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# **Psychosocial Needs of Parents and Children Utilising Paediatric Outpatient Clinics**

A thesis  
submitted in fulfillment  
of the requirements for the degree  
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**Rosalind Jane Leamy Case**

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## Abstract

When a child is diagnosed with a severe health problem, they and their families are at increased risk of experiencing psychological distress and disorder. The objectives of this study were twofold: firstly, they were to examine the relationships amongst child illness, parental and child distress, quality of life and medical regimen adherence; and secondly, to understand the degree of parent interest in receiving psychological support and paediatricians' perceptions of family psychosocial needs. Participants were 152 parents of children utilising a paediatric outpatient clinic who completed a battery of self-report questionnaires including the Depression Anxiety Stress Scale, Quality of Life Scale, and Strengths and Difficulties Questionnaire. Information regarding demographics and child health status were collected and paediatricians completed a measure of health status, medication adherence and perceived need for psychosocial support for each participant. Parent ratings of stress symptoms were significantly higher than in normative populations and their children were rated as having a significant degree of emotional, hyperactivity, conduct and peer problems. Increased levels of depression, stress and anxiety in parents were associated with higher ratings of child hyperactivity and peer problems. Parent stress and anxiety levels were also related to emotional symptoms in children. A large proportion of the sample perceived paediatric psychology services as being important and were interested in accessing such support. Parent interest was associated with having an older child, congenital illness, elevated distress scores on the Depression Anxiety Stress Scale and higher mean ratings of quality of life. Paediatricians suggested that many families could benefit from psychosocial input for issues relating to their child's health problem and child's age and quality of life were shown to also account for a large proportion of the variance in these ratings. Implications for the delivery of paediatric health psychology services are discussed.

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## Contents

	Page
Abstract.....	i
Acknowledgements.....	ii
Contents.....	iii
List of Tables and Figures.....	iv
Introduction.....	1
Methodology.....	26
Results.....	33
Discussion.....	47
References.....	65
Appendix A: Introductory Letter to Parents / Guardians.....	82
Appendix B: Information Sheet for Parents / Guardians.....	84
Appendix C: Information Sheet for Youth aged 12-16 years.....	87
Appendix D: Consent Form.....	89
Appendix E: Background Information Form.....	91
Appendix F: Paediatrician Rating Form.....	94
Appendix G: Depression Anxiety Stress Scale.....	96
Appendix H: Quality of Life Scale.....	98
Appendix I: Strengths and Difficulties Questionnaire.....	100

## List of Tables and Figures

Table		Page
Table 2.1	Frequencies of Children's Ethnicities	27
Table 3.1	Frequencies of Children's Ages	33
Table 3.2	Illness Types and Categories	35
Table 3.3	One Sample T-Test - DASS Means	38
Table 3.4	DASS Subscale Score Frequencies	39
Table 3.5	One Sample T-Test - SDQ Subscale Score Means	40
Table 3.6	SDQ Subscale Score Frequencies	41
Table 3.7	Spearman Correlations between parent (DASS) and child (SDQ) measures	42
Table 3.8	Spearman Correlations between DASS total scores, SDQ total scores and Mean QOL	43
Table 3.9	Summary of Logistic Regression Analysis for Variables Predicting Parent Interest in Support	44
Table 3.10	Summary of Logistic Regression Analysis for Variables Predicting Parent Interest in Support - with DASS subscales included	45
Table 3.11	Summary of Logistic Regression Analysis for Variables Predicting Paediatrician Indications of Psychosocial Need	46

Figure		Page
Figure 1.1	Model of Stress Appraisal and Coping developed by Lazarus and Cohen (1977)	3
Figure 1.2	Transactional Stress and Coping Model in Childhood Chronic Illness developed by Thompson, Gustafson, George and Spock (1994)	5

## CHAPTER ONE: INTRODUCTION

### **Introduction**

When a child is diagnosed with a significant health problem, they and their families are at increased risk of experiencing psychological distress and disorder (Cohen, 1999; Silver, Westbrook & Stein, 1998). There is a wealth of international literature which has examined the presence of distress in paediatric health populations, and the relationships among parental and child distress, adherence with medical regimens, and health outcomes (Armstrong & Kerns, 2002; Clay & Hopps, 2003; Lavigne & Faier-Routman, 1992; Mash & Wolfe, 2007). However, there are no published studies which have examined these issues in a New Zealand context. There also seems to be a lack of research examining the accessibility to and desire for paediatric health psychology services in New Zealand.

The purpose of this study is to identify the level of distress among children seeking paediatric treatment and their parents, and to understand more about the relationships among child illness, family psychological functioning and social variables. The first part of this thesis will review the relevant literature, with two particular foci: a) The epidemiology of child health, disabilities and health service use in New Zealand and, more specifically, in the Waikato district; and b) International findings regarding child and parent psychological functioning,

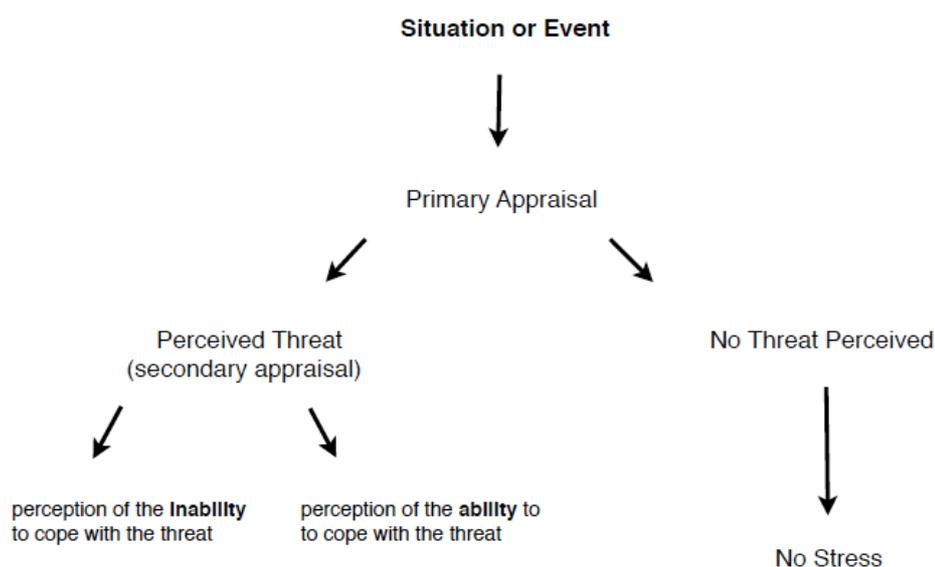
quality of life and medical adherence. Finally, a set of study questions will be proposed, from which the current research objectives were derived.

### ***A Theoretical Model of Coping with Illness***

Chronic and acute illnesses differ in their course, treatments and outcomes, and this affects how they are perceived and how they impact on children and families (Rolland, 1987; Tak & McCubbin, 2002). Understanding this process is aided by the use of a theoretical framework such as Lazarus and Cohen's (1977) model of stress appraisal and coping (see Figure 1.1). This model holds that when situations or events occur, an appraisal takes place in which an individual evaluates the significance of the event and determines whether it is a threatening, positive or irrelevant one. If a threat is perceived, this leads to a secondary appraisal whereby the individual determines what, if any, options and resources they have available to help them cope with the threat. The appraisal process is followed by actual coping efforts.

While some researchers have attempted to provide taxonomies of coping strategies, such as Skinner, Edge, Altman and Sherwood's (2003) review which produced a list of 400 coping strategies within 13 categories, many researchers in this area understand coping strategies as falling into two broad categories: 'problem-focused' and 'emotion-focused' (Baker & Berenbaum, 2007; Walker, Smith, Garber, & Claar, 2007). Problem-focused coping strategies are defined as those which entail an attempt to modify or address issues which are perceived as being related to a stressor. For example, if the parent of a child with diabetes was

to set an alarm to alert the family when it was time for the child to test their blood glucose level or inject insulin, this might be considered to be problem-focused in that it is a proactive attempt to address a challenge (i.e. adherence) posed by the child's illness.



*Figure 1.1: Model of Stress Appraisal and Coping (Lazarus and Cohen, 1977).*

Equally, a parent who angrily confronts a paediatrician for a perceived problem with their child's care might also be considered to be utilising a problem-focused coping strategy. These two quite different examples illustrate the diversity of behaviours contained within this definition.

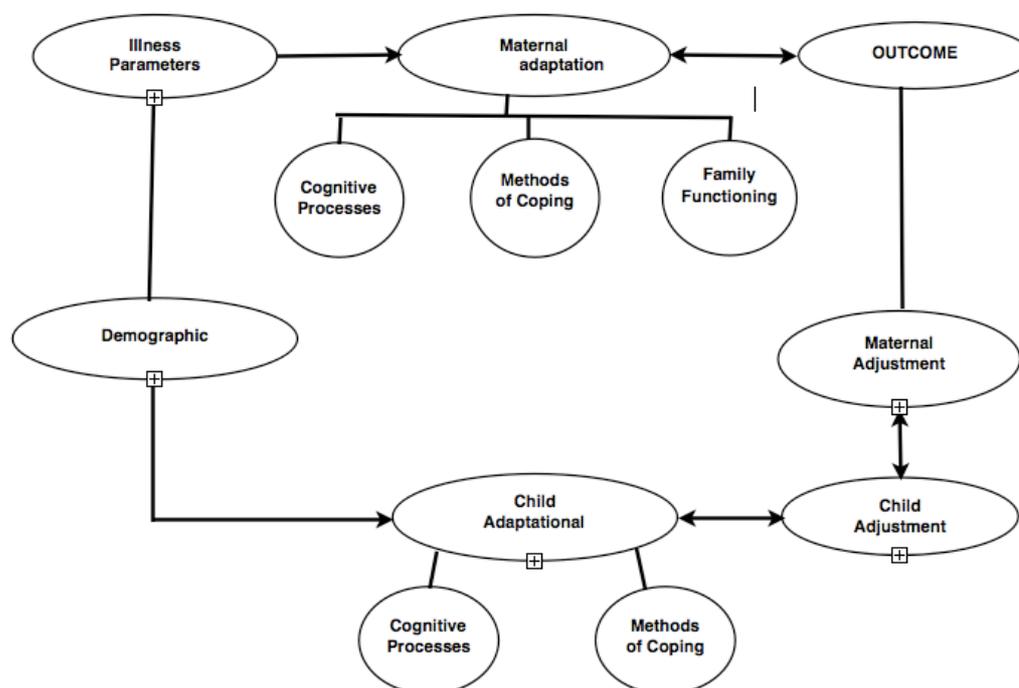
Emotion-focused coping strategies refer to attempts by an individual to modify how they perceive or feel about the stressor, as opposed to an attempt to actually modify it. Parents who tell themselves that they must "think positively"

are using an emotion-focused strategy, as are the parents who deny the seriousness of their child's condition or fantasise that a cure will be developed in the near future.

Numerous attempts by researchers to understand which variables contribute to or detract from coping and adjustment have revealed that single-factor explanations are not sufficient (Mash & Wolfe, 2007). Thompson, Gustafson, George and Spock (1994) acknowledged this in their development of the *transactional stress and coping model for chronic childhood illness* (see Figure 1.2). This biopsychosocial model seeks to explain the coping process and demonstrates the variety of influences which may impact on a family's adjustment to child illness. The transactional model includes the parameters of the illness (such as type and severity) and personal factors (such as age and gender) to explain the child's individual adjustment. However, the model proposes that it is other processes, such as maternal adjustment and family functioning, which ultimately mediate health outcomes for children. As in Lazarus & Cohen's (1984) model of coping, the transactional model maintains that the appraisal of threat determines the degree of stress experienced by an individual, with higher levels of stress being associated with poorer adjustment and lower self-efficacy (Brown, 2006). But it goes further in that it specifies the particular types of variables that are likely to act as protective or risk factors for adjustment.

The key aspects of the transactional model are maternal and child adaptation. Maternal adaption is itself a complex system in which a mother's appraisal of her

child's illness will interact with her beliefs about her child's and her own ability to cope, perceptions of support, and general outlook. These cognitive processes may affect and be affected by the particular coping strategies available to a mother and the effectiveness of these strategies. Furthermore, family functioning also interacts with a mother's cognitive processes and coping strategies.



*Figure 1.2: Transactional Stress and Coping Model in Childhood Chronic Illness (Thompson, Gustafson, George, & Spock, 1994).*

These three factors form a complex of variables whose outcome is 'maternal adaptation'. Child adaptation is similarly affected by a child's own cognitive processes and the coping strategies they are able to implement in response to their illness. The final outcome of the stressful event in this model can be seen as the product of a wider system in which variables relating to maternal adaptation and

adjustment, child adaptation and adjustment, sociocultural/demographic variables, and illness parameters are interrelated.

### ***Child Illness and Family Psychological Functioning***

There is a broad literature base examining the relationships between specific illness types (e.g. asthma, epilepsy, and leukaemia) and psychological distress in children and parents (Goldbeck, 2006; Ievers & Drotar, 1996; Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008). However, very few researchers have assessed the presence of psychological distress in populations within which children are affected by milder, non-life-threatening medical conditions (e.g. gastric reflux, constipation, ear infections), or the range of problems and conditions seen in the typical paediatric clinic. Therefore, the majority of this literature review will focus on the significant body of literature relating to chronic, severely debilitating and life-threatening paediatric conditions.

### ***Parental Psychological Functioning***

#### ***Stress***

The relationship between parental psychological functioning and child health is reciprocal; parental distress may impact on a child's health and, equally, a child's health may impact on parental distress (Goldbeck, 2006; Ievers & Drotar, 1996; Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008). As we have seen, a diagnosis of serious illness in a child acts as an acute stressor for parents, and may activate a process in which parents attempt to cope with and adjust to the significance and implications of their child's condition (Glover &

Poland, 2002; Lindahl-Norberg, 2005; Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008). A consistent definition of stress does not appear in the literature, and La Greca and Lemanek (1996) point out that it is important for researchers to be aware of the nature of the stressors which they are investigating. In regards to paediatric health, stressors may be seen as being acute (such as emergency surgery) or ongoing (chronic ill health); they may also be conceptualised as being brief and intense, or ongoing and irritating (La Greca & Lemanek, 1996). It is within the scope of this study to consider all of these types of stressors due to the broad range of parental experiences being examined.

In response to a diagnosis (seen here as a primary, initial stressor) parents may experience feelings of uncertainty and confusion as they interact with medical systems and attempt to understand and ameliorate the potentially unknown course and prognosis of their child's illness, while some parents report feeling intense grief at the 'loss' of their healthy child (George, Vickers, Wilkes, & Barton, 2006, Pelchat et al., 1999; Silver, Westbrook & Stein, 1998). Parents may also suffer from acute psychological stress and exhaustion as they adjust to the demands, management tasks and possible hospitalisations associated with their child's new diagnosis (Barrera, D'Agostino, Gibson, Gilbert, Weksberg, & Malkin, 2003; Krulik, Turner-Henson, Kanematsu, al-Ma'aitah, Swan, & Holoday, 1999; Mu, 2006).

High levels of perceived stress have been documented amongst parents of children with a variety of disorders, including epilepsy, cancer, asthma, cystic

fibrosis, developmental disorders, organ and bone transplants, and HIV (Bachanas, Kullgren, Schwartz, McDaniel, Smith, & Nesheim, 2001; Canning, Dew & Davidson, 1996; Ievers & Drotar, 1996; Iseri, Ozten, & Aker, 2006; Streisand, Kazak, & Tercyak, 2003). The more severe or life-threatening a child's illness is, the more likely it is the stress that parents' experience will manifest as emotional or psychological distress, although other mediating factors may also impact on distress levels. A number of factors have been found to be predictive of increased levels of parental distress related to child illness. Dunst and Trivette (1986) conducted analyses which found that when other variables such as income, child age, and gender were controlled for, lower levels of social support were associated with poorer personal well-being in parents and negative cognitive styles. These findings were replicated by Tak and McCubbin (2002), who again highlighted family support systems as being a key aspect of coping with childhood illness. In a wide review of the literature relating to psychological stress and paediatric cancer, Vrijmoet-Wiersma et al. (2008) suggested that the coping strategies implemented by families in the face of a child health stressor are dependent upon the phase of the illness and recommended screening parents for distress several times in the first six months post-diagnosis, and again one to two years subsequent to the completion of treatment.

When coping attempts are unsuccessful in reducing stress and it transitions from being an acute to a chronic state, the resulting physiological arousal may contribute to the development of psychological disorders such as depression and anxiety disorders (Halgin & Whitbourne, 2007). Accordingly, it is pertinent to

examine the literature relating to these types of psychological disorders and how they relate to child illness.

### *Anxiety*

Anxiety is psychological state which is characterised by fear, worry and apprehension. It is experienced as a distressing emotion or mood state and often involves physiological as well as psychological symptoms (Noyes & Hoehn-Saric, 1998). The fear and concern for a child's well-being that many parents experience when they learn of their child's diagnosis might be accurately described as anxiety, and recognised as a normal reaction to such an event. However, the anxiety experienced by some parents is significant and ongoing. While most parents experience a decrease in anxiety to near normal levels by five years post-diagnosis, some individuals will continue to experience more distress than the parents of healthy children even after such a period has elapsed (Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Parents with high levels of anxiety are also at risk of developing Post Traumatic Stress Disorder (PTSD) (Best, Streisand, Catania, & Kazak, 2001). Elevated anxiety levels have been identified in parents of children with a variety of disorders, and have been found to be associated with poor health outcomes and lower family functioning (Brook & Shemesh, 1991; Iseri, Ozten, Aker, 2006). The significance of learning that one's child has a chronic and potentially life-threatening illness is highlighted by the specific inclusion of this type of event as a qualifying diagnostic criterion for PTSD in the fourth edition of the *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)* (American Psychiatric Association, 1994). Iseri, Ozten and

Aker (2006) assessed symptoms of PTSD and Major Depressive Disorder (MDD) in parents of children with epilepsy. Symptoms of PTSD and Major Depressive Disorder (MDD) differ in that PTSD is conceptualised as an anxiety disorder characterised by recurrent, intrusive thoughts about a traumatic event, physiological reactivity to cues which represent the event, and hypervigilance, there are also similarities between the two disorders (such as diminished interest in previously enjoyed events, negative cognitions, restricted affect, avoidance, sleep difficulties, irritability, etc.) (Halgin & Whitbourne, 2007). Iseri, Ozten and Aker's (2006) found that more than 30% of their sample met diagnostic criteria for both disorders, with 56% of participants with PTSD receiving a diagnosis of MDD. Parents were more likely to demonstrate re-experiencing and arousal symptoms of PTSD (such as intrusive thoughts, psychological reactivity, irritability and hypervigilance) related to their child's diagnosis than avoidance or numbing type symptoms.

### *Depression*

It is possible that parents will react to their child's diagnosis with symptoms of depression (Vrijmoet-Wiersma, van Klink, Kolk, Koopman, Ball, & Egeler, 2008). For example, up to 50% of parents will react to a child's diagnosis of cancer with depressive symptoms, with a similar rate of prevalence at 3-month follow-up (Fife, Norton, & Groom, 1987; Manne, Lesanics, Meyers, Wollner, Steinherz, & Redd, 1995). While some research has indicated that these symptoms tend to decrease over time (see Boman, Lindahl & Bjork, 2003), other findings suggest that depressive symptoms in parents of children diagnosed with a life-

threatening illness may be maintained for longer than six months, particularly if symptoms were initially severe (Manne, Miller, Meyers, Wollner, Steinherz, & Redd, 1996).

Voeller and Rothenburg (1993) found that the parents of children diagnosed with epilepsy often experienced depressive symptoms such as guilt and sadness. Some parents viewed their children's illness as "a disaster" and described feeling overwhelmed by the responsibility of managing their child's epilepsy. Similarly, parents of children with developmental disorders (e.g. Autistic Spectrum Disorders) have been found to experience significant levels of distress with low social supports and disruptive child behaviours operating as predictive factors for parental low mood (Abbeduto, Seltzer, Shattuck, Krauss, Orsmond, & Murphy, 2004; Pottie, Cohen, Ingram, 2009). Research into the relationship between child illness and parental distress supports the implications contained within Thompson et al.'s (1994) transactional model of coping as it demonstrates that a variety of factors relating to the child's illness parameters, parent coping abilities and social variables impact on the psychological adjustment of parents.

### *Caregiver Quality of Life*

Parents of children with chronic illness are at increased risk of experiencing poor quality of life (QOL) as a result of the significant stressors and emotional distress which they may face (Everhart, Fiese, & Smyth, 2008). There are many determinants of quality of life; as a construct it reflects numerous factors, such as social participation, close relationships, financial security, meaningful work and

community participation (Everhart, Fiese, & Smyth, 2008; Flanagan, 1982). Caregiver quality of life may be impaired when families experience stressors which impact on any domain of their functioning: social, family, physical, emotional, spiritual, functional or financial (Boling, Macrina, & Clancy, 2003). Understanding how a child's illness impacts on parental quality of life is important in order to understand the burden of the child's symptoms and treatment regime on the family (Haltermann et al., 2004). Poor caregiver quality of life has been found to be related to increased symptom severity in numerous paediatric illnesses, such as asthma (Haltermann et al., 2004), recurrent ear, nose and throat infections (Berdeaux, Hervie, Smajda & Marquis, 1998), cancer (Goldbeck, 2006), inflammatory bowel disease (Hommel, Davis, & Baldassano, 2008), and cystic fibrosis (Boling, Macrina, & Clancy, 2003).

### ***Child Distress***

Children with chronic illness face a wide range of daily changes which can impact on their development and adjustment, and are more likely to experience emotional and behavioural problems as a result of the symptoms and treatment of their condition (Mash & Wolfe, 2007). Figures from the Ontario Child Health Study (Cadman, Boyle, Szatmari, & Offord, 1987) indicate that children with chronic illness are almost two and a half times more likely to experience psychological disorders than their healthy peers, regardless of disease type or severity. However, children who experience higher degrees of physical impairment experience the most challenges in their behavioural and social functioning (Gortmaker, Walker, Weitzman, & Sobol, 1990).

There is also a subset of children who present to paediatric clinics due to somatic complaints which have an underlying psychological cause, such as headaches, stomach aches, and joint pain (Egger, Costello, Erkanli, & Angold, 1999). This may be related to children lacking the insight, confidence or expressive ability to accurately identify and describe their emotions, as well as the physiological impact of stress on health and wellbeing (Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003). Kramer and Garralda (1998) found that while 38% of adolescents receiving primary care health services met diagnostic criteria for a psychological disorder, only 2% had presented for treatment of psychological distress. While the authors suggest that this is indicative of the underlying somatic nature of many physical complaints for which young people receive care, it is also possible that such a finding simply reflects the high prevalence of emotional and behavioural problems experienced by children with health conditions.

### *Emotional Problems*

Children with chronic illness are more likely to experience emotional problems in the form of depressive or anxiety symptoms than healthy children (Hysin, Elgen, Gillberg, Lie, & Lundervold, 2007; Lavigne & Faier-Routman, 1992). Children and adolescents with asthma are significantly more likely to experience symptoms of depression, anxiety disorders and PTSD (Goodwin, Fergusson & Horwood, 2004; Koltek, Wilkes & Atkinson, 1998). These psychological disorders in youth with asthma are associated with increased

hospitalisations, emergency room visits, symptom severity, functional impairment, and requests for medication (Katon, Lozano, Russo, McCauley, Richardson & Bush, 2007; Noewen, Freeston, Labbe, & Boulet, 1999; Richardson, Lozano & Russo, 2006). Katon et al. (2007) examined the prevalence of anxiety and depression in adolescents with asthma and a comparison group, and found that those with asthma were twice as likely to meet DSM-IV criteria for an anxiety or depressive disorder (16.3% of youth with asthma, compared to 8.6% of youth without asthma). It is possible that a reciprocal relationship exists between asthma and anxiety, with asthma symptoms (such as breathlessness) having the potential to exacerbate anxiety symptoms (such as fear) and vice versa (Lehrer, Feldman, Giardino, Song, & Schmaling, 2002). Some researchers have proposed that aspects of this relationship could be explained by an underlying biological component, such as the theory that neurotransmitters that are involved in the constriction of airways may be the same as those that regulate mood and arousal (McCauley, Katon, Russo, 2007). The strong association between anxiety and asthma symptoms, and the identification of anxiety as a potential risk factor in the development of asthma suggests that the relationship between anxiety disorders, such as panic disorder, and asthma symptoms is complex and involves multiple pathways (Hasler, Gergen, Kleinbaum, 2005).

A few studies have examined the long-term outcomes of individuals who survive childhood cancer and found that the majority are well-adjusted, and are less likely to experience depressive symptoms than their peers (Gray et al., 1992; Holmes & Holmes, 1975; Shelby, 1999). However, other literature suggests that

there is a subset of cancer survivors who are significantly at risk of developing low mood and experiencing poor psychosocial adjustment. Chen et al. (1998) investigated psychosocial difficulties in adult survivors of childhood leukaemia and found that higher treatment intensity (e.g. chemotherapy and radiotherapy dosages) was a predictor of poor psychosocial outcomes in adulthood. Individuals who had undergone high-intensity cancer treatments in their youth were more likely to engage in 'health-compromising' behaviours (e.g. smoking) and experience low mood, and have lower academic functioning than their peers (Chen et al., 1998).

### *Behaviour Problems*

Chronically ill children have been found to demonstrate less adaptive temperaments than their healthy peers (Guerin, Gottfried, & Thomas, 1997), which is pertinent as the presence of particular temperamental traits (for example, fussiness and persistence) in children have been associated with behaviour difficulties (Anderson, 1999; Baum et al., 2007). Children with chronic illness are at increased risk of developing behavioural problems (Glazebrook, Hollis, Heussler, Goodman, & Coates, 2003). Behaviour problems are more common in children with conditions which have a neurological component (such as epilepsy or cerebral palsy); however, children with non-neurological illnesses are still more likely to experience conduct difficulties than healthy children (Baum et al., 2007; Wagner, Smith, Ferguson, Horton, & Wilson, 1999). An elevated risk of behaviour problems has been identified in children with a variety of chronic conditions, such as asthma, congenital heart defects, cancer, epilepsy, diabetes and

sickle cell disease (Baum et al., 2007; Cohen, Lumley, Naar-King, Partridge, & Cakan, 2004; Thompson, Armstrong, Link, Pegelow, Moser, & Wang, 2003).

### *Social Difficulties*

Having a chronic illness may contribute to a child experiencing social difficulties (Reiter-Purtill & Noll, 2003). Children with chronic illness have been found to demonstrate less aggression and more submissive behaviour than their healthy peers, which may contribute to increased vulnerability to peer relationship problems (Meijer, Sinnema, Bijstra, Melienbergh, & Wolters, 2000). La Greca (1990) investigated factors that may predispose children with health problems to peer problems and identified several contributing factors: chronic illness may impact on a child's view of him or herself in such a way that self-esteem is diminished, which the author suggested may impact negatively on peer relationships, and social anxiety may arise out of fear that an embarrassing symptom of illness may occur in a social setting (such as a seizure or episode of hypoglycaemia); and limitations or social restrictions may be experienced as a result of disability or intensive treatment regimes which interrupt social activities. Investigations into this issue have demonstrated that frequent visits to doctors, hospitalisations, school absences and differences in activities are significantly associated with peer problems and the victimisation of chronically ill children (Noll, Kozlowski, Gerhardt, Vannatta, Taylor, & Passo, 2000; Storch et al., 2004). The hypothesis that a child's view of him or herself may be a contributing factor to the development of peer problems has been supported by research which has

demonstrated that high self-esteem is associated with decreased social difficulties (McCarroll, Lindsey, MacKinnon-Lewis, Chambers, & Frabutt, 2009)

### *Relationship between Child and Parent Functioning*

Also of significance is the relationship between parental psychological functioning and child behavioural and emotional problems. When parents experience poor psychological adjustment, their child is more likely to experience poor health outcomes (Stone, Banerjee, Dupuis, Leleszi, Allasio, & Singh, 2006). Psychological distress in parents is also associated with increased use of paediatric inpatient and outpatient specialist services; however, the pathways between these variables are unclear; it may be that distressed parents seek more input from medical specialists, or it is possible that it is distressing to have a child who is so unwell that they require such a high degree of medical assistance (Sills, Shetterly, Xu, Magid, & Kempe, 2007).

### *Medical Regimen Adherence*

When psychological distress and functional impairment is present in parents and children with chronic health conditions, this has the potential to impact further on the child's main presenting illness through the lowering of medical regimen adherence. Adherence refers to the extent in which a patient follows a treatment plan or medical regimen as prescribed to them by health practitioners (Modi & Quittner, 2006). While much of the literature in the medical field has previously referred to this as 'compliance', there is a movement away from such a term as some consider that it implies that patients who don't adhere to their medical

regimen are 'lazy' or 'forgetful' (Donovan & Blake, 1992). Use of the term 'adherence' as opposed to 'compliance' reflects the acknowledgement that the patient is an active, autonomous participant who collaborates with their doctor in developing a treatment plan, and who may or may not follow medical advice for a variety of valid reasons (Frain, Bishop, Tschopp, Ferrin & Frain, 2009).

The primary type of adherence required in many illnesses is that of medication, a key aspect of most medical treatments. This is particularly true in the case of chronic illness, as medication is seen to be the main (and sometimes only) way to delay progression of disease or prevent death (Bartlett, 2002). However, adherence may also refer to physical therapy regimes (such as in the treatment of cystic fibrosis), and dietary and lifestyle recommendations (Modi & Quittner, 2006). When the patient is the child, the burden of adherence is often shared by the family and, in particular, the parents or primary caregiver.

Non-adherence is a significant issue for children with chronic health conditions, and one which is also costly to the health system (Berg, Dischler, Wagner, Raia, & Palmer-Shevlin, 1998; Clay & Hopps, 2003). Prevalence rates of non-adherence are estimated to be approximately 50% in children and 65-75% in adolescents (Logan, Zelikovsky, Labay, & Spergel, 2003; Rapoff, 1999, cited in Frain, Bishop, Tschopp, Ferrin, & Frain, 2009). Adherence is found to be particularly poor in disorders which require complex and intensive treatment regimes, such as diabetes, cystic fibrosis and asthma (Modi & Quittner, 2006).

Individuals with chronic conditions face a number of barriers to adherence. Some are tangible, such as side effects, financial cost, time and a lack of resources (Naspitz & Tinkelman, 2001). Other challenges may be posed by psychological and social barriers, which may exist for parents or children and can inhibit their ability or desire to adhere to a medical regime (Gerson, Furth, Neu & Fivush, 2004). For example, family functioning has been identified as a key factor in post-transplant medication adherence, with children from families with two parents and lower levels of family stress demonstrating significantly higher levels of adherence to a treatment regime (Foulkes, Boggs, Fennel, & Skibinski, 1993). Children with poor medical adherence have also been found to have increased levels of psychiatric symptomatology, adjustment difficulties and lower self-esteem than those with good adherence (Griffin & Elkin, 2001). A lack of parental understanding about a child's condition and treatment may also act as a barrier to adherence (Griffin & Elkin, 2001), as may communication or relationship difficulties with the care provider (Modi & Quittner, 2006)

Gerson, Furth, Neu, & Fivush (2004) assessed the relationship between medication adherence and psychosocial variables in children who had received kidney transplants and their families. Their study indicated that lower levels of medication adherence were associated with elevated parental stress levels, child behaviour problems and poor communication between parents and children. High parent stress levels, family conflict, lack of parent education and child behaviour problems have also been identified as being predictors of poor adherence in a number of other paediatric health conditions, such as asthma ( DeMore, Adams,

Wilson & Hogan, 2005; Lemanek, 1990), cystic fibrosis (Anthony, Paxton, Bines & Phelan, 1999) and diabetes (Amir, Rabin & Galatzer, 1990; Dunn, Beeney, Hoskins, & Turtle, 1990).

It is clear that significant relationships exist among child illness, parent coping strategies, parent and child distress and medical adherence. However, these relationships have not previously been explored in a New Zealand context. In order to understand more about the interactions between paediatric health conditions and psychological problems, it is important to firstly consider the prevalence and severity of health and disability issues faced by children in New Zealand from an epidemiological perspective.

### ***Epidemiology of Child Health in New Zealand***

In 2007, UNICEF reported that New Zealand ranked 23rd out of 24 countries in terms of child health and safety outcomes. The leading causes of death for infants are were perinatal conditions, sudden infant death syndrome (SIDS), congenital anomalies, influenza and pneumonia. Cancer and leukaemia were two of the main causes of death in the 5-14 year age group (Statistics New Zealand, 1998). One way of examining child health is by examining hospital admission rates. According to data collected by Statistics New Zealand (1999), child hospitalisation rates increased significantly from 1974 to 1995, doubling from 89.6 to 197.5 per 1000. Preschoolers were most likely to be hospitalised, and rates for boys were 20% higher in 1995 than they were for girls. The main reasons for hospitalisations were perinatal conditions, respiratory infections, ear conditions,

congenital conditions and general illness symptoms. Despite this increase in hospitalisations, overall health outcomes for children have improved throughout the latter half of the 20th century and there has been a steady decrease in child mortality rates since the 1950s (Statistics New Zealand, 1998).

The New Zealand Household Health Survey (Statistics New Zealand, 1999) found that approximately four out of five children saw a general practitioner at least once in 12 months, with 21.3% of these children seeing a doctor six or more times in the previous year. The majority of children saw general practitioners for assessment and treatment of a mild or temporary condition, while 12.3% sought input for a chronic illness (for the purposes of this study, the term 'chronic' will refer to childhood illnesses which have a duration of more than 12 months). In an international context, the health of children in New Zealand is ranked as being poor in comparison to other western countries (UNICEF, 2007).

Approximately 11% of New Zealand children experience physical, intellectual, sensory or psychological disabilities, including chronic disease (Ministry of Health, 1998). Chronic illnesses may be congenital in nature (such as cases of heart defects and cleft palate) or may be acquired later in a child's life (such as cases of asthma or diabetes). Disabilities such as chronic illness are more likely to affect school-aged children, Maori and males than pre-schoolers, Europeans and females (Ministry of Health, 1998). Children living in the 'Midland' (Waikato) district are slightly more likely to have disabilities than those

in the Northern and Central regions of New Zealand (with prevalence rates of 11.9%, 10% and 11.7% respectively) (Statistics New Zealand, 1999).

The New Zealand Household Health Survey (Statistics New Zealand, 1999) also indicated that the most common types of disabilities in children were chronic, acquired, health conditions such as cancer, diabetes, asthma, epilepsy or failure to thrive (Ministry of Health, 1998). These types of chronic illnesses affect approximately 3.6% of the general child population (or 33% of the disabled child population). Chronic illnesses of a congenital origin have similar prevalence rates and are believed to exist in about 4% of all infants born in New Zealand (Tuohy, Counsell, & Geddis, 1993). Fifty one per cent of children with disabilities were limited in their ability to participate in school activities, including in-classroom learning, social interactions, and attendance and participation at school camps and field trips (Statistics New Zealand, 1999). Almost one-third of children with disabilities required in-class learning assistance in the form of a teacher-aide, special equipment or services (Statistics New Zealand, 1999). Thus, the disability that results from childhood illness can have a substantial impact on the daily life of the child and family, affecting school, recreation and family interactions.

According to the New Zealand Ministry of Health (2004) there are a growing number of health inequalities present amongst New Zealand children which are primarily caused by socio-economic deprivation factors such as low income and employment, poor and overcrowded accommodation, and reduced access to education and health services. Costs associated with general practitioner visits and

a lack of access to transport have both been associated with lower levels of engagement for Maori with health services, which may contribute to poorer health outcomes (Ministry of Health, 2006) However, it seems there are also factors specifically relating to ethnicity, independent of socio-economic factors, which impact upon health outcomes for New Zealand children. Children of Maori and Pasifika ethnicity tend to have poorer health than non-Maori, regardless of their families' income, level of education and occupation (Ministry of Health, 2004). Maori experience disproportionate rates of conditions such as ear infections and respiratory illnesses, and hospitalisation rates for diseases such as asthma are significantly higher than that of Pakeha, particularly for individuals living in rural areas (Pattemore et al., 2004; Smylie & Adomako, 2009). Understanding more about what factors contribute to these health disparities is a crucial aspect of improving the health of Maori children.

Wang, Ngui & Yap (2009) investigated service use at the Waikato Hospital paediatric outpatient clinic and found that half of all paediatric patients attend general paediatric clinics, where they may be seen for a variety of illnesses. The remainder of children attend specific clinics, such as cardiology, endocrinology, radiology, oncology, cystic fibrosis, haematology, rheumatic fever, renal, and spina bifida, which are scheduled so that children with these types of conditions are seen on the same day and by a paediatrician with specialist knowledge in particular areas. Multi-disciplinary teams operate within the diabetes clinic and the 'Bodywise' obesity programme, and include clinical psychologists.

Approximately 21.5% of patients treated in these clinics identify as Maori, and 63.5% as European, with approximately 52% of male gender and 48% female. The most common conditions seen in the outpatient clinics are epilepsy (13.8%), developmental delay (11.8%), asthma (8.1%), intellectual disability and learning problems (7.5%), attention deficit/hyperactivity disorder (6.8%) and failure to thrive (6.3%). Other conditions include constipation / encopresis, eczema, allergies, gastroesophageal reflux, obesity, heart murmurs and congenital heart disease, urinary tract infections, abdominal pain and enuresis (Wang, Ngui, & Yap, 2009). The information gathered in this evaluation is useful in that it describes basic patient demographics and the medical illnesses treated in this clinic, however Wang Ngui & Yap's (2009) study did not gather information regarding psychosocial functioning or parental perspectives on distress.

### ***Summary***

It is evident from the literature reviewed that children with health conditions are more likely to experience distress, behavioural and social problems than their healthy peers. It is also clear that having an unwell child elevates parents' risk of experiencing clinically significant levels of stress, anxiety and depression, and may impact on their perceived quality of life. It also seems that there are significant associations between parent and child psychological functioning, which together serve to mediate adjustment, adherence and overall health outcomes. However, it remains unclear to what degree these problems exist for parents and children in New Zealand, and how these variables might interact with the paediatric health profile which is specific to this country, and in a bicultural

context. Health consumers' perceptions of service need in this context also remain unclear. Thus, the goals of this study were to try to gain a deeper understanding of the levels of stress, distress and dysfunction, and quality of life, among paediatric patients and their families, and to assess their perceptions of need for services which might address their psychological needs. This study aims to fill this research gap with a particular set of research questions in mind:

1. How distressed are parents and children utilising a local paediatric health service? How are child and parent distress related to each other?
2. What services do parents currently utilise and what level of interest do they have in access to health psychology services which target the particular problems faced by families in this population?
3. How do paediatricians perceive patients and their families and what level of psychosocial need do they consider currently exists for these individuals?

## CHAPTER TWO: METHODOLOGY

### *Ethical Approval*

Ethical approval to conduct this study through a District Health Board organisation was obtained from the Ministry of Health Northern Y Ethics Committee. Part of the ethics application involved engaging in consultation with Te Puna Oranga (Maori Health) and seeking their approval of the study. Ethical approval was also obtained from the University of Waikato Psychology Department for research with human participants.

### *Participants*

Participants in this study were 152 parents/guardians of children with appointments with paediatricians at general and specialist outpatient clinics at Waikato Hospital. Most (139) of the adult respondents were female, while the remaining 13 were male. The children's ages ranged from 0 to 16 years, with a mean age of 5.8 years. Seventy-five (49.3%) of the children were male and 77 (50.7%) female. Ethnicity information was coded according to a 'total response' method, whereby individuals who reported more than one ethnic group were counted once for each group reported. This method is recommended by Statistics New Zealand (2005) in the reporting of ethnicity statistics and means that the total number of responses may be greater than the total number of participants. Thirty four (22.4%) reported multiple ethnicities. The majority of the children were identified as being New Zealand European, followed by Maori, Other European,

New Zealander, Cook Island Maori, Indian, Samoan, Niuean and Tongan (see Table 2.1).

Table 2.1

*Frequencies of Children's Ethnicities*

Ethnicity	N	%
New Zealand European	113	74.3
Maori	40	26.3
Other European	13	8.6
New Zealander	7	4.6
Other	6	3.9
Indian	4	2.6
Cook Island Maori	4	2.6
Samoan	3	2.0
Niuean	2	1.3
Tongan	1	0.7

*Materials and Scoring*

The materials used in the study were:

- Introductory Letter to Parents / Guardians - (Appendix A)
- Information Sheet for Parents/Guardians - (Appendix B)
- Information Sheet for Youth aged 12-16 years - (Appendix C)
- Consent Form - (Appendix D)
- Background Information Form - (Appendix E)
- Paediatrician Rating Form - (Appendix F)
- Depression Anxiety Stress Scale (DASS-21; Lovibond & Lovibond, 1995)  
- (Appendix G)
- Quality of Life Scale (QOLS; Flanagan, 1978) - (Appendix H)
- Strengths and Difficulties Questionnaire (SDQ; Goodman, 1997) -  
(Appendix I)

### *Background Information Form*

The background information questionnaire was designed by the primary researcher and collected information regarding demographics, illness type, severity and chronicity, and previously received psychosocial support. The questionnaire also included two 4-point likert scales which asked the parent to rate the following questions: ‘How important do you think it is to provide counselling, support, or psychological services for children and families with medical illnesses?’ and ‘If counselling, support or psychological services were available, would you be interested in using them for yourself or your family?’. A final section asked parents to submit any further comments regarding the psychological and/or emotional needs of children with chronic health conditions and their families.

### *Depression Anxiety Stress Scale*

The Depression Anxiety Stress Scale short form (DASS-21; Lovibond & Lovibond, 1995) was used to assess the level of distress in the parent respondents. The DASS-21 is a well-validated short version of the DASS-42 with internal consistency of .97, .92 and .95 respectively for the Depression, Anxiety and Stress subscales and test-retest reliability of .71 for depression, .79 for anxiety and .81 for stress (Antony, Bieling, Cox & Enns, 1998; Brown, Chorpita, Korotisch, & Barlow, 1997). The DASS is one of a few measures which distinguishes well between depression and anxiety, as well as more generalised stress symptoms such as agitation (Antony, Bieling, Cox & Enns, 1998). It contains 21 statements which participants rate on a 4-point Likert scale (*Did not apply to me at all to*

*Applied to me very much, or most of the time*) indicating to what degree they experienced symptoms of distress commonly associated with either depression, anxiety or stress over the past week. Subscale scores are summed to yield scores in the three distress categories, and all scores may be added together to indicate a total score of general distress.

### *Quality of Life Scale*

The Quality of Life Scale (QOLS; Flanagan, 1978) is a 16-item self-report questionnaire which measures quality of life across five conceptual domains: material well-being; relationships; social, community and civic activities; personal development; and recreation (Burckhardt, Anderson, Archenholtz & Hagg, 2003). Items are rated on a 7-point Likert scale and the responses were “terrible” (1), “unhappy” (2), “mostly dissatisfied” (3), “mixed” (4), “mostly satisfied” (5), “pleased” (6), and “delighted” (7). The scale yields a total score but may be summarised by a mean score across all items.

### *Strengths and Difficulties Questionnaire*

The Strengths and Difficulties Questionnaire (SDQ) is a brief questionnaire that measures psychological adjustment in children and young people aged 4-17 years (Goodman, 1997). The parent-rated version was used for the purposes of this study, but teacher and child self-report versions of the SDQ may also be used (Svedin, Priebe, 2008). Positive and negative behaviours and attributes across five domains (emotional symptoms, conduct problems, hyperactivity, peer problems, and prosocial behaviour) are rated on a 3-point Likert scale, with the following

responses: “certainly true” (2), “somewhat true” (1), and “not true” (0). The SDQ is normed in such a way that roughly 80% of children in non-clinical populations are expected to obtain scores in the ‘normal’ range for each subscale and the overall total score, 10% in the ‘borderline’ range and 10% in the ‘abnormal’ range. Diagnostic hypotheses generated by the SDQ correlate highly with those made by clinicians and it is commonly used as a screening and monitoring tool in child and adolescent primary care and mental health services in Australia, New Zealand, and further abroad (Hayes, 2007; Mathai, Anderson, & Bourne, 2004; Ministry of Health, 2009). While the capacity of the SDQ to identify psychological disorders is highest when data is collected from multiple sources, the predictive values of parent and teacher reports are approximately equal (Goodman, Ford, Simmons, Gatward, & Meltzer, 2000). A recent study in Australia (Maybery, Reupert, Goodyear, Ritchie, & Brann, 2009) included a large (N=598) normative sample, and that sample is used for comparison with the current data.

#### *Paediatrician Rating Form*

The paediatrician rating form was also designed by the primary researcher and consisted of two five-point Likert Scales which asked the paediatrician to rate the patient’s overall adherence to his/her medication regime and the patient’s current health status. The form also included a question regarding the paediatrician’s opinion as to whether the family might benefit from further psychosocial support/counselling for issues relating to the child’s health problem, which required a yes/no answer. Space was provided for further comment by the paediatrician.

### *Procedure*

Participants were selected by the primary researcher on the basis of their child's upcoming appointment at a paediatric outpatient clinic. Families were chosen if they were attending a clinic on specific days when the primary researcher would be present. Clinics were chosen from general and specialty paediatric clinics, but excluded those clinics which have psychologists available as part of their service (i.e. diabetes, obesity). Potential participants were sent an information pack containing an introductory letter to parents, information sheets, consent forms and questionnaires, with their clinic appointment letter. Parents were able to read the background information in advance, complete the questionnaire at home and bring the documentation with them to their clinic appointment if they wished. Participants were informed that if they preferred, they could meet with the primary researcher before their appointment to discuss any issues, give consent and complete the questionnaire during their time in the clinic waiting room.

On the day of their child's appointment, potential participants were approached by the primary researcher, who met with them and asked if they would like to participate and if so, checked whether they had brought the completed questionnaire with them or would prefer to complete one while they waited to see the paediatrician. In total, 167 parents were asked to participate and 15 declined involvement in the project, citing reasons such as not wishing to fill out forms or disclose personal information, or reduced ability to understand or convey information in English. Of those who agreed to participate, 12 completed

the questionnaires at home before their child's appointment, with six of those returning the information by post and the remaining six bringing the completed survey with them to their appointment. Children over the age of 12 were asked for their assent on the consent form to ensure that they were aware of and agreed to their parent/guardian providing information relating to their health. The child of each participant was allocated a code which was applied to the individual questionnaire and the separate paediatrician rating form. The paediatrician rating form was then attached to the front cover of the patient's file for the paediatrician to complete after seeing the parent and child. Paediatricians completed 100% of these forms, which were immediately returned to the researcher attached to the corresponding parent's completed questionnaire.

## CHAPTER THREE: RESULTS

The results section will begin by presenting the demographics of participants and descriptive information regarding the outcomes of the study measures, followed by the analyses related to each of the research questions.

### *Demographic Information*

One hundred and fifty two participants completed the battery of questionnaires. Subsequently, paediatricians completed rating forms for all 152 participants. Demographic information regarding gender and ethnicity is detailed in the methodology section.

Approximately half of the children were aged under five years, while approximately one third were primary school-aged. Almost one fifth of the sample were adolescents (see Table 3.1.).

Table 3.1

### *Frequencies of Children's Ages*

	x	< 2 yrs	2-4 yrs	5-8 yrs	9-11 yrs	12-16 yrs
Child's Age	5.8 yrs	23%	26.3%	21.1%	11.2%	18.4%

One hundred and forty-three parents reported their annual household income. Eighteen (12.6%) parents reported a household income under \$20,000 per annum, 22 (15.4%) between \$20,000 and \$34,999, 20 (14.0%) between \$35,000 and

\$49,999, 26 (17.1%) between \$50,000 and \$69,999, 34 (23.8%) between \$70,000 and \$99,999, and 23 (16.1%) over \$100,000.

The mean number of people in a household was 4.4, with a range of two to eight. The mean number of young people (under 18 years) in a household was 2.4, with a range of one to five. Fifty seven (39.3%) people travelled 15 or fewer kilometres to their hospital appointment, 41 (28.3%) travelled 15-29 kilometres, 30 (20.5%) travelled 30-49 kilometres, eight travelled 50-74 kilometres, four (2.8%) travelled 75-99 kilometres, and five (3.5%) travelled more than 100 kilometres.

#### *Illness type, severity and chronicity*

Fifty-three different illness types were reported by participants. For the purposes of analysis, each diagnosis was classified into one of four categories (see Table 3.2). Twenty-six (17%) did not report a diagnosis. One hundred and six children (70%) had only one illness in one category, 17 (11.2%) had illnesses in two categories and three (2%) in three categories. No children were reported to have illnesses across all four categories.

The mean number of paediatrician and general practitioner (GP) appointments attended by the child in the previous 12 months was 6.67, with a range of 1-36. Forty-seven (30.7%) parents reported that their child had attended 1-3 appointments, 43 (28.7%) attended 4-5 appointments, 14 (9.4%) attended 7-9 appointments, 29 (19.4%) attended 10-15 appointments and 12 (8.1%) attended

15 or more appointments. Six children had attended no medical appointments in the previous year and two participants did not report this data.

Table 3.2

*Illness Types and Categories*

<b>Illness Category</b>	<b>Illness Type</b>
Chronic Illness (54)	Asthma (19) Epilepsy(17) Cancer (6) Diabetes (3) Renal (2) Hearing (2) Vision (2) Rheumatic Heart Disease (1) Arthritis (1) Multicentric Reticular Histiocytosis (1)
Congenital Illness (43)	Cardiac (11) Cystic Fibrosis (7) Spina Bifida (7) Prematurity (6) Hydrocephalus (3) Cerebral Palsy (2) Down Syndrome (1) Foetal Alcohol Syndrome (1) Turner Syndrome (1) Hypospadias (1) Tuberous Sclerosis (1) Cleft Lip / Palate (1) Coeliac Disease (1)
Developmental / Psychological Disorder (15)	Neurodevelopmental (6) Attention Deficit / Hyperactivity Disorder (5) Tic Disorder (1) Autism Spectrum Disorder (1) Anorexia Nervosa (1) Schizencephaly (1)
Mild-Moderate Illness (56)	Gastric Reflux (10) Bladder Problems (incl. UTI) (7) Bowel Problems (incl. constipation) (7) Allergies (4) Failure to Thrive (3) Abdominal Pain (3) Respiratory (3) Ear Infections (2) Eczema (2) Obesity (1) Eosophinic Esophagitis (1) Dizziness (1) Headaches (1) Meconium Aspiration (1) Pneumothorax (1) Swallowing Difficulties (1) Voice Problems (1) Enuresis (1) Vitamin D deficiency (1) Hypoglycaemia (1) Fainting (1) Low muscle tone (1) Fifth Disease (1) Genu Varum (1)

Parents indicated the length of time their child had been receiving treatment for their health conditions. Seventeen (11.6%) had been receiving treatment for less than a month, 25 (17%) for one to five months, 25 (17%) for six to 12 months, 32 (21.8%) for one to three years and 48 (32.7%) for more than three years. Five participants (3.3%) did not report this data.

The mean number of hospital admissions in the previous year was 0.79, with a range of 0-12. Ninety-seven (63.8%) parents reported that their child had not been admitted to hospital in the previous 12 months. Forty-three (28.3%) reported 1-2 admissions, five (3.3%) reported 3-4 admissions and seven (4.7%) were admitted to hospital five or more times. Twenty-nine (19.3%) children were attending their first appointment at the outpatient clinic, while 121 (80.7%) were follow-up appointments, and two participants did not report the appointment type.

### *Psychosocial Support*

One hundred and twenty-eight (84.2%) parents reported that they and their children had not received any psychological input, counselling or formal emotional support for issues relating to their child's health problem, and 24 (15.8%) reported accessing these types of services. Five (3.3%) families received support from True Colours, a local service specialising in the emotional support of families with young people experiencing chronic or life-threatening illness. Eleven (7.2%) families received support from other non-governmental organisations, charitable trusts, community houses, and support groups (e.g. Parent to Parent, CARE Services, Cancer Society, Parenting Workz). Four (2.6%)

parents reported that their children had received specialist mental health services from a psychiatrist or psychologist.

Of the 151 participants who rated the perceived importance of psychological support and their personal interest in receiving psychological support, 80 (53%) rated the provision of psychological services for families experiencing child illness as 'very important', 53 (35.1%) as 'quite important', 17 (11.3%) as 'somewhat important', and one (0.7%) as 'not important'. Forty-nine (32.5%) parents rated themselves as being 'very interested' in receiving psychological support, 39 (25.8%) reported being 'quite interested', 39 (25.8%) were 'somewhat interested', and 24 (15.9%) were not interested.

#### *Paediatrician Ratings.*

Paediatricians rated the medication adherence of the participants' children. This rating did not apply to 53 children in the sample, as they were not currently receiving pharmacological treatment. Of the 99 remaining children, 75 were perceived as having 'high' or 'very high' adherence (42.9% and 32.7% respectively). Nineteen (19.4%) were perceived as having moderate adherence, four (4.1%) were perceived to have 'low' adherence, and one child (1.0%) was rated as 'very low'.

Paediatrician ratings of the child's current health status indicated that 44 children were perceived as having 'very good' health (28.9%), 64 were 'quite good' (42.1%), 38 were 'moderate' (25%), 5 were 'poor' (3.3%), and 1 was 'very

poor' (0.7%). Paediatrician ratings of the families' need for psychosocial input on a dichotomous (yes/no) scale indicated that paediatricians thought that 59 (38.8%) families could benefit from psychological support for issues relating to their child's illness.

#### *Depression Anxiety Stress Scale*

One-sample T-tests were carried out in order to examine whether there were significant differences between the mean DASS subscale scores in the sample and in a normative sample (Lovibond & Lovibond, 1995). Mean DASS stress scores were found to be significantly higher in parents in this sample than that in the normative sample. Mean total DASS scores were significantly higher than those seen in parents in the normal sample (see Table 3.3). Scores on the DASS Depression and Anxiety subscales were not significantly different from the normative sample.

Table 3.3

#### *One Sample T-Test - DASS Means*

	Current Sample		Normative Sample		2-tailed <i>p</i>
	<b>x</b>	<b>sd</b>	<b>x</b>	<b>sd</b>	<b>Sig.</b>
DASS Depression	5.90	7.33	5.55	7.48	.554
DASS Anxiety	4.28	6.15	3.56	5.39	.154
DASS Stress	11.55	9.41	9.27	8.04	.004**
DASS Total Score	21.74	20.55	18.38	3.35	.048**

Using a clinical cut-off of 10 on the depression subscale of the DASS-21, 8 on the anxiety subscale and 15 on the stress subscale, the majority of participants

reported symptoms in the normal range. A small proportion of parents reported subscale scores in the mild to moderate clinical ranges. A higher degree of severe and extremely severe symptoms were reported on the stress subscale than on the depression and anxiety subscales. None of the parents had depression scores in the ‘extremely severe’ range (see Table 3.4 below for all DASS subscale ranges).

Table 3.4

*DASS Subscale Range Frequencies*

DASS Scores	Normal		Mild		Moderate		Severe		Extremely Severe	
	N	%	N	%	N	%	N	%	N	%
Depression	127	83.6	11	7.4	13	8.8	1	0.7	-	-
Anxiety	120	78.9	9	6.0	13	8.8	4	2.6	6	4.1
Stress	110	72.3	15	10.1	11	7.4	11	7.4	5	3.3

*Strengths and Difficulties Questionnaire*

One-sample T-tests were carried out in order to assess whether there was a significant difference between SDQ score means in this sample and an Australian normative sample (Maybery, Reupert, Goodyear, Ritchie, & Brann, 2009). Means, standard deviations and significance are recorded in Table 3.5. The mean emotional problem scores of children in this sample was significantly higher than that of children in a normal population. Mean conduct problem scores in this sample were significantly higher than those in the normal population. The mean scores on the hyperactivity scale of the SDQ were also significantly higher than that of children in the normative group. Mean peer problems scores were significantly higher than normal sample mean. Finally, the mean SDQ total

difficulties scores in the current sample were found to be significantly higher than normal. No significant difference was found between the mean scores on the prosocial subscale.

Table 3.5

*One Sample T-Test - SDQ Subscale Score Means*

	Current Sample		Normative Sample		Sig.
	<b>x</b>	<b>sd</b>	<b>x</b>	<b>sd</b>	
SDQ emotional	3.27	2.55	2.12	2.09	.000
SDQ conduct	2.30	2.41	1.62	1.72	.017
SDQ hyperactivity	4.79	2.88	3.27	2.38	.000
SDQ peer problems	2.79	1.99	1.63	1.75	.000
SDQ prosocial	7.47	1.93	7.71	1.65	.289
SDQ total difficulties	13.13	1.99	8.65	5.84	.000

As outlined in the materials component of the methodology section, in a normative sample approximately 80% of children would be expected to obtain scores in the ‘normal’ range of the SDQ, 10% in the ‘borderline range and 10% in the ‘abnormal’ range.

Seventy six parents completed the SDQ as their children met the age criteria for use of the scale (age between four and 16 years). Of these 76 participants, approximately one-third of the children were rated as having peer problems in the ‘abnormal’ range and one-fifth in the ‘borderline’ range. Almost one-third of the children were rated as having emotional symptoms in the ‘abnormal’ range, with nine in the ‘borderline’ range. A quarter of the children were rated as demonstrating levels of hyperactivity in the ‘abnormal’ range, with 12 in the

‘borderline’ range. Over one-fifth of the children were rated as having conduct problems in the ‘abnormal’ range and 11 in the ‘borderline’ range. Over a quarter of the children obtained total difficulties scores in the ‘abnormal’ range. Finally, the SDQ prosocial subscale indicated that the majority of children were perceived by their parents to demonstrate a ‘normal’ degree of prosocial behavior (See Table 3.6 for SDQ subscale score frequencies).

Table 3.6

*SDQ Subscale Score Frequencies*

SDQ Scores	Normal		Borderline		Abnormal	
	N	%	N	%	N	%
Emotional Symptoms	45	59.2	9	11.9	22	28.9
Conduct Problems	48	63.2	11	14.4	17	22.4
Hyperactivity	50	65.8	15	10.1	11	7.4
Peer Problems	38	50.0	16	20.8	22	28.9
Prosocial	63	82.9	8	10.5	5	6.6
Total Difficulties	44	57.8	11	14.4	21	27.6

*Correlational Analysis*

In order to address the following research questions, correlations and regressions were carried out. The first objective was to assess the degree of relationship between parent and child psychological distress scores. Spearman correlations between the DASS and the SDQ subscales were carried out in order to assess the degree of relationship between specific psychological symptoms present in parents and children (see Table 3.7 below). Spearman correlations were chosen as many of the subscales of these measures of distress and problem behaviours were not

normally distributed. Scores on the DASS stress subscale were significantly correlated with scores on the SDQ emotional, hyperactivity and peer problem subscales. Scores on the DASS anxiety subscale were also correlated with scores on the SDQ emotional, hyperactivity and peer problem subscale. DASS depression subscale scores were significantly correlated with the SDQ hyperactivity and peer problems subscales.

Table 3.7

*Spearman's Correlations between parent (DASS) and child (SDQ) measures*

		SDQ emo	SDQ conduct	SDQ hyper	SDQ peer	SDQ prosocial
DASS Stress	Spearman	.341**	.144	.294**	.380**	-.087
	Sig (2-tailed)	.003	.214	.009	.001	.454
	N	76	76	77	77	76
DASS Anxiety	Spearman	.339**	.052	.334**	.416**	-.044
	Sig (2-tailed)	.003	.653	.003	.000	.709
	N	76	76	77	77	76
DASS Depression	Spearman	.212	.142	.335**	.386**	-.140
	Sig (2-tailed)	.066	.221	.003	.001	.226
	N	76	76	77	77	76

\*\* Correlation is significant at the 0.01 level (2-tailed)

The next question in the analysis was regarding the relationships between distress scores and parent ratings of quality of life. In order to assess this, Spearman correlations between the total DASS and SDQ and mean QOL scores were conducted. Total scores on the DASS were significantly correlated with total SDQ scores. A negative correlation between the DASS total scores and mean QOL ratings was identified (see Table 3.8).

Table 3.8

*Spearman's Correlations between DASS total scores, SDQ total scores and QOL*

		DASS Total	SDQ Total
DASS Total Score	Spearman	-	.401**
	Sig (2-tailed)		.001
	N		76
SDQ Total Score	Spearman	.401**	-
	Sig (2-tailed)	.001	
	N	76	
Mean QOL	Spearman	-.524**	-.155
	Sig (2-tailed)	.001	.181
	N	152	77

\*\* Correlation is significant at the 0.01 level (2-tailed)

The next objective of the analysis was to understand what factors contributed to parents' level of interest in psychological services. Logistic regression analyses were carried out in order to identify which variables served as predictors of parents' level of interest in receiving psychological services. The parent rating was dichotomised, combining 'not interested' and 'somewhat interested' into "less interested in services" (42% of total), and 'quite interested' and 'very interested' into "more interested in services" (58% of total). This allowed for the use of logistic regression, which does not require the assumptions of normality of predictor variables as does multiple regression, and also allowed for more clear comparisons between analyses of parent and paediatrician opinions. Child's age, number of admissions and paediatrician visits, treatment length, illness types, DASS total score and Quality of Life were entered as predictors based on

empirical and theoretical factors expected to predict desire for services. The results of this indicated that parent interest in receiving support was predicted by child's older age ( $p = .013$ ), congenital illness ( $p = .030$ ) and DASS total scores ( $p = .000$ ) (see Table 3.9). A Nagelkerke R square estimate of .37 indicated that this combination of variables explained 37% of the variance of this outcome (see Table 3.9).

Table 3.9

*Summary of Logistic Regression Analysis for Variables Predicting Parent Interest in Support*

Variable in the equation	B	S.E	<i>p</i> value	Lower C. I. (95%)	Exp(B)	Upper C. I. (95%)
Child's Age	.125	.050	.013**	1.027	1.133	1.250
Admissions	.259	.171	.131	.936	1.295	1.812
Paediatrician Visits	-.050	.044	.250	.873	.951	1.036
Tx Length	-.173	.179	.334	.592	.841	1.195
Congenital Illness	1.422	.654	.030**	1.150	4.147	14.948
Developmental Illness	.745	.863	.388	.388	2.106	11.428
Chronic Illness	.333	.576	.563	.452	1.395	4.313
Mild-Moderate Illness	.685	.602	.255	.610	1.984	6.457
DASS Total Score	.077	.019	.000**	1.041	1.080	1.120
Quality of Life	.423	.312	.175	.828	1.526	2.813
Constant	-5.695	2.651	.032		.003	

A second logistic regression was conducted in order to further explore the contribution of parental distress to desire for services. In this analysis, three DASS subscales were substituted for the DASS total score. The final model is shown in Table 3.10; significant predictors included age ( $p = .009$ ), congenital illness ( $p = .020$ ), and the DASS depression subscale ( $p = .001$ ), as well as Quality of Life ( $p$

= .049). This combination of variables produced a Nagelkerke R square of .43, suggesting that the model explains approximately 43% of the variance in parent desire for psychological services.

Table 3.10

*Summary of Logistic Regression Analysis for Variables Predicting Parent Interest in Obtaining Psychological Support for Family - with DASS Subscales Included*

Variable in the equation	B	S.E	p value	Lower C. I. (95%)	Exp(B)	Upper C. I (95%)
Child's Age	.137	.053	.009**	1.034	1.147	1.271
Admissions	.215	.174	.217	.881	1.240	1.745
Paediatrician Visits	-.021	.044	.639	.899	.980	1.067
Tx Length	-.182	.186	.329	.579	.834	1.201
Congenital Illness	1.646	.709	.020**	1.292	5.187	20.823
Developmental Illness	.926	.921	.315	.415	2.524	15.345
Chronic Illness	.415	.583	.476	.483	1.515	4.747
Mild-Moderate Illness	.738	.624	.237	.615	2.092	7.112
DASS Stress	.046	.039	.239	.970	1.047	1.129
DASS Anxiety	-.059	.064	.355	.831	.943	1.069
DASS Depression	.274	.083	.001	1.119	1.316	1.547
Quality of Life	.666	.337	.049**	1.004	1.946	3.770
Constant	-7.667	2.894	.008		.000	

In order to understand more about how paediatrician's perceive patients and families' psychosocial needs, logistic regression analyses were conducted in order to establish which variables were associated with paediatricians indications that families would benefit from psychosocial support. Child's age, number of admissions and paediatrician visits, treatment length, illness types, DASS total score and Quality of Life were entered as predictors. This analysis revealed that child's older age and mean quality of life scores predicted paediatricians' ratings

of support need (see Table 3.11). The Nagelkerke square of .28 suggested that the significant variables in this model explained 28% of variance in paediatrician's opinions about the need for psychosocial support.

Table 3.11

*Summary of Logistic Regression Analysis for Variables Predicting Paediatrician Indications of Psychosocial Need*

Variable in the equation	B	S.E	<i>p</i> value	Lower C. I. (95%)	Exp(B)	Upper C. I. (95%)
Child's Age	.142	.048	.003**	1.050	1.153	1.266
Admissions	.025	.125	.844	.803	1.025	1.309
Paediatrician Visits	-.013	.038	.731	.916	.987	1.064
Tx Length	.059	.166	.722	.766	1.061	1.469
Congenital Illness	-1.106	.574	.054	.107	.331	1.019
Developmental Illness	-.998	.741	.178	.086	.369	1.576
Chronic Illness	-.539	.541	.320	.202	.584	1.686
Mild-Moderate Illness	-.812	.570	.154	.145	.444	1.357
DASS Total Score	.007	.012	.582	.983	1.007	1.030
Quality of Life	-.688	.294	.019**	.282	.503	.894
Constant	4.504	2.302	.050		90.421	

## CHAPTER FOUR: DISCUSSION

The main aims of this project were to explore the how the distress levels of parents and children utilising paediatric health services relate to each other and what level of psychosocial need and interest exists in this population. The results of the study indicate that parents in this sample experience significantly higher degrees of psychological stress than those in normal populations and perceive their children to experience a significant degree of emotional, behavioural and social difficulties. Parents report a high level of support for and interest in the provision of paediatric psychology services and paediatricians perceive that a significant proportion of this group could benefit from psychosocial input.

### *Distress Levels*

According to the results of the DASS-21, parental distress in the form of anxiety and depression did not differ significantly from that found in normative samples (Lovibond & Lovibond, 1995). However, mean stress levels were significantly higher than normative means, which indicated that for this sample, stress may have been the greatest personal difficulty that parents encountered. This finding replicates the results of a number of other studies which suggest that clinically significant levels of stress are a problem for the parents of unwell children and can be considered in terms of a theoretical framework of stress and coping (Lazarus & Folkman, 1977; Thompson, Gustafson, George, & Spock, 1994). The literature suggests that a number of aspects of child illness (such as diagnosis, management tasks and engagement with medical services) act as

stressors to which parents must respond with coping strategies (Krulik et al., 1999; Thompson, Gustafson, George, & Spock, 1994). The levels of clinically significant stress present in this sample are of concern as they are not only distressing to parents, but may place them at increased risk of developing more severe psychological disorders, such as clinical depression and anxiety (Halgin & Whitbourne, 2007).

Scores on the emotional problems, hyperactivity, conduct and peer problems subscales of the SDQ were significantly higher than those seen in normal populations, which indicated a considerable degree of distress and behavioural problems were present in this sample (Maybery, Reupert, Goodyear, Ritchie, & Brann, 2009). This finding is particularly important as it highlights that the psychological needs of children with physical illnesses are significant and suggests they are at higher risk of emotional and behavioural difficulties as a result of their medical condition. It reflects the literature which indicates that children with health conditions have increased vulnerability to emotional symptoms related to depression and anxiety (Hysin, Elgen, Gillberg, Lie, & Lundervold, 2007; Katon et al., 2007; Wagner et al., 2009), behavioural problems and hyperactivity (Glazebrook, Hollis, Heussler, Goodmand, & Coates, 2003), and social difficulties (La Greca, 1990; Reiter-Purtill & Noll, 2003).

The relationships between parental and child distress were illustrated by moderate correlations between a number of these variables. Essentially, the results suggest that anxious or stressed parents are more likely to perceive their children

as having emotional problems, hyperactivity and peer problems. Similarly, depressed parents are also likely to perceive that their children are hyperactive or have peer problems, however there was no association between depression in parents and emotional problems in children. These results support the hypothesis that a significant association exists between the psychological functioning of parents and children. The lack of association between depression in parents and emotional problems in children contradicts research which suggests depressed parents are more likely to rate their children as experiencing similar difficulties (Thompson, Gustafson, Hamlett, & Spock, 1992) and is worthy of further investigation. The remainder of these correlations clearly demonstrated that distress levels in parents and children, as measured by the DASS-21 and SDQ, are significantly related to each other. A causal relationship cannot be ascertained on the basis of this correlation, but there remains the possibility that a reciprocal relationship exists between these factors, with parent distress influencing child distress and vice versa.

Also of significance was the substantial negative correlation between total DASS scores and mean ratings of quality of life ( $r = -.524$ ). This relationship between higher overall distress and poorer quality of life supports the findings of previous studies which have suggested that the significant stress and distress experienced by parents of children with ill health may impact on quality of life (Boling, Macrina, & Clancy, 2003; Everhart, Fiese, & Smyth, 2008). While the causal direction of this relationship is unclear, it is possible that psychological distress has a detrimental effect on the factors which determine quality of life,

such as close relationship, community and social participation, and work (Everhard, Fiese, & Smyth, 2008).

### *Parent Interest in Support*

In exploring the service use profile of this population, and parents' levels of interest in and support for paediatric health psychology services, it was noteworthy that the vast majority of families had not received any formal psychological support for issues relating to their child's health condition. Those that had received input tended to engage with support agencies such as community house and non-governmental providers such as *Parenting Workz* and *True Colours*. As the number of families who had received formal support was so small, it was not possible to assess whether this group's overall psychological functioning differed from those who had not received input. Further investigations into possible differences between these two groups would be worthwhile in providing a deeper understanding of the possible benefits of psychosocial support in paediatric populations.

In spite of this lack of service use (or possibly availability), 88% of parents perceived the provision of paediatric health psychology service use to be 'very' or 'quite' important. This was supported by qualitative comments regarding access and availability, many of which noted that even if one did not feel that such services were a current personal requirement, it was very important to know that if psychosocial needs increased services would be available to support families.

Over half (58%) of the sample described themselves as being ‘quite’ or ‘very’ interested in receiving psychological support. This represented a significant proportion of the sample and suggests that parents not only perceive their families’ psychosocial needs as being high, but also place value upon the delivery of such services. Such a degree of interest indicates that the delivery of paediatric health psychology services might be seen to have a great deal of support at a community level and may be viewed by stakeholders as an area worthy of further investigation.

Variables which predicted parent interest in support included child’s older age, congenital illness and overall parental distress as measured by the DASS total score. However, these factors only explain 37% of this outcome, which suggests that there are other, unidentified variables which are important in this equation. In regards to child’s age, it is possible that as children grow, emotional and behavioural problems may appear to be more significant or have a more serious impact on functioning. It may also be that parents do not consider that younger children could benefit from psychological input. However, the question regarding interest in support did not merely refer to the child’s needs, but also the parents’. Further investigation is needed in order to understand what other factors might explain this association. The parents of children with congenital illness are also more likely to be interested in receiving support. This finding may relate to the nature of congenital illness (i.e. a condition that is present from birth) and the possibly ongoing, chronic aspects of such children’s difficulties.

The finding that overall parental distress is a predictor of parental interest in support indicates that parents who report a high level of difficulties perceive that psychological input for them and their family may help to address their difficulties and alleviate their distress. This suggests that asking parents whether they are interested in receiving psychological support may be a valid aspect of screening for distress and may provide some degree of insight into the level of difficulty which exists.

When DASS subscales were included in the regression analyses investigating parental interest in psychological support, child's age and congenital illness remained significant. DASS depression scores were also associated with parental interest in support, which may suggest that while depression levels in this sample did not significantly differ from those in normative samples, parents who do experience depressive symptoms consider their level of need to be higher than parents who experience clinical symptoms of anxiety and stress.

The analysis which included DASS subscales revealed an interesting finding regarding quality of life. Parents with higher mean ratings of quality of life were more likely to be interested in services. This variable was only significant ( $p = .049$ ) in this particular equation and is somewhat puzzling in that it seems to contradict the finding that higher distress levels are associated with greater interest in support. The direction of this relationship was opposite to that found between paediatricians' indications of need and quality of life, which will be examined later in the discussion. It could be that the positive relationship between quality of

life and service interest reflects the possibility that those with higher quality of life are more likely to engage in relationships with health practitioners and experience decreased medical service access difficulties; however, further research is required in order to understand this association.

#### *Paediatrician Perceptions of Support Need*

Paediatricians' indications that almost 40% of the sample could benefit from psychosocial input for issues relating to their child's illness are significant and suggest that medical practitioners detected a high level of need in a large proportion of their patients. The logistic regression analysis that examined which variables might contribute to such opinions again highlighted the significance of child's older age. Explanations for this association may be similar to those regarding the relationship between parent interest in support and child's age, in that children's emotional and behavioural presentation will likely change as they grow older and may become more concerning as they mature. It is also possible that children who are older may have been receiving treatment for longer periods of time and therefore paediatricians may have greater knowledge of these families' difficulties, although it is noteworthy that treatment length was not a significant predictor of support need and therefore would not entirely account for this association.

Quality of life ratings were also associated with paediatrician's ratings of support need, however this relationship was in the opposite direction to that of parent interest and quality of life—those with lower quality of life were more

likely to be nominated as needing services. It would seem that paediatricians detected that some families were experiencing lower levels of quality of life and considered this to be an issue which could be addressed by psychosocial intervention.

### *Implications for Service Delivery*

The combination of distress in this population, parent interest in psychological services and paediatricians' views that a large proportion of the sample would benefit from psychosocial support, raises a number of questions regarding the possible delivery of health psychology services to families accessing outpatient paediatric clinics at Waikato Hospital. While the results do not yield clear answers to such questions, it is appropriate here to review the implications of the current findings and examine possible solutions to some of the issues raised.

### *Identifying Need*

The results of this study suggest that approximately 20-30% of families accessing paediatric clinics experience clinically significant levels of psychological distress. For the purposes of this research, we were able to administer psychometric evaluations to an entire sample of families and identify the level of need present in these individuals. However, there may be difficulties outside of a research context in assessing and ascertaining the needs of parents and children in this population due to issues related to the routine use of psychometric tools, which are more closely examined later in this discussion.

The results of the logistic regression analysis that evaluated which variables predicted paediatricians' perceptions that families would benefit from psychosocial input showed that while quality of life was significant as a predictor, DASS and SDQ scores were not. It would seem that identifying which parents and children are experiencing significant distress is complex and such symptoms may not be easily detected by medical personnel. This difficulty may be confounded by factors such as limited appointment times, a specific focus on physiological problems in-session, and families feeling reluctant to disclose psychological issues to their paediatrician. Thus, it seems that assessment of which families have the highest level of psychological needs may not be most accurately made by paediatricians alone.

Self-report psychometric inventories such as the DASS or SDQ are relatively simple to administer and may be suitable to use as screening devices for the detection of emotional and behavioural problems (Mitchell, Burns & Dorstyn, 2008; Warnick, Bracken, & Kasl, 2008). However, such devices are not valid diagnostic tools and it is generally advised that they be administered by practitioners who are trained in their scoring and interpretation (Goodman, 1997; Lovibond & Lovibond, 1995). Nonetheless, the SDQ has been found to be valid as a screening tool in both community and clinical samples and it is possible that it may be appropriate for use in paediatric outpatient clinics in New Zealand (Warnick, Bracken, & Kasl, 2008).

Administering psychometric screening devices to parents may be seen as being inappropriate to those who consider the individual child to be the only ‘patient’ in a paediatric medical appointment. Certainly it seems possible that parents may be confused or offended if, on arriving at a paediatrician visit, they were to find themselves being asked to consent to psychological screening themselves. While the literature clearly demonstrates the relationships between child and parent distress, adherence and health outcomes, such interactions may not be commonly understood and the rationale for using a tool such as the DASS as a screening method for parents may be quite unclear. It raises difficult questions regarding the appropriateness of parental screening and would perhaps require a dramatic reconceptualisation of who the ‘client’ is in paediatric settings - is it, as it has been traditionally, the child? Or do health practitioners and psychologists need to move towards viewing the entire family as being ‘the patient’? If so, what would that mean for the allocation of health funding and resources? And how would parents and medical practitioners view such a change? Answering such questions is well outside the scope of this discussion, but if district health boards are to seriously consider the wider provision of health psychology services, it seems these are questions which at the very least need to be openly debated by clinicians and policy-makers.

It might be argued that in an ideal world, all families receiving paediatric health care would have the opportunity to meet with a psychologist on entry to the service. Indeed, in the Waikato this is the case for children and adolescents with diabetes, who are referred to the Diabetes Service Clinical Psychologist upon

diagnosis and may choose to receive ongoing psychological input and support with coping, adjustment and adherence. However, the sparseness of such clinical resources, and the high number of children accessing general paediatric clinics in the Waikato may make it difficult to provide such a service on a large scale. It may be that an efficient mode of psychological screening would need to be developed in order to identify individual psychological needs in this population.

### *Entry Criteria*

If an appropriate method of identifying psychological need in local paediatric health population were to be identified, this would raise a number of issues related to what level of need might indicate that psychosocial support services are required. For example, if a psychometric screening tool such as the SDQ were to be used in a paediatric outpatient clinic, it would seem that a particular score (or range of scores) would need to constitute a service entry criteria cut-off. It could be that an SDQ score in the borderline or abnormal range might indicate the need for further psychological assessment. However, if the results of this study are extrapolated to the general paediatric population, this might lead to approximately 20-30% of children utilising outpatient clinics being referred for specialist psychological assessment. Wang, Ngui & Yap's (2009) evaluation of the Waikato Hospital paediatric outpatient clinics indicated that approximately 500 children were seen per month in the clinic. If 20-30% of these children were to receive psychological input, this would be approximately equal to 100-150 children per month, without yet accounting for the potential needs of parents and siblings. The

resource and practical implications of this level of service make it unlikely to be implemented.

Therefore, it seems that the mere presence of distress might not be the most appropriate form of entry criteria to a hypothetical health psychology service. It may be that such a service would be required to adopt entry rules which limited the provision of services to the most severe of cases, as is seen in the national district health board mental health services which are ostensibly mandated to provide services to the most unwell 3% of the general population (Ministry of Health, 2003). However, this raises ethical issues around the detection of psychological needs and the possibility that a health psychology service may not be able to provide services those identified as high need. In this case, it would be important that other appropriate services were identified to which parents and children could be referred if necessary.

### *Service Type*

Psychological interventions such as cognitive behaviour therapy have been found to be effective methods of treating depression, anxiety and stress in adults; emotional, behavioural and social difficulties in children; and poor medical regimen adherence (Christie & Wilson, 2005). Therefore it does not seem unreasonable to suggest that psychological therapies be utilised in order to address such difficulties in New Zealand paediatric settings. However, it is possible that for some parents and children there may be other appropriate types of intervention and support which could effectively address their psychosocial needs. A number

of paediatrician comments in this study suggested that several families are currently being effectively supported by counselling services such as True Colours, which assist them in dealing with grief, adjustment and practical issues relating to their child's health conditions. Several comments also pointed to the supportive presence of Child Youth and Family social workers, who may help families in dealing with parenting practices, accessing medical appointments and other social issues.

It is possible that some families under stress may benefit from increased short-term respite care hours, which are currently provided by the Ministry of Health to carers of children with serious disabilities and chronic illness (Ministry of Health, 2009). The results of this study suggest that distress levels are not strongly associated with illness severity or chronicity, however, which may indicate that families of children who do not qualify for disability assistance and respite care may have a similar level of need as those who do.

#### *Timing of Delivery*

The literature suggests that most families tend to have higher levels of distress in the months immediately following their child's diagnosis. Previous research also indicates that distress tends to decrease over time; however for a sub-set of families such difficulties may persist for much longer periods. The results of the current study indicate that in our sample, distress levels were not associated with treatment length. This suggests that the needs of some families accessing paediatric outpatient clinics are high even after long periods of time have

elapsed post-diagnosis. While this finding reflects much of the literature that refers to families' ongoing psychological needs, it also challenges the theory posited by some researchers that distress levels are at their highest immediately following diagnosis. The quantitative results are supported by qualitative comments by the parents: for example, the comment that families require "more support and acknowledgement of the various stages of the illness. For example, I got through the initial grief at three years - now need 'offload' support at seven year mark." This example clearly illustrates the variety of challenges (in this case, emotional and practical) faced by parents and children in this population, and the dynamic nature of their needs.

The suggestion here is that it is not appropriate to assume that families simply need help in the initial stages of illness as they are adjusting to the shock of a child's diagnosis and the demands of health management tasks. Stages of parent grief may be re-visited at various points in the course of a child's illness, and the changing developmental and social needs of children may lead to different types of problems arising at various times in a young person's life (Chen et al., 1998; Wijnberg-Williams, Kamps, Klip, & Koekstra-Weebers, 2006). Some children may also experience a gradual deterioration in health, particularly those with chronic or terminal illnesses, possibly leading to an increase in psychological needs over time (Katon et al., 2007). Paediatrician comments also referred to this possibility, with several highlighting the likelihood that as a child's health condition worsened, their family may need increased support.

The quantitative results in this study suggest that many parents and children in paediatric outpatient clinics are experiencing distress, and could benefit from the delivery of psychological or social intervention, and that a large proportion of families are interested in receiving such support. Paediatricians also recommend that many families could benefit from some form of psychosocial input. Furthermore, both paediatrician and parent comments suggest that such services need to be available to families on a voluntary, ongoing basis, so that issues relating to their child's health problem may be appropriately addressed as they arise.

#### *Limitations of the Research*

One limitation of this study is that measures of parent distress relied on self-report and measures of child distress relied on parent-report. Self and parent-report inventories may be subject to perception bias and may also be skewed by social desirability bias.

Another limitation of this study is that the vast majority of parent respondents were female, resulting in a lack of information regarding the psychological functioning of male caregivers in the study. This was largely due to the tendency for children to be accompanied by female caregivers to their paediatrician appointment. When male caregivers were in attendance, it was usually alongside their female partners and in all but one of these instances it was the female who opted to complete the battery of questionnaires. Further research might need to

deliberately approach fathers or other family members in order to understand the impact of child illness on the broader family.

The paediatrician rating form developed by the researcher is a non-validated tool which may have resulted in a number of limitations. Paediatricians provided feedback during the development of this tool which resulted in the original item regarding overall medical regimen adherence being changed to reflect only medication adherence. This resulted in the question being marked as ‘non-applicable’ for a larger number of children who were not prescribed medication, but may have received other lifestyle, diet or physiotherapy instructions from their physician. Paediatrician perceptions of adherence may also be subject to bias, and we have no information as to the validity of these ratings.

The second paediatrician-rated item regarding the child’s current health status, tended to yield ratings of ‘good’ to ‘very good’, even in the case of children with chronic, life-threatening illnesses. Using a subjective rating method such as a Likert scale to measure a largely objective phenomenon such as physical health may have resulted in paediatricians providing ratings which reflected ‘relative’ health status (e.g. compared to prior or future wellbeing, or to other patients with similar conditions).

The final question on the Paediatrician rating form, which asked whether families could benefit from psychosocial input for issues relating to their child’s health problems, may have been limited by differences in paediatricians’

understanding of the definition of the word ‘psychosocial’. It is possible that this word may have been interpreted to mean a number of different types of input, such as psychiatric, counselling or social work. Answers may also have reflected differing understandings about what type or level of problems indicate the need for formal psychosocial assistance.

Another limitation of this study is that only families who attended their child’s appointment were included in the sample, while there were a number of children and parents who did not attend (known colloquially within clinics as ‘DNA’s’). As lack of access and engagement with medical practitioners is a significant issue in the health field, it is possible that the needs of some at-risk families were not able to be evaluated, which could have led to a positive skew in the data.

### *Conclusions and Future Directions*

This research reflects international findings and adds significantly to what is known about the psychological needs and level of interest in receiving psychological support of families in paediatric health populations in New Zealand. Future research might look more closely at the specific nature of parent and children’s problems and what factors contribute to the development of psychological distress in health populations. Further examination of the qualitative aspects of families’ experiences of child illness may yield a greater understanding of which factors families perceive as being associated with their

difficulties and what type of services would provide the most assistance in each instance.

Future research might also examine the differences between families who have received psychological input and those who have not, in terms of their distress levels and demographic profiles. Further investigation is also necessary in order to explain why the age of a child is associated with both paediatricians' perceptions of family support needs and parents' level of interest in support.

The issues outlined in this discussion relating to the delivery of health psychology services in New Zealand certainly warrant a great deal of further examination by clinicians, service providers, funders and policy analysts. As the results of this study suggest that the psychological needs of this population are significant, it would seem that it is important for all those involved in the development and provision of paediatric health care to give serious consideration to the role that paediatric psychology services may have in medical settings such as outpatient clinics, and how the psychological and physical well-being of New Zealand families might be further improved through the use of psychosocial interventions.

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### Appendix A: Introductory Letter to Parents / Guardians

This appendix contains the introductory letter sent to parents / guardians prior to their child's paediatrician appointment, inviting them to participate in the research.

Psychology Department  
University of Waikato  
Private Bag 3105  
Hamilton

7 January 2009

Dear Parent / Guardian

I am a Clinical Psychology student at the University of Waikato conducting a Masters of Social Science research project which will look at the psychological needs of children and families attending the paediatric clinics at Waikato Hospital.

As part of this project, I am interested in finding out more about some of the problems faced by parents and children with medical issues. As your child has an upcoming appointment at a paediatric clinic, I would like to invite you to participate in this project by filling out the attached questionnaire.

**The information you provide will remain confidential. Participation is voluntary. If you choose not to participate, the healthcare your child receives will not be affected.**

Please find enclosed an information sheet, consent forms and the questionnaire. If you would like to participate, please read the information sheet, sign both consent forms, and complete the questionnaire. You can send the questionnaire back using the stamped, self-addressed envelope enclosed.

If you would prefer to meet with me in person to complete the questionnaire or ask questions, I will be available to meet with parents in the waiting room of your child's next clinic. If you would like to participate in this way, please bring the consent forms and questionnaire along when you attend your child's appointment.

If you have any queries, please do not hesitate to contact me on (### ####).

Thank you very much for your time.

Yours sincerely

Rosalind Case  
Chief Investigator

## Appendix B: Information Sheet - Parents / Guardians

This appendix contains the Information Sheet for Parents / Guardians designed by the primary researcher.

## **Paediatric Psychological Needs Assessment Information Sheet**

Contact: Rosalind Case, Department of Psychology, University of Waikato  
Telephone:  
Email:  
Supervisor: Dr Carrie Barber (University of Waikato)

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### **What is this study about?**

You are invited to participate in a research project to evaluate the psychological and emotional needs of parents and children with health conditions. Participation is voluntary. The reason for this study is to find out what the needs of parents and children are so that access to appropriate counselling and psychological support services can be improved.

### **What does the study involve?**

The study involves a written questionnaire which will ask you for information about your child's and your own feelings and behaviours. This questionnaire should take about 10-20 minutes to complete.

If you choose to participate in this study, your child's paediatrician will also complete a form which will rate your child's health status, medication adherence and whether he/she believes that further support would be useful for your family.

**If you have received this questionnaire in the mail, you can choose to complete it and either post it (stamped self-addressed envelope is enclosed) or bring it with you to your child's next clinic appointment.**

Or, if you would rather, you may complete the questionnaire in the waiting room at your child's next appointment. Rosalind Case from the University of Waikato will be attending this clinic and will be available to answer questions about the study and assist you with completing the questionnaire.

**What will happen to my information?**

All of the information you provide will remain confidential. Your completed questionnaire will be held in a locked filing cabinet in the Psychology Department at the University of Waikato and will be destroyed at the completion of the project. If you would like to receive a copy of the summary of findings from this research, these will be provided.

**If you choose to participate in this study, what are your rights?**

The researchers will respect your rights to:

- Withdraw from the study at any time
- Ask questions about the study at any time
- Decline to answer questions
- Remain anonymous in the study findings
- Be given a summary of the research findings

Choosing to participate or declining participation in this study will not affect the standard healthcare your child receives. If you have any concerns about your rights, an independent Health and Disability Advocate can be telephoned on 0800 423 638.

If you have any further questions relating to this study, please contact Rosalind Case.

Thank you.

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**Contacts for psychological assistance outside the study**

There are no psychological risks envisaged with participation this study. However, if you find anything upsetting and wish to obtain outside support, you may wish to contact one of these agencies

- Lifeline Waikato  
Ph: 0800LIFELINE

- Linkage  
129 Tristram St  
Hamilton  
Ph 839 2828  
(For referrals to other organisations)

### Appendix C: Information Sheet - Youth

This appendix contains the Information Sheet for Young Persons aged 12-16 years, designed by the primary researcher.

# Paediatric Psychological Needs Assessment Information Sheet for Patient/Young Persons

Contact: Rosalind Case, Department of Psychology, University of Waikato

Telephone:

Email:

Supervisor: Dr Carrie Barber (University of Waikato)

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## **What is this study about?**

Your parent/guardian has been asked to participate in a study about the psychological and emotional needs of parents and children who are attending the hospital children's clinics. The reason for this study is to find out more about the needs of parents and children so local healthcare services can be improved.

Your parent or guardian does not have to participate in the study. Participation is voluntary and there will not be any effect on your health care if you or your parent/guardian do not wish to be involved.

## **What does the study involve?**

The study involves a written questionnaire which will ask your parent/guardian about their feelings and behaviours, and how they think you might be feeling and behaving. It will take them about 10-20 minutes to do the questionnaire. You do not have to be with them during this time, but it is okay if you would like to be.

This study will also ask your paediatrician from the hospital clinic to fill out a form. The form will ask your paediatrician to rate your current health, how you are taking care of your illness, and whether he/she believes that further support would be useful for you or your family.

## **What will happen to my information?**

All of the information provided by your parent/guardian and paediatrician will be private and confidential. When the results of this study are summarised for doctors and health care workers, your name will not be used and no one aside from the researchers will see the questionnaires that your parent/guardian and paediatrician complete.

## Appendix D: Consent Form

This appendix contains the Consent Form signed by participants prior to engagement in the study.

University of Waikato  
 Psychology Department  
**CONSENT FORM**

PARTICIPANT'S COPY

**Research Project:** Assessment of the Psychosocial Needs of Parents and Children using Paediatric Outpatient Services in the Waikato

Name of Researcher: Rosalind Case-Doube

Name of Supervisor: Dr Carrie Barber

I have received an information sheet about this research project or the researcher has explained the study to me. I have had the chance to ask any questions and discuss my participation with other people. Any questions have been answered to my satisfaction.

I agree to participate in this research project and I understand that I may withdraw at any time. I agree that the patient's paediatrician may provide information about the patient to the researcher (as detailed in the Participant Information Sheet). If I have any concerns about this project, I may contact the convenor of the Research Ethics Committee (Dr Robert Isler, phone" 838 4466 ext. 8401, e-mail [r.isler@waikato.ac.nz](mailto:r.isler@waikato.ac.nz)).

Parent/Guardian Name: \_\_\_\_\_

Signature: \_\_\_\_\_

Patient Name: \_\_\_\_\_

**If the patient is 12 years or older, he/she should sign below to indicate they have read the Patient Information Sheet and agree that the parent/guardian and paediatrician participating in this study can provide information about them to the researcher.**

Patient Signature: \_\_\_\_\_ (if aged over 12 years)

Date: \_\_\_\_\_

## Appendix E: Background Questionnaire

This appendix contains the Background Questionnaire designed by the primary researcher.

### Background Information

Child's age: \_\_\_\_\_

Child's Gender: Male / Female

Child's ethnicity:

NZ Maori / NZ European / Other European Samoan / Cook Island Maori / Tongan / Niuean / Chinese / Indian / Other (*please specify*): \_\_\_\_\_

Number of people living in your household: \_\_\_\_\_ How many of these people are under 18? \_\_\_\_\_

Approximate household income (*please circle one*):

\$0 - \$19,999    \$20,000-\$34,999    \$35,000-49,999    \$50,000-69,999

\$70,000-\$99,999    \$100,000 +

How far did you travel to your appointment today? Approximately \_\_\_\_\_ kms

How many times would you estimate your child has visited a paediatrician or other doctor in the past 12 months? \_\_\_\_\_

How many times has your child been admitted to hospital in the past 12 months? \_\_\_\_\_

What illness/illnesses is your child currently receiving treatment

for? Asthma    Diabetes    Cancer    Rheumatic Heart  
Disease    Epilepsy    Permanent Hearing Problems    Vision Problems

Something else (*please specify*) \_\_\_\_\_

What is the purpose of your child's appointment today? (*please circle one*)

Initial Assessment    Follow Up Assessment

Treatment

How long has your child been receiving medical treatment for the illness for which s/he is being seen today?

0-1mth    1-6 mths    6-12mths    1-3 yrs    3+  
years    (*please circle one*)

Has your child or family received any counselling or other emotional support related to your child's medical concerns? Yes / No(*please circle one*)

If yes, who / what service provided this?

\_\_\_\_\_

**PLEASE CIRCLE A NUMBER FROM 1-4**

**How important do you think it is to provide counselling, support, or psychological services for children and families with medical illnesses?**

Not important	Somewhat important	Quite important	Very Important
1	2	3	4

**If counselling, support or psychological services were available, would you be interested in using them for yourself or your family?**

Not interested	Somewhat interested	Quite Interested	Very Interested
1	2	3	4

**If you have any further comments you would like to make about the psychological and/or emotional needs of children with chronic health conditions and their families, please do so below:**

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## Appendix F: Paediatrician Rating Form

This appendix contains the Paediatrician Rating Form designed by the primary researcher.

**University of Waikato  
Paediatric Psychosocial Needs Assessment  
Paediatrician Rating Scale**

This form is for research purposes only and is not to be included with the patient's file. On completion, please return the form to reception to be forwarded on to the Chief Investigator, Rosalind Case-Doube from the University of Waikato. All details will be anonymised. If you have any queries, please contact Rosalind Case-Doube on 07 855 1495 or 021 135 9744. Thank you for your participation in this project.

ID: \_\_\_\_\_

**PLEASE CIRCLE A NUMBER FROM 1-5 (or select N/A if non-applicable)**

**How would you rate the patient's overall adherence to their medication regime? N/A**

Very low	Low	Moderate	High	Very High
1	2	3	4	5

**How would you rate the patient's current overall health status?**

Very poor	Poor	Moderate	Quite good	Very Good
1	2	3	4	5

In your professional opinion, could the patient or his / her immediate family benefit from psychosocial support (in the form of psychological services or counselling) for issues relating to their health problems?

**Yes / No** (please circle one)

**Comments:** \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Appendix G: Depression Anxiety Stress Scale - Short Version (DASS-21)

This appendix contains Lovibond & Lovibond's (1995) short version of the Depression Anxiety Stress Scale (DASS-21).

# DASS 21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you *over the past week*. There are no right or wrong answers. Do not spend too much time on any statement.

*The rating scale is as follows:*

- 0 Did not apply to me at all
- 1 Applied to me to some degree, or some of the time
- 2 Applied to me to a considerable degree, or a good part of time
- 3 Applied to me very much, or most of the time

1	I found it hard to wind down	0	1	2	3
2	I was aware of dryness of my mouth	0	1	2	3
3	I couldn't seem to experience any positive feeling at all	0	1	2	3
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3
5	I found it difficult to work up the initiative to do things	0	1	2	3
6	I tended to over-react to situations	0	1	2	3
7	I experienced trembling (eg, in the hands)	0	1	2	3
8	I felt that I was using a lot of nervous energy	0	1	2	3
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3
10	I felt that I had nothing to look forward to	0	1	2	3
11	I found myself getting agitated	0	1	2	3
12	I found it difficult to relax	0	1	2	3
13	I felt down-hearted and blue	0	1	2	3
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3
15	I felt I was close to panic	0	1	2	3
16	I was unable to become enthusiastic about anything	0	1	2	3
17	I felt I wasn't worth much as a person	0	1	2	3
18	I felt that I was rather touchy	0	1	2	3
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3
20	I felt scared without any good reason	0	1	2	3
21	I felt that life was meaningless	0	1	2	3

## Appendix H: Quality of Life Scale

This appendix contains Flanagan's (1978) Quality of Life Scale (QOL).

### QUALITY OF LIFE SCALE (QOL)

Please read each item and circle the number that best describes how satisfied you are at this time. Please answer each item even if you do not currently participate in an activity or have a relationship. You can be satisfied or dissatisfied with not doing the activity or having the relationship.

	Delighted	Pleased	Satisfied	Mixed	Mostly Dissatisfied	Mostly Unhappy	Terrible
1. Material comforts home, food, conveniences, financial security . . . . .	7	6	5	4	3	2	1
2. Health - being physically fit and vigorous . . . . .	7	6	5	4	3	2	1
3. Relationships with parents, siblings & other relatives . . . . .	7	6	5	4	3	2	1
4. Having and rearing children . . . . .	7	6	5	4	3	2	1
5. Close relationships with spouse or significant other . . . . .	7	6	5	4	3	2	1
6. Close friends . . . . .	7	6	5	4	3	2	1
7. Helping and encouraging others, volunteering, giving advice . . . . .	7	6	5	4	3	2	1
8. Participating in organizations and public affairs . . . . .	7	6	5	4	3	2	1
9. Learning- attending school, improving understanding . . . . .	7	6	5	4	3	2	1
10. Understanding yourself . . . . .	7	6	5	4	3	2	1
11. Work - job or in home . . . . .	7	6	5	4	3	2	1
12. Expressing yourself creatively . . . . .	7	6	5	4	3	2	1
13. Socializing . . . . .	7	6	5	4	3	2	1
14. Reading, listening to music, or observing entertainment . . . . .	7	6	5	4	3	2	1
15. Participating in active recreation . . . . .	7	6	5	4	3	2	1
16. Independence, doing for yourself . . . . .	7	6	5	4	3	2	1

## Appendix I: Strengths and Difficulties Questionnaire

This appendix contains Goodman's (1997) Strengths and Difficulties Questionnaire.

## Strengths and Difficulties Questionnaire

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

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

Parent / Teacher / Other (Please specify):

**Thank you very much for your help**