UNIVERSITY OF SOUTHAMPTON

Psychosocial adjustment in children and adolescents with chronic illness

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Doctor of Philosophy

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July 2000

UNIVERSITY OF SOUTHAMPTON

ABSTRACT

FACULTY OF SOCIAL SCIENCE

PSYCHOLOGY

Doctor of Philosophy

Psychosocial adjustment in children and adolescents with chronic illness

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Substantial improvements in life expectancy and health status among young people with chronic illness over the last four decades have meant an increasing number of young people and their families are dealing with the psychosocial demands of chronic illness. While many young people adjust to these demands, others experience marked difficulty and this suggests that factors implicated in adjustment function to increase and decrease risk for difficulty. Current research perspectives and theoretical models defining the psychosocial consequences of chronic illness indicate condition-related parameters, individual and family factors influence adjustment. However, it is not clear if categorical, condition-specific parameters, such as diagnostic classification, or non-categorical parameters common to a number of chronic conditions, for example chronicity or severity, are more or less influential. In addition, mechanisms forecasting outcome are poorly understood and the role of peer and friendship relations in children's adjustment to chronic illness has received limited attention.

This thesis contains a multi-site, cross-sectional study of young people with either asthma, diabetes mellitus, cystic fibrosis or epilepsy and their parents. The study sought to establish the utility of categorical and non-categorical condition parameters in understanding the psychosocial effects of chronic illness, examine the validity of the risk resistance framework put forward by Wallander *et al.*, (1989b) and delineate the role of peer and friendship relations in adjustment outcomes. In contrast to many other studies using parent report of adjustment, child and adolescent report was the principal index of psychosocial adjustment. Outcomes were defined on the basis of overall difficulty, emotional difficulty, denoting internalising behaviours, such as nervousness, and behavioural difficulty reflecting externalising behaviours, for example hyperactivity and conduct problems. Furthermore, the involvement of child, maternal, paternal, teacher and health professional reports aimed to strengthen study findings by linking predictor and criterion variables representing independent sources.

Findings suggest that both categorical and non-categorical parameters are implicated in adjustment outcomes. However, the predictive utility of these parameters differed considerably by informant. Whereas parameters were highly instrumental in parent report of adjustment, this was not the case for child report. Nonetheless, parameters were related to child and parental management of chronic illness and suggested that non-categorical parameters were more influential. The risk resistance framework gained partial support, receiving confirmation of conceptual structure for selected pathways. However, the risk resistance moderating mechanism was not validated. Friendship intimacy and teacher report of peer relations were positively associated, although only increases in school adjustment, as reported by teachers were related to a decline in child report of overall and behavioural difficulties. In addition, lower levels of functioning were linked to decreases in school adjustment and to a lesser and non-significant degree to peer relations. Level of functioning was not however, related to friendship properties such as, play/association or intimacy. While emotional difficulties and level of functioning showed few effects in terms of the quality and properties of children's friendships, peer relations and school adjustment, higher levels of emotional difficulty and low functioning together were linked to less favourable school adjustment.

To some extent, findings are consistent with previous research in that the experience of chronic illness for young people is more closely associated with emotional than behavioural difficulties. Other findings are new and require further studies to clarify the role of condition-related parameters and assess the impact of children's functional status on social functioning in relation to psychosocial adjustment. Additional understanding may be gleaned from studies which employ longitudinal designs, include both categorical and non-categorical condition parameters and a multi-informant approach.

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Acknowledgments

My thanks go to the children, their parents, teachers and health professionals who participated in this study and gave so generously of their time. Without the support and co-operation of participants there would be no research to report on. Special thanks go to Sabrina and Paul who will never know how helpful their contributions were. This study would not have been possible without the substantial assistance of clinicians, clinical nurse specialists and out-patient staff at the five hospital sites. Their help was invaluable in facilitating the recruitment process. I am also grateful to Ineke Pit-ten Cate, Dave Daley, Sarah Stevenage and Tony Roberts in the Department of Psychology for their assistance and Steve Clements in the Department of Social Statistics for his useful statistical advice. I would also like to thank my supervisor Professor Jim Stevenson and advisor Dr Roger Ingham for their help during the last four years and the Economic and Social Research Council and Department of Psychology for their financial support. Finally and not least, I am indebted to my family and friends, particularly Julie and Mary for their encouragement and understanding.

Chapter 1: Introduction: Chronic childhood illness and psychosocial adjustment

Advances in medical treatment mean that an increasing number of young people and their families live with chronic childhood illnesses such as asthma, diabetes or epilepsy, and deal with physical, financial and psychological issues that healthy peers rarely experience. For instance, complicated treatment regimens, side effects of treatment, unpredictable symptom onset, fear of acquiring infections from peers, whether a condition limits life expectancy, loss of career opportunities, interference with schooling, parental employment and family activities represent some of the demands that place increased stress on child and family resources and psychosocial well-being. However, while some young people with chronic illness seem to encounter substantial psychological difficulty, others experience few problems. Such marked variation raises important questions about the factors that influence how an affected child and family manage the challenges posed by chronic childhood illness. Yet, to some extent, current knowledge remains unclear about the way in which psychosocial, and in particular, condition-related parameters such as condition duration or course, are associated with and determine a child's current and future well-being.

Since the vast majority of children are embedded in families, any attempt to widen understanding must address in what way the family environment contributes to, and is associated with a child's adjustment to chronic illness. However, children are also situated within peer groups. Gaining peer group acceptance, fitting in and friendship relations are increasingly viewed as crucial to social and emotional development and psychosocial well-being. The family and peer environments are implicated in the psychological welfare of children reflecting particular relationships. Whereas a child is positioned for the most part, and of necessity in a dependent relationship with their parents, peer relationships are more or less equitable. A peer environment characterised by similarities in age, interests, size and experiences presents opportunities to strengthen understanding of individuality and gain psychological independence through assimilation with and separation from the peer group. It may be expected, therefore, that the nature of a child's peer relationships is likely to be of equal importance in guiding adjustment and as such demands examination.

Accordingly, this thesis embodies an investigation of the respective influence of psychosocial and condition-related factors in dealing with, and adjustment to, chronic illness among children and adolescents with either asthma, diabetes mellitus, cystic fibrosis or epilepsy. The thesis is based on a single study and aims to present a detailed examination of the afore mentioned factors and extend the current focus of theoretical models beyond the family to include peer and friendship relations. In essence, the study seeks to address some of the shortcomings in previous research which include equivocal and limited findings in relation to the role of condition-related parameters in adjustment to, and management of, chronic illness, restricting examination of psychosocial factors to the family, and involvement of no more than one or two informants. A further aim endeavoured to shift the more usual research approach away from parent report of psychological difficulty, and bring the child's perception of difficulty into focus. In addition, evidence from multivariate conceptual models put forward to explain child adjustment, and described in this chapter, reflects investigation of model components. There is no evidence confirming the validity of an entire framework. If research and intervention design are to move forward, the relative utility of the whole framework needs to be established. Therefore the study sought to examine the validity of one particular model. Overall, it is hoped that further clarification may broaden understanding of children's adjustment to chronic illness and may perhaps assist in the prevention of long-term difficulties.

An overview of thesis contents is provided in the following synopsis. In addition to this profile, subsequent chapters begin by defining the respective content and aims.

1.1 Thesis outline

The thesis is organised into eight chapters which are briefly summarised. Chapters 1 and 2 explore the social, theoretical and empirical setting. In Chapter 1 medical developments providing the backdrop to current demands for improved understanding of adjustment to chronic illness are outlined. We then move on to consider present research perspectives, theoretical models, their strengths and weaknesses, evidence for links between condition-related parameters and adjustment, and conclude with an evaluation of definitional and methodological issues. Chapter 2 focuses on the family and peer environments impinging on the psychosocial well-being of children. In this chapter social factors defining family structure, for example, single parent, stepfamily status and current theoretical approaches to the family and peer relationships are put forward. Empirical evidence relating adjustment to the family and peer relationships is introduced and examined. The aim of both chapters is to provide the reader with a broad overview of the historical, social and research context framing the present study drawing attention to the current state of knowledge, highlighting pertinent areas which are problematic and lack clarity.

In Chapter 3 we focus on the study methodology. The limitations of previous studies are reviewed in relation to the rationale and design of the current study, methods and explanation of the physiological and functional implications of each chronic condition are put forward. Factors influencing selection of the chronic conditions under study are also discussed. Chapter 4 presents details of study measures and briefly considers issues surrounding the selection process. Chapter 5 describes the development of a new measure evaluating condition severity and delineates the process of obtaining participant access, ethical approval, participant recruitment and data collection.

In Chapter 6, descriptive and statistical analyses are presented. In this chapter, the study sample is described, research questions and associated hypotheses linked to the effect of condition-based parameters on child and parental coping and child adjustment are tested. In addition, the viability of the risk resistance model, also termed the disability-stress-coping model, is evaluated and extended. This model provides a conceptual map and mechanism for predicting adjustment outcome, and is presented later in this chapter. In Chapter 7, the quality and properties of children's friendships, peer relations and school adjustment are examined in relation to level of emotional symptoms and functioning (i.e. parent rating of physical, psychological and social functioning relevant to the daily activities of living). In the final chapter findings are discussed and suggestions for future research presented.

1.2 Medical developments

During the last four decades advances in medical knowledge and technology within industrialised nations have produced widespread health benefits. Most apparent among the numerous health gains are significant increases in life expectancy and health status for adults and children with chronic conditions. What constitutes a chronic childhood illness is a matter of some debate (Perrin *et al.*, 1993; Bradford, 1997), although it is generally agreed that these conditions reflect a prolonged course. For example, Pless and Pinkerton (1975: 90-91), defined chronic illness in childhood as "a physical, usually non-fatal condition which lasted longer than three months in a given year, or necessitated a period of continuous hospitalisation of more than one month". Eiser (1990: 3) states that "Chronic diseases are conditions that affect children for extended periods of time, often life. These diseases can be "managed" to the extent that a degree of pain control or reduction in attacks (of asthma), bleeding episodes (in haemophilia) or seizures (in epilepsy) can generally be achieved. However, they cannot be cured". While issues of definition and classification remain under discussion, it is generally estimated that between 10-15 percent of children below the age of 16 years are affected by chronic illness (Cadman, *et al.*, 1987; Rutter *et al.*, 1970; Weiland *et al.*, 1992).

The impact of medical developments on child health is illustrated by the dramatic change in prognosis for children with conditions such as cystic fibrosis, leukaemia and cancer. For example, of children diagnosed with acute lymphoblastic leukaemia in 1968, one percent were expected to live for five years or more. By 1984, 50 to 60 percent were expected to survive for the same time period (Milner & Hull, 1984). More recent estimates indicate that for children diagnosed under the age of 10 years in the United States more than 70 percent will be cured (Bleyer, 1990). In addition, the median life expectancy of British children with cystic fibrosis has gradually increased over the last 30 years. Whereas in the mid 1970s the median age for survival was 20 years, it is currently estimated, for children born in 1990, to be 40 years (Elborn *et al.*, 1991; cf. Dodge *et al.*, 1997). In addition the health status of children with non-life threatening conditions such as asthma, diabetes mellitus, epilepsy and phenylketonuria (inability to metabolise phenylalanine, an amino acid) has greatly improved. The implementation of a national screening program and developments in pharmaceutics and health education have prevented the onset of mental retardation in children with phenylketonuria, reduced unpleasant and harmful drug side effects and the early occurrence of complications such as retinopathy (visual impairment) in children with diabetes.

Such impressive and rapid progress has demanded a concurrent shift in clinical practice from a curative medical model towards long-term management of illness. At the same time this has drawn attention to the psychological and psychosocial consequences of chronic illness for children and adolescents (Eiser, 1994). Although, the implications for psychosocial and physical well being, developmental progress and adherence to medical recommendations are increasingly recognised, influential factors forecasting psychosocial outcome are poorly understood. Furthermore, the processes and mechanisms that facilitate optimal developmental progress and psychosocial adjustment remain distinctly unclear.

1.3 Psychosocial adjustment

Research on psychosocial adjustment involving children and adolescents with chronic conditions has developed with growing momentum in the last two decades, principally within North America. European research, in comparison to the research conducted in North America, is less well established in terms of an empirical base and theoretical development. Overall, however, epidemiological, meta-analytic and many clinic-based studies suggest that children with chronic conditions are at increased risk for psychosocial difficulties in comparison to healthy peers (Rutter *et al.*, 1970; Cadman *et al.*, 1987; Gortmaker *et al.*, 1990; Lavigne & Faier-Routman, 1992; Wallander, *et al.*, 1988a). For example, an epidemiological study conducted in Canada found children with chronic conditions without disability to be at twice the risk for psychiatric problems in comparison to their healthy counterparts. Children with disabilities such as, impaired mobility or sensory loss were found to be at three times the risk (Cadman *et al.*, 1987). However, findings reveal considerable variation in psychosocial outcome (Rutter *et al.*, 1970; Wallander, *et al.*, 1988a). While some children and families experience severe problems, many demonstrate remarkable resilience and would suggest that contributory factors operate to increase or decrease the likelihood of a poor outcome.

1.4 Research perspectives defining adjustment outcome

In the course of the last thirty years researchers have developed complex theoretical models and conceptual approaches to explain variation in psychosocial outcome. Two central perspectives underpin present research efforts, the categorical and non-categorical approaches. Each approach can be traced to research reflecting a medical, clinical orientation.

The categorical approach operates on the premise that psychosocial consequences are condition-specific and related to restrictions imposed by the condition. In this respect, the categorical approach is closely aligned to medicine which classifies pathology in terms of organic systems such as, respiratory or gastrointestinal. For example, gastrointestinal system restrictions may be associated with dietary modifications that affect participation in social activities.

On the other hand, the non-categorical approach, which stems from a wide ranging review of studies involving children differing in terms of diagnosis and disability (Pless & Pinkerton, 1975) offers a radical alternative. This approach takes the view that children with chronic conditions share similar experiences and psychosocial effects relate predominantly to generic dimensions rather than condition-specific features. For example, chronicity, course, age of onset and visibility rather than diagnostic label are considered to reflect more variation in terms of psychosocial outcome (Pless & Pinkerton, 1975; Pless and Perrin, 1985). From this standpoint, it would be expected that children would differ in level of psychological difficulty on the basis of for example, differences in age of condition onset or whether their condition was visible or not, rather than condition differences. Others have included aspects such as the nature of condition onset (acute, insidious), whether the condition involves cosmetic features, mental retardation, a sensory or motor component or necessitates intrusive treatment regimens (Stein & Jessop, 1982). Similarly, Rolland (1987) has put forward a typology based on the psychosocial demands arising from nature of onset, course (i.e. constant, progressive, relapsing, episodic), degree of life threat and incapacitation, integrating condition-related factors and their psychosocial ramifications within a family cycle framework. In terms of psychosocial outcome, the non-categorical approach would predict that within condition group variation exceeds between condition group variation, and no condition group differences. In contrast, the categorical approach forecasts the reverse, in other words condition group differences would be apparent.

Much of the related research defines psychosocial consequences in terms of adjustment outcomes reflected in the level of behavioural and emotional difficulties, social competence, academic functioning, self-concept and self-esteem. Methodological approaches are invariably questionnaire based and include one or more informants such as parent, teacher, clinician and sometimes child. Physical outcomes for example, degree of glycaemic control (an index of optimal blood glucose) or height and weight are also considered in a number of investigations, particularly where treatment adherence is of central concern (e.g. diabetes mellitus). Research designs are usually cross-sectional and not infrequently, involve clinic-based patients. Less evident are population based epidemiological or longitudinal designs. However, studies have tended to focus on specific conditions, most prominently childhood cancer. Studies that have included several conditions demonstrate inconsistent findings.

For example, Wallander and colleagues (1988a) using maternal report, found very few differences in child adjustment as a function of diagnostic condition in terms of internalising behaviours (depression, withdrawal), externalising behaviours (hyperactivity, conduct difficulties) and social competence. Stein and Jessop (1989) found no significant differences among children with either, asthma, haemaglobinopathy (e.g. sickle cell disease), spina bifida and / or hydrocephalus and seizure conditions on the basis of parent reported child hostility, peer relations, dependency, withdrawal, anxiety/depression and productivity. In addition, an epidemiological study found elevated scores on a measure of behavioural and emotional difficulty (e.g. head- strong, antisocial behaviour, mood) across a number of chronic conditions (Gortmaker *et al.*, 1990). Alternatively, Eiser *et al.* (1992) also using maternal report, found differences in child adjustment indices such as, frustration/hostility, dependence and withdrawal, were related to age, gender and condition category. This pattern was not found for paternal report, however. Thompson and colleagues (1998) also found that children with cystic fibrosis reported significantly more psychological symptoms related to attention deficits and oppositional behaviour than children with sickle cell disease. Such findings cast some doubt on the validity of the non-categorical approach, although methodological differences in terms of design and the measures used may be responsible for discrepant findings.

These opposing views nevertheless, remain somewhat contentious (Stein, 1996). Debate appears to centre on the validity of each approach in addressing research questions and less explicitly on the usefulness of a non-categorical generic approach in intervention design and service planning. As Stein (1996) asserts, inclusion of several condition groups is unlikely to assist attempts to evaluate condition-specific treatments, such as drug or rehabilitative therapy. She goes on to suggest that the intended generalisability of findings is an important consideration. For example, studies examining generic condition effects or configuration of service use amongst chronically ill children is not served by focussing on a single condition and prevents application beyond the study sample. In other words, Stein sensibly contends, research objectives should guide selection of approach.

On the other hand, there is some evidence to suggest that the nature of the condition is influential in explaining psychosocial outcome and indeed that behavioural difficulties may be condition-specific (Thompson *et al.*, 1998). Those maintaining the utility of a modified categorical approach (Thompson & Gustafson, 1996) acknowledge that children with chronic illness and their families share common experiences but imply condition-based factors require consideration in tailoring appropriate interventions. At the same time, they claim that this approach takes account of illness related tasks and general and condition-specific processes augmenting adjustment. Moreover, it is suggested the approach benefits evaluation and development of expertise in treatment of rare conditions.

However, neither approach is theoretically developed. For example, it is unclear whether one generic dimension is more influential than another. Indeed, it is not transparent, from a theoretical standpoint, why psychosocial effects should be condition-specific. Although the reasons for this are vague, both the categorical and non-categorical approaches stem from clinical as opposed to theoretical or purely academic fields of enquiry. Therefore it is possible the commitment to, and funding opportunities for, development of clinical applications overrides articulation of theory or conceptualisation. Research goals generally centre on achieving a better understanding of the modifiable factors that influence adjustment and permit development of prevention programmes and interventions.

Nevertheless, while proposed theoretical models (Thompson *et al.*, 1994; Wallander *et al.*, 1989b) support an increased emphasis on a modified categorical or non-categorical approach, they bear similarity in that chronic illness is assumed to produce stress and increase the risk of psychosocial difficulty for an affected child and family. Accordingly, each model is outlined within a stress and coping framework. Moreover, multiple features, such as child coping, family relationships and psychosocial resources such as self-esteem, self-efficacy and social support are considered to be important determinants of child outcome. In addition, child development aspects receive little emphasis. Differences largely stem from the nature and function of processes assumed to guide psychosocial adjustment and attention to features such as health locus of control. We now turn to look at these, and other theoretical models pertinent to the study of adjustment to chronic illness to examine what current models offer to guide empirical efforts. This section concludes with a summary of the models, identifying features useful to developing understanding of psychosocial adjustment. Since condition-related parameters frame the research perspectives outlined above, the section that follows will introduce issues related to the role of these parameters in adjustment and review the evidence.

1.5 Theoretical models defining adjustment outcome

There are four theoretical models relevant to psychosocial adaptation or psychosocial adjustment in relation to childhood chronic illness. At present two models receive the greatest attention. These are the disability-stress-coping model put forward by Wallander *et al.* (1989b), (see also Wallander & Varni, 1992), and the transactional stress and coping model advanced by Thompson *et al.* (1992b). A third model, the risk/resiliency model proposed by Rutter (1987), although not specifically addressing chronic illness in children is apposite nonetheless. This model focuses on factors and mechanisms that promote or ameliorate the development of psychopathology in children and adolescents. Finally, the life-crisis model (Moos & Tsu, 1977, Moos & Schaefer, 1984) while currently much less influential, offers an alternative framework in terms of emphasising tasks required to facilitate optimal adaptation.

Existing models, as suggested in the previous section, are generally orientated towards providing conceptual frameworks amenable to intervention development and chiefly focus on extant variables regarded as modifiable. Trends in model development demonstrate increasing awareness that adjustment is determined by multiple factors. However, it is worth noting the seemingly interchangeable use of the terms adaptation and adjustment, an issue which will be examined later. The term adjustment is used here and throughout the thesis, unless a model indicates otherwise, to provide consistency. The first three models are selected for consideration, highlighting their respective contributions to conceptualisation of psychosocial adjustment, strengths and weaknesses, and extent of empirical support. Each model varies in terms of complexity and empirical attention and therefore consideration mirrors these differences.

1.5.1 Disability-stress-coping model

The multi-dimensional model put forward by Wallander and colleagues reflects the integration of ideas presented by Pless and Pinkerton (1975), Moos and Schaefer (1984) and Lazarus and Folkman (1984). Wallander and colleagues offer two versions to explain variation in outcome for mothers and children respectively. The focus here, however, is the model referring to child adaptation. Although the ideas presented by Moos and Schaefer are related to maternal adaptation, a brief outline is included for completeness. Introducing the notion of a non-categorical approach, Pless and Pinkerton (1975) proposed that children with chronic illness irrespective of diagnosis share common experiences such as the increased probability of hospitalisation, clinic attendance, daily treatment requirements and related psychological sequelae. Following their extensive review, they concluded that, given the evident commonalities, consideration of general dimensions characterising chronic conditions rather than condition category would be more likely to benefit intervention development.

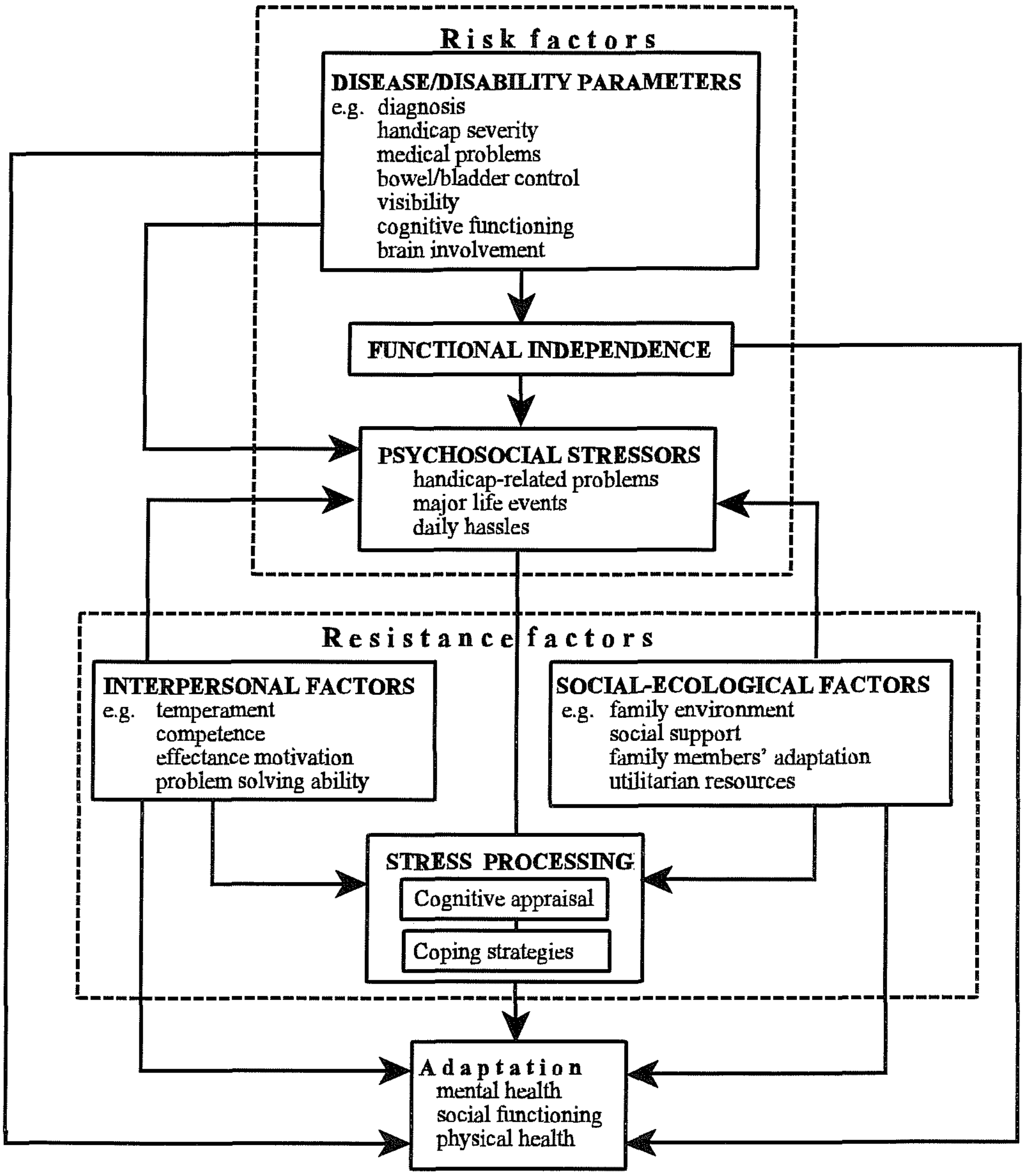
Moos and Schaefer (1984) argue that illness is a life crisis that presents the individual with a set of general and illness specific adaptive tasks requiring the application of coping skills/strategies. These tasks include, for example, dealing with feelings ensuing from condition consequences, sustaining optimism/hope, maintaining an adequate self-image and feelings of competence and control, adapting to changes in image and levels of activity expectations, and readjusting goals. Coping skills are thought to reflect personal and background features (age, intelligence, cognitive and emotional development, philosophical or religious beliefs, prior coping experiences), illness characteristics (diagnosis, type of symptoms and location, course, prognosis) and factors within the physical and socio-cultural environment (sources of stress and support). They suggest the consequences of illness offer an opportunity for psychological growth and can be viewed as a "turning point".

The seminal and highly influential work of Lazarus and Folkman (1984) focuses on cognitive aspects of stress and coping. They propose that stress resides in the cognitive appraisal of an event. Appraisal governs outcome in that an individual takes account of whether the event represents harm/loss, threat or challenge and assesses the resources at their disposal for example, social-friends, personal-beliefs, problem solving skills and health. Resources are considered in relation to meeting event demands, evaluating the cost involved and likely outcome, and determines the course of action. This produces what they term a problem and / or emotion focussed coping response. Problem focussed responses refer to actions such as seeking out emotional, informational or instrumental support. Emotion focussed responses such as, relaxation, withdrawing from the situation, re-appraisal of the significance of the event or denial are linked to attempts to assuage emotional reactions.

Much of the research undertaken by Wallander and colleagues has concerned children with motor and sensory disabilities for example, spina bifida, limb amputees, cerebral palsy which explains their disability-stress-coping-model title. However, their research program has also included youngsters with chronic illness such as, chronic obesity, haemophilia and juvenile diabetes. Also applicable to the model are a number of studies, conducted by Varni, involving children with either cancer or limb deficiencies. Wallander *et al.* (1989b) and Wallander and Varni (1992) suggest adaptation (mental health, social functioning and physical health) is a function of the interplay between risk and resistance factors that correspond to stress and coping respectively. Outcome is believed to be a dynamic process, in line with the view held by Pless and Pinkerton (1975). Factors operate in a reciprocal bi-directional fashion reflecting the ongoing interaction between individual and family variables and environmental context (see Figure 1).

Figure 1

Conceptual model of risk and resistance factors and the differential psychosocial adjustment of chronically ill and handicapped children. From Wallander,Varni, Babani, Banis and Wilcox (1989b). Printed with permission of the author and publishers.



Risk factors relate principally to condition parameters, level of functional independence and psychosocial stressors for example, condition-related problems, daily hassles, major life events and are assumed to produce direct and or indirect effects on adaptation. For instance, a primary cognitive impairment interfering with motor activity may alter aspects of behaviour and emotion. Alternatively, a highly visible condition such as limb amputation or disfigurement may cause psychosocial stress and indirectly affect adaptation.
Resistance factors are linked to intrapersonal (temperament, competence, problem solving), social-ecological factors (family functioning, social support, financial resources), stress appraisal and coping response. They suggest resistance factors modify the impact of risk factors producing indirect effects on adaptation. Intrapersonal and social-ecological factors are considered to affect cognitive appraisal of and response to stressors.

However, while the assumption that intrapersonal and social-ecological factors diminish the probability of a maladaptive outcome is plausible, the expectation that factors may operate in the opposite direction is perhaps less self evident. Inspection of resistance factors suggest that, in certain circumstances, they could function to enhance risk. For example, a child's temperament may well increase the risk of maladaptation if it predisposes a child to perceive experiences in a negative light. Furthermore, it seems unlikely that a family environment characterised by unclear expectations or guidelines on behaviour would ameliorate risk, but rather magnify it. A related point also highlights a potential problem. Some environmental aspects remain relatively stable and may moderate the effect of change impacting on adaptation. For example, family members' temperamental features are likely to affect interaction patterns and reflect their expectations of each other. Style of family functioning, such as parenting philosophy and clarity of generational boundaries may also be fairly stable. Therefore both positive and negative adaptation may be attenuated or exacerbated by stable family characteristics. It is not clear that resistance factors can be assumed to uniformly reduce risk.

Wallander *et al.* have indicated that families managing chronic childhood illness are at greater risk of maladjustment because they are subject to a higher number of stressors in comparison to families in which chronic illness is not a factor. This is a reasonable supposition, consistent with evidence from population and clinic-based studies showing an increased probability of psychological maladjustment in children with chronic conditions in comparison to healthy peers. Nevertheless, until recently, with the exception that child functional dependence increases maternal care giving and creates chronic strain for both child and mother, it was unclear what these stresses might be (Eiser, 1990). However, studies have since classified adolescent disability related stressors and coping strategies (Wallander & Varni, 1995) and begun to address the specific difficulties youngsters face and how they deal with these problems. In addition, stressors associated with mothering a child with a motor or sensory disability have been identified (Wallander & Noojin, 1995). Although, individual and family factors prior to the onset of the disease are not taken into account. It seems probable this would be influential in predicting psychosocial adjustment (cf. Fife *et al.*, 1987), a factor identified in earlier models (Lipowski, 1970; Pless & Pinkerton, 1975). For example, a child or her / his family with few coping resources, experiencing stresses, such as paternal suicide, foster care, or behavioural problems, before the onset of illness may well increase vulnerability to psychological difficulty.

Nonetheless, the research program undertaken by Wallander and colleagues, focussing on model components, indicates that condition severity correlates modestly with social adjustment, but does not seem to be associated with behavioural adjustment (Wallander *et al.*, 1989c). Wallander and Varni (1998) also point out that degree of limb loss in youngsters with limb deficiencies has been found to be linked to adolescent but not child self-esteem. They have also found that diagnostic condition, or type of cancer is not associated with psychosocial adaptation, supporting the notion of a non-categorical approach (Wallander *et al.*, 1988a; 1989c; Varni *et al.*, 1996). Further, Wallander and Varni (1998) state that in children and adolescents with cancer, functional difficulties appear to be related to increased emotional and somatic problems. A study undertaken by Varni and colleagues involving children with cancer indicates that perceived generic (i.e. daily hassles) and disease related stress, family cohesiveness and expressiveness significantly predicts concurrent and prospective adaptation (i.e. negative affectivity) post diagnosis (Varni & Katz, 1997, cited in Wallander & Varni, 1998; Varni *et al.*, 1996). Findings suggest that increased stress is related to higher levels of negative affectivity and increased family cohesiveness and expressiveness is associated with decreases in externalising and internalising behaviours. In children with limb deficiencies Varni *et al.* (1989b) found that high levels of generic stress were modestly associated with low self esteem. In addition, perceived classmate support, in contrast to parent, teacher and friend social support was found to predict decreases in depressive symptoms, anxiety, internalising and externalising behaviours and increase general self-esteem in children with newly diagnosed cancer (Varni *et al.*, 1994 cited in Wallander & Varni, 1998). Wallander *et al.* (1988b) also report that aspects of child and maternal temperament contribute to explaining significant portions of variance in child internalising behaviours and social competence.

However, other studies suggest support for hypothesised relationships is mixed. For example, Wallander *et al.* (1989c) examined the prediction that risk factors, that is disability parameters and chronic strain, would be related to child (i.e. internalising and externalising behaviours) and maternal adaptation (i.e. psychological distress). Chronic strain is hypothesised to arise from decreases in child functional autonomy requiring a high level of maternal care-taking and interference with role activities for both child and parent. They found, however, no significant predictive link. In another study they evaluated the proposed relationship between utilitarian (financial resources, maternal education) and psychological resources for example, family conflict, organisation and child psychological adaptation (Wallander *et al.*, 1989b). It was assumed these resources would modify the risk of maladaptation. Evaluation of independent contributions made by psychological and utilitarian resources indicated that, of the five subscales used to measure family environment, only family conflict predicted behavioural adaptation. Family dimensions explained respectively, eight, nine and 20 percent of the variability in behavioural and social competence outcomes. Increased family cohesion, conflict and decreased family control were predictive of increased social competence. Higher levels of maternal education however, predicted decreases in internalising and externalising behaviours and an increase in social competence. Increases in family income also predicted increased social competence. Utilitarian resources explained respectively, seven, four and 24 percent of the variability in behavioural and social competence outcomes. Similar results emerged from hierarchical regression analyses, although increased family organisation predicted a decrease in maternal reported internalising behaviours. Together, family resources account for 17 percent of the variability in behavioural adaptation and 44 percent in social functioning. Results from another study focussing on behavioural adaptation indicate predictive utility is limited (e.g. Wallander *et al.*, 1989a).

This conceptual model has undoubtedly proved useful in terms of focussing research questions. However, mixed findings suggest methodological and analytical difficulties. In parallel with many other studies, emotional and behavioural difficulties and social competence were assessed using the Child Behaviour Checklist (CBCL-Achenbach &

Edelbroch, 1983 cited in Wallander *et al.*, 1988a). However, Perrin *et al.* (1991) suggest there are inherent problems associated with its use. The CBCL was not standardised on a chronically ill population and raises questions of applicability to this group. Indeed, it is designed to identify those children in manifest difficulty and may therefore miss those chronically ill children who demonstrate mild difficulties but nevertheless need help. It also includes physical health items, for example "eye problems, vomiting or stomach aches", although respondents are instructed that symptoms should be "without medical cause" this may be difficult to determine. In view of the increased likelihood that children with chronic illness will experience these symptoms, scores may be under or overestimated and give a misleading impression of psychological difficulty. Wallander and colleagues have addressed this problem by examining scores with and without somatic items. Nonetheless, scores on social competence items may also be lowered because items refer to participation in social activities. Low involvement may be due to reduced opportunities, rather than any lack of willingness to take part. Thus to infer that children are less socially skilled would be unwarranted.

The almost exclusive use of mothers as informants on many of the variables suggest that the data can at best provide a partial window into the process of adaptation. Perspectives held by children and adolescents are liable to prove insightful, however, they seldom appear in studies. Furthermore, the interface between child, family and the medical team is likely to frame client theories of health and illness, guide co-operation with medical regimens and how crises are managed (Bradford, 1997). From a clinical point of view, this would seem an important variable to bear in mind. Moreover, the inclusion of a wide age range such as four to sixteen years, in several studies, with minimal consideration of developmental shifts on adaptation, circumscribes interpretation of findings. Studies also fail to illuminate causal direction through the predominant use of cross-sectional designs and correlational analyses and rarely test proposed moderator effects (Holmbeck, 1997). Furthermore, the feasibility of the risk resistance mechanism requires that the entire model be tested. To date there has been no evaluation.

1.5.2 Transactional stress and coping model

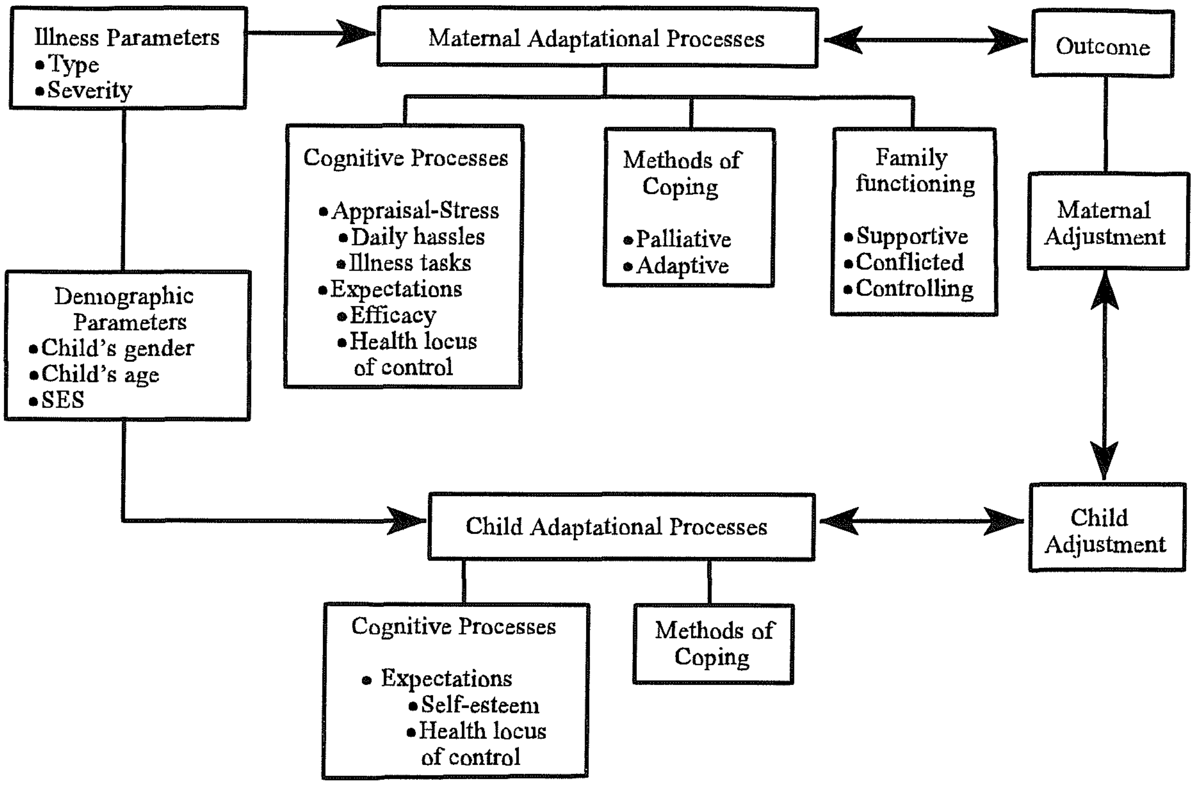
The transactional stress and coping model, presented by Thompson *et al.* (1992b; 1994), which they define as a biopsychosocial model, derives from ecological-systems theory

(Bronfrenbrenner, 1977) and the stress and coping concepts advanced by Lazarus and Folkman (1984). Bronfrenbrenner argues that human development can be understood in terms of embedded ecological systems. These systems refer to the social contexts in which individuals conduct their daily activities and are judged to be as instrumental as individual attributes in shaping developmental progress. Ecological systems are conceived as a series of concentric circles embracing the individual. For example, the microsystem refers to relations within the immediate social context, such as home or school. This is followed by the mesosystem (a combination of contexts important at specific age points for example, adolescent peer group, school, family), exosystem (work, neighbourhood, mass media, government agencies, communication, transport facilities) and the macrosystem (cultural norms, both formal such as in the classroom, and informal for example, queuing for services, ideology). Each level incorporates relations embedded in the previous system. Outer systems, while increasingly remote, nevertheless impinge on developmental pathways.

Thompson *et al.* (1992a; 1992b; 1993b) take the view that chronic childhood illness is a potential stressor requiring child and family adaptation. Biomedical, developmental and psychosocial variables are assumed to mediate the relationship between illness and outcome (see Figure 2). The model also emphasises temporal shifts in adaptation. Specifically condition characteristics including congenital or acquired, age of onset, course, type of disablement - cognitive, motor or sensory - visibility and treatment requirements including tablets, injections, inhalants, physical therapy/exercise, diet, are assumed to interact, in a reciprocal manner, with developmental processes. Adaptive tasks, for both child and family, arise from normative developmental transitions such as, adolescence. However, the authors are careful to point out that central themes of the model are transactional child and family processes which modify outcome above the contributions made by condition-based factors and characteristics such as child age, gender or social status. Parenting style, in particular maternal adjustment, is thought to bear upon child adjustment. This derives from ecological-systems theory which suggests that child adjustment will be affected by the stress experienced by others within the family. Three groups of processes are delineated as relevant to maternal adjustment. First, cognitive variables: stress appraisal of illness tasks and daily hassles, and expectations of efficacy and health locus of control. Second, modes of coping: palliative and adaptive; and third, family functioning: supportive, controlling, conflicted. Child adjustment is thought to be related to two groups of processes, first, cognitive: expectations of self-esteem and health locus of control and second, modes of coping.

Figure 2

Transactional stress and coping model for chronic childhood illness. From Thompson, Gustafson, George and Spock (1994). Printed with permission of the author and publishers.



Evaluation of the model has sought to validate the role of these processes in maternal and child adjustment and establish a link between maternal and child adjustment. Recent cross-sectional and longitudinal studies conducted by one or more of the original authors suggest that between 30 and 68 percent of the variability in adjustment (child and/or mother) can be explained by adaptational processes. Illness and demographic variables combined explained at most 20 percent of the variance in adjustment. Findings also point to alteration of adaptational processes by the specific nature of the illness affecting child adjustment (Thompson *et al.*, 1998). This contrasts with the non-categorical approach, which suggests that variation *within* a condition group will be greater than *between* condition groups. However, to date studies have compared only two condition groups and suggest this finding requires replication. Nonetheless, Thompson and Gustafson (1996) maintain that a modified categorical approach to understanding psychosocial adjustment will support customised interventions, service delivery and policy development.

However, at present very little attention appears to have been paid to aspects such as social support, child perspectives on coping or the impact of ongoing relationships with medical staff. While child approaches to coping with pain are included, and the intention is to evaluate child views on social support and stress, more general features of coping do not appear. Moreover, it is not clear why the mother should figure so prominently. Given the lack of emphasis on highlighting the contribution of fathers or grandparents to child adjustment, focussing on maternal adjustment seems somewhat restrictive. On the other hand, in light of the extensive role mothers generally play in child rearing this may be appropriate. However, in view of evidence showing that children develop multiple attachments (Wolkind & Rutter, 1985; Schaffer, 1977), and present trends in maternal employment, the mother may not be the significant parent in the child's life. For example, the proportion of mothers working full-time in 1997 increased by nearly 20 percent of the total number of full-time workers in 1984, and part-time workers increased by 25 percent (Social Trends, 1998). A more inclusive approach might shed further light on this issue. In addition, variables proposed as mediators, traditionally defined as "to be the medium for bringing about (a result) or for conveying" (Concise Oxford Dictionary, 1990) are not analysed as such and suggests a discrepancy between conceptualisation and statistical analyses. The approach to date, has been to determine the predictive utility of adaptational process variables in explaining outcome.

1.5.3 Risk/resiliency model

The developmental model proposed by Rutter (1987) grew out of longitudinal research on risks associated with childhood psychiatric disorder. Essentially, adaptation and outcome are conceived in dynamic and temporal terms. It became clear that some children, despite adversity, defined as circumstances creating either chronic stress or multiple stressors, did not, as expected, develop disorders. This subsequently led researchers to formulate the concept of resiliency and investigate the factors which produced this phenomenon. Research suggested that in the presence of acknowledged risk for example, early institutionalised care, loss of a parent in childhood or a parent with psychiatric disorder, individual and environmental factors appear to afford protection against, or increase vulnerability to, psychopathological disorder. Protective factors might be a supportive adult for example, a teacher or a neighbourhood friend who is consistently available for advice. Alternatively, a strong sibling attachment could also function in a similar way. Factors that might enhance the probability of psychopathology could be a limited peer network, low self-esteem or low self-efficacy. In essence, antecedent risk is assumed to interact with factors which produce protective or vulnerability effects and moderate outcome. Rutter points out that both individual responses to stress and the effect on developmental trajectories are vital considerations. Implicit within this model is the idea that early experiences shape subsequent functioning and accords with the models proposed by Lipowski (1970) and Pless and Pinkerton (1975). Rutter has also suggested that protective processes include changing the meaning attached to the risk factor, physical and emotional distancing, succeeding in dealing with challenges which are stressful, enhancing self-esteem and perceptions of control. Nonetheless, the model remains unclear about the mechanisms which mediate psychosocial adaptation.

1.5.4 Summary of theoretical models

Despite shortcomings, when taken together, each theoretical model offers useful features to guide our understanding of psychosocial adjustment. For example, Wallander and colleagues (1989b) include child functional autonomy, an important factor in view of consequences for developmental progress, an aspect not emphasised by Thompson *et al.* (1992a; 1992b; 1993b; 1994). This differential emphasis may reflect the condition groups each research team investigates. For example, Wallander *et al.* tend to focus on child disability, Thompson *et al.* have involved children with sickle cell disease and / or cystic fibrosis in their research program. Nonetheless, whether a condition involves motor disability or not, if it prevents participation in activities essential to socialisation it probably constitutes a risk factor. Thompson *et al.* (1994), in contrast to Wallander *et al.* (1989b), accentuate biomedical aspects and have underscored the importance of parenting style and family context and, in line with Kazak (1997), call for a move towards including family systems theory in research approaches. However, within both models relationships with peers and medical staff and the influence of child developmental stage receive little consideration. The role peer relationships play in adjustment outcomes remains unclear and the psychosocial stresses of chronic illness appear to shift during development. For example, whereas children may not view treatment adherence as intrusive since responsibility usually rests with parents, adolescents may find treatment burdensome. Although the latter is a not a focus of this thesis, attention needs to be paid to these issues. On the other hand, Thompson *et al.* (1994) clearly view adjustment in terms of a developmental process, illustrated by their theoretical grounding and adoption of longitudinal study designs. In this respect their formulation corresponds with Rutter's model. While there is little evidence focussing on chronic illness in children using Rutter's model, the approach is helpful because it highlights the role of early experiences in framing future outcomes and attempts to identify the effects of factors in circumstances of known psychosocial risk. However, the risk resistance model, the term used here to define the disability-stress-coping model, in contrast to the model advanced by Thompson and colleagues, does posit an explicit mechanism that seeks to account for individual variation in psychosocial outcome. Nevertheless, the involvement of family context features in all models, albeit to differing degrees and points to the importance of family relationships and attitudes in steering adjustment.

Before turning to examine the role of the family environment and peer relationships in Chapter 2, we now look in closer detail at relationships between condition-based parameters and child adjustment outcomes. Within the categorical and non-categorical research perspectives outlined earlier, condition-related parameters are assumed to play a central role in child adjustment. However, it is unclear which approach provides better understanding of psychosocial outcome in youngsters with chronic illness. In order to clarify utility condition-related parameters will be investigated in relation to child adjustment. The purpose of following section is to elucidate findings from research on condition-related parameters and emphasise where knowledge gaps remain. This will be followed by a consideration of terminological problems and the methodological limitations of studies focussing on psychosocial adjustment to chronic childhood illness.

1.6 Condition-related parameters and adjustment outcome

While it is stated that condition-based parameters rarely show direct links to adjustment outcomes, the evidence is mixed. Few studies include categorical and non-categorical parameters within the same study where direct comparisons would demonstrate the utility of each approach and underscore the relative impact of each parameter. Moreover, if parameters are not associated with adjustment why are they the platform on which research approaches are based? It is possible that condition parameters have a greater impact on proximal factors such as how children and families manage problems within a framework defined by the consequences of these parameters. For example, one might expect that condition duration, reflecting increased experience, would facilitate illness related coping efforts. However, evidence highlighting associations between condition-based factors and coping is exceptionally scarce. Accordingly, this investigation seeks to test hypotheses that state generic condition parameters will be more influential than condition category in relation to coping and adjustment. An additional aim of the study, explained in further detail in Chapter 3, is to test the feasibility of the entire model put forward by Wallander and colleagues.

At this point, it would be helpful to review the evidence linking condition-based parameters (i.e. condition category, severity, age of onset, duration and visibility) to child adjustment and establish what previous research can tell us. Although findings, outlined below, are equivocal for some parameters, others are markedly less so.

1.6.1 Condition category

Wallander and Thompson (1995) suggest the most consistent finding regarding condition category is the link between conditions that involve the brain and an increase in behavioural problems and poor social functioning (Breslau, 1985; Walker *et al.*, 1992; Austin & Huberty, 1993; Breslau, 1993; Howe *et al.*, 1992; Hoare & Mann, 1994). In addition, studies report children with epilepsy to have significantly more thought and attention problems than children with diabetes (Hoare & Mann, 1994) and variations in intellectual functioning appear to have a compensatory relationship with psychological adjustment (Perrin *et al.*, 1993).

On the other hand, a meta-analysis evaluating depression in children and adolescents with chronic medical problems shows young people with either asthma, recurrent abdominal pain or sickle cell disease appear to be at risk for increased depressive symptoms in comparison to children with cancer, diabetes and cystic fibrosis (Bennett, 1994). Bennett suggests condition demands in the latter group (i.e. frequent and regular treatment requirements) call for increased family involvement which may offset risk. Alternatively, the nature of asthma, recurrent abdominal pain and sickle cell disease suggest uncertainty regarding symptom onset and consequently may increase depressive symptoms. However, Bennett also points out that similar levels of depressive symptoms are reported in other studies comparing children with asthma, cancer, diabetes and sickle cell disease. For example, Thompson *et al.* (1998) found that children with sickle cell disease or cystic fibrosis demonstrated similar rates of anxiety disorder. However, externalising behaviours were higher in children with cystic fibrosis compared to children with sickle cell disease.

1.6.2 Condition "severity"

The concept of condition severity has given rise to debate regarding how it should and is operationalised (Stein *et al.*, 1987). Issues centre on definition and the relative value of condition-specific (e.g. asthma-pulmonary functioning, diabetes-glycaemic control, rheumatoid arthritis-number of joints affected) and generic indices (e.g. functional status, condition demands, school absence) in determining psychosocial outcomes. Given the controversy studies have differed in terms of conceptualisation and measurement, rarely however, are condition-specific and generic indices considered simultaneously. Of all generic dimensions condition severity is the variable most frequently studied and has been found to be significantly associated with psychosocial outcomes (Lavigne & Faier-Routman, 1993).

However, commenting on a meta-analysis evaluating psychological adjustment correlates in children with chronic physical conditions (Lavigne & Faier-Routman, 1993) Wallander and Thompson (1995) argue it is likely that severity is confounded with condition type. Wallander and Thompson state that many studies do *not* report links between severity and adjustment outcomes for example, in children and adolescents with sickle cell disease (Hurtig *et al.*, 1989; Rodrique *et al.*, 1996; Noll *et al.*, 1996), sickle cell disease type (Brown *et al.*, 1993), asthma (MacLean *et al.*, 1992) and cystic fibrosis (Thompson *et al.*, 1992a). Yet, studies reporting no link often focus on one condition, and suggest that condition severity may produce somewhat different findings for studies involving several conditions or if considered generically. However, clinician assessments of severity were not associated with self-reported anxiety in adolescents with different chronic conditions (Kellerman *et al.*, 1980). Further, in children with either sickle cell disease or cystic fibrosis Thompson *et al.* (1998) found severity along with demographic factors did not significantly contribute to explanation of variability in psychological symptomatology. Nevertheless, the study reported by Kellerman *et al.* (1980) does not specify assessment criteria for severity, and severity measures employed by Thompson *et al.* (1998) were condition-specific.

On the other hand, a body of evidence involving a number of chronic conditions suggests condition-specific and generic measures of severity are associated with psychological well-being and social functioning. For example, Thompson *et al.* (1993) report that sickle cell anaemia as opposed to less severe manifestations of sickle cell disease was a significant predictor of parent reported increases in internalising behaviours. Moreover, Kliewer and Lewis (1995) also found condition severity on the basis of type of sickle cell disease was a significant predictor of child reported hope which itself was positively correlated with self-concept and negatively related to anxiety. Children with the severe form reported significantly lower levels of hope in comparison to children with the milder form. Brown *et al.* (1993) also report higher levels of school absence for the previous 12 months in children with sickle cell disease significantly predicted increases in parent and teacher assessment of internalising behaviours, and the number of days hospitalised predicted a significant decrease in daily living skills as measured by the Vineland Adaptive Behaviour Scales (Sparrow *et al.*, 1984 cited in Brown *et al.*, 1993). In addition, this group report a predictive relationship between severity in terms of emergency room visits and days hospitalised in the previous 12 months and parent report of adaptive social behaviour in children with sickle cell disease (Brown *et al.*, 1995). Findings indicated that an increase in the number of emergency room visits and a decrease in the number of days hospitalised were predictive of increases in adaptive interpersonal, play, leisure and coping behaviour.

Daniels *et al.*, (1987) also report a positive relationship between increased severity and psychological adjustment difficulties for children with rheumatoid disease and Perrin *et al.* (1989) report a trend between higher levels of severity (i.e. objective health status) and decreased social functioning in children with asthma, although parent ratings of severity demonstrated a curvilinear relationship with social functioning. Children who were perceived to have mild or severe disease were rated by parents as significantly less well adjusted than children with moderate disease. Moreover, a nine month longitudinal study involving a large sample of inner city children with asthma suggests behavioural difficulties are associated with later condition morbidity. Baseline caregiver report of increased behavioural problems, controlling for initial morbidity and demographic variables were significantly correlated with higher levels of subsequent asthma symptoms defined by an averaged score of wheezing episodes in previous two weeks at three, six and nine months post enrollment, and lower functional status reflected in an averaged score of three measurements taken over nine months following enrollment (Weil *et al.*, 1999). In children with cystic fibrosis, low physical status has been found to correlate modestly with parent reports of increased social withdrawal (Drotar *et al.*, 1981) and improvements in nutritional status have been found to predict parent reported increases in social competence explaining 18.5 percent of variance in scores (Cappelli *et al.*, 1988).

Likewise, children with the most severe congenital cardiac anomalies were found to have the highest level of depressive symptom scores which were positively related to number of cardiac catheterisations, operations and clinic visits (Youseff, 1988). In addition, Greenberg *et al.* (1989) found that children who experienced marked cosmetic changes and substantial limitations in daily activity having undergone treatment for cancer were more depressed than a comparable group, also treated for cancer, without these difficulties. Stein and Jessop (1984) also found that caregiver reports of more restrictions affecting daily activities (i.e. functional status) across a range of chronic conditions were related to decreases in child psychological adjustment. A subsequent study reported similar findings for a comparable sample (Jessop & Stein, 1985). Children rated by their mothers as having low functional status were also rated higher on symptoms of withdrawal and anxiety-depression, compared to children with high functional status.

Furthermore, a study involving children with physical disabilities such as, spina bifida and cerebral palsy found that increased disability was negatively associated with mother rated social competence (Wallander *et al.*, 1989c). Children and adolescents with spina bifida requiring medical procedures to treat hydrocephalus have also been found to experience significantly more scholastic, academic and social competence difficulties as rated respectively, by themselves and their mothers, in contrast to those not needing this intervention (Holmbeck & Faier-Routman, 1995). In a recent study of children with complex partial seizure epilepsy, Schoenfeld *et al.* (1999) found seizure frequency over the past 12 months was modestly and positively correlated with parent report of child internalising behaviours and modestly and negatively correlated to social competence.

Associations between self-esteem and severity have been reported, although the findings are mixed. For example, in adolescents with epilepsy, Westbrook *et al.* (1992) found that seizure type and frequency were negatively related to self-esteem. In addition, Cappelli *et al.* (1988) found increases in child report of athletic self-esteem in children with cystic fibrosis were predicted by increases in nutritional status explaining 39.5 percent of variance in scores. Although parental perceptions of condition severity in children and adolescents with either asthma or diabetes were not related to child report of global self-worth, an increase in the number of hospitalisations in the previous six months predicted a significant reduction in self-worth (Holden *et al.*, 1997). However, Varni *et al.* (1989b) found no such relationships in children with limb deficiencies.

1.6.3 Age of condition onset

Findings related to effects of age of condition onset on psychosocial outcomes are mixed and limited. Rovet *et al.* (1987a) report that boys with late onset diabetes (i.e. after four years of age) had more behavioural problems, primarily internalising, than either boys with early onset diabetes (i.e. before three years of age) or girls with diabetes. Girls with early onset diabetes, in comparison to population norms, had lower levels of social competence and school performance. Brown *et al.* (1991) also found that later age of condition onset predicted increases in teacher report of externalising difficulties in youths with diabetes. On the other hand, Hoare and Mann (1994) found that onset of epilepsy or diabetes before the age of four years was associated with more difficulties for example, withdrawal and attention problems. The effect was more pronounced for boys than girls. Furthermore, Schoenherr *et al.* (1992) found that age of condition onset was positively associated with self ratings of depressive symptoms and predictive of teacher report of internalising and externalising difficulties in children and adolescents with either diabetes, sickle cell disease or leukaemia. This suggests that as age of condition onset advances the likelihood of emotional and behavioural difficulties increases.

Similarly, Schoenfeld *et al.* (1999) report a significant and positive association between age of onset and parent rated somatic complaints in children with complex partial seizure epilepsy. However, consistent with findings reported by Frank *et al.* (1997) anxiety/depression was significantly and negatively related to age of onset. Frank and colleagues found age at diagnosis was inversely related to self-reported anxiety in children with cancer. In adolescent cancer survivors increases in age at diagnosis predicted a decrease in self-reported school achievement and social competence (Rait *et al.*, 1992). In contrast, Morris and colleagues (1997) found that age and age at diagnosis were modestly and positively correlated with parent report of internalising behaviours (although scores were within the normative range) in a small sample of children and adolescents with leukaemia. On the other hand, increases in academic functioning in a group of children and adolescents with brain tumours were modestly associated with increase in age at diagnosis (Carlson-Green *et al.*, 1995).

However, Brown and colleagues (1993) found age at onset was unrelated to self and parent reports of anxiety, depression and behavioural difficulties in children and adolescents with diabetes. Similarly, Reid *et al.* (1995) found no links between age of condition onset and self reports of depressive symptomatology or teacher reports of social skills and behavioural problems in children and adolescents with diabetes. Kovacs *et al.* (1990) also did not find age of onset was associated with self reports of self-esteem, anxiety or depression in children with diabetes. Moreover, the absence of a relationship between age of onset and self-esteem has been replicated in other studies involving youth with diabetes (Rovet *et al.*, 1987a; Hanson *et al.*, 1990). Although, Ryan and Morrow (1986) found that girls, in contrast to boys with early onset diabetes report lower levels of self-esteem.

1.6.4 Condition duration

Evaluation of condition duration effects on psychosocial outcome appear in few studies and present inconsistent findings. For example, a low but significant negative correlation between time since diagnosis and self rated anxiety was found for adolescents with a range of chronic conditions (Kellerman *et al.*, 1980). This finding held when age was controlled for and suggests that shorter condition duration is associated with higher levels of anxiety. However, Hoare and Mann (1994) found treatment duration that extended beyond one year was associated with less optimal adjustment outcomes for children and adolescents with either epilepsy or diabetes. Daniels *et al.* (1987) also found that condition duration was positively correlated with psychosocial difficulties for youth with rheumatoid disease. Moreover, Worchel *et al.* (1988) report an increase in self-ratings of depression with increased condition duration in children with cancer. A six year longitudinal study of children following diagnosis of diabetes (Kovacs *et al.*, 1990) found ratings of anxiety and depression were significantly modified by condition duration. Reports of anxiety increased as duration lengthened, particularly for girls. In contrast to children recording high levels of anxiety and or depression after diagnosis whose ratings remained fairly stable, children reporting low levels of depressive symptoms showed a mild increase in symptoms as duration increased. The average levels of symptomatology, however, are lower than means for normative samples. Alternatively, Brown *et al.* (1991) also found shorter condition duration, controlling for age and gender, predicted increases in teacher report of externalising difficulties in youths with diabetes. Length of treatment has also been found to correlate positively with mothers' ratings of child depressive symptomatology in children with asthma (Furukawa *et al.*, 1988). Lastly, an increase in time since diagnosis was found to predict decreases in intellectual functioning in children and adolescents with brain tumours (Carlson-Green *et al.*, 1995).

Alternatively, condition duration was not related to parent report of behavioural difficulties or social competence in children and adolescents with juvenile arthritis (Daltroy *et al.*, 1992); self reports of depressive symptomatology and teacher report of social skills and behavioural problems in children and adolescents with diabetes (Reid *et al.*, 1995); or youth report in children and adolescents with chronic fatigue syndrome or juvenile rheumatoid arthritis (Carter *et al.*, 1999). Likewise, Holden *et al.* (1997) found no effects for condition duration in relation to child report of self-worth in a number of domains such as, physical appearance and athletic competence in children and adolescents with either asthma or diabetes. Brown and colleagues (1993) also found no relationship between duration and self report of anxiety, depression or parent report of behavioural difficulties in children and adolescents with diabetes. Similarly, no associations were found between duration and self ratings of depressive symptoms and teacher report of internalising and externalising difficulties in children and adolescents with either, diabetes, sickle cell disease or leukaemia (Schoenherr *et al.*, 1992).

1.6.5 Condition visibility

Condition visibility has been hypothesised to have significant implications for psychosocial well-being. However, this has rarely been subject to empirical test, although available studies have produced mixed but intriguing results. For instance, a study involving adults with haemophilia found self-reported increases in visibility were associated with increased social difficulties. However, visibility, was not the most important predictor of reported emotional problems (Molleman & Knippenberg, 1987). In a study of children with limb deficiencies, although level of satisfaction with physical appearance was not related to degree of limb loss (i.e. proportion of upper or lower limb loss), increases in satisfaction were found to be highly and negatively correlated with self-reported depression and anxiety

(Varni & Setoguchi, 1991). Two other studies focussing on youngsters with a range of chronic conditions report inconsistent findings. Wolman *et al.* (1994) found no differences in self-reported emotional well-being as a function of visibility in adolescents with and without visible chronic conditions. However, Jessop and Stein (1985) found that children reported by clinicians to have a normal appearance, compared to children with abnormal appearance, had a poorer outcome on a number psychosocial variables as reported by their mothers. Findings reported by Jessop and Stein (1985) suggest high visibility to be associated with more favourable psychosocial outcomes. It may be that high, compared to low visibility defines social interactions more clearly and reduces uncertainty thus increasing psychological stability. Obviously, further studies are needed to establish the viability of condition visibility as a correlate of adjustment outcome.

1.6.6 Summary of links between condition-related parameters and adjustment outcome

It is difficult to draw firm conclusions from the evidence relating to age of condition onset or duration. Although, in conditions where treatment requirements (e.g. cancer, diabetes), and / or the condition itself (e.g. epilepsy) may potentially interfere with intellectual functioning, early onset may increase vulnerability by modifying development of cognitive skills. Although the developing brain demonstrates remarkable plasticity, it is also highly susceptible to insults such as profound hypoglycaemia (i.e. low blood glucose), which is less easily detected in the young child, and sustained long term treatments such as anticonvulsants (Rovet *et al.*, 1987b; Ryan, 1988; Hoare & Mann, 1994). Disruption of cognitive skills, crucial to educational and social functioning is highly likely to forecast deleterious outcomes (see Vannatta *et al.*, 1998a). Such a view invites conceptualisation of proximal (cognition) and distal (social, mental health) outcomes as suggested by Hommeyer *et al.* (1999). Condition-based parameters, in line with Wallander *et al.* (1989b) are presumed to have direct and indirect effects. These factors are directly related to proximal outcomes such as level of functioning, but operate indirectly via functioning on social and mental health outcomes.

Findings suggest that for some children late onset or shorter condition duration are marked by an increase in emotional difficulties and may well reflect an initial adjustment process. However, few studies involve explicit longitudinal comparison of children living with a condition from birth with children having conditions with a later onset. Such studies would be helpful in clarifying the course of adjustment and underline developmental implications for the adjustment process. Findings related to condition category are fairly clear in that children who have conditions that involve the brain, in contrast to those that do not, are more likely to develop emotional and behavioural difficulties, although it remains unclear which conditions, that do not involve the brain, are associated with more or less risk for difficulty.

Results from studies including measurement of condition severity strongly suggest that this index has substantial implications for psychological and behavioural functioning in a range of chronic conditions. It is worthwhile noting that severity measures have differential implications for adjustment outcomes. For example, Holmbeck and Faier-Routman (1995) found treatment for hydrocephalus in children and adolescents with spina bifida was related to academic and social competence. However, a comparable index such as, thoracic, lumbar or lumbar-sacral lesion level, was not associated with outcome indices. Evaluation of the above findings suggests the role of condition-based variables might be more clearly identified through the use of conceptual models that define differential consequences in relation to particular outcomes.

1.7 Definitional and methodological issues

As indicated earlier, many studies frequently use "adaptation" and "adjustment" interchangeably, but it is not clear whether these terms are comparable. In point of fact, definitions often appear implicit and taken for granted. Given conceptual links to study design, methodology and application this issue is of some significance and in need of clarification. However, Wallander and Varni (1992) have indicated that adjustment is multi-faceted, a view also apparently held by Thompson and Gustafson (1996). Adjustment is judged to represent psychosocial functioning, reflecting behaviour, self-esteem and social integration, suggesting inherent complexity. Yet, while early work conducted by Wallander and Varni consistently specifies outcome in terms of adaptation, at the same time they use measures reflecting adjustment. The unspoken assumption suggests they are equivalent (see Wallander & Varni, 1998).

Both adaptation and adjustment denote predominantly temporal and environmental dimensions; that is, in terms of consequences for the individual, they represent dynamic and relative processes. However, consideration of terminological use generally suggests that adaptation, in comparison to adjustment, is viewed as a process, although, Pless and Pinkerton (1975) have employed adjustment in this sense. On the other hand, adjustment, commonly referred to in the literature on child psychopathology and a seemingly potent methodological influence on current research approaches, reflects an orientation focussing on for example, lack of skills, competence and self confidence. Given the intrinsic emphasis on individual differences in psychopathological orientations, it could be argued that adjustment accords greater weight, in contrast to adaptation, to the individual's capacity to accommodate to environmental circumstances. Whereas adaptation, could be viewed as prioritising the influence of the environment, adjustment appears to accentuate the individual's contribution to outcome. Whatever the definitional distinction might be, it is not clear whether agreement has been achieved, and the issue demands consideration.

Although recognition of social context is seemingly apparent, attention to broader aspects of the social context, such as culture reflecting practices, attitudes and values passed from one generation to the next and / or one community to another, is usually absent. There is a need to take account of the socio-cultural and temporal context in which individual environmental transactions take place and make lasting or temporary contributions to development and psychosocial outcome. Perhaps this is transparent. At the same time, however, it presents several methodological problems. Such problems deserve further attention in view of potential implications for treatment. Given the over-riding reference to adjustment it is essential that it receives careful scrutiny. It is not unreasonable to suppose that features of adjustment will vary not only in relation to specific events and circumstances, for example, at school, home or summer camp, but also in time. Social expectations of "appropriate, acceptable" behaviour are likely to shift. For example, illegitimate births are now less likely to be viewed as breeching social convention than they would have been thirty years ago. Would this apply to views on age appropriate behaviour in children? It seems so; an evaluation of psychological adjustment in children with sickle cell disease demonstrated that assessments of adjustment altered over a period of 10 months (Thompson *et al.*, 1994). If we consider these points in relation to reports on child and adolescent adjustment, informants and study design become important issues. In making judgements about behaviour, informants are likely to be guided by normative rules set by social and cultural expectations, and indeed make comparisons within the context of their own social groups. Moreover, Harris (1995) has suggested that children's behaviours are highly context specific and increasingly reflect differences defined by private (i.e. home) and public (i.e. school, peer group) environments. The idea that adjustment is contextually and temporally dependent therefore suggests longitudinal designs and multiple informants may be a more suitable approach to capturing what constitutes adjustment.

Furthermore, the majority of research attention centred on psychosocial adjustment in children with chronic illness appears to be located in the United States. Thus definitions of stress, adjustment, maladjustment, health and illness are related to this cultural reference point. It seems the social framework in which families are situated requires consideration in understanding why and if chronic illness is viewed as stressful. The economic infrastructure characterising many industrially developed nations dictates the organisation of work, leisure and health care systems and influences how individuals define notions of illness and perceive the impact in the short and long term. Given the current expansion of communication systems and growing opportunities for access, it seems likely that researchers, clinical practitioners and individuals managing chronic conditions will increasingly share similar notions of illness and its psychosocial impact. Moreover, government goals that aim to sustain economic viability and growth are likely to perpetuate this mutually reinforcing pattern of interaction.

It is not clear, however, whether theoretical models developed in the United States, would be applicable to other countries which are less well developed and / or differ in terms of notions of health and illness. Cultural history clearly influences conceptions of, and attitudes towards illness, treatment and its consequences (Payer, 1990). Therefore, present models need to be viewed within their cultural context. Indeed, it is somewhat surprising, given the cosmopolitan society of the United States that the contribution of culture has not been incorporated more extensively into models. These factors, however, have not escaped the attention of American family researchers who comment on the importance of cultural values and traditions in shaping family attitudes and adaptation to chronic childhood illness or disability. McCubbin *et al.* (1993) also point out that there are the marked variations in terms of cultural influence within ethnic groups suggesting that stereotypical notions are inappropriate. This point, more importantly has consequences for intervention.

Until recently, conceptual models and their respective intervention approaches were founded on the expectation of psychopathology. However, current trends suggest a tentative shift towards the view that families with chronically sick children are ordinary families in abnormal circumstances, facing particular challenges (Eiser, 1990; Bradford, 1997). Nonetheless, while interventions seek to foster independence and the withdrawal of professional involvement, integration of a child and family into a social/cultural setting which holds negative notions of illness may be somewhat more difficult than anticipated. According to Wallander and Varni (1998) adjustment needs to be delineated in "developmental-normative terms". However, adjustment may also require that attention be paid to other social and cultural factors and needs to be explicitly defined with this in mind. Some of the issues raised here are intended to highlight conceptual difficulties, but are beyond the scope of the current investigation.

Although theoretically driven research on adjustment is increasing, there is also a broad empirical literature focussing on aspects relating to adjustment such as, coping and family functioning. While studies have furthered understanding, there are methodological difficulties associated with a number of studies which place significant limitations on findings. Problems include the use of small convenience samples, cross-sectional designs, self-report measures and recruitment of participants from one or at the most two hospital sites (Drotar, 1997b). In addition, owing to an over-reliance on maternal reports of child adjustment, very little is known about how fathers are implicated in adjustment outcomes. Thus, the representativeness and generalisability of findings are called into question. Moreover, a marked limitation resides in correlational analyses linking independent and dependent variables that rely on a single source and undermines validity. These difficulties are related to some extent, to pragmatic constraints inherent to research within this population. For example, the prevalence of chronic childhood illness in the general population is relatively low and affected children are likely to be scattered over a wide geographical area. Furthermore, there are time and cost implications associated with longitudinal research designs and with attempts to include fathers who are more likely to be in full-time work and therefore less accessible.

Notwithstanding these problems, a crucial question for future research centres on further clarification of the role played by condition-related parameters and the usefulness of a risk resistance framework in shaping psychosocial outcomes. Evidence from such studies would be a valuable step towards identifying features that increase vulnerability to psychosocial difficulties.

Chapter 2: Family structure, family functioning peer relationships and child adjustment

The social, emotional and psychological frame of reference for almost all children is defined by their family and peer group. Thus, efforts to understand why some children adjust to the demands of chronic illness whereas others encounter difficulties, irrespective of genetic factors, require consideration of the family and peer group. It is likely that contextual factors, such as the nature of the family unit, family functioning and peer relationships have significant implications for child adjustment. Although a number of social constraints influence the family unit for example, government policy on family tax incentives, they are beyond the scope of this thesis. Here we briefly consider the impact of social attitudes shaping the family unit. In addition, family functioning and peer relationships are examined from conceptual and empirical standpoints.

First, we explore the social context framing family structure and examine evidence linked to child adjustment in healthy and chronically ill children. This is followed by an overview of theoretical approaches to the family and family functioning and empirical findings relating family functioning to adjustment in children with chronic illness. A conceptual model applicable to families managing chronic childhood illness is described and accompanied by findings linking family, often defined as parental coping, with family functioning, child adjustment and physical well-being. Associations between child coping and family functioning and parental coping are also put forward. Finally, we examine the theoretical and empirical context of children's peer relationships. It is anticipated this chapter will furnish the reader with an understanding of conceptual approaches to the family, family functioning and peer relationships and how these factors contribute to the adjustment of children with chronic illness.

2.1 Family context

It is widely accepted that the family has a substantial and far-reaching impact on the psychological, social and emotional well-being of its members. Further the family is acknowledged as the pre-eminent agent of human socialisation, informing social and cultural adaptation. Families are unique when compared to other social groups. They endure for longer time periods, are inter-generational and reflect biological, social and legal relationships which also place them within a larger kinship and social network (Klein &

White, 1996). However, family configuration within industrialised developed nations has shifted to a large extent over the last thirty years, mirroring the influence of broader social changes. The traditional unit of a heterosexual couple and their offspring which remains intact for their lifetime, while persistently idealised in the media, has altered significantly. Several interrelated factors have been instrumental in transforming family structure. For example, the changing role of women in society (and inevitably men); an increase in the divorce rate; the demands of minority groups (e.g. homosexual) for social, legal and political equality in terms of marriage and adoption of children; increases in pre-marital cohabitation and the liberalisation of attitudes towards illegitimacy.

In the United Kingdom, for instance, between 1971 and 1996 the divorce rate for males and females over 16 years rose from 5.9 per 1000 of the married population to 13.5. In addition, it is estimated that if divorce rates continue at the 1993/1994 level that for every five marriages two will terminate in divorce (Social Trends, 1998). Just under 75 percent of decrees are awarded to wives who are more likely to petition for divorce. Moreover, the percentage of non-married women between the ages of 18-49 years cohabiting in 1996-1997 has doubled since 1981 (Social Trends, 1998, 1999). Such changes denote a fundamental shift in women's expectations of marriage. Furthermore, a divorce rate currently forecasting 1 in 3 marriages will breakdown, an evident social trend towards serial monogamy and a high level of teenage pregnancy has contributed to a marked increase in the number of lone mothers and stepfamilies. The proportion of one parent families with dependent children increased from seven to 19 percent between 1972 and 1996-1997; in 1991 there were roughly half a million stepfamilies with dependent stepchildren (Social Trends, 1998). Patterns of family configuration show that whereas one parent families are frequently headed by mothers there are three times the number of stepfathers as stepmothers. Substantively, family life is perhaps less stable and generally more fragmented than it once was. It seems probable that changes in family structure will have ramifications for family functioning and the socialisation and adjustment of child members.

2.2 Family structure and child adjustment

In her commentary on stepfamilies and children's adjustment, Dunn (1995) states that 12.5 percent of dependent children in Britain, if present trends are maintained, will live at sometime in a family where a biological parent has either remarried or acquired a new partner before they are 16 years. According to Dunn, shifts in family structure, for the majority of children, occur before they are 10 years old. For example, in 1997 seventy percent of divorces involved couples with children under the age of 10 years (Social Trends, 1999). She also points out that children living in stepfamilies are reported to have an increased likelihood of troubled social relationships, internalising and externalising behaviours, problems with health and sustaining educational progress. However, there is substantial variation in outcome suggesting that factors operate to protect against or increase the probability of a deleterious outcome. It is clear from research examining the link between family relations and child outcome in stepfamilies that they differ markedly, in terms of family functioning and relationships, from other family configurations (Dunn, 1995). Early studies of concurrent and longitudinal relationships between family structure and child social adaptational status (social competence) and psychological well-being in a poor urban population, show that children in mother alone and mother/stepfather families were at increased risk for social maladaptation in comparison to mother/father and mother/grandmother families (Kellam *et al.*, 1977). Moreover, the studies revealed striking diversity in family form and suggests, given the subsequent social shifts underlined earlier, that such variations in family structure may have become widespread.

2.2.1 Family structure and chronic childhood illness

Studies evaluating the effect of family structure on children with chronic illness demonstrate links with physical well-being and adjustment. For example, Marteau *et al.* (1987) found that children living with biological parents or a single parent had better diabetic control than those living with a step parent or adoptive parents. A study conducted by Eiser *et al.* (1992) compared parent (mother, father) reports of child adjustment and activity restrictions imposed by either diabetes, epilepsy, asthma, leukaemia and cardiac disorders. They found that single mothers, in comparison to two parent families, evaluated their children's behaviour and condition restrictions more negatively.

In the United States, Overstreet, *et al.* (1995) report a negative additive effect of diabetes and family structure in their comparison of traditional (nuclear) and nontraditional (single parent, stepfamilies) families of children with and without diabetes. Nontraditional families of children with diabetes were found to have lower levels of family cohesion (family unity, support for one another) than all other groups. Further, the scores on the measure of family environment for this group on the whole were low, suggesting general disturbance of family functioning. In addition, both diabetic status and family structure produced significant main effects in relation to behavioural difficulties such as, conduct disorder, socialized aggression, attention problems and anxiety, suggesting that children with diabetes living in a nontraditional family are at considerable risk for behavioural problems. These children showed behavioural problems that were nearly two standard deviations above the mean, in comparison to 1.3 standard deviations for children who had *either* diabetes *or* who lived within nontraditional families. Also children with diabetes in nontraditional families, compared to traditional families, had significantly poorer levels of glycaemic control.

Stein and Jessop (1984), in their study of inner city children with a wide range of chronic illnesses, found that the association between child health status and psychological adjustment varied with family composition. Specifically, poorer psychological adjustment was correlated with living with a birth mother and another adult other than the father (e.g. grandmother, female relative). The weakest association was found for children living with both parents with the correlation for children living with lone mothers falling between the two groups. However, sample size limitations led Silver *et al.* (1996) to conduct a subsequent study with a larger ethnically mixed sample (Hispanic, Black, White, Mixed). They found a suggestive relationship between family structure and physical health and psychological adjustment in urban children with chronic illnesses such as asthma, sickle cell disease, epilepsy, congenital heart disease, cleft lip or palate, endocrine disorders and cancer. Sixteen percent of the sample had several conditions. Findings indicated that family structure probably plays a moderating role in the relationship between illness severity, as measured in terms of functional status (i.e. ability to accomplish age appropriate activities), and psychological adjustment represented in assessment of global behavioural adjustment profile and externalising and internalising behaviour problems. The association between poor functional status and difficulties in adjustment and behaviour was found to be stronger in single parent and stepfamily compositions, in comparison to both parents and mother with a family relative configurations. This was particularly marked for stepfamilies. However, while there were no differences between family groups on the global measure of adjustment, regression analyses controlling for socio-demographic characteristics, showed that an interaction between functional status and family category produced a significant increase in the variance explaining adjustment. Moreover, links between children displaying internalising and externalising difficulties and a stepfamily structure were independent of socio-demographic factors.

On the other hand, epidemiological analysis of socio-economic risks associated with parent reported behaviour problems in children and adolescents has shown family structure to be independent of, but more influential than, chronic health status. Gortmaker *et al.* (1990) showed that severe behavioural difficulties were 1.55 times higher for those with a chronic health condition in comparison to healthy counterparts. However, the predicted risk for a family configuration in which one biological parent was absent was 2.05 and independent of having a chronic health condition. As noted earlier, lone mothers are more likely to rate their children as less well adjusted. Nonetheless, these studies, for the most part, indicate that children who have a chronic condition in either single parent or stepfamilies appear to be at further risk of experiencing psychological difficulties.

Awareness of the conspicuous role families play in psychosocial adjustment of children with chronic illness has led to calls among some paediatric psychologists (Kazak, 1997) for the recognition and incorporation of family theory into future research. While acknowledgment of the family is apparent, indicating a holistic view of psychosocial adjustment, few researchers explicitly include family theory in research programmes. Of those who do, including family researchers, several theoretical formulations influence contemporary approaches. Formulations include family development theory, systems theory, ecological theory and to a lesser extent symbolic interactionist theory. All of these theories, outlined below, endeavour to conceptualise family evolution, organisation and / or family functioning.

2.3 Family theories

The central theme underpinning *family development theory*, which originates in work undertaken by sociologists and social demographers (Lively, 1932; Loomis 1934; Glick, 1947 cited in Klein & White, 1996), is recognition of patterned changes in family life over time. Specific foci are developmental transitions, such as becoming parents and fostering independence in adolescent children. These transitions are linked to social norms which govern expectations about when these events should occur.

Systems theory, arising from the general systems theory movement which gained widespread application in the social sciences during the second half of the twentieth century, is closely associated with the practice of family therapy (von Bertalanffy, 1968) and views the family as an integrated functional system of subsystems (e.g. parental dyad, child parent dyad). It assumes that every aspect of the family system is interrelated, that interpretation relies on an appreciation of the whole family system and that there is a reciprocal relationship between environment and system. In other words the system modifies the environment and the environment transforms the system, suggesting "circular causality" (Frude, 1991). System stability (homeostasis) and therefore structure, is achieved by a servo mechanism, that is, a negative feedback loop. For example, if family tensions exceed a threshold, this will activate the mechanism and force a reversal to a pre-existing family system. Alternatively, positive feedback such as mounting conflict may either be diffused with activation of the servo or evolve a workable modification, introducing structural variation into the system. The latter resolution is advantageous in that it permits adaptation to change. Families are also frameworks of communication systems. As communication between subsystems and the entire system is unceasing, a family can be considered to be self-reflexive, building their own personal version of reality, the major feature being the representation the family holds of itself (Frude, 1991). Lastly, the system analogy is considered merely a means to understanding the family and does not approximate reality.

Ecological family theory focuses on environmental adaptation, highlighting the role of individual biological and social characteristics, ecological niches which refer to a set of related environments associated with particular activities that function to maintain adaptation and the processes which regulate adaptation. This theory derives from three key areas. First, from evolutionary theory and the study of genetics, where individuals are regarded as biological organisms with genetic attributes which limit their abilities (ontogenic development). Second, population genetics has shown that population shifts occur via a process of natural selection which means that at the level of the family, survival is governed by successful adaptation to a changing environment. Third, early studies on human consumption and production (Klein & White, 1996), suggest that through education humans can become aware of their interactions with the environment and organise themselves for the benefit of the wider environment, a phenomenon known as family resource utilisation.

The view advanced Bronfenbrenner (1979), which features in Thompson's biopsychosocial model described in Chapter 1, represents a variation of this theory and has proved to be instrumental in family and education research and developmental psychology. Whereas orthodox theory focuses on relations between features of the ecosystem that is, the environmental context and the principles forecasting these links, Bronfenbrenner seeks to explain the interaction between the person and their environment and consequences for development. Bronfenbrenner combines ecological theory and Lewin's field theory (1935) emphasising the interaction between biological attributes and the social aspects of the proximal (e.g. family relationships) and distal (e.g. community, culture) environment. Thus behaviour is not simply the sum effect of biological traits and the environment but indeed represents a multiplicative effect between the two.

Elements of *symbolic interactionism theory* feature in family stress theory which has been incorporated in several studies focussing on children with chronic illness (Venters, 1981; Patterson & McCubbin, 1983; Holiday, 1984; Patterson & Garwick, 1994). Central to symbolic interactionism and its use in family stress theory is the concept that meanings attributed to events are constructed from interpretation of the consequences of that event for those involved. Therefore, attempts to comprehend behaviour have to take account of the meanings held by individuals. This implies first, that individuals have minds, are self reflective and have a notion of self. Second, that meanings are construed in relation to context and event. Third, it suggests that acquisition of meanings must chiefly stem from society rather than the individual and in line with ecological theory highlights the process and significance of socialisation. Symbolic interactionism also refers to the notion of roles and has implications for understanding families. Role taking, that is acting out and adopting behaviour typical say of a nurse, parent, friend or teacher begins in social interaction during childhood and play activities (e.g. practice of perspective taking, acquiring a theory of mind, indulging in games of pretence). However, this requires that roles are understood in terms of the *shared* rules which govern role behaviour. Thus family roles, such as, mother, grand-parent, brother etc, are influenced and probably controlled by internalised expectations of role behaviour.

Each theory places differential emphasis on family development, functioning, meanings and adaptation and at the same time provides a diverse and complex picture of family dynamics. Within paediatric psychology researchers appear to favour a blend of ecological and systems theory (Kazak, 1989; Thompson & Gustafson, 1996). Nonetheless, while these researchers focus on specific aspects of family context such as social support and parenting, other less theoretically modelled research tends to favour inclusion of family functioning measures based on systems theory. Others have focussed on family climate, involving features such as conflict, achievement orientation and organisation (Daniels *et al.*, 1987; Wallander *et al.*, 1989b). Such measures, however, lack a theoretical foundation.

Family researchers (Patterson, 1988; McCubbin *et al.*, 1996) in developing family stress theory combine pre-existing theoretical elements. For example, the biopsychosocial perspective presented by Patterson (1988) in her Family Adjustment and Adaptation Response Model (FAAR) focuses on three levels; the individual, the family and the community unifying concepts at each level. The model takes account of processes involved in family readjustment following crisis (e.g. chronic illness, bereavement). However, the family system is considered pivotal in mediating transactions with both individual and community levels. The model derives from the ABCX Family Crisis Model conceived by Hill (1958); "A (the stressor event) interacting with B (the family crisis meeting resources) interacting with C (the definition the family makes of the event) produce X (the crisis)" (Hill, 1958). Patterson's model has relevance for adjustment to chronic childhood illness because it focuses on family capacity to balance family demands and resources. However, the model benefits from an understanding of family functioning and is put forward following an exploration of approaches to family functioning and empirical links to child adjustment.

Conceptual frameworks advanced to explain family functioning stem from the field of family therapy. While a number offer various interpretations, the majority are founded on systems theory and share conceptual similarities. Four approaches are outlined. Coverage is neither exhaustive nor detailed but aims to present the reader with a flavour of research perspectives that influence studies focussing on children with chronic illness. We then turn to the evidence demonstrating links between features of family functioning and adjustment in children with chronic illness.

2.4 Family functioning approaches

According to Minuchin (1974), who introduced the notion of the psychosomatic family, the family is composed of a structure which originates in functional demands that guide the way a family interacts. These interactions are termed *transactional patterns* which are founded on repeated transactions which govern how, when and with whom a member relates (e.g. parent makes request and child complies). Thus behaviour is set by the experience of prior transactions in similar contexts and with the same individuals. These patterns organise and order family behaviour.

The functional units of the family system are subsystems arising in the process of differentiation. Subsystems are individuals or dyads for example, marriage partners, father and child. Each family member is involved in different subsystems in which s/he has varying levels of power offering the opportunity for development of relationships which embody the acquisition of different interpersonal skills. Subsystems are circumscribed by *boundaries,* these are the rules which define who participates and how. The function of the boundary is to ensure maintenance of family system differentiation. Boundaries must remain conspicuously clear if functioning is to proceed smoothly. However, family adaptation is viewed as a dynamic ongoing process, poor boundary definition may reflect a transitional process and is not necessarily pathological.

Referring to the parental subsystem, Minuchin highlights intrinsic tensions associated with the parenting/socialising function. On the one hand, parents are expected to maintain a safe environment, teach their children and encourage autonomy which requires supervision and control. Children, on the other hand, will not achieve independence without challenging parental authority. When parenting also involves management of chronic childhood illness these tensions may confound successful adaptation. For example, Minuchin demonstrated links between interactions governing family relationships and detrimental physiological changes in child diabetic members (Minuchin, 1974).

A study conducted by Wood *et al.* (1989) lends support to Minuchin's formulation. They compared families with children who had either Crohn's disease (chronic inflammation of the ileum), ulcerative colitis (chronic ulceration and inflammation of the colon) or recurrent abdominal pain syndrome in terms of the family characteristics outlined by Minuchin, disease activity and chronicity. Wood and colleagues found that enmeshment (i.e. over involvement), rigidity, overprotection, poor conflict resolution, triangulation (i.e. deflection of conflict between two members onto another family member) and marital dysfunction were all correlated with disease activity. Chronicity was clearly associated with the nature of the marital relationship and triangulation. However, while Minuchin presents a plausible and compelling model, it takes a predominantly observational stance toward the family. In addition, conclusions appear to be drawn on the basis of work with disturbed families.

Others in the field have taken a different approach and included self report techniques, such as the following models. The Beavers Systems Model derives from clinically based observations and research with "healthy and nonlabeled families". Although founded on identification of dysfunction, it incorporates evaluation of healthy functioning and seeks to assess family competence and style (Beavers & Hampson, 1990).

Competence focuses on family structure (manifest power, parental coalition, closeness), mythology (family perceptions), goal directed negotiations (effective/ineffective problem solving), autonomy (clear expression of thought and feeling, acknowledgement of responsibility for actions, degree of openness to declarations of others), family affect (variety of feelings, mood, vibes, level of unresolved conflict, empathy-appropriate and responsive) and global health pathology scale (accommodating to dysfunctional). Competence provides insight into how well the family handles and succeeds in accomplishing its role. For example, offering support, assisting the development of family members, fixing and maintaining generational boundaries, providing leadership, augmenting independence and separation in the next generation, communicating well and resolving conflict.

Family styles are divided into two categories, centripetal and centrifugal. A centripetal orientated family is inwardly focussed, seeking to obtain happiness, satisfaction and contentment within this sphere. A centrifugal system is characterised by weak and highly permeable external boundaries and children are liberated prematurely. Families demonstrating this style of interaction look outside the family for satisfaction, happiness and contentment. While a centripetal style is appropriate in the early stages of family life a shift to a centrifugal style with the onset of adolescence is apposite. Problems occur when families adopt a style which is incompatible with current circumstances, or retains a style becoming maladaptive, losing plasticity. However, what happens in circumstances where both young children and adolescents are involved in the family unit is unclear.

Nonetheless, a recent study involving adolescents with sickle cell disease supports the role of family competence in adolescent adjustment. Kell *et al.* (1998) found that both adolescent and parent report of increased family competence, controlling for demographic and medical factors, predicted decreases in internalising and externalising behaviours. These findings suggest the construct of family competence holds predictive utility. In terms of family styles it seems likely that the illness stage may play a prominent role as suggested by speculations made by Rait *et al.* (1992). It is suggested that a lack of family cohesion reported by adolescent cancer survivors may denote a move from a centripetal to centrifugal functioning mode following the long period in which child illness formerly dominated family life. This move may also reflect a desire to eliminate illness related discussions likely to arouse emotional distress. An alternative explanation suggests survival may signify an emotional shift from the burden of living with ongoing uncertainty, and functioning on a day to day basis (Roskies, 1972) to reconsideration of future plans and goals.

The McMaster Model of family functioning centres on family structure, organisation and interactions, features repeatedly identified as distinguishing between healthy and poorly functioning families. The model originates in "The Family Categories Schema" devised during the study of 110 non-clinical families (Epstein *et al.*, 1962, cited Epstein *et al.*, 1978) and has undergone some revision since then. It is based on the notion of an "open system" taking on board the "concepts of communication theory, learning theory and the transaction approach" assessing features such as family affective involvement, problem solving and roles. Family functioning is assumed to centre on the accomplishment of a set of basic, developmental and hazardous tasks. Basic tasks reflect the provision of primary needs such as shelter and food. Developmental tasks refer to family support in relation to promoting optimal individual development (e.g. infancy, childhood, adolescence) and successful negotiation of developmental family transitions such as, marriage, or birth of first child. Hazardous tasks focus on events that signal major change and the potential to destabilise the family unit for example, illness, relocation, accidents.

Finally, the “Circumplex model” proposed by Olson *et al.* (1979) highlights fundamental properties considered relevant in differentiating families - communication, adaptability and cohesion. *Communication* reflects the ability of family members to indicate their desires and preferences clearly and is linked to cohesion and adaptability.

Adaptability relates to family capacity to modify its structure, roles and rules in response to internal or external demands. Families that are overly adaptive are termed "chaotic", families which do not adapt are termed rigid. Both types of the families are at risk for particular problems when confronted with change.

Cohesion refers to the affective attachment between family members and their personal autonomy. A family showing low family cohesion is described as "disengaged", members operate as discrete units, lacking a sense of a family association or family identity. On the other hand, highly cohesive families are described as "enmeshed", attachments are very close, members tend to identify with the family at the expense of personal identity. The family has little involvement with matters outside the family unit.

While the model advanced by Olson *et al.* (1979) points to the importance of three dimensions it discriminates families on the basis of cohesion and adaptability. Since 1992 however, *adaptability* has been replaced by the term *flexibility* to avoid definitional ambiguities. It was frequently assumed that *adaptability* referred to adaptation, a term denoting linearity (Olson, 1994). However, the term adaptability appears consistently in recently published studies (e.g. Grey *et al.*, 1998). Each dimension is subdivided into four categories, allowing families to be identified into sixteen types reflecting a curvilinear model.

These models provide useful insight into features of the family environment that may be expected to influence and pattern psychosocial adjustment. Although, a marked limitation resides in how little models have to say about lone parent family functioning and the relevance of cultural factors. Nonetheless, there is substantial evidence, reviewed in the next section, pointing to the impact of chronic childhood illness on family functioning and links to child adjustment.

2.5 Family functioning and child adjustment

Studies illustrating the effect of chronic illness on family functioning and associations with child adjustment usually rely on self-report questionnaires. Alternative methods, such as observation are rarely employed. Measures most commonly used are the Family Environment Scale (FES, Moos & Moos, 1986) or various versions of the Family

Adaptability and Cohesion Scales (FACES, Olson *et al.*, 1979) which are associated with the circumplex model. The Family Environment Scale (Moos & Moos, 1986) is an inductively derived measure comprising ten subscales, with nine items in each scale (shorter forms contain 4 items per scale). The scale evaluates three principle dimensions, relationships, personal growth and system maintenance. The relationship dimension includes cohesion, expressiveness and conflict. Cohesion reflects family members' commitment to one another and level of available help and support; expressiveness focuses on the degree to which members are permitted to express feelings openly and conflict indicates the level of open confrontation, hostility and disagreement within the family.

The personal growth dimension assesses family goals for individual members. This dimension includes independence, achievement orientation, intellectual-cultural orientation, active-recreational orientation and moral-religious emphasis. Independence reflects the degree to which members are autonomous and self-sufficient; achievement orientation centres on the level to which occupations (school or job) are framed and defined as accomplishments; intellectual-cultural orientation centres on the degree of concern with political, social and cultural issues; active-recreational orientation focuses on involvement in social activity and leisure; moral-religious emphasis as it suggests centres on the degree to which moral and ethical principles are highlighted within family values. The system maintenance dimension includes organisation and control. Organisation reflects the level of clarity in family roles and responsibilities and control indicates to what extent family rules guide daily activity.

In addition, the FES has been subjected to factor analysis and reduced to 3 constructs representing family support, control and conflict (Kronenberger & Thompson, 1990). These constructs have been used in the programme of research conducted by Thompson and colleagues outlined in Chapter 1. Family support is associated with commitment, expressiveness and involvement in social leisure activities; conflict represents a high degree of confrontation and lack of organisation, commitment and support; control is linked to a strengthened level of control, moral/religious and achievement orientations and a reduced emphasis on independence.

Extensive use of these measures has led to the development of a sizable knowledge base and suggests constructs such as conflict, adaptability and cohesion are both meaningful and useful in advancing understanding and intervention design. However, at the same time the majority of studies are subject to the limitations outlined at the end of Chapter 1.

Effects of chronic illness on family dynamics have been demonstrated in families caring for children with phenylketonuria or leukaemia. These families report lower cohesion, adaptability and higher conflict than families managing a healthy child (Kazak *et al.*, 1988; Madan-Swain *et al.*, 1994; Morris *et al.*, 1997). In addition, adolescent survivors of cancer (i.e. leukaemia and lymphoma) completing treatment at least three months earlier, were found to rate their families as significantly less cohesive than a normative sample (Rait *et al.*, 1992). Further, significantly more families compared to the normative sample were categorised within the disengaged (low cohesion) family grouping, according to the family typology provided by Olson (1979). However, some studies have found no differences in family functioning between families managing current demands or the psychological sequelae following treatment for chronic childhood illness and healthy counterparts (Gowers *et al.*, 1995; Kazak *et al.*, 1997) and suggests that some families accommodate the demands of chronic illness easily and others do not.

However, studies strongly suggest family factors are related to child adjustment, self-esteem and social functioning. Moreover, these factors by and large have differential implications for child adjustment outcomes. Behavioural difficulties in terms of internalising (i.e. withdrawal, anxiety) and externalising behaviours (i.e. acting out) seem to demonstrate distinct patterns of association. For example, predictors which included family factors, maternal social support and condition category differed for maternal report of internalising and externalising behaviours in children with either, diabetes or asthma (Hamlett *et al.*, 1992). Whereas family cohesion and conflict were significant predictors of externalising behaviours explaining roughly 19 percent of the variance in scores, condition category (i.e. asthma) and decreases in perceived adequacy of support significantly predicted increases in internalising behaviours. The direction of the relationship between family factors and externalising behaviours is not reported but nevertheless points to family functioning variables playing a more significant role in the emergence of externalising as opposed to internalising behaviours.

Similarly, the pattern of relationships between family features and internalising and externalising difficulties differed for children with leukaemia and healthy children attending routine ambulatory outpatients examinations (Morris *et al.*, 1997). Regression analyses for children with leukaemia indicated decreases in family cohesion predicted increases in internalising behaviours and increased family conflict was found to significantly predict an increase in externalising behaviours. For healthy children decreases in family intellectual/cultural orientation significantly predicted an increase in internalising behaviours. No associations were found for externalising behaviours in healthy children. Nonetheless, children's adjustment scores all fell within a non-clinical range. Furthermore, family conflict was found to correlate modestly and positively with parent report of child externalising behaviours in boys with Duchenne Muscular Dystrophy, a congenitally acquired fatally progressive condition affecting the muscles in boys only. However, family conflict did not predict externalising behaviours in regression analyses. These behaviours were more strongly associated with parent reported stress in maintaining the child's emotional well-being and parental use of emotional coping strategies (Thompson *et al.*, 1992). Nevertheless, a recent multi-site study involving a large sample of children and adolescents with sickle cell disease found maternal reports of increased family conflict predicted maternal reported increases in internalising and externalising behaviours (Thompson *et al.*, 1999). The amount of variance explained by family conflict in externalising behaviours however, was nearly twice that found for internalising behaviours. A study involving children with limb deficiencies also found that maternal report of increased family conflict predicted maternal reports of increased internalising and externalising behaviours (Varni *et al.*, 1989a). On the other hand, increased family cohesion, moral/religious emphasis and organisation predicted reductions in internalising and externalising behaviours.

Escalation of family conflict has been found to predict an increase in parent report of externalising behaviours in children and adolescents with different chronic conditions (Wallander *et al.*, 1989b). In addition, a decline in family control and increases in family cohesiveness and conflict significantly predicted increased social competence. An unexpected finding is the association between family conflict and social competence and suggests two possibilities. It may be that effective parental management of conflict provides a model for children's own behaviour. Alternatively, increased family conflict may precipitate withdrawal from the family environment promoting peer contact which may foster the development of social skills.

Overall the evidence points to a robust relationship between increased family conflict and the expression of externalising behaviours, factors related to internalising behaviours are less clear. In addition, children in families reporting high family cohesion seem to be less likely to demonstrate internalising or externalising behaviours. Although, these findings need to be carefully considered given the methodological caveats highlighted in Chapter 1.

Family factors such as, cohesion, adaptability or control are also implied in the adjustment of children with either sickle cell disease, cystic fibrosis or brain tumours. For children with sickle cell disease, increased family adaptability has been shown to be associated with a parallel increase in parent ratings of internalising behaviours (Brown *et al.*, 1993). In contrast, adolescent report of increased family adaptability was associated with decreased depressive symptomatology in adolescents with diabetes (Grey *et al.*, 1998). Moreover, comparison of maternal reports of family cohesion and adaptability and frequency of behavioural problems in children with either asthma, cystic fibrosis or no chronic illness suggests family factors may mediate links between chronic illness and behavioural difficulties (Lewis & Khaw, 1982). Although, frequency of difficulties in children with asthma or cystic fibrosis were negligible, children with chronic illness demonstrated significantly more difficulties than healthy children. However, statistical control of family cohesion and adaptability eliminated differences in behavioural problems between children with cystic fibrosis and healthy children. Findings suggest that family factors are likely to be associated with adjustment difficulties and denote that effects of chronic childhood illness are not unique to the child but produce consequences for the entire family. The effects for children with asthma are unclear as analyses involving these children were not reported. A study focussing on behavioural and cognitive outcomes in youngsters with brain tumours found family control at time of diagnosis was negatively correlated with subsequent child adaptive behaviour. However, in regression equations controlling for demographic and illness factors neither control or cohesion were predictive of later maladaptive or adaptive behaviour, intellectual or achievement functioning (Carlson-Green *et al.*, 1995). This would suggest that family functioning variables may play a more influential role in the initial phase of adjustment to onset of chronic childhood illness.

In the previous studies relationships between family functioning and child adjustment hinged mainly on parent report and provide little insight into relationships that depend on the perspectives held by children and adolescents. Findings from studies involving child and adolescent report suggest, in line with parent report that family factors are linked to child adjustment. For instance, increases in family cohesion have been shown to be significantly related to increases in overall mental health defined by psychological distress and positive well-being, among adolescent cancer survivors. The family dimensions of cohesion and adaptability, controlling for demographic and illness factors are reported to account for 20 percent of the variance in scores (Rait *et al.*, 1992). Associations were also found between child report of post-traumatic stress symptoms and parent report of general family functioning in children and adolescents successfully treated for leukaemia (Kazak *et al.*, 1997). The anger subscale for survivors was found to be negatively correlated with mothers' reports of general family functioning. Thus an increase in anger symptoms was associated with a decline in family functioning however, the strength of the correlation was low to moderate.

In a study of adolescents with diabetes, links were found between adolescent report of family factors, depression and quality of life (Grey *et al.*, 1998). Measurement of quality of life involved perceptions of condition impact, satisfaction and worry, and family factors centred on family warmth and guidance (i.e. Diabetes Family Behaviour - McKelvey *et al.*, 1993, cited in Grey *et al.*, 1998). Family guidance was modestly and negatively associated with condition impact and family warmth was positively associated with satisfaction, but negatively correlated with depressive symptoms. Such findings imply perceptions of high condition impact and depressive symptoms are respectively associated with decreased family guidance and family warmth. Unfortunately, family variables were not predictive of quality of life dimensions in regression equations that included coping strategy use and depression scores.

Family conflict, independence and control have also been found to influence stress outcomes (i.e. anxiety and depression) associated with recent negative life events in adolescents with spina bifida (Murch & Cohen, 1989). An interaction between negative events and family conflict revealed that in the presence of high family conflict an increasing number of negative events substantially increased depression scores, however in low conflict families the same number of negative events had a marginal effect on depression scores. A similar effect was found for family control. An interaction between negative events and family independence indicated that within high compared, to low independence families, an increase in the number of negative life events predicted a marked increase in anxiety levels.

Studies have also reported associations between family functioning and child self-esteem. For example, in families emphasising high independence compared to low independence an increase in the number of recent negative events reported by adolescents with spina bifida significantly reduced self-esteem (Murch & Cohen, 1989). In other words, high family independence is beneficial to self-esteem when stress is low, but detrimental when stress is high. It is possible that within the context of increased stress, effects of condition-based factors such as limited mobility, may be both emphasised by and clash with family held values of independence. Although interaction effects for family cohesion were not found for adolescents in the Murch and Cohen study, increased family cohesion and decreased family adaptability predicted increased self esteem in adolescent cancer survivors (Rait *et al.*, 1992). Family dimensions, controlling for demographic and illness factors are reported to account for a sizable component of variance in self-esteem scores. Likewise, Varni *et al.* (1989b) found increased family organisation and decreased family conflict were related to increases in child report of self-esteem in youngsters with limb deficiencies. These two studies suggest that low family adaptability and high organisation are propitious to child self-esteem. It seems probable that highly structured family environments exert control over emotional reactions to uncertainties accompanying chronic illness and contribute to psychological stability thereby enhancing self-esteem. Minimising the impact of condition consequences seems to produce a similar effect. For instance, maternal report of lower condition effects on financial, social and family functioning, personal strain and mastery, in children and adolescents with cystic fibrosis predicted increases in child report of physical appearance self-esteem (Cappelli *et al.*, 1988). Thus children in families demonstrating few condition-related consequences reported higher self-esteem in terms of their physical appearance irrespective of pulmonary and nutritional status.

There is a convincing body of evidence linking family functioning and child adjustment across a number of chronic conditions. However, there are two significant difficulties associated with the self-report methodology. First, self-report measures evaluating expressed attitudes and beliefs often fail to match observational data (Beavers & Hampson, 1990). Second, Olson and McCubbin (1983 cited in Frude, 1991) have found that family members' perceptions differ; for instance, wives were found to view the family as more cohesive than did their husbands and adolescents perceived the family as less cohesive than did their parents. While dissimilar perceptions suggest a lack of reliability, they also support the idea of role differentiation and may indicate intervention points. A combination of insider and outsider views of the family or a self-report measure which has been shown to correlate well with observational methods appears to be the optimal methodological approach. A self report measure which meets this requirement is the Family Assessment Device (FAD) associated with the McMaster Model of family functioning. Stevenson-Hinde and Akister (1995) point out that this measure is highly sensitive, in comparison to instruments associated with the circumplex model, in classifying clinical families, and have shown that the FAD correlates with the observational instrument developed for the model.

In spite of these problems, evidence from comparisons with families managing healthy children illustrating the impact of illness on family functioning is inconsistent and implies that chronic illness poses a significant challenge to some families but not to others. This would suggest that family differences may be attributable to how demands are perceived, the resources a family have available to meet demands and the way in which they are managed. The family stress FAAR model put forward by Patterson (1988; Patterson & Garwick, 1994) is helpful in specifying a conceptual framework which suggests family coping is a key factor in family and child adjustment.

2.6 Family adaptation and adjustment response model

Within this model the family is defined as a social system which seeks to attain optimal family functioning and sustain equilibrium by employing "capabilities" (resources and coping behaviour) to accommodate "demands" (stresses and strains). The meanings families assign to their experience of demands and capabilities are vital to accomplishing balanced functioning. Outcomes of attempts to achieve optimal functioning are delimited in the model and reflect family adjustment or family adaptation. Family adjustment reflects a family system characterised by stable and unchanging interaction. Families are able to deal with demands as they fall within current resources sufficient to meet the demand. On the other hand, when perceived demands go beyond present capabilities this produces imbalance. If it continues it leads to crisis and forces the family system into a process of adaptation. This process is guided by the family's efforts to re-establish balanced functioning and includes developing new ways of dealing with demands, decreasing the number of demands and / or redefining the nature of demands.

Patterson (1988) uses the concept of "demand pile-up" to illustrate the explanatory power of the model. A demand is defined as an event or circumstance that requires change in the family system which in turn produces system tension. The tension remains until efforts are undertaken to meet the demand; when no resource is available stress occurs. Importantly, the appearance of stress does not simply represent acknowledgment of the demand, but actually reflects recognition of inadequate resources in relation to the demand. Demands arise within the context of firstly, episodic stressors for instance, death, individual and family developmental transitions and, secondly, strains which are consistently present such as, chronic illness, role tension-not meeting personal or family expectations and maladaptive transactional patterns-resulting from previous efforts at adaptation. It has been suggested that role strain, chronic problems and episodic stressors are the features which contribute to, and produce ongoing stress (Pearlin & Schooler, 1978; Pearlin *et al.*, 1981, cited in Patterson, 1988). Both stressors and strains are involved in demands and seemingly interact. It is likely that they produce multiplicative effects.

Family capabilities are defined as "a potentiality the family has available to it for meeting demands" (Patterson, 1988). The two main features are resources and coping behaviours. Resources identified as relevant to demand resolution are linked to individual, family and community levels.

Individual resources are first, intelligence, which increases the probability of demand recognition and understanding and supports mastery; second, knowledge, skills, experience and training which can be brought to bear on gaining access to employment and the accomplishment of tasks related to daily living; third, disposition, for example extroversion, which may mediate effective coping behaviour; fourth, physical and socio-emotional health and fifth a feeling of self-efficacy or internal locus of control and a high sense of self-worth. While both self-efficacy and positive self-worth are, according to the stress literature, essential to the process of coping and handling demands they are the most likely to be eroded in circumstances of chronic stain or demand pile-up.

Family resources are reflected in many of the family therapy models. Foremost amongst these are cohesion and adaptability. Other resources are family organisation which centre on structural aspects such as well defined roles, rules and parental alliance and unequivocal generational boundaries. Competent communication is also crucial. Features specified in the McMaster model of family functioning such as, clear, unambiguous interactions which maintain verbal and non-verbal concordance are thought to facilitate smooth functioning.

Accessible community resources are medical and health-care services, church, school and possibly employers. Perhaps more remote, but nonetheless available, are government polices which provide support.

Within the stress literature empirical efforts have focussed almost exclusively on social support. This is because it is assumed to afford protection against mental and or physical illness in circumstances of stress. However, research evaluations have considered social support in different ways, for instance, emotional, informational or instrumental such as financial help or assistance with chores. This suggests that social support can, and is viewed in terms of its objective and subjective value. While informational or instrumental support may be viewed as objective support the subjective value attributed to support is indicated by appraisal in terms of its affective impact. Indeed, it seems likely as Patterson (1988) suggests, that, in comparison to objective support this may have a greater impact on physical and mental health. Of note is the contrast between social support and a family's social network. The network reflects the number of people the family has contact with, and should not be taken as the level of support available. Some individuals within a social network may exert demands. For a discussion of relationships between network characteristics and distress in parents of children with chronic conditions the reader is referred to Kazak (1992). However, support may be obtained from a spouse and relatives, or those in which ties are less intimate (neighbours).

While support can be acquired from health care workers there appears to be some dispute amongst researchers whether this can be termed social support since "mutuality and reciprocity", generally implicit within informal supportive exchanges, are absent. Patterson (1988) suggests that these more formal networks are useful in terms of supplying "esteem and appraisal" particularly if workers do not weaken individual or family feelings of control.

Family coping is viewed as the mechanism whereby resources are brought to bear on demands. Coping behaviour is defined as action(s) which are undertaken, by an individual or family, to deal with or handle a demand(s). Some of these behaviours can be categorised as patterns of responses aimed at particular goals; for example, "maintaining family integration and co-operation" as demonstrated in a study of parents caring for a child with cystic fibrosis (McCubbin *et al.*, 1983a). Coping efforts function to sustain or recover the balance between demands and resources. Examples may include coping directed towards diminishing the number, and / or perceived intensity, of demands for instance, seeking a job to improve economic provision; obtaining further resources, such as appropriate health services for a family member with a chronic disorder. Coping also comprises resource maintenance so that within the context of shifting demands resources can be reassigned to meet objectives. For example, sustaining social relationships which furnish the family with emotional and informational support. In addition, handling and overcoming tension created by ongoing strain is another important aspect of coping. Recognition that tension exists is obviously crucial, but ways in which it can be relieved are organised family activities and effective, clear communication of emotion. Finally, coping can include a strategy of re-interpretation of circumstances to enable demand management. This reflects the model notion of meanings in that perceptions are deliberately altered. Alternative problem solving approaches can be devised, for example performance expectations are reduced or the value of existing family competencies is highlighted.

The adaptation adjustment response model is explicit in delineating a role for family coping in predicting family adjustment. However, coping has generally been measured from the standpoint of the individual, particularly mothers. Accordingly, associated measures have often been derived from theoretical formulations seeking to account for individual differences in coping. Whether individual approaches can be regarded as measures of family coping is doubtful. Although a few studies have examined the relationship between family coping (i.e. mothers and fathers) and family functioning. There is some evidence, presented in the following section, to suggest that parental coping responses are linked to parental and family factors and child physical well-being. In addition, child coping has been found to be associated with family functioning and parental coping.

2.7 Parental and child coping, condition attitudes, child physical well-being and family factors

In a study of two parent and single parent families caring for children and adolescents with cystic fibrosis Venters (1981) examined relationships between family functioning and coping using the family stress formulation put forward by Hill (1958). Family functioning was assessed in terms of family "cohesion, positive communication and satisfaction". Venters identified two coping strategies associated with level of family functioning, "endowing the illness with meaning", that is the ability to attribute a spiritual or scientific explanation, and "sharing the burdens of the illness", such as delegating condition-related tasks among family members. These strategies were significantly and linearly associated with families categorised into high, medium and low family functioning. Families demonstrating high family functioning were more likely to attribute a definition and share condition demands in comparison to families with medium and low functioning. This suggests families able to make sense of their situation and balance demands are probably in a better position to sustain themselves and move forward as a united family.

In another study involving mothers of children with sickle cell disease maternal report of increased family adaptability was predictive of increases in maternal use of engagement coping strategies, such as active problem solving and cognitive restructuring for management of child pain (Sharpe *et al.*, 1994). However, family functioning did not forecast use of disengagement coping strategies, such as passive wishful thinking and social withdrawal, although increased use of these strategies was predicted by lower social status and increases in child depressive attributional style and internalising behaviours.

Parental beliefs, with respect to condition-related consequences, also appear to shape coping behaviour. Austin and McDermott (1988) found more positive parent attitudes to child epilepsy for example, "Epilepsy in my child has helped my child to become more understanding of others with problems"; "Epilepsy in my child is unpredictable" were significantly associated with increases in the helpfulness of family centred and self-care coping patterns. For example, maintaining family integration and co-operation, social support and self-esteem. These results suggest attitude disposition is an important marker for the helpfulness of coping efforts.

In addition, a 10 year longitudinal study relating family factors to physical well-being in children with cystic fibrosis suggests patterns of family coping reflecting attention to family, self and medical needs, that is balanced coping is associated with better long-term pulmonary functioning in children (Patterson *et al.*, 1993).

Family functioning variables have been found to be associated with child coping in children with sickle cell disease. For example, maternal report of increased family cohesion has been shown to be related to child reported increases in active coping strategies (Kliewer & Lewis, 1995). This seems to suggest a family environment characterised by close emotional ties among members is likely to promote adaptive coping behaviour. On the other hand, in another sample child report of increased use of disengagement (i.e. avoidant, passive) coping strategies was found to be associated with maternal report of decreased family adaptability (Sharpe *et al.*, 1994). Findings indicate a more flexible family environment tends to encourage less use of passive coping behaviour.

In terms of links between parental and child coping, Gil *et al.* (1991) found among children and adolescents with sickle cell disease, parent reported increases in pain related coping efforts were significantly correlated with child reported decreases in use of negative thinking. Also, increased use of passive adherence among parents was significantly correlated with increased child use of passive adherence. These findings imply that parents who are more likely to deal with their own pain by using active coping efforts and less inclined to use passive adherence are likely to foster a reduction in child use of negative thinking and passive adherence. Alternatively, parents favouring use of passive adherence may encourage this behaviour in their children. Moreover, in a subsequent study of children and adolescents with sickle cell disease maternal increases in use of social support and emotion-focussed engagement were correlated with decreases in child reported use of expressing emotions (Brown *et al.*, 1993). On the other hand, parents of children with sickle cell disease reporting increased use of active coping strategies and decreased use of cognitive restructuring predicted an increase in child reported use of avoidant coping strategies (Kliewer & Lewis, 1995). While the link between active and avoidant coping seems counterintuitive, it is suggested that parents may take responsibility for difficulties placing children in a passive role. However, some studies report no link between child and parent coping or parental coping suggestions and child report of active or avoidant coping in children with sickle cell disease (Sharpe *et al.*, 1994; Kliewer & Lewis, 1995).

Although these studies are suggestive of links between family factors and child coping, methodological differences, in terms of the measurement and conceptualisation of coping, and the general lack of evidence indicate further studies are needed before conclusions can be drawn.

Plainly, from a theoretical and an empirical standpoint, the family is a critical component in fostering psychological well-being and the management of childhood chronic illness. It is less clear to what extent peers are involved in psychosocial adjustment. As children progressively spend more time with peers it would be reasonable to expect that these relationships will be a significant factor. In the next section we focus on theoretical approaches to peer relations and examine the evidence highlighting the impact of chronic illness on peer relationships. This section introduces the broad literature on peer relations so the evidence may be understood within and in relation to the larger theoretical and empirical context.

2.8 Peer relationships and friendship

While it is recognised that peer relationships play an increasingly important role in cognitive, social emotional and moral development, empirical support has been surprisingly scant. Until twenty to thirty years ago it was widely held that socialisation operated inside a one-way parent to child interaction. However, Bell (1968) suggested that findings from human and animal studies were consistent with a bidirectional or two-way reciprocal model of parent and child interaction. Drawing attention to constitutional differences between children, Bell highlighted differential effects on parental behaviour. More importantly, however, Bell's proposal suggested children were active participants in the socialisation process. The idea that children were instrumental in this transaction led to the realisation that peer relations, previously ignored, were an essential component of socialisation. The developmental significance of peer interaction and links between poor peer relationships and adjustment difficulties has resulted in a considerable expansion of research activity within the last fifteen years (Dunn & McGuire, 1992). This research is guided by various theoretical perspectives emphasising the influence of temperamental and environmental factors suggesting the developmental interdependence of social, emotional and cognitive domains of functioning.

Central themes reflect a range of theoretical and applied interests and a marked distinction between the notion of discrete episodes of peer interaction and stable, ongoing peer relationships. For example, researchers concerned with the impact of peer interaction on cognitive development have highlighted evidence of co-operation in problem solving tasks, underscoring the mapping of social conventions, such as equity in terms of fairness, to this process (Light & Glachan, 1985; Doise, 1990, cited in Light & Littleton, 1994). Others have attempted to identify features characteristic of positive peer relations, for instance "Being sincere, having status" and possession of empathetic communication skills (Jarvinen & Nicholls, 1996; Mobbs *et al.*, 1995). These studies have sought to emphasise the relevance of such qualities in the development of interventions. Alternatively, researchers seeking to understand the development of social competence are concerned with the history of peer and friendship relations and associations with concurrent and later adjustment. For instance, Hoza *et al.* (1995) found concurrent and predictive links between peer status and friendship and behavioural correlates such as social withdrawal and aggression. Other work has focussed on the origins of interpersonal competence. Rudolph *et al.* (1995) have suggested experience of family relationships intercede between concepts of self, family and peers and bear upon social skills and levels of peer acceptance. Another area centres on the functional aspects of peer relations, such as resource provision. For example, East and Rook (1992) have examined the extent to which social and / or emotional support protects against deleterious socio-emotional outcomes. Another area of interest focuses on the influence of temperament/personality. Evidence emerging from behaviour-genetic studies suggests that the constitutional differences in children make a substantial contribution to the variance (above 25 percent) found in family environment measures (Plomin, 1994, cited in Hartup & Lishout, 1995). It seems highly probable that constitutional differences will affect peer relations. Indeed, an attempt to evaluate this link found an association between quality of peer relations and temperament (Stocker & Dunn, 1990). Taken together, studies point to the significance of temperament, developmental stage, the family and social environment in peer related behaviour.

Consideration of peer relationships and friendships in the development and adjustment of children and adolescents with chronic illness has received limited attention and yields inconclusive findings. For example, in a review of studies focussing on peer relations and social adjustment in children with chronic illness Spirito *et al.* (1991) indicate little evidence exists to suggest that children with chronic illness experience difficulty compared to healthy peers. However, 75 percent of the studies reviewed, rely on parent or self reports of peer relationships and do not involve teacher or peer report which are likely to be, at least as, if not more informative. One may draw a similar conclusion from a review of social competence in youngsters with chronic conditions involving the nervous system (Nassau & Drotar, 1997). Nonetheless, Eiser *et al.* (1992) found that children with either epilepsy or asthma, according to maternal report, have poorer relationships than children with either diabetes, leukaemic or cardiac conditions. Although, Stein and Jessop (1989) also using maternal report, found no differences in peer relations as a function of condition difference.

However, a study of children and adolescents with either cancer, brain tumour, sickle cell disease and matched healthy peers, found significant differences in dimensions of social reputation as reported by teachers. Children with brain tumours were viewed as more sensitive-isolated (i.e. a child who is frequently left out, whose feelings are easily upset, seems lonely) than matched counterparts (Noll *et al.*, 1992). Moreover, a later study of 28 children surviving brain tumours found these children were rated by themselves, peers and teachers as more sensitive-isolated than healthy matched peers (Vannatta *et al.*, 1998b). While Noll *et al.* (1992) found no differences for children with sickle cell disease, a subsequent study involving peer report of social reputation, peer nominations of liking and reciprocated nominations found that girls with sickle cell disease were seen as showing less sociability-leadership (i.e. a child who has lots of friends, a leader) than matched healthy peers. In addition, males were viewed as less aggressive-disruptive (i.e. a child who is bossy, bullies and teases peers) than healthy counterparts. Nomination usually entails youngsters being asked to nominate classmates on measures of liking for example, best friend, someone you like to play with, or disliking such as, someone you don't like to play with. Peer group status is mirrored in the number of nominations a child receives. In terms of peer liking and reciprocated nominations, children with sickle cell disease were nominated less often as best friends and girls in comparison to boys received significantly fewer nominations, but no group differences were found on various measures of emotional well-being (Noll *et al.*, 1996).

Although Noll *et al.* (1992) found that youngsters with cancer were perceived as showing more sociability-leadership and less aggressive-disruptive than healthy counterparts previous studies have found that children with cancer were perceived by peers and teachers as more isolated (Spirito *et al.*, 1991; Noll *et al.*, 1990 cited in Noll *et al.*, 1992). However, children involved in an earlier study had experienced longer and more intense treatment protocols than children in the later study, findings suggest perceptions, and possibly the child's behaviour, changes over the illness course (Noll *et al.*, 1992). Similarly, a recent study involving children and adolescents surviving bone marrow transplantation (BMT), a procedure administered to treat cancer, aplastic anaemia or severe immune deficiency, between nine months to eight years earlier, found these youngsters were perceived by peers to be more passive-anxious (shy, displays a preference to play alone) and passive-isolated (rejected by peers, left out) than matched healthy peers (Vannatta *et al.*, 1998a). These behaviours together represent the dimension of sensitive-isolated used in the above studies. They also found that BMT survivors received fewer best friend and reciprocated peer nominations and were more often seen to be "sick a lot" and " missing a lot of school" than matched counterparts.

On the other hand, children with moderate to severe asthma were not found to differ from matched healthy counterparts in peer report of sociability-leadership, aggressive-disruptive, sensitive-isolated or level of peer acceptance (Graetz & Shute, 1995). However, they were perceived by peers to be sicker and have higher levels of school absence. Moreover, significant associations were found between an increase in the number of hospitalisations and increased self reported loneliness and peer perceptions of being sensitive-isolated, and decreased liking nominations. Thus while children with asthma do not appear to be socially compromised, in comparison with healthy peers, those experiencing more hospitalisations are at some risk. Children with either asthma or diabetes were also not found to differ from healthy peers in management of problematic peer situations, such as peer group entry and peer provocation, as reported by teachers (Nassau & Drotar, 1995). However, La Greca (1992) has shown that, among adolescents with diabetes, friends provided more support for "feeling good about diabetes" in contrast to family members. This suggests that friends may be vital in de-emphasising adolescent perceptions of difference.

Eiser (1993) has suggested that there is a need to establish integrative links with current theory and research. To some extent, clarifying the impact of chronic illness on peer relationships relies on a clear understanding of the role of social relationships in psychosocial development. On the other hand, attempts to define the nature of relationships in which chronic disorder is a factor are likely to be useful. For example, focussing on whether level of functioning and / or extensive school absence are related to outcome may inform normative developmental processes. If these factors are relevant as suggested (Spirito *et al.*, 1991; Eiser, 1993), then at what point in the developmental course do they assume importance? If effects are found, do they persist?

Theoretical frameworks presently steering much of this work suggest experience in family relationships is highly influential. For example, social learning theory claims that children learn relationship behaviours modelled within the family and use them to conduct exchanges with peers and friends. Alternatively, attachment theory states that the internalised working models of relationships developed in infancy are extrapolated to peer and friendship relations. However, mechanisms augmenting these processes remain conspicuously unclear. Stocker and Dunn (1990) also highlight the suggestion that constitutional aspects such as temperament exert an influence producing the same or similar responses from relationship companions. Others have argued that the characteristics of peer relationships and friendships might differ from family relationships (Stocker & McHale 1990, cited in Stocker & Dunn, 1990). Participants within a relationship bring unique features, such as differing biographies, personalities, beliefs and expectations, diminishing the likelihood that friendships will be comparable to familial relationships.

Moreover, parent-child relationships and peer relationships/friendships differ in power relations, developmental function and the point at which they appear in the developmental course. Hartup (1989) has defined them respectively as vertical and horizontal. Within the parent-child relation the balance of power is asymmetrical, in ideal circumstances it affords protection and security. Conversely, the distribution of "social power" within a child-child relation is thought to be, in varying degrees, equal. Elementary social skills acquired in the parent-child relation are developed with peer relation experience of reciprocity, collaboration and competition. Hartup (1989) suggests that it is within the framework of horizontal relationships that "intimacy" is first encountered and attained. While various theoretical approaches may differ in emphasis, it seems probable that both environmental and temperamental factors are involved, as suggested in the five year longitudinal study by McCoy *et al.* (1994). They found temperament in addition to quality of parental relationship forecasted "best friendship indirectly, through the quality of their sibling relationship".

Further theoretical orientations suggest peer relations are important in terms of psychosocial adjustment. These theories refer to the acquisition of social skill, self confidence and notion of, and sensitivity to, self. For example, Hartup (1977, cited in Burkowski and Hoza, 1989) has argued that social experience with peers is necessary for the development and acquisition of social skills and moral values. Similarly, Piaget highlighted the role of conflict during peer interaction in the development of "social perspective taking skills" and co-operation (1932, cited in Burkowski and Hoza, 1989).

Furthermore, Berndt (1982) has emphasised the proposition advanced by Douvan and Adelson (1966, cited in Berndt, 1982) which suggests that the social support preadolescents and early adolescents derive from their friendships serves to diminish anxiety surrounding the changes occurring during this period of development. Fine (1981, cited in Burkowski and Hoza, 1989) has put forward the idea that against the backdrop of peer relations children feel secure enough to experiment with various forms of social expression, thereby providing the context in which social and interpersonal self assurance can grow. Moreover, Sullivan (1953) has stated that peer relations assist development of the self concept. He believed two social experiences during childhood and early adolescence fostered the acquisition of a robust self concept. Firstly, he suggested peer group acceptance between ages of seven and nine years led to the acquisition of high self esteem, peer group exclusion would lead to feelings of inferiority. Secondly, the opportunity to develop a "chumship", which he described as a "co-equal" friendly, warm and reciprocal relation with a same sex peer, provided preadolescents with their first chance to reflect upon themselves as others view them, gain an appreciation of others' perspectives and most importantly, to receive confirmation for aspects of self-worth. In addition, Sullivan considered the chumship an essential component of self concept. He suggested that it could be viewed as a therapeutic environment in which the effects of previous negative social experiences may be ameliorated.

The assumptions underpinning theoretical positions point to the developmental importance and quality of social experience. For example, support for attachment theory is suggested by the finding that children who achieve secure attachments in infancy are inclined to form positive peer relationships (Lieberman, 1977; Cohn, 1990, cited in Chase Lonsdale *et al.*, 1995; Bullock, 1993). Moreover, Rudolph *et al.* (1995) found evidence for the generalisation of interpersonal mental representations across self, family and peer. This study suggested that negative representations of self and others were linked to maladaptive social behaviour and diminished peer group acceptance. Rubin *et al.* (1996) evaluated the relationship between self-discrepancies (i.e. differences between beliefs about actual-self, self as one is and firstly, ideal-self-how one would like to be and secondly, ought-self, self as how one should be) and peer relationships. They found that children receiving peer nominations for behaviour typical of social detachment, that is, active withdrawal or exclusion by the peer group, were those who demonstrated low discrepancies and evaluated themselves as low in social competence. Thus a correspondence was found between peer perceptions and children who held themselves to be less able and possibly less motivated to achieve self related goals. Alternatively, the presence of parental psychopathology and maladaptive relationship modelling may affect the development of socio-emotional competence (cf. Goodman *et al.*, 1993). Furthermore, the accumulation of evidence indicating a relationship between peer group status, for example popular, neglected, average, rejected or controversial, and concomitant and later adjustment suggests assumptions may be well founded (Parker & Asher, 1987). However, while it has now become possible to identify the behavioural antecedents in relation to specific outcomes, the strength of the association and causal pathways are as yet undefined.

The view advanced by Sullivan indicates that peer group acceptance precedes the development of intimate dyadic relations and that they are distinct in origin. While contemporary research suggests an influential developmental role for both friendships and peer relationships the sequence of development implied by Sullivan remains unclear. Nonetheless, the proposed contrast between peer relationships and friendship is emphasised in the empirical literature. For instance, Stocker and Dunn (1990) found "measures of children's peer relationships and friendships were generally not associated". They also stated that "findings suggest that children's experiences in relationships with friends and peers may be relatively independent". Jarvinen and Nicolls (1996) also found that adolescents' notions of friendship were not linked to peer group status. However, some evidence suggests a developmental relationship between sociometric category and enduring friendships. Howes (1990, cited in Dunn & McGuire, 1992) found that five to six year olds categorised as popular or rejected were equally inclined to form friendships within and spanning status categorisation. By age eight, however, popular children did not establish friendships with rejected children. Findings are consistent with theoretical proposals put forward by Harris (1999) who suggests peer relations and friendship during childhood have differential implications for concurrent and long term well-being.

Theoretical formulations and empirical findings described above highlight the relevance of peer relationships and friendship to developmental change and psychosocial adjustment. However, children are clearly involved in two psychologically meaningful environments the family, and the peer group. Each is likely to play an important role in the way that young people accommodate the consequences of chronic illness into their daily life. Extending evaluation beyond the family is likely to contribute to a fuller appreciation of psychosocial actors influencing well-being among youngsters with chronic illness.

Chapter 3: Study rationale, design, methods and chronic conditions

In chapter 3 an overview of the study rationale, design, methods and description of the conditions under investigation are put forward. The aim of this chapter is to explain, by further defining the current research context, the reasons motivating the present study and related methodology. In addition, condition descriptions seek to highlight for the reader, the respective physiology, functional consequences and psychosocial implications. Although, variables identified as relevant to study objectives are indicated here, selected measures are presented in Chapter 4.

Drotar (1997b) has called for clinical research in paediatrics to move towards evaluation of interventions. Pointing to the demands exerted by the system of managed care (care augmented by health insurance companies of which elements are being adopted in the UK with a view to future financial constraints), psychologists are under increasing pressure to establish the health and economic benefits of psychological interventions. Moreover, the drive for incorporation of evidence based medicine into clinical practice in the UK suggests British psychologists, in time, will be called upon to do the same.

In focussing on adjustment to chronic childhood illness, researchers have identified a number of factors including maternal and child coping and parenting as targets for treatment. Parenting interventions described by Thompson and Gustafson (1996) appear to focus predominantly on mothers, characterising much of the literature in that little attention is paid to fathers. It is suggested that psychological techniques such as behavioural, cognitive-behavioural and social skills training, stress management and facilitation of child and family problem solving will diminish psychological morbidity and enhance health status. These techniques focus on increased levels of anxiety and functional difficulty in children, chronic emotional strain in mothers and improvement of family support in the management of chronic childhood illness. For example, behaviour modification, relaxation or cognitive restructuring and family support services are employed to develop effective coping strategies and promote health care behaviours. However, there appears to be much less emphasis on the implementation of techniques aimed at the family. For example, in their review of psychosocial interventions for children with chronic illness Bauman *et al.* (1997) state that just three of the fifteen studies meeting criteria for inclusion evaluated family functioning. While theoretical integration of family systems has begun and treatment goals are articulated to include child and family, individual based therapies appear to take priority over family interventions. The reasons for this are unclear. Thompson and Gustafson (1996) imply that individual based interventions that curtail stress, increase coping skills and social support indirectly produce positive effects on family functioning. Alternatively, it is possible that individualised treatments, in contrast to family interventions, produce clinically significant results, or practical obstacles, for instance time, cost and client co-operation confound the organisation or implementation of family therapies. Nonetheless, psycho-educational treatments, such as multiple family discussion groups or cognitive behavioural techniques combined with family therapy, are increasingly evident (Steinglass, 1998; Kazak *et al.*, 1999).

However, although Drotar argues convincingly that intervention studies will add to understanding and no doubt illuminate causal pathways, applications based on current knowledge present difficulties. While much has been learnt in the last thirty years, there are several problems associated with previous studies on psychosocial adjustment in children with chronic illness.

3.1 Study rationale

First, studies have generally, although not exclusively, drawn samples from one site and failed to take account of variation in clinician management protocols (Eiser, 1990; Drotar, 1994). Second, as Eiser (1990) has pointed out, developmental aspects, and significantly the role of peers in defining the social experience of children (James, 1993), are rarely considered in models of adjustment. Given the well documented trend for increasing functional autonomy and importance of peer relationships in developing social skills and notions of self-worth (Sullivan, 1953), factors which prevent or disrupt progress may impact upon adjustment, and require examination. Third, on the whole there is a predominant focus on mothers as primary informant. There are only a small number of studies which include both mothers and fathers (Eiser, 1993). As most families are traditionally structured and therefore include fathers, current findings may be biassed and provide only fragmentary insight into how children and adolescents might adjust to chronic illness. Are fathers instrumental to this process? What evidence there is suggests that they play a supportive role (Nagy & Ungerer, 1990); nonetheless, wider social changes forcing a shift in traditional gender roles and family configuration, suggests much needs to be learnt. More importantly, however, Wallander and colleagues to date, and in line with others have been inclined to involve parents rather than children as informants and also seem to conduct analyses that provide one informant source for independent and dependent variables. It would seem vital, in terms of enhancing understanding and intervention development, that children's perceptions are explored and findings are strengthened by attempting to link independent information sources.

The present study ventures to address some of these short comings. In addition, the relative utility of the non-categorical and categorical approaches in serving explanations of outcome is not clearly resolved. Very few studies have sought to establish to what degree generic dimensions of chronic childhood illness, for example, age of onset, duration, visibility and illness course, or condition category might account for variation in psychosocial outcome. It seems probable that condition category and generic dimensions are mutually involved. However, it remains unclear in what way these aspects contribute to explaining diversity in outcome. To some extent, findings reported by Holden *et al.* (1997) are helpful. They found independent effects for gender and diagnostic condition (asthma, diabetes) in relation to child reports of self-competence as measured in terms of global and domain specific aspects of self-esteem, and mothers' reports of family functioning. However, when demographic factors and general features of illness such as, duration, severity and number of hospitalisations were statistically controlled, variance linked to diagnostic condition diminished and was no longer statistically significant; the association between gender and self competence remained robust, however. These results suggest, the authors argue, the need to incorporate both general and condition-specific variables in the assessment of ongoing adjustment.

A further difficulty is related to the evaluation of proposed theoretical models. This has tended to centre on particular components rather than the whole model. Eiser (1992) has commented that much research has either focussed on children or their parents and failed to examine interdependence between child and family. A broader approach which includes more variables, placing the child and family in an ecologically substantive setting, offers the opportunity to establish the validity of proposed relationships. Moreover, it is likely to refine research questions and inform further empirical and theoretical endeavours. A recent prospective investigation goes some way to addressing this issue (Chaney *et al.*, 1997). This study focussed on children with diabetes and involved child and **both** parents. The authors found that elevation in fathers' distress (adjustment) over time was related to a decline in child adjustment. In addition, decreases in paternal adjustment were found to be predicted by increases in maternal adjustment. The findings illustrate rather elegantly the reciprocal nature of adjustment among family members and the importance of an inclusive approach to investigation.

Lastly, analytic techniques need to move forward in line with conceptual developments. Multivariate frameworks demand procedures such as path analysis or structural equation modelling and are likely to prove advantageous in demonstrating conceptual utility and identification of valid model components. Such efforts would be expected to support a fuller understanding of the factors which ameliorate and enhance adjustment and benefit the development of empirically and theoretically derived interventions. Some of the proposals outlined here have been put forward recently by Wallander and Varni (1998).

3.2 Study design

In designing the study several objectives were considered. An overriding goal was to evaluate the claim that general features of chronic childhood illness, in contrast to condition category, are crucial in determining variability in psychosocial adjustment. However, as suggested in Chapter 1, condition-related features may have more relevance to how parents and children manage problems than adjustment. Moreover, it is not known with any great certainty in what way these features are associated with coping, or indeed whether they have differential consequences for mothers, fathers and children. In addition, as research evaluating the risk resistance model has concentrated on model components it is not clear if the proposed mechanism advanced by Wallander and colleagues is tenable. Further, there is very little research addressing issues such as the quality of children's friendships and the role of friendship in adjustment.

In essence, the present study was designed to examine the relative contribution of condition-related parameters in explaining variation in psychosocial outcome, to test the viability of the risk resistance framework and to evaluate the impact of condition-related parameters on parental (highlighting differences between mothers and fathers) and child coping and family functioning. In addition, the theoretical model would be extended to include peer and friendship relations, and the role of condition parameter modified parental coping in adjustment examined. The risk resistance framework was selected because, in contrast to the transactional stress and coping model, it makes fairly explicit predictions about the way in which factors increase and decrease risk and to gauge validity requires a test of the entire model. The aim was to attempt a more inclusive examination of variables put forward in this model bringing the child's perception of difficulty into view within a cross-sectional design. Furthermore, as previous research suggests that predictive factors are configured differently depending on the outcome of interest (i.e. internalising or externalising behaviours), the study aimed to evaluate factors predicting overall difficulty, emotional and behavioural difficulties respectively.

However, given the number of children under 16 years affected by chronic illness is relatively limited, conditions demonstrating a low incidence were excluded. Four conditions-asthma, diabetes mellitus, cystic fibrosis and epilepsy-were chosen on the basis of availability (i.e. number and age range), regular hospital attendance, physiological differences in terms of the body system affected, differences in life expectancy and variation in age of onset, condition course and chronicity. Children were not excluded from the study if more than one condition was present for example, asthma and eczema or cystic fibrosis and diabetes. This takes into account the psychosocial impact of additional care requirements and, importantly, consequences for adjustment consistent with the non-categorical approach. Factors included in the Wallander *et al.* (1989b; Wallander & Varni 1992) conceptual model and selected for the present study were condition severity (i.e. family care demands), family functioning, child quality of life (i.e. functional status), child and parental coping and estimates of behavioural strengths and difficulties denoting level of adjustment. It was expected that peer relations which included peer group relations and friendship would also play a meaningful role; accordingly, this was built into the conceptual framework. In addition, to lend ecological coherence, and provide opportunities to link independent information sources, it seemed desirable to include child, parental that is, mothers and fathers, teacher and health professional assessments.

Two further goals reflected a need to accommodate differences in clinician management and a developmental perspective, and therefore sought to include five hospital sites and cross-sectional age banding. All hospital sites are located in the South of England. Three hospitals supply district general services, one site renders community hospital services and the fifth is the centre for regional services which provides specialist expertise. Attempts were made to ensure that each condition group could be recruited from each site; however, this proved problematic. The intention was to recruit 200 children and adolescents between the ages of eight to sixteen years into eight age bands, drawing at the start, 50 percent of the sample from the regional service site. The remainder of the sample were to be drawn in equal numbers from the other sites. This approach was taken because the number of children managed at the regional site was greater than that at district general sites. The strategy aimed to ensure that condition group recruitment reflected variation in clinician management. However, two of the eight clinicians within the participating district hospitals were trained at the regional site and may offer treatment protocols comparable to that of the regional centre. The age range was chosen because children between these ages may be expected to report reliably on their experience and therefore permits access to the child's perspective.

At the outset it was anticipated that comparisons would be made between affected children and their families and a small group of families caring for healthy children, in terms of family functioning, adjustment, peer and friendship relations. However, difficulties emerged in the course of the study and precluded the involvement of a control group. More precisely, the original aim was to recruit this group from one geographical area, following enrollment of the main study sample. The recruitment process however, proceeded much more slowly than anticipated, and in fact led to a reduction the expected sample size. It also became clear there were significant logistical problems for instance, time and resource demands associated with matching participants appropriately for example, age, gender and socio-economic status. Ideally children and families should be drawn from the same school and community. As study participants were scattered over a wide geographical area, and resided in rural and urban communities, it was unlikely that children and families would be matched satisfactorily with a group located in a predominantly urban area. Consequently, the plan to include this group had to be abandoned. Since determining the validity of the categorical and non-categorical approaches rests on condition group comparisons, the effect on research objectives proved to be minimal.

Study enrollment was specified by the following criteria - that children had had the condition for a period of at least six months, that they were receiving education in English, were considered to have a mental age of at least eight years, and were not judged as learning disabled. These criteria avoid the introduction of exacerbated difficulties experienced at the time of diagnosis and that children are sufficiently competent in terms of reading ability to complete the questionnaires or in terms of understanding if reading difficulties were present. Moreover, in light of the possibility that children may be dwelling in adoptive, foster and alternative family forms (e.g. grandparents) these children would be included if resident for a minimum period of one year. The multi-site design outlined here, while not placed to establish causal relationships, sought, through the sample size, to improve statistical power and the opportunity to generalise (Drotar, 1994). A power calculation indicated that with a sample size of 200 it would be possible to detect effects of five variables contributing to 20 percent of the variance in a dependent variable with more than 95 percent power and alpha set at .05. However, for a number of reasons the expected sample size of 200 was not achieved, further details are put forward in Chapter 5 which outlines the study process. In addition, it was also anticipated that qualitative data would support further understanding of the impact of condition demands on family life, however statistical analyses and interview coding required a considerable investment of time and prevented evaluation.

In summary, the study seeks to evaluate the role of condition-based variables such as, condition category, age of condition onset and duration in child adjustment, to examine the effects of condition-based variables on family functioning and child and parental coping, to test and extend the risk resistance framework and to explore, in a subsample of study participants, friendship quality and properties for example, intimacy, peer relations and school adjustment in relation to level of emotional difficulty and daily functioning. Research questions and related hypotheses are specified and presented in Chapter 6.

3.3 Methods

Obtaining insight into the psychosocial factors guiding adjustment require that methods elicit a child's and her / his family's subjective appraisal of condition effects. To a broad extent methods are dictated primarily by the need to probe perceptions and beliefs that reflect personal experience. However, at the same time the purpose of the study is to move forward from description to prediction and largely demands a quantitative approach. On the other hand, less structured approaches are a useful adjunct in that these methods assist the interpretation of quantitative data and thereby advance understanding at a descriptive level. Nonetheless, it is necessary to consider choice of method in conjunction with the constructs examined, comparability to other studies and capacity to integrate findings into the current knowledge base.

Many studies largely use, although not exclusively, established questionnaire measures to investigate links between factors associated with psychosocial adjustment in children with chronic illness. While it is essential that the study can be in judged in relation to other studies, the use of questionnaires alone places constraints on the data obtained; it would helpful to broaden the methodology. Combining questionnaires with interview supports documentation of demographic details, constructs previously defined as germane, and provides an opportunity for participants to introduce relevant biographical aspects. From a practical point of view these methods accomplish two objectives. First by varying the methodological format, it maintains involvement and, second, allows participants to expand on areas that they feel important to explore. This is achieved partly because the interview process provides a context for the development of a relationship, which encourages participants to relax and elaborate on their experiences. This may be assisted by setting information gathering in a conducive environment such as participants' homes.

Furthermore, relying on a single source tends to weaken conclusions that may be drawn from the findings. Involving several sources, such as child, both parents, teacher and health professional, expands assessment of the various contexts in which the child is involved, highlights differences and strengthens reliability. An additional issue needing consideration is the applicability of methods to child respondents. Research suggests that children of between eight and sixteen years may be judged competent informants (Light *et al.*, 1991). However, it has also been shown that responses may be biassed to expectations that younger children hold about what an adult wants to hear (Light, 1986). Therefore it was incumbent on the researcher to make clear that answers should reflect their personal experience but were neither right or wrong. Accordingly, the study sought to combine self-report questionnaires with interview and to involve multiple informants. Further, details related to achieving participant access, gaining ethical approval and the recruitment and data collection process are delineated in Chapter 5.

3.4 Methods of analysis

The statistical approach to answering research questions aims to distinguish variables, within the research perspectives outlined, which have the greatest predictive utility in relation to outcome indices. At the same time, analyses can reveal the empirical validity of competing frameworks. In identifying influential variables it is possible to build on existing theory and, where sufficient evidence exists, design interventions that may be expected to produce beneficial effects. The use of hierarchical regression procedures can achieve this goal. Similarly, detecting which variables are related to dependent variables, such as coping strategy use and coping efficacy, using simpler procedures such as two-way analysis of variance, permits theoretical development and pinpoints targets for intervention. It is also important to determine if mothers and fathers differ in their approach to coping and whether parents configure their coping activity, and in what way it is linked to adjustment outcome. This would provide a more complete picture than previous studies which have tended to focus on mothers only. Path analytic techniques are also helpful in testing the validity of conceptual structure contained within a model and can illustrate the nature, and strength of relationships (i.e associations) between variables. Selection of path analysis using a simultaneous regression equations also represents an advance on statistical approaches utilised in the majority of studies in that it shows how predictor variables are related to each other. Exploratory analyses focussing on the role of emotional symptoms and functioning in peer and friendship relations arise from findings in earlier analyses and a need to clarify the impact of functioning within the domain of peer relationships.

Within these analyses it is necessary to establish whether resistance factors moderate the relationship between risk factors and adjustment outcome. There are several ways that this may be done, but the various methods are chiefly related to the mode of analysis, for example analysis of variance, hierarchical regression or simultaneous equation modelling. Here, two way analysis of variance was used. The evaluation of moderating or interactive effects involves three variables, the independent variable (risk factor), the moderator (resistance factor) and the dependent variable (adjustment index). Within two-way analysis of variance continuous independent and moderator variables are converted to high and low levels that include the whole range of responses. Interactive effects are demonstrated if the moderator variable interacts with the independent variable and alters the relationship between the independent and dependent variable.

Analyses related to main hypotheses are presented in the second part of Chapter 6, section one, and subsidiary hypotheses within sections two and three. Subsidiary exploratory hypotheses were included for completeness. Exploratory analyses are also presented in second part of Chapter 6, sections four and five, in addition to Chapter 7. Analyses for which the sample size calculation is applicable are contained within the second part of Chapter 6, section one and refer to the role of condition-related variables in predicting child report of adjustment.

In using analysis of variance, hierarchical regression and path analysis techniques it will be possible to address questions that centre on the benefit of the categorical and non-categorical approaches, and the risk resistance framework to understanding of adjustment outcomes. Further, techniques will support identification of condition-related parameters associated with parental and child coping and exploratory analyses evaluating the impact of emotional and functional status factors on peer and friendship relations.

3.5 Chronic conditions

It would be worthwhile at this point to establish the nature of the conditions that children involved in the present study experience. While cystic fibrosis and diabetes mellitus are life long conditions, childhood asthma and epilepsy may resolve spontaneously or may develop a chronic course. Descriptions of the conditions follow to assist the reader in understanding the prevalence, physiology, symptomatology and potential psychosocial impact of each condition.

3.5.1 Asthma

Asthma is a respiratory disease typified by intermittent attacks of acute breathlessness and is probably the most common chronic illness of childhood in Britain. About one in five children experience one or more wheezing attacks before the age of 10 years, although 70 percent of those diagnosed with asthma will grow out of it by the age of 12 years (Mann & Rutter, 1986). A recent survey of prevalence in Great Britain indicated that 12.8 - 13.5 percent of children between the ages of five to seventeen years are diagnosed with asthma (Stracchan *et al.*, 1994) suggesting a substantial number of children are affected. Age of onset in childhood is variable, although early onset is probable if respiratory syncytial viral infection occurs in the first six months of life (Creer *et al.*, 1992). Clinical symptoms are related to the onset of broncho-constriction (narrowing of the airways) limiting expiration. This is accompanied by dilation of the blood vessels supplying the mucous membranes lining the bronchial tree, producing swelling and increasing mucous secretion. Constriction of the airways is mediated by the parasympathetic branch of the autonomic nervous system innervating the smooth muscle of the bronchi. Attacks are treatable in almost all cases, but can prove fatal if intervention fails in severe attacks. Epidemiological analysis has revealed asthma to be linked to contact with allergens, infections and / or emotionally disturbing situations. The aetiology of this disorder suggests that hyper-reactivity of the bronchial tract, immunological reactions to allergens and psychological factors are contributory elements.

While the cause of this condition is unclear, a family history of asthma, and often eczema, appears to constitute a major risk factor. Variations in disease severity suggest heterogeneity in terms of underlying physiology. Leffert (1985) has put forward four categories to describe these variations. First, children who present with intermittent acute attacks are usually found to have adequate baseline pulmonary function (little or no obstruction) and a high level of bronchial reactivity. Second, children who experience chronic tiredness, difficulties in accomplishing school and athletic activity, and show poor growth reflect a marked decrease in baseline pulmonary functioning (chronic obstruction, variable) and minimal bronchial reactivity. Third, the children most severely affected show poor baseline pulmonary functioning and a high level of bronchial reactivity. These children experience significant respiratory problems contending with intermittent attacks in addition to a measure of persistent chronic obstruction. The final group are those the least affected who show minimal or mild bronchial reactivity and optimal pulmonary functioning.

Acute exacerbations of asthma are treated with inhaled and, during severe attacks requiring medical intervention, intravenous bronchodilators, steroids and antibiotics, depending on clinical assessment of cause. Preventative therapy, which includes inhalers containing both bronchodilators and steroids involves daily and as required medication when exercise is taken. This type of treatment is likely to apply to more severely affected children. In addition, given the role of particular allergens, for instance house dust mite, in precipitating attacks, families are advised to purchase items such as duvets and mattress covers to minimise attacks. Similarly, they may also be cautioned to remove pets from the home; this can be very distressing, given the strong attachment families often develop for pets. The course of the condition is somewhat unpredictable, punctuated with intermittent acute attacks. In terms of psychosocial consequences asthma has been found to be linked to a high level of school absence (Eiser, 1990). Findings also indicate absence has been observed by peers to be greater for children with asthma than healthy counterparts (Graetz & Shute, 1995). The implications suggest educational attainment and social development may be compromised.

3.5.2 Diabetes mellitus

The reported annual incidence of diabetes under 15 years in the British Isles varies between 6.8 per 100,000 in Northern Ireland, to 19.8 per 100,000 in Scotland (Metcalfe & Baum, 1991). Rates suggest diabetes is a relatively common chronic condition of childhood with diagnosis gradually increasing with age, peaking in preadolescence / early adolescence. However, a recent study in the Oxford region points to a significant rise in the annual rate for children between birth and nine years, predominantly in the birth to four years age range (Gardner *et al.*, 1997). Childhood diabetes is usually the type defined as insulin dependent; the alternative, non-dependent insulin diabetes, generally occurs in late adulthood. Childhood diabetes is a systemic disorder which stems from destruction of the insulin producing cells (i.e. Islets of Langerhans) in the pancreas. While the cause remains obscure, it is thought that a genetic predisposition and viral infection are contributory factors (Drash & Berlin, 1985). Consistent with this view, a study of monozygotic twins (identical compliment of genes) found an insulin dependent diabetes concordance rate of 36 percent, if diabetes were determined predominantly by genetic factors the concordance rate would be nearer 100 percent (Olmos *et al.*, 1988 cited in Dorman *et al.*, 1995). Insulin, a polypeptide hormone, is vital for glucose metabolism and the provision of energy for maintenance of organic and behavioural activity. Insulin is released when food is ingested leading to the utilisation of glucose from peripheral tissues such as muscle. It regulates the release of glucose from the liver, a central store, and is involved in protein synthesis and growth. Insulin also governs fat metabolism by instigating the shift of surplus dietary carbohydrate into fat reserves. This is achieved by stimulating the uptake of circulating fat by adipose (fat) tissue and preventing the drain of fatty acids and glycerol from adipose tissue. Bearing in mind the widespread involvement of insulin in energy production and consumption, absence obviously produces catastrophic effects, reversing the processes described above. If untreated, this condition will lead to death.

Diabetes is irreversible and results in secondary complications, which occur between 10 to

20 years following diagnosis. Complications arise from microvascular damage sustained as a consequence of the necessary, but nevertheless long-term, artificial manipulation of glycaemic control, also referred to as diabetic or metabolic control. They include retinopathy (i.e. visual deterioration), neuropathy (i.e. loss of tactile sensation), nephropathy (i.e. deterioration in kidney functioning) and cardiovascular disease (i.e. atherosclerosis, narrowing of the arteries). Treatment principally seeks to maintain optimal glycaemic control by minimising episodes of hypoglycaemia (low blood glucose) and hyperglycaemia (high blood glucose) aiming to prevent early onset of complications and sustain growth, development and psychological adjustment. However, diabetes may be especially challenging, having major consequences for child and family in terms of life style changes. Children need daily injections of insulin, substantial changes in the timing and to some extent content of dietary intake and to be *continually* vigilant of demands to balance insulin, diet and exercise. For example, during a typical day a child with diabetes has two injections of insulin, one in the morning, one in the evening, s/he will need to eat a minimum of three meals, take snacks between these meals and conduct blood glucose tests to monitor glycaemic control. If s/he takes extra exercise s/he may need to eat prior to taking that exercise to cover energy expenditure. Dietary changes reflect a shift to what would be considered a healthy balanced diet, and include low intake of foods and beverages containing large amounts of sucrose, an increase in high fibre carbohydrate and decreased fat intake (Brenchley & Govindji, 1995). The course of the condition is generally predictable although, at times such as developmental transitions for example adolescence and pregnancy, diabetes is usually less easy to manage. In terms of psychosocial adjustment of children with diabetes evidence suggests that the family plays an influential role. Families inclined towards autonomy, organisation and involvement in social and recreational activities, in comparison to families not emphasising these characteristics were found to increase self-esteem in adolescents with diabetes (Hauser *et al.*, 1985). However, evidence also points to a deleterious impact on adjustment as a consequence of the perceived requirement to maintain good glycaemic control (Close *et al.*, 1986; Fonagy *et al.*, 1987; Kyngas & Barlow, 1995).

3.5.3 Cystic fibrosis

Cystic fibrosis is one of the commonest inherited disorders affecting Caucasians. The reported incidence in Britain between 1968 - 1977 was 1 in 2466 and 1 in 2486 between

1978 - 1985 and in the United States 1 in 2000 (Lewis, 1995: Matthews & Drotar, 1984). It is inherited via an autosomal recessive route, and therefore requires that both parents transmit their respective gene for the condition to occur. Essentially, cystic fibrosis results from an abnormality in the mucous secreting glands of the respiratory, gastrointestinal systems and exocrine glands. The consistency of the mucous is thick and tenacious which produces gastrointestinal malabsorption, increased susceptibility to intestinal obstructions, liver disease, rectal prolapse, diabetes mellitus and respiratory problems. Children may present with symptoms at birth, for example acute intestinal obstruction or several years later. However, the majority of children are diagnosed within the first year of life, showing signs such as failure to gain weight as expected despite adequate intake, chronic cough, or appearing generally unwell. Malabsorption problems, for example, production of frequent fatty odorous stools derive from pancreatic enzyme deficiency and can lead to poor growth. Respiratory complications, such as bronchiectasis (permanent lung damage) result from heightened sensitivity to, and recurrent infection. The viscous nature of lung mucous tends to attract bacterial, viral and fungal organisms and at the same time prevents recovery because the mucous is difficult to cough up. Consequently, acquired infections are more likely to become chronic, lead to obstructive airways disease and produce cumulative, irreversible lung damage.

The life expectancy associated with cystic fibrosis, in comparison to healthy individuals, is limited. Over the last forty years, advances in medical treatment and technology have increased survival. Whereas death in childhood or adolescence was a common outcome between 1940 and 1970, many now reach adulthood. It is probable that current research efforts, for example the Human Genome Project and gene therapy, will produce further benefits in terms of life expectancy. However, variations in outcome also suggest that cystic fibrosis is not homogenous. Irrespective of advances in treatment some children are less severely affected than others. Notwithstanding the inevitability of a shortened life span, cystic fibrosis varies in terms of the organs involved for instance, pancreatic enzyme deficiency does not occur in 15 percent of those affected, and the degree to which physiological abnormalities produce their effects. Nonetheless, the social, emotional and psychological demands placed on children and families are substantial. Treatment involves daily medication, nutritional supplements, and physiotherapy. Tablets are taken with meals to assist digestion, inhalations and physiotherapy are given to loosen and clear the lungs of sticky mucous, and more importantly, prevent infection. Some children demonstrate significant gastrointestinal problems and may require interventions such as gastrostomy - an external opening into the stomach for delivery of nutritional supplements - to maintain growth and development and promote pubertal changes. The course of this condition is generally predictable, characterised by progressive deterioration in lung function evidenced by increasingly frequent hospitalisations to treat lung infection.

Findings from studies evaluating adjustment in children with cystic fibrosis are mixed. Drotar *et al.* (1981) found that although children with either cystic fibrosis or asthma had higher rates of parent reported difficulty compared to healthy siblings and peers. However, rates were comparable to populations norms. In addition, no differences were found between children with cystic fibrosis and healthy counterparts in teacher report of school adjustment. Lewis and Khaw (1982) found no differences in child reported self-concepts in youngsters with either cystic fibrosis or asthma and healthy children. Simmons *et al.* (1985) have demonstrated that adolescents (12-15 years) with increased behavioural difficulties, compared to norms, have good self-concepts. However, whereas self concept was significantly and negatively correlated with behaviour difficulties in girls, this was not the case for boys. The finding is significant in that adolescents reported on self-concept and parents on behavioural difficulties, eliminating the methodological problem of source variance. In addition, they found health locus of control, which refers to personal beliefs regarding whether control over events relies on self, others or chance, was positively correlated with self concept in boys but not girls. Thus more positive self concept scores were associated with an internal locus of control. The authors interpret results to suggest more use of denial amongst girls than boys and that girls, in contrast to boys, also conformed to behavioural expectations and consequently showed fewer difficulties. Furthermore, Cappelli *et al.* (1988) found no differences between the mean score and scale norms on maternal reports of anxiety, family functioning, condition impact and child behaviour problems and child report of anxiety and self-concept. They did find that maternal anxiety and over-protection were linked with behavioural difficulties. However, given that all these variables were based on maternal reports source variance may bias findings.

3.5.4 The epilepsies

There are several types of epilepsy which occur in childhood although not all are chronic, those that resolve have a protracted course of several years. The epilepsies are currently categorised by syndrome, seizure type and electroencephalogram (EEG-recording of brain wave activity) findings, although elements of syndrome and seizure type classification share similarities (cf. O'Donohoe, 1994). Syndrome groups are defined in terms of aetiology. Primary epileptic syndromes refer to ideopathic epilepsies that have no known cause; the seizures represent the condition. Secondary syndrome epilepsies are symptomatic and arise from neurological disorders. Epilepsy may result from acute and chronic health related events. For example, acute events such as birth injury, road traffic accidents-particularly those involving head injury, ingestion of toxic substances and bacterial meningitis may all lead to epilepsy. Chronic conditions, such as cerebral palsy, brain tumour, tuberous sclerosis-an inherited brain disorder, metabolic disorders and chromosomal abnormalities are also implicated. Almost all epilepsies linked to acute or chronic disorders are related to brain damage or malformation, and in most cases cognitive impairment. However, idiopathic epilepsy is not *necessarily* associated with cognitive impairment. Epidemiological evidence suggests the overall prevalence rate for epilepsy is 7.2 per 1000 and 5.4 per 1000 for epilepsy that does not involve brain abnormality (Rutter *et al.*, 1970, cited in Kim, 1994).

The epilepsies are characterised by intermittent seizures which, depending on diagnostic classification, vary considerably in origin and presentation and many involve loss of or diminished consciousness. Electroencephalograms usually reveal abnormal electrical discharges (excessive synchronous activity in a cluster of cortical neurones) which disrupt brain activity and predispose the individual to seizures. Epilepsy reflects the recurrence of these cortical discharges.

Seizures are classified as generalised or partial. Generalised seizures involve both hemispheres and loss of consciousness, partial seizures are subdivided into simple partial seizures which do not involve loss of consciousness and complex partial seizures. Partial seizures imply localised disturbance in brain activity, either type may precede a generalised seizure (O'Donohoe, 1994). Five categories that reflect generalised and partial seizures are described, childhood absence epilepsy (formerly petit-mal), generalised tonic-clonic seizures (grand-mal), focal motor, temporal lobe and myoclonic and drop attacks.

The incidence of childhood absence epilepsy is 12 per 100, 000 of the population (Mann &

Rutter, 1986) and therefore comparatively uncommon, occurring most often during mid to late childhood. Seizures present as brief absences lasting for example, 10 seconds. Typically, a child fails to respond to repeated direct questions, despite appearing to attend, or suddenly stops an ongoing activity then resumes as if uninterrupted. This is frequently associated with a vacant stare, and on occasion flickering eyelids. Attacks vary enormously in frequency. The prognosis for this condition is generally favourable, resolving naturally in adolescence. However, sometimes absence epilepsy may be replaced by grand-mal epilepsy which forecasts a less encouraging outcome, being suggestive of ongoing pathology.

Grand-mal epilepsy is the most common of all the epilepsies. Seizures may be preceded by an aura (awareness of seizure onset) and are characterised by the abrupt loss of consciousness, falling to the ground and a stiffening of the whole body usually termed the tonic phase. This is followed by generalised rhythmic jerking involving the whole body, defined as the clonic phase. The fit can last from between 10 to 15 minutes and may be accompanied by incontinence and tongue-biting. A prolonged seizure or a series of seizures for example, above 30 minutes in young children, one hour in older children, (O'Donohoe, 1979) without recovery of consciousness constitute a condition called status epilepticus. Bearing in mind that status epilepticus may lead to irreversible brain damage, it is considered a medical emergency requiring immediate hospitalisation. Prognosis in grand-mal epilepsy is somewhat variable. Seizure control is more readily achieved in some children than others, although why this is so remains unclear. Of the children who present with grand-mal epilepsy between the ages of one to ten years approximately 85 percent will ultimately remit (Mann & Rutter, 1986). However, if accompanied by absence seizures or if onset occurs in adolescence outcomes are less optimal.

The seizures typical of focal motor epilepsy usually start with limb twitching and jerking on one side of the body that may extend to the rest of the body and on occasion followed by a grand mal fit. The prognosis for this category, in older children, is extremely good, with seizures usually desisting between one to two years following onset (Milner & Hull, 1984).

Temporal lobe epileptic seizures include diminished consciousness, without falling on the whole, unusual sensations or involve semi-coherent actions. The sensations may be visual, auditory, olfactory or emotional. In some cases sensations may be magnified, for example objects seem large, contorted, sounds overly loud or inaudible, strange tastes, accentuation of feelings of sadness or fear, or distorted for instance, objects are perceived as contorted, misshapen, loss of contact with reality. Verbal behaviour may occur during the attack, although it may or may not be comprehensible. Often, children display chewing, sucking, or swallowing actions in the course of the attack, which appear to be related to delusions of taste. Behaviour is usually linked to the sensations experienced, although coherent in terms of the child's interior world, it is does not appear so to observers. Attacks last several minutes and the child has little recall of the event on recovery; this is common to most types of epilepsy. Grand-mal seizures, more often than not also occur. EEG findings usually reveal abnormalities located in the temporal lobe of the brain. Children with temporal lobe epilepsy demonstrate more learning and behavioural difficulties in comparison to other epilepsies (Milner & Hull, 1984). The seizures typical of this epilepsy may also be difficult to control.

Myoclonic and drop attacks are brief seizures characterised, in myoclonic attacks, by unexpected symmetrical shock-like jerks associated, in some cases, with marked head flexion or extension; the attack may be so strong that it brings the child to the ground. On the other hand drop attacks, reflect a sudden loss of muscle tone and a fall to the floor. According to Milner and Hull (1984) these attacks are typical of symptomatic epilepsy which is linked to the chronic disorders highlighted above. They are, however, somewhat intractable.

All the epilepsies described above are treated with daily anti-convulsant medication. This may involve several drugs and in severe cases, implementation of dietary restrictions and / or surgery. Treatment aims to reduce and control the occurrence of seizures enabling normal daily activity and maintenance of optimal developmental progress. Long-term medication, however, may produce drug intolerance, toxicity and side effects such as behavioural difficulties (Kim, 1994), which interfere with developmental progress. Reduction in the ability to attend and concentrate affect learning and may lead to widespread effects, such as delays in educational progress and social and emotional growth. This may be reinforced by a lowering of expectations among teachers and parents. Major issues for children and families confronted with epilepsy centre on prevention of seizures, maintenance of physical safety and concerns about future prospects for instance, employment or driving, and stigmatisation. Myths about epilepsy continue to pervade social understanding, particularly for the epileptics most apparent to others, creating prejudice and uncertainty. A belief that epilepsy represents the visitation of supernatural or demon forces endures to some extent, shaping social attitudes, and can have serious consequences for a child's psycho social well-being. Seizures by their nature are abrupt, unexpected and distressing, not only for an affected child but also observers. Given limited media exposure and scant public awareness, seizure behaviour appears rather frightening to observers. Social misconception combined with the apparent loss of behavioural control may set the child apart from her or his peers and lead to loss of self-esteem, decreased confidence, low educational attainment, impaired social development and growth of personal autonomy. Thus children with epilepsy face significant challenges that have the potential to produce a marked effect on psycho social adjustment. The course of the condition may be unpredictable depending on diagnosis and seizure control.

Findings from studies involving children with epilepsy suggest that they generally adapt less well than other children with chronic illness. Hoare (1984) found that children with newly diagnosed epilepsy had a higher rate of psychiatric disturbance in comparison to children with newly diagnosed diabetes. Austin *et al.* (1994) who compared children between the age of eight to twelve years with either epilepsy or asthma found that children with epilepsy experienced difficulties in more quality of life areas that children with asthma. Of the four areas assessed, children with asthma had difficulty in the physical domain whereas children with epilepsy had difficulty in psychological, social and school areas. Carlton-Ford *et al.* (1995), in their analysis of the 1988 US National Health Interview Survey, found that children between the ages of six to seventeen years with epilepsy were reported by parents to have, in comparison to children without a history of epilepsy, significantly higher odds of home behaviour problems, depressed mood and impulsiveness. They interpret findings to suggest that parental reaction to, and definition of, epilepsy may create self-fulfilling prophecies and moderate social and psychological adjustment.

Although each condition is unique in terms of physiological consequences, there are commonalities that unite them. For example, all conditions have a protracted course and many children living with either asthma, diabetes, cystic fibrosis, or epilepsy regularly attend hospital clinics to receive management and treatment advice. Moreover, all children irrespective of condition need to adhere to treatment regimens to maintain physical well-being, and may at any time require hospitalisation or experience a deterioration in their level of functioning. These factors may interfere with schooling and daily functioning and have psycho social implications that cut across diagnostic classification.

It is hoped the preceding chapters defining the research context, study design and physiology of medical conditions present a strong case for undertaking the current study. In Chapter 4, the study measures and associated psychometric properties are examined.

Chapter 4: Study measures

Chapter 4 presents detailed descriptions of study measures, incorporating evidence for reliability and validity. The aim of this chapter is to provide the reader with an understanding of the source, development and psychometric properties of study measures, and factors guiding selection. As the risk resistance framework constitutes a central part of the investigation, questionnaire measures will be configured within the model and presented at the end of the chapter to illustrate how the instruments are related to the framework.

Study measures were chosen on the basis of relevant psychosocial adjustment models, a literature search, theoretical formulations put forward in Chapter 2 and appraisal of practical constraints such as, time and participant acceptability. In addition, since the study aimed to highlight and investigate factors related to the child's perspective consideration was given to inclusion of measures that drew on child perceptions of condition effects, difficulties and management of problems. Psychometric properties and applicability to research questions were also key considerations. Central questions, as indicated in Chapter 3, were linked to the validity of the categorical and non-categorical approach in explaining adjustment and identification of effects on parental and child coping. Further questions centred on the utility of the risk resistance framework, the role of peer and friendship relations within this model and exploration of friendship quality and properties, peer relations and school adjustment in relation to level of emotional difficulty and daily functioning.

Variables assessed from the parent(s) perspective in questionnaire format included family functioning, parental coping, child behavioural strengths and difficulties (adjustment) and quality of life (functional status). Parent report on adjustment was introduced during the early part of the study as it became evident that some children hold a rather different view from their parents. However, it was not anticipated that parental report would be a focal component of subsequent analyses. The parent(s) also took part in an interview that established child medical details for example, condition(s), age at diagnosis and treatment requirements, family demographics for instance, number of children, parental occupation and gross occupational annual income, and briefly explored perceptions of condition impact on daily life since diagnosis.

Variables assessed from the child's standpoint in questionnaire form included family functioning for those over 10 years, ways of coping with an everyday and chronic illness problem, behavioural strengths and difficulties (adjustment), quality of life (functional status) and perception of condition effects. Children were also interviewed about their two best friendships. In addition, assessments were requested from teachers on school adjustment and social competence, and health professionals provided estimates of condition severity in terms of family care demands. Measures are described below and incorporated in the appendix.

4.1 Parent Assessment of Medical and Demographic Information

In light of study objectives seeking to establish the role of condition-related parameters in adjustment, and evidence suggesting demographic factors such at parental education and financial resources (Wallander *et al.*, 1989b) are influential, medical and demographic information was obtained from parents by devising a structured interview schedule. Of the generic condition parameters evaluated in the present study, age of condition onset, duration and condition severity are the factors that appear most frequently in studies. Condition course is often determined on the basis of health service utilisation. The underlying assumption suggests increased use of services reflect problems in management, and may be associated with psychological difficulties. While plausible, this is not always the case. For example, evidence suggests that children with diabetes who have optimal glycaemic control, rather than poor control, and consequently are less likely to use health services, are reported by parents to experience negative mood (Rovet & Ehrlich, 1988; Weissberg-Benchell & Glasgow, 1997). However, perceptions of visibility and condition course are rarely included in studies. While findings are somewhat inconsistent, studies have shown visibility to be an important variable. For example, as indicated in Chapter 1 Stein and Jessop (1985) found that the more visible a condition the better the psychological outcome, although this may change during adolescence when body image assumes greater relevance to psychosocial well-being.

Generic features included in this investigation were age of condition onset, that is the age at which diagnosis is confirmed by a medical practitioner; duration, defined as how long the condition has been present and taken to be from the point of diagnosis to study admission; course, reflecting perceptions of whether the condition is constant, progressive, recurring or episodic and may include any combination; condition severity, for a subsample of parent participants who were involved in validating this measure, and whether the child's condition is visible to others. Other aspects included were health service utilisation in the past 12 months and estimates of condition-related days missed from school in the past 12 months, whether the condition demonstrates a recognisable pattern in symptom manifestation, perceived certainty of condition course and future impact on daily life. Condition-specific factors incorporated were type and level of treatment requirements. Past and present condition-related effects on daily life and identification of an event that had particular significance were briefly explored. Initial interviews with parents suggested that sometimes past events held an emotional impact for either one or both parents and, to some extent, continued to influence current management. In terms of demographic factors, those considered apposite to family management of ongoing demands were family structure and size, child birth position, child and parental educational attainment, parental occupation, annual occupational income, nationality, home ownership status and benefits and services received from the state. However, subsequent statistical analyses focus on a subset of above variables as features tend to overlap, for instance family size and home ownership status are often expressed in occupational status and / or educational attainment.

4.2 Coping Health Inventory for Parents

The coping health inventory for parents was developed in North America specifically to evaluate parental coping behaviour in response to dealing with family life while supporting the care of a poorly and / or chronically ill child. It deals with the notion of chronic stress and stems from theoretical formulations associated with family stress theory. This measure has principally been used with indigenous populations. A modified anglicized version, comprising 33 items, is available; however, given few substantial differences between items it was decided to retain the original measure. The measure is defined by a conceptual structure reflecting three coping patterns obtained through factor analysis of 80 items presented to a sample of 185 parents of children with cystic fibrosis. Thirty items were judged not applicable by parents and a further 5 items were eliminated on the basis of minimal variance. The remaining 45 items accounted for 71.1 percent of the variance. Coping pattern 1 (19 items) is termed "Family integration, co-operation and an optimistic definition of the situation". Coping pattern 2 (18 items) is defined as "Maintaining social support, self-esteem and psychological stability". Coping pattern 3 is labelled "Understanding the health care situation through communication with other parents and consultation with health care team". The scales were found to inter-correlate moderately. Respondents are asked to report on whether they use listed coping behaviours and helpfulness if used, for example not helpful, minimally helpful and so on.

Reliability

Internal consistency - Cronbach's α reported for items within each scale (i.e. coping pattern) were respectively 0.79, 0.79 and 0.71 (McCubbin *et al.*, 1983a). Further studies conducted by this group document the same range for internal reliability (McCubbin & Patterson, 1983b; McCubbin *et al.*, 1983c; McCubbin, 1984). Kager and Holden (1992) record an alpha reliability of 0.87 for total score, including all subscales and Austin and McDermott (1988) report alpha values ranging between 0.84 and 0.89.

Test / Re-test - No data are available.

Validity

The authors provide a set of normative data (means and standard deviations) for mothers and fathers derived from a sample of 308 parents of children with chronic conditions such as cystic fibrosis and cerebral palsy. The scales have been shown to distinguish between low and high conflict families caring for a child with cerebral palsy. Using discriminant analysis the authors report increased levels of helpfulness in all coping patterns for both mothers and fathers in high, compared to low conflict families. The scales have also been found to correlate with the Family Environment Scale (Moos, 1976 cited in McCubbin *et al.*, 1996). For example, in a study of parents of children with cystic fibrosis (McCubbin *et al.*, 1983a) coping patterns 1 and 3 correlated positively with family cohesiveness ($r = .21$, $p < .01$; $r = .19$, $p < .05$) for mothers. Coping pattern 2 was found to be related to family expressiveness ($r = .19$, $p < .05$). For fathers coping pattern 1 was positively associated with family cohesiveness ($r = .36$, $p < .01$) and negatively related to family conflict ($r = -.21$, $p < .05$). Moreover, coping in fathers was associated with family system maintenance. Coping patterns 1 and 3 were related to family organisation ($r = .32$, $p < .01$; $r = .22$, $p < .05$, respectively). Coping pattern 3 was also found to be related to family control ($r = .19$, $p < .05$)

4.3 Family Assessment Device

The Family Assessment Device (FAD) is based on the McMaster model of family functioning and was developed in North America. In contrast to other measures the FAD is based on a theoretical model, demonstrates excellent psychometric properties and measurement reflects conceptualisation. Although measures such as, the Family Adaptability and Cohesion Scales (FACES) and Family Environment Scale (FES) are widely used, concerns have been raised about FACES in terms of subscales failing to reflect the curvilinear model proposed by Olson (1979) and the FES lacks a theoretical foundation (Tutty, 1995). The FAD comprises 60 items organised into seven subscales which focus on family problem solving, roles, communication, affective responsiveness, affective involvement, behaviour control and general functioning (a summary scale evaluating total family well-being). The scale has been expanded from the original 53 item version to improve the internal reliability of three subscales. Items were based on "goal attainment scale point descriptions" arising from a previous study and additional items were devised specifically to incorporate the six dimensions of the McMaster Model. Items were chosen from six separate pools based on internal consistency and independence. Research using the Family Assessment Device has generally taken place in America although it has been used in Britain and shown to retain discriminatory power.

The measure has been validated with a non-clinical sample, but is primarily designed for clinical use. The first six subscales parallel the features of family functioning identified in the model. *Problem solving* relates to family ability to surmount problems posing threats to functional stability and maintain optimal family functioning. The model proposes that a seven step sequence guides efficient problem solving. *Communication* refers to whether information is conveyed adequately via clear indications of content and to whom the information is directed. *Roles* refers to whether patterns of interaction accomplish particular family functions such as, nurturance and personal development and augment and sustain family systems. Evaluation of task allocation is also included here; in particular, whether tasks are appropriately and unambiguously delegated, and if they are performed responsibly. *Affective responsiveness* centres on the level to which individual family members may experience apposite emotion in relation to a series of stimuli. *Affective involvement* refers to the degree to which family members attend and value each other's affairs and worries. Families who function well usually show a moderate level of involvement. *Behaviour* *control* reflects assessment of the way in which the family demonstrates and regulates behaviour. Items in this subscale evaluate behaviour in various circumstances for instance, "dangerous, psychological and social" and attend to differing patterns of control for example, "flexible, rigid, laissez-faire and chaotic". The final subscale elicits assessments of overall functioning on a health/pathology dimension. Respondents are asked to indicate level of agreement (disagree, strongly disagree, agree or strongly agree) with items describing families in terms of whether statements portray their family over the previous two months.

Further elaboration of model dimensions described above can be found in "The McMaster Model of Family Functioning" (Epstein *et al.*, 1978). Additional work has led to the development of an observational measure, The Clinical Rating Scale (CRS). Contrary to other findings regarding disagreement between insider and outsider family perspectives (Beavers & Hampson, 1990), the CRS has been shown to correlate well with the FAD in a British non-clinical sample of intact families with a four year old (Stevenson-Hinde & Akister, 1995).

Reliability

Internal consistency - each scale is reported to have respectable inter-item correlation, ranging from 0.72 (roles) to 0.92 (general functioning) (Epstein *et al.*, 1983).

Test / Re-test - For a one week interval correlations range from .66 to .76 (Miller *et al.*, 1985).

Validity

The scale has been shown to have concurrent and discriminant validity. Significant correlations were found between scale constructs and the integration and coping dimensions of the Family Unit Inventory (Van der Veen & Olson, 1981 cited in Miller *et al.*, 1985). In discriminant analysis conducted with clinical and non-clinical groups the measure correctly predicted 67 percent of a non-clinical group and 64 percent of the clinical group (Epstein *et al.*, 1983). Furthermore, a greater proportion of families with a member admitted to a psychiatric hospital were found to score in the unhealthy range on all subscales compared to families in which all members were well (Miller *et al.*, 1985). In addition, Kabacoff *et al.* (1990) conducted a factor analysis which showed that over 90 percent of items loaded onto the factors hypothesised in the McMaster model of family functioning. Low negative correlations between subscales and the Marlow-Crowe Social Desirability Scale indicate the measure to be relatively free of demand characteristics (Miller *et al.*, 1985). However, a recent analysis of the original data using latent modelling techniques suggests subscales overlap and are expressed more parsimoniously in two factors, connection and commitment, although the general functioning subscale was found to summarise family functioning satisfactorily (Ridenour *et al.*, 1999).

4.4 Perceived Experience of Condition Scale

Eiser *et al.* (1995) developed this measure to evaluate the perceived illness experience of children and young people with cancer. Child and parent versions are available. The intention was to examine subjective judgements in terms of the extent to which a condition creates difficulties (stresses) for the child. This departs from the traditional focus on objective factors, such as functional limitations produced by treatment, and incorporates a multi-dimensional approach to assessment. Following her suggestion that it may be suitable for assessment of young people with other long-term conditions the measure was selected to investigate utility in relation to the conditions under study and take into account the child's perspective. The measure comprises 36 items derived from semi-structured interviews with children and adolescents who were currently undergoing treatment for cancer or recently completed their treatment protocol. Concerns centred on physical appearance, interference with activity, peer rejection, integration into school, manipulation, parental behaviour, disclosure, preoccupation with illness and food and broadly matched areas identified in a literature review. The measure was developed in the UK and includes 9 subscales reflecting these concerns; there are four items in each subscale. The questionnaire was estimated to be suitable in terms of readability for adolescents with seven years schooling (Flesch score = 60-70). However, reliability and validity were established with a group of participants who ranged in age from eight to twenty-four years (mean age, 14.6 years).

Further evidence for reliability and validity were reported in 1999. This study involved young people (eight to twenty-five years, mean age, 17 years) who had undergone limb salvage procedures for bone tumours. The measure was modified for the present study as one item proved inappropriate and because of philosophical objections raised by clinical personnel. In effect this meant that one item was eliminated from the physical appearance subscale and the word illness, included in practically every item statement, was replaced by condition. Respondents are asked to indicate on a five point Likert scale to what extent they agree or disagree with listed statements.

Reliability

Internal consistency - Alpha coefficients for each subscale range from 0.59 (pre-occupation with illness) to 0.73 (parental behaviour); total score for the entire questionnaire is reported as 0.84 (Eiser *et al.*, 1995). However, coefficients ranged from 0.21 (interference with activity) to 0.79 (peer rejection) for subscales and 0.91 (total score) for young people treated for bone tumours. Low reliability for the interference with activity subscale is attributed to sample homogeneity (Eiser *et al.*, 1999).

Test / Re-Test - No data are reported for the self-report version. For parental report over a two month period the correlations are documented as .92 for total score, .54 (physical appearance), .67 (interference with activity), .56 (disclosure), .78 (school), .51 (peer rejection), .53 (family-replaces parental behaviour), .66 (manipulation), and .85 (pre-occupation with illness) (Eiser *et al.*, 1995).

Validity

The scale was found to correlate with established measures of physical and psychological functioning. The total score and physical appearance, interference with activity subscales correlated significantly with the physical symptom items of the Rotterdam symptom checklist (Watson *et al.*, 1992), .42 ($p< .05$), .38 ($p< .05$) and .61 ($p< .01$) respectively. Total score and physical appearance, interference with activity, manipulation subscales were also significantly correlated with psychological symptom items of the same measure, .48 ($p< .01$), .43 ($p< .05$), .57 ($p< .01$) and .40 ($p< .05$) respectively. The Functional Disability Inventory (Walker & Greene, 1991) correlated significantly with total score (.48, $p< .05$) and the interference with activity subscale (.40, $p< .05$). A restrictions scale, which comprised seven items assessing the impact of the condition on involvement in particular activities such as sport and going out alone, correlated with interference with activity (.40, p< .05) and parental behaviour (.37, p<. 05) (Eiser *et al.*, 1995).

Additional evidence for concurrent and construct validity are put forward in a study of young people treated for bone cancer (Eiser *et al.*, 1999). Significant positive correlations between mother and child report on all subscales confirm concurrent validity. Construct validity is suggested by significant correlations with the SF-36, a general health measure that focuses on for example, physical, social and emotional functioning, pain and mental health (Jenkinson *et al.*, 1993 cited in Eiser *et al.*, 1999). The areas of general health, vitality and mental health showed the strongest degree of association in that higher levels of functioning were related to decreases in perceived illness impact. A supplementary measure assessing functioning following reconstructive procedures devised by Enneking *et al.* (1993, cited Eiser *et al.*, 1999) was also found also correlate significantly with two subscales (i.e. preoccupation with illness, food) and the total score. Higher functioning was linked to less preoccupation with illness, infrequent food difficulties and less perceived illness impact.

4.5 Strengths and Difficulties Questionnaire

The strengths and difficulties questionnaire (SDQ) is a screening measure designed to assess emotional and behavioural adjustment (Goodman, 1997). The questionnaire, recently developed in the UK, comprises the following five subscales conduct problems, emotional symptoms, hyperactivity, peer problems and prosocial behaviour. These subscales were derived from factor analysis of an expanded Rutter parent questionnaire that included items focussing on child strengths. The Rutter questionnaire yields scores on total deviance, conduct problems, emotional symptoms and hyperactivity. The SDQ has 25 items, five in each subscale, 10 items refer to behavioural strengths and 14 to behavioural difficulties, the remaining item is neutral. While none of the items are replications of Rutter items, five are similar. The other items were altered and combined following informal trials and recommendations from colleagues. The SDQ generates a total difficulties score which may be used to identify young people demonstrating behavioural problems. There are additional questions which request respondents to indicate whether difficulties are present and focus on the chronicity and impact of difficulties on daily activities. However, since responses are not included in analyses they will not be further elaborated here. Versions available for use include parent report, teacher report (four to sixteen years) and a self-report for young people between the ages of 11 to 16 years. It has distinct advantages over other measures in terms of brevity, inclusion of strengths such as, prosocial behaviour, and improved treatment of inattention and peer relationships. It is anticipated that the questionnaire may be used for clinical purposes to determine changes in behavioural adjustment. However, as yet no confirmatory data are available. Respondents are asked to select one of three options with reference to the validity of statements (i.e. not true, somewhat true, certainly true) in terms of the previous six months.

Reliability

Internal consistency - Cronbach's α are available for the self-report version. Reliabilities range from 0.61 for peer problems to 0.82 for the total difficulties score (Goodman *et al.*, 1998).

Test / Re-Test - Stability has been assessed on the parent report version in a sample of five to fifteen year olds within the general population. Intra-class correlations for a three to four week gap are total difficulties score .85, emotional symptoms .70, conduct problems .74, hyperactivity .74, peer problems .83 and prosocial behaviour .82 (Goodman, 1998; personal communication).

Validity

The SDQ parent and teacher report has been shown to have concurrent and discriminatory validity. Goodman (1997) evaluated parent and teacher questionnaires (SDQ and Rutter scales) on 403 children attending either a psychiatric or dental clinic. Correlations between the SDQ and Rutter scale for parent report (n=346) ranged from .78 (emotional symptoms score) to .88 (total deviance/difficulties score). Correlations for teacher report (n=185) were between .87 (emotional symptoms score) to .92 (total deviance/difficulties score). Correlations between parents and teachers completing the same measure varied for the SDQ between .37 (prosocial behaviour) to .62 (total difficulties score). Correlations for the Rutter scale varied between, .47 (emotional symptoms score) to .57 (conduct problems score). The total difficulties score on the SDQ measure was significantly higher than the corresponding correlation for the Rutter scale ($p < .02$). Discriminatory and predictive validity are indicated by statistical procedures assessing the sensitivity and specificity of both the SDQ and the Rutter scale using the total deviance/difficulties score. The technique used to establish these features involves calculation of the receiver operating characteristic (ROC). Sensitivity and specificity are properties of the measure which correctly identify individuals whose scores fall respectively into the clinically significant and non-significant range. Both measures were shown to achieve similar levels of sensitivity and specificity. A measure that discriminates with absolute precision would receive a score of one, with 0.5 indicating a chance level of discriminatory power. The scores for the parent report SDQ and Rutter scale were .87, .85 for the SDQ teacher report and .84 for the Rutter scale.

Further indications of predictive, construct and discriminatory validity are suggested by a study comparing parent report of the SDQ and Child Behaviour Checklist (CBCL, Achenbach, 1991 cited in Goodman & Scott, 1999). One hundred and thirty-two mothers of children between the age of four to seven years recruited from psychiatric and dental clinics completed both measures. Mothers of children attending psychiatric clinics were also interviewed about their child's difficulties using the Parental Account of Symptoms (Taylor *et al.*, 1986 cited Goodman & Scott, 1999). Mean scores for total and subscales on each measure that is, externalising/conduct, inattention/hyperactivity, internalising/emotional and social/peer were found to be equally predictive in terms of recorded scores for high (psychiatric) and low (dental) risk groups. Moreover, ROC techniques revealed no significant difference between the measures for total and subscales in terms of discriminatory power. Correlations between total and subscale scores as shown above ranged from .59 (social/peer) to .87 (total score), all coefficients were significant at the .001 level implying substantial construct validity. Comparison of correlations between the interview scales and externalising/conduct, inattention/hyperactivity and internalising/emotional symptoms subscales suggest the SDQ is more effective than the CBCL in achieving criterion validity. Interview and SDQ correlations were all higher than corresponding correlations for the CBCL, for example SDQ correlations were, .64, .43 and .53 whereas CBCL correlations were, .52, .15 and .44. In fact correlations for the inattention/ hyperactivity domain were significantly different. Structural equation modelling techniques were used to determine to what extent externalising, internalising and inattention scales were associated within each measure. Findings revealed a strong fit between externalising and inattention for both measures. However, whereas constraining correlations to be equal for externalising and internalising and internalising and inattention produced no significant difference in model fit for the CBCL, this was not the case for the SDQ. Placing the same equality constraints on the SDQ produced a significant deterioration in model fit. This implies that the SDQ, in contrast to the CBCL, possesses greater precision in distinguishing problem domains.

A recent pilot study (Goodman *et al.*, 1998) has also established concurrent and discriminatory validity for the self report version. Two samples of 11-16 year olds, one community based (n=83) the other psychiatric clinic attenders (n=116) and their parents and teachers were invited to take part. Data were obtained from child, parent and teacher for 54 of the community sample and 54 of the clinic attenders. Inter-rater correlations between parent and child for clinic attenders ranged from .46 (total difficulties score) to .68 (conduct problems), all correlations being highly significant ($p< .0001$). For the same group, correlations between teacher and child ranged from .38 (total difficulties score) to .46 (conduct problems), with the exception of the prosocial behaviour subscale correlations were significant ($p< .01$-$.001$). In community sample correlations between parent and child ranged from .29 (hyperactivity and peer problems) to .52 (emotional symptoms), all correlations were statistically significant ($p< .05$-$.001$). The correlations between teacher and child varied between .13 (hyperactivity) to .38 (total difficulties score). The only correlations achieving statistical significance were the total difficulties score ($p< .001$) and emotional symptoms ($p< .05$). Discriminatory and predictive validity for self-report is indicated by the mean difference between the samples in the total difficulties score. The clinic attenders scored 1.4 standard deviations above the community sample ($t=8.9$, 197 df, $p< .001$). The ROC procedure produced a score of .82 denoting strong discriminatory power.

4.6 Child-Health Related Quality of Life

The child health related quality of life (CQOL) taps into the various aspects of daily living relevant to children and adolescents and aims to assess physical, psychological and social functioning (Graham *et al.*, 1997). Developed in the UK the measure evaluates, from both child and parent perspectives, getting about and using hands, self-care, bowel and bladder control, school, out of school activities, friends, family relationships, discomfort due to bodily symptoms, worries, mood (depression), seeing, communication, eating, sleep and appearance. These areas stem from a review of current quality of life measures and semi-structured interviews with 30 parents of 10-14 year old children with either chronic physical conditions, such as cystic fibrosis, orthopaedic and neurological conditions; psychiatric conditions, for example difficulties associated with conduct - antisocial behaviours or emotion - depression / anxiety, or a combination; or conditions involving cognitive delay (IQ< 70). Thirty children in either of the first two groups were also included in this process. The interviews sought to access child and parent descriptions of how the condition affected daily life. The questionnaire format requests ratings that encourage the respondent to compare the level of functioning, over the past month, to that of children of the same age. Problems that a child might encounter in a particular domain are provided to guide evaluation. For example, in the area of getting about and using hands "clumsy; difficulty running; difficulty walking; unable to control movements; uses wheelchair; confined to bed". As illustrated the degree of functional impairment increases as the rater moves through the problems. The final problem is placed on the right hand side of the rating scale to indicate that this is considered the greatest level of impairment. On the left hand side of all functional scales the statement "Better than children of the same age" is presented. In addition ratings are also made on level of upset (extremely upset to not upset at all) and satisfaction (very satisfied to not satisfied at all). Each rating is made on a seven point notched Likert scale. Ratings are summed and generate total functional, upset and satisfaction scores. The measure also incorporates an overall rating of quality of life as in the following, "Better than children of the same age.....Very poor quality of life".

The measure has undergone minor modifications since development. For example, in the original version the functional scales presented raters with the statement "As well as any other child of the same age" instead of "Better than children of the same age". Estimates of reliability and validity presented below were obtained on the basis of the original version.

Reliability

Internal consistency - Cronbach's α scores for functional, upset and satisfaction scores for mothers (n=75) are reported as 0.81, 0.86, 0.86 respectively. For children (n=75) the equivalent coefficients are 0.85, 0.85 and 0.87 (Graham *et al.*, 1997).

Test / Re-Test - For an interval of one-two months the correlation for the combined function score in mothers of children with cognitive delay (n=19) was.83, in mothers of children with chronic physical conditions (n=15), .77 and for children with chronic physical disorders (n=15), .64. Individual correlations for mothers varied between .11 to 1, most fell between

.4 to .7 and for children ranged between -.22 to .90 , again most fell between .4 to .7. Ratings provided by mothers of children with cognitive delay showed the greatest consistency (Graham *et al.*, 1997).

Validity

The study conducted by Graham *et al.* (1997) shows the CQOL to have concurrent and discriminatory validity. Children between the ages of nine to fifteen years with either chronic physical conditions (n=26) and their mothers (n=25), psychiatric conditions (n=25) and their mothers (n=25), or without chronic conditions (n=25) and mothers of children in the same age range with cognitive delay (n=26) completed the CQOL. Eleven randomly chosen children in each group, were independently evaluated on the Children's Global Assessment Scale (CGAS-Shaffer *et al.*, 1983). The CGAS measures psychological and social functioning and has been used by child psychiatrists to detect and monitor change in psychosocial status. Correlation between the CGAS scores and mothers' total function score was .64 ($p < .01$). Analysis of children's mean scores for each of the function scales indicated a significant difference between the groups. In terms of mean overall quality of life rating, respective scores for the control/comparison, chronic physical condition, psychiatric condition groups were 1.12, 1.77 and 2.50 ($p < .001$). The mean combined function score showed a similar pattern 17.32 (control), 25.56 (chronic physical condition), and 31.56 (psychiatric condition) ($p < .001$). Mothers' mean ratings showed significant group differences. The mean overall quality of life ratings for mothers of children with chronic physical conditions, psychiatric conditions and cognitive delay were 2.42, 2.29 and 3.77 respectively ($p < .03$). Mean combined function scores respectively were 29.13, 31.92 and 46.00 ($p < .001$). Intra-class correlations were calculated on the function, upset and satisfaction scales to estimate agreement between mothers and children. In the chronic physical condition group correlations for individual function domains varied from -.01 to .80, the combined score correlation was .57. In the psychiatric condition group correlations for this scale varied between .15 to .79, the combined score correlation was also .57. Correlations between mothers and children in each group on the upset and satisfaction scales were not dissimilar to those obtained for functioning.

4.7 Kidcope

Kidcope is a self-report checklist which evaluates strategies children and adolescents employ to deal with problems (Spirito *et al.*, 1988). Based on the transactional (process) model of stress and coping advanced by Lazarus and Folkman (1984) the measure was specifically designed to explore "natural and spontaneous" coping and distinguish strategies beneficial to management of various stressors following diagnosis of illness. Kidcope is a screening device supporting clinical assessment.

Developed in North America, Kidcope evaluates emotional reaction to a problem, the way it is managed, reflecting cognitive and behavioural efforts and to what extent actions are felt to be effective. Two versions are available, one for children between the ages of seven to twelve years, the other for young people between the ages of 13-18 years. The former version is simpler in terms of the language used. Assessment may take one of two approaches - either a problem is devised by the researcher and / or children generate their own real life problem. Young people are evaluated on both the type and degree of emotional reaction they experience. For example, whether the problem made them nervous or anxious, cross or angry, sad or depressed not at all, a little, somewhat, pretty much or very much. They then report on the actions they took or would take to deal with the problem. The younger version offers 15 alternatives, the older version 10. Both versions however, reflect the same 10 general coping strategies - distraction, social withdrawal, cognitive restructuring, self-criticism, blaming others, problem solving, emotional regulation, wishful thinking, social support and resignation. In the older version, respondents may choose between four alternatives to indicate how often they use a strategy for example, not at all, sometimes, a lot or almost all the time. Younger children are offered a yes / no format. If selected they then report how effective it was, options for older children are not at all, a little, somewhat, pretty much or very much and younger children: not at all, a little or a lot.

Initial development of the checklist included items (strategies) derived from a pool of 24 items that reflected coping patterns generally produced by factor analysis of adult coping scales. Items were chosen purposely to include "problem solving, social support, emotional regulation, avoidance and distraction". However, factor analysis of the checklist indicated conceptual difficulties with some of the items. Consequently, the authors decided to choose

10 frequently cited and conceptually consistent coping categories from the literature. The items were rewritten to reflect these coping categories. Thus in the adolescent version each category is associated with one item. An anglicised version of Kidcope is available (Pretzlik, 1997). Modifications reflect minor changes in wording and the introduction of a colour coded strips to improve evaluation of the emotional response and strategy efficacy features of the measure. Given the design and focus of the current study and accompanying practicalities it was felt that this approach would prove time consuming. However, a few minor alterations, modelled on Pretzlik (1997), have been incorporated into the American measure to increase acceptability to a British audience. In this study children were asked to complete two versions referring to management of a standardised everyday problem that is, parental anger on returning home late, and a self-nominated illness problem. The introduction of two scenarios permitted examination of similarities in strategy use.

Reliability

Internal consistency - Given there is only one item per coping strategy on the adolescent version and two items on several strategies in the child version estimates of internal consistency are inappropriate.

Test / Re-Test - Interval frequency correlations for adolescents between 12-18 years generating a personal problem range between .56 (emotional regulation) to .75 (wishful thinking) for a three day interval (n=60); .41(problem solving, social support) to .70 (social withdrawal) for a seven day interval (n=42); .15 (social withdrawal) to .43 (emotional regulation, social support) for a 10 week interval (n=142). Corresponding correlations for strategy efficacy varied between .30 (wishful thinking) to .74 (problem solving) for the three day interval; .01 (cognitive restructuring) to .50 (distraction) for the seven day interval; .07 (blaming others) to .34 (distraction, emotional regulation, social support) for the 10 week interval. When using a standardised problem, frequency correlations ranged between .04 (social withdrawal) to .56 (social support) for a two week interval (n=34). Equivalent efficacy correlations varied between .21 (distraction) to .58 (blaming others) (Spirito *et al.*, 1988). Generally correlations for frequency and efficacy are significant ($p < .05$) for shorter time periods. Nonetheless, correlations for a 10 week period achieve statistical significance, although increased sample size may have influenced findings. One and two week interval reliabilities in a small group of nine to ten year olds reporting on a personal stressor ranged between .13 (distraction) to .80 (wishful thinking) for the seven day period and .16 (cognitive restructuring) and .64 (social support) for a 14 day period. Overall, phi coefficients were found to weaken with time (Spirito *et al.*, 1991).

Reliabilities for a seven day interval using the anglicized version in children aged seven to ten years (n=32) are reported for self nominated personal everyday and illness related problems. Spearman's rank order correlations for the emotional element varied between .69 to .79 (p< .001) for an everyday problem, and .70 to .77 (p< .001) for an illness related problem; coping strategy kappa coefficients ranged from .21 (cognitive restructuring) to .93 (self-criticism) for the everyday problem, and .35 (problem solving) to 1 (social support) for the illness related problem. Only two coping strategies failed to reach statistical significance in the everyday problem scenario and three strategies in the illness related problem scenario. Strategy efficacy was assessed by Mann-Whitney U tests and no significance differences were found for either the everyday or illness linked problem (Pretzlik, 1997).

Validity

Kidcope has been shown to have concurrent validity for adolescent populations. The Coping Strategies Inventory (CSI) and the Adolescent-Coping Orientation for Problem Experiences Inventory (A-COPE) (Tobin *et al.*, 1984; Patterson & McCubbin, 1983 both cited in Spirito *et al.*, 1988) were administered in conjunction with Kidcope group of 14-15 year olds. Forty-two students completed the CSI, 49 students A-COPE, Kidcope was completed on the basis of a personal problem. Both the CSI and A-COPE are reported to be reliable and valid. Eight of the subscales on the CSI are fairly similar to Kidcope items. It was thought there would be strong correlations between these items. As expected they did indeed correlate highly on seven of the eight subsales. Correlations between Kidcope and CSI on these items ranged from .33 (distraction with problem guidance) to .77 (self-criticism with self-criticism). Five of the correlations were significant (p< .05). Of the 12 factors which comprise A-COPE, several match Kidcope items and those that did achieved the some of the highest correlations as predicted. Correlations ranged between -.08 (distraction with engaging in demanding activity) to .62 (distraction with seeking diversions). However, correlations were less robust than those found between Kidcope and CIS. It is suggested that A-COPE factors are somewhat specific and inconsistent with

Kidcope items when compared to CSI items.

There appears to be no evidence supporting validity of the younger American version of Kidcope. Nevertheless, Pretzlik (1997) has established validity for the emotional element of the anglicized Kidcope in youngsters between the ages of seven and sixteen years with leukaemia or aplastic anaemia. Children's distress ratings following a blood test were found to correlate positively with the level of distress observed during the procedure ($r=.56$, $p< .001$, $n=53$).

4.8 Walker-McConnell Scale of Social Competence and School Adjustment

The Walker-McConnell Scale is primarily a teacher rating measure of behavioural and social competency and was selected to evaluate peer relations and school adjustment. The scale was developed in North America to support identification of vulnerable youngsters and intervention efforts. The authors indicate evidence suggests that whereas enhanced social skill has been found to be related to academic advancement and good communication skills, the early appearance of socially incompetent behaviour is associated with difficulties in later life (Walker & McConnell, 1995a). There are two versions, elementary and adolescent which include similar subscales assessing school adjustment and peer relations. The elementary version is applicable to children in kindergarten to 12 years of age, the adolescent version to children from 13 to 18 years. Both versions reflect subscale constructs obtained from factor analytic procedures, and have undergone rigorous psychometric evaluation and validation. In addition, the authors have established scale norms; however, normative data are confined to the United States. The elementary version constitutes 43 items and was first published in 1988. This version has three subscales - teacher preferred behaviour (subscale 1), peer preferred behaviour (subscale 2) and school adjustment (subscale 3). The adolescent version became available in the early 1990s, contains 53 items and includes four subscales, self-control (subscale 1), peer relations (subscale 2), school adjustment (subscale 3) and empathy (subscale 4).

Items were derived from an initial pool of 100 items which were devised or chosen on the basis of four considerations. First, a review of concurrent professional literature on social competence, social skills and behavioural adjustment. Second, consideration and interpretation of existing teacher measures focussing on the same areas. Third, inclusion and / or possible alteration of items contained in a management package that centred on effective school behaviour or peer relations developed by Walker and associates. Fourth, items chosen from the SBS Inventory of Teacher Behavioural Standards and Expectations (Walker & Rankin, 1983, cited Walker & McConnell, 1995a) reflecting teacher perceptions of appropriate school behaviour. Inspection of items, in terms of word simplicity, avoidance of overlap, aptness to social competence and school adjustment domains and representativeness of teacher and peer preferred behaviour items, led to item revision and elimination and resulted in a final pool of 83 items. The adolescent version reflects the same items and an additional 10 items to reflect "self-related adjustment" with revisions of nine existing items. It is suggested that during adolescence features of social competency are increasingly self regulated and demand inclusion. Respondents are offered a five point scale to indicate the frequency of behaviours incorporated in listed statements. Higher scores reflect higher levels of social competence and school adjustment.

Elementary version

Reliability

Internal consistency - Calculation of Cronbach's α for total score and the three subscales for a normative sample were respectively 0.97, 0.96, 0.95, 0.96. Moreover, estimates of internal reliability at each age level (i.e. five years, six years etc.) all exceed 0.90 and were not influenced by age (Walker & McConnell, 1995a).

Test / Re-Test - Perhaps not surprisingly, studies appraising stability suggest higher correlations for shorter time periods within the same context. Nonetheless, studies conducted by Walker *et al.* (1987) and Shinn *et al.* (1987) reported by Walker & McConnell (1995a) suggest acceptable correlations for substantial time intervals. In a sample of pupils including youngsters with and without anti-social difficulties assessed in the fall (autumn) and spring significant associations obtained for total score and subscales 1, 2 and 3, were .65, .67, .61 and .70 ($p < .001$). In the same sample, a one year interval test retest produced significant correlations for total score and the subscales, .69, .69, .50 and .70 ($p < .001$). Evaluation following a two year interval showed the strength of these associations had diminished. Walker and McConnell (1995a) also report findings from a study by Patterson *et al.* (1995) focussing on assessment of the peer-preferred subscale over three years;

correlations for the first, second and third years were, respectively .48, .42 and .32. Age was not found to be related to scale scores.

Validity

The elementary version has undergone *extensive* checks on various aspects of validity. A selection of studies illustrating discriminant, concurrent and construct validity will be reported here. The reader is referred to the Walker-McConnell Scale of Social Competence and School Adjustment Technical Manual (Elementary Version-1995a) for additional information. The scale has been shown to discriminate between groups of children (second and fourth grade) based on their sociometric status. Sociometric groupings derive from children assigning class peers positive or negative nominations, reflecting the extent to which the peer is liked/disliked. Depending on the nature and number of nominations a child receives, children are allocated to either rejected, neglected, average or popular group category. Hops (1987, cited in Walker & McConnell, 1995a) used stepwise discriminant analysis to assess the utility of the Walker-McConnell subscales in differentiating group allocation and found the peer-preferred behaviour subscale entered first and was the only variable involved. This subscale correctly classified 46.03 percent male second graders, 43.66 percent male fourth graders, 35.59 percent female second graders and 44.19 percent female fourth graders. These results were statistically significant at the .001 level of probability indicating the strength of the peer-preferred behaviour subscale in discriminating rejected children from other groups. A study conducted by Firmen (1991, cited in Walker & McConnell 1995a) compared two groups of children ranging in age from kindergarten to Grade three, one group were in foster care the other living with their parents. The foster care group were subdivided into children who had undergone one to two placements and those who had experienced three or more. The latter group were found to have significantly lower total scale and subscale scores than foster children having one to two placements. Both foster groups differed significantly from children living with their parents, demonstrating discriminatory power.

The scale has also been shown to have concurrent validity (Dishion, 1987, cited in Walker & McConnell 1995a). Dishion used the peer-preferred subscale to assess teacher and parent views of peer relations in 100 fifth grade males at risk for the acquisition of antisocial behaviour. Teacher subscale assessments correlated significantly with parent subscale assessments (.32 p< .01), teacher ratings of the extent to which the child was accepted/rejected by their peers (.28 p< .01) and teacher and parent evaluation of social relations as measured by the Achenbach Child Behaviour Checklist (CBCL). Teacher and parent correlations were respectively -.70 (p< .01) and -.28 (p< .01). Correlations between teacher assessments and parent and child telephone reports of peer relations were low, however. Another study, involving children showing behavioural and academic difficulties ranging in age from kindergarden to Grade five found peer preferences ratings were significantly and positively correlated with total and all subscale scores (McConnell *et al.*, 1984, cited in Walker & McConnell 1995a).

In terms of construct validity, Walker and McConnell (1995a) indicate there is a general consensus in the peer relations literature that social skills underpin social competence and are significant behavioural correlates of sociometric standing and popularity. Evidence from the Dishion (1987) study supports construct validity and the suggestion that poor peer social skills are linked to both antisocial behaviour and persist over time. In this study teachers completed the peer-preferred behaviour subscale following sociometric evaluations conducted two years earlier. Significant correlations were obtained between subscale ratings and peer nomination composite score (a combination of positive and negative nominations) .45 (p<. 01), positive nominations .45 (p<. 01) and negative nominations .30 (p<. 01). The strength of the correlations connecting sociometric status with teacher ratings two years later attests the peer preferred behaviour subscale as an appropriate and valid index of social competence.

Adolescent version

Reliability

Internal consistency - Cronbach's α are reported as 0.98 (total score), 0.95 (subscale 1- self-control), 0.95 (subscale 2 - peer relations), 0.96 (subscale 3 - school adjustment) and 0.89 (subscale 4 - empathy) (Walker & McConnell, 1995b).

Test / Re-Test - So far three studies have estimated stability. The social skills of 43 adolescents in a residential / day treatment centre for behaviourally disturbed children were assessed by their teachers over a 5 week interval. Test- retest correlations were .83 (total score), .83 (self-control), .82 (peer relations), .83 (school adjustment) and .76 (empathy). A further study involved 50 adolescents attending middle and high school in two districts (suburban and rural). Correlations of teacher assessment for a one month interval were .89 (total score), .85 (self-control), .90 (peer relations), .89 (school adjustment) and .87 (empathy). These correlations were found to be more stable than the previous estimate. In the remaining study parents of young adult children provided ratings one year apart. Correlations were .61 (total score), .73 (self-control), .72 (peer relations), .64 (school adjustment) and .69 (empathy) (Walker & McConnell, 1995b).

Validity

Both concurrent and discriminant validity have been established for the adolescent version. The scale correlates highly with two psychometrically sound measures. First the School Social Behaviour Scales (SSBS-Merrell, 1994) which assesses antisocial behaviour and social competence and may be used by teachers and other professionals. Correlations between the total score on the Walker-McConnell Scale and total scores for each construct on the SSBS were .94 for social competence and -.70 anti-social behaviour. Second, the Social Skills Rating System (SSRS-Gresham & Elliott, 1990 both cited in Walker & McConnell, 1995b) includes three subscales evaluating the social competence domains of co-operation, assertion and self-control and has established norms; moreover, it is designed for adolescents. The secondary version of the SSRS-T yields a total scale score and total scores for each subscale. Correlations between the Walker McConnell scale and the SSRS-T range from .35 (SSRT-assertion with Walker-McConnell self-control) to .92 (SSRS-T self-control with Walker-McConnell self-control), the total scale score correlation between the two measures being.72. All correlations were significant at the .05 level of probability.

The scale has been shown to discriminate between learning disabled, severely emotionally disturbed students, young people on parole or probation and students not in difficulty. The mean scores for each subscale indicate that students not in difficulty score higher and therefore rated more socially competent than other groups. For example, the mean scores on the peer relations subscale for students not in difficulty was 73.55 (n=10) in contrast to 47.62 (n=91) for the severely emotionally disturbed, 50.83 (n=30) for those on parole or probation, 60 (n=45) for youngsters who were learning disabled in resource rooms and 37.96 (n=11) for learning disabled in self-contained rooms.

4.9 Friendship Interview

An interview protocol derived from a preexisting schedule (Berndt and Perry, 1986) expands assessment of social relations by focussing on the link between friendship and psychological well-being. Peers are an influential factor in the process of socialisation and friendship may play a vital role in the development of personal and social self concepts (Mead, 1934; Sullivan, 1953; Goffman, 1963; James, 1993). Children and adolescents with long-term physical conditions may experience fewer opportunities to establish and maintain friendships because of prolonged and / or frequent school absence, or illness. At the same time this may contribute to perceptions that highlight differences from peers. Friendship, in contrast to other relationships, is implicitly based on equity and provides the context in which notions of reciprocity, commitment, loyalty and intimacy are acquired. Developmental shifts in cognitive ability demonstrate an increasing awareness of these concepts and the significance of co-operation in social relations (Hartup, 1989). Synonymously, the arena of peer relations and friendship appears to foster both differentiation in definitions of self and group identification (James, 1993). Similarity and difference appear to be equally important. Chronic illness may represent an additional stress in negotiating this critical developmental pathway.

The schedule devised by Berndt and Perry (1986) for American children between the ages of eight years three months to fourteen years two months is composed of 31 questions, 30 of which are sets of paired (closed and open) questions. Their study sought to explore perceptions of support in relation to friends and acquaintances. Questions reflect six underlying constructs - play/association, prosocial behaviour, intimacy, loyalty/faithfulness, self-esteem/attachment and conflict. Five paired questions are associated with each construct, the remaining question is introductory and not included in analysis. The constructs reflect characteristics previously defined in the literature as linked to children's conceptions of friendship. Paired question sets document both frequency of an action and why this was so, or whether an appropriate action would occur and why. For example, "Do you ever spend your free time with..........?"; if answered yes "How often do you.......?". Children are shown the equivalent of a visual analogue in the form of labelled boxes which increase in size to reflect greater interaction for instance, once in a while.......all the time and asked to choose the appropriate box. Following selection they are asked "Why do.........?". If a child indicated that they did not spend their free time with their friend, they are asked

"Why not?". An appropriate action question would ask, for example, "If you felt sad or upset would..........try to cheer you up?". Further questioning follows the route outlined above; in this case, however, if a child answers yes they are asked " How would s/he cheer you up?". Thus questions use both open and closed elements and centre on perception of concrete support and potential support.

The interview protocol designed for the present study sought to examine the contribution of friendships, in terms of similarity, frequency of contact, degree of intimacy and conflict to psychological well-being. Three of the constructs used by Berndt and Perry (1986) are included in the protocol - play/association, intimacy and conflict. Specific questions were systematically re-ordered for each interview schedule to minimise order effects. For example, on one schedule the repeated question sequence would be intimacy, play/association and conflict, on the other play/association, followed by conflict then intimacy. Additional questions explore features of friendship that might be considered important to maintaining friendships. For example, the friend's liked and disliked characteristics, the assistance they give each other, similarities and differences, attributes of friends they would like to have and the things they believe make them friends. Also incorporated into the protocol are questions on the length of the friendship, where the friend is located for instance, school, neighbourhood or other and whether the two friends nominated are first, second or third best friends. Subsequent analyses focus on the role of friendship constructs in predicting psychosocial outcomes and factors associated with friendship quality (i.e. positive and negative attributes). Responses to questions relating to for example, preferred and disliked characteristics and instrumental support were somewhat similar to responses given for questions measuring these constructs, and were therefore not included.

Principal considerations in selecting constructs were based on incorporating information relating to emotional support and developmental shifts. Intimacy was chosen for two reasons. First, disclosure of personal information is considered the defining feature of an emotionally supportive relationship. Second, intimacy demonstrates age related changes in that it becomes an increasingly important feature of the friendship relation. The play/association construct taps frequency of interaction. High levels of interaction in adolescents have been shown to be typical of those who have supportive friendships (McGuire & Weisz, 1982). In addition, supportive and intimate friendships have been reported to be generally more stable (Berndt *et al.*, 1986; Hartup, 1993 cited in Keefe & Berndt, 1996) and adolescents who have stable friendships appear to have better psychological adjustment (Hartup, 1993 cited in Keefe & Berndt, 1996). The presence of supportive friendships has also been shown to be linked to higher self-esteem in social, behavioural and scholastic domains among early adolescents (Keefe & Berndt, 1996). However, evidence also indicates increased interaction to be associated with drug use, disruptive behaviour and poor educational attainment. Conflict has been shown to be a characteristic of supportive relationships in adults and evidence points to increasing differentiation between the positive and negative features of friendship with age (La Gaipa, 1979).

Reliability

Internal consistency - Reliabilities (Cronbach's α) calculated for closed question ratings of friend's support on the six constructs ranged from 0.54 (self-esteem/attachment) to 0.76 (prosocial behaviour). Overall reliability for all closed questions using mean ratings was 0.89. Results were similar for each age group (second, fourth, sixth and eighth graders) and ranged between 0.80 to 0.93 (n=122). Alpha coefficients for acquaintance ratings ranged between 0.66 (self-esteem/attachment) to 0.83 (prosocial behaviour). Reliability based on mean ratings for all questions involving each grade were between 0.84 to 0.92. Open questions were coded in terms of whether responses were positive or negative. Internal reliability is reported as -0.08 (friends), 0.47 (acquaintances) for positive comments, and 0.49 (friends), 0.22 (acquaintances) for negative comments indicating low to moderate correlations among comments (Berndt & Perry, 1986).

Test / Re-Test- No data are available for closed questions.

Validity

Validity has not been assessed. However links to conceptions of friendship suggest face validity.

4.10 Clinician Assessment of Condition Severity

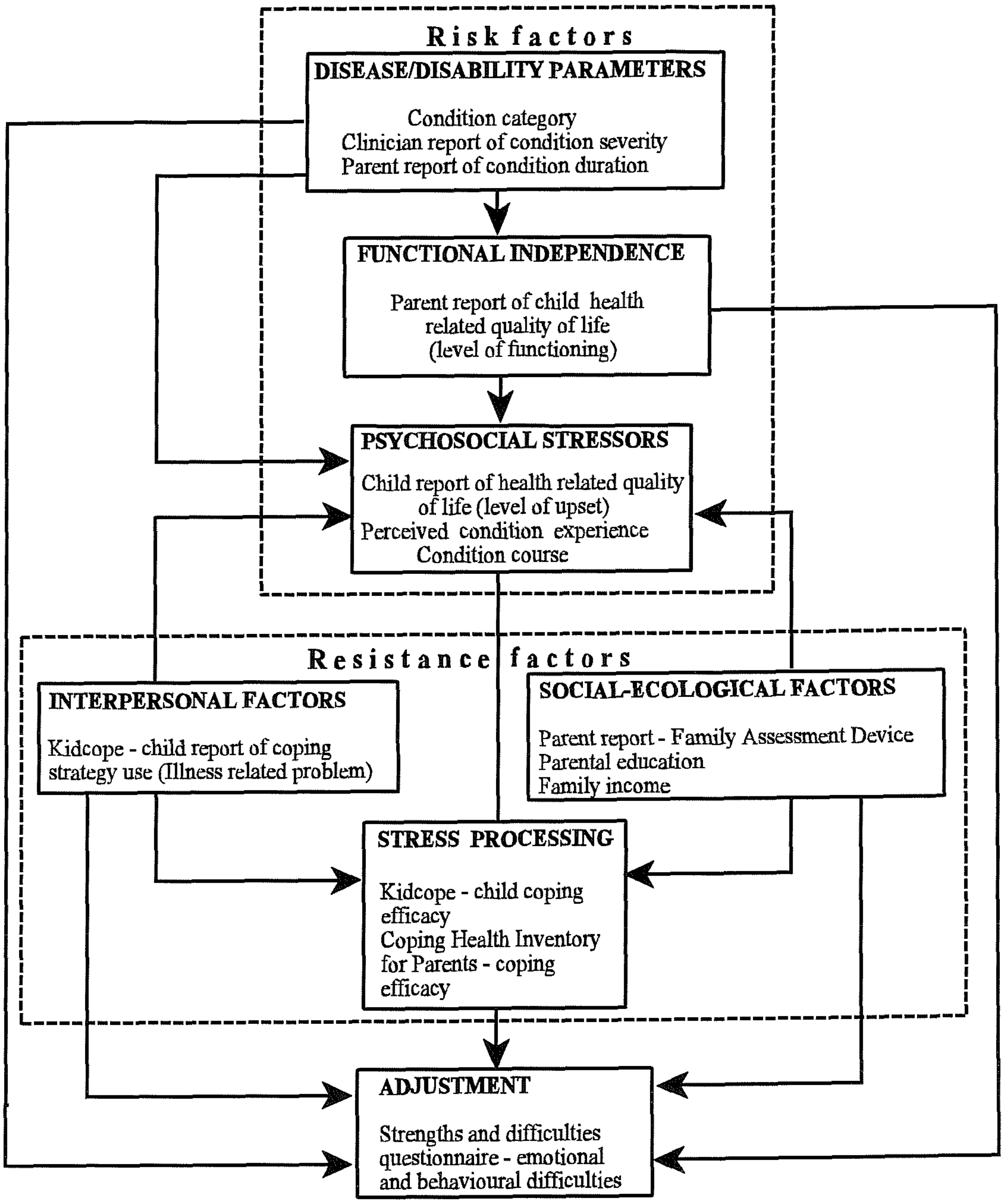
Chronic physical conditions may vary in symptom manifestation and concomitant physiological and functional severity. Ostensibly, condition severity affects daily functioning and therefore requires consideration in relation to psychosocial well-being. Consequently, a measure was designed to evaluate condition severity in terms of clinician or clinical nurse specialist judgement of physiological parameters and the common family demands of chronic childhood illness.

The above measure aimed to provide indices of condition-specific and generic severity that permits examination of relative utility in relation to adjustment outcome. It would be expected, if the non-categorical perspective is correct, that is chronic conditions produce common psychological and social consequences, generic assessments will demonstrate greater variation within condition groups than between condition groups. Moreover, inclusion of clinician/health professional perspectives strengthens the study methodology by providing additional information and the potential to improve reliability. The measure was developed during the study and was integral to the research process, therefore further details, incorporating psychometric properties, together with a synopsis of the research procedure are elaborated in Chapter 5.

Figure 3 below presents a summary of study measures and associated variables within the risk resistance framework. Since the model does not stipulate a role for peer and friendship relations and school adjustment they are not included. These variables and respective relationships with existing factors and the reasons underlying placement of measures and exclusion of others are considered in greater detail in Chapter 6. The model is put forward here to indicate how the measures provisionally correspond to factors specified in the framework.

Figure 3

Study measures represented within the risk resistance framework



Chapter 5: The development, reliability and validity of a condition severity measure, and study process

In the previous chapter it was pointed out that evaluation of condition severity demanded the development of a new measure. Chapter 5 describes the conceptual and practical considerations involved in producing this measure and provides evidence for reliability and validity. This is followed by an outline of the research process in terms of accomplishing participant access, ethical approval, recruitment and data collection. The aim of this chapter is to explain to the reader the process guiding achievement of study objectives.

5.1 Assessment of condition severity

Condition severity is believed to be a significant marker of variation in psychosocial outcome. Somewhat paradoxically however, definitions of severity often rely on objective indices that are condition-specific and fail to capture the generic demands imposed by chronic childhood illness. Since the present study was concerned to evaluate the generic features of severity, as judged by health professionals, study measures included an established clinician assessment of care demands. However, despite receiving the approval of clinicians at the first recruitment site, the questionnaire created difficulties for respondents in terms of length and clarity indicating the measure needed to be replaced. Development of the present measure followed an unsuccessful search for a substitute and within the context of ongoing participant recruitment. In light of the previous problems and clinical pressures on health professionals it was decided to keep the new measure as short as possible to reduce time constraints and encourage completion. Accordingly, health professionals (principally consultant paediatricians) would be asked to make two ratings, each on a seven point Likert scale reflecting, level of physiological functioning, and family care demands.

The rationale underpinning measurement of condition severity was based on a need to take account of objective condition parameters that is, variations in physiological functioning and generic across condition demands. Physical variation or symptom fluctuation mirror the alteration of physical processes that interfere with functioning and / or well being. For example, in the case of leukaemia, an increase in the number of immature white blood cells suggests intensification of abnormal cell generation that may produce lethargy, breathlessness and spontaneous bleeding. Physical parameters may be measured and compared to standardised norms, such as a blood test estimating the number of immature white blood cells in the peripheral circulation or child height and weight. Such measures are considered primary indicators of illness severity. Thus a high immature white cell count or child height and weight indices falling below established norms suggest that illness has substantially disrupted physiological functioning. As investigations measuring physical parameters are undertaken on the basis of diagnosis this is a condition-specific assessment that limits interpretation to within condition comparisons.

The generic assessment includes family context and seeks to evaluate condition severity in terms of the common demands that chronic childhood illness presents for a family. Individual family variation in demands may be considered a secondary manifestation of the illness arising from psychological and physical demands associated with condition consequences. An example would be the level of physical care a child may need, such as a child with cystic fibrosis whose treatment involves administration of overnight nasogastric feeding or intravenous antibiotics every three months, compared to a child with asthma who requires an inhaler four times a day. Children receiving the former treatments demand more parental time and training than children whose treatments are less intensive. However, any treatment, to a greater or less degree, may serve as a potent reminder of the child's dependence on interventions to maintain physical and psychosocial well-being and developmental progress. Moreover, the generic nature of the assessment permits interpretation across condition groups.

Inclusion of an age anchor in ratings (i.e. comparison to a child of the same age) assumes that physiological variation in severity may be both independent of age as in asthma for instance, and age related as in cystic fibrosis. For example, while childhood asthma can vary a great deal, this condition does not, on the whole, progressively limit physical functioning; however, cystic fibrosis generally does. Thus for children with cystic fibrosis it might be expected that older children would have more severe disease. This approach also assimilates the shift in responsibility for care demands from family to child. Both ratings were retrospective evaluations of severity over the previous twelve months, taking account of symptom fluctuations associated with seasonal variation. Assessments were based on the following considerations.

5.2 Physiological functioning

Clinicians involved with the management of chronic conditions are primarily concerned with treatment interventions which alleviate symptoms, prevent long-term complications, maintain developmental progress and age appropriate physical functioning. Judgements of physiological functioning are likely to be based on physiological markers and treatment requirements. Both are under constant review as symptoms, functioning (i.e. capacity to undertake daily activity) and treatment efficacy are appraised over time and against each other. Levels of treatment intervention are likely to parallel physiological functioning. For example, to attain optimal daily activity, control of symptoms, prevention and / or minimisation of long-term complications, intervention may range on a dimension from high to low. Children requiring a consistently high level of intervention to achieve these goals may be regarded as severely affected by their condition. Correspondingly, those needing less intervention may be perceived as less severely affected. Physiological markers are deemed crucial indicators of physiological functioning. Such markers would include pulmonary functioning in children with asthma and / or cystic fibrosis, height and weight in children with cystic fibrosis, glycaemic control in children with diabetes and fit frequency or EEG recordings may determine treatment efficacy in children with epilepsy. In essence retrospective evaluation of these markers shape and drive prospective management and cannot be separated from treatment decisions and inevitably, physiological functioning. Ratings therefore requested clinicians to consider treatment requirements in their evaluations.

5.3 Family care demands

The overriding aim of the proposed measure was to acquire an index of family care demands that identified variations and would be helpful in demonstrating relationships with other factors. In addition, a generic assessment would test the validity of the non-categorical approach allowing comparisons to be made within and between condition groups.

However, clinician assessments of demands created by chronic illness may be based on prior experience of other families in a similar position. In other words, the demands imposed by asthma will elicit a judgement based on a comparison to other families with an asthmatic child. Training, clinical experience and the professional practice of specialisation in particular body systems may encourage a classificatory response. In addition, clinicians may pay greater attention to physiological features, such as symptoms. Moreover, their experience is necessarily selective given children visiting a paediatric specialist are likely to display overt symptoms which interfere with physical functioning and would therefore be more severely affected than children managed by a general practitioner. To address these difficulties, it was felt guidance on responding would benefit from explicit inclusion of factors assumed to produce extra demands and challenge family dynamics. For example, scheduling of medication, dietary manipulation, supervision of child adherence to treatment, recording keeping, whether a child can be left in the care of others, explanation of needs to school staff and attendance at hospital clinics. Ratings specified respondents' focus on these kind of demands for a particular family in comparison to any other family with a child of the same age who also had a chronic condition. Research goals were concerned with comparison of demands for families caring for a child with chronic illness and therefore families where illness was not present were excluded. It was also made clear that respondents should consider the actual demands *not* how the family dealt with demands. It was expected this would produce ratings that reflected variations in common challenges facing families caring for a child with chronic illness.

5.4 Assessment of reliability and validity

Introduction of a new measure required and received ethical approval from the five medical committees prior to assessment of reliability and validity. As there were only two ratings examination of reliability focussed on test-retest. A clinician managing children with diabetes was asked to complete ratings on twenty five children who had taken part in the study, and were under his care. The clinician indicated that evaluation required the inclusion of his colleague, a clinical nurse specialist, who was also closely involved with management. Ratings therefore reflect their combined evaluation. Two weeks later they were asked to repeat ratings on twelve randomly selected children, without referring to their previous ratings. In assessing reliability the involvement of half the original sample was based on recognition of the clinical constraints on health professionals; it was felt the number would be feasible and aimed to lessen demands on their time and encourage co-operation. Bearing in mind there are very few, if any comparable measures of generic family care demands available and although not ideal, validity was established by comparison to parent estimate of family demands. Parents received the same measure as health professionals. Forty-eight parents of children with either asthma, diabetes, cystic fibrosis or epilepsy completed the measure as part of the data collection process. Since participant recruitment was ongoing and varied at this stage, between five hospital sites and nine clinicians there were difficulties linked to obtaining clinician ratings at the time of participation. To maximise co-operation and completion across sites and clinicians, it was decided that health professionals would complete ratings on all the children who had participated and under their care on conclusion of the recruitment process. Therefore, the health professional family demand ratings associated with evaluation of validity, were made between one to five months after parent ratings. Pearson correlation coefficients were calculated to determine levels of reliability and validity and are shown in Table 1.

Table 1

Pearson correlations demonstrating test-re-test reliability and validity of condition severity ratings

Condition severity	*Reliability* Test -retest Coefficient (sig) (n=12)	*Validity* Parent estimate family care demands Coefficient (sig) (n=48)
Physiological functioning	0.09 (.76)	-
Family care demands	0.75 (.004)	0.36 (.01)

The correlation coefficient for physiological functioning revealed low reliability, however, the correlation referring to family care demands was moderate to high and statistically significant indicating a high level of reliability. The correlation between health professional and parent estimates of family care demands was modest but statistically significant suggesting evaluations were a valid concurrent index of condition severity. In light of these findings, proposed ratings of physiological severity were abandoned. The assessment of family care demands was retained as the measure of condition severity.

To some extent, estimates of construct reliability are undermined by the small sample size and involvement of one condition group. However, time pressures including the ongoing demands of participant recruitment, delays in obtaining ethical permission, logistical difficulties associated with involving other health professionals prevented a more extensive evaluation incorporating a larger sample and two or more conditions. Although, the methods used to determine reliability and validity are perhaps not optimal, they represent what could be achieved in the circumstances given the multi-site design, resources pressures and clinical demands on health professionals. On the other hand, given associations rely on two ratings of one item and therefore less likely to demonstrate reliability, it may be suggested the moderate to high correlations are indicative of adequate reliability and validity.

In the following sections the research process is described. Issues related to gaining participant access, obtaining ethical approval, recruitment, data collection and participation rate are discussed.

5.5 Participant access

Prominent in guiding this process were research goals and pragmatic considerations. As the present study sought to demonstrate the strength of either the categorical or non-categorical approach in explaining adjustment to chronic illness it was important to ensure study conditions (i.e. illnesses) would permit a satisfactory test of both approaches. The nature of the conditions selected, in terms of condition experience and psychosocial consequences, suggest commonality and difference coexist and present the opportunity to establish the validity of either approach. While diabetes and cystic fibrosis are life long conditions, asthma and epilepsy may resolve. However, all conditions require medical treatment to control symptoms and may be associated with periods of hospitalisation. On the other hand, the long-term complications and life expectancy associated with each condition varies. However, to guarantee comparability of experience, it was essential that children who enrolled were currently managed by a consultant paediatrician and receiving hospital based care.

Practical issues, such as participant availability, time and financial costs were obviously relevant. Significant constraints on participant availability were imposed by the proportion of children under 16 years affected by chronic illness (i.e. 10 to 15 percent), and limiting study eligibility to eight to sixteen year olds. Consequently, encouraging and promoting participation was a key issue. Careful consideration suggested personal introduction during a child's attendance at out patient clinics would assist co-operation and aid recruitment. In addition, it was planned that data collection took place within the home to facilitate authenticity of participant perceptions and completion of questionnaires. This approach sought to maximise involvement of families and enhance quality of information by minimising logistical and financial difficulties for families and placing the process in a familiar environment. Accordingly, given time and financial costs required for clinic attendance and home visits, hospital sites were chosen on the basis of participant availability and distance. At the outset it was anticipated that four hospital sites would be sufficient, however, during the course of negotiation it became necessary to include a further site. For various reasons, such as children were already committed to another study, it was not possible to gain access to one condition (diabetes) at two of the original sites. Consequently attempts were made to establish access at another hospital site. This process began in December 1996.

In view of the preference amongst clinicians for condition specialisation, fifteen consultant paediatricians were identified as managing children with the conditions outlined. Clinicians were located at seven hospital sites, one site provided regional paediatric services, the remaining six sites provided district general services. Preliminary contact was made by letter explaining study details and requested a meeting to discuss matters raised. Nine clinicians were interested and able to take part. Subsequent meetings with each clinician sought to confirm feasibility, resolve concerns, queries and outline how recruitment would proceed. This resulted in access to participants with either asthma, cystic fibrosis or epilepsy at four sites, and participants with diabetes mellitus at three sites. In total, clinicians providing services at five sites which included one regional, three district general and one community hospital in the South of England agreed access. One clinician provided clinic access at a community hospital but was based at a district general site.

5.6 Obtaining ethical approval

Research involving patients receiving hospital based care cannot be undertaken without the approval of the local (i.e. hospital site) medical ethics committee. Approval rests on submission of study details supported by documentation for example, questionnaire measures and a rigorous assessment procedure. Since participants were to be drawn from five hospital sites, five separate applications were required.

The strategy governing this process, which involved substantial delays was influenced by several factors. It was planned that data collection would begin at the regional site for paediatric services. This site has the largest proportion of children available, and given limitations highlighted above, could absorb, without limiting availability, a small group of participants to pilot the data collection procedure. In addition, obtaining approval at this site was considered a priority since half the sample would be drawn from this site. At the same time it would benefit and guide the approach to subsequent applications by allowing evaluation of the time taken to enroll participants.

Following the first submission in June 1997, the committee requested further information and modification before approval was granted. The whole process took four months. An application presented to the Department of Psychology ethical committee in parallel with the initial submission also received approval. Simultaneous applications were sent to the remaining committee sites in February 1998. While many of the difficulties associated with the first application had been resolved, it was imperative from a scientific point of view that the protocol and study measures were standardised across hospital sites. A letter accompanied each application pointing out that standardisation was integral to the study and requested urgent notification of any proposed alteration. In this way sufficient time was available to incorporate modifications and inform other committees prior to full approval. Moreover, the recruitment process was progressing more slowly than expected and time pressures suggested making applications earlier rather than later. Each committee approved the study without any further changes. However, one committee invited the investigator for interview before approval was granted. This involved questioning on matters such as, recruitment rate and action to be taken if a child or parent expressed concern for their well-being. Following this interview the committee requested statistical evidence regarding implications for detection of effects with a reduction in sample size and authorisation from the medical director of the paediatric unit. Accordingly, analyses conducted on the current sample using multivariate regression techniques and a power calculation on the projected sample size were evaluated by a professional statistician. Details, including the power estimate, statistician recommendations and the permission of the medical director were sent to the committee which subsequently led to approval. Another committee indicated concern and obtained a review of the study by a clinical psychologist prior to granting approval.

5.7 Outline of study process

Fulfilling study aims in terms of sample size and representativeness proved problematic. During preparation power calculations suggested a sample size of two hundred. Equivalent representation across hospital sites in terms of condition and age were planned through recruitment of each condition into eight age bands for example, eight to nine years, nine to ten years. Formulation of a sampling grid specifying hospital site, condition and age navigated participant selection to achieve representativeness. However, as recruitment proceeded it became readily apparent the anticipated sample size was not feasible. Difficulties arose in terms of for example, fewer children were available than expected and / or unwillingness to take part and pointed to an eventual sample of one hundred and thirty families. In March 1998, on the basis of the current recruitment rate, it was necessary to amend the expected sample size and evaluate statistical power. Revised power calculations implied that although power to detect 20 percent of the variance in a dependent variable using five predictors did not appear to be compromised, power for detection of interaction terms explaining a further five percent of variance would be reduced from 78 percent to 50 percent with alpha set at .05. In addition, the reduced sample size limits statistical power and suggests that caution would be needed in interpreting non-significant findings.

The recruitment process involved regular attendance at consultant out-patient clinics which differed by consultant and ranged from weekly to monthly. Study enrollment began in October 1997 at the regional centre followed by simultaneous inclusion of district general sites in May-June 1998. Recruitment sought to optimise participant involvement but in accordance with NHS executive ethical guidelines, minimise pressure to take part. Children and their parent(s) were approached during routine attendance at out patient clinic where introduction varied by consultant preference. For instance, several consultants permitted the researcher to sit in the consulting room and mediated introduction. Alternatively, introduction took place in the waiting room following consultation. Others were content for the researcher to approach participants independently. Variations were unavoidable given the number of clinicians and sites involved. It was essential, if the study was to continue smoothly that co-operation of health professionals was maintained and allowances were made for these preferences. Children eligible for involvement were identified from clinic lists, or with the assistance of medical and nursing staff. While several sites held clinics for specific conditions for example, diabetes or asthma, others were mixed. In clinics where children with a variety of conditions were seen the researcher outlined requirements to nursing staff who were then able to identify suitable candidates. At the start, all children identified as qualifying for study entry scheduled for appointments and who attended, were approached. As recruitment proceeded sample requirements were continually reviewed and particular children were targeted on the basis of age and / or condition group to achieve a representative age range within condition groups. However, very occasionally children were not identified and slipped through the filter, one family were not approached on consultant advice, and three families received invitation via letter.

Once initial contact with child and parent(s) had been made study details were briefly explained, i.e. purpose and what this would entail if interested in taking part. It was emphasised that families were not obliged to take part and there would be no effect on future medical care if they declined participation. A decision on involvement was not required immediately. The child and parent(s) were each given an introductory letter explaining who the researcher was and the institution conducting the study, and an information sheet defining study aims, what would be asked, assurances on confidentiality and data protection rights. At this point, prospective participants were offered the opportunity to ask questions. Child and parent(s) were invited to consider participation during the following week. The involvement of both parents was explicitly sought. Families were contacted by telephone to confirm their decision. If both parent(s) and child agreed, arrangements were made to visit them at home.

Home visits were organised at parental convenience. Appointments often occurred in the evening ensuring inclusion of fathers who usually worked full-time. Family members were seen together to obtain informed written consent guaranteeing that all received the same introductory details. Verification that the information sheet had been read and understood was sought and study aims reiterated. Clarification of details also highlighted the research nature of the investigation and withdrawal at any time would not affect future medical care. As questionnaires were a major component of the study, a check was also made on the presence of reading difficulties in mothers, fathers and children. This also indicated whether assistance would be needed. Questions regarding the study or any matter of concern were invited. Participants were made aware there were no right or wrong answers and it would be helpful if answers reflected their true experience. Questions were welcomed throughout the visit and afterwards. Each family were given the researcher's telephone number in the event of queries, questions or concerns arising from participation. Explanation of how data collection would proceed was given, and prior commitments, such as meetings, child's bedtime or attendance at youth club, were reviewed and permitted optimal use of available time.

Written consent was obtained from child and parent(s). In one instance a child was under guardianship of the local authority. In these circumstances, informed consent was also obtained from the child's social worker. On another occasion the consent form and questionnaire measures were read out and responses recorded for a parent who had a severe visual impairment. To ensure that child and parents expressed views freely they were seen separately, with a few exceptions this was possible. Where parent(s) declared an interest in being present during the child's interview, children were asked for their permission.

Parent(s) were interviewed (mother and father together) while their son or daughter was occupied with questionnaire completion. However, if child and / or parents had preexisting arrangements or the child required assistance the data collection protocol was modified accordingly. Questionnaires were explained to all children, and read out to children with reading difficulties. Following completion of the parental interview the child was interviewed about their best friends and parents completed the relevant questionnaires. The interview was recorded on audio tape with the child's consent, alternating the order of the two schedules between participants. Two questionnaires covering child quality of life and adjustment were completed by the mother if parents indicated she was the principal caretaker. If, however, parents stated both were involved in daily care then one measure was given to each parent. Measures were alternated to avoid systematic bias. Parents were also advised that questionnaires should be completed separately and to avoid collusion. Measures were generally presented in a fixed order unless situational factors such as the child's bedtime imposed an alternative approach. As the study included teacher assessments permission was sought from child and parent(s) to approach a teacher who knew the child well. The visit closed with a final opportunity to ask questions now that data collection was complete.

In circumstances where parents expressed concerns about the welfare of their child it was planned that they would be put in touch with local services or a report would be made to their paediatrician with their consent. On one occasion, it was necessary to bring an adolescent's distress to the attention of health professionals, in another instance parents raised anxiety about their child's behaviour and were advised to seek the opinion of their general practitioner.

Following the interview head teachers were approached by letter, to request teachers nominated by child and parents and who had known the child for the previous four months of the current or previous academic year to complete the Walker-McConnell scale of social competence and school adjustment. Both head teachers and teachers were provided with a brief description of the study and informed that they were not obliged to take part. Of the 133 teachers approached 127 responded representing a 95.48 percent response rate. Three children and one mother were unwilling for their teacher to be approached, two children were receiving home tuition and six teachers failed to return the questionnaire following two reminders. Assessments of condition severity (i.e. family care demands) were obtained from either the consultant paediatrician or clinical nurse specialist managing the child. However, assessment of reliability and validity delayed completion until the end of the study.

The procedure outlined above emerged from pilot interviews which resulted in minor alterations to the parental interview schedule. Additional questions briefly explored current and past impact of the child's condition on family life and available sources of support and are not included in analyses. The updated version of Child Health Related Quality of Life was also introduced early in the investigation. This version included small changes in wording. To check for potential measurement bias, the parent ratings of overall performance on the older and updated version were compared and found to differ significantly. Participants completing the older version reported lower levels of functioning than participants completing the updated version. However, further examination of other variables such as health professional report of condition severity, child report of overall performance, level of upset and satisfaction, perceived condition experience and behavioural and emotional difficulties consistently indicate that participants completing the older version were reported to have higher levels of condition severity, lower levels of functioning, more upset, less satisfaction and experience a higher condition impact and more behavioural and emotional difficulties than participants completing the updated measure. This would suggest that replacing the older version has not unduly biassed measurement.

It also became clear that completion of all measures for younger children was problematic. Consequently, the original intention to focus on children's three best friends was reduced to two and measures were prioritised (i.e. Strengths and Difficulties Questionnaire, Perceived Experience of Condition and friendship interview). However, on many occasions it proved impossible to obtain all measures in one visit and required a further appointment. In the event of a second visit, parent questionnaires were left with participants underscoring the need for separate completion. Participants involved in pilot interviews are included in the entire sample as modifications were not relevant to, or unlikely to influence analyses. The recruitment process finally concluded in February 1999.

5.8 Participation rate

In total, two hundred and nineteen children and their parents were approached, and included two sets of grandparents, one set of adoptive parents and one foster mother. One hundred and forty agreed to take part representing a 63.9 percent participation rate, although two children declined involvement. While the majority of youngsters who took part fell within an age range of eight to fifteen years and eleven months, five were between 16 and 17 years of age, and one had recently reached 17 years of age. However, rates as shown in Table 2, varied across hospital sites ranging from 60.3 to 75.6 percent. Higher participation rates were observed at sites covering rural rather than urban communities. The regional site reflected the lowest participation and was probably associated with the increased emphasis on research at the centre. Therefore children and families receiving care at this site were more likely to be invited to, and have taken part in studies.

Table 2

Proportion of families participating by hospital site

Site	Number approached	Number participating (%)
1	131	79 (60.3)
2	24	15 (62.5)
3	19	12 (63.1)
4	37	28 (75.6)
5	9	6 (66.6)

While on several occasions repeated efforts to contact those approached were unsuccessful, reasons offered for non-involvement included, lack of time, child already taken part in several studies, child unwilling, child unwell, family difficulties, felt to be intrusive, child did not perceive herself to be any different from others and moving house. A few explanations indicated parents were not keen to highlight condition consequences suggesting the sample may be biassed towards families willing to discuss issues.

We conclude coverage of the study process here and move in Chapter 6 to descriptive and statistical data analysis.

Chapter 6: Descriptive analyses and study findings for condition-related effects and validity of the risk resistance framework

In Chapter 6 the study sample is described, procedures guiding treatment of the data are outlined, research questions and hypotheses are put forward and tested. The aim of this chapter is to delineate the characteristics of the sample, address research questions, evaluate hypotheses and highlight study findings. Additional analyses focussing on effects of emotional difficulty and functional status on children's social functioning are elaborated in Chapter 7. The first part of the chapter is devoted to descriptive analyses, and moves on to deal with substantive research questions in the second part. The latter part is divided into five sections which centre on questions related to specific areas, the role of condition-related factors in child adjustment, the effects of condition factors on family functioning and parental and child coping and the evaluation and extension of the risk resistance framework. Results are summarised at the end of each section to assist the reader in assimilating the key findings.

6.1 Part I - Descriptive data analysis

Preliminary analyses sought to provide descriptive sample details and to identify gender differences that needed to be taken into account in subsequent analyses. In addition, given conceptual formulations guiding much of this work, an evaluation of condition differences, in terms family resources, generic condition dimensions, health service utilisation and school absence will assist and support interpretation of findings. For example, if families caring for a child with asthma have fewer available resources in comparison to other condition groups and findings suggest these children experience greater difficulty than children with other conditions it would be unclear whether this is attributable to lack of resources or the factors under evaluation.

A brief description of the sample including demographic details is presented with analyses of condition differences in gender, age level, family structure, family resources (e.g. education, income, occupational status), generic dimensions of chronic illness, such as age of onset etc., uptake of health services in the previous 12 months and school absence. Gender differences were examined in relation to variables to be considered in later analyses.

One hundred and forty families participated in the study and data were obtained from 136 mothers, 2 grandmothers, 100 fathers, 1 grandfather and 138 children. The sample included legal guardians, that is, one set of grandparents, one set of adoptive parents, a foster mother and a grandmother. Also included were four youngsters receiving additional school support for behavioural or learning difficulties. Another youngster attended a school providing services specific to his care requirements and, according to his parents, help with learning difficulties stemming from long school absences because of illness. These youngsters were judged to be sufficiently competent to participate and required minimal to moderate assistance to complete measures. In terms of diagnostic classification, conditions such as asthma, diabetes or cystic fibrosis, in contrast to epilepsy, are respectively defined by a single clinical manifestation. Epilepsy, on the other hand, may present in several different forms. The children and adolescents involved in this study reflected a range of diagnoses. Of the 24 children who took part, nine had grand-mal epilepsy, one temporal lobe epilepsy and 12 were diagnosed with absence epilepsy. The two remaining youngsters had experienced grand mal seizures, however one was being observed for symptoms following recent withdrawal of treatment, the other had had only one seizure. All children, with the exception of the adolescent undergoing observation, were receiving treatments that corresponded to their diagnoses.

Within the sample are one family who considered their child's asthma to be secondary to and less salient than an inherited condition. Although this child's asthma is associated with another condition, it was of sufficient severity to require ongoing medical intervention. Forty percent of the children involved in the study had other conditions apart from the condition which met the study criterion of being in receipt of hospital based care.
These conditions were generally related to the primary condition, for example children with asthma also had eczema, allergies and / or hay fever. Thirty three percent of children with cystic fibrosis also had asthma and several children with epilepsy were reported to have asthma. Children with diabetes were the least likely to have another physical condition. Nevertheless, these conditions with very few exceptions did not require the attention of a further specialist clinician.

For a number of reasons it proved impossible to obtain complete sets of data from participants, therefore numbers contributing differ by measure. For example, while two sets of parents were willing to take part the children declined, some parents did not wish to disclose information (e.g. income), or occasionally children were unwilling to continue or unable to concentrate. Nonetheless, the numbers available were adequate. Missing values were examined for systematic bias in non-report and replaced by the modal value for the respective response category or prorated (questionnaire measures and friendship closed questions only). However, where parents reported that questions were not applicable, such as level of bowel or bladder control in relation to health related quality of life, responses were replaced with the value reflecting high performance, satisfaction and no upset. On the measure of child coping, four children failed to indicate frequency of coping strategy use and helpfulness, or reported strategy helpfulness but did not specify use for one of the ten coping strategies. Missing frequency of use responses were replaced by absence of use and where helpfulness scores were reported without stipulating use missing responses were replaced by the lowest frequency of use score. There was one response missing from the measure completed by health professionals. This response referred to a child recently discharged from hospital care and was replaced by a score reflecting low condition severity (i.e. family care demands). The percentage of missing responses on each measure, was calculated by dividing the number of missing responses by the total number of potential responses that could be made and multiplying by 100. For example, 25 responses on the Strengths and Difficulties Questionnaire multiplied by the number of children completing the measure (i.e. 138) equals 3450. There were only two missing responses, therefore the percentage missing is equal to .05 percent. The percentage of missing responses from any one measure ranged between .04 to .85 percent. One questionnaire (teacher report) with over 15 percent of the responses missing was eliminated from analyses.

Since the self-report version of the Strengths and Difficulties Questionnaire is designed for use with 11 to 16 year olds, differences were evaluated for children below 11 years of age by condition group and gender. Results indicated no significant differences and accordingly all reports are included in present and subsequent analyses.

Analyses that refer to condition differences are reported in their entirety, only statistically significant findings for gender differences are put forward. Condition differences in demographic child and family factors, generic condition dimensions, healthcare utilisation and school absence are presented first, followed by examination of gender differences.

Child gender and age, family structure, income, parental level of education, occupational status, age of condition onset, condition duration, number of condition course features, condition severity and visibility, use of health services and school absence were subjected to chi-square tests to determine statistically significant differences. Gender differences were examined by individual informant that is, child, parent(s), health professional and teacher using parametric or non-parametric test where applicable. Table 3 summarises the measures evaluated. Throughout the analyses presented here and in Chapter 7 variable distributions were examined to determine appropriate use of parametric and non-parametric tests.

Table 3

Summary of measures evaluated for gender differences

Measure
Child report
Strengths and Difficulties Questionnaire (SDQ-Total difficulties score, subscale scores)
Child Health Related Quality of Life (Upset, total subscale score)
Perceived Experience of Condition Scale (Total score)
Kidcope (Number of strategies used and efficacy in common and illness problem contexts)
Friendship (Combined schedules)
Parent report
Medical details (i.e. Age of onset, duration, number of condition course features)
School absence
Uptake of health services in previous 12 months
Strengths and Difficulties Questionnaire (Total difficulties score)
Health related Quality of Life (performance)
Coping Health Inventory for Parents
Family Assessment Device (General functioning subscale)
Health Professional report
Condition severity (i.e. Family care demands) over previous 12 months
Teacher report
Walker-McConnell scale of School Adjustment and Social Competence

6.2 Demographic factors

The following tables display frequencies and total percentages for each factor by condition category, statistical results are presented in Table 10. Results are based on all participants contributing information however, the data relating to parents whose children declined involvement plays a limited role in analyses aimed at testing hypotheses. Exclusion of their data in descriptive analyses does not alter the results shown in Table 10.

Tables 4 and 5 show distributions for gender and age level. Boys and girls are fairly evenly distributed across condition groups although there are slightly more boys who have asthma or diabetes and girls who have cystic fibrosis or epilepsy. There are, however no significant differences between condition groups in terms of the number of boys or girls participating.

Table 4

Distribution of gender by condition category

	Gender	
Condition	Female	Male
Asthma	19	25
Diabetes mellitus	18	19
Cystic fibrosis	18	15
Epilepsy	14	10
Total (%)	69 (50.0)	69 (50.0)

Table 5 indicates that whereas the youngest age band is under-represented, children between the ages of 144-167 months are over-represented. The pattern of involvement by age level and condition is similar with the exception of children with cystic fibrosis. In comparison to other condition groups, fewer adolescents with cystic fibrosis took part. However, no significant differences were found for age level by condition category.

Table 5

Distribution of age level by condition category

Condition	Age level 96-119 months	120-143 months	144-167 months	Above 168 months
Asthma	9	9	16	10
Diabetes mellitus	6	8	11	12
Cystic fibrosis	8	13	9	3
Epilepsy	3	4	8	9
Total (%)	26 (18.8)	34 (24.6)	44 (31.9)	34 (24.9)

In terms of family structure 68 percent of the sample involved two-parent biological parents. Alternative family forms were roughly balanced between single parents, and stepfamilies, adoptive, foster and grandparents (see Table 6). The pattern of involvement across conditions is remarkably similar. Condition differences were examined by collapsing frequencies for family structure into two categories comprising two parent biological parents and alternate family forms. No significant differences emerged for family structure by condition category.

Table 6

Distribution of family structure by condition category

Condition	Family structure Single parent	Two-parent biological parents	Two-parent alternative forms (stepfather, grandparents, adoptive, foster-parent)
Asthma	6	29	10
Diabetes mellitus	7	25	4
Cystic fibrosis	4	21	7
Epilepsy	4	17	2
Total (%)	21 (15.4)	92 (67.6)	23 (16.9)

The distribution of annual occupational income is shown in Table 7. On the whole income bands are evenly distributed across the sample. However, there appear to be more families caring for a child with cystic fibrosis in the lowest income band relative to higher bands in comparison to families caring for children with other conditions. Nonetheless, family income was not found to differ significantly by condition category.

Table 7

Distribution of annual occupational income by condition category

	Total annual occupational income		
Condition	Up to £14,999	£15,000 to £24,999	Above £30,000
Asthma	14	13	12
Diabetes mellitus	4	12	14
Cystic fibrosis	12	7	9
Epilepsy	6	9	6
Total (%)	36 (30.5)	41 (34.7)	41 (34.7)

Table 8 displays level of parental education by condition category. Distribution of maternal educational qualifications by condition category suggest that relative to other condition groups a higher number of mothers of children with diabetes have gained A'levels/Degree qualifications. Inspection of the distribution for fathers presents a similar picture. Comparison of mothers and fathers indicates that a higher percentage of mothers than fathers have acquired O'Levels/GCSE and above. As cell frequencies for fathers fell below five, categories were reduced to two bands, none/CSE and O'Levels and higher. However, no significant condition differences were found in educational level for either mothers or fathers.

Table 8

Distribution of parental highest educational qualification by condition category

	Highest qualification					
	Mothers			Fathers		
Condition	None-CSE	O'levels /GCSE	A'levels-Degree	None-CSE	O'levels /GCSE	A'levels -Degree
Asthma	19	20	5	18	9	5
Diabetes mellitus	16	9	13	12	7	9
Cystic fibrosis	14	10	9	8	10	3
Epilepsy	6	12	5	11	6	0
Total	55	51	32	49	32	17
(%)	(39.9)	(37.0)	(23.2)	(50.0)	(32.7)	(17.3)

Occupational status for mothers and fathers is shown in Table 9. Occupations were coded according to the Standard Occupational Classification (OPCS, 1990). Categories were collapsed into non-manual and manual occupations. The later category included full-time house-wives/house-husbands and participants in HM Forces. Participants excluded from classification were either unemployed, students, retired or disabled.

Table 9

Distribution of occupational status by condition category

	Occupational status			
	Mothers		Fathers	
Condition	Non-manual	Manual (including house-wifery)	Non-manual	Manual (including house-husbandry and HM Forces)
Asthma	14	29	15	15
Diabetes mellitus	18	19	14	12
Cystic fibrosis	10	23	9	11
Epilepsy	10	13	8	10
Total (%)	52 (38.2)	84 (61.8)	46 (48.9)	48 (51.1)

On the whole, for mothers in all condition categories the pre-eminent occupation is manual. However, mothers of children with diabetes, in comparison to other condition groups are more evenly distributed between both occupational levels. For fathers, occupational status is evenly balanced between non-manual and manual occupations. No statistical differences were found for either mothers or fathers in terms of occupational status by condition category.

Table 10

Chi-square tests for condition differences in family structure, income, education and occupational status

Variable	Pearson Chi-square (Sig)
Gender (n=138)	$\chi^2 = 1.78$ (.61)
Age level (n=138)	$\chi^2 = 11.59$ (.23)
Family structure (n=136)	$\chi^2 = 0.73$ (.86)
Family income (n=118)	$\chi^2 = 7.81$ (.25)
Maternal education (n=138)	$\chi^2 = 2.19$ (.53)
Paternal education (n=98)	$\chi^2 = 3.73$ (.29)
Maternal occupational status (n=136)	$\chi^2 = 3.43$ (.32)
Paternal occupational status (n=94)	$\chi^2 = 0.53$ (.91)

Results, shown in Table 10 indicate demographic factors do not differ by condition category and imply that gender, age level, family structure and family resources are evenly distributed among condition groups. It can be assumed therefore that these factors are not confounded with condition differences.

6.3 Generic condition dimensions, health service utilisation and school absence

The general dimensions of chronic illness were found to differ by condition category. Table 11 shows mean scores for age of onset, proportion of life condition present, perceived number of condition course features, condition severity and visibility.

Age of condition onset, duration, visibility and number of condition course features were ascertained from parent report. Age of onset reflected the date of medical diagnosis and duration was calculated by subtracting date of diagnosis from the child's age at the time of enrollment and dividing duration by the child's age. This method sought to eliminate the confounding effect of age on duration. Number of condition course features was based on whether parents viewed their child's condition as constant (there all the time), progressive (getting worse as time goes by), relapsing (comes and goes regularly), episodic (appears intermittently). Scores therefore range from 0 to 4. This approach was taken to take account of parent perceptions of condition course. While a condition was generally, although not exclusively, viewed as constant, it was also perceived to accommodate other features. For example, parents may be continually aware that their child has a condition which exerts ongoing demands and may also increase at times when symptoms increase or as time passes. In the case of asthma, for instance, daily treatment requirements represent a constant and unremitting demand. However, when symptoms are accentuated further demands, such as the need to obtain medical advice or hospitalisation, create additional stresses. If parents perceive condition related strains and stresses to conform to a single or multiple features then treating condition course in terms of the number of features seems to afford greater precision and validity than regarding it purely as either constant or recurring and so on. Estimates of condition severity indicating family care demands over previous 12 months were obtained from either the consultant paediatrician or clinical nurse specialist, and ranged from 1 to 7. Condition visibility reflected parents' perception of whether the condition was visible to others in terms of an ordinal dimensional scale, yes (1), yes and no (2), no (3).

Table 11

Mean scores for age of onset, proportion of life condition present, condition severity, number of condition course features and condition visibility and One way analysis of variance by condition category

	Condition				
	Asthma (n = 44)	Diabetes mellitus (n = 37)	Cystic fibrosis (n =33)	Epilepsy (n = 24)	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Kruskal-Wallis Chi-sq (Sig)
Age condition onset (months)	34.57 (32.81)	90.45 (40.83)	20.12 (30.22)	102.22 (40.19)	$\chi^2 = 72.96$ (.00001)
Proportion of life condition present	.77 (.18)	.38 (.26)	.84 (.23)	.36 (.21)	$\chi^2 = 70.65$ (.00001)
Condition severity	4.29 (1.79)	4.51 (1.46)	4.09 (1.90)	2.58 (1.50)	$\chi^2 = 19.14$ (.0003)
Number of condition course features	1.88 (.75)	1.13 (.34)	1.90 (.91)	1.50 (.97)	$\chi^2 = 26.57$ (.00001)
Condition visibility	2.65 (.68)	2.89 (.39)	2.84 (.50)	2.79 (.58)	$\chi^2 = 4.52$ (.21)

All dimensions, with the exception of condition visibility, were found to differ significantly by condition category. With respect to age of onset and proportion of life condition present, children with asthma or cystic fibrosis were reported to have a younger age of condition onset and longer condition duration in comparison to children with either diabetes or epilepsy. In terms of condition severity, children with epilepsy were perceived to have lower levels of family care demands compared to other condition groups, children with diabetes, on the other hand are considered to exert the highest demand. The number of condition course features also differentiated groups. Inspection of the mean scores indicate that children with diabetes are reported to have fewer condition course features than children with other conditions and in particular when compared to children with either asthma or cystic fibrosis.

Health service utilisation in the previous 12 months also revealed differences by condition category. Table 12 presents mean scores for number of hospitalisations, day patient admissions, visits to accident and emergency and general practitioner for condition (i.e. condition category) related illness in the last 12 months.

Table 12

Mean scores for uptake of health services for condition-related illness in last 12 months and One-way analysis of variance by condition category

	Condition				
	Asthma (n = 44)	Diabetes mellitus (n = 37)	Cystic fibrosis (n =33)	Epilepsy (n = 24)	
	Mean (SD)	Mean (SD)	Mean (SD)	Mean (SD)	Kruskal-Wallis Chi-sq (Sig)
Number of hospitalisations in last 12 months	.79 (1.42)	.51 (1.28)	1.18 (1.62)	.04 (.20)	$\chi^2 = 17.41$ (.0006)
Number of times visited A&E in last 12 months	.27 (.75)	.02 (.16)	.06 (.34)	0	$\chi^2 = 9.50$ (.02)
Number of times day ward patient in last 12 months	.11 (.49)	.02 (.16)	1.24 (2.34)	0	$\chi^2 = 41.23$ (.00001)
Number of times visited GP in last 12 months	5.54 (7.02)	1.08 (1.70)	2.60 (3.49)	.54 (.97)	$\chi^2 = 25.95$ (.00001)

A & E (Accident and emergency); GP (General Practitioner)

Comparison of means for number of hospitalisations indicate children with cystic fibrosis were more likely to experience hospitalisation in the previous 12 months than other condition groups, children with epilepsy were the least likely to be hospitalised. In addition children with cystic fibrosis were more likely to experience day ward admission in comparison to other condition groups. Condition groups differed significantly in accident and emergency attendance. Mean scores show that children with asthma were more likely to visit accident and emergency in comparison to other condition groups. General practitioner visits in the previous 12 months also revealed significant differences. Children with asthma were reported to visit their general practitioner more frequently than children with either diabetes, cystic fibrosis or epilepsy.

Generally, children with asthma or cystic fibrosis appear to be more likely in comparison to children with either diabetes or epilepsy to utilise acute and primary care services. Children with cystic fibrosis experience more hospitalisations in comparison to other condition groups and children with asthma are more likely to visit accident and emergency and their general practitioner than other condition groups. The finding that children with asthma are more likely to use emergency services is consistent with findings reported by Holden *et al.* (1997). Children with asthma were shown to differ significantly from children with diabetes in terms of emergency room visits in the previous six months. The rate of attendance for children with asthma was higher than that of children with diabetes.

Parental estimates of school absence of in the previous 12 months demonstrated differences by condition category. Two children, both who have cystic fibrosis were receiving home tutoring and therefore eliminated from the analysis. Table 13 presents mean number of days missed by condition category.

Table 13

Mean number of school days absent in last 12 months and One way analysis of variance by condition category

Condition	Mean (SD)	Kruskal-Wallis Chi-sq (Sig)
Asthma (n = 44)	19.39 (19.92)	$\chi^2 = 32.68$ (.00001)
Diabetes mellitus (n = 37)	5.33 (9.96)	
Cystic fibrosis (n = 31)	14.74 (14.55)	
Epilepsy (n = 24)	5.85 (10.70)	

The comparison of mean frequencies for school absence suggests that children with asthma and cystic fibrosis miss more schooling than either children with diabetes or epilepsy.

Children who have asthma appear to be the most severely affected of all condition groups, although the standard deviation implies there is wide variation within this group. However, this finding is consistent with the other studies as suggested by Eiser (1990).

To summarise, condition differences were found for generic condition dimensions, uptake of health services and school absence. Children with asthma or cystic fibrosis have a younger condition onset and longer condition duration, a higher mean number of condition course features, have used more health care resources and missed more school days over previous 12 months in comparison to children with either diabetes or epilepsy. In contrast to children with epilepsy, these children also have higher levels of condition severity.

6.4 Gender differences

Gender differences emerged for both child and teacher report, no differences were found for measures completed by parent(s) or health professionals.

Child report

Significant differences were found in two areas, prosocial behaviour and coping efficacy for management of an illness related problem. Prosocial behaviour scores were derived from a subscale of the Strengths and Difficulties Questionnaire. Coping efficacy was obtained from assessment of the strategies used and reported helpfulness in dealing with a self-nominated illness problem. Efficacy scores were calculated by dividing helpfulness ratings by the number of strategies used. This approach aims to take account of expended effort in relation to perceived benefit since it seems probable that efficacy will be judged against how much effort is required and reflects the inclusion of strategies used but not found helpful.

Table 14 shows mean scores for the prosocial behaviour. Girls were found to rate themselves as significantly more prosocial than boys.

Table 14

Mean scores for prosocial behaviour and Mann-Whitney test by gender

Gender	Mean (SD)	Z (Sig)
Female (n=69)	8.23 (1.39)	Z = -2.69 (.007)
Male (n=69)	7.42 (1.81)	

In addition girls, in contrast to boys reported lower coping efficacy when dealing with an illness problem. Table 15 shows mean scores for coping efficacy. A t-test for independent samples indicates that girls differ significantly from boys in their reported levels of efficacy for strategies used to deal with an illness related problem.

Table 15

Mean coping efficacy for management of an illness related problem and t-test by gender

Gender	Mean (SD)	t (Sig)
Female (n=52)	1.01 (.49)	t = -2.41 (.01)
Male (n=49)	1.23 (.40)	

Teacher report

Teachers reported on social competence and school adjustment. The elementary and adolescent versions of the Walker-McConnell measure share a substantial number of items, however, additional items are included in the adolescent version and prevent amalgamation of the whole scale. Gender differences emerged on the adolescent version.

Two of the four subscales and total score revealed significant differences. Overall, girls received higher scores indicating better adjustment in comparison to boys. Table 16 shows the mean scores for the school adjustment and empathy subscales and total score.

Table 16

Mean scores for school adjustment, empathy and total score and Mann-Whitney tests by gender

	Subscale		
	School adjustment	Empathy	Total score
Gender	Mean (SD)	Mean (SD)	Mean (SD)
Female (n=24)	63.33 (8.04)	21.87 (3.49)	205.33 (19.08)
Male (n=26)	52.23 (13.64)	18.50 (5.28)	177.07 (40.81)
Z (Sig)	Z = -2.90 (.003)	Z = -2.34 (.01)	Z = -2.44 (.01)

The remaining subscales (self-control and peer relations) produced comparable findings and were statistically significant at the .06 level of probability. Gender differences were limited to the above findings and suggests this factor does not appear to be influential. These findings, with the exception of differences associated with coping efficacy do not affect the following analyses.

In the second part of Chapter 6 we turn to key research questions focussing on condition factors in relation to psychological variables and the risk resistance framework.

6.5 Part II - Introduction to research questions

Theoretical approaches and conceptual frameworks suggest psychosocial outcomes for children affected by long-term illness are defined by condition category and / or general dimensions characterising chronic illness. However, understanding of respective effects is somewhat equivocal and uncertain. Stresses engendered by condition category, for example, whether fatal or not, or features such as condition severity may produce differential consequences for individual family members in terms of stress management, family functioning and importantly, associated outcomes. As Patterson and Garwick (1994) suggest "There is little empirical research that has systematically examined differential impacts on the family, based on characteristics of the chronic condition itself". The relative effect of these factors calls for detailed evaluation and clarification. In addition, the adequacy of the entire risk resistance framework remains in doubt. Moreover, theoretical assumptions are unclear regarding which factors operate in what way on what *outcomes*.

Differing outcomes intuitively suggest the involvement of dissimilar factors. It is also possible however, that different outcomes may reflect common factors, or indeed that similar outcomes may entail dissimilar factors. Further understanding of the way in which various factors are configured and predict outcome may refine theory and benefit intervention development.

Psychosocial outcomes linked to chronic illness in childhood are defined as adjustment difficulties in nosological systems such as the Diagnostic Statistical Manual-IV (1995). This classificatory system is based on clinical, and more recently epidemiological research stipulating the diagnostic criteria for mental health conditions. Adjustment difficulties are associated with psychosocial stressors and expressed in behavioural and emotional problems. Research evaluating the prevalence of behavioural difficulties in children have identified two broad groups of behaviours. These are internalising and externalising difficulties, reflecting inhibitory and exhibitory behaviours respectively. Internalising difficulties are allied to emotional factors, and manifest symptoms in terms of depression and / or heightened anxiety, somatic complaints and withdrawal. Characteristic behaviours are lethargy, general disinterest or involvement in daily activity, social withdrawal and nervousness. Children may also lack self-esteem and confidence, and appear reluctant to engage in novel situations. On the other hand, externalising difficulties are often highly visible and, in contrast to internalising difficulties, usually have a greater impact on others. Behavioural difficulties include hyperactivity, poor concentration and / or conduct problems, such as disruption of school activities or for example, stealing.

Internalising difficulties are generally associated with stressful life events, externalising difficulties, may be similarly influenced but do not seem to be the more common response to stressful events. Both types of difficulty appear to be related to biological factors, such as gender. For example, boys are reported to have a higher incidence of externalising difficulties than girls, and girls in contrast to boys, are more prone to develop depression during adolescence (Compas *et al.*, 1993). Chronic illness may be viewed as a life event generating additional ongoing demands above and beyond that expected in a family where chronic illness is not a factor. Moreover, a frequent feature of a family life is enduring anxiety about the affected child's future well-being and functioning, such as capacity to have children and employment options. These factors are likely to produce chronic stress and suggest children may experience, and meta-analyses confirm (Lavigne & Faier-

Routman, 1992; Bennett, 1994), more internalising than externalising difficulties. With this in mind the following set of analyses examine the impact of variables on predominantly child report of total difficulties derived from the Strengths and Difficulties Questionnaire, and specific subscales that represent internalising difficulties (emotional symptom subscale score), and externalising difficulties (hyperactivity and conduct problem subscale scores combined). The respective subscales and terms corresponding to internalising and externalising difficulties are used interchangeably in the following presentation and chapters.

Before dealing with substantive questions, details of outcome variables and correlations for common measures among different informants are presented in Tables 17 and 18 to illustrate descriptive information. Summary statistics for adjustment indices indicate children, in contrast to parents, report higher levels of total difficulties, emotional symptoms, and hyperactivity and conduct problems combined. Moreover, this pattern held when the reports of children and parents within the same family were examined. This would suggest that at a group level children and parents differ in their appraisal of emotional and behavioural difficulties.

Table 17

Summary statistics for adjustment indices by informant

Outcome variable	Mean	Standard Deviation	Median	Mode	Range
Child report (n=138)					
Total difficulties	13.02	6.12	13	16	0-29
Emotional symptoms	3.96	2.35	4	2	0-9
Hyperactivity and conduct problems combined	6.75	3.63	7	6	0-16
Parent report (n=117)					
Total difficulties	11.21	6.25	10	12	0-30
Emotional symptoms	3.31	2.22	3	3	0-9
Hyperactivity and conduct problems combined	5.58	3.82	5	2	0-15

However, at an individual level the correlations between parent and child report on outcome indices, shown in Table 18 suggest there is strong association between informants on estimates of total difficulties, emotional symptoms and hyperactivity and conduct problems combined.

Table 18

Correlation coefficients between child and parent report of adjustment indices, child health related quality of life and coping efficacy

Informants	Variable		
Parental and child report (n=116)	Total difficulties	Emotional symptoms	Hyperactivity and conduct problems combined
Spearman Coefficient (Sig)	.48 (.0001)	.40 (.0001)	.50 (.0001)
Parental and child report (n=117)	Level of functioning child health related quality of life	Level of upset child health related quality of life	Level of satisfaction child health related quality of life
Pearson Coefficient (Sig)	.38 (.0001)	34 (.0001)	.41 (.0001)
Mother and child report (coping efficacy for illness related problem) (n=100)	Coping efficacy (family-centred behaviours)	Coping efficacy (self-care behaviours)	Coping efficacy (health-care situation)
Pearson Coefficient (Sig)	.09 (.34)	.02 (.79)	.08 (.37)
Father and child report (coping efficacy for illness related problem) (n=75)			
Pearson Coefficient (Sig)	-.002 (.98)	.01 (.88)	.05 (.62)

Modest agreement also exists in parent and child assessment of child health related quality of life in terms of functioning, degree of upset and satisfaction. Alternatively, no significant links were found between child, and either maternal or paternal coping efficacy. These findings imply that within individual families perceptions of health related functioning and difficulties are shared by family members but that the helpfulness of coping efforts are unrelated. The latter finding may reflect either the influence of developmental factors in relation to coping resources available to deal with problems (e.g. greater experience among parents), differences in the perceived stressfulness of condition-related problems and value of associated coping efforts or the use of different measures.

Statistical analyses sought to achieve two objectives. First, to establish the effects of condition category and the general dimensions of chronic illness on family functioning, parental and child coping and child adjustment outcome. Second, to evaluate the validity of the risk resistance framework (Wallander *et al.*, 1989b) and extend this model.

The analysis is presented in five sections that correspond to research questions and associated hypotheses. Section 1 addresses effects of condition category and generic dimensions on behavioural adjustment. Both child and parent report of adjustment are examined. Owing to the limited availability of parent report and the emphasis on gaining insight into factors related to the child's perspective, subsequent sections take child report as the index of outcome. In section 2 the effects of condition category and generic dimensions on parental coping and parent differences in coping are evaluated. In addition relationships to child report of adjustment are investigated. In section 3 the consequences of condition category and generic dimensions for child coping and adjustment outcome are examined. Section 4 presents a path analysis procedure evaluating the risk resistance framework. The final section extends the path analytic model investigating the role of friendship properties (i.e. play/association, intimacy) and teacher report of peer relations and school adjustment in relation to outcome. The variations in sample size reflected in each set of analyses are due to missing data. Variable distributions within each analysis were screened for outliers and several scores were identified as falling three standard deviations above or below the mean. Since there were very few outliers and scores deviated minimally from this criterion they were retained in analyses.

6.6 Section 1 -The role of condition category and generic dimensions in predicting adjustment outcome

Key questions arising from the non-categorical approach centre on emphasising the relative impact of generic dimensions rather than condition specificity on adjustment outcome, which may be framed in the following:

- What impact do general dimensions and condition category have on adjustment outcome (child report; parent report)?

Hypothesis

- Generic dimensions will be more influential than condition category in forecasting adjustment outcome (child report; parent report)

To address this question hierarchical regression techniques (forced entry) were employed. Blocks of variables were specified according to theoretical considerations. Therefore condition category preceded generic dimensions (i.e. age of condition onset, proportion of child's life condition present, condition severity -family care demands, number of condition course features and condition visibility). Total difficulties score, emotional symptoms score and hyperactivity and conduct problem scores combined were treated consecutively and regressed upon predictors. Estimates of internal reliability (i.e. Cronbach's alpha) for dependent variables were respectively .80, .63 and .77 indicating adequate to high reliability. Prior to these analyses demographic factors such as family structure, parental education, occupational status and income were examined to determine whether inclusion of these factors altered the role of condition-related variables in predicting outcome. Parental education, occupational status and income were highly and positively correlated with each other and family structure was associated with outcome variables. Since more data were available for mothers, examination included maternal education and family structure. Although family structure and level of maternal education were significant predictors of child and parent report of child difficulty these variables failed to explain any further variance attributed to condition-related variables or alter the findings. Consequently results for the role of condition factors in child report of difficulty are displayed in Tables 19, 20 and 21, parent report are shown in Tables 22, 23 and 24.

Table 19

Regression of total difficulties score (child report) upon condition category and generic dimensions (n=138)

Variable (df 8, 129)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-1.24	-0.09	-0.66	.50	0.002			
Diabetes mellitus	-3.31	-0.24	-1.85	.06	-0.15			
Cystic fibrosis	-4.39	-0.30	-2.14	.03	-0.16	.04	2.16	.09
Generic dimensions								
Age of condition onset	-0.01	-0.11	-0.37	.70				
Proportion of life condition present	-1.67	-0.08	-0.27	.78				
Condition severity	0.57	0.16	1.77	.07				
Number of condition course features	0.19	0.02	0.26	.79				
Condition visibility	0.68	0.06	0.71	.47		.07	1.34	.22
Constant	12.70		1.88	.06				

The regression equation explained 7.7 percent of the variance in total difficulties scores but failed to reach statistical significance. Condition category, in contrast to generic dimensions accounted for more of the variance in total difficulty score. Of particular note is the finding that children with cystic fibrosis, relative to other condition groups report significantly lower difficulty scores.

Table 20

Regression of emotional symptoms score (child report) upon condition category and generic dimensions (n=138)

Variable (df 8, 129)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	0.02	0.005	0.04	.96	0.08			
Diabetes mellitus	-0.89	-0.16	-1.28	.20	-0.11			
Cystic fibrosis	-0.67	-0.12	-0.83	.40	-0.05	.01	0.80	.49
Generic dimensions								
Age of condition onset	-0.007	-0.16	0.52	.60				
Proportion of life condition present	-0.95	-0.12	-0.39	.69				
Condition severity	0.21	0.16	1.70	.09				
Number of condition course features	-0.21	-0.07	-0.75	.45				
Condition visibility	0.23	0.05	0.62	.53		.04	0.77	.62
Constant	4.21		1.60	.11				

The second regression equation also failed to reach statistical significance. Condition category and generic dimensions explained a mere four percent of the variance in emotional symptom scores. In addition, no variable proved to be a significant predictor of emotional symptom scores. Nonetheless, while the amount of variance explained is small, generic dimensions, in contrast to condition category explain more of the variance in scores.

Table 21

Regression of hyperactivity and conduct scores (child report) upon condition category and generic dimensions (n=138)

Variable (df 8, 129)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-0.81	-0.10	-0.73	.46	-0.01			
Diabetes mellitus	-1.22	-0.15	-1.15	.24	-0.09			
Cystic fibrosis	-2.90	-0.34	-2.38	.01	-0.21	.05	2.59	.05
Generic dimensions								
Age of condition onset	0.002	0.03	0.11	.90				
Proportion of life condition present	0.94	0.08	0.25	.79				
Condition severity	0.23	0.11	1.24	.21				
Number of condition course features	0.29	0.06	0.68	.49				
Condition visibility	0.16	0.02	0.29	.76		.07	1.34	.22
Constant	5.40		1.35					

The results for the regression of hyperactivity and conduct scores combined on condition category and generic dimensions again failed to achieve statistical significance. In total variables account for 7.7 percent of the variance in scores. However, condition category accounts for more of the variance than generic dimensions. Specifically, children with cystic fibrosis, in comparison to other condition groups are significantly less likely to report hyperactive or conduct problem behaviour.

The picture presented by parents, while based on fewer participants, is somewhat different to that of children. Estimates of internal reliability (i.e. Cronbach's alpha) for total difficulties, emotional symptoms and hyperactivity and conduct problems combined were respectively .82, .66 and .81 suggesting moderate to high internal consistency. Results for regression of parent report of child difficulty on condition and generic dimensions are shown in Table 22.

Table 22

Regression of total difficulties score (parent report) upon condition category and generic dimensions (n=117)

Variable (df 8, 108)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-4.84	-0.33	-2.51	.01	-0.05			
Diabetes mellitus	-6.03	-0.43	-3.45	.0008	-0.31			
Cystic fibrosis	-6.52	-0.46	-3.20	.001	-0.17	.08	3.69	.01
Generic dimensions								
Age of condition onset	0.007	0.06	0.20	.83				
Proportion of life condition present	0.03	0.001	0.006	.99				
Condition severity	1.19	0.33	3.45	.0008				
Number of condition course features	0.60	0.08	0.83	.40				
Condition visibility	-0.72	-0.06	-0.65	.51		.20	3.42	.001
Constant	11.86		1.75	.08				

The regression equation is statistically significant explaining 20 percent of the variance in total difficulty scores. Much of the variance appears to be accounted for by condition severity. Nevertheless, condition category appears to be an influential factor. Relative to children with epilepsy (reference category) children with either asthma, diabetes or cystic fibrosis are reported to be less likely to have emotional or behavioural difficulties. Children with either diabetes or cystic fibrosis are the least likely of all condition groups to have difficulties. Condition severity, however, is a significant predictor explaining some 12 percent of the variance. The direction of the beta value suggests that as condition severity increases there is a corresponding increase in behavioural difficulties.

Table 23 presents results for regression of emotional symptom score on condition category and generic dimensions.

Table 23

Regression of emotional symptoms score (parent report) upon condition category and generic dimensions (n=117)

Variable (df 8, 108)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-0.92	-0.18	-1.41	.16	0.09			
Diabetes mellitus	-1.69	-0.34	-2.84	.005	-0.15			
Cystic fibrosis	-1.28	-0.25	-1.85	.06	-0.03	.02	0.94	.42
Generic dimensions								
Age of condition onset	0.004	0.09	0.32	.74				
Proportion of life condition present	0.49	0.07	0.24	.80				
Condition severity	0.62	0.49	5.28	.00001				
Number of condition course features	0.14	0.05	0.60	.54				
Condition visibility	-0.54	-0.12	-1.43	.15		.26	4.93	.00001
Constant	2.71		1.17	.24				

The regression equation accounts for 26 percent of the variance in emotional symptom scores. Twenty four percent is explained by generic dimensions, principally condition severity. Within the condition category block, which accounts for just two percent of the variance, children with diabetes are reported by parents to be significantly less likely, than other condition groups, to show emotional symptoms. Condition severity is a highly significant predictor of emotional symptoms, suggesting that increases in severity rise in parallel with emotional symptoms.

Results for the final equation, regression of hyperactivity and conduct problem scores are presented in Table 24.

Table 24

Regression of hyperactivity and conduct scores (parent report) upon condition category and generic dimensions (n=117)

Variable (df 8, 108)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-1.80	-0.20	-1.43	.15	-0.01			
Diabetes mellitus	-2.19	-0.25	-1.93	.05	-0.21			
Cystic fibrosis	-3.45	-0.40	-2.60	.01	-0.22	.07	3.17	.02
Generic dimensions								
Age of condition onset	0.007	0.09	0.30	.76				
Proportion of life condition present	1.28	0.10	0.32	.74				
Condition severity	0.22	0.10	1.00	.31				
Number of condition course features	0.006	0.001	0.01	.98				
Condition visibility	0.23	0.03	0.32	.74		.08	1.32	.24
Constant	4.81		1.09	.27				

The regression equation failed to reach statistical significance, accounting for eight percent of the variance in the combined hyperactivity and conduct problem scores. In parallel with findings for children, condition category was found to be more influential than generic dimensions in forecasting externalising difficulties. Parent report indicated that children with either diabetes or cystic fibrosis were significantly less likely in comparison with children with asthma or epilepsy to display hyperactive or conduct problem behaviour.

6.6.1 Section 1 - Summary of findings for condition-related parameters and adjustment outcome

Overall, findings from the three equations relating to child report suggest that together condition category and generic dimensions to do not explain a significant amount of the variance in child report of behavioural or emotional difficulty. Nevertheless, condition category is a significant predictor of reported difficulty. Children with cystic fibrosis are significantly less likely, in comparison to children with either asthma, diabetes or epilepsy to experience difficulty. Much of this may be attributed to a reduction in externalising behaviours. Interestingly, generic dimensions while not significant predictors appear to play a greater role in forecasting emotional symptoms. The suggestion is that consequences of factors such as condition course or severity may generate stress and produce emotional symptoms. However, findings do not support the hypothesis that generic dimensions would be more influential than condition category.

Findings from regression equations for parent report indicate that both condition category and generic dimensions explain a significant proportion of the variance in total difficulties scores. However, comparison of regression procedures for emotional symptoms and hyperactivity and conduct problems combined point to emotional symptoms being a major contributor to total difficulty scores. Condition category is a significant predictor for total difficulties and externalising difficulties, accounting for eight and seven percent of the variance respectively. Children with diabetes, relative to other condition groups appear to be least at risk for experiencing both internalising and externalising difficulties. On the whole, children with cystic fibrosis, compared to remaining condition groups are the least likely to display externalising difficulties. Nonetheless, generic dimensions were found to explain a significant amount of variance in total difficulties and emotional symptom scores. In each equation, condition severity appears to be the principal predictor suggesting that health professional estimates of family care demands increases total difficulties and specifically emotional symptoms. Strikingly, this pattern is not found for externalising difficulties, condition category is the more important predictor of outcome, a finding that is consistent with child report. However, in general findings highlight differences for child and parent report, suggesting the value and importance of including multiple perspectives in the research process. These results, in contrast to child report, suggest support for the hypothesis in terms of internalising difficulties.

6.7 Section 2 -The effects of condition category and generic dimensions on parent coping and family functioning and the role of parent coping in predicting adjustment outcome

Key questions raised by the non-categorical approach relate to the effects of condition category and generic dimensions on maternal and paternal report of coping and family functioning. In addition, few studies question in what way parents differ in coping and perceptions of family functioning and explore the impact of these differences on adjustment outcome. Questions aim to address differential consequences for parents and ascertain whether these differences influence child adjustment. By focussing on both parents, it is possible to highlight a broader picture of factors contributing to outcome.

- What are the effects of condition category and generic dimensions on parent coping?
- What are the effects of condition category and generic dimensions on parent report of family functioning?
- Do parents differ in terms of condition category and generic dimensions in coping and reports of family functioning?
- Are differences in parent coping moderated by condition category and / or generic dimensions? Are moderated effects predictive of adjustment outcome?

Family functioning is examined using the general family functioning subscale of the Family Assessment Device. This subscale, in contrast to the remaining subscales which have been shown to overlap, provides an adequate summary of family functioning (Ridenour *et al.*, 1999). Coping is evaluated by individual subscales of the Coping Health Inventory for Parents and represents the mean coping efficacy score that is, helpfulness score divided by number of behaviours used, for that subscale. Scale 1 is defined by behaviours that are helpful in maintaining family integration and co-operation and an optimistic definition of the situation. Scale 2 reflects behaviours helpful in maintaining social support, self-esteem and psychological stability. Scale 3 is linked to behaviours that assist understanding of the health care situation through communication with other parents in the same situation and health care professionals.

Internal reliabilities for the family functioning summary scale and coping subscales using raw responses for the entire sample indicate high internal consistency. Computation of Cronbach's alpha for maternal report of family functioning was .82 (n=137), and .83 for paternal report (n=99). Alpha coefficients for maternal report on coping scales 1, 2 and 3 (n=137), were .77, .84 and .79 respectively, and for paternal report (n=98) .83, .89 and .81. The generic dimensions, age of condition onset and proportion of the child's life condition present were recoded into four equal categories reflecting, advancing age of condition of onset and increasing duration. In addition, condition course features were recoded into three levels as only six children were reported to have either none or four course features.

A subsample of 95 couples for which data were available were involved in the current analysis. A mixture of parametric and non-parametric tests was used to evaluate the following hypotheses:

Hypotheses

- Generic dimensions will be more influential than condition category in moderating parent report of family functioning

- Generic dimensions will be more influential than condition category in moderating parent coping

Given the limited evidence in respect to paternal coping and perspectives on family functioning no specific hypotheses were formulated on parent differences. The approach here was exploratory. If differences were apparent, and moderated by condition parameters, analysis of effects on adjustment outcome were planned. Effects of condition category and generic dimensions were initially examined by one way analysis of variance. Moderating effects, that is whether condition-related parameters interact with parent gender and modify reports of family functioning and coping were evaluated with two-way analysis of variance. Results of one way analyses for fathers are shown in Table 25 and results for mothers in Table 26.

Table 25

One way analysis of variance for paternal report of family functioning and coping efficacy by condition category and generic dimensions

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
Variable	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Condition category (df 3, 91)	F=1.94 (.12)	F=0.98 (.40)	F=3.02 (.03)	F=0.09 (.90)
Generic dimensions				
Age of condition onset (df 3, 91)	F=0.33 (.80)	F=0.76 (.51)	F=1.33 (.26)	F=0.41 (.74)
Proportion of life condition present (df 3, 91)	F=0.64 (.58)	F=1.35 (.26)	F=0.51 (.67)	F=1.19 (.31)
Condition severity (df 6, 88)	F=1.33 (.25)	F=0.99 (.43)	F=1.88 (.09)	F=0.42 (.86)
Number of condition course features (df 2, 92)	F=0.14 (.86)	F=0.60 (.54)	F=1.35 (.26)	F=0.07 (.93)
Condition visibility (df 2, 92)	F=0.39 (.67)	F=1.35 (.26)	F=0.51 (.60)	F=2.83 (.06)

For fathers condition category revealed differences for coping efficacy in terms of behaviours that assist maintenance of self-esteem, social support and psychological stability. Fathers of children with asthma were found to differ significantly, ($p< .05$) from fathers of children with epilepsy. Fathers of children with asthma report higher efficacy scores than fathers of children with epilepsy. Generic dimensions, however, did not reveal significant differences.

Table 26

One way analysis of variance for maternal report of family functioning and coping efficacy by condition category and generic dimensions

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
Variable	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Condition category (df 3, 91)	F=0.98 (.40)	F=0.50 (.67)	F=0.87 (.45)	F=0.28 (.83)
Generic dimensions				
Age of condition onset (df 3, 91)	F=1.87 (.13)	F=0.65 (.57)	F=0.18 (.90)	F=1.50 (.21)
Proportion of life condition present (df 3, 91)	F=1.00 (.39)	F=1.34 (.26)	F=0.28 (.83)	F=2.78 (.04)*
Condition severity (df 6, 88)	F=0.73 (.61)	F=2.04 (.06)	F=0.97 (.44)	F=1.30 (.26)
Number of condition course features (df 2, 92)	F=0.61 (.54)	F=5.16 (.007)	F=0.53 (.58)	F=2.44 (.09)
Condition visibility (df 2, 92)	F=0.18 (.82)	F=0.23 (.79)	F=3.11 (.04)	F=1.02 (.36)

*=variances differ significantly

For mothers, significant differences were found for generic dimensions but not condition category. Condition duration, number of condition course features and condition visibility revealed differences in coping efficacy for scales 3 , 1 and 2 respectively. Although efficacy for behaviours that support understanding of the health care situation generally decreased as condition duration lengthened variances for groups were significantly different. Group differences were examined using a Kruskal-Wallis test but failed to reach the level of statistical significance ($p< .06$). An increase in the number of condition course features produced a decline in the mean efficacy of behaviours linked to family well-being. Mothers of children with three to four condition course features reported significantly lower levels of efficacy compared to mothers of children with either no, one or two condition course features. The efficacy of behaviours maintaining social support and psychological stability were significantly higher for mothers when the condition was not visible to others. However, no groups differed significantly from one another.

Parent differences were evaluated to establish if condition category and generic dimensions moderate family functioning and coping. Two-way analysis of variance procedures were conducted for each variable. Graphical representations are helpful in illustrating the pattern of parental responses, and therefore included to support interpretation. Table 27 displays results for parent differences in relation to condition category.

Figures 4, 5, 6 and 7 present parent differences in family functioning and coping efficacy by condition category.

Table 27

Two-way analysis of variance for general family functioning and parental coping efficacy by parent and condition category

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.006 (.94)	F=8.02 (.005)	F=20.95 (.0001)	F=23.69 (.0001)
Condition category	F=1.68 (.17)	F=1.32 (.26)	F=3.46 (.01)	F=0.05 (.98)
Two -way interaction				
Parent x Condition category	F=1.24 (.29)	F=.23 (.87)	F=0.90 (.43)	F=0.26 (.84)

Main effects emerged for parent and condition category in parent coping but not family functioning. All three scales show a significant difference between parents in the efficacy of coping behaviours. Comparison of mean scores indicate that mothers report higher efficacy scores than fathers. Condition category produced effects for efficacy of behaviours that maintain social support and self-esteem. Effects appear to be attributable to mean differences between fathers. Fathers of children with asthma report somewhat higher scores than fathers of children with epilepsy. No interaction effects were found.

Figure 4

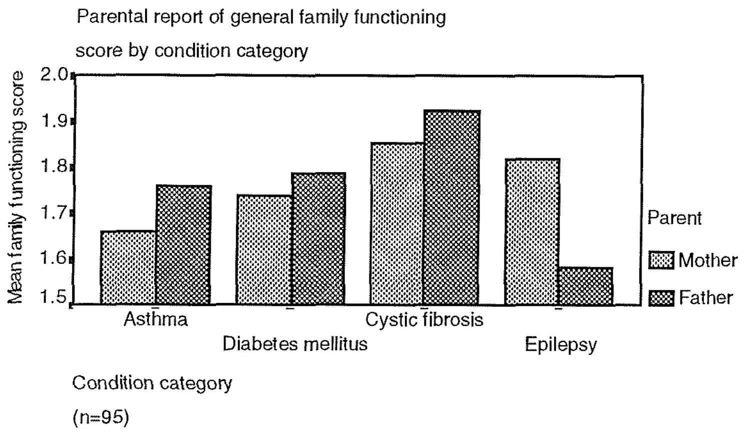


Figure 4 shows parents generally appear to agree on perceptions of family functioning, however, this does not hold for parents of children with epilepsy. Although not statistically significant there appear to be differences by condition category. For example, parents of children with cystic fibrosis report higher mean scores, suggesting that family functioning, while within the healthy range is perhaps less optimal than other condition groups.

Figure 5

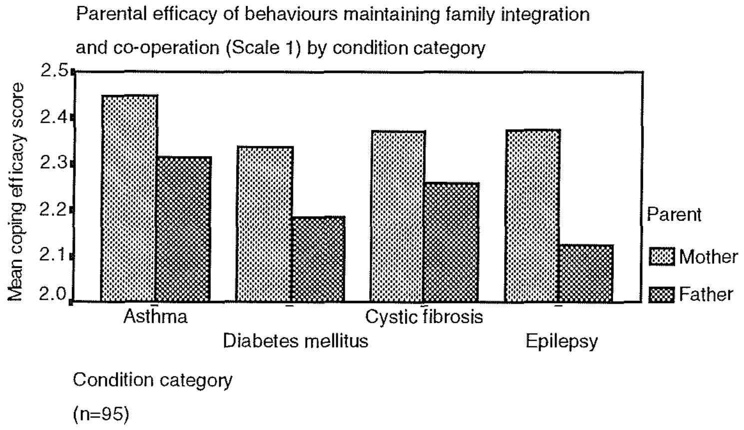


Figure 5 indicates that parents differ in reported efficacy of behaviours maintaining family integration and co-operation. Mothers in all condition groups report higher efficacy with mothers of children with asthma reporting the highest efficacy scores. Condition differences for fathers seem to be greater than mothers. Fathers of children with asthma, in line with their partners, report the highest efficacy scores while fathers of children with epilepsy report the lowest scores.

Figure 6

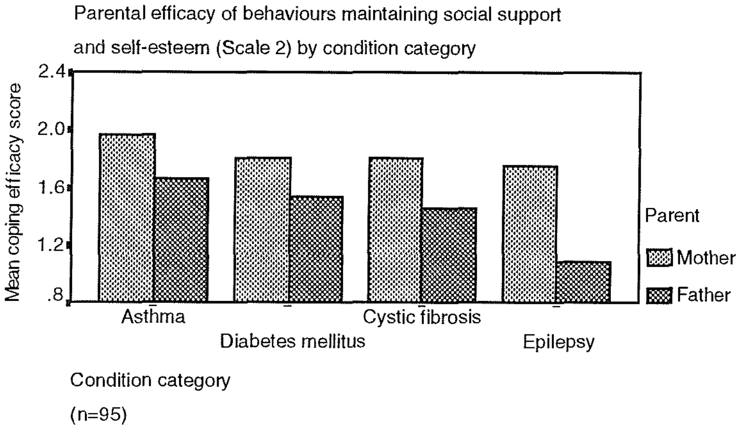


Figure 6 illustrates parent differences in efficacy of behaviours maintaining social support and self-esteem. Mothers in all condition groups report higher efficacy scores than fathers. Condition group appears to have little effect on efficacy score for mothers. Nonetheless, mothers of children with asthma were again found to report higher scores on average than other condition groups. The effects of condition category appear to be more pronounced for fathers. Fathers of children with asthma report the highest scores while fathers of children with epilepsy report the lowest scores.

Figure 7

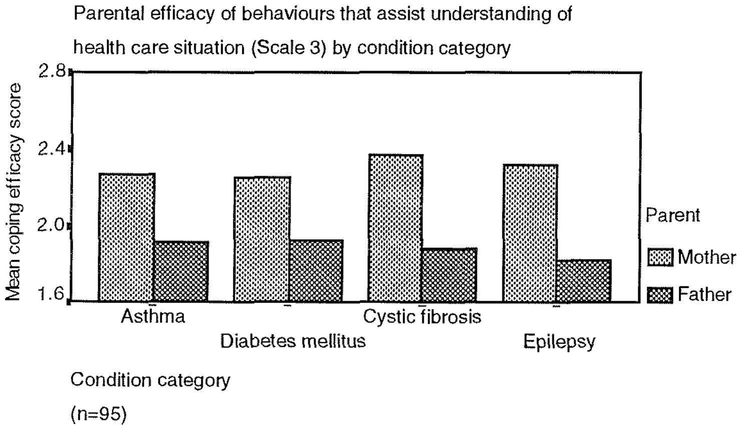


Figure 7 confirms statistical findings, mothers in comparison to fathers, across all condition groups report substantially higher efficacy for behaviours assisting understanding of the health care situation. There appears to little effect of condition category for either fathers or mothers.

Analyses focussing on generic dimensions are presented in the following order, age of condition onset, proportion of child's life condition present, condition severity, number of condition course features and condition visibility. Table 28 below, displays results for effects of parent by age of condition onset.

Table 28

Two-way analysis of variance for general family functioning and parental coping efficacy by parent and age of condition onset

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.06 (.79)	F=6.62 (.01)	F=19.12 (.0001)	F=19.16 (.0001)
Age of condition onset	F=1.78 (.15)	F=1.36 (.25)	F=.82 (.48)	F=0.68 (.56)
Two -way interaction				
Parent x Age of condition onset	F=0.37 (.76)	F=0.07 (.97)	F=0.96 (.41)	F=0.90 (.44)

Findings reveal a main effect for parent report of coping but not family functioning. Age of condition onset did not produce effects for either coping or family functioning. No interaction effects were found. Comparison of mean efficacy scores indicate that mothers report higher efficacy scores that fathers. Figures 8, 9, 10 and 11 illustrate mean response for parent by dimension level.

Figure 8

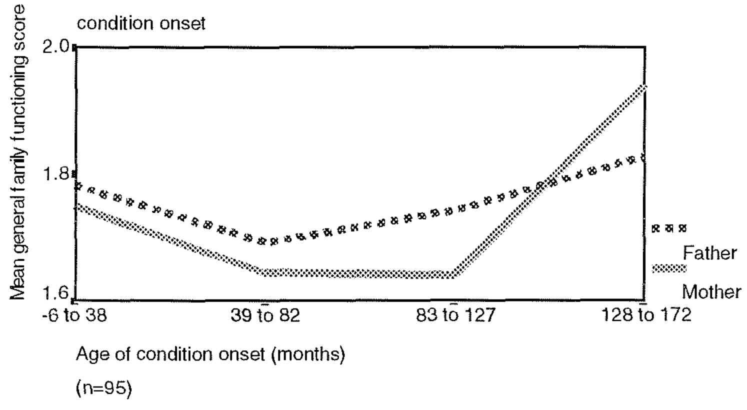


Figure 8 depicts, as suggested by statistical analysis, that parents generally differ little in their perceptions of family functioning in regard to age of condition onset. However, later condition onset appears to affect mothers' reports suggesting a trend for family functioning to be viewed as less than optimal.

Figure 9

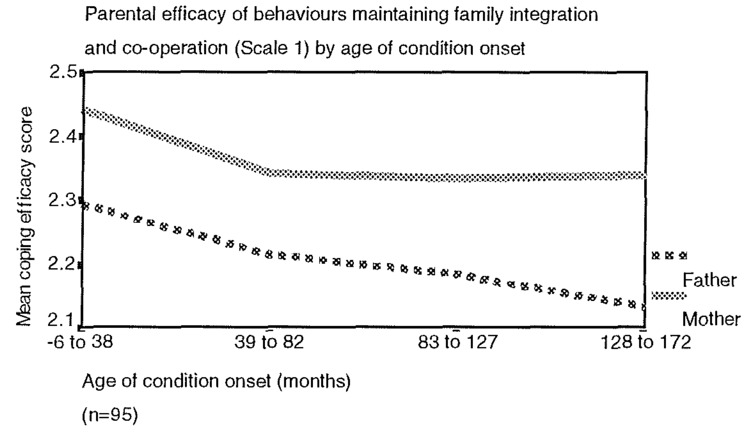


Figure 9 demonstrates, consistent with findings, marked differences between parents in the overall efficacy of behaviours that maintain family integration and co-operation. In addition, however, there is a linear trend for fathers to report a reduction in efficacy as age of onset increases. While there also appears to be a slight decrease in efficacy for mothers, the pattern is less pronounced.

Figure 10

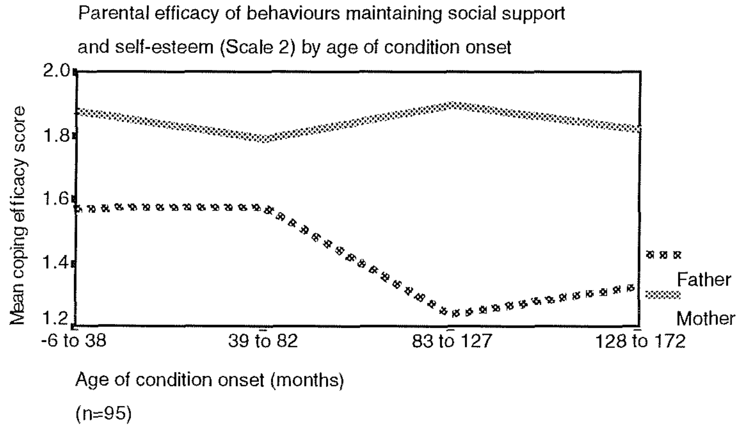


Figure 10 also illustrates substantial differences in parent coping efficacy for behaviours that maintain social support and self-esteem. There appears to be little effect for age of condition onset on mothers, however later condition onset seems to reduce efficacy in fathers.

Figure 11

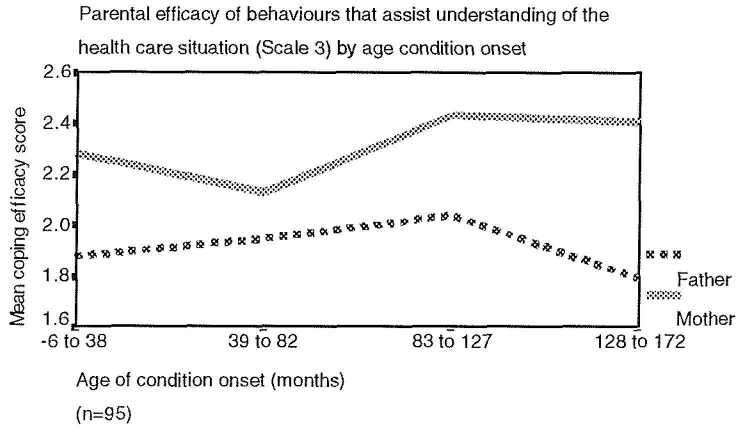


Figure 11 depicts marked parent differences in efficacy of behaviours that assist understanding of the health care situation. Age of condition onset appears to have little effect on the coping efficacy of either parent. However, differences appear to increase with later condition onset. Table 29 show results for analyses of parent by proportion of child's life condition present. Figures 12, 13,14 and 15 display mean parent response by level of dimension.

Table 29

Two-way analysis of variance for family functioning and parental coping efficacy by parent and proportion of child's life condition present

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.02 (.86)	F=5.22 (.02)	F=14.33 (.0001)	F=17.11 (.0001)
Proportion of life condition present	F=1.59 (.19)	F=0.80 (.49)	F=0.28 (.83)	F=1.28 (.28)
Two -way interaction				
Parent x Proportion of life condition present	F=0.05 (.98)	F=1.88 (.13)	F=0.57 (.63)	F=2.18 (.09)

The pattern of results shown in Table 29 is similar to effects found for age of condition onset. A main effect for parent is evident in terms of coping efficacy but not family functioning. Notably, effects are highly significant for scales 2 and 3. As indicated previously mothers report higher efficacy scores, in comparison to fathers, on all scales. A main effect for the proportion of life a condition is present failed to reveal significant effects in parallel with interaction terms. Nonetheless, the interaction terms for efficacy of behaviours that assist understanding of the health care situation suggest a trend for mothers to report a reduction in efficacy as condition duration increases.

Figure 12

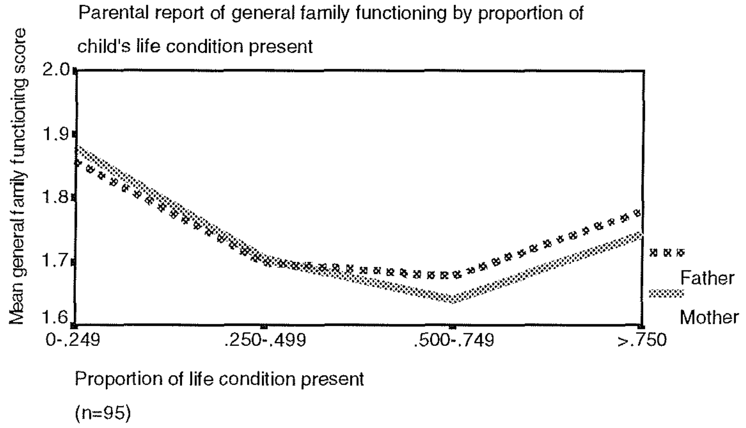


Figure 12 suggests, in line with statistical findings that parents do not differ in their perceptions of family functioning. However, increases in the proportion of life a condition is present seems to have a beneficial effect on family functioning. Decreases in mean scores reflect an inclination toward healthier family functioning as condition duration lengthens.

Figure 13

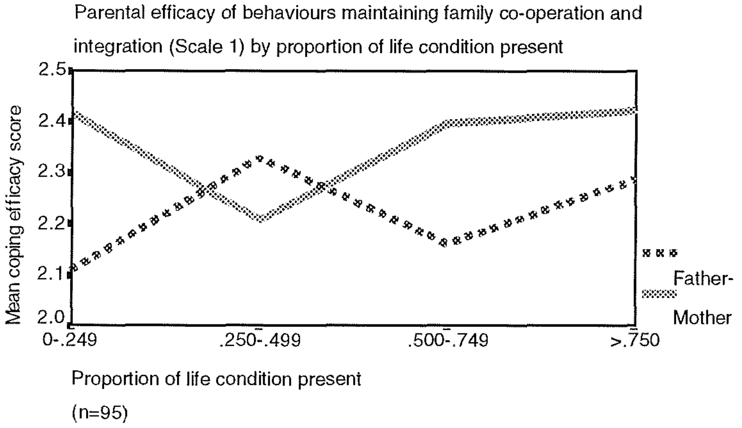


Figure 13 highlights, consistent with statistical findings parent differences in coping efficacy for behaviours that maintain family integration and co-operation. For fathers, increases in the proportion of life a condition is present demonstrates a parallel increase in efficacy. Mothers show a decrease in efficacy at the outset but return to original efficacy levels as duration lengthens.

Figure 14

Parental efficacy of behaviours maintaining social support and self-esteem (Scale 2) by proportion of child's life condition present

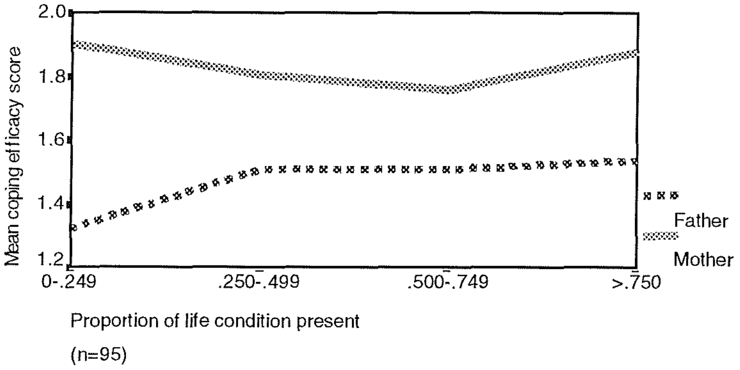


Figure 14 shows parents differ markedly in terms of reported efficacy of behaviours that maintain social support and self-esteem. The proportion of life a condition is present appears to have little or no effect on reported efficacy for both parents.

Figure 15

Parental efficacy of behaviours that assist understanding of the health care situation (Scale 3) by proportion of child's life condition present

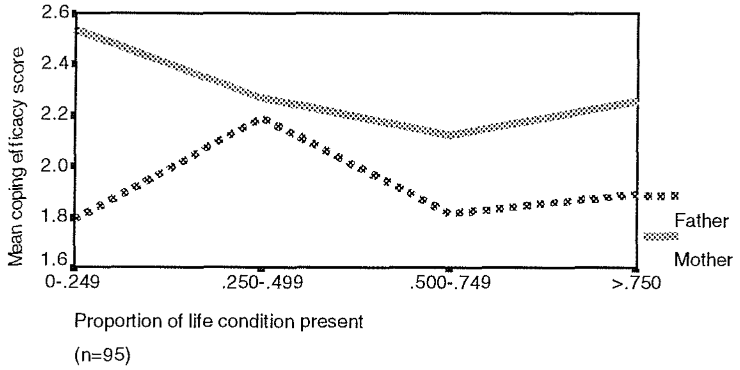


Figure 15 depicts parent differences in reported efficacy of behaviours that aid understanding of the health care situation and confirms statistical findings. For mothers, efficacy declines as the period a condition is present increases. The pattern for fathers indicates an increase in efficacy at the outset which declines as condition duration lengthens.

Table 30 presents results for analyses of parent by condition severity. Figures 16, 17, 18 and 19 illustrate corresponding patterns for parents by dimension level.

Table 30

Two-way analysis of variance for general family functioning and parental coping efficacy by parent and condition severity

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.09 (.75)	F=5.34 (.02)	F=15.65 (.0001)	F=18.98 (.0001)
Condition severity	F=1.93 (.07)	F=1.08 (.10)	F=1.86 (.08)	F=0.92 (.48)
Two -way interaction				
Parent x Condition severity	F=.12 (.99)	F=1.05 (.38)	F=1.19 (.31)	F=0.52 (.78)

Results reveal main effects for parental coping, and consistent with previous findings no effects were found for family functioning. Condition severity marginally fails to achieve statistical significance, but suggests trends in family functioning and coping efficacy for scales 1 and 2. Interaction terms were not found to be statistically significant. Comparison of mean coping efficacy scores for parent show that mothers report higher efficacy scores than fathers. The difference is most marked for coping efficacy scales 2 and 3. Parents were not found to differ in their perceptions of family functioning.

Figure 16

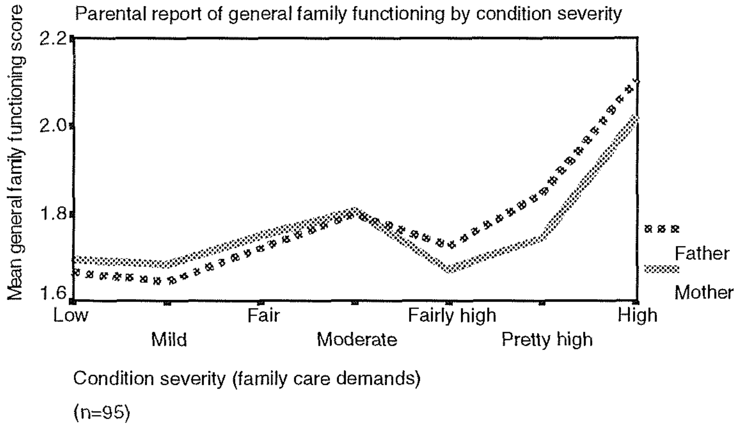


Figure 16 substantiates findings, showing effects of condition severity on parent report of family functioning. Parents differ very little and both perceive a deterioration in family functioning as condition severity (i.e. family care demands) increases.

Figure 17

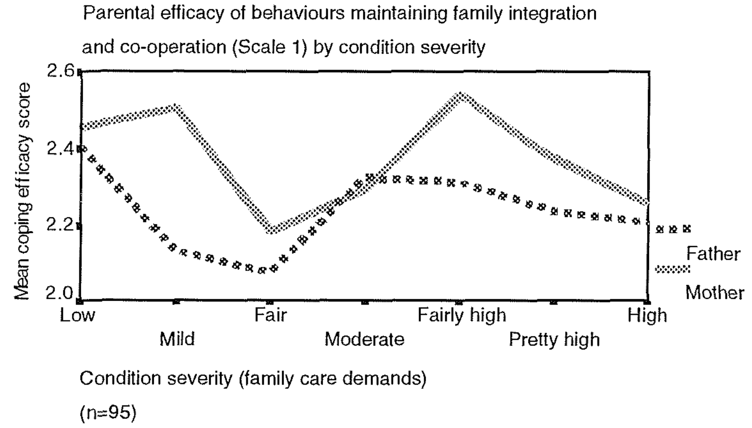


Figure 17 illustrates parent differences in terms of efficacy of behaviours maintaining family integration and co-operation by level of condition severity. As suggested by findings, mothers generally report higher efficacy scores with both parents showing a slight decline in efficacy as condition severity increases.

Figure 18

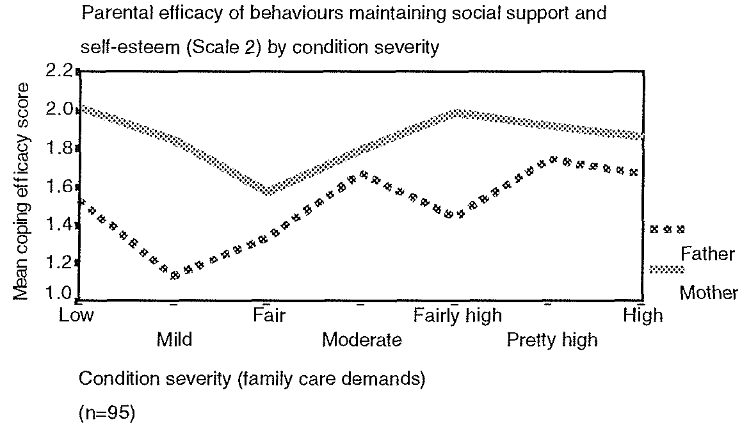


Figure 18 demonstrates a marked difference between parents in coping efficacy for behaviours maintaining social support and self-esteem, although differences reduce as condition severity increases. More precisely, fathers in contrast to mothers tend to report an increase in efficacy as condition severity increases.

Figure 19

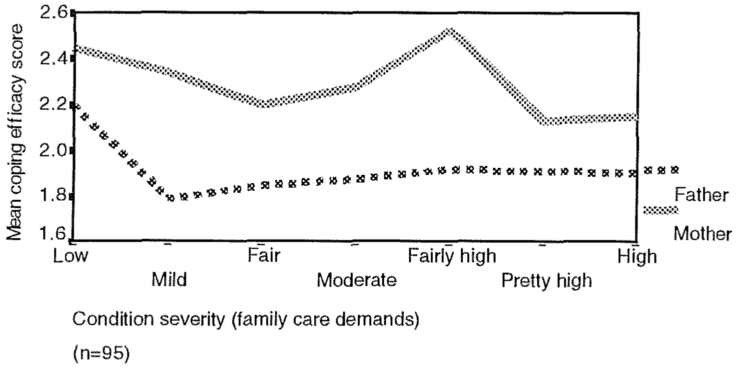

Parental efficacy of behaviours that assist understanding of the health care situation (Scale 3) by condition severity

Figure 19 also shows a marked difference between parents in coping efficacy of behaviours that assist understanding of the health care situation. Mothers, in comparison to fathers, report higher efficacy scores. Differences do not appear to be affected by condition severity. However, there appears to be a slight decline in efficacy for both parents as condition severity increases.

Table 31 shows the results of analyses for parent by number of condition course features. While course features were recoded into three levels figures retain the original five levels incorporating three participants with no, and three participants with four condition course features. Figures 20, 21, 22 and 23 display mean parent scores for generic dimension level.

Table 31

Two-way analysis of variance for general family functioning and parental coping efficacy by parent and number of condition course features

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.001 (.98)	F=1.63 (.20)	F=8.19 (.005)	F=12.75 (.0001)
Number of condition course features	F=0.65 (.52)	F=0.72 (.48)	F=0.37 (.69)	F=0.98 (.37)
Two -way interaction				
Parent x Number of condition course features	F=0.10 (.90)	F=4.20 (.01)	F=1.72 (.18)	F=.78 (.46)

Main effects were not found for family functioning but emerged for coping. Scales 2 and 3 showed a main effect for parent indicating a striking difference between parents in the efficacy of self and health care behaviours. An interaction effect was found for efficacy of behaviours maintaining family integration and co-operation. Examination of mean scores revealed that increases in the number of condition course features were characterised by a decline in coping efficacy for mothers and an increase in efficacy for fathers.

Figure 20

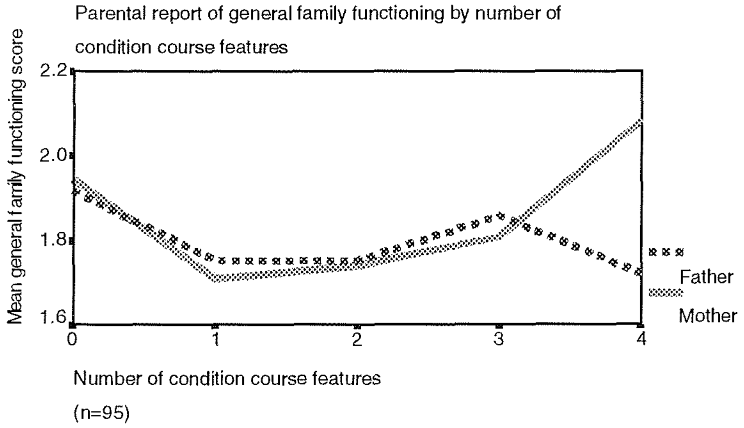


Figure 20 indicates parents do not differ in perceptions of family functioning when there are few condition course features. However, if the condition is perceived to be, constant, progressive, recurring, and episodic parental perceptions appear to differ substantially. Essentially, mothers report a decline in family functioning, fathers, on the other hand, perceive family functioning to improve.

Figure 21

Parental efficacy of behaviours maintaining family co-operation and integration (Scale 1) by number of conditon course features

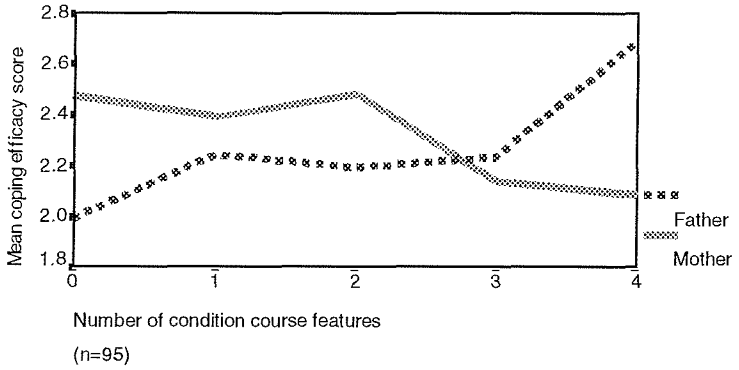


Figure 21 suggests parents differ in terms of efficacy for behaviours maintaining family integration and co-operation, although the pattern of difference changes as the number of features rises. While not statistically significant, mothers report higher mean efficacy scores than fathers. Nonetheless, an increase in condition course features produces markedly different responses in each parent. For mothers, reported efficacy declines, for fathers efficacy increases.

Figure 22

Parental efficacy of behaviours maintaining social support and self-esteem (Scale 2) by number of condition course features

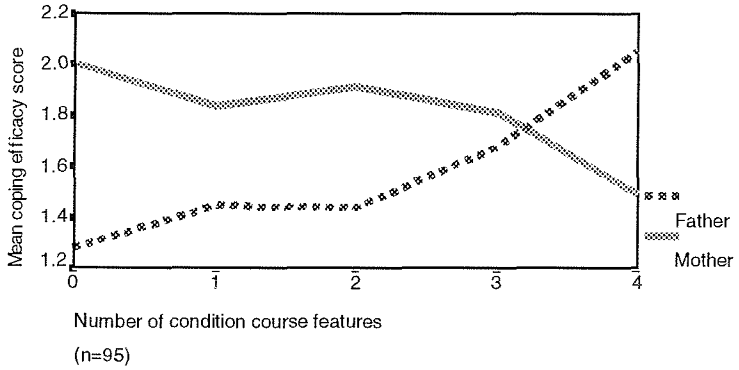


Figure 22 similarly shows parent efficacy for behaviours maintaining social support and self-esteem differs when number of condition course features are low. However, as course features increase mothers' efficacy scores decrease, whereas fathers' scores show a substantial increase.

Figure 23

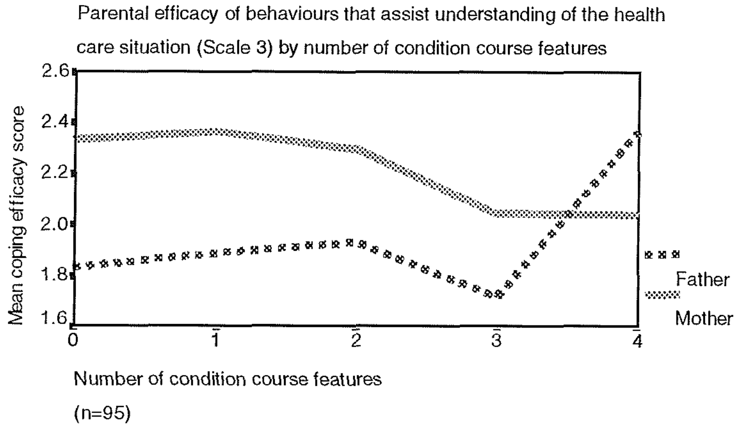


Figure 23 suggests that the efficacy of behaviours assisting understanding of the health care situation differs for parents when the number of condition course features is low. The pattern shifts when course features are high, particularly for fathers, who report higher efficacy than mothers. Table 32 displays the results of analyses for parent by condition visibility.

Table 32

Two-way analysis of variance for general family functioning and parental coping efficacy by parent and condition visibility

	General family functioning	Coping efficacy Scale 1	Coping efficacy Scale 2	Coping efficacy Scale 3
	F (Sig)	F (Sig)	F (Sig)	F (Sig)
Main effects				
Parent	F=0.009 (.92)	F=0.11 (.73)	F=0.58 (.44)	F=1.20 (.27)
Condition visibility	F=0.52 (.59)	F=0.48 (.61)	F=0.28 (.75)	F=0.86 (.42)
Two -way interaction				
Parent x Condition visibility	F=0.05 (.94)	F=1.24 (.29)	F=2.61 (.07)	F=3.50 (.03)

Category groups reflect nominal responses to the question "Is your child's condition visible to others?". Responses were classified in the following way yes- condition is visible, yes and no- condition is both visible and not visible, and no- condition is not visible to others. Figures 24, 25, 26, and 27 show parent responses by generic dimension level.

No main effects were found for either parent or condition visibility in terms of coping efficacy or family functioning. Interaction effects emerged for efficacy of behaviours that aid understanding of the health care situation, but just fails to reach significance for efficacy of behaviours maintaining social support and self-esteem. Comparison of mean scores indicate fathers differ by visibility group. Fathers who report condition visibility to others as yes and no record higher efficacy scores than the two remaining groups.

Figure 24

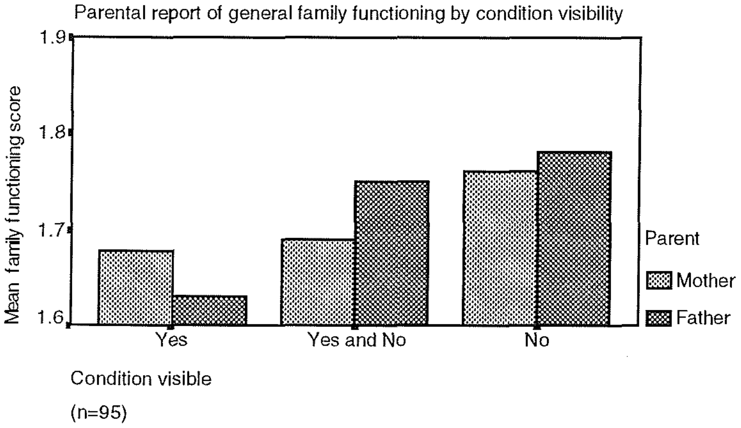


Figure 24 suggests that generally parents differ little in their perceptions of family functioning. Condition visibility, however appears to exert a marginal effect in that family functioning declines slightly as condition visibility decreases.

Figure 25

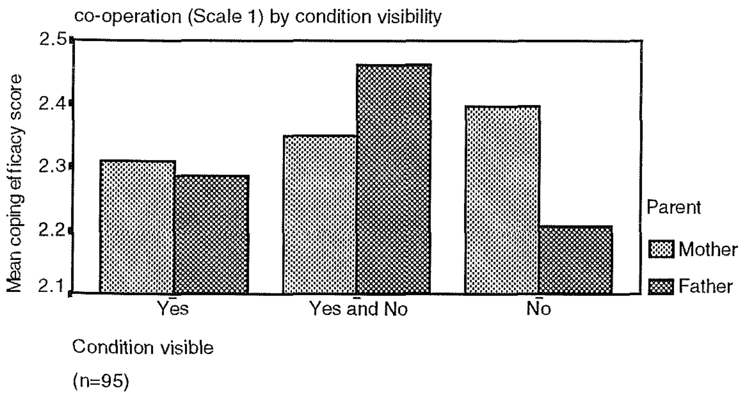


Figure 25 indicates the margin of parent differences in efficacy of family centred behaviours increases as condition visibility decreases. Mothers generally report increasing levels of efficacy with decreases in visibility. The picture for fathers is less clear. Whereas fathers report higher scores than mothers when visibility is ambiguous (i.e. yes and no) this pattern is reversed and magnified when the condition is not visible to others.

Figure 26

Parental efficacy of behaviours maintaining social support and self-esteem (Scale 2) by condition visibility

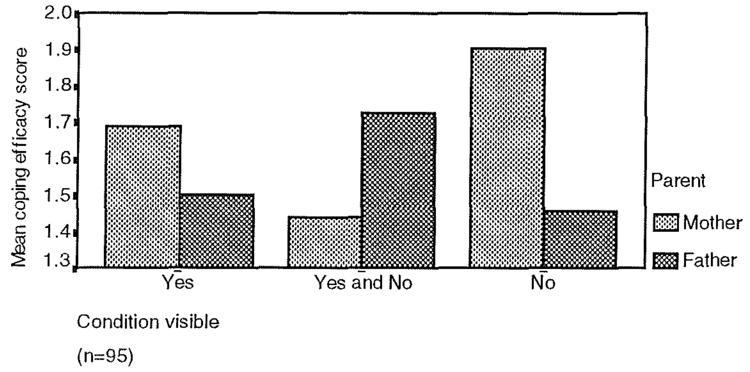


Figure 26 suggests parent efficacy for behaviours maintaining social support and self-esteem is altered by condition visibility. For mothers, efficacy decreases when visibility is ambiguous, but rises for those who report that the condition is not visible to others. This pattern is reversed for fathers. The magnitude of the difference between mother and fathers is greatest when the condition is stated to be not visible to others.

Figure 27

Parental efficacy of behaviours that assist understanding of the health care situation (Scale 3) by condition visibility

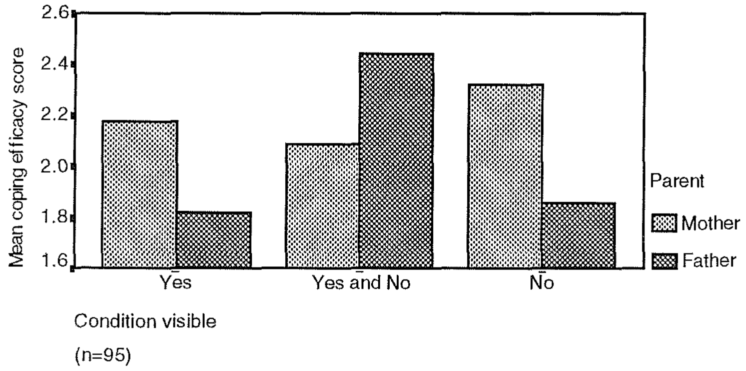


Figure 27 denotes differences in parent efficacy for behaviours that benefit understanding of the health care situation is modified by condition visibility. Effects are more marked for fathers. Mothers, in comparison to fathers report higher levels of efficacy when the condition is either not visible, or highly visible to others. When condition visibility is ambiguous fathers report higher efficacy scores than mothers.

The final question focussed on whether effects of parent coping, moderated by condition category and generic dimensions were predictive of adjustment outcome. Differences in coping efficacy were found to be moderated by number of condition course features for the efficacy of family centred behaviours, and condition visibility for the efficacy of health care behaviours. Hierarchical regression procedures (forced entry) were selected to evaluate this question. To simplify analyses difference scores were calculated for scales and used to determine effects (i.e. fathers' scores were subtracted from mothers' scores). Dummy variables were created for difference scores, number of condition course features and condition visibility. Difference scores were allocated to positive difference, in other words mothers' scores were higher than fathers, and negative difference scores. Number of course features were divided into low (i.e. none, one, two) and high (i.e. three and four). Similarly condition visibility was categorised into visible (i.e. yes, yes and no) and not visible. Variables were entered in the blocks described in Section 1, condition category was followed by generic dimensions, the third block comprised main effect and interaction terms. Outcomes were examined in terms of overall difficulty, emotional symptoms, and hyperactivity and conduct problems combined. Results for regression of total difficulties on predictors are shown in Table 33. However, very few statistically significant effects were found for moderating effects of condition visibility and are therefore not presented.

The regression equation was statistically significant explaining 19 percent of variability in child report of difficulty.

Table 33

Regression of total difficulties score (child report) upon condition category, generic dimensions and parental coping efficacy (n=95)

Variable (df 10, 84)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-0.40	-0.03	-.187	.85	0.10			
Diabetes mellitus	-3.09	-0.22	-1..50	.13	-0.13			
Cystic fibrosis	-5.77	-0.37	-2.36	.02	-0.26	.08	2.95	.03
Generic dimensions								
Age of condition onset	-0.02	-0.20	-0.59	.55	0.006			
Proportion of life condition present	-5.03	-0.25	-0.70	.48	-0.16			
Condition severity	0.84	0.25	2.28	.02	0.22			
Condition visibility	1.46	0.13	1.27	.20	0.07	.13	2.01	.06
Coping efficacy- Main effects, interaction terms								
Number of condition course features (high)	3.48	0.19	1.21	.22				
Coping efficacy difference negative (scale 1)	2.80	0.20	1.82	.07				
High number features x Coping efficacy difference negative	-2.61	-0.11	-0.69	.48		.19	2.02	.04
Constant	10.59		1.41	.16				

Condition category accounted for a significant portion of the variance. Generic dimensions explained a further five percent of variance. Differences in parental coping efficacy and interaction terms did not produce significant effects. The negative difference main effect term marginally fails to reach statistical significance. Findings suggest that children with cystic fibrosis relative to other condition groups are significantly less likely to report difficulty. In addition, increases in condition severity are predictive of increased difficulty.

While not statistically significant the negative coping efficacy difference score for family centred behaviours is linked to increased difficulty. However, findings for the interaction term suggest differences in efficacy in the presence of a high number of condition features are associated with decreased difficulty. Results for regression equations forecasting internalising and externalising difficulties are shown in Tables 34 and 35.

Table 34

Regression of emotional symptoms score (child report) upon condition category, generic dimensions and parental coping efficacy (n=95)

Variable (df 10, 84)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	0.49	0.09	0.57	.56	0.15			
Diabetes mellitus	-0.43	-0.08	-0.53	.59	-0.06			
Cystic fibrosis	-0.85	-0.14	-0.88	.37	-.015	.04	1.26	.29
Generic dimensions								
Age of condition onset	-0.003	-0.08	-0.23	.81	0.01			
Proportion of life condition present	-1.01	-0.13	-0.35	.72	-0.09			
Condition severity	0.23	0.18	1.58	.11	0.16			
Condition visibility	0.52	0.12	1.15	.25	0.09	.07	0.96	.46
Coping efficacy- Main effects, interaction terms								
Number of condition course features (high)	-0.98	-0.14	-0.86	.38				
Coping efficacy difference negative (scale 1)	0.71	0.14	1.18	.24				
High number features x Coping efficacy difference negative	1.43	0.16	0.96	.33		.11	1.08	.38
Constant	2.18		0.73	.46				

Findings for the equation forecasting internalising difficulties indicate that predictors did not explain a significant proportion of the variance in emotional symptom scores. In fact no single predictor proved to be statistically significant.

Table 35

Regression of hyperactivity and conduct problem scores (child report) upon condition category, generic dimensions and parental coping efficacy (n=95)

Variable (df 10, 84)	B	Beta	T	Sig	Beta In	R^2	F	Sig
Condition category								
Asthma	-1.38	-0.17	-1.03	.30	-0.005			
Diabetes mellitus	-1.73	-0.20	-1.38	.17	-0.10			
Cystic fibrosis	-4.64	-0.49	-3.09	.002	-0.29	.09	3.1	.02
Generic dimensions								
Age of condition onset	-0.009	-0.11	-0.33	.73	-0.06			
Proportion of life condition present	-0.90	-0.07	-0.20	.83	-0.006			
Condition severity	0.35	0.17	1.58	.11	0.17			
Condition visibility	0.79	0.11	1.13	.25	0.05	.12	1.77	.10
Coping efficacy- Main effects, interaction terms								
Number of condition course features (high)	3.42	0.31	1.95	.05				
Coping efficacy difference negative (scale 1)	1.11	0.13	1.18	.24				
High number features x Coping efficacy difference negative	-2.36	-0.17	-1.02	.30		.18	1.87	.05
Constant	5.21		1.13	.25				

The regression equation predicting externalising difficulties although not statistically significant explained 18 percent of the variance in scores. Condition category accounted for a significant proportion of the variance. Nine percent of variance is attributable to condition category with generic dimensions contributing a further three percent. The main effect and interaction terms for difference in parental coping efficacy produced a marginally significant effect for a high number of course features only. Results indicate whereas increased overall difficulty is related to the coping efficacy difference score a high number of condition course features is predictive of increased externalising difficulties. Nonetheless the interaction term functions in the same way for externalising difficulties as for overall difficulty.

6.7.1 Section 2 - Summary of findings for effects of condition-related parameters on parent coping, family functioning and the impact of parent differences in coping on adjustment outcome

Statistically significant group differences in family functioning and coping efficacy by condition category and generic dimensions were found for fathers' and mothers' coping efficacy. Fathers of children with asthma, in contrast to fathers of children with epilepsy were found to report higher levels of efficacy for behaviours maintaining social support and self-esteem. On the other hand, mothers of children with a high, compared to low number of condition course features were found to report lower coping efficacy for family centred behaviours. Examination of parent differences in reports of family functioning and coping by condition group and generic dimensions revealed close agreement on family functioning but marked differences in coping efficacy. Interaction effects emerged for generic dimensions in terms of coping efficacy offering support for the first hypothesis that generic dimensions would be more influential than condition category. Effects were found for number of condition course features and condition visibility. On the whole, mothers appear to perceive their coping efforts to be more efficacious than fathers, however this pattern is reversed when the number of condition course features increases and when condition visibility is equivocal. Findings did not confirm the hypothesis that generic dimensions would be more influential than condition category in moderating family functioning.

The pattern of results from regression equations suggest moderated effects are not predictive of child report of difficulty. However, statistically significant predictors differ for the various outcomes. Intriguingly, although neither the main effect or interaction terms forecast child report of emotional symptoms the direction of effects contrasts with that found for externalising difficulties. Increases in the difference score associated with a high number of condition course features are related to increases in emotional symptoms and decreases in externalising behaviours. It may be that behavioural difficulty linked with high condition course features is sensitive to increases in paternal efficacy. This does not seem to be the case for emotional difficulties which may be more responsive to maternal coping efficacy. Alternatively, the range of scores in the internalising difficulties measure (i.e. 0-10), in comparison to externalising difficulties (0-20) constrains variability and may have masked potential effects. It is also possible that insufficient statistical power precluded detection of effects.

6.8 Section 3 - Relationships between condition-related parameters and child coping and adjustment outcome

Fundamental questions remain regarding the role of condition category and generic dimensions in child management of everyday and condition-related problems. Research in paediatric psychology has generally addressed developmental issues, the role of emotional support, how children deal with specific situations such as medical related stressors, or alternatively compared clinical (i.e. psychiatric; chronic illness) and non-clinical populations. Although the literature is growing, little seems to be known about how, or if, condition category or generic dimensions are related to child coping. As suggested by Compas *et al.* (1992) "illnesses may be distinguished in terms of nature of onset, chronicity, severity of current symptoms, prognosis, and degree of physical impairment. The ways in which coping of children and adolescents may vary as a function of any of these dimensions needs to be delineated.". In addition, while studies involving youngsters with sickle cell disease, diabetes or cancer (Gil *et al.*, 1991; Reid *et al.*, 1994; Reid *et al.*, 1995; Frank *et al.*, 1997) suggest strategies alleviating emotional distress and often defined as avoidant coping, are associated with less optimal adjustment it is less clear whether the number of strategies used and coping efficacy are related to adjustment. Also, links between problem related distress and strategy use, the number of strategies used, coping efficacy and adjustment are uncertain.

In this section children's responses to a standardised *hypothetical* common everyday problem (i.e. a parent difficulty) and *self-nominated* illness problem are examined in terms of the afore mentioned factors. Two scenarios were examined to explore similarities in strategy use and the notion of coping style. While individual and situational factors are believed to influence coping efforts theoretical approaches vary in the relative emphasis accorded to these factors. For example, Lazarus and Folkman (1984), suggest that coping responses are dependent on situational factors and shape individual appraisals of harm, threat, loss and challenge. On the other hand, others such as Roth and Cohen (1986) highlight dispositional factors suggesting that individuals tend to approach stressful situations in a similar way. However, the evidence relating to children, provides inconsistent support for both theories. Since the question of coping style is not central to this thesis, it receives limited attention in the following analyses. Accordingly, the following questions were formulated:

- What are the effects of condition category on child coping (strategies used; efficacy)?

- What are the effects of generic dimensions on child coping (strategies used; efficacy)?

- What are the effects of child coping (strategies used; efficacy) on adjustment outcome?

- How is problem related distress linked to strategy use and adjustment outcome?

To some extent the analysis is exploratory, however, the non-categorical framework would suggest that generic dimensions may be more important than condition category. Sources of variation are assumed to lie within dimensions rather than condition category and would be expected to affect emotional and behavioural responses. Illness problems are generally considered to be less controllable than everyday problems, and factors such as condition severity may constrain a child's response. For example, if condition severity is high and limits physical functioning this may reduce available options and encourage use of emotional strategies such as, wishful thinking. Alternatively, age of condition onset may be associated with lengthy experience of dealing with difficulties, building problem solving skills that bear on coping efficacy. Generally studies do not appear to include self-reports of efficacy, although there are exceptions involving children and adolescents without chronic illness (e.g. Wierzbicki & Carver, 1989; Stark *et al.*, 1989; Spirito *et al.*, 1989) or youth with conditions such as diabetes or recurrent headache (e.g. Brotman Band & Weisz, 1990; Reid *et al.*, 1995; Holden *et al.*, 1998). The reasons for this are not entirely clear but the term has been used by researchers to denote the extent to which behaviours are adaptive. On the other hand, the lack of attention may reflect predominance of theoretical paradigms which tend to centre on localised situational behaviours and are unconcerned with outcome. However, given the *ongoing* and variable nature of features intrinsic to chronic illness for example, condition course and severity, it would seem reasonable and desirable to evaluate these relationships.

As indicated in Chapter 4, assessment of coping involved the use of Kidcope. Children were asked to report on the strategies used to deal with a standardised everyday problem and a self-nominated illness problem. The standardised problem referred to management of parental anger on returning home late. It was anticipated this type of event would either be within the realm of personal experience, or at least a situation with which children could readily identify. Ratings of strategy helpfulness and emotional response to the problem, that is level of anger, nervousness and sadness were also requested.

Responses on the Kidcope measure for child and adolescent versions were treated so that scores for each version were comparable. In this way child and adolescent versions could be combined to increase the sample size. Frequency of use for child coping strategies were coded 0 for children who reported they would not or did not use the strategy, and 1 for children who would or did use the strategy and follows the approach adopted by Spirito *et al.*, (1995). Scores used in analyses were based on the total number of strategies used to manage the problem, reflecting the level of problem focussed effort. In terms of coping efficacy, a score of 0 was assigned for strategies reported as ineffective, 1 for strategies reported as a little helpful for children and a little and sometimes helpful for adolescents; 2 for strategies reported as helping a lot for children and pretty and very much for adolescents. A mean coping efficacy score was derived by summation of scores and divided by the number of strategies used to manage a problem, and was identical to the approach used to determine parental coping efficacy. Strategies were scored according to the author's instructions and reflected, among other things, amalgamation of two items to represent the strategy of emotional regulation. However, combination of the two items incorporates two different types of regulation, screaming and shouting and / or calming oneself down. All children completed the measures in the same order with the common problem scenario being presented first. It was expected completion of the self nominated problem would be assisted by providing a pre-defined problem first.

Instructions relating to the illness problem specified that the difficulty had occurred in the last month. However, several children were unable to recall a problem in that time period and were asked to recall the most recent difficulty. Time periods ranged from one to six months. With the exception of one child, illness problems refer to their condition category. One child identified a problem associated with another condition for which he was also receiving hospital based care. Nominated illness problems fell into the following four categories hospital and treatment, school and interference with activity, physical (predominantly) and psychological symptoms and finally emotional. Examples of hospital and treatment problems were attending clinic, hospital admission, having to comply with treatment. Problems such as missing school, lessons or exams, and illness interfering with sports, play, concentration and sleep fell into the school and interference with activity category. Physical / psychological symptoms included for example, pain, distress, tiredness and forgetfulness. Emotional difficulties included, feeling different, loss of career opportunities, teasing, bullying and limitations on autonomy. Although relationships between problem categories and strategy use will not be examined here inter-rater reliability was established to validate the classification. The Kappa coefficient was .60 suggesting a moderate level of agreement. Efficacy was determined by dividing the efficacy score by the number of strategies used which takes into account strategies used and ineffective thus highlighting the balance between effort expended and perceived benefit.

A subsample of 101 children contributed data to the current analysis. This set of analyses is rather lengthy and, in contrast to earlier analyses where results are reviewed at the end of the section, findings will be summarised at various points throughout the presentation. In view of the dichotomous nature of the data, non-parametric techniques were used to evaluate the following hypotheses:

Hypotheses

- Strategy use will be associated with generic dimensions but not condition category

- Differences in coping efficacy will be related to generic dimensions rather than condition category

- Avoidant or negative strategies will be associated with adjustment outcome

The data were examined by number of strategies used, coping efficacy, individual strategy use and emotional response in each scenario. However, a brief evaluation of the number strategies used and reported efficacy sought to examine age related effects. Graphical displays are provided to assist interpretation. Table 36 presents descriptive statistics and effects for age related analyses.

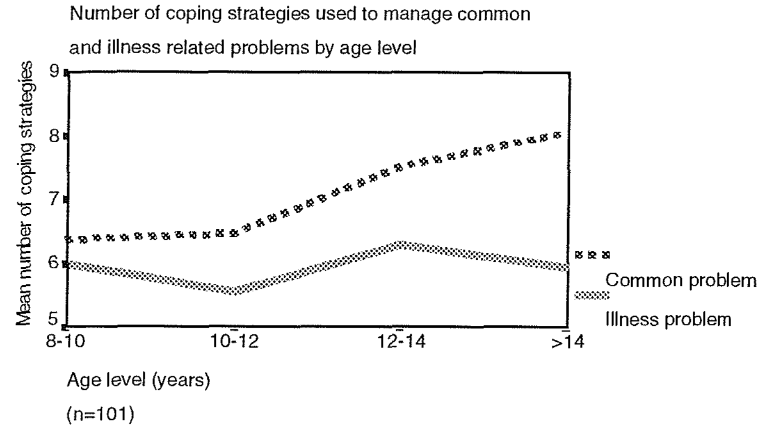
Table 36

Number of coping strategies used and reported efficacy by age level

	Age level					
	8-10yrs	10-12yrs	12-14yrs	> 14yrs		
Variable	Mean (SD) (n=8)	Mean (SD) (n=25)	Mean (SD) (n=39)	Mean (SD) (n=29)	One way ANOVA / Kruskal-Wallis (Sig)	Paired tests t-test / Wilcoxon (Sig)
Number of strategies used (Common problem)	6.37	6.48	7.53	8.06	$\chi^2=20.38$	
	(1.06)	(1.35)	(2.02)	(1.36)	(.0001)	
Number of strategies used (Illness problem)	6.00	5.56	6.30	5.93	$\chi^2=3.16$	Z=-5.99
	(.92)	(1.66)	(1.79)	(2.05)	(.36)	(.00001)
Coping efficacy (Common problem)	1.48	1.24	1.18	1.16	F=2.58	
	(.21)	(.30)	(.31)	(.30)	(.05)	
Coping efficacy (Illness problem)	1.23	1.08	1.08	1.15	F=0.33	t=-2.37
	(.59)	(.48)	(.44)	(.45)	(.80)	(.02)

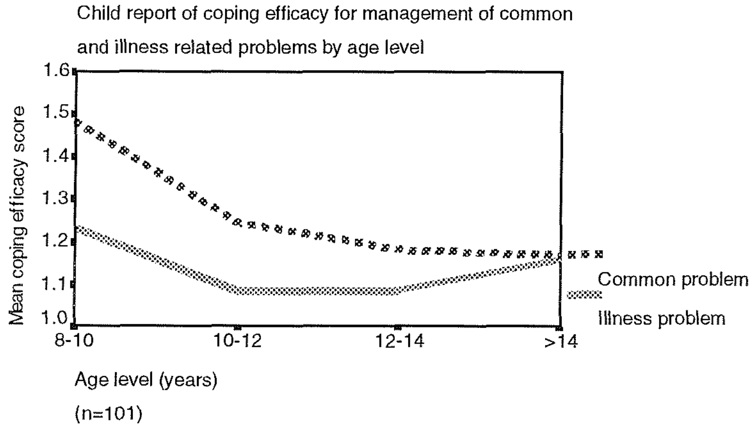
Results indicate age related effects for the number of strategies used and coping efficacy for the common problem context. In addition, there were significant differences for variables by problem context. Younger children, in contrast to adolescents, report they would use fewer strategies when handling a common problem. This effect was not found for the experienced illness problem context. Effects are summarised in Figure 28.

Figure 28



All age groups report they would use fewer strategies when dealing with an illness problem. In terms of coping efficacy both contexts are associated with a decline in efficacy as age increases. There were significant differences in coping efficacy by problem context. Overall, although the difference for children over 14 years is negligible, age groups report lower efficacy for management of an illness problem as shown in Figure 29.

Figure 29



6.8.1 Section 3 - Summary of age related effects for number of strategies used and coping efficacy

Age related effects for the number of strategies used and coping efficacy by problem context suggest situational factors influence coping responses. These findings indicated effort and perceived benefit differed by problem and age. Whereas eight to ten year olds used a similar number of strategies to handle both problems, youths above 14 years reported using considerably more strategies to deal with the common problem. Differences in coping efficacy showed the reverse effect and imply perceptions of strategy effectiveness in eight to ten year olds, compared to adolescents seem to be more sensitive to context. The overall trend for management of a common problem indicated the number of strategies used increased with age and reflects a corresponding decline in strategy helpfulness. Dealing with an illness problem however, failed to show age effects but appeared to be associated with a marginal decline in efficacy with increasing age.

In subsequent analyses we focus on effects of condition category and generic dimensions on number of strategies used and coping efficacy. In addition, associations between children's emotional response to problems and coping efforts, in terms of the number of strategies used and efficacy are evaluated. Results are shown in Tables 37 and 38. This is followed by evaluation of effects on utilisation of individual strategies and finally, relationships between strategy use and adjustment outcome.

As the number of children within specific levels of condition course features and condition visibility were small these dimensions were recoded and condensed respectively into three and two categories.

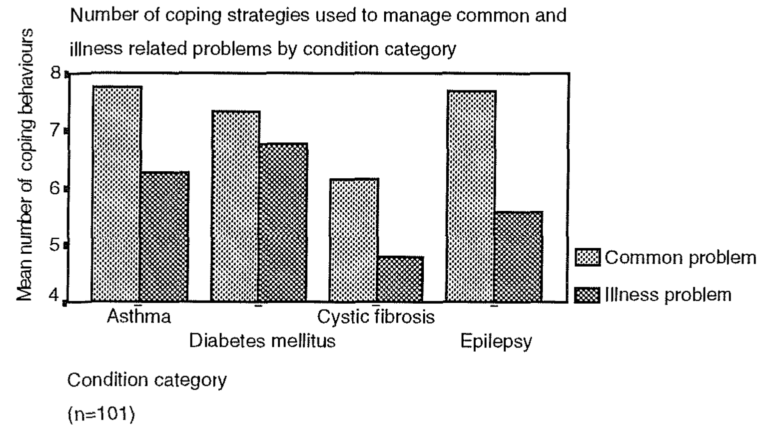
Table 37

Kruskal-Wallis one-way analysis of variance and Mann-Whitney tests for number of strategies used and reported efficacy by condition category and generic dimensions

	Number of strategies used (Common problem)	Number of strategies used (Illness problem)	Coping efficacy (Common problem)	Coping efficacy (Illness problem)
Variable	Chi-square / Z (Sig)	Chi-square / Z (Sig)	Chi-square / Z (Sig)	Chi-square / Z (Sig)
Condition category (df 3)	χ^2=10.23 (.01)	χ^2=15.23 (.001)	χ^2=5.21 (.15)	χ^2=1.06 (.78)
Generic dimensions				
Age of condition onset (df 3)	χ^2=4.57 (.20)	χ^2=4.83 (.18)	χ^2=9.83 (.02)	χ^2=0.21 (.97)
Proportion of life condition present (df 3)	χ^2=2.66 (.44)	χ^2=7.27 (.06)	χ^2=6.02 (.11)	χ^2=.35 (.94)
Condition severity (df 6)	χ^2=7.75 (.25)	χ^2=12.45 (.05)	χ^2=12.73 (.04)	χ^2=7.38 (.28)
Number of condition course features (df 2)	χ^2=0.28 (.86)	χ^2=1.02 (.59)	χ^2=0.06 (.96)	χ^2=2.30 (.30)
Condition visibility	Z=-0.66 (.50)	Z=-0.53 (.59)	Z=-1.31 (.18)	Z=-1.10 (.27)

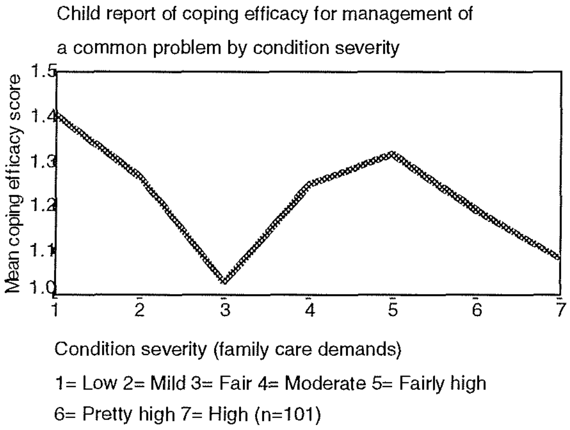
Findings revealed significant effects for condition category in the number of strategies used and generic dimensions in terms of coping efficacy. Figure 30 shows children with cystic fibrosis appear to use fewer strategies than other condition groups in managing both common and illness related problems. In addition, all condition groups are shown to use fewer strategies to manage illness problems.

Figure 30



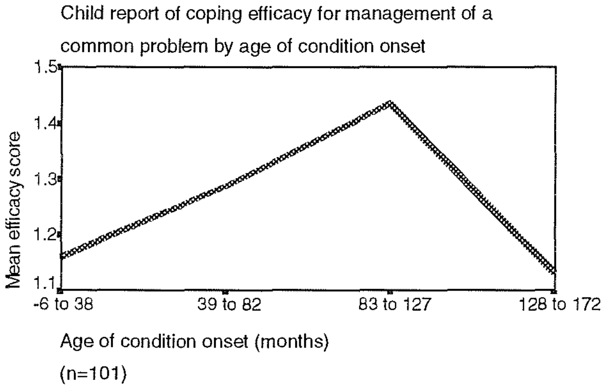
Differences in coping efficacy were found for condition severity and age of condition onset in the common problem context, but surprisingly no effects emerged for the illness problem context. Effects for condition severity as shown in Figure 31 suggest while coping efficacy generally declines as condition severity increases substantial differences exist between low and fair levels.

Figure 31



Age of condition onset also revealed significant differences. Figure 32 indicates efficacy increased with later condition onset but declined to levels reported for early onset in children diagnosed after 127 months.

Figure 32



The number of strategies used and coping efficacy were examined in terms of children's emotional response to problems. Responses were recorded on a five point dimensional scale and reflected ratings of nervousness, sadness and anger. Spearman's rank order correlations were computed in relation to number of strategies and coping efficacy for each problem to determine associations. Results are shown in table 38.

Table 38

Spearman rank order correlations between emotional response to problem and number of strategies used and coping efficacy

	Emotional response to problem		
	Level of nervousness	Level of sadness	Level of anger
Variable	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Number of strategies used (Common problem)	0.12 (.21)	0.04 (.67)	0.24 (.01)
Number of strategies used (Illness problem)	0.12 (.19)	0.21 (.02)	0.16 (.09)
Coping efficacy (Common problem)	-0.04 (.66)	0.04 (.64)	0.11 (.24)
Coping efficacy (Illness problem)	-0.09 (.33)	-0.33 (.001)	-0.13 (.17)

Significant associations were found for the number of strategies used in both problem contexts and for coping efficacy when dealing with an illness problem. Increases in the number of strategies used were linked to an increase in reported anger for management of a common problem and an increase in sadness when handling an illness problem. Coping efficacy for management of an illness problem was found to decline as reported levels of sadness increased.

6.8.2 Section 3 - Summary of effects for condition category and generic dimensions on number of strategies used and coping efficacy and associations between emotional response to problems and coping efforts

Both condition category and generic dimensions produced effects for the number of strategies used and coping efficacy respectively. Children with cystic fibrosis seem to use fewer strategies than other condition groups to deal with both common and illness related problems. Effects for generic dimensions were linked to coping efficacy for the hypothetical common problem context. Coping efficacy, while showing a gradual decline with increases in condition severity dropped sharply between low to fair levels. Effects for age of condition onset are less transparent, coping efficacy increases with later condition onset but falls dramatically for children diagnosed after the age of ten to eleven years. Findings for coping efficacy suggests support for the second hypothesis that generic condition dimensions will be more influential than condition category.

Associations between children's emotional response to problems and number of strategies used and coping efficacy suggest sadness may play a pivotal role in guiding coping responses. While higher ratings of anger are related to increased strategy use for the common problem, higher levels of sadness are linked to an increase in the number of strategies used and a decline in coping efficacy for management of an illness problem.

Prior to evaluation of condition and generic dimension effects on individual strategies, strategies were examined to determine if use differed by problem context. Accordingly, each strategy was subjected to paired McNemar tests for dichotomous variables. Results are shown in Table 39.

Table 39

Chi-square values for comparison of strategy use by problem context

Strategy	Chi-square/ Binominal	Sig	Direction of effect
Distraction	χ^2= 9.81	.001	cp > ip
Social withdrawal	χ^2= 9.02	.002	cp > ip
Cognitive restructuring	χ^2= 0.32	.57	cp = ip
Self-criticism	χ^2= 38.94	.00001	cp > ip
Blaming others	χ^2= 10.61	.001	cp > ip
Problem solving	χ^2= 4.96	.02	cp > ip
Emotional regulation	Binominal	.01	cp > ip
Wishful thinking	Binominal	1.00	cp = ip
Social support	χ^2= 2.37	.12	cp = ip
Resignation	χ^2= 0.73	.39	cp = ip

cp = common problem, ip = illness problem

While a number of children used the same strategies for each situation significant shifts were linked to distraction, social withdrawal, self-criticism, blaming others, problem solving and emotional regulation. These strategies were significantly more likely to be used to deal with a common problem than an illness related problem. However, of the ten strategies blaming others was least likely to be used in either situation. Cognitive restructuring, wishful thinking, social support and resignation appear equally likely to be used in either situation. A brief examination of gender differences in strategy use revealed no significant effects.

Analyses of coping strategies involved for condition category, Kruskal-Wallis one way analysis of variance, and for generic dimensions Mann-Whitney tests. Specifically, condition category was the independent variable for strategy use and significant differences in generic condition dimensions were determined by whether a child used the strategy or not. Results for each strategy are reported separately and in the order presented in Table 39. Findings illustrating children's use of distraction are shown in Table 40.

Table 40

Condition category and generic dimension differences by use of distraction

	Use of distraction (Common problem)	Use of distraction (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 2.97 (.39)	χ^2= 6.40 (.09)
Generic dimensions		
Age of condition onset	Z= -0.43 (.66)	Z= -0.27 (.78)
Proportion of life condition present	Z= -0.18 (.85)	Z= -0.12 (.89)
Condition severity	Z= -0.50 (.61)	Z= -0.65 (.50)
Number of condition course features	Z= -0.42 (.66)	Z= -1.59 (.11)
Condition visibility	Z= -1.51 (.12)	Z= -1.22 (.22)

Children who used this strategy in either situation were not found to differ significantly from children who did not use distraction in either condition category or generic dimensions.

Table 41

Condition category and generic dimension differences by use of social withdrawal

	Use of social withdrawal (Common problem)	Use of social withdrawal (Illness problem)
Variable	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Condition category	$\chi^2 = 2.29$ (.51)	$\chi^2 = 4.02$ (.25)
Generic dimensions		
Age of condition onset	Z= -0.17 (.86)	Z= -2.66 (.007)
Proportion of life condition present	Z= -0.28 (.77)	Z= -2.69 (.007)
Condition severity	Z= -2.89 (.003)	Z= -0.25 (.79)
Number of condition course features	Z= -2.00 (.04)	Z= -0.24 (.80)
Condition visibility	Z= -0.19 (.84)	Z= -0.08 (.93)

Significant differences for use of social withdrawal in both problem situations were found for generic dimensions. In the common problem context strategy use differed by condition severity and number of condition course features. Those using the strategy, in contrast to those who did not, were found to have higher levels of condition severity and more condition course features. Dealing with an illness problem produced effects for age of condition onset and proportion of life condition present. Children using the strategy, relative to children not using it had later condition onset and shorter condition duration.

Table 42

Condition category and generic dimension differences by use of cognitive restructuring

	Use of cognitive restructuring (Common problem)	Use of cognitive restructuring (Illness problem)
Variable	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Condition category	χ^2= 0.89 (.80)	χ^2= 3.21 (.36)
Generic dimensions		
Age of condition onset	Z= -1.08 (.27)	Z= -0.83 (.40)
Proportion of life condition present	Z= -0.92 (.35)	Z= -0.71 (.47)
Condition severity	Z= -1.05 (.28)	Z= -1.01 (.31)
Number of condition course features	Z= -1.03 (.30)	Z= -0.38 (.69)
Condition visibility	Z= -1.60 (.10)	Z= -1.09 (.27)

Children's use of cognitive restructuring was not found to differ in problem context or by condition category or generic dimension.

Table 43

Condition category and generic dimension differences by use of self-criticism

	Use of self-criticism (Common problem)	Use of self-criticism (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 7.02 (.07)	χ^2= 6.98 (.07)
Generic dimensions		
Age of condition onset	Z= -0.87 (.38)	Z= -0.73 (.46)
Proportion of life condition present	Z= -0.63 (.52)	Z= -0.68 (.49)
Condition severity	Z= -0.37 (.70)	Z= -1.39 (.16)
Number of condition course features	Z= -1.32 (.18)	Z= -0.44 (.65)
Condition visibility	Z= -0.04 (.65)	Z= -1.21 (.22)

No differences were found in children's use of self-criticism in either situation or in terms of condition category or generic dimensions.

Table 44

Condition category and generic dimension differences by use of blaming others

	Use of blaming others (Common problem)	Use of blaming others (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 5.22 (.15)	χ^2= 7.05 (.07)
Generic dimensions		
Age of condition onset	Z= -1.83 (.06)	Z= -2.41 (01)
Proportion of life condition present	Z= -1.10 (.26)	Z= -2.37 (.01)
Condition severity	Z= -1.21 (.22)	Z= -0.83 (.40)
Number of condition course features	Z= -0.17 (.85)	Z= -070 (.48)
Condition visibility	Z= -0.19 (.84)	Z= -0.66 (.50)

Children's use of blaming others revealed significant differences for the generic dimensions of age of condition onset and proportion of life condition present in relation to the self-nominated illness problem. Although children generally did not use this strategy, those who did were found, in comparison to children who did not report using it, to have later condition onset and shorter condition duration.

Table 45

Condition category and generic dimension differences by use of problem solving

	Use of problem solving (Common problem)	Use of problem solving (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 4.39 (.22)	χ^2= 4.26 (.23)
Generic dimensions		
Age of condition onset	Z= -1.04 (.29)	Z= -0.53 (.59)
Proportion of life condition present	Z= -1.50 (.13)	Z= -0.41 (.68)
Condition severity	Z= -1.01 (.31)	Z= -0.12 (.90)
Number of condition course features	Z= -0.74 (.45)	Z= -1.13 (.25)
Condition visibility	Z= -0.26 (.79)	Z= -0.22 (.82)

Findings for the problem solving strategy indicated that condition category and generic dimensions were not significantly related to use in either problem context.

Table 46

Condition category and generic dimension differences by use of emotional regulation

Variable	Use of emotional regulation (Common problem) Chi-square/ Z (Sig)	Use of emotional regulation (Illness problem) Chi-square/ Z (Sig)
Condition category	χ^2= 6.43 (.09)	χ^2= 12.59 (.005)
Generic dimensions		
Age of condition onset	Z= -1.39 (.16)	Z= -2.60 (.009)
Proportion of life condition present	Z= -1.38 (.16)	Z= -2.94 (.004)
Condition severity	Z= -0.48 (.62)	Z= -0.13 (.89)
Number of condition course features	Z= -0.41 (.67)	Z= -1.23 (.21)
Condition visibility	Z= -0.50 (.61)	Z= -0.13 (.89)

While no effects emerged on the use of emotional regulation for management of a common problem, dealing with an illness problem was linked to condition category and the generic dimensions of age of condition onset and proportion of life condition present. Children with cystic fibrosis were less likely, and children with diabetes were more likely, compared to other condition groups to use this strategy. Children using this strategy, compared to children who did not were found to have a later condition onset and inversely, shorter condition duration.

Table 47

Condition category and generic dimension differences by use of wishful thinking

	Use of wishful thinking (Common problem)	Use of wishful thinking (Illness problem)
Variable	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Condition category	χ^2= 0.94 (.81)	χ^2= 3.30 (.34)
Generic dimensions		
Age of condition onset	Z= -0.10 (.91)	Z= -0.25 (.79)
Proportion of life condition present	Z= -0.39 (.69)	Z= -0.71 (.47)
Condition severity	Z= -0.74 (.45)	Z= -0.82 (.40)
Number of condition course features	Z= -0.41 (.68)	Z= -1.36 (.17)
Condition visibility	Z= -0.03 (.97)	Z= -0.81 (.41)

Children's use of wishful thinking revealed no effects for condition category or generic dimensions for management of either problem.

Table 48

Condition category and generic dimension differences by use of social support

	Use of social support (Common problem)	Use of social support (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 4.63 (.20)	χ^2= 3.92 (.26)
Generic dimensions		
Age of condition onset	Z= -1.49 (.13)	Z= -0.95 (.33)
Proportion of life condition present	Z= -1.13 (.25)	Z= -0.66 (.50)
Condition severity	Z= -0.55 (.57)	Z= -0.57 (.56)
Number of condition course features	Z= -0.34 (.72)	Z= -0.54 (.58)
Condition visibility	Z= -1.02 (.30)	Z= -1.44 (.14)

Children's reported use of social support, in either situation was not found to be significantly related to condition category or generic dimensions.

Table 49

Condition category and generic dimension differences by use of resignation

	Use of resignation (Common problem)	Use of resignation (Illness problem)
	Chi-square/ Z (Sig)	Chi-square/ Z (Sig)
Variable		
Condition category	χ^2= 3.99 (.26)	χ^2= 6.05 (.10)
Generic dimensions		
Age of condition onset	Z= -2.34 (.01)	Z= -1.52 (.12)
Proportion of life condition present	Z= -1.64 (.10)	Z= -0.98 (.32)
Condition severity	Z= -1.33 (.18)	Z= -0.90 (.36)
Number of condition course features	Z= -1.45 (.14)	Z= -1.07 (.28)
Condition visibility	Z= -0.30 (.76)	Z= -1.33 (.18)

Children's use of resignation revealed significant differences for management of a common problem. Those children who reported using resignation were found to have a later age of condition onset than children who did not use this strategy. Dealing with an illness problem produced no effects for condition category or generic dimensions.

6.8.3 Section 3 - Summary of findings for condition-related parameters and use of individual strategies by problem context

Comparison of strategy use by problem type indicated that six of the ten strategies would be used more often to deal with a hypothetical common problem than an experienced illness problem. Children's reported use of the remaining four strategies was not found to differ by problem context. This may suggest than everyday problems are more amenable to solutions. On the other hand, the hypothetical situation, in comparison to the illness problem may call for an imagined response in some children and, given the scenario was a parent problem encourage social desirability.

Condition category and generic dimensions by individual strategy use revealed effects for use of social withdrawal, blaming others, emotional regulation and resignation. Differences extended to both problem situations. Children's use of social withdrawal was linked to differences in condition severity and number of condition course features for the common problem, and differences in age of condition onset and proportion of life condition present for the illness problem. In addition, use of blaming others and emotional regulation revealed differences in age of condition onset and proportion of life condition present for management of an illness problem. Children using these strategies, in comparison to counterparts were found to have *higher* levels of condition severity and number of condition course features, later condition onset and shorter condition duration. Children's use of emotional regulation also differed by condition category. Children with cystic fibrosis were the least likely of all condition groups to use this strategy to deal with an illness problem. Finally, use of resignation to manage the common problem occurred more often in children with a later condition onset than children with early onset. On the whole differences were associated with generic dimensions rather than condition category suggesting support for the first hypothesis that strategy use would be linked to generic condition dimensions as opposed to condition category.

In the final set of analyses relationships between coping efforts and adjustment outcomes are investigated for each problem context. The number of strategies used and coping efficacy are examined for associations with adjustment outcome, and individual strategy use is evaluated for differences in adjustment outcome. These analyses include evaluation of the hypothesis that avoidant or negative strategies will be associated with adjustment outcome. Positive strategies comprise - cognitive restructuring, problem solving, emotional regulation and social support; negative strategies include - distraction, social withdrawal, self criticism, blaming others, wishful thinking and resignation (Spirito *et al.*, 1996). Spearman's rank order correlation and Mann-Whitney tests are used to establish if child report of total difficulties, emotional symptoms, and hyperactivity and conduct score combined demonstrate links and effects in relation to each outcome. Results are presented in Tables 50 and 51.

Table 50

Spearman rank order correlations between adjustment outcome and number of strategies used and coping efficacy

	Adjustment outcome		
	Total difficulties score	Emotional symptoms score	Hyperactivity and conduct problem score combined
Variable	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Number of strategies used (Common problem)	0.09 (.33)	0.09 (.36)	0.17 (.08)
Number of strategies used (Illness problem)	0.27 (.006)	0.34 (.0001)	0.23 (.01)
Coping efficacy (Common problem)	-0.05 (.59)	-0.10 (.30)	-0.05 (.56)
Coping efficacy (Illness problem)	0.01 (.85)	-0.15 (.11)	0.08 (.40)

Statistically significant associations were confined to the number of strategies used to manage an illness problem. Parallel increases were found between total difficulties, emotional symptoms and hyperactivity and conduct scores combined and number of strategies used. However, the strength of the association is greatest for emotional adjustment.

Table 51

Differences in adjustment outcome by individual strategy use

	Adjustment outcome		
	Total difficulties score	Emotional symptoms score	Hyperactivity and conduct problem score combined
Strategy and problem context	Z (Sig)	Z (Sig)	Z (Sig)
Distraction (Common problem)	-0.31 (.75)	-0.80 (.41)	-1.39 (.16)
Distraction (Illness problem)	-0.36 (.71)	-1.41 (.15)	-0.16 (.87)
Social withdrawal (Common problem)	-1.27 (.20)	-0.56 (.57)	-1.44 (.14)
Social withdrawal (Illness problem)	-2.53 (.01)	-2.94 (.003)	-1.52 (.12)
Cognitive restructuring (Common problem)	-2.20 (.02)	-1.65 (.09)	-1.52 (.12)
Cognitive restructuring (Illness problem)	-1.10 (.26)	-1.94 (.05)	-0.15 (.87)
Self-criticism (Common problem)	-1.88 (.05)	-1.00 (.31)	-1.96 (.04)
Self-criticism (Illness problem)	-1.08 (.27)	-1.31 (.18)	-1.22 (.21)
Blaming others (Common problem)	-1.77 (.07)	-1.10 (.27)	-2.41 (.01)
Blaming others (Illness problem)	-0.31 (.75)	-0.55 (.57)	-1.43 (.15)
Problem solving (Common problem)	-0.03 (.97)	-0.51 (.60)	-0.10 (.91)
Problem solving (Illness problem)	-1.62 (.10)	-2.73 (.006)	-0.50 (.61)
Emotional regulation (Common problem)	-1.33 (.18)	-1.52 (.12)	-0.61 (.57)
Emotional regulation (Illness problem)	-1.49 (.13)	-1.23 (.21)	-1.14 (.25)
Wishful thinking (Common problem)	-1.86 (.06)	-1.37 (.16)	-1.18 (.23)
Wishful thinking (Illness problem)	-1.84 (.06)	-2.06 (.03)	-0.55 (.57)
Social support (Common problem)	-0.11 (.91)	-0.21 (.83)	-0.82 (.41)
Social support (Illness problem)	-1.63 (.10)	-1.89 (.05)	-2.22 (.02)
Resignation (Common problem)	-0.27 (.78)	-0.80 (.42)	-0.11 (.91)
Resignation (Illness problem)	-1.10 (.26)	-0.56 (.56)	-1.84 (.06)

Difference trends are underlined

Findings reported here need to be treated with caution in light of the number of statistical tests undertaken. A Bonferroni correction for 60 tests suggests statistical significance should be readjusted to .0008 for an alpha level of .05. Nevertheless, trends indicate differences in adjustment outcome by strategy use. However, effects were modified by problem context and strategies used. Differences in total difficulties were linked to use of social withdrawal when dealing with an illness problem and cognitive restructuring in the common problem context. Essentially, children using social withdrawal reported a *greater* level of difficulty and children using cognitive restructuring reported significantly *less* difficulty in comparison to children who did not use these strategies. Differences in emotional symptom scores were associated with management of the illness problem only. Children using social withdrawal, wishful thinking and problem solving experienced significantly *more* emotional symptoms than children not using these strategies. Differences in hyperactivity and conduct problem scores combined were related to both scenarios. For management of the common problem children using self-criticism and blaming others reported *higher* levels of hyperactivity and conduct problems than children who did not select these strategies. Children using social support to deal with an illness problem were also found to report significantly *more* hyperactivity and conduct problems than children not using this strategy.

Although guarded, given the number of tests undertaken, findings suggest tentative support for the third hypothesis that avoidant or negative strategies would be associated with adjustment outcome. Children using social withdrawal, wishful thinking, self-criticism and blaming others demonstrate higher levels of overall difficulty, emotional symptoms, and hyperactivity and conduct problems combined than children who do not use these strategies. In addition, children using the positive strategy of cognitive restructuring have significantly lower levels of difficulty compared to children not using this strategy. On the other hand, children who use the positive strategy of problem solving also report higher levels of emotional symptoms than those who not use problem solving. In addition, use of social support is linked to higher levels of hyperactivity and conduct problems.

Strategy use was also evaluated for associations with emotional responses to problems. A Bonferroni correction for 30 correlations suggests significance is reset to .001 for an alpha level of .05, and .0003 for an alpha level of .01. Results for management of a common problem are shown in Table 52 and the illness related problem in Table 53.

Table 52

Spearman rank order correlations between emotional response and strategy use for management of a common problem

	Emotional response to common problem		
	Level of nervousness	Level of sadness	Level of anger
Strategy	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Distraction	0.03 (.74)	-0.10 (.28)	-0.03 (.72)
Social withdrawal	0.03 (.70)	0.12 (.20)	0.27 (.005)
Cognitive restructuring	-0.16 (.10)	-0.13 (.18)	-0.01 (.31)
Self-criticism	0.04 (.67)	0.07 (.44)	0.07 (.43)
Blaming others	0.13 (.12)	-0.03 (.71)	0.20 (.02)
Problem solving	0.005 (.95)	0.09 (.34)	0.13 (.19)
Emotional regulation	0.30 (.002)	0.36 (.0001)**	0.37 (.0001)**
Wishful thinking	0.40 (.0001)**	0.37 (.0001)**	0.17 (.08)
Social support	-0.14 (.14)	-0.01 (.91)	0.23 (.01)
Resignation	0.05 (.61)	-0.20 (.04)	-0.21 (.03)

* p< .05 ** p< .01 after Bonferroni's correction

Findings for emotional responses to a common problem indicated higher ratings of nervousness were significantly associated with increased use of wishful thinking and related to use increased use of emotional regulation. Higher levels of sadness were significantly associated with increased use of emotional regulation and wishful thinking and also related to decreased use of resignation. Reports of increased anger were found to be significantly associated with children's use of emotional regulation and linked to increased use of social withdrawal, blaming others and social support and decreased use of resignation.

Table 53

Spearman rank order correlations between emotional response and strategy use for management of an illness problem

	Emotional response to illness problem		
	Level of nervousness	Level of sadness	Level of anger
Strategy	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Distraction	-0.02 (.80)	0.19 (.05)	0.09 (.42)
Social withdrawal	0.12 (.21)	0.17 (.08)	0.04 (.64)
Cognitive restructuring	-0.25 (.01)	-0.26 (.006)	-0.12 (.20)
Self-criticism	0.15 (.11)	0.13 (.19)	0.01 (.87)
Blaming others	-0.06 (.53)	-0.10 (.28)	0.05 (.61)
Problem solving	0.04 (.62)	0.22 (.02)	0.06 (.52)
Emotional regulation	0.14 (.15)	0.01 (.89)	0.32 (.001)*
Wishful thinking	0.06 (.51)	0.32 (.001)*	0.11 (.26)
Social support	0.05 (.51)	0.11 (.23)	0.17 (.08)
Resignation	0.06 (.52)	-0.03 (.69)	-0.13 (.18)

* p< .05 ** p< .01 after Bonferroni's correction

Statistically significant findings for the illness problem situation point to higher ratings of sadness and increased use of wishful thinking and higher levels of anger and increased use of emotional regulation. However, higher levels of nervousness and sadness were also related to decreased use of cognitive restructuring. In addition, increases in reported sadness were linked to increased use problem solving.

Emotional responses for each problem context were also examined for associations with adjustment outcome. Results are shown in Table 54.

Table 54

Spearman rank order correlations between emotional response to problems and adjustment outcome

	Emotional response to common problem			Emotional response to illness problem		
	Level of nervousness	Level of sadness	Level of anger	Level of nervousness	Level of sadness	Level of anger
Outcome variable	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Total difficulties	0.29 (.002)	0.32 (.001)	0.13 (.16)	0.08 (.42)	0.14 (.15)	0.07 (.44)
Emotional symptoms	0.33 (.001)	0.39 (.0001)	0.10 (.30)	0.21 (.03)	0.29 (.002)	0.10 (.27)
Hyperactivity and conduct problems combined	0.12 (.21)	0.12 (.22)	0.11 (.25)	-0.001 (.99)	0.006 (.94)	0.03 (.72)

Significant associations were linked to overall difficulty and perhaps, not surprisingly, emotional symptoms. No associations were found between emotional problem response and hyperactivity and conduct problems combined. Increases in total difficulties were related to a corresponding increase in reported nervousness and sadness for the common problem. Emotional symptoms however, were related to elevation of nervousness and sadness for both problem contexts.

6.8.4 Section 3 - Summary of findings for relationships between strategy use, coping efficacy and problem related emotional response and adjustment outcomes by problem context

Associations between strategy use and adjustment outcome indicate that the number of strategies children report using increased with overall difficulty, emotional symptoms and hyperactivity and conduct problems combined. However, the strongest link was related to emotional symptoms. No associations were found for coping efficacy. Results emerging from evaluation of differences in outcome by strategy use need to be treated cautiously given the number of tests involved. Findings revealed lower levels of overall difficulty were related to use of cognitive restructuring when handling a common problem, and higher levels of difficulty were linked to use of social withdrawal for management of an illness problem. Increased levels of hyperactivity and conduct problems combined were typified by higher use of self-criticism and blaming others when handling a common problem and social support in the illness problem context. Elevated emotional symptoms were linked to use of social withdrawal, wishful thinking and problem solving when dealing with an illness problem.

Examination of children's emotional responses to problems and strategy use indicated higher levels of nervousness were significantly associated with increased use of wishful thinking and related to increased use of emotional regulation when dealing with a common problem. For management of an illness problem higher levels of nervousness were related to decreased use of cognitive restructuring. Similarly, higher ratings of sadness were significantly associated with increased use of wishful thinking and related to increased use of emotional regulation and decreased use of resignation in the common problem context. Likewise, in the illness problem context higher levels of sadness were significantly associated with increased use of wishful thinking and related to increased use of problem solving and decreased use of cognitive restructuring. Anger was significantly and positively associated with increased use of emotional regulation in both problem contexts. In addition, higher levels of anger were related to increased use of social withdrawal, blaming others and social support and decreased use of resignation for management of a common problem. Significant associations demonstrate similarities in strategy use and emotional response within and across problem contexts. For example, increased nervousness and sadness were associated with increased use of wishful thinking for the common problem. However, higher levels of sadness are also associated with increased use of wishful thinking for the illness problem. Furthermore, children were more likely to use emotional regulation to deal with both problems when reporting high levels of anger.

Correlations between emotional response and adjustment outcome by problem type indicated increases in total difficulties were linked to higher levels of nervousness and sadness for the common problem only. The same association however, extends to both problem scenarios for increases in emotional symptoms. This would suggest that for this group common and illness problems present difficulty and are associated with increased distress. These children, in contrast to children reporting hyperactivity and conduct problems, are significantly more likely to use wishful thinking in both contexts and less likely to use cognitive restructuring for the illness problem. This pattern of strategy use implies a less optimal approach to problem solving. Nonetheless, illness problem responses are also characterised by increased use of problem solving suggesting active involvement. Overall, strategy use appears to reflect a balance between positive and negative strategies. However, children reporting higher levels of sadness in response to the illness problem seem to use a predominantly emotion focussed approach.

6.9 Section 4 - Evaluation of the risk resistance framework

Within paediatric psychology multivariate models of adjustment to chronic illness are increasingly used to guide research into factors that modify, mediate and forecast psychosocial outcomes. However, studies involving the conceptual model advanced by Wallander and colleagues (1989b) have generally assessed model components. Consequently, the validity of the entire framework is untested in terms of the proposed moderating role of resistance factors in relation to risk factors. The moderating mechanism suggests for example, the interactive effect (multiplicative, additive) between family functioning, a resistance factor, and psychosocial stressors, a risk factor, changes the relationship between psychosocial stressors and adjustment outcome. The term resistance implies a factor defined as such would presumably offset risk effects, therefore family functioning would be expected to interact with risk factors and via this pathway indirectly diminish risk for adjustment difficulties. Accordingly the following questions were formulated:

- Is the risk resistance framework tenable?

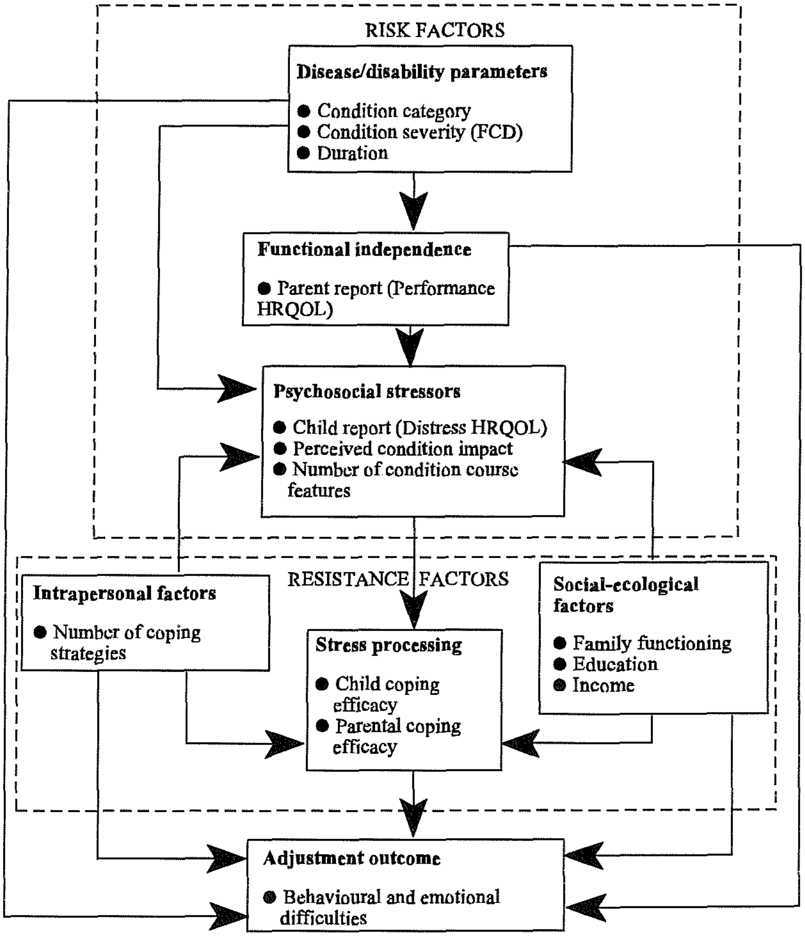
- Are risk factors moderated by resistance factors?

In this section analyses aim to examine model utility, incorporating all identified factors, using the simultaneous equation modelling technique of path analysis. Application of path analysis, employing software packages designed to calculate simultaneous regression equations, facilitates tests of conceptual model structure, and in certain circumstances can address questions of causal priority. However, the issue of concern here is the validity of the structure proposed in the risk resistance framework. The process guiding model specification is described and proceeds towards examination of factors in relation to child report of total difficulties, emotional symptoms and hyperactivity and conduct problems combined. Findings from this group of analyses are taken forward with the inclusion of peer factors and described in Section 5. In the current sample, efforts to maximise numbers led to the involvement of 85 mothers and their children. While study objectives originally sought to include fathers in the present analysis, unfortunately insufficient data were available. This section concludes with a summary of the findings.

Study measures were operationalised in the following way and configured to resemble specified factors as shown in Figure 33. Disease/disability factors comprise condition category, severity (i.e. family care demands over the past 12 months) and duration (i.e.

Figure 33

Conceptual framework following risk resistance model put forward by Wallander and colleagues (1989b)



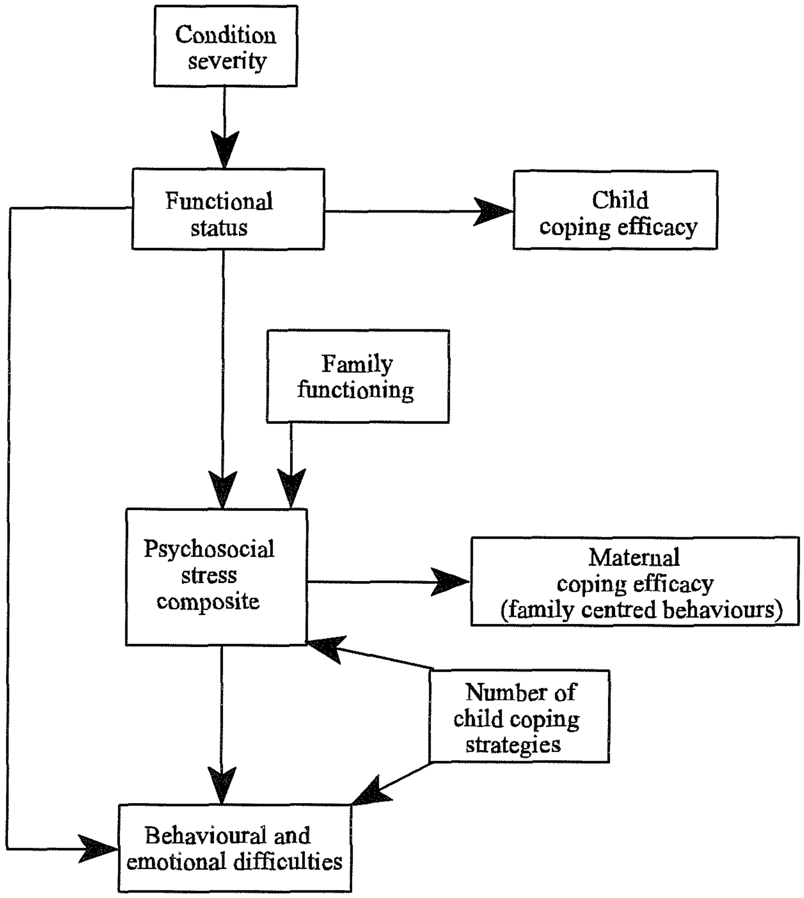
proportion of life condition present). Functional independence is represented in the parental estimate of child functioning in the daily activities of living and taken from the measure of Child Health Related Quality of Life. Psychosocial stressors, traditionally assessed in terms of daily hassles and major life events, were operationalised to reflect child report of upset associated with accomplishment of daily activity taken from the Child Health Related Quality of Life, and condition impact derived from the total score for the perceived experience of condition scale and lastly, the number of condition course features as reported by parents. The Cronbach's α estimate of internal consistency for the perceived experience of condition scale was .87 (n=138), indicating high reliability. It may be expected these variables would function as ongoing stressors for both child and parent. Intrapersonal factors, delineated in the model amongst others as problem solving skill, were defined as the number of coping strategies children reported using in dealing with an illness related problem. Social-ecological factors were typified by maternal report of general family functioning, highest academic qualification and family income. Inclusion of these variables reflected psychological and material family resources. Stress processing was conceived in terms of outcome, in other words the perceived value of coping efforts, that is, coping efficacy. Adjustment outcome, in this particular analysis was represented in child report of overall difficulty that is, the total difficulties score obtained from the Strengths and Difficulties Questionnaire. Coping efficacy was determined by summing the number of coping behaviours used and efficacy scores separately and dividing efficacy by number of behaviours. Essentially this produces an efficacy score, as indicated earlier, that takes account of level of derived benefit in relation to effort expended. Children's coping efficacy referred to management of an illness related problem and sought to reflect similarity between child and parent in the type of stressor (i.e. illness) related to coping efforts.

Psychosocial stressors were standardised and summed to produce a single composite variable. As child distress was measured in the opposite direction to perceived condition impact and number of course features, this variable was reverse scored prior to standardisation. Pathways were examined consecutively using multiple regression forced entry techniques to establish the validity of individual paths and refine the specified model prior to simultaneous path analysis using the structural equation modelling (SEM) application EQS developed by Bentler (1995).

Results are not presented but summarised in the following text. The role of maternal coping efficacy was established by evaluating each subscale separately (Scale 1, family centred behaviours; Scale 2, self-care behaviours; Scale 3, health care behaviours). However, preliminary analyses revealed distribution of family income to be skewed and unresponsive to transformation, and non-significant effects for condition duration, maternal education and coping efficacy scales 2 and 3. In addition, child coping efficacy was unrelated to specified variables, it was however, associated with functional independence and therefore retained. Given these findings, family income and non-significant variables were eliminated from subsequent path analyses. However, SEM techniques require large sample sizes to evaluate group and moderating effects. Since an insufficient number were available to include condition category or test the moderating effects of resistance factors, condition category was excluded and interaction effects were examined with two-way analysis of variance tests. The results are shown in Table 55 and follow evaluation of models predicting respectively, child report of overall difficulty, emotional symptoms, and hyperactivity and conduct problems combined. The modified model suggested by consecutive path analyses is shown in Figure 34.

Figure 34

Proposed model of relationships between condition, individual and family factors predicting child report of behavioural and emotional difficulty

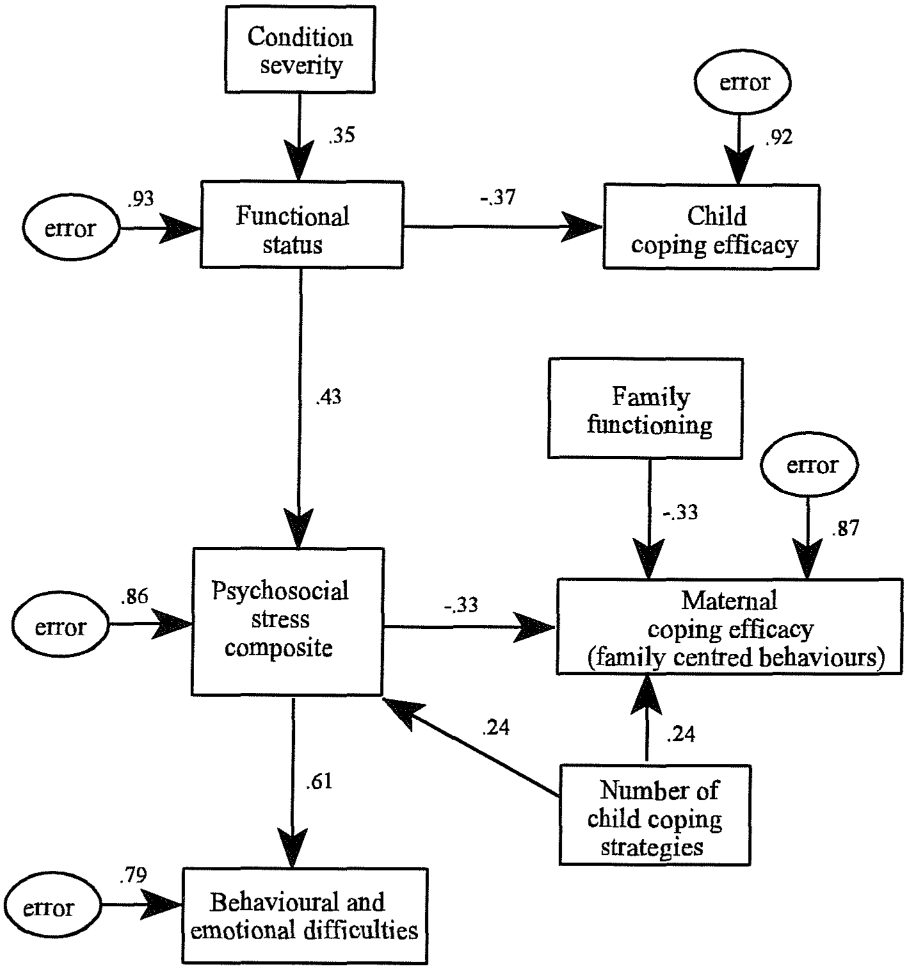


This model was subjected to simultaneous equation modelling using EQS. Results indicated the fit between the observed and expected covariance matrices approached statistical significance ($\chi^2 = 27.24$, df 19, $p < .09$). Although the specified model represented the data adequately, paths were not confirmed between first, functional status and reported difficulty; second, number of child coping strategies and reported difficulty; and third, family functioning and psychosocial stress. Inspection of standardised residuals and results for the Lagrange multiplier test which evaluates the statistical significance of changes in chi-square values for additional paths, suggested modifications. Maternal coping efficacy was found to covary with both family functioning and number of child coping strategies. Consequently these paths were added, direction being defined by the conceptual framework, non-significant paths were eliminated.

Evaluation of the revised model produced substantial improvement. Results and fit indices are shown in Figure 35, statistically significant parameter estimates are displayed adjacent to their respective paths. Subsequent model testing focussed on internalising (emotional symptoms) and externalising (hyperactivity and conduct problems combined) difficulties and are shown in Figures 36 and 37 respectively.

Figure 35

Path model of standardised parameter estimates between condition, individual and family factors predicting child report of behavioural and emotional difficulty (n=85)
Chi-sq = 10.51 (df 20) p = .95 NFI = .91 NNFI = 1.13 CFI = 1.00



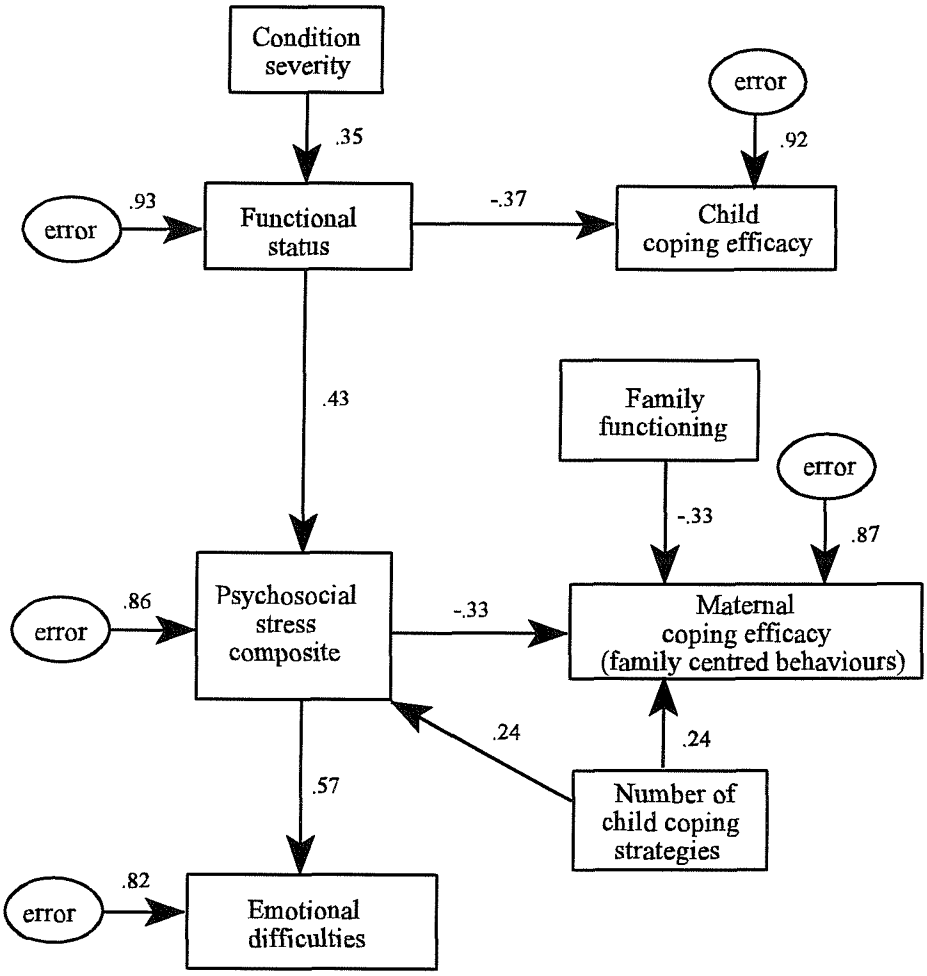
NFI = Bentler-Bonett Normed Fit Index NNFI = Bentler-Bonett Non-Normed Fit Index
CFI = Comparative Fit Index (Values of 1 or near 1 are desirable, indicating a good fit)

The comparative fit index suggests a highly satisfactory fit between the stipulated model and observed data, and indicates model validity. Parameter estimates, interpreted on the basis of size (strength of association) and direction (positive / negative association) imply the strongest relationships among model components lie in the paths between functional status and psychosocial stress and psychosocial stress and adjustment outcome. Findings suggest functional status and stress play a crucial role in forecasting behavioural and emotional difficulties. Specifically, health professional reported increases in condition severity, that is family care demands are linked to parent reported decreases in child functional status. Moreover, decreases in level of functioning are also associated with increases in psychosocial stress and a decline in child report of coping efficacy when dealing with an illness problem.

Notably, increases in psychosocial stress are linked to decreases in maternal coping efficacy, increased use of child coping strategies and escalation of behavioural and emotional difficulties. Decreases in maternal coping efficacy for family centred behaviours are also linked to a decline in family functioning, alternatively increases in maternal efficacy are associated with increased use of child coping strategies for management of an illness problem.

Figure 36

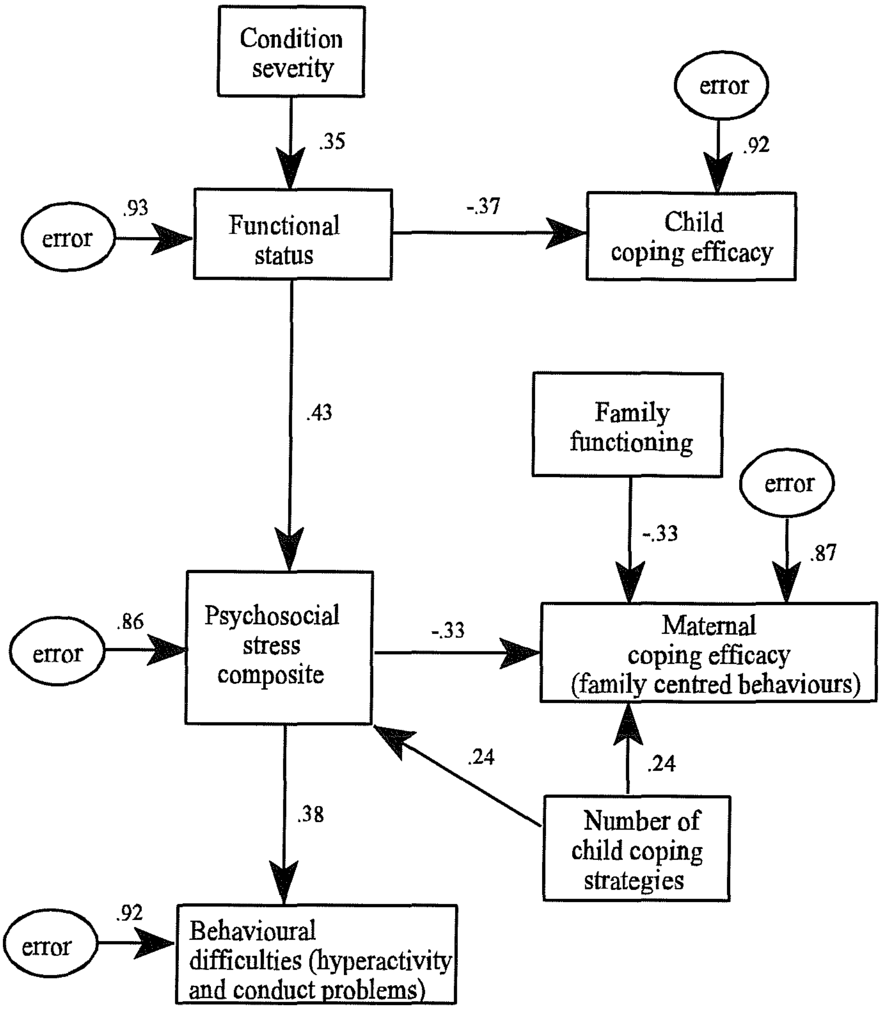
Path model of standardised parameter estimates between condition, individual and family factors predicting child report of emotional difficulty (n=85)
Chi-sq = 12.56 (df 20) p = .89 NFI = .89 NNFI = 1.12 CFI = 1.00



Fit indices for prediction of internalising difficulties suggest the model represents the data extremely well. Parameter estimates, with exception of the path between psychosocial stress and emotional difficulties replicated the previous model. The strength of the relationship between stress and emotional symptoms, although slightly weaker than when both behavioural and emotional difficulties are involved remains substantial.

Figure 37

Path model of standardised parameter estimates between condition, individual and family factors predicting child report of behavioural difficulty (hyperactivity and conduct problems) (n=85)
Chi-sq = 9.94 (df 20) p = .96 NFI = .89 NNFI = 1.20 CFI = 1.00



Model evaluation for prediction of externalising difficulties produced highly satisfactory fit indices. Parameter estimates, excluding the path between psychosocial stress and behavioural difficulties, mirrored those found in previous models. However, the estimate for this pathway is considerably reduced from estimates found for prediction of overall difficulty and emotional symptoms.

The results of tests evaluating the moderating effects of resistance factors are reported in Table 55. Here, the predictor (stress) and moderators were split into high and low groups prior to analysis. Specifically, stress composite scores were divided at the median, and maternal coping efficacy and number of child coping behaviours were split at the mean. Family functioning was pre-determined by a cutoff score of 2 which represents the distinction between healthy and unhealthy functioning. Higher scores reflect a trend towards unhealthy functioning.

Table 55

Two-way analysis of variance for adjustment outcome by psychosocial stress composite and resistance factors

	Adjustment outcome		
	Total difficulties	Emotional symptoms	Hyperactivity and conduct problems combined
Variable	F (Sig)	F (Sig)	F (Sig)
Main effects			
Stress	F=22.66 (.0001)	F=20.82 (.0001)	F=8.19 (.005)
Family functioning	F=0.85 (.35)	F=2.99 (.08)	F=0.005 (.94)
Two -way interaction			
Stress x family functioning	F=0.001 (.97)	F= 1.03 (.31)	F=1.24 (.26)
Main effects			
Stress	F=29.14 (.0001)	F=16.33 (.0001)	F=18.56 (.0001)
Maternal coping efficacy	F=0.23 (.63)	F=0.97 (.32)	F=1.84 (.17)
Two -way interaction			
Stress x coping efficacy	F=0.61 (.43)	F=0.10 (.74)	F=1.50 (.22)
Main effects			
Stress	F=24.73 (.0001)	F=14.77 (.0001)	F=14.02 (.0001)
No. of child coping strategies	F=0.86 (.35)	F=7.45 (.008)	F=0.001 (.98)
Two -way interaction			
Stress x No. of coping strategies	F=0.09 (.76)	F=0.60 (.44)	F=0.001 (.98)

Results for two-way analysis of variance of stress and resistance factors, defined by family functioning, maternal coping efficacy and number of child coping strategies revealed significant main effects for stress on all outcomes. A significant main effect also emerged for number of child coping strategies in relation to internalising difficulties. Univariate tests indicated that children using a high rather than low number of strategies and experiencing high as opposed to low stress, reported significantly more emotional symptoms. However, since interaction effects were not established no evidence of moderation was found.

6.9.1 Section 4 - Summary of findings for evaluation of the risk resistance framework

Findings for the three models suggest partial support for the risk resistance framework. Paths were verified between condition severity and functional status and functional status and psychosocial stress; intrapersonal factors, in terms of number of child coping strategies and psychosocial stress; social-ecological factors, that is family functioning and stress processing as represented by maternal coping efficacy; intrapersonal factors and stress processing, and finally psychosocial stress and adjustment outcome. Comparison of the parameter estimates predicting internalising and externalising difficulties suggest the experience of chronic illness is more commonly associated with emotional difficulty. Stress appears to be the crucial factor, playing a larger role in prediction of emotional symptoms than difficulties characterised by hyperactivity and conduct problems.

However, while factors assumed to enhance risk produce expected effects, resistance factors, that is family functioning, maternal coping efficacy and number of child coping strategies, failed to ameliorate the impact of psychosocial stress created by condition-based variables. Moderating effects of resistance factors on psychosocial stress were not found.

6.10 Section 5 - Extension and evaluation of a modified risk resistance framework

In this section the model derived from preceding analyses is extended to include peer context factors and evaluated. Given the acknowledged relevance of peer relationships to psychosocial well-being, it seemed likely these relationships would assume an important role in determining outcome and required examination. Since there is no precedent for this modification specifications for peer factors were defined by both the literature on peer relations in children with chronic illness and research questions. While limited, evidence suggests factors such as level of functioning, school absence and physical appearance are influential (La Greca, 1990). However, data for measures of school absence and physical appearance, a subscale of the perceived experience of condition scale, were not distributed normally. These variables were unresponsive to transformation and therefore excluded.

Research questions were concerned with the effect of functional status on peer context factors and the role peer factors play in predicting outcome. Questions were framed in the following:

- What is the relationship between functional status and peer context factors?

- How are peer context factors implicated in adjustment outcome?

Teachers, who had known children for the previous four months, or the last four months of the academic year were asked to report on social competence and school adjustment. Children were also interviewed about their relationships with two best friends, reporting on the level of play/association, conflict and intimacy. Children's responses to questions on these friendship properties reflected quantitative estimates. Since two of the subscales on the teacher completed questionnaire were common to both elementary and adolescent versions and contained highly similar items, they were selected for inclusion in the analysis rather than using total scale scores. Accordingly, the peer relations and school adjustment subscales on each version were standardised separately and then combined. Computation of Cronbach's alpha for raw scores on the two subscales for the entire sample (n=126) ranged from .89 to .94, indicating high internal consistency.

Friendship play/association and intimacy were chosen for the present evaluation for two reasons. First, it was likely these friendship properties would be affected by functional status and relate to outcome. Second, difficulties were encountered with conflict questions and led to a reduction in the number of questions for which data were accessible. Data from the two interviews were combined into a summary score for each feature, reflecting the summation of subscale mean scores divided by two. Estimates of internal consistency involving the whole sample (n =112-117) by interview and scale suggested that responses were highly reliable. Cronbach's alpha for the intimacy scale ranged between .74 and .80, and .75 to .79 for the play/association scale.

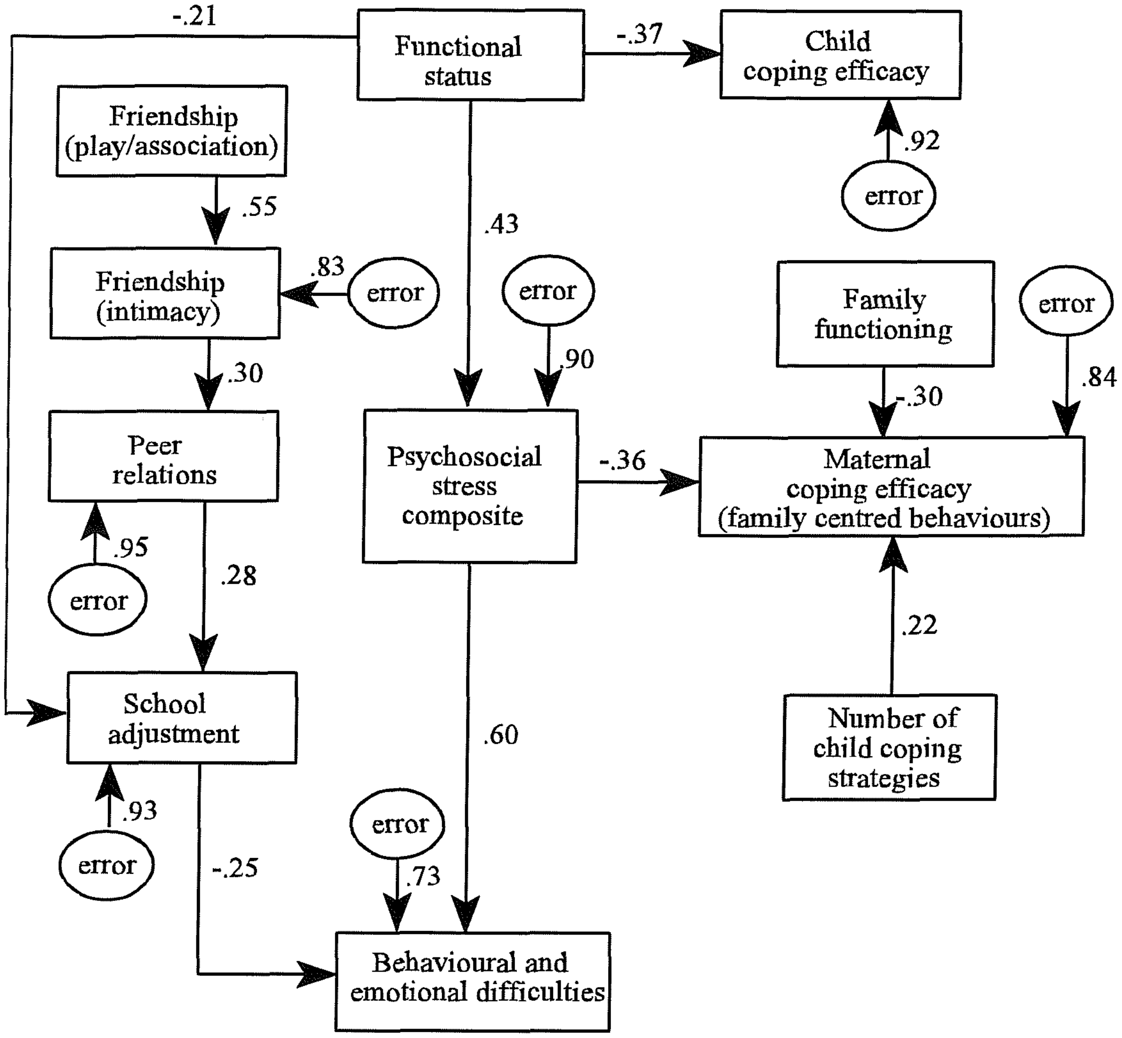
The sample included in the present analysis, for which complete sets of data were available totalled 73. Routine examination of variable distributions using the Kolmogorov-Smirnov test, indicated that condition severity failed to meet criteria for normality and was therefore removed prior to analytic procedures. All other variables were derived from the same source as stipulated in model testing described in Section 4.

From a developmental standpoint adequate friendship relations emerge from peer group acceptance in middle to late childhood. However, as developmental aspects were not under consideration the model specifies friendship features preceding peer relations. In light of the age range involved it was likely that friendship formation would already have occurred. It also seems probable that the calibre of friendship relations denotes social competence which may also underpin peer group relations. Moreover, peer relations would be expected to bear upon school adjustment which may be linked to reported difficulty.

As in all previous analyses outcomes were examined in terms of overall difficulty, internalising and externalising difficulties. Model testing entailed examination of links between of functional status and child report of friendship play/association and teacher report of peer relations. In addition, links between friendship intimacy and outcome were evaluated. However, analyses failed to confirm these paths but suggested a connection between functional status and school adjustment. Finally the path between number of child coping strategies and psychosocial stress failed to reach statistical significance and was therefore eliminated. Figure 38 presents results for overall difficulty.

Figure 38

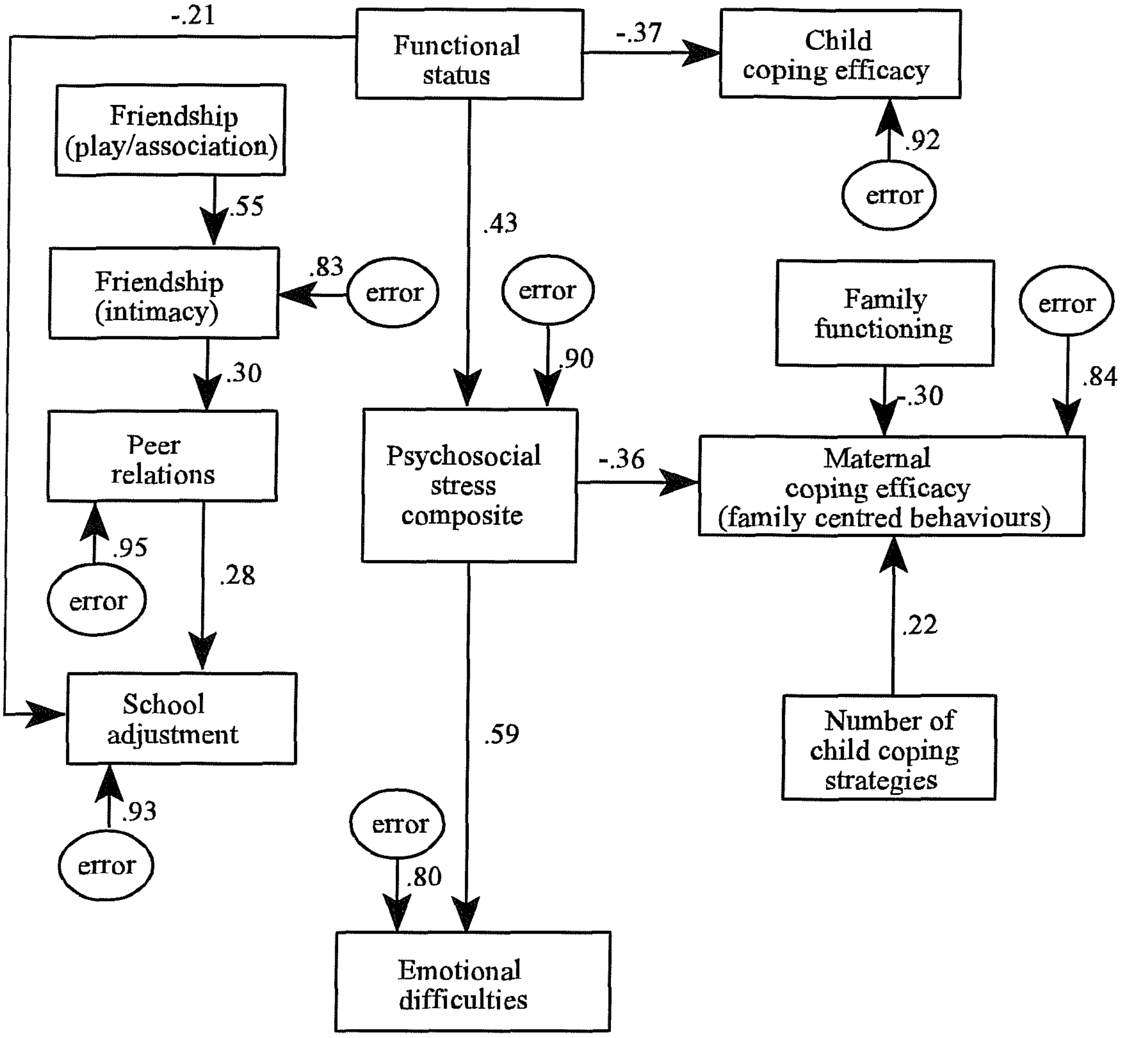
Path model of standardised parameter estimates between individual, family and peer factors predicting child report of behavioural and emotional difficulty (n=73)
Chi-sq = 47.52 (df 44) p< .33 NFI = 0.74 NNFI = 0.96 CFI = 0.97



Fit indices suggest a satisfactory match between the model specified and observed data. Similar parameter estimates were obtained for variables specified in the original model. Paths between friendship association and intimacy suggest that increased contact is matched by a corresponding increase in intimacy. Friendship intimacy predicts teacher estimates of peer relations in that higher levels of intimacy are associated with better peer relations. The path between peer relations and school adjustment indicates that better peer relations are linked to higher levels of school adjustment. Teachers' ratings of school adjustment were predicted by parent report of child functional status. As the level of functioning declines school adjustment deteriorates. Lower levels of school adjustment are also linked to increases in child report of difficulty. Results for model relationships predicting internalising difficulties are shown in Figure 39 and externalising difficulties in Figure 40.

Figure 39

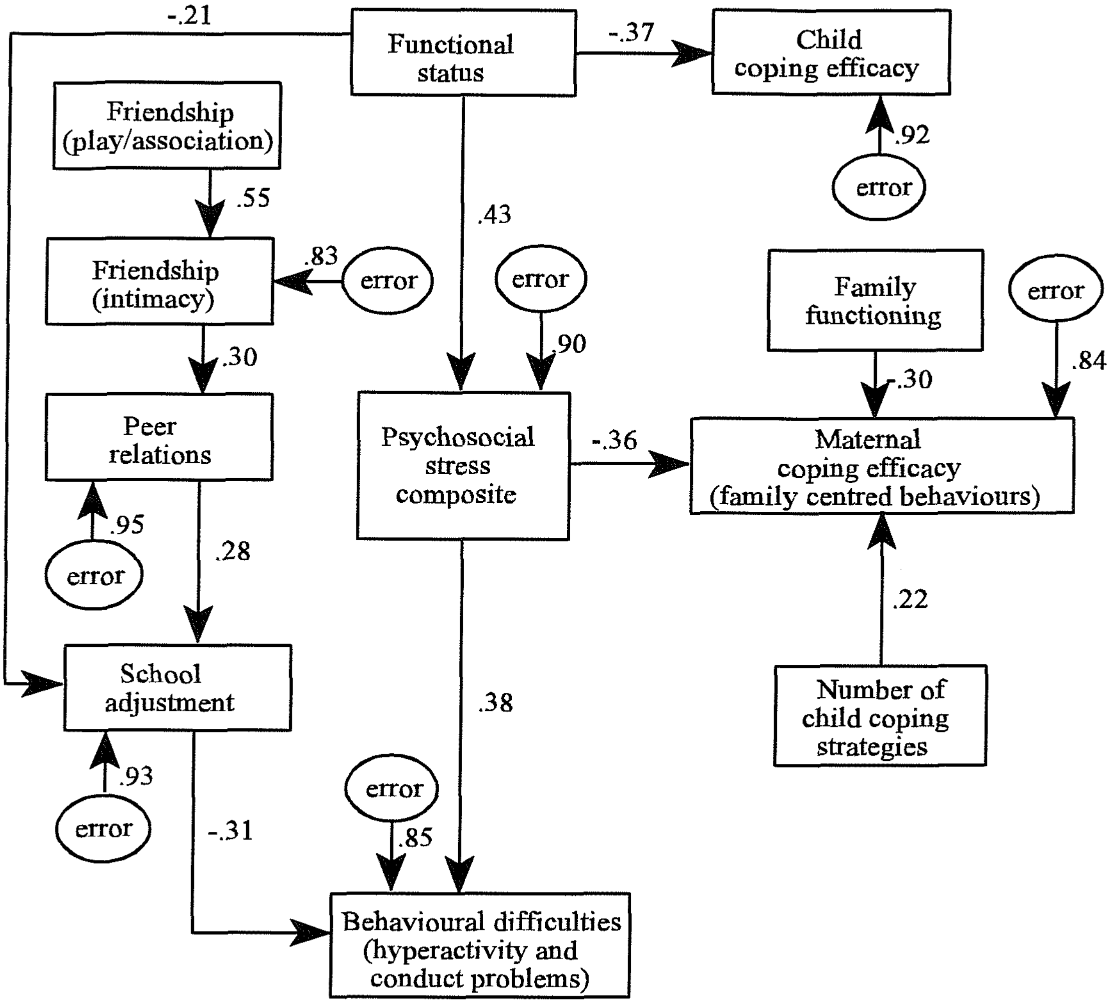
Path model of standardised parameter estimates between individual, family and peer factors predicting child report of emotional difficulty (n=73)
Chi-sq = 47.81 (df 45) p< .35 NFI = 0.72 NNFI = 0.97 CFI = 0.97



Fit indices are satisfactory, however while parameter estimates are essentially the same as the previous model, the link between school adjustment and outcome was not confirmed. Exploration of the model revealed a link between friendship intimacy and emotional difficulty, unfortunately emotional symptoms predicted intimacy rather than the other way round.

Figure 40

Path model of standardised parameter estimates between individual, family and peer factors predicting child report of behavioural difficulty (hyperactivity and conduct problems (n=73)
Chi-sq = 46.64 (df 44) p< .36 NFI = 0.71 NNFI = 0.96 CFI = 0.97



Findings for prediction of behavioural difficulties indicate a satisfactory fit between the model and observed data. Nonetheless, parameter estimates reveal a weakening of the relationship between psychosocial stress and the outcome variable. However, the link between school adjustment and behavioural difficulty is re-established and strengthened. This would imply, as suggested earlier that externalising difficulties, in comparison to internalising difficulties are a less likely outcome for children with chronic illness. Nonetheless, increases in externalising difficulties appear to be associated with a marked decline in school adjustment.

6.10.1 Section 5 - Summary of findings for extended risk resistance framework

Evaluation of moderating effects for resistance factors were not required in the present analyses since parameter estimates for these factors (family functioning, maternal coping efficacy) were similar to models tested in Section 4 in which no evidence for moderating effects was found. In parallel with findings for the previous models, stress exerts a considerably stronger impact in relation to child report of internalising difficulties compared to externalising difficulties. However, the models also suggest that while school adjustment is not related to internalising difficulties it demonstrates a robust relationship with externalising difficulties. This implies that externalising difficulties, in contrast to internalising difficulties are disruptive of school adjustment.

The extended models are helpful in defining relationships between a children's health and psychological status and the peer context. Children's level functioning appears to have significant implications for school adjustment indicating that chronic illness in childhood and adolescence may pose difficulty for social relations in a school setting. However, although paths between functional status and friendship association and peer relations, were not confirmed friendship intimacy was related to emotional difficulty, but not in the expected direction. Reports of increased emotional symptoms were linked to increased intimacy suggesting that young people may be using their friendships to gain support and relieve distress.

This concludes examination of substantive research questions. In the next chapter we explore effects of emotional symptoms and functioning linked to friendship and peer related factors.

Chapter 7: The role of emotional symptoms and functional status in friendship quality and properties, peer relations and school adjustment

In the previous chapter statistical analyses revealed a positive relationship between emotional symptoms and friendship intimacy. This suggests children reporting higher levels of emotional symptoms may be using their friendships to obtain emotional support and implies that intimacy could perhaps serve some kind of protective function. If this is a plausible assumption then the quality (i.e. positive and negative features) of friendship relations for children with high emotional symptom scores might be expected to demonstrate more positive and fewer negative features, than children with low scores. In Chapter 7 we explore this assumption and examine children's friendships in relation to emotional symptoms, functional status, peer relations and school adjustment. The aim of this chapter is to present details of the statistical analyses guiding this exploration and outline findings. The conceptual and methodological approach framing analyses is delineated and followed by comparison of friendship quality and properties, peer relations and school adjustment in children reporting either a high or low level of emotional symptoms and who also differ in terms of parent reported functional status. In line with the structure of Chapter 6 findings will be summarised at the end of the chapter.

7.1 Overview of rationale for analysis

While a number of studies focussing on peer relationships have established correlates of social functioning in children with chronic illness, few have sought to investigate the role of friendship. However, a study conducted by Varni and colleagues (1989b) demonstrates that child report of general self-esteem in children with limb deficiencies is significantly and positively associated with perceived classmate and friend support. La Greca (1992), as indicated in Chapter 2, also reports that among adolescents with diabetes, friends provided more support for "feeling good about diabetes" in contrast to family members. Findings from studies of friendship relations focussing on children without chronic illness indicate positive and negative features are associated with self-esteem and school adjustment. For instance, Berndt and Miller (1993 cited in Berndt, 1996) interviewed one hundred and fifty three 11-12 year olds about their three best friends and found positive features were significantly and positively related to scholastic competence, social acceptance, behavioural conduct, global self-worth and school value. Negative features, on the other hand were significantly and negatively related to scholastic competence, behavioural conduct, school value and involvement. In another study, teacher ratings of disruption were significantly and positively correlated with negative friendship features (Berndt & Keefe, 1995). These findings suggest that friendship quality is related to psychosocial well-being and within the context of chronic illness may assume a significant role in defining adjustment outcomes.

Analyses presented in Chapter 6 indicate increases in friendship intimacy, reflecting the frequency with which intimate exchanges occur, predicted enhanced peer relations. However, it is unclear whether friendship quality, for children differing in level of emotional symptoms is similarly linked to peer relations and school adjustment. In addition, it seems probable that a child's level of functioning is relevant in steering opportunities to establish and maintain friendships. La Greca (1990) has suggested findings point to a strong link between functional limitations and poor peer relationships. However, whether limitations present difficulties for friendship relations is less apparent. It is possible the quality of friendships may be linked to both functional status and emotional symptoms. If increases in emotional symptoms represent responses to functional limitations, then it may be anticipated that friendship quality would decline in parallel with functioning. Alternatively, if this is not the case, what are the expected effects for children who report low emotional symptoms yet have low functioning? Evidence delineating the role of emotional and functional status factors in friendship is remarkably scarce and accordingly this chapter presents an exploration of friendship quality, that is positive and negative features, and friendship properties (i.e. play/association, intimacy, absence of conflict), peer relationships and school adjustment in relation to the level of emotional symptoms and functioning.

7.2 Method and coding protocol

The interviews from which levels friendship properties were derived included exploration of responses given by the children. For example, if a child responded yes to the question "When you have problem at home or at school do you talk to Tracey about it " they were invited to indicate both, how often this happened and explain why they talked to their friend about problems. Responses specifying frequency of exchanges were guided by a series of five boxes increasing in size to reflect increasing interaction. Scores were assigned in line with the child's selection and ranged between 0 and 4. While the properties of play/association and intimacy were based on mean scores for five questions, absence of conflict reflected three. Two of the questions on the latter scale seemed to create difficulty for children and were therefore excluded. The absence of conflict of scale, in contrast to previous analyses, is included here for exploratory purposes. Responses to the second question, focussing on why interactions occurred, could be coded into various features reflecting positive and negative attributes and thus provided an index of friendship quality.

Friendship quality was ascertained using coding procedures devised by Berndt and Perry (1986), authors of the interview schedule. These guidelines were based on content analyses of children's responses to interview questions referring to acquaintances and friends. Of particular interest here however, is the balance between positive and negative features which may reveal in what way the global content of friendships is linked to intimacy, play/association, absence of conflict, peer relations, school adjustment, emotional difficulty and functional status. Children were interviewed about two friends and asked whether the nominated friend was their first, second, third, fourth or fifth best friend. However, some children declared their friends to be equal. Interview schedules comprised identical questions but in a different order and all responses were recorded on audio tape. Schedules were also alternated between participants to counter order effects.

To determine the effects of emotional symptoms and functioning, children reporting high scores on the emotional symptoms subscale of the Strengths and Difficulties Questionnaire with high or low functioning were contrasted to children reporting low emotional symptoms with either high or low functioning. Functional status scores were obtained from parent report of health related quality of life (i.e. total score on the performance subscale). Eighteen children with high emotional symptoms and eighteen children with low emotional symptom scores, nine with high functional status scores and nine with low functional status scores within each group were selected for analysis. High and low emotional symptoms and functional status groups were determined by dividing scores for the 106 youngsters completing both interview schedules at the mean, and allocating participants into high and low groups respectively. Selection was also narrowed to children whose teachers had provided estimates of peer relations and school adjustment. Inclusion was initiated by choosing two children with the most extreme high or low emotional symptom scores. Additional participants meeting selection criteria were recruited into the sample via a random selection procedure. The sample size reflects constraints imposed by time and data availability. Twenty three girls and thirteen boys were involved, ages ranged from 8.08 to 17.02 years and all condition groups were represented however, the majority (38 percent) of children had asthma. Group means and standard deviations for emotional symptoms, functional status and age are presented in Table 56.

Table 56

Means and standard deviations for functional status, emotional symptoms and age by high and low functional status and emotional symptoms groups

	Functional status	Emotional symptoms	Age (months)
Group	Mean (SD)	Mean (SD)	Mean (SD)
High emotional symptoms (n=18)	40.44 (14.44)	7.00 (1.08)	157.04 (31.68)
Low emotional symptoms (n=18)	42.44 (12.09)	1.72 (1.27)	152.77 (24.47)
High functional status (n=18)	31.11 (5.40)	3.94 (2.96)	160.51 (24.43)
Low functional status (n=18)	52.00 (9.24)	4.77 (2.90)	149.30 (30.80)
High emotional symptoms & high functioning (n=9)	28.88 (5.94)	6.66 (1.00)	165.05 (28.85)
High emotional symptoms & low functioning (n=9)	52.00 (9.05)	7.33 (1.11)	149.02 (33.99)
Low emotional symptoms & high functioning (n=9)	33.33 (3.93)	1.22 (.97)	155.97 (19.73)
Low emotional symptoms & low functioning (n=9)	52.00 (9.97)	2.22 (1.39)	149.58 (29.33)

Scores for children in the high emotional symptom group ranged between five to nine, and from zero to three for children in the low emotional symptom group. The possible range for scores on this subscale is zero to ten. Functional status scores may range between 15 and 105. For children in the high functional status group scores ranged between 21 to 38 and 42 and 69 for the low functional status group.

Children's interview responses were transcribed and coded in accordance with instructions. Only the first response given by the child was coded, following Berndt and Perry (1986) this " made scores comparable for different subjects and limited the effects of individual differences in verbal fluency". However, some first responses were substantially longer than others, and irrespective of length received two codes if appropriate.

The coding schedule provided seven positive and five negative categories which included categories for miscellaneous positive and negative responses. An additional category defined "I don't know" and responses unrelated to the question as no response. Positive friendship features included *liking/friendship*, e.g. "She's my best friend", "we're close friends"; *prosocial/polite behaviour*, e.g. "It's umm..easy to be with her, easy to get on with her", "we always share ideas"; *positive association*, e.g. "She's definitely good for company and she's funny", "it's fun and we like to play with each other", "we sort of like doing the same things"; *emotional support /understanding*, e.g. "she understands and she knows what it's like", "she listens to what I....how I feel"; *absence or quick resolution of problems*, e.g. "I'm not that sort of person really.....I don't get in fights that much", "we don't really disagree with things"; *trust*, e.g. "I could probably trust her more than my other friends", "I know that he won't tell anyone "; *miscellaneous positive* and irrelevant responses reflect contact in the absence of choice or playful teasing "just someone to talk to" "umm... well he's always around". Negative friendship features entailed, *absence of friendship or interaction*, e.g. "we don't get to see a lot of each other", "we don't live very near"; *antagonistic/impolite behaviour* including discord in peer network and lack of emotional support or understanding, e.g. "..we disagree about what we're gonna do...she gets annoying", "she goes off with the year 6 girls and I feel left out", "he teases me about things I like"; *lack of trust*, e.g. "I be worried that she'd spread it"; *importance of other relationships and / or obligations* which includes spending more time with others, preference for other's company, shares intimate knowledge with others, e.g. "I'm mostly with Holly", "I can go and see a teacher and talk about it to them"; *miscellaneous negative* and irrelevant which comprise responses that suggest other child is reluctant to share, is unlikely to able to help, or child indicates that they do not wish to confide in this particular child, e.g. "I don't really have many problems at home..so umm...and if I do I just sort them out myself", "Umm....she always comes in our house when I wanna go in hers".

7.3 Inter-rater and internal reliability of coding procedure

Estimates of inter-rater reliability were established prior to statistical analysis. Ten interview schedules, five relating to children with high emotional symptom scores, two with high, and three with low functional status scores, and five with low scores, three with high and two with low functional status scores were randomly selected and recoded by a psychology research fellow. The researcher was blind to both participants' emotional symptom and functional scores. Level of agreement was determined by calculating the number of question responses on which codes matched completely or partially and dividing this number by the total number of questions on the schedule. Partial agreement occurred in responses where either one of two codes awarded by a coder matched the other. Although the optimal method for calculation of agreement is the Kappa statistic the large number of codes prevented application. Consequently chance agreement is not incorporated into the present measure and overestimates agreement. However, the size of statistic indicates that level of agreement is satisfactory. Partial and complete agreement for the ten schedules ranged from .65 to 1.00. The average level for complete agreement was .71, and for complete and partial agreement together was .82, suggesting the coding procedure was reliable.

A check on the internal reliability of positive and negative friendship features involved using responses to non-coded schedule questions. These questions focussed on aspects children reported liking and disliking about their friends. For example, a likeable attribute was reported as "She understands what help I need", a dislikable attribute "She fights a lot". Children's first responses were employed to count the number of likeable and dislikable attributes of their friends. The means for positive and negative friendship features were established by dividing the reported number of respective features by the number of available categories, that is seven and five respectively. Since interest centred on the balance between positive and negative features, a difference score was achieved by subtracting the mean for negative features from the mean for positive features. Proportions of positive and negative features to the total number of features reported and the difference between these proportions were also calculated. The latter, in contrast to the former, takes account of differences between groups in the overall number of reported positive and negative features, that is reporting bias. It was decided that both mean and proportional scores would be examined. Likeable and dislikeable attribute scores were correlated with mean and proportional positive and negative friendship features and difference scores. Results are shown in Table 57. Although 36 children were involved responses were available for a sample size of 32.

Table 57

Pearson correlation coefficients between number of likeable and dislikable attributes of friends and mean / proportional positive and negative features and difference score (n=32)

	Mean positive features	Proportion positive features	Mean negative features	Proportion negative features	Mean difference score	Proportion difference score
	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)	Coeff (Sig)
Number likeable attributes	0.45 (.009)	0.39 (.02)	-0.33 (.05)	-0.39 (.02)	0.41 (.01)	0.39 (.02)
Number of dislikable attributes	-0.03 (.84)	-0.28 (.10)	0.35 (.04)	0.28 (.10)	-.020 (.26)	-.028 (.10)

Findings indicated number of likeable attributes was significantly and positively correlated with mean and proportional positive features and difference scores. Likeable attributes were also significantly and negatively correlated with the proportional negative features score, but not the mean score. In addition, dislikeable attributes and mean negative features were significantly and positively correlated. Negative associations between dislikable attributes and proportional positive features and difference scores were also apparent, although associations were not statistically significant. Results confirm the internal reliability of positive features, however, while most of the correlations for negative features were not statistically significant the strength and direction of effects tend to support internal reliability.

7.4 Evaluation of friendship quality by level of emotional symptoms and functional status

To test the assumption that friendship quality would favour children with high compared to low emotional symptoms and investigate differences between children with high and low functioning, mean frequencies were calculated for friendship feature and no response categories, overall mean and proportional levels of positive and negative responses and difference scores. The data for many features reflected skewed distributions and accordingly Mann-Whitney tests were used to evaluate the significance of group differences. Since examination of proportional scores for individual features yielded the same findings these results are not reported. Results for high and low emotional symptom groups are shown in Table 58 and high and low functioning in Table 59.

Table 58

Mean frequencies and Mann-Whitney tests for positive, negative friendship features, mean and proportional positive, negative and difference scores by high (n=18) and low (n=18) emotional symptom groups

	Low emotional symptom score	High emotional symptom score	Mann-Whitney test
Friendship feature	Mean (SD)	Mean (SD)	Z (Sig)
Liking and friendship	1.61 (1.78)	.83 (.92)	Z = -1.18 (.23)
Prosocial/Polite behaviour	2.05 (.2.12)	1.27 (1.22)	Z = -0.80 (.41)
Positive association	3.72 (2.42)	3.88 (1.87)	Z = -0.08 (.93)
Emotional support	2.11 (1.32)	2.61 (2.25)	Z = -0.17 (.85)
Absence or quick resolution of problems	.44 (.78)	.94 (.99)	Z = -1.63 (.10)
Trust	2.38 (1.57)	3.50 (2.50)	Z = -1.17 (.24)
Miscellaneous positive	2.00 (1.37)	1.94 (1.86)	Z = -0.52 (.60)
Mean positive features	2.04 (.45)	2.1 (.78)	Z = -0.42 (.66)
Proportion of positive features	.73 (.14)	.71 (.19)	Z = -0.04 (.96)
Absence of friendship or interaction	.55 (.98)	.66 (1.18)	Z = -0.11 (.90)
Antagonistic/ Impolite behaviour	1.77 (1.30)	2.44 (1.42)	Z = -1.58 (.11)
Lack of trust	.94 (1.34)	.61 (1.03)	Z = -0.59 (.55)
Different friends	.38 (.60)	.55 (.98)	Z = -0.15 (.87)
Miscellaneous negative	1.61 (1.42)	1.16 (1.42)	Z = -1.03 (.29)
No response	1.72 (1.56)	1.27 (1.48)	Z = -0.94 (.34)
Mean negative features	1.05 (.54)	1.08 (.78)	Z = -0.06 (.94)
Proportion negative features	.26 (.14)	.28 (.19)	Z = -0.04 (.96)
Mean difference score	.99 (.92)	1.05 (1.45)	Z = -0.23 (.81)
Proportion difference score	.46 (.29)	.43 (.39)	Z =-0.04 (.96)

No significant differences were found for friendship features or summary scores for high and low emotional symptom groups. However, comparison of mean frequencies show children experiencing a low, compared to high level of symptoms report higher levels of liking, prosocial/polite behaviour, lack of trust and miscellaneous positive and negative features and lower levels of antagonistic/impolite behaviour, lack of interaction and reliance on other friends. On the other hand, children with a high, in contrast to low level of symptoms report a higher degree of positive association, emotional support, trust and absence of problems. The mean number of positive features, negative features and difference score indicate children with high, compared to low emotional symptoms report slightly more positive features and negative features and appear to have friendships characterised by more positive features than negative features.

Proportional scores for mean positive, negative and difference scores suggest however, that children with low emotional symptoms report a higher number of positive features and a lower level of negative features than children with high emotional symptoms. Thus children with a low level of emotional symptoms, in comparison to their counterparts have friendships characterised by more positive than negative features. The different outcomes may be explained by the finding that children with high emotional symptoms tend to report marginally more positive and negative features, although not significantly more than children with low emotional symptoms.

Table 59

Mean frequencies and Mann-Whitney tests for positive, negative friendship features, mean and proportional positive, negative and difference scores by high (n=18) and low (n=18) functional status groups

	High functional status		Low functional status		Mann-Whitney test	
Friendship feature	Mean	(SD)	Mean	(SD)	Z	(Sig)
Liking and friendship	1.11	(1.40)	1.33	(1.53)	Z = -0.58	(.55)
Prosocial/Polite behaviour	1.33	(1.57)	2.00	(1.90)	Z = -1.12	(.26)
Positive association	4.44	(1.65)	3.16	(2.40)	Z = -1.66	(.09)
Emotional support	2.55	(1.85)	2.16	(1.85)	Z = -0.90	(.36)
Absence or quick resolution of problems	.50	(.85)	.88	(.96)	Z = -1.38	(.16)
Trust	2.61	(1.57)	3.27	(2.58)	Z = -0.54	(.58)
Miscellaneous positive	1.77	(1.59)	2.16	(1.65)	Z = -0.83	(.40)
Mean positive features	2.04	(.44)	2.14	(.79)	Z = -0.30	(.76)
Proportion of positive features	.73	(.14)	.71	(.19)	Z = -0.04	(.96)
Absence of friendship or interaction	.50	(.98)	.72	(1.17)	Z = -0.46	(.64)
Antagonistic/ Impolite behaviour	2.33	(1.41)	1.88	(1.36)	Z = -1.07	(.28)
Lack of trust	.83	(1.09)	.72	(1.31)	Z = -0.70	(.48)
Different friends	.61	(.97)	.33	(.59)	Z = -0.78	(.43)
Miscellaneous negative	1.05	(1.30)	1.72	(1.48)	Z = -1.41	(.15)
No response	1.55	(1.54)	1.44	(1.54)	Z = -0.21	(.83)
Mean negative features	1.06	(.56)	1.07	(.70)	Z = -0.01	(.98)
Proportion negative features	.26	(.14)	.28	(.19)	Z = -0.04	(.96)
Difference score	.98	(.93)	1.06	(1.44)	Z = -0.23	(.81)
Proportion difference score	.46	(.28)	.43	(.39)	Z = -0.04	(.96)

Once again, no significant differences were found for friendship features or summary scores for high and low functional status groups, although positive association was found to differentiate groups at the .10 level of significance. Children with high functioning reported higher levels of positive association in comparison to children with low functioning.

However, given the number of statistical tests undertaken this finding needs to be viewed with care. Nonetheless, comparison of mean frequencies by high and low functioning groups show children with high, compared to low functioning report in addition to positive association, higher levels of emotional support, antagonistic/impolite behaviour, lack of trust and reliance on other friends and lower levels of absence of interaction, miscellaneous positive and negative features. Alternatively, children with low, compared to high functioning report a higher degree of liking, prosocial/polite behaviour, trust and absence of problems. The mean number of positive features, negative features and difference score indicate children with low functioning report slightly more positive features and negative features and, in contrast to children with high functioning, seem to have friendships characterised by more positive features than negative features.

However, proportional scores for mean positive negative and difference scores suggest that overall children with high, compared to low functioning report a higher number of positive features and a lower level of negative features. In other words, children with high functioning, in contrast to their counterparts have friendships characterised by more positive than negative features. The disparity is attributable to children with low functioning reporting marginally more positive and negative features, although not significantly more than children with high functioning.

The above findings suggest mean differences in positive and negative friendship features appear to be related to both level of symptoms and functioning. Therefore paired t-tests were conducted to examine the balance of positive and negative friendship features by both high and low emotional symptoms and functional status. Results are shown in Table 60.

Findings point to group variation in the strength of difference between positive and negative friendship features.

Table 60

Mean and proportional positive and negative friendship feature scores and paired t-tests by low and high emotional symptom and functional status groups

	Variable					
	Positive features	Negative features	t-test	Positive features	Negative features	t-test
Group	Mean (SD)	Mean (SD)	t (Sig)	Proportion (SD)	Proportion (SD)	t (Sig)
High emotional symptoms & high functioning (n=9)	2.01 (.54)	1.13 (.63)	-2.39 (.04)	.71 (.15)	.28 (.15)	-4.04 (.004)
High emotional symptoms & low functioning (n=9)	2.26 (.99)	1.04 (.82)	-2.05 (.07)	.72 (.24)	.27 (.24)	-2.83 (.02)
Low emotional symptoms & high functioning (n=9)	2.07 (.35)	1.00 (.51)	-4.19 (.003)	.74 (.13)	.25 (.13)	-5.74 (.0001)
Low emotional symptoms & low functioning (n=9)	2.01 (.56)	1.11 (.60)	-2.47 (.039)	.71 (.16)	.28 (.16)	-3.88 (.005)

The t-values for mean scores imply the balance between positive and negative features is less distinct for children with high, compared to low emotional symptoms suggesting overall that these children perceived their friendships to have marginally more negative features. The respective means for negative features in high and low emotional symptom groups were 1.08 and 1.05 (see Table 58). In terms of functional status, t-values for mean scores convey a similar picture for children with low levels of functioning with mean scores for negative features in children with low functioning being 1.07, compared to 1.06 for high functioning children (see Table 59). Comparison of results for all groups indicates the balance between positive and negative features for children with high emotional symptoms and low functioning is markedly less clear than other groups. Although the picture presented by positive and negative mean scores suggests this group reported more positive and fewer negative features than youngsters with either high symptoms and high functioning or children with low symptoms and low functioning. However, the highly significant difference between positive and negative features for children with low symptoms and high functioning implies these children have friendships characterised by more positive features than negative features in comparison to other groups. Inspection of standard deviation scores suggest however, greater variation in the balance between positive and negative features, compared to other groups in children with high emotional symptoms and low functioning. In contrast, children with low emotional symptoms and high functioning show greater homogeneity in the balance between positive and negative features than other groups. Results for proportional scores render comparable findings.

While on the one hand mean difference scores indicate that children with either high emotional symptoms or low functioning have friendships characterised by more positive features, proportional difference scores point to children with either low emotional symptoms or high functioning to have more positive features than children with either high emotional symptoms or low functioning. Proportional scores have the advantage of eliminating differences in overall reporting by groups and may represent a more stringent measure of the balance between positive and negative friendship features. Nonetheless, paired t-tests for both mean and proportional mean and negative features and proportional difference scores indicate, contrary to expectation that children with high, compared to low emotional symptoms have friendships reflecting a marginally higher number negative features. Although these children do report higher levels of positive association, emotional support, absence of problems and trust than children with low emotional symptoms. Paired t-tests and proportional difference scores also suggest the friendships of children with low, in contrast to high functioning, are typified by a slightly higher number of negative features.

7.5 Evaluation of friendship properties, peer relations and school adjustment by level of emotional symptoms and functional status and associations with friendship quality

Subsequent analyses further investigate the balance between positive and negative friendship features in relation to play/association, intimacy and absence of conflict and teacher report of peer relations and school adjustment. First, differences in friendship properties, peer relations and school adjustment are examined by high and low emotional symptom and functional status groups. Second, patterns of association among variables are evaluated and includes analysis of group differences. Finally, two way analyses of variance are used to evaluate interaction effects. Means, standard deviations and t-tests were computed for both high and low emotional symptoms and functional status groups. Results are shown in Tables 61 and 62.

Table 61

Mean frequencies and t-tests for friendship, peer and school variables by high (n=18) and low (n=18) emotional symptom groups

	Low emotional symptoms	High emotional symptoms	t-test	
Variables	Mean (SD)	Mean (SD)	t	(Sig)
Friendship play/association	.46 (.10)	.44 (.13)	0.43	(.67)
Friendship intimacy	.36 (.15)	.42 (.16)	-1.28	(.21)
Friendship absence of conflict	.84 (.10)	.82 (.12)	0.75	(.45)
Peer relations (zscore)	.26 (.90)	.20 (.88)	0.18	(.86)
School adjustment (zscore)	.34 (.73)	.16 (.87)	0.68	(.50)

Findings revealed no significant differences by level of emotional symptoms. Nonetheless, whereas mean scores for friendship play/association and absence of conflict were indistinguishable, children with high emotional symptoms were found to report higher levels of intimacy. Mean scores for peer relations and school adjustment suggest children with high emotional symptoms were judged by their teachers to have poorer peer relations and school adjustment than counterparts reporting low emotional symptoms.

Table 62

Mean frequencies and t-tests for friendship, peer and school variables by high (n=18) and low (n=18) functional status groups

	High functional status	Low functional status	t-test
Variables	Mean (SD)	Mean (SD)	t (Sig)
Friendship play/association	.45 (.10)	.44 (.13)	0.12 (.90)
Friendship intimacy	.39 (.15)	.39 (.16)	-0.16 (.87)
Friendship absence of conflict	.83 (.11)	.83 (.11)	-0.14 (.88)
Peer relations (zscore)	.51 (.71)	-.04 (.96)	1.99 (.05)
School adjustment (zscore)	.51 (.69)	.002 (.84)	1.98 (.05)

Results displayed in Table 60 indicate that friendship properties do not differ by level of functioning. However, differences in peer relations and school adjustment, although not quite reaching statistical significance imply that children with low functional status receive lower scores than children with a high level of functioning. Findings suggest that teachers judge children with low functioning to have less optimal peer relations and school adjustment than children with a high level of functioning.

Associations between friendship play/association, intimacy, absence of conflict, peer relations, school adjustment, mean and proportional difference scores were computed for low and high emotional symptom and functional status groups to establish patterns of association for groups. Group differences in correlation coefficients were examined using Fisher's transformation procedure. Functional status scores are included in the evaluation of high and low emotional symptom groups and correspondingly emotional symptom scores are included evaluation of functional status groups. Results for associations are shown in Tables 63, 64, 65, and 66. The alpha level is readjusted given the probability that significant results are more likely to occur by chance. An alpha of .05 means that for a set of 8 correlations the significance level is reset at .006. The results of Fisher's transformation procedure demonstrating trends for group differences are shown in Table 67.

Table 63

Pearson correlation coefficients between friendship and peer variables and functional status for children reporting low emotional symptom scores (n=18)

	Coeff (Sig)						
Variable	1	2	3	4	5	6	7
1. Functional status							
2. Play/association	-.10 (.47)						
3. Intimacy	-.15 (.53)	.62* (.005)					
4. Absence of conflict	.19 (.43)	.17 (.48)	-.02 (.90)				
5. Peer relations	-.13 (.50)	.38 (.11)	.36 (.13)	-.10 (.68)			
6. School adjustment	.17 (.48)	.18 (.45)	-.02 (.93)	.29 (.23)	.43 (.06)		
7. Mean difference score	-.17 (.49)	.76** (.0001)	.70** (.001)	.41 (.08)	.53 (.02)	.30 (.21)	
8. Proportional difference score	-.21 (.39)	.72* (.001)	.75** (.0001)	.43 (.07)	.46 (.05)	.21 (.39)	.97** (.0001)

* p< .05 ** p< .01 after Bonferroni's correction

Table 64

Pearson correlation coefficients between friendship and peer variables and functional status for children reporting high emotional symptom scores (n=18)

	Coeff (Sig)						
Variable	1	2	3	4	5	6	7
1. Functional status							
2. Play/association	.10						
	(.69)						
3. Intimacy	.20	.74**					
	(.40)	(.0001)					
4. Absence of conflict	.07	.13	.11				
	(.76)	(.60)	(.65)				
5. Peer relations	-.58	.31	.26	-.05			
	(.01)	(.20)	(.29)	(.83)			
6. School adjustment	-.46	.25	.36	.11	.56		
	(.05)	(.31)	(.13)	(.66)	(.01)		
7. Mean difference score	.31	.76**	.78**	.54	.07	.23	
	(.20)	(.0001)	(.0001)	(.01)	(.78)	(.34)	
8. Proportional difference score	.20	.80**	.80**	.53	.13	.26	.98**
	(.41)	(.0001)	(.0001)	(.02)	(.59)	(.28)	(.0001)

* p< .05 ** p< .01 after Bonferroni's correction

Statistically significant associations were found for both emotional symptom groups in terms of mean and proportional difference scores and friendship properties. Play/association and intimacy were positively correlated with each other and both difference scores. In addition, difference scores not surprisingly, were highly and positively correlated with each other. Also there were comparable, although not significant trends for a positive association between mean and proportional difference scores and absence of friendship conflict, and between peer relations and school adjustment. However, trends also point to differences in that a decline in functional status for children with a high level of emotional symptoms was associated with a parallel decrease in peer relations and school adjustment. Alternatively, for children with low emotional symptoms, mean and proportional difference scores were positively correlated with peer relations and school adjustment suggesting increases in the difference score, that is higher friendship quality were related to better peer relations and school adjustment.

Table 65

Pearson correlation coefficients between friendship and peer variables and emotional symptoms for children with high functional status scores (n=18)

	Coeff (Sig)						
Variable	1	2	3	4	5	6	7
1. Emotional symptoms							
2. Play/association	-.04						
	(.86)						
3. Intimacy	.27	.49					
	(.27)	(.03)					
4. Absence of conflict	-.23	.21	-.04				
	(.34)	(.40)	(.85)				
5. Peer relations	.13	.14	.12	-.07			
	(.60)	(.56)	(.62)	(.76)			
6. School adjustment	.18	-.07	-.01	-.02	.54		
	(.46)	(.76)	(.93)	(.90)	(.01)		
7. Mean difference score	-.17	.65**	.56	.54	.08	-.02	
	(.47)	(.003)	(.01)	(.01)	(.73)	(.92)	
8. Proportional difference score	-.17	.69**	.63**	.56	.05	-.10	.97**
	(.49)	(.002)	(.005)	(.01)	(.82)	(.68)	(.0001)

* p< .05 ** p< .01 after Bonferroni's correction

Table 66

Pearson correlation coefficients between friendship and peer variables and emotional symptoms for children with low functional status scores (n=18)

	Coeff (Sig)						
Variable	1	2	3	4	5	6	7
1. Emotional symptoms							
2. Play/association	-.16						
	(.50)						
3. Intimacy	.05	.77**					
	(.83)	(.0001)					
4. Absence of conflict	-.20	.11	.08				
	(.41)	(.63)	(.74)				
5. Peer relations	-.30	.47	.46	-.06			
	(.22)	(.04)	(.05)	(.80)			
6. School adjustment	-.55	.42	.33	.42	.39		
	(.01)	(.07)	(.17)	(.08)	(.11)		
7. Mean difference score	-.001	.81**	.85**	.47	.36	.44	
	(.99)	(.0001)	(.0001)	(.04)	(.14)	(.06)	
8. Proportional difference score	-.06	.81**	.84**	.45	.39	.45	.98**
	(.79)	(.0001)	(.0001)	(.05)	(.10)	(.05)	(.0001)

* p< .05 ** p< .01 after Bonferroni's correction

Comparison of associations by functional status group indicated statistically significant positive associations between proportional difference scores and both play/association and intimacy in each group. Mean and proportional difference scores were also highly and positively correlated and there were nonsignificant trends for positive associations between absence of friendship conflict and proportional and mean difference scores in both groups. Links for mean difference scores differed by group however, whereas significant associations emerged between play/association and intimacy for children with low functional status, only play/association was significantly associated with the mean difference score in children with high functional status. Moreover, the strength of these associations is substantially greater for low, compared to high functioning children and suggests that for these children friendship quality is closely associated with play/association and intimacy.

Differences between the groups appeared in terms of the significant and positive relationship between play/association and intimacy for children with low functioning. Although this association in children with high functioning shows the same trend it does not reach statistical significance. In addition, there was a stronger relationship between peer relations and school adjustment in children with high, compared to low functional status. Trends were also apparent with respect to children with low functioning in that emotional symptoms were inversely related to school adjustment. Furthermore, friendship play/association was positively related to peer relations and the mean and proportional difference scores were positively correlated with school adjustment. The latter finding suggests friendship quality increases in line with school adjustment.

To establish group differences associations were examined using Fisher's transformation procedure. This procedure produces a z value representing standard deviation units with values above 1.96 for two tailed tests indicating statistical significance. However, no significant differences were found, although suggestive trends emerged. Only results showing z values above 1.20 are included in Table 67 to illustrate trends.

Table 67

Transformed correlation coefficients demonstrating trends for group differences in associations

		Transformed Coeff	Transformed Coeff	z
Correlated variables	Group	Either low symps or functioning	Either high symps or functioning	
Emotional symptom groups				
Peer relations and mean difference score		0.59	0.07	1.42
Functional status groups				
Play/association and intimacy		1.02	0.53	1.34
Intimacy and mean difference score		1.25	0.63	1.69
Intimacy and proportional difference score		1.22	0.74	1.31
School adjustment and mean difference score		0.47	0.02	1.23

Trends suggest that functional status plays a greater role in defining group differences than emotional factors. For emotional symptom groups the only z value exceeding 1.20 referred to the link between friendship quality and peer relations. The strength of this relationship was found to be greater in children reporting a low, compared to high level of emotional symptoms. For functional status groups four coefficients reached z values of 1.20. All links, that is play/association and intimacy, friendship quality and intimacy, and friendship quality and school adjustment were consistent in showing stronger associations for children with low, compared to high functioning.

Lastly, two-way analysis of variance tests were conducted on mean positive, negative and difference scores, friendship properties, peer relations and school adjustment to determine main and interaction effects of high and low emotional symptoms and functional status. As proportional scores do not alter substantive results mean scores are utilised. Age was correlated with dependent friendship variables and therefore controlled as a covariate in relevant analyses. Results are show in Tables 68, 69 and 70.

Table 68

Two - way analysis of variance for mean positive and negative friendship features and difference score by high and low emotional symptom and functional status groups (n=36)

	Mean positive features	Mean negative features	Difference score
	F (Sig)	F (Sig)	Fig (Sig)
Covariate			
Age	10.82 (.003)	6.19 (.01)	9.31 (.005)
Main effects			
Emotional symptom group	0.05 (.81)	0.13 (.71)	0.006 (.93)
Functional status group	1.35 (.25)	0.21 (.65)	0.72 (.40)
Two -way Interaction			
Emotional symptoms x functional status	1.22 (.27)	0.49 (.48)	0.91 (.34)

Neither level of emotional symptoms nor functional status were found to produce significant main or interaction effects after controlling for age in friendship positive and negative features or difference score. Findings indicate these factors do not differentiate groups in terms of the positive and negative features of friendship or the balance between the two.

Table 69

Two - way analysis of variance for play/association, intimacy and absence of conflict friendship properties by high and low emotional symptom and functional status groups (n=36)

	Play and association	Intimacy	Absence of conflict
	F (Sig)	F (Sig)	Fig (Sig)
Covariate			
Age	8.74 (.006)	4.07 (.05)	3.84 (.05)
Main effects			
Emotional symptom group	0.49 (.48)	1.27 (.26)	0.84 (.36)
Functional status group	0.23 (.63)	0.33 (.56)	0.29 (.58)
Two -way Interaction			
Emotional symptoms x functional status	0.01 (.90)	0.01 (.90)	0.28 (.59)

No main or interaction effects after controlling for age, were found for friendship play/association, intimacy or absence of conflict. Emotional symptoms and functional status do not appear to be influential.

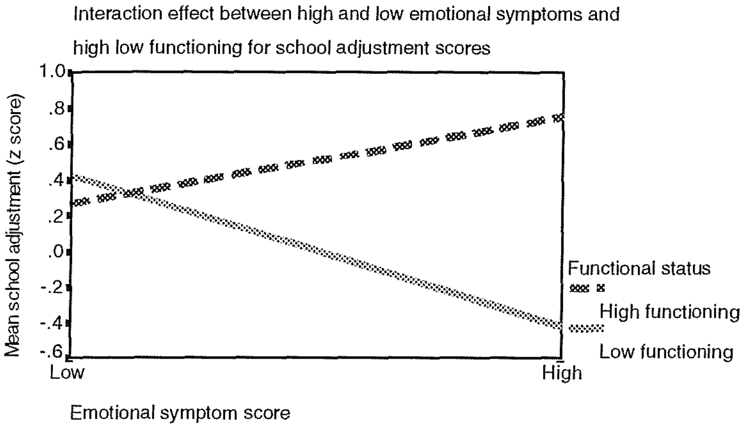
Table 70

Two - way analysis of variance for peer relations and school adjustment by high and low emotional symptom and functional status groups (n=36)

	Peer relations	School adjustment
	F (Sig)	F (Sig)
Main effects		
Emotional symptom group	0.03 (.85)	0.59 (.44)
Functional status group	4.05 (.05)	4.70 (.03)
Two -way Interaction		
Emotional symptoms x functional status	2.65 (.11)	8.00 (.008)

Main and interaction effects were found for school adjustment. A main effect of functional status group emerged for school adjustment, peer relations however, only marginally failed statistical probability at the five percent level. Comparison of mean scores indicated that children with low levels of functioning were judged by their teachers to have lower levels of peer relations and school adjustment than children with high functional status. A significant interaction effect emerged for school adjustment and is shown in Figure 41. While children with either high or low functioning and low emotional symptoms did not differ markedly in level of school adjustment, differences were substantially magnified for children reporting a high level of emotional symptoms. Whereas high emotional symptoms and high functioning increases school adjustment, the opposite appears to hold for low functioning children. Findings imply that a combination of high symptoms and low functioning is linked to decreased school adjustment. Peer relations scores displayed a similar picture, although this failed to reach statistical significance.

Figure 41



7.6 Summary of findings for the role of emotional symptoms and functional status in friendship quality and properties, peer relations and school adjustment

Findings from analyses of friendship quality for children with high and low emotional symptoms and functional status indicated few group differences. Children who report high or low emotional symptoms do not differ significantly in terms of the balance between positive and negative friendship features. Comparable findings were found for children when grouped by high and low functional status scores.

Nevertheless, the friendships of children with either high emotional symptoms or low functional status appear to be characterised by slightly more negative features than the friendships of children with either low symptoms or high functioning. Paired t-tests comparing positive and negative friendship features indicated children with high emotional symptoms and low functioning were likely to have the least positive friendships, and children with low symptoms and high functioning the most positive friendships of all groups. However, in contrast to other groups, there is substantial variation in the balance between positive and negative friendship features in children with high emotional symptoms and low functioning.

Evaluation of differences in friendship properties (i.e. play/association, intimacy, absence of conflict), peer relations and school adjustment by emotional symptom and functional status group revealed marginally significant differences in peer relations and school adjustment for functional status groups. Differences for peer relations are generally consistent with previous findings (La Greca, 1990). However, comparison of means for friendship properties by high and low emotional symptom and functional status groups suggest that emotional factors play a marginally greater role in determining levels of play/association, intimacy and absence of conflict.

Patterns of association amongst friendship properties, quality, peer variables, functional status and emotional symptoms suggest that increases in friendship quality are linked to a corresponding increase in peer relations for children with low emotional symptoms. This pattern however, does not hold for children with high emotional symptoms where decreases in functional status reflect a concomitant decline in peer relations and school adjustment. In point of fact, formal examination of group differences in the strength of the link between friendship quality and peer relations suggests these variables are more strongly related in children reporting low, compared to high levels of emotional symptoms. Findings comparing high and low functional status groups indicated that for children with low functional status, friendship properties, that is play/association and intimacy are positively associated with peer relations whereas friendship quality is positively associated with school adjustment. If respective group differences are considered together, findings imply that within high emotional symptom and low functional status groups increases in emotional symptoms and decreases in functional status scores are associated with a decline in peer relations and / or school adjustment. Children within the low emotional symptoms and high functioning groups do *not* show this profile. Bearing in mind that high and low emotional symptom groups comprise children with high and low functioning and functional status groups similarly comprise children with high and low emotional symptom scores this pattern is particularly striking.

However, the negative association between emotional symptoms and school adjustment for children with low functioning may be offset by high friendship quality as suggested by the positive correlations between school adjustment and the difference scores. The strength of the correlations between friendship properties and quality for children with low compared to high functioning may suggest that whereas children with high functioning are less likely to require emotional or instrumental support children with low functioning may rely on friends for this support which shapes perceptions of friendship. Although no significant group differences were found in the strength of relationships, trends lend support to this interpretation. Evaluation of interaction effects between emotional symptoms and functional status scores for friendship properties, quality, peer relations and school adjustment indicate that low functional status and high emotional symptoms are linked to detrimental outcomes for school adjustment, and to a lesser extent peer relations. No significant effects were found for friendship properties or quality.

Chapter 8: Discussion and Conclusions

In Chapter 8, results reported in Chapters 6 and 7 will be discussed in relation to previous findings and within the context of study limitations. The aim of this chapter is to demonstrate how study findings inform understanding of adjustment to chronic illness, evaluate methodological limitations and suggest directions for future research. Findings will be reviewed in the order presented in Chapter 6, followed by findings put forward in Chapter 7, an overview of study limitations, conclusions and suggestions for further research.

This thesis focussed on the role of condition-related parameters in parental and child coping and adjustment outcomes in children and adolescents with either asthma, diabetes, cystic fibrosis or epilepsy. In addition, condition severity, family and peer context factors were examined in relation to the risk resistance framework, a conceptual model which aims to explain the marked variation in psychosocial outcome among children with chronic illness. The investigation took as its starting point the contrasting approaches advanced to illuminate the psychosocial effects of condition-related parameters. While the categorical approach suggests that psychosocial effects are condition-specific the non-categorical approach states that dimensions common to all chronic illnesses are more important. The non-categorical approach suggests for example, that condition chronicity, age of onset or course reflect more variation in terms of psychosocial outcome than condition category. The present study sought to determine which approach provided the better understanding of child adjustment to, and management of chronic illness. A further objective centred on establishing the utility of the risk resistance framework and extending the model by including peer context factors in explaining adjustment outcomes. Additional objectives involved shifting the more traditional approach away from parent report of difficulty to focus on the child's perspective, inclusion of multiple informants to strengthen validity, a multi-site approach to take account of variation of in clinician management protocol and establishing a role for child friendship in psychosocial adjustment. These features were introduced to address some of the shortcomings of previous research, facilitating efforts to relate predictor and criterion variables reflecting independent sources, and provided the opportunity to extend understanding of the factors associated with children's adjustment to chronic illness.

However, attention is briefly drawn to factors which bear upon interpretation of study findings. Practical difficulties encountered in the course of data collection place certain restrictions on the data. For a small number of participants data collection incorporated a time delay which exceeded three weeks. Consequently correspondence between child and parent report in the time period to which evaluations referred, for example functional status or adjustment index, were compromised. In addition, development of a new condition severity measure during the recruitment process created delays between participant study entry and health professionals' completion of the measure. Thus, for those entering the study in the early stages the evaluation period of 12 months followed rather than corresponded with study entry. Nevertheless, as the numbers involved are small it is expected that these factors will have a limited impact.

8.1 Are there links between the condition-related parameters of chronic illness and child and adolescent adjustment outcomes?

Findings from multiple regression procedures evaluating the impact of condition category and generic condition dimensions on child and parent report of overall difficulty, emotional symptoms, and hyperactivity and conduct problems combined produced rather different results depending on the informant. For children and adolescent report of difficulty these factors explained a mere 7.7 percent of the variance in scores. Findings indicate these factors have little predictive utility. However, youngsters with cystic fibrosis, compared to other condition groups, were found to be significantly less likely to report overall difficulty or externalising behaviours such as, hyperactivity and conduct problems. Although a brief examination of demographic factors of family structure and maternal education did not alter these findings, residing in alternative two parent family forms, such as stepfamilies or grandparents, compared to biological parents was associated with increases in child report of overall difficulty, emotional symptoms, and hyperactivity and conduct problems combined. Living within a single parent household was associated with increase in child report of overall difficulty only. In addition, higher levels of maternal education were significantly associated with a decrease in child report of emotional symptoms.

Parent report, in marked contrast to child report, revealed that condition-related parameters explained between eight to 26 percent of the variance in scores. Both condition category and generic dimensions were significant predictors of outcome. In terms of overall difficulty, children with either asthma, diabetes or cystic fibrosis, relative to youngsters with epilepsy were significantly less likely to be experiencing difficulties as reported by their parents. However, condition severity was also a highly significant predictor with increases reflecting higher levels of parent reported difficulty. Both condition category and generic dimensions predicted variations in parent reports of child emotional symptoms. However, generic dimensions, specifically health professionals' reports of condition severity accounted for a significant portion of the variance. According to parents, children with diabetes, relative to children with either asthma, cystic fibrosis or epilepsy were reported to have significantly lower levels of emotional symptoms. However, increases in condition severity predicted significant increases in emotional symptoms. Among the regression equations, condition parameters accounted for the least amount of variance in parents' reports of hyperactivity and conduct problems combined. Although generic dimensions failed to account for a significant portion of the variance, condition category was associated with decreases in hyperactivity and conduct problems, specifically for children with diabetes and cystic fibrosis compared to children with either asthma or epilepsy. Once again, although demographic factors did not radically modify associations between condition parameters and outcome, family structure was a significant predictor of overall difficulty and hyperactivity and conduct problems combined. Both two parent alternative family forms and single parent families predicted significant increases in parent reported difficulty.

Findings are also consistent with the view that health utilisation or school absence over the previous 12 months do not appear to be influential. Evaluation of condition differences, presented in Chapter 6, suggested children with asthma or cystic fibrosis used more health services and missed more school than children with either diabetes or epilepsy. In fact, children with cystic fibrosis seem to be the least likely to experience psychosocial difficulties compared to their counterparts.

A notable outcome of this analytic strategy is the marked disparity in findings according to informant and highlights the value of a multi-informant approach in research design. While the sample sizes were different, parent report revealed higher predictive utility than child report. Although parent, compared to child report, is often regarded as more reliable, findings may suggest children are less vulnerable to the influence of these parameters than parents perceive them to be. Alternatively, children, compared to parents, may be less likely to take account of parameters, such as condition severity in relation to psychosocial well-being. Whatever the explanation, parameters seem to have greater relevance for parents than children and this finding probably requires further consideration in research and application.

Findings confirm a role for both condition category and the generic dimension of condition severity and are consistent to some extent with earlier studies. Children with either asthma, diabetes or cystic fibrosis were generally less likely to report, from their own or their parents' perspective, emotional or behavioural difficulty compared to children with epilepsy. Previous studies have indicated that conditions which involve the brain are more likely to be associated with difficulty than conditions than do not (Howe *et al.*, 1993; Hoare & Mann, 1994). In addition, analyses involving parent report revealed condition severity to be a significant predictor of overall difficulty and emotional symptoms. Wallander and Thompson (1995) suggest that condition severity is not related to outcome however, several studies presented in Chapter 1 indicate otherwise and current findings are consistent with these findings (e.g. Drotar *et al.*, 1981; Daniels *et al.*, 1987; Thompson *et al.*, 1993). Although interpretation of results relating to condition severity need to be carefully considered against previous findings in light of marked differences in conceptualisation and operalisation mirrored in current approaches to measurement.

Existing measurement methods can be divided into two distinct groups, condition-specific and generic. Condition-specific measures are frequently based on physiological parameters unique to the condition, for instance pulmonary function in a child with asthma. Generic measures focus on features common to all chronic conditions, such as level of functioning or school absence. Extant findings reflect the application of each approach within contrasting research designs involving different informants, and make it difficult to draw any firm conclusions from present findings. At the same time, both condition-specific and generic measurement approaches have been shown to be linked to adjustment outcome (see section 1.6.2 Chapter 1). Associations using condition-specific indices have included seizure frequency in youth with epilepsy, disease type in children with sickle cell disease (the more severe form, sickle cell anaemia is associated with greater risk for health complications, such as stroke and vaso-occlusive crises), and number of cardiac cathterisations in youngsters with congenital heart problems. Generic indices have involved the use of, for example number of days hospitalised in the previous 12 months, school absence or restrictions affecting daily activities. Both methods take increases in these variables to indicate greater condition severity. While a number of studies using generic measures have found links between condition severity and adjustment, they differ from the present study in measurement of condition severity. The measure used within the current study took a novel approach and sought to index condition demands for the family rather than use an index which centres on illness consequences for the child, such as level of school absence. It was felt that because children are dependent on their family for care and protection the effects of illness need to be viewed within this broader context since there can be implications for *both* child and family members. Accordingly, emphasis is placed the difference between condition severity as conceptualised here compared to other studies, and the need to replicate current findings before these relationships gain validity. Irrespective of the method adopted in this study there remains considerable variation in measurement and suggests that understanding of the way in which condition severity is associated with adjustment may be advanced with an agreed approach to measurement. However, even comparable condition-specific severity measures are not consistently related to outcome indices. Holmbeck and Faier-Routman (1995) found, among youngsters with spina bifida, that whereas treatment for hydrocephalus was related to outcome, lesion level was not (higher and more exposed lesion levels are usually associated with greater disability). Thus, the definitional and methodological issues related to the conceptualisation of condition severity require further appraisal. Nevertheless, although condition-specific measures allow within condition group comparisons, generic measures can be employed for both within and between condition group comparisons. This would suggest that generic measures, in contrast to condition-specific measures have greater utility for comparison of study findings that involve one, or several condition groups and across time. Nonetheless, it is crucial that measurement of condition severity is conceptually independent of adjustment outcome. Whereas a generic measure, such as level of functioning may be biassed if parents tend to limit a child's activities, condition-specific measures using physiological parameters can eliminate this bias. Ideally, measurement of condition severity should be indirect, free from subjective bias and where comparisons among condition groups are required, generic. The present measure involving an independent information source assessment of family condition demands aimed to meet these criteria.

Overall, findings are compatible with the view that both categorical and non-categorical approaches benefit understanding of the psychosocial effects of chronic illness. Although associations between demographic factors and child adjustment outcome were not presented, it is noteworthy that these factors seem to be important markers of risk and resistance. In particular, links between family structure and adjustment are compatible with findings reported in Chapter 2 which suggest that family configurations other than two parent biological are associated with more child difficulty (Eiser *et al.*, 1992; Overstreet, *et al.*, 1995). Furthermore, the role of maternal education is significant, children of mothers with higher levels of education reported lower levels of emotional symptoms than children of mothers with low or moderate levels of education, and suggests that high maternal education may offer protection against emotional difficulty.

8.2 Are condition-related parameters linked to parental coping and family functioning?

Examination of relationships between condition-related parameters and parental coping and family functioning revealed significant differences between mothers and fathers in terms of coping efficacy but no differences in perceptions of family functioning. Mothers generally reported higher levels of efficacy in comparison to their partners. However, reports of family functioning for mothers and fathers were remarkably similar demonstrating no significant discrepancies.

The role of condition-related parameters in maternal and paternal report of coping efficacy and family functioning revealed a significant effect of condition category for fathers' coping efficacy in relation to behaviours that maintain self-esteem, social support and psychological stability. Fathers of children with asthma reported these behaviours to be significantly more efficacious than fathers of children with epilepsy. However, as very few studies have focussed on families managing demands imposed by childhood epilepsy, and comparisons involving fathers do not appear in the literature, it is difficult to draw conclusions from this finding. A significant effect was also found for maternal report of coping efficacy for family centred behaviours and number of condition course features. Mothers of children with three to four, compared to mothers of children with either no, one or two condition course features reported significantly lower levels of coping efficacy. Although there are no previous studies including perceptions of condition course features, it is probable that more features may interfere with activities such as, family outings and diminish the efficacy of family centred behaviours.

Evaluation of moderating effects for individual parent and condition-related parameters in relation to coping efficacy and family functioning yielded effects for the number of condition course features and condition visibility. An increase in the number of condition course features yielded reverse effects on the reported coping efficacy of family centred behaviours for mothers and fathers. Whereas an increase in the number of condition course features was marked by a decline in maternal efficacy, fathers reported a substantial increase in coping efficacy. Findings suggest a compensatory response pattern between parents and, given coping efforts referred to family centred behaviours, this configuration may be associated with congruence in parent report of family functioning. While parents may differ in the way they manage the demands of chronic illness, threats to family integrity such as the decrease in maternal efficacy reflect upon their joint responsibility and demand that deficits are balanced and family well-being is maintained. Condition visibility also demonstrated differences for mothers and fathers in terms of coping efficacy for healthcare behaviours. Mothers, in contrast to fathers, report higher efficacy when the condition is either visible or not visible, fathers on the other hand report higher efficacy than mothers when condition visibility is ambiguous, in other words when the condition is both visible and not visible to others. This would suggest that mothers, in comparison to fathers find healthcare behaviours more helpful when the condition is either visible or not visible and fathers when it is equivocal.

Findings suggest both the categorical and non categorical approaches are helpful in defining parental reports of coping efficacy. On the other hand, condition-related parameters do not appear to influence family functioning, although increases in condition severity as reported by health professionals were found to produce a non-significant decline in family functioning.

The number of studies in which condition parameters feature in parental reports of coping appears to be severely limited. However, in a year long study of adjustment in parents of children with cancer or haematologic disorder Nelson *et al.* (1994) report a significant positive correlation between parental perception of condition severity and intrusion coping for example, "I thought about his illness when I didn't mean to" within 6 months of diagnosis. However, while higher condition severity was initially related to increased intrusion coping, this relationship had dissipated 12 months later. Eiser and Havermans (1992) found coping in mothers and fathers of children with either diabetes, asthma, cardiac conditions, epilepsy or leukaemia was related to condition category and duration. Coping reflected strategies associated with autonomy such as, " get away by myself", medical care for example, "believe my child is getting the best care possible", social support/information such as, "talk with other parents and learn about their experiences" and family support for instance, "get other family members to help". They found maternal use of social support and paternal use of medical care significantly decreased as time since diagnosis increased. In addition, condition category produced significant effects for strategy use. Parents of children with either cardiac conditions or leukaemia were more likely to use medical care strategies in comparison to other condition groups. Results from this study suggest that generic and condition category factors may moderate parental coping activity and are consistent to some extent with the current findings. However, contrary to the findings from the present study, no differences were found between fathers of children with either asthma or epilepsy and effects were found for condition duration.

Since, to the researcher's knowledge there are no studies focussing on condition visibility and parental coping, interpretation of parental differences in efficacy scores for healthcare behaviours by level of condition visibility is difficult. However, the greatest differences between parents occur when the condition is not visible to others. As mothers' efficacy scores are higher than fathers' this may suggest both that mothers, in contrast to fathers, are more involved in maintaining child health and these behaviours are useful when others are unaware of the condition. Increased condition visibility on the other hand, may perhaps assist parents in establishing the cause of health related difficulties and indeed elicit informal help from others. Nevertheless, results indicate that categorical and non-categorical approaches need to be considered in studies that centre on parental coping.

Furthermore, parent differences in coping efficacy are consistent with additional findings presented by Eiser and Havermans (1992). The authors found parents differed significantly in terms of the reported helpfulness of strategies. Mothers, in comparison to fathers indicated higher levels of helpfulness on factors reflecting maintenance of autonomy, sustaining medical care, gaining social support / information, and family support. Moreover, strategy use has also been found to differ for mothers and fathers when compared to parents of youngsters without chronic illness. While mothers of children with spina bifida were found to use significantly more denial, less active coping and planning strategies than mothers of able bodied children, fathers of children with spina bifida were significantly more likely to use venting emotions than fathers of able bodied children (Holmbeck *et al.*, 1997). However, McCubbin (1984) found no differences in coping between mothers and fathers of children with cystic fibrosis.

The little evidence there is seems to suggest mothers and fathers tend to use different strategies to deal with stresses associated with caring for a child with chronic illness. Findings suggest differences may be linked to social expectations defined by gender roles. Within many Western industrialised societies norms designating gender role behaviour typically differ for males and females. For example, mothers, in contrast to fathers, are generally less inhibited about expressing emotional distress, and perhaps more crucially are permitted and prepared to acknowledge difficulties. Consequently, expression of maternal distress compared to paternal distress is both highly visible and normalised. This may leave fathers disadvantaged in stressful circumstances who may feel disinclined or unable to admit difficulty and accordingly coping strategies may reflect more discrete ways of handling stress for example, increased involvement in work and / or consumption of alcohol. This is not meant to imply strategy use is gender specific but rather that gender roles are likely to influence how men and women manage stress and more importantly from the researcher's point of view, what strategies they *will report* using or helpful. Although, as Beresford (1994) has stated parent differences in coping may stem from methodological problems. For example, coping measures often cater to child-related difficulties experienced by mothers, fathers' experience of managing chronic illness or disability may be somewhat different. Thus what might be stressful for mothers is not necessarily so for fathers.

On the other hand, Barbarin *et al.* (1985) indicate the correspondence in coping strategy use between mothers and fathers of children with cancer is affected by factors such as perceptions of marital quality, partner support and marital functioning. Complementary coping styles linked to problem solving were related to enhanced marital functioning and partner support. However, use of optimism by both parents, in other words parallel coping styles, was also related to enhanced marital functioning. These findings suggest that correspondence in parental coping is dependent on strategy and other features unique to the partnership. It would perhaps be premature to conclude that parent differences in coping are pervasive and more refined analyses are needed.

8.3 Are condition moderated effects of parent differences in coping efficacy related to child adjustment outcome?

The effect of condition moderated parent differences in coping were examined in relation to child adjustment outcomes. As indicated earlier condition-related parameters moderating parental coping were linked to the number of course features and condition visibility. However, no significant effects were found suggesting that the compensatory pattern of parental coping did not affect child report of overall difficulty, emotional symptoms or hyperactivity and conduct problems combined.

Although the present study failed to detect effects, other studies have found that respective associations between mothers' and fathers' coping and child physical well-being or adjustment display differences and similarities. For example, a study of children with cystic fibrosis found parental differences in coping activity were differentially related to physical well being (McCubbin *et al.*, 1983c). Based on assessments using the Coping Health Inventory for Parents (McCubbin *et al.*, 1983a) a low positive correlation was found between mothers reporting on the helpfulness of behaviours maintaining family integration, co-operation and optimism and improvements in child height/weight indices. For fathers, a low positive correlation emerged between height/weight improvements and the helpfulness of behaviours maintaining social support, self-esteem and psychological stability. However, a low to moderate correlation was found for improvements in pulmonary functioning and increased helpfulness of behaviours maintaining social support, self-esteem and psychological stability in both mothers and fathers. Moreover, for parents of children with severe physical disability increased use of wishful thinking in mothers and fathers significantly predicted decreases in child adaptation. However, decrease in the quality of family relationships was also a significant predictor of decreased child adaptation among fathers (Sloper & Turner, 1993).

The limited findings display a complex pattern of relationships between fathers' and mothers' coping and child well being, although no study has attempted to examine the effect of parent differences on child adjustment. Current efforts that focus exclusively on mothers provide an incomplete picture and investigation of the combined role of maternal and paternal coping as the present study has attempted, would greatly enhance understanding of the way in which parents configure their management of stresses associated with chronic childhood illness. The inability to establish a relationship here may be due to a lack of statistical power.

8.4 Are condition-related parameters linked to child and adolescent coping? Are there associations between child and adolescent coping and adjustment outcomes?

Child and adolescent coping was examined in relation to condition parameters and adjustment outcomes within the context of dealing with a standardised hypothetical common problem, (i.e. dealing with parental anger) and a self nominated illness problem. Coping efficacy, in line with the approach adopted for parent coping was established by dividing the total efficacy score by the number of strategies used. A brief examination of age related effects for the number of strategies used and coping efficacy indicated that younger children use fewer strategies and report higher efficacy scores than adolescents when dealing with the common problem. No age related effects were found for the illness problem. However, children and adolescents reported using significantly more strategies and higher efficacy scores when handling a common problem compared to an illness problem. These results suggest coping repertoires may increase with age, but helpfulness generally declines with age, although findings for the illness problem context imply this pattern is constrained by situational variables. The decrease in number of strategies used to deal with an illness problem in all age groups may reflect the level of control available when dealing with an illness problem. Such problems are believed to be less controllable than other problems and may therefore elicit a lower level of effort. In addition, efforts are perceived to be less helpful in the illness, compared to common problem context. Moreover, descriptive analyses highlighted that when managing an illness problem boys report significantly higher levels of coping efficacy than girls. On the other hand, children were presented with the common problem scenario prior to nominating an illness problem and findings may reflect order effects. Nevertheless, the effects of condition-related parameters counter this suggestion to some degree. For example, youngsters with cystic fibrosis were found to use significantly fewer strategies than other condition groups in both problem contexts.

Findings suggest that strategy use is related to both condition category and generic condition dimensions. Evaluation of the number of strategies used for both types of problem revealed, as indicated, that youngsters with cystic fibrosis report using a lower number of strategies than other condition groups. Age of condition onset and condition severity, on the other hand, were linked to coping efficacy in the common problem context. Generally, increases in condition severity were related to a decline in coping efficacy, and age of condition onset until 7-10½ years demonstrated increases in coping efficacy, but after this age efficacy declined to levels reported for early condition onset.

Statistically significant associations were also found between the number of strategies used, coping efficacy and children's emotional response to problems in terms of level of nervousness, sadness and anger. Specifically, the number of strategies used increased as reported levels of anger rose in the common problem context, and with increases in the level of sadness for the illness problem context. Decreases in coping efficacy were negatively related to reported sadness for management of an illness problem.

Few studies report on the number of strategies used to deal with difficulties and therefore interpretation of findings is problematic. Although, since at least 50 percent of the strategies included in present study refer to cognitive approaches to coping, findings for age related increases in strategy use are compatible, in part, with two reported studies. Olson *et al.* (1993) compared cognitive strategy use in chronically ill and healthy children and adolescents for three hypothetical stressors (i.e. public speaking, dental and medical treatment) and a self nominated stressor. Spontaneous reports of coping strategies were classified as coping, for example positive self-talk or attention diversion, and catastrophising, for instance focus on negative affect or fear, or anxious anticipation. The authors found that coping strategies, as opposed to catastrophising strategies, increased with age and varied significantly by age in both groups, consistent with findings reported by Brown *et al.* (1986 cited Olson *et al.*, 1993). In addition, Curry and Russ (1985) report a significant positive correlation between age and spontaneous report of cognitive coping strategies in eight to ten year olds undergoing dental treatment. They also found a positive moderate correlation between the variety of cognitive strategies used and age, indicating that coping repertoires become increasingly differentiated with age. However, present findings do not match Spirito *et al.* (1994) who found acutely ill and chronically ill children reported using more coping strategies than adolescents to deal with hospital related problems. The link between efficacy and sadness for management of an illness problem, is consistent with results reported for a non-clinical sample of children. Wierzbicki and Carver (1989) found that children's efficacy ratings for activities helpful in countering depression were negatively and modestly related to self-reported depressive symptoms. Thus as depressive symptomatology increased the perceived efficacy of efforts declined. However, the positive association between the number of strategies used and ratings of sadness is incompatible with Wierzbicki (1989) who reported a low to moderate negative correlation between depressive symptomatology in a non-clinical group of children and adolescents and the number of activities generated to manage depression. The positive association between the number of strategies used and higher anger ratings for management of a common problem is novel. There are no other studies reporting a comparable finding. It seems likely, in light of a similar link between levels of sadness and strategy use in the illness problem context, that higher levels of emotion may represent a motivational stimulus for physical action and increase strategy use.

Evidence demonstrating effects of condition-related parameters in relation to child coping efficacy is scant. However, while Reid *et al.* (1995) found no links between age of condition onset or duration and coping efficacy in children and adolescents with diabetes dealing with condition related stressors, Thompson *et al.* (1998) found ratings of self-efficacy for condition management in children with either cystic fibrosis or sickle cell disease were negatively and modestly associated with self-reported psychological symptoms in children with cystic fibrosis. In addition, higher health status as defined by objective health indices (i.e. Shwachman score reflecting "general activity level, pulmonary function, nutrition and chest roentenogram (X-ray) ") was modestly and positively correlated with clinician ratings of coping efficacy in adolescents and adults with cystic fibrosis (Moise *et al.*, 1987). Current findings are consistent with those reported by Reid *et al.* (1995) but as so few studies compare condition groups it is probably too early to draw conclusions.

Comparison of individual strategy use by problem context indicated that children would use distraction, social withdrawal, self-criticism, blaming others, problem solving and emotional regulation more frequently to deal with a common problem than an illness problem. Cognitive restructuring, wishful thinking, social support and resignation were used equally in both problem contexts. *No* strategy was found to be used more frequently in the illness problem context. These findings may suggest that everyday common problems, in contrast to illness problems, offer more opportunities for resolution. Analysis of individual strategy use in relation to condition parameters indicated effects for the use of social withdrawal and resignation in the common problem context and social withdrawal, blaming others and emotional regulation for the illness problem context. Children using social withdrawal to manage the common problem were found to have higher levels of condition severity and number of condition course features compared to children who did not report use. Youngsters using resignation to deal with the common problem were found to have later condition onset than those who did not use this strategy. Strategy use for the illness problem produced generally consistent findings. Children with later condition onset and / or shorter condition duration were more likely to use social withdrawal, blaming others and emotional regulation within this problem context. However, children with cystic fibrosis were the least likely of all condition groups to use emotional regulation to manage an illness problem. These findings suggest that both the categorical and non-categorical approach are relevant to our understanding of coping responses in youngsters with chronic illness.

Very few studies have examined condition parameters in relation to coping activity and present equivocal findings. In addition, the use of different measures and designs make comparison with current findings difficult. For example, in a study of children with cancer Smith *et al.* (1990) found effects for time since diagnosis and number of medical procedures (i.e. lumbar puncture, bone marrow aspiration). Children with a shorter condition duration (i.e. one to six months) and fewer procedures (i.e. one to ten) were found to use a coping style characteristic of information avoidance. On the other hand, children diagnosed for more than seven months and who had experienced 11 or more medical procedures used a coping style typified by information seeking. However, a longitudinal study following children with newly diagnosed diabetes (Kovacs *et al.*, 1990) found children rated aspects of their condition as more upsetting, and treatment as more difficult to deal with as time since diagnosis increased. A further study examining coping styles in adolescents with diabetes found longer condition duration was marginally, but significantly associated with increased use of a ventilation and avoidance coping style (Hanson *et al.*, 1989). Conversely, shorter condition duration was significantly associated with coping characterised by utilisation of personal and interpersonal resources.

Alternatively, Boland and Grey (1996) found condition duration was unrelated to coping behaviour in children with diabetes between the age of eight and twelve years. Similarly, Reid *et al.* (1995) found no links between age of condition onset or duration and use of approach and avoidance coping in children and adolescents with diabetes. Furthermore, Spirito *et al.* (1995) also found no differences in strategy use in children and adolescents with various chronic conditions including cystic fibrosis, for respective illness nominated problems.

Nevertheless, current findings are suggestive in that shorter condition duration and / or later condition onset are linked to use of the negative strategies of social withdrawal and blaming others for management of an illness problem and as such are similar to those reported by Smith *et al.* (1990). However, since the average of age of onset for diabetes in the present sample is later than either children with asthma or cystic fibrosis results are inconsistent with Kovacs (1990). Present findings indicate that later condition onset and shorter condition duration may be markers for adjustment difficulties. On the other hand, these youngsters also report using emotional regulation which is defined by Spirito (1996) as a positive strategy therefore difficulties may be offset by the use of this strategy. However, this strategy comprises two approaches to emotional regulation that may represent a positive and negative response to problems that is, shout, scream or calm oneself down. An intriguing finding is the decreased use of emotional regulation for an illness problem among youngsters with cystic fibrosis, compared to other condition groups and counters findings reported by Spirito *et al.* (1995). A tentative parallel may be drawn with children with cancer who, like children with cystic fibrosis, live with life threatening illness. Children with cancer have been found to use a repressive coping style that minimises affective distress and generally report lower levels of depressive symptomatology than healthy counterparts (Phipps & Srivastava, 1997 cited in Phipps & Srivastava, 1999). Similarly, in a study of adolescents and adults (i.e. 18-40 years) with cystic fibrosis Moise *et al.* (1987) found an illness related coping style characterised by attenuation of condition-related difficulties was associated with higher levels of self-worth and lower levels of irrational anxiety. The finding that children using social withdrawal to manage a common problem have higher levels of condition severity and number of condition course features may reflect the impact of functional restrictions, that is options are limited, or the problem may be perceived to be beyond their level of competence. For example, in children with cystic fibrosis low physical status has been found to correlate modestly with parent reports of increased social withdrawal (Drotar *et al.*, 1981). Children with later condition onset also use resignation, a negative strategy, in the common problem context which seems to suggest that older age at onset, compared to early onset presents more difficulties for management of common and illness related problems. Overall, however, generic condition dimensions were more influential than condition category in defining individual strategy use.

Evaluation of relationships between the number of strategies used, coping efficacy, individual strategy use, emotional response to problems and adjustment outcomes highlighted several significant links. Significant positive correlations emerged between the number of strategies used to deal with an illness problem and child report of total difficulties, emotional symptoms, and hyperactivity and conduct problems combined. The strongest association was found for emotional symptoms. Findings for individual strategy use need to be viewed with caution given the multiple tests involved in analysis. Nonetheless, results revealed interesting trends. In terms of individual strategy use in the common problem context children who used cognitive restructuring reported lower levels of overall difficulty and those who used self criticism and blaming others rated themselves higher on levels of hyperactivity and conduct problems than children who did not use these strategies. Strategy use in the illness problem context reflected difference trends in all three adjustment outcomes. Specifically, children using social withdrawal reported higher levels of overall difficulty and emotional symptoms than children who did not use this strategy. Higher levels of emotional symptoms were also related to use of problem solving and wishful thinking. In addition, children who used social support, compared to those who did not reported higher levels of hyperactivity and conduct problems combined.

Associations between emotional responses to problems and strategy use indicated for the common problem higher levels of nervousness were significantly linked to increased use of wishful thinking and revealed a trend for increased use of emotional regulation; higher levels of sadness were significantly associated with increased use of wishful thinking and emotional regulation, and showed a trend for decreased use of resignation; higher levels of anger were significantly associated with increased use of emotional regulation and demonstrated trends for increased use of social withdrawal, blaming others and social support and decreased use of resignation. Fewer significant associations were found for the illness problem context. There was a non-significant link between higher levels of nervousness and decreased use of cognitive restructuring and higher levels of sadness were significantly associated with increased use of wishful thinking and revealed trends for decreased use of cognitive restructuring and increased use of problem solving. Higher levels of anger were significantly associated with increased use of emotional regulation. Associations between children's emotional response to problems and adjustment outcome were confined to child report of overall difficulty and emotional symptoms. In essence, higher levels of nervousness and sadness in the common problem context were associated with higher levels of overall difficulty and emotional symptoms. However, associations between increased nervousness and sadness and emotional symptoms also extended to the illness problem context.

The highly significant link between increased emotional symptoms and the number of strategies used for management of an illness problem is compatible with results reported by Worchel *et al.* (1987). They found children and adolescents with cancer using more behavioural control strategies to deal with medical procedures and everyday activities, such as teasing, tended to report higher depressive symptomatology. Worchel and colleagues comment that children who report using a high number of behavioural control strategies may reflect a frantic search for an appropriate solution. On the other hand, an equally plausible explanation suggests increased strategy use may indicate heightened distress. Findings reported by Curry and Russ (1985) tend to support this view. They found a moderate positive association between the number of anaesthetic injections a child received during dental treatment and the use of cognitive coping strategies. This suggests situational factors likely to increase perceived stress invoke a corresponding increase in coping efforts. Further, Spirito *et al.* (1994) found that acutely and chronically ill children and adolescents who reported increased nervousness and sadness on dealing with a hospital problem used significantly more active strategies (i.e. cognitive restructuring, problems solving, emotional regulation and social support) than youngsters who were not nervous or sad. The results from these studies strengthen current findings.

Relationships between strategy use and overall difficulty and emotional symptoms are consistent, to some extent, with findings reported for psychiatrically hospitalised adolescents (Spirito *et al.*, 1996). Adolescents who reported high, compared to low levels of depression were significantly more likely to use social withdrawal and blaming others, and significantly less likely to use cognitive restructuring to deal with a hypothetical parent related problem. There is very little evidence linking strategy use with hyperactivity and conduct problems, although Ebata and Moos (1991) found that adolescents with conduct problems who reported increases in behaviour problems were less likely to use the strategy of positive reappraisal. It is possible children reporting higher levels of hyperactivity and conduct problems feel both unable to control their behaviour and aware of the impact behaviours have on others. This may lead to increased use of self-criticism, and a willingness to blame others for the difficulties they experience. On the other hand, the use of social support for management of an illness problem among children reporting higher levels of hyperactivity and conduct problems suggests that in situations less amenable to control, and in contrast to children reporting higher levels of emotional symptoms, these children seek the assistance of others.

Significant associations and non significant trends between children's emotional response to problems and individual strategy use in the common problem context indicates the greatest number of links in relation to anger. It may be that the standardised problem which involved friends persuading the child to stay out longer than anticipated aroused increased anger rather than nervousness or sadness and consequently reflected a higher number of links. Although the most robust associations were found between children's use of emotional regulation and anger and sadness, and use of wishful thinking and nervousness and sadness. There were both similarities and differences in associations for problem contexts. For example, in contrast to the common problem, higher levels of nervousness and sadness for management of an illness problem were related to reduced use of cognitive restructuring and sadness was associated with increased use of problem solving. However, similar associations were found between higher levels of sadness and use of wishful thinking, and increased anger and use of emotional regulation for both problems. While the relationship between sadness and cognitive restructuring is compatible with the association found for psychiatrically hospitalised adolescents highlighted earlier (Spirito *et al.*, 1996), Spirito *et al.* (1995) found that children and adolescents with different chronic conditions such as sickle cell disease or cancer who reported being nervous were significantly *more* likely to use cognitive restructuring than those who did not report being anxious. However, Spirito *et al.* (1994) using regression analyses, found higher ratings of nervousness predicted increased use of problem solving, and higher ratings of sadness predicted increased use of social support and wishful thinking in acutely and chronically ill children and adolescents reporting on management of hospital related problems. The latter study offers some support for current findings. Associations between children's emotional response to problems and adjustment outcomes suggests consistency across problem context in terms of a positive association between child report of emotional symptoms and levels of nervousness and sadness. This appears to suggest that children reporting higher emotional symptoms are also likely to react to problems with higher levels of nervousness and sadness and may reflect a dispositional bias.

The overall pattern of effects and associations suggests that problem type appears to be influential in determining strategy use and links with adjustment outcome. However, associations emotional responses to problems and emotional symptoms were similar and suggest that emotional factors may override the impact of problem type. Nonetheless, this similarity does not translate into a correspondence between emotional response and strategy use for both problems. The only significant association that demonstrated similarity across problem context was increased use of wishful thinking and higher levels of sadness.

8.5 Is the risk resistance framework tenable?

Evaluation of the risk resistance framework put forward by Wallander et (1989b) sought to determine model utility in relation to prediction of total difficulties, emotional symptoms, and hyperactivity and conduct problems combined using the statistical technique of path analysis. Variables were operationalised to reflect the factors identified within the framework and preliminary analyses focussed on consecutive paths to establish validity and permitted model specification (see Figure 34). The analyses confirmed paths between the following: condition severity and functional status; functional status and the psychosocial stress composite, reflecting child perceptions of condition impact, levels of distress associated with achievement of the daily activities of living, and the number of condition course features; functional status and child report of total difficulties and coping efficacy for the illness related problem; maternal report of family functioning and the psychosocial stress composite; the psychosocial stress composite and maternal coping efficacy for family centred behaviours and child report of total difficulties, and finally number of child coping strategies and the psychosocial stress composite and child report of total difficulties.

The model was subjected to a path analysis using simultaneous equation modelling techniques incorporated within the software application EQS. Results suggested further modifications would improve the fit between the model specified and observed data. Accordingly paths were altered and matched to specifications defined within the risk resistance framework (see Figure 35). In essence, the path between functional status and child total difficulties was eliminated and paths between first, maternal report of family functioning and coping efficacy and second, child coping strategies and maternal coping efficacy were introduced. Since the sample size prevented evaluation of moderating effects for resistance factors in relation to risk factors within EQS, effects were examined using two-way analysis of variance.

The revised model produced a highly satisfactory fit between the specification and observed data. Findings for each adjustment outcome were highly similar with the exception of the path between the psychosocial stress composite and adjustment index. The strength of this association for overall or total difficulties and emotional symptoms ranged between .57 to .61. However, the association diminished to .38 for hyperactivity and conduct problems combined. This finding suggests stress has greater predictive utility in relation to child report of overall and emotional difficulty compared to externalising behaviours, such as hyperactivity and conduct problems combined. Other paths indicated that increases in health professionals' reports of condition severity predicted decreases in parental report of functional status. Decreases in functional status also predicted a decline in child report of coping efficacy and increases in psychosocial stress. Maternal reported decreases in family functioning, that is less optimal family functioning, and increases in psychosocial stress were associated with a decline in maternal coping efficacy for family centred behaviours. In addition, child reported increases in number of strategies used to manage an illness problem were related to increased psychosocial stress and maternal coping efficacy. Resistance factors were *not* found to modify the relationship between risk factors and adjustment outcome. Overall the findings offered partial support for the framework advanced by Wallander *et al.* (1989b), and suggest the risk resistance mechanism requires further validation. Nevertheless, a particular strength of this analysis, compared to many other studies (but see Hommeyer *et al.*, 1999), is the use independent sources for several predictor and criterion variables.

Although no previous study has evaluated the whole model and precludes comparisons, validation of proposed pathways suggests the model does have a feasible conceptual structure. The association between condition severity and functional status matches, in part, findings reported by Hommeyer *et al.* (1999) the only study to relate these variables in a similar manner. In this study the authors defined condition severity among children with spina bifida on the basis of lesion level, whether children had received treatment for hydrocephalus and level of orthopaedic aids required to support mobility. They found treatment for hydrocephalus predicted functional outcomes in terms of parent reported decreases in scholastic competence and teacher reported increases in attention problems. However, no study has reported an association between functional status and child report of coping efficacy. This finding suggests that children's level of functioning is related to the perceived value of coping efforts. While efficacy is not associated with adjustment outcome in the current study, ongoing experience of low efficacy may produce a somewhat different outcome and warrants further investigation. The link between family functioning and maternal coping efficacy finds no comparable association in the literature but suggests that family centred coping efforts are intimately linked to general family functioning. It is not clear why so few studies report links between the broader family context and coping efforts. Present findings are consistent with the idea that a favourable family atmosphere fosters perceptions of increased coping efficacy. The relationship between increased maternal coping efficacy and child reported increases in the number of strategies used to manage an illness problem is consistent with findings from studies that suggest parental and child coping are related (e.g. Gil *et al.*, 1991; Brown *et al.*, 1993; Kliewer & Lewis, 1995). However, Sharpe *et al.* (1994) reports no such relationship. Present findings may suggest that children's coping efforts are supported by maternal coping efficacy. Associations between psychosocial stress and maternal and child coping seem appropriate indicating that when psychosocial stress is high children increase the number of strategies they use and maternal coping efficacy declines. The increase in child coping efforts corresponds with results reported by Curry and Russ (1985) who found that children used more strategies to manage dental treatment as the number of anaesthetic injections, and presumably stress, increased. In addition, the link between maternal coping efficacy and psychosocial stress concurs with findings presented by Kager and Holden (1992). In their study of youngsters with diabetes, child report of negative life events was inversely related to the reported helpfulness of behaviours derived from all three scales of the Coping Health Inventory for Parents (CHIP) among mothers. The relationship between psychosocial stress and adjustment outcome corresponds, in terms of overall difficulty and emotional symptoms, with findings presented by Quiggins and Varni (1996 cited in Wallander and Varni, 1998). They found increases in perceived disease related stress were linked to higher levels of negative affectivity and behavioural problems in children with cancer. However, there do not seem to be reports of differential relationships between stress and outcome for internalising (i.e. emotional symptoms) and externalising (i.e. hyperactivity and conduct problems combined) behaviours. Clearly, the results reported here indicate that increases in psychosocial stress demonstrate a stronger relationship with emotional than behavioural difficulties, and fit well with meta-analytic findings (Lavigne & Faier-Routman, 1992; Bennet, 1994) which point to higher prevalence of internalising, compared to externalising difficulties among youngsters with chronic illness.

One explanation for the failure to validate the risk resistance mechanism could be that the sample size limited detection of effects. Alternatively, selected variables may be inappropriate, although findings suggest relationships are plausible and coherent. On the other hand, the model may be incorrectly specified. It is possible the interplay between stress, coping responses and family functioning reflect a level of complexity that is not easily captured. However, factors constituting psychosocial stress cannot be defined irrespective of perceived impact. If factors do not represent difficulty then it seems unlikely that resistance factors such as coping and family functioning will be inadequate or disadvantageous. Alternatively, if psychosocial stress is perceived to be high, this may stem from inefficient coping methods and poor family functioning, or indeed may reflect upon coping and family health and exacerbate the effects of stress. Longitudinal studies may be one way of teasing out causal precedence and influential factors that predict outcome. While difficult to achieve, tracking children and families prior to diagnosis would allow individual and family assessment prior to onset and provide insight into the impact of stress in relation to coping and family resources post diagnosis.

8.6 Do peer and friendship relations contribute to explanation of adjustment outcomes?

The model developed in previous analyses was taken forward to examine the role of peer context factors in prediction of adjustment outcome. Children's reports of friendship play/association and intimacy and teacher reports of peer relations and school adjustment were used to develop the model and determine in what way social functioning was related to other factors and outcome. These analyses were guided by the literature and research questions as few studies have employed the statistical approach adopted here or attempted to configure family and peer factors within a single conceptual framework.

Barring exclusion of condition severity from this set of analyses, the configuration of individual and family factors remained unchanged. Organisation of friendship and teacher reported variables were based on the following considerations. It was expected friendship intimacy would emerge from play/association and that levels may indicate social competence and therefore would be associated with peer relations. In addition, it was envisioned that peer relations would reflect upon school adjustment which would be linked to emotional and behavioural difficulties. Accordingly friendship play/association preceded friendship intimacy followed by teacher estimates of peer relations and school adjustment and child report of difficulty (see Figure 38). Past research (La Greca, 1990) has suggested that functional status has implications for social functioning and therefore may be related to friendship play/association and peer relations. Moreover, it might be anticipated that friendship intimacy would have consequences for adjustment outcome. Since the degree of intimacy that friends share probably represents a corresponding level of emotional support it would be reasonable to assume that high levels of intimacy may offset reports of difficulty. Therefore potential links between these variables were examined. However, path analytic procedures did not confirm these paths or validate the path between the number of child coping strategies and psychosocial stress incorporated in the previous model. The procedures did however, suggest a link between functional status and school adjustment and indicated emotional symptoms predicted friendship intimacy, the opposite direction to that proposed. The latter path was not incorporated into the final model.

The extended model, including the path between functional status and school adjustment was evaluated in relation to total, or overall difficulties, emotional symptoms, and hyperactivity and conduct problems combined. Fit indices for each model were satisfactory suggesting that model specifications represented the observed data well. Excluding the paths between psychosocial stress and outcome index and school adjustment and outcome, path parameter estimates were duplicated for each adjustment outcome. In parallel with earlier findings psychosocial stress showed a much weaker relationship with hyperactivity and conduct problems combined, compared to emotional symptoms. However, the association between school adjustment and outcome indices varied considerably. In contrast to child report of overall difficulty and hyperactivity and conduct problems combined, emotional symptoms were *not* linked to school adjustment. Moreover, children's reports of hyperactivity and conduct problems combined demonstrated a stronger relationship with school adjustment than overall difficulty. These findings suggest, somewhat plausibly, that behavioural difficulties have a greater impact in relation to school adjustment than emotional difficulties. It seems probable hyperactivity and conduct problems, compared to emotional difficulties, create more disruption within a school environment and from the teacher's perspective, register a greater impact. However, it is possible that emotional difficulties, which are less obvious to observers than overt behavioural difficulties may reflect teachers' failure to notice the effect of these difficulties in relation to school adjustment. Equally, emotional difficulties may genuinely not interfere with school adjustment.

The strength and direction of relationships between factors derived from the original model were generally similar and will not be reiterated. The path between functional status and school adjustment indicated that lower levels of parent reported functional status were associated with lower levels of school adjustment. This finding is consistent with Youseff (1988) who found that increases in condition severity among children and adolescents with congenital heart disease were linked to increased behavioural problems as assessed by teachers. Consideration of the present finding together with the absence of a link between friendship variables and functional status suggests that level of functioning has greater implications for public rather than private behaviour. In other words, behaviours defined by the public arena and observed by teachers may reflect comparisons to a "normative" reference group in which less optimal functioning becomes highly visible. Within more intimate relationships, such as friendship functional limitations may be both less salient and accommodated. However, links between friendship and peer related variables suggested that increases in friendship play/association did indeed predict increases in friendship intimacy and higher levels of intimacy predicted better peer relations. Teacher reported peer relations were positively related to school adjustment suggesting that more adequate peer relations predicted higher school adjustment. Furthermore, increases in teacher reported school adjustment predicted a decline in child reported overall difficulty and the subsales of hyperactivity and conduct problems combined.

The links established between child friendship properties and peer relations are novel, no previous study has evaluated associations between these two aspects of social functioning in youngsters with chronic illness. Although one may speculate that social competence underpins the nature of this association, validation requires further research. Friendship variables, on the whole were not related to adjustment indices, although friendship intimacy appears to be dependent on level of emotional difficulty. The general lack of relationships may be attributable to methodological limitations. Adjustment indices often focus on the nature of public rather than private behaviour and may fail to tap features crucial to dyadic relationships such as friendship. Nonetheless, and unexpectedly, higher levels of emotional symptoms predicted increased friendship intimacy. Moreover, given the direction of the relationship, emotional symptoms seem to generate intimacy. Therefore, children reporting more emotional difficulties may gain a concurrent level of emotional support from their friendships.

Once again the findings reported here are strengthened by the use of independent sources for predictor and criterion variables. In addition, teacher report of peer relations and school adjustment reflects involvement of an informant having intimate knowledge of these factors and minimises the effect of social desirability. Many studies including assessment of peer relations appear to rely on child or parent report. Variables represent a coherent pattern of associations and further understanding of the role that functional status plays in shaping social functioning in children and adolescents with chronic illness. However, the sample size may have placed limitations on detection of effects.

8.7 Are level of functioning and emotional symptoms related to friendship quality and properties, peer relations and school adjustment?

Although two studies have demonstrated the effect of friendship support on psychological well-being among youngsters with chronic illness (Varni *et al.*, 1989b; La Greca, 1992) and links between friendship quality and school adjustment have been established for children without chronic illness (Berndt & Keefe, 1995), no study has examined in what way emotional factors and functional status are related to friendship, peer relations and school adjustment in youngsters with chronic illness. In light of the link between emotional symptoms and friendship intimacy and importance of functional status in social functioning, the final set of analyses evaluated the impact of emotional symptoms and level of functioning in relation to friendship quality and properties, peer relations and school adjustment. These analyses included a subsample of 36 children and adolescents and sought to expand exploration of effects and links among variables emerging from previous analyses.

Friendship and peer related factors were evaluated in relation to the independent effects of child reported emotional symptoms and parent reported functional status by comparing youngsters with either high or low levels of emotional symptoms and either high or low levels of functioning. The moderating effects of both emotional symptoms and functioning were also examined. Estimates of friendship quality and properties were gained from interview schedules reflecting children's responses to questions about their two best friends. The positive and negative features of friendships were derived from coding procedures applied to open questions incorporated within interview schedules and defined friendship quality. Examples of positive friendship features included prosocial/polite behaviour, emotional support and trust, negative friendship features entailed for example, antagonistic/impolite behaviour, lack of trust and different friends. Friendship properties, which included play/association, intimacy and absence of conflict were obtained from closed questions requesting the frequency of events to which questions referred.

Friendship positive and negative features were examined separately and in terms of mean and proportional scores. The latter score was incorporated to eliminate effects of reporting biases and make comparisons to mean scores. Difference scores for mean and proportional scores were calculated to elucidate the balance between positive and negative friendship features and determine the overall quality of children's friendships.

Comparison of positive and negative friendship features by level of emotional symptoms and functional status revealed no significant differences. However, there was a trend for children with high, compared to low functional status to report higher levels of positive association suggesting that high functioning is favourably linked to the enjoyment children gain from activities shared with friends. Summary proportional difference scores suggested that children with a low, compared to high level of emotional symptoms had marginally more positive friendships. The same finding emerged for children with high compared to low levels of functioning suggesting that friendship quality is related to both factors. Accordingly paired t-tests for positive and negative friendship features evaluated the effect of variation in level of symptoms and functioning on the overall quality of children's friendships. The results suggested that children with low functioning and high symptoms have the least positive friendships and children with low symptoms and high functioning the most positive friendships. These findings suggest that children with both emotional difficulties and functional limitations experience less amicable friendship relations. However, within this group, compared to other groups standard deviation scores suggested marked variation in friendship quality. This would imply that among these children other factors might interact with emotional symptoms and functioning and may influence friendship quality.

Findings linked to the effect of emotional symptoms and functional status in relation to friendship properties, peer relations and school adjustment also failed to demonstrate any significant group differences. However, youngsters reporting high, in contrast to low emotional symptoms did report higher levels of friendship intimacy and children with high, compared to low functional status were reported to have better peer relations and school adjustment. Latter group differences marginally failed the criterion of statistical significance. These findings tentatively suggest that while emotional factors play a greater role in friendship, functional status assumes a more prominent role in peer relations and school adjustment. A possible explanation may be that whereas emotional commitment underpins dyadic relations, group relations defined by compliance with social conventions demand optimal functioning to support and enhance group well-being; functional limitations may impede this goal.

Associations among variables were examined and significant differences by level of emotional symptoms and functional status determined. No significant group differences in the strength of associations were found, although trends were apparent. Z values above 1.20 were selected to illustrate the largest differences. In emotional symptom groups the strength of the correlation between peer relations and friendship quality was greater in children reporting low, compared to high emotional symptoms. This seems to imply high emotional symptoms undermines the link between peer relations and friendship quality and raises an interesting question. If social competence governs the link between these two variables do high emotional symptoms compromise social skills in either peer or friendship relations, or both? Further studies are required to address this question. More differences emerged by functional status level. Here associations between play/association and intimacy, friendship intimacy and friendship quality and school adjustment and friendship quality were consistent in showing stronger associations in youngsters with low, compared to high functional status. This suggests that friendship properties and quality are closely linked in children with low, compared to high functioning and may indicate that friendships assume greater relevance to these children. It may be children with low functioning gain both emotional and instrumental support from their friends which offsets difficulties associated with functional limitations and, moreover, seems to benefit school adjustment.

Analyses evaluating the interactive effects of emotional symptoms and functional status in relation to friendship quality, friendship properties, peer relations and school adjustment revealed a significant effect for school adjustment. Children with high and low functioning and low emotional symptoms did not differ significantly, but these differences were amplified for children reporting high emotional symptoms. Similar effects were found for peer relations but failed to reach statistical significance. Findings suggested that the combined effects of high emotional symptoms and low functioning were linked to less advantageous school adjustment and peer relations.

Overall, findings suggest the friendships of children with high, in contrast to low emotional symptoms are, indeed characterised by higher levels intimacy, but also involve slightly more negative features suggesting that friendships may be both close and difficult. While somewhat contradictory a high level of symptoms may represent a propensity toward exaggerated affect. Consequently, dyadic encounters reflecting intimate and antagonistic exchanges are interpreted within the context of heightened emotional reactions. No doubt emotional factors set the tone and quality of social relationships and are probably more influential in dyadic rather than peer group relationships. It appears however, that high emotional symptoms and low functioning combined are linked to reduced friendship quality and unfavourable effects for school adjustment and peer relations. The independent effects of high emotional symptoms and low functioning in relation to friendship quality, in contrast to the combined effect of these factors seems to be less marked. What is not clear is whether emotional symptoms, for children with low functioning, stem from perceptions of functional limitations or represent a temperamental disposition, or both. Further research on psychosocial adjustment might usefully address questions that explain how emotional factors operate in relation to functional status, and within the framework of friendship and peer relations.

8.8 Methodological limitations

A number of problems limit interpretation of study findings. A primary difficulty resides in the cross sectional design reflecting concurrent assessment and correlational analyses which restrict causal inference. Although associations between variables are informative and support the identification of instrumental factors, they tell us little about whether for example, family functioning promotes coping efficacy or visa versa. In addition, constraints imposed by sample size prevented the testing of condition differences within the risk resistance framework and may have compromised statistical power. Moreover, identifying effects of psychosocial factors is problematic, such as child coping in terms of individual strategy use in relation to outcome indices, and suggests large sample sizes are needed to establish the role of these factors.

Adjustment is an ongoing and variable process and further study would benefit from a longitudinal design and comparison of two condition groups. Such an approach could address issues of causal priority, statistical power and determine whether condition differences modify factors forecasting psychosocial outcome. Moreover, studies which illuminate causal relations would be helpful in the planning and evaluation of interventions and in turn offer opportunities for substantiation of causal links. However, there are difficulties such as participant attrition and maturational issues that require consideration when using longitudinal designs.

The representativeness of the study sample could also be called into question. Explanations given for non-participation suggested that some families did not wish to discuss issues and therefore may be under represented. Consequently, those willing to take part may in fact be those families able to confront and deal with difficulties.

The self-report methodology also raises the problem of social desirability. However, since data gathering took place in the home, a context that would presumably de-emphasise social constraints, this problem may have been countered to some extent. If this process had occurred in a hospital context, an environment that heightens the salience of illness and difference, the influence of demand characteristics may have been greater. Findings may have gained additional support through the use of techniques such as observation, although time and resource constraints precluded application in the present study. On the other hand, the inclusion of multiple informants in this investigation lends support to findings.

However, it is possible that results obtained from administration of Kidcope, the measure used to evaluate child coping, reflected order effects. Two measures were given in fixed order and since children consistently reported using fewer strategies for the second problem findings may denote fatigue. Nevertheless, differential effects for age and condition-related parameters by problem context suggest the data are reliable. In addition, the data on children's friendships mirrored the participants' view reflecting partial insight into the friendship relation and would be strengthened by confirmation of reciprocity. Since friendships are characterised by mutuality, confirmation of reciprocity would validate the relationship and reinforce findings. Moreover, it would then be possible to raise the question of whether reciprocated friendships differ from unreciprocated friendships in terms of benefits to psychosocial well-being.

The reliability and validity of the condition severity measure could perhaps be viewed as less than optimal. Although the procedures adopted were satisfactory this measure would profit from further assessment and given that it relies on a single rating, a multi-dimensional approach. In addition, condition parameters, such as age of condition onset and duration would have been strengthened through corroboration with health records. Also, it is not clear whether the approach used to determine parental coping efficacy is comparable to the usual summation of helpfulness scores on the Coping Health Inventory for Parents (McCubbin *et al.*, 1983a). In this investigation scores were summed and divided by the number of behaviours used to reflect an effort to perceived efficacy ratio. It was assumed the approach depicted the way coping efforts might be viewed and deals with the confounding of behaviours used and reported helpfulness. It would be worthwhile investigating the validity of this assumption.

In terms of the measurement and conceptualisation of condition course features, this variable was assumed to translate into demands engendered by the nature of the condition as experienced across time. However, more condition features may not necessarily reflect a corresponding increase in parents' experience of condition demands. It is possible that a single feature may incorporate demands that are equal to or more than a condition reported to include more features. Nonetheless, conditions that involve more features are highly likely to create additional demands. Accordingly, conditions that are viewed as progressive and episodic, or constant, recurring and episodic would incorporate more demands than a condition viewed as for instance, purely constant or progressive. This view is supported by findings that indicate children report, on average, more total difficulties and higher condition impact as measured by the perceived experience of condition scale, and parents report a decrease in child level of functioning as the number of condition course features increases from low (i.e. zero to one) to high (i.e. three to four). However, it is feasible that condition feature categories may not necessarily be equal in terms of demands. For example, a condition reported as being progressive but showing no other features may be more demanding that a condition perceived as recurring and demonstrating no other features or visa versa. Therefore, although the present measurement approach may be a valid assessment of how parents perceive their child's condition features, the assumption that categories are similar in the nature of their respective demands needs to be evaluated more fully.

A further limitation lies in the use of quantitative methods to explore appraisal of stress. Within the transactional model put forward by Lazarus and Folkman (1984), problem related stress relies on the significance of the event for an individual. It is the subjective experience of stress and coping resources which determines in what way an individual will respond. Quantitative methods make assumptions about the variables under study and may be less valid, although more reliable, than qualitative methods which reflect subjective perspectives. In addition, quantitative methods can be limited in detail, somewhat artificial and fail to take account of influential contextual factors that may explain variation in response within and across individuals. By contrast, qualitative methods place emphasis on the meanings individuals assign to their experience, are verbally rather than numerically descriptive in content, and also highly detailed. This matter focuses on the value and appropriateness of first (participant) and third (researcher) person perspectives within the research process. While first person approaches centralise subjective experience in understanding the issues that are important and salient, third person approaches assume that experiences have a similar meaning for participants and vary only in terms of degree. Essentially, research methods need to be considered in relation to conceptualisation of the phenomenon under study and research objectives. Within the present study the aim was to understand in what way a number of variables predicted a particular outcome. In this sense there was a need to take a quantitative approach, but at the same time the actual experience of chronic illness may be different for some families than that conceived. On the other hand, it may be argued that in using measures comparable to previous studies and a composite measure of stress that included three variables rather than one and involved two informants, current findings may be placed within the broader empirical context with some confidence.

An additional drawback is related to the limited exploration of child developmental issues. It is highly likely that developmental factors play an influential role in forecasting child adjustment. For example, children, in contrast to adolescents, would be expected to have less responsibility for condition management, such as taking prescribed medication.

Therefore care demands, excluding children with impaired mobility or sensory loss, are likely to be greater for adolescents than children and for parents of children than parents of adolescents. It might be expected that those experiencing higher care demands may encounter more difficulties than those dealing with fewer care demands. It may also be possible that condition-related parameters have differential effects on children and adolescents in terms of adjustment difficulties and coping strategy use. It is clear from the literature that there appears to be an increase in the use of emotion focussed strategies in adolescence, and this may indicate that condition-related parameters would have a greater impact on adolescents than children (see Hanson *et al.*, 1989 for an example of condition duration effects in adolescents).

In terms of current approaches to the evaluation of coping in children and adolescents this has included the use of self-report and observational methodologies. The latter is usually employed in studies focussing on concurrent medical/dental stressors, however, retrospective self-report involving open questions or coping checklists is the methodology adopted in the majority of studies. Coping activity in healthy children is frequently assessed using hypothetical stressors that are defined by investigators in terms of content and degree of stressfulness or level of controllability. These stressors may or may not be within the realm of the child's experience, but other studies involving youngsters with and without chronic illness have entailed self-nominated problems. Nonetheless, methods are somewhat limited to a quantitative approach, vary in conceptualisation and measurement and would benefit from a qualitative emphasis. Given that conceptualisation has drawn on the adult literature on coping it is not clear that investigators have understood and entered into the child's world sufficiently well to be able to specify what may or may not be stressful for children or adolescents. On the other hand, requesting children to nominate difficulties goes some way to addressing this problem in highlighting which problems present difficulties for children and adolescents. For instance, Spirito *et al.* (1994) asked children and adolescents who were either acutely ill (e.g. fractures, appendicitis) or chronically ill (e.g. cancer, ulcerative colitis) to nominate hospital related problems. Problems were classified into three groups; hospital facilities (e.g. poor food, lack of privacy), illness (e.g. hospitalisation prompts worries linked to illness) and pain (e.g. condition related or following a medical procedure). Age effects were found for the type of problem, in that younger children reported significantly more pain related problems in comparison to adolescents, and adolescents reported significantly more illness related problems than children (see also

Spirito *et al.*, 1995). These differences may suggest concerns are delineated by an ability to recognise long term advantages to well-being. Whereas children tend to locate interactions with the environment in the present or short-term future, adolescents can cognitively project themselves forward, realising that concurrent actions have long-term implications. Consequently, childrens' concerns centre on pain and adolescents focus on the effects of their condition but, in comparison to children, adolescents are more likely to recognise the future value of undergoing painful medical procedures. Such findings benefit understanding of which problems present difficulty and at what point in the developmental course problems assume significance.

While this approach is a significant step forward, further research might include quantitative and qualitative methods (e.g. open-ended interview, diaries) within longitudinal designs, to more readily identify the factors such as age, stage in illness course and setting that influence the salience of events. It may be then be possible to define with greater accuracy the contribution of individual and contextual factors to determining how children perceive and deal with stressful events and ongoing strains.

Finally, several problems can arise from conducting multiple analyses, which include increasing the probability of obtaining a significant result that is likely to have occurred by chance and, alternatively, minimising the likelihood that non-significant results are correctly identified. These issues are commonly referred to as Type 1 and Type 2 errors. Emphasis is generally put on avoidance of committing a Type 1 error, which means reporting a result as significant when it is untrue. Attempts to limit this difficulty are achieved by applying a more conservative level of probability under which a result will be judged to be statistically significant as in the Bonferroni method. However, in reducing the likelihood of committing a Type 1 error the chances of making a Type 2 error are increased, that is reporting a finding as non-significant when it is untrue. Within the present study the approach centred on diminishing the probability of Type 1 errors in a number of analyses. Consequently, the likelihood of Type 2 errors together with the lack of statistical power indicate that significant findings may be under reported. Although, given the sizeable number of tests undertaken an increase in the occurrence of Type 1 errors is also a strong possibility, and in both cases suggests further evaluation is required.

The difficulties inherent in conducting research within this population, for example the small number of children available to take part indicate this will be an ongoing problem. Relatively recently there has been a move to using effect size, that is the expected size of an association between a predictor and the criterion or dependent variable. Detection of small, medium or large effect sizes is related to sample size and statistical power. In using effect size, difficulties of over identifying statistically significant results common within large samples and under identifying non-significant results are limited. This approach is also informative about the links between variables within and between studies using different measures. Accordingly, further studies which include different samples, focus on fewer variables and take account of effect size may be better placed to minimise these statistical problems.

8.9 Conclusions

The present study addressed the following research questions. First, the explanatory potential of the categorical and non-categorical approaches in relation to the psychosocial effects of chronic illness. Second, the utility of the risk resistance framework in forecasting adjustment to chronic illness. Third, the role of peer context factors in prediction of adjustment outcome and fourth, the effects of emotional factors and functional status in relation to children's social functioning. Several results are consistent with earlier findings but others are novel. Nevertheless, findings generally support the extant literature in that children and adolescents with chronic childhood illness were more likely to experience emotional than behavioural difficulties.

Condition-related parameters reflected greater predictive utility for parent report of adjustment, compared to child report and revealed effects in relation to parental and child coping. These parameters were not linked to family functioning, although a trend was found between increases in condition severity and a decline in family functioning. While generic condition dimensions such as age of condition onset or condition severity demonstrated a larger number of effects supporting hypotheses, condition category also contributed to explanation of effects and adjustment outcome. Accordingly, in line with view advanced by Thompson and Gustafson (1996) further research would benefit from inclusion of both approaches. In addition, the marked difference in the role of these parameters predicting adjustment outcome for child and parent report suggest multiple informants should be an integral component of any subsequent research design and may strengthen internal and external validity and / or highlight questions that require further investigation.

This study is the first to compare the categorical and non-categorical approaches by evaluating the relative impact of condition-related parameters in relation to psychosocial outcome and child and parent coping using both child and parent report. Moreover, analyses included comparison of mothers' and fathers' reports of coping efficacy. Rarely are both parents involved in studies. Coping efficacy differed by condition category in fathers and by number of condition course features in mothers. Mothers and fathers differed from one another in reports of coping efficacy and in relation to two generic condition dimensions, number of condition course features and condition visibility. However, parent differences in coping as moderated by these parameters did not predict adjustment outcome. Children's reports of coping for everyday and illness related problems were linked to condition category, condition severity, number of condition course features, age of condition onset and condition duration. Strategy use also reflected associations with children's emotional responses to problems and adjustment outcome. Of particular interest were several findings demonstrating consistent effects in relation to management of an illness related problem. Specifically, later condition onset and / or shorter condition duration were linked to increased use of social withdrawal, emotional regulation and blaming others. Across all adjustment indices higher levels of difficulty were associated with an increase in the number of strategies used, but trends for increased use of specific strategies differed for adjustment outcomes. The findings suggest that condition parameters, such as age of condition onset and condition duration, may be helpful indicators of difficulty since strategy use seems to represent a less optimal approach to problem solving. Increases in the number of strategies used to deal with illness related problem may also be a useful marker of emotional difficulties. This adjustment index, compared to other indices demonstrated the strongest association with increases in strategy use. Moreover, children's emotional responses to both common and illness problems also indicated that higher levels of nervousness and sadness were linked to higher levels of emotional symptoms (difficulties). These findings, in particular the impact of condition-related parameters, are new and require replication, but nevertheless may assist practitioners in understanding which factors increase difficulty for mothers, fathers and children.

The risk resistance model put forward by Wallander *et al.* (1989b) gained partial support suggesting the conceptual structure for confirmed pathways is tenable. In contrast to previous studies that test model components, the present study attempted an evaluation of the entire model. However, moderating effects of resistance factors in relation to risk factors were not confirmed. This finding and unverified pathways may be attributable to insufficient statistical power. Principal findings were related to the differential effects of psychosocial stress on adjustment indices. The strength of the relationship between to hyperactivity and conduct problems combined and psychosocial stress was substantially weaker than for emotional difficulty and suggested the experience of chronic illness is more closely associated with emotional than behavioural difficulties. Functional status also appears to be a crucial marker for psychosocial stress and child report of coping efficacy. These findings may offer opportunities to identify children vulnerable to difficulty.

The extended model focussed on the role of children's social relationships in forecasting adjustment outcome. Earlier findings regarding the link between psychosocial stress and adjustment outcome were replicated. However, predictive links were established between child report of friendship intimacy and teacher report of peer relations, and functional status and school adjustment. Striking differences were found between the strength of the association between school adjustment and outcome. Although school adjustment predicted hyperactivity and conduct problems combined, no link was found for emotional difficulties. These findings suggested that while lower levels of functioning are associated with a deterioration in school adjustment, school adjustment did not mediate prediction of emotional difficulties, but may mediate reports of hyperactivity and conduct problems. However, although mediation was not formally tested reduced levels of functioning do not seem to fit with increased levels of hyperactivity and conduct problems and this certainly demands further investigation. Interestingly, the positive association between children's friendship intimacy and peer relations suggests a common factor may underlie these features of social functioning, although further evaluation suggests this may be modified by level of functioning. This study is the first to examine the impact of emotional factors and functional status in relation to both children's friendships and peer relationships. Few significant findings emerged from this analysis, but tentatively point to lower friendship quality among children with increased emotional difficulty and lower levels of functional status. Moreover, the presence of both factors have a profound and damaging effect on children's school adjustment, and to a lesser extent peer relations. Findings obviously require confirmation in further studies, and would be helpful in identifying children who may be at risk for difficulties in their social relationships.

In conclusion, the categorical and non-categorical approaches and the risk resistance framework can be viewed as useful conceptual tools to advance understanding of the factors that influence children's adjustment to chronic illness. However, the utility of the risk resistance mechanism remains unclear. It is not self evident that resistance factors, or risk factors for that matter, can be defined to consistently reflect these properties. For example, resistance factors such as social support and family functioning may be less than optimal and presumably would not be expected to afford protection against risk factors. It may be more helpful to regard them purely as mediators and / or moderators. On the other hand such a conceptualisation is a useful way to think about how factors operate on children's adjustment and serves efforts to identify influential factors. The present study has highlighted the significance of condition-related parameters for psychosocial well-being and child and parental coping, extended the focus of previous studies beyond the family to include the peer environment and evaluated the impact of emotional and functional well-being in relation to children's social functioning. It is hoped findings enlighten understanding and may perhaps assist practitioners in their endeavours to prevent and treat psychosocial difficulties among children and adolescents with chronic illness.

8.10 Suggestions for future research

The implications of condition-related factors for psychosocial well-being and coping need to be delineated further. Current findings suggest that both the categorical and non-categorical approaches are influential and would advance understanding if effects could be determined with further precision. For example, within a longitudinal design it would be possible to establish at what stage difficulties are encountered or ameliorated and which parameters influence these outcomes.

Furthermore, psychosocial outcomes expressed in terms of behavioural difficulties such as conduct problems among youngsters with chronic illness, although less common are not well understood and certainly warrant investigation. Present findings indicate behavioural, compared to emotional difficulties, demonstrate a weaker relationship with psychosocial stress and would suggest that other factors are more influential. Since behavioural difficulties, in contrast to emotional difficulties, appear to have deleterious impact on school adjustment factors that contribute to these outcomes needed to be identified and explicated.

At the present time the area of social functioning among children with chronic illness receives limited attention and is in need of further research. In particular, the role of functional status needs to be clarified, current findings suggest that low, compared to high functioning children are likely to experience difficulties in their peer relationships, but at the same time may gain more support from their friendships. Additional research that defines the role of functional status in healthy and chronically ill children may demonstrate the impact of illness on social functioning and the conjunction of peer relationships and friendship more clearly. Moreover, comparison of condition groups could highlight whether condition differences in functional status or the consequences of chronic illness, such as level of school absence, produce differential effects in social functioning. Also it would be helpful to consider functional status in relation to whether reciprocated and non-reciprocated friendships differ for healthy and chronically ill children.

Functional limitations coupled with emotional difficulties seem to create substantial difficulty in terms of school adjustment and to some degree, peer relations. However, it is unclear to what extent constitutional or environmental factors such as chronic illness contribute to emotional difficulties. The majority of research on adjustment to chronic illness focuses on environmental aspects, little is known about the role of temperamental factors. A useful adjunct to current research approaches that might address this issue is the twin design adopted by behavioural genetists. This research strategy aims to determine the relative contribution of genetic and environmental factors to psychological phenomena by comparing identical and non-identical twins. Further, constitutional factors may well be implicated in perceptions of stress, a major component of current theoretical models. This suggests that the incorporation of additional methods, such as experimental tasks that include physiological indicators of stress, for example cortisol levels, may strengthen findings. However, there would considerable difficulties in gathering sufficient numbers bearing in mind the population prevalence of twin births and chronic illness among children under 16 years. Such a study would probably need to be organised at a national level. An alternative approach would be possible by using self-report measures of constitutional factors, although findings from a twin design would be more powerful.

The unremitting pace of medical developments suggests the number of children and families living with chronic childhood illness looks set to rise and places increased pressure on paediatric psychologists to address the psychosocial ramifications that accompany short and long term survival. Studies that can further understanding will be ideally positioned to assist practitioners, children and their families in dealing with the psychological consequences of chronic illness in childhood and adolescence. The recommendations put forward here may throw further light on the complex and variable process of adjustment to chronic illness.

References

Allen, R.E. (Ed.) (1990). *The Concise Oxford Dictionary.* Oxford: Clarendon Press.

Austin, J.K. & Huberty, T.J. (1993). Development of Child Attitude toward Illness Scale. *Journal of Pediatric Psychology*, 18, No. 2, 467-480.

Austin, J.K. & McDermott, N. (1988). Parental attitude and coping behaviors in families of children with epilepsy. *Journal of Neuroscience Nursing,* 20, No. 3, 174-179.

Austin, J.K., Shelton Smith, M., Risinger, M.W. & McNelis, A.M. (1994). Childhood epilepsy and asthma: Comparison of quality of life. *Epilepsia,* 35, No. 3, 608-615.

Barbarin, O.A., Hughes, D. & Chesler, M.A. (1985). Stress, coping and marital functioning among parents of children with cancer. *Journal of Marriage and the Family,* 47, 473-480.

Bauman, L.J., Drotar, D., Leventhal, J.M., Perrin, E.C. & Pless, I.B. (1997). A review of psychosocial interventions for children with chronic health conditions. *Pediatrics,* 100, No. 2, 244-251.

Beavers, W.R. & Hampson, R.B. (1990). *Successful Families. Assessment and Intervention.* New York, London.: W. W. Norton & Company.

Bell, R.Q. (1968). A reinterpretation of the direction of effects in studies of socialisation. *Psychological Review,* 75, 81-95.

Bentler, P.M. (1995). *EQS Structural Equations Program Manual.* Encino, California: Multivariate Software, Inc.

Brenchley, S. & Govindji, A. (1995). Dietary management of children with diabetes. In C.J. H. Kelnar (Ed.), *Childhood and adolescent diabetes,* 271-281. London, Glasgow: Chapman & Hall Medical.

Bennett, D.S. (1994). Depression among children with chronic medical problems; A meta-analysis. *Journal of Pediatric Psychology,* 19, No. 2, 149-169.

Beresford, B.A. (1994). Resources and strategies: How parents cope with care of a disabled child. *Journal of Child Psychology and Psychiatry,* 35, No. 1, 171-209.

Berndt, T.J. (1982). The features and effects of friendships in early adolescence. *Child Development,* 53, 1447-1460.

Berndt, T.J. (1996). Exploring the effects of friendship quality on social development. In W. M. Bukowski, A.F. Newcomb & W.W. Hartup (Eds.), *The company they keep. Friendship in childhood and adolescence.* Cambridge, UK, New York, Melbourne: Cambridge University Press.

Berndt, T.J. & Keefe, K. (1995). Friend's influence on adolescent's adjustment to school. *Child Development*, 66, 1312-1329.

Berndt, T.J. & Perry, T.B. (1986). Children's perceptions of friendships as supportive relationships. *Developmental Psychology*, 22, No. 5, 640-648.

Bleyer, W.A. (1990). Acute lymphoblastic leukemia in children. *Cancer*, 65, 689-695.

Boland, E.A. & Grey, M. (1996). Coping strategies of school-age children with diabetes mellitus. *Diabetes Educator,* 22, No. 6, 592-597.

Bradford, R. (1997). *Children, families and chronic disease. Psychological models and methods of care.* London, New York: Routledge.

Breslau, N. (1985). Psychiatric disorder in children with disabilities. *Journal of the American Academy of Child Psychiatry*, 24, 87-94.

Brotman Band, E. & Weisz, J.R. (1990). Developmental differences in primary and secondary control coping and adjustment to juvenile diabetes. *Journal of Clinical Child Psychology,* 19, No. 2, 150-158.

Brown, R.T., Eckman, J., Baldwin, K., Buchanan, I. & Dingle, A.D. (1995). Protective aspects of adaptive behavior in children with sickle cell syndromes. *Children's Health Care*, 24, No. 4, 205-222.

Brown, R.T., Kaslow, N.J., Doepke, K., Buchanan, I., Eckman, J., Baldwin, K. & Goonan, B. (1993). Psychosocial and family functioning in children with sickle cell syndrome and their mothers. *Journal of American Academy of Child and Adolescent Psychiatry*, 32, No. 3, 545-553.

Brown, R.T., Kaslow N.J., Sansbury, L., Meacham, L. & Culler, F.L. (1991). Internalizing and externalizing symptoms and attributional style in youth with diabetes. *Journal of American Academy of Child and Adolescent Psychiatry,* 30, No. 6, 921-925.

Bukowski, W.M. & Hoza, B. (1989). Popularity and friendship. Issues in theory, measurement and outcome. In T.J. Berndt & G.W. Ladd (Eds.), *Peer relationships in child development.* New York: John Wiley.

Bullock, J.R. (1993). Children's loneliness and their relationships with family and peers. *Family Relations,* 42, 46-49.

Cadman, D., Boyle, M., Szatmari, P. & Offord, D.R. (1987). Chronic illness, disability, and mental and social well-being: Findings of the Ontario Child Health Study. *Pediatrics*, 79, No. 5, 805-912.

Cappelli, M., McGrath, P.J., MacDonald, N.E. Boland, M., Fried, P. & Katsanis, J. (1988). Parent, family and disease factors as predictors of psychosocial functioning in children with cystic fibrosis. *Canadian Journal of Behavioural Science*, 20, No. 4, 413-423.

Carlson-Green, B., Morris, R.D. & Krawiecki, N. (1995). Family and illness predictors of outcome in pediatric brain tumours. *Journal of Pediatric Psychology,* 20, No. 6, 769-784.

Carlton-Ford, S., Miller, R., Brown, M., Nealeigh, N. & Jennings, P. (1995). Epilepsy and children's social and psychological adjustment. *Journal of Health and Social Behavior*, 36, September, 285-301.

Carter, B.D., Kronenberg, W.G., Edwards, J.F., Marshall, G.S. Schikler, K.N. & Causey, D.L. (1999). Psychological symptoms in chronic fatigue and juvenile rheumatoid arthritis. *Pediatrics*, 103, 975-979.

Chaney, J.M., Mullins, L.M., Frank, R.G., Peterson, L., Mace, L.D., Kashani, J.H., & Goldstein, D.L. (1997). Transactional patterns of child, mother and father adjustment in insulin-dependent diabetes mellitus: A prospective study. *Journal of Pediatric Psychology,* 22, No. 2, 229-244.

Chase-Lansdale, P.L., Wakschlag, L.S. & Brookes-Gunn, J. (1995). A psychological perspective on the development of caring in children and youth: The role of the family. *Journal of Adolescence,* 18, 515-556.

Close, H., Davies, A.G., Price, D.A. & Goodyer, I.M. (1986). Emotional difficulties in diabetes mellitus. *Archives of Disease in Childhood,* 61, 337-340.

Compas, B.E., Orosan, P.G. & Grant, K.E. (1993). Adolescent stress and coping: Implications for psychopathology during adolescence. *Journal of Adolescence,* 16, 331-349.

Compas, B.E., Worsham, N.L. & Ey, S. (1992). Conceptual and developmental issues in children's coping with stress. In A.M. La Greca, L.J. Siegal, J.L Wallander & C.E. Walker (Eds.), *Stress and coping in child health.* New York, London: The Guilford Press.

Creer, T.L., Stein, R.E.K., Rappaport, L. & Lewis, C. (1992). Behavioral consequences of illness: Childhood asthma as a model. *Pediatrics,* 90, No. 5, 808-815.

Curry, S.L. & Russ, S.W. (1985). Identifying coping strategies in children. *Journal of Clinical Child Psychology,* 14, No.1, 61-69.

Daltroy, L.H., Larson, M.G., Eaton, H.M., Partridge, A.J., Pless, I.B., Rogers, M.P. & Liang, M.H. (1992). Psychosocial adjustment in juvenile arthritis. *Journal of Pediatric Psychology,* 17, No. 3, 277-289.

Daniels, D., Moos, R., Billings, A.G. & Miller III, J.J. (1987). Psychosocial risk and resistance factors among children with chronic illness, healthy siblings and healthy controls. *Journal of Abnormal Child Psychology*, 15, No. 2, 295-308.

Dodge, J.A., Morison, S., Lewis, P.A. Coles, E.C., Geddes, D., Rissell, G., Littlewood, J. M. & Scott, M.T. (1997). Incidence, population and survival of cystic fibrosis in the UK, 1968-95. *Archives of Disease in Childhood*, 77, 493-496.

Dorman, J.S., O'Leary, L.A. & Koehler, A.N. (1995). Epidemiology of childhood diabetes. In C.J.H. Kelnar (Ed.), *Childhood and adolescent diabetes,* 139-159. London, Glasgow: Chapman & Hall Medical.

Drash, A.L. & Berlin, N. (1985). Juvenile diabetes. In N. Hobbs & J.M. Perrin (Eds.), *Issues in the care of children with chronic illness.* San Francisco: Jossey Bass Publishers.

Drotar, D. (1994). Psychological research with pediatric conditions: If we specialize, can we generalize? *Journal of Pediatric Psychology*, 19, 403-414.

Drotar, D. (1997a). Relating parent and family functioning to the psychological adjustment of children with chronic health conditions: What we have learned? What do we need to know? *Journal of Pediatric Psychology*, 22, No. 2, 149-165.

Drotar, D. (1997b). Intervention research: Pushing back the frontiers of pediatric psychology. *Journal of Pediatric Psychology*, 22, No. 5, 593-606.

Drotar, D., Doershuk, M.D., Stern, R.C., Boat, T.F., Boyer, W., & Matthews, L. (1981). Psychosocial functioning of children with cystic fibrosis. *Pediatrics,* 67, No. 3, 338-343.

DSM-IV Task Force (1995). *Diagnostic and Statistical Manual of Mental Disorders. DSM-IV* (4th ed). American Psychiatric Association: Washington D.C.

Dunn, J. & McGuire, S. (1992). Sibling and peer relationships in childhood. *Journal of Child Psychology and Psychiatry,* 33, No 3, 67-105.

Dunn, J. (1995). Stepfamilies and children's adjustment. *Archives of Disease in Childhood,* 73, 487-489.

East, P.L. & Rook, K.S. (1992). Compensatory patterns of support among children's peer relationships: A test using school friends, nonschool friends and siblings. *Developmental Psychology,* 28, No 1., 163-172.

Ebata, A.T. & Moos, R.H. (1991). Coping and adjustment in distressed and healthy adolescents. *Journal of Applied Developmental Psychology,* 12, 33-54.

Eiser, C. (1990). *Chronic childhood disease. An introduction to psychological theory and research.* Sydney, New York, Port Chester, Melbourne: Cambridge University Press.

Eiser, C. (1992). Psychological consequences of chronic disease in children. In S. Maes, H. Leventhal & M. Johnson (Eds.), *International review of health psychology,* 145-165. Chichester U.K.: John Wiley & Sons.

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

Eiser, C. (1994). Making sense of chronic disease. The eleventh Jack Tizard memorial lecture. *Journal of Child Psychology and Psychiatry*, 35, No. 8, 1373-1389.

Eiser, C. & Havermans, T. (1992). Mothers' and fathers' coping with chronic childhood disease. *Psychology and Health*, 7, 249-257.

Eiser, C., Havermans, T., Craft, A. & Kernahan, J. (1995). Development of a measure to assess the perceived illness experience after treatment for cancer. *Archives of Disease in Childhood*, 72, 302-307.

Eiser, C., Havermans, T., Pancer, M. & Eiser, J.R. (1992). Adjustment to chronic disease in relation to age and gender: Mother's and father's reports of their child's behavior. *Journal of Pediatric Psychology*, 17, No. 3, 261-275.

Eiser, C., Kopel, S., Cool, P. & Grimer, R. (1999). The Perceived Illness Experience Scale (PIE): Reliability and validity revisited. *Child: Care, Health and Development*, 25, No. 3, 179-190.

Elborn, J.S., Shale, D.J & Britton, J.R. (1991). Cystic fibrosis: Current survival and population estimates to the year 2000. *Thorax*, 47, 881-885.

Epstein, N.B., Bishop, D.S. & Levin S. (1978). The McMaster Model of Family Functioning. *Journal of Marriage and Family Counselling,* 4, 19-31.

Epstein, N.B., Baldwin, L.M. & Bishop, D.S. (1983). The McMaster Family Assessment Device. *Journal of Marital and Family Therapy,* 9, No. 2, 171-180.

Fife, B., Norton, J.& Groom, G. (1987). The family's adaptation to childhood leukemia. *Social Science and Medicine*, 24, No. 2, 159-168.

Fonagy, P., Moran, G.S., Lindsay, M.K. & Kortz, A.B. (1987). Psychological adjustment and diabetic control. *Archives of Disease in Childhood,* 62, 1009-1013.

Frank, N.C., Blount, R.L. & Brown, R.T. (1997). Attributions, coping and adjustment in children with cancer. *Journal of Pediatric Psychology*, 22, No. 4, 563-576.

Frude, N. (1991). *Understanding family problems-A psychological approach.* Chichester, New York: John Wiley & Sons.

Furukawa, C.T., DuHamel, T.R., Weimer, L., Shapiro, G.G., Pierson, W.E. & Beirman, C.W. (1988). Cognitive and behavioral findings in children taking theophylline. *Journal of Allergy and Clinical Immunology*, 81, 83-88.

Gardner, S.G., Bingley, P.J., Sawtell. P.A., Weeks, S. & Gale, E.A.M. (1997). Rising incidence of insulin dependent diabetes in children aged under 5 years in the Oxford region: Time trend analysis. *British Medical Journal*, 315, 713-717.

Gil, K.M., Williams, D.A.,Thompson, R.J. & Kinney, T.R. (1991). Sickle cell disease in children and adolescents: The relation of child and parent pain coping strategies to adjustment. *Journal of Pediatric Psychology,* 16, 643-663.

Goffman, E. (1963). *Stigma. Notes on the management of spoiled identity.* London: Penguin Books.

Goodman, R. (1997). The strengths and difficulties questionnaire: A research note. *Journal of Child Psychology and Psychiatry*, 38, No. 5, 581-586.

Goodman, R. (1998). Personal communication.

Goodman, R., Meltzer, H. & Bailey, V. (1998). The strengths and difficulties questionnaire: A pilot study of the validity of the self-report version. *European Child and Adolescent Psychiatry,* 7, 125-130.

Goodman, R. & Scott, S. (1999). Comparing the Strengths and Difficulties Questionnaire and the Child Behavior Checklist: Is small beautiful? *Journal of Abnormal Child Psychology,* 27, No. 1, 17-24.

Goodman, S.H., Brogan, D. Lynch, M.E. & Fielding, B. (1993). Social and emotional competence in children of depressed mothers. *Child Development,* 64, 516-531.

Gortmaker, S.L., Walker, D.K., Weitzman, M. & Sobol, A.M. (1990). Chronic conditions and behavioral problems in children and adolescents. *Pediatrics*, 85, No. 3, 267-276.

Gowers, S.G., Jones, J.C., Kiana, S., North, C.D. & Price, D.A. (1995). Family functioning: A correlate of diabetic control? *Journal of Child Psychology and Psychiatry,* 36, No. 6, 993-1001.

Graetz, B. & Shute, R. (1995). Assessment of peer relationships in children with asthma. *Journal of Paediatric Psychology,* 20, No. 2, 205-216.

Graham, P., Stevenson, J. & Flynn, D. (1997). A new measure of health-related quality of life for children: Preliminary findings. *Psychology and Health*, 12, 655-665.

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

Grey, M., Sullivan-Bolyai, S., Boland, E.A., Tamborlane, W.V. & Yu, C. (1998). Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes Care,* 21, No. 6, 909-914.

Hanson, C.L., Cigrang, J.A., Harris, M.A., Carle D.A., Relyea, G. & Burghen, G.A. (1989). Coping styles in youths with insulin dependent diabetes mellitus. *Journal of Consulting and Clinical Psychology*, 57, No. 5, 644-651.

Hanson, C.L., Rodrique, J.R., Henggeler, S.W., Harris, M.A. Klesges, R.C. & Carle, D.L. (1990). The perceived self-competence of adolescents with insulin dependent diabetes mellitus: Deficit or strength? *Journal of Pediatric Psychology,* 15, 605-618.

Harris, J.R. (1995). Where is the child's environment? A group socialization theory of development. *Psychological Bulletin,* 102, No. 3, 458-489.

Harris, J.R. (1999). *The nurture assumption: Why children turn out the way they do.* London: Bloomsbury.

Hartup, W. (1989). Social relationships and their developmental significance. *American Psychologist,* 44, No. 2, 120-126.

Hartup, W. (1995). Personality development in social context. *Annual Review of Psychology,* 46, 655-87.

Hauser, S.T., Jacobson, A.M., Wertlieb, D., Brink, S. & Wentworth, S. (1985). The contribution of family environment to perceived competence and illness adjustment in diabetic and acutely ill adolescents. *Family Relations,* 34, 99-108.

Hill, R. (1958). Social stresses on the family. Generic features of families under stress. *Social Casework,* 49, 139-150.

Hoare, P. (1984). The development of psychiatric disorder among school age children with epilepsy. *Developmental Medicine and Child Neurology,* 26, 3-13.

Hoare, P. & Mann, H. (1994). Self-esteem and behavioural adjustment in children with epilepsy and children with diabetes. *Journal of Psychosomatic Research,* 38, No. 8, 859-869.

Holaday, B. (1984). Challenges of rearing a chronically ill child. *Nursing Clinics of North America,* 19, No. 2, 361-368.

Holden, E.W., Chmielewki, D. Nelson, C.C., Kager, V.A. & Foltz, L. (1997). Controlling for general and disease-specific effects in child and family adjustment to chronic childhood illness. *Journal of Pediatric Psychology,* 22, No. 1, 15-27.

Holden, E.W., Rawlins, C. & Gladstein, J. (1998). Children's coping with recurrent headache. *Journal of Clinical Psychology in Medical Settings,* 5, No. 2, 147-158.

Holmbeck, G.N. (1997). Toward terminological, conceptual and statistical clarity in the study of mediators and moderators: Examples from the child-clinical and pediatric psychology literatures. *Journal of Consulting and Clinical Psychology,* 65, No. 4, 599-610.

Holmbeck, G.N. & Faier-Routman, J. (1995). Spinal lesion, shunt status, family relationships, and psychosocial adjustment in children and adolescents with spina bifida myelomeningocele. *Journal of Pediatric Psychology,* 20, No. 6, 817-832.

Holmbeck, G.N., Gorey-Ferguson, L., Hudson, T., Seefeldt, T., Shapera, W., Turner, T. & Uhler, J. (1997). Maternal, paternal and marital functioning in families of preadolescents with spina bifida. *Journal of Pediatric Psychology,* 22, No.2, 167-181.

Hommeyer, J.S., Holmbeck, G.N., Wills, K.E. & Coers, S. (1999). Condition severity and psychosocial functioning in pre-adolescents with spina bifida: Disentangling proximal functional status and distal adjustment outcomes. *Journal of Pediatric Psychology,* 24, No. 6, 499-509.

Howe, G.W., Feinstein, C., Reiss, D., Molock, S. & Berger, K. (1993). Adolescent adjustment to chronic physical disorders-I. Comparing neurological and non-neurological conditions. *Journal of Child Psychology and Psychiatry,* 34, No. 7, 1153-1171.

Hoza, B., Molina, B.S.G., Bukowski, W.M. & Sippola, L. K. (1995). Peer variables as predictors of later childhood adjustment. *Development and Psychology,* 7, 87-802.

Hurtig, A.L., Koepke, D. & Park, K.B. (1989). Relation between severity of chronic illness and adjustment in children and adolescents with sickle cell disease. *Journal of Pediatric Psychology,* 14, 117-132.

James, A. (1993). *Childhood Identities. The self and social relationships in the experience of the child.* Edinburgh: Edinburgh University Press.

Javinen, D. W. and Nicholls, J. G. (1996). Adolescent's social goals, beliefs about causes of social success and satisfaction in peer relations. *Developmental Psychology,* 32, No. 3, 435-441.

Jessop, D.J. & Stein, R.E.K. (1985). Uncertainty and its relation to the psychological and social correlates of chronic illness in children. *Social Science and Medicine*, 20, No. 10, 993-999.

Kabacoff, R.I., Miller, I.W., Bishop, D.S., Epstein, N.B. & Keitner, G.I. (1990). A psychometric study of the McMaster Family Assessment Device in psychiatric, medical and nonclinical samples. *Journal of Family Psychology*, 3, No. 4, 431-439.

Kager, V. & Holden, E. (1992). Preliminary investigation of the direct and moderating effects of family and individual variables on the adjustment of children an adolescents with diabetes. *Journal of Pediatric Psychology*, 17, No. 4, 491-502.

Kazak, A.E. (1989). Families of chronically ill children: A systems and social-ecological model of adaptation and change. *Journal of Consulting and Clinical Psychology,* 57, No. 1, 25-30.

Kazak, A.E. (1992). The social context of coping with childhood chronic illness: Family systems and social support. In A.M. La Greca, L.J. Siegal, J.L Wallander & C.E. Walker (Eds.), *Stress and coping in child health.* New York, London: The Guilford Press.

Kazak, A.E. (1997). A contextual family/systems approach to pediatric psychology: Introduction to the special issue. *Journal of Pediatric Psychology*, 22, No.2, 141-147.

Kazak, A.E., Reber, M. & Snitzer, L. (1988). Childhood chronic disease and family functioning: A study of phenylketonuria. *Pediatrics* 81, No. 2, 224-230.

Kazak, A.E., Simms, S., Barakat, L.P., Hobbie, W., Foley, B., Golomb, V. & Best, M. (1999). Surviving cancer competently intervention program (SCCIP): A cognitive-behavioral and family therapy intervention for adolescent survivors of childhood cancer and their families. *Family Process,* 28, Summer, 175-191.

Keefe, K. & Berndt, T.J. (1996). Relations of friendship quality to self-esteem in early adolescence. *Journal of Early Adolescence*, 16, No. 1, 110-129.

Kell, R.S., Kliewer, W., Erikson, M.T. & Ohene-Frempong, K. (1998). Psychological adjustment of adolescents with sickle cell disease: Relations with demographic, medical and family competence variables. *Journal of Pediatric Psychology*, 23, No.5, 301-312.

Kellam, S.G., Ensminger, M.E. & Turner, R.J. (1977). Family structure and the mental health of children. *Archives of General Psychiatry*, 34,1012-1022.

Kellerman, J., Zeltzer, L., Ellenberg, L., Dash, J. & Rigler, D. (1980). Psychological effects of illness in adolescence. I. Anxiety, self-esteem, and perception of control. *The Journal of Pediatrics,* 97, No. 1, 126-131.

Kim, W.J. (1994). Psychiatric aspects of epileptic children and adolescents. *Journal of American Academy of Child and Adolescent Psychiatry*, 30, No. 6, 874-886.

Klein, D.M. & White, J. M. (1996). *Family theories: An introduction.* Thousand Oaks, London, New Delhi: Sage Publications.

Kliewer, W. & Lewis, H. (1995). Family influences on coping processes in children and adolescents with sickle cell disease. *Journal of Pediatric Psychology,* 20, No. 4, 511-525.

Kovacs, M., Satish, I., Goldstein, D. & Stewart, J. (1990). Psychological functioning of children with insulin-dependent diabetes mellitus: A longitudinal study. *Journal of Pediatric Psychology,* 15, No. 5, 619-632.

Kronenberger, W.G. & Thompson, R.J. (1990). Dimensions of family functioning in families with chronically ill children: A higher order factor analysis of the Family Environment Scale. *Journal of Clinical Child Psychology,* 19, No. 4, 380-388.

Kyngas, H. & Barlow, J. (1995). Diabetes: An adolescent's perspective. *Journal of Advanced Nursing,* 22, 941-947.

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

La Greca, A.M. (1990). Social consequences of pediatric conditions: Fertile area for future investigations and intervention. *Journal of Pediatric Psychology,* 15, No. 2, 285-307.

La Greca, A.M. (1992). Peer influences in pediatric chronic illness: An update. *Journal of Pediatric Psychology*, 17, No. 6, 775-784.

Lavigne, J.V. & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology*, 17, No. 2, 133-157.

Lavigne, J.V. & Faier-Routman, J. (1993). Correlates of psychological adjustment to pediatric physical disorders: A meta-analytic review and comparison with existing models. *Journal of Developmental and Behavioral Pediatrics*, 14, 117-123.

Lazarus, R.S. & Folkman, S. (1984). *Stress, appraisal and coping*. New York: Springer Verlag.

Leffert, F. (1985). Asthma. In N. Hobbs & J.M. Perrin (Eds.), *Issues in the care of children with chronic illness,* 366-379. San Francisco, London: Jossey Bass Publishers.

Lewin, K. (1935). *A dynamic theory of personality.* New York: McGraw-Hill.

Lewis, P.A. (1995). The epidemiology of cystic fibrosis. In M.E. Hodson & D.M. Geddes (Eds.), *Cystic Fibrosis*, (1-13). London, Weinheim, New York: Chapman & Hall Medical.

Lewis, B.L. & Khaw, K.T. (1982). Family functioning as a mediating variable affecting psychosocial adjustment of children with cystic fibrosis. *Behavioral Pediatrics,* 101, No. 4, 636-640.

Light, P. (1986). Context, conservation and conversation. In M. Richard & P. Light (Eds.), *Children of social worlds*. Cambridge: Polity Press.

Light, P., Sheldon, S. & Woodhead, M. (1991). *Child development in social context. Learning to think.* Milton Keynes: Routledge in association with The Open University.

Light, P. & Littleton, K. (Seminar handout, 1994). Cognitive approaches to groupwork.

Lipowski, Z. (1970). Physical illness, the individual and the coping process. *Psychiatry in Medicine,* 1, 91-108.

Madan-Swain, A., Brown, R.T., Sexton, S.B., Baldwin, K., Pais, R. & Ragab, A. (1994). Adolescent cancer survivors. Psychosocial and familial adaptation. *Psychosomatics,* 35, No. 5, 453-459.

Mann, N.P. & Rutter, N. (1986). *Clinical cases in paediatrics.* Edinburgh, London, New York: Churchill Livingstone.

Marteau, T.M., Bloch, S., & Baum, J.D. (1987). Family life and diabetic control. *Journal of Child Psychology and Psychiatry,* 28, No. 6, 823-833.

Matthews, L.W. & Drotar, D. (1984). Cystic fibrosis-A challenging long-term chronic disease. *Pediatric Clinics of North America*, 31, No. 1, 133-152.

MacLean, W.E., Perrin, J.M., Gortmaker, S.L. & Pierre, C.B. (1992). Psychological adjustment of children with asthma - effects of illness severity and recent stressful events. *Journal of Pediatric Psychology,* 17, No. 2, 159-171.

McCoy, J.K., Brody, G.H. & Stoneman, Z. (1994). A longitudinal analysis of sibling relationships as mediators of the link between family processes and youth's best friendships. *Family Relations,* 43, 400-408.

McCubbin, H.I., McCubbin, M.A., Patterson, J., Cauble, A.E., Wilson, L. & Warwick, W. (1983a). CHIP-Coping Health Inventory for Parents: An assessment of parental coping patterns in the care of the chronically ill child. *Journal of Marriage and the Family*, 45, 359-370.

McCubbin, H.I. & Patterson, J. (1983b). Family stress and adaptation to crisis: A Double ABCX model of family behavior. In *Family studies Review Yearbook,* (87-107). Beverley Hills, California: Sage.

McCubbin, H.I., Patterson, J., McCubbin, M.A., Wilson, L. & Warwick, W. (1983c). Parental coping and family environment: Critical factors in the home management and health status of children with cystic fibrosis. In D. Bargozzi, A. Jurich & R. Jackson (Eds.), Marital and family therapy: New perspectives in theory, research and practice, (107-135). New York: Human Sciences Press.

McCubbin, H.I., Thompson, A.I., McCubbin, M.A., Elver, K.M., Futrell, J.A. & Masshardt, W. E. (1996). *Family assessment: Resiliency, coping and adaptation. Inventories for research and practice.* University of Wisconsin Publishers: Madison, Wisconsin.

McCubbin, H.I., Thompson, E.A.,Thompson, A.I., McCubbin, M.A. & Kaston, A.J. (1993). Culture, ethnicity, and the family: Critical factors in childhood chronic illnesses and disabilities. *Pediatrics*, 91, No. 5, 1063-1070.

McCubbin, M.A. (1984). Nursing assessment of parental coping with cystic fibrosis. *Western Journal of Nursing Research*, 6, No. 4, 407-421.

McGuire, K.D. & Weisz, J.R. (1982). Social cognition and behavioral correlates of preadolescent chumship. *Child Development*, 53, 1483-1484.

Mead, G.H. (1934). *Mind, self and society.* C.W. Morris (Ed.). Chicago, Illinois: University of Chicago Press.

Metcalfe, M.A. & Baum, J.D. (1991). Incidence of insulin-dependent diabetes in children aged under 15 years in the British Isles during 1988. *British Medical Journal,* 302, 443-447.

Minuchin, S. (1977). *Families and family therapy.* London and New York: Routledge.

Milner, A.D. & Hull, D. (1984). *Hospital Paediatrics.* Edinburgh, London: Churchill Livingstone.

Miller, I.W., Epstein, N.B., Bishop, D.S. & Keitner, G.I. (1985). The McMaster Family Assessment Device: Reliability and Validity. *Journal of Marital and Family Therapy,* 11, No. 4, 345-356.

Mobbs Henry, F., Reed, V.A. & McAllister, L.L. (1995). Adolescents' perceptions of the relative importance of selected communication skills in their positive peer relationships. *Language, Speech and Hearing Services in Schools,* 26, 263-272.

Molleman, E. & van Knippenberg, A.D. (1987). Social and psychological aspects of haemophilia. *Patient Education and Counselling,* 10, 175-189.

Moise, J.R., Drotar, D., Doershuk, C.F. & Stern, R.C. (1987). Correlates of psychosocial adjustment among young adults with cystic fibrosis. *Journal of Developmental and Behavioral Pediatrics,* 8, No. 3, 141-148.

Moos, R.H. & Moos, B.S. (1986). A social climate scale. *Family environment scale manual.* Palo Alto California: Consulting Psychologists Press Inc. (1-65).

Moos, R.H. & Schaefer, J.A. (1984). The crisis of physical illness: An overview and conceptual approach. In R.H. Moos (Ed.), *Coping with physical illness 2: New Perspectives*, (3-25). New York: Plenum.

Moos, R.H. & Tsu, V.D. (1977). The crisis of physical illness: An overview. In R. H. Moos (Ed.), *Coping with physical illness*, 3-21. New York: Plenum.

Morris, J.A.B., Blount, R.L., Cohen, L.C., Frank, N.C., Madan-Swain, A. & Brown, R.T. (1997). Family functioning and behavioral adjustment in children with leukaemia and their healthy peers. *Children's Health Care*, 26, No. 2, 61-75.

Murch, R.L. & Cohen, L.H. (1989). Relationships among life stress, perceived family environment and psychological distress of spina bifida adolescents. *Journal of Pediatric Psychology,* 14, No. 2, 193-214.

Nagy, S. & Ungerer, J.A. (1990). The adaptation of mothers and fathers to children with cystic fibrosis: A comparison. *Children's Health Care*, 19, No. 3, 147-154.

Nassau, J.H. & Drotar, D. (1995). Social competence in children with IDDM and asthma: Child, teacher, and parent reports of children's social adjustment, social performance, and social skills. *Journal of Pediatric Psychology,* 20, No. 2, 187-204.

Nassau, J.H. & Drotar, D. (1997). Social competence among children with nervous system related chronic health conditions. *Journal of Pediatric Psychology,* 22, No. 6, 771-793.

Nelson, A.E., Miles, M.S., Reed, S.B., Davis, C.P. & Cooper, H. (1994). Depressive symptomatology in parents of children with chronic oncologic or hematologic disease. *Journal of Psychosocial Oncology*, 12, No. 4, 61-75.

Noll, R. B., Ris, M. D., Hobart Davies W., Bukowski, W.M. & Koontz, K. (1992). Social interactions between children with cancer in sickle cell disease and their peers: Teacher ratings. *Journal of Developmental and Behavioral Pediatrics,* 13, No. 3, 187-193.

Noll, R.B., Vannatta, K., Koontz, K., Kalinyak, K., Bukowski, W.M. & Hobart Davies, W. (1996). Peer relationships and emotional well-being of youngsters with sickle cell disease. *Child Development,* 67, 423-436.

O'Donohoe, N. (1979). *Epilepsies of childhood.* London, Boston: Butterworths.

O'Donohoe, N. (1994). Classification of epilepsies in infancy, childhood and adolescence. In E.M. Ross & R.C. Woody (Eds.), *Bailliere's Clinical paediatrics. International Research and Practice Vol 2 No. 3 Epilepsy* (471-484). London, Philadelphia, Sydney, Tokyo: Baillere Tindall.

Office for National Statistics (1998). *Social Trends 28.* London: The Stationary Office.

Office for National Statistics (1999). *Social Trends 29.* London: The Stationary Office.

Office of Populations, Censuses and Surveys (1990). *Standard Occupational Classification (Vols 1, 2, 3).* London: HMSO.

Olson, A.L., Johansen, S.G., Powers, L.E., Pope, J.B. & Klein, R.B. (1993). Cognitive coping strategies of children with chronic illness. *Journal of Developmental and Behavioral Pediatrics,* 14, No. 4, 217-223.

Olson, D.H. (1994). Commentary. Curvilinearity survives: The world is not flat. *Family Process*, 33, 471-478.

Olson, D.H., Spenkle, D.H. & Russell, C.S. (1979). "Circumplex model of marital and family systems: I. Cohesion and adaptability dimensions, family types and clinical applications" *Family Process*, 18, 3-15.

Overstreet, S., Goins, J., Chen, R.S., Holmes, C.S., Greer, T., Dunlap, W.P. & Frentz, J. (1995). Family environment and the interrelation of family structure, child behavior, and metabolic control for children with diabetes. *Journal of Pediatric Psychology,* 20, No. 4, 435-447.

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

Patterson, J.M. & Garwick, A.W. (1994). The impact of chronic illness on families: A family systems perspective. *Annals of Behavioral Medicine,* 16, No. 2, 131-142.

Patterson, J.M. & McCubbin, H.I. (1983). The impact of family life events and changes on the health of a chronically ill child. *Family Relations,* 32, 255-264.

Patterson, J.M. (1988). Families experiencing stress. I. The family adjustment and adaptation response model II. Applying the FAAR model to health-related issues for intervention and research. *Family Systems Medicine,* 6, No. 2, 202-237.

Payer, L. (1990). *Medicine and culture: Notions of sickness and health.* London: Gollancz.

Perrin, E.C., Ayoub, C.C. & Willett, J.B. (1993). In the eyes of the beholder: Family and maternal influences on the perceptions of adjustment of children with chronic illness. *Journal of Developmental and Behavioral Pediatrics,* 14, No. 2, 94-105.

Perrin, E.C., Newacheck, P., Pless, I.B., Drotar, D., Gortmaker, S.L., Leventhal, J., Perrin, J.M., Stein, R.E.K., Walker, D. K. & Weitzman, M. (1993). Issues involved in the definition and classification of chronic health conditions. *Pediatrics,* 91, No. 4, 787-793.

Perrin, E.C., Stein, R.E.K. & Drotar, D. (1991). Cautions in using the Child Behavior Checklist: Observations based on research about children with chronic illness. *Journal of Pediatric Psychology,* 16, No. 4, 411-421.

Perrin, J.M., MacLean, W.E. & Perrin, E.C. (1989). Parental perceptions of health status and psychologic adjustment of children with asthma. *Pediatrics,* 83, No. 1, 26-30.

Phipps, S. & Srivastava, D.K. (1999). Approaches to the measurement of depressive symptomatology in children with cancer: Attempting to circumvent the effects of defensiveness. *Journal of Developmental and Behavioral Pediatrics*, 20, No. 3, 150-156.

Pless, I.B. & Perrin, J.M. (1985). Issues common to a variety of illnesses. In N. Hobbs & J.M. Perrin (Eds.), *Issues in the care of children with chronic illness* (41-60). San Francisco London: Jossey Bass Publishers.

Pless, I.B. & Pinkerton, P. (1975). *Chronic childhood disorder: Promoting patterns of adjustment.* London: Henry Kimpton.

Pretzlik, U. (1997). *Children coping with a serious illness. A study* exploring coping and distress in children with leukaemia or aplastic anaemia. Amsterdam: SOC-Kohnstamm Institute, University of Amsterdam.

Rait, D.S., Ostroff, J.S., Smith, K., Cella, D.F., Tan, C. & Lesko, L.M. (1992). Lives in the balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Family Process,* 31, 383-397.

Reid, G.J., Dubrow, E.F. & Carey, T.C. (1995). Developmental and situational differences in coping among children and adolescents with diabetes. *Journal of Applied Developmental Psychology,* 16, 529-554.

Reid, G.J., Dubow, E.F., Carey, T.C. & Dura, J.R. (1994). Contribution of coping to medical adjustment and treatment responsibility among children and adolescents with diabetes. *Journal of Developmental and Behavioral Pediatrics,* 15, No. 5, 327-335.

Ridenour, T.A., Daley, J.G. & Reich, W. (1999). Factor analyses of the Family Assessment Device. *Family Process,* 38, No.4, 497-510.

Rodrigue, J.R., Streisand, R., Banko, C., Kedar, A. & Pitel, P.A. (1996). Social functioning, peer relations, and internalizing and externalizing problems among youths with sickle cell disease. *Children's Health Care,* 25, No. 1, 37-52.

Rolland, J.S. (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process,* 26, 203-221.

Roskies, E. (1972). *Abnormality and normality. The mothering of thalidomide children.* Icthaca, London: Cornell University Press.

Roth, S. & Cohen, L.J. (1986). Approach, avoidance, and coping with stress. *American Psychologist,* 41, No. 7, 813-819.

Rovet, J.F. & Ehrlich, R.M (1988). Effect of temperament on metabolic control in children with diabetes mellitus. *Diabetes Care,* 11, 77-82.

Rovet, J., Ehrlich, R. & Hoppe, M. (1987a). Behaviour problems in children with diabetes as a function of sex and onset of disease. *Journal of Child Psychology and Psychiatry,* 28, No. 3, 477-491.

Rovet, J.F., Ehrlich, R.M. & Hoppe, M. (1987b). Intellectual deficits associated with early onset of insulin-dependent diabetes mellitus in children. *Diabetes Care,* 10, No. 4, 510-515.

Rubin, E.H. Cohen, R., Housten, D.A. & Cockerel, J. (1996). Children's self-discrepancies and peer relationships. *Social Cognition,* 14, No. 1, 93-112

Rudolph, K.D., Hammen, C. & Burge D. (1995). Cognitive representations of self, family and peers in school-age children: Links with social competence and sociometric status. *Child Development,* 66, 1385-1402.

Rutter, M., Tizard, J. & Whitmore, K. (1970). *Education, health and behaviour.* London: Longman Press.

Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry,* 57, 316-331.

Ryan, C.M. (1988). Neurobehavioral complications of Type 1 diabetes. *Diabetes Care,* 11, No. 1, 86-93.

Ryan, C. M. & Morrow, L.A. (1986). Self-esteem in diabetic adolescents: Relationship between age at onset and gender. *Journal of Consulting and Clinical Psychology*, 54, 730-731.

Schaffer, R. (1977). *Mothering.* Glasgow: Fontana Press.

Schoenfeld, J., Seidenberg, M., Woodard, A., Hecox, K., Inglese, C., Mack, K. & Hermann, B. (1999). Neuropsychological and behavioral status of children with complex partial seizures. *Developmental Medicine and Child Neurology,* 41, 724-731.

Schoenher, S.J., Brown, R.T., Baldwin, K. & Kaslow, N.J. (1992). Attributional styles and psychopathology in pediatric chronic illness groups. *Journal of Clinical Child Psychology,* 21, 380-387.

Shaffer, D., Gould, M. S., Brasic, J., Ambrosini, P., Fisher, P., Bird, H. & Aluwhalia, S. (1983). A children's global assessment scale (C-GAS). *Archives of General Psychiatry,* 40, 1228-1231.

Sharpe, J.N., Brown, R.T., Thompson, N.J. & Eckman, J. (1994). Predictors of coping with pain in mothers and their children with sickle cell syndrome. *Journal of American Academy of Child and Adolescent Psychiatry,* 33, No. 9, 1246-1255.

Silver, E.J., Stein, R.E.K. & Dadds, M.R. (1996). Moderating effects of family structure on the relationship between physical and mental health in urban children with chronic illness. *Journal of Pediatric Psychology,* 21, No. 1, 43-56.

Simmons, R.J., Corey, M., Cowen, L., Keenan, N., Robertson, J. & Levison, H. (1985). Emotional adjustment of early adolescents with cystic fibrosis. *Psychosomatic Medicine*, 47, No. 2, 111-122.

Smith, K.E., Ackerson, J., Blotchy, A. Berkow, R. (1990). Preferred coping styles of pediatric cancer patients during invasive medical procedures. *Journal of Psychosocial Oncology,* 8, 59-70.

Sloper, P. & Turner, S. (1993). Risk and resistance factors in the adaptation of parents of children with severe physical disability. *Journal of Child Psychology and Psychiatry,* 34, No. 2, 167-188.

Spirito, A., DeLawyer, D. & Stark, L.J. (1991). Peer relations and social adjustment of chronically ill children and adolescents. *Clinical Psychology Review,* 11, 539-564.

Spirito, A., Francis, G., Overholser, J. & Frank, N. (1996). Coping, depression and adolescent suicide attempts. *Journal of Clinical Child Psychology*, 25, No. 2, 147-155.

Spirito, A., Overholser, J. & Stark, L. (1989). Common problems and coping strategies II: Findings with suicide attempters. *Journal of Abnormal Child Psychology*, 17, No. 2, 213-221.

Spirito, A., Stark, L.J., Gil, K.M. & Tyc, V.L. (1995). Coping with everyday and disease-related stressors by chronically ill children and adolescents. *Journal of American Academy of Child and Adolescent Psychiatry,* 34, No. 3, 283-290.

Spirito, A., Stark, L.J., Grace, N. & Stamoulis, D. (1991). Common problems and coping strategies reported in childhood and early adolescence. *Journal of Youth and Adolescence,* 20, No. 5, 531-544.

Spirito, A., Stark, L.J. & Tyc, V.L. (1994). Stressors and coping strategies described during hospitalization by chronically ill children. *Journal of Clinical Child Psychology,* 23, No. 3, 314-322.

Spirito, A., Stark, L. J. & Williams, C. (1988). Development of a brief coping checklist for use with pediatric populations. *Journal of Pediatric Psychology*, 13, No. 4, 555-574.

Stein, R.E.K. (1996). Commentary: To be or not to be.......Non-categorical. *Journal of Developmental and Behavioral Pediatrics*, 17, No. 1, 36-37.

Stein, R.E.K., Gortmaker, S.L., Perrin, E.C., Perrin, J.M., Pless, I.B., Walker, D.K. & Weitzman, M. (1987). Severity of illness: Concepts and measurements. *The Lancet,* December, 1506-1509.

Stein, R.E.K. & Jones Jessop, D. (1984). Relationship between health status and psychological adjustment among children with chronic conditions. *Pediatrics,* 73, No. 2, 169-174.

Stein, R.E.K. & Jones Jessop, D. (1989). What diagnosis does not tell: The case for a noncategorical approach to chronic illness in childhood. *Social Science and Medicine,* 29, No. 6, 769-778.

Steinglass, P. (1998). Multiple family discussion groups for patients with chronic medical illness. *Families, Systems and Health,* 16, Nos. ½, 55-70, 1998.

Stevenson-Hinde, J. & Akister, J. (1995). The McMaster Model of family functioning: Observer and parental ratings in a nonclinical sample. *Family Process*, 34, 337-347.

Stocker, C. & Dunn, J. (1990). Sibling relationships in childhood: Links with friendships and peer relationships. *British Journal of Developmental Psychology,* 8, 227-244.

Strachan, D.P., Anderson, H.R., Limb, E.S., O'Neill, A. & Wells N. (1994). A national survey of asthma prevalence, severity and treatment in Great Britain. *Archives of Disease in Childhood*, 70, 174-178.

Sullivan, H.S. (1953). *The interpersonal theory of psychiatry.* H. S. Perry & M. L. Gawell, (Eds). London: Tavistock Publications Ltd.

Thompson, R.J., Armstrong, F.D., Kronenberger, W.G., Scott, D., McCabe, M.A., Smith, B., Radcliffe, J., Colangelo, L., Gallagher, D., Islam, S., and Wright, E. (1999). Family functioning, neurocognitive functioning, and behavior problems in children with sickle cell disease. *Journal of Pediatric Psychology,* 24, No. 6, 491-498.

Thompson, R.J., Gil, K.M., Burback, D.J., Keith, B.R. & Kinney, T.R. (1993). Role of child and maternal processes in the psychological adjustment of children with sickle cell disease. *Journal of Consulting and Clinical Psychology,* 61, No. 3, 468-474.

Thompson, R.J., Gil, K.M., Keith, B.R., Gustafson, K.E., George, L.K. & Kinney, T.R. (1994). Psychological adjustment of children with sickle cell disease: Stability and change over a 10-month period. *Journal of Consulting and Clinical Psychology*, 62, No. 4, 856-860.

Thompson, R.J. & Gustafson, K.E. (1996). *Adaptation to chronic childhood illness.* Washington: American Psychological Association.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W. & Spock, A. (1992a). Psychological adjustment of children with cystic fibrosis: The role of child cognitive processes and maternal adjustment. *Journal of Pediatric Psychology,* 17, No. 6, 741-755.

Thompson, R.J., Gustafson, K.E., Hamlett, K.W. & Spock, A. (1992b). Stress, coping and family functioning in the psychological adjustment of mothers of children with cystic fibrosis. *Journal of Pediatric Psychology*, 17, 573-585.

Thompson, R.J., Gustafson, K.E., Gil, K.M., Godfrey, J. & Bennett-Murphy, L.M. (1998). Illness specific patterns of psychological adjustment and cognitive adaptational processes in children with cystic fibrosis and sickle cell disease. *Journal of Clinical Psychology*, 54, No. 1, 121-128.

Thompson, R.J., Zeman, J.L., Fanurick, D. & Sirotkin-Roses, M. (1992). The role of parent stress and coping and family functioning in parent and child adjustment to Duchenne Muscular Dystrophy. *Journal of Clinical Psychology,* 48, No. 1, 11-19.

Tutty, L.M. (1995). Theoretical and practical issues in selecting a measure of family functioning. *Research on Social Work Practice,* 5, No. 1, 80-106.

Vannatta, K., Zeller, M., Noll, R.B. & Koontz, K. (1998a). Social functioning of children surviving bone marrow transplantation. *Journal of Pediatric Psychology*, 23, No. 3, 169-178.

Vannatta, K., Gartstein, M.A., Short, A. & Noll, R.B. (1998b). A controlled study of peer relationships of children surviving brain tumours: Teacher, peer and self ratings. *Journal of Pediatric Psychology*, 23, No. 5, 279-287.

Varni, J.W., Katz, E.R., Colegrove Jr., R. & Dolgin, M. (1996). Family functioning predictors of adjustment in children with newly diagnosed cancer: A prospective analysis. *Journal of Child Psychology and Psychiatry,* 37, No. 3, 321-328.

Varni, J.W., Rubenfeld, L.A., Talbot, D. & Setoguchi, Y. (1989a). Family functioning, temperament and psychologic adaptation in children with congenital or acquired limb deficiencies. *Pediatrics,* 84, No. 2, 323-330.

Varni, J.W., Rubenfeld, L.A., Talbot, D. & Setoguchi, Y. (1989b). Determinants of self-esteem in children with congenital/acquired limb deficiencies. *Journal of Developmental and Behavioral Pediatrics*, 10, No. 1, 13-16.

Varni, J.W. & Setoguchi, Y. (1991). Correlates of perceived physical appearance in children with congenital/acquired limb deficiencies. *Journal of Developmental and Behavioral Pediatrics,* 12, No. 3, 171-176.

Venters, M. (1981). Family coping with chronic illness: The case of cystic fibrosis. *Social Science and Medicine*, 15A, 289-297.

von Bertalanffy L. (1968). General system theory and psychiatry. From S. Areiti (Ed.), *American Handbook of Psychiatry* Vol 3. New York: Basic Books Inc. In *General system theory. Foundations developments, application.* New York: George Braziller.

Walker, L. & Greene, J.W. (1991). The functional disability inventory: Measuring a neglected dimension of health status. *Journal of Pediatric Psychology,* 16, 39-58.

Walker, H.M. & McConnell, S.R. (1995a). *Walker-McConnell scale of social competence and school adjustment. Elementary Version. User's manual.* San Diego, London: Singular Publishing.

Walker, H.M. & McConnell, S.R. (1995b). *Walker-McConnell scale of social competence and school adjustment. Adolescent Version. User's manual.* San Diego, London: Singular Publishing.

Walker, L.S., Ortiz-Valdes, J.A. & Newbrough, J.R. (1992). The role of maternal employment and depression in the psychological adjustment of chronically ill, mentally retarded and well children. In M.C. Roberts & J.L. Wallander (Eds.), *Family issues in pediatric psychology* (181-194). Lawrence Erlbaum Associates Inc.

Wallander, J.L., Feldman, W. & Varni, J.W. (1989a). Physical status and psychosocial adjustment in children with spina bifida. *Journal of Pediatric Psychology*, 14, No. 1, 89-102.

Wallander, J.L., Hubert, N.C. & Varni, J.W. (1988b). Child and maternal temperament characteristics, goodness of fit and adjustment in physically handicapped children. *Journal of Clinical Psychology,* 17, No. 4, 336-344.

Wallander, J.L. & Noojin, A.B. (1995). Mothers' report of stressful experiences related to having a child with a disability. *Children's Health Care,* 24, No. 4, 245-256.

Wallander, J.L. & Thompson, R.J.Jr. (1995). Psychosocial adjustment of children with chronic physical conditions. In M. Roberts (Ed.), *Handbook of Pediatric Psychology.* (2nd ed.,124-141). New York: Guilford Press.

Wallander, J.L. & Varni, J.W. (1992). Adjustment in children with chronic physical disorders: Programmatic research on a Disability-stress-coping model. In A.M. La Greca, L. J. Siegal, J.L Wallander & C.E. Walker (Eds.), *Stress and coping in child health.* New York, London: The Guilford Press.

Wallander, J.L. & Varni, J.W. (1995). Appraisal, coping and adjustment in adolescents with a physical disability. In J.L. Wallander & L.J. Seigal (Eds.), *Adolescent health problems. Behavioral perspectives.* New York, London: The Guilford Press.

Wallander, J.L. & Varni, J.W. (1998). Effects of pediatric chronic physical disorders in child and family adjustment. *Journal of Child Psychology and Psychiatry,* 39, No. 1, 29-46.

Wallander, J.L., Varni, J.W., Babini, L.,Banis, H.T. & Wilcox, K.T. (1988a). Children with chronic physical disorders: Maternal reports of their psychological adjustment. *Journal of Pediatric Psychology,* 13, No. 2, 197-212.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T. & Wilcox, K.T. (1989b). Family resources as resistance factors for psychological maladjustment in chronically ill and handicapped children. *Journal of Pediatric Psychology*, 14, No. 2, 157-173.

Wallander, J.L., Varni, J.W., Babani, L., Banis, H.T., DeHaan, C. & Wilcox, K.T. (1989c). Disability parameters, chronic strain and adaptation of physically handicapped children and their mothers. *Journal of Pediatric Psychology*, 14, No. 1, 23-42.

Watson, M. Law, M. & MacQuire, G.P. (1992). Further development of a quality of life measure for cancer patients: The Rotterdam symptom checklist (revised). *Psycho-Oncology*, 1, 35-44.

Weil, C.M., Wade, S.L., Bauman, L.J., Lynn, H., Mitchell, H. & Lavigne, J.V. (1999). The relationship between psychosocial factors and asthma morbidity in inner-city children with asthma. *Pediatrics,* 104, No. 6, 1274-1250.

Weiland, S.K., Pless, I.B. & Roghman, K.J. (1992). Chronic illness and mental health problems in pediatric practice: Results from a survey of primary care providers. *Pediatrics*, 89, No. 3, 445-449.

Weissberg-Benchell, J. & Glasgow, A. (1997). The role of temperament in children with insulin-dependent diabetes mellitus. *Journal of Pediatric Psychology,* 22, No. 6, 795-809.

Westbrook, L.E., Bauman, L.J. & Shinnas, S. (1992). Applying stigma theory to epilepsy: A test of a conceptual model. *Journal of Pediatric Psychology,* 17, No. 5, 633-658.

Wierzbicki, M. (1989). Children's perceptions of counter-depressive activities. *Psychological Reports,* 65, 1251-1258.

Wierzbicki, M. & Carver, D. (1989). Children’s engagement in antidepressive activities. *Journal of Genetic Psychology*, 150, No. 2, 163-174.

Wolkind, S. & Rutter, M. (1985). Separation, loss and family relationships. In M. Rutter, & L. Hersov (Eds.), *Child and adolescent psychiatry: Modern approaches*, 34-57. Oxford, London, Edinburgh: Blackwell Scientific Publications.

Wolman, C., Resnick, M.D., Harris, L.J. & Blum, R.W. (1994). Emotional well-being among adolescents with and without chronic conditions. *Journal of Adolescent Health,* 15, 199-204.

Wood, B.L., Watkins, J.B., Boyle, J.T., Nogueira, J., Zimand, E. & Carroll, L. (1989). The "Psychosomatic Family" model: An empirical and theoretical analysis. *Family Process,* 28, 399-417.

Worchel, F.F., Copeland, D.R. & Barker, D.G. (1987). Control-related coping strategies in pediatric oncology patients. *Journal of Pediatric Psychology,* 12, No. 1, 25-38.

Worchel, F.F., Nolan, B.F., Willson, V.L., Purseer, J.S., Copeland, D.R. & Pfefferbaum, B. (1988). Assessment of depression in children with cancer. *Journal of Pediatric Psychology,* 13, 101-112.

Wright, F.S. (1984). Epilepsy in childhood. *Pediatric Clinics of America,* 31, No. 1, 177-188.

Youseff, N.M.A. (1988). School adjustment of children with congenital heart disease *(Monograph) Maternal-Child Nursing Journal,* 17, 217-301.

APPENDIX

Study measures are incorporated in the appendix and arranged in the following order:

1. Parent assessment of medical and demographic information
2. Coping health inventory for parents
3. Family assessment device
4. Perceived experience of condition scale
5. Strengths and difficulties questionnaire

    (1) Child report
    (2) Parent report

6. Child health related quality of life (child and parent report)

    (1) Child report
    (2) Parent report

7. Kidcope

    (1) Child report - Common problem
    (2) Child report - Illness problem
    (3) Adolescent report - Common problem
    (4) Adolescent report - Illness problem

8. Walker-McConnell scale of social competence and school adjustment

    (1) Elementary version
    (2) Adolescent version

9. Friendship interview schedule (including example of visual analogue scale)
10. Clinician assessment of family care demands
11. Parent assessment of family care demands

MEDICAL AND GENERAL INFORMATION

Code Number	Date		

Medical information

1. First name of your child... 1.1 Diagnosis...

1.2 Did the condition appear suddenly or develop slowly?

Suddenly ☐

Developed slowly ☐

Details (including date of diagnosis)...

....

....

1.3. How long was the interval between symptoms appearing and diagnosis?

Number of days, weeks, months ☐

1.4. How long was the interval between symptoms appearing and treatment starting?

Number of days, weeks, months ☐

1.5. How long was the interval between diagnosis and treatment starting?

Number of days, weeks, months ☐

1.6. Do you view the condition as either, constant (there all the time), progressive (getting worse as time goes by), recurring (it comes and goes regularly). episodic (it appears intermittently)?
You may select more than one descriptor

Constant (there all the time) ☐

Progressive (getting worse as time goes by) ☐

Recurring (it comes and goes regularly) ☐

Episodic (it appears intermittently) ☐

1.7. Given your past experience of living with the condition, is there a pattern in the course of the condition from month to month?

Yes ☐ No ☐

Yes-can you tell me more about this pattern
No-did you have any expectations about the course of the condition?

....

....

....

1.8. In your view, is your child's condition obvious to others ?

Yes ☐ No ☐

In what circumstances is it visible?

....

....

....

1.9 How often has your child been in hospital in the last 12 months, as a result of her/his condition?

Number of times ☐

1.10. How long did your child stay in hospital each time s/he was admitted?

Date	Number of days

1.11. What treatment did your child need each time s/he was in hospital? For example, oral drugs, inhaled drugs, intravenous infusion, changes in diet, change in mediation, physiotherapy, ventilation , surgery

Date	Treatment

1.12. How many days has your child missed school due to the condition, over the past 12 months?

Number of days

☐

1.13. How many times, in the last 12 months has your child been to the following, because of their condition?

Number of times

Casualty (A&E) ☐

Day ward patient ☐

General Practitioner ☐

1.14. How many tablets (syrups) does your child take daily because of their condition?

Number of tablets (syrups)

☐

1.15. How many nebulisers does your child take daily because of their condition?

Number of nebulisers

☐

1.16. How many inhalers does your child take daily because of their condition?

Number of inhalers

☐

1.17. How many injections does your child take daily because of their condition?

Number of injections
☐

1.18 Does your child require any other medication?

Yes	No
☐	☐

What are they?...

1.19. Do you feel you understand your child's condition ?

Yes	No
☐	☐

1.20. Do you feel you understand your child's treatment approach?

Yes	No
☐	☐

Details on understanding of condition and treatment ....

....

....

....

....

....

....

1.21 Given what you know about...........'s condition and your past experience in caring for................., how do you feel about the future course of the condition? On a scale of 1 to 7 with 1 being certain and 7 being no idea where would you place your selves on this scale?

Certain						No idea
1	2	3	4	5	6	7

1.22 Similarly how do you feel about the future impact of the condition on your daily lives? On a scale of 1 to 7 with 1 being certain and 7 being no idea where would you place yourselves on this scale?

Certain						No idea
1	2	3	4	5	6	7

Comments ....

....

....

....

....

....

....

....

Further comments
a. At the present time do you feel the condition has much of an impact on your daily lives?

....

....

b. What was it like in the past?

....

....

....

c. Was there any event, linked to the condition, which was particularly important and had a strong impact on you?

....

....

....

d. Do you find sources of support, such as hospital staff, school, colleagues at work, friends, neighbours, church, self-help groups, family helpful

....

....

....

....

General Information

YOUR CHILDREN

2. How many children do you have?

☐

2.1. When were they born and what sex are they?

Date of birth	Sex

2.2. Where does...go to school?

School name and address

☐

2.3. Is ....performing educationally above or below what you would expect for his/her age?

	Academic (e.g. English, maths)	Non-academic (e.g. P.E., drama, music)
Above age expectations	☐	☐
What you expect	☐	☐
Below age expectations	☐	☐

2.4. Does...participate in remedial classes?

Yes	No
☐	☐

IF YES, WHICH SUBJECTS AND HOW FREQUENTLY?

Subject	Number of classes per week

YOU

3. What is your occupation? (Full or part-time-FT/PT)

Male partner

Female partner

3.1. What is your total occupational income (gross)?

Joint annual occupational income			
Up to £5000 (£96 per week)		£20,000-£24,999	
£5000-£9999 (£96-£192 per week)		£25,000-£29,999	
£10,000-£14,999		£30,000-34,999	
£15,000-£19,999		Above £35,000	

3.2. Which of these describes you? (Both partners)

English/Scottish/Welsh ☐

Irish ☐

Other European ☐

West Indian/Caribbean ☐

African ☐

Hindi	☐
Urdu	☐
Punjabi	☐
Gujurati	☐
Bengali	☐
Vietnamese	☐
Chinese	☐
Other Asian	☐

3.3 What educational qualifications do you have?

Male partner

Academic		Vocational	
None	☐	GNVQ	☐
CSE	☐	BTec	☐
O-levels/GCSE	☐	HND	☐
A-levels (including AS levels)	☐	Other (details)	☐
Degree	☐		
Post-doctoral	☐		
Other (please give details)	☐		

....

....

Female partner

Academic		Vocational	
None	☐	GNVQ	☐
CSE	☐	BTec	☐
O-levels/GCSE	☐	HND	☐

A-levels (including AS levels)	☐	Other (details)	☐
Degree	☐		
Post-doctoral	☐		
Other (please give details)	☐		

....

....

3.4. Do you own your own home?

Yes ☐ No ☐

3.5. Do you receive any financial assistance from the state?

Yes(details) ☐ No ☐

Benefits received..

....

....

3.6. Do you or your family receive support from other agencies?

Yes(details) ☐ No ☐

Services received..

....

....

THANK-YOU FOR YOUR HELP

COPING-HEALTH INVENTORY FOR PARENTS

Code Number	Date		

PURPOSE

The Coping-Health Inventory for Parents was developed to record what parents find helpful to them in the management of family life when one or more of its members is ill for a brief period *or* has a medical condition which call for continued medical care. Coping is defined as personal or collective (with other individuals, programs) efforts to manage the hardships associated with health problems in the family.

DIRECTIONS

- To complete this inventory you are asked to read the list of "Coping behaviours" below, one at a time.
- For each coping behaviour you used, please record how helpful it was.

  How helpful was this coping behaviour to you and/or your family: Circle **one** number

  3 = *Extremely* helpful
  2 = *Moderately* helpful
  1 = *Minimally* helpful
  0 = *Not* helpful

- For each Coping Behaviour you did not use please record your "Reason".

  Please RECORD this by *Checking* ☑ **one** of the reasons:

  Chose not to use it ☐ or Not possible ☐

PLEASE BEGIN : Please read and record your decision for each and every Coping Behaviour listed below.

	Extremely helpful	Moderately helpful	Minimally helpful	Not helpful	Do cope way	not this because
COPING BEHAVIOURS	3	2	1	0	Chose not to	Not possible
1. Talking over personal feelings and concerns with spouse.	3	2	1	0	☐	☐
2. Engaging in relationships and friendships which help me to feel important and appreciated.	3	2	1	0	☐	☐
3. Trusting my spouse (or former spouse) to help support me and my child(ren)	3	2	1	0	☐	☐
4. Sleeping	3	2	1	0	☐	☐
5. Talking with medical staff (nurses, social worker etc.) when we visit the medical centre.	3	2	1	0	☐	☐
6. Believing that my child(ren) will get better.	3	2	1	0	☐	☐
7. Working, outside employment.	3	2	1	0	☐	☐
8. Showing that I am strong.	3	2	1	0	☐	☐
9. Purchasing gifts for myself and/or other family members	3	2	1	0	☐	☐
10. Talking with other individuals/parents in my same situation.	3	2	1	0	☐	☐
11. Taking good care of all the medical equipment at home.	3	2	1	0	☐	☐
12. Eating.	3	2	1	0	☐	☐
13. Getting other members of the family to help with chores and tasks at home.	3	2	1	0	☐	☐
14. Getting away by myself.	3	2	1	0	☐	☐
15. Talking with the Doctor about my concerns about my child(ren) with the medical condition.	3	2	1	0	☐	☐
16. Believing that the medical centre/hospital has my family's best interest in mind.	3	2	1	0	☐	☐
17. Building close relationships with people.	3	2	1	0	☐	☐
18. Believing in God.	3	2	1	0	☐	☐
19. Develop myself as a person.	3	2	1	0	☐	☐
20. Talking with other parents in the same type of situation and learning about their experiences.	3	2	1	0	☐	☐
21. Doing things together as a family (involving all members of the family)	3	2	1	0	☐	☐
22. Investing time and energy in my job.	3	2	1	0	☐	☐
23. Believing that my child is getting the best medical care possible.	3	2	1	0	☐	☐

	Extremely helpful	Moderately helpful	Minimally helpful	Not helpful	Do not cope this way because	
COPING BEHAVIOURS	3	2	1	0	Chose not to	Not possible
24. Entertaining friends in our home.	3	2	1	0	☐	☐
25. Reading about how other persons in my situation handle things.	3	2	1	0	☐	☐
26. Doing things with family relatives.	3	2	1	0	☐	☐
27. Becoming more self reliant and independent.	3	2	1	0	☐	☐
28. Telling myself that I have many things I should be thankful for.	3	2	1	0	☐	☐
29. Concentrating on hobbies (art, music, jogging etc.)	3	2	1	0	☐	☐
30. Explaining our family situation to friends and neighbours so they will understand us.	3	2	1	0	☐	☐
31. Encouraging the child(ren) with medical condition to be more independent.	3	2	1	0	☐	☐
32. Keeping myself in shape and well groomed.	3	2	1	0	☐	☐
33. Involvement in social activities (parties etc.) with friends.	3	2	1	0	☐	☐
34. Going out with my spouse on a regular basis.	3	2	1	0	☐	☐
35. Being sure prescribed medical treatments for child(ren) are carried out at home on a daily basis.	3	2	1	0	☐	☐
36. Building a closer relationship with my spouse.	3	2	1	0	☐	☐
37. Allowing myself to get angry.	3	2	1	0	☐	☐
38. Investing myself in my child(ren).	3	2	1	0	☐	☐
39. Talking to someone (not professional counsellor/doctor) about how I feel.	3	2	1	0	☐	☐
40. Reading more about the medical problem which concerns me.	3	2	1	0	☐	☐
41. Trying to maintain family stability.	3	2	1	0	☐	☐
42. Being able to get away from the home care tasks and responsibilities for some relief.	3	2	1	0	☐	☐
43. Having my child seen at the medical centre/hospital on a regular basis.	3	2	1	0	☐	☐
44. Believing things will always work out.	3	2	1	0	☐	☐
45. Doing things with my children.	3	2	1	0	☐	☐

FAMILY ASSESSMENT DEVICE

Code Number	Date		

Following are a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family.

For each statement there are four possible responses:

1 = Strongly agree	Select 1 if you feel that the statement describes your family very accurately.
2 = Agree	Select 2 if you feel that the statement describes your family for the most part.
3 = Disagree	Select 3 if you feel that the statement does not describe your family for the most part.
4 = Strongly disagree	Select 4 if you feel that the statement does not describe your family at all.

Try not to spend too much time thinking about each statement, but respond as quickly and honestly as you can. If you have trouble with one, answer with your first reaction. Please be sure to answer *every* statement and mark all your answers in the *space provided to the left* of each statement.

_______ 1. Planning family activities is difficult because we misunderstand each other.

_______ 2. We resolve most every day problems around the house.

_______ 3. When someone is upset the others know why.

_______ 4. When you ask someone to do something, you have to check that they did it.

_______ 5. If someone is in trouble, the others become too involved.

_______ 6. In times of crisis we can turn to each other for support.

_______ 7. We don't know what to do when an emergency comes up.

_______ 8. We sometimes run out of things we need.

_______ 9. We are reluctant to show our affection for each other.

_______ 10. We make sure members meet their family responsibilities.

_______ 11. We cannot talk to each other about the sadness we feel.

_______ 12. We usually act on our decisions regarding problems.

_______ 13. You only get the interest of others-when something is important to them.

_______ 14. You can't tell how a person is feeling from what they are saying.

_______ 15. Family tasks don't get spread around enough.

_______ 16. Individuals are accepted for what they are.

_______ 17. You can easily get away with breaking the rules.

_______ 18. People come right out and say things instead of hinting at them.

_______ 19. Some of us just don't respond emotionally.

_______ 20. We know what to do in an emergency

_______ 21. We avoid discussing our fears and our concerns.

_______ 22. It is difficult to talk to each other about tender feelings.

_______ 23. We have trouble meeting our bills.

_______ 24. After our family tries to solve a problem, we usually discuss whether it worked or not.

_______ 25. We are too self-centred.

_______ 26. We can express feelings to each other.

_______ 27. We have no clear expectations about toilet habits.

_______ 28. We do not show our love for each other.

_______ 29. We talk to people directly rather than go-betweens.

_______ 30. Each of us has particular duties and responsibilities.

_______ 31. There are lots of bad feelings in the family.

_______ 32. We have rules about hitting people.

_______ 33. We get involved with each other only when something interests.

_______ 34. There's little time to explore personal interests.

_______ 35. We often don't say what we mean.

_______ 36. We feel accepted for what we are.

_______ 37. We show interest in each other when we can get something out of it personally.

_______ 38. We resolve most emotional upsets that come up.

_______ 39. Tenderness takes second place to other things in our family.

_______ 40. We discuss who is to do the household jobs.

_______ 41. Making decisions is a problem for our family.

_______ 42. Our family shows interest in each other only when they can get something out of it.

_______ 43. We are frank with each other.

_______ 44. We don't hold any rules or standards.

_______ 45. If people are asked to do something, they need reminding.

_______ 46.We are able to make decisions about how to solve problems.

_______ 47. If the rules are broken we don't know what to expect.

_______ 48. Anything goes in our family.

_______ 49. We express tenderness.

_______ 50. We confront problems involving feelings.

_______ 51. We don't get along well together.

_______ 52.We don't talk to each other when we are angry.

_______ 53. We are generally dissatisfied with the family duties assigned to us.

_______ 54. Even though we mean well, we intrude too much into each others' lives.

_______ 55.There are rules about dangerous situations .

_______ 56. We confide in each other.

_______ 57. We cry openly.

_______ 58. We don't have reasonable transport.

_______ 59.When we don't like what someone has done, we tell them.

_______ 60. We try to think of different ways to solve problems.

THANK-YOU FOR YOUR HELP

RCEIVED EXPERIENCE OF CONDITION SCALE

Code Number	Date		

About yourself **NOW**

re are some things other people have said about their experience of having a chronic condition. Please read them carefully. ould like you to tick the box to show what **you** think.

u mav feel that some did apply to you when you were younger, but not now.

nly want to know about **NOW**:-

	Disagree				Agree
My condition stops me from doing games or sports I like	☐	☐	☐	☐	☐
I feel my condition has made me look different	☐	☐	☐	☐	☐
I get teased or picked on more than other people	☐	☐	☐	☐	☐
. I find it difficult to control my weight	☐	☐	☐	☐	☐
. I easily let my feelings get the better of me	☐	☐	☐	☐	☐
. I wonder why I became ill	☐	☐	☐	☐	☐
7. I use my condition to get out of things I don't want to do	☐	☐	☐	☐	☐
8. I am not always able to join in with what my friends are doing	☐	☐	☐	☐	☐
9. I find it hard to learn things because of my condition	☐	☐	☐	☐	☐
10. I get cross about how much my condition spoils my life	☐	☐	☐	☐	☐
11. I worry about other people who have the same condition I have	☐	☐	☐	☐	☐
12. I am afraid other people won't like me because of my condition	☐	☐	☐	☐	☐
13. I only tell people about my condition if I really have to	☐	☐	☐	☐	☐
14. There are some days I can't be bothered to eat	☐	☐	☐	☐	☐
15. If my condition upsets me I try not to show it	☐	☐	☐	☐	☐

	Disagree				Agree
I feel sad about the way I look	☐	☐	☐	☐	☐
I am worried about aches and pains	☐	☐	☐	☐	☐
I feel left out of things at school or work	☐	☐	☐	☐	☐
The way I look has changed because of my condition and treatment	☐	☐	☐	☐	☐
Other people expect too much of my work	☐	☐	☐	☐	☐
I hate being reminded of my condition	☐	☐	☐	☐	☐
I feel other people try to put me down	☐	☐	☐	☐	☐
3. My parents make a fuss of me because of my condition	☐	☐	☐	☐	☐
4. I get cross when people ask about my condition	☐	☐	☐	☐	☐
5. My parents make a fuss about what I eat	☐	☐	☐	☐	☐
6. My condition makes many problems for my family	☐	☐	☐	☐	☐
27. I am usually too tired to go out in the evening	☐	☐	☐	☐	☐
28. I worry that people talk about me behind my back	☐	☐	☐	☐	☐
29. My parents treat me like a baby	☐	☐	☐	☐	☐
30. I can get away with a lot more in school or at work because of my condition	☐	☐	☐	☐	☐
31. I wish I knew other people with my condition	☐	☐	☐	☐	☐
32. I am afraid of doing sports where I might get hurt	☐	☐	☐	☐	☐
33. My parents use my condition to stop me doing things	☐	☐	☐	☐	☐
34. Some days I find the smell of food puts me off	☐	☐	☐	☐	☐
35. I feel I get blamed for things that aren't my fault	☐	☐	☐	☐	☐

THANK-YOU FOR YOUR HELP

Strengths and Difficulties Questionnaire

$S^{11\text{-}16}$

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

Your Name .... Male/Female

Date of Birth ....

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

Do you have any other comments or concerns?

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

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

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
☐	☐	☐	☐

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

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

- Do the difficulties upset or distress you?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

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

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

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

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Your Signature ....

Today's Date ....

Thank you very much for your help

Strengths and Difficulties Questionnaire

P$^{4-16}$

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

Child's Name .... Male/Female

Date of Birth :...

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

Do you have any other comments or concerns?

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

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

No	Yes - minor difficulties	Yes - definite difficulties	Yes - severe difficulties
☐	☐	☐	☐

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

- How long have these difficulties been present?

Less than a month	1-5 months	6-12 months	Over a year
☐	☐	☐	☐

- Do the difficulties upset or distress your child?

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

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

	Not at all	Only a little	Quite a lot	A great deal
HOME LIFE	☐	☐	☐	☐
FRIENDSHIPS	☐	☐	☐	☐
CLASSROOM LEARNING	☐	☐	☐	☐
LEISURE ACTIVITIES	☐	☐	☐	☐

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

Not at all	Only a little	Quite a lot	A great deal
☐	☐	☐	☐

Signature .... Date ....

Mother/Father/Other (please specify:)

Thank you very much for your help

CHILD HEALTH-RELATED QUALITY OF LIFE (CQOL) – CHILD QUESTIONNAIRE

NFER-NELSON
INFORMING YOUR DECISIONS

We would like to get a picture of your life over the past month, and also how you feel about it. The questions are divided into different areas covering various aspects of your daily life. We ask you to place a tick on the scale to indicate where you believe yourself to be in comparison with any other child of the same age. Please read the example below very carefully; it shows you how to answer the questions, before starting to complete the form.

Example

A. Drawing

Possible problems that children have with drawing include: Not being able to copy simple shapes; difficulty in drawing animals; always making mistakes and having to start again; not being able to draw at all.

If you can draw better than other children of the same age as you, you should tick here.

Better than children of the same age	✓							Cannot draw at all

If you cannot draw at all, you should tick this box along the scale.

Better than children of the same age							✓	Cannot draw at all

If you can draw about as well as children of the same age as you, you should tick here.

Better than children of the same age				✓				Cannot draw at all

If you have some problems with drawing, you may tick about here.

Better than children of the same age						✓		Cannot draw at all

CHILD HEALTH-RELATED QUALITY OF LIFE (CQOL) – CHILD QUESTIONNAIRE

NFER-NELSON
INFORMING YOUR DECISIONS

Please place a tick (✓) along the scale to indicate where you believe yourself to be in comparison with any other child of the same age.

1. Getting about and using your hands

Possible problems include: Clumsy; difficulty running; difficulty walking; unable to control movements; uses a wheelchair; confined to bed.

Over the past month how well have you been able to perform these activities?

Better than children of the same age								Confined to bed

How upset have you been by how you have performed in these activities?

Extremely upset								Not upset at all

How satisfied have you been with the way you are performing in these activities?

Very satisfied								Not satisfied at all

2. Doing things for yourself

Possible problems include: Cannot do up buttons or laces; cannot use a knife to cut food; needs help with feeding; difficulties in washing or dressing; totally unable to look after self.

Over the past month how well have you been able to do these things?

Better than children of the same age								Totally unable to look after self

How upset have you been by not being able to do these things?

Extremely upset								Not upset at all

How satisfied have you been with the way you do these things?

Very satisfied								Not satisfied at all

3. Soiling or wetting

Possible problems include: Bed wetting; wetting self during the day; some soiling; no control over bladder and bowels.

Over the past month how well have you been with this?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ No control

How upset have you been by how you are in these things?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way you are in these things?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

4. School

Possible problems include: Finding school boring, unable to sit still for long; finding school work difficult; needing extra help at school; attending a special class at school; going to a special school fulltime; not able to go to school at all.

Over the past month how well have you been getting on at school?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not able to go to school at all

How upset have you been by the way you get on at school?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way you get on at school?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

5. Out of school activities

Possible problems include: Not very good at sport and other outdoor activities; can only do a few out of school activities, such as listening to music with friends or playing computer games; cannot go swimming; unable to take part in any out of school activities.

Over the past month how well have you been able to do these things?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Unable to take part in any out of school activities

How upset have you been by your performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

6. Friends

Possible problems include: No special friends; a lot of arguing and bickering; few close friends; often teased or bullied; no friends at all.

Over the past month how well have you got on with your friends?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ No friends at all

How upset have you felt by the way you get on with other children?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way you get on with other children?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

7. Family relationships

Possible problems include: Not well-behaved; unpleasant arguments with parents; constant quarrels with parents and brothers or sisters.

Over the past month how have you been getting on with your family?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Constant arguments

How upset have you felt by the way you get on with your family?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way you get on with your family?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

8. Discomfort due to bodily symptoms

Possible problems include: Itchiness; discomfort; tiredness; breathlessness; feeling sick; vomiting; fits or faints; severe pain.

Over the past month how well have you been in these ways?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Severe pain and/or other discomfort

How upset have you been by these sorts of problems?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the number of times you get these sorts of problems?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

9. Worries

Possible problems include: Panicking; easily frightened; worries often; worries all the time.

Over the past month how worried have you been?

Better than children of the same age								Worried all the time

How upset have you been by anxious, worried feelings?

Extremely upset								Not upset at all

How satisfied have you been with your level of anxiety and worried feelings?

Very satisfied								Not satisfied at all

10. Depression

Possible problems include: Feeling sad; feeling unhappy; feeling miserable; feeling life is hopeless; being depressed most of the time.

Over the past month how has your mood been?

Better than children of the same age								Depressed all the time

How upset have you been by your mood?

Extremely upset								Not upset at all

How satisfied have you been with your mood?

Very satisfied								Not satisfied at all

11. Seeing

Possible problems include: Unable to read small print; needs glasses; cannot see well enough to get about; unable to recognize a friend on the other side of the street even with glasses; totally blind.

Over the past month how well have you been able to see?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Totally blind

How upset have you been by your sight?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your sight?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

12. Communication

Possible problems include: Some difficulty understanding what other people are saying; unable to hear very well; not able to make yourself understood; difficulty communicating in other ways; totally unable to let people know what you need.

Over the past month how well have you been able to understand things and make your needs known?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Totally unable to let people know what you need

How upset have you been by not being able to understand things and make your needs known?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your ability to understand things and make your needs known?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

13. Eating

Possible problems include: Faddy; picky; greedy; raids fridge; can't stop eating; starving self; only takes liquids; can't eat by mouth; not eating at all or always stuffing self with food.

Over the past month how well have you been eating?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not eating at all or always eating too much

How upset have you been by how you are in this respect?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with yourself in this respect?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

14. Sleep

Possible problems include: Some difficulty getting to sleep; waking during the night, once, twice or several times; waking up very early in the morning; tired during the day; hardly sleeping at all or constantly tired.

Over the past month how well have you been sleeping?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Hardly sleeping at all or constantly tired

How upset have you been by the way you sleep?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your sleep?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

15. Appearance

Possible problems include: Spots on face; birth marks; skinny; fat; very small for your age; body has an unusual shape; an unusual appearance.

Over the past month how has your appearance been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Very unusual appearance

How upset have you been by the way you look?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way you look?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

Now try to consider all the different areas this questionnaire has covered.

Over the past month how do you think the quality of your life has been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Very poor quality of life

Please add here any comments about yourself that would help us to understand your answers better.

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Thank you for being so helpful.

For office use only

Global ☐

Combined
- Function ☐
- Satisfaction ☐
- Upset ☐

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CHILD HEALTH-RELATED QUALITY OF LIFE (CQOL) – PARENT QUESTIONNAIRE

NFER-NELSON
INFORMING YOUR DECISIONS

We would like to get a picture of your child's life over the past month, and also how you feel about this. The questions are divided into different areas covering various aspects of your child's daily life. We ask you to place a tick on the scale to indicate where you believe your child to be in comparison with any other child of the same age. Please read the example below very carefully; it shows you how to answer the questions, before starting to complete the form.

Example

A. Reading

Possible problems that children have with reading include: Difficulty reading hard words; making many spelling mistakes; unable to understand what he or she is reading; a reading age of a child several years younger; unable to read at all.

If your child can read better than other children of the same age, you should tick here.

Better than children of the same age ☑ ☐ ☐ ☐ ☐ ☐ ☐ Cannot read at all

If your child cannot read at all, you should tick this box along the scale.

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☑ Cannot read at all

If your child has some reading difficulties, you may tick here.

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☑ ☐ Cannot read at all

Or you may tick somewhere around here.

Better than children of the same age ☐ ☐ ☑ ☐ ☐ ☐ ☐ Cannot read at all

CHILD HEALTH-RELATED QUALITY OF LIFE (CQOL) – PARENT QUESTIONNAIRE

NFER-NELSON
INFORMING YOUR DECISIONS

Please place a tick (✓) along the scale to indicate where you believe your child to be in comparison with any other child of the same age.

1. Getting about and using hands

Possible problems include: Clumsy; difficulty running; difficulty walking; unable to control movements; uses a wheelchair; confined to bed.

Over the past month how well has your child performed in this area?

Better than children of the same age								Confined to bed

How upset have you been by your child's performance in this area?

Extremely upset								Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied								Not satisfied at all

2. Doing things for his- or herself

Possible problems include: Cannot do up buttons or laces; cannot use a knife to cut food; needs help with feeding; difficulties in washing or dressing; totally unable to look after self.

Over the past month how well has your child performed in this area?

Better than children of the same age								Totally unable to look after self

How upset have you been by your child's performance in this area?

Extremely upset								Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied								Not satisfied at all

3. Soiling or wetting

Possible problems include: Bed wetting; wetting self during the day; some soiling; no control over bladder and bowels.

Over the past month how well has your child been in this area?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ No control

How upset have you been by your child's performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

4. School

Possible problems include: Finding school boring, unable to sit still for long; finding school work difficult; needing extra help at school; attending a special class at school; going to a special school fulltime; not able to go to school at all.

Over the past month how well has your child been getting on at school?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not able to go to school at all

How upset have you been by your child's performance at school?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's performance at school?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

5. Out of school activities

Possible problems include: Not very good at sport and other outdoor activities; can only do a few out of school activities, such as listening to music with friends or playing computer games; cannot go swimming; unable to take part in any out of school activities.

Over the past month how well has your child performed the above?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Unable to take part in any out of school activities

How upset have you been with your child's performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been by your child's performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

6. Friends

Possible problems include: No special friends; a lot of arguing and bickering; few close friends; often teased or bullied; no friends at all.

Over the past month how well has your child been able to get on with friends?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ No friends at all

How upset have you felt by the way your child gets on with other children?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way your child gets on with other children?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

7. Family relationships

Possible problems include: Not feeling very affectionate towards the family; not well-behaved; unpleasant arguments with parents; constant quarrels with parents and brothers or sisters.

Over the past month how well has your child been getting on with your family?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Constant arguments

How upset have you felt by your child's performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

8. Discomfort due to bodily symptoms

Possible problems include: Itchiness; discomfort; tiredness; breathlessness; feeling sick; vomiting; fits or faints; severe pain.

Over the past month how well has your child been with regard to the above?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Severe pain and/or other discomfort

How upset have you been by your child's pain or other physical symptoms?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's ability to cope with this?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

9. Worries

Possible problems include: Panicking; easily frightened; worries often; worries all the time.

Over the past month how anxious and worried has your child been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Worried all the time

How upset have you been by your child's anxious, worried feelings?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's level of anxiety and worried feelings?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

10. Depression

Possible problems include: Feeling sad; feeling unhappy; feeling miserable; feeling life is hopeless; being depressed most of the time.

Over the past month how has your child's mood been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Depressed all the time

How upset have you been by your child's mood?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's mood?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

11. Seeing

Possible problems include: Unable to read small print; needs glasses; cannot see well enough to get about; unable to recognize a friend on the other side of the street even with glasses; totally blind.

Over the past month how well has your child's sight been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Totally blind

How upset have you been by your child's sight?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's sight?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

12. Communication

Possible problems include: Some difficulty understanding what other people are saying; unable to hear very well; not able to make yourself understood; difficulty communicating in other ways; totally unable to let people know what you need.

Over the past month how well has your child performed in this area?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Totally unable to communicate his or her needs

How upset have you been by your child's performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

13. Eating

Possible problems include: Faddy; picky; greedy; raids fridge; can't stop eating; starving self; only takes liquids; can't eat by mouth; not eating at all or always stuffing self with food.

Over the past month how well has your child been eating?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not eating at all or always eating too much

How upset have you been by your child's performance in this area?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's performance in this area?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

14. Sleep

Possible problems include: Some difficulty getting to sleep; waking during the night, once, twice or several times; waking up very early in the morning; tired during the day; hardly sleeping at all or constantly tired.

Over the past month how well has your child been sleeping?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Hardly sleeping at all or constantly tired

How upset have you been by the way your child sleeps?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with your child's sleep?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

15. Appearance

Possible problems include: Spots on face; birth marks; skinny; fat; very small for his or her age; body has an unusual shape; has an unusual appearance.

Over the past month how has your child's appearance been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Very unusual appearance

How upset have you been by the way your child looks?

Extremely upset ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not upset at all

How satisfied have you been with the way your child looks?

Very satisfied ☐ ☐ ☐ ☐ ☐ ☐ ☐ Not satisfied at all

Now try to consider all the different areas this questionnaire has covered.

Over the past month how do you think the quality of your child's life has been?

Better than children of the same age ☐ ☐ ☐ ☐ ☐ ☐ ☐ Very poor quality of life

Please add here any comments about your child that would help us to understand your answers better.

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Thank you for being so helpful.

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Global ☐

Combined
- Function ☐
- Satisfaction ☐
- Upset ☐

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CP/7-12yrs

Code Number

First name:____________________ Date:__________

Age:______________ Date of birth:_________ Sex:__________

Instructions: I am trying to find out how children deal with different problems not related to their condition. For example, let's imagine that it's a hot summer day in the holidays and you and your friend(s) decide to go out to your favourite place to cycle, roller blade or something like that. You tell your mother where you are going and who you are going with and say that you'll be back at 5 o'clock in the evening. However, after a while your friend(s) think that it would be a better idea to go on somewhere else, so you go with them. You enjoy yourself so much that you forget the time. Your parent(s) are very cross when you arrive home two hours late.

1. Would this situation make you feel nervous?

   Not at all   A little   Somewhat   Pretty much   Very much

2. Would this situation make you feel sad or unhappy?

   Not at all   A little   Somewhat   Pretty much   Very much

3. Would this situation make you feel cross or angry ?

   Not at all   A little   Somewhat   Pretty much   Very much

Did something like this ever happen to you?   Yes   No

Now, please turn over this sheet and circle whether you would use any of the following ways to help deal with this problem.

P-7/12

	Would you do this?		How much would it help?		
1. Just try to forget it.	Yes	No	Not at all	A little	A lot
2. Do something like watch telly or play a game to forget it.	Yes	No	Not at all	A little	A lot
3. Stay on my own.	Yes	No	Not at all	A little	A lot
4. Keep quiet about the problem.	Yes	No	Not at all	A little	A lot
5. Try to see the good side of things.	Yes	No	Not at all	A little	A lot
6. Blame myself for causing the problem.	Yes	No	Not at all	A little	A lot
7. Blame someone else for causing the problem.	Yes	No	Not at all	A little	A lot
8. Try to sort out the problem by thinking of answers.	Yes	No	Not at all	A little	A lot
9. Try to sort out the problem by doing something or talking to someone.	Yes	No	Not at all	A little	A lot
10. Shout, scream or get angry.	Yes	No	Not at all	A little	A lot
11. Try to calm myself down.	Yes	No	Not at all	A little	A lot
12. Wish the problem had never happened.	Yes	No	Not at all	A little	A lot
13. Wish I could make things different.	Yes	No	Not at all	A little	A lot
14. Try to feel better by spending time with others like family, grown-ups, or friends.	Yes	No	Not at all	A little	A lot
15. Don't do anything because the problem couldn't be solved.	Yes	No	Not at all	A little	A lot

CI/7-12yrs

Code Number

First name:____________________ Date:_________

Age:______________ Date of birth:_________ Sex:__________

Instructions: I am a trying to find out how children deal with problems related to their condition. Think about something that has to do with your condition that has been difficult for you in the past month. Please describe the situation to me:

1. Did this situation make you feel nervous?

   Not at all A little Somewhat Pretty much Very much

2. Did this situation make you feel sad or unhappy?

   Not at all A little Somewhat Pretty much Very much

3. Did this situation make you feel cross or angry?

   Not at all A little Somewhat Pretty much Very much

Now, please turn over this sheet and circle whether you used any of the following ways to help deal with this problem.

CI-7/12

	Did you do this?		How much did it help?		
1. I just tried to forget it.	Yes	No	Not at all	A little	A lot
2. I did something like watch telly or played a game to forget it.	Yes	No	Not at all	A little	A lot
3. I stayed on my own.	Yes	No	Not at all	A little	A lot
4. I kept quiet about the problem.	Yes	No	Not at all	A little	A lot
5. I tried to see the good side of things.	Yes	No	Not at all	A little	A lot
6. I blamed myself for causing the problem.	Yes	No	Not at all	A little	A lot
7. I blamed someone else for causing the problem.	Yes	No	Not at all	A little	A lot
8. I tried to sort out the problem by thinking of answers.	Yes	No	Not at all	A little	A lot
9. I tried to sort out the problem by doing something or talking to someone.	Yes	No	Not at all	A little	A lot
10. I shouted, screamed or got angry.	Yes	No	Not at all	A little	A lot
11. I tried to calm myself down.	Yes	No	Not at all	A little	A lot
12. I wished the problem had never happened.	Yes	No	Not at all	A little	A lot
13. I wished I could make things different.	Yes	No	Not at all	A little	A lot
14. I tried to feel better by spending time with others like family, grown-ups, or friends.	Yes	No	Not at all	A little	A lot
15. I didn't do anything because the problem couldn't be solved.	Yes	No	Not at all	A little	A lot

CP/13-18yrs

Code Number

First name:______________ Date:_________

Date of birth:_________ Age:______

Sex:__________ School:____

Instructions: I am trying to find out how young people deal with different problems and stresses not related to their illness. For example, let's imagine that it's a hot summer day in the holidays and you and your friend(s) decide to go out to your favourite place to cycle, roller blade or something like that. You tell your mother where you are going and who you are going with and say that you'll be back at 5 o'clock in the evening. However, after a while your friend(s) think that it would be a better idea to go on somewhere else, so you go with them. You enjoy yourself so much that you forget the time. Your parent(s) are very cross when you arrive home two hours late.

1. Would this situation make you feel nervous or anxious?

   Not at all A little Somewhat Pretty much Very much

2. Would this situation make you feel sad or depressed?

   Not at all A little Somewhat Pretty much Very much

3. Would this situaion make you feel cross or angry ?

   Not at all A little Somewhat Pretty much Very much

4. In general, is this situation one that you could change or do something about? Yes No

5. In general, is this situation one that must be accepted or gotten use to? Yes No

6. In general, is this situation one that you would need to know more about before you could act? Yes No

7. In general, is this situation one in which you would have to hold yourself back from doing what you wanted to do? Yes No

Did something like this ever happen to you? Yes No

Now, please turn over this sheet and circle whether you would use any of the following ways to help you deal with this problem.

CP-13/18

INSTRUCTIONS: Please read each item and circle which phrase applies (if any). Then answer both questions to the right of each item, circling the best answer.

	How often would you do this?				How much would it help?				
	Not at all	Some-times	A lot of the time	Almost all the time	Not at all	A little	Some-times	Pretty much	Very much
1. Think about something else; try to forget it; and/or do something like watch telly or play a game to get it off my mind.	0	1	2	3	0	1	2	3	4
2. Stay away from people; keep my feelings to myself; and just handle the situation on my own.	0	1	2	3	0	1	2	3	4
3. Try to see the good side of things and/or concentrate on something good that could come out of the situation.	0	1	2	3	0	1	2	3	4
4. Realise I brought the problem on myself and blame myself for causing it.	0	1	2	3	0	1	2	3	4
5. Realise that someone else caused the problem and blame them for making me go through this.	0	1	2	3	0	1	2	3	4
6. Think of ways to solve the problem; talk to others to get more facts and information about the problem and/or try to actually solve the problem.	0	1	2	3	0	1	2	3	4
7. a. Talk about how I was feeling; shout, scream or hit something.	0	1	2	3	0	1	2	3	4
b. Try to calm myself by talking to myself, praying, taking a walk, or just trying to relax.	0	1	2	3	0	1	2	3	4
8. Keep thinking and wishing this had never happened; and/or that I could change what had happened.	0	1	2	3	0	1	2	3	4
9. Turn to my family, friends, or other adults to help me feel better	0	1	2	3	0	1	2	3	4
10. Just accept the problem because I know I couldn't do anything about it.	0	1	2	3	0	1	2	3	4

CI/13-18yrs

Code Number

First name:______________ Date:_________

Date of birth:_________ Age:______

Sex:__________ School:____

Instructions: I am trying to find out how children deal with problems related to their condition. Think about something that has to do with your condition that has been difficult for you in the past month. Please describe the situation below:

1. Did this situation make you feel nervous or anxious?

   Not at all A little Somewhat Pretty much Very much

2. Did this situation make you feel sad or depressed?

   Not at all A little Somewhat Pretty much Very much

3. Did this situation make you feel cross or angry ?

   Not at all A little Somewhat Pretty much Very much

4.	In general, is this situation one that you could change or do something about?	Yes	No
5.	In general, is this situation one that must be accepted or gotten use to?	Yes	No
6.	In general, is this situation one that you needed to know more about before you could act?	Yes	No
7.	In general, is this situation one in which you had to hold yourself back from doing what you wanted to do?	Yes	No

Now, please turn over this sheet and circle whether you used any of the following ways to help deal with this problem.

CI-13/18

NSTRUCTIONS: Please read each item and circle which phrase applies (if any). Then answer both questions to the right f each item, circling the best answer.

	How often did you do this?				**How much did it help?**				
	Not at all	Some-times	A lot of the time	Almost all the time	Not at all	A little	Some-times	Pretty much	Very much
1. I thought about something else; tried to forget it; and/or went to do something like watch telly or play a game to get it off my mind.	0	1	2	3	0	1	2	3	4
2. I stayed away from people; kept my feelings to myself; and just handled the situation on my own.	0	1	2	3	0	1	2	3	4
3. I tried to see the good side of things and/or concentrated on something good that could come out of the situation.	0	1	2	3	0	1	2	3	4
4. I realised I brought the problem on myself and blame myself for causing it.	0	1	2	3	0	1	2	3	4
5. I realised that someone else caused the problem and blamed them for making me go through this.	0	1	2	3	0	1	2	3	4
6. I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to actually solve the problem.	0	1	2	3	0	1	2	3	4
7. a. I talked about how I was feeling; shouted, screamed or hit something.	0	1	2	3	0	1	2	3	4
b. Tried to calm myself by talking to myself, praying, taking a walk, or just trying to relax.	0	1	2	3	0	1	2	3	4
8. I keep thinking and wishing this had never happened; and/or that I could change what had happened.	0	1	2	3	0	1	2	3	4
9. Turned to my family, friends, or other adults to help me feel better	0	1	2	3	0	1	2	3	4
10. I just accepted the problem because I know I couldn't do anything about it.	0	1	2	3	0	1	2	3	4

CI-13/18

INSTRUCTIONS: Please read each item and circle which phrase applies (if any). Then answer both questions to the right of each item, circling the best answer.

	How often did you do this?				How much did it help?				
	Not at all	Some-times	A lot of the time	Almost all the time	Not at all	A little	Some-times	Pretty much	Very much
1. I thought about something else; tried to forget it; and/or went to do something like watch telly or play a game to get it off my mind.	0	1	2	3	0	1	2	3	4
2. I stayed away from people; kept my feelings to myself; and just handled the situation on my own.	0	1	2	3	0	1	2	3	4
3. I tried to see the good side of things and/or concentrated on something good that could come out of the situation.	0	1	2	3	0	1	2	3	4
4. I realised I brought the problem on myself and blame myself for causing it.	0	1	2	3	0	1	2	3	4
5. I realised that someone else caused the problem and blamed them for making me go through this.	0	1	2	3	0	1	2	3	4
6. I thought of ways to solve the problem; talked to others to get more facts and information about the problem and/or tried to actually solve the problem.	0	1	2	3	0	1	2	3	4
7. a. I talked about how I was feeling; shouted, screamed or hit something.	0	1	2	3	0	1	2	3	4
b. Tried to calm myself by talking to myself, praying, taking a walk, or just trying to relax.	0	1	2	3	0	1	2	3	4
8. I keep thinking and wishing this had never happened; and/or that I could change what had happened.	0	1	2	3	0	1	2	3	4
9. Turned to my family, friends, or other adults to help me feel better	0	1	2	3	0	1	2	3	4
10. I just accepted the problem because I know I couldn't do anything about it.	0	1	2	3	0	1	2	3	4

EMENTARY VERSION REORDER FORMS
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Profile/Rating Form

The Walker-McConnell Scale of Social Competence and School Adjustment

Elementary Version

*For Information/copies, contact Singular Publishing Group, Inc.
4284 41st St. San Diego, CA 92105
Call Toll free 1-800-521-8545

I. Student Demographic Information

Student Name ____________________

Date ____________________

Sex: ☐ Male ☐ Female

School ____________________

Age: ______ Years ______ Months

Teacher ____________________

Grade ______

II. Rating Instructions

Please read each item below carefully and rate the student's behavioral status in relation to it. If you have not observed the student displaying a particular skill or behavioral competency defined by an item, your answer would be a 1 indicating Never. If the student exhibits the skill at a high rate of occurrence your answer would be a 5, indicating Frequently. If the student's frequency is in between these two extremes, your answer would be 2, 3, or 4 indicating your best estimate of the rate of occurrence. RECORD YOUR ANSWER FOR EACH ITEM IN THE BLANK BOX UNDER THE CORRESPONDING SUBSCALE COLUMN.

Please answer each item. YOU NEED NOT MARK OR CHECK THE NUMBERS IN THE RATING FORMAT SECTION.

III. Items and Rating Formats

	Rating Format					Subscale		
Item	Never		Sometimes		Frequently	1	2	3
1. Other children seek child out to involve her/him in activities.	1	2	3	4	5		☐	
2. Changes activities with peers to permit continued interaction.	1	2	3	4	5		☐	
3. Uses free time appropriately.	1	2	3	4	5			☐
4. Shares laughter with peers.	1	2	3	4	5		☐	
5. Shows sympathy for others.	1	2	3	4	5	☐		
6. Makes friends easily with other children.	1	2	3	4	5		☐	
7. Has good work habits (e.g., is organized, makes efficient use of class time, etc.).	1	2	3	4	5			☐
8. Asks questions that request information about someone or something.	1	2	3	4	5		☐	
9. Compromises with peers when situation calls for it.	1	2	3	4	5	☐		
10. Responds to teasing or name calling by ignoring, changing the subject, or some other constructive means.	1	2	3	4	5	☐		
11. Spends recess and free time interacting with peers.	1	2	3	4	5		☐	
12. Accepts constructive criticism from peers without becoming angry.	1	2	3	4	5	☐		
13. Plays or talks with peers for extended periods of time.	1	2	3	4	5		☐	
14. Voluntarily provides assistance to peers who require it.	1	2	3	4	5		☐	
15. Assumes leadership role in peer activities.	1	2	3	4	5		☐	

	Rating Format					Subscale		
Item	Never		Sometimes		Frequently	1	2	3
16. Is sensitive to the needs of others.	1	2	3	4	5	☐		
17. Initiates conversation(s) with peers in informal situations.	1	2	3	4	5		☐	
18. Expresses anger appropriately (e.g., reacts to situation without becoming violent or destructive).	1	2	3	4	5	☐		
19. Listens carefully to teacher instructions and directions for assignments.	1	2	3	4	5			☐
20. Answers or attempts to answer a question when called on by the teacher.	1	2	3	4	5			☐
21. Displays independent study skills (e.g., can work adequately with minimum teacher support).	1	2	3	4	5			☐
22. Appropriately copes with aggression from others (e.g., tries to avoid a fight, walks away, seeks assistance, defends self).	1	2	3	4	5	☐		
23. Responds to conventional behavior management techniques (e.g., praise, reprimands, timeout).	1	2	3	4	5			☐
24. Cooperates with peers in group activities or situations.	1	2	3	4	5	☐		
25. Interacts with a number of different peers.	1	2	3	4	5		☐	
26. Uses physical contact with peers appropriately.	1	2	3	4	5	☐		
27. Responds to requests promptly.	1	2	3	4	5			☐
28. Listens while others are speaking (e.g., as in circle or sharing time).	1	2	3	4	5	☐		
29. Controls temper.	1	2	3	4	5	☐		
30. Compliments others regarding personal attributes (e.g., appearance, special skills, etc.).	1	2	3	4	5		☐	
31. Can accept not getting her/his own way.	1	2	3	4	5	☐		
32. Is socially perceptive (e.g., "reads" social situations accurately).	1	2	3	4	5		☐	
33. Attends to assigned tasks.	1	2	3	4	5			☐
34. Plays games and activities at recess skillfully.	1	2	3	4	5		☐	
35. Keeps conversation with peers going.	1	2	3	4	5		☐	
36. Finds another way to play when requests to join others are refused.	1	2	3	4	5	☐		
37. Is considerate of the feelings of others.	1	2	3	4	5	☐		
38. Maintains eye contact when speaking or being spoken to.	1	2	3	4	5		☐	
39. Gains peers' attention in an appropriate manner.	1	2	3	4	5	☐		
40. Accepts suggestions and assistance from peers.	1	2	3	4	5	☐		
41. Invites peers to play or share activities.	1	2	3	4	5		☐	
42. Does seatwork assignments as directed.	1	2	3	4	5			☐
43. Produces work of acceptable quality given her/his skill level.	1	2	3	4	5			☐
					Subtotals:	☐	☐	☐

(Add subtotals for each column) **Total Scale Score:** ☐

DOLESCENT VERSION REORDER FORMS
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Profile/Rating Form
The Walker-McConnell Scale of Social Competence and School Adjustment
Adolescent Version

*For Information/copies, contact Singular Publishing Group, Inc.
4284 41st St. San Diego, CA 92105
Call Toll free 1-800-521-8545

I. Student Demographic Information

Student Name ____________________

Sex: ☐ Male ☐ Female

Age: ______ Years ______ Months

Date ____________________

School ____________________

Teacher ____________________

Grade ________

II. Rating Instructions

Please read each item below carefully and rate the student's behavioral status in relation to it. If you have not observed the student displaying a particular skill or behavioral competency defined by an item, your answer would be a 1 indicating Never. If the student exhibits the skill at a high rate of occurrence your answer would be a 5, indicating Frequently. If the student's frequency is in between these two extremes, your answer would be 2, 3, or 4 indicating your best estimate of the rate of occurrence. RECORD YOUR ANSWER FOR EACH ITEM IN THE BLANK BOX UNDER THE CORRESPONDING SUBSCALE COLUMN.

Please answer each item. YOU NEED NOT MARK OR CHECK THE NUMBERS IN THE RATING FORMAT SECTION.

III. Items and Rating Formats

Item	Rating Format					Subscale				
	Never		Sometimes		Frequently	1	2	3	4	
1. Relates well to the opposite sex.	1	2	3	4	5		☐			
2. Changes activities with peers to permit continued interaction.	1	2	3	3	5		☐			
3. Displays self-control in difficult situations.	1	2	3	4	5	☐				
4. Shares laughter with peers.	1	2	3	4	5		☐			
5. Takes pride in her/his appearance.	1	2	3	4	5		☐			
6. Makes friends easily with others.	1	2	3	4	5		☐			
7. Has good work habits (e.g., is organized, makes efficient use of class time, etc.)	1	2	3	4	5			☐		
8. Asks questions that request information about someone or something.	1	2	3	4	5			☐		
9. Compromises with peers when situation calls for it.	1	2	3	4	5	☐				
0. Responds to teasing or name calling by ignoring, changing the subject, or some other constructive means.	1	2	3	4	5	☐				
1. Does what he/she agrees to do.	1	2	3	4	5			☐		
2. Accepts constructive criticism from peers without becoming angry.	1	2	3	4	5	☐				
3. Participates or talks with peers for extended periods of time.	1	2	3	4	5		☐			
4. Voluntarily provides assistance to peers who require it.	1	2	3	4	5					☐
5. Accepts the consequences of his/her actions.	1	2	3	4	3	☐				
6. Has a sense of humor	1	2	3	4	5		☐			
7. Initiates conversation(s) with peers in informal situations.	1	2	3	4	5		☐			
8. Expresses anger appropriately (e.g., reacts to situation without becoming violent or destructive).	1	2	3	4	5	☐				

Item	Rating Format					Subscale				
	Never		Sometimes		Frequently	1	2	3	4	
19. Listens carefully to teacher instructions and directions for assignments.	1	2	3	4	5			☐		
20. Copes effectively with being upset or depressed.	1	2	3	4	5	☐				
21. Displays independent study skills (e.g., can work adequately with minimum teacher support).	1	2	3	4	5			☐		
22. Appropriately copes with aggression from others (e.g., tries to avoid a fight, walks away, seeks assistance, defends self).	1	2	3	4	5	☐				
23. Responds to conventional behavior management techniques (e.g., praise, reprimands, timeout).	1	2	3	4	5			☐		
24. Cooperates with peers in group activities or situations.	1	2	3	4	5		☐			
25. Interacts with a number of different peers.	1	2	3	4	5		☐			
26. Uses physical contact with peers appropriately.	1	2	3	4	5	☐				
27. Responds to requests promptly.	1	2	3	4	5			☐		
28. Listens while others are speaking.	1	2	3	4	5			☐		
29. Feels good about herself/himself.	1	2	3	4	5					☐
30. Compliments others regarding personal attributes (e.g., appearance, special skills, etc.).	1	2	3	4	5				☐	
31. Can accept not getting her/his own way.	1	2	3	4	5	☐				
32. Is socially perceptive (e.g., reads social situations accurately).	1	2	3	4	5					☐
33. Attends to assigned tasks.	1	2	3	4	5			☐		
34. Participates in games and activities skillfully.	1	2	3	4	5		☐			
35. Keeps conversation(s) with peers going.	1	2	3	4	5		☐			
36. Selects another activity when requests to join others are refused.	1	2	3	4	5				☐	
37. Is considerate of the feelings of others.	1	2	3	4	5				☐	
38. Maintains eye contact when speaking or being spoken to.	1	2	3	4	5			☐		
39. Gains peers' attention in an appropriate manner.	1	2	3	4	5	☐				
40. Accepts suggestions and assistance from peers.	1	2	3	4	5	☐				
41. Invites peers to interact or share activities.	1	2	3	4	5		☐			
42. Does seatwork assignments as directed.	1	2	3	4	5			☐		
43. Produces work of acceptable quality given her/his skill level.	1	2	3	4	5			☐		
44. Uses free time appropriately.	1	2	3	4	5			☐		
45. Shows sympathy for others.	1	2	3	4	5				☐	
46. Assumes leadership role in peer activities.	1	2	3	4	5		☐			
47. Answers or attempts to answer a question when called on by the teacher.	1	2	3	4	5			☐		
48. Spends free time interacting with peers.	1	2	3	4	5		☐			
49. Is sensitive to the needs of others.	1	2	3	4	5				☐	
50. Controls temper.	1	3	3	4	5	☐				
51. Is personally well organized.	1	2	3	4	5			☐		
52. Appropriately stands up for his/her rights.	1	2	3	4	5				☐	
53. Others seek student out to involve her/him in activities.	1	2	3	4	5		☐			
					Subtotals:	☐	☐	☐	☐	☐

(Add subtotals for each column) **Total Scale Score:** ☐

Friendship Interview Schedule

Code Number (1)	Date		

To help me understand children's friendships I'm going to ask you some questions about your two best friends. Please say what ever you feel, the answers you give will not be seen by your parents or anybody who is not part of the research team. You do not need to give me your friend's full name, just their first name and tell me whether s/he is your first, second or third best friend.

Is..a school, neighbourhood or another type of friend?

School ☐ Neighbourhood ☐ Other ☐

1. How long have you been friends with............................?

2. Do you ever spend your free time with...? (1)

YES How often do........................? 1 2 3 4 5 Why do...............?

NO Why don't you?

3. Do you ever feel like it's hard to get along with.............................? (2)

YES How often do.......................? 1 2 3 4 5 When do.............?

NO Why is it easy to get along with..........................?

4. If you told........................a secret, could you trust him/her not to tell anyone else? (1)

YES How often do you tell him/her secrets? 1 2 3 4 5 Why do you tell them to him/her?

NO Why not?

5. Does........................ever think of fun things for the two of you to do together? (1)

YES How often............? 1 2 3 4 5 What kinds of things does......................?

NO Why not?

6. If you and ....were arguing about something, would he/she listen to your side? (1)

YES How often does...............? 1 2 3 4 5 Why would........................?

NO Why not?

7. Does............................... know a lot about what you like and how you feel about things? (2)

YES How much does.................? 1 2 3 4 5 What kind of things does...................?

NO Why not?

8. When you want someone to have fun with, do you get together with....................? (2)

YES How often do.............? 1 2 3 4 5 Why do....................?

NO Why not?

9. Do you ever get into fights or arguments with.....................................? (1)

YES How often do...................? 1 2 3 4 5 What kinds of things do you fight about?

NO Why not?

10. When you have a problem at home or at school, do you talk to.......................about it? (1)

YES How often do..................? 1 2 3 4 5 Why do.............?

NO Why not?

11. Do you and ....ever go to each other's houses on weekends or after school? (1)

YES How often do....................? 1 2 3 4 5 Why do............?

NO Why not?

12. Does..........................ever annoy or bug you? (2)

YES How often does..............? 1 2 3 4 5 What kinds of things does s/he do?

NO Why not?

13. Would you tell.......................things that you wouldn't tell anyone else? (1)

YES How often do............? 1 2 3 4 5 Why do......................?

NO Why not?

14. Do you and...................ever just sit around and talk about things like school, sports, or anything else? (2)

YES How often do...............? 1 2 3 4 5 What kinds of things?

NO Why not?

15. If you said you were sorry after you had a fight with................would he/she stay angry at you? (1)

YES How often does...................? 1 2 3 4 5 Why does......................?

NO Why not?

16. If you got bad marks at school, would you tell.........................about it? (1)

YES How often would you tell..............about things like that? 1 2 3 4 5 Why would.....?

NO Why not?

Tell me about why you like your friend? Prompt....last time you had fun together?

....

....

What are the things that you don't like about your friend? Prompt....well what's different about this person and others who are not your friend?

....

....

How does s/he make you feel most of the time? Prompt....how do you feel when you are with your friend? ......all the time?

....

....

Does s/he help you? Prompt......do you help your friend? What do you do for your friend?

....

....

In what ways?

....

....

In what ways are you similar to your friend?

....

....

In what ways are you different to your friend?

....

....

Would you like to be like your friend?

....

....

Do you think you make a good pair? Prompt......Why do you think you are such good friends?

....

....

....

....

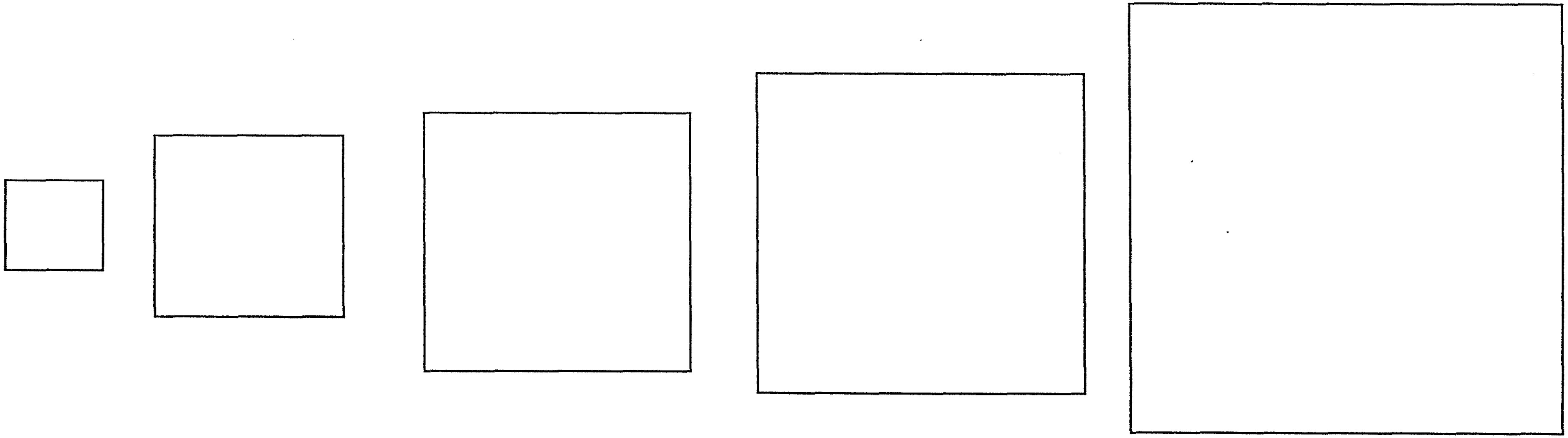
Not at all

Not very much

A little bit

Quite a bit

A whole lot



Clinician assessment of family care demands

To understand what role condition parameters play in psychological adjustment of children with chronic illness I would like you rate the child in terms of family care demands.

Name..Code No...................Date............................

Respondent -Please circle.. Clinician / Nurse specialist

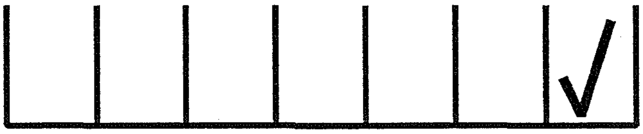
Family care demands

In considering the common demands and challenges that a child with a chronic condition creates for a family (e.g. scheduling of medication and treatments, supervision of child adherence to treatment, recording keeping, whether child can be left in the care of others, explanation of needs to school staff and others, for example if child sleeps over at friend's house, attendance at hospital clinics), over the past year how would you rate the severity of family demands of your child's condition in comparison to any family with a child of the same age who also has a chronic condition ?

Example

If you believe the child's condition to be extremely demanding you may tick here.

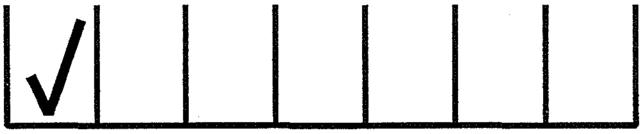
Low family care demand



High family care demand

If you believe the child's condition to be minimally demanding you may tick here.

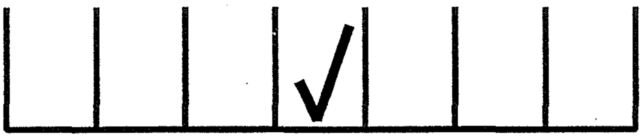
Low family care demand



High family care demand

If you believe the child's condition to be moderately demanding you may here.

Low family care demand



High family care demand

If you believe the child's condition to be somewhat demanding you may tick around here.

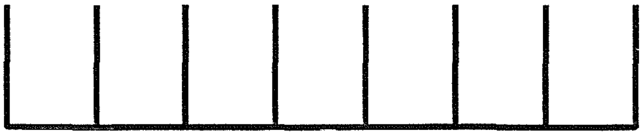
Low family care demand

High family care demand

Please place a tick (✓) along the scale (you may choose any part of the scale) to indicate where you believe the severity of family care demands to be in comparison to any family with a child of the same age who also has a chronic condition.

Over the past year how would you rate the severity of family demands of this child's condition ?

Low family care demand



High family care demand

THANK-YOU FOR YOUR HELP

Parent assessment of family care demands

In considering the common demands and challenges that a child with a chronic condition creates for a family (e.g. scheduling of medication and treatments, supervision of adherence to treatment, recording keeping, whether you can leave your child in the care of others, explanation of needs to school staff and others, for example, sleepovers at a friend's house, attendance at hospital clinics), over the past year how would you rate the severity of family demands of your child's condition in comparison to a family with a child of the same age who has also a chronic condition ?

Example

If you believe your child's condition to be extremely demanding you may tick here.

Low family care demand							✓	High family care demand

If you believe your child's condition to be minimally demanding you may tick here.

Low family care demand	✓							High family care demand

If you believe your child's condition to be moderately demanding you may here.

Low family care demand				✓				High family care demand

If you believe your child's condition to be somewhat demanding you may tick around here.

Low family care demand			✓					High family care demand

Please place a tick (✓) along the scale (you may choose any part of the scale) to indicate where you believe the severity of family care demands to be in comparison to any family with a child of the same age who also has a chronic condition.

Over the past year how would you rate the severity of family demands of your child's condition ?

Low family care demand								High family care demand