mothers discussed how their outlook on parenting and life in general had changed as a result of the illness. This appeared to be a relatively common theme running throughout the transcripts, but perhaps is one that is out of

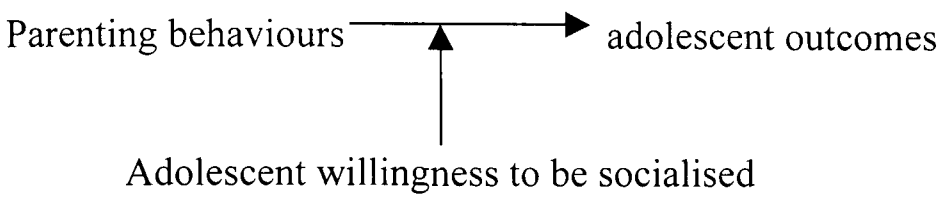
place in a generic measure of parenting. However, the child's illness was certainly a key component of the reassessment of priorities and the best way to parent, and these changes are in no way assessed in traditional questionnaire assessments of parenting. Unsurprisingly, considering the generic nature of the instrument, there were also no items in the questionnaire concerning how fears of relapse and side-effects of the illness affected parenting behaviours. These two themes were prominent in the transcripts and certainly had an impact on the way children were reared. Again, the interview analysis highlighted the discrepancy between what mothers feel are important child-rearing issues and what is routinely assessed in parenting measures. In future work it is suggested that parenting measures be more grounded and represent mother's views more closely, by being based on actual parenting interviews. This is a topic returned to in the future directions section of Chapter 11.

The second theme that emerged from the interview analysis concerned the control that the child had during mother-child interactions. Interactions were by no means always mother driven. This is not an altogether surprising finding given recent discussions about the bi-directional relationship between mothers and children (Holden, 1997; Holden & Miller, 1999). Another increasingly popular way to think about this relationship is to consider the child as a moderator, i.e., the child's readiness to interact with the parent may moderate the pathway between parenting behaviours and child outcomes. For example, Darling and Steinberg (1993) reported that an adolescent's willingness to be socialised by the parent moderates the impact of their parents behaviour on the adolescent's outcomes (see Figure 10.1).

This emergent pattern is very interesting in light of a number of items from the questionnaire measure, e.g., "*I encourage my child to talk about his/her troubles*" and "*I help my child to understand the impact of behaviour by encouraging him/her to talk about the consequences of his/her own actions*". In situations such as these, the child may dominate the interaction and be unwilling to talk to the parent, leaving the

parent unsure of how to respond to such items – the parent may try to engage the child in discussion but fail.

Figure 10.1 Moderating effect of adolescent willingness to be socialised on the pathway between parenting behaviours and adolescent outcomes (Darling & Steinberg, 1993)



In future work, it may be useful to assess dialogue between mothers and their children in order to assess this environment in more depth. This would allow an investigation of the subtle ways mothers and their children interact, and to assess in detail both the bi-directional and moderating theories. Requesting mothers and children to engage in conversation and then analysing these excerpts qualitatively would be a potentially interesting move forward in the study of parenting.

Finally, the last theme to emerge from the interview analyses was that of developmental changes in parenting behaviours. That parenting did not change with the child's chronological age on the generic measure was a most intriguing finding. However, it may have been that parents did not know how to respond to some of the questionnaire items. For example, the item "*I do not allow my child to get angry with me*" is very awkward. What does it mean by 'not allow'? With a teenager it might be impossible to curtail arguments, while it might be more feasible to stop a toddler arguing with his/her parents. A number of other items seem rather unusual, especially considering that the majority of the sample in study two were adolescents. For example, "*I allow my child to annoy someone else*", "*I allow my child to interrupt others*", and "*I believe it is unwise to let children play a lot by themselves without supervision*". These items appear inappropriate for completion by parents of older

children. While it is difficult to suggest how parenting measures may be improved, it is worth bearing in mind that parenting does change across time and the format of future measures should attempt to incorporate these changes.

Methodological problems

In addition to these concerns with the questionnaire items, there are also doubts about the format of the questionnaire, in particular the instructions for completion. Specifically, as there is no time scale in the instructions for completion, it is impossible to tell if parents responded in the past or present. For example, if the issue of spoiling is returned to, many parents may have spoiled their child during the illness, but ceased to do so after treatment ended. However, since the research visit concerned the 'illness', parents may have been inclined to answer the item thinking of the past, not the present.

A number of concerns have also emerged regarding the scoring of the instrument, and in particular, the specific make-up of the resultant subscales. For instance, if we think back to the information presented in Chapter 4, authoritative parenting consists of obtaining a balance between high control with high warmth, authoritarian consists of high control with low warmth, while permissive parenting consists of low control with high warmth (Maccoby & Martin, 1983). While the questionnaire is designed to give parents a score for each of the three constructs, they are not broken down into control and warmth elements specifically. Considering the literature reviewed in Chapter 4 concerning different aspects of control (behavioural and psychological), it is easy to see how subtle differences between parents may be lost. As discussed previously, classifying parents as 'controlling' does not capture the subtle ways parents *actually* control their children, and often can lead to confusing and inconsistent results (Gray & Steinberg, 1999). To give an example, while a diagnostic difference between parents of survivors of CNS tumours and ALL in terms of their levels of *behavioural* control may be expected (see rationale, Chapter 8), there is less

reason to expect a difference in terms of psychological control or warmth. These subtle differences would be lost in this particular questionnaire.

Finally, a fundamental problem may be that the generic measure of parenting is too old or inappropriate for use with the current sample. The measure was based on the CRPR (Block, 1965) and further refined by Robinson et al. (1995), before being piloted in the current thesis (Chapter 7). While the pilot work resulted in adequate internal consistency estimates (alphas = 0.62 – 0.77), some of the items may have been awkward for parents to complete comfortably. While the most dated items were removed after the first pilot study (e.g., *"I believe that a child should be seen and not heard"*), some of the items continued to appear clumsy or even slightly threatening (e.g., *"I teach my child that bad behaviour will always be found out"*). Parenting has changed since the 1960s and parenting measures should reflect these changes.

To summarise, the relationship between parenting behaviours and child variables gave mixed results. While behavioural control did relate to the QOL of CNS survivors (proxy report), the generic measure gave disappointing results and did not relate to medical, demographic or child QOL variables. However, these results were discussed in relation to the themes that emerged during the interview analysis and methodological concerns with the measure. This qualitative-quantitative comparison highlighted major differences in traditional parenting questionnaires and what mothers spontaneously discussed as being challenging child-rearing issues.

10.3.2 Family members' adaptation / maternal mental health

Predictions regarding maternal mental health were partially confirmed: mothers of survivors of CNS tumours reported more worries than did mothers of survivors of ALL, but were no more depressed nor did they have poorer well-being. Mothers of survivors of ALL and CNS tumours did not have a poorer well-being than published norms for healthy women. However, mothers of children with CNS tumours were significantly more depressed than were a healthy sample of women. There was not,

however, any clear pattern regarding why some mothers scored above the threshold on the CES-D. This could not be attributed to the child's diagnosis, thereby leading to rejection of the hypothesis outlined in Chapter 8.

One future avenue of research would be to investigate why some mothers adapt to their child's illness and others do not, since this could have great clinical implications. As a suggestion, one fruitful area of investigation may lie in the assessment of support services parents receive. Again, drawing on the interview analysis discussed in Chapter 9, many parents discussed the role family and friends played in, during, and after the child's treatment; others discussed professional support, or the role charities had. It could be hypothesised that parents who did not perceive much support (personal or professional) may be more depressed and anxious than parents who reported adequate support. Interestingly, social support and utilitarian resources are two other components of the social-ecological category within Wallander et al.'s (1989b) model (see Figure 2.1). In their own empirical work, Wallander et al. (1989d) reported that psychosocial family resources and utilitarian services were significant predictors of maternal adaptation in their sample of mothers of handicapped children (see Chapter 2 for details of this study).

It was perhaps not surprising that mothers did not differ on the SF36 sub-scales since many of these assess physical health. There seems to be less reason why mothers of children with cancer would have poorer physical health than mothers of healthy children. However, it was expected that they would differ on more psychological issues, such as mental health, role limitations due to emotional problems and social functioning. While both mothers of survivors of ALL and CNS tumours significantly differed from the norms on the latter, they did not differ on the two former sub-scales. One explanation could be that mothers of survivors of childhood cancer are particularly resilient. It may be that after this length of time, regardless of their child's physical and psychological status, they had adjusted their lives to accommodate these problems. While they did worry more, they did not have significantly poorer mental

health. This is intriguing given that the worry scale is about their child's future health and functioning, whereas the mental health measures are about their own functioning. Perhaps mothers are resilient enough to cope with their own negative feelings, but continue to concern themselves about their child. Alternatively a more worrying explanation is that only mothers who were adjusting well agreed to take part in the study in the first place. Mothers who were adjusting poorly may not have wanted to take part in research assessing their own and their child's functioning.

As predicted, poorer maternal mental health correlated with poorer child and proxy-rated QOL. Correlations between each of the mental health measures and the five QOL sub-scales were reported in Table 9.13. This allowed an examination of the specific subscales that were strongly correlated with maternal mental health. Considering both the SF36 and depression measures first, the only nonsignificant correlations were with the child's physical functioning, while the most powerful correlations were with the child's emotional functioning. The child's school functioning did not correlate with SF36 scores. These results appear to demonstrate that it is *how* the child feels that matters to the mother, more than *what* they can externally achieve in terms of physical or school capabilities. Perhaps after all these children have been through, these achievements do not matter so much to mothers. In contrast, all five QOL sub-scales correlated very strongly with maternal worries. Therefore, while the child's external functioning did not effect maternal SF36 and depression scores, they are still cause for considerable worry.

Similar patterns emerged for the survivor self-reported QOL data and maternal mental health correlations. School functioning had the lowest correlations with both mental health questionnaires, SF36 and depression, while emotional functioning had the highest correlations. This seems to suggest that again, how the child feels has the strongest impact on maternal mental health rather than what they achieve. The correlations between worries and child self-reported QOL showed no real pattern. However, it appeared that social functioning had the strongest effect on maternal

worries. This is perhaps not surprising given that a number of items in the worry scale addressed future social relationships, such as finding a boy/girlfriend and getting married. It may be that mothers worry more where their child is having social problems.

Finally, confirming the presence of the new pathway between disease / disability factors and mother's mental health (see figure 8.1), mothers of children who were older at diagnosis worried more about their child, had poorer mental health (SF36) and were more depressed. These results concur with study one: better parental mental health is significantly associated with younger age at diagnosis. Furthermore, mothers of children who were older at assessment had poorer mental health, were more depressed generally, and likely to score at-risk levels of depression.

To summarise, mother's mental health and degree of worries were strongly related to child QOL (self- and proxy-reported). Evidence for a new link between disease / disability factors and mother's mental health was also provided, suggesting that it be accommodated with Wallander et al.'s (1989b) model. The next section discusses predictors of child and proxy-rated QOL in more depth, incorporating those variables significant at the bivariate level.

10.4 Child self-reported QOL

The child's diagnosis was the sole predictor of child QOL when the whole group was assessed. However, two additional regressions assessing the ALL and CNS groups separately revealed that maternal mental health predicted QOL for the ALL group, but no variable predicted the QOL of CNS tumour survivors. This replicates the finding in study one (Chapter 6): for children with ALL, QOL increases as their mothers mental health increases.

Parenting behaviour variables however, did not predict ALL survivors self-reported QOL (unlike study one in which force predicted poorer child QOL). Post-hoc

explanations for this may be that children of this age may be less dependent upon parents and more reliant on peers. Supporting this view, Harris (1998) suggested that peers have a much more important role than do parents, causing much upset to traditional developmental theorists. Alternatively, thinking back to one of the themes discussed earlier (section 10.3.1), a possible explanation may be that the generic measure did not adequately assess parenting in this age group. Recall that some of the items may have been awkward for parents of adolescents to complete and also that developmental changes were amongst those themes that could not be coded within the parenting framework. This may explain why parenting did not appear to influence the QOL of ALL survivors.

Explanations for the lack of predictions within the CNS group are more difficult however. One reason may be that these children have so many cognitive and psychological late-effects that their mother's mental health and parenting behaviours did not have any additional effect on them over and above their own problems. Again, borrowing from the interview analysis, it seemed as if some mothers sheltered their children from their own feelings of depression or anxiety. This is a matter returned to and discussed in the next section.

It is difficult to predict what would influence the QOL of CNS survivors, considering the paucity of past research assessing the functioning of CNS survivors. One exception would be to think about peer relationships, which have previously been assessed within this group. For example, Vannatta et al. (1998b; see Chapter 2) reported that children with CNS tumours were described by teachers, peers and self-report as being socially isolated. Children with CNS tumours were selected less often as a best friend by peers, but general liking ratings were no different from peers. Similar findings were reported by Noll et al. (1992), but no self-reports were obtained in this study. Similarly, peer relationship problems *were* commonly discussed by mothers during their interviews. For example,

Q: How does she get on with other kids her age?

She doesn't. .. Well, she doesn't as far as we're aware. She comes home upset most times, saying she hasn't got any friends, she can't mix with people. We never have any of N's friends around here. She never even asks for anybody to come around...she tends to mix more with the, the boys in her class than she does the girls. I think the girls have ridiculed her and they've, they've picked and bullied. At one time we had to stop that, because they don't understand. Children are cruel. They just don't understand.
(mother of a 14-year old survivor of a CNS tumour)

It might be predicted that if we had gathered information concerning the child's peer relationships systematically, or administered questionnaire assessments of peer relationships, the QOL of CNS survivors may have been predicted. Again, there is much scope for future work.

10.5 Mothers proxy ratings

For the whole group, the child's diagnosis, maternal worries and well-being (SF36) predicted the child's QOL. Behavioural control was also a predictor, although narrowly missed reaching traditional significance levels. However, between cancer-group comparisons again showed different trends. For mothers of survivors of ALL, maternal worries and well-being predicted QOL scores (not behavioural control). In contrast, for mothers of survivors of CNS tumours, behavioural control was a predictor of QOL scores (not worries or well-being).

Similar to the ALL survivor self-reported findings, parenting behaviours did not predict proxy-rated QOL among mothers of ALL survivors. Again, the parenting interview data can be used to aid interpretation of the quantitative results. In particular, the lack of the parenting framework to accommodate developmental trends and the awkward wording of certain items for completion by mothers of adolescents may help explain the lack of a parenting influence among this group.

Findings for mothers of survivors of CNS tumours findings were unexpected. While behavioural control was expected to play an important role in the child's QOL, it was

also expected that mothers mental health would effect how they perceived their child's QOL (as it did with the ALL proxy reports). However, this was not found. Post-hoc explanations provided by the interview data indicate that mothers try to protect or shield their children from their own worries in an attempt not to concern their child. For example,

I try to get philosophical and think I'm wasting good time just worrying and all it does is make me feel poorly. So if something's going to be, it will be. If something comes along now, then I'll wait and see, because I've done it before, jumped to that conclusion and Its been a virus or something and then you're thinking I've done all that worrying, and that has an effect on D, it worries him if I worry. So I try not to.
(mother of an adolescent with post-cancer cognitive and physical impairments)

Perhaps these mothers have tried not to exacerbate their child's already extensive long-term consequences by adding their own worries and concerns. When completing the QOL proxy questionnaire they may have put their own concerns to one side. This may also explain why maternal mental health did not predict the self-reported QOL of CNS survivors (see above, section 10.4). To give an example, despite being worried about the child, this mother had to put these feelings to one side to allow her child to be 'normal':

She can make a cup of tea, she can use a kettle, but she finds the cooker very difficult. I think a lot of it is because she has to use her left hand. She's right-handed really, but it was her right-hand side that was affected with the tumour, so she uses her left hand now. But she does find things quite difficult really..she forgets how to do stuff. I suppose that's when I just step in and take over, because I'm frightened of her hurting herself.

Q: Would you leave her alone in the house?

Mrs.: I have started doing, because I've had to I've been really worried about leaving her in the house, but I've had to, and I have to keep telling myself that she's 15 now and that sometimes I do have to go out.
(mother of a 15-year old girl survivor of a CNS tumour)

To summarise, for survivors of ALL and their mothers, QOL scores were predicted

by the mothers mental health, but not their parenting behaviours. However, for the CNS group, the mother's QOL scores were predicted by parenting behaviours, but not their mental health. The self-reported QOL of survivors of CNS tumours could not be predicted. Interpreting these results was helped immensely by the data provided by the interview analysis. Again, this points to the strengths of gathering both qualitative and quantitative data.

10.6 Mother's mental health and worries

The final regression analyses (Table 9.20) assessed the variables from a different perspective, i.e., QOL data (survivor and proxy reported) was used to predict maternal mental health and worries. In all three cases (SF36, depression and worries), the mother's proxy-rated QOL was a significant predictor of mother's functioning, while the child's self-reported QOL was not. Other patterns emerged: diagnosis (CNS, ALL) did not predict mother's mental health, but did predict degree of worries, while chronological age had a significant effect on mother's depression. These results demonstrate the strong relationship between maternal mental health and how they view their child. This 'depressive bias' was first discussed in Chapter 2 (see specifically Manne et al., 1995; 1996) and shows the power of mother's mental health in predicting child functioning. It would be useful to assess this finding furthermore, by perhaps, recruiting other respondents such as the father or teacher. Is the mother too subjective to rate the child's objective functioning? Or perhaps the mother has a particularly realistic view of the child and has managed to rear the child to have a very optimistic self-image. This is a very interesting issue and ought to be assessed furthermore.

10.7 Limitations and Strengths

First, the size of the included sample was only 67.2% of the recruitable hospital list. There was no way to compare participant with non-participants since we did not receive any non-respondent data from the hospital. All recruitment was conducted in the hospital by the late-effects nurse. Despite the small number of children included

compared with the projected sample, the sample size was large relative to many other cancer studies.

According to Cohen (1992), the present sample of 77 children / 75 parents is almost large enough to detect medium effect sizes with alpha = 0.05 and a power of 0.80 in correlational and regression analysis (including 4 IVs in the latter) (Cohen stated N = 85 and 84 respectively, similar to the present sample size). Therefore, although the sample was smaller than expected, the power of the calculations was adequate for the present analyses.

Second, while we attempted to obtain adolescent reports of their parent's behaviours, we were unable to use this data as we obtained too few reports. However, obtaining child self-reports is to be recommended in future work since it is widely accepted that the child's own views of their parents may be a more important predictor of child outcomes than parental self-reports (Buri, 1989; Smetana, 1995).

Notwithstanding these limitations, study two showed many strengths. The sample included two groups of children with cancer: those with CNS tumours and those with ALL. Considering the lack of specific cancer work, it was a move forward to acknowledge the unique problems involved with different diagnoses. Second, QOL was assessed from both the child's and mother's perspective. Results showed that these viewpoints can differ, depending on the diagnosis. Third, adolescent self-reported BI data was obtained. Studies of BI are scarce, and rarer still are accounts of children with CNS tumours. Fourth, parenting was assessed using two very different methodologies, something not previously done in the cancer literature. In particular, the interview data was particularly useful when interpreting both expected and unexpected quantitative results. Fifth, the assessments of maternal mental health were improved in this study. The CES-D is a more everyday assessment of mood, rather than the GHQ-32, the assessment of severe depression used in study one.

CHAPTER ELEVEN.

GENERAL DISCUSSION

11.1 How appropriate is Wallander et al.'s (1989b) model of risk and resistance for work in this area?

In Chapter 2, Wallander et al.'s (1989b) risk and resistance model was introduced, followed by key findings from their own research (Wallander et al., 1989a-d). Within this thesis, disease/disability factors (risk factors) and social-ecological factors (resistance factors) were assessed in relation to the child's adaptation / QOL. This section discusses whether the current findings provide evidence for these pathways, and how the results can build upon the existing model.

11.1.1 Do disease / disability factors relate to the child's QOL?

While Wallander et al. (1989b) stressed the theoretical importance of disease / disability factors in directly influencing the child's adaptation, they failed to find any strong empirical evidence for this pathway. These findings led Wallander et al. to put forward a non-categorical approach to studying chronic childhood illnesses (see Chapter 2), which suggests that the similarities between chronic illnesses are greater than their differences. However, a number of conflicting findings with this approach have emerged from both the current work and previous cancer literature suggesting that it is unwise to group together children with different chronic illnesses. For example, within study two, children who had been diagnosed with and treated for a CNS tumour (i.e., brain involvement, a risk factor) had significantly poorer QOL and BI than children with malignancies not involving the CNS (section 9.5). In fact, for the child's self-reported QOL (section 9.7), diagnosis was a stronger predictor than any psychological variable entered into the regression equation. Similarly, mothers of survivors of CNS tumours reported poorer proxy-ratings of their child's QOL than mothers of survivors of ALL (section 9.5). Previous cancer research (see Chapter 2) has also shown that children with CNS tumours had more problems than children with cancers not involving the brain, such as being absent from school more often (Lansky et al., 1983) and having more social relationship problems (Noll et al., 1992; Vannatta et al., 1998a). Therefore, there is opposing evidence for Wallander et al.'s non-categorical approach, with CNS involvement emerging as a particularly important risk factor.

In the current thesis neither on- or off-treatment status nor time since diagnosis, were related to child QOL. This contrasts with research published by Varni et al. (1998; 1999) who reported that children receiving active treatment had poorer QOL than those who had completed treatment, as measured by both the PCQL-32 and the PedsQL. One explanation for this may be that Varni et al. recruited large groups of children, whereas only a very small sample of children on-treatment were recruited in study one, perhaps too small for sufficient statistical power. Alternatively, as discussed in section 6.6, this may be a US-UK difference, attributable to the use of anaesthetic during painful medical procedures.

The presence of a new pathway between disease / disability factors and parental mental health (a social-ecological resistance factor) was shown in both studies one and two (see figures 6.1 and 8.1). In particular, older age at diagnosis emerged as a significant risk factor, being related to poorer parental mental health in both studies one and two. Additionally, mothers of children with CNS tumours were significantly more worried about their children than mothers of ALL survivors.

These results indicate a need to re-think which disease / disability factors are important to study in relation to child and family members' adaptation. Both past cancer research and work presented in this thesis have shown that disease / disability factors can individually effect both child QOL (brain involvement) and parental mental health (age at diagnosis and brain involvement).

11.1.2 Do Social-ecological resistance factors relate to the child's QOL?

Two social-ecological factors were studied in relation to child QOL: family members' adaptation and family environment. The former was operationalised as mother's mental health, health-related worries, and in study one, stress and child vulnerability. The family environment was assessed using measures of parenting behaviour.

Wallander et al. (1989d) reported that maternal functioning (general 'malaise') was not related to the child's adaptation to handicap. This contrasts with studies

one and two in that maternal mental health did relate to child adaptation (QOL). First, for children with ALL (both studies), poorer self-reported QOL was related to poorer maternal mental health. Second, in study two, mothers who worried more had children with poorer QOL (self- and proxy-reported). These results concur with previous cancer literature which has shown positive links between maternal mental health and child adaptation, both during (e.g., Manne et al., 1995, 1996; Mulhern et al., 1992) and after treatment (e.g., Kazak & Barakat, 1997; Sloper et al., 1994) (see Tables 2.1 and 3.1 for a summary of this research).

Previous support for the relationship between the family environment and child adaptation has been provided in a number of ways in this thesis, both theoretically and empirically. Theoretically, the relationship between the family environment and child adaptation was clearly shown in chapters 4 and 5. These chapters demonstrated the relationship between optimal parenting behaviours, such as authoritativeness and positive discipline practices, and positive child outcomes, in both healthy (Chapter 4) and paediatric oncology (Chapter 5) samples.

Empirically, within study one, parents endorsement of force in normal childhood situations significantly predicted the self-reported QOL of children with ALL (Chapter 6). Within study two, while the questionnaire assessment failed to predict child QOL (self- or proxy-reported), the mother's self-reported use of behavioural control (interview data) predicted the QOL of (a) the whole group and (b) survivors of CNS tumours (proxy report). These findings point to the importance of normal parenting behaviours in affecting the child's QOL and underscores the importance of including normal aspects of development within theories predicting child adaptation.

The interview analysis also provided a richness of data not yet reported in the cancer literature. This data was used to help explain the quantitative parenting results and illustrate the limitations of current parenting assessments (see Chapter 10). Specifically, three themes emerged from the interview that mothers discussed spontaneously. These patterns were fully discussed in Chapter 10 and highlighted the discrepancy between what mothers felt was problematic in rearing a child with

cancer and the items included within the generic measure of parenting developed in Chapter 7.

11.1.3 Child adaptation

Within Wallander et al.'s (1989b) model, child adaptation was defined as representing the child's mental health, physical and social functioning. Within this thesis, child adaptation was assessed using a multidimensional measure of QOL, which was chosen for its close resemblance to Bradlyn et al.'s (1996) definition of QOL (section 2.3.1). In addition to the key concepts outlined by Wallander et al. as representing child adaptation, the QOL measure assessed the child's disease and treatment functioning (study one), well-being (study two) and school/cognitive functioning (both studies). These sub-scales appeared to be as important to the child's functioning as the core elements of child adaptation suggested by Wallander et al. Therefore, it is suggested that these additional concepts be included within future studies assessing the child's adaptation to illness.

One concern, however, is the lack of attention in paediatric oncology work given to the child's body image (BI). In practice children who have had treatments that have caused obvious physical deformities have been excluded, such as survivors of CNS tumours (see Chapter 2). BI was not included as an aspect of child adaptation in either Wallander et al.'s (1989b) model or in either QOL measure used in this thesis. However, in study two a separate measure of BI was completed by adolescent survivors. Results showed that BI was significantly poorer among survivors of CNS tumours than ALL survivors. While this may not be a surprising result considering the expected differences between the groups (see section 8.2.1 for discussion about differences in treatment, prognosis and associated long-term consequences), it does point to the fact that BI is negatively affected in these adolescents and as such should be considered for inclusion within QOL measures, or at least models assessing child adaptation. At the moment, there appears to be a paucity of BI instruments, especially for younger child completion.

11.2 Clinical implications

There is the expectation that 'all's well that ends well' (Van Dongen-Melman et al., 1995), however it is becoming increasingly clear that this is not necessarily the case. As more children survive their initial diagnosis and treatment, the associated long-term physical and psychological consequences become clearer (see Chapter 1). Therefore, it is imperative that children and their families are fully informed of the potential difficulties and health concerns that they may encounter (Hawkins & Stevens, 1996). This section of the general discussion is concerned with outlining the clinical implications that have emerged for children and their parents from this thesis. Finally, where recommendations cannot be made, suggestions will be made for future work.

Of course, information can often be stressful and many children and parents may react negatively to receiving information, written or verbal, that contains worrying news. However, it is important that families are fully educated about *where* to obtain information when they are most able to cope with it.

One of the best places to inform children and their parents of these long-term consequences is at medical follow-up appointments. After treatment has ended and the child remains well and in remission, appointments are usually scheduled annually. However, recent evidence suggests that approximately 17% of long-term survivors fail to turn up to these appointments (Eiser, Hill, & Blacklay, 2000). Reasons for this degree of absenteeism may be that some children were diagnosed and treated when they were very young, so there is an ambivalence about attending a clinic for an illness they do not remember (Eiser et al., 2000). Or, they may simply be unaware that the illness they had in the past may have ongoing implications. Therefore, it is important that during treatment children and parents are educated about the benefits of follow-up clinics, in the hope that they will consistently attend.

11.2.1 Medical and Psychosocial information needs

When dealing with children, providing written information can be a challenge. Material must be (1) presented at a developmentally appropriate level (which

implies there must be numerous versions to cover the age spectrum), and (2) delivered in a non-threatening manner. While a great deal of comic-book type material exists for newly diagnosed young children, little information is available for long-term survivors.

To address this need, the Cancer Research UK Child and Family Research Group (with whom the author is part of) have written two booklets for long-term cancer survivors. The first targeted young adults over 16 years of age ("*Surviving childhood cancer*"; Eiser, Hill, & Blacklay, 2000) and the second targeted survivors between 10-16 years. The first of these books was written in a fairly adult manner, with a core booklet detailing different cancer treatments, survival statistics etc., and an accompanying set of cards, discussing issues such as fertility, or cancer-specific information (e.g., information on artificial limbs for those who had bone tumours). It was intended that the booklet be passed on by the oncologist during annual check-ups, with the accompanying cards given out to survivors when appropriate. Understandably, certain issues, such as compromised fertility, are exceptionally difficult to discuss and the card system allows these issues to be addressed only when the survivor is ready to accept the information.

The second booklet, for 10-16 years olds, was written in a more child-friendly manner, and is currently being evaluated in a large paediatric oncology clinic in England. This booklet ("*What's the point of coming to the clinic - a guide for young people who have had cancer*"; edited by Eiser, Davies & Blacklay, 1999) details what cancer is, discusses treatments that the child may have had (e.g., chemotherapy and surgery), and has a strong health promotion guide concerning how to stay well as the child approaches adulthood.

The booklet was written with a social learning theory emphasis, with the booklet being introduced by a young cancer survivor called Sam, who asks a series of questions about his illness (e.g., what is cancer? what is a tumour?). Children may be more inclined to read the booklet and learn more from it if it is written from a child's, as opposed to a doctor's, perspective (hence the social learning emphasis). The author was involved with piloting this booklet, by visiting families, asking

them what information they would like their child to be given, their thoughts and feelings about earlier drafts of the booklet and how it could be improved.

Clearly, the medical needs of survivors appear to have been met, or at least trying to be met. However, the lack of information about psychosocial consequences of childhood cancer for both children and their parents prevents these documents from being comprehensive. This is where the results from this thesis can best be utilised and suggestions are made that include non-written avenues of imparting information to families. Children in the UK receive little professional psychosocial support (e.g., from psychologists or counsellors). Follow-up clinical appointments are medically oriented; there is usually only time to assess the child's illness status and monitor long-term damage. But some children do need psychosocial follow-up, especially children who have had a particularly poor prognoses and an invasive treatment regime.

As an example, one way of offering psychosocial support would be to create interventions aimed at children re-entering school after diagnosis. This can be a very difficult time for children, as they may have missed considerable periods of school, lost touch with friends, and look very different from how they once did (see Chapter 2 for literature reviews of the impact of cancer on schooling). The school experience was a topic frequently discussed by mothers during their interviews. For example, mothers discussed how their children found it difficult to make new friendships or fit in with old ones (see Chapter 10). Many others discussed incidences of bullying following school re-entry.

While most mothers mentioned that a representative from the hospital (usually a social worker) visited the school and talked about childhood cancer to teachers post-diagnosis, the main focus of this talk appears to have been to educate teachers of the risks of chicken-pox and measles to the immuno-suppressed child. It did not seem as if the psychological difficulties involved with school re-entry were discussed. However, drawing from the results of the current studies, it is hypothesised that educating teachers and peers about the difficulties faced by

children with cancer may help diminish the problems faced by these children in school.

To some extent, work of this nature has already begun in the US. Drawing from a recent review of the school experience of the child with cancer (Vance & Eiser, 2001), one of the most detailed and in-depth interventions conducted to date (Katz et al., 1988) compared children receiving standard care with those receiving a four-part intervention programme. The programme consisted of conferences about childhood cancer and presentations in the child's presence to provide peers with information and follow-up support after the child returned to school. The intervention resulted in a lowering of child depression and increased self-esteem, and parents reported a reduction in child behaviour problems.

While the above intervention was aimed at peers, teachers and children, Varni, Katz, Colegrove & Dolgin, (1993) developed a more detailed intervention programme specifically for children. This social skills training programme was aimed at providing children with necessary strategies and skills to answer questions from peers and teachers about their illness (e.g., why they look different, why they are absent frequently). Children were taught to identify problems, consider their cause and explore alternative ways of resolution. Parents reported a decrease in behaviour problems and greater school competence for those who had had the programme.

While this type of intervention is extremely useful, what became clear from the interview data was that finishing high-school, as well as re-entering school during treatment could be a problematic time. Therefore, providing information about opportunities after school could potentially help reduce distress during this period. Two issues that emerged in particular were employment and insurance concerns. First, certain careers exclude cancer survivors because they once had a cancer diagnosis (e.g., the armed forces), while other jobs may not be suitable for survivors given their physical or psychological late-effects. For example, some chemotherapy drugs cause weakened heart muscles, precluding survivors from labour-intensive posts, such as construction work. Others with poor mobility,

balance or coordination problems may find future employers lack understanding. The second issue concerns obtaining insurance coverage. Many mothers talked about how they could not insure their child's life (which could later effect securing a mortgage for example) or even insure them whilst on holiday. Thankfully, however, a select few insurance brokers will now insure cancer survivors, but this information needs to be communicated to children and parents.

On this issue, it is suggested that help could be offered to children and parents in at least two ways. First, considering the positive evaluations from Varni et al.'s (1993) work, it is suggested that this kind of information could be communicated in a similar manner, i.e. by providing survivors with the necessary skills and strategies to manage the problems they encounter as they prepare to leave school. For example, they could be trained to have the social skills necessary to interact with future employers, or to communicate their past illness history to fellow colleagues. Second, if resources are not available to provide information in this way, a leaflet could be developed and passed on to teenagers when attending clinic, preferably some time prior to school leaving age so that individuals can accommodate this information into their plans. Interventions of this sort may prepare the survivor with the necessary skills to overcome their limitations and to move beyond them in the workplace.

Two overwhelming needs discussed by mothers during their interviews concerned the uncertainty they felt over relapse and long-term consequences of the illness. For many, the threat of relapse or fears about health problems was a constant worry, so much so that it affected their day-to-day functioning. For example, some parents would not plan holidays or other family gatherings that were more than a few weeks away. Similarly, others would not go abroad on holiday for the fear of their child becoming ill while in a strange country.

Considering the results of this study, especially the interview data, it is clear that some information is needed. While obviously, this information could not document whether or not particular children would relapse, or have certain physical problems later in life, it could provide medical statistics about numbers

of children who do relapse with particular cancer diagnoses and particular problems associated with treatment protocols. While this information may seem unnecessarily severe or daunting, the data in the interview analysis suggested that mothers would welcome this. Even more fundamentally, this information could simply make it clear that it is normal to worry about these things. Many mothers appear to need to know that what they are feeling is appropriate and 'normal'.

However, mothers also discussed a need for more than just written information, especially during times when they were feeling particularly worried about their child. They need other sources of support. For many, this need for support intensified as time since diagnosis increased and appointments were offered on a annual basis. Many mothers discussed how they felt increasingly cut off from hospitals, with many saying that in situations where they were worried about their child, they felt unable to contact the hospital for reassurance as the medical team had new patients to deal with and did not have time for them. While this is perhaps not a view shared by medical staff, the perception from mothers is that NHS departments are so busy and under-staffed that the medical team are not available for "chats" about the child's status. Therefore it is suggested that parents be given information providing (1) telephone numbers of the hospital in case parents are concerned about their child (reinforcing that they *can* call), and (2) a section detailing local support networks, parenting groups, web site addresses, charity phone numbers etc. There are a great many cancer charities who continue to provide both emotional and financial support long after diagnosis. During visits, some mothers discussed the great source of support and comfort played by these charities, while others did not seem to know of their existence. Therefore, it is suggested that this information be collated and given to families. Many parents have moments of panic where a quick reassuring phone-call may be all they need to alleviate their fears.

While thinking about how best to get information across to patient, the author has constructed a website, providing information on the work currently undertaken by Cancer Research UK Child and Family Research group, references of published work to date, and importantly, a page of links for information on local and

national parent support groups, cancer charity pages etc. This website (*www.shef.ac.uk/childfamilyresearch*) is listed on all employee e-mail pages and group stationary (which parents will see). It remains to be seen whether this source is used by parents, but the worldwideweb may be an increasingly common forum for disseminating information.

11.2.2 Implications for maternal mental health

This thesis shows that mothers who are not functioning well have children with poorer self-reported QOL. One potential clinical implication would be to identify those mothers with poor mental health and help them in some way in order to prevent the associated decline in child QOL. One particular provision could be to make professional counselling available to these mothers. However, within the current thesis, those mothers who scored at-risk on the GHQ-28 (study one) or the CES-D (study two) could not be predicted by any of the independent variables included in the assessments. It was suggested in Chapter 10 that other avenues of research could be investigated, such as assessing amount and type of social support available to families and assessing whether this significantly relates to at-risk levels of depression. Therefore, while a clear trend between mother's mental health and child QOL has been shown, suggestions cannot be made regarding the criteria with which to predict mother's outcomes. At this stage, it can only be suggested that mothers who do have poor mental health are monitored routinely. Considering the literature linking mother and child outcomes (see Chapter 3) and the empirical results reported in this thesis, it seems clear that if mothers are provided with adequate support, the result could be to 'kill two birds with one stone', by inadvertently helping the child too. There remains much scope for future work in this area.

11.2.3 Implications for parenting a child with cancer

A major part of this thesis considered the parenting difficulties involved in rearing a child with cancer. While it is not the purpose of this thesis to preach how to be a 'good parent', it is the forum for discussing those aspects of child-rearing mothers found awkward or challenging. Therefore one important clinical implication of this thesis could be to highlight these difficulties, in order to reassure parents that

they are not alone in worrying about certain aspects of child-rearing or to provide suggestions about how to cope with difficult circumstances. The interview analysis reported in Chapter 9 provided a wealth of rich data on this very topic. There is no one best way of disseminating this information, although suggestions include providing a leaflet in clinic, having a clinic nurse available to discuss these issues, or creating a web-page where these issues are discussed (e.g., via e-mail or 'chat' rooms).

The interview data was categorised within a pre-existing parenting framework assessing warmth, psychological autonomy and behavioural control (see Chapter 8). Coded within the warmth dimension, many mothers discussed their involvement with the child's schooling and future employment. The process of obtaining a "statement of special needs" was discussed at length, as were the difficulties with getting their child a job or into college, considering their residual physical and psychosocial concerns. This echoes what was discussed previously, specifically parents need to be informed about school and employment opportunities, and given advice about how to proceed through the statementing process and obtain educational support for their child.

Mothers also discussed how difficult it was to increase their child's body image or general self-esteem. In practice, this must be very difficult, especially if even years after treatment the child's weight, height and hair never returned to its pre-illness status. Considering both past research and current empirical findings, it is suggested that adolescents and / or those with CNS tumours would have the greatest body image concerns, therefore it would seem that these families in particular should be given as much support as they need. In study two, mothers discussed ways of trying to go about this complex task, including helping the child buy and wear clothes that made them feel good about themselves, exercising together to help weight problems, or if necessary, going through the appropriate channels to get professional support. Care must be taken not to tease a child about their body image if they do feel particularly self-conscious.

In terms of psychological autonomy, communication emerged as a varied and usually sensitive issue. Mothers often found it difficult to discuss issues with their child, and equally children often refused to communicate about their illness with their parents. This points to the necessity of having age-appropriate information booklets for children, so in the case where they do not discuss the illness with parents, or feel shy or embarrassed asking questions at clinic, they remain informed. However, parents should be encouraged to be there for the child at all times and be sensitive to questions about their illness. Many parents discussed keeping photographs or other memorabilia from the illness time (e.g., teddy-bears that the child took to theatre with them or radiotherapy masks), in order to fill in certain gaps in the child's memory. Most children appeared to appreciate these items as in many instances they served as conversation starters in mother-child dyads where communication about the illness was awkward. Finally, if parents are finding it near impossible to discuss the illness, they should be encouraged to share these concerns with staff at the follow-up clinic. Medical staff have been cited as invaluable sources of information.

According to the interviews, the most difficult parenting situations arose in circumstances where behavioural control was necessary. Setting rules, encouraging mature behaviour and monitoring children, appeared to open up a can of worms. While some mothers failed to set reasonable demands on their child, others refused to allow their child to grow and be 'normal' at all. Of course, these are problems faced by all parents, but are perhaps exacerbated when the child has had cancer.

Many parents, especially of CNS tumour survivors, tried their best to encourage mature behaviour from their child. However, there is little point in borrowing from developmental literature about what is considered age- or developmentally-appropriate behaviour since these children are not considered 'normal'. These children sometimes need 24 hour care – they are not normal teenagers who are becoming independent from their parents. However, some mothers went to extraordinary lengths to encourage their child to be as independent as possible. In

particular, some mothers were acutely worried about how the child would care for themselves after their own death. For example:

I would like to see him in a little flat of his own, or you know eventually, you know ... Providing for himself and being independent....But supporting himself which is why I've pushed to be so independent for him, so that you know if I die tomorrow, he can go to Iceland and, and go and get a frozen meal and stick it in a microwave and, you know he won't starve.....And I think he could do that, you know cos his life skills, you know we've worked on them a lot and you know I'm blowing my own trumpet again here but I have put an awful lot of work in, from the day after his operation you know....You know because over repetition has been good for him **(mother of a CNS survivor with residual physical complications)**

So thinking back to Chapter 2 and the discussion about how the diagnosis of cancer affects children of different stages, it is impossible to say how each particular diagnosis and treatment will effect the child *once treatment has been completed.* However, we can learn from mothers in this study about how to try to approach these difficulties.

Setting limits on certain sports and activities was a common theme throughout, and appears common sense in some situations. For example, children with poor balance and coordination may be not allowed to play rugby, a rough contact sport they may have once enjoyed prior to their illness. An important parenting strategy to communicate to parents is to compromise with the child, e.g., by encouraging them to do other activities that they are interested in. Therefore, when helping parents to deal with situations such as these, it could be suggested that compromising about activities may be a way of improving the child's QOL, by decreasing their frustration at not being able to do things they once could, and by showing them that they can still be good at others. Theoretically, it is suggested that by reducing the discrepancy between what one wants to do (ideal self, in this case rugby) and what one can do (actual self, perhaps in this case golf), QOL improves (Calman, 1984). In this way, this reappraisal of reality may help young survivors cope with their illness.

However, it is also clear that a number of mothers had great difficulty allowing their child any sort of freedom at all. In certain situations, for example mothers imposed strict boundaries on their child's behaviour due to the fear of an imminent relapse. For example, one mother did not allow her child to play hockey as it was after a match some years ago, after a collision on the pitch, that the child developed bruising which later led to an ALL diagnosis. This cause and effect link in the mother's mind was making it difficult for her daughter to participate in normal school activities and therefore feel normal. Similarly, a number of mothers did not allow their child to stay overnight at friends, or go on school trips for the fear that something would happen to their child when they were away. While these worries are understandable given what these families have gone through, they are not enabling the child to feel normal and to develop autonomy. If parents and children are given correct medical information and are aware of the real risks of relapse, they might be more willing to allow their child a certain amount of freedom.

From a more clinical perspective, parents could be trained to use systematic desensitisation strategies. Systematic desensitisation refers to a progressive reduction in the perception of threatening stimuli, allowing individuals to become more and more accustomed and less fearful of the object or situation in question. This is a technique used routinely in overcoming phobias. For example, someone who has a spider phobia may gradually expose themselves to spiders, by first viewing a picture of one in a book, to standing in the same room as a spider, to actually holding the spider in their hands. Used in a similar ways, parents could be trained to systematically desensitise themselves of the fear associated with their child being out of their sight and something going wrong. Steps between allowing the child to go on a week-long school trip, for example, could include first allowing their child to go to a friend's house for an hour or two, then for a full day, then allowing their child to stay at their friend's overnight. In situations such as these, parents will gradually become less worried that something will go drastically wrong and slowly permit the child to take part in more activities.

The other end of the spectrum concerned those mothers who could not set rules for their child or continually spoiled them. Many mothers talked about feeling guilty for telling their child off or felt that the child had been through so much that they could not say no to them. This is a pattern that many mothers said had been there from diagnosis, at a time when family members showered the ill child with presents and treats. In many cases, this behaviour resulted in defiant behaviour from the child and the mother feeling unhappy and confused. Many families, according to the transcripts, were told at diagnosis not to spoil their child and to continue to treat them as normal. However, perhaps if a booklet provided evidence from mothers about the difficulties they would later face if they did not adhere to this advice, perhaps even by directly quoting some mothers, more families may not find themselves in this difficult situation years later. Alternatively, parents can again be encouraged to use strategies where they learn to become more and more strict about setting rules and sticking to them, similar to systematic desensitisation, but in reverse.

Finally, there are at least three aspects of rearing a child that this thesis cannot comment on: (1) rearing a newly diagnosis child, (2) fathering a child with cancer and (3) parenting from the child's perspective. While the focus of interviews in study two were concerned with rearing survivors, mothers did routinely make references to the early treatment stages, in particular the struggles they had with treatment adherence, medical procedures and frequent hospitalisations. It is suggested that parenting survivors is much different from parenting a newly diagnosed child since they can be (1) in many respects, 'back to normal', and (2) and generally much older. Therefore, in future research, it is suggested that a parenting resource, similar to the one discussed here, is constructed in order to help parents rear their child during this very difficult time.

Mothers were the sole respondents in study two and gave their views on how they and their partners parented the child. Therefore, some second-hand views of how fathers feel about rearing a child with cancer are available. However, it is clear that this is not sufficient and we must attempt to include fathers in future research in order to provide relevant and clinically useful information that could be of use

to them. The information provided in this thesis can realistically only be directed towards mothers. While much of the difficulties faced by mothers will be shared by fathers, there will undoubtedly be situations that fathers find challenging that have not been raised in this thesis. Again, there is much scope for future work.

Third, we are unable to consider the child's views of how they are parented from data in this thesis. While children were interviewed as part of study two, the questions were focused on the child's functioning and how they felt about their illness. Children were not specifically asked their views about their parents or parenting behaviours. Obtaining this data in future research would result in a more balanced view of the parent-child relationship and potentially lead to more appropriate clinical interventions.

To summarise, a great many clinical implications have emerged from this thesis. Specifically, informational needs can be addressed for both children and their families from both a medical and psychosocial perspective. Mothers highlighted specific areas of concerns, such as re-entering and leaving school, worries over relapse and late-effects. Suggestions were made regarding how this information could be disseminated by drawing upon past research which has made use of intervention programmes (e.g., Varni et al., 1993) and clinical techniques, such as systematic desensitisation.

11.3 Limitations

The results in this thesis need to be interpreted in light of certain limitations. These will be discussed below.

11.3.1 Sample size

The final samples in both studies could be considered modest in size. However, power calculations conducted in both studies indicate that the samples were big enough to satisfy our statistical analysis.

Given the rarity of childhood cancer, there is a delicate balance between sample homogeneity and sample size. While on one hand the aim was to recruit children

within a narrow age-range, on the other hand, this inevitably results in a smaller final sample. The decision was taken to keep the sample as homogeneous as possible which would allow specific conclusions to be made about specific samples. This improves on past research that may have larger samples, but the results are more difficult to interpret.

11.3.2 Father and sibling data

Mothers were the main focus of attention in this thesis. Father and sibling data were not collected for a number of reasons. First, mothers usually accompanied their child to clinic (study one). Second, home visits (study two) were conducted just after school hours (approximately 4-5pm) when many fathers were still at work. Third, on the occasion fathers were at home, they were encouraged to take part, but generally declined. Fourth, each visit lasted approximately two hours, so it was unrealistic to extend the visit any longer to obtain other family member's perspectives, and finances restricted visiting a second time.

11.3.3 Visit location

In study one, parents and children completed the questionnaires separately while waiting for a routine clinic appointment. Although this meant that ratings were independent, there were disadvantages and some data were lost due to time restraints in the clinic. The clinic setting may be stressful for some families and result in inflated scores on psychological measures. Home visits remain preferable where possible as families are usually less stressed than when at clinic, although these can be time consuming and expensive. As a direct result, home visits were conducted in study two. This was a more relaxed atmosphere for both mother and child.

11.3.4 Cross-sectional vs. Longitudinal data

Due to the cross-sectional nature of this work, cause and effect cannot be determined, i.e. we cannot say with any certainty whether the parent's mental health and parenting behaviours affected the child's QOL or whether the reverse was true. Prospective studies are needed to expand upon the relationship between these variables (see below).

11.4 Future directions

A number of possible future directions emerged from this thesis, in addition to the clinical implications discussed in section 11.2.

First, considering the rich source of data provided by the interviews, a suitable assessment of parenting a child with cancer could be developed. This measure could contain items representing the major constructs outlined and discussed in Chapter 8, namely warmth, psychological and behavioural control, but also the three major themes that emerged from the data that could not be accommodated within the parenting framework. These were child-rearing difficulties, child-led situations and developmental difficulties. While this is a mammoth task, the author is currently collating an item pool derived from key phrases from the maternal interviews. Potentially, if such a questionnaire existed, it could serve to pinpoint those difficulties experienced by mothers with the aim of intervening as and when was necessary.

A second future direction involves the use of longitudinal designs to assess across-time changes in the parent-child relationship. Rather than adhering to old-fashioned uni-directional views of parents solely influencing their child, it is more realistic and worthwhile to assess bi-directional or moderating patterns (Holden, 1997). It is important that interactions between the child's QOL, parental mental health, and changes in parenting across time are assessed. Subtle examination of the parent-child relationship will help with the development of intervention work and ultimately help us predict which parents and children adjust well to the diagnosis, and those who do not. It is no longer sufficient to conduct cross-sectional studies; a more detailed understanding of the intricacies involved in the parent-child relationship is urgently required. In response to this need, the Child and Family Research Group are currently involved in a prospective study concerning children diagnosed with ALL, CNS tumours or bone tumours from diagnosis through to two years post-diagnosis. While results are not available at

this time, it is hoped that a greater understanding of the delicate nature of the parent-child relationship will be achieved.

Final comment

While survival rates for most childhood cancers have increased over recent years, this amazing medical feat has been tempered by an increased awareness of the associated long-term physical and psychosocial consequences of the illness and subsequent treatment. Survival most certainly comes at a cost. It is important that appropriate medical, psychosocial and support services are available to both the child and family not just during treatment, but for many years after diagnosis. While the child may survive the initial disease, it is clear from the current research that the legacy of cancer lasts much longer than the treatment, causing families to experience a range of negative feelings, uncertainty and worries which remain with them always.

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Elissa Jelalian, Personal Communication. November 1998.

APPENDIX ONE

STUDY ONE: PARENT QUESTIONNAIRE BOOKLET

NB: Questionnaire names and authors have been added for the reader's information

While you are at the clinic today, we would like to ask you and your child to take part in a research project. The main aim is to find out what it is like for children to grow up with a long-standing illness. We plan to use a computer to help your child describe his/her own experiences.*

While your child is busy, we would be very grateful if you could complete the enclosed questionnaires. These will help us interpret your child's experiences and also includes questions about views of your child's health now and in the future; and any concerns you may have yourself about caring for your child.

(* this is the second QOL measure NOT reported in this thesis; please see Vance et al., 2001 for details of this measure)

Instructions

Please read the following questions and indicate which answer most applies to you.

Please give your first answer. Remember there are no wrong or right answers, only what you think.

Parent demographic Information

Your name: Your age:

Relationship to child (please circle one):

Mother / father /step-mother / step-father / grandmother / grandfather / other

Name of child: Age of child: Sex of child: M / F

What is the name of your child's illness?

_____

How old was your child when s/he was diagnosed with cancer?

_____

When did s/he start treatment?

_____

Are you currently (please tick):

In full-time employment

In part-time employment

In full-time education

In part-time education

Unemployed / housewife/househusband

At what age did you finish full-time education? _____

Ethnic origin (please tick):

Asian

Black

White

Other (please specify):

Martial status (please tick):

Married / living together

Divorced

Single

Other, please describe:

These first questions are about your child and his/her current health. Please indicate how you think your child's health <u>now</u> compares with that of other children you know.

CHILD VULNERABILITY SCALE (FORYSTH ET AL., 1996)

	Strongly agree	**Agree**	**Not sure**	**Disagree**	**Strongly disagree**
My child gets more colds than other children I know					
I often think about calling the doctor about my child.					
When there is something going around my child catches it.					
In general my child seems less healthy than other children.					
I often have to keep my child indoors because of health reasons.					
Sometimes I get concerned that my child doesn't look as healthy as s/he should.					
I get concerned about circles under my child's eyes.					
I often check on my child at night to make sure s/he is ok.					

The next section is about any worries or concerns you may have about your child in the <u>future</u>.

MATERNAL WORRY SCALE (DEVET & IREYS, 1998)

I worry that my child……	**Most of the time**	**Often**	**Some-times**	**Not at all**
will look different from others because of the health condition				
will have a harder time finding a girlfriend / boyfriend because of the health condition.				
won't get married because of his/her condition				
will get worse or get very sick again				
won't be able to do things s/he wants to do because of the health condition				
will have a hard time getting around or going places compared to others				
will always have to take medication				
will have future side effects from the treatment				
will grow up too fast because of the health condition				
won't be able to handle things in the future on his/her own				
will need medications or will need stronger medications				

The next questionnaires are concerned with your own experiences.

First, how much do you find the following problematic?

ILLNESS STRESS SCALE (ADAPTED FROM CHESLER & BARBARIN, 1987)

	Not a problem	Some-times a problem	Problem	Very much a problem
My child's reaction to the treatment.				
The fear that my child might get worse				
Travelling to medical centres.				
Staying at the hospital for extended periods.				
The effect of illness on other children in family.				
The effect on my partner.				
Being overprotective.				
Spoiling my child.				
Not being able to cope with home treatment programmes				
Worry about relapse.				
Knowing how to discipline my child				
Fear of other children / partner getting sick.				
Anxiety about coming to clinics.				
Knowing when to take my child to the hospital				
Knowing what to do when my child is unwell				

Second, how do you manage when your child doesn't do exactly what s/he is supposed to do? Please think about each of the situations described below, and choose one response that you would be most likely to make (mark this with a '1'). Then please choose the one that you would try next if the first one didn't work (mark this with a '2').

DISCIPLINE STRATEGIES QUESTIONNAIRE (JELALIAN ET AL., 1997)

If my child continually dawdled while getting dressed each morning and absolutely would not hurry up when told I told him/her, I would
____explain that he/she must be at school on time and therefore needs to get dressed faster
____yell at him/her to hurry up or tell my child that if he/she didn't hurry up he/she would lose a privilege, such as TV, that night
____tell my child that if he/she got dressed on time he/she would get a treat such as being able to watch TV before school
____ignore my child while he/she was getting dressed and hope that he/she is ready on time.
____go in and dress my child
____other_____

If my child argued with me about rules, I would
____tell my child that every family has rules and how important rules are to a family
____sternly tell my child that he/she must follow rules
____tell my child if he/she continued to argue about the rules he/she would have to sit in the corner for a while
____give my child a compliment any time he/she did obey the rules
____modify the rules so my child would not argue about them
____other_____

If my child refused to eat a variety of foods at meal time I would
____tell my child he/she did not have to eat the food he/she did not want
____tell my child that if he/she did not eat his/her food he/she would not get dessert
____tell my child he/she could not leave the table until he/she ate her food or I would feed her
____tell my child he/she could pick her favourite food for dessert if he/she ate his/her food
____explain to my child that he/she should eat the food on her/his plate because he/she might like it, or because it will help him/her grow big and strong
____other_____

Of my child continually interrupted me when I was busy, I would
____tell him/her if he/she waited until I was finished I would answer his/her question and then compliment him/her for waiting patiently
____send him/her into his/her room
____tell my child he/she should not interrupt me when I am busy
____try to find out what my child needed and get it for him/her
____put my child in a chair and make him/her sit until I finished what I was doing
____other_____

If my child refused to do chores or to do what I ask, I would
____tell him/her that if s/he did what he/she was supposed to s/he could earn a special treat.
____tell my child if he/she did not do what he/she was told he/she would have to go to his/her room
____take my child by the hand and make him/her do the chore
____just do the chore myself and not talk to my child about it anymore
____explain to my child that it is important to listen to his/her parents and do his/her chores
____other_____

If my child continually refused to go to bed on time, I would
____allow my child to go to bed when he/she felt tired or go in and lie down with her/him until he/she fell asleep
____tell my child that if he/she did not to go bed on time then he/she would not be allowed to play the next day
____explain to my child the importance of a regular bed time and getting enough sleep
____tell my child that if he/she went to bed out time he/she could stay up an extra 10 minutes the next evening
____carry or walk my child to his/her room and place him/her in bed
____other_____

If my child became angry and threw a temper tantrum whenever he/she did not get his/her way, I would
____tell him/her to sit in a chair until he/she calmed down
____tell my child that big boys/girls do not act like that
____give my child what he/she wanted so he/she would stop having a tantrum
____tell my child that he/she could earn a prize for being calm and cooperative
____not give my child his/her own way and make him/her settle down
____other_____

If my child acted defiant when I told him/her to do something I would
____make him/her do what I asked him/her to do
____tell him/her what a good boy/girl he/she is when he/she does obey me
____tell my child that I do not like him/her behaviour when he/she acts this way
____walk away and not force the issue
____tell him/her if he/she did not do what he/she was told I would sent him/her to his/her room
____other_____

If my child were continually slow in getting ready for bed, I would
____make my child to go bed 15 minutes earlier the next night
____tell my child that if he/she did not get to bed on time he/she would be tired the next day
____tell my child I would read a bedtime story to him/her if he/she got ready for bed on time
____put my child in his/her pyjamas and put him/her to bed
____allow my child to get ready for bed at his/her own pace
____other_____

If my child continually sought my attention by nagging at me at inconvenient times, such as when I am on the phone, I would

____not give into his/her demands and tell him/her that if he/she continued to nag he/she would be sent into another room

____stop what I was doing and attend to my child

____tell my child he/she can not bother me all the time and he/she needs to do things for his/herself

____set up a rule where my child could earn a special treat at the end of the day if he/she did not nag me when I was busy

____take him/her into another room

____other_____

Third, how much does your child's illness affect your feelings about yourself as a parent?

PARENTAL STRESS SCALE (BERRY ET AL., 1995)

	Strong-ly agree	**Agree**	**Not sure**	**Dis-agree**	**Strongly disagree**
I am happy in my role as a parent.					
There is little or nothing I wouldn't do for my child if it was necessary.					
Caring for my child sometimes takes more time and energy than I have to give.					
I sometimes worry whether I am doing enough for my child.					
I feel close to my child.					
I enjoy spending time with my child					
My child is an important source of affection for me.					
Having children gives me a more certain and optimistic view for the future.					
The major source of stress in my life is my child.					
Having a child leaves little time and flexibility in my life.					
Having a child has been a financial burden.					
It is difficult to balance different responsibilities because of my child.					
The behaviour of my child is often embarrassing or stressful to me.					
If I had to do over again, I might decide not to have children.					
I feel overwhelmed by the responsibility of being a parent.					
Having a child has meant having too few choices and too little control over my life.					
I am satisfied as a parent.					
I find my child enjoyable.					

And finally, these questions are entirely for you to answer about yourself....

THE GENERAL HEALTH QUESTIONNAIRE GHQ-28 (GOLDBERG, 1978)

Please read this carefully. We should like to know if you have had any medical complaints and how your health has been in general, *over the past few weeks.* Please answer ALL the questions on the following pages simply by underlining the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

It is important that you try to answer ALL questions.
Thank you very much for your co-operation.

Have you recently

A1	**Been feeling perfectly well and in good health?**	Better than usual	Same as usual	Worse than usual	Much worse than usual
A2	**Been feeling in need of a good tonic?**	Not at all	No more than usual	Rather more than usual	Much more than usual
A3	**Been feeling run down and out of sorts?**	Not at all	No more than usual	Rather more than usual	Much more than usual
A4	**Felt that you were ill?**	Not at all	No more than usual	Rather more than usual	Much more than usual
A5	**Been getting any pains in your head?**	Not at all	No more than usual	Rather more than usual	Much more than usual
A6	**Been getting a feeling of tightness or pressure in your head?**	Not at all	No more than usual	Rather more than usual	Much more than usual
A7	**Been having hot or cold spells?**	Not at all	No more than usual	Rather more than usual	Much more than usual

B1	**Lost much sleep over worry?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B2	**Had difficulty in staying asleep once you are off?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B3	**Felt constantly under strain?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B4	**Been getting edgy and bad-tempered?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B5	**Been getting scared or panicky for no good reason?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B6	**Found everything getting on top of you?**	Not at all	No more than usual	Rather more than usual	Much more than usual
B7	**Been feeling nervous and strung-up all the time?**	Not at all	No more than usual	Rather more than usual	Much more than usual

C1	**Been managing to keep yourself busy and occupied?**	More so than usual	Same as usual	Rather less than usual	Much less than usual
C2	**Been taking longer over the things you do?**	Quicker than usual	Same as usual	Longer than usual	Much longer than usual
C3	**Felt on the whole you were doing things well?**	Better than usual	About the same	Less well than usual	Much less well
C4	**Been satisfied with the way you've carried out your tasks?**	More satisfied	About the same as usual	Less satisfied than usual	Much less satisfied
C5	**Felt that you are playing a useful part in things?**	More so than usual	Same as usual	Less useful than usual	Much less useful
C6	**Felt capable of making decisions about things?**	More so than usual	Same as usual	Less so than usual	Much less capable
C7	**Been able to enjoy your normal day-to-day activities?**	More so than usual	Same as usual	Less so than usual	Much less than usual

D1	**Been thinking of yourself as a worthless person?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D2	**Felt that life is entirely hopeless?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D3	**Felt that life isn't worth living?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D4	**Thought of the possibility that you might make away with yourself?**	Definitely not	I don't think so	Has crossed my mind	Definitely have
D5	**Found at times you couldn't do anything because your nerves were too bad?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D6	**Found yourself wishing your were dead and away from it all?**	Not at all	No more than usual	Rather more than usual	Much more than usual
D7	**Found that the idea of taking your own life kept coming into your own mind?**	Definitely not	I don't think so	Has crossed my mind	Definitely have

THANK-YOU FOR TAKING PART IN OUR RESEARCH!!!

APPENDIX TWO

STUDY ONE: CHILD QUESTIONNAIRE BOOKLET

PEDIATRIC CANCER QUALITY OF LIFE INVENTORY (VARNI ET AL., 1998)

Please indicate how much of a problem each of the following has been for you over this past month.:

Physical functioning	Never	Some-times	Often	Always
1. Participating in sports activities				
2. Doing chores around the house (e.g. for example, taking out the rubbish)				
3. Walking or moving around				
4. Lifting something up				
5. Running				

Psychological functioning	Never	Some-times	Often	Always
1. Feeling afraid				
2. Feeling sad				
3. Worry about the future				
4. Worrying about side effects from medical treatments				
5. Worrying that the cancer will come back or relapse				
6. Worrying about whether or not your medical treatments are working				

Social functioning	Never	Some-times	Often	Always
1. Arguing or fighting with other people				
2. Not getting your way				
3. Being teased about how you look				
4. Telling your friends that you can't do things with them as much as before				
5. Not doing the same things that most kids your age do				

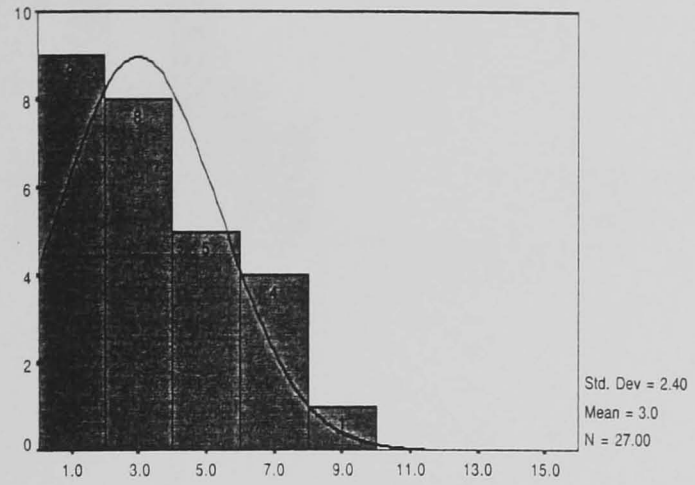
Cognitive functioning	Never	Some-times	Often	Always
1. Forgetting things				
2. Remembering what you reads				
3. Paying attention at school				
4. Writing school papers or reports				
5. Difficulty paying attention to things				
6. Keeping up with homework assignments				
7. Solving maths problems				

Disease and treatment symptoms	Never	Some-times	Often	Always
1. Becoming anxious when going to the hospital				
2. Becoming nauseated during medical treatments				
3. Food not tasting very good to you				
4. Becoming nauseated while thinking about medical treatments				
5. Being anxious about needles (i.e. injections, blood tests, IV's)				
6. Aches in joints and /or muscles				
7. Being anxious about bone marrow aspirations (BMA's) and lumbar punctures (LP's)				
8. Hurts or aches				
9. Medical procedures (i.e. BMA's & LP's) hurt you a lot				

APPENDIX THREE

STUDY ONE: DESCRIPTIVE DATA

child PedsQL sub-scale



Descriptives

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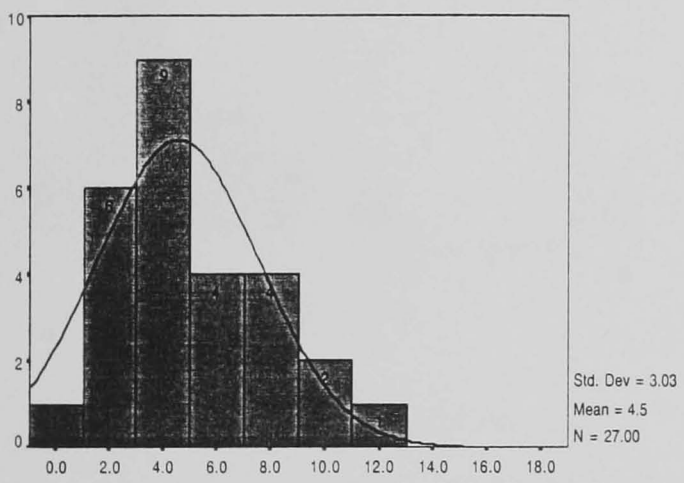
SE Skew = 0.45
z = 1.20[1]



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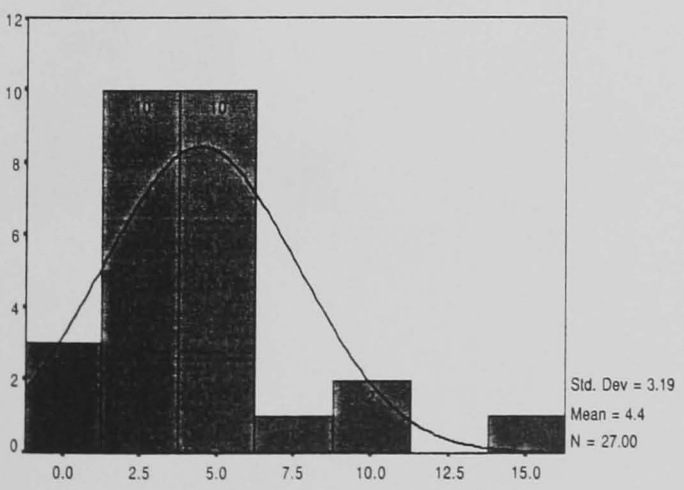
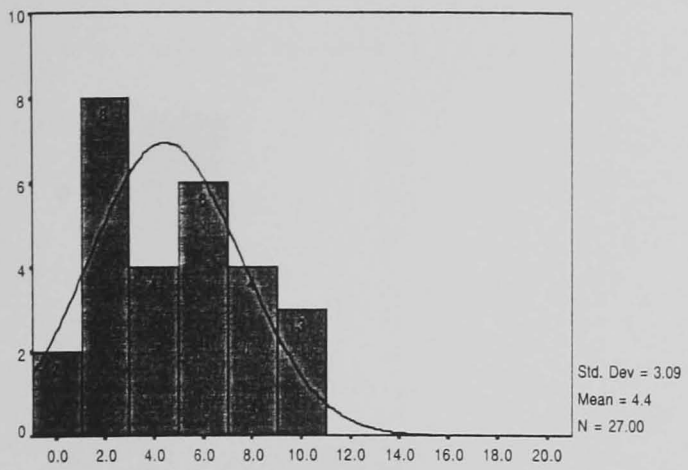


Skewness = 1.76
Kurtosis = 3.67
SE Skew = 0.45
Z = 3.91

[1] To calculate Z scores = skewness / standard error of skew (Howitt & Cramer, 1997); values over 1.96 represent significantly skewed data.

child PedsQL sub-scale



child cognitive functioning sub-scale

Descriptives

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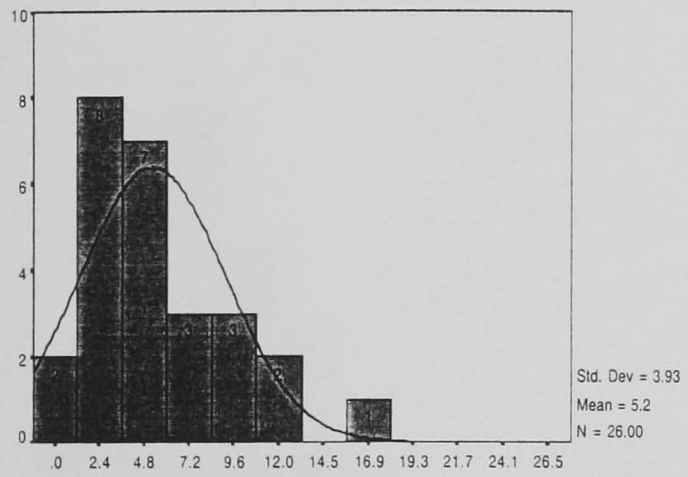
Z = 0.62



child disease and medical aspects sub-scale

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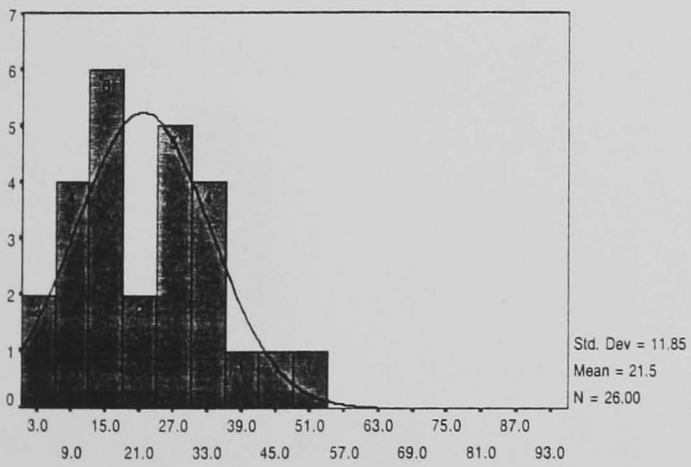
Kurtosis = 1.80
SE Skew = 0.46
Z = 2.67

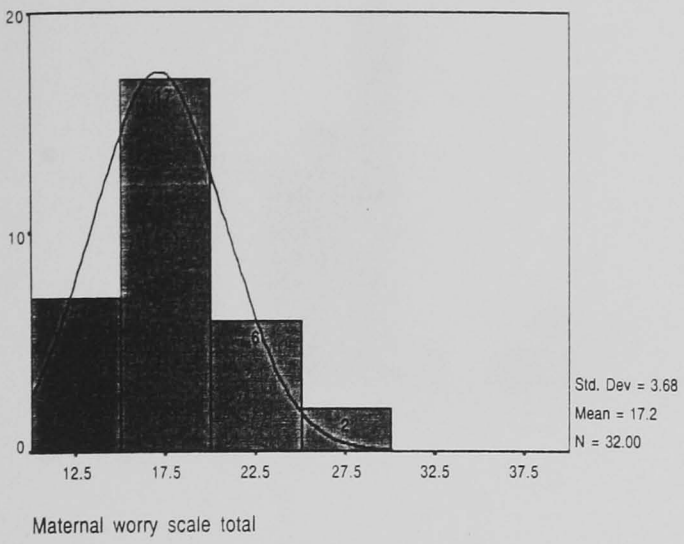


child Varni overall QoL score

Skewness = 0.54
Kurtosis = -0.08
SE Skew = 0.46
Z = 1.17

Parent completed measures

Descriptives



Skewness = 0.57
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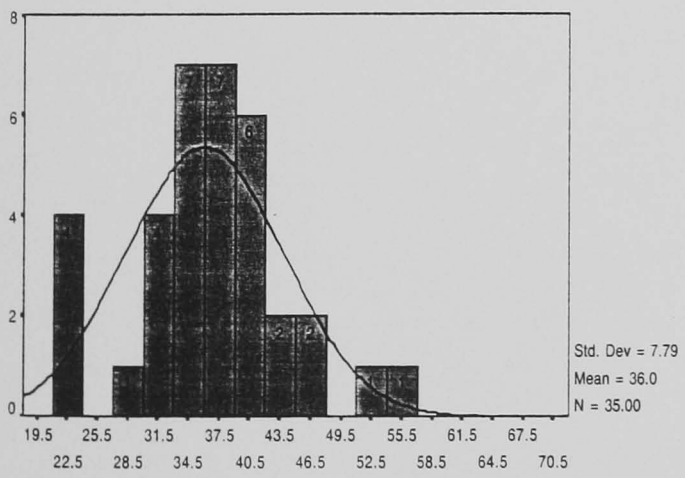
z = 1.39

Skewness =0.54
Kurtosis = -0.03
SE Skew = 0.40
Z =1.35



Skewness =0.20
Kurtosis = 0.58
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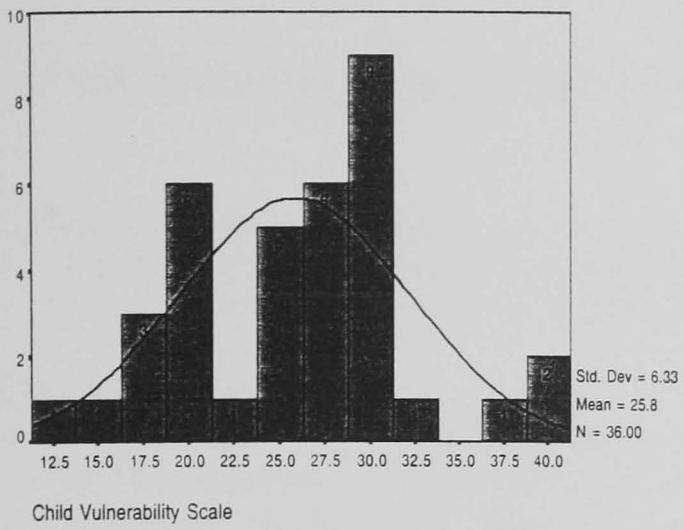
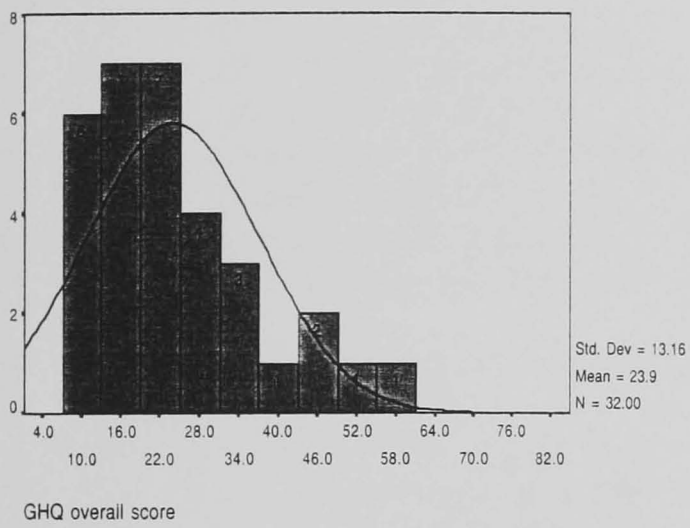
Z =0.50

Parent completed measures



Descriptives

Skewness = 0.15
Kurtosis = -0.07
SE Skew = 0.39
z = 0.28



Skewness =1.15
Kurtosis = 0.74
SE Skew = 0.41
z =2.80

APPENDIX FOUR

STUDY TWO: MATERNAL INTERVIEW

Current health and functioning

- Could you tell me about your child now? How is he/she getting along?
- What sort of child is X? Does he/she worry about things or is he/she happy-go-lucky?

Changes in child

- Do you think you are a different parent now as a result of the illness?
- Do you think your child is different as a result of the treatment?
- What were you like before? What are you like now?

Employment and education

- What school is your child attending now?
- Has you child repeated any part of the school year?
- Has your child needed any extra help in school?
- Has your child missed out on anything in school, because of the treatment?
- What are your child's plans for the future, in relation to education and work?
- Often children are scared to go to school because they have been away for some time. Has your child had any problems with going back to school, being afraid of being picked on?
- Often children are scared of going back to school because they look different. How would you help your child to cope with the event of children staring and saying something about your child not having any hair.
- When your child went back to school after the treatment, how did you go about informing the school. Did you talk to the teachers? Did you feel they understood and were helpful to you and your child.

(younger children)

- Some children do not want to go to school because they feel tired and still a bit weak from the treatment. Has your child had any problem with going back to school? (prompt: Would you tell her that she should go because she will learn a lot in school and it is good fun, or would you tell her that she won't have any friends if she doesn't go and will feel left out).
- Often children don't want to do their homework because they are tired and don't feel well. How has your child coped with feeling tired and getting on with every day things? (prompt: Would you say that she needs to do her homework because she has missed so much already and she doesn't want to be behind anymore, or would you say that she should do her homework because it will be easier at school and she will make more progress).
- What GCSE's is your child intending to take (A-levels).
- What plans does your child have in terms of work?
- Have these choices been influenced by the illness at all?
- (For those who have left education) What about your child's job prospects in the future, for example, promotion?

Physical activity

- What sort of activities does your child like to do?
- Are there any activities that your child is no longer able to do because of the illness?
- How has your child coped with these changes?
- Are there any activities that your child has taken up, and is particularly good at?
- Have you had to restrict your child's activities because you felt she was not yet strong enough to participate, for instance in certain school activities, like PE or school trips? (prompt: would you tell your child it is better she doesn't participate because she will be stronger sooner and be able to do all those things, and would be you explain to your child that she will probably feel ill again if she participates?)

Eating

- Sometimes eating can be a problem after treatment. Does your child have any difficulties with eating, perhaps being a faddy eater?
- How do you try to resolve this?

Adolescent issues

*Can you tell me about issues that are difficult now that your child is a teenager
such as :
going out
coming home late
wearing unacceptable clothes
arguments with your child
*How do you try and deal with these situations

Explaining illness

- How did you go about telling your child about the illness.
- Did the doctors give you any idea of what kind of reactions to expect from your child?
- How did you answer questions about the child having to go to hospital?
- Do you think children should know everything about the illness and what might happen in the future?

Body Image

- Lots of children who are seriously ill have concerns about how they look, especially their hair and weight. Do you feel your child has any concerns about how she/he looks?
- How has your child coped with any changes in her appearance? Has she changed the clothes she wears as a result of the illness?
- How have you tried to help your child cope with these issues?

Relationship with family and friends

- How has the child's illness affected the family?
- Are you closer to your child as a result of the illness?
- Has it changed the relationship with his/her siblings?
- Do you feel that the treatment has affected your child's relationships with friends?
- Have friends stayed in contact?

Future

- If you think about the future, what plans does your child have in relation to work and education?
- Do you think that the illness has made a difference to your child's plans for the future?

APPENDIX FIVE

STUDY TWO: CHILD QUESTIONNAIRE BOOKLET

ID# _____

Date: _____

PedsQL

Pediatric Quality of Life Inventory

Version 3.0

CHILD REPORT (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES (problems with…)	*Never*	*Almost Never*	*Some-times*	*Often*	*Almost Always*
1. It is hard for me to walk more than a block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I feel very tired	0	1	2	3	4

ABOUT MY FEELINGS (problems with…)	*Never*	*Almost Never*	*Some-times*	*Often*	*Almost Always*
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with…)	*Never*	*Almost Never*	*Some-times*	*Often*	*Almost Always*
1. I have trouble getting on with other kids	0	1	2	3	4
2. Other kids do not want to be my friend	0	1	2	3	4
3. Other kids tease me	0	1	2	3	4
4. I cannot do things that other kids my age can do	0	1	2	3	4
5. It is hard to keep up when I play with other kids	0	1	2	3	4

ABOUT SCHOOL (problems with…)	*Never*	*Almost Never*	*Some-times*	*Often*	*Almost Always*
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

DIRECTIONS
Part Two: Well-Being

Please tell us **how much each sounds like you** during the **past ONE month** by circling:

0 if it **never** sounds like you
1 if it **almost never** sounds like you
2 if it **sometimes** sounds like you
3 if it **often** sounds like you
4 if it **almost always** sounds like you

*In the past **ONE month**, how much does this **sound like you** …*

ABOUT ME	*Never*	*Almost never*	*Some-times*	*Often*	*Almost Always*
1. I feel happy	0	1	2	3	4
2. I feel good about myself	0	1	2	3	4
3. I feel good about my health	0	1	2	3	4
4. I get support from my family or friends	0	1	2	3	4
5. I think good things will happen to me	0	1	2	3	4
6. I think my health will be good in the future	0	1	2	3	4

*In the past **ONE month**…*

IN GENERAL…	*Bad*	*Fair*	*Good*	*Very Good*	*Excellent*
1. In general, how is your health?	0	1	2	3	4

BODY IMAGE (teen completed only) (Kopel et al., 1998)

Please read the following statements, which include descriptions of how other people have described their feelings about how they look. Choose one number to describe whether you agree or disagree with each one.

Strongly disagree	**1**	**2**	**3**	**4**	**5**	**Strongly agree**

I am happy with the way I look	1	2	3	4	5
I am not able to move as quickly as I would like	1	2	3	4	5
I feel people stare at me in the street	1	2	3	4	5
I am self-conscious about the way my arms and shoulders look	1	2	3	4	5
I think my body is well-proportioned	1	2	3	4	5
I am self-conscious about the way my stomach looks	1	2	3	4	5
I wish I was more physically fit	1	2	3	4	5
My body is strong enough for all I want to do	1	2	3	4	5
I worry about knocking things over	1	2	3	4	5
I am self-conscious about the way my hair looks	1	2	3	4	5
I think I get tired more easily than my friends	1	2	3	4	5
I am as well developed physically as my friends	1	2	3	4	5
I feel people avoid me because of the way I look	1	2	3	4	5
I feel my appearance makes it difficult for people to like me	1	2	3	4	5
I worry about falling over	1	2	3	4	5
I am very satisfied with my weight	1	2	3	4	5
I am self-conscious about the way my face and neck look	1	2	3	4	5
I am afraid people will laugh at me because of the way I look	1	2	3	4	5
I think I look good in a swimsuit	1	2	3	4	5

THANK YOU FOR TAKING PART IN OUR STUDY!!!

APPENDIX SIX

STUDY TWO: PARENT QUESTIONNAIRE BOOKLET

Introduction (parent-child booklet)*

Thank-you for agreeing to help in our study. We would be very grateful if you could complete the enclosed questionnaires. These will include questions about your views of your child's health now and in the future, and any concerns you may have about caring for your child. There are also some questions about your won health.

Please read the following questions and tick the box which most nearly describes your views. Remember there are no right or wrong answers, only what you think. Please give your first answer. If there are any questions you feel you do not want to complete, please write 'N/A' (for not applicable). All the data will be coded anonymously and entered into a computer for analysis. Please try not to leave out any questions.

A summary of the results will be available in the clinic in approximately 6 months. However, if you would like the summary to be sent to you directly, please tick the box below.

☐ Yes, I would like the summary sent to my home directly.

* The parent-teen booklet was identical except the PedsQL used was the parent-teen form, where the word 'child' was replaced by 'teen'.

Demographic Questionnaire

Child's name _____

Sex _____

Child's birthday _____

Mother's name _____

Address _____

_____

_____

Telephone _____

Mother's birthday

_____

Mother's age

_____

Child's siblings

-brother(s) birth date

_____

-sister(s) birth date

_____

Name of your child's illness_____

Child's age on diagnosis _____

ID# _____

Date: _____

PedsQL
Pediatric Quality of Life Inventory

Version 3.0

PARENT REPORT for CHILDREN (ages 8-12)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month,** how much of a **problem** has your child had with …*

PHYSICAL FUNCTIONING (problems with…)	*NEVER*	*ALMOST NEVER*	*SOME-TIMES*	*OFTEN*	*ALMOST ALWAYS*
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores around the house	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with…)	*Never*	*Almost Never*	*Some -times*	*Often*	*Almost Always*
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him/her	0	1	2	3	4

SOCIAL FUNCTIONING *(problems with…)*	Never	Almost Never	Some -times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other	0	1	2	3	4

SCHOOL FUNCTIONING (problems with…)	*Never*	*Almost Never*	*Some -times*	*Often*	*Almost Always*
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with schoolwork	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or	0	1	2	3	4

DIRECTIONS
Part Two: Well-Being

Please tell us **how much each sounds like your child** during the **past ONE month** by circling:

0 if it **never** sounds like your child
1 if it **almost never** sounds like your child
2 if it **sometimes** sounds like your child
3 if it **often** sounds like your child
4 if it **almost always** sounds like your child

*In the past **ONE month**, how much does this **sound like your child** …*

ABOUT ME…	*Never*	*Almost never*	*Some-times*	*Often*	*Almost Always*
Feels happy	0	1	2	3	4
Feels good about himself or herself	0	1	2	3	4
Feels good about his or her health	0	1	2	3	4
Gets support from family or friends	0	1	2	3	4
thinks good things will happen to him or her	0	1	2	3	4
thinks his or her health will be good in the future	0	1	2	3	4

*In the past **ONE month**…*

IN GENERAL…	*Bad*	*Fair*	*Good*	*Very Good*	*Excellent*
1. In general, how is your child's health?	0	1	2	3	4

The next section is about any worries or concerns you may have about your child in the <u>future</u>.

MATERNAL WORRY SCALE (*DEVET & IREYS, 1998)*

SAME AS IN STUDY ONE - PLEASE SEE APPENDIX ONE

PARENTING STYLES AND DIMENSIONS QUESTIONNAIRE (VERSION III; SEE CHAPTER EIGHT)

Please think about the following statements and decide how frequently they apply to you. Every family is different, so please be as honest as you can.

	Never	Almost never	Some-times	Often	Almost always
I encourage my child to talk about his/her troubles.	☐	☐	☐	☐	☐
I state punishments to my child and do not actually do them.	☐	☐	☐	☐	☐
I give praise when my child is good.	☐	☐	☐	☐	☐
I tell my child that I appreciate what he/she accomplishes.	☐	☐	☐	☐	☐
I do not allow my child to get angry with me.	☐	☐	☐	☐	☐
I am easy going and relaxed with my child.	☐	☐	☐	☐	☐
I have strict, well established rules for my child.	☐	☐	☐	☐	☐
I joke and play with my child.	☐	☐	☐	☐	☐
I give my child reasons why rules should be obeyed.	☐	☐	☐	☐	☐
I show sympathy when my child is hurt or frustrated.	☐	☐	☐	☐	☐
I help my child to understand the impact of behaviour by encouraging him/her to talk about the consequences of his/her own actions.	☐	☐	☐	☐	☐
I believe children should not have secrets from their parents.	☐	☐	☐	☐	☐
I explain to my child how I feel about his/her good and bad behaviour.	☐	☐	☐	☐	☐
I emphasise the reasons for rules.	☐	☐	☐	☐	☐
I give comfort and understanding when my child is upset.	☐	☐	☐	☐	☐
I show respect for my child's opinions by encouraging him/her to express them.	☐	☐	☐	☐	☐
I allow my child to give input into family rules.	☐	☐	☐	☐	☐

Please turn over....

	Never	Almost never	Some-times	Often	Almost always
I allow my child to go out with friends without my permission	☐	☐	☐	☐	☐
I am confident about my parenting abilities.	☐	☐	☐	☐	☐
I take my child's desires into account before asking him/her to do something.	☐	☐	☐	☐	☐
I take into account my child's preferences in making plans for the family.	☐	☐	☐	☐	☐
I believe it is unwise to let children play a lot by themselves without supervision.	☐	☐	☐	☐	☐
I am unsure on how to solve my child's misbehaviour.	☐	☐	☐	☐	☐
I am responsive to my child's feelings and needs.	☐	☐	☐	☐	☐
I find it difficult to discipline my child.	☐	☐	☐	☐	☐
I am afraid that disciplining my child for misbehaviour will cause him/her to not like me.	☐	☐	☐	☐	☐
I explain the consequences of my child's behaviour.	☐	☐	☐	☐	☐
I spoil my child.	☐	☐	☐	☐	☐
I threaten my child with punishment more often than actually giving it.	☐	☐	☐	☐	☐
I give into my child when he/she causes a commotion about something.	☐	☐	☐	☐	☐
I ignore my child's misbehaviour.	☐	☐	☐	☐	☐
I show patience with my child.	☐	☐	☐	☐	☐
I allow my child to annoy someone else.	☐	☐	☐	☐	☐
I allow my child to interrupt others.	☐	☐	☐	☐	☐
I talk it over and reason when my child misbehaves.	☐	☐	☐	☐	☐
I teach my child to keep control of his/her feelings at all times	☐	☐	☐	☐	☐
I believe that criticism makes a child improve.	☐	☐	☐	☐	☐
I teach my child that bad behaviour will always be found out.	☐	☐	☐	☐	☐
I control my child by warning that some situations are very dangerous.	☐	☐	☐	☐	☐
I treat my child like a friend.	☐	☐	☐	☐	☐

SF - 36 HEALTH SURVEY
(Jenkinson, Layte, Wright, & Coulter, 1996)

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(circle one)

Excellent 1
Very good 2
Good 3
Fair 4
Poor 5

2. Compared to one year ago, how would you rate your health in general now?

(circle one)

Much better now than one year ago 1
Somewhat better now than one year ago 2
About the same as one year ago 3
Somewhat worse now than one year ago 4
Much worse now than one year ago 5

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(circle one number on each line)

ACTIVITIES	Yes, Limited A Lot	Yes, Limited A Little	No, Not Limited At All
a. **Vigorous activities,** such as running, lifting heavy objects, participating in strenuous sports			
b. **Moderate activities,** such as moving a table, pushing a vacuum cleaner, bowling, or playing golf			
c. Lifting or carrying groceries			
d. Climbing **several** flights of stairs			
e. Climbing **one** flight of stairs			
f. Bending, kneeling, or stooping			
g. Walking **more than a mile**			
h. Walking **half a mile**			
i. Walking **one hundred yards**			
j. Bathing or dressing yourself			

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Were limited in the **kind** of work or other activities	1	2
d. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(circle one number on each line)

	YES	NO
a. Cut down on the **amount of time** you spent on work or other activities	1	2
b. **Accomplished less** than you would like	1	2
c. Didn't do work or other activities as **carefully** as usual	1	2

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(circle one)

Not at all 1
Slightly 2
Moderately 3
Quite a bit 4
Extremely 5

7. How much bodily pain have you had during the past 4 weeks?

(circle one)

None 1
Very mild 2
Mild 3
Moderate 4
Severe 5
Very Severe 6

8. During the past 4 weeks how much did pain interfere with your normal work (including both work outside the home and housework)?

(circle one)

Not at all 1
A little bit 2
Moderately 3
Quite a bit 4
Extremely 5

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks

(circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of life?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and low?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

circle one)

All of the time 1
Most of the time 2
Some of the time 3
A little of the time 4
None of the time 5

11. How TRUE or FALSE is <u>each</u> of the following statements for you?

(circle one number on each line)

	Definitely true	Mostly true	Don't know	Mostly false	Definitely false
a. I seem to get ill more easily than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

CENTRE FOR EPIDEMIOLOGICAL STUDIES-DEPRESSION (CES-D; RADLOFF, 1977)

Please think about the following statements and tick the box which most applies to you.

DURING THE PAST WEEK I:

	None (less than 1 day)	Some (1-2 days)	Occasional (3-4 days)	most/all (5-7 days)
was bothered by things that don't usually bother me	☐	☐	☐	☐
had no appetite	☐	☐	☐	☐
couldn't shake the blues even with the help of friends or family	☐	☐	☐	☐
felt I wasn't as good as other people	☐	☐	☐	☐
had trouble keeping my mind on what I was doing	☐	☐	☐	☐
felt depressed	☐	☐	☐	☐
felt everything I did was an effort	☐	☐	☐	☐
felt hopeful about the future	☐	☐	☐	☐
thought my life had been a failure	☐	☐	☐	☐
felt fearful	☐	☐	☐	☐
had restless or no sleep	☐	☐	☐	☐
was happy	☐	☐	☐	☐
talked less than usual	☐	☐	☐	☐
felt lonely	☐	☐	☐	☐
felt that people were unfriendly	☐	☐	☐	☐
enjoyed life	☐	☐	☐	☐
had crying spells	☐	☐	☐	☐
felt sad	☐	☐	☐	☐
felt that people disliked me	☐	☐	☐	☐
could not 'get going'	☐	☐	☐	☐

THANK YOU FOR HELPING US WITH OUR STUDY

APPENDIX SEVEN

STUDY TWO: PARENTAL INTERVIEW DIMENSIONS CODING TABLE

ID:

1. Warmth

- **Involvement**

- **Responsiveness**

- **Description of relationship / loving**

2. Psychological autonomy / reverse of psychological control

- **Open bi-directional communication**

- **Encouraging expression of opinions / respecting opinions**

- **Induction / reasoning (non-coercive discipline)**

3. Behavioural control

- **Limitsetting**

- **Maturity demands**

- **Monitoring**

NOTES

(ANY ADDITIONAL NOTES WERE WRITTEN HERE)

Additionally coded categories

1. General thoughts on child-rearing / philosophy on child-rearing

- Difficulties

- Mother's attitude towards parenting

2. Concerns with illness

- Side-effects of medication

- Relapse / death

Weightings - high – medium - low

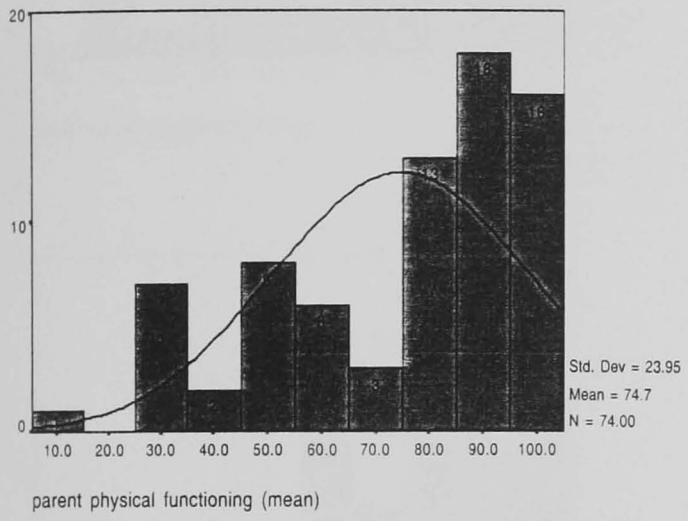
	High*	Medium	Low
Warmth			
Involvement			
Responsiveness			
Loving			
Psychological autonomy			
Communication			
Encouraging opinions			
Induction / reasoning			
Behavioural control			
Limit setting			
Maturity demands			
Monitoring			

* The number of excerpts would be written in each box. For example, if the mother discussed high involvement twice and medium involvement once, she would receive 2 and 1 points respectively in these boxes. These points would then be converted into scores (3 for a high, 2 for medium). Therefore, she would receive a total score of 8 / 3 = 2.67 for involvement (3 high x 2 examples + 2 medium x 1 example = 8 / divided by the number of excerpts (N=3) = 2.67).

APPENDIX EIGHT

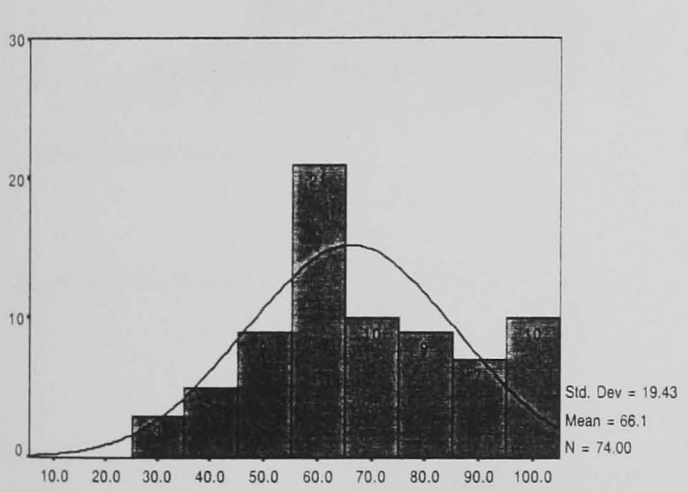
STUDY TWO: DESCRIPTIVE DATA

Mother-proxy PedsQL sub-scale

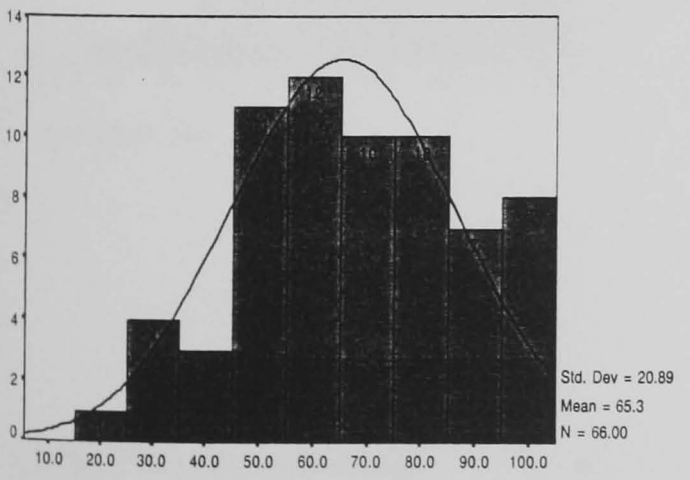


Descriptives

Skewness = -0.83,
Kurtosis = -0.45
SE Skew = 0.28,
z = -2.97

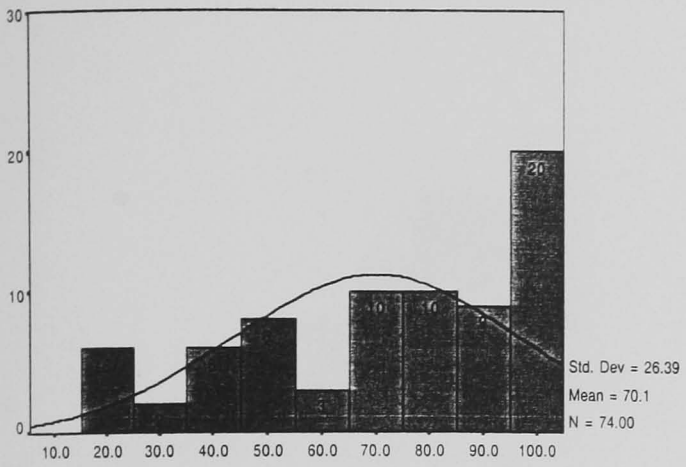


Skewness = 0.24,
Kurtosis = -0.76
SE Skew = 0.28,
z = 0.86



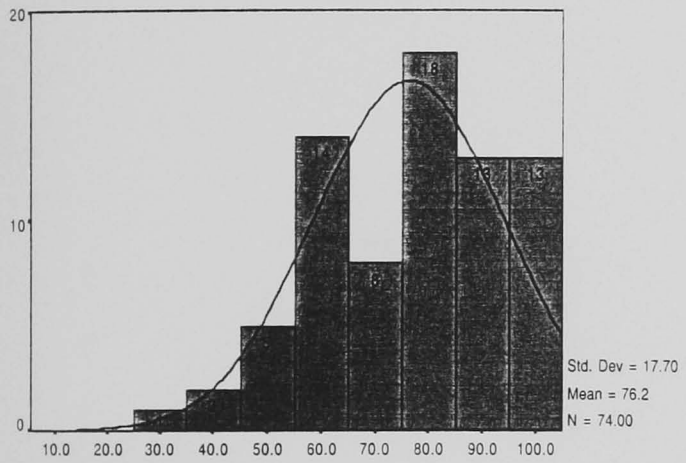
Skewness = -0.12,
Kurtosis = -0.76
SE Skew = 0.30,
z = -0.42

Mother-proxy PedsQL sub-scale

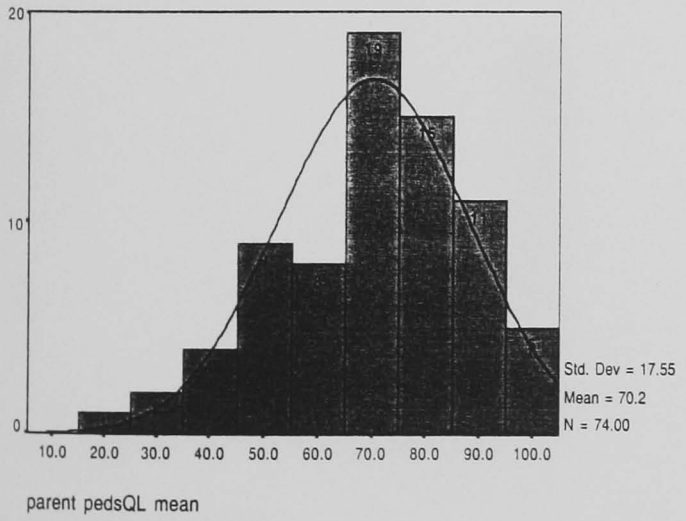


Descriptives

Skewness = -0.56,
Kurtosis = -0.84,
SE Skew = 0.28,
z = -1.99



Skewness = -0.47,
Kurtosis = -0.29,
SE Skew = 0.28,
z = -1.68

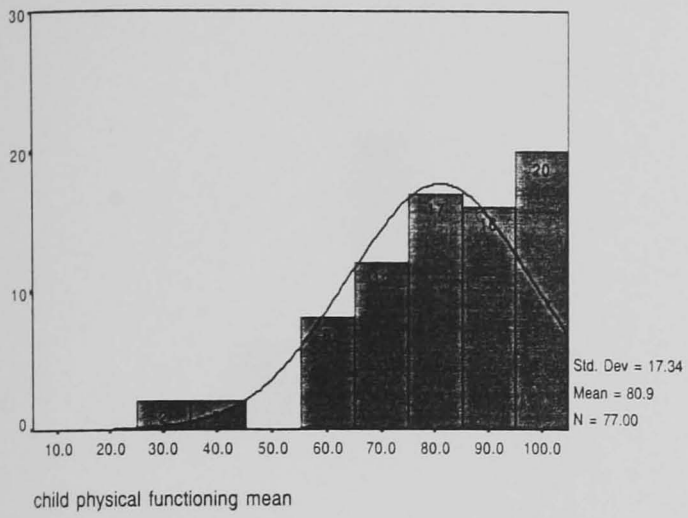


Skewness = -0.50,
Kurtosis = -0.30,
SE Skew = 0.28,
z = -1.78

Child PedsQL sub-scale

Descriptives

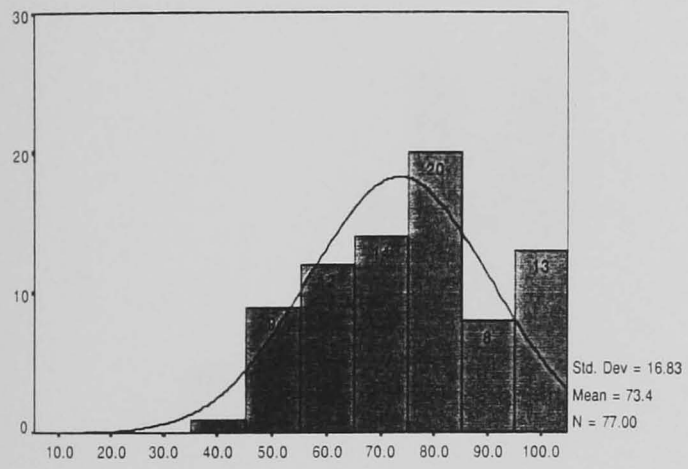
Child PedsQL sub-scale



child physical functioning mean

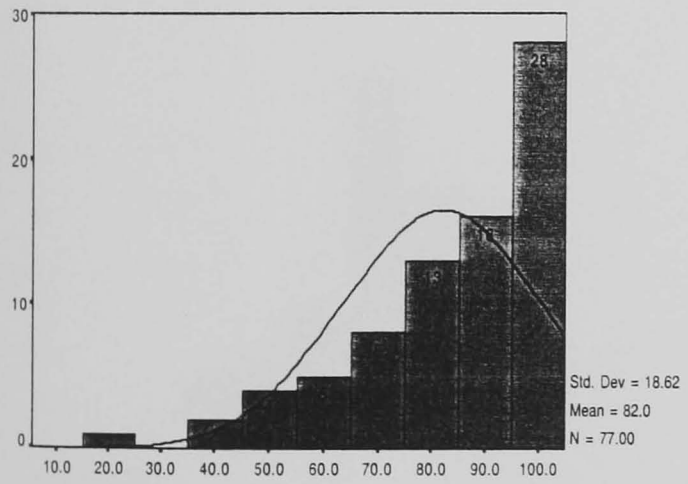
Descriptives

Skewness = -1.07
Kurtosis = 1.26
SE skew = 0.29
z = -3.96



child emotional functioning mean

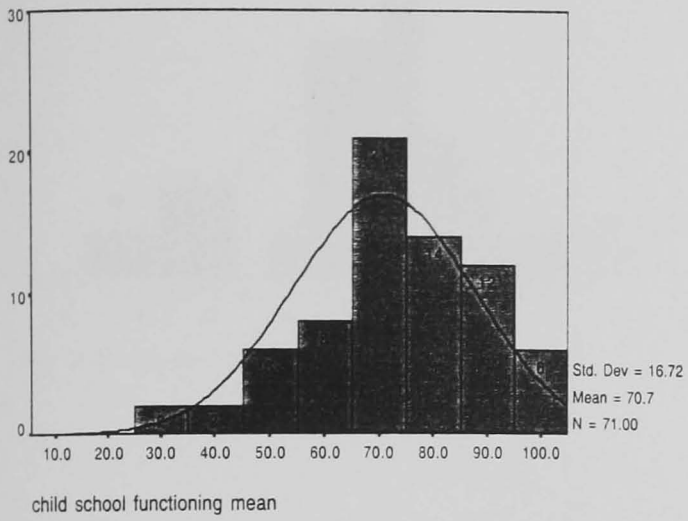
Skewness = 0.05
Kurtosis = -0.97
SE skew = 0.27
z = 0.18



child social functioning mean

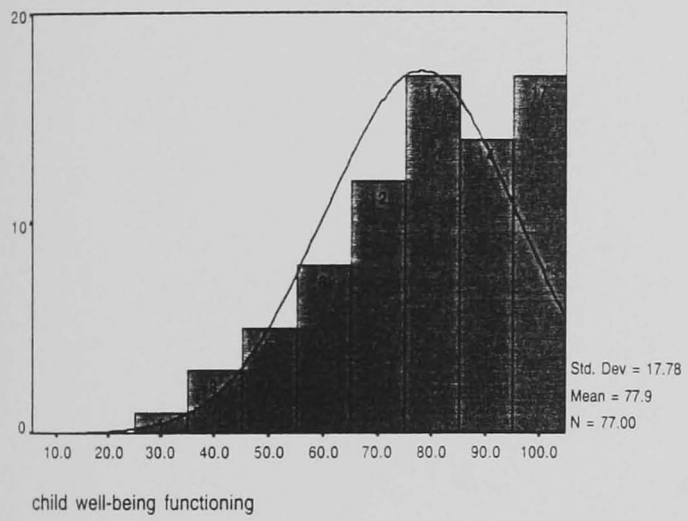
Skewness = -1.17
Kurtosis = 0.99
SE skew = 0.28
z = -4.33

Child PedsQL sub-scale

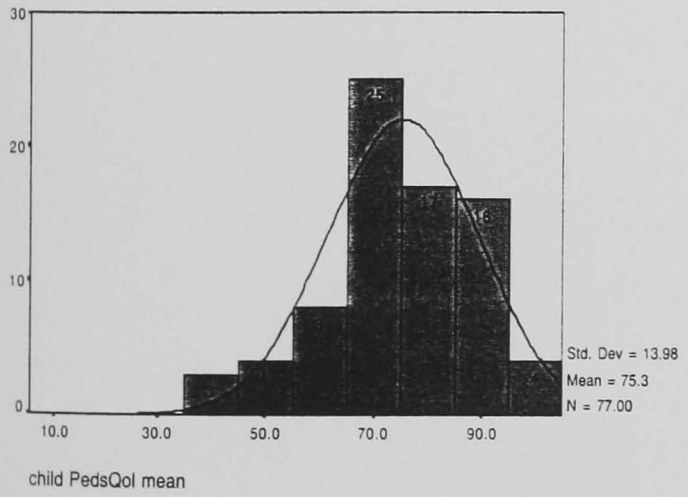


Descriptives

Skewness = -0.44
Kurtosis = 0.06
SE skew = 0.28
z = -1.54



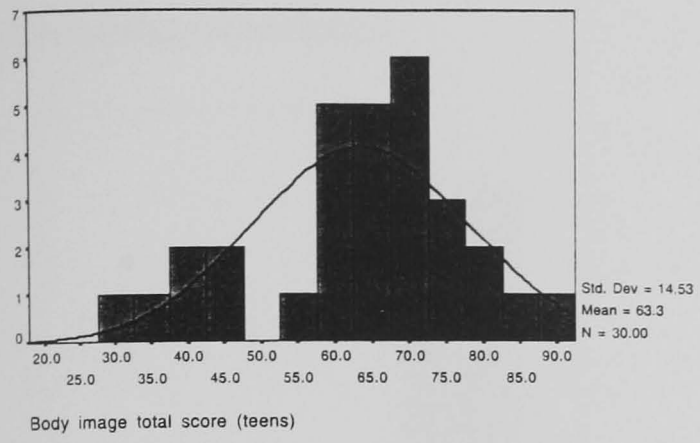
Skewness = -0.58
Kurtosis =-0.43
Se skew = 0.27
z = -2.14



Skewness = -0.49
Kurtosis = -0.19
Se skew = 0.27
z = -1.81

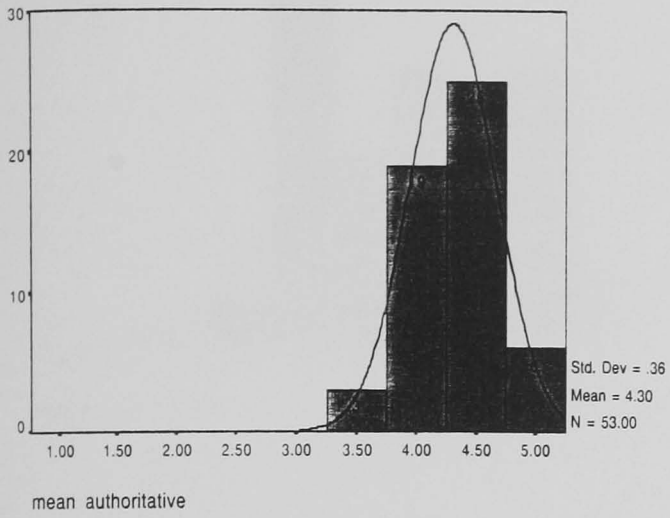
Adolescent Body Image

Descriptives



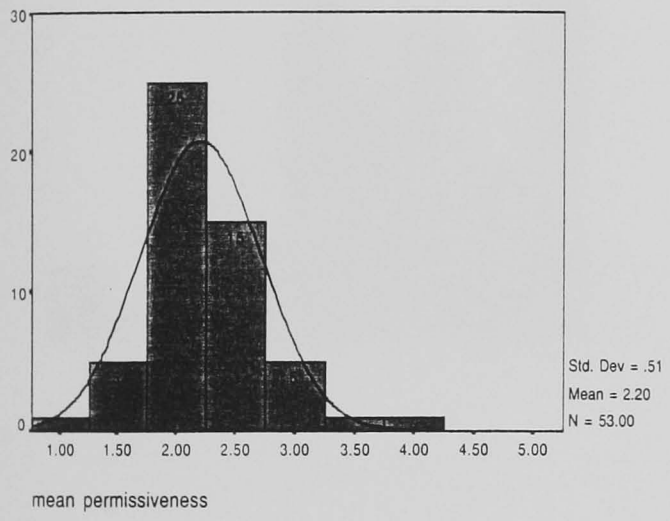
Skewness = -0.53
Kurtosis = -0.23
SE Skew = 0.43
Z= -1.22

Parenting Behaviours

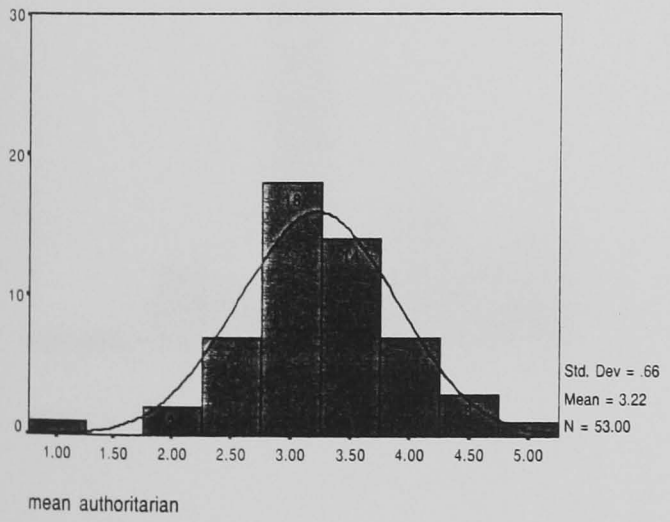


Descriptives

Skewness = -0.28
Kurtosis = -0.53
SE Skew = 0.33
z = -0.82



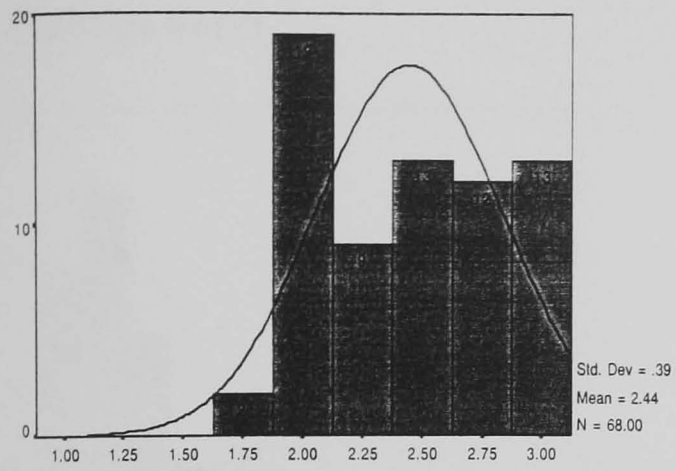
Skewness = 0.75
Kurtosis = 1.21
SE Skew = 0.33
z = 2.27



Skewness = -0.41
Kurtosis = 1.49
SE Skew = 0.33
z = -1.21

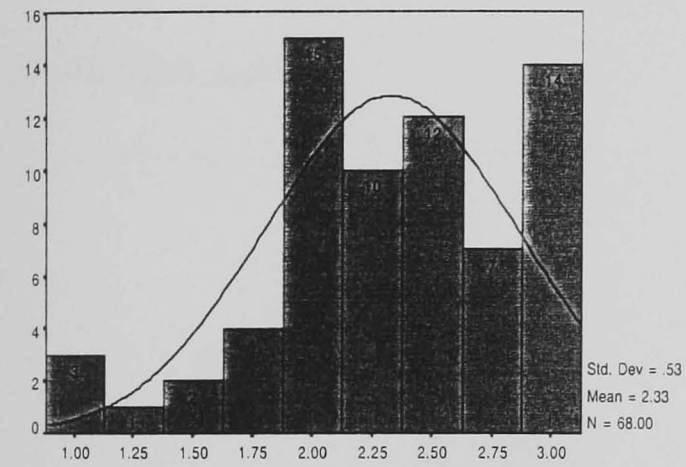
Parent interview dimensions

Descriptives



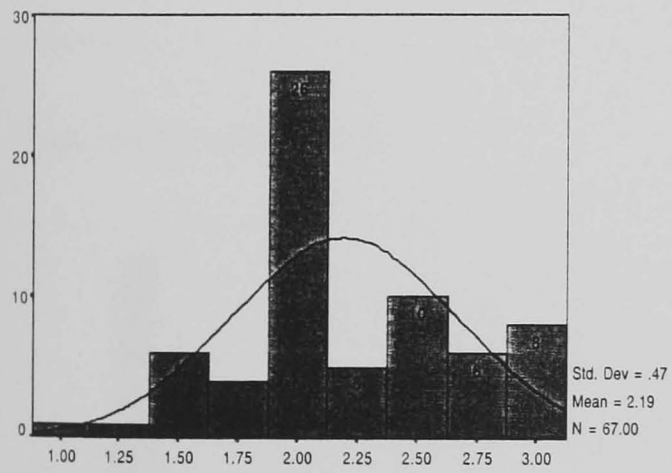
Parenting int: Warmth

Skewness = -0.00
Kurtosis = -1.32
SE Skew = 0.29
z = -0.01



Parent int: Psych autonomy

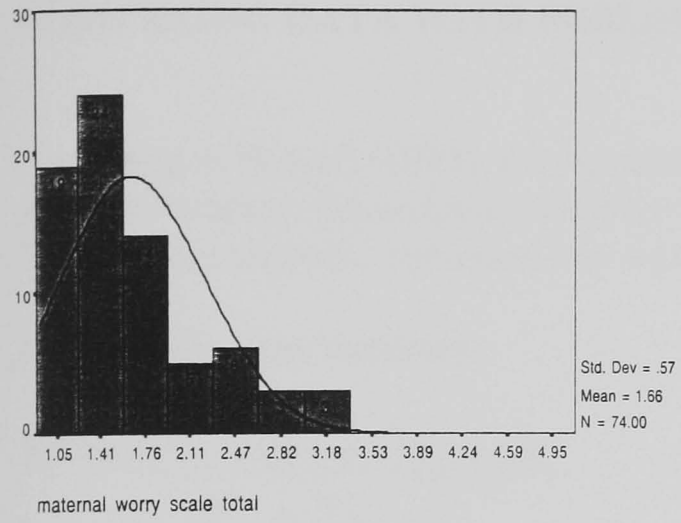
Skewness = -0.60
Kurtosis = -0.06
SE Skew = 0.29
z = -2.07



Parent int: beh control

Skewness = 0.09
Kurtosis = -0.42
SE Skew = 0.29
z = 0.28

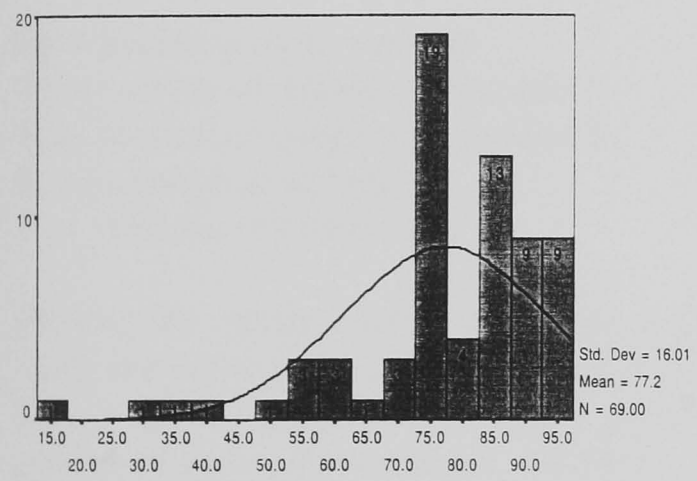
Parental worry



Descriptives

Skewness = 1.20
Kurtosis = 0.56
SE skew = 0.28
z = 4.30

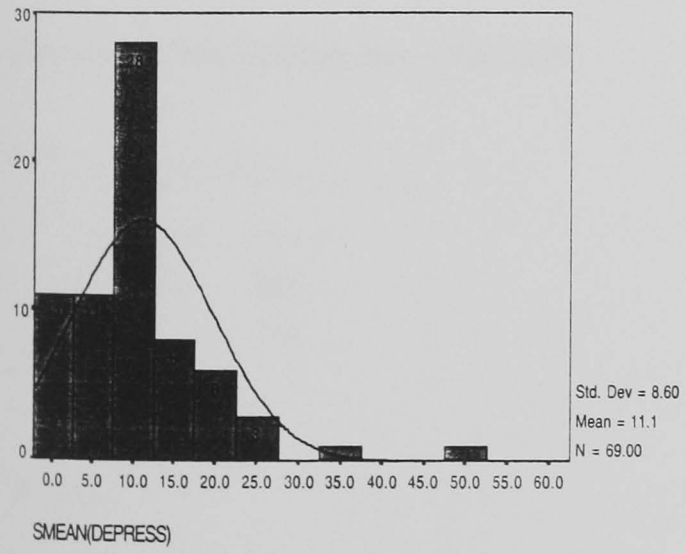
SF-36 total score



Descriptives

Skewness = -1.64
Kurtosis = 2.88
SE Skew = 0.28
z = -5.88

Depression total score



Descriptives

Skewness = 2.13
Kurtosis = 6.07
SE Skew = 0.28
z = 7.63

APPENDIX NINE

COMPARING DATA WITH PUBLISHED NORMS – CHAPTER NINE

According to Howell (1992), the calculation takes place in three parts. First, you must pool the variance. Second, you calculate the *t* statistic. Third, taking the degrees of freedom into account, you assess the significance of *t*.

First. Pooling the variance

$$Sp = \frac{(N_1-1)S_1 + (N_2-1)S_2}{N_1 + N_2 - 2}$$

Where,

Sp = pooled sample variance
N_1 = number of subjects in sample 1
N_2 = number of subjects in sample 2
S_1 = variance of sample 1
S_2 = variance of sample 2

Pooling the variance for both samples is a more conservative approach, as opposed to using the variance for each sample individually. This takes into consideration the hugely skewed sample sizes, which are usually found when comparing data with published norms (for example, the SF36 scores which were normed using 1200 women; see below for details). Therefore, the *pooled* variance will be much closer to the variance of the normed data (due to the increased effect the large sample will have).

Second. Calculating the *t* statistic

$$t = \frac{X_1 - X_2}{\sqrt{\frac{Sp}{N_1} + \frac{Sp}{N_2}}}$$

Where,

X1 = mean of sample one's scores
X2 = mean of sample two's scores

Third. Assessing degrees of freedom (df) and assessing significance of *t* statistic

Degrees of freedom and the *t*-distribution can be checked in any major text book (for example, Howell, 1992, p. 648).

By assessing the desired level of significance and the df, you can assess whether your *t* value was significant or not.

Published norms

(1) SF26 (Jenkinson, Coulter, & Wright, 1993)

Published norms were available for women between the ages of 18-64 years. The age-range from 35-54 (N=1183 – 1211 in each sub-scale) was chosen as it was the most appropriate comparison for women recruited in this study.

Variable	*Published mean (SD)*	*Current study mean (SD)*	
		ALL	*CNS*
Physical functioning	89.4 (16.1)	89.30 (16.11)	91.50 (11.93)
Social functioning	86.7 (20.5)	74.47 (19.75)	75.56 (21.20)
Role limitation (physical)	84.0 (32.0)	83.33 (16.11)	79.76 (32.33)
Role limitation (emotional)	80.3 (33.6)	80.18 (33.76)	76.41 (33.00)
Mental health	71.6 (17.8)	71.14 (20.49)	65.52 (22.89)
Energy / vitality	58.2 (19.9)	63.78 (20.90)	52.62 (22.34)
Pain	79.4 (22.0)	83.18 (24.93)	82.15 (24.77)
General health perception	74.1 (20.3)	73.35 (22.36)	68.81 (26.24)

(2) CES-D (Hann, Winter & Jacobsen, 1999)

Variable	*Published mean (SD)*	*Current study mean (SD)*	
		ALL	*CNS*
Total depression	*8.1 (7.0)*	*11.46 (11.69)*	*13.30 (13.77)*

(3) PedsQL – child report (Varni, Seid, & Kurtin, in press)

Published norms are available for 401 healthy children.

Variable	*Published mean (SD)*	*Current study mean (SD)*	
		ALL	*CNS*
Physical functioning	*84.41 (17.260*	*85.28 914.37)*	*72.24 (19.59)*
Psychosocial health (without well-being)	*82.38 915.51)*	*78.33 (13.33)*	*69.53 (13.36)*
Total QOL (without well-being)	*83.00 (14.79)*	*80.18 (14.37)*	*70.14 (19.59)*

(4) PedsQL – parent proxy report (Varni et al., in press)

Published norms are available for 717 parents of healthy children

Variable	*Published mean (SD)*	*Current study mean (SD)*	
		ALL (N=45)	*CNS (N=24)*
Physical	*89.32 (16.35)*	*83.77 (20.57)*	*59.71 (21.74)*
Psychosocial health (without well-being)	*86.58 (12.79)*	*73.71 (16.95)*	*57.91 (18.13)*
Total QOL (without well-being)	*87.61 (12.33)*	*76.50 (16.10)*	*58.76 918.34)*